

Spousal Well-Being of Service Members With Traumatic Brain Injury: A Qualitative
Study

Leslie Freeman Davidson

Dissertation submitted to the Faculty of the
Virginia Polytechnic Institute and State University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY
in
Human Development

Elizabeth G. Creamer, Co-chair
Paul D. Renard, Co-chair
Marcie Boucouvalas
Mary A. Corcoran

December 10, 2010
Falls Church, VA

Keywords: well-being, brain injury, spouses, military, grounded theory, post-
concussive syndrome

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Abstract

Brain injury has become the signature wound of Operation Iraqi Freedom/Operation Enduring Freedom (OIF/OEF), based on estimates that 10% of all returning warriors may have sustained a brain injury secondary to blast exposures. Traumatic brain injury (TBI) affects the lives of survivors as well as their loved ones, and the consequences associated with TBI inform well-being for all involved. This research uses grounded theory to understand contributing factors of female spousal well-being, specifically the female partners of servicemen who have sustained mild to moderate traumatic brain injury (mMTBI) during combat in OIF/OEF. Through the use of sequential interviews and transcript analysis, the Combat Related Traumatic Brain Injury (CoRTs) Model of Spousal Well-Being emerged illustrating the dynamic relationships among supports, role engagement, the process of redefining self, perceptions of personal empowerment and subjective wellbeing. Four key conclusions were identified from these findings: a) mMTBI affects the life of the surviving service member as well as the life of his partner, b) the myriad consequences of combat-related mMTBI on the female spouse prompted these women to engage in a journey of redefining self, c) communities of influence became the centerpiece from which participants could move forward with their lives or remain in their current state, and d) successful engagement in roles of choice provided study participants experiences from which to establish their new self, fostered perceptions of empowerment, and informed well-being. The CoRTs Model of Well-Being and conclusions provide a framework for future programming

designed to target the needs of veterans and family members whose lives have been disrupted by brain injury sustained in combat.

DEDICATION

I dedicate this dissertation to my amazing family. First to Kane, my husband and best friend, whose patience and encouragement became a cornerstone to my many years of doctoral work. Second, to my two young daughters Raya and Tallah, who have always known me to be working on this research and constantly remind me of life's most important treasures. Additionally, I would like to dedicate this work to the memory of my mother, Lizabeth H. Freeman, who felt the two most important things she could leave her daughter was a desire to embrace lifelong learning and the ability to laugh at myself; she had no idea. Finally, I would like to dedicate this research to the spouses of the hundreds of thousands of men and women returning from war very different than when they left. This research began when you asked for a voice. I sincerely hope I have provided at least a whisper.

“I believe that true identity is found . . . in creative activity springing from within. It is found, paradoxically, when one loses oneself. Woman can best refind herself in some kind of creative activity of her own.”

—Anne Morrow Lindbergh

ACKNOWLEDGMENTS

I would like to thank those people who have been instrumental during my dissertation journey.

First, I wish to thank my co-advisors, Dr. Elizabeth Creamer and Dr. Paul Renard. Together, they have provided unyielding encouragement, support, expertise, and guidance throughout this process. Their understanding of research, scholarship, and scholarly writing has been a guide, a much-needed thorn, and a constant source of inspiration. Additionally, I would like to thank my committee members, Dr. Marcie Boucouvalas and Dr. Mary Corcoran, for their insights, knowledge, comments, guidance, and impromptu meetings for spur-of-the-moment thoughts and encouragements.

I would like to thank Dr. Tracy Fitzsimmons and Dr. Melissa Jones, whose friendship, love, and unwavering confidence in my abilities carried me from beginning to end. I would like to thank Fredda Ruppenthal for her assistance with childcare and last-minute kid duties, and I would like to thank Michele Eldredge for her skillful work shepherding me through the doctoral program. I would like to acknowledge Theodor Seuss Geisel, as he provided much needed contemplative exercises after long hours of analysis, writing, and more analysis. Lastly, I would like to thank my students who inspire me to do extraordinary things under sometimes less than extraordinary circumstances.

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List of Abbreviations

ASC	Alteration of consciousness
ASR	Acute stress reaction
CoRTs	Combat Related Traumatic Brain Injury Spousal
DOD	Department of Defense
DVBIC	Defense and Veterans Brain Injury Center
ETOH	Alcohol
FY	Fiscal year
GWOT	The Global War on Terror
IED	Improvised explosive device
LOC	Loss of consciousness
mMTBI	Mild to moderate traumatic brain injury
mTBI	Mild traumatic brain injury
MTBI	Moderate traumatic brain injury
ODS	Operation Desert Storm
OEF	Operation Enduring Freedom
OIF	Operation Iraqi Freedom
OWB	Objective well-being
PCS	Postconcussive syndrome
POW	Prisoner of war

PTA	Posttraumatic amnesia
PTSD	Posttraumatic stress disorder
RoS	Reconstruction of self
sTBI	Severe traumatic brain injury
SWB	Subjective well-being
TBI	Traumatic brain injury
WHO	World Health Organization
WIA	Wounded in action
WRAMC	Walter Reed Army Medical Center
WWP	Wounded Warrior Project

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Chapter 1: Introduction

War and the consequences of large-scale conflict have been a constant throughout human history. In an attempt to understand bloody conflict, society quantifies this phenomenon through cost and benefits analysis, lengthy discussions of financial liabilities, death tolls, hills taken by the allies, or defeats of the enemy. Many would argue that these numbers add up to tangible outcomes that we, as individuals and society, use to advance personal and political agendas. Policy and programs are often developed based on these statistics but ignore the unique struggle of the individual soldier and his or her family. Our warriors experience devastating injury and disability that affects their physical, psychological, cognitive, and social well-being as well as the well-being of their loved ones.

Brain injury has become the signature wound of Operation Iraqi Freedom/Operation Enduring Freedom (OIF/OEF), and mild to moderate traumatic brain injury (mMTBI) makes up more than 75% of these wounds (Warden, 2006). mMTBI may go unnoticed during deployment and during the initial reintegration to civilian life. Symptoms may include changes in frustration tolerance, memory, attention, or social skills. As time goes on, and the individual reintegrates back to pre-deployment life, these deficits may affect daily activities, social skills, and task performance. It is not unexpected for these deficits commonly associated with mMTBI to become more evident as the individual attempts to return to daily routines and pre-combat roles such as parent roles, household roles, and work roles (Ruff, 2005). An unstructured environment and new routines often exacerbate symptomatology.

The veteran and his or her partner may experience consequences of war for months and years after combat wounds have healed. The impact of these injuries on the well-being of family members is largely unknown. Collateral damage inflicted on the home-front is often overlooked by the decision makers in a time of war. This research is designed to understand contributing factors to subjective well-being (SWB) of the brain-injured army soldier's spouse—specifically, the female partners of soldiers who have returned from OIF/OEF with mild to moderate brain injury. Through the use of constructivist grounded theory, data obtained through sequential interviews will contribute to the design of a theory explaining contributors to SWB. Potentially, these constructs may be used when designing services for the veterans' families.

Understanding the experiences of these women; the factors that contribute to well-being; and how they cope with multiple changes, learn and negotiate new roles, and find new meaning in their lives will shed light onto the immediate, intermediate, and long-term manner by which the military trains, treats, and rewards servicemen and their families after they are no longer able to complete their military mission.

Background

Although there is a 30-year history of literature explaining the consequences of brain injury on family members, the scholarly literature has not explored short- and long-term life changes that affect the spouses of wounded soldiers beyond a superficial level. Over the past three decades, the focus of the research has been on family members of civilians who have sustained severe brain injury, or as in many cases, no level of injury is identified (Allen et al., 1994; Gosling & Oddy, 1999; Hall et al., 1994; Katz, Kravetz, & Grynbaum, 2005; Montgomery, Oliver, Reisner, & Fallat, 2002; Sinnakaruppan & Williams, 2001; Wedcliffe & Ross, 2001; Wood, Lioffi, & Wood, 2005). Literature findings include high levels of stress,

burden, and financial strain. These findings are attributed to the devastating consequences of traumatic brain injury (TBI), a diagnosis that often presents with long-term physical, cognitive, and social behavioral disabilities. Currently, the U.S. military and civilian population is experiencing an influx of brain injury as a result from OIF/OEF. It may be expected that issues identified in the civilian literature may also be applicable to the military family.

Injuries as a Result of War

The United States has been involved in “The Global War on Terror” (GWOT) since the invasion of Afghanistan (under the code name OEF) on October 7, 2001, as a direct retaliation for the attack on the United States on September 11. OIF was initiated March 19, 2003. The invasion of Iraq expanded the war on terror and increased the commitment of about 17,000 soldiers deployed to Afghanistan to an additional 100,000 plus U.S. troops deployed to Iraq. Five and a half years later, GWOT includes OIF/OEF as well as numerous smaller conflicts worldwide. The number of military men and women deployed is steadily rising, with the total number exceeding 1.6 million (approximately a quarter of that at any given time). As deployment numbers have increased so have the number of war casualties. Each casualty overseas affects the lives of many loved ones back home. According to the U.S. Department of Defense (DOD, 2010), as of November 17, 2010, 5804 fatalities have been associated with OIF/OEF. The official reports from the DOD for nonmortal wounds are estimated to be at just over 41,100, with about half of those unable to return to duty. Of those who are unable to return to duty within 72 hours an estimated 15–20% suffer from brain injury, and an unknown majority from mMTBI. The exact number of those who sustain brain injury is not available at this time, but estimates up to 10-15% of all those deployed have been given (Associated Press, 2007; Warden, 2006). A primary reason for this high statistic is twofold. First, the mechanism of

injury, the improvised explosive device (IED), presents itself in multiple phases, each of which places the soldier at risk for brain injury (Taber, Warden, & Hurley, 2006). Second, current survival rates after brain trauma in the battlefield, once a primary cause of death of the soldier, are high because of the outstanding care and medical technology so close to the battle sites.

Injuries Across Time

As illustrated in Table 1.1, the survival rate of severely wounded soldiers in this current conflict far exceeds any seen in the past.

Table 1.1
Battle Deaths and Nonmortal Wounding During American Wars

Conflict	Number deployed ^a	Percent battle deaths ^b	Percent nonmortal wounding	Ratio of battle deaths to nonmortal wounding
American Revolution (1775–1783)	217,000	2%	3%	2:3
War of 1812 (1812–1815)	286,730	0.8%	1.5%	0.8:1.5
Indian Wars (1817–1898)	106,000	1%	Unknown	
Mexican War (1846–1848)	78,718	2%	5%	2:5
Civil War: Union (1861–1865)	2,213,363	6%	13%	6:13
Civil War: Confederate (1861–1865)	1,050,000	7%	Unknown	6:13 ¹
Spanish American War (1898–1902)	306,760	>1%	.5%	~1:1
World War I (1917–1918)	4,734,991	1%	4%	1:4
World War II (1941–1945)	16,112,556	2%	4%	1:2
Korean War (1950–1953)	5,720,000	0.6%	2%	0.6:2
Vietnam War (1964–1975)	3,403,000	1.5%	4.5%	1.5:4.5
Desert Shield/Desert Storm (1990–1991)	694,550	0.02%	>1%	0.02:1
War on Terrorism ² (2001–9/30/2005)	185,329	0.9%	8.6%	1:8.6 (1:16)
American Wars Total	43,185,893 ^c	1.5%	3.5%	1.5:3.5 ³

¹Estimates of nonmortal wounding to deaths in the Confederate Army are estimated to be similar to those of the Union Army (Fox, 1885, p. 554).

²The statistics put out by the Department of Veterans Affairs, Office of Public Affairs, “America’s Wars,” September 30, 2006, identified the ratio of those killed to those injured to be 16:1, stating that the number of those wounded by document publication was 50,508 compared with 2,333 deaths.

³The combined total number of battle deaths to nonmortal wounding is historically and statistically neither historically nor statistically significant. Changes in military and medical technology override any meaningful summary of this information (personal communication, P. Renard, June 4, 2007).

^aNumbers deployed before Vietnam reflect service members worldwide.

^bDoes not include other deaths in service.

^cU.S. military service members during wartime.

This unprecedented high rate of survival may be attributed to the outstanding medical care wounded soldiers receive in the field as well as the lifesaving technologies in military field hospitals. Their survival is a testament to the Medical Corp of the U.S. military as well as the resources provided to it by the U.S. government.

The survival rate for the wounded in the GWOT is almost 2–4 times that of any other past war. Given this rate of survival, several familial and financial consequences must be considered during the long-term planning for veterans who return with injuries. As new territory of long-term rehabilitation is being entered, the potential needs of veterans and their families are poorly understood. Literature has explored the emotional impact of TBI on the family in a non-military context(Allen et al., 1994; Banks, 2003; Hall et al., 1994; Linn, Allen, & Willer, 1994; Pellitier, 1994), but absent from the research is an exploration of the affect of a soldier's TBI on the family or more specifically their spouse.

Spouses Affected by War Injuries

According to the U.S. Army's Office of Army Demographics, in FY2009, there were 854,112 family members of active duty soldiers. This number included 251,318 spouses (54% of active duty soldiers are married) and 457,645 children (46% of active duty soldiers have children). The number of female spouses was 231,282.

Based on the number of service members who have been medically evacuated from the battlefield, it may be assumed that tens of thousands of spouses will have to deal with a loved one returning from Iraq with severe injury and/or possible long-term disability. The experiences of these spouses seemingly go unnoticed in the research literature and the media, despite the fact

that their lives have been significantly changed. The social, emotional, and financial implications of mMTBI on family and understanding the contributors to the well-being of spouses must be better understood to ensure that veterans gain the support and resources they need after their service.

Traumatic Brain Injury

It has been estimated that 10–20% of all returning soldiers suffer from TBI. The vast majority of these injuries are mild to moderate in severity. Mild TBI (mTBI), also known as postconcussive syndrome (PCS), is difficult to diagnose because there is little consensus on a definition of mTBI. The symptoms are variable in nature as well as severity, leaving specifics for diagnosis somewhat ambiguous (Bryant, 2001). Although three definitions of mMTBI have been adopted to assist in this research, the most current definition, adopted by the DOD (released October 1, 2007), will act as the primary source for defining severity of injury. Other secondary sources include a definition identified by the World Health Organization (WHO, 2001) as well as one adopted by the Defense and Veterans Brain Injury Center (DVBIC; Warden, 2006). Secondary sources have been used to assist in understanding the complex nature of this complicated and often variable injury. According to the WHO, as described by Carroll and colleagues (2004a), mTBI is

... an acute brain injury resulting from mechanical energy to the head from external physical forces. Operational criteria for clinical identification include one or more of the following: confusion, [loss of consciousness] for 30 min or less, [posttraumatic amnesia] less than 24 hrs and other transient neurological abnormalities such as focal signs, seizures, and an intracranial hemorrhage not

requiring surgery. Deficits cannot be due to drugs, alcohol, medications, or other injuries or problems (psychological), or by penetrating cranio-cerebral injury. (p. 114)

The DVBIC (Warden, 2006) developed a definition that will be used throughout this study and will be explained in greater detail in Chapter 2. The definition incorporates many of the elements outlined in the WHO definition.

mMTBI in a Military Context

TBI has been identified as the signature wound of the current conflicts in Iraq and Afghanistan. It has been estimated that up to 20% of the 1.5 million service members who are or have been deployed in OEF/OIF may have sustained a TBI (Associated Press, 2007; Warden, 2006).⁴ In the case of mTBI, the scholarly literature states that associated symptoms often will resolve within 3 months in 75–85% of the cases (Carroll et al., 2004b). Symptoms continue in the remaining 15–25%, potentially affecting daily functioning, ability to return to work, and ability to engage in family roles and leading to long-term physical and psychosocial disability (Ruff, 2005).

The symptoms associated with mMTBI vary from individual to individual. Similarly, the context in which the person participates will affect their performance. For this reason, brain injury is unpredictable and causes frustration and—at times, fear—among family members of those injured (Hall et al., 1994; Gosling & Oddy, 1999). In the case of severe TBI (sTBI), the soldier will often present with outward physical signs of injury, which is not always true in less severe cases. For example, soldiers who are exposed to single or multiple blast explosions from

⁴The numbers associated with TBI and mTBI vary significantly from source to source. The numbers presented are best estimates reported by DVBIC.

an IED may sustain brain trauma with no immediate outward signs of injury. Their symptoms may initially present as a brief alteration of consciousness (AOC) or behavioral changes (Taber et al., 2006). Currently, there is no way of identifying the number of mMTBIs sustained in OIF/OEF. These injuries are often hidden behind more seemingly urgent life-threatening combat wounds such as limb loss, burns, spinal cord injury, or fractures.

It is common for soldiers who have sustained mMTBI to have other concomitant injuries. Typically, the wounded warrior with brain trauma will fall into one of the following four categories: 1) the warrior who sustained a brain injury only, 2) the warrior who sustained brain trauma and also presents with posttraumatic stress disorder (PTSD) or acute stress reaction (ASR), 3) the warrior who presents with brain trauma and polytrauma, that is, multiple traumatic injuries, and 4) the warrior who presents with all three (MTBI, polytrauma, and PTSD/ASR). These multiple variables introduce several factors that make initial diagnosis and identification of mMTBI difficult. The type of injury along with the potential concomitant issues may determine the impact on the well-being of the warrior's spouse.

mMTBI and Stress Disorders

Several recent and controversial studies have explored mMTBI and ASR. The cognitive symptoms associated with these two diagnoses are similar in nature (Bryant & Harvey, 1998; Hoge et al., 2008). Symptoms include sleep disturbances; difficulty with attention, concentration, and memory; irritability; and social isolation. In addition, symptoms associated with mMTBI are more evident and persistent in individuals who present with PTSD (Bryant, 2001; Bryant & Harvey, 1997). ASR and PTSD, like mMTBI, have become a primary concern for veterans who have returned home and struggle to resume their roles in the family and community (Hoge et al., 2008).

Currently, it is difficult to determine the number of returning service members who have mMTBI with a PTSD overlay. The mechanism of injury (over half from a blast) and the combat environment place the service member who has sustained mMTBI at high risk for an ASR/PTSD overlay (Hoge et al., 2008). It is important to consider the strong possibility of comorbidity when identifying contributing factors to spousal well-being.

Implications for Veterans and Spouses

Initial symptoms associated with mMTBI include headache, dizziness, nausea and vomiting, sleep disturbances, sensitivity to noise and light, slowed thinking and reaction time, memory problems, irritability, depression, and visual changes (Carroll et al., 2004b). On the home front, persistent symptoms associated with mMTBI often lead to long-term limitations in activity performance and social participation. The disability associated with brain injury may lead to anxiety, stress, depression, and social problems (Ponsford, 2005). Returning to roles and activities that were routine, such as work, school, and family, may be challenging or impossible depending on the level of impairment. Cognitive deficits such as problems with attention and memory make seemingly easy daily tasks such as medication management a challenge (Steadman-Pare, Colatonia, Ratcliff, Chase, & Vernich, 2001).

Although symptoms persist in fewer than 30% of those who sustain a mTBI, and an unknown percent in those whose injury may be classified as moderate, the impact that deficits have on the warrior's ability to participate as a productive member of their family and society may be significant (Ruff, 2005). Relationships with friends and family members frequently shift after injury (Wood et al., 2005).

mMTBI and Marital Relationships

Spouses of individuals with brain injury report unpredictable patterns of behavior, and these erratic behaviors place significant burden on marital relationships (Wood et al., 2005). Thomsen (1992) reported that marital difficulties often emerge 2.5–15 years post-injury because the individual with a head trauma often will demonstrate a worsening of symptoms as time from the initial incident increases. Subsequently, spouses often experience isolation, increased levels of burden, loss of identity, and greater stress. Behaviors such as heightened irritability and social isolation become more pronounced after the first 2 years, often leading to marital discourse. Hoofien, Gilboa, Vakil, and Donovanick (2001) discussed the need for families who have a loved one with head trauma to receive continued psychosocial support to maintain quality of life, and Ergh, Rapport, Coleman, and Hanks (2002) noted that caregiver distress and family dysfunction were directly related to neurobehavioral dysfunction in the brain-injured family member. It is well understood that in a non-military context, the life of the spouse significantly changes after their loved one sustains a head injury. It can therefore be assumed that many of these findings generalize to the military family. However, the well-being of the surviving warrior's partner may be affected on a greater level than that of a civilian spouse given the added stress of transitioning from military to civilian life.

Subjective Well-Being

The concept of well-being can be broken down into three areas: 1) objective well-being, 2) SWB, and 3) a combination SWB and objective well-being. The latter refers to external evaluation criteria, including age, health, gender, and marital status, to name a few. Researchers who are interested in objective well-being state the importance of these variables and measure happiness accordingly (Diener & Suh, 2000). SWB, according to Diener (2006), on the other

hand,

refers to all of the various types of evaluations, both positive and negative, that people make of their lives. It includes reflective cognitive evaluations, such as life satisfaction and work satisfaction, interest and engagement, and affective reactions to life events, such as joy and sadness. Thus, subjective well-being is an umbrella term for the different valuations people make regarding their lives, the events happening to them, their bodies and minds, and the circumstances in which they live.

(p. 399)

SWB considers those variables that individuals believe are essential to their happiness, and research in this area explores the individual and unique perceptions within this domain.

Although no research has been completed on SWB of spouses of veterans with brain injury, Rosen and Moghadam (1994) discussed predictors of general well-being in army wives. Their findings included social supports, personality, general life satisfaction, and level of stress. The scholarly literature does not discuss transition as a construct to well-being. Despite their absence in current research, the multiple transitions these women experience over a short period of time warrant discussion because these changes may contribute to the well-being of spouses.

Transitions Experienced by the Military Spouse

Transition is a constant in army life. Military families rarely live in one place for longer than 3 years, and family members are often deployed or sent for training for undetermined amounts of time. Many family members become used to the constant changes and adapt accordingly. The family of the injured army soldier also goes through several life transitions; these changes are often more complicated and less structured than the ones they are used to in

“normal” army life. For the families of injured service members, multiple changes occur, often simultaneously. These transitions often include relocating away from friends and support, leaving the life of the army, and giving up work to provide care to a spouse. The experience associated with transitions may include multiple short-term changes as well as long-term changes with no identified goal in sight. The many transitions experienced by the spouses of mMTBI survivors potentially exacerbate changes in well-being.

A military spouse’s perception of the world may shift after their loved one’s deployment and return. This shift in perception may be dependent on the multiple transitions that occur both unexpectedly and simultaneously: military to civilian and spouse of an able-bodied service member to spouse of a disabled veteran. This grounded theory study is designed to identify and explore the contributors to spousal SWB, specifically, loved ones of veterans with mMTBI. This research is an attempt to gain knowledge about how these women understand their level of well-being as they navigate their seemingly chaotic and complex new world.

Statement of the Problem

Twenty-first century urban warfare has introduced widespread use of IEDs. Often placed roadside, injuries from IEDs resemble nothing like what has been seen since World War I. Although IEDs have been used in the past (“booby traps” in the Vietnam War), the current magnitude and frequency are preceded only by shelling in World War I. Injuries sustained from IED blasts frequently leave soldiers with multiple traumas: head injury, burns, severe extremity wounds, and eye injuries. Similarly, proximity of soldiers to these blasts can cause brain injuries that may initially go undiagnosed due to lack of apparent physical injury. The symptoms of mMTBI are often behavioral issues, and these issues are frequently misdiagnosed as combat stress or PTSD (Bryant, 2001; Ponsford, 2005).

The medical resources currently provided to field hospitals are outstanding. The care provided by field hospitals and the individuals who staff them (doctors, nurses, physician's assistants, occupational therapists, physical therapists, medics, and aides) exceeds most community hospitals in the United States and has increased the survival rate of severely injured soldiers. However, as soldiers who sustain brain injury are surviving, they are experiencing profound long-term disabilities, including physical, cognitive, and psychological disabilities (Hall et al., 1994). Furthermore, after these soldiers begin the rehabilitation phase of their recovery, resources and knowledge are often inadequate. Efficacy of treatment for mMTBI is limited, and the course of hospitalizations for individuals with mMTBI can range from none to an excess of 12 months. Once they return home, these soldiers reintegrate into families, work places, and communities that are ill-prepared to grasp the nature of the needs of wounded warriors and their partners.

