Family Reintegration Experiences of Soldiers with Combat-Related Mild Traumatic Brain Injury

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Paul C. Lewis

Dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing in the Graduate School of Duke University

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ABSTRACT

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Abstract

More than 300,000 soldiers have returned from Southwest Asia (i.e., Iraq and Afghanistan) with combat-related mild traumatic brain injuries (mTBIs) associated with exposure to improvised explosive devices (IEDs). Despite less visible physical injuries, these soldiers demonstrate varying levels of physical and cognitive symptoms that impact their post-mTBI family reintegration. The existing literature acknowledges post-mTBI changes in the injured individual affect family functioning; however, the impact of specific factors, such as coping and adaptation on the post-injury family functioning has not been explored. The intent of this dissertation study was to explore the problems and challenges of military family reintegration following mTBI.

Study participants included active duty soldiers with mTBI who were between 2 and 24 months post-deployment and their civilian spouses. Strauss and Corbin’s grounded theory methodology was used to collect and analyze the data. This dissertation study consists of three papers, each of which explored experiences that surround family reintegration following mTBI. Both joint and separate individual interviews were conducted with soldiers and their spouses to explore their post-mTBI family reintegration experiences. Nine soldiers with mTBI and their spouses participated for a total of 27 interviews.

The first paper is a comprehensive literature review examining commonly reported mTBI signs/symptoms, and the impact of these symptoms on the injured individuals and their families. The findings suggest that psychological distress symptoms
such as depression and anxiety are common in injured individuals and their families after mTBI.

The second paper explores the family reintegration processes of post-mTBI soldiers and their spouses. The majority of participants interviewed, soldiers and their spouses, indicated soldiers’ symptoms such as irritability, memory loss, and cognitive deficit affected their family reintegration. Some participants reported they had accepted the changes and were working toward a “new normal,” whereas others indicated these changes were unacceptable and continued their efforts to resume pre-injury functioning.

The third paper examined soldiers’ and their spouses’ experiences when seeking treatment for mTBI-related symptoms. The majority of interviewed soldiers and spouses indicated that a delayed diagnosis, difficulty accessing mental health care, and having to navigate an unfamiliar military healthcare system were their biggest challenges. Post-mTBI soldiers experienced significant disruption due to mismatched expectations among themselves and other family members concerning their post-injury capabilities. Findings from these studies indicate more research is needed in order to develop effective post-injury rehabilitation programs for soldiers with mTBI and their families.
Dedication

I dedicate this dissertation to my family, especially…

to my husband Frank, for his love, patience, and support;

to Christine, for her understanding and taking on a caregiver’s role;

to Angie, for being my precious angel and inspiration;

to my mother SooDuk, for instilling the importance of higher education

and diligence

and to all veterans who have served our country.
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1. Family Reintegration of Soldiers with Combat-Related Mild Traumatic Brain Injury

1.1 Purpose of the Dissertation

Traumatic brain injury (TBI) has emerged as one of the major causes of morbidity among soldiers who served in Iraq and Afghanistan (Defense and Veterans Brain Injury Center Working Group [Defense], 2006). Traumatic brain injury is defined as a non-degenerative, non-congenital insult to the brain from an external mechanical force (for example, blunt-force trauma or a jolt to the head) with an associated diminished or altered state of consciousness at the time of injury that may lead to cognitive, physical, or psychosocial impairment (Centers for Disease Control and Prevention [CDC], 2006). Traumatic brain injury is typically classified by the level of severity and is commonly differentiated as mild, moderate, or severe (CDC, 2006). The majority of soldiers who are diagnosed with combat-related TBI are classified as mild (Daggett, Bakas, & Habermann, 2009; Defense, 2006; Hoge et al., 2008; Zoroya, 2006).

Soldiers deployed to Iraq and Afghanistan who have experienced an mTBI as a result of an improvised explosive device (IED) often experience few or no obvious physical injuries but may experience headaches, fatigue, extensive cognitive deficits (difficulty comprehending, memory and attention problems), and emotional disturbances (Daggett, Bakas, & Habermann, 2009; Hoge, Auchterlonie, & Milliken, 2006). Soldiers with these residual mTBI symptoms may have difficulty resuming pre-injury responsibilities and activities, and often experience post-injury adjustment difficulties.
(Zasler & Serio, 2007). While there is wide acceptance that a brain injury affects not only the injured individual but also their family members (Anderson, Parmenter, & Mok, 2002; Blais & Boisvert, 2005; Ergh, Rapport, Coleman, & Hanks, 2002; Gleckman & Brill, 1995), there is limited information about the effects of mTBI on post-injury military family reintegration.

For the purpose of this dissertation study, “family” was defined as a soldier and their spouse, with or without children in the household. Family reintegration was defined as the processes that soldiers and their spouses use to restore and re-establish family relationships (Doyle & Peterson, 2005; Resnik, Plow, & Jette, 2009). Restoring and re-establishing the family relationship are considered essential for the soldiers’ post-deployment adjustment (Zasler & Serio, 2007). Therefore, the focus of this dissertation study was to explore and describe the post-mTBI family reintegration as experienced by soldiers returning from Iraq and Afghanistan and their spouses.

This study is one of the first to examine reintegration experiences of both injured soldiers and their spouses. Findings from this dissertation study may be helpful in laying the groundwork for the development of quantitative measures of successful family reintegration. The findings may also be useful for tailoring effective military family reintegration programs and policies.

1.2 Background and Significance

I’m having trouble concentrating at work, and it seems like I forget everything . . . Could that explosion be causing my problems? My wife made me come see you—I didn’t want to. (Mr. L., cited in Lineberry, Bostwick, & Rundell, 2006)
Since 2003, more than 1.9 million service members have been deployed to Iraq and Afghanistan (Committee on the Initial Assessment of Readjustment Needs of Military Personnel, 2010; Doyle & Peterson, 2005; Johnson et al., 2007). Bradshaw (2008) and other researchers note that mTBI is undertreated and is a widespread combat injury experienced by these returning service members (Bradshaw, 2008; Schneiderman, Braver, & Kang, 2008; Terrio et al., 2009). They report that 12% to 22% (or 260,000 to 320,000) may have sustained some level of mTBI (Bradshaw, 2008; Schneiderman et al., 2008; Terrio et al., 2009).

Mild TBI often is not associated with an abnormal computed tomography (CT) or magnetic resonance imaging (MRI) profile (Cassidy et al., 2004; Medicine, 1993), thus making it difficult to detect and recognize after injury. Mild TBI in civilians is often the result of vehicular accidents, sports injuries, or falls, whereas for soldiers, mTBI is most often related to IED explosions, land mines, and antitank weapons. It is important to note that combat-related TBI tends to result in more complicated injuries and higher rates of disability than non-combat related TBI (Defense, 2006).

According to Post Deployment Health Screening (PDHS) statistics, over 20% of combat veterans meet the criteria for mTBI (Bradshaw, 2008; Zoroya, 2006). Moreover, some mTBI-affected soldiers may be getting re-deployed without receiving proper medical intervention due to difficulty in diagnosing affected soldiers. These factors may
lead to problems for soldiers as they readjust to friends, family, and community (Hoge et al., 2006).

Reintegration after prolonged separation is difficult for any family; however, families of soldiers with combat-related injuries like mTBI may face additional challenges in resuming pre-existing family roles and responsibilities (Committee, 2010; Zeitzer & Brooks, 2008). Soldiers with mTBI often manifest a high number of co-existing psychiatric conditions, such as depression, post-traumatic stress disorder (PTSD), and other mental illnesses in addition to symptoms resulting directly from the injury (Doyle & Peterson, 2005). Studies suggest that symptoms of mTBI can magnify existing negative aspects of family relationships and adjustment difficulties (Daggett et al., 2009; Doyle & Peterson, 2005; Hoge et al., 2008; Resnik et al., 2009). Despite increased support from the military for family reintegration, and despite a trend toward more thorough assessment and diagnosis of mTBI, there continues to be a lack of family reintegration support programs specifically designed to help the mTBI population. Special programs for spouses of soldiers with mTBI are particularly neglected; typically, such programs are not included in the soldier’s treatment plan (Hoge et al., 2006).

The existing literature on family issues following mTBI has focused primarily on civilian injury situations which may not address the needs of post-mTBI soldiers returning from combat. Existing literature suggest that psychological distress is a common experience for both the injured individual and their family members during post-injury adjustment (Douglas & Spellacy, 2000; Kreutzer, Gervasio, & Camplair,
Individuals with head injuries and their families reported increased levels of stress, anxiety and depressive symptoms (Douglas & Spellacy, 2000; Kreutzer et al., 1994a; Livingston, 1987). However, the majority of studies that explored the prevalence of distress focused only on caregivers and failed to explore the relationship between post-mTBI changes in the injured person and their family members’ distress. Furthermore, civilians with mTBI usually are not apart from the family at the time of injury, whereas soldiers with mTBI usually are away, often for a prolonged period of time. Thus, soldiers with mTBI face the added challenge of returning to a family that may have changed due to life events during the soldier’s absence (Committee, 2010).

