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## IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS OF AN OIF/OEF VETERAN & A CIVILIAN WITH TRAUMATIC BRAIN INJURY

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# IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS OF AN OIF/OEF VETERAN & A CIVILIAN WITH TRAUMATIC BRAIN INJURY

## Abstract

In the past, when thinking of injured soldiers returning home from war, pictures of individuals in wheelchairs with amputations might come to mind. It was hard to ignore those visible injuries. Soldiers returning home from Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF) in Afghanistan can have unseen wounds, some in the form of Traumatic Brain Injuries (TBI). In the past individuals with TBI died of their injuries. Currently, advances in technology has drastically change our image of what an injured individual with TBI looks like, whether veterans or civilians. Unseen wounds such as TBIs pose a new set of challenges for an injured individual's reintegration into society. **Objective:** The purpose of this study was to gain insight into the experiences and needs of an OIF/OEF veteran and a civilian with TBI from their perspective. **Method:** A qualitative study was conducted using semi-structured intensive interviews with two participants (one civilian and one veteran) who suffered a traumatic brain injury. The interview information is presented in case study format that allowed for in-depth exploration of each participant's experience. **Findings:** Some of the core themes that emerged from the interviews included isolation, depression, somatic complaints, self-medication, and inability to return to work. **Conclusion:** The findings suggest that the road to recovery after a TBI contains challenges on a personal, familial, and community level. Implications for social work education, practice, policy, and future research are also addressed.

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**IN THEIR OWN WORDS:  
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A CIVILIAN WITH TRAUMATIC BRAIN INJURY**

**Aswood M. LaFortune**

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in

Social Work

Presented to the Faculties of the University of Pennsylvania

in

Partial Fulfillment of the Requirements for the

Degree of Doctor of Social Work

2012

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**IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS**

**IN THEIR OWN WORDS:  
EXPLORING THE UNSEEN WOUNDS OF AN OIF/OEF VETERAN &  
A CIVILIAN WITH TRAUMATIC BRAIN INJURY**

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# IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS

## DEDICATION

I dedicate this dissertation first and foremost to my Lord and personal savior, Jesus Christ. To my mother, thank you for your love, support, prayers, and your emphasis on education. To the brave men and women in the military who make the ultimate sacrifice, thank you.

*I can do all things through Christ, because He gives me strength.*  
***Philippians 4:13***

# IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS

## ACKNOWLEDGEMENTS

I would like to thank the many people who made the accomplishment of this dissertation a reality. I am grateful for all the support, commitment, and encouragement that I have received throughout this process. This journey has been an uphill battle and my success is a testament to the sacrifices my loved ones have made.

My grandmother was one of my biggest supporters and I know she would have been so excited to see me complete this dissertation. Even though she is no longer here with me, I know she believed in me and that has made a world of difference. From the day I was born my mother has made all the necessary sacrifices to get me to this point. You have been caring, loving, and selfless in giving up your own goals to make it possible for me to reach mine. I am so humbled that you allowed me to stand on your shoulders. To my brothers, thank you for a wonderful childhood and for the kind of love that knows no bounds.

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## **IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS**

To the two participants, I am humbled by your courage and determination. This dissertation would not be possible without your willingness to share such a difficult period of your life with a complete stranger. I am blessed for having met you.

I owe a great deal of gratitude to Mrs. Jackson and Biage Alexandre who spent numerous hours reading and editing chapters of this dissertation. Thank you for listening to my ideas, sharing your thoughts with me, and keeping me grounded in my time of stress. To my support system at BBC, thank you for all the prayers and encouragement. To Maggy, Lude, Luders, Melory, Mildred, Edzer, Nahomie, grandma, grandpa, Fr. Edmond, Mrs. Bousseau, thank you for cheering me along the way. You all have been with me from the start of this journey and I am blessed to have you in my life.

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Je t'aime.

# IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS

## ABSTRACT

IN THEIR OWN WORDS:

EXPLORING THE UNSEEN WOUNDS OF AN OIF/OEF VETERAN &  
A CIVILIAN WITH TRAUMATIC BRAIN INJURY

Aswood M. LaFortune

Richard J. Gelles, PhD

In the past, when thinking of injured soldiers returning home from war, pictures of individuals in wheelchairs with amputations might come to mind. It was hard to ignore those visible injuries. Soldiers returning home from Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF) in Afghanistan can have unseen wounds, some in the form of Traumatic Brain Injuries (TBI). In the past individuals with TBI died of their injuries. Currently, advances in technology has drastically change our image of what an injured individual with TBI looks like, whether veterans or civilians. Unseen wounds such as TBIs pose a new set of challenges for an injured individual's reintegration into society. **Objective:** The purpose of this study was to gain insight into the experiences and needs of an OIF/OEF veteran and a civilian with TBI from their perspective. **Method:** A qualitative study was conducted using semi-structured intensive interviews with two participants (one civilian and one veteran) who suffered a traumatic brain injury. The interview information is presented in case study format that allowed for in-depth exploration of each participant's experience. **Findings:** Some of the core themes that emerged from the interviews included isolation, depression, somatic complaints, self-medication, and inability to return to work. **Conclusion:** The findings suggest that the road to recovery after a TBI contains challenges on a personal, familial, and community level. Implications for social work education, practice, policy, and future research are also addressed.



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## LIST OF ABBREVIATIONS

ACRM	American Congress of Rehabilitation Medicine
CT	Computerized Tomography
CDC	Centers for Disease Control and Prevention
DOD	Department of Defense
DVBIC	Defense and Veterans Brain Injury Center
FST	Forward Surgical Team
GCS	Glasgow Coma Scales
GWOT	Global War on Terror
IED	Improvised Explosive Device
IZ	International Zone
LOC	Loss of Consciousness
MRI	Magnetic Resonance Imaging
MTBI	Mild Traumatic Brain injury
OIF	Operation Iraqi Freedom
OEF	Operation Enduring Freedom (in Afghanistan)
OND	Operation New Dawn (in Iraq)
PTA	Posttraumatic Amnesia
PTSD	Posttraumatic Stress Disorder
TBI	Traumatic Brain Injury
VAMC	Veterans Administration Medical Center
VHA	Veterans Health Administration

## **Chapter I: Understanding Traumatic Brain Injury**

*“It’s hard because, you know you’re not the same...  
but people can’t see that.”*

--Ezra suffered a TBI in Iraq

### **Introduction**

Traumatic brain injury (TBI) is currently identified as the “signature wound” for soldiers returning from Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF) in Afghanistan (Hoge et al., 2008; Okie, 2005). Among surviving soldiers wounded in combat, TBI appears to account for a larger proportion of casualties than it has in other recent U.S. wars (Hoge, Auchterlonie, & Milliken, 2006; Okie, 2005). Okie (2005) noted that nearly “Twenty-two percent of the wounded soldiers from Iraq and Afghanistan treated at Landstuhl Regional Medical Center in Germany had injuries to the head, face or neck” (p. 2044; Jackson, Hamilton, & Tupler, 2008). Unlike veterans who have lost limbs or who are disfigured, veterans with TBI have wounds that are usually invisible to their families and to society at large. The term “soldier” refers to a member of the Army branch of the military and the term “veteran” refers to a soldier who has served at least 180 days in a warzone. For the purpose of this study “veteran” may be used to refer to members of all branches of the U.S. Armed Forces.

The percentage of injured soldiers dying in combat has drastically decreased from thirty percent in World War II to only ten percent in the current conflicts in Iraq and Afghanistan (Gawande, 2004). Soldiers are now surviving blast injuries that were impossible to survive in past wars (Jackson et al., 2008; Warden, 2006). Upgrades to the body armors and helmets are

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often credited for the increased survival rates (Okie, 2005). A recent study (Tanielian & Jaycox, 2008) conducted with returning OEF/OIF veterans concluded that there are a staggering number of veterans returning home with TBI diagnosis. As TBI rates among soldiers continue to rise, it is important to understand the impact that TBI has on their lives and or their future.

This dissertation will address the current phenomenon of increased TBI diagnosis in U.S. troops returning from Operation Iraqi Freedom and from Operation Enduring Freedom in Afghanistan. I provide a review of the modern literature on TBI, its prevalence in the U.S., and the role of blast attacks on increased TBI rates in U.S. troops. In addition, I present case studies of two individuals with TBI discussing their experiences adjusting to life, work, and relationships post injury. Finally, I will address implications for social work practice with those who experience TBI, including suggestions for intervention with the individual and with family members.

### **What is a Traumatic Brain Injury?**

In order to understand the nature of TBI and how it affects soldiers on the battlefield, an overview of TBI is necessary. The leading causes of TBI in the United States are falls, motor vehicle accidents (MVA), struck by/against, assaults, sports-related injuries, and recreational activities (Langlois, Ruthland-Brown, & Wald, 2006; Vaishnavi, Rao, & Fann, 2009). The definition of TBI used by the American Congress of Rehabilitation Medicine (ACRM, 1993) is “any extra cranial mechanical force to the brain that leads to any of the following:

1. Any period of loss of consciousness;
2. Any loss of memory for events immediately before or after the event;
3. Any alteration in mental state at the time of the event” (ACRM, 1993; Kim et al., 2007).



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This study uses the above definition of traumatic brain injury. Jackson et al. (2008) explained that the force of the jolt or blow that causes the head to accelerate and then decelerate abruptly is what causes the axons in the brain to be injured (Taber, Warden, & Hurley, 2006). There are three types of TBI: (1) diffuse axonal injury, (2) contusions, and (3) traumatic subdural hemorrhage. Of the three, diffuse axonal injury is most common (Taber et al., 2006). “Diffuse axonal injury transpires when shearing and stretching and/or angular forces pull on axons and small vessels” (Taber et al., 2006, p.144; Vaishnavi et al., 2009). Contusions occur when the brain moves within the skull enough to impact bone, causing bruising of the brain parenchyma (Taber et al., 2006). Traumatic subdural hemorrhage occurs when the brain moves within the skull with enough force to tear the tributary surface veins that bridge from the brain surface to the dural venous sinus (Taber et al., 2006).

There are four criteria for determining the severity of a traumatic brain injury: 1- Loss of consciousness (LOC), 2- Brain functioning (BF), 3- Posttraumatic amnesia (PTA), and 4- The Glasgow coma scale scores (GCS) (Jackson et al., 2008; Joseph & Masterson, 1999). The severity of a TBI can be diagnosed as mild, moderate, or severe depending on the location and or the intensity of the damage (Jackson et al., 2008). Table 1 presents the types of TBI and the required criteria.

Table 1  
*Criteria for Diagnosing TBI*

	Loss of Consciousness	Brain Functioning	Posttraumatic Amnesia	Glasgow Coma Scale Score
Mild TBI	< 30 minutes	Normal MRI and CT	< 24 hours	13-15
Moderate TBI	< 6 hours	Abnormal MRI and CT	< 7 days	9-12
Severe TBI	> 6 hours	Abnormal MRI and CT	> 7 days	3-8

Data obtained from Jackson et al., 2008; Joseph & Masterson, 1999; Okie, 2005

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A diagnosis of mild TBI is determined by LOC for less than 30 minutes, a CT scan and MRI displays normal BF, PTA is less than 24 hours, and the GCS score range is 13-15. (Jackson et al., 2008; Joseph & Masterson, 1999; Okie, 2005). A diagnosis of moderate TBI is confirmed if LOC is less than 6 hours, a CT scan and MRI displays abnormal BF, PTA is less than 7 days, and the GCS score range 9-12 (Jackson et al., 2008; Joseph & Masterson, 1999; Okie, 2005). A diagnosis of severe TBI is recognized if LOC is more than 6 hours, a CT scan and MRI displays abnormal BF, PTA is more than 7 days, and the GCS score ranges 3-8 (Jackson et al., 2008; Joseph & Masterson, 1999; Okie, 2005). Table 2 displays the most common symptoms associated with a TBI.

Table 2  
*Most Common Symptoms Associated with a TBI*

Mild TBI	Moderate TBI	Severe TBI
Headaches	Ringing in the ears	Loss of consciousness (longer than 30 minutes)
Dizziness	Mental Confusion	Personality change
Nausea/Vomiting	Sensitive to auditory stimuli and light	Loss of coordination
Easily irritated or angered	Change in sleep patterns	Weakness or numbness in the extremities
Trouble concentrating	Trouble with memory and concentration	Slurred speech
Trouble with memory and concentration	Impulsivity (lack of inhibition)	Severe, persistent, or worsening headaches

Data obtained from Jackson et al., 2008; Joseph & Masterson, 1999; Okie, 2005

Joseph and Masterson (1999) explained “Those with severe TBI typically show personality, cognitive and emotional changes related to frontal, temporal, limbic, or diffuse white-matter damage” (p. 438). According to Jackson et al. (2008), victims of moderate TBI may experience residual neurocognitive deficits later in life. Severe TBI cases garner the most attention, yet even a mild TBI, such as a concussion, may cause long term cognitive problems (Jackson et al.,

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2008). Table 2 indicates the most common TBI symptoms broken down into the three categories described above: mild, moderate and severe. It is important to clarify that individuals with a moderate TBI diagnosis may also experience a number of the mild TBI symptoms. The same is true for individuals with severe TBI as they may suffer symptoms from all three categories.

5.3 million Americans are estimated to be living with a longstanding disability from a TBI including cognitive, physical, psychosocial, occupational, and emotional difficulties (Kim et al., 2007; Vanderploeg, 2008). In closed-head injuries resulting from motor vehicle accidents, falls, or assault, doctors may not even consider a TBI. Vaishnavi et al. (2009) argue that post-injury disabilities, which include neuropsychiatric disorders, are often not apparent to the individual or others immediately. That is one of the many reasons why Vaishnavi et al. (2009) has identified TBI as a “silent epidemic” (p. 199).

### **Prevalence**

Each year, approximately 1.7 million people sustain a TBI; of them, 52,000 die from their injuries and 275,000 are hospitalized (CDC, 2012; Faul, Xu, Wald, & Coronado, 2010). Lefebvre, Pelchat, Swaine, Gelin, & Levert (2005) describe TBI as “a major public health problem by virtue of its rate and prevalence and high incidence” alone (p. 585). Since the start of military operation (OEF) in 2001, more than 1.5 million U.S. military personnel have been deployed to Iraq or Afghanistan (Hoge et al., 2008). September 1, 2010 marked the end of the combat operation in Iraq and the start of a stability operation identified as Operation New Dawn (OND). It was estimated that during OND, approximately 50,000 troops will remain in service in Iraq (Operation New Dawn, 2010).

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In a two-year period between January 2003 and February 2005, more than 450 patients with closed head TBI were treated at Walter Reed Medical Center (Hoge et al., 2008; Okie, 2005). Tanielian and Jaycox (2008) estimated that approximately 320,000 veterans will experience a probable TBI during their deployment. According to Taber (2006) “The Defense and Veterans Brain Injury Center (DVBIC) has reported that 59% of an at risk group of injured soldiers returning from Afghanistan or Iraq suffered at least a mild TBI while in combat” (p. 144). The costs of TBI for soldiers extends beyond the dollar signs, as soldiers returning home often encounter difficulties readjusting at work, managing new family dynamics, and reintegrating into the community. Soldiers may also encounter co-occurring problems such as substance abuse and homelessness, while others may attempt to commit suicide (Tanielian & Jaycox, 2008). There is also a hefty price tag that comes with treatment for soldiers diagnosed with TBI. Tanielian and Jaycox (2008) estimated that the total cost of treatment within the first year for 2,726 military TBI cases diagnosed as of June 2007 could range between \$591 million to \$910 million. Considering the extent of these conflicts and the number of multiple deployments per soldier; the personal and financial cost of TBI will continue to rise (Vasterling et al., 2006). The effects of combat-related TBI on soldiers are still poorly understood, thus leaving a gap in knowledge regarding the extent of the problem and how to handle TBI (Tanielian & Jaycox, 2008).

This study will review the current knowledge on TBI; explore blast-related attacks on the battlefield, and examine the impact of TBI on the quality of life of an OEF veteran.

### **Blast-related Injuries**

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The bulk of traumatic brain injuries (TBI) reported by OIF/OEF soldiers are due to a blast or explosive type of attack (Okie, 2005; Taber et al., 2006). In order to understand how a blast can cause a brain injury, it is important to comprehend the anatomy of a blast. Taber et al. (2006) explained, “The changes in atmospheric pressure that cause primary blast injuries arise because a high-explosive detonation results from the nearly instantaneous conversion of solid or liquid into gases” (p. 142; Scott, Belanger, Vanderploeg, Massengale, & Scholten, 2006). As the gasses expand, extreme pressure differences occur as the blast wave reaches the body, resulting in both stress and shear waves that causes the injuries (Okie, 2005; Taber et al., 2006; Vaishniva et al., 2009). Table 3 demonstrates the four basic types of blast-related injuries.

Table 3  
*Four Categories of Blast-related Injuries*

Four Categories of Blast-related Injury	Source of Injury
Primary Blast Injury	Over-pressurization of blast waves that induces changes in the atmospheric pressure
Secondary Blast Injury	Projectiles put in motion by the blast hitting people and the extent of the damage is based on proximity of primary blast
Tertiary Blast Injury	Effects of the wind that may forcefully propel the victims into walls, the ground, or other objects
Quaternary Blast Injury	Relates to burns, asphyxia, and exposure to toxic inhalants as a result of the blast

Data obtained from Jackson et al., 2008; Scott et al., 2006; Taber et al., 2006

Taber et al. (2006) wrote “The brain is vulnerable to both secondary and tertiary blast injury” (p.143). The increased cases of blast-related attacks in Iraq and Afghanistan have been reflected in the increased rates of TBI cases (Taber et al., 2006).

Insurgents in Iraq “often use explosive devices loaded with metal fragments that causes greater penetrating force” and consequently more damage to their target (Jackson et al., 2008

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p.44). This type of weapon is known as an improvised explosive device (IED) (Vaishnavi et al., 2009). The types of attacks may result in either penetrating head injury where the skull is fractured or a closed-head injury where there is no visible damage to the head or skull. Closed-head TBI is broadly referred to as a diffuse axonal injury (Jackson et al., 2008) and in this study the terms may be used interchangeably. The violent nature in which a TBI is sustained has generated questions about whether TBI and PTSD are mutually exclusive. Considering the events that cause a TBI are also often psychologically traumatic, Joseph and Masterson (1999) and Sbordone and Liter (1995) suggest that PTSD may be present in individuals with TBI. Joseph and Masterson (1999) further explained that since PTSD and TBI symptoms overlap and so often resemble each other, it is nearly impossible to make a differential diagnosis. Joseph and Masterson (1999) thus concluded “As the symptoms of TBI include amnesia for the traumatic episode and loss of consciousness during the event, it has been argued that TBI and PTSD must be mutually incompatible disorders” (p. 439). In response to the questions about TBI and PTSD, Jackson et al. (2008) determined that the development of new measures that can differentiate between PTSD and TBI are needed. TBI is a major health concern for returning OIF/OEF service members. This study will focus on how a TBI affects the quality of life of a veteran. Consequently, blast-related injuries; specifically TBI has become a concern for soldiers, their families and the Department of Defense (DOD).

### **TBI: The Signature Wound of OIF/OEF**

U.S. troops have not been involved in such a large ground operation as they are currently involved in Iraq and Afghanistan since Vietnam (Hoge et al., 2006; Okie, 2005). As a direct result of their ground position, soldiers are more likely to be exposed to blast-related

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attacks that result in increased rates of TBI. Scott et al. (2006) explained “More than half of all combat-related injuries sustained by U.S. troops in Iraq and Afghanistan are the result of explosive munitions” (p. 265). According to Scott et al. (2006) “Common injuries in blast-related polytrauma include open wounds, traumatic amputations, injuries to the brain, spinal cord, eye, musculoskeletal system; and psychiatric problems” (p. 265). TBI is not a new type of war injury, but increased rates means that TBI is the “signature wound” for veterans returning from Iraq and Afghanistan (Okie, 2005). Table 4 displays a list of past U.S. wars indicating the number of soldiers wounded or killed and also the percentage of lethal wounds. As the chart indicates, soldiers are surviving closed and penetrating head injuries that were impossible to survive in past wars (Gawande, 2004; Jackson et al., 2008).

Table 4  
*Survival Rates in U.S. Wars*

War	No. of troops wounded	No. of troops killed	Lethality of War Wound (%)
Revolutionary War 1775-1783	10,623	4,435	42%
War of 1812 1812-1815	6,765	2,260	33%
Mexican War 1846-1848	5,885	1,733	29%
Civil War (Union Forces) 1861-1865	442,295	140,414	33%
Spanish-American War 1898	2,047	385	19%
World War I 1917-1918	257,404	53,402	21%
World War II 1941-1945	963,403	291,557	30%
Korean War 1950-1953	137,025	33,741	25%
Vietnam War 1961-1973	200,727	47,424	24%
Persian Gulf War 1990-1991	614	147	24%
OIF/OEF 2001-2004	10,369*	1,004*	10%*

Data obtained from Gawande, 2004; \*Ongoing war, figures may change

The statistics presented above for OIF/OEF change almost daily, even as the U.S. military makes plans to withdraw troops from the battlefield. Since 2004, the number of soldiers wounded and killed in OIF/ OEF has undoubtedly increased as presented in Table 5

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below. As of May 2012 the Department of Defense (DOD) released a report updating the number of troops wounded and killed between 2003 and 2010.