Currently, the U.S. Army reports in 2009, there were more than 381,000 active duty spouses (Army Well-Being, 2009). The impact that brain injury has on the spouse is significant, and the literature has yet to explore the implications of head injury secondary to war trauma on the partners of soldiers or the impact of mMTBI on the family unit. As the family transitions from the military to the civilian world, it is presented with challenges and choices very different from what has been familiar.

Past studies have looked into the spousal experiences of soldiers with PTSD, prisoners of war, and those who have engaged in lengthy combat. These studies examine conflicts over the past 75 years and across the globe. Findings from this research highlights the effects of a soldier's experience on the spouse, ranging from no noticeable influence on quality of life and marriage (Lee, Vaillant, Torrey, & Elder, 1995) to secondary traumatization experienced by loved ones

years after the soldiers return (Solomon, 1992). The literature, however, has a critical gap. It has yet to explore the impact of combat-related head trauma and concomitant injuries on the lives of the female spouse.

Specifically, the research has not delved into the experiences of these women and the factors contributing to their well-being. The high survival rates of OIF/OEF along with the primary mechanism of injury (IEDs) have produced a new type of veteran and therefore a new type of spousal experience that has yet to be understood. Based on this gap in the literature, two research questions have been identified to frame this grounded theory research.

Research Questions

An extensive review of the scholarly literature demonstrates several knowledge gaps. The following research questions have been developed based on these gaps as well as the multiple variables that potentially influence the lives of women whose spouses have returned from combat with mMTBI. In the case of female spouses of recently brain-injured soldiers:

1. What factors do these women offer to explain their own well-being?
2. How do these women describe the influence of these identified factors on their well-being?

Purpose Statement

The purpose of this research is to develop theory explaining contributors to spousal wellbeing of wounded service members with mMTBI. This research is designed to identify and understand how factors, identified by the study participants, affect experiences and personal identity. The qualitative design provides for an understanding of experience through the eyes of those who have lived it. Development of a theoretical understanding of spousal experiences may

provide a foundation for future program development and service initiatives necessary to assist families of wounded warriors.

Significance of the Study

Being a service member of the U.S. military goes far beyond the men and women in uniform. Millions have committed themselves to the military way of life on the home front, and the struggles and triumphs of war are reflected in their stories. Specifically, the stories of women whose husbands returned from the battlefield with mMTBI reveal the complexities of a journey to find a new way of life. Brain injuries, burns, neck and spinal cord injuries, amputations, and combinations of these types of wounds are becoming commonplace in the field hospitals in Iraq and Afghanistan. The long-term disabilities associated with these injuries are becoming a profile of the contemporary veteran. The impact of these injuries and subsequent disabilities on the family, specifically the spouse, is potentially profound but largely unknown.

Understanding the experiences of the spouses of wounded soldiers, their well-being, and how they cope in their daily lives will contribute to the development of a theoretical framework from which services and resources for veterans and the military families can be developed. In addition, the findings of this research will help to shape policy and practice on all levels of decision making.

Finally and most importantly, this grounded theory research will provide these women with a voice and a venue to share their experiences as understood only by them. Application of these findings will lead to subsequent research and services that will provide spouse-centered programs, help to empower families, generate research lines, and ease the burden experienced by spouses of service members with mMTBI.

Chapter 2: Literature Review

The following chapter outlines the scholarly literature relevant to understanding the constructs of subjective well-being (SBW) and the experiences of women whose spouses have returned from Operation Iraqi Freedom/Operation Enduring Freedom (OIF/OEF) with mild to moderate traumatic brain injury (mMTBI). Literature from several disciplines, including, but not limited to, the fields of occupational therapy, adult learning, disability studies, and psychology, has been incorporated into this review of the scholarly literature. Specifically, this literature review converges scholarly work in several topical areas, including SBW, brain injury, the impact of traumatic brain injury (TBI) on the family and the spouse, military culture, the experiences of women whose spouses have returned from war, and transition, a phenomenon that is constant in the military. Because grounded theory research views the review of scholarly literature as an iterative process (Charmaz, 2006), theoretical literature is explored in Chapter 5 as it informs the findings.

Purpose Statement Restated

As discussed in Chapter 1, the purpose of this grounded theory research is to develop theoretical constructs outlining factors contributing to the spousal SBW specific to OIF/OEF veterans with mMTBI. The study uses multiple data sources to gain comprehensive understanding of what these women perceive as contributors. Theory developed from this study will provide a critical foundation for effective development of programs designed to meet the needs of family members of OIF/OEF's wounded warriors.

Research Questions

The research questions, also outlined in Chapter 1, follow. In the case of female spouses of recently brain-injured soldiers:

1. What factors do these women offer to explain their own well-being?
2. How do these women describe the influence of these identified factors on their well-being?

Mild to Moderate Traumatic Brain Injury

Currently, the scholarly literature presents multiple definitions for TBI as well as several diagnostic criteria used to identify severity of injury. In addition, a number of symptoms are used for diagnosis of injury severity (Davis et al., 2007). In an attempt to better diagnose and provide medical treatment to the troops injured in theater and rehabilitation to the soldiers who have returned home after injury, the Department of Defense has provided an updated working definition of TBI as well as classification criteria for severity of injury. This definition will be used for this study. According to a memo released by the Assistant Secretary of Defense on October 1, 2007, a TBI is

... 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;
- Any loss of memory for events immediately before or after the injury;

- Any alteration in mental state at the time of injury (confusion, disorientation, slowed thinking, etc.);
- Neurological deficits (weakness, loss of balance, change in vision, praxis, paresis/plegia, sensory loss, aphasia etc.) that may or may not be transient; and
- Intracranial lesion. (p. 1)

In addition to defining TBI, severity of injury criteria were outlined in this document (p. 3). mTBI consisted of normal structural imaging, LOC less than or equal to 30 minutes, alteration of consciousness (AOC) from a moment to 24 hours, and post traumatic amnesia (PTA) less than or equal to 24 hours. MTBI consisted of either normal or abnormal imaging, LOC 30 minutes to 24 hours, AOC less than 24 hours, and PTA greater than one day and less than 7 days. STBI, again presented with normal or abnormal imaging, LOC greater than 24 hours, AOC greater than 24 hours, and PTA greater than one day. In addition, the Department of Defense (2007) stated, “It is recognized that the cognitive symptoms associated with post-traumatic stress disorder [PTSD] may overlap with symptoms of mild TBI. Differential diagnosis of brain injury and PTSD is required for accurate diagnosis and treatment” (p. 3).

Natural Course of mMTBI

The natural recovery course of mMTBI⁵ is variable. Currently, there is no known reason why some individuals seem to suffer little to no long-term effects from their injury whereas others demonstrate significant limitations in daily activities with a seemingly identical scenario. Individuals who have sustained mild TBI (mTBI) may demonstrate symptoms immediately after

⁵mTBI is also understood in the literature as concussion. If symptoms linger greater than 3 months, the term postconcussion syndrome, or dysexecutive syndrome, is often used.

the incident or days to weeks later. The unpredictable nature of mTBI and the seemingly unapparent reason for this variability make it a challenge for health care professionals to prepare patients and families for potential long-term issues that may emerge (Ponsford et al., 2000).

If the symptoms associated with mTBI persist for greater than three months individuals are diagnosed with (PCS) (Mittenberg & Strauman, 2000; Ruff, 2005). Individuals with PCS have a history of head trauma and experience symptoms in at least three of the following categories (Mittenberg & Strauman, 2000):

- Category One: headache, dizziness, malaise, fatigue, and noise intolerance
- Category Two: irritability, depression, anxiety, and emotional lability
- Category Three: difficulty with subjective concentration, memory, or intellectual disabilities without neuropsychological evidence or marked impairment
- Category Four: insomnia, reduced alcohol tolerance
- Category Five: preoccupation with the previous symptoms and fear of brain damage.

Although there is little known as to why difficulties persist in some cases and seemingly resolve themselves in others, Ruff (2005) provides some explanation. One explanation is that individuals with PCS have sustained microscopic brain damage that is responsible (in part) for the physical, cognitive, and emotional sequelae of mTBI (Cohen et al., 2007). Others argue PCS is the result of the interaction among cognitive inefficiencies, distractions from physical symptoms, and situational stressors, all of which exacerbate symptoms associated mTBI (Montgomery, 1995). The emotional ramifications associated with functional deficits can lead to long-term depression, social isolation, behavioral issues, and family burden. The work outlined above informs my research as this grounded theory study explores spousal experiences service

members with mMTBI. In most cases, symptoms associated with their injuries persisted and are reflective of those in the PCS literature.

mMTBI in a Military Context

TBI has been identified as the signature wound of the current conflict in Iraq and Afghanistan. It has been estimated that up to 10–20% of the 1.5 million service members who are or have been deployed in OIF/OEF may have sustained TBI (Warden, 2006; Associated Press, 2007).⁶ If the incidence of mTBI mirrors that of the civilian population, 70% of those brain injuries are likely characterized as minimal in severity (Ruff, 2005), whereas another 20% may be classified as moderate.

A critical problem in addressing the needs of service members with mMTBI is that these injuries may be difficult to diagnosis or identify. Unlike that of soldiers who sustain severe TBI, military personnel who are exposed to single- or multiple-blast explosions from improvised explosive devices (IEDs) may sustain mild head trauma with no immediate outward signs of injury. Their symptoms may initially present as a brief alteration of consciousness (AOC) or behavioral changes (Warden, 2006). Identifying the number of mMTBIs is not currently possible because many are initially masked with other more dire diagnoses such as limb loss, burns, spinal cord injury, or fractures.

Service members who present with TBI typically fall into one of the following four categories: 1) the warrior who sustained a TBI only, 2) the warrior who sustained TBI and also presents with PTSD, 3) the warrior who presents with TBI and polytrauma, and 4) the warrior who presents with all three (TBI, polytrauma, and PTSD). As previously mentioned, these multiple variables introduce several factors that make initial diagnosis and assessment difficult.

⁶The numbers associated with TBI and mTBI vary significantly from source to source. The numbers presented are best estimates reported by DVBIC.

Additionally, these types of multiple diagnoses potentially have a varying impact on the well-being of the warrior's spouse.

Mechanism of Injury in the Military

According to the Department of Defense, the mechanism by which soldiers sustain mMTBI may be “the head being struck by an object, the head striking an object, the brain undergoing an acceleration/deceleration movement without direct external trauma to the head, a foreign body penetrating the brain, forces generated from events such as a blast or explosion, or other force yet to be defined” (Assistant Secretary of Defense, 2007, pp. 2–3). For those service members returning from OIF/OEF, the primary cause of TBI is exposure to a blast (Taber et al., 2006).

These blasts are typically caused by the detonation of an IED, which is a bomb placed roadside, hidden within walls, or put in small confined buildings. When detonated, IEDs cause an explosion sending both physical matter and blast waves that travel for hundreds of yards at speeds up to 1,600 feet per second. These blast waves occur in two phases, and injury typically can occur in one of four points in the blast. The first phase consists of a high-pressure shock wave and comes from the IED itself. This shock wave begins with significant air displacement followed by debris from the bomb site. During this initial phase, injury can occur from the airwaves themselves and or from flying debris. This initial phase is followed by a “secondary wind.” The secondary wind consists of the displaced air returning to the point of displacement, or the point where the bomb initially was detonated. These two phases associated with the blast cause a coup-counter coup type of injury as the brain moves within the skull and contact is made to the bony prominences in the front of the skull as well as the back. Individuals who are

exposed to blasts may be left without a scratch on their body. They may, however, present with brain trauma caused by the brain shifting within the skull cavity.

Often, symptoms associated with the brain injury are not apparent after the first exposure. Additionally, service members are frequently exposed to multiple blasts. In the cases where multiple blast exposures are noted, the minimal neuronal damage that occurs with a single blast is compounded and symptoms may emerge as exposure proximity and numbers increase. To date, it is not possible to evaluate potential risk of mMTBI as it correlates to the number of or proximity to blast exposures (Taber et al., 2006; Warden, 2006).

mMTBI and Stress Disorders

Some scholars have closely associated PTSD with mMTBI (Bryant & Harvey, 1998; Hoge et al., 2008). It has been estimated that up to 80% of returning soldiers with brain injury also suffer from depression or PTSD. Additionally, it has been determined that the long-term consequences of injury vary significantly from individual to individual despite the severity of injury (Ponsford et al., 2000). The variability of mMTBI related consequences, and the high probability of comorbid mental health issues are considered throughout the data collection and analysis phase of this study.

Acute stress reaction (ASR) and PTSD are emerging as a significant secondary diagnosis after TBI (Hoge et al., 2008). Professionals constantly grapple with the dual diagnosis because cognitive symptoms associated with ASR and PTSD mirror many of those apparent in mMTBI (Bryant & Harvey, 1998). Their shared symptomatology includes sleep disturbances; difficulty with attention, concentration, and memory; irritability; and social isolation (Table 2.2). In addition, symptoms associated with mTBI are more evident and persistent in individuals who present with PTSD (Bryant & Harvey, 1997, 1998). PTSD, like mTBI, has become a key issue

affecting service members returning from OIF/OEF. According to Matthew S. Goldberg, Deputy Assistant Director for National Security, in a report to Congress on October 17, 2007, “. . . PTSD is also difficult to diagnose. Among OIF and OEF veterans who have received [Veterans Administration] medical care, about 37 percent have received at least a preliminary diagnosis of mental health problems, and about half of those (17 percent) have received a preliminary diagnosis of PTSD.” Hoge et al. (2008) reported increased incidence of PTSD with soldiers who sustained brain injury.

Table 2.2.

Symptom Comparison Between Mild Traumatic Brain Injury and Acute Stress

Reaction/Posttraumatic Stress Disorder

Symptom	mTBI	ASR/PTSD
Memory, attention, concentration	X	X
Irritability	X	X
Sleep disturbances	X	
Visual changes/disturbances	X	
Balance and vestibular issues	X	
Psychological distress with cues that symbolize traumatic event		X
“Flashbacks” during day or night or during sleep		X
Impaired functioning limiting participation in activities	X	X
Nausea and/or vomiting (at time of incident)	X	
Chronic headache	X	

Note. mTBI = mild traumatic brain injury; ASR = acute stress reaction; PTSD = posttraumatic stress disorder.

From DVBIC (2006).

At this time, it is difficult to determine the number of returning service members who have mMTBI with a PTSD overlay. The mechanism of injury (primarily blast related) and the combat environment place the service member with mMTBI at high risk for an ASR/PTSD overlay (Kennedy et al., 2007). Determining the cause of symptoms (mMTBI, ASR/PTSD, or a combination of both) is critical for the veteran and family members. Intervention methods will vary depending on the primary issues causing limited functioning.

Implications for Service Members, Veterans, and Families

Once wounded warriors return home to their families, persistent symptoms associated with mMTBI may lead to long-term activity limitations and social participation restrictions. The long-term disability often associated with mTBI may lead to anxiety, stress, depression, and social problems (Ponsford, 2005); these symptoms are also reflected in PTSD. Activities such as returning to work or school may be challenging or impossible depending on the level of impairment. Returning to roles such as a spouse or parent presents challenges because irritability and decreased frustration tolerance affect relationships. Cognitive deficits such as problems with attention and memory make seemingly easy daily tasks such as medication management a challenge (Steadman-Pare et al., 2001). Additionally, these issues have been reported as primary concerns of family members of individuals with brain injury (Hall et al., 1994).

The symptoms associated with mMTBI and associated stress reactions provide a background to understand the litany of issues the participants of this study may deal with on a day-to-day basis. The impact of these issues is understood only within a contextual frame. A discussion of culture and the lives of the military spouse will help frame the picture of these women's experiences.

Military Culture

To understand the lives of military spouses, it is essential to gain insight into the culture of the military and the military family. “Culture is to a society what memory is to individuals. It refers to tools and ideas that are shared and transmitted to succeeding generations” (Triandis, 2000, p. 13). Culture is reflected in the values, experiences, attitudes, and mores that lie within an organization, community, family, or group of friends. Strong cultural influences bring forward an alignment of these attributes, and they are reflected in the tasks, goals, and relationships with a cultural group. Anthropologists have long been aware of the significance cultural influences have on every day activities as well as the state of mind of an individual or a group. Similarly, the study participants have been indoctrinated into an able-body culture, specifically one in the military where the physical skill of a person is highly valued. The injury of a spouse and the subsequent disability arguably bring forward a new way of life with new challenges. As the study participants have transitioned from military culture to civilian culture and able-bodied culture to the culture of the disabled, they have had to negotiate each culture’s unique rules, values, attitudes, norms, and mores. Their stories will foster understanding of the manner by which they negotiate these changes and how these changes may influence well-being.

The U.S. military has a strong culture that prides itself on the values and expectations of those who serve and their families. One of the first words of advice a spouse of a service member receives is, “the soldier is married to both the military and their spouse. It is important to realize the military will come first” (Raddatz, 2007). In addition, the military culture has a language that frames the world around them. In a sense, military is a culture to its own (Daley, 1999). Terminology is both formal and informal, but the significance of this “language” and communication pattern is consistent with what many anthropologists would consider “isolated

communities.” In addition, a strict chain of command is in place that must be respected and valued. This chain of command is reflected in the communication patterns, living quarters, social circles, and every aspect of the military family’s life. The organization is driven by military protocol. Creativity, personal voice, and self-expression are not only looked down upon but lead to isolation, skepticism, and possible discharge. Other essential components of military culture are customs and courtesies. Although many of the customs originated with civilian culture, they have become essential to the military, with the most recognizable and important being that of the salute.

Many of the aspects of military culture that are expected of the soldier overflow to the family as relocation and deployments are a mainstay. Families are often indoctrinated into a large support system in which they develop deep friendships and support networks. They are also provided with schools for their children, places to shop, and banks as well as opportunities to engage in all every day activities. For many military families, there is no need to leave an installation. The culture of the military provides for itself. Unfortunately, many of the members are ill-equipped to deal with the civilian world if circumstances force them from one culture to another (Bowen & Neenan, 1989). Additionally, the culture of the military and mindset of the services add to marital stress. These stressors potentially shape the experiences of spouses and their well-being.

Stressors in Military Marriages

Stressors in areas of home life may influence SWB (Ryff and Keyes, 1995). Military marriages go through numerous stressors that are not associated with typical civilian marriages. These stressors include, but are not limited to, constant relocation, deployment for unspecified periods of time, safety issues, and at times confidentiality. Stressors often will increase during

deployment and include factors such as finances, communication, and legal issues (Blount, Curry, & Lubin, 1992; Rosen & Durand, 1995). Although these problems correlate with length of deployment, they do not affect marital satisfaction.

Research has indicated that a balance can be met between the stressors and coping strategies of military spouses (Rosen, 1989). Veterans with PTSD who have support from family are better able to adapt to civilian life and successfully adjust socially (Jordan et al., 1992; Lee et al., 1995; Port, Engdahl, & Frazier, 2001; Seo, 2000). Programs devoted to therapeutic intervention with service members who suffer from PTSD and their spouses have identified improvements in communication between the couples and general increased marital satisfaction (Sweany, 1987).

Military families experience changes and uncertainty not common in the civilian population. These experiences may influence SWB. These stressors include lengthy separations and the adjustments family members make toward these separations (Rosen, 1995; Rosen, Durand, Westhuis, & Teitelbaum, 1995; Rosen, Westhuis, & Teitelbaum 1994). The military has designed programs surrounding “phases of deployment.” These phases, and the associated programs, are designed to facilitate transition for the soldier as well as the family. The current conflict has changed the rules in phases of deployment. The phases, discussed in the next section, that occur in country have been shortened, and deployment phases that occur in theater have been lengthened. These changes have placed unprecedented stress on military families, spouses, and marriages.

Phases of Deployment

To understand contributors to well-being of the spouses of service members, it is important to understand the military’s sense of normalcy. In addition to explaining some of the

cultural aspects of the military, a discussion of phases of deployment will provide insight into one of the greatest stressors of the military marriage: separation.

There are four phases of deployment: 1) predeployment, the point that the soldier has not left for war; 2) deployment, the point by which the soldier receives orders, goes through necessary training, and is shipped to Afghanistan or Iraq; 3) redeployment, the phase that the soldier has been sent home from war and recalled to duty; and 4) postdeployment, when the soldier has returned home. Although military wives experience spousal absences on a regular basis, deployment to war is very different. The amount of time away is often unknown, there is a significantly increased danger factor, and in some cases, the spouse's duty station is undisclosed.

With deployment comes role shifts for military spouses. Many duties that have been shared are now the sole responsibility of the warrior's wife. These women often venture into tasks and roles they never thought they would need to learn, including parenting tasks, home maintenance work, employment, and finances, just to name a few (Davidson, 2006). This shift in role participation is often initially a challenge but potentially leads to increased self-efficacy as spouses master new skills and tasks. Upon a soldier's return, the resumption of old roles and routines may become a point of contention between partners. Although long separations are a primary stressor in military marriages, phases of deployment frequently influence occupational and roles engagement. The deployment phase shapes the spouse and her intrinsic self over time, and during postdeployment, return of the partner creates stress, which is even greater when a loved one returns with mMTBI.

Returning Soldiers and Family Issues

To understand the experiences of women whose loved ones return home with mMTBI, it is important to gain an understanding of the experience of soldiers who return home after

deployment. Rosen and associates (1994, 1995) investigated the issues of healthy soldiers returning home after Operation Desert Storm (ODS) in the early 1990s. Their findings included the need for families to resume a routine and communicate fears and expectations as well as for couples to make lifestyle adjustments.

Most of the literature exploring the experiences of veterans after returning from combat situations has focused on veterans who suffer from PTSD or emerged from a long-term study of World War II veterans 40 years after the war. Elder and Clipp (1988, 1989) explored the emotional behaviors of World War II veterans and those affective qualities gained or lost secondary to combat. These researchers described both positive and negative outcomes resulting from combat-related experiences. Specifically, they identified individual resiliency is greater in soldiers who engage in more combat. The greatest benefit, as reported by these veterans, is the maturity gained during war. The most significant disruption, according to the study, is reported as “life disruptions.” Additionally, these researchers hypothesize that, although resiliency is greater in veterans who experience higher amounts of combat, the higher the intensity, the greater the risk of emotional and behavioral problems later in life.

Literature exploring the effects of PTSD on marriages and the influence of the war experiences of veterans, after their return home, has variable conclusions. Calhoon (1984) determined a positive correlation between PTSD and marital distress. In the same study, he explored disruptions in communication between partners and noted the impact this communication barrier has on marital satisfaction. Calhoun et al. (2002) later argue that caregiver burden was greater when symptoms of PTSD were greater.

A phenomenon that has been studied in the past and has been touched on in recent literature is secondary traumatization. This phenomenon, described first by Figley (1983),

involves individuals who are close to a victim experiencing significant emotional trauma that mirrors that of the victim. These individuals become victims of the trauma as well. Secondary traumatization has been noted in spouses and children of Holocaust survivors (Freyberg, 1980), family members of Vietnam veterans (Maloney, 1988), and children of Israeli prisoners of war (POW) (Solomon, 1992). Although some studies have explored secondary traumatization with regard to PTSD, other studies are emerging that explore the phenomenon in spouses of individuals with PCS or mTBI. Azri, Solomon, and Dekel (2000) explored the level of distress and care-giving burden in wives of war veterans who suffered from PTSD and PCS. They found that symptoms of secondary traumatization were evident in the spouses of veterans with PCS, and the associated symptoms increased levels of distress and burden. It would be reasonable to conclude that spousal experiences of trauma, reflecting that of the wounded warrior, will inform the well-being of the spouse.