The reviewed literature identified the different effects of family relationship on responses to mTBI. For example, Gan and colleagues found that spouses were more apt to experience depression than other family members (Gan, Campbell, Gemeinhardt, & Mcfadden, 2006). Hammond and colleagues reported changes in spousal perceptions, interactions, responsibilities, and reactions to brain injury impacted post-injury marital stability and satisfaction by influencing the family to move toward either adjustment or dysfunction (Hammond et al., 2011).

Hoge and colleagues published three studies that provided empirical data on service members who deployed to Iraq and Afghanistan and their resulting mental health issues of all types (Hoge et al., 2004; Hoge et al., 2006; Hoge et al., 2008). Findings suggested a high overall level of mental illness after deployment among sample
participants. Among those service members with mTBI, it was found that negative beliefs about mental health care and a perceived decrease in unit support increased perceptions of stigma and barriers to care (Hoge et al., 2004).

The dual stressors of a long physical separation followed by sudden reintegration may lead to emotional stress for a parent/spouse returning to the family (Johnson et al., 2007). In 2007, the Presidential Task Force on Military Deployment Services identified a need for well-structured behavioral health programs for service members and their families across all military branches (Johnson et al., 2007). They reported that Army medical treatment facilities and larger medical centers often depend on local civilian providers and assigned psychologists to develop and implement programs targeting post-deployment issues (Johnson et al., 2007). Although there are various programs designed to help with general post-deployment family reintegration, there appears to be a lack of evidence regarding the ability of these programs to meet the specific needs of post-mTBI soldiers and their families (Johnson et al., 2007).

A major gap in the current literature on family reintegration/adjustment following an mTBI is the absence of an empirically derived framework for describing and understanding family reintegration experiences and coping processes. Clearly, there is a compelling need to understand the unique family reintegration process of soldiers returning with combat-related mTBI, as well as their spouses. Such knowledge could help researchers and clinicians develop more effective support programs and devise outcome measurements of their effectiveness. Conversely, if military reintegration programs fail to
address this specific aspect of reintegration, there is a potential for increased rates of depression, substance abuse, anti-social behavior, divorce, homelessness, crime, and suicide among this population (Daggett et al., 2009; Hoge et al., 2008; Ommaya, Salazar, Dannenberg, Chervinsky, & Schwab, 1996).

1.3 Overall Purpose of Dissertation and Specific Aims

The overall purpose of this dissertation was to explore the reintegration experiences of both the soldier and his/her spouse, as well as the processes they use to achieve family reintegration after mTBI. The existing literature has focused almost exclusively on either the injured family member or their caregiver, but not both. As a result, existing military reintegration programs have not been grounded in data around the reintegration difficulties that soldiers with mTBI and their families may encounter during post-deployment. Notably, there is a scarcity of published research on marital adjustment for soldiers returning from Iraq and Afghanistan with combat-related mTBI and their spouses.

To address these issues, this dissertation has three research aims to illustrate the experience of family reintegration after mTBI. These aims and their related research questions are organized into three separate chapters, chapters 2, 3, and 4. The first aim was to give an overview of mTBI then review of the effects of mTBI on the re-adjustment/reintegration into the family. This review includes the most commonly reported signs/symptoms of mTBI, the impact of mTBI on injured individuals and their families, and suggestions for developing interventions to support and strengthen
individual and family adjustment following mTBI. (The first aim is addressed in Chapter 2.)

The second aim of this dissertation was to describe post-mTBI family reintegration experiences. To address this aim, the research question asked was: “How do soldiers with mTBI and their spouses describe post-mTBI family reintegration?” (The second aim is addressed in Chapter 3.)

The third aim was to explore the challenges and management strategies soldiers and their spouses experience during post-mTBI recovery and rehabilitation. To address this aim, the following research questions were asked: “What were the difficulties, challenges, or problems in obtaining post-mTBI treatment?” and “What management strategies do soldiers and their spouses use to cope with the challenges?” (The third aim and related study questions are addressed in Chapter 4.)

Chapter 5 provides a summary of dissertation findings, discusses implications of the research, identifies study limitations, and offers recommendations for future research.
2. Literature Review: Individual and Family Adjustment After Mild Traumatic Brain Injury

2.1 Introduction

Defined as a non-degenerative, non-congenital insult to the brain from an external mechanical force (for example, blunt-force trauma or a jolt to the head), traumatic brain injury (TBI) is associated with a diminished or altered state of consciousness at the time of injury and often leads to cognitive, physical, and/or psychosocial impairment (CDC, 2006). TBI is classified by level of severity and is commonly differentiated as mild, moderate, or severe (CDC, 2006). Table 1 provides a classification of TBI.

Traumatic brain injury has become a leading cause of morbidity worldwide (CDC, 2003; Ingebrigsten, Romner, & Knock-Jensen, 2000; Naalt, 2001). In the United States, more than 1.7 million Americans experience TBI each year, with 80% of cases classified as mild TBI (mTBI) (CDC, 2010; Kraus & McArthur, 1999). Annually, in Europe and Canada, 100 to 200 of every 100,000 people experience TBI, and an estimated 80% to 90% of these are classified as mild (Ingebrigsten et al., 2000; Martin, 2003; Naalt, 2001). The number of people who experience mTBI may be significantly higher than those reported because many individuals who sustain a mTBI do not seek care due to a lack of symptom presentation at the time of the injury (CDC, 2010).

An increasing number of veterans who served in Afghanistan and Iraq are reported to be affected by mTBI (Daggett et al., 2009; Defense and Veterans Brain Injury Center Working Group, 2006; Hoge et al., 2008; Zoroya, 2006). Mild TBI is thus a
growing concern in both the military and civilian populations, because of its treatment costs and potential long-term effects. Studies suggest that mTBI negatively affects the injured individual’s quality of life and post-injury family reintegration as a result of changes in cognitive function (e.g., concentration, memory) and the development of psychological disorders (anxiety, depression) (Hoge et al., 2008; Kreutzer, Gervasio, & Camplair, 1994b; Tepper, Beatty, & DeJong, 1996; Yeates, Henwood, Gracey, & Evans, 2007). Despite the seriousness of these effects, there has been little research on individual and family adjustment following mTBI. Yet understanding post-mTBI family adjustment is vital for effective treatment of individuals and families.

Early diagnosis and treatment are important aspects of successful adjustment after any brain injury; however, numerous factors complicate early detection and treatment following mTBI. They include varying symptoms and interpretation post-mTBI; impairments that are not immediately noticeable; and the absence of formal rehabilitation resources that target the variable trajectory of mTBI. Highly idiosyncratic psychological/cognitive symptoms and a lack of associated physical signs make it difficult even for professional clinicians to recognize mTBI (CDC, 2003, 2010; Daggett et al., 2009). Symptoms reported immediately following mTBI most frequently include headaches, nausea, vomiting, dizziness, blurred vision, and tinnitus (CDC, 2006; Hoge et al., 2006). Delayed symptoms may include confusion, irritation, and anxiety; fatigue or lethargy; sleep pattern changes; behavioral or mood changes; and impaired memory, concentration, attention and/or reasoning (CDC, 2006; Stroke, 2008).
Treatment of mTBI also presents challenges, because recovery can be influenced by factors unrelated to the injury, such as pre-existing psychosocial difficulties (for example, depression and anxiety) and pre-injury coping behaviors (Carlson, Kehle, & Meis, 2009). Unfortunately, little research has examined treatment and recovery strategies specific to mTBI, and existing studies have focused on strategies for managing moderate or severe TBI, which may be inappropriate or ineffective for mTBI (Comper, Bisschop, Carnide, & Tricco, 2005).

Brain injury not only affects the injured individual but also may have profound implications for the individual’s family (Gervasio & Kreutzer, 1997; Wood & Yurdakul, 1997). Although research has been conducted on the impact of moderate-to-severe TBI on family caregivers, and on individual family caregivers’ adjustment after an injury, limited research has examined the impact of mTBI on families (Doyle & Peterson, 2005). This review therefore examines individual and family adjustment following mTBI. This review identifies the most frequent signs/symptoms of mTBI; explores the impact of mTBI on injured individuals’ and their family’s post-injury adjustment; and provides direction for developing and testing nursing interventions to support and strengthen individual and family adjustment following mTBI.

2.2 Method

The literature review began with a search of the PubMed online medical database of English language publications, using the key terms mild traumatic brain injury and
brain injury. These were combined with the Medical Subject Heading (MeSH) terms family and family adjustment and recovery of function. The MeSH term used for brain injury was acute or chronic injury to the brain, including the cerebral hemispheres, cerebellum, and brain stem. The MeSH term used for family was a social group consisting of parents or parent substitutes and children. The MeSH term for recovery of function was partial or complete return to the normal or proper physiologic activity of the affected organ (or part of that organ) following disease or trauma.

A combination of these keywords produced 418 articles published between 2001 and 2011. This time frame was chosen to reflect current knowledge of readjustment after mTBI. The review was limited to adult brain injury because children are assumed to have different needs and follow a recovery trajectory that differs from that of adults (Forsyth, 2010; Suskauer & Huisman, 2009). The abstracts of the 418 articles were scanned for relevance to the literature review. Articles were retained if the abstract listed mTBI outcomes for individuals and/or their family. Articles were excluded if they focused only on severe TBI, or only on individual TBI treatment and diagnosis. Only 19 articles fit these criteria. Those articles were placed in a matrix format to identify recurrent themes (see Tables 2, 3, & 4). Findings are briefly summarized here.