Table 5  
*OIF/OEF Casualties 2003-2010*

U.S. Casualty Statistics 2003-2010 Fatalities of as of May 23, 2012				
	No. of troops wounded	No. of troops Killed	Total Deaths	Lethality of War Wounds %
Operation Iraqi Freedom	31,928	3,479	4,409	11%
Operation Enduring Freedom	16,024	1,538	1,855	10%

Data obtained from the Department of Defense, <http://www.defense.gov/news/casualty.pdf>

\*OPERATION IRAQI FREEDOM- includes casualties that occurred between March 19, 2003 and August 31, 2010, in the Arabian Sea, Bahrain, Gulf of Aden, Gulf of Oman, Iraq, Kuwait, Oman, Persian Gulf, Qatar, Red Sea, Saudi Arabia, and United Arab Emirates. \*\*OPERATION ENDURING FREEDOM- includes casualties that occurred in Afghanistan only.

The kevlar body armor and helmets worn in battle are highly regarded for saving the lives of wounded soldiers, thus decreasing the lethality of war wounds. Okie (2005) wrote, “By effectively shielding the wearer from bullets and shrapnel, the protective gear has improved overall survival rates and kevlar helmets have reduced the frequency of penetrating head injuries” (p. 2045). The helmets have improved survival rates, but they do not prevent the kinds of diffuse axonal injuries often caused by a blast (Okie, 2005).

Gawande (2004) also credited the Forward Surgical Teams (FSTs) stationed on the battlefield for the increased survival rates. Gawande (2004) wrote “Each FST is equipped to establish a functioning hospital on the battlefield with four ventilator-equipped beds and two operating tables within a difficult-to-fathom 60 seconds” (p. 2472). FSTs have enough supplies to resuscitate, evaluate, and perform surgery on as many as 30 wounded soldiers. The main responsibility of the FSTs’ on the battlefield is to stabilize the injured and prepare the wounded for transport to better equipped facilities including Combat Support Hospitals (CSH).

Depending on the severity of the injury, further transport to a higher level of care facility



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including level IV hospitals located in Kuwait, Spain, and Germany may be required (Gawande, 2004). Wounded soldiers who require care for longer than 30 days are transferred back to the U.S. to either Walter Reed Medical Center (WRMC) in Washington D.C. or to Brooke Army Medical Center in San Antonio, Texas (Gawande, 2004, p. 2473). The average time of transport from battlefield to arrival in the United States for further medical care is now less than four days whereas in Vietnam, it was 45 days (Gawande, 2004). Veterans who previously would have suffered visible injuries now struggle with TBI symptoms that are not always noticeable to family or to society (Jackson et al., 2008).

This chapter explored the circumstances regarding how blast-related attacks affect soldiers on the battlefield. The next chapter will focus on the current research on TBI in both the civilian and military population and then explore the current treatment models for working with the population of veterans suffering from a TBI.

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## **Chapter II: Traumatic Brain Injury: Civilians vs. Veterans**

### **TBI in the Civilian Population**

This chapter will provide a broad exploration of the current knowledge on TBI in various populations and the impact that TBI has on an individual's life. This section will explore the current body of research on TBI in the civilian population. As indicated previously, falls, motor-vehicle accidents (MVA), assaults, and sports-related injuries are the most common causes of TBI in the civilian population (Langlois et al., 2006; Vaishnavi et al., 2009). As a result of the injuries, up to "one-third of mild TBI patients develop chronic symptoms, and delayed symptoms onset is not uncommon" (Jackson et al., 2008 p. 44). Often times, individuals with postconcussive syndrome may complain of fatigue, memory problems, headaches, postural imbalance, insomnia, irritable or depressed mood, and/or interpersonal conflicts (Cernich, Chandler, Scherdell & Kurtz, 2012; Jackson et al., 2008). Jackson et al. (2008) described postconcussive syndrome as "an array of cognitive, physical, and emotional symptoms that can occur following mild TBI" (p. 44). Studies (Fujii and Ahmed, 2001; Koponen et al., 2002; Vaishnavi et al., 2009) exploring psychiatric difficulties after TBI vary in their conclusions. In a 30-year follow up study evaluating psychiatric disorders after TBI, Koponen et al. (2002) reported a high rate of Axis I and II disorders 30 years after the initial TBI (p. 1318). Fujii and Ahmed (2001) wrote, "Lifetime incidence rates of TBI survivors who later demonstrate psychotic symptoms vary across studies, but they are generally low" (p. 61). On the other hand, Vaishnavi et al. (2009) concluded that nearly 40 percent of TBI victims later develop at least two psychiatric disorders. Fujii and Ahmed (2001) rebutted that argument writing, "individuals who develop psychosis secondary to TBI are more likely to have had a preexisting neurological condition" (p. 62). Koponen et al. (2002) concluded "TBI not only

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temporarily disturbs brain function but may cause decade-long or even permanent vulnerability in some individuals” (p. 1318). There is a consensus that a correlation between a TBI and the development of psychosis/other mental illness exists (Fujii & Ahmed, 2002; Jackson et al., 2008; Koponen et al., 2002; Vaishnavi et al., 2009), but the nature and strength of the correlation remains unclear (Fujii & Ahmed, 2001).

There are 5.3 million TBI survivors in the U.S. with a chronic disability (Kim et al, 2007), yet members of the general public still have misconceptions about individuals with TBI (Swift & Wilson, 2001). Family members, friends, and peers at work expect more of a brain-injured person if the person has no external sign to indicate his or her injury (Swift & Wilson, 2001). Emanuelson, Anderson, Bjorklund, & Stalhammar (2003) wrote, “In patients with post-concussion symptoms one year after a MTBI, psychological well-being and life satisfaction were reported to be impaired” (p. 332). Individuals with TBI who do not display physical symptoms often appear to be physically fit, which makes it difficult for them to request disability benefits. To understand how an individual with TBI experiences his or her community, Swift and Wilson (2001) asked research subjects to discuss their struggles after the injury. Participants reported frustration with obtaining services and dealing with service providers as their major complaints. Swift and Wilson (2001) noted that participants “believed that there are many individuals within the social services system who do not have an adequate understanding of brain injury” (p. 157). According to Swift and Wilson (2001), participants also reported that “providers are hampered by the organizational structure which has no separate category in which to place brain-injured individuals” (p. 157). TBI research in the civilian population (Fujii & Ahmed, 2001; Fujii & Ahmed, 2002; Koponen et al., 2002; Nochi, 1995; Nochi, 1997; Nochi, 2000; Swift & Wilson, 2001; Vaishnavi et al., 2009) is studied using both quantitative and qualitative perspectives. The

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body of research (Fujii & Ahmed, 2001; Fujii & Ahmed, 2002; Koponen et al., 2002; Nochi, 1995; Nochi, 1997; Nochi, 2000; Swift & Wilson, 2001; Vaishnavi et al., 2009) reveals that TBI can drastically affect the lives of its victims. Research on TBI in the military is at its infancy and to understand the nature of a combat related TBI, it is important to explore the ways in which TBI occur in combat.

### **Combat-related TBI**

To understand the debate regarding high rates of TBI in the military, the role of IED attacks in combat-related TBI will first be explored. This section reviews blast-related attacks, the military's recognition of TBI, and the importance of examining TBI from the perspective of the individual. Achte and colleagues studied the effects of TBI on combat veterans after war in the 1960s (Achte, Hillbom, & Aalberg, 1969). Koponen et al. (2002) regarded Achte's study as, "The most extensive study on psychiatric disorders after traumatic brain injury" (p. 1315). Yet to date, the bulk of research on traumatic brain injury has been conducted with civilians treated at clinics and hospitals (Hoge et al., 2008). Consequently, researchers know little about "the epidemiology of mild traumatic brain injury during deployment and its association with adverse health outcomes after deployment" (Hoge et al., 2008, p. 454).

The Veterans' Administration has conducted several studies to explore the needs of military personnel returning from combat. One recent study found that "88% of military personnel treated at an echelon II medical unit in Iraq had been injured by IEDs" (Taber et al., 2006, p. 142). Taber et al. (2006) went on to explain, "97% of the injuries to one Marine unit in Iraq were due to explosions; 65% generated by IEDs and 32% created by mines; of which 53% caused injuries to the head or neck" (p. 142). Such blast-related attacks have increased the number of soldiers returning home with "Polytrauma in unpredictable patterns" (Scott et al.,

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2006 p. 265). TBI is increasingly recognized as a “major public health problem” (Trudel, Nidiffer, & Barth, 2007, p. 1007) because of the increased rates of TBI cases in both the community and in the military. The Defense and Veterans Brain Injury Center (DVBIC) reports an increased number of TBI cases in the military between 2000 and 2010. The information presented in Table 6 indicates a total of 178,876 TBI cases in the military.

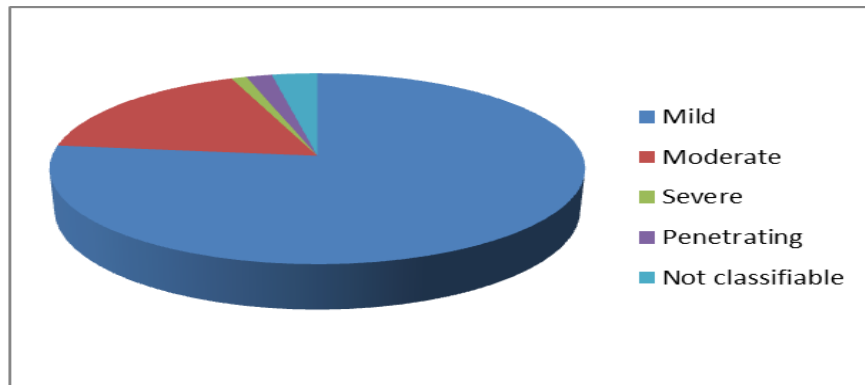
Table 6  
*TBI in the U.S. Military*

Traumatic Brain Injuries in the U.S. Military												
Calendar Year	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010*	Total
Incident Diagnoses	10,963	11,830	12,469	12,886	13,271	12,025	16,873	23,002	28,557	27,862	7604*	178,876

Data obtained from the Defense and Veterans Brain Injury Center, <http://www.dvbic.org/TBI-Numbers.aspx>.

It is important to clarify that the number of TBI cases in 2010 reflects data collected from January to March and not the entire year. Of the 178,876 TBI cases, the DVBIC breaks down the severity of the injuries into five categories: (1) mild, (2) moderate, (3) severe, (4) penetrating, and (5) not classifiable. Figure 1 below illustrates this breakdown: 137,328 mild cases, 30,893 moderate cases, 1,891 severe cases, 3,175 penetrating injury cases, and 5,589 as not classified.

Figure 1  
*Severity of TBI Diagnoses*



Data obtained from the Defense and Veterans Brain Injury Center, <http://www.dvbic.org/TBI-Numbers.aspx>

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Since TBI victims may not have visible wounds; questions regarding diagnosis, treatment, and benefits have become a topic of much debate. Bryant (2008) raised questions about whether TBI will become a “new syndrome” attributed to the wars in Iraq and Afghanistan (p. 526). Bryant (2008) wrote...

If troops currently serving in Iraq or Afghanistan are informed about a postconcussive syndrome and persistent problems emerging from mild traumatic brain injury, a new syndrome could arise from the current conflict in which soldiers attribute a range of common stress reactions to the effects of brain injury (p. 526).

In an editorial piece addressing the results of a TBI study (Hoge et al., 2008), Bryant (2008) questioned whether a spike in TBI research would cause soldiers to over identify war-related symptoms with TBI. Bryant (2008) later admitted that soldiers with mild TBI “are at a greater risk for health-related problems” (p. 526). Years before Bryant’s questions, the military began to recognize the unique challenges that TBI poses for soldiers. The recognition led to the establishment of the Defense and Veterans Brain Injury Center (DVBIC) in 1992 (Trudel et al., 2007). Trudel et al. (2007) argued the military acknowledged the “need to provide effective treatment approaches” for military personnel with TBI (p. 1007). The DVBIC was established prior to the conflicts in Iraq and Afghanistan, yet since those wars, the rate of combat-related TBI has risen sharply. Despite Bryant’s (2008) concerns that TBI will be labeled as the syndrome for OIF/OEF veterans, the military recognizes that soldiers exposed to IED blast can suffer traumatic injuries. Exposure to a blast even once may cause minor injuries, yet soldiers in Iraq and Afghanistan are often exposed to several blast attacks or explosions. Jackson et al. (2008) explain, “While receiving only mild postconcussive effects from one blast, a second or third blast of equal force could result in a more severe injury” (p. 45). In a recently published study, Boston University researchers (McKee et al., 2012) concluded, “We analyzed the brains

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of 85 individuals with a history of repetitive mild TBI and found evidence of chronic traumatic encephalopathy (CTE) in 80%” of the participants (p. 18).

Among the concerns with TBI in the military is that “blast related brain injuries go undiagnosed and untreated as medical attention is focused on visible injuries” (Belanger, Scott, Scholten, Curtiss, & Vanderploeg, 2005, p. 404; Scott, 2006). Belanger et al. (2005) explain if “military medicine’s approach to treatment continues to follow a symptom-based model” closed head TBI cases will remain under-diagnosed and untreated. It is concerning that blast-related head injuries can continue to go under diagnosed “despite data that suggests that brain injuries are common occurrences from blast injuries” (Belanger et al., 2005 p. 404; Scott et al., 2006). Jackson et al. (2008) explain that blast-related TBI affects many areas of the brain including “frontal, temporal, and subcortical regions” (p. 45), which may lead to other physical or psychological injuries (Fujii & Ahmed, 2001). Soldiers with TBI often have symptoms affecting several areas of brain functioning including headaches, sleep disturbances and sensitivity to light and noise (Okie, 2005). Many veterans reported “persistent postconcussive symptoms, such as irritability, memory problems, headache, and difficulty concentrating” (Okie, 2005, p. 2045).

Data to determine whether soldiers are seeking services for TBI symptoms or whether any stigma exists about TBI are scarce. Yet, stigma around treatment for mental health services in the military, especially by active duty officers, remains intact. According to Erbes, Westermeyer, & Engdahl, (2007) many returnees are “reluctant to seek mental health care, even if they are experiencing distressing psychiatric symptoms” (p. 359). Hoge et al. (2004) also concluded that stigma and other barriers to care keep OIE/OEF veterans from seeking services for mental health problems. Returning OIF/OEF veterans with TBI may experience similar concerns with stigma (Kim, 2009) that veterans with PTSD have around how they are perceived

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by peers and leaders and thus the opportunity to receive care. To date, the information known about combat-related PTSD as a result of decades of research is not currently available for combat-related TBI. Vasterling et al. (2006) concluded that “war-related neuropsychological impairment has significant public health implications” (p. 519) especially considering this predominately young military population. A qualitative exploration is imperative according to Nochi (2000) because “It is not well known what coping with the changed lives means in the experiences of people with TBI” (p. 1796).

Current TBI research involving veterans and active duty soldiers is limited and varied in objectives and research designs. Two of the four identified studies (Trudel, Nidiffer, & Barth, 2007; Vanderploeg, Schwab, Walker, Fraser, & Sigford, 2008) focused on how rehabilitation approaches and treatment models can best address the needs of veterans with TBI. Both studies addressed important aspects of treatment, but did not explore the veterans’ experiences or quality of life post TBI. In his study, Hoge et al. (2008) had active duty Army soldiers and Army Reservists complete anonymous surveys about self-reported history of combat-related mild TBI. Hoge et al. (2008) concluded that self reported history of TBI “lacks specificity in predicting postdeployment, physical health problems among injured soldiers” (p. 462). The last study discovered a connection between mild TBI in combat veterans with PTSD (Trudeau, Anderson, Hansen, Shagalov, & Schmoller, 1998). The study subjects (veterans) with no knowledge about the nature of the study reported being present during various types of explosions while filling out a concussion survey. The study essentially calls for further exploration of veterans with TBI. It is important to acknowledge that the study was completed in 1998 prior to OIF/OEF and the subjects included veterans from World War II, the Korean War, Vietnam, the Cold War, and



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Desert Storm (Trudeau et al., 1998). I was unable to locate any current VA/ DVBIC qualitative research study that explores the quality of life of IOF/OEF veterans with TBI.

This section has explored how IED attacks have increased TBI in the military and the need for further research from the perspective of the TBI victims. The following section will explore the experiences of individuals living with a traumatic brain injury.

### **Living with a TBI: “There Goes my Everything”**

In so many ways, a TBI is different from many other injuries such as a broken arm, a broken leg, or even cancer; it is not better or worse, just different. This section will survey the literature on the experiences of individuals who live with TBI and the misconceptions that exist about this population. Individuals who suffer a closed-head mild TBI may not have any visible signs of their injury. Wittig, Tilton-Weaver, Party, & Mateer (2003) reported that individuals with brain injury frequently have limited awareness of the nature of their deficits, the impact of these deficits on everyday life, or their need for rehabilitation (p. 97). Family may experience stress as they struggle to understand why their loved one looks the same, but acts differently (Albert, Im, & Brenner, 2002). Professionals who are not knowledgeable about TBI may experience several challenges working with an individual with TBI (Judd & Wilson, 2005). Wittig, et al. (2003) indicated that both family and professionals may have to contend with “Persistent anger, frustration, and aggression” from the individual with TBI (p 97). Most individuals who sustain TBI are treated and often return to their daily lives with few difficulties (Trudel, Nidiffer, & Barth, 2007). According to Trudel et al. (2007), others “experience residual disability, unmet care needs, or are initially unsuccessful in reentering the home, military, vocational and community life” (p. 1008). The difficulty integrating into one’s community after a TBI can be affected by several factors, including the individual’s ability to understand his or

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her injury. Also included are, the communities' misconception about TBI and most importantly the way the insurance companies (Masel & DeWitt, 2010) and providers view TBI. Research to date suggests that access to services poses unique challenges when an individual with TBI has an "invisible disability" where the primary struggles are cognitive and not physical (Langlois et al., 2006, p. 377).

Masel and DeWitt (2010) wrote "traumatic damage to the brain is currently viewed by insurance companies and health care providers as an event which likens a broken brain to a broken bone" (p. 1529). From this perspective, it would appear that "once fixed, the brain would not require further treatment beyond a relatively brief period of rehabilitation" (Masel & DeWitt, 2010, p. 1529). Such an attitude may be the case for some individuals, but for others further rehabilitation and support around reintegration is required. Masel & DeWitt (2010) argue that TBI should be classified as "the beginning of a chronic disease process, rather than an event or final outcome" (p. 1529). A shift in classification would raise the kind of awareness that would allow the insurance companies to provide the course of treatment necessary for the clinical condition. A shift in treatment process would allow providers to identify the need for additional support for individuals who struggle after the initial rehabilitation. Without the proper classification, providers with limited TBI knowledge may minimize the severity of mild closed-head TBI cases. Several researchers (Brown et al, 2004; Masel & DeWitt, 2010) stated there is a "statistically significant reduction in long-term survival of individuals with mild TBI compared to the general population" (Masel & DeWitt, 2010, p. 1530). Although mortality rate after TBI is closely associated with severe and moderate cases, mild TBI have a significant impact on an individual's life. This information is especially alarming because there are far greater numbers of mild TBI cases than moderate and severe cases (Langlois et al., 2006; Masel & DeWitt, 2010).

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Understanding the potential severity of mild TBI has shed light on another major issue related to how society views individuals with TBI.

Studies in the late 1980s (Gouvier, Prestholdt, & Warner, 1988; Aubrey, Dobbs, & Rule, 1989) exploring the communities' perception about individuals with TBI revealed several misconceptions. Gouvier et al. (1988) wrote about his participants, "31% believed that people with head injuries look and act retarded" (p. 337). Aubrey et al. (1989) indicated that less than fifty percent of the participants agreed that cognitive symptoms can result from car accident, compared to over eighty percent who agreed with physical symptoms. Gouvier et al. (1988) and Aubrey et al. (1989) speculated that the general public's misconception about TBI is partly due to the inaccurate media portrayal of head injury. Vaughn, Frank, Leach, O'neal, and Sylvester (1994) conducted a similar study about the public's perception and their findings were contrary to that of Aubrey et al. (1989) and Gouvier et al. (1988). Vaughn et al. (1994) suggested that the general public's perception about the seriousness of head injury is at an appropriate level. A similar study by Swift and Wilson (2001) revealed that community misconceptions about individuals with brain injuries still exist. In a recent study, Guilmette and Paglia (2004) concluded there was "No significant change in the level of knowledge about moderate to severe brain injury has taken place within the last 8–13 years and that geographical region is also unrelated to TBI misconceptions" (p. 188). Swift and Wilson (2001) concluded "lay people may be sympathetic to an accident victim complaining of physical symptoms, but may be less sympathetic to expressions of cognitive problems" (p. 151). Nochi (1998) wrote about a study participant's experience seeking services after a TBI:

Richard, who sustained a "mild" brain injury, struggled to be recognized as a TBI survivor... His injury was not serious enough to be a brain injury in the eyes of

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medical professionals although it *actually* affected his whole life in a dramatic way (Nochi, 1998, p. 874).

If Richard's experience reflects that of other individuals with TBI, it is evident that more education and policy is needed to support the population that experiences TBI. Masel & DeWitt (2010) noted that even individuals with TBI may be unaware that TBI may "initiate a chronic disease process" (p. 1530). This "disease process", according to Masel & DeWitt (2010), may lead to seizure disorder, sleep disorders, Alzheimer disease, psychiatric disorders, sexual dysfunction, incontinence, and metabolic dysfunction (p. 1530-1535; Vaishnavi et al., 2009). Masel & DeWitt (2010) argue "the term survivor does not address the reality of brain injury" as the term indicates that one has "outlived" the illness (p. 1536). Masel & DeWitt (2010) noted that over 90,000 Americans who annually sustain a TBI become disabled (p. 1536; Thurman, Alverson, Dunn, Guerrero, & Sniezek, 1999). Masel and DeWitt (2010) also argued that "5.3 million Americans now have lifelong condition that might be termed chronic traumatic brain injury disease" as a result of their brain injury (p.1536).