Subjective Well-Being and Spouses

Well-being may be defined as the overall sense of emotional and physical wellness that is indicative of a lack of distress over current life situations at a given time (Adler & Hillhouse, 1996). Throughout the scholarly literature, well-being has been classified into three primary categories: 1) objective well-being (OWB), 2) SBW, and 3) a combination of the two (Diener & Suh, 2000; Ryff & Keyes, 1995; Veenhoven, 1991). For the purpose of this research, emphasis is placed on how individuals perceive their own well-being, or SWB. Diener and Suh (2000) discussed the underlying principles of SWB:

. . . Because people who cannot attain their values and goals are likely to be less satisfied and happy, it is likely that measures of [SWB], to some degree, represent a

judgment of the culture from an internal perspective, from the viewpoint of the members of that societySWB can represent the degree to which people in each society are accomplishing the values they hold dear. . . . SWB is based on the idea that how each person thinks and feels about his or her life is important. (p. 4)

Scholars in this area agree that SWB includes both the affective and cognitive evaluation of one's self (Diener & Fujita, 1994). The affective component explains how one feels about his or her situation (happy or sad), and the cognitive component refers to how one thinks about various characteristics in his or her life (e.g., roles, marriage, job). It is widely agreed upon that if one is to understand SWB, both the affective and cognitive elements must be explored. Several theoretical constructs have been developed to explain the phenomenon of SWB. These constructs attempt to explain cultural influences (Diener & Diener, 1995), personality traits (Adkins, Martin, & Poon, 1996; DeNeve & Cooper, 1998), and critical life events (Sigrun-Heide & Klauer, 1991). In addition, the literature discusses several potential internal and external issues that may influence SWB. These issues include individualism, finances, social equality and human rights (Diener & Diener, 1995), and culture (Diener & Shu, 2000), to name a few.

Rosen and Moghadam (1991) investigated contributors of well-being in army wives. In this two-phase research study, it was determined that personality traits, supports, general life satisfaction, and stress are primary contributors. Additionally, these researchers determined that knowledge of a spouse's schedule was a contributor to well-being. This study was conducted on spouses of healthy active duty soldiers.

Disability and Disability Culture

An exploration of service member's spousal wellbeing requires an understanding of military culture as well as the culture of disability. Disability and disability culture are included in this literature review to provide context to a critical transition that study participants made—from an able-bodied community to a community of people with disabilities. Furthermore, until society, as a whole, is able to change its perception of people with disabilities, this transition will continue to be a difficult one. The following was noted by Finkelstein (1980):

Once social barriers to the re-integration of people with physical impairments are removed, the disability itself is eliminated. These requirements are for changes to society, material changes to the environment, and changes in attitudes by people in the community as a whole. The focus is decisively shifted on the source of the problem—the society in which disability is created. (p. 33)

Soldiers and their families potentially experience shifts in perceptions of self and priorities after mMTBI. Society in general has little understanding of the cognitive and behavioral consequences of this injury. Frequently, no physical scar is visible that can shed light on the disability, so society as a whole views the wounded warrior as having behavior issues. This lack of understanding lends itself to viewing the wounded warriors as disabled, thus isolating them from social participation.

There are primarily four models of disability that have been widely received by the general public and are based within historical or social perspectives (Badley, 1995): 1) the medical model, 2) the rehabilitation model, 3) the disability model, and 4) the deviance model.

The models to which one subscribes provide a frame of reference to perceive and understand the concept of disability.

“Disability scholars have long argued that what is called physical or mental “disability” is not simply an attribute of a person but a complex collection of conditions, activities, and relationships, many of which are created by the social environment” (Bickenbach, Chatterji, Badley, & Ustun, 1999). This contemporary definition considers context and environment as primary contributors to a disability. Scholars who subscribe to this view have placed an emphasis on the multiple individual and contextual factors that set up barriers to participation.

Before the late 1960s, individuals with disabilities were studied using one of two primary models: the theoretical umbrella of social deviance and the medical model. Social deviance is an area of study concerned with individuals who do not fall within the norm of social behavior (Freidson, 1995). They may include individuals who present with disabilities, social outcasts, criminals, or delinquents. Similarly, until about 20 years ago, deviant behavior was thought to be under the control of the individual, and research in this area focused on the individual as opposed to social and contextual contributing factors. In the case of soldiers with mMTBI, the social deviant model would define them as outcasts or “lazy warriors” who put themselves before the unit.

The medical model views disability as a consequence of the individual. This model places an emphasis on the underlying changes in body structure leading to impairment(s) of the person as the cause of disability, and little, if any, consideration is given to the environment in which the individual participates. The medical model would view the warrior with mMTBI as not healthy enough to do his or her job or participate. Despite the fact that the two constructs are based within different disciplines (anthropology or social science and medicine), both frames of

reference present a narrow view of disabilities, a view that casts the survivor away from familiar social structures. The studies exploring the experiences of women whose spouses returned from war with injury and illness often viewed disability through the lens of one of these two constructs.

As these soldiers returned from war, scholars began to look at contributing societal factors when studying deviant behavior. Theorists began to explore the interplay between contextual, social, cultural, and environmental factors and their contribution to behaviors outside the norm of society (Fougeyrollas, 1997). Today, it seems ludicrous for the contemporary rehabilitation specialist to view individuals with disabilities in the same way as criminals (unless the researcher hypothesizes that criminal behavior is secondary to an underlying disability), but that is what is happening with warriors with mMTBI. Their invisible wounds are often missed, and their behavior and conduct are being labeled as criminal.

Contemporary views of disability are considered within a social or social-political perspective (Oliver, 1990), the interactive model (Lemert, 1962), the environmental approach to disabilities (Amundson, 1992), and the International Classification of Functioning, Disability, and Health (2002). Each of these disability models, although having its own characteristics, assert that disability is not strictly a health issue based on an individual's impairment or medical condition (Bickenbach et al., 1999), but "far more important is the salient role played by features of the world built and designed by people in the creation of the disadvantages that people with disabilities experience" (p. 1173).

This shift, from the focus on the individual as being the cause of disablement (an individual model) to the interaction between the individual and the environment fostering disablement (interactive model), precipitated discussions, provided a climate for legislation, and

sparked political actions that have attempted to topple the environmental barriers contributing to disability (Fougeyrollas et al., 1998). This contemporary model is one that is most widely adopted and currently accepted in today's American culture. It is the cornerstone to how individuals in the United States potentially view disability and the wounded warriors who return with amputations, spinal cord injury, and other severe physical disabilities. However, it has not been applied to invisible injuries such as mMTBI, PTSD, or depression.

Since the mid 20th century, the definitions and the understanding of disability have significantly changed. What were once afflictions kept behind closed doors have become a subculture of America that is highly networked, empowered, and visible. The families of the soldiers who have chronic disabilities secondary to their combat injuries are launched into this culture at the same time they are attempting to negotiate the civilian world. The culture of disability in the United States is based on self-advocacy, support networks, resources, insurance company policy, and constant education. It is also based on the social understanding of disability associated with varying diagnoses. Women whose loved ones have returned with mMTBI may become immersed in disability culture in the United States. This transition from able bodied to disabled is both a difficult and potentially empowering transition.

Experiences of Families

The last area of the literature of relevance to the current study is the experiences of families whose loved ones have sustained a disability. Literature examining the family reaction to an acquired disability is critical to understanding the identified research questions. Although the literature does not examine military families, researchers have investigated the impact of disabilities on families in both the short and long term. Families who have members with an acquired disability may go through significant changes in their daily lives as evident in the

research completed by Hall et al. (1994). These researchers determined that individuals who had a family member with a sustained head injury complain of their personal lack of leisure involvement, fatigue, and forgetfulness. They describe, anger, and self-centeredness on the part of the survivor. Despite these complaints, there is no indication of increased stress over time. Similarly, Montgomery et al. (2002) discussed that brain injury in children affects the family dynamics in a negative way, gives rise to changes in sibling behavior, presents a significant financial burden on the family, and affects family integrity. Wood and colleagues (2005) reported similar findings in families with spouses with TBI. Other studies on such families also found changes in child relationships, the adoption of new roles and responsibilities, feelings of being tied down, and loneliness (Thomsen, 1992; Wedcliffe & Ross, 2001).

Padrone (1994) determined that psychotherapy for family members of individuals with acquired physical disabilities can assist with grief adjustment and developing a balance in life as well as determined that grief is necessary to better cope with the inevitable changes. Other methods of coping that have proved successful in the literature include the use of family and friends as well as religious groups as primary points of support (Wedcliffe & Ross, 2001).

It is not yet understood how military families react to their loved ones who have sustained a disability secondary to war or if their experiences are different than those discussed previously. It is important, however, to gain insights into their experiences to ensure that programs developed to target this group are meeting their needs and are based on a strong theoretical framework.

Literature Gap

The literature explores some of the effects of deployment and return from combat on family members. Scholarly work during the past 40 years has also attempted to explain the

impact of TBI and acquired disability on the family. It does not, however, explore how the sequelae of mild to moderate brain injury sustained in war affects spousal well-being. This grounded theory study is designed to delve into the experiences of spouses of wounded warrior who have returned from OIF/OEF with brain injuries. The current literature gap has offered an opportunity to gain insights into spousal SBW and explore how constructs of well-being affect the daily lives of these heroes on the home front.

Chapter 3: Methods

Overview

As previously discussed, the purpose of this research is to explore and generate theory designed to help better understand the lived experiences and multiple contributing factors that influence the subjective well-being (SWB) of spouses of recently disabled soldiers. Specifically, this grounded theory research will explore the experiences of women whose loved ones have returned from Operation Iraqi Freedom/Operation Enduring Freedom (OIF/OEF) with mild to moderate traumatic brain injury (mMTBI). This chapter focuses on methods of inquiry. An explanation of the research design, participant selection, instrumentation, data collection procedures, data analysis, ethical considerations, trustworthiness, and potential limitations is provided.

Restatement of Research Questions

The research questions, also outlined in Chapter 1, follow. In a sample of female spouses of recently brain-injured soldiers:

1. What factors do these women offer to explain their own well-being?
2. How do these women describe the influence of these identified factors on their well-being?

Qualitative Design

“Qualitative research is multi-method in focus, involving and interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings

people bring to them. Qualitative research involves the study's use and collection of empirical materials . . . that describe routine and problematic moments and meanings in individual's lives" (Denzin & Lincoln, 1994, p. 2).

There are four reasons why this research lends itself to qualitative design. First, little to no scholarly literature exists exploring the proposed topic or individual research questions. Second, despite the numerous initiatives being developed to assist military families of soldiers with brain injury, these programs lack a theoretical base. Third, the experiences of study participants are individual and subject to personal interpretation. Each participant will provide her own unique story; qualitative methodology embraces these differences. Fourth, this study is suited for qualitative design because of its exploratory nature as is evident in the identified research questions.

Naturalistic inquiry, through the use of inductive methods of investigation and analysis, is designed to understand the nature and/or essence of a phenomenon (Merriam, 1988), thus providing the flexible canvas necessary to gain insights into the lives of study participants.

Grounded Theory Methodology

In an attempt to construct an understanding of study participants' experiences, I must accept, understand, and embrace the multiple realities and experiences these women share. Because qualitative research has been chosen for this study, a grounded theory is the methodology of choice. Consistent with the purpose of my study, grounded theory leads to the understanding of concepts and construction of theory (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1990). During the development of the research questions, data collection methods, and analysis, this research was rooted in an epistemology targeting an exploration of situational constructs and their relationships and dependencies. The specific grounded theory

methods used throughout the study design are consistent with Charmaz's (2006) contemporary and constructivist view of grounded theory research. Although this is the primary method I have adopted for this research, note that during my analysis, have included a more traditional method outlined by Strauss and Corbin (1990) and Glaser (1978). Glaser is a positivist and understands qualitative data in almost quantitative terms. Charmaz is a constructivist, and her methods for theoretical coding lend themselves to multiple truths. I have leaned toward Charmaz's methods, although I have adopted Strauss and Corbin for initial coding and Glaser's families to help frame my analysis during the theoretical coding phase.

Grounded theory adopts and embraces multiple data sources to construct a conceptual understanding of what the lives of the participants are like. Charmaz (2006) states, "grounded theory methods are consist of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories 'grounded' in the data themselves. The guidelines offer a set of general principles and heuristic devices rather than formulaic rules. Thus data form the foundation of our theory and our analysis of these data generates the concepts we construct" (p. 2). Adoption of grounded theory weaves concepts and ideas that have emerged through thoughtful and rigorous analysis.

Consistent with a grounded theory approach, multiple and unique data collection techniques are used. These include in-depth interviews, use of Facebook postings, and participants blogs.

Data analysis of the initial interviews gave rise to participant selection and questions used in subsequent interviews. Additionally, it is important to reiterate that the literature review (outlined in Chapter 2) is iterative. Throughout the analysis of my data, I returned to the literature to inform my conclusions.

Role of the Researcher

My role for this study included research and study development, interviewing, data collection, and analysis. In addition to these duties, one of the researcher's primary roles was interview question development. Subsequent interview questions reflected categories and themes that had emerged from analysis of previously collected data.

I also identified interview prompts that were used to assist participants in discussing details and/or exploring their experiences on a deeper level than may have been initially offered. Unlike quantitative research, where the instrument is the research tool, in grounded theory, the researcher becomes the primary instrument for inquiry (Charmaz, 2006).

For this study, I was the sole interviewer, data collector, and interpreter of data. As previously mentioned, I designed interview questions, scheduled interviews, and followed up. Questions developed for the second interview were based on findings of the first. According to Charmaz (2006), "when adopting the grounded theory approach, the researcher continually shapes and reshapes data and collection methods . . . a keen eye, open mind, discerning ear, and steady hand can bring you close to what you study" (p. 15).

Charmaz (2006) discussed the fact that "grounded theorists' background assumptions and disciplinary perspectives alert them to look for certain possibilities and processes in their data. These assumptions and perspectives often differ among disciplines but nonetheless shape research topics and conceptual emphasis" (p. 16).

My background includes 17 years as an occupational therapist, 10 years as an educator, as well as graduate work in infant and child mental health, human development, adult learning, and human resource development. Additionally, I have extensive professional experience working with individuals with brain injury and their families in military and civilian facilities.

According to Patton (2002), the individual conducting fieldwork must be well trained in the specific strategy for data collection in order to be credible, which in the case of the proposed study includes interviewing, observation, and conversation. My roles as an educator, clinician, and researcher have given me experience in qualitative research design and data analysis. In addition, as an occupational therapist, I have extensive experience in interviewing, observation, and analysis of data. As the researcher, I was aware of my strengths and limitations. I sought assistance in areas in which I did not feel confident.

Theoretical Sensitivity

“Theoretical sensitivity refers to the attribute of having insight, the ability to give meaning to data, the capacity to understand, and the capacity to separate the pertinent from that which isn’t” (Strauss & Corbin, 1990, p. 42). This phenomenon is an essential element in grounded theory research. My experiences and core beliefs have shaped my understanding of the artifacts collected over the course of the study and have influenced my choice of methodology.

In studying people’s lives, I strongly believe there are multiple truths. This constructivist view of the world, and my affinity to the celebration of individualism, has led me to not only grounded theory but Charmaz’s philosophy of this methodology. In addition, I have a personal interest in individuals and how people tell their personal story. The value I place in the power of story-telling leads me to qualitative methods, and the importance I place on the need for theoretical constructs to be the cornerstone for programmatic design has led me to grounded theory. Strauss and Corbin (1990) stressed that it is only through theoretical sensitivity that the researcher is able to “develop theory that is grounded, conceptually dense, and well integrated” (p. 42). My theoretical sensitivities have facilitated grounded, conceptually dense, and integrated

theory. A further discussion of my personal background and assumptions are provided in Appendix A).

Participants

The following section explains the process of study participant selection, their role, screening methods, sample size, and criteria for study inclusion. Because of the nature of grounded theory research, “sampling methods are often a fluid and dynamic process” (Charmaz, 2006, p. 104). Some of the participant selection criteria were dependent on categories and themes that emerged through rigorous analysis of initial sampling and data.

Recruitment

Initially, research participants were recruited through three possible channels. First, a posting was placed on The Bob Woodruff Family Fund for TBI website. This foundation, designed to assist nonprofit organizations servicing members of the armed forces who have sustained a head injury, provided verbal assurance that a recruitment posting was welcome. Second, individual families who were involved in the Wounded Warrior Project (WWP) were contacted for possible participation. Third, fliers explaining the study were posted in the Fisher House in Silver Spring, Maryland, a temporary residence for family members of soldiers who were admitted to Walter Reed Army Medical Center. I also broadened my recruitment plan by placing a post on postings on Facebook group sites that provided support for spouses of wounded service members.

The following specific step-by-step procedures explain how participants were recruited for the initial interview:

1. Each recruitment site was contacted and sent information (U.S. postal service or email delivery) for recruitment (Appendix B). The sites were invited to contact me directly with any questions.
2. Personnel at each site solicited interested participants by providing information about the research study (this was done by website postings, flier, or word of mouth). Participants could then contact me for further details.
3. Potential participants were given more details about the study and asked to complete an informed consent (by mail or email) (Appendix C).
4. Once potentially interested participants had their questions answered, and they indicated that they might be interested in participation, they were contacted by phone and screened to determine eligibility. A telephone questionnaire was administered to gain demographic information: age, number of children, years married before deployment, and date and nature of spouse's injury (Appendix D).
5. Participants were selected based on criteria identified and notified about selection by phone or mail within 5 working days of screening.
6. Once informed consent was completed and participants met the inclusion criteria, a follow-up phone call was made to schedule the first interview.

Sampling

The emergent nature of sampling methods, consistent with grounded theory research, lends itself to two types of sampling: initial and theoretical (Charmaz, 2006). This research outlines initial sampling in detail and provides a general description of the theoretical sampling techniques that were used for participant selection for interviews. Study participants were chosen with the intent of gaining a rich understanding of their experience. In order to do this,

participants represented an array of personal characteristics. This variability reflected the research questions, emergent ideas from the initial literature review, and relevance to the research design and study purpose.

Initial Sampling

This study began with initial sampling methods, frequently adopted with grounded theory research (Charmaz, 2006). Targets of 20 research participants were identified, although this was modified due to saturation. The number of participants varied after the first interview as analysis of data helped define the trajectory of follow-up participants' characteristics and data sources.

Initial Sample Criteria

Study participants who were invited to engage in the first interview phase of the study resided across the United States and one participant lived in Japan. Although participants who participated in the initial sample shared similar inclusion criteria (Table 3.1), variability in demographics was achieved. These differences included the length of time since injury, number and ages of children, years in the military, years married, and participant age (this variability was evident from the questionnaire completed before signing on to the study).

Table 3.1

Selection Criteria and Rationale for Initial Sampling

Criteria	Rationale for Criteria
Married at least 1 year before deployment to OIF/OEF	Significant changes occur in marriages during the first year. Studies use this criteria to ensure transition to marriage does not influence participant response (Dekel & Solomon, 2006)
Have a spouse who has sustained a mild to moderate brain injury while deployed to OIF/OEF in the past 8 years	The study specifically looks at subjective well-being of spouses whose loved ones have sustained a mild to moderate traumatic brain injury
Have a spouse who had been discharged from an inpatient rehabilitation facility and returned home at least 3 months prior the first interview	Study participants must have been living with their spouses for 3 months in order to begin their new roles and normalcy
Participants must be willing to share their experiences over the course of sequential interviews	Although not all participants were asked to complete both interviews, follow-up with all participants was necessary member checking during the theoretical sampling phase of the research
Participants must agree to be digitally recorded	Interviews were recorded for the purpose of transcription—this ensured that all comments and conversation were captured

Theoretical Sampling

The first round of interviews used initial sampling procedures. Subsequent interviews adopted theoretical sampling methods and occurred after the analysis of the initial data. Themes that emerged from analysis of completed interviews became the basis of theoretical sampling for

the follow-up interviews. The practice of using emerging constructs to guide sampling, is referred to as theoretical sampling (Charmaz, 2006). “This process ultimately ensured construction of full and robust categories and leads to clarification of the relationships between the identified categories” (p. 103).

In addition to using identified themes and categories as the basis of follow-up interviews, an iterative literature review provided further information for subsequent participant criteria. The sample size in follow-up interviews was determined by saturation, the time when key themes and experiences repeated themselves from participant to participant (Creswell, 1998).

Procedure/Data Collection

The primary data source used to inform this study was sequential interviews. Table 3.2 illustrates the data source, expected participants, objectives for the data collection method, and follow up work that was completed.

Interviews

A series of three in-depth interviews were the primary data source for this study. The sequential interview process was conducted between January 15, 2008, and February 12, 2010. All interviews were conducted by phone. A sequential interview protocol (Kvale, 1996) was adopted that outlines the need for initial contact, follow-up on specifics, and a third follow-up that includes clarification and termination.⁷ Each of these 45- to 60-minute interviews was semi-structured in nature, and questions reflected the primary themes of the research at each phase (Table 3.2).

⁷For the purpose of this study, the third interview was member checking.

Table 3.2.
Data Collection Methods

Data source	Expected Number of Participants	Objectives	Follow-Up Work
First interview	Approximately 15	General information about experience and understanding of contributors to subjective well-being	Transcribe, analyze, explore theoretical literature, generate questions for interview 2
Second interview	Approximately 6	Member checking, more detailed information based on themes presented in interview 1	Transcribe, analyze

Interview Questions

A semistructured interview was used to gain insight into the experiences and understanding of participants. The interview was chosen as the primary data source for this study because it provided detailed and rich information as understood from the women whose wellbeing was explored (Charmaz, 2006). The semistructured interview was formatted to facilitate a two-way communication process. For this research, key questions were identified and, based on responses; follow-up questions facilitated in-depth and reflective sharing by the interviewee. The role of the participants was to articulate their circumstances, as they understand them, have lived them, and experienced them. It was their job to think deeply about their situations and share their beliefs honestly and candidly. Although the initial interview questions, outlined below, were preplanned, as is the case in semistructured interviews, follow-up questions varied in content and emphasis. Variability was based on the specifics shared by individual

participants. Box 3.1 outlines questions for the first interview and potential probes. The protocol for interview one (Appendix E) was used.

Box 3.1

Interview One Questions

1. Tell me your story.
 2. How would you define well-being?
 3. Can you discuss how the brain injury your loved one sustained during his deployment influences your well-being?
 4. Share with me how you believe _____ (name of spouse) brain injury may influence your daily life; changed how you live day to day.
 5. You have gone through a number of changes since his injury. I would like you to share a bit about your experiences with change.
 6. Can you discuss how your experiences may vary given the time of year?
-

As discussed previously, the questions and format for interview two were based on the analysis of the transcripts of the first interview and a follow-up of the theoretical literature. Box 3.2 outlines questions for the follow-up interview. The protocol for this follow-up interview is given in Appendix F.

Box 3.2

Interview Two Questions

1. Can you discuss your wellbeing over the last six months?
2. Can you share with me if you feel as though your identity has changed since your loved one's injury?
3. How, if at all, has identity contributed to or taken away from your personal well-being?
4. Can you share with me your thoughts and experiences with this idea of control as being a contributor to your well-being. (Probe for some of the following: control over information, environment, and health care.)
5. Can you share with me how the supports informed your sense of well-being? (Probe for military, friends, family, and organizations.)

Although the primary objective of the follow-up interview was to gain a deeper understanding of participant experiences and understanding of constructs to well-being, a third discussion was used as a method of member checking.

Interview Data Management

Interview data completed by phone were digitally recorded through the use of Skype and Audacity. Recorded material was stored on a password-protected file. The only individuals with access to the audio files included the transcription service hired for the project and myself. All interview recordings were uploaded into a password-protected audio file. I was the only person with access to the protected files. Audio files were transcribed into a Microsoft Word file by an outside transcription service and myself. Therefore, the only other individuals with access to the audio file and transcripts were the transcription service and members of the dissertation committee. The transcription service used was required to provide a confidentiality statement before being awarded the contract.

Data Analysis

Data analysis reflects methods consistent with grounded theory research as outlined by Strauss and Corbin (1990). As previously discussed, the methods introduced by Charmaz (2006) have been the basis for the methodology applied; Strauss and Corbin's more traditional methods of analysis have been adopted because they provide increased structure to the process.

Analysis began at the time of the initial interview and continued beyond the data collection process. Coding, the heart of analysis in grounded theory research, eventually "allow[s] us to visit and revisit our participant's lives. It is through coding we try to understand participant's views and actions from their perspectives. Through systematic digging we attempt to interpret their tacit meaning" (Charmaz, 2006, p. 47). Coding

procedures utilized throughout this study were multiphasic and iterative. Additionally, the methods of analysis were continual and rigorous, with ongoing comparative methods being used throughout the process to make sense of those data. The phases of coding included open coding, axial coding, selective coding, and theoretical coding (Figure 3.1). Each had a critical role in understanding the nature of the phenomenon, and each occurred multiple times throughout the analytic process. It was understood, throughout the process of analysis, that data analysis was not a linear process but dynamic and continuous. Although these stages of coding are explained individually, it is important to be aware that each phase overlapped the last and that the margins between them were not always clear.