2.3 Results

Recurrent themes were categorized as the effects of mild TBI on individual; families; and family adjustment after mTBI. They were related to the injured individual and the family’s response to mTBI, including psychological distress (depression and
anxiety) and other factors affecting post-injury family adjustment (social support, coping style, and pre-injury family function). In the studies reviewed, *family functioning* was defined as the processes by which the family operates as a whole, including communication and manipulation of the environment to deal with challenges and solve problems (Malec et al., 2007; Ponsford & Schonberger, 2010; Sady et al., 2010; Testa et al., 2006).

### 2.3.1 Mild TBI Effects on Individuals

Published studies indicated a wide range of symptoms after mTBI. Livingston’s longitudinal study was one of the first that differentiated TBI severities and examined the impact of head injuries on families (Livingston, 1987). Livingston concluded that injured individuals experienced multiple cognitive, physical, and psychological symptoms after mTBI (Livingston, 1987). He recommended rehabilitation programs that examine factors, such as previous illness experiences, current life stressors as well as the injured individual’s perception of his or her recovery progress.

#### 2.3.1.1 Cognitive Symptoms

The most frequently cited cognitive losses following mTBI include impairment of memory, attention, and executive functioning (Erez, Rothschild, Katz, Tuchner, & Hartman-Maeir, 2009). This finding was consistent with earlier studies that reported similar impairment (Barth et al., 1983; Maddocks & Saling, 1996). Erez et al. reported that the majority of these cognitive losses are present during the acute stages following mTBI, and 10% to 20% of individuals may continue to experience cognitive (e.g.,
memory impairment) and neurological symptoms (e.g., balance problem) even after one year (Binder, Rohling, & Larrabee, 1997; Erez et al., 2009). Published findings have suggested that individuals with moderate to severe TBI are unaware of their cognitive loss (Malec, Testa, Rush, Brown, & Moessner, 2007; Yeates et al., 2007); however, Erez and colleagues found that mTBI individuals with persistent cognitive losses typically were aware of their cognitive deficits and the functional implications (Erez et al., 2009). They found significant deficits in executive functions (e.g., planning and reasoning), attention, emotional regulation, and decision making. However, all participants in their study reported intact self-awareness and appropriate recovery goals (Erez et al., 2009).

Ponsford and colleagues compared symptoms following mTBI and other types of general trauma at 1 week and 3 months post-injury. Individuals with mTBI (n=123) and 100 matched trauma controls reported comparable physical recovery; however, the mTBI group reported significantly greater ongoing memory and concentration problems (Ponsford, Cameron, Fitzgerald, Grant, & Mikocka-Walus, 2011). This finding is consistent with earlier studies that reported one- and five-year post-injury cognitive declines (i.e., memory/problem solving and comprehension/expression) in 13%-15% of individuals with all types of TBI (Hammond, Hart, Bushnik, Corrigan, & Sasser, 2004; Millis et al., 2001).

2.3.1.2 Physical Symptoms

In a study of factors influencing self-rated health in traffic-related mTBI, Zhang et al. (2009) found that nearly 30% of people who suffered a traffic-related mTBI reported
poor health six weeks post-injury. Both Zhang et al. (2009) and Cassidy et al. (2004) reported that pain (e.g., neck and low back) was a significant factor in poorer post-injury health. Other studies have found that physical symptoms such as headache, sleep problems, fatigue, dizziness, nausea, blurred vision and increased sensitivity to light and noise are common (Paniak et al., 2002; Ryan & Warden, 2003). Balance impairment has also been reported, even when there was no neurological deficit on clinical examination (Zhang et al., 2009).

From their study of post-injury outcomes in individuals with mTBI and other types of trauma, Ponsford et al. (2011) concluded that the majority of pain and physical symptoms resolved within three months post-injury. However, others have found that while many physical symptoms disappeared within the first year following mTBI (Carroll et al., 2004; Paniak et al., 2002), between 10% and 15% of individuals with mTBI experienced some form of chronic physical symptom that lasted beyond a year (Masson et al., 1996; Rutherford, Merrett, & McDonald, 1979). Lannsjo and colleagues found that multiple symptoms, both physical and mental, persisted over time after mTBI, based on questionnaire responses from 2,523 mTBI participants three months after emergency room visits (Lannsjo, Geijerstam, Johansson, Bring, & Borg, 2009).

Brown et al. (2004) suggested that ethnicity may affect injured individuals’ post-injury physical functioning and pain. They examined the influence of race-based perceptions on post-mTBI health functioning among 135 individuals who experienced mTBI and 83 who experienced general trauma. They reported poorer post-mTBI physical
health functioning in African Americans than in European or Hispanic Americans. One limitation of this study, however, was the inclusion of subjects as young as 16 years old; age may have had a significant impact on findings due to the developmental stages of the participants.

### 2.3.1.3 Psychological Symptoms

Post-mTBI, the injured individual may experience a high degree of psychological distress (depression, anxiety) (Livingston, 1987; Oddy, Humphrey, & Uttley, 1978; Ponsford, Olver, Ponsford, & Nelms, 2003; Resnick, 1993; Van Horn, 2009; Wedcliffe & Ross, 2001). Malec et al. found comparable early and late post-injury depression rates in three clinical trauma groups (mTBI, moderate-severe TBI, orthopedic injury) (Malec et al., 2007). Their findings suggested that an injured individual’s self-assessment of impairment was the factor most significantly associated with depression. Ponsford and Schonberger found that approximately 53% of subjects reported clinically significant anxiety symptoms after mTBI, and over 45% reported clinically significant depressive symptoms (Ponsford & Schonberger, 2010). These findings are not surprising, however, given Erez and colleagues’ findings of self-awareness of cognitive deficits and functional limitations after mTBI, which may contribute to anxiety and depression in this group (Erez et al., 2009).

Few studies have addressed factors associated with depression and anxiety following mTBI; however, sadness, sleep disturbances, poor concentration, and memory impairment have all been associated with depression and anxiety following brain injury.
Depression and anxiety among brain-injured individuals have also been strongly correlated with poor post-injury recovery and poor family adjustment (Kreutzer et al., 1992; Livingston, 1987; Ponsford et al., 2003; Ponsford & Schonberger, 2010).

### 2.3.2 Mild TBI Effects on Family Members

Seven of the studies reviewed here were concerned with mTBI effects on family or post-injury family outcome; however, the studies defined *family* in various ways. For example, Sady et al. (2010), Ergh et al. (2002), and Kreutzer et al. (2009) defined family as caregivers; while Ponsford and Schonberger (2010) and Weddell and Leggett (2006) defined family as relatives. Gan et al. (2006) defined family as mothers, spouses, and siblings, but Testa et al. (2006) did not clearly identify family. In this literature review, family is defined as whomever the injured individual identifies as family, including nuclear family, various other kin, or primary caregivers.

Several of the studies reviewed found that family responses to perceived changes in the injured person were strongly correlated with the family’s psychological distress, such as depression and anxiety, as well as family functioning (Gervasio & Kreutzer, 1997; Kreutzer et al., 1992; Ponsford & Schonberger, 2010; Wood & Yurdakul, 1997). Family responses included psychological distress, responses to functional changes in injured individuals, and perceived burden (Kreutzer et al., 1992; Kreutzer et al., 1994b; Livingston, 1987; Testa et al., 2006; Yeates et al., 2007).
2.3.2.1 Psychological Distress of Family Members

Psychological distress is a common experience for families during post-injury adjustment (Douglas & Spellacy, 2000; Kreutzer, Gervasio, & Camplair, 1994a; Livingston, 1987). Even though affective and emotional symptoms varied among these studies, high levels of stress, depression, and anxiety were commonly reported by caregivers and families. Livingston assessed the impact of all levels of head injury on families (Livingston, 1987). Among families of individuals with mild head injury, over 50% (n = 41) reported significant anxiety. Furthermore, the family’s depression scores did not differ significantly between mild and severe head injuries. This finding was confirmed by later studies: except in cases of extremely severe TBI, the severity of TBI is not directly related to the degree of family distress (Kreutzer et al., 1994b; Livingston, 1987; Oddy et al., 1978; Testa et al., 2006).

Kreutzer and colleagues examined the prevalence of psychological distress and family functioning among families of 62 injured individuals following all types of TBI (Kreutzer et al., 1994a). They found that almost 50% of families reported increased distress, 33% reported elevated anxiety, and 25% reported depression (Kreutzer et al., 1994a). The caregivers in this study, mostly mothers (45%) and wives (40%), reported unhealthy functioning as compared to published norms for non-patient and medical patient samples (Kreutzer et al., 1994a). Their study suggested that spouses were more likely than other family members to experience depression.
Blais and Boisvert examined the post-injury psychological and marital satisfaction of 70 individuals with TBI and their spouses (Blais & Boisvert, 2005). They found that spouses’ perceptions of injured individuals’ communication skills had significant effects on both psychological and marital satisfaction (Blais & Boisvert, 2005). While TBI severity was not specified in the study, this finding is consistent with those of other studies in which spouses were generally more distressed than other family members (parents and siblings, for example) (Gan et al., 2006; Nabors, Seacat, & Rosenthal, 2002; Wood & Yurdakul, 1997).