TBI can significantly impact family and caregivers especially in cases where there are no visible injuries. Albert et al. (2002) described the psychosocial impact on family and caregivers as profound (p. 176). Chamberlain (2005) wrote, "The majority of survivors may show no physical evidence of their injury and can give the impression to their friends, family and colleagues of functioning without a disability" (p. 407). In some cases where the family notices a change or disability in their loved one, it is not always clear how to address the issue. In addition, "families must contend with personality changes and cognitive impairment, management of the medical and social services needs" (Albert et al., 2002, p. 176). The majority of TBI research has been conducted through the medical-model lens, rather than from the perspective of the individual living with the injury (Nochi, 1998). According to Emanuelson et al. (2003), in spite

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of the emphasis placed on quality of life as an outcome measure in TBI research, quality of life is rarely explored.

This section explored the literature on TBI related to the struggles of living with TBI and the misconceptions that exist about individuals with TBI. The following section will explore the kinds of treatment that are available to individuals with TBI.

### **Treatment with TBI populations**

Despite the high incidence of TBI, empirical data to guide psychiatric treatment remain scarce making the population difficult to treat (Vaishnavi et al., 2009). This section explores the current treatment models for working with individuals with TBI. Prior to delving into the treatment needs, it is important to understand how a TBI affects the brain. For example, the site of damage will substantially influence the type of disability and whether that disability will be “visible, physical, hidden or cause psychological problems” (Swift & Wilson, 2001, p. 154). To determine disturbances in language, attention, or memory, cognitive changes can be diagnosed via mental status exams or through neuropsychological testing (Okie, 2005). Other disturbances caused by TBI may include mood changes, depression, anxiety, loss of executive functioning, inappropriate laughter, and emotional outbursts (Chamberlain, 2005; Okie, 2005; Swift & Wilson, 2001). Chamberlain (2005) identified loss of executive functioning as a major disability for an individual with TBI. Chamberlain (2005) wrote, “Loss of executive functioning can seriously impair the ability to function in everyday life, especially in employment tasks” (p. 408; Trudeau et al., 1998). Cognitive, behavioral, emotional, and interpersonal difficulties can result in significant challenges for the individual as well as for his or her family and caregivers (Albert et al., 2002; Wittig, Tilton-weaver, Party, & Mateer,

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2003). Damage to the brain can result in a wide range of symptoms and dysfunction. One of the major misconceptions about the behavior of individuals with TBI, according to Deaton (1987), is that behavioral problems are deemed “organic” meaning the behavior cannot be changed (p. 151). Some of the behavioral problems caused by a TBI include amotivation, impulsivity, social inappropriateness, and agitation (Vaishnavi et al., 2009). There is a presumption that individuals with TBI are unable to benefit from psychotherapy (Judd & Wilson, 2005).

Assumptions and misconceptions impact how individuals with TBI feel they are treated by family, caregivers, and providers. According to Swift and Wilson (2001) individuals with TBI often complain “that there is a lack of understanding of the problems of brain injury both amongst members of the general public and also health professionals who do not have experience in this area” (p. 149). Chamberlain (2005) noted that several study participants reported insensitivity and lack of empathy by health professionals, especially towards individuals with invisible symptoms. The nature of a TBI creates stressors for all parties involved, but there are ways to provide adequate care and treatment. First, it is essential that the therapist understands the nature and severity of organic brain damage (Judd & Wilson, 2005). Then the process of treatment begins with education about the effects of brain injury with much attention being paid to the individual’s feelings of anger, frustration, and despair. Judd and Wilson (2005) indicate that survivors may experience “diminishing self-esteem related to a loss of ability to perform at pre-injury levels” (p. 439). Nochi (1998) wrote, “Individuals with TBI often feel that one is receiving messages from others or society, which says that he or she is not the person whom he or she believes him or herself to be” (p. 873). For example, the injured individual may feel depressed and therefore unable to go to work, but the individual’s family may see him or her as a healthy individual who should be able to go to work. To address these concerns, a social

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worker/ therapist can explore the meaning that clients have given to their experience, their post-injury identity and the psychosocial consequences of these changes (Judd & Wilson, 2005).

Through the treatment process, the injured individual can begin to reconstruct the self (Gelech & Desjardins, 2011). A Cognitive Behavioral Therapy approach can help the individual develop coping skills, create compensatory strategies and later address the redefinition of the self (Judd & Wilson, 2005). A combination of educational, psychosocial, and cognitive strategies is the most effective way to address the multi-faceted challenges encountered by therapists working with the population of those with TBI (Judd & Wilson, 2005).

To provide competent evidenced-based treatment, therapists working with the brain injured population require appropriate training and organizational support (Wittig et al., 2003). A review of social work journals yielded no research articles that addressed treatment needs of the brain-injured population. Social workers in different settings will be providing services to soldiers/veterans diagnosed with TBI and their families for decades to come. Research to date fails to explore TBI from the perspective of the individuals (Nochi, 1997, p. 534). In an attempt to understand the effects of TBI on an individual's life, I interviewed a civilian and a veteran with TBI for this study.

### **Limitations in the Existing Empirical Research**

More than 1.5 million U.S. military personnel have deployed to Iraq or Afghanistan since the start of the U.S. Global War on Terror (GWOT) operations in 2001 (Hoge et al., 2008; Vasterling et al., 2006). The literature review indicates that returning OIF/OEF soldiers face several mental health concerns (Hoge et al., 2006; Milliken, Auchterlonie, & Hoge, 2007); yet, little information is known about the need of soldiers who suffered a combat-related TBI. Research with the population of those with TBI is especially important as traumatic brain injury

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(TBI) is being identified as the “signature wound” for veterans returning from Iraq and Afghanistan. Vasterling et al. (2006) argued that to date “the consequences of war-zone deployment on neuropsychological health remain poorly understood” (p. 519). Currently, there is no way to determine the precise number of TBI cases or to detail the burden of TBI among OIF and OEF soldiers (Jackson et al., 2008). The Department of Defense and the Veterans Administration has developed the Post-Deployment Health Assessment (PDHA; DD2796) and Post-Deployment Health Reassessment (PDHRA; DD2900) in an effort to more accurately screen and diagnose mild TBI in the military (Tepe and Fendley, 2009). Research studies (Deb, Lyons, Koutzoukis, Ali, & McCarthy, 1999; Koponen et al., 2002) in the civilian population indicate that there is a correlation between TBI and risk of developing a mental health disorder. If the TBI research findings in the civilian population are any indication of what veterans with TBI may experience in the future, then social workers need to be prepared to treat service members with TBI. It is imperative that social workers understand how returning soldiers are coping with the symptoms of TBI and how they comprehend the impact TBI has on their quality of life.



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## **Chapter III: Methodology**

In order to understand the experiences of individuals with TBI, I employed the use of a comprehensive literature review and an in-depth intensive interview with two participants. The remainder of this chapter details the research questions and design.

### **Research Questions**

What impact does a Traumatic Brain Injury (TBI) have on the quality of life of an OIF/OEF veteran returning home from combat and a civilian recovering in the community?

- In what ways has the TBI affected the participants' ability to return to work and to reconnect with support systems?
- How has the TBI affected the participants' personal life and sense of self?
- In what ways can TBI be treated or addressed that will help veterans, civilians, and their support systems?

### **Reflexivity: Insider Research**

The term "insider research" is used to describe research projects where the researcher has direct involvement or connection with his or her research setting (Robson, 2002). That definition reflects my experience, as I live with an individual who sustained a TBI. Using an insider's lens to explore the needs of individuals with TBI affords the researcher specific insights that an outsider may lack. For example, living with someone with a TBI was influential in my decision to explore this subject from the injured individual's perspective. Reflexivity also

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allows the researcher the opportunity to examine one's self during the study, which is "a strength and success of qualitative research" (Padgett, 2008, p. 18).

### **Research Design**

Along with an extensive literature review, I interviewed two individuals with a TBI in order to investigate the impact of TBI on the quality of life. Padgett (2008) explained that the qualitative approach helps to "capture the lived experience from the perspectives of those who live it and create meaning from it" (p. 16). During the intensive interviews, both participants discussed their experiences in adjusting to life after their head injuries. Specific areas of focus included experiences seeking treatment, difficulties at work, psychological state, somatic symptoms, supports and relationships. I will present the information gathered through the intensive interviews in a case study format in chapters 4 and 5.

### **Sampling**

The initial sampling population was N=10 to be made up of 5 veterans and 5 civilians who suffered a traumatic brain injury. Inclusion criteria: male and female civilians or member of the U.S. Armed Forces (Army, Air Force, Navy, Marine Corps, National Guards or Reservist) who suffered a head injury between 2001 and 2010. Participants would have been involved in a motor vehicle accident, motorcycle accident, gunshot to the head, a fall, or blast-related attack during which the participant was exposed to any extra cranial mechanical force to the brain. The force would have caused any period of loss of consciousness; any loss of memory for events immediately before or after the event; or any alteration in mental state at the time of the event (Kim et al., 2007; ACRM, 1999). Exclusion criteria include individuals under

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the age of 18 and individuals who suffered a TBI prior to 2001. Also excluded would be individuals who sustained a TBI secondary to hypoxia or stroke.

The sampling procedure is purposive in order to obtain participants who can provide the necessary and most reliable information based on their personal experiences. Yet, recruiting individuals with traumatic brain injury proved to be rather difficult in both the civilian and veteran populations. First, I consulted with an Army Staff Sergeant and with an individual with TBI about different recruitment strategies that I could use to reach out to veterans and to civilians with TBI. Using the information from the consulting sessions, I created a recruitment flyer that I emailed to peers in the social work community, rehabilitation hospitals, and the VA system. Specifically for the civilians with TBI, I submitted my flyer and IRB approval to the Brain Injury Association of Pennsylvania and I was informed my materials were being reviewed by the agency's executive committee. I attended several TBI conferences in an attempt to connect with both civilians with TBI and with providers who work with this population in an effort to advertise my study. My efforts to recruit veterans followed a similar path as I reached out to three Veterans Administration (VA) employees who reported that because of clinical and research regulations in the military, it would be impossible to recruit within the VA system. I reached out to several local veteran organizations, two of them did not respond to my requests and a third reported they did not provide services to veterans with TBI. I also submitted my flyer and IRB approval to the Defense Veteran Brain Injury Center (DVBIC) and after several steps, DVBIC informed me that my flyer was approved and posted at the agency. Months after the flyer was posted, I did not receive any calls from veterans about my study. I reached out again to the Army Staff Sergeant with whom I consulted previously and he connected me with a veteran who suffered a TBI in Afghanistan who later agreed to

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participate in my study. As a result of these challenges, the sampling population for this study is now N=2 (1 veteran and 1 civilian). The unexpected change in sampling process led to a shift in qualitative approach from traditional grounded theory to case study.

### **Case Studies**

In qualitative research, case studies as an approach have an extended and honorable history (Feagin, Orum, & Sjoberg, 1991; Stake, 2005; Yin, 2003). Padgett (2008) explained that case study “refers to approach, method, and product” (p. 33). As a method, case studies create an opportunity for knowledge development that dictates systematic processes of data collection and analysis (Donmoyer, 1990). Padgett concludes that “case studies draw on the ability of the qualitative researcher to extract depths and meaning in context” (p. 33). This is especially important because case study methods are not explicitly described as other qualitative methods.

### **Data Collection**

As indicated above, I reached out to peers in the social work community and several civilian and veteran organizations to advertise and promote this study. I contacted the two individuals who agreed to participate in the study via email to schedule a time to conduct the recorded intensive interview. I emailed each participant a study packet that included a cover letter that explained the purpose of the study, assured confidentiality, emphasized that participation was voluntary, and included the written statement of research form. The written

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statement of research form explicitly indicated the plan to audiotape the interviews. On the day of their interview, each participant had the opportunity to review the written statement of research form. I conducted the semi-structured intensive interview that lasted approximately 1.5 to 2 hours. I interviewed each participant once as planned and a few months later I conducted a brief interview follow up to gather additional information about pre-TBI presentation.

### **Human Subjects**

Both participants reviewed the written statement of research form and agreed to participate in the study. Participants received a modest non-coercive stipend of \$10 cash card for their participation. As noted previously, both participants were assured confidentiality, and otherwise conformed to standards for the protection of human subjects. The study packet contained a list of national agencies each participant could contact for support services if needed after the interview.

### **Analysis**

The intensive interviews were transcribed and coded using Grounded Theory (GT), a method for analyzing qualitative data, which was originally introduced by Glaser and Strauss (1967). The analysis followed the guidelines described in detail by Charmaz (2006). Padgett (2008) wrote, “GT entails inductive coding from the data, memo writing to document analytic decisions, and weaving in theoretical ideas and concepts without permitting them to drive or constrain the study’s emergent findings” (p. 32). A modified version of GT was used in the

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analysis including open coding to identify the initial codes and later focused codes. Through this coding process and memo writing, provisional concepts and themes were developed.

Using the intensive interview data from both participants, I created two case study presentations. I later used case study analysis as a method to evaluate each of the cases.

According to Padgett, “A primary feature of case study analysis is going “deep” before going “out” (to larger issues or theories) or, for some studies, going “across” (to other cases)” (p. 143).

Although N= 10 was the intended sampling for this study, the case study approach with N=2 allows for in depth exploration of each individual’s experience post TBI. Padgett (2008) concludes that multiple case study analysis comes with the challenge of maintaining the integrity of the cases. Although the participants in this study have their differences, the common denominator is their experience post TBI and that similarity should remain intact during cross case analysis.

The following chapters are comprised of the two case studies written using information gathered through the intensive interviews. The case studies are not a representative sample of any population, but rather used to illustrate what has been shown in the literature as well as other areas of concerns not addressed in research. It is important to note that names, dates, and other information has been changed or disguised to protect the participants’ identity.

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### **Chapter IV: Case Study – Ruth**

#### **Life Pre-Injury**

Ruth is a 35 year-old married civilian mother of a toddler son who resides in a medium sized city on the southeast region of the United States. Ruth reported she is the third of her parents' five children and that she has fond memories of her childhood. After completing her undergraduate degree, Ruth lived in London for two years before returning to the states to attend graduate school. Ruth stated, "I com... completed my masters and was working full-time at a psychiatric hospital" for about 5 years. Ruth was living at home with her husband of ten years and their infant son. Ruth and her husband worked full-time and their son was in a daycare center during the day. Ruth stated, "Everything in my life was good... um my husband and I were happy with our baby boy." Ruth reported having positive and supportive relationships with her parents as well as with her in-laws, all of whom visited often to help her after the baby was born. About her relationships with her siblings, Ruth reported that her siblings live out of state, but "we talk often and get together on holidays." Ruth reported she felt she had a good support system including friends she made working at the hospital and members of her church.

Ruth reported she considered herself to be athletic because she enjoyed outdoor activities including biking and hiking. While talking about her activities, Ruth became quiet and then stated, "I really um... really miss doing those activities. I'm... I still can't ride a bike, go hiking, or jogging." Ruth reported her goal in life was to have another baby within a few years so that her son would have a sibling. In thinking about her life after her son was born, Ruth said, "I had reached a lot of... a lot of my life goals because I was married to a won, won... wonderful man, I had my baby, a masters degree, I was doing the activities that I enjoyed with my family and

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friends and I was really in a... in a good space.” Ruth reported she was happy and feeling confident about where she was in her life. Ruth reported she has never had a previous head injury and also denied any drug or alcohol use.

### **The Injury**

Approximately six months after having her son, Ruth was a passenger in a friend’s car that was involved in a motor vehicle accident. Ruth identified her injury as a traumatic brain injury explaining, “I would call it um... um... maybe do classify it as a traumatic brain injury because of um... the car accident ... my head hit the windshield which um... caused my brain injury.” Ruth clarified that she was wearing her seatbelt when she got into the car, but could not recall whether the air bags deployed. Ruth reported that the specifics of the accident are still vague stating, “I don’t... don’t remember all the details, but um... my friend um... told me she that my um, my um... my head hit the windshield”. Ruth explained that she remembered the ambulance ride to the hospital where she was monitored overnight and discharged the following day. Ruth stated, “The doctors said I had a mild con...concussion ... He [ER MD] said a concussion after a car accident was not uncommon and, and that um... I should be fine.” Ruth denied experiencing any physical injuries as a result of the car accident and reported that she “returned to work two days later”.

### **Life Post-Injury**

Several weeks after the accident, Ruth explained that she started to feel “some sensations” and a few weeks later she had a seizure. Ruth explained, “It rendered me um... paralyzed on the right side.” Ruth stated, “The neurologist said the seizures were due to the head



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injury I sustained in um... in the car accident.” According to Ruth, the injuries sustained during the seizure left her with “cognitive and physical disabilities”. Ruth explained, “So then I had to work through paralysis and you know... physical and occupational therapy... so I was in the rehab hospital for six months before I um... I could regain feeling in my right side.” Ruth described her concussion and subsequent seizure as having “interfered” with her life.

Ruth reported, “I didn’t have enough um feelings to um... walk um... um dress myself, like walking um and um lift things up... It was very fine motor and gross motor problems.” Ruth reported feeling “dizzy” and experiencing “rolling vision”, which caused her to fall several times. Ruth reported having a difficult time dealing with her physical limitations including the inability to feed or dress herself and learning to walk again. Ruth described feeling like her body was betraying her stating, “I really couldn’t control...um I couldn’t control what my body was doing and it was very depressing.” In addition, Ruth also reported cognitive difficulties stating “Cognitively I had poor word recall and um yeah just like memory loss”... “Reading takes a lot longer um... I need everything written down now... I can’t retain information... I always need to have everything written down, so I can review it a couple of times.”

Ruth reported feeling frustrated with the process of the head injury after the car accident. Ruth explained, “The [ER] doctors said... you have a concussion as if, you know, um... no big deal and then a month later... I’m, I’m paralyzed .... I guess the diagnosis was not diff... difficult, the difficult part was trying to wrap... wrap my brain around (laughter)... that’s a crazy choice of words... wrap my brain around how a concussion got out... out of um... control to the point where I was paralyzed. I spent a lot of time thinking... thinking about that... yeah.”

After completing rehab, Ruth went to live with her parents who provided total care for her on a daily basis. Ruth recounted, “It’s like... it’s kinda like, alright these people care a lot

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about me, they're here to... they need to interfere with my life, but I kinda hate that I'm in this position where someone has to interfere with my life." Ruth recalled that living with her parents was very difficult because she was away from her husband and son, in pain, and dependent on others to care for her. Ruth reported feeling depressed and very isolated during this time. Ruth explained, "I was also depressed because I couldn't control what was going on and I didn't have um... like I had no control ...yeah you, you do feel isolated a lot in the whole process."

Ruth reported that being dependent on others to take care of her was what she found most difficult about her experience. Ruth stated she did not mind depending on her husband except almost overnight, he became the sole caretaker and provider for their son. Ruth stated, "I don't mind depending on my husband, but... with my husband it's more like guilt... Like I felt guilty about taking up all of the tendency [sic], especially with the baby... like I'm... I don't want to be... I don't want to be the one that's dependent because I have a child that should be the one that is getting all the help." Ruth admitted that at first she was really unsure about how to handle everyone's offer to help. Later she realized that her issue with dependence was not about the people [family or friends], but rather about "my relationship with dependency". Ruth attempted to explain, "I want to be independent and... but then on the other hand, I can ask you for help... I don't... It's hard... It's a hard like... the relationships of dependency and me not... me wanting to be independent." Despite not wanting to be dependent on others, Ruth noted several times that the support of her family, friends and church got her through the difficult time after her TBI.

Ruth reported those within her support system were very encouraging. Ruth recounted how she eventually learned to "direct their help" [those who wanted to help her]. Ruth explained, "In a very practical way, not in a like use them, but um... yeah I learned like... I was like this is... who you ask for help in this situation and okay cause you're not going to get... you know,

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you know who's going to be helpful and who's not." Ruth reported that her husband was very helpful when she returned home because he was responsible for providing care for her and their son. Ruth reported that had her husband not been assisting her with taking her medication, she might have taken more than the prescribed dose as she was in so much pain. Ruth recalled, "When I was really sick like... with pain I um... I would want more... like I had the really strong pain medications and um... yeah at some point, I was like 'oh if I take a couple of these it might work better' ... "I had somebody with me, you know, like somebody that would notice. Like... he counted the pills just because he would... like I would forget to take a medicine. So I was like okay, he's really watching me on this, so even if I thought about having... you know, doing something different I couldn't." Ruth reported that even when she took an extra pill, she would make it a point to mention it to her husband. Ruth stated, "I would even have to say... 'oh, I took a percocet and a this and a that' ... Perhaps if I was alone, you know on an extended time, I might... I could see taking... yeah I could see abusing the pain medication." Ruth reported that in many ways she was grateful that her husband was there to monitor her medication. According to Ruth, not only was her husband emotionally supportive he was also spiritually supportive. Ruth recalled a time when she was feeling depressed and wanted to give up and her husband said, 'faith is everything'... "so he was like," 'you have to believe... "so like that was all throughout it's been... he's been supportive."