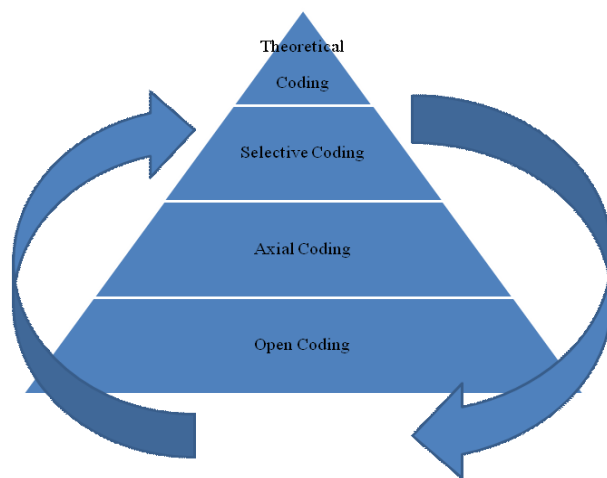


Figure 3.1. Iterative coding process.

Open Coding

Open coding refers to the process of identifying concepts and placing labels on the happenings in data (Strauss and Corbin, 1990). These concepts go on to become more detailed as the researcher brings them together into categories. This inductive and deductive process

typically is completed in four steps: “labeling the data or a labeling phenomenon, discovering categories, naming the categories, and developing them” (Strauss and Corbin, 1990, p. 63).

Open coding was used for data analysis. This process was completed through detailed examination of the phrases and words participants used throughout the interview process. Labels were placed in the margins, and code notes were used. These labels were used for category identification and naming. Code notes and memos were completed in a notebook and translated into a customized excel software to assist in the management of data for this study.

In addition to line-by-line coding of transcripts, notes taken during the interview process were revisited and used to identify key ideas and potential categories. These notes were also used to help determine possible follow-up questions.

As discussed previously, the research included two 45- to 60-minute interviews. The first phase of analysis led to the identification of categories and themes. The identified categories were confirmed or disconfirmed on subsequent interviews and elaborated on during subsequent interviews. A similar, but abbreviated, open-coding process occurred during the analysis of the second interview.

Axial Coding

Once a coding system is established, axial coding is used to identify subcategories and build relationships among concepts (Strauss & Corbin, 1990). Axial coding utilizes “a coding paradigm involving conditions, context, action/interactional strategies and consequences” (p. 96). The objective of this data analysis phase is to “reconstruct all that you have dismantled in the open coding phase” (Strauss & Corbin, 1990, p. 96). A developed paradigm model provides the guideline from which to identify and build connections. This process brings forward a matrix of concepts, categories, and subcategories that ultimately helped develop theory. Given the

nature of this study and the constant iterative nature of coding, axial coding often occurred at the same time as or before open coding. For this research, categories, subcategories, and memos were managed in Excel.

Selective Coding

The third phase of coding, according to Strauss and Corbin (1990), is selective coding, which is considered the first phase for theory development. Axial coding allowed me to develop a strong foundation from which a higher order of classification and integration occurred. The process of selective coding was not linear. This phase of coding embraced a constant reciprocal interaction among categories, subcategories, emerging ideas, and connections for the purpose of telling a story. The steps for selective coding, according to Strauss and Corbin (1990), are “develop a story line, relate sub categories to the core category by way of the paradigm, relate categories on the dimensional level, validate the relationships against data, and fill in the categories” (p. 118). These steps were reflected throughout my selective coding process.

Theoretical Coding

According to Strauss and Corbin (1990), once the story has been established and a strong relationship between the core category and subcategories has been identified, theoretical coding is used. To complete the coding process for this research, I adopted Glaser’s (1978) and Charmaz’s (2006) steps of theoretical coding. I leaned toward Charmaz’s methods, although I adopted Glaser’s “families” to help frame my analysis. Charmaz (2006) discusses theoretical coding as “conceptualizing how the substantive codes may relate to each other as hypothesis to be integrated into a theory” (p. 72).

Theoretical coding builds on the work completed and adds another analytical dimension to the process. It turned the story developed from analysis of participant’s experiences into

theory. To accomplish theoretical coding for this research, a coding list, similar to the one introduced by Glaser (1978, 1998), was used as a reference.⁸ Charmaz (2006) advocates for theoretical playfulness, stating that this playfulness allows for trying out ideas and seeing “where they lead” (p. 70). In this research, this advice was taken during all phases of coding—from category identification to theory development.

The multistep coding process adopted for the analysis of this research data incorporated themes identified in the initial literature review, findings from theoretical literature (discussed in Chapter 5), and the research questions asked in this study. In addition, theoretical sensitivities were considered throughout the coding process.

Qualitative Software

Although the initial phase of analysis was completed by hand, a custom Excel program was developed to store and organize information. This program included links to documents, ideas and comments about documents and document text, as well as labels. It assisted in the management and organization of significant amounts of qualitative data and also in finding patterns, themes, and relationships that may have otherwise been missed.

Ethical Considerations

Kvale (1996) discussed several ethical questions that must be considered before implementing a study utilizing interviews. These questions have been identified and answered in an attempt to better explain the ethical considerations of this inquiry process. The questions

⁸Some of the families discussed by Glaser (1998) included the six C's (causes, context, contingencies, consequences, covariances, and conditions), process, degree, dimension, strategy, interactive, identify self, cutting point, means-goal, cultural, consensus, mainline, theoretical, elaboration, unit, models, basics, paired opposite, representation, scale, structural functional, boundary, unit identity, and average. Although these families were identified in this research to help build a theoretical understanding of contributors to well-being, many will not apply to the data collected and other families may emerge.

outlined by Kvale include information about the benefit of the study, methods of informed consent, confidentiality, potential harm to study participants, and the researcher's potential influences on findings. Each of these ethical considerations has been deliberated and are reflected throughout my methodology.

Protection of Confidentiality

“Confidentiality implies that private data identifying the subjects will not be reported” (Kvale, 1998, p. 114). To maintain confidentiality of all study participants, pseudonyms were given and identifying features that were important to the specific interview were changed. All transcripts and materials were stored in a locked cabinet. Digital audio recordings, Word files, and Excel databases were stored in a password-protected file(s). The only individuals who had access to these transcripts were myself, and the transcription service hired for this project.

Informed Consent

All potential participants were provided with informed consent forms that were approved by the Virginia Tech Institutional Review Board (Appendix G). After they were provided with a written and verbal description of the study, the study's rationale, confidentiality measures, potential risks, and procedures, participants were asked to sign an agreement of understanding and participation. In addition, participants were informed that they may remove themselves from the study at any point during the data collection phase or the interpretation phase.

Potential Consequences to Study Participants

In discussing the power of the interview process, Patton (2002) explains the potential consequences or harm that may occur to the study participants. He states, “Because qualitative methods are highly personal and interpersonal, because naturalistic inquiry takes the researcher into the real world where people live and work, and because in-depth interviewing opens up what

is inside people, qualitative inquiry may be more intrusive and involve greater reactivity than surveys, tests, and other quantitative approaches” (p. 405). Interviews provide individuals with an opportunity to explore and reflect on circumstances they had not considered previously, but these circumstances may open up emotional wounds and insights into experiences that may be considered emotionally painful. These potential consequences are often unforeseen but should not be unexpected by the interviewer or the interviewee (Patton, 2002). These risks were discussed with study participants before they agreed to sign onto the study.

Researchers are obligated by law to report any evidence of abuse or neglect. Therefore, information that is shared by the interviewee, although under the premise of confidentiality, if illegal, must be reported to the proper authorities.

Given the potential sensitivity of the subject, research participants may be uncomfortable with the questions, especially those that delve into areas of their personal well-being and how recent transitions may contribute to their current state. Participants were informed that they could refuse to answer any questions without penalty and withdraw from the study at any time.

Ensuring Trustworthiness

A limited number of data collection methods and a small number of participants often place findings under scrutiny. To enhance the validity of the research, I adopted a sequential interview process. Credibility and quality of the research were essential to the findings. Triangulation was adopted to ensure the credibility of this qualitative study.

Triangulation of sources provided a way to verify the interpretation of meaning. Methods of triangulation included the use of follow-up interviews and phone correspondence for member checking as well as triangulation by potential study participants who were not interviewed because they did not meet study criteria. Triangulation of data was also completed with subject

matter experts. The latter included program leaders, case workers, and therapists who were currently working with families of veterans with mMTBI. In addition, coding was reviewed and discussed by qualitative research experts. These verification methods provided clarity and validity to the interpretation of findings.

Summary

This chapter has discussed, in detail, the research methods used to gain insight into the understanding of SWB of women who are undergoing life changes as a result of their spouse's brain injury sustained in combat. In an effort to understand the components that contributed to the well-being of the partners of service members with recent head injuries, I adopted data collection and analysis methods that were consistent with both qualitative research and the strategy of grounded theory. Lengthy sequential interviews were used as the primary source of data. Transcripts were initially examined through a line-by-line coding process of open coding. As categories emerged, axial coding, sequential coding, and theoretical coding procedures were used to define a theory of military spousal well-being. Data were managed in a custom Excel program. Issues around trustworthiness were addressed through the use of member checks, reading online postings of similar groups of women, and use of subject matter experts.

Chapter 4: Findings

I saw him and I hadn't seen him since he'd been wounded or since he left in May so I was crying, I was like oh, I'm so happy to see you. And he kind of hugged me and it was a little stiff and he kind of patted my back he goes, "All right, that's enough, that's enough." He never would have done that, he would have been – held me, he would have been like it's okay, I miss you, I love you. . . he was very different. He was very, very different. It turned out, he was not the man I married anymore. (Jill)

Spouses of survivors of combat related mild to moderate traumatic brain injury (mMTBI) survivors, discussed reconstruction of self (RoS) as the epicenter of their experiences with well-being. Factors such as the relationships that participant's developed with supports, their adoption of new roles and routines, and perceptions of personal empowerment contribute to their well-being.

Theory developed from this research has been coined the Combat related TBI spousal (CoRTs) model of well-being. The theory describes how well-being was influenced by the phenomenon of RoS and supporting constructs. CoRTs model found its roots in the stories of 18 women whose husbands returned from Iraq or Afghanistan with a mild to moderate traumatic brain injury. These participants reflected a mosaic of military and civilian wives who, despite their differences across age, race, education, and location, shared the experience of having their loved one return from war very different from when he left.

This chapter will discuss the findings of my research. Specifically, I will reiterate the purpose of this research (as discussed in chapter one), discuss and define states of well-being

experienced by participants, and introduce you to the women who joined me in my study. The CoRTs model will be presented along with the related grounded theory statement. In addition, this chapter will present an in depth discussion of the core factors influencing this theory as well as those themes that emerged.

Purpose Statement

The purpose of this grounded theory research has been to develop theory designed to understand contributors to spousal well-being of OIF/OEF mMTBI survivors. I believe recognition of how contributors influenced experiences of well-being will provide a foundation for future program development and service initiatives necessary to assist partners of our wounded warriors and their families.

States of Well-Being

Throughout this study, participants discussed the fluctuating nature of their personal well-being. The stories they shared illustrated a journey filled with highs and lows. For the purpose of this study, well-being is defined as a perceived state of physical, emotional, and spiritual health, which allowed an individual to engage in self-selected meaningful, productive, and goal oriented activities that brought happiness to their lives.

I categorized participants, on the basis of their stories, by state of their well-being based on their stories; low, emerging or high. The state of each woman's well-being reflected their highest level experienced around the time of the interview(s). For example, Leigh presented with low well-being during our first interview. Six months later, during the follow-up conversation, her experiences were consistent with an emerging state of well-being. Leigh is therefore discussed as a participant whose state of well-being was emerging. On the other hand, Ingrid demonstrated emerging well-being during our first interview. During her follow-up interview, six months later, it

was apparent her well-being was low. This participant was placed in the group with emerging well-being since her level of well-being was based on her highest level presented. Each of the three states of well-being reflected the varied experiences of participants.

Low well-being had been defined as an inability to engage in self selected meaningful, productive, and goal oriented activities that bring happiness to life because of life circumstances and/or health (physical, emotional, and/or spiritual health). Participants who experienced low well-being, consistently ran into external barriers that prevented opportunities to engage in roles and activities of choice. The three women, who shared a state of low well-being, Betsy, Emily, and Quince, could not begin to engage in the journey of RoS. Each consistently experienced feelings of detachment from friends, family, and their life, as they had known it. These women expressed feeling of disempowerment and felt they had little control over what had happened to their loved one, what was happening to themselves, and powerless over their future and the future of their families.

Emerging well-being is defined as the ability to begin to engage in self selected meaningful, productive, and goal oriented activities that bring happiness to life because of life circumstances and/or health (physical, emotional, and/or spiritual health). Half of the women (9 out of 18) who shared their stories experienced emerging states of well-being. Ann, Carl, Gina, Helen, Ingrid, Jill, Leigh, Nancy, and Penny, shared how they established relationships with supports. They discussed how these relationships facilitated engagement in choice roles by offering respite and encouragement. The primary challenge they reported was being able to maintain their relationships with supports and establish routines that met their needs and the needs of their loved ones. This challenge often was met, although inconsistently, and participants with emerging well-being began to engage in roles and activities of choice. They

attempted to balance choice and circumstantial roles throughout the RoS process. Participants with emerging reported their experiences provided opportunities and courage to initiate and maintain their journeys with RoS.

High well-being is defined as the consistent opportunity to engage in self selected meaningful, productive, roles and goal oriented activities that bring happiness to life because of life circumstances and/or health (physical, emotional, and/or spiritual health). Six participants, Dede, Fran, Kim, Missy, Olivia, and Reese shared high levels of well-being. These women were either in the process of redefining, or had already redefined who they were by adopting new roles of choice, established relationships with supports, and participated in activities that were both meaningful and productive. Collectively, these experiences gave new meaning to their situation. These women all engaged in choice roles, balancing these with roles that were circumstantial. These participants shared how they had opportunities to identify and at times reach their own personal goals. Participants who had a high level of well-being felt a sense of personal empowerment and embraced their journey with RoS as a contributor to those perceptions of empowerment. Their ongoing and successful reconstruction self had become essential to their current state of high personal well-being.

The experiences shared by participants, despite their state of well-being was shaped by a confluence of constructs that will be discussed in my statement of grounded theory. In order to understand the factors that shape spousal well-being, it is important to appreciate the interrelationships between the identified constructs.

Participants

The 18 participants reflected a spectrum of backgrounds, ages, and life experiences. Table 4.1 outlines demographic data collected on participants. The names of participants have been

changed for confidentiality reasons and the first letter of their pseudonym corresponds with the participant number given at the time of consent. In a similar vein, each participant's spouse has also been provided with a pseudonym, which has a corresponding first letter. The information provided in Table 4.1 was obtained during my initial phone contact (less their state of well-being). Information was recorded on an intake form (Appendix A). Participant's level of well-being was assigned following a review of the interview transcript analysis.

Table 4.1

Demographics of Participants

Participant	State or Country of Residence	Time Since Spouse's Injury	Highest Level of Education	State of Well-Being
Betsy	TX	7 months	Bachelor's degree	Low
Emily	VA	2 years	Bachelor's degree	Low
Quince	CA	7 years	Bachelor's degree	Low
Ann	MN	4 years	High school + 1 year	Emerging
Carol	WA	3 years	High school +	Emerging
Gina	MA	2 years	High school	Emerging
Helen	NY	3 years	10th grade	Emerging
Ingrid	VA	1.5 years	High school	Emerging
Jill	NH	2 years	High school	Emerging
Leigh	NY	1.5 years	High school	Emerging
Nancy	VA	5 years	High school +	Emerging
Penny	NC	2 years	Bachelor's degree	Emerging
DeDe	VA/NC	2 years	Bachelor's degree	High
Fran	Japan	≤1 year	High school +	High
Kim	VA	6 years	Bachelor's degree	High
Missy	DC	3 years 6 months	Bachelor's degree	High
Olivia	NC	1 year 6 months	Bachelor's degree	High
Reese	VA	5 years	High school	High

In summary, all participants but one had children, ranging from babies to adult children, and four were pregnant at the time of an interview. The level of education of participants ranged from completion of tenth grade to a college degree with the majority of participants graduating from high school with some college courses. Participants lived throughout the United States including California, Texas, Washington, Virginia, the District of Columbia, North Carolina, New York, New Hampshire, and Minnesota. One participant was living in Japan on an Air Force Base. The state of well-being of participants varied with three experiencing low states of well-being, nine emerging states, and six experiencing high states of well-being.

Statement of Grounded Theory

Spouses of survivors of OIF/OEF with mMTBI described how their partner's injury led to a dramatic shift in the areas of personal participation, role engagement, routines, and relationships. The active and conscious process of negotiating this shift is called reconstruction of self (RoS), and this phenomenon has emerged as the epicenter to well-being of study participants. The CoRTs Model of Well-Being (Figure 4.1) illustrates the dynamic relationships among subjective well-being, RoS, and contributing factors as discussed by study participants. Conditions and context provided the canvas from which experiences with RoS took shape. core condition; the level of independence of the mMTBI survivor, affected the participant's experience in that the assistance he needed created a level of burden for the participant. Similarly, the context of their experiences; the communities of influence either provided opportunities to build bridges or erected walls from which participants could experience RoS. Successful and meaningful engagement in roles and routines, or lack there of, shaped experiences with RoS. Positive experiences with this phenomenon fostered perceptions of personal empowerment, which reinforced both RoS and contributed to high levels of well-being.

Participant's inability to forge relationships with a support network created patterns and routines that reflected circumstantial roles and prevented opportunities to develop choice roles, a necessary step for RoS. For women who were unable to begin the process of RoS, feeling of disempowerment gave way to low states of well-being. Regardless of the level of well-being, experiences with RoS became central to participant's state of well-being.

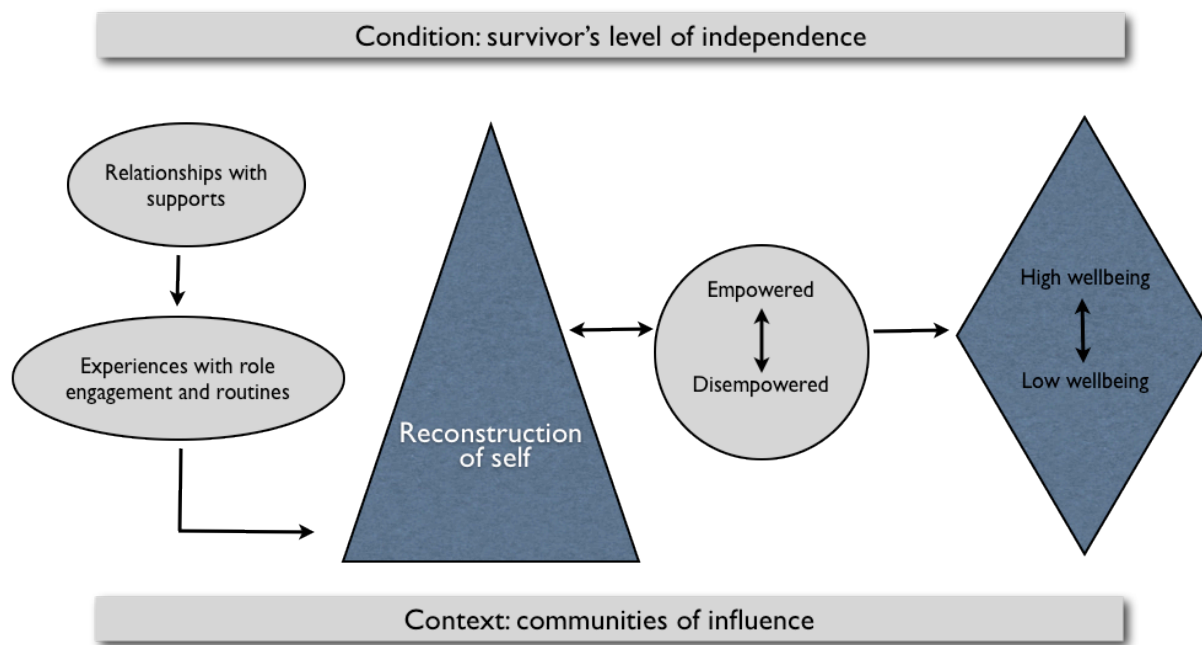


Figure 4.1. The CoRTs Model of Well-Being.

The CoRTs Model of Well-Being

This section will explain in detail the CoRTs Model of Well-Being. I will begin with a discussion of context, specifically communities of influence and how these shape the CoRTs model, followed by the core condition influencing the theory; survivors level of independence. I will then discuss the overarching theme and subthemes that emerged from my analysis.

Context: Communities of Influence

From the time of notification of their loved ones injury, spouses of wounded warriors were tossed into a labyrinth of communities, each taking on a central role in participant's lives at different points in time. These have been identified as communities of influence and refer to social structures in which participants and their families routinely engaged. Participants engaged with these communities in a manner that informed experiences with RoS. Engagement may be by necessity, as is the case of spouse engaging with the medical community during their partner is hospitalized, or by choice as would be the case when a participant called a friend for support or help. Each community had its own objectives, interest, culture, rules and general understanding of circumstances. Examples of communities of influence, discussed by participants include a hometown, their church, the military community, the community of health care providers, a community of friends, and virtual communities (Figure 4.2).



Figure 4.2. Communities of influence.

During the process of engagement, each community's understanding and appreciation of mMTBI shaped became central to resuming a "normal" life.⁹ The women who joined me in my research identified three specific areas from which communities of influence shaped the CoRTs model. These included each community's understanding of mMTBI, the stigma associated with invisible injuries, and the community's experiences with military and veteran issues.

Community Understanding of mMTBI

After returning home, the communities where participants live and participate mirror a lack an understanding and awareness of how this "hidden injury" manifests its self. Participants, despite their state of well-being, discussed how communities shaped the experiences of their lives based on knowledge of mMTBI and the associated deficits. Women often found themselves isolated and stigmatized by their loved one's diagnosis or the community's understanding (or lack of understanding) of "hidden injuries." Ingrid's experience with transition from the hospital community to her hometown demonstrated the see-saw experiences of many participants. Friends had difficulty understanding the changes in Ivan, and instead of trying to understand, isolated the family:

We had tons of support at the hospital. It seemed like we will be okay. We were all in the same situation and understood what each was going through. Things fell apart when we left, (when) we got home. We had no idea how hard it was going to be at home. Nobody there understood how hard it was for us everyday so it got to a point where we just stayed to ourselves. . . . Ivan [her husband] looks fine so everyone expected him to be the same, like a total goof off prankster. He can't

⁹Participants engage with multiple communities across the continuum of care as well as at one point in time. Many of the experiences shared illustrated how levels of understanding could fluctuate significantly within single community. For example a physician's lack of understanding and perceived apathy versus a social workers support and outreach, both whom are located within the same hospital.

joke anymore he just doesn't think like that now but I guess they don't understand and I don't know if I expect them to or not, maybe a little would help. I am pretty much on my own to deal with it, with Ivan of course but you know, on my own really. (Ingrid)

Challenges associated with transitions among communities where understanding of mMTBI and the associated deficits vary was a theme shared by participants despite their level of well-being. Engagement within communities that possessed little understanding of mMTBI left participants feeling isolated, angry and abandoned.

On the flip side, participant engagement with communities that had an in depth understanding of the issues associated with mMTBI fostered feelings of hope and support while facilitating active engagement.¹⁰ Penny discussed how attending a weekend get-away program specifically for families of wounded warriors was an essential step to her experiences with well-being:

There are these weekend events and they happen about twice a year and for three day our whole family goes someplace, last time it was a lodge in Wyoming. These weekends were the best thing that could have been offered to us. While we are there and after we leave we all feel part of something big and that we can make a difference in lot of people's lives and our life too. We are part of a great big family who is there to support each other. (Penny)

Those communities participants engaged with throughout their experiences provided a canvas from where other factors shaped their well-being. Each of these communities had varying degrees of knowledge and understanding about the consequences of mild and moderate traumatic brain injury. In the case of contexts where there was strong understanding, participants

¹⁰Social networking emerged as a way to engage in communities where participants often found understanding and support: Facebook, Twitter, Blogger.

felt supported and welcome. In the case where communities had little knowledge or experience with mMTBI, participants felt stigma often laid the foundation for their experiences.