Gleckman and Brill (1995), Anderson et al. (2002), and other researchers have found high levels of stress in families of injured individuals with all levels of TBI and have reported that the majority of these families required professional intervention (Machamer, Temkin, & Dikmen, 2002; Minnes, Graffi, Nolte, Carlson, & Harrick, 2000; Rappaport & Herero, 1989). Changes in family relationships, such as deterioration in marital relationships and increased negative interactions between the injured individual and children, have also been reported (Wedcliffe & Ross, 2001).

2.3.2.2 Functional Changes in the Injured Individual and Family Responses

Despite a lack of physical injuries, Erez and colleagues reported significant post-mTBI changes in social contacts, leisure activity, driving ability, and money management in the majority of their study subjects (Erez et al., 2009). The inability of injured individuals to function as before is distressing both to the injured individuals and to their families. The injured individuals’ reactions (e.g., anger, depression) to their altered
functioning influence other family members’ psychological well-being as well (Kreutzer et al., 1994b; Livingston, 1987; Ponsford et al., 2003). The injured individual’s awareness of these changes, taken together with the family’s reaction to functional impairment, appears to play a significant role in the injured individual’s recovery following mTBI. Yeates et al. (2007) found that some families of brain-injured persons developed a paternalistic attitude toward their injured family member and perceived the injured member as being more disabled and dependent than she or he actually was.

Testa and colleagues examined the effects of changes in neurobehavioral functioning on the family among 47 individuals with mild TBI, 75 with moderate/severe TBI, and 44 with orthopedic injuries, at discharge and 1-year follow-up (Testa et al., 2006). Testa et al. defined neurobehavioral functioning as physical, cognitive, behavioral, and emotional symptoms associated with all types of TBI and neurological disability. At hospital discharge, over 40% of families of the mTBI group reported family distress and this persisted, with 30% reporting distress at 1-year follow-up. These findings are consistent with those of other studies in which family depression was correlated with the injured individual’s levels of irritability, uncontrolled anger, and aggression (Kreutzer et al., 1994a; Oddy et al., 1978; Ponsford et al., 2003).

Changes in the injured individual’s personality as well as behavioral, emotional, and cognitive changes, have been found to predict the extent of the family’s distress (Kreutzer et al., 1994a; Livingston, 1987). In particular, Ergh et al. (2002) found the incidence of socially inappropriate behaviors by the injured individual in public to be a
significant predictor of post-injury family depression and anxiety. This finding is consistent with the findings of both Livingston and Kreutzer et al. that greater numbers of symptom complaints and changes in the injured individual were directly related to greater psychosocial distress among families (Kreutzer et al., 1994a; Livingston, 1987).

2.3.2.3 Perceived Burden

Lowenthal defined caregiver burden as the costs to the psychological, physical, and financial resources of a family (Lowenthal, 1964). Families have reported that caregiver burden affected family functioning across all severity levels of TBI (Kao & Stuifbergen, 2004; Moore, Stambrook, & Peters, 1993; Nabors et al., 2002). Gan et al., who examined predictors of post-injury functioning of families of 66 brain injured individuals, found that higher caregiver burden resulted in poorer family functioning (Gan et al., 2006). This finding was supported by later studies in which lower levels of perceived caregiver burden were associated with better adjustment of the injured individual. Factors affecting caregiver burden included age and gender of the injured individual, the caregiver’s education level and marital status, and perceived emotional needs of the caregiver (Gosling & Oddy, 1999; Kao & Stuifbergen, 2004; Moore et al., 1993; Nabors et al., 2002). Additionally, household income, the caregiver’s role in the family, and the presence of young children affected caregiver burden (Kao & Stuifbergen, 2004; Nabors et al., 2002). Younger age, low household income and less education were highly correlated with greater caregiver burden (Nabors et al., 2002). Family caregivers who were not married reported a higher level of unmet needs and more
social isolation (Nabors et al., 2002). Furthermore, the presence of caregiver’s unmet needs was a predictor of affective/behavioral, cognitive, and physical burden for the caregiver (Nabors et al., 2002). This finding is consistent with Kreutzer et al., (1994b) who found that non-spouse caregivers reported more unmet caregiver needs.

High caregiver burden is more common in families with young adult TBI individuals. Kao and Stuifbergen, who examined the relationship between young adult TBI survivors and their caregiver mothers, found that brain-injured adults over 18 years tended to have low self-esteem and low satisfaction with their quality of life (Kao & Stuifbergen, 2004). Mothers caring for young injured adults experienced particular challenges in balancing their desire to protect their injured son or daughter, and the need to let them become independent (Kao & Stuifbergen, 2004). Furthermore, the stresses of caring for a young injured adult created marital discord and resentment between the caregiving mother and her spouse (Kao & Stuifbergen, 2004).

2.3.3 Factors Affecting Family Adjustment

Studies indicate that multiple factors affect family adjustment following mTBI. Gan et al. found that higher caregiver burden and female gender of the injured individual predicted poorer family functioning (Gan et al., 2006). They also found that brain-injury related impairments and injured individuals’ awareness of their impairments did not predict post-injury family adjustment. These findings contradicted the findings of Ponsford et al. that the number of post-injury changes in injured individuals and the duration of post-traumatic amnesia (PTA), a state of confusion immediately following
TBI, predicted post-injury family adjustment (Ponsford et al., 2003). Both Ponsford et al. and Kreutzer et al. found that the injured individual’s emotional and personality changes were strongly associated with levels of post-injury family stress and adjustment (Kreutzer et al., 1992; Ponsford et al., 2003).

2.3.3.1 The Family’s Reaction to MTBI

Weddell and Leggett’s study of 87 post-TBI individuals and their families found that the family’s reactions to the injury, including family distress, were the strongest predictors of the family’s judgments of the injured individuals’ personality changes following TBI of all severity (Weddell & Leggett, 2006). In turn, the family’s reactions to changes in the injured individual affected the injured individual’s perceptions of post-injury personality change as well as family adjustment (Weddell & Leggett, 2006). For example, after controlling for severity of impairment, these researchers found that injured individuals with all levels of TBI were more prone to judge their own personality as having changed when families were more critical of their behavior (Weddell & Leggett, 2006). Families who were highly critical tended to view the injured individual’s behavior as evidence of personality change, even though this same behavior may have been present prior to the injury (Weddell & Leggett, 2006).

Ponsford and Schonberger reported that neurobehavioral changes in the injured individual had a significant impact on post-injury family responses and function (Ponsford & Schonberger, 2010). They examined post-injury family function at two years (n = 301) and five years (n = 266). They found that neurobehavioral changes in the
injured individual, including irritability, uncontrolled anger, and aggression directly affected family anxiety and depression, as well as family function. This finding supported previous findings that family member depression was related to the injured individual’s neurobehavioral changes (Kreutzer et al., 1994a; Oddy et al., 1978; Ponsford et al., 2003).

Hammond and colleagues investigated spouses’ reactions to changes in post-TBI injured individuals and the effects on post-TBI marital relationships using two gender-specific focus groups, each with five spouses (Hammond, Davis, Whiteside, Philbrick, & Hirsch, 2011). They found that changes in spousal perceptions, interactions, and responsibilities all appeared to affect marital relationship and satisfaction by pushing couples either toward adjustment (pulling together) or toward dysfunction (pulling apart) (Gosling & Oddy, 1999; Hammond et al., 2011).

2.3.3.2 Coping and Problem Solving Strategies

Injured individuals at all levels of TBI and their spouses have been found to have a significantly lower coping and problem-solving capacity than the general population. Changes in coping behaviors following brain injury are often maladaptive and negatively affect aspects of community reintegration, such as the ability to maintain steady employment (Dawson, Cantanzaro, Firestone, Schwartz, & Stuss, 2006; Moore & Stambrook, 1995). Blais and Boisvert, who examined coping and social problem-solving strategies of injured individuals and their spouses, found significantly lower scores on
these characteristics among injured individuals and their spouses than in matched control
groups from the general population (Blais & Boisvert, 2005).

Dawson and colleagues found that at six months post-injury emotional pre-
occupation coping was most often used, followed by distraction coping (Dawson et al.,
2006). This finding supports earlier work by Moore and Stambrook, who reported that
post-injury changes in coping behaviors were maladaptive and negatively affected
adjustment to community and family (Moore & Stambrook, 1995). Moore and colleagues
found that families with young children faced unique developmental challenges when a
husband sustained a TBI, especially if the injury imposed an added financial strain on the
family (Moore et al., 1993).

People with TBI often use an initial coping strategy of outright denial or
minimization of the disability, and this can result in social isolation and poor family
function (Dawson et al., 2006; Nilsson, Bartfai, & Lofgren, 2010). Nilsson and
colleagues examined post-mTBI rehabilitation programs that provided illness
management strategies and found that injured individuals’ post-injury symptoms affected
their daily lives and post-injury adjustment (Nilsson et al., 2010).