Ruth reported finding much comfort in knowing that members of her church were equally supportive. Ruth stated, "I had... my priest um... visited me in the hospital, my um... the nun from my church visited me." Ruth recounted how her faith played a significant role in her life and later in her recovery, "I think my faith has... my faith has always been there, but I think um... it's bigger now... Um like I feel like I have actually... have the experience of talking to

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God.” Ruth described the intricacies of faith that she discovered during the long nights she spent alone in the hospital and rehabilitation facility. Ruth said, “I realized that you can lose it [faith] fast like I can feel it in the depth of despair, I can feel it um, but I... um, so it’s easy to feel it in the depth of despair, but to walk it every day like it’s hard to keep it, you know, it’s a, it’s almost... you’re trying not to make it fleeting.” Ruth reflected, “Just witnessing my own faith kind of, yeah has kinda given myself strength... if you don’t have faith, you don’t have anything.” Ruth continued, “I’ve always been a person that went to church every Sunday and strong in my faith, but this was like I’m... in the midst of all of this, it was a privilege to get close to God, like being able to get close to God.”

Ruth reported that although the most difficult part of her brain injury is in the past; her daily life is still very much affected. Ruth stated that her inability to return to work is one of the most debilitating ways that her head injury affected her life. Ruth explained, “I can’t go back to work because I have a disability... “I worked at a hospital [prior to her TBI] and I don’t know if I feel comfortable going back there”... “I think they’ll make me feel more like [pause] you are ‘Ruth... you are disabled, you... you’re not in this workplace anymore’ and you’re reminding me of that part that... or making that part stronger that knows I’m, know I’m disabled... that reminder, ‘see Ruth you’re not at work anymore, look you’re, you’re disabled.’” Ruth reported feeling anxious that others will see her as disabled and even though it’s hard to admit she sometimes sees herself as “less than” because she is unable to return to work. Ruth reported that although she always wanted time off [from work] to plan her career and start a family, but now that she is unable to return to work after the TBI, she feels lost. Ruth explained, “I could’ve, could’ve decided to stay home and um... you know, raise our child and that would’ve been my... my choice, but it wasn’t my choice this, this just happened to me.” Ruth continued, “It’s...

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it's...um when I thought I had a choice... I wasn't sure what to do and now that I don't have a choice, it feels... um it just feels like I've been robbed."

Ruth also reported finding it especially difficult to meet new people and make friends since her TBI. Ruth explained, "I think it's changed like... making friends, new friends... It's hard to say... because... I guess because I'm not working or maybe just because of everything"... "It's hard to have like that introductory [sic]... like... phrase... you know like, like when you meet somebody you say... you shake their hand and say I am and you know, I do... so it's just... it's hard not to go into the TBI thing." Ruth attempted to explain how she reacts in situations when she meets new people. Ruth stated, "I'm try to think of a scenario or situation where I almost demean myself with it like 'oh, I'm a sick person or I'm on disability' which I shouldn't say that, I should say, I'm, you know, at home with my child and I'm working through an illness." Ruth continued, "I'm like why did I make it sound like that? Why did I demean myself about it? It's hard to like, like I guess give myself a place within the disability realm. It's confusing cause yeah... I am... I am disabled, but yeah... I don't... yeah I don't know how to live... I don't know how to balance that out right now. I don't know how to define... like... how [laugh] to label myself... how to balance out who I am, how I am disabled and being disabled." Ruth reported since the injury, there are times when she has negative thoughts about herself, but she tries to remain optimistic and focus on the positive aspects of her life.

Ruth reported she is not currently involved with a TBI peer support groups stating, "I don't have a lot of time, so I don't want to waste time in getting involved with a group that I don't know if I'd relate to anyway ... I don't have... like I don't... I just feel like I can't... I don't have time to get involved. I have a therapist so that's my...that's probably the most I can

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get out of it.” Ruth stated, “The therapist turned out to be a very good therapist who was also covered by my insurance.” Among the issues addressed in therapy, according to Ruth, are depression, anxiety, and “learning to adjust” to her new limitations.

Ruth admits that a major part of her recovery has been coming to terms with the idea that she’s a different person since the injury. Ruth explained that sometimes she wonders, “what if I wasn’t in her [friend] car that night.... my life might be different.” Ruth reported she understands that she still has a long road ahead of her and she will continue to fight until she gets better. Ruth continued, “I’m not going to get pulled down... this is... so that kinda propelled me to get everything I could’ve out of the hospital”... “So, you know, so I got knocked down again, but I’m... but I gotta keep... gotta keep going.” Ruth continued, “I feel like I’m... I have more wisdom now... especially since I’m a little... a couple of years out, I feel like I can make this into a good thing.” Ruth reported that this experience has been profound and one of her future goals is to help others with TBI.

About sharing her story, Ruth reported, “I think for me it’s always good to tell my story um... it helps me just... So yeah I think that’s... that it’s good... and to see how far I’ve come. Two and a half years... I feel like... I’m going to get to a point... like say five years out where I’m not allowed to complain anymore” ... “Like I’m going to be... am I going to be a normal person then? Then I’m not allowed... I mean... I hope I am a normal person, but at that point like how much am I... am I still special? And how much can I still complain about this? So... yeah... so catch me when I’m... when I’m resilient”. With regards to her support systems Ruth stated, “I think their um... like proud of me.” With her therapist and support systems in place, Ruth reported she is hopeful she will continue to make progress each day. Ruth views this stage

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in her recovery as a challenge stating, “I challenge myself... my... myself to get back to a place where I can drive again, run again and enjoy those activities again.”

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### **Chapter V: Case Study - Ezra**

#### **Life Pre-Injury**

Ezra is a 36 year-old single African-American male with no children, who lives in a small city in the northeast region of the United States. After high school, Ezra joined the Army National Guard. Ezra reported being the first member of his family to join the military. After completing basic training and other necessary trainings for the Guard, Ezra returned home where “I lived with my dad, stepmom, and my two older brothers.” Ezra reported his biological mother died of natural causes when he and his siblings were young. Ezra explained, “Dad remarried when I was six and she’s (stepmom) been a great mom to us.” Ezra reported enrolling in college part-time while working full time at a security firm. Ezra recalled, “I continued to... you know, to do my one weekend a month and, and two weeks a year” as required by the Guard.

In his personal life, Ezra reported he was “doing a lot of growing up.” Ezra explained, “I started driving, you know, driving my stepmom... um my stepmom to her church activities and soon I found myself attending some of the activities with her and you know, before I knew it, I joined the church”... “My routine started to change and soon I found myself at church on Sundays, bible study meetings, and young adult activities.” Ezra continued, “Soon I accepted the Lord and was baptized... I um... also in the process I made a new group of friends just as I was losing contact with, with, with some of my buddies from high school.” Ezra reported he met a woman explaining, “I started dating this woman from church and we became inseparable.”

Ezra reported once President Bush declared war in Iraq in 2002; he was activated from part-time National Guardsman to active duty soldier and deployed stateside in support of that war. Ezra explained that during a stateside deployment, Guardsman are tasked with performing



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the duties that the active duty “soldiers on military bases were doing prior to being deployed overseas.” While deployed stateside, Ezra reported feeling supported by his church, his friends, his girlfriend, and family. Ezra recalled a situation where he felt supported, “The first time my unit was getting deployed my pastor, my deacon counseled and prayed with me”. Ezra reported feeling touched when “they [church leaders] said they would write, send emails, and check on me, yet months came and went and I didn’t receive a call or correspondence from anyone.” Ezra reported the promise made to keep contact was appreciated, but when they failed to follow through; he felt betrayed.

Ezra reported his family and girlfriend were supportive during the time he served stateside and during his first couple of deployments overseas. Ezra recalled that when he returned home he would spend time with family and friends going to the movies, the mall, bowling, camping, amusement parks, etc. Ezra reported when he got together with his brothers and/or his father, they would go watch a baseball or a hockey game; two sports that he enjoyed watching. Ezra reported that he felt like he had a positive support network stating, “Nothing negative I can think about.” Discussing the goals he had set for himself prior to the head injury, Ezra stated, “I think I had, I had um... some of the same goals that most people have, you know, get married, have children, finish school, have a career, the works.” At the time of his 3<sup>rd</sup> deployment overseas, Ezra reported he and his girlfriend were talking about getting married and he felt like he had solid relationships with his support system. Ezra reported he had no prior head injury, no drug use or excessive alcohol use prior to his injury.

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### The Injury

It was during his 3<sup>rd</sup> deployment in 2006 that Ezra reported he was injured while traveling in the international zone, which he refers to as the “IZ.” Ezra explained, “We were driving in the IZ and we were getting mortared, we used to get like thirty or so mortared a day and there was an explosion um... you know in our area and it knocked me down” Ezra clarified that while getting mortared, a blast caused the vehicle that he and his company were riding in to flip over knocking them down. Ezra reported he was not driving the vehicle at the time of the accident. When asked to explain what a mortar was Ezra stated, “The mortar itself is, is a... is a, is a tube that sits on the ground when you put the grenade in there and it launches it, but it’s indirect meaning that it could land anywhere.” According to Ezra, he was taken to several military facilities for “EKGs”...and “CAT Scans” before returning to the United States. He reported he did not experience any physical injuries and did not require any further treatment or rehabilitation. Ezra self identified his injury as a “TBI” explaining, “The injury that I sustained and you know um... I don’t know my head and the ACH [combat helmet], you know the combat helmet was hit... pretty hard so, that’s what they called it... or that’s what the doctors’ diagnosed it as.” Ezra explained that the doctors at his local VA diagnosed him “with both PTSD and mild TBI”. Ezra later described several symptoms that he’s experienced since returning home, “... I get blurred vision um...from time to time I just um... you know tremble uncontrollably, and headaches, you know it’s, you know it’s a daily thing actually that’s one of those things that I have a claim in for... um... it’s for the headaches, I have some lower back injuries, some shoulder pain that also goes with my headaches and um... these are, you know, part of it”.

When asked to describe the specifics about his head injury, Ezra stated, “Besides the actual words traumatic brain injury, I mean um... all I understand is, you know... I don’t

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know... my, my, my, my ACH [combat helmet], you know, my um... my helmet saved my life otherwise it would have been worse and um that's really what I understand." Ezra reported about his TBI, "It gets explained and I understand what they're saying, but how I feel is very different." In addition to "difficulty remembering things", Ezra also stated "... I still have problem sleeping sometimes you know; you know it will take me hours to fall asleep or I'll wake up in, you know, cold sweats and stuff like that."

### **Life Post-Injury**

In describing how different areas of his life have been affected, Ezra stated, "I mean the biggest part for me is just avoiding you know crowds, you know like large groups of people um... i.e. movie theaters or malls or anything like that, uh... I try to avoid those um... places like that, uh... I just... you know, I find it difficult to deal with the noise and flashing lights, you know, at the movies um... movie theater is um... too much." Ezra indicated that his decisions to avoid many of these places affect his life and relationships because those are activities he used to enjoy with friends and family. Ezra reported the activities that he used to enjoy are no longer interesting. Ezra stated, "You know... so you try to find other ways to you know, just kinda have fun and live life."

Ezra was not very talkative about his family, but discussed extensively how the lack of education for soldiers' families and other support system leads to misunderstandings about a soldier's way of life in combat and its consequences on the soldier's relationship with family and friends upon return. Ezra stated, "...the same way that they give soldiers you know training prior to coming back; they try to train us somewhat prior to returning... I feel like family should get the same training." Ezra reported believing that the military should provide additional training

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and education to families about what to expect when the soldier returns home. Ezra explained that families should be told “hey look this person’s been in this area, been doing this job and it’s not going to be easy for them to return back to this, so you need to know that when he or she returns back from overseas this is how they’re most likely going to be and that you have to be sympathetic to that, but because there is no such thing... it’s just like, like yeah two pieces um... um... two individual pieces of an puzzle that doesn’t match and you’re trying to put them together and no matter what, they’re not going to fit... that’s where the problem starts.”

According to Ezra, educating families prior to a soldier’s return home may help to create understanding and decrease the tension within the family unit. He explained, “I think I would show them a video of what... you know kinda like a few months of... being overseas is like is what I would show them. How we live um... you know, we work in teams, we’re basically... we’re all that we have um... as a team we’re self sufficient um... and it’s an everyday thing... there’s no... there's never any down time or down days. You might have some... well I’ll change that, there’s never any down days; you might have some down time, but not down days. So, you know, you’re basically working there literally trying to survive um... being in a warzone and you know, you never know when something can go wrong, so that’s what I would show them and teach them on how extreme it is over there so then when we come back over here to us it’s still very much extreme, so that’s one of those things I would definitely teach them.” It is those experiences during combat that Ezra reported have translated to behaviors that might be seen as driving at “top speed” or “checking our vehicles” and checking rooms because that’s what they did in combat. Ezra explained, “We all know we’re home and we’re safe, but um... it’s one of those things that you can’t help, but do.” Effectively making the transition home is a difficult and even an isolating process for the soldier. Ezra attempted to explain this phenomenon, “You

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get trained to do one thing you know stateside and then you actually get to do it overseas in the theater of war, you know, in the combat area where, you know, there are enemies and so you have to do your job how you know how it needs to be done, but then you come back home and everyone's had that home life, you know, and all of sudden that is not, you know, what you used to do originally so it makes it extremely hard because you know the people that's been at home they still do the normal things. Now you have to get back home and you try to step into that role, but it's just not the same... that's how I feel."

Ezra reported that to avoid having such issues escalate, it is important for a soldier to get involved with the VA before "things go wrong." He explained that currently troops returning from combat are screened by their branch of the military for physical and mental health and then it's up to the individual to determine if and when to seek services at the VA. According to Ezra this practice is not sufficient because by the time the soldier realizes that he or she needs help it is "often after things starts going downhill." Thus Ezra concluded, "I think the VA should be introduced to soldiers before they get out of uniform" ... "Soldiers should go directly to the VA; don't listen to what your commander tells you um... as far as whether or not you may or may not have PTSD or traumatic brain injury." With this scenario Ezra feels a soldier's issue can be addressed at the VA where services are always free to veterans.

Regarding his own experience readjusting back home after the TBI, Ezra reported difficulties in many areas including feeling misunderstood, lack of support from his religious community, and frustration with the process to get benefits for his TBI and other injuries. Ezra described feeling like his family members were not knowledgeable about TBI or combat related stressors that lead to him feeling misunderstood by family. He stated, "Well I think some people... I think my stepmom tries um...she tries to understand you know but um... I think the

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rest of the family you know um... my dad and brothers are, are... still very much clueless on um... what exactly is going on with me... In their own ways... I guess they are you know... you know supportive but um... I just feel like, you know, they don't... they really don't understand um... but for the most part, you know family.... being, you know, family they care, but when it comes to the actual um... TBI part, I don't... I don't think they really understand that." Ezra shared this example saying one of the activities that he used to enjoy with his father and brothers prior to the TBI was going to a baseball or a hockey game, but now he cannot manage being in an arena with so many people and therefore declines their invitation to spend time together, which has put a strain in their relationship. The feeling that others just don't understand him has caused Ezra to distance himself from his family and support system reporting, "so it's very hard for me then to come out and say 'hey this is how I feel and this is what I think is wrong.'" Ezra explained, "I stayed away from them all because I think that... they don't understand um... and no matter how you try to explain it... how much you try to explain it, it's, it's not easy. Um... it's the same thing with girlfriends... especially with girlfriends, you know."

Ezra reported memory loss is another issue that stems from his TBI and when his ex-girlfriend would ask him to do something, if he said he forgot, she would say he just didn't want to do it and that would lead to an argument. Ezra stated, "We had so... so many arguments you know... I guess she thought I just, just didn't want to work and I wanted to be lazy." Ezra said his girlfriend broke up with him about seven months after he returned home with the head injury. Ezra stated, "I get irritable very easily now" and he indicated that's why he makes an effort to avoid tense or stressful situations. Ezra reported their arguments were occurring more often and it was probably best for them not to be together. Ezra indicated that he is currently dating, but is not in a serious relationship. Ezra continued, "I think everyone wants an easy solution, you

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know, ‘can’t you just forget about it? Pretend it never happened’ um...and it, it... it just... it doesn’t work like that.” In discussing his experiences with feeling misunderstood by civilians; Ezra told a story of a soldier who shared a similar struggle after telling others about his experience in war and why he would return to the battlefield. Ezra explained, “...there was a soldier during the nineties um... during the whole Black Hawk Down incident back in ninety-three with Bill Clinton as President and the soldier said basically ‘when I go home and I tell people about what happened to me, you know, they’re going to ask me if I’m a war junkie, if I could go back... would I go back’ and you know his friends would say are you a war junkie, why would you go back?’ and basically he said, he was not going to tell them anything... he’s not going to tell those people anything because they won’t understand that it’s about the person next to you, it’s about the person that spent that time um... dodging the same bullets, dodging the same bombs, dodging the same mortars as you. “So it’s very different to then to be able, you know, to talk to, you know a civilian person about it versus um... talking to, you know, a comrade... somebody that was there with you. They absolutely get it because they were there.”

To that end, Ezra reported that he has recently connected with a female soldier with whom he served overseas and she has been someone that can truly understand him. About their friendship, Ezra stated, “We were in a place like that together, it’s, you know, it’s great knowing that I do have that person because then I can say remember when we did this and they’re going to say ‘yeah, yeah we were here, we were there’ and they remember it versus when you’re basically telling a story to somebody that wasn’t there. That’s one of those things that I’d just rather not do.” Along with this soldier friend, Ezra also identified a civilian friend whom he feels he can talk to without fearing that he will be judged. He explained, “... I feel like it’s not always easy... people to just sit there and listen, and listen, and listen and she was really good at that.

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She was um... and that's why I was able to share with her until this very day I still share things with her. Between the two of them, I feel like I have support on both the military side and the civilian side, you know." It seems like the support he receives from these two friends makes up for the limited support from family and significant other.

Ezra's presentation seemed most animated when discussing how his faith was affected after the TBI. At first, he stated that he did not know if his faith had been affected, but quickly stated, "Since my TBI, some things have changed drastically". Ezra explained, "I use to go to church all the time and do all these things, but uh... you know, I felt like when I came back from overseas, you know, when I was going... you know, getting deployed back and forth, I felt like the same, you know, group of people... mainly the, you know religious community, my church and so on and so forth; I felt like basically, you know, when I deployed they... the ones that said 'hey we would support you' um... you know, I felt like um... they bailed out on me." In describing how his church responded to his multiple deployments Ezra explained, "... it really hurt me to know that... seeing people um... you know that, that try to support me you know, later on basically (5 second pause) wasn't there anymore. Even after the um... you know, the TBI, the support wasn't there anymore um... and at that point... I just kept to myself, you know." Ezra reported that he no longer attends services at that church and is not currently affiliated with any church. In addition to feeling misunderstood by family, disappointed with his religious community, he also reported having a difficult time seeking services and benefits for his TBI within the VA system.

Describing his experience seeking treatment, Ezra stated, "The VA is really hard for me because you know, they're... my problem with the VA is a lot of the new reps, you know... the, the VA as it changes now um... a lot of the people they're still civilians you know so... I find it



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kinda hard to tell people about my experience overseas when they're civilians themselves." Ezra again reported having difficulty sharing issues related to his military experience with civilians even those working at the VA. He described the experience working with his VA social worker, "I have a social worker, her name is Karen, she's really good um... she's been checking up on me and we have a long relationship um... but you know for the most part, she's made things happen um... for me to get some of my disability benefits but no um... no treatment um... and you know, I like to go see her from time to time". Ezra reported he went to a Vet Center in an attempt to find other veterans that he can talk to who can relate to his experience. Regarding that effort Ezra stated, "The vet center although is kind of what I was looking for but it was still hard for me at the vet center... everyone in the vet center is a vet themselves whether Air Force, Army, Marines, Navy, Coast Guard uh... they're all vets.... but when I started going to them I found it difficult to talk... for whatever the reason was um... so um... I think I might have gone once or twice and then I just... I uh... I gave up... after that." The Vet Center did not meet his expectations and Ezra explained, "It was difficult... the people I kept talking to... I was hoping there would be at least soldiers or marines who, you know, had boots on the ground... possibly were fighting um... so on and so forth, but everyone I kept talking to were Air Force... and although, you know, there...it's, it's, it's a branch of the military and they're respectable people and um... I respect that they do, but the mission is so different, you know, that of an airman uh... versus a soldier or a Marine. I went twice and I didn't go anymore." Realizing he was not going to find what he was looking for at the Vet Center, he decided to continue to work with his VA social worker to get benefits for his disability.

Ezra reported numerous frustrations with the process to gain benefits for the TBI disability incurred while overseas. He stated, "It was very hard, I spent you know, the better part

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of let's see... since 2006... [mumbling under his breath] so it's been like six years or more like five years trying to get um... disability um.. trying to go in and see people and um... so it wasn't easy at all. It was actually really hard. And the thing with TBI... people with physical... the soldiers or troops rather with physical injuries gets taken... in my, my opinion, get taken care of a lot better... a lot faster um... because it is... it hinders, you know, what they do um... versus us, you know, who have an unseen... wound.” He reported that he can appreciate having all of his limbs; he believes he would get better and timely treatment with a physical wound. Ezra explained, “You know people always say ‘at least you have both your arms and both your legs’ and so on and so forth and it's just um... ... it would be better to actually have, you know, a physical injury knowing that I would be taken better care. It is extremely frustrating... it's extremely frustrating to know that, you know, it would have to go to that extreme, but I don't know... you just... what can you do?”