Stigma Associated With Invisible Injuries

Participants discussed how the lack of community understanding was often coupled with the social stigmas associated with hidden injuries.¹¹ These stigmas included; “the soldier is weak, lazy, and faking his symptoms. He is just trying to get out of another deployment, or he is self-medicating. Get him off the drugs and alcohol and he will be as good as new.” These stigmas existed in a variety of communities—military, civilian, health and spiritually based. Women who shared their experiences with social stigma found it to be a significant barrier to social participation and choice role engagement. The pervasive nature of this bias left them and their loved ones feeling misunderstood, isolated, and unsupported.

Leigh experienced stigma within the military medical community. Her experiences left her frustrated and disheartened by the very same community she felt should understand mMTBI. The stigma that permeated the medical facility, in which Leo was evaluated, led to an inability to effectively diagnose and care for her husband. Her explanation of how the medical community “understood” Leo’s condition was as devastating as the injury itself. Leigh’s experience was common among the participants, regardless of their current level of well-being:

Nobody believed us. . .they said he was depressed or that it was PTSD. At first the doc didn’t believe that all of this was going on or they even said that he was like this before his injury. These docs and the medical board people didn’t care because he didn’t lose a leg or something and all he lost was his head but since he

¹¹Hidden injuries of war are considered to be those vulnerabilities that do not manifest themselves physically but behaviorally and include but are not limited to mild brain injury/dyexecutive syndrome, postcombat-related stress and behavioral health issues, visual deficits, and sensory processing disorders.

didn't bleed they said he wasn't hurt or anything like that. They think he's no different because their tests didn't tell them he was not right. At the hospital they said he was lazy and that made him feel like he was crazy. . . He can't get a purple heart because they can't see anything wrong. He fights for his country and I lose the man I was married to and we have nothing to show for it. (Leigh)

For many participants, once they left the military facility, they ventured into communities of influence that had very little understanding of the military culture. In the case where participants ended up living in towns unfamiliar with Army, Navy, or Marine culture their experiences with well-being were very different than those who found themselves within this familiar social context.

Community Understanding of Military Culture

In addition to community understanding of mMTBI and hidden injuries, a community's perceptions of the military and veterans framed experiences of participants. Ft. Bragg, North Carolina, and communities surrounding Ft. Hood, Texas, were filled with cars and trucks toting bumper stickers stating, "we support our troops," and "I served." Many members of these communities shared experiences of deployed spouses and parents. Frequent and lengthy deployments created an environment where Skype became a lifeline for families to connect, and members of these communities were acutely aware of the reality of two wars. The support and understanding of the military within these communities was strong and community members looked to one another for support.

By contrast, towns and cities far from military posts did not experience the everyday struggles of the military family. The bumper stickers seen on most cars at Ft. Bragg were rarely seen in towns hundreds of miles from the closest military post. Participants who had been living

on a military base during their spouses' deployment and later moved to communities that had little knowledge or understanding of military culture, felt isolated and often misunderstood. Carol, Gina, Nancy, and Penny discussed how a lack of understanding of military culture created a barrier of understanding and communication between themselves and the communities they chose as their home. Barriers had been created between themselves and close family members (who were non-military). Nancy discussed how the decision to move to northern Virginia placed them in a community that did not understand military experience, as she had known it:

We decided to move back to where I grew up so that we could get some help with the kids and my mom could help me when I went back to school. I guess we just didn't think it through at all. We aren't near a military base even though there are lots of military around the DC area. It is hard to explain what we are going through. It is a bit of culture shock. Everyone is nice and, but we just have nothing in common here and the kids are having a hard time adjusting. My mom hasn't even been around much to help out so who knows. Nona (her nine year old daughter) says all the time, "Mom we're not in Kansas anymore." I remind her that we sure aren't. (Nancy)

Context provided a foundation from which participant's experiences with well-being took shape. These communities either contributed or detracted from well-being and are foundational to the process of RoS. Conditions, like contexts shaped the experiences of RoS and the well-being of participants. The level of independence of their partner¹² was the primary condition that shaped the experiences of these women (see Figure 4.1).

¹²Conditions are illustrated at the top of the CoRTs Model of Well-Being.

Primary Condition

One primary condition—the level of independence of the survivor—emerged as either a roadblock or a launching pad for participants. This condition permeated experiences with RoS and how successes and failures throughout this journey shaped well-being. Additionally, the level of independence of the survivor molded relationships participants had developed with supports. These relationships with supports provided opportunities to engage in roles and routines of choice or circumstance. Finally, the level of independence of the wounded warrior provided participants the freedom or the level of burden that ultimately charted a course that shaped the bridged RoS and well-being: perceptions of empowerment.

The level of independence of the surviving war heroes varied significantly. This variability was often due to chronic symptoms associated with the brain injury or concomitant injuries and behavioral health diagnoses¹³. Participants shared how chronic functional limitations prevented their partner from driving, returning to work and school, unable to tolerate social settings, manage medication, engage in parenting roles, manage money, or be home alone for extended periods of time. Participants whose spouses required constant assistance were the most likely to report feelings of disempowerment. The level of burden experienced by participants secondary to their partner's impairments influenced their ability to develop relationships with supports, dictated many of their primary roles and routines in which they engaged, and became foundational for experiences with RoS. This was true in the case of Gina whose partner returned home with persistent cognitive and behavioral changes due to his

¹³Multiple diagnoses were the rule versus the norm for the survivors of mMTBI. This question was not asked on the intake assessment nor was it directly asked in the interview. Fifteen of the 18 women interviewed discussed dual-morbidity in their spouse. These were primarily behavioral health related; post traumatic stress, anxiety, and depression. One participant discussed their loved one's severe burns, and amputation of digits or lower or upper extremity amputations were noted by six participants.

injuries. She is the only caretaker at home and his constant need for supervision is burdensome and exhausting:

I am the only one who drives right now, I have to be sure he takes his meds. I am on the phone all the time with the case managers and making appointment and advocating for the things we need. It is my job to take care of all of the kids' needs and manage the house and money stuff. I wake up at 5 and don't get to bed until 1 in the morning. Sometimes I have to think really hard about when the last time I took a shower was. (Gina)

Most participants had loved ones who showed progress over time. As the partner made functional gains, less assistance and supervision were required on the part of the participant. . Furthermore, as the burden of care was lessened, it became possible for spouses to participate in new roles of personal choice that helped shape RoS and foster higher levels of well-being. For example, DeDe related her increase in well-being as her husband's condition improved:

Just to see the changes in him, of him regaining that cognitive ability that he had before, you know, those problem solving abilities, which really helps me feel better and know that things are gonna be ok. The more he can do, the more confident I am, the better I feel, the more I am able to reach out to other people, thus gaining that social support that I need. Because it's kind of hard to reach out for the support when you're just so focused on your own issues and your own problem, and taking care of his needs all of the time. Once he began to get better I had that confidence in myself and our situation helps me to reach out for the help that I needed from other people. (DeDe)

In general, women who described their partner's health and level of functional independence as poor, presented with lower or emerging states of well-being. The chronic burden of caring for their spouse often prevented participants from developing relationships with supports that were necessary for respite. It was through respite that these women found opportunities to explore roles and routines of choice, roles needed for the process of RoS. Betsy and Quince both discussed how the limitations associated with the brain injury limit their partner's independence and how that, in turn prevents them from engaging in activities of their choosing. Kim discussed the emotional issues that limited Kevin's ability to function on his own. Quince shared her experiences with Quentin's cognitive deficits and how these placed him at risk for further injury. Despite the underlying reason for their partner's limitations, their experiences were quite similar. Their partner's disability placed a burden on each of these participants and created feelings of isolation. Through isolation, these women were unable to develop relationships needed for RoS. Betsy discussed how her spouse's emotional well-being affected her own. She felt detached from him as well as those around her. His isolation became her own and her life was becoming his:

I think the first few nights (after he came back) he didn't even sleep. I don't even think he came to bed with me. And, after that I started noticing that he was having more emotional problems. I needed to back off our marital problems and to start to address his needs more than our needs. I thought this would get better but it didn't it just got worse. He needed me for everything and wouldn't leave the house. I think that's when reality hits maybe. When I understand that there are certain needs of mine that are not being met by peers or friends, or him, you

know, it seems like just all comes crashing down. It was about him now, always him. (Betsy)

Quince shared her fear that the cognitive deficits that lingered since his injury would put Quentin, their children, or their home at risk. She would only leave the house when there was someone to supervise him and while gone she constantly worried about what was happening at home. Her constant fear prevented her from being able to make choices that would enable her to create new roles of personal meaning, roles that would create opportunities for engagement in RoS:

I keep thinking that I am going to come home and the house will burn down or that the kids will be upstairs drinking with Quentin or that he takes them out shooting or something. His memory is so bad but his judgment is like not even there. He doesn't think and that is really scary and dangerous too. I feel like the kids are about to go out on their own but I have a new toddler that needs to be watched all of the time. (Quince)

The condition of the partner's level of independence offered opportunities to participants as well. Participants who demonstrated high levels of well-being reported their spouse was as either independent with most activities, or somewhat dependent but roles of opportunity had been created around the loved one's disability. In the cases of Dede, Fran, Kim and Reese, the progress their spouse had made over time, and his current level of independence, provided opportunities to develop relationships with supports, adopt roles of choice and successfully experience RoS. Fran discussed her loved one's gains over time and how this progress allowed her to refocus her goals to the future:

Once Frank became healthier and stronger and we knew he could return to duty things got better. Everyone was happier and we got our family back, kind of like our old lives. I didn't have to worry about him so much anymore and I could start taking care of myself again and the baby too. We started to look at where we were going to be in a few years and it is good, really good. (Fran)

Kim's life improved once her spouse was willing to leave the house and go to church:

Kevin's health changed after he was back for 3 years, for the better I mean. His doctor found a therapist who worked on his memory and did some job coaching with the VA (Veteran Affairs). They also changed the medications he was on and he got much better, like overnight. I remember his saying that he wanted to go to church. I couldn't believe it. He had refused to go there and I just stopped asking. I had to stop because he couldn't be home with the kids for that long. When we went, the whole family went, the pastor came up to us after and I thought she was going to start to cry. I did. After that, our phone started ringing again and we began to go out, not a lot but a little at a time. (Kim)

The CoRTs model identifies two foundational elements from which constructs of well-being develop; the context; or communities of influence and the condition; or survivors' level of independence. Both shaped the experiences of study participants because they provided a canvas from which the CoRTs Model of Well-Being unfolded. These foundational constructs gave rise to one overarching theme and three supportive themes, all which are illustrated in the CoRTs model and will be discussed in detail.

Emergent Themes

Analysis of data collected from participants unfolded into a single overarching theme and three subthemes explaining contributors to subjective well-being that integrate elements of the model in Figure 4.1. An exploration of these constructs, their relationship to each other, and to the participant's life was used to create an understanding of the essence of spousal well-being. Each of these themes is discussed in depth in the next section. Discussion includes an overview, a review of common experiences among all participants, unique experiences by level of well-being, and a general summary. Box 4.1 highlights the overarching theme and related subthemes. Although these themes are discussed individually their contribution to spousal well-being are interrelated in such a way that no single factor, or relationship can be discussed without consideration and understanding of the others.

Overarching Theme: Reconstruction of self (RoS) is central to the well-being of the spouses of service members returning from combat with mild to moderate traumatic brain injury.

Theme 1: Relationships with supports provide opportunities to develop roles of choice

Theme 2: Participation in roles and related routines affect RoS

Theme 3: Perceptions of personal empowerment persuade well-being as well as RoS

Box 4.1. Themes of this study.

Overarching Theme

The overarching theme emerged from this study, and has already been introduced. The ability to redefine self became the key construct to well-being, regardless of state of well-being. This phenomenon, which I have called reconstruction of self (RoS), emerged as the epicenter to understanding contributors to the well-being of the combat-related mMTBI survivors' spouse.

There were a number of common experiences among participants as they related to this overarching theme. Women who joined me in my study reported RoS as a constantly changing phenomenon. The dynamic nature of RoS took shape from participant's experience with acquisition of new roles and establishment novel routines. Participants shared how, from the moment of their loved ones' returned home, their lives changed. Their personal understanding of who they were, goals, and dreams were launched into a state of metamorphosis, placing participants on the journey of RoS. Their journey, however, took numerous unpredictable turns and twists. For example, Helen's experience with well-being was emerging. She was continually tried to engage in activities for her own personal benefit but these were frequently challenged by the needs of her partner. Her experiences with self changed moment by moment as she struggled to begin the process of RoS:

We are all changing who we are all the time (speaking about spouses of wounded warriors). Every day seems to be different and I don't know where I will be tomorrow much less next year. This whole experience has made me a very different person, that is for sure, but I still don't understand where I'm at just yet.

(Helen)

Participants shared the fluctuating nature of the RoS experience. There were, however, a number of experiences that were reflective of the continuum of well-being experienced by these women.

As the journey of RoS paved a path to personal well-being for the majority of participants, an unfortunate few reported their route rocky and treacherous. The demands of their life circumstances gave these women little opportunity to explore a new self and, in turn, little to no opportunity to actively reconstruct their lives and redefine self. Emily shared her

experiences of trying to juggle a newborn, a five-year-old son with special needs, her husband's return from war, and her future goals:

In the morning when I wake up I take a deep breath before I open my eyes
because once they are open I have no idea what to expect from the baby or Ed. . .
My life is minute by minute and that is all I can do right now so when it comes to
who I am that will change too, all the time. I guess my life is about what they
need of me and I'm 25 years old but can't see into the future right now much less
plan for it. I know I am wrong about that but that is how I feel and so I don't think
ahead. (Emily)

Emily's sense of uncertainty and living in the here-and-now was shared with peers experiencing low states of well-being. The participants who struggle with engaging in RoS reported feeling trapped by their current circumstances and were engaged in a constant struggle to establish routines, adopt new roles, pursue healthy relationships, and get their personal needs met. These participants discussed logistical barriers to RoS. Their inability to actively engage in RoS had, in turn, left them feeling disempowered, as Betsy described:

Nothing I do anymore that is a reflection of who I want to be, it is a reflection of
who I need to be. (Betsy)

Betsy, Emily and Quince all encountered numerous barriers that prevented them from engaging in RoS. The experiences of women who shared emerging states of well-being were different in that they encountered barriers but had opportunity for some successes. These successful experiences provided opportunities to move forward and motivation to explore roles of choice while breaking from roles of circumstances.

The majority of participants discussed how they were able to begin the process of RoS. They reported frustrations related to the inconsistency of their daily experiences and the tiresome lack of predictability of their days. The juxtapositions of successes and failures provided hope and doubt when reflecting on role participation and understanding of self. At times these participants felt competent and uncertain at the same time, as was expressed by Penny. Her sentiments were shared by a number of spouses who experienced emerging states of well-being:

I feel lost and can't really change things. I just take care of things all the time and sometimes I don't even do that too well. My identity? I wish I could figure that out again. Things change pretty quick and I don't seem to keep up much or have any control over how things are going. . . But things go okay some days and I don't know why but they just do and then I see myself and am like oh yeah okay. On bad days, I'm not sure what to do and then it is too late. . .too late to figure out who I am then. It takes too much energy. (Penny)

In a number of instances beginning the process of RoS was a see-saw experience that was stabilized by support systems. This was illustrated by Helen's discussion of her relationship with her girlfriend of ten years and how this relationship provided the support needed for RoS. Helen spoke about her friend's ability to help her redefine self:

I thought I had lost everything when we left the military and we had to start over. Harper (best friend) sat me down and helped me discover these things about myself that I didn't even know. They weren't all good but it helped me start again and that is where I am right now, still working on who we are and what is next. (Helen)

Close female friendships became a constant source of encouragement for many participants experiencing emerging states of well-being. These relationships often helped participants feel grounded during the most difficult times and celebrated during the successes. Female friendships frequently provided the external motivation needed for participants to engage in the RoS process.¹⁴

A number of women discussed their “new self” that emerged from their experiences with RoS. These participants reported a sense of personal satisfaction with their personal growth and an understanding of empowerment that stemmed from RoS. Participants who discussed successful experiences with RoS reported how they developed relationships with a number of supports, which in turn provided them with the assistance they needed to explore roles of choice. These roles ultimately drove the process of RoS. Kim discussed how her confidence developed as she was given opportunity to take on new roles and experienced success with the related routines. The confidence Kim exuded provided her a sense of personal satisfaction and empowerment. Others who reported developing a new sense of self shared Kim’s experience. The trajectory Kim established through participation in roles of choice provided for a larger sense of purpose and a new understanding of who she was:

I finally got reconnected with my friends at church and also met a girl who was in my situation like four years before. I started helping her out and she gave me some resources too. Things all seemed to fall together and I began working with the kids at church and teaching too. I began a blog and supported other families like us. The church was a door just opened for us and for me and then I could get back to where I wanted to be and look forward for all of us. (Kim)

¹⁴Female friendships became a key factor for women whose well-being was emerging during the discussion of Theme 1; relationships with supports influence role engagement and routines (see page 44).

Similar to Kim's new sense of self, women who had a positive experience with RoS took on roles of their own choosing, including helping others. The routines related to service roles became central to their RoS experience. These roles provided participants with a sense of personal empowerment. They became increasingly motivated to stay on course throughout their RoS journey. Olivia reported a lack of satisfaction with her life prior to her partner's return home from combat. His injury initially left her alienated and in denial about their family circumstances. Through a community group, she was given an opportunity to share her experience with other women whose loved ones had recently returned home with devastating injuries. This group and her role in it, opened up the doors for RoS:

I found what I am really good at and I think I never had that before, not even before the Wars. Helping other people (helped me) learn how to move forward making their lives easier is what I am good at and it makes me happy. When I feel like I can contribute the kids are better off, Oli [her husband] seems better and we are in a good place right now. It works for all of us. (Olivia)

In summary, the overarching theme reflected in the CoRTs Model of Well-Being states that RoS is central to the well-being of the spouses of service members returning from combat with mild to moderate traumatic brain injury. Participants discussed how, after their partner's return home, their lives were thrown into turmoil. They found themselves living with a partner very different than the one she had married. These new life circumstances were such that participants begin a journey to redefine self. The CoRTs Model of Well-Being illustrates the relationships existing among constructs contributing to well-being and the relationship of these factors to the process of RoS.

Although the CoRTs Model of Well-Being identifies RoS as the epicenter to well-being for these women, the importance of this phenomenon cannot be understood without consideration and understanding of the supporting themes. Three supporting themes emerged which topic areas include relationships participants developed with support, participants' experience with role engagement, and perceptions of empowerment.

Theme 1: Relationships With Supports

The relationships participants developed with supports became central to the CoRTs model. Supports were both formal and informal. Formal supports included governments and non-profit organizations while informal supports included friends, family members, and social networking. Supports, formal and informal, provided spouses burden relief and validation of their experiences. Each participant's ability to engage with supports was often a reflection of the overarching condition outlined in the CoRTs model (i.e., the level of independence of the surviving service member).

Sixteen of the 18 women who participated in this research discussed how engagement with supports shaped their experiences with well-being through participation in roles and RoS. Reese shared how she went through the first six months on her own and how her struggles affected everyone in her family. When she asked for help for the first time, although somewhat reluctantly, she was overcome with a sense of relief and recognized herself as a single entity detached from Robert for the first time since his injury. Reese shared how asking for assistance opened the door redefining self:

I remember when I said, "sure that would help a lot", for the first time. I mean and that was a really big step for me but I did it and I was able to breath for the first time since the blast. It was only like two hours and I got my hair cut and

nails done and I went into the bathroom and remember thinking- - oh yeah hi, I know you, where have you been? And I just started to cry, you know because right then I knew I was still there and so now I ask for help when I need it. . .all five of us, we work as a family and we have issues but we are all important, each of us and we are also important as a unit. We can only do that if we ask for help from each other and from people outside the house. (Reese)

Women engaged with a variety of support types. The typologies of supports were often a reflection of context and where their partner was on his continuum of recovery.¹⁵ For example, during the acute medical phase, spouses often identified medical personnel and family members of other wounded service members as foremost supports. Six months later, after their spouse had been medically discharged from military duty, primary supports included close friends, places of worship, online support groups and family members.

The relationships participants developed with supports and the opportunities supports provided for choice role engagement became key to the RoS experience. For many women, these relationships provided an opportunity to gain insights their current situation; offering a glimpse into what their future may hold. The support many of these individual and agencies provided was informational only. Participants found information helped them understanding their current situations and provided clarity about the consequences of mMTBI and validation of their daily experiences. Missy discussed how she had little understanding of brain injury and that Mike had not been diagnosed with mMTBI initially. She described how she couldn't get any facts from the military medical community and began to investigate things on her own. She saw an opportunity to provide information where there was little and seized it. Her role as an

¹⁵Context refers to the circumstances to which support was needed and continuum of care refers to the phase of care the wounded warrior is currently participating in—acute care, inpatient rehabilitation, outpatient rehabilitation, veteran services.

educator and advocate reflected little on who she had been prior to Mike's injury, but was a reflection of who she had become:

I'm like the matter of fact person. I just needed to know what was going on and then I could figure out what I needed to do to move on and get my family to follow. The "we don't know for sure" f--k that! . . . So here I am the lady letting all these other people know about brain injury and how it happens to the family... People who knew me before think I was the one who got hit on the head [laughter]; I was always quiet as a mouse. (Missy)

In most cases participants were experiencing a life that was very different than anyone had expected or planned for. They quickly discovered a disconnect between being told there may be some minimal changes or no changes at all once you get home, to the reality of being married to an individual who required assistance with some or most tasks. This created confusion and frustration on the part of participants. The relationships participants developed with supports (formal and informal) often provided information that validated their daily experiences. The guidance of these supports provided a sense of clarity to their current situation. Fran had struggled with an understanding about her experiences at home with Frank. She had been assured that his symptoms would decrease when they returned home and that much of the behavioral issues therapists had identified in the clinics were stress related, not secondary to his brain injury. Once they returned home, his symptoms worsened and these were reinforced by his constant failures to engage in activities that were simple for him prior to his deployment. The assistance Fran sought from the medical community was met with excuses and long time-tables. Some of Fran's stress was alleviated when she found other spouses who had shared her experiences through Facebook:

I was going crazy I knew it [something more was wrong] because nothing they said was going to happen would happen when we got home. I was told to just calm down and wait a couple of weeks to adjust. I would call and call but I got sent to so many places I finally gave up and got on Facebook. I found a group for family members of wounded army guys and I just posted something thinking I may hear back. It was amazing, three or four people were going through the same thing. I was relieved I guess and got a better sense of what was going on with Frank, with us. Things weren't better but at least I knew I wasn't just nuts. (Fran)

Additionally, strong relationships with supports provided respite and relief of circumstantial roles, easing burdens associated with caring for spouses. Respite freed participants to engage in choice roles and routines that became essential to RoS. However, a few women discussed an inability to forge relationships with supports. They reported how conditions and context—lack of time to contact and engage with supports, physical distance from places where support was available, and lack of understanding of how to access support—prevented them from developing the connections that were needed for these productive and trusting relationships. Consequently, these women did not receive the respite needed to explore choice roles. For instance, Penny shared how her initial resistance to develop relationships with support systems created personal challenges. While discussing her feelings of isolation and burden brought about by her situation, she went on to share how she could not pursue her own interests and felt lost. She blamed much of this on her reluctance to seek help and the logistical barriers that existed:

At first, I thought. . . sure, I can do this by myself. And when people asked if we needed any help I always just said “no” because I didn't think I needed any. . . and now I wish I had gotten help because now, people don't ask. . .they don't

come around or ask. Now, I know finding support is really important to the whole family and for me, for what I can do and handle. It can make a difference for where I am at in all the areas of my life. . .I had no idea what I was going to need for such a long time. (Penny)

The majority of women, however, engaged with a variety of supports, many of which provided the respite necessary to adopt roles of personal choice and move forward towards RoS. Women who were able to develop relationships reportedly found the respite needed to identify, explore, and manage self-selected roles and novel routines (to varying degrees), both of which became central to their experiences with RoS. Ingrid shared her experience with a formal support agency and how this support group provided services and respite needed to pick up the pieces and move forward as a family:

I just didn't have any strength left to do all the things we needed to get done. Everything fell apart all at once. . . We prayed together (as a family) for someone to help us. I was able to make one call to the wounded warrior program and then things began to come together. They (the wounded warrior program) knew the things I needed and were able to find me people to talk to. I guess that call made the difference because we could move forward as a family and I could move on with all of the changes that were going to happen. . .I get help now and I know it is okay to ask for this. . .I have begun to figure out where I going and it is good, for now at least I think I pretty much know what my future holds. . .Our lives are pretty much different than they were a couple of years ago and I for sure am different in almost all ways ... in a good sense. (Ingrid)

The relationship Ingrid built with the wounded warrior project provided her with many of the tools she needed to begin her journey of RoS, tools that included assistance in the home, connections with financial support, and emotional encouragement. In addition, the project provided her with an opportunity to provide assistance to other women in similar circumstances, a role she both embraced and developed over time, a role she expressed is central to her current and future happiness.