A positive attitude toward problem-solving and acknowledgement of the injury
were associated with a better quality of post-injury adjustment and marital satisfaction
(Blais & Boisvert, 2005). Changes in coping strategies used by the injured person from
pre-injury to post-injury appeared to have a significant impact on post-injury family
adjustment.
2.3.3.3 Pre-Injury Family Functioning

Pre-injury family functioning has predicted post-injury family functioning following all types of TBI (Testa et al., 2006). Sady et al. looked at 141 dyads of a family member and an injured individual, and found that positive pre-injury family functioning was associated with better post-injury family adjustment for mild to moderate injury (Sady et al., 2010). Furthermore, the injured individual’s depression at hospital discharge was strongly correlated with the development of family depression and poor family functioning (Malec et al., 2007). These findings were consistent with an earlier study which reported that a significant number of families had some form of psychological distress at the injured individual’s discharge from the hospital and this affected post-injury adjustment (Testa et al., 2006).

2.3.3.4 Social Support

Social support appears to reduce caregiver burden and positively affect family readjustment. Ergh and colleagues, who examined family function and family distress post-TBI, found that social support had a strong positive relationship to family functioning and was a moderator of families’ psychological distress (Ergh et al., 2002). In another study, social peer mentoring and peer-partner intervention provided high satisfaction and significant improvement in perceived post-injury social support (Struchcn et al., 2011). Sady et al., however, found no association between the family’s pre-injury social support and post-injury social adjustment for mild or moderate injuries.
(Sady et al., 2010), although lower family distress was associated with better social adjustment (Struchten et al., 2011).

2.4 Discussion

Common themes discussed in the literature include injured individuals’ responses to mTBI; the family’s reaction to mTBI and altered family relationships; and changed family functioning. Individuals recovering from mTBI and their families may have a difficult time maintaining the same relationships they had prior to the injury. Furthermore, poor family function before the injury negatively affects injured individuals’ rehabilitation outcomes at all levels of TBI severity.

Psychological distress, including depression and anxiety, are prevalent in both injured individuals and their families following mTBI. Notably, depression has been found to be related to the injured individual’s post-injury impairment awareness, but not to injury severity, placing the mTBI population who has intact awareness at high risk for psychological distress. On the other hand, this increased awareness of their deficits can assist providers in planning the most effective rehabilitation to improve function after injury.

The family’s perceptions of post-injury changes in individuals following mTBI affect post-injury family relationships. In particular, the marital relationship is significantly affected after injury as the marriage partners go through a process of adjustment. After the injury, both partners have to adapt to a new life situation and renegotiate their roles and responsibilities. Often, spouses are not included in the injured
person’s rehabilitation and the spouse’s needs are frequently neglected. Findings from the studies reviewed here suggest that spouses should therefore be included in the injured person’s rehabilitation plan. Additionally, spouses should be provided with opportunities to deal with role changes and the emotional aspects of adjustment.

Alterations in family functioning, such as decreased coping and problem-solving, are often reported after mTBI. Family burden following mTBI appears closely related to the injured individual’s behavioral and personality changes. This suggests that families of individuals with mTBI may experience significant challenges even if the physical injury is small. Research also has found increased levels of stress and strain (e.g., financial and caregiver burden, and problems with household roles and responsibilities) among married couples post mTBI (Hammond et al., 2011; Webster, Daisley, & King, 1999).

Through their interpretation of the injured individual’s disabilities, the family may unknowingly prevent injured individuals from full awareness of their disability and subsequent recovery by performing tasks for them unnecessarily. In cases of mild TBI, families may be unsure which changes are attributable to the brain injury and which might have occurred in the absence of a brain injury. This uncertainty, along with differing views of post-injury impairment held by the injured individual and his or her family, can affect post-injury relationships. Families may also unintentionally marginalize injured individuals, thus negatively affecting the injured individual’s post-injury adjustment and relationships.
People with mTBI may experience less impairment in physical or affective functioning than those with moderate or severe TBI. However, subtle cognitive impairment following mTBI, combined with a family’s expectations of the injured individual’s functioning, has the potential to engender conflict and misunderstanding. For example, families may not understand that an individual who has sustained mTBI can have difficulty performing everyday activities, such as balancing a check book, keeping appointments, or helping with a child’s homework. The literature suggests that individuals at greatest risk for post-injury family distress/dysfunction are those who had poor family function before the injury. Of particular note, families with young children who have financial difficulties and minimal social support may experience the greatest stress when one member of the family sustains an mTBI.

2.5 Implications for Future Research

The literature on individual and family adjustment after a mild TBI has some limitations which future research needs to address. First, there is a need for longitudinal studies related to diagnoses and treatment which can shed light about current difficulties with early post-mTBI identification and interventions. Second, further study is needed to better understand how post-injury family function is affected by factors, such as the injured individual’s post injury changes and family’s response to these changes. Lastly, further research that provides a better understanding about post-mTBI family adjustment/reintegration challenges and management strategies can assist providers in designing individualized rehabilitation support programs for affected families.
2.6 Conclusion

In summary, there is little published research on the impact of mTBI on post-injury readjustment for families. The existing literature on mTBI effects on the marital dyad has focused almost exclusively on either the injured individual or the spouse, but not both. The majority of studies have dealt only with the uninjured spouse’s perspectives, limiting our understanding of couple dynamics and the ways in which they are affected by mTBI. Moreover, the majority of the studies reviewed have used self-report by primary caregivers, who were seen as representing the family; however, findings based on caregiver perspectives may not accurately reflect the perspectives of other, non-caregiver family members.

The World Health Organization identified key determinants of mTBI in 1992; however, definitions, assessment, and treatment of mTBI remain highly variable (Petchprapai & Winkelman, 2007). Inconsistencies in definitions of mTBI from one study to another make it difficult to distinguish injured individuals’ and their families’ reactions to mTBI injury from reactions to other TBI levels of injury. Additionally, instruments used to measure post-injury family function and other predictors differ across studies. Finally, samples and the timing of data collection differ across studies. Homogeneous samples (e.g., Caucasian, middle-class) and inconsistent post-injury data collection time points (e.g., immediately after injury vs. 2 years post-injury) may limit the generalizability of the studies to broader populations.
There is little in the published literature about caring for injured individuals’ post-mTBI or on helping families assist with management of symptoms. Military service members are one group that could benefit from targeted studies of family adjustment after mTBI. There has been a drastic increase in mTBI with military service members due to prolonged deployments in armed conflict areas. Unfortunately, no published studies have specifically examined post-injury reintegration processes for military families following an mTBI. Such studies should be undertaken to lay the groundwork for developing and testing interventions to help individuals with mTBI and their families achieve better outcomes.
### Table 1: Classification of TBI Severity

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
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<tbody>
<tr>
<td>Structural imaging</td>
<td>Normal</td>
<td>Normal or abnormal</td>
<td>Normal or abnormal</td>
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<tr>
<td>Loss of consciousness (LOC)</td>
<td>0-30 min</td>
<td>&gt; 30 min and ≤ 24 hours</td>
<td>&gt; 24 hours</td>
</tr>
<tr>
<td>Post-traumatic amnesia (PTA)</td>
<td>0-1 day</td>
<td>&gt; 1 and ≤ 7 days</td>
<td>&gt; 7 days</td>
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<tr>
<td>Glasgow Coma Scale</td>
<td>13-15</td>
<td>9-12</td>
<td>&lt; 9</td>
</tr>
</tbody>
</table>

(Adapted from Centers for Disease Control and Prevention; CDC, 2003)
<table>
<thead>
<tr>
<th>Source</th>
<th>Purpose/Problem</th>
<th>Sample</th>
<th>Design</th>
<th>Findings</th>
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</thead>
<tbody>
<tr>
<td>Brown, McCauley, Levin, Contant, &amp; Boake (2004)</td>
<td>Examined the relationship between race-based perceptions and post-injury adjustment after mTBI</td>
<td>135 mTBI and 83 general trauma</td>
<td>Correlational</td>
<td>Ethnicity impacted the patient’s post-injury perception of health and functioning</td>
</tr>
<tr>
<td>Erez, Rothschild, Katz, Tuchner, &amp; Hartman-Maeir (2009)</td>
<td>Investigated the relationship of executive functioning and self-awareness after mTBI</td>
<td>13 mTBI</td>
<td>Correlational</td>
<td>After mTBI, individuals were at increased risk for persistent deficits in executive functioning</td>
</tr>
<tr>
<td>Hammond, Hart, Bushnik, Corrigan, &amp; Sasser (2004)</td>
<td>Examined cognitive, communication, and social changes experienced by individuals after TBI</td>
<td>292 TBI</td>
<td>Correlational</td>
<td>Significant improvements were seen in memory/problem solving, and worsening in social interactions over 5-year post-injury period</td>
</tr>
<tr>
<td>Lannsjo, Geijerstam, Johansson, Bring, &amp; Borg (2009)</td>
<td>Examined symptom prevalence after mTBI</td>
<td>2523 mTBI</td>
<td>Correlational</td>
<td>A significant number of participants reported persistent symptoms 3 months post-injury</td>
</tr>
<tr>
<td>Malec, Testa, Rush, Brown, &amp; Moessner (2007)</td>
<td>Identified patient features associated with early and late depression after TBI</td>
<td>106 TBI, 87 mTBI, &amp; 82 orthopedic injury</td>
<td>Correlational</td>
<td>Presence and severity of TBI not directly related to depression; pt’s self-assessment of impairment at discharge was the strongest predictor of depression</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td><strong>Purpose/Problem</strong></td>
<td><strong>Sample</strong></td>
<td><strong>Design</strong></td>
<td><strong>Findings</strong></td>
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<tr>
<td>Ponsford, Cameron, Fitzgerald, Grant, &amp; Mikocka-Walus (2011)</td>
<td>Compared outcomes after mTBI and general trauma</td>
<td>123 mTBI &amp; 100 general trauma</td>
<td>Correlational</td>
<td>No significant difference observed in physical recovery, but mTBI group reported more cognitive impairment after 3 months</td>
</tr>
<tr>
<td>Zhang, Carroll, Cassidy, &amp; Paniak (2009)</td>
<td>Examined self-rated health and factors influencing health after mTBI</td>
<td>929 mTBI</td>
<td>Descriptive</td>
<td>Traffic-related mTBI subjects reported a decline in self-perceived general health</td>
</tr>
</tbody>
</table>
Table 3: MTBI Effects on Family Members