As indicated earlier, Ezra reported that he has been working with his VA social worker who helped him secure disability benefits. He later clarified that his current benefits are for his PTSD diagnosis and he still has open claims with the VA for the TBI disability benefits. Ezra detailed his experience trying to get TBI benefits thus far, “I have been diagnosed with TBI, I just haven't gotten compensation for it um... to get diagnosed with a TBI I think... more or less with the TBI... they [the VA] look for consistency in what you're saying to them um... I've met many people along the way, you know, all these people ask me the same questions in different ways um... so, you know, I feel like basically, if the story is not consistent than you might have to start all over again which is really frustrating.” Ezra reported he has an open claim for his TBI injury that requires him to constantly check in with the VA where he is often asked to provide details regarding his injury. Ezra explained, “Some of the questions are, you know, what

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happened, where it happened, um... where were you, dates and time, which you know is kinda hard to do because part of having a TBI is not remembering things so well.” Ezra continued, “That’s what’s so frustrating about um... waiting for the VA to give me my, my, my TBI disability benefits as if, you know, I’m not dealing with all these issues. I’m up all night, I get headaches that last for days, and I still get ringing in my ears at times, you know, I’m just not the same. I don’t look disabled and sometime I... um, you know, tell myself I’m not, but technically that’s what getting disability benefits means; you’re disabled. I guess, you know, as long as you can walk and talk um... people don’t see that I’m disabled” Despite these frustrations, Ezra appeared to be well aware that the process of waiting for the TBI benefits is not a matter that will be resolved soon. Of his experience Ezra stated, “I’ve been going through the VA system um... for a very long time and within the VA system, I’ve met a lot of people um... Vietnam vets you know that um... that themselves are still going through the VA system trying to get you know their disability statuses changed or fixed or upgraded so um... I think I’m in it for the long haul.” While waiting for his TBI benefits to get approved, Ezra reported he had to get a part-time job as he was unable to resume his pre-injury position, which has been depressing for him.

Ezra reported feeling overwhelmed with the inability to return to work post injury and he explained, “...it’s hard because, you know, you’re not the same, but people can’t see that. You know uh... um... I used to, to, to work as a manager for a firm and, I work my tail off um... put in a lot of hours to get there and now I’m back, but I can’t do my job. People uh... they look at you and they, I don’t know... they see you’re fine and ask why you can’t go back to work and you know, what do you say ‘I’m scared... I can’t deal with the hundreds of people coming in and out of the building daily’, you know um... I can’t say that.” Ezra reported that these difficulties caused him to leave the full-time position where he has worked for years and worked a part-time

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job on the overnight shift where he only has to interact with a few individuals. Ezra stated that making this decision has decreased his anxiety, but has also affected his income. Ezra emphasized that the inability to continue his career has affected him on many levels explaining, “It, it’s still depressing that you had a career plan and you know, a, a, a job that you enjoyed and now you just can’t do it uh... you know every now and then, I used to have the worthless feeling, in fact you know I think I still do kinda have it, but um not as bad as it used to be.” It appeared that his TBI had drastically affected the career path that Ezra had planned for himself prior to that deployment.

Ezra reported that he does not know any soldiers who are currently self-medicating to manage their TBI, but that he could imagine how an individual can get to the point where they would self medicate. He explained why he believes soldiers’ self medicate, “Well sometimes you know even though forgetting things is one part of a TBI um... it’s the, it’s when the time comes that you remember it um... where you remember some of the things that you... you know, you would most often forget um... come to think about it; the things you forget is basic average everyday things, the military part is the part that you don’t forget that never quits, and so that when I would think they would self medicate because you know it’s, once you... once you get like that it’s... it’s you know... you just want to forget it. It’s often times, drinking or drugs, I would think is um... when they would... when they would do it.” Ezra reported that to some degree, he too has self medicated in order to manage the effects of TBI and perhaps also the effects of going to war. He stated, “I have not with drugs, but with alcohol and you know I think to a lesser extent, I have... I have um... you know... sometimes you know, you think about things and you just, you.., you know, you just don’t want to and you just want them to go away

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and so you know, so you drink and you drink and you know to either feel happy or to, you know, feel better.”

Despite these issues, Ezra indicates that getting support and services for his TBI is essentially better than for active duty soldiers on a military base for several reasons including family support and peer pressure stating, “Um... I think it would probably be worse because um... you know, on active duty... it’s a collective you know... commander says everyone is fine; everyone is fine.” Ezra further explained, “... that it has been the case where when a commander says it’s fine you know, the soldiers with the worse problems decide ‘yeah, it’s fine; if the commander says I’m fine, then I’m fine’ and they go off and next thing you know either they go and kill somebody or they hang themselves.” Ezra reported that serving as a guardsman has afforded him better opportunities to receive support for his TBI. He explained, “It’s different as a guardsman because um... the reason why it’s different is because you get a lot more... on the civilian side and you know and that’s the difference between the, the active military because, you know, when you’re in the active military there’s no civilians around that can say ‘hey, look your attitude is changing’ versus um... the guards where, you know, family and friends are constantly around... so after a tour or two, you know you come back home they can see that change in you and based on that you know, you know, you know, you know... those that cares about you, usually will tell you, ‘ hey, look you know what, I think it would be a good idea um... possibly seek help so on and so forth versus being around soldiers that has the same problem as you and everyone is looking at each other saying ‘yup, there’s no problem.’”

Ezra reported feeling like with the exception of a few supporters, most people don’t understand him and as a result he has withdrawn from them and stays to himself. This injury according to Ezra has effectively caused him to develop a new sense of self explaining, “You

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know you try to find other ways to you know, just kinda have fun and live life. I, I have new interest and do, you know, new activities like going fishing um... something quiet and, and relaxing um... but for the most part, you know, it's... that's, that's about it." Ezra reported that in many ways this injury has affected him and also made him stronger. He stated, "I've gotten stronger in the sense that um... I refuse to let it define me um... I try to find ways of um... dealing with it um... without, you know, attempting to self medicate cause I've seen what that can do, but for the most part; just not letting it define me uh... defining who I am is the biggest part, basically." He reported feeling like he is still working his way through this injury and getting stronger in the process.

Ezra's case has proven to be multi-faceted in that not only has he suffered and been diagnosed with a TBI, he also experienced being in ground combat in both the wars in Iraq and Afghanistan. This combat experience has raised questions about the fact that he has been diagnosed at the VA with both TBI and PTSD. Ezra has also reported inability to follow previous career path, feeling misunderstood and difficulty finding others to connect with who share his experience. These issues will be discussed further in the findings section.

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## **Chapter VI: Findings**

### **Thematic Analysis**

Individuals living with a traumatic brain injury (TBI) often encounter various struggles, including personality changes and cognitive impairments. Both study participants confirmed that they too have experienced a number of struggles since their traumatic brain injury. Twelve core themes emerged from the case studies. In this chapter, I will examine the twelve core themes: physical symptoms, cognitive impairments, somatic complaints, isolation and depression, self-medication, “my changed life”, inability to return to work, Am I disabled, treatment & resources, religious community, family/support systems, and acceptance.

### **Post-Injury Struggles**

Nearly six million TBI survivors in the United States suffer with a chronic disability as a result of their injuries (Kim et al., 2007). Both Ruth and Ezra reported experiencing difficulties with physical symptoms, cognitive impairments, and somatic complaints after sustaining their TBI. Jackson et al. (2008) described the physical and cognitive symptoms as “postconcussive syndrome” that can result from a mild traumatic brain injury. Individuals with postconcussive syndrome according to Jackson et al. (2008) often complain of fatigue, memory problems, headaches, postural imbalance, insomnia, irritable or depressed mood, and/or interpersonal conflicts. The themes examined in this section includes physical symptoms, cognitive impairments, and somatic complaints.

### **Physical Symptoms**

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Physical symptoms after a traumatic brain injury often depend on the type of trauma and or severity of the trauma, but delayed symptom onset is not uncommon (Jackson et al., 2008). Although Ruth and Ezra were both involved in motor vehicle accidents, their accidents can be classified differently. While Ruth was in a car with a friend, Ezra was on the battlefield in Iraq where a blast caused the accident. Both Ruth and Ezra described experiencing physical symptoms weeks after the initial injury. Ruth, who was told she had a mild concussion, reported having seizures and paralysis only a few weeks after the accident. Ezra denied experiencing any physical injuries at the time of the accident, but later indicated several physical symptoms that he attributed to his injury, including back and shoulder pain. Ezra did not initially associate his physical symptoms to his traumatic brain injury until he realized the symptoms did not exist prior to the accident. In the literature, physical symptoms are most often associated with moderate to severe TBI, yet for both Ruth & Ezra, physical symptoms were present even with a mild TBI diagnosis.

### **Cognitive Impairments**

MRI or CT scan is used to determine the level of brain function after a TBI. As indicated in Table 1 (p. 8), a mild TBI is diagnosed when MRI and CT scan is within normal range. Ruth and Ezra reported they were informed that their initial MRI & CT scan displayed normal brain function; yet, over time they began to experience cognitive impairments that drastically impacted their lives. Both Ruth and Ezra reported difficulties with memory loss, poor word recall, frustration over how long it takes to read, and inability to retain information. Despite the “normal range” MRI and CT scan results, Ruth and Ezra’s ability to function in many areas of their lives was affected.



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### **Somatic Complaints**

Although somatic symptoms are not explored in the literature, the two participants in this study reported several somatic complaints. Ruth described experiencing dizziness, headaches, and nausea. Ezra similarly complained of headaches and also reported difficulties with uncontrollable trembles, blurred vision, and trouble regulating his sleep pattern. Such symptoms can be debilitating, yet very difficult to pinpoint and to treat. For both Ruth and Ezra, the person they believed themselves to be did not always reflect how they looked on the outside. As a result, family and friends began to see them and treat them differently than how they perceived themselves.

The social expectations associated with the physical, cognitive, and somatic complaints are important to explore considering both participants' experiences. Ruth reported physical symptoms including paralysis, which caused her to be hospitalized and then go through physical and occupational therapy. Ezra's reported physical symptoms were less debilitating than the symptoms that Ruth described. The social expectation placed on physical symptoms may lead one to sympathize more with Ruth's experience because Ezra's physical symptoms were less visible. Consequently, the individuals' experiences are not validated because they do not appear ill when others look at them. For example, Swift & Wilson (2001) concluded that lay people may be less sympathetic to accident victims' expressions of cognitive problems compared to physical symptoms. The participants' complaints of cognitive and somatic difficulties follow a similar pattern because of the invisible nature of their illness and symptoms. As devastating as the invisible symptoms may be to the individual, they are forms of less acceptable illness because essentially the person does not look sick.

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### Psychological Difficulties

Most individuals who suffer a mild traumatic brain injury (TBI) resume the course of their lives with few adverse affects (Trudel, Nidiffer, & Barth, 2007), while others struggle to recover. Studies investigating psychological changes after TBI (Emanuelson, Anderson, Bjorklund, & Stalhammar, 2003; Jackson et al., 2008; Koponen et al., 2002; Vaishnavi et al., 2009) concluded that there is a correlation between TBI and the development of psychological disorders, although the nature of the correlation is not always clear (Fujii & Ahmed, 2001). Both participants reported that their TBI significantly affected their psychological wellbeing. The themes examined in this section include isolation & depression, self-medication, “my changed life,” inability to return to work, “Am I disabled”, and treatment & resources.

### Isolation & Depression

One of the major themes that Ruth and Ezra discussed during their interviews was the isolation and depression that they experienced post-injury. Ruth described feeling severely isolated and alone in her pain and she struggled with the thought that no one understood how she felt.

Ruth explained:

*There's all these people around me and nobody is helping me with this... with this pain and why isn't anybody helping me get out of this... this... this painful state... um and then I was also depressed because I couldn't control what was going on and I didn't have um... like I couldn't control my body.*

Ruth reported the depression was equally a result of the pain she experienced and also because she felt so helpless to control her body or what was happening to her. Ruth reported

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finding it difficult to separate the isolation and depression because it all seemed to intertwine in her experience. Ezra, like Ruth reported experiencing both isolation and depression. Ezra described his isolation as self-induced because he felt misunderstood by his support systems. Ezra reported the more he felt misunderstood, the more isolated he became, and consequently started feeling depressed. Ezra, who was diagnosed with PTSD at the VA, explained that during this time he also experienced PTSD symptoms including social anxiety and flashbacks. Ruth and Ezra were able to verbalize that they experienced these symptoms as a result of their TBI, but it is unclear whether they understood the correlation between their trauma and those symptoms.

### **Self-medication**

Another theme was self-medication as both participants reported they struggled to manage their pain. Ruth reported she was prescribed painkillers like Percocet and she often considered taking more than the prescribed dose because she was in so much pain. Ruth explained during the interview that her husband closely monitored her pain medication because of her memory problems and that is what likely saved her from abusing her pain medication. However, Ezra admitted to using alcohol to self-medicate as a way to manage the effects of war including his TBI and PTSD symptoms. Ezra explained that he often felt like he would drink either to feel happy or to feel better. Furthermore, Ezra reported that he felt like he self-medicated not only because he wanted “to feel less depressed”, but also because he wanted to forget some of the things that he had seen in the theater of war. Ezra’s PTSD symptoms may have accounted for additional symptoms that resulted in his self-medication. Ezra’s military experience and PTSD will be addressed later in this chapter.

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Individuals who sustain a TBI may experience physical or even psychological pain that they are expected to manage. During the interviews, it became clear how both participants turned to over-medicating or alcohol in desperation as a way to manage their pain. Society's view of an addict is rarely a young professional mother or a decorated military Sergeant, but without adequate support, both Ruth and Ezra could see themselves going down a slippery slope of addiction as a result of their TBI. Ruth regarded her husband's counting her medication as a deterrent from over medicating. Ezra reported he consumes alcohol at times to manage his symptoms, but he does not feel he is currently over-drinking.

### **Adjustment to Disability: "My Changed Life"**

Both Ruth and Ezra reported that their lives, in terms of ability to care for self and to resume pre-injury activities, had drastically changed since their traumatic brain injury. Ruth explained that what changed most drastically for her was that she had to be dependent on others. Ruth talked about depending on rehabilitation staff to feed and bathe her and later depending on her parents to help her complete her activities of daily living. Ruth also reported at the time of the interview that she still cannot drive, she cannot provide for her son independently, and she continues to struggle with everyday tasks. Ezra, who was not as physically limited as Ruth, still reported his life was never the same after his head injury. Ezra did not have to depend on others to care for him physically, but he was unable to resume other pre-injury activities. Ezra viewed his changed life from the perspective of the many activities he had to give up and what those activities meant to his identity. Ezra, who described himself as an avid movie goer and sports fan, reported he was unable to enjoy these activities any longer. Ezra reported difficulties managing large crowds of people, flashing lights, and loud noise in most sport venues or movie

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theaters. More importantly these were activities that he previously enjoyed with friends, family members, and peers. Ezra's inability to participate in such activities has affected his relationships. Ezra explained that he was essentially forced to find alternative ways to pass time and to keep himself distracted. I will address Ezra's experiences with his support systems in detail later in this chapter.

In many ways, Ruth and Ezra described an inability to reintegrate into their former communities post-injury. Currently, a TBI is viewed as an event that "once fixed, the brain would not require further treatment beyond a relatively brief period of rehabilitation" (Masel & DeWitt, 2010, p. 1529). In reality; after the tests, diagnosis, treatment, and rehabilitation, Ruth and Ezra returned home and continued to experience the effects of their head injuries. It is the chronic nature of TBI that has caused several researchers to call for a change in how a TBI is classified from an "event" to the "beginning of a chronic disease process" (Masel & DeWitt, 2010, p. 1529). I will address the issue of classification further in the next chapter.

### **Adjustment to Disability: Inability to Return to Work**

Another major theme for Ruth and Ezra was their continued inability to resume their careers since their injuries. More than 2 1/2 years post-head injury, Ruth reported she is unable to return to work because she has a disability. Ruth explained she does not like going to her old job because her former colleagues may make her feel more disabled. Ruth was unable to say for sure how her former colleagues feel about her inability to return to work because she did not know.

Ruth explained:

*... You are less of a person because of your medical condition... So... see, see, look no work... yeah... but yeah feeling like if people are pitying me, then there's a reason why.*

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Ruth went on to explain that seeing her former colleagues while she is still unable to return to work feeds that part inside her that tells her that she is “less than” because of her limitations. Ruth verbalized that she is disabled, but she struggled with the thought that others would view her as disabled. Ruth appeared to be projecting her feelings of inadequacy onto her former colleagues perhaps because she was unable to sit with the thought that this is how she feels about herself. Ezra was equally passionate about his struggle to resume his pre-injury career path.

Ezra, unlike Ruth, made an attempt to return to work and reported he was unable to manage the environment. Ezra reported that he failed to transition to full-time employment and his boss, who is a veteran, has agreed to allow him to work on a part-time basis and at a different capacity within the agency. Ezra seemed most upset by the inability for others to see that he was still very much injured despite his physical presence. Ezra appeared upset when he talked about how difficult it has been to try to find the words to explain to family, friends, and his girlfriend why he is unable to return to his previous position.

Ezra explained:

*...it's hard because, you know, you're not the same, but people can't see that. People uh... they look at you and they, I don't know... they see you're fine and ask why you can't go back to work and you know, what do you say 'I'm scared... I can't deal with the hundreds of people coming in and out of the building daily', you know um... I can't say that" ... "It, it's still depressing that you had a career plan and you know, a, a, a job that you enjoyed and now you just can't do it uh... you know.*

Ezra seemed fearful of the response he would get if he were to reveal why he was unable to cope with the environment at work. Although Ezra did not verbalize this, he appeared to be

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concerned that he would be viewed as “less than” if he were to explain himself. Judd and Wilson (2005) concluded that individuals with TBI may experience “diminishing self-esteem related to a loss of ability to perform at pre-injury levels” (p. 439). More than simply the inability to return to work, one can only imagine how holding on to these feelings can affect Ezra’s sense of self-worth. Much like Ruth, Ezra had no evidence that anyone would see him differently, but he appeared to be stuck on the thought that others would not understand. Ezra projects that others will think he is lying about his injuries especially because he looks physically healthy, but he has not been able to resume full-time employment.

Ruth appeared ambivalent about whether she wanted her colleagues to view her as disabled, yet Ezra was frustrated because he did not look injured and he feared that people would not understand his disability. Both Ruth and Ezra likely project their feelings onto others because they are stuck in a cycle where they are concerned that they will be seen as different because they feel different, although they look the same. Ultimately, it is this invisibility that makes TBI a complicated illness. The nature of this illness causes the injured, their family and peers to question whether there is indeed a disability and whether mental health treatment is needed.

### **Adjustment to Disability: “Am I Disabled?”**

Another major theme for both participants was the question, “Am I Disabled?” Ruth and Ezra reported they struggled to come to terms with whether they were disabled and how that disability would affect their lives. Ruth initially concluded that she was disabled because she was physically unable to work. Yet now that she can walk and take care of herself, but still unable to return to work; she is unsure where she fits as a disabled person.

Ruth explained:

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*It's hard to like, like I guess give myself a place within the disability realm. It's confusing cause yeah... I am... I am disabled, but yeah... I don't know how to define... like... how (laugh) to label myself... how to balance out who I am, how I am disabled and being disabled.*

When I asked Ruth if she attends a TBI peer support group, she said she was not sure if she would be able to relate to others in the group. That was an interesting response because it raises the questions about how individuals with TBI look and act and why Ruth would think she might not relate to others in the group. The range of presentation by individuals with TBI is so varied that even amongst individuals with TBI, there remains some bias.

Ezra discussed a similar experience wondering about his disability. Towards the end of the interview, Ezra clarified that he knows he is disabled, because he received VA disability benefits for his PTSD. Ezra reported feeling frustrated that although the VA has diagnosed him with a TBI, he has yet to be approved for TBI benefits. Ezra reported this issue makes him irritated because he fought for his country and yet the VA has essentially called him a liar because they have not paid his TBI claim. Unlike Ruth, Ezra also faces the additional challenge of appearing to be a physically healthy man despite feeling shattered inside.

Ezra explained:

*I don't look disabled and sometime I... um, you know, tell myself I'm not, but I guess, you know, as long as I can walk and talk um... people can't see that I'm disabled.*

Ezra also appeared especially preoccupied about how others view him especially because the effects of his injuries are not visible. Although Ezra is one individual who has expressed these feelings, studies (Judd & Wilson, 2005; Nochi, 1998) have shown that some individuals with TBI may feel that they are receiving messages from family, peers, or society that say he or



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she is not the person whom they believe themselves to be. Essentially, Ruth and Ezra have an illness they have never experienced and neither of them is involved in any support groups to help them understand their illness or to engage with other people with TBI. Their responses indicate that they are unsure of how to be sick as they have had no one to role model for them how to behave when you have a TBI and your symptoms are invisible.

As indicated previously, as a society we have an acceptable view of what someone with an illness should look like. For example, we expect an individual with cancer perhaps to be bald as a result of chemotherapy or a person with crutches to have some sort of a leg injury because we can visibly see that injury. As a society, we have socially acceptable ways to respond to an individual who appears to be injured such as giving up our seat on a bus or holding a door. Unfortunately, for an individual with a mild closed-head TBI with no visible injury, it is difficult for the individual's family, peers, or strangers to know that this person is injured. The invisibility of a mild closed-head TBI creates a conundrum that leaves both the individual and the others (family, peers or strangers) without a road map on the socially appropriate way for the injured individual to act or for others to treat them.

### **Treatment & Resources**

Both participants reported they were not involved in specific treatment for their TBI, but rather they are meeting with social workers on a regular basis. Ruth explained that she was not sure if she belonged in or would benefit from a TBI peer support group. Ruth reported that since leaving the rehab, she attends individual therapy to address her depression and anxiety, but there is no specific focus on her TBI. Ezra reported he receives all of his services at the VA and after his injury he was assigned a VA social worker for support. Ezra spoke highly of the social

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worker for helping him secure his PTSD benefits. Ezra reported he still checks in with the social worker as he continues to wait for his TBI benefits and he classifies their meetings as case management and not therapeutic sessions. Ezra reported he is not currently involved in any peer support groups for his TBI, but he unsuccessfully sought support at a Vet Center hoping to be able to talk with veterans who could understand his experience.