The indirect implications of supports to the experience of RoS are twofold. First, supports provided participants with an opportunity to understand their current situation. Participants found this knowledge to validate their circumstances, a validation that was necessary for them to move forward with RoS. Secondly, relationships with supports provided participants opportunities for respite. Help with their often burdensome routines associated with roles of circumstance provided freedom for participants to engage in self-selected salient roles that ultimately helped shape the RoS experience.

RoS was not directly affected by the relationships participants develop with supports. It is more appropriate to say that the indirect implications supports had on RoS were based on how participants developed these relationships and the active role women took in accepting and using the assistance available to them. In the cases when participants were unable to develop relationships with supports, the burden of circumstantial role engagement that lacked meaning erected a barrier between role engagement and RoS. Women who actively engaged with supports found it easier to begin the process of RoS, a process essential to their state of well-being.

Theme 2: Experiences With Role Engagement

The second theme reflected in the CoRTs Model of Well-Being discusses how participation in roles and related routines directly affect the process of RoS. Sixteen of the eighteen women who shared their experiences for this research discussed role participation as being a catalyst or a barrier for RoS. The implications of role participation on RoS were three fold. First, the daily rituals associated with participant roles and routines constructed patterns that women understood as a reflection of self. Second, engagement with meaningful roles of their own choosing was necessary to begin the process of RoS. Third, participants who successfully began the process of RoS were able to balance circumstantial and choice roles. This balance was necessary to meet the needs of their families and their own personal needs. Role participation needed to be meaningful and a reflection of personal choice in order to facilitate RoS.

The manner by which participants understood self was frequently a reflection of their daily patterns, that is, rituals established by participation in roles and associated routines. Women whose daily patterns reflected participation in strictly circumstantial roles understood themselves as passive participants in their own life experiences. Their days reflected habits and routines that were based on the circumstantial roles, a consequence of their partners' injuries and subsequent disabilities. These spouses reported feeling powerless over their current selves. The daily patterns of their lives created logistical and emotional barriers preventing them from beginning the process of RoS. Carol's daily routines reflected the circumstantial roles she assumed after her partner's discharge from the military. She rarely left the house or visited with friends and the patterns of her day were shaped by Cal's needs:

I have become a product of my situation and my whole life is within the walls of my house. Is this the way I want it to be? Definitely not but it is who I am right now and I don't see it changing any time soon . . . I guess it is a good thing my house is pretty big [laughter]. (Carol)

Development and participation of meaningful roles of choice often held a very different outcome. Participants whose daily life patterns reflected routines that were personally meaningful were able to begin the process of RoS. In these cases, women reported participation in meaningful roles as providing opportunity for a new set of habits and rituals to take place. The recognition and active engagement in these routines became central to how roles informed their RoS. Dede shared how her job was central to the process of RoS. She described how this provided her an opportunity to remove herself from engaging in circumstantial roles that were burdensome and meaningless. Engaging in meaningful choice roles provided her with daily patterns and routines that were her own, a provision necessary to RoS:

Having a job to go to where I'm helping other people and doing something else is really what helped me . . . my life doesn't revolve around appointments and medications and what is my husband need now, does he need a nap? While I wanted to do those things, it helped to know that I had other responsibilities that were important to me too. (Dede)

In addition to patterns and routines, the opportunities participants had, or lack there of, to engage in roles of personal choice informed RoS. This experience became a bridge or a barrier to RoS. Temporary role shifts were typical for the majority of military spouses post-deployment, regardless of their partner's health. The experiences of participants in this study do not reflect what is typical in the larger population. For these women, role-shifts became long-lasting,

sometimes permanent. Over time, roles of circumstance reportedly became increasingly burdensome and lacked meaning for participants. Women discussed how engagement in circumstantial roles began to take away an understanding of self but, in some cases left little opportunity to re-examine and redefine self.

Emily and Betsy, discussed how initially they enjoyed providing for their “hero.” They believed that they had taken on the role of caretaker and single parent for only a short period of time. This unexpected “short time” became long-lasting and roles of spouse were replaced by parental type duties. Betsy comments about how the relationship she had with her spouse developed after he returned from deployment:

I definitely feel like I've had to take the caregiver role or like the mother role. I feel like I have to remind him that he has to get up and go to work, I have to remind him of his appointments. I say stuff to him and he doesn't register it. Nothing happens, he doesn't do what I ask him to do. . . But, even still, I guess we're going on 6 months later but I do feel in a lot of ways that he is more like a child and not you know, a spouse on my same level. (Betsy)

In the case of Emily, she mourned lost meaningful roles and felt “trapped” by her new ones. She sought emotional and physical intimacy and recognition of their partnerships, a recognition she did not receive. The experiences of Emily and a number of women whose lack of meaningful role engagement was evident; RoS became a distant opportunity.

For a greater number of spouses, the ability to engage in choice roles began slowly. They experienced small glimpses of successful meaningful role participation. These sparks became the catalyst participants needed to explore roles of choice, igniting the process of RoS. For instance, Gina shared how she was provided an opportunity to meet another woman and offer her

support when she moved into the area. This broke Gina's routine and understanding of her roles. She became a mentor, a role that was hers by choice and meaningful to her understanding of self. A call she received from her children's school was the catalyst that began the process of RoS:

Things were pretty bad for a while. I just was overwhelmed and couldn't do anything else. . . I got a call from the school and I was sure it was because of something that had happened since the kids were always getting in trouble at that point. It was the counselor and she asked me to come in to meet with another mom whose kids had just enrolled at school. . . I was like a mentor for the family and then for the school too, so they could help work with some of the issues at home. Gloria's husband didn't have a brain injury but had been burned pretty bad and had PTSD so a lot of the things we were going through were the same, and the kids too. . . I guess I just needed a kick to get me doing something, like I struggle to get out of the house still, but it gets better most of the time. (Gina)

Across the board, women whose partner returned from war with mMTBI possessed a desire to engage in roles and activities of their choosing. They shared a need to resume meaningful roles they understood as core to "self."

The third underlying issue associated with participation in roles and RoS illustrated how participants who successfully began the process of RoS reportedly balanced circumstantial and choice roles. In these instances, the choice roles participants engaged in complemented circumstantial roles. Participants shared how engagement in choice roles provided a sense of personal "completion." This balance provided opportunities to meet personal and collective needs and goals, while gaining a better understanding of what was best for their partner. Success in choice role related activities reportedly fostered confidence and independence in participants

as well as the partner, something that was rarely seen in women who lacked balance between choice and circumstantial roles. Dede discussed the importance of her job and other roles she has taken on since her partner's return from war with mMTBI. She balanced her work and volunteer roles with circumstantial roles that had been acquired after Don's injuries:

It is important to me, my job (that is) and get away from the house. I also volunteer with family assistance. I am learning about myself and how strong I am now. My life is different than lots of women I meet in my situation, but I work hard on myself. I do a lot of things and so does Don. We are growing together after this. (Dede)

In the cases of Missy, Dede, Reese, and Kim, RoS was a reflection of their experiences with participation in choice roles and the balance they achieved between roles of choice and circumstance. For these four participants, circumstantial roles had become meaningful and contributed to RoS. Missy was able to return to work part-time after she asked a family member to check in on Mike when she wasn't around and he was at home. Returning to work provided her with the balance she needed to understand how the routines related to her circumstantial roles at home were meaningful to who she was becoming. Missy no longer viewed the work she did at home as as burdensome; the routines, which are part of any healthy relationship, became roles of choice:

I understand what he needs, and I am there for that, I wouldn't give that up. I am able to be there for him now since I went back to work, even if it is part time. I had to figure things out and I knew I was more than just his wife and mom, that was important. He relies less on me too now and can do more on his own. (Missy)

The link between experiences with role engagement and RoS is demonstrated in three ways. Participants understood their self through the patterns and daily rituals associated with circumstantial and choice roles; RoS is a byproduct of participant's participation in meaningful choice roles; and women who began the process of RoS found a balance between choice and circumstantial roles. Women who were unable to participate in meaningful choice roles and whose lives reflected their spouse's needs consistently were prevented from beginning the process of RoS. However, participants who found opportunities to engage in meaningful roles of choice began the process of RoS and re-evaluated their circumstantial roles as creating routines reflected in most healthy marriages.

Theme 3: Perceptions of Personal Empowerment

The final theme illustrated in the CoRTs Model of Well-Being relates to participants' perceptions of personal empowerment. This theme states that perceptions of personal empowerment inform RoS as well as subjective well-being. Three key underlying topics are reflected within this theme.

1. Perceptions of empowerment are both informed and persuaded by participant experiences with RoS.
2. Perceptions of empowerment are both informed and persuaded by the state of the participant's well-being.
3. The continuum of perceived empowerment bridges RoS with the continuum of participant well-being.

Women who joined me in this study discussed how the continuum of empowerment distracted or contributed to states of their well-being.

The theme of personal empowerment came to the forefront as women whose partners returned from war with mMTBI consistently reported a need for control over their current life circumstances. From the time of their partner's injury, participants shared how the locus of control was routinely in the hands of medical professionals, military decision makers, and bureaucrats. As these women began to take control of the decision making process, they gained a greater sense of empowerment, an understanding that turned into action, shaping both RoS and well-being.

Participants consistently reported how their understanding of personal control informed and was persuaded by their experiences with RoS. Productive experiences with RoS helped participants gain the confidence necessary to actively make decisions. Successful decision-making became a motivator to continue and enhance RoS. Nancy shared how success with her first college level course motivated her to set greater personal goals. This success provided her with a sense of personal empowerment, one she used to begin planning a career for herself:

It started with just taking that one class but I am pretty sure I will go back to school now—I will go back and get my teaching degree. (Nancy)

The nature of the experiences these women had with RoS frequently led to changes in their understanding of personal skills and abilities. Helen expressed how volunteering through her local church's literacy program provided her an opportunity to feel successful. Her success in this role left her feeling empowered by the experience, which in turn reinforced decisions she had made throughout the RoS process:

For the first time I realized I was good at that (teaching reading) and I wanted to go back. Now that is one thing I do now and then. (Helen)

Additionally, instances like these demonstrate how perceptions of empowerment initially emerged from the RoS process. Empowered by success, experiences with RoS were reinforced and enhanced.

In addition to those women who discussed how successful experiences with RoS informed their understanding of personal control, a number of participants shared how little to no control over their daily lives created chronic barriers to the RoS process. These women reportedly understood themselves as unable to participate in RoS. Their understanding of perceived disempowerment was the primary reason why. Quince had made long term plans based on retirement from the military after twenty years. She felt as though the role of Army wife was a reflection of the dues she needed to pay and looked forward to the time when the Army did not dictate where she lived, shopped, and banked. Quince's experience was a familiar struggle among participants who were unable to feel any sense of control over their lives:

Control is something I feel like is nonexistent in my life right now. . .if I had control over things that have been going on I am sure my life would be different. The Army had control over everything for ten years, like where we lived and when Quentin was deployed and we always thought that after he retired we could have our own lives. Now that Quentin is "retired" (stated in a sarcastic tone) we have nothing that we planned for. . .They own us, not really, but really they do.

(Quince)

Quince's struggle with control over her future was reflected by her perceptions of disempowerment, a perception that reinforced her barriers to RoS.

The second issue reflected in Theme 3 discusses how empowerment informs and is persuaded by the state of well-being. Women discussed a synergistic relationship between

perceptions of empowerment and well-being. Gina shared her understanding of how control contributed to her “good days” or state of well-being:

It’s gotten to the point where if I know I can handle the situation, and I have a say in the matter, I am pretty confident. The outcome is good usually then. I have gotten to be a pretty good advocate of what he needs and I can, a lot of times, have people listen to me. This puts me in a good place, emotionally I mean since I feel like we matter. It also makes it easier the next time around. So yeah, there are some days when I think I can feel in control. Control is good when you are in my situation. Just know that there are lots of times things are out of control and those are really bad days, like the ones I had when we first left the base. (Gina)

In addition to empowerment informing well-being, the opposite was reported among spouses. Jill shared how she was able to make decisions and take control over situations if she was feeling good about herself and her ability. Jill reflected about how she was able to maintain an understanding of personal control and continue to work on herself when she has days or weeks that met with disappointments and frustration:

There are good days, really good ones and I think I can do pretty much anything. So I hang onto those when things aren’t right. It makes things easier because I know I will get back there. (Jill)

The third issue informing the final theme of the CoRTs model discusses how perceived empowerment bridged RoS with the continuum of participant well-being. The implications of this bridge are salient to the CoRTs model in that this bridge provides an understanding of how RoS, the epicenter of our model, is critical to the well-being of our participants. Carol sense of

purpose and control over her life and the lives of her family is reflected in this excerpt of Carol's discussion of what she thinks her future will look like:

I am 26 years old and I am going to have another baby. I am the only one who can change my own life so I know that now. I can make the lives of my kids, like, okay or I can help make them great so that is how I look at life and how I am right now. . . Some days are better than others for sure but I know that it's me. . and now I get therapy too to make me understand what I can do. Some things I can change and a lot I can't, and I think I am okay with that now; this has helped a lot and put things in perspective so that I can move on which I couldn't for a while.

(Carol)

Carol's understanding of how her actions could potentially shape her situation, RoS, was reflected in her perception of self-empowerment and how this could inform the well-being of herself and her family. This experience was reflected among participants who consciously decided to seek out more than their current lives were providing.

In addition to providing a bridge to enhance well-being, the women with whom I spoke discussed how perceptions of empowerment bridged their inability to engage in RoS with their current state of well-being. Penny shared how her need for control provided her with predictability in her daily routine. When the unexpected happened and she lost control of the situation, she was unable to adapt and the RoS process shifted:

I am a bit of a control freak so that helps and it also is a problem because you can't predict things that are going to happen . . . I have things lined up like a month in advance and that is the only way I can be sure things will get done so I had this women take care of the kids on Tuesday and Thursday afterschool so I

can go to therapy with Paul. One day she was a no show . . . I couldn't get in touch with her or anything and I thought something really bad happened, which it didn't, but everything just got unraveled . . . I look back now, and looking back crazy that that one thing would just get me crazy but it did. . . I counted on her much more than I thought and when she didn't show up, I felt my world was topsy-turvy, yeah chaos is what it was for 2 weeks because I lost 1 day of help . . . I kind of questioned myself after that. (Penny)

In summary, the final theme to emerge from the CoRTs Model of Well-Being has highlighted the empowerment-disempowerment continuum. This theme states that perceptions of empowerment inform RoS and states of well-being. Three key points related to participant's perception of self-empowerment. First, perceptions of empowerment contributes to and were shaped by participant experiences with RoS. Second, disempowerment persuaded and was informed by the state of participant well-being. Third, perceptions of empowerment bridged experiences with RoS with states of well-being. This theme highlights how perceptions of empowerment shape RoS and well-being. Participants who understood they have control over their lives and the decisions being made had positive experiences with RoS and higher states of well-being.

Summary

The CoRTs Model of Well-Being reflects the experiences of 18 women who, over the course of a year and a half shared their insights and reflections for the purpose of this study. Participants shared how their states of well-being changed over time and circumstance and how the disabilities associated with their partner's injury along with the communities they engaged provided a canvas from which their experiences with well-being emerged. The CoRTs model gave

rise to one overarching theme and three supportive themes, together illustrating how their partner's injury led to a dramatic shift in their daily lives and ultimately in well-being.

RoS was central to the well-being of the spouses of service members returning from combat with mMTBI. Participants who were unable to engage in the RoS process were restricted by external barriers such as their partner's physical and cognitive limitations, had poor access to supports, and lacked the time needed to engage in the process. These participants routinely experienced low states of well-being. However, women who found an opportunity to redefine self and participate in the process of exploring self were frequently on the higher end of the well-being continuum. Central to the state of well-being, success with RoS was influenced by a number of factors, all of which are reflected in the supportive themes of the CoRTs.

The relationships participants developed with both formal and informal supports provided two key services: respite from the burden of caring for their partner and validation of their experiences. Engaging and accessing supports required participants to develop relationships with these entities. The efforts and logistics of forging these relationships were insurmountable for some. For others, however, these relationships provided the opportunities necessary to adopt meaningful roles of their choosing, a necessary step for RoS.

The second supportive theme explaining the CoRTs Model of Well-Being relates to participation in roles and related routines that affected reconstruction of self. Participants reported three key ways by which participation of roles informed RoS. First, women discussed how their daily rituals and patterns were a reflection of how they understood their self. Some participants engaged in routines that mirrored the needs of their spouse. The daily patterns and routines of these participants built walls preventing them from redefining who they were. Other participants adopted roles of their own and built patterns reflective of their self as opposed to

their spouse or situation. The second way by which roles affected RoS is reflected in engagement of circumstantial roles versus meaningful roles of choice. Women who were unable to begin the process of RoS were trapped in circumstantial roles that held little meaning. Last, participants who successfully began the process of RoS were able to balance circumstantial and choice roles, a balance necessary to meet the needs of their families and their own. In these cases, circumstantial roles that had been considered burdensome and meaningless began to emerge as part of the RoS experience and the related routines began to hold meaning for the participants. The participants' ability to successfully engage in roles and the subsequent RoS gave rise to feelings of personal empowerment.

Perceptions of personal empowerment persuade well-being as well as RoS emerged as the third and final supportive theme reflected in the CoRTs Model of Well-Being. The manner by which perceptions of personal empowerment informed these two key constructs was threefold. Participants reported how perceptions of empowerment were informed by and was persuaded by the experiences they had with RoS. Participants who successfully engaged in RoS through adoption of new meaningful roles gained a greater sense of personal control or empowerment. Similarly the perceptions of empowerment of these women consistently reinforced their experiences with RoS and well-being. Participants who experienced perceptions of personal empowerment reported a higher states of personal well-being. These states of participant's well-being reinforce their understanding of personal control. Lastly, perceptions of empowerment bridged RoS with the continuum of participant well-being. RoS emerged as the epicenter to well-being for spouses who sustained mMTBI during combat. Perceptions of personal empowerment emerged as the bridge between this key factor and the outcome of well-being were linked.

The partners of service members with mMTBI experienced profound challenges to their well-being and sense of self. The CoRTs Model of Well-Being illustrates those constructs that contributed to their state. This theory highlights the importance of the RoS process along with conditions, context, supports, role engagement, and perceptions of empowerment. The inter-relationship among these factors shaped the well-being of spouses on the home front.

Chapter 5: Discussion and Recommendations

My exploration into contributors of well-being for women whose husbands have returned from OIF/OEF with mMTBI gave rise to the Combat Related Traumatic Brain Injury Spousal (CoRTs) Model of Well-Being. Prior to this research, scholarly literature had explored familial experiences with TBI (Allen et al., 1994; Ergh et al., 2002; Hall et al., 1994; Katz, Kravetz, & Grynbaum, 2005; Linn et al., 1994; Montgomery et al., 2002; Testa, Malec, Moessner, & Brown, 2006), spousal experiences with returning warriors (McCubbin & Dahl, 1976; McCubbin, Dahl, Lester, Benson, & Robertson, 1976; McCubbin, Dahl, Lester, & Ross, 1975; Rosen et al., 1995; Solomon, 1992), spousal experiences with brain injured soldiers (Rosenbaum & Najenson, 1976), the effect of combat-related PTSD on loved ones (Arzi, Solomon, & Dekel, 2000; Biddle, Elliot, Creamer, Forbes, & Devilly, 2002; Bryant & Harvey, 1998; Calhoun, Beckham, & Bosworth, 2002; Jordan et al., 1992; Nelson & Wright, 1996; Yazdani, 1996), and theories of well-being (Adkins, Martin, & Poon, 1996; DeNeve & Cooper, 1998; Diener & Fujita, 1994; Rosen & Moghadam, 1991; Ryff, 1989; Ryff & Keys, 1995; Strack, Argyle, & Schwarz, 1991; Sigrun-Heide & Klauer, 1991). Absent from the scholarly literature is a theoretical model of well-being that could be applied to the experiences of female spouses of warriors who sustained mMTBI. This chapter will discuss four key conclusions from my research, implications for praxis and limitations. In addition, I will discuss how theoretical literature in the areas of self-efficacy, identity saliency, and role strain can inform the CoRTs model and how my research findings can inform the literature in these areas.

Overview of the Study

This research was designed to answer two key questions. First, in the case of female spouses of recently brain-injured service members, what factors do these women offer to explain their own well-being? Second, how do these women describe the influence of these factors on their well-being? Over the course of this research, a third question emerged—how do the contributors to well-being shape one another? To answer these questions, I used constructivist grounded theory in the spirit of Kathy Charmaz (2006). Eighteen women whose spouses returned from war with mMTBI joined me over the course of 18 months. Their experiences are reflected in a theoretical model that identified contributors to their well-being. Through careful analysis of sequential semi-structured interview transcripts, the CoRTs Model of Well-being (see Figure 4.1) was developed. The primary constructs and their relationships are outlined in the statement of grounded theory and themes, both discussed in Chapter 4. The findings described in Chapter 4 gave rise to four key conclusions.

Conclusions

Conclusion One

mMTBI is an injury affecting the life of the military spouse as well as the life of the surviving service member.

The majority of spouses who joined me in this research had partners who had long-lasting cognitive and behavioral consequences secondary to their mMTBI. Some service members who return with mMTBI find their symptoms and consequences of this injury to be negligible. For a large minority, however, the long-term cognitive and behavioral ramifications associated with their injuries shaped their everyday lives, and in turn the lives of their spouses. Cognitive deficits associated with mMTBI may include impaired attention, memory, problem solving, and executive functioning (Ruff, 2005). Behavioral changes included difficulty with anger

management, fatigue, apathy, poor motivation, and isolation (Ruff et al., 1996). The changes experienced by surviving service members limited activity engagement and social participation. Participants discussed how their partners returned home often unable to drive, return to work, engage in childcare, or undertake home responsibilities. Not only did these deficits affect the wounded warriors' participation in daily activities, but they also affected the daily activities of the warrior's spouse. These women discussed the level of burden such that some were unable to leave their spouse unattended for any period of time, others quit school or work to attend to the needs of their partner and family; and still others became responsible for follow-up appointments, paperwork, therapy sessions, and advocacy. These women took on responsibilities so that, for many, their life resembled little of what it once had been. The consequences of mMTBI transformed the daily lives of the survivor's spouse.

Conclusion Two

The myriad consequences of combat-related mMTBI on the female spouse were significant enough that these women often engaged in a journey of redefining self.

As mentioned previously, injuries sustained in war resulted in a service members returning home very different than when deployed. These injuries often resulted in life changes experienced by study participants. These included multiple role shifts, changes in social structures, contextual changes, and reevaluation of life goals. The confluence of life changes experienced by these women launched them into a reexamination of who they understood they were. Participants reevaluated meaning in their lives and redefined self in order to fit into their "new normal."

The manner by which participants understood their lives and the loss of who they were varied. For some, their new routines reflected circumstantial roles that had little meaning to who

they were. Others reflected on the successes of women like them only to realize redefining self could bring personal meaning to their lives and their family. Despite the underlying reason why these women felt the need to embark on RoS, this desire to redefine self emerged in dealing with their partners' injuries and was experienced by all participants.

Conclusion Three

Communities of influence became the centerpiece from which participants could move forward with their lives.