<table>
<thead>
<tr>
<th>Source</th>
<th>Purpose/Problem</th>
<th>Sample</th>
<th>Design</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Blais &amp; Boisvert (2007)</td>
<td>Examined relationships between individuals with TBI and their spouses' personal characteristics and compared these with their level of psychological and marital adjustment</td>
<td>70 TBI patients and their spouses</td>
<td>Correlational</td>
<td>Personal characteristics (e.g., coping and communication) had a strong correlation with psychological and marital adjustment following TBI</td>
</tr>
<tr>
<td>Ergh, Rapport, Coleman, &amp; Hanks (2002)</td>
<td>Examined predictors of family dysfunction and caregiver distress</td>
<td>60 pairs of pts with TBI and caregivers</td>
<td>Correlational</td>
<td>Neurobehavioral disturbance was the strongest predictor of caregiver distress and family function (FF) following TBI</td>
</tr>
<tr>
<td>Kao &amp; Stuifbergen (2004)</td>
<td>Examined the meaning of the experience and the relationship between young adult TBI survivors and their mothers</td>
<td>12 (9 males and 3 females) injured adults and their mothers</td>
<td>Phenomenological</td>
<td>Survivors acquired the sense of being abnormal from various causes, including social pressures and dynamics within the family</td>
</tr>
<tr>
<td>Testa, Malec, Moessner, Brown, (2006)</td>
<td>Identified risk factors for poor family functioning and neurobehavioral problems after TBI or orthopedic injuries (OI)</td>
<td>TBI (n=75); mTBI (n=47); OI (n=44)</td>
<td>Correlational</td>
<td>Patients at greatest risk for distress at follow-up were those with family dysfunction at discharge, severity of injury (both OI and TBI) was not a significant factor</td>
</tr>
<tr>
<td><strong>Source</strong></td>
<td><strong>Purpose/Problem</strong></td>
<td><strong>Sample</strong></td>
<td><strong>Design</strong></td>
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<tr>
<td>Dawson, Cantanzaro, Firestone, Schwartz, &amp; Stuss (2006)</td>
<td>Examined coping behavior change following TBI and its impact on the injury outcome</td>
<td>73 significant others of TBI survivors</td>
<td>Correlational</td>
<td>Changes in coping strategies by injured person had more impact on productivity (return to work/school) outcomes than demographics and injury severity</td>
</tr>
<tr>
<td>Gan, Campbell, Gemeinhardt, &amp; McFadden (2006)</td>
<td>Examined predictors of family system functioning after TBI</td>
<td>66 TBI and 148 family members</td>
<td>Correlational</td>
<td>FF not predicted by neuropsychological scores or impairments; mothers, spouses, and siblings reported greater distress than a normative sample; the strongest predictors of FF were caregiver strain and client gender (female)</td>
</tr>
<tr>
<td>Hammond, Davis, Whiteside, Philbrick, &amp; Hirsch (2011)</td>
<td>Examined effect on the marital relationship of a spouse with TBI</td>
<td>5 spouses of individuals with TBI</td>
<td>Qualitative</td>
<td>Changes in family dynamics due to TBI and spouses’ perceptions of those dynamics impacted the marital relationship</td>
</tr>
<tr>
<td>Kreutzer, Stejskal, Ketchum, Marwitz, Taylor, &amp; Menzel (2009)</td>
<td>Evaluated the Brain Injury Family Intervention (BIFI) for families of persons with TBI and identified factors related to outcomes</td>
<td>53 TBI and their families</td>
<td>Quasi-experimental</td>
<td>Unmarried caregivers and those with longer acute-care stay reported higher unmet needs and greater perceived obstacles to receiving services</td>
</tr>
<tr>
<td>Source</td>
<td>Purpose/Problem</td>
<td>Sample</td>
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<tr>
<td>Nilsson, Bartfai, &amp; Lofgren (2010)</td>
<td>Explored mild Acquired Brain Injury (mABI) and mTBI group rehabilitation program</td>
<td>10 mABI/mTBI</td>
<td>Qualitative</td>
<td>There was gradual change in the participants’ awareness of deficits and in the resulting adaptation to their new lives</td>
</tr>
<tr>
<td>Ponsford &amp; Schonberger (2010)</td>
<td>Investigated family functioning (FF) and relatives’ emotional state (2 and 5 years) following TBI</td>
<td>301 (at 2 years) and 266 (at 5 years) TBI</td>
<td>Correlational</td>
<td>General FF not related to injury severity; behavioral changes in the TBI individual were strong predictors of poor FF; poorer FF was related to the presence of anxiety and depression symptom in the injured person</td>
</tr>
<tr>
<td>Sady, Sander, Clark, Sherer, Nakase-Richardson, &amp; Malec (2010)</td>
<td>Investigated the relationship of pre-injury caregiver and family functioning to community integration outcomes in persons with TBI</td>
<td>141 TBI and their caregivers</td>
<td>Qualitative</td>
<td>Lower caregiver distress was associated with improved social integration in persons with mild/moderate injury. There was a significant interaction btw injury severity and caregiver’s perceived social support; no association was observed between caregiver social support and productivity outcome for mild/moderate injuries</td>
</tr>
<tr>
<td>Weddell &amp; Leggett (2006)</td>
<td>Assessed neuropsychological and psychosocial determinants of judgment of personality change (PC) after TBI</td>
<td>87 TBI</td>
<td>Correlational</td>
<td>Memory loss and impaired olfaction predicted relatives’ PC judgments; however, participants’ and relatives’ reactions predicted PC judgments best</td>
</tr>
</tbody>
</table>

Abbreviations: btw = between; FF = family function; mon = month; outpts = outpatients; QOL = quality of life; pt = patient; sx = symptom
Finding the New Normal: Accepting Changes After Combat-Related Mild Traumatic Brain Injury

I used to be able to come home from work and maybe do something around the house. Now I come home from work, and I didn’t do much at work but I’m spent. . . So [it was a process of] finding a new normal and being able to recognize your limitations. (SO5)

3.1 Introduction

Reintegration after prolonged separation is difficult for any family; however, families of soldiers who suffer from invisible injuries like mild traumatic brain injury (mTBI) may face additional challenges in resuming family roles and responsibilities (Committee, 2010; Zeitzer & Brooks, 2008). Mild TBI is considered the most widespread and undertreated “signature wound” of soldiers who served in Iraq and Afghanistan (Bradshaw, 2008; Terrio et al., 2009; Zoroya, 2006). Approximately 320,000 (20%) of the more than 1.9 million service members who served in Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF) meet the diagnostic criteria for mTBI (Bradshaw, 2008; Terrio et al., 2009; Zoroya, 2006). Many soldiers are not diagnosed with mTBI, but report headaches, mood swings, insomnia, concentration problems, and memory loss that likely are the results of an undiagnosed combat-related mTBI (Hoge et al., 2008; Mental Health Advisory Team, 2008).

Mild TBI is defined as an injury to the brain as a result of blunt trauma or a jolt to the head (CDC, 2006; Defense, 2006). Often, there are no obvious neurological deficits or abnormal computed tomography (CT) findings (Medicine, 1993; Cassidy et al., 2004).
Erez and colleagues reported significant changes in the abilities of people with mTBI, including the ability to maintain social contacts, do leisure activities, drive, and manage money (Erez et al., 2009). In other studies, sequelae of psychological distress, such as depression and anxiety, were prevalent for both injured individuals and their families following mTBI (Kreutzer et al., 1994b; Kreutzer et al., 1992; Livingston, 1987; Ponsford et al., 2003). Although research has been conducted on the impact of moderate-to-severe TBI on family caregivers, there is limited research describing the impact of mTBI on family adjustment.

The existing literature focuses on either the injured individual or their family, separately, while neglecting the issue of how the family works together toward post-mTBI reintegration. Clearly, there is a compelling need to understand how soldiers and their spouses identify the special challenges, sources of support, and overall rehabilitation process of post-mTBI family reintegration. Therefore, the purpose of this study was to explore family reintegration processes of post-mTBI soldiers and their spouses as described in their own words. For this study, “family” is defined as soldiers and their spouses, with or without children in the household. Family reintegration is defined as the reunion processes that soldiers and their spouses use to restore and re-establish family relationships. Three research questions guided this study:

1. How do soldiers with mTBI and their spouses describe family reintegration?

2. What difficulties, challenges, or problems do these families experience?
3. What strategies do these soldiers and their spouses use to cope with the challenges of family reintegration after mTBI?