There are few data guiding psychiatric treatment, making treatment with individuals with TBI a definite challenge (Vaishnavi et al., 2009). Until recently, there was a misconception that the behavior of individuals with TBI including amotivation, impulsivity, social inappropriateness, and agitation cannot be changed in therapy (Deaton, 1987; Vaishnavi et al., 2009). It was widely believed that individuals with TBI could not benefit from therapy because their behavioral problems were organic (Judd & Wilson, 2005; Vaishnavi et al., 2009). Despite Ruth's post TBI struggles, she reported that she feels like she has benefited from her therapy sessions in terms of decreasing her depression and helping her better manage her anxiety. Although Ruth's experience on its own cannot be generalized, recent studies (Judd & Wilson, 2005; Vaishnavi et al., 2009) highlight several therapy models that may be effective in treating individuals with TBI. An important aspect of treatment with individuals who have sustained a TBI would include addressing the loss of their former self, learning to cope with the grief that comes with that loss, and eventually learning to build a new self/identity.

### **Support Systems**

TBI can significantly impact family and caregivers, especially in cases where there are no visible injuries. The family, caregivers, and support network of an individual with TBI may encounter significant challenges due to the emotional and interpersonal changes caused by the

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injury (Albert et al., 2002; Wittig et al., 2003). Ruth and Ezra discussed their struggles and triumph with regards to their support networks' understanding of their disability and acceptance of their new self. The themes examined in this section include religious community, family/support systems, and acceptance.

### **Religious Community**

One of the most prominent themes for both participants was the role of their religious community. Both Ruth and Ezra reported that prior to the TBI; they were involved in religious activities in their home church and religious community. After her head injury, Ruth reported she was excited that several members of her church including, a priest and nun, visited her. Ruth talked a lot about her faith and how in her moments of despair she could feel herself growing closer to God. According to Ruth, her faith played a significant role in her recovery. Ezra reported he felt supported by his church community until after his first deployment (stateside). Ezra was looking forward to having supportive communication with church leaders, but felt abandoned when they failed to reach out to him. Ezra reported that even after his TBI, he received very limited support from the church community and consequently he stopped attending church. At the time of the interview, Ezra reported he was not looking for a church home and not currently attending any religious services.

There were two major issues raised about this theme first, it appeared that Ruth had a strong spiritual background available for her to access in her time of despair. Perhaps Ruth's relationship with God and not the church members' visits was what caused her to identify her religious community as a positive aspect of her experience. Ezra seemed to think he had a secure bond with members of his church and when they disappointed him, he felt hurt and abandoned.

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The second issue is a matter of human connection because although Ruth had her faith; she actually received visits from church members who made her feel cared for and supported. Ezra on the other hand, reported he did not receive the support of his church and he also experienced strains in his other relationships. When I initially asked about the role of faith and religion since the injury, Ezra stated none. He was quiet for a few seconds and then he went on to tell me what happened with his church members and leaders. Ezra appeared to be troubled that people upon whom he relied had failed him. It is difficult to determine the exact role that religious community played in the treatment needs of individuals with TBI, but Ruth and Ezra reported their religion/religious community significantly impacted their lives.

### **Family/Support systems**

The role of family and support systems was a significant theme for both participants. Ruth noted several times that the support of her family and friends got her through this difficult time in her life. Ruth reported that several family members and friends have told her that she does not ask for enough help. She did not ask for help because she did not want to be dependent on others to care for her. Ruth often talked about not wanting to be a burden to her parents. Ruth reported that she felt her family was supportive. For example, they helped her with making decision and with disciplining her son rather than doing it for her because she was injured. Ezra also talked about family, but he felt that although his family wanted to be supportive, they could not understand his needs.

Ezra reported his family and girlfriend were supportive during the time he served stateside and during his first two deployments overseas, but after his TBI he felt misunderstood. Ezra was very adamant that he would try to explain to family/friends again and again how he

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felt, but they could not understand. Ezra reported that with regards to his TBI diagnosis, his stepmother made an effort to understand his diagnosis, but his father and brothers were “clueless.”

Ezra explained:

*I think everyone wants an easy solution, you know, ‘can’t you just forget about it?’*

*Pretend it never happened’ um...and it, it... it just... it doesn’t work like that.*

Ezra reported that his relationship with his siblings and father has disintegrated even more now because he cannot engage in activities that they used to enjoy together prior to his TBI. Ezra also reported that in some ways, his TBI affected his relationship because he was easily agitated, irritable, and cranky which would often lead to arguments with his girlfriend. Ezra reported that because of these arguments, poor memory recall, and income stressors because of his inability to return to full time employment, his girlfriend broke off their relationship. Ezra admitted that although his family and girlfriend tried, they could not understand him. For both Ruth and Ezra, their family and significant others had to deal with their injuries and without proper education, they too likely did not know how to help their loved ones. Especially for Ezra who looked physically healthy, his family and girlfriend were probably baffled about how they should treat him when he does not look like a sick person. Clearly Ezra’s family/girlfriend had expectations of him that he could not fulfill and that realization made him withdraw from them.

### **Acceptance**

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Acceptance of their new self was another theme that developed during these interviews. Ruth admitted that a major part of her recovery has been coming to terms with the idea that she is a different person since the injury. Ruth reported that she feels the struggle post injury has made her stronger, but she feels she has room to continue to make progress. Looking to the future, Ruth wondered when she is five years removed from her injury and she is “*resilient*,” will she then be a “*normal*” person. Ezra, who continues to struggle with many TBI symptoms, reported that although his head injury has affected his life in many ways, it has also made him stronger. Ezra explained that he refused to allow his TBI to define him in terms of restricting his life because he has learned to adapt to his limitations. Ezra, who is now five-years post injury, explained that he has reconnected with old comrades and he is learning new activities as a way to make up for areas of his life that have been affected. Both participants discussed feeling stronger and learning to accept their new lives, although both of them appeared to have a long road to recovery ahead of them. This story is that of one veteran and one civilian and therefore cannot be generalized; yet, their experiences allow us to gain an in-depth view of how two individuals’ lives were affected by a traumatic brain injury.

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## Chapter VII: Discussion

### **Introduction**

The purpose of this study was to examine the impact of Traumatic Brain Injury (TBI) on the quality of life of OIF/OEF veterans returning home from combat. In particular, I was interested in the veteran's perspective because of the reported increased TBI rates among soldiers returning from war in Iraq and Afghanistan. Literature reviews of studies on veterans with TBI (Hoge, 2008; Trudeau, Anderson, Hansen, Shagalov, & Schmoller, 1998; Trudel, Nidiffer, & Barth, 2007; Vanderploeg, Schwab, Walker, Fraser, & Sigford, 2008) revealed only quantitative and no qualitative studies published in scholarly journals. There were no studies that explored the quality of life post-injury from the injured veterans' point of view. Yet, TBI studies with civilians (Deb, Lyons, Koutzoukis, Ali, & McCarthy, 1999; Koponen et al., 2002) indicate there is a correlation between TBI and the risk of developing a mental health disorder. Carlson et al. (2012) concluded that "Nearly one-third of discharged [rehabilitation] patients had incurred subsequent, medically treated injuries, with falls being the most frequent source of injury" (p. 22).

Considering that TBI is labeled as the "signature wound" for returning OIF/OEF veterans (Hoge et al., 2008; Jackson, Hamilton, & Tupler, 2008; Okie, 2005), it is important to understand the impact that a TBI has on veteran's reintegration into his or her community post-injury. To date, the majority of TBI research employs the medical model rather than the perspective of the individual living with the injury (Nochi, 1998). Thus, having identified a significant gap in the literature, I had hoped this study would contribute to a growing body of knowledge about the impact of traumatic brain injury on returning OIF/OEF veterans.

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The initial goal was to interview 5 veterans and 5 civilians with TBI, but the population was difficult to access. As a result, I chose to focus and complete in-depth interviews and case study on two individuals (one civilian and one veteran) who suffered a TBI. Both participants provided poignant testimonies about their experiences since their injuries. The case studies offered the opportunity to compare and contrast both participants' experiences.

The study sought to answer the following questions: What impact does a Traumatic Brain Injury (TBI) have on the quality of life of an OIF/OEF veteran returning home from combat and a civilian recovering in the community? 1) In what ways has the participants' TBI affected their ability to return to work and reconnect with support systems? 2) How has the TBI affected the participants' personal life and sense of self? 3) In what ways can TBI be treated or addressed that will help veterans, civilians, and their support systems? This chapter discusses the study questions and the participants' experiences with regards to loss of self, the impact of an invisible wound, and building a new self. I also address the implications for social work practice and future research.

### **Living with a TBI: "Interfered with my Life"**

Ruth's case study detailed in Chapter IV afforded an opportunity to gain valuable insight into the experience of a civilian living with a traumatic brain injury. Ruth provided a glimpse into a life that she describes as having been interfered by her head injury. It is important to emphasize that Ruth's experience is that of one civilian and thus cannot be generalized to other civilians with TBI.

Consistent with the literature, Ruth described several ways that her TBI affected her quality of life, including having to depend on others, her inability to return to work, and



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continued difficulty with her memory. Ruth reported feeling depressed because she could not control her body and consequently had to depend on family to care for her physically. Ruth reported feeling distressed that as an adult she was reduced to being treated like a child, even when she started feeling better. Ruth explained feeling lucky that her family was available to care for her, but accepting that she needed help as an adult was a quandary. Ruth reflected on this dilemma and concluded that her struggle accepting help had less to do with her family or friends, but with what she identified as “my relationship with dependency.” Prior to her TBI, Ruth was a self-sufficient young working mother with a master’s degree; yet post injury; she was instantly incapable of resuming most pre-injury activities. What Ruth identified as her “relationship with dependency” appeared to reflect her ambiguous feelings about how to manage her significant loss of self. For Ruth, it was not that people had to take care of her, but more that she was forced to live a life completely different than she had previously known.

### **Living with a TBI: “When No One Understands”**

Ezra’s case study in Chapter V provides a detailed account of his experience readjusting home after his traumatic brain injury. Ezra’s experience is that of a single soldier and cannot be generalized to other veterans with TBI; yet, he provides us a starting point to explore how a combat veteran’s life can be affected by TBI.

In terms of quality of life, I expected responses about difficulties with cognitive symptoms or inability to return to work as indicated in the literature review. Ezra addressed both of those issues, but he spoke passionately about feeling misunderstood by his support systems. Ezra reported several TBI-related symptoms, including irritable mood, personality changes, and forgetfulness, which he believed played a role in his girlfriend breaking up with him. Ezra

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reported that after his TBI, he was unable to engage in hobbies and activities that he previously enjoyed with family and friends. The more he felt misunderstood, the more he isolated and consequently the more depressed he felt. Ezra reported that the lack of education for soldiers' families and support systems is what leads to misunderstandings about a soldier's way of life in combat and its consequences on the soldier's relationship with family and friends upon return.

Ezra described the urge to consume alcohol in order to self-medicate his symptoms away. Ezra reported he has not engaged in treatment at the VA because he feels that as a civilian, the VA social workers' cannot understand him as a veteran. Despite his personal experiences, Ezra reported the VA should screen returning veterans for TBI several times, thereby creating a safety net to catch veterans who develop a problem after the initial screening. Ezra reported that currently, VA services are voluntary and usually by the time a veteran/soldier or his or her family reaches out for help, the problem would have already started affecting the individual/family.

One of my initial hypotheses was that veterans on a military base would have better access to TBI care and services rather than reservists who returned to the community. When I asked Ezra, he explained that in his experience the contrary is true. Ezra indicated that he has more opportunity for support and services in the community as a reservist for several reasons including peer pressure.

Ezra explained:

*Um... I think it would probably be worse because um... you know, on active duty... it's a collective you know... commander says everyone is fine; everyone is fine"... "... that it has been the case where when a commander says it's fine you know, the soldiers with the worse problems decide 'yeah, it's fine; if the commander says I'm fine, then I'm fine' and*

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*they go off and next thing you know either they go and kill somebody or they hang themselves” ... “It’s different as a guardsman because um... the reason why it’s different is because you get a lot more... on the civilian side and you know and that’s the difference between the, the active military because, you know, when you’re in the active military there’s no civilians around that can say ‘hey, look your attitude is changing’ versus um... the guards where, you know, family and friends are constantly around... so after a tour or two, you know you come back home they can see that change in you and based on that you know, you know, you know, you know, you know... those that care about you, usually will tell you, ‘ hey, look you know what, I think it would be a good idea um... possibly seek help so on and so forth versus being around soldiers that has the same problem as you and everyone is looking at each other saying ‘yup, there’s no problem.*

Ezra confirmed one of my hypotheses that veterans with an invisible (TBI) wound would have experienced more difficulties gaining access to services and benefits. Researchers (Belanger, Scott, Scholten, Curtiss, & Vanderploeg, 2005; Scott, 2006), concluded that TBI in the military is under-diagnosed because medical attention is primarily focused on visible injuries. Ezra alluded to the overlooking of veterans with closed-head injury compared to veterans with visible injuries. Ezra reported he is certain that he would receive better care and would not have to wait so many years for his (TBI) disability benefits if he had a visible injury. In sharing his personal experiences, Ezra was able to shed new light about some of the effects of TBI for combat veterans seeking benefits.

### **Loss of Self**

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In describing her inability to care for self, to return to work, and difficulty socializing, Ruth appears to reflect the loss of self that she experienced post injury. Throughout her interview, Ruth appears to talk about her post-injury self almost as if speaking about someone else. Ruth described her pre-injury self as intelligent, active, and outgoing, yet post injury she had become depressed, anxious, and isolated. Ruth reported finding it so difficult meeting new people or even making friends because she just does not know how to introduce herself. Ruth described the struggle of how to start a conversation with a new person without going into details about her head injury especially now that her physical symptoms are less visible. It was almost as if her TBI had come to define her new life.

Although Ezra was unable to verbalize the same as Ruth, his story implied experiencing loss of self including how his life was affected and especially his current difficulties maintaining relationships. Ezra was also frustrated by his inability to return to his previous career nearly five years post-injury. Ezra reported that although he remains a reservist, he has not been redeployed to a war zone since his TBI. Much like Ruth, Ezra described his pre-injury self as sociable, friendly, and he enjoyed group activities; yet, since his TBI he has become depressed, isolated, and withdrawn. Ezra's question about loss of self was most apparent as he contemplated, "Am I disabled?" Despite his previous statements about how his life has drastically changed, Ezra described knowing that he is disabled because he is currently receiving disability benefits.

Whether they realize it or not, both Ruth and Ezra has been involved in a meaning making process as they try to understand their new identity post-injury. Nochi (2000) noted that as researchers, we still do not entirely comprehend how individuals who sustain a TBI cope with their changed lives (p. 1796). Ezra, who reported he has not received treatment for his TBI, has not had the opportunity to apply labels to the feelings and trauma that he has experienced. Ruth

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who started treatment after her TBI reported she has learned to use various coping skills primarily to manage her depression and anxiety. Perhaps in treatment Ezra would also be able to work on building a new self; a concept that I will explore in details later in this chapter.

### **Getting Stuck in the Grieving Process**

The first step in learning to cope with the loss of self, experienced by Ruth and Ezra, is to accept the loss and then begin the grieving process for the old self. Starting and completing the grieving process can be difficult because mourning opens the flood gates for profound grief (Herman, 1997). The grieving process can also be affected by the extent and location of the brain damage, the individual's capacity to understand the invisible nature of his or her TBI, and also the individual's ability to participate in the treatment process. Herman (1997) wrote, "Since mourning is so difficult, resistance is probably the most common cause of stagnation in the second stage of recovery" (p. 189). Individuals who have a difficult time completing the stages may find themselves stuck in the grieving process.

Ruth and Ezra reported making changes in their lives to cope with new deficits since their injuries. Ruth described the need to have all information written down due to her poor memory recall and Ezra reported changing his work schedule and taking up new hobbies where he does not have to interact with a lot of people. In making such efforts, it appears that Ruth and Ezra have come to some understanding that they are different and they have to make the necessary adjustments to accommodate the new self. Even though Ezra has made some effort to cope with his loss, he also admits that he occasionally uses alcohol to self-medicate. Years after their TBIs, Ruth and Ezra appeared most concerned about the disparity between their physical appearance and their broken brains. Considering that the invisibility of their TBI is an important issue for

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both participants, the next section will address the impact of an invisible wound. The stages of recovery including moving past the grieving process will be addressed later in this chapter.

### **The Impact of an Invisible Wound**

As indicated in the previous chapter, the invisibility of a traumatic brain injury can be a source of stress for individuals and their support systems on many different levels. Ezra felt like his support systems would not understand his inability to return to his pre-injury employment nearly five years post-injury. Ruth described a similar experience as she wondered if her former co-workers would think of her as “less than” because of her inability to return to work post-injury. Ruth explained that now that most of her physical symptoms are less pronounced, it is more difficult for others, such as her former co-workers to see that she is still very much injured. Ruth reported it is equally difficult for her to make new friends because although she appears fairly healthy she feels the need to explain her illness. Ruth reported she feels like she is “demeaning” herself by having to explain her situation and that experience caused her to have negative thoughts about her illness and recovery.

Ezra reported experiencing stressors from many directions as he felt misunderstood at home and doubted by the VA. Ezra reported feeling upset that VA staff does not believe that he has a TBI because they cannot see how many aspects of his day-to-day life have been affected. As indicated in the literature review, difficulty securing TBI benefits poses a unique challenge when an individual with TBI has an “invisible disability” where the primary struggles are cognitive and not physical (Langlois et al., 2006, p. 377). Ezra described feeling insulted that the VA diagnosed him with TBI and more than five years later, they have not settled his TBI claim.

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Although Ruth and Ezra were likely projecting their own feelings, it is understandable that families may experience stress as they struggle to understand why their loved one looks the same, but acts differently (Albert et al., 2002). Ezra described feeling discouraged that he appears physically healthy while struggling with memory loss, depression, insomnia, and chronic headaches that no one could see or understand. Ezra admitted that he would have preferred to lose a limb in Iraq because then people could see that he is an injured individual.

### **Sick Role**

Although Ruth or Ezra did not know it at the time, there is a theory (sick role) that dates back to the 1950s that could explain their experiences. The concept of the sick role was introduced by the sociologist Talcott Parsons in 1951 as part of his theory of social action (Segall, 1976; Twaddle, 1969). Parson (1957) identified three specific criteria for accepting the social role of being sick. The first step begins with recognition by self (the injured) and others that the illness is beyond the individual's control. Parsons (1975) explained that the second feature of the sick role is the "exemption from ordinary daily obligations and expectations, for example, staying at home in bed instead of going to school or office" (p. 262; Segall, 1976). Finally, the sick individual is expected to view his or her sickness as "undesirable" and thus seek help in an effort to "facilitate recovery" (Parsons, 1975, p. 262; Segall, 1976). In order to understand how much the sick individual is affected, Segall (1976) explains the sick role also affect ones' "social, cultural, and personal factors" (p. 165). One of the criticisms of Parsons' theory was that the sick individual could get use to being exempt from normal obligations and thus develop a desire to remain in the sick role. As with any other invisible illnesses, like

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depression or anxiety disorder, it can be difficult for others to understand the intensity and impact of an illness that is not visible.

During their interviews, Ruth and Ezra confirmed that their TBI had significantly impacted several areas of life including personality changes, difficulty managing relationships, and hindered their career plans. Sick role theory can be used to understand many of the experiences that the participants identified during their interviews.

### **TBI through a Sick Role Lens**

TBI can significantly impact the individual, family, and caregivers, especially in cases where there are no visible injuries. For example, family members, friends, and peers tend to expect more of a brain-injured person if the person has no external sign to clearly indicate his or her injury (Swift & Wilson, 2001). In fact, the question for individuals with TBI becomes how will anyone know they are hurting when their pain is invisible? Even in some cases like Ezra where the family notices a change in personality, it is not always clear how they should address the issue. I will now use sick role theory to explore more thoroughly the impact of TBI on Ruth and Ezra on a personal and social level.

Despite the negative MRI and CT scan results given to Ruth and Ezra, they continued to suffer the effects of their brain injuries. On a personal level both Ruth and Ezra had to manage the invisible effects of their injury including emotional and cognitive symptoms. Ruth reported feeling depressed because she could not control her body and her family could not understand. Aside from her physical symptoms, Ruth reported experiencing headaches, rolling vision, dizziness, forgetfulness, and difficulty concentrating. The symptoms were real, but her family could not see the impact that these symptoms had on her. Ezra had similar experiences as he



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described invisible symptoms that his family, friends, and peers were not able to see. Ezra reported no one could see his blurred vision, ringing in his ears, forgetfulness, and irritable mood that often led to angry outbursts. According to Ezra, his girlfriend witnessed his outburst, but could not see or understand the symptoms that led up to the episodes.

Parsons' (1957) sick role theory indicates that the self (injured individual) and the other (i.e. Family, significant other, peers) have to accept the sick person is ill through no fault of his or her own. It appears that the first step in Parson's theory is true for Ruth and Ezra as they and their family has come to accept that a head injury occurred and neither Ruth nor Ezra were at fault. Accepting the injury is the first step, but understanding exactly how the injury will impact the individuals, their families, and support systems remains unclear. Ruth and Ezra's experience from this point forth will share similarities and also differences.

Post-injury, both Ruth and Ezra struggled to understand who they were, what their roles were within their family units and in their communities. Ruth talked about wondering who she was because essentially she was unable to perform tasks and duties that she had expected of herself as a young mother and wife. Ezra on the other hand, discussed experiencing a lot of anxiety that his girlfriend thought he was lying when he was forgetful or how his irritable mood and poor frustration tolerance got in the way of the boyfriend he once imagined himself to be. In many ways, Ruth and Ezra struggled to figure out their roles within their skins and family units because the roles they previously played were no longer accessible. The emotions and feelings expressed by Ruth and Ezra reminded me of the second stage of Parson's sick role that dictates acceptance of the sick role. According to Segall (1976), once the sick person and the other have accepted the sick role, it is important to understand that the sick person is exempt from his/her

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responsibilities (i.e. working, school, and household chores) including normal social role obligations.