Participants found themselves engaged with numerous communities after their partner's return home. Communities of influence included military communities with which participants had longstanding and new relationships, and communities of friends and family. Despite the objectives of these communities of influence, those that understood the consequences of mMTBI often were more capable of providing support and resources necessary to assist participants with the process of RoS. Communities with little understanding and background in the area of this hidden injury often unknowingly erected barriers to this process. Participants experienced frequent transition among communities. They encountered bridges and walls within inter-related communities, often leaving them conflicted and paralyzed by the inconsistency of support and understanding.

Some of the communities of influence offered formal programming designed to assist families of injured warriors. These programs were designed to address the needs of participants within their current context; however, when participants transitioned from one setting to another, they often discovered that services were obsolete or not available. Participants expressed frustration with the provision of short-term support services and the lack of long-term assistance that could prepare them for the challenges that lay ahead.

In addition to formal communities providing support, communities of influence also refers to family and friends. Participants longed for support sustainable over time and across the continuum of care. A number of participants found sustainable support in the form of female friendships, specifically female friendships they had cultivated for many years prior to their partner's injury. Time and time again I heard of how close female friendships provided the encouragement and assistance needed to redefine self and the confidence to engage in roles they did not know they had the capacity to master. The long-term connectedness among women was essential to the well-being of participants as well as relationships with supports that were sustainable over time.

Conclusion Four

Successful engagement in roles of choice provided participants a framework from which to establish their new self, fostered perceptions of empowerment, and contributed to well-being.

After their husband's return from war, spouses found themselves immersed in roles and related routines shaped by circumstances. Participants abandoned personally meaningful roles in order to care for their loved one and facilitate the multiple transitions that followed medical discharge from the military. Roles of choice were replaced by roles of circumstance that were not of their choosing. For some, these roles of circumstance became the mainstay of their daily routines and they found little pleasure or fulfillment from the associated routines and activities. Over time, however, some participants developed a balance between the roles of circumstance and roles of choice. From this balance emerged improved states of well-being as women became engaged with others and a larger social network. Participants who experienced the highest state of well-being often adopted positions of leadership in organizations assisting other women in similar life situations. Their roles of circumstances matured into roles of choice providing a

sense of personal empowerment over circumstances that felt uncontrollable at one time. Empowerment brought high levels of well-being as well as affirmation for RoS.

Theoretical Literature

Scholarly literature informed this research during the planning, methods, and analysis phases of this research. During the planning phase, literature was used to frame my understanding of the current research related to my topic and research questions. Throughout the methods phase, the scholarly literature contributed to the analysis of my first interview transcripts and the development of questions for the second interview. Finally, the development of the CoRTs model and conclusions invited a re-examination of the theoretical literature as it relates to key sub-themes of the CoRTs Model of Well-Being in hopes that existing theoretical frames would inform findings and how the CoRTs model may inform existing theoretical frames.

My search found numerous theories from which three were chosen based on their applicability to the most central themes in the CoRTs Model of Well-Being. These three included Bandura's theory of self-efficacy (1994), Goode's theory of role strain, and theories of identity salience (Stryker & Serpe, 1982). None of the theories mentioned above have been applied directly to constructs of subjective well-being, however. Additionally, these theories have been adopted throughout the literature of education, psychology, and sociology, but are absent in any literature pertaining to the well-being of my chosen participant population.

Bandura's Theory of Self-Efficacy

The CoRTs Model of Well-Being identified perceptions of empowerment as influencing both well-being and the process of RoS. In addition, the model discusses the importance of role engagement and how experiences with roles contribute to redefining self. Women, who shared

experiences with successful engagement in roles of choice, discussed how these experience, in turn fostered perceptions of empowerment.

Self-efficacy theory is not a theory of empowerment but the belief in one's ability to succeed. This theory explains multiple internal processes that can influence performance, and in the case of spouses of mMTBI survivors, performance in daily routines that emerged post-deployment. Self-efficacy theory informs the CoRTs model in that it can provide a reason as to why the level of success with regard to role engagement had such a profound effect on the experiences of these women—an affect that shaped well-being.

Although not initially associated with well-being, Bandura's (1977) theory explains self-efficacy as influencing performance. According to his theory, a strong sense of self-efficacy enhances human accomplishment. A number of scholars, following up on Bandura's work suggested a connection between self-efficacy and well-being (Rottmann, Dalton, Christensen, Frederiksen, & Johansen, 2010). Conversely, his theory discusses how a poor sense of self-efficacy can negatively affect performance outcomes and shape not only success but activity choice.

Self-efficacy theory identifies four “processes”: (a) cognitive, (b) motivational, (c) affective, and (d) selection. Cognitive processes refer to the manner by which an individual thinks about a task and skill level needed to succeed at that task. Motivational processes refer to the intrinsic motivation necessary for an individual to engage in an activity. Affective processes outline how an individual feels during and after engaging in the activity. Selection processes refer to how and why an individual chooses tasks.

In relation to the CoRTs Model of Well-Being, cognitive processes could be interpreted as participants' experiences of success and failure in new roles and RoS. Participants

understanding of their skill levels was informed by the outcomes of activity engagement. Motivational processes are reflected in the participant's desire to enhance or abandon the newly adopted roles and RoS. These motivational processes reflected cognitive processes and facilitated barriers or bridges to RoS and perceptions of empowerment. The third process discussed in the self-efficacy theory, the affective process, contributes to each participant's state of well-being. Lastly, selection shapes choice roles and the RoS. Bandura's theory of self-efficacy illuminates some of the underlying, internal reasons why, as defined by the CoRTs model, participants were able or unable to adopt roles of choice or engage in activities necessary to redefining self.

In applying self-efficacy theory to CoRTs, we can better understand a number of key questions that arose during my analysis:

1. Does the participant believe she will be able to successfully complete an activity or engage in a role of personal choice?
2. What motivates the participant to engage in activities and what is her level of motivation to engage in an activity that may shape RoS?
3. How does the survivor's spouse feel after engaging in an activity when successful or unsuccessful, and how does she make choices in roles and routines?

Although these questions would inform the CoRTs model, an explanation of the external factors that contribute to performance is absent from self-efficacy theory. Ignoring external influences on beliefs of personal capacities, particularly when it involves trauma, leaves a void that is critical to understanding the experiences of women whose partners returned from war with mMTBI.

Identity Theory

The literature surrounding identity theory goes back three quarters of a century. Since then, theoretical models associated with identity theory have branched out to include internal mechanisms of identity (Stryker, 1968), social influences on self and identity (Mead, 1934) and identity saliency (Stryker & Serpe, 1982) to name a few. To inform the CoRTs model, I will focus on identity saliency. Understanding this phenomenon will help to inform the relationship between RoS and well-being. Identity saliency is described as the importance a person places on a specific identity. Salient identities transcend multiple contexts. The primary roles the individual engages in reflect the identities considered to be most salient. Additionally, identity saliency theory states that the higher levels of saliency for a specific identity, the greater the likelihood that participation in activities and choices will reflect that identity.

What happens when the identity most salient to an individual, is no longer viable given a change in circumstance? Many of the participants in my study experienced a shift in their lives that prevented them from maintaining their identity of military spouse, a salient identity for most women. In addition, these women were often removed from the social setting that reinforced that identity and all that surrounds it. The loss of salient identity challenged some participant's understanding of self. Participants who began to engage with communities that provided reinforcement of their experiences, provided opportunities to take on new roles, and recognized the importance of the roles they had adopted began to engage in the process of RoS. It appeared that the process became essential to redefining self, a shift from one salient identity to the emergence of another. In turn, consistent engagement in roles reflected from their most current salient identities contributed to participant well-being.

Identity salience theory discusses how external and internal factors influence an understanding of self and promote importance of one identity over another. It does not, however, discuss saliency shifts secondary to significant life events. The CoRTs model may provide an opportunity to explore why saliency of identity changes over time and circumstance and what facilitates the emergence of new salient identities.

Role Strain Theory

Role strain theory surmises that stress or “strain” occurs when the obligations, secondary to role participation demand too much from any one individual. Goode (1960) believed every individual has limited resources, and as role related obligations are added the benefits of role engagement become increasingly limited and performance in role activities suffers.

The partner of a service member who returned from war with mMTBI adopted numerous roles and related routines that reflected their new life circumstances. These roles included caregiver, primary breadwinner, single parent, patient advocate, chauffeur, money manager and the list goes on and on. In addition to taking on new roles, these women attempted to continue in familiar roles. Mother, friend, lover, wife, supporter, volunteer, teacher, and employee were all roles identified by study participants. The new and old roles frequently required conflicting obligations of time and resources; they presented participants with situational inconsistencies that created tension (e.g., looking out for the safety of their family by asking their spouse not to drive). Many participants found themselves drowning in commitment as they attempted to take on all the roles that would keep the social structure of the family afloat.

Role strain theory validates my assertion that role participation has emerged as bridge or barrier to RoS. Participants who were able to establish relationships with supports found assistance to relieve numerous role related obligations. Support systems provided respite for

women whose partner needed supervision while they participated in choice role activities, provided emotional support and opportunities to share experiences, and provided assistance with transportation and paperwork. Relief from these commitments helped participants to find time to engage in choice roles, roles that in turn often provided a bridge to RoS.

The theories of self-efficacy, identity saliency, and role strain inform the CoRTs Model of Well-Being through validating a number of assumptions considered throughout my analysis as well as explaining the relationships among constructs to well-being. In addition to these bodies of literature, there is a wide body of scholarly literature discussing the development of self, most of which explains the development of self through childhood experiences. There are however, a number of theories that discuss self as a developmental process occurring in adulthood. These include self concept theory, (Shavelson, Hubner & Stanton, 1976), self verification theory (Chen, Chen, & Shaw, 2004), and Epstein's (1983) cognitive self-theory to name a few. A rich understanding of each of these theories can potentially contribute to a better understanding of RoS.

Cognitive self-theory seems particularly relevant to understanding the process of RoS. Epstein (1983) discussed the concept of self as a personal understanding of your relationship with the world that is based on a series of personal understandings. He goes on to discuss how self is a construct of two primary systems from which we take-in and perceive information. The first, experiential, reflects our understanding of our world from past experiences. The second, rational, describes our logical interpretations of experiences and observations, accounting and making sense of new experiences and information. Cognitive self theory may help us better understand participant's development of RoS through exploring and better understanding the way participants process information and understand both past experiences and new realities.

In addition to the assumptions identified by these theoretical frameworks, there are a number of personal assumptions that informed by findings. These assumptions were briefly mentioned in my discussion of theoretical sensitivities in Chapter 3. However, fuller implications these assumptions did not become apparent until my findings were outlined in the CoRTs model.

Limitations and Considerations

Several limitations and key considerations must be presented in order to better understand the findings of this research. Limitations included my personal bias, the limited amount of time for interviews, and the fact that interviews were often subject to participant recall error. A number of other limitations included recruitment strategies targeted communities where participants were involved. I was therefore unable to tap into a population of women who had little to no contact with organizations providing support services.

The theory generated from my research is based on the experiences of 18 women. My findings reflect their experiences only. Although saturation was obtained, any qualitative researcher hesitates to make any claims about the applicability of their findings to a broader population. In addition, participants' experiences illustrate a snapshot of their daily lives across a 6- to 9-month time span. This theory does not provide in-depth insights into their daily life experiences.

Participants represent a spectrum of age, backgrounds, experiences and living situations. This may be considered both a strength and a limitation. Opening up the criteria for participation provided an opportunity to understand common experience across backgrounds and situations as opposed to narrowing the focus. I hope more targeted follow-up studies will provide greater depth to these findings. Follow-up studies could be specific to one branch of military service, include only career military as opposed to National Guard and Reservists, or provide exclusion

criteria that would omit spouses of service members who sustained any orthopedic or medical conditions not directly related to the mMTBI. Targeted sample may provide a better understanding of the experiences related to specific conditions and circumstances.

The women who shared their stories experienced changes in their lives after their partners returned with mMTBI. For the majority of survivors of mMTBI, the functional consequences are few. The level of disabilities of the service members married to participants did not mirror what would be expected from the literature. It immediately became apparent my sample did not reflect the “common” experiences of partners whose spouse sustained mMTBI, but one that reflected partners with disabilities that had long-term consequences.

The issue of comorbidity is an important consideration when evaluating research about service members returning from military service with injuries. Although this study targeted partners of service members who sustained mMTBI in theater, these wounded warriors manifested multiple diagnosis and comorbidity. There was no way to determine if the experiences of participants reflected issues associated with mMTBI only or limitations secondary to co-morbidities. Participants dealt with a host of impairments experienced by their partners. These included cognitive and behavioral issues secondary to the brain injury as well as limitations consistent with behavioral health issues such as post traumatic stress, anxiety, or depression, and physical injuries such as limb loss, burns, loss of an eye, or peripheral nerve damage. Only one of the 18 participants shared that she was unaware of any concomitant injuries. The other 17 identified behavioral health issues, specifically PTSD as being a significant source of functional limitations for their spouse. Despite the source of deficits, mMTBI existed as the common thread. Weeding out the differences of experiences, based on co-morbidities, in my opinion would be needless and unwarranted for study. The everyday lives

of participants changed due to the injuries their spouses sustained in combat. The changes in their lives are a reflection of a myriad of circumstances, including mMTBI and, for the majority of participants, associated co-morbidities.

Another key consideration for future research is the predeployment state of well-being and health (both physical and mental) of the participants. My research explored the state of well-being after mMTBI but did not take into consideration the spousal well-being before the injury. During my follow-up phone calls for trustworthiness, one of my participants asked if I knew how many of the participants I spoke with had been on some type of antidepressant or were seeking help before their spouse's injury. Her comment forced me to take pause as I had not considered this to be a major factor for consideration.

The final key consideration I would like to point out is the absence of faith and spirituality in my findings. Before conducting my interviews, I had expected faith and spirituality to emerge as a key factor influencing participant well-being. Its absence forced me to review many of the transcripts and my methods of analysis only to confirm that only a few of the participants discussed this as a contributor to well-being. More often faith and spirituality were discussed within the context of a community of influence. My interview questions did not directly ask about this and only on rare occasion did my probing delve into this arena. Despite revisiting my data and exploring the absence of this theme, I continue to be somewhat perplexed about why it did not emerge as a key contributor.¹⁶ Potential reasons may include the phrasing of interview questions, the absence of prompts to elicit more information about faith and spirituality, or the fact that participants' faith had been challenged by circumstances so it was not a contributor to well-being at the time they were interviewed.

¹⁶Faith and spirituality refers to formal religion as well as nontraditional spiritual beliefs.

The limitations and key considerations outlined above also give rise to several opportunities for future research. Some have been identified already while others follow.

Recommendations for Praxis

The CoRTs Model of Well-Being and conclusions from my research have potential implications spanning policy, programming, and health care in the 21st century. In order to apply the following recommendations for praxis, empirical testing of the CoRTs Model must be done to further develop and test the theory. This section discusses implications and recommendations based on the four conclusions presented above as well as my professional knowledge of programming and policy. My findings can help shape policy development and programming across the continuum of care. I first discuss how my model can shape the areas of adult learning and human resource development and follow up with a discussion of policy and programming in general.

Adult Learning and Human Resource Development

This research has been conducted as a requirement for a degree in adult learning and human resource development. Readers of this study may ask how identification of construct of well-being for spouses of warriors who have sustained mMTBI can inform these fields. I will attempt to explain how these findings may inform each of these individually and collectively

Malcom Knowles (1968) discussed adult learners as autonomous and self directed, utilizing life experiences and knowledge, being goal and relevancy oriented, and as seeking practical knowledge. Many of these core principles transcend adult learning theorists. The CoRTs Model of Well-Being depicts a schematic for how adults undergo the process of RoS and in doing so, are challenged with acquiring a number of new skill sets needed to negotiate lives changed by trauma. I hypothesize that these women learned their new skills not from formal

training but from peers, trial and error, and social networks that are developed across the continuum of care. As they tap resources from these areas, I hypothesize that they are able to develop relationships with supports, and participate in roles of choice or circumstance, which in turn potentially shape experiences with RoS.

Human resource development is another area to which the CoRTs Model of Well-Being may be applied. To date, countless support agencies have been developed for family members of wounded warriors. Although these have been developed with the best of intentions, many of these organizations and employees may be unaware of the complex interaction between factors that shape the experiences of their targeted clientele. Although the CoRTs Model of Well-Being is specific in terms of the population it reflects, the theory may provide these support agencies insights into key factors that must be addressed in order to improve outcomes. My research highlights how spouses of wounded service members have specific needs not reflected in the needs of their partners. In addition, their needs require long-standing active engagement and relationship development. More specifically, this model may provide trainers and program developers a deeper understanding of the contextual and social influences affecting the well-being of these women. The theoretical model may provide program developers insights into life experiences and key areas of relevancy for women who are seeking client-centered services that reflect their needs.

Policy

Policies adopted by the U.S. Department of Defense, Department of Veterans Affairs, federal, state, and local governments are designed to meet the immediate mission(s) of specific agencies as well as immediate social needs. The development of policy as it applies to wounded warriors and their families is an ongoing process. Modifications in policy often reflect urgent

issues such as suicide for returning warriors, treatment and diagnosis of behavioral health issues of service members, and identification and treatment of mMTBI. To date, the long-term ramifications of mMTBI on larger social structures is unknown. Policy decisions therefore have yet to be implemented pertaining to this concern. Findings from this research provide a glimpse into the effect of mMTBI on the survivor's spouse. Social policy, although generally reactive, may consider proactive initiatives based on findings from this research and research exploring similar questions. Understanding the effect of mMTBI on the spouse can shape policies for provision of services from an individual to a system, specifically a family system. Adoption and implementation of programs using the CoRTs is needed to determine outcomes of such programming. Until that is done, policy changes will not occur.

The majority of therapy and support programming is currently targeted to the surviving warrior, while the physical, emotional, and spiritual needs of the spouses often go unnoticed. Findings from this research can inform targeted program initiatives designed to promote role balance, respite, and community education, to name a few. In addition, recommendations for spousal and survivor (dual) participation in programming may facilitate burden and role strain for the spouse. These program initiatives potentially shape the long term consequences of this type of injury on the family unit and the greater social structure.

Health Care

Health care in the United States is largely and traditionally reactive. Management of illness and injury tends to address the immediate needs of the patient within the context of the health system. In addition, health services are valued primarily curative as opposed to preventive. However, wellness health care is beginning to emerge as an important consideration for long-term preventative health. Findings of this study may be used to help develop this area.

Currently, consideration regarding the effect of injury or illness to family members and communities is not a health priority in the US. Understanding the ways that military injuries may affect the lives and well-being of spouses and families may act as a cornerstone to address what I believe is a key problem with the US health care industry—a myopic view of illness and injury.

Figure 5.1 discusses some of the program goals that may be adopted based on my findings and practice recommendations. These recommendations are primarily geared towards the area of practice but policy and health care culture change will be needed in order for programming to be sustainable over time.

Programs and services designed to provide assistance to wounded warriors are currently provided by military, veteran, governmental, and civilian agencies. Each of these agencies has numerous policies and regulations as well as benefit criteria designed to ensure assistance is given to those who most need it. Unfortunately, the litany of paperwork and policies are typically burdensome and poorly understood. Frequently, as their needs change, families seek support from multiple agencies. No one agency provides the multiple services needed. In an attempt to tap into service providers, spouses are frequently met with denials, return of paperwork, requests for more information, all of which add to burden and frustration. In some cases, the agencies designed to facilitate access do nothing more than create roadblocks.

The CoRTs Model of Well-Being may provide these agencies an opportunity to explore how current policy facilitates or impedes program objectives. Policy changes in the areas of communications, access to services, reimbursement, and benefits may be reformed if an understanding of the network of contributors to well-being is understood by various agencies.

For example, an agency may have a policy providing services to spouses of warriors who are currently receiving rehabilitation. This model explains that communities of influence and the survivor's level of independence may be a better measure of who is in need of agency services. Similarly, program development and measurement of program outcomes may be able to adopt the CoRTs Model of Well-Being in order to ensure services target the areas influencing spousal well-being.

Goal: Communities of influence are both aware of and support the struggles of spouses whose partners' return from war with mMTBI.

Practice recommendations:

1. Develop community-based education initiatives that bring civilian and former military together for discussion of understanding and needs.
2. Provide incentives to local communities to support former military families and families of wounded warriors.
3. Inform communities of those most important issues around well-being for families.
4. Enhance community responsibility to providing services to spouses with and in addition to the warrior.

Goal: Spouses of mMTBI survivors are given opportunities to explore roles of choice

Practice recommendations:

1. Design and implement face-to-face and online therapeutic programs designed to identify and generate role development for spouses.
2. Develop opportunities for respite from care so role of choice can be explored.
3. Provide mentorship opportunities to help women explore role options by discussing issues with others in similar circumstances.
4. Provide affordable education opportunities so these women can explore career changes that are of personal interest and meet their personal needs.
5. Develop opportunities for activities that present these women with personal success and feelings of power.

Figure 5.1. Suggested Program Goals.

Assistive Services

Support services developed to assist with challenges experienced by families of wounded warriors provide valuable assistance in a number of areas including finances, emotional support, provision of health services, education services, and assistance with the complex bureaucratic trail often outlined for each service member. Despite their best efforts, families continue to experience multiple strains and perceive a lack of understanding of their personal needs. The experiences of participants suggest that the majority of support services developed since March 2002 ignore those salient constructs that affect the overall well-being of family members, specifically spouses of warriors with mMTBI.

The findings of this study can potentially shape the theoretical frames from which support agencies develop service provision and communicate across the continuum of care and life. Additionally, the CoRTs Model of Well-Being can be used to help develop policy as it relates to dealing with spouses of warriors with mMTBI from “theater to theater.” Like a puzzle, an understanding of the various pieces and how they fit together is imperative when developing the full picture of experiences and how they contribute to participant well-being. The wide range of support services currently available leave significant gaps that are next to impossible to negotiate on a consistent basis. As the model is further developed and tested, adopting the CoRTs Model of Well-Being could contribute to the necessary modifications in policy for eligibility for assistance, access to services, and communication between supports. This model provides a deeper understanding of relationships between key factors shaping spousal well-being of our returning service members with mMTBI. The applicability of my

research is not only the identification of constructs shaping well-being, but the manner by which they affect well-being and can shape lives of participants and their families for years to come.

Opportunities for Future Research

The grounded theory generated from this inquiry is only the tip of the iceberg as it relates to research opportunities in the area of well-being for the spouses of our wounded warriors. My findings open the door to more questions than answers for this population. As previously mentioned, the first area of follow-up research is to continue to develop the CoRTs Model and begin the process of empirical testing. In addition, future opportunities of research include an exploration of contributors to the long term well-being of this spousal population and their families, outcomes research for community based programming, incidences of behavioral health diagnosis and relevance to well-being, exploration of gender issues.

The first area of future research is that of long-term well-being and contributing factors. The majority of women who were interviewed for this study experienced dramatic change in their lives since their partner's return home from war. Although the time since their partner's injury varied from one year to seven years, this research did not explore how well-being and RoS evolved over time. A longitudinal study of the spousal experiences would provide an understanding of the developmental nature of RoS and how well-being is experienced long-term. Additionally a longitudinal study of constructs of well-being would provide insights into their dynamic nature over time. Research questions in this area may include:

- How does the well-being of spouses of survivors of mMTBI change over time?
- What life events shape spousal well-being?
- How do these women rate their well-being at given points in time?
- Do contributors to well-being change over time for these women?

Another area for follow-up inquiry is community based programming. As mentioned previously, there has been a significant push to provide support services for families of wounded warriors in recent years. Although these services are needed across the continuum of care, timely and consistent access to services can be a challenge for spouses who have little time to explore and take advantage of programs. In addition, these services are often available for families who have experienced severe injury and do not provide the necessary services for those with “mild” injuries. Throughout this research participants discussed challenges associated with access to community based programming. Research exploring access and outcomes, online social networking, extended “camp” type programs, and community based respite would help inform future development of programs targeted for this population. Research questions pertaining to community based programming include:

- How do programs currently meet the needs of families who have a loved one with a mMTBI?
- How does the platform of delivery influence outcomes of programming (web based vs. face to face)?
- Do programs that transcend context provide for the perceived needs of spouses?
- How do programs address issues associated with role strain and identity saliency?