3.2 Method

The intent of this study was to generate an explanatory theory of post-mTBI family reintegration processes through the analysis of concepts and themes found in interviews with soldiers and their spouses. The focus of this study was on dyadic relationships (the soldier and his/her spouse) and family functioning after mTBI. Such knowledge will enable researchers and clinicians to develop data-based and challenge-specific family reintegration support programs for these families. Strauss and Corbin’s grounded theory methodology was used to explore post-mTBI family reintegration following deployment.

3.2.1 Sampling

Participants were recruited by self-referral, healthcare provider referral from the TBI clinic at a large Army Medical Center, or direct approach in the clinic. Research flyers describing the study and giving the investigator’s contact number were posted and distributed. After viewing a recruitment flyer, interested soldier volunteers left their contact information with their providers. The providers then gave this contact information directly to the investigator so the study could be explained and consent given. If prospective dyads met the study inclusion criteria, the spouse was contacted by phone to get verbal consent and scheduled a face-to-face meeting. All prospective volunteers were
given at least one full day (between the first contact and the first meeting) to consider participation in the study prior to participating. During the initial in-person contact with both the soldier and his/her spouse, the investigator discussed the interview timetable and obtained signed, IRB-approved informed consent from each participant.

Participants were active duty soldiers with deployment-related mTBI and their legally married civilian spouses who spoke English. All soldiers were between 2 and 24 months post-deployment. Dual-military families (i.e., where the spouse was also a soldier) were excluded because of a potentially different dynamic in the family reintegration process. Sampling was directed by theoretical sampling methods, which means that recruitment of study participants was guided by emerging and theoretically relevant constructs drawn from analysis of collected data (Strauss & Corbin, 1998). In the Army, over 60% of soldiers are married and less than 30 years old (Defense Manpower Data Center, 2008); therefore, the first two couples for this study were selected to reflect this demographic. The first two couples were junior enlisted soldiers and spouses with young children. The data from the first couple interview was compared with the second couple interview. A common challenge reported by the first two couples was the soldier’s post-injury functional limitations. Therefore, the third couple was deliberately chosen to include a soldier without functional limitation to examine the applicability of the emerging concepts. Another concept that emerged from the first two couple interviews was the importance of “maintaining a daily routine” by couples with children; therefore, the investigator deliberately sought couples without children to assess the applicability of
the identified categories. Thus, sampling decisions continued to evolve during the data collection process (Strauss & Corbin, 1998). This sampling strategy allowed the investigator to broaden and refine emerging categories during the theory building phase.

3.2.2 Data Collection

This study received approval from the Institutional Review Board of a large Southeastern university. The primary method for data collection was face-to-face, semi-structured interviews. Conjoint interviews were conducted first to determine each dyad’s shared views of family reintegration. These shared views were further explored during separate individual interviews. Nine dyads yielded a total of 27 interviews (9 conjoint soldier-spouse interviews, 9 spouse interviews, and 9 soldier interviews).

During the first part of each interview, the investigator used broad, open-ended queries, such as: Tell me about your family’s experiences of being reunited after deployment. Separate face-to-face interviews, first with the soldier and then with the spouse, were conducted approximately 1 week after the initial joint interview. The investigator asked probing follow-up questions as needed to encourage participants to describe, clarify, and elaborate on the details of the dyad’s individual family reintegration experience. An example of a follow-up question is: Given what you have said about your daily routine, is that a change from before the soldier’s deployment?

In both joint and separate individual interviews, the open-ended questions were influenced by the ongoing analysis, and the direction of subsequent interviews was guided by the emerging theory (Charmaz, 2006; Pandit, 1996; Strauss & Corbin, 1990,
Both joint and separate interviews averaged one hour in length. Participants were recruited and interviewed until data saturation was reached, that is, until no new themes of family reintegration challenges or coping strategies were identified (Charmaz, 2006; Pandit, 1996). Quality control and rigor of data collection was maintained through the use of mentor-guided interview techniques and established data collection protocols. These included independent coding corroboration with colleagues and 100% auditing of the first five joint interview transcripts by two expert mentors. Dependability of the data was assured through participant validation of the key points of the interview at its conclusion and explicit procedures for data selection, analysis, and synthesis.

### 3.2.3 Instruments

Family data (number of members, length of marriage, and number of deployment separations previously experienced) was collected (see Appendix I). Soldiers and spouses independently completed the Hospital Anxiety and Depression Scale (HADS) (see Appendix II) and Marital Adjustment Test (MAT; see Appendix III) before the interview. Additionally, soldier participants only completed the Posttraumatic Stress Disorder Checklist Military Version (PCL-M) (see Appendix IV) before the interview. Collected information was used to provide a context for understanding soldiers’ and spouses’ views of their family reintegration challenges and management strategies. The HADS, MAT, and PCL-M were included to (a) quantify the severity of symptoms of anxiety, depression, marital distress in soldiers and their spouses and (b) determine the severity of PTSD symptoms in the soldiers. Of particular interest was the association within couples
with regard to level of anxiety, depression, and marital adjustment reported by each member of the dyad. The association among these measures of psychological distress was also explored in the soldiers and spouses separately to provide a better understanding of the interrelationship between the various distress measures.

3.2.3.1 Depression and Anxiety

The 14 item, Likert scale, self-report HADS was developed by Zigmond and Snaith (1983) to identify both anxiety and depression symptoms in the general adult population (Herrmann, 1997; Johnston, Pollard, & Hennessey, 2000). The individual items were rated using a Likert scale ranging from 0 to 3. Five of the 14 items were reverse coded. An anxiety total score was derived by summing the scores for the seven anxiety-related items, while the depression total score was from the summing of the seven depression-related items. The total score for each subscale had a possible range of 0 to 21, with higher scores indicating greater severity of distress (Herrmann, 1997). Anxiety and depression scores of 11 or greater on either subscale were considered significant co-morbidity (Herrmann, 1997). The HADS reported high internal consistency; Cronbach's α value ranged from 0.87 to 0.88 for all the items of the scale with anxiety 0.83 and for depression 0.84 (Herrmann, 1997). Construct validity was demonstrated by item-scale correlations from 0.54 to 0.80 (Johnston et al., 2000).

3.2.3.2 Marital Adjustment

Both soldier and spouse completed a measure of marital adjustment. The Locke Wallace’s MAT is a short (15-item) questionnaire with each question weighted
differently. The MAT measures marital adjustment in several general categories (e.g.,
communication, finances, sexual satisfaction) identified as important concerns for
spouses of a brain-injured person, and proved relevant for contemporary relationships
(Cross & Sharpley, 1981; Freeston & Pléchaty, 1997). Possible total scores range from 2-
158 points with a suggested cut score of 100 (100 or greater corresponding with positive
marital adjustment and less than 100 indicating maladjustment) (Locke & Wallace,
1959). Locke and Wallace reported reliability of .90 from their original studies and
subsequent studies demonstrate internal consistency (α = .83) (Cross & Sharpley, 1981).

3.2.3.3 Soldier’s Post-traumatic Stress Disorder (PTSD) Symptoms

The soldier’s PTSD symptom severity was assessed with the PCL-M, a 17-item,
self-report measure that is specific to military experiences (Bliese et al., 2008). PCL-M
scores range from 17-85 points and cutoff score of 50 or greater has been established as
the referral standard for a PTSD diagnosis (Weathers et al., 1993). Reliability and validity
of instruments are represented in the table below (see Table 5).
<table>
<thead>
<tr>
<th>Construct</th>
<th>Instrument</th>
<th>Reliability and validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression and Anxiety</td>
<td>Hospital anxiety and depression scale (HADS)</td>
<td>Cronbach $\alpha$ 0.87-0.88; test-retest reliability 0.94 (.90 for anxiety &amp; .84 for depression) (Herrmann, 1997). Concurrent validity, correlation of the scale with subscales with Beck Depression Inventory (BDI) and the State-Trait Anxiety Inventory (STAI) 0.72-0.75 (Johnston et al., 2000). Measures depression and anxiety symptoms in general population and was validated in several studies (Johnston et al., 2000; Michopoulos et al., 2008).</td>
</tr>
<tr>
<td>Marital Adjustment</td>
<td>Locke &amp; Wallace’s Marital Adjustment Test</td>
<td>Cronbach $\alpha$ 0.77; test-retest reliability 0.82 for men and 0.84 for women. Criterion-related validity with cut score of 100 (higher score indicating well-adjustment and lower score indicate mal-adjustment). Construct measure slightly different between men and women; however, correlation between partners were all significant (Freeston &amp; Pléchaty, 1997).</td>
</tr>
<tr>
<td>PTSD Symptoms</td>
<td>Post-traumatic Stress Disorder Checklist Military Version (PCL-M)</td>
<td>Internal consistency $\alpha$ coefficient 0.97 for all 17 symptoms; item-scale total correlations 0.62-0.87; test-retest reliability 0.96 (Weathers et al., 1993). Convergent validity demonstrated by strong correlations between PCL and the Mississippi Scale (0.93), MDS-Minnesota Multiphasic Personality Inventory-2 (0.77), Impact of Event Scale (0.90), and Combat Exposure Scale (0.46) (Bliese et al., 2008; Weathers et al., 1993). Optimal cutoff 50 with sensitivity of 0.82, specificity of 0.83, and Kappa of 0.64 (Weathers et al., 1993).</td>
</tr>
</tbody>
</table>
3.2.4 Data Analysis

Descriptive statistics were used to summarize the sample sociodemographics characteristics, including the quantitative measures of psychological and marital distress. The mean, standard deviation (SD), median, and range were determined for continuous variables, while number and percentage were calculated for categorical variables. Because of small sample size and non-normal distributions of some continuous variables, both the mean and median were evaluated. Scatterplots and Spearman correlation coefficients ($r_s$) were used to visualize and explore the relationship among HADS anxiety, HADS depression, and MAT marital adjustment scores in soldier and his/her spouse in this small sample size of nine couples. Scatterplots and Spearman correlation coefficients ($r_s$) were also examined to explore the relationship among the PTSD and other measures of emotional distress in the soldiers. Statistical significance testing was not conducted due to the small sample and the correlation coefficient of determination ($r_s^2$) was calculated to obtain the observed effect size for this sample. The small sample size, however, limited any conclusions one might draw from these correlations coefficients.