For Ruth and Ezra, there is a need to understand and embrace their new roles, but clearly it has not been easy for either of them. At one point during the interview, Ezra mentioned that he wished he had lost a limb in Iraq because then others could see that he is truly an injured veteran. Ezra yearned so much to have his injury recognized and validated that he would have traded a limb, so that there would be no doubt that he is injured. With regards to work and meeting new people, Ruth struggled with being viewed as disabled, while in fact her TBI has rendered her disabled and unable to work. Gelles & Levine (1995) explains, “When a situation is ambiguous, individuals hesitate, look for clues about how to behave, explore the various possibilities, test the limits” (p.151). For Ruth and Ezra and their support systems; there are no scripts for understanding how individuals with TBI or his and her family are to behave. Ruth and Ezra, in many ways, were looking for an opportunity to act and behave as injured individuals; essentially play the sick role. In order for that to happen, both the sick individual and their family/support system have to allow the sick individual to be exempt from previously accepted social roles. A non-injured individual is expected to go to work and engage in activities that are not expected from a cancer patient or a soldier who is missing limbs. It is the invisible nature of their TBI that causes the disconnect that Ruth and Ezra experience between how they look physically and how they feel inside.

### **Sick Role in the Community**

As important as it is for Ruth and Ezra to act out the sick role within their family unit, it is equally important for the sick role to extend into their larger community and support system.

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This is especially important in the community, because over the course of their adult lives Ruth and Ezra had carefully constructed social identities to match the individuals they perceived themselves to be. Gelles & Levine (1995) defined social identity as “The positions we occupy in society, as student, daughter, friends, poet, vegetarian, and the like” (p. 152). In many ways, Ruth presented a social self as a young, educated, self-sufficient, mother, and wife. Ezra presented his social self as a son, a boyfriend, and most importantly a veteran. According to Gelles & Levine (1995), “Social identities are fragile” and when an individual like Ezra experiences a traumatic brain injury, his well constructed identity may have suffered some bumps and bruises (p. 152). This proved true for Ruth and Ezra because in many ways their well-assembled social identities were shattered as a result of their TBI. Consequently, it is essential that the sick individual’s community and support network also recognizes the illness and the individual’s exemption from usual social roles. For Ruth and Ezra that community and support network should include work or previous work environment and church or religious community.

Ezra reported when he first joined his church he felt supported, but the support dwindled away after he was first deployed state-side in support of the Global War on Terror (GWOT). By the time he returned home from Iraq with a head injury, Ezra reported feeling hurt and rejected that his religious community were not supportive. Ezra described how he slowly withdrew from the church and consequently lost that support network. Ezra explained that he still has yet to join a new church. When asked about how his religion or faith had been affected by his TBI, Ezra’s answer primarily focused on feeling rejected by the church and not his personal relationship with his God. It appeared that Ezra had placed a lot of value on his relationships with church members and when he felt rejected by them this experience may have affected his belief system. Ezra’s experience was closely tied to this support network at church, so when he perceived church

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members as failing to understand his need for support as a deployed soldier and later as an injured veteran, he emotionally withdrew from that support network. Where Ezra felt his religious support network misunderstood him, Ruth had a drastically different experience as she felt her recovery would have been more difficult without her faith and religious support network.

When asked how her faith/religious beliefs have been affected by her injury, Ruth reported the nuns at her church visited her and other members brought Holy Communion to her while she was at the rehab facility. Unlike Ezra who never exhibited physical symptoms, Ruth described experiencing a seizure and paralysis during the early stages of her illness. Perhaps Ruth's visible injuries (in the beginning of her injury process) played a significant role in the amount of support that she received during her recovery. In many ways, Ruth had an opportunity to act out the sick role part because of her physical injuries. Ruth's ability to continue to play the sick role part on a community stage became more difficult over time as she began to improve physically. By the time of the interview, Ruth was two and a half years post-injury and was now struggling with the paradox of appearing healthy when she was still struggling with many invisible TBI symptoms. Ruth then went on to focus on her personal beliefs and how she felt she grew closer to God in her time of need.

For all the differences in their experiences by the time of the interviews, both Ruth and Ezra were facing similar post-TBI identity struggles. One can imagine that for many years Ruth and Ezra meticulously created social identities within their respective fields as a professional and a veteran who proudly served his country. Yet in an instant their well-constructed social identities were fractured. As Ruth and Ezra work to rebuild their new identities and make sense of their new roles, it is important that their community/support network recognize their sick role and inability to perform at pre-injury levels. Despite the similarities between them, the most

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conspicuous difference between Ruth and Ezra is his combat experience pre-injury. Ezra's military experience and the nature of a combat-related TBI are in need of further exploration and I address these issues in the following section.

### **Combat-Related TBI: It's Complicated**

Research looking at the impact of traumatic brain injury (TBI) on returning OIF/OEF veterans is still in its infancy. Vasterling et al. (2006) argue that to date "the consequences of war-zone deployment on neuropsychological health remain poorly understood" (p. 519). Despite the years of education and support services around PTSD and mental health issues in the military Erbes et al., (2007) concluded that stigma around mental health services remains intact. TBI in many ways mimic other mental illnesses and substance abuse in that the symptoms and the individuals' struggle can be invisible to family members and society at large. It seemed like for Ezra, there was added pressure of dealing with his support systems, navigating the VA benefits system, all awhile managing his symptoms and self expectations. Ezra particularly struggled with not getting the recognition of an injured veteran, but that is difficult when you're a six foot, 240 pound man, with all your limbs intact, and no visible wound to your head.

The invisible effects of combat cannot be erased or even easily forgotten as Ezra explained; but, rather combat changes their lives radically (Herman, 1997). In many ways, our society evaluates whether returning veterans are functional rather than recovered from their combat experience and injuries. Herman (1997) explains that as a society, we have a tendency to forget about the needs of veterans after the war ends. Herman (1997) wrote...

Within a few years after the end of the war (World War II), medical interest in the subject of psychological trauma faded once again. Though numerous men with long-lasting psychiatric disabilities crowded the back wards of veterans' hospitals,

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their presence had become an embarrassment to civilian societies eager to forget (p. 23).

Much like those World War II veterans diagnosed as shell shocked so many decades ago, OIF/OEF veterans still struggle with invisible illness that few understand. Veterans with TBI have more than just the brain injury to contend with several stressors including suicidal ideations and interpersonal relationships. According to Brenner, Ignacio, & Blow (2011) veterans with TBI, seeking services at the VA, are at a higher risk for suicide than veterans without TBI. A Department of Defense Task Force (2010) report indicated that within the 5 years from “2005 to 2009, more than 1,100 members of the Armed Forces took their own lives, an average of 1 suicide every 36 hours” (p. ES-1). It is impossible to determine the exact circumstances that led to these individuals’ suicide. Yet, Gill, Sander, Robins, Mazzei, & Struchen (2011) concluded that individuals (civilian) with TBI report a decrease in friendships, difficulty with intimacy, increasing loneliness with time, and difficulty forming new relationships. These circumstances can affect the individual’s ability to reintegrate into their family unit, work environment, and their community. For veterans with TBI, these circumstances may be exacerbated by PTSD symptoms and or other effects of war. For example, Ezra described the need to sweep (check) his apartment even though he knows he is not in danger, or the need to engage in dangerous behaviors like speeding to match the adrenaline he experienced in combat. As a result, combat-related TBI is complicated because it affects the individual, his or her family, support systems, military career, and sense of self.

### **Understanding the Trauma in Traumatic Brain Injury**

The invisibility of a traumatic brain injury is similar to mental illness or a substance abuse disorder in that the individual usually appear physically well despite unseen emotional or

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cognitive symptoms. This section will explore the trauma that takes place during and after the incident that resulted in the traumatic brain injury. For Ruth and Ezra the initial trauma was caused by a vehicle accident and a blast leading to a vehicle accident that caused their head injuries and subsequent symptoms. Yet unlike a mental illness or a substance abuse disorder, the TBI was imposed upon them in an instant with no time to plan on how to cope with such an injury. Ruth and Ezra described parts of their post-injury lives as being “out of control,” which perhaps may be related to the fact that neither Ruth nor Ezra were driving or in control of the vehicles involved in their accidents. This may seem like a minor issue, but trauma ultimately robs victims of their sense of power and control. Herman (1997) explained, “After a trauma, the human system of self-preservation seems to go onto permanent alert, as if the danger might return at any moment (p.35). In many ways Herman’s statement reflected Ezra’s explanation of how he remained alert and on edge after returning home to the point where he would still sweep his car and home for mines and enemies even when he knows he’s no longer on the battlefield. Although removed from immediate danger, his mind remained alert and on patrol.

In addition to the initial trauma of the accidents, Ruth and Ezra incurred secondary trauma that would leave a lasting effect on their personal, familial, and social lives. Weeks after the initial trauma, Ruth described having seizures and then experiencing paralysis that ultimately impacted her life in countless ways. For Ezra, the secondary trauma was immediate as several members of his unit (in the vehicle) were critically injured requiring urgent first aid care. Whereas Ruth believed she was fine until weeks later when she started to exhibit symptoms, Ezra’s secondary trauma was immediate as he had to tend to wounded comrades despite being wounded himself. At some point that day, Ezra reported he and most of his unit were transferred to hospitals for testing and further care.

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Ruth and Ezra continued to experience additional trauma both on a visible and invisible levels. As previously indicated, Ruth required hospitalization and rehabilitation to manage her paralysis. As she recuperated physically, her other emotional and cognitive symptoms persisted and eventually Ruth came to the conclusion that she was no longer the person she knew pre-injury. Ruth described the effects of her TBI including the inability to return to work as suffering a loss.

Ruth explained:

*I could've, could've decided to stay home and um... you know, raise our child and that would've been my... my choice, but it wasn't my choice this, this just happened to me... It's... it's....um when I thought I had a choice... I wasn't sure what to do and now that I don't have a choice, it feels... um it just feels like I've been robbed.*

Upon returning home, Ezra also faced other forms of trauma including feeling misunderstood by family, significant other, his VA social worker, and failure to return to work. As a result of these stressors, Ezra reported feeling depressed, he withdrew from support networks, and at times he self-medicated these symptoms away with alcohol. At some point in his interview Ezra reported that he refrains from telling civilians about his combat experience because they would never understand why he would want to be on the battlefield rather than being safe at home.

Ezra explained:

*I think I would show them [family, friends, and civilians] a video of what... you know kinda like a few months of... being overseas is like is what I would show them. How we live um... you know, we work in teams, we're basically... we're all that we have um... as a team we're self sufficient.*



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In many ways, Ezra's TBI caused him to part with the few people whom he felt most understood him. He was essentially taken away from the environment (as dysfunctional as it may seem) where he felt part of a family, part of a team and where he felt understood. On the battlefield he knew his role and could play it well, but at home he struggle to understand his role and to get others to accept him in that role even though he did not look the part. As he attempts to reintegrate into his pre-injury role as a son, boyfriend, and a professional, he felt misunderstood and inadequate because he is unable to meet certain social expectations.

Ezra explained:

*I think everyone [family, friends, and civilians] wants an easy solution, you know, 'can't you just forget about it? Pretend it never happened' um...and it, it... it just... it doesn't work like that.*

Although most individuals who experience a head injury due to vehicle accidents or even combat-related TBI often return to their daily activities with no problem, others like Ruth and Ezra suffer long after the initial trauma. Thus any reasonable discussion about TBI treatment cannot fail to address the trauma that is experienced by the individual on both a micro and macro level. Considering how the experiences of physical and psychological trauma can result in feelings of helplessness and loss of control, Herman (1997) suggests, "The guiding principle of recovery is to restore power and control to the survivor" (p. 159). In many ways, Ruth and Ezra are still making progress, but could benefit from treatment to address the loss of self and begin the recovery process to building a new self.

Treatment addressing the needs of individuals with TBI needs to be threefold. Herman (1997) explains "At each stage of recovery, comprehensive treatment must address the characteristics biological, psychological, and social components of the disorder" (p.156). Ruth

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and Ezra are at different stages of their recovery process considering that Ruth has been in treatment and Ezra has yet to engage in the treatment process. In understanding that each individual is different, it is impossible to create a treatment plan specifically to address Ruth or Ezra's need at this time, but evidenced-based practice highlights several treatment models that may be effective for treating individuals with TBI. For example, "direct exposure" and "flooding" are two techniques predominantly used to treat combat veterans (Herman, 1997 p.181). Although primarily used to treat veterans with PTSD, either technique may be effective for treating Ezra. Other potential treatment models that could benefit Ruth and Ezra include Cognitive Behavioral Therapy (CBT), Narrative Therapy (NT), and Mindfulness techniques. Ruth reported her treatment has helped decreased her depression and anxiety symptoms and perhaps continued treatment would help her to start the process of learning resocialization skills, learning to accept new limitations, and thus embracing the new self.

### **Implications for Social Work Education**

I conducted this study because when one of my family members suffered a TBI, I felt helpless as my TBI knowledge was nonexistent. I searched social work journals to look for information about what was "wrong" with my family member or what I could do to help, but I found no research articles. My goal was not to treat my family member, but rather to educate myself about traumatic brain injury. I found articles from other disciplines (i.e. nursing, neurology, rehabilitation) that helped me to better understand the illness and potential issues that may arise for both the individual and his or her family. Having gone through that experience, I wanted to raise awareness about the needs of individuals with TBI.

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The need for education and training is now greater considering that TBI has become the “signature wound” for veterans returning from military operations in Iraq and Afghanistan (Hoge et al., 2008; Okie, 2005). Department of Veterans Affairs social workers may be well trained to manage the needs of veterans (Franklin, 2009; Manske, 2006) including various models for treating veterans with TBI (Makin-Byrd, Gifford, McCutcheon, & Glynn, 2011; McNamee, Howe, Nakase-Richardson, & Peterson, 2012; Perlick, Straits-Tröster, Dyck, Norell, Strauss, Henderson, & Cristian, 2011). Franklin (2009) explained that “Social workers have been serving veterans since 1926, when the first social work program in the Veterans Bureau was established” (p. 163). What about social workers in community settings? Social workers in the community may have to interact with individuals with TBI and how can they be expected to provide quality care if they do not receive the proper education and training. Savitsky, Illingworth, & DuLaney (2009) wrote, “A critical first step for civilian social workers is to obtain appropriate education and training about military culture, military and government systems of care, the issues currently affecting military and veteran populations, and appropriate policy and practice interventions” (p. 336). Without sufficient training and education the quality of service provided to individuals with TBI may be inadequate and harmful. Researchers (Chamberlain, 2005; Nochi, 1998; Swift & Wilson, 2001) note that individuals with TBI seeking services complain that professionals with limited TBI experience exhibited lack of empathy, insensitivity, and limited understanding of TBI especially when the individual had no physical symptoms.

In this study, Ezra reported feeling misunderstood by his VA social worker and frustrated that the disability department at the VA doubted his disability because he did not have any visible symptoms. Whether a social worker is responsible for assessing the individual for benefits or provide care on an inpatient mental health unit, or family therapy in a private practice

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setting, an individual with a TBI should expect to receive adequate services. Thus, it is imperative that schools of social work provide TBI education and training as well as best treatment practices for individuals with TBI including returning OIF/OEF veterans like Ezra.

### **TBI: In the Classroom**

There are a number of ways that schools of social work/schools of policy & practice can provide the necessary education and training for social workers including clinical practice courses, electives, and field placements. According to Buck (2011), “Administrators, supervisors, and faculty members should take ethical responsibility for educating social workers about the realities of brain injury: TBI is a major public health concern, is difficult to diagnose, has symptoms that are nearly indistinguishable from other conditions” ( p. 301). Clinical practice courses would allow students to learn to identify and apply a range of evidenced-based practice models that addresses the needs of combat veterans, soldiers, and military families. Elective courses can address military-specific knowledge including military culture, military family function, and military workplace environment.

### **TBI: In the Field**

Social workers interested in working with veterans or veterans with TBI, should complete field placements working with veterans or veterans with TBI in various military settings (Savitsky et al., 2009). Franklin (2009) explained, “To continue our tradition of caring for veterans while keeping pace with the increasing demand for our services, this pipeline of educated and trained social workers must remain in place and continue to grow” (p. 166). As a result, field placements would provide social work students an opportunity to explore the

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treatment needs of combat (OIF/OEF, Gulf War, Vietnam, Korea, & WWII) veterans and also learn how to manage transference and countertransference that may occur during the treatment process. This training process will help social workers develop the knowledge, skills and experience necessary to work with veterans and their family within the military system.

### **TBI: Diagnostic Code Needed**

The mental health diagnostic courses typically explore the etiology, classification, differential diagnosis, and prognosis of mental disorders. A section of the course should address traumatic brain injury, differential diagnoses, stigma surrounding TBI, and barriers to support services. Teaching about TBI diagnosis may be difficult as the current edition of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM IV-TR) does not contain a diagnostic code for TBI. Appendix B of the DSM-IV-TR, 2000 (p. 760-761) describes the features, associated features, differential diagnosis, and research criteria for postconcussional [sic] disorder- which describes impairment in cognitive functioning as a result of a closed head injury. When the current DSM-IV-TR (2000) was published, it was determined that further research was required to gain insight into what happens after a traumatic brain injury (DSM-IV-TR, 2000 p. 759-760). Until the release of the much anticipated DSM-V, it remains important for social workers to learn to use the current postconcussional [sic] disorder criteria to evaluate the presentation and symptoms of an individual with TBI. For example in my study, both Ruth and Ezra endorsed at least four of the eight DSM-IV-TR, 2000 (p.760) identified cognitive disturbance symptoms (i.e. anxiety, depression, headache, irritability) more than 2 years post TBI. Consequently it is important for schools of social work to include information about TBI in

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the diagnostic course, especially because a TBI can occur at any age. The lack of standardized criteria for TBI also impacts treatment that I will address further in the policy section.

The number of veterans returning from Iraq and Afghanistan with a TBI has led to increased discourse about TBI and the needs of individuals with TBI. Yet, the leading causes of TBI in the U.S. (approximately 1.7 million people annually) are due to car accidents, assaults falls, recreational activities and sports-related injuries (Langlois, Ruthland-Brown, & Wald, 2006; Vaishnavi, Rao, & Fann, 2009). Therefore whether social workers are interested in working with veterans or not, comprehensive evidenced-based knowledge about treatment of individuals with TBI is essential.

### **Implications for Social Work Practice**

The current diagnosis and treatment approach to caring for individuals with TBI follows the basic medical model that treats visible wounds. From that point of view, Masel & DeWitt (2010) argue that “Traumatic damage to the brain is currently viewed by insurance companies and health care providers as an event which likens a broken brain to a broken bone” (p. 1529). Using that approach, Ruth should have been able to return from the rehab facility and resume her daily activities. Yet Ruth continued to struggle and, in fact, has been unable to return to work more than two years post-injury. Masel & DeWitt (2010) calls for a shift in classification and in the treatment process that would allow providers to identify individuals like Ruth and Ezra who continued to struggle and are in need of additional support.

To create a shift in the process as described by Masel & DeWitt, it is important to address some of the assumptions and misconceptions that exist about individuals with TBI. For example, individuals with TBI may exhibit behavioral problems like amotivation, impulsivity, and

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agitation that are deemed organic (Deaton, 1987; Vaishnavi et al., 2009) and thus cannot benefit from psychotherapy (Judd & Wilson, 2005). In addition to these misconceptions, an individual with TBI also has to deal with the stigma of being labeled as “disabled.” Ruth described having a difficult time meeting new people because she was unsure how to introduce herself or going to see her former coworkers because she was unsure how they would think of her because she has not been able to return to work. Ezra described keeping from his family why he has not resumed his career because he believes they would view him as less of a man. In discussing stigma in the military, Ezra described a situation where a soldier may not report an injury especially if the unit leader says everyone is okay, then the soldier agrees that he is okay even when he is not. Despite the issues and the prevalence of TBI in the community and in the military, empirical data guiding psychiatric treatment remain insufficient, thus making treatment difficult (Vaishnavi et al., 2009).

### **Practice: Evaluation**

Social workers practicing with individuals and families affected by TBI should be aware of several issues that may affect their clients. The most important information to collect as part of the assessment is the intensity and location of the brain injury, as this may determine the types of symptoms the individual exhibit. Considering the invisible symptoms of TBI, the clinician has to be mindful that the client’s presentation may not always reflect his or her reported symptoms. This is especially important because in my study, both Ruth and Ezra struggled with others not being able to see them as injured, despite how much they struggled with invisible symptoms. Treatment for each client will vary, but the therapist should be ready to address the loss of self

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(Gelech & Desjardins, 2011), dealing with the grief of that loss and eventually moving towards creation of a new self.

To address such concerns, the clinician should explore the meaning that clients have given to their experience, their post-injury identity and the psychosocial consequences of these changes (Judd & Wilson, 2005.) The clinician should also be aware that in many ways a TBI often “initiate a chronic disease process,” which may lead to epilepsy, sleep disorders, alzheimer, psychiatric disorders, sexual dysfunction, incontinence, and metabolic dysfunction (Masel & DeWitt, 2010, p. 1530). In my study Ruth sought treatment and reported it helped to decrease her depression and anxiety symptoms. Ezra, on the other hand had a difficult time managing his symptoms, yet he remained skeptical that anyone could really understand him. This brings up an important aspect of the treatment process, which is education for the individual, his/her family, and support systems. Griffin et al. (2012) concluded that family/caregivers often underestimate the time commitment needed to provide care for an individual with TBI. For example, Ruth reported she had to depend on family to help her bathe and dress when she was first discharged from the rehabilitation facility. Thus a social worker/clinician working with individuals with TBI should be prepared to educate families about their roles as caregivers, the possibility of burnout, and the need care for themselves.