A third area of inquiry is exploration of the health of the spouse of survivors pre-deployment. As discussed earlier, during my follow-up conversations with participants, it became evident that it would be helpful to study how the state of physical and mental health of participants, before and after their loved one’s injury, influenced experiences with well-being and RoS. Opportunities for inquiry in this area may be essential in programming for the

wounded warrior and their families and may reshape the CoRTs Model of Well-Being. Research questions may include:

- How does the predeployment health of these women influence experiences with well-being?
- How does well-being reflect the physical, emotional, and spiritual health of these women?
- How does the health of these women reflect influence the health of their partners?
- How does physical, emotional, and spiritual health influence the process of RoS?

Postsecondary traumatization, (taking on PTSD like symptoms from their spouses) has been discussed in the literature as a consequence of combat on the family members of warriors (Solomon, 1992) . My research did not explore the incidence of this phenomenon, but follow-up inquiry, asking the following questions, may provide greater insights into the constructs of well-being for the mMTBI spousal population:

- What is the incidence of postsecondary traumatization in spouses of brain injured service members?
- How does postsecondary traumatization shape relationships with supports, engagement in roles and the process of RoS?
- How does post secondary traumatization shape well-being these women?

The fourth area to explore is gender issues and how gender shapes constructs of well-being and RoS. The individuals who joined me in my research were all women whose husbands sustained mMTBI. I would encourage follow-up research with men whose female spouses sustained mMTBI. Opportunities for research in the area of gender and how this potentially

shapes the constructs of well-being would provide a greater sense of experiences post injury and I suspect a very different model would emerge. Areas of inquiry include:

- What differences exist between constructs of well-being for female spouses versus male spouses?
- How do male spouses understand contributors to their well-being?
- How do male spouses explain the relationship among these contributors?
- How do male spouses negotiate role strain when their wives return with mMTBI?

The final area of research I would like to highlight has to do with the multiple diagnoses of participant spouses. Again, this was highlighted in the key considerations discussion above but, given the design of my study, there is no way to determine which of the multiple diagnosis contributed to experiences of participants. A similar study targeting single diagnostic criteria may be helpful.¹⁷

Other areas of research opportunities include the effect of variables such as branch of service, number of children of participants, religion and spirituality, geographic location of participants, and financial stability. All of these emerged as contributing factors to RoS and well-being in some participants and warrant further investigation.

Conclusion

“Collateral damage” on the home front has been ignored while potentially hundreds of thousands of warriors returned from wars in Iraq and Afghanistan with mMTBI (Warden, 2006). Partners of those injured on the battlefield experience trauma of their own. Spouses of service members who had sustained mMTBI found themselves living lives very different than the ones experienced prior to deployment. The well-being of these women was compromised and the

¹⁷Comorbidity of brain injury and PTSD is common, making it difficult to conduct a study that delineates diagnostic criteria as an inclusion criteria.

complex relationship of contributing factors found its epicenter with RoS. The stories of 18 women over the course of 18 months gave rise to the CoRTs Model of Well-Being, a theoretical model produced through grounded theory methodology that may provide a framework from which future policy and practice may be developed.

Four key conclusions have been outlined each potentially informing the future of care for veteran's families: mMTBI is an injury affecting the life of the surviving service member as well as the life of his partner; the myriad consequences of combat-related mMTBI on the female spouse were significant enough so that most of these women engaged in a journey of redefining self. Communities of influence became the centerpiece from where participants could move forward with their lives or remain in their current state of well-being. Successful engagement in roles of choice provided participants a framework from which to establish their new self, fostered perceptions of empowerment, and informed well-being.

It has only been in the last few years that mMTBI has been widely recognized in the media, military, and mainstream society. Recognition has brought forward changes in services, policy, health care provision, and benefits for those injured. I expect the effect of this injury on the service member's family may come to light in subsequent years. Recognition of the struggles of these women and an understanding of contributing factors to their well-being potentially will inform future changes in policy, programs, and health care. The spouses of injured service members are the home front heroes of OIF/OEF. These women deserve opportunities to participate in activities of personal choice that contribute to their personal well-being.

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APPENDIX A

PERSONAL BACKGROUND AND ASSUMPTIONS

When discussing the findings of this study, there are three key assumptions I would like to outline, all of which informed the analytical phase of this study. These three assumptions include my perspective of the world and personal experiences shaped by 20 years of experience in the field of occupational therapy, my constructivist epistemology, and my assumption that well-being is a relatively dynamic process and changes from moment to moment.

The View of an Occupational Therapist

The first and potentially most important assumption discussed is the frame of reference by which I understand the world. I have been an occupational therapist for almost 20 years. During this time, I have crafted the lens with which I view the world, focusing on activity engagement and participation. I constantly dissect contextual variables as to how they either promote or impede an individual's ability to meet personal goals. As an occupational therapist, I seek to understand the level of skill it takes to complete a task and scrutinize the multiple exchanges occurring between person and activity. I believe activity engagement and participation is the essence of personal being. As an occupational therapist, I assume our understanding of self is deeply anchored in the activities we engage in on a daily basis, the meaning we attribute to those activities, the individuals with whom we spend time, and the places we find most comforting.

Throughout this study, participants spent much of their time crafting a picture of their everyday lives and how parts of this craft informed their state of well-being. Throughout the data collection phase as well as the analysis, I am sure I unwittingly focused on participant issues that are reflective of my

understanding of the world, but cannot identify those biases. I attempted to the best of my ability to eliminate bias when I reflected on its presence.

Constructivist Epistemology

The second assumption I would like to outline is in many ways similar to the one outlined above—my constructivist epistemology. I believe that understanding of reality is based on the interpreter's contextual understanding. Reality and knowledge are individually shaped and are variable versus objective and static. The CoRTs Model of Well-Being, developed from this grounded theory research, is based on each participant's understanding of their experiences and my analysis and understanding of their stories. The impact of this assumption on my findings is best reflected in a statement outlined by von Glasersfeld (1995). He explained constructivist epistemology as understanding that "concepts, models, theories, and so on are viable if they prove adequate in the contexts in which they were created" (p.7). The context in which the CoRTs model was created refers to the experiences and understanding of participants at the point in time I interviewed them as well as the manner by which I understood the stories they shared and interpreted those data.¹⁸

Well-Being as a Dynamic Process

The third assumption I would like to outline for this research is the fact that well-being is a dynamic process. I believe the lives of all individuals change on a daily basis and this was also true for study participants. In addition to changes in their lives secondary to their loved one's injury, participants went through a number of significant life events over the course of the year—having babies, loss of parents and friends, moving to new communities, and health issues—a seemingly infinite list.

¹⁸Efforts to ensure trustworthiness were used but do not counterbalance the power of personal interpretation and understanding.

For these women, their state of well-being fluctuated because of life events in addition to life changes associated with their spouse's injury. During the course of the study, it became increasingly obvious that because of its dynamic nature, well-being varied from participant to participant. It also became apparent that the reason for these fluctuations is a topic for a different study. I was unable to determine the true underlying reason for participants' state of well-being at any given point in time. The findings of this study only reflect the state of well-being experienced at the time of each participant's interviews. In addition to outlining assumptions, a number of limitations and considerations will shed light on the significance of the CoRTs Model of Well-Being.

APPENDIX B

RECRUITMENT LETTER

January 3, 2009

To Whom This May Concern:

I am currently a doctoral student in Human Development at Virginia Tech. I want to thank you for assisting me in recruiting participants for my research. As you know, the purpose of my research is to explore the well-being of the recently disabled soldier's spouse. Specifically, this research, will explore the experiences of women whose loved ones have returned from Iraq and Afghanistan with mild to moderate traumatic brain injury. I believe an understanding of their issues, through their own words, will help provide a foundation for service initiatives designed to assist families of our wounded warriors.

I am looking for individuals who are willing to participate in one or more of the following:

- 1) One to three hour long interviews that will be audio-recorded. The majority of these interviews will take place over the phone although I am looking for a few individuals who are willing to speak with me face to face during the second interview.
- 2) Participate in an online blog for five weeks. The blog site is password protected and participation will be confidential.

Additionally participants for the interviews must meet the following criteria:

- 1) Have been married for at least one year prior to deployment
- 2) Have had their spouse living at home for at least three months since their injury
- 3) Be willing to be audio-recorded

If you know of anyone who would be willing to speak with me, please provide them with my cell phone or email. Thank you for your assistance in my research.

Warm regards,

Leslie Freeman Davidson

PhD candidate, Virginia Tech

703.969.1967 (cell)

lesoogle@gmail.com

APPENDIX C

INFORMED CONSENT FORM

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY

Informed Consent for Participants
in Research Projects Involving Human Subjects

Title of Project: **Subjective Well-being; the Spousal Experiences Of Operation Freedom's Soldiers with Brain Injury**

Investigator(s) **Dr. Elizabeth Creamer, Dr. Paul Renard, and Leslie Freeman Davidson**

I. Purpose of this Research

The purpose of this study is to understand contributing factors of well-being in women whose husbands have returned from combat with mild and moderate brain injury.

II. Procedures

You will be asked to participate in one or more of the following activities. You can identify which activity you may want to participate in:

- Complete a brief online questionnaire

and

- Participate in a 45-60 minute telephone interview (you may be asked to do this one time, two times, or three times)
and/or
- Participate in a 45-60 minute face-to-face interview at the setting of your choice (face to face interview would replace the second telephone interview referenced above)

You will be asked to talk about your thoughts and experiences as they apply to your well-being (good and bad) since your loved one has returned from war. You will be asked to discuss how your partner's brain injury has changed your life and how you cope with those changes. You may be asked to discuss your support systems, how you see yourself and your roles, and how you understand change. If you participate in the interviews, they will be audio-recorded.

III. Risks

Throughout the study you will be asked to share your daily experiences. You will be discussing the impact of your spouses' brain injury on your well-being, your roles, and your life in general. These conversations are potentially upsetting. You can however refuse to answer any questions at any time. You can also choose to end the interview with not penalty. At the end of the interview sessions you will be provided with information about support for family members whose loved ones have a brain injury as well as military and veteran support services.

IV. Benefits

There are a number of family support initiatives being created to help spouses of our brain injured warriors. These services are based on the needs of those who have been most vocal. This study is designed to determine what you feel contributes to your well-being. In turn, it is hoped that support programs can address those contributors and provide a strong foundation for program development.

V. Extent of Anonymity and Confidentiality

There will be no names on any of the information you provide during the study. All reports will protect your identity.

Only individuals who are directly involved in this study will have access to your information. Audiotapes and questionnaires will be destroyed at the end of the study.

All study information will be kept confidential except in the cases where child abuse is suspected or participants lead the interviewer to believe that there may be a threat to themselves or to someone else. If child abuse or threats are suspected, the interviewer is required by law to inform the proper authorities.

VI. Compensation

There is no monetary compensation monetary for participation in this study. You may feel a sense of accomplishment in being able to provide us with information that will be used to inform and help others.

VII. Freedom to Withdraw

Participation in this study is voluntary. Study participants are free to withdraw at any time during the study at no penalty. Participants are free to not answer any questions they choose during the course of the study.

VIII. Your Responsibility

- You will be asked to identify how many interviews you would like to participate in; one, two or three.

Depending on your response you will be asked to

- Complete an online questionnaire
- If you choose to participate in at least one interview that will last 45-60 minutes. During this interview you will be asked to share your thoughts and understanding of what contributes to your well-being and how your partners' brain injury during military service contributes to your happiness. You will be asked about life changes you may have experienced since his return and how you cope with these life changes. The interviews will be audio-taped.
- If you choose to participate in the follow-up interviews questions will be based on findings from the previous ones. Interviews will ask you to share your thoughts and experiences

about a number of topics that may include, what do you think well-being means?, life stressors, supports, and what you believe contributes to your wellbeing.

Subjects Permission

I have read the Consent Form and conditions of this project. I have had all my questions answered. I hereby acknowledge the above and give my voluntary consent:

_____ Date _____
(Participant signature)

_____ Date _____
(Witness-optional)

Should I have any pertinent questions about this research or its conduct, and research participant's rights, and whom to contact in the event of a research-related injury to the subject, I may contact:

Leslie Freeman Davidson

703/969-1967

Investigator

lesoogle@gmail.com

Dr. Paul Renard

703/538-8475

Faculty Advisor

prenard@vt.edu

Dr. Marcie Boucouvalas

703/ 538-8469

Faculty Advisor

marcie@vt.edu

APPENDIX D

TELEPHONE QUESTIONNAIRE FOR DEMOGRAPHIC INFORMATION

Participant # _____

Date of contact # _____

Demographic information

1. Can you please provide the following information.

Name (first only):

State currently living:

Country:

Email Address:

Contact phone number:

2. How long has it been since your partners brain injury

0-1 yr

1-2 yr

2-4 yrs

greater than 4 years ago

3. How many children do you have and what are their ages?

0

1

2

3

4 or more

4. How long were you married prior to your spouses deployment?

less than one year

1-2 yrs

2-4 years

5-7 years

7 or more years

5. What is your highest level of education?

Junior High School

High School

Associate Degree

Bachelors Degree

Graduate Degree

Comments

6. Rate the level of support you feel you currently have

no support

little support

a fair amount of support

a great deal of support

Comment

7. How happy do you think you are right now?

The unhappiest I have ever been in my life

Unhappy

Fairly happy

Happy

The happiest I have ever been in my life

Comment

8. Are you willing to participate in an interview to discuss well-being. The interview will be audio-taped and take about 45-60 minutes.

Yes, I am willing to participate in one interview

Yes, I am willing to participate in one or two interviews

Yes, I am willing to participate in one, two or three interviews

No, I am not willing to be interviewed

Other (please specify)

9. Are you willing to participate in a research study where I will post at least two blogs a week for five weeks. My blog comments will be based on a theme presented to me that has to do with my well-being.

Yes

No

Possibly, I would like to know more

Comment

APPENDIX E

PROTOCOL FOR INTERVIEW ONE

Interview Questions

(This is a semi-structured interview. If study participants begin to discuss a topic in depth or a theme begins to emerge I will follow that idea if I believe it is critical to the study. The following questions are designed for the purpose of the interview but some interviews may not contain information on all of the questions and other questions may arise based on the information shared with me during our exchange).

Interview 1

I want to thank you for agreeing to be interviewed for my study. As I mentioned in my emails and during our last discussion I am interested in what contributes to the well-being of women whose husbands have returned from war with mild and moderate brain injury.

This interview is being recorded and all of the information you share with me is confidential.

You can refuse to answer any of the following questions or end the interview at any time. Before we begin do you have any questions?

Turn on audio-tape

1. Before we discuss wellbeing, I would like you to tell me a little bit about yourself. Can you tell me your story?

Probes; background, children, religion, supports, values, where did you grow up. .

.

2. As you know, my research is about well-being. How would you define well-being?

Probe for both positive and negative definition

3. _____ (name of spouse) came home with a brain injury after being deployed for this war. Share with me how you believe his injury may influence your daily live or how you live day to day?

Probes; wellbeing, activities and roles, relationship with spouse and others. . .

4. You have gone though a number of changes since _____ (name) returned, Can you share with me some of these changes? Do you think these have impacted your well-being?
5. Does your well-being change from time to time? Can you explain how and why?

APPENDIX F

PROTOCOL FOR INTERVIEW TWO

I want to thank you for being available to speak with me again. In addition, wanted to remind you of the purpose of my research and update you on some of my findings since the last time we spoke. As mentioned before my doctoral research is exploring contributors of well-being in spouses of our warriors who have returned home with mild and moderate brain injury. Until now, I have had the opportunity to speak with thirteen women and have gained insights into contributors you feel are important. The purpose of this follow- up interview is to gain a better understanding of a few of these contributors so my questions may seem a bit more targeted than last we spoke. This interview should take about 45-60 minutes and it will be recorded. You can ask for me to turn off the recorder at any time and you may stop the interview at any time. In addition, I would encourage you to present different view-points. Before we begin do you have any questions?

Question 1

When we last talked you were able to provide me with a definition of well-being. Well-being was described as a sense of physical and emotional health and feelings of happiness and contentment. Although we spent a bit of time discussing this, I did not ask you to describe your personal well-being, relative to that definition, I would like to take the first few minutes to gain a sense of your well-being over the last 6 months. (If needed add probes including; has it remained the same?, changed? what may have contributed to the

changes over that time?)

Question 2

Many of the women I spoke with discussed changes in identity as a contributor to their well-being. When I talk about identity I mean your personal sense of self and who you are.

In identifying identity as a contributor to well-being, a number of women discussed their roles, what they did with their time, and how they felt they were valued.

Can you share with me if you feel as though your identity has changed since your loved one's injury? How, if at all has identity contributed or taken away from your personal well-being?

Question 3

a) The second factor many of the women I spoke with identified as a contributor to well-being was the idea of control. For example, the majority of women talked about how, during the initial notification of their loved one's injury, they felt they had no control over what was being done or decided, as well as control over the information being shared. I would like you to share with me your thoughts and experiences with this idea of control as being a contributor to your well-being. Probe for the some of the following: control over information, environment, healthcare

Question 4


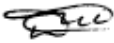
The third theme that I heard during my interviews was the significance of supports as a contributor to well-being. We spoke at length about the supports you had and did not have throughout your journey since your husband's injury. Can you share with me how the supports

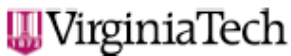
either contributed or took away from your sense of well-being? probe for military, friends, family, organizations

Thank you for your time and your candidness during these interviews. I am hoping to have the results of my research completed in the next couple of months and at that time you may hear from me to get feedback about what I learned from your thoughts and ideas. Again I want to thank you for your help with this effort and most of all thank you for the sacrifices you and your family have made.

APPENDIX G

APPROVAL OF CONSENT FORMS

 VirginiaTech		Office of Research Compliance Institutional Review Board 2000 Kraft Drive, Suite 2000 (0497) Blacksburg, Virginia 24061 540/231-4991 Fax 540/231-0959 e-mail moored@vt.edu www.irb.vt.edu <small>FWA00000572(expires 1/20/2010) IRB # is IRB00000867</small>
DATE: December 16, 2008		
MEMORANDUM		
TO:	Elizabeth G. Creamer Leslie Davidson Paul Renard	Approval date: 12/16/2008 Continuing Review Due Date: 12/1/2009 Expiration Date: 12/15/2009
FROM:	David M. Moore 	
SUBJECT: IRB Expedited Approval: "Subjective Well-Being: Female Spouses of Returning Soldiers with Mild and Moderate Brain Injury", IRB # 08-765		
<p>This memo is regarding the above-mentioned protocol. The proposed research is eligible for expedited review according to the specifications authorized by 45 CFR 46.110 and 21 CFR 56.110. As Chair of the Virginia Tech Institutional Review Board, I have granted approval to the study for a period of 12 months, effective December 16, 2008.</p> <p>As an investigator of human subjects, your responsibilities include the following:</p> <ol style="list-style-type: none">1. Report promptly proposed changes in previously approved human subject research activities to the IRB, including changes to your study forms, procedures and investigators, regardless of how minor. The proposed changes must not be initiated without IRB review and approval, except where necessary to eliminate apparent immediate hazards to the subjects.2. Report promptly to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.3. Report promptly to the IRB of the study's closing (i.e., data collecting and data analysis complete at Virginia Tech). If the study is to continue past the expiration date (listed above), investigators must submit a request for continuing review prior to the continuing review due date (listed above). It is the researcher's responsibility to obtain re-approval from the IRB before the study's expiration date.4. If re-approval is not obtained (unless the study has been reported to the IRB as closed) prior to the expiration date, all activities involving human subjects and data analysis must cease immediately, except where necessary to eliminate apparent immediate hazards to the subjects. <p>Important: If you are conducting federally funded non-exempt research, please send the applicable OSP/grant proposal to the IRB office, once available. OSP funds may not be released until the IRB has compared and found consistent the proposal and related IRB application.</p> <p>cc: File</p>		
<p style="text-align: center;"><i>Invent the Future</i> VIRGINIA POLYTECHNIC INSTITUTE UNIVERSITY AND STATE UNIVERSITY <i>An equal opportunity, affirmative action institution</i></p>		




Office of Research Compliance
Institutional Review Board
2000 Kraft Drive, Suite 2000 (0497)
Blacksburg, Virginia 24061
540/231-4991 Fax 540/231-0959
e-mail moored@vt.edu
www.irb.vt.edu

FVA00000572(expires 1/20/2010)
IRB # is IRB00000667

DATE: November 17, 2009

MEMORANDUM

TO: Elizabeth G. Creamer
Leslie Davidson
Paul Renard

FROM: David M. Moore 

Approval date: 12/16/2008
Continuing Review Due Date: 12/1/2009
Expiration Date: 12/15/2009

SUBJECT: **IRB Amendment Approval:** "Subjective Well-Being: Female Spouses of Returning Soldiers with Mild and Moderate Brain Injury", IRB # 08-765

This memo is regarding the above referenced protocol which was previously granted approval by the IRB on December 16, 2008. You subsequently requested permission to amend your IRB application. Since the requested amendment is nonsubstantive in nature, I, as Chair of the Virginia Tech Institutional Review Board, have granted approval for requested protocol amendment, effective as of November 17, 2009. The anniversary date will remain the same as the original approval date.

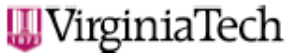
As an investigator of human subjects, your responsibilities include the following:

1. Report promptly proposed changes in previously approved human subject research activities to the IRB, including changes to your study forms, procedures and investigators, regardless of how minor. The proposed changes must not be initiated without IRB review and approval, except where necessary to eliminate apparent immediate hazards to the subjects.
2. Report promptly to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.
3. Report promptly to the IRB of the study's closing (i.e., data collecting and data analysis complete at Virginia Tech). If the study is to continue past the expiration date (listed above), investigators must submit a request for continuing review prior to the continuing review due date (listed above). It is the researcher's responsibility to obtain re-approval from the IRB before the study's expiration date.
4. If re-approval is not obtained (unless the study has been reported to the IRB as closed) prior to the expiration date, all activities involving human subjects and data analysis must cease immediately, except where necessary to eliminate apparent immediate hazards to the subjects.

cc: File

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Office of Research Compliance
Institutional Review Board
2000 Kraft Drive, Suite 2000 (0497)
Blacksburg, Virginia 24061
540/231-4991 Fax 540/231-0959
e-mail moored@vt.edu
www.irb.vt.edu

FWA00000572(expires 1/20/2010)
IRB # is IRB00000667

DATE: December 10, 2009

MEMORANDUM

TO: Elizabeth G. Creamer
Leslie Davidson
Paul Renard

FROM: David M. Moore 

Approval date: 12/16/2009
Continuing Review Due Date: 12/1/2010
Expiration Date: 12/15/2010

SUBJECT: **IRB Expedited Continuation 1:** "Subjective Well-Being: Female Spouses of Returning Soldiers with Mild and Moderate Brain Injury", IRB # 08-765

This memo is regarding the above referenced protocol which was previously granted expedited approval by the IRB. The proposed research is eligible for expedited review according to the specifications authorized by 45 CFR 46.110 and 21 CFR 56.110. Pursuant to your request, as Chair of the Virginia Tech Institutional Review Board, I have granted approval for extension of the study for a period of 12 months, effective as of December 16, 2009.

Approval of your research by the IRB provides the appropriate review as required by federal and state laws regarding human subject research. As an investigator of human subjects, your responsibilities include the following:

1. Report promptly proposed changes in previously approved human subject research activities to the IRB, including changes to your study forms, procedures and investigators, regardless of how minor. The proposed changes must not be initiated without IRB review and approval, except where necessary to eliminate apparent immediate hazards to the subjects.
2. Report promptly to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.
3. Report promptly to the IRB of the study's closing (i.e., data collecting and data analysis complete at Virginia Tech). If the study is to continue past the expiration date (listed above), investigators must submit a request for continuing review prior to the continuing review due date (listed above). It is the researcher's responsibility to obtain re-approval from the IRB before the study's expiration date.
4. If re-approval is not obtained (unless the study has been reported to the IRB as closed) prior to the expiration date, all activities involving human subjects and data analysis must cease immediately, except where necessary to eliminate apparent immediate hazards to the subjects.

cc: File

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