### **Practice: Why ask about Suicide?**

An entire dissertation would be needed to appropriately explore the topic of suicide after TBI. Yet it seems negligent of me to not discuss the topic, considering the literature indicates there is an elevated suicide rate in individuals with TBI than the general population (Benner,



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Ignacio, & Blow, 2011; Simpson & Brenner, 2011; Simpson, Tate, Whiting, & Cotter, 2011).

One of the first steps in the treatment process is gathering information about the client in order to understand his or her circumstances, symptoms and treatment needs. Asking about suicide is an important aspect of that process and considering the literature, it is especially important to ask individuals with a TBI or TBI history. Tsalousides (2011) explained, “The high rates of reported SI [suicidal ideations] overall indicate the level of distress that individuals with TBI continue to experience, even several years after the injury” (p. 272). There are important precursors (depression, hopelessness, anxiety, and PTSD) to suicidal ideations that a social worker/clinician should consider during an evaluation of an individual with TBI. This is especially important because individuals with TBI have the tendency to self-isolate. In my study, Ruth reported she still experiences anxiety and difficulty meeting new people, which decreased opportunities for her to socialize with others. Thus a social worker/clinician working with individuals with TBI, like Ruth, have to consider “interventions to maximize social support and reduce social isolation, a problem to which individuals with TBI are particularly vulnerable” (Tsalousides, 2011, p. 273).

For a non-VA social worker/clinician working with an individual like Ezra, treatment challenges would include diagnosis: TBI and PTSD as well as his report of self isolation. In addition to these issues, the social worker would have to consider Ezra’s military background and the alarming rates of suicide among service members. Benner, Ignacio, & Blow (2011) explained, “Veterans with a history of concussion/cranial fracture were 1.88 times more likely to die by suicide than those without a history of TBI” (p. 261). This information is not to say that either Ruth or Ezra is going to commit suicide, but to illustrate the importance of a proper risk assessment.

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During an assessment, the social worker may also identify protective factors that may help guide treatment. In my study, Ruth identified her faith, religious community, and family support as protective factors. Ezra's protective factors included friends and military comrades whom he felt understood his experiences. It remains clear that research evaluating the correlation between suicide and TBI as well as the effectiveness of psychotherapy interventions (Dennis, Ghahramanlou-Holloway, Cox, & Brown, 2011) is needed to guide practice with this population. In many ways, individuals like Ruth and Ezra, not only lost friends and co-workers, they also lost themselves as their emotional and cognitive difficulties effectively shifted the pre-injury roles (i.e. mother, soldier, professionals) that they once played at home and at work.

### **Practice: Family Involvement**

During the treatment process, it is important to explore the effects of the individuals' TBI injury on the spouse and family. Ruth reported struggling with having to depend on her family to help her take care of herself and her child. Ezra reported experiencing strains in his relationships with his family, peers, and significant other. Both participants described how their roles within their family unit shifted post-injury. A social worker/clinician working with individuals with TBI like Ruth and Ezra should consider addressing with the client, their spouse/family how this shift has affected their lives. Hammond, Davis, Whiteside, Philbrick, & Hirsch (2011) explained, "Injured spouses change overnight into having a different personality, almost as if the original spouse died, except the surviving spouse must deal with the aftermath of the changes" (p. 73). Part of the difficulty for the individual and his or her family is communication or lack thereof. For example, Ezra reported that some of his TBI symptoms including the inability to return to work, difficulty with memory, and poor communication led to the end of his relationship.

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According to Hammond et al. (2011) “TBI may also interfere with effective interpersonal communication through subtle language deficits, or impaired physical function, cognition, nonverbal expression, recognition of others’ feelings, and expressed emotions” (p. 73-74). Traumatic brain injury can drastically affect the core of an individual’s relationships by impacting his or her social roles, responsibilities, communication skills, and behaviors toward family/friends, and spouse. Considering such stressors and difficulties, a social workers/clinician working with individuals with TBI should consider family involvement in the treatment process. The Department of Veterans Affairs has started to incorporate family-involved treatment with returning veterans and two recent studies (Makin-Byrd et al., 2011; Perlick et al., 2011) have described the use of such treatment approach. Such an approach may help to acknowledge the ways that family and support systems have been affected, while addressing concerns regarding shifting roles within the family unit as they arise. Treatment is also a great opportunity for the social worker/clinician to identify risk factors, protective factors, and also provide psychoeducation for both the individual and family.

### **Practice: Using Sick Role Theory**

Parsons’ sick role theory appears to best explain the experiences that Ruth and Ezra discussed of appearing physically well, while suffering emotionally and cognitively. The social work profession has refined and utilized theories from sociology and psychology to create clinical interventions that we still use with our clients today. Clinicians can use sick role theory to help individuals with TBI understand that they are “sick” and thus should be treated as a sick individual. Currently, individuals with TBI, like Ezra, need a role model to help them understand how to accept being sick when you do not have physical signs of illness. It is equally important

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for the clinician to model for the family/support systems how to accept and understand the individual with TBI may appear physically well, but is unable to perform pre-injury duties and normal social roles as expected. In his frustration and desperation with not knowing how to cope with this paradox, Ezra reported he would prefer to have lost a limb rather than having a TBI, because at least then others (family, girlfriend, co-workers and the VA) could see that he is a wounded veteran. A combination of educational, psychosocial, and cognitive strategies are likely the most effective way to address the multifaceted challenges encountered by therapist working with individuals with TBI and their family (Judd & Wilson, 2005). In addition, a refined version of sick role theory can be developed into a clinical intervention to be used with this population.

### **Implications for Policy**

Classification and advocacy are two policy issues that must be addressed in order to improve the quality of life of individuals with TBI. Both of these policy issues affect how a traumatic brain injury is diagnosed and treated. Masel & DeWitt (2010) argue that proper classification would raise awareness that would allow the insurance companies to provide the course of treatment necessary for the clinical condition. Without the proper classification, social workers/clinicians with limited TBI knowledge may minimize the severity of mild closed-head TBI cases. This is especially important because approximately 1.7 million people sustain a TBI each year in the U.S. and within the military; there have been 178,876 diagnosed TBI cases since 2000; 137,328 of which were mild cases. Despite the prevalence of TBI in both civilian and military population, the DSM-IV-TR (2000) does not currently have a code for diagnosing TBI. A social worker/clinician working with Ruth or Ezra would have to consult the postconcussional

## **IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS**

[sic] disorder information listed in the DSM-IV-TR (2000) appendix B (p. 760) to evaluate symptoms and make a diagnosis.

### **Classification**

Why is classification so important? The current medical model classification of TBI from an insurance perspective is that after initial emergency services and rehabilitation, the injured individual should be healed and thus requires no additional services (Masel & DeWitt, 2010). Yet individuals like Ruth and Ezra, continue to suffer long after their initial evaluation and rehabilitation and thus require additional support and services. Reid-Arndt (2010) argues that counseling and case management (p. 143) services postacute care is potentially beneficial considering the frequency of comorbidities and sequelae post TBI. For example, Pappadis (2011) explained, “High rates of depression and anxiety have been documented at periods ranging from 1 to 50 years after injury” (p. 301). If TBI were to receive a diagnostic classification as a mental health disorder and not just a medical incident, insurance companies would cover the additional services that could help individuals like Ruth and Ezra.

It is important for policy makers to “recognize that the prevalent system in the United States focuses on the management of acute illness and does not effectively ameliorate the effects of longer-term disability common following TBI” (Reid-Arndt, 2010, p. 137). TBI awareness and research can help to facilitate support for the creation of a DSM diagnostic code as a chronic disorder in order to guide treatment and case management needs of individuals with TBI. In order to address such concerns, social workers/clinicians need to raise awareness through advocacy.

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### **Advocacy**

Advocacy should help to raise awareness about the effects of TBI and it should help to identify evidenced-based models for treatment with the goal of improving the quality of life of individuals with TBI (veterans as well as civilians). Several researchers (Brown et al., 2004; Masel & DeWitt, 2010) explained that there is a “statistically significant reduction in long-term survival of individuals with mild TBI compared to the general population” (Masel & DeWitt, 2010, p. 1530). Despite the limited severity rating of mild TBI, we have no way of knowing how many of the 137,328 mild military TBI cases, identified between 2000-2010 (see Table 6 & Figure 1 on p. 15), may develop into other chronic mental illnesses. TBI cases in the military may be even more complicated because essentially “the consequences of war-zone deployment on neuropsychological health remain poorly understood” (Vasterling et al., 2006, p. 519). To gain that knowledge, efforts should be made to “garnering support from relevant federal agencies for research and treatment activities related to TBI and to fund state TBI infrastructure” (Reid-Arndt, 2010, p. 144). Ultimately without adequate research, discussions about changes in diagnostic criteria or classification of TBI remain bleak. In the meantime, social workers and rehabilitation providers should advocate in support of “legislations that would allow individuals with TBI to be eligible for needed support from other state agencies” (Reid-Arndt, 2010, p. 143). Consequently, advocacy is needed on a micro level while working with an individual like Ruth or Ezra or on a macro level addressing legislation and policy.

### **Future Research**

This study was a small first step in understanding the impact that traumatic brain injury has on the quality of life of veterans returning from Iraq and Afghanistan. Several of the themes

## **IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS**

that emerged from this study, including the invisible symptoms, somatic complaints, self-medication, isolation, depression, and inability to return to work, should be studied further with a larger population. Future research can focus on these themes as a way to understand how TBI can affect various aspects of an individual's quality of life. Researchers should conduct quantitative studies that will shed light on the magnitude of TBI and also qualitative research that provides an in-depth view of the individual's experience. Future studies should incorporate the participants' family, support networks, and community supports as a way to gain insight from both a micro and macro perspective.

### **Limitations**

The sampling size of N=2 was the chief limitation of this study. Qualitative studies have a reputation of being less rigorous because of sample size, data collection methods, and potential for biases on the part of the participant and researcher. This study, much like all qualitative research, is not meant to be generalized to the larger population, but was the best method for gathering the kinds of information needed to answer the research questions. Recruitment was another limitation of this study, as it was difficult to recruit from agencies that work with and support Veterans with TBI. Both participants were referred to me by individuals who knew I was conducting the study. Time was also another limitation as I was asking the participants to recall events both pre and post injury years later. Other than the TBI, the participants varied in education level, marital status, race, sex, and occupation. Yet despite their differences, there were significant similarity in the stories they told. My interview guide did not initially inquire about the participants' life pre-injury and in search of information about what life was like pre-

## **IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS**

injury, I conducted brief follow up phone interviews with each participant to gather this information.

### **Strengths**

I identified a gap in knowledge concerning the quality of life of veterans with TBI and this study provided insight into the multifaceted nature in which an individual's life can be impacted. The two study participants shared personal stories about how their injury altered their lives and left them stronger, but forever different. The benefit of a qualitative study was the opportunity to meet with each participant allowing both to tell his and her story without any time restriction. The nature of a qualitative study created an environment during which the participants did not have to feel pressured or worried about time. The use of the case study method to present the interview information afforded me the opportunity to genuinely share the participants' stories in their own words. This was very important to me as the bulk of the existing research was not conducted from the injured individuals' point of view and I wanted to hear these participants' voices tell their stories. This study also highlights the significance of ongoing research and education about the experiences of individuals with TBI.

### **Conclusions**

The goal of this study was to explore the impact of TBI on the quality of life of returning OIF/OEF veterans from their own perspective. The inclusion of a civilian participant into the study provided important insight into the similarities and differences in how civilians and veterans experienced this illness. With still limited understanding of how a TBI affects the injured, there is so much work to be done to address the needs of individuals with TBI. For



## **IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS**

example, the classification that identifies a TBI as an event is one of the issues that require further exploration. For both Ruth and Ezra their TBI was the start of a debilitating disorder that continues to significantly impact their lives several years post-injury.

Consequently TBI should be classified as a chronic disorder in order to address the needs of individuals who require additional treatment and support. Ezra discussed the need for additional education and support for military families in order to help decrease the strain placed on the family as a soldier/veteran attempts to reintegrate upon returning home. There is also a significant need for schools of social work to integrate education and training about the needs of individuals with TBI especially returning OIF/OEF veterans with TBI. Buck (2001) stated, “Social workers are being called to join with brain injury advocates to raise awareness and demand a coordinated, national response to the needs of individuals with TBI” (p. 301). The needs of civilians and veterans with TBI extend beyond the Veterans Administration system and rehabilitation hospitals around the U.S. and consequently social workers as providers and advocates should be prepared to respond to those needs.

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## Appendix A: IRB Approval

University of Pennsylvania  
Office of Regulatory Affairs  
3624 Market St., Suite 301 S  
Philadelphia, PA 19104-6006  
Ph: 215-573-2540/ Fax: 215-573-9438  
**INSTITUTIONAL REVIEW BOARD**  
(Federalwide Assurance # 00004028)

28-Feb-2012

Richard Gelles  
Attn: Aswood LaFortune  
[gelles@sp2.upenn.edu](mailto:gelles@sp2.upenn.edu)  
[laswood@sp2.upenn.edu](mailto:laswood@sp2.upenn.edu)

PRINCIPAL INVESTIGATOR:	Richard Gelles
TITLE:	In Their Own Words: Exploring the Unseen Wounds of OIF/OEF Veterans with Traumatic Brain Injury
SPONSORING AGENCY:	No Sponsor Number
PROTOCOL #:	815209
REVIEW BOARD:	IRB #8

Dear Dr. Gelles:

The above-referenced research proposal was reviewed by the Institutional Review Board (IRB) on 27-Feb-2012. It has been determined that the proposal meets eligibility criteria for IRB review exemption authorized by 45 CFR 46.101, category 2.

**This does not necessarily constitute authorization to initiate the conduct of a human subject research study. You are responsible for assuring other relevant committee approvals.**

Consistent with the federal regulations, ongoing oversight of this proposal is not required. No continuing reviews will be required for this proposal. The proposal can proceed as approved by the IRB. This decision will not affect any funding of your proposal.

Please Note: The IRB must be kept apprised of any and all changes in the research that may have an impact on the IRB review mechanism needed for a specific proposal. You are required to notify the IRB if any changes are proposed in the study that might alter its IRB exempt status or

## **IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS**

HIPAA compliance status. New procedures that may have an impact on the risk-to-benefit ratio cannot be initiated until Committee approval has been given.

If your study is funded by an external agency, please retain this letter as documentation of the IRB's determination regarding your proposal.

**Please Note: You are responsible for assuring and maintaining other relevant committee approvals.**

If you have any questions about the information in this letter, please contact the IRB administrative staff. Contact information is available at our website:  
<http://www.upenn.edu/regulatoryaffairs>.

Thank you for your cooperation.

Sincerely,

Kyle Stephens  
University of Pennsylvania, IRB  
email: [kstep@upenn.edu](mailto:kstep@upenn.edu)  
Date: 2012.02.29

IRB Administrator

# **IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS**

## **Appendix B: Written Statement of Research**

### **Introduction & purpose:**

You are being invited to participate in a research study of individuals with traumatic brain injury/head injury. The purpose of this study is to learn more about how civilians and veterans experience their life after a head injury. Specific areas of focus will include utilization of services, experience seeking benefits, physical symptoms, relationships with family/support and other difficulties you may have experienced since your injury. You are invited to participate because you fit into a group of individuals who may be able to provide the most reliable information based on your personal experiences. Please ask any questions that you have, now or at any other time.

### **What is involved?**

Participation in this research study is completely voluntary. You have the right to say no. You may change your mind at anytime and withdraw. If you agree to participate, we will schedule the interview at a time and place that is convenient for you. During the interview, you will be asked to talk about your experience adjusting to life since your head injury. I will ask your opinions about struggles you may have encountered at home, at work or in your relationships since the injury. There is no right or wrong answers to these questions. You can refuse to answer any single question that should make you feel uncomfortable and uneasy. We want to learn about your experiences and opinions. The interviewer will take notes and also audio record the interview. The interview will last between 1 to 2 hours.

### **Confidentiality:**

The information that you share with me will be kept confidential. This means that your name, personal information will never used in any report or publication. Any materials that can potentially identify you as an individual, such as signed consent forms, will be discarded after the study. The audio recording and the transcripts of your interview will be coded separately in order to maintain confidentiality. As previously indicated, we will destroy any documents that have identifying information about you once the research study is complete.

### **Risk of participating:**

We will be careful to keep your information confidential. Discussing your struggles since the head injury might make you feel uncomfortable. If you feel uncomfortable or upset after the interview, we can provide contact information for agencies where you can seek services.

## **IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS**

### **Benefits of participating:**

You will help me learn about how individuals with a head injury experience life after the injury. Understanding your struggles may help future social workers and other providers to create treatment and support services to better help individuals with TBI in the future.

### **Compensation:**

You will be given a \$10 cash certificate for participating at the close of the interview.

### **If you have questions about the research or about your rights as a participant in research:**

Please contact the interviewer, who will be glad to speak with you:

Aswood LaFortune, MSW, LSW  
School of Social Policy and Practice  
University of Pennsylvania  
(215) 316-9917  
[laswood@sp2.upenn.edu](mailto:laswood@sp2.upenn.edu)



## IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS

### Participation is voluntary:

Participation in this research study is completely voluntary. You have the right to say no. You may change your mind at anytime and withdraw. There will be no negative consequences if you decide not to participate. You may choose not to answer specific questions or to stop participating at any time.

### Summary and Signature:

I am being asked to participate in a research study. If I agree, I will be interviewed about my experiences with treatment, service needs, relationships and difficulties since sustaining my head injury.

I will receive compensation of a \$10 cash certificate for participating at the close of the interview.

I do not have to agree to be interviewed. I am also free to stop participating at any time. I understand that I can refuse to answer any single question that makes me feel uncomfortable or uneasy. By signing this form, I am freely agreeing to be interviewed. Any questions that I have about the project have been answered. I have received a copy of this consent form with information about how to ask more questions later if I have any.

Date: \_\_\_\_\_

Name of Interviewer: \_\_\_\_\_

### Interviewer:

Aswood LaFortune, MSW, LSW  
School of Social Policy and Practice  
University of Pennsylvania  
(215) 316-9917  
[laswood@sp2.upenn.edu](mailto:laswood@sp2.upenn.edu)

# IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS

## Appendix C: Interview Guide

### Intensive Interview Guide (Civilian & Veteran)

Let me start by saying, thank you for your time and participation of this study. I am interested in learning about how individuals with a head injury experience life after the injury.

#### Questions:

- 01). What do you call the injury you sustained (i.e. TBI, brain injury, head injury) and why?
- 02). Please tell me how your injury occurred?
- 03). What types of physical injuries, if any, did you sustain during that incident?
- 04). What treatment, if any, did you receive for your head injury?
- 05). What was your experience like seeking treatment and/or benefits for your head injury?
- 06). What is your understanding of the diagnosis you were given and the treatment you received?
- 07). Can you tell me about any medical difficulties (blurred vision, dizzy spells, difficulty with memory) or physical changes (headaches, nervousness, hand trembles; numbness or tingling in parts of your body) that you have experienced since your head injury?
- 08). What areas in your life, if any (i.e. unintended change in weight, change in sleep pattern, change in sense of direction or difficulty understanding what you read), has been affected by your head injury?  
  
Probe: Can you tell me about them?
- 09). Have you experienced any feelings of worthlessness, hopelessness about the future, do you feel easily annoyed or irritable or had any thoughts of suicide?
- 10). What was your perception of how your family/friends treated you within the first year after your head injury?

## **IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS**

Probe: What is your current perception?

11). In what ways has your social supports, work and your religion/faith been affected by your head injury?

12). How has your views of yourself changed or stayed the same since your injury?

13). Do you know anyone who has self medicated with drugs or alcohol as a result of their head injury?

Probe: Have you self medicated because of your head injury?

14). What impact, if any, did the cost of your medical care have on the types of treatment you received?

Probe: Were there any treatment options that you felt was not explored due to cost or your insurance company?

15). Tell me some of the ways that your injury made you stronger?

### **Pre-injury Questions**

16). Please tell me about your life before your head injury with regards to your work and daily activities?

17). Describe for me your relationship (pros and cons) with your family, significant other, friends and other support systems prior to your head injury?

Probe: What was your religious experience like prior to your injury?

18). What kinds of recreational activities and areas of interest that you enjoy prior to your head injury?

19). Tell me about some of your life goals with regards to your personal life, work, and school prior to your head injury?

## **IN THEIR OWN WORDS: EXPLORING THE UNSEEN WOUNDS**

Probe: Are there any of those goals that you still plan to accomplish?

20). Has this interview affected you and should we talk about it?

I really appreciated your time so far and now I'm going to take a few minutes to ask you some background questions.

### **Background information:**

- Age
- Gender
- What do you consider your race?
- Marital status
- Number of children (if any)
- Occupation/ current job
- What is the highest grade you completed in school?
- Have you ever been diagnosed with a mental illness and do you know what it was?

### **Additional background information for Veteran:**

- Age of initial enlistment?
- What is your highest/current rank?
- How many times have you reenlisted?
- How many tours of duty have you completed in total?
- Were you injured in any of your previous tours of duty? If yes, type of injury?
- Are you currently on active duty?
- If no, when were you discharge from the Army?
- What type of discharge did you receive?

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### Appendix D: Additional Articles

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