Qualitative data collection and analysis occurred simultaneously, followed by a gathering of more focused data to answer emerging analytic questions. This process built the relationships between data while filling conceptual gaps in the analysis (Strauss & Corbin, 1998). Digitally recorded interviews were transcribed verbatim and then analyzed using constant comparison in identifying and clarifying characteristics of the dyads’ post-
mTBI family reintegration. Relevant literature was incorporated after initial data collection and analysis in order to enrich the description of emerging theory and examine collected data within the framework of pre-existing constructs.

Open coding involved line-by-line examination, comparison, conceptualization, and categorization of transcripts. Axial coding involved reassembling data based on relationships and patterns (both within and among the codes) that were identified during open coding. Categories were then created by linking open codes that shared a common theme. Categories that emerged with high frequency and connected with other categories were considered core categories (Charmaz, 2006; Pandit, 1996; Strauss & Corbin, 1998). During the final phase of selective coding, the core category that best described the process of reuniting with family was defined as the phenomenon and analyzed systematically using the six c’s (causes, contexts, contingencies, consequences, covariances, and conditions), which are central to grounded theory methodology.

The investigator noted all phrases used repeatedly by participants and explored them more deeply using prompts such as: *Was what you are describing a “result” of what happened? Or was it a “cause” of what happened?* Constant comparative methods in the form of clarifying prompts such as these continued until theoretical saturation was achieved (Charmaz, 2006; Strauss & Corbin, 1998). Memos were used to document the investigator’s thoughts and impressions of what the data might mean and how they related to other data, which then led to hypotheses about the relationships among data.
3.3 Findings

The sociodemographic characteristics of the participants are presented in Table 6. Participants included nine soldiers and nine spouses. Majority of soldier participants (n=8) were male. More than 50% of the soldiers (n=5) and 75% of the spouses (n=7) were White. The soldiers’ rank ranged from specialist to field grade officers. More than 65% of couples (n=6) had 1 or 3 children at home. Fifty-six percent (n=5) and 44% (n=4) of soldiers reported clinically significant depression and anxiety symptoms, defined as a score 11 or greater of each of the depression and anxiety subscales of the HADS. Ten percent (n=1) of spouses disclosed clinically significant anxiety symptoms based on the HADS subscale score. Fifty-six percent (n=5) of soldiers reported unsatisfactory marital relationship, as indicated by a score of less than 100 on MAT; whereas, 22% of the spouses (n=2) reported dissatisfaction with their marriage. Sixty-seven percent of soldiers revealed clinically significant PTSD symptomatology on the PCL-M scale, represented by a score of 50 or above.
Table 6: Soldier and Spouse Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Mean (SD)</th>
<th>Median</th>
<th>Range</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Soldier</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>33.4 (7.5)</td>
<td>33</td>
<td>21-44</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>14.4 (2.4)</td>
<td>14</td>
<td>12-18</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td></td>
<td>5</td>
<td>(56)</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td></td>
<td>1</td>
<td>(11)</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td></td>
<td>2</td>
<td>(22)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>1</td>
<td>(11)</td>
<td></td>
</tr>
<tr>
<td>Rank</td>
<td></td>
<td>2</td>
<td>(22)</td>
<td></td>
</tr>
<tr>
<td>Enlisted</td>
<td></td>
<td>4</td>
<td>(44)</td>
<td></td>
</tr>
<tr>
<td>NCO</td>
<td></td>
<td>3</td>
<td>(33)</td>
<td></td>
</tr>
<tr>
<td>Officer</td>
<td></td>
<td>3</td>
<td>(33)</td>
<td></td>
</tr>
<tr>
<td>Deployment time</td>
<td>9.0 (3.7)</td>
<td>11</td>
<td>3-12</td>
<td></td>
</tr>
<tr>
<td>HADS Depression</td>
<td>9.7 (3.6)</td>
<td>10</td>
<td>3-14</td>
<td></td>
</tr>
<tr>
<td>HADS Anxiety</td>
<td>9.1 (3.3)</td>
<td>9</td>
<td>2-13</td>
<td></td>
</tr>
<tr>
<td>MAT Score</td>
<td>92.1 (35.4)</td>
<td>99</td>
<td>41-130</td>
<td></td>
</tr>
<tr>
<td>PCL-M Score</td>
<td>52.0 (11.3)</td>
<td>56</td>
<td>30-67</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>33.9 (9.2)</td>
<td>35</td>
<td>20-49</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>13.3 (1.7)</td>
<td>13</td>
<td>12-16</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td>7</td>
<td>(78)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td></td>
<td>1</td>
<td>(11)</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td></td>
<td>1</td>
<td>(11)</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td></td>
<td>4.1 (2.8)</td>
<td>3</td>
<td>1-9</td>
</tr>
<tr>
<td>HADS Depression</td>
<td>7.0 (3.7)</td>
<td>7</td>
<td>2-15</td>
<td></td>
</tr>
<tr>
<td>HADS Anxiety</td>
<td>116.4 (17.9)</td>
<td>121</td>
<td>90-148</td>
<td></td>
</tr>
<tr>
<td>MAT Score</td>
<td></td>
<td>8</td>
<td>1-25</td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td></td>
<td>2</td>
<td>(22)</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td></td>
<td>3</td>
<td>(33)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td>4</td>
<td>(11)</td>
<td></td>
</tr>
</tbody>
</table>

Age = in years; Children = number of children at home; Deployment time = length of deployment in months; Education = in years; Enlisted = E1-E4; NCO (Non-Commissioned Officer) = E5-E9; Officer = CW1-O6; Time in marriage = in years
Table 7 presents the Speaman correlation coefficients for the soldier and spouse scores with regard to HADS anxiety symptoms, HADS depression symptoms, and the MAT marital adjustment scores.

**Table 7: Spearman Correlation Coefficients for Couples**

<table>
<thead>
<tr>
<th></th>
<th>Spouse MAT</th>
<th>Spouse Depression</th>
<th>Spouse Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Soldier MAT</td>
<td>-0.06</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Soldier Depression</td>
<td>-0.61</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Soldier Anxiety</td>
<td>-0.12</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

A moderate negative linear association between the depression symptoms scores ($r_s = -0.61$, $r_s^2 = 0.37$) in the nine couples was observed. Higher depression symptoms scores in the soldier were associated with lower depression symptoms scores in the spouse. Weak within-couple correlation were indicated on the other measures.

Table 8 present the Spearman correlation matrix for the HADS depression symptoms, HADS anxiety symptoms, MAT marital adjustment, and PCL-M based PTSD symptom scores for the soldiers and spouses separately.

**Table 8: Spearman Correlation Coefficients for Soldiers and Spouses**

<table>
<thead>
<tr>
<th></th>
<th>Depression</th>
<th>Anxiety</th>
<th>MAT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Soldier</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MAT</td>
<td>-0.10</td>
<td>0.03</td>
<td></td>
</tr>
<tr>
<td>PCL-M</td>
<td>0.23</td>
<td>0.74</td>
<td>-0.36</td>
</tr>
<tr>
<td><strong>Spouse</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.53</td>
<td>-0.65</td>
<td>-0.76</td>
</tr>
<tr>
<td>MAT</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Depression = HADS depression subscale scores; Anxiety = HADS anxiety subscale scores; MAT = marital adjustment scores; PCL-M = PTSD scores.
The core variable of this study was the family’s attempt at seeking a new normal. A new normal was defined by participants as the couple’s new, post-mTBI expectation of the family unit or family routine. The idea of a new normal is supported by the following themes: facing up to the soldier’s unexpected homecoming, managing unexpected changes in the family routine, experiencing mismatched expectations, and adjusting to new expectations for the family.

3.3.1 Facing the Unexpected: Homecoming

A majority of spouses said that reuniting with their post-mTBI soldier was unexpected when it happened. All spouses in this study stated they had to adjust to changes in soldiers and their family routine.

3.3.1.1 Adjusting to having the soldier back home

A majority of soldiers and spouses described their homecoming experience as different from other homecomings or different than what they had envisioned. Some soldiers who had accompanying physical injuries had been medically evacuated home, and this unexpected early return from deployment led to emotional stress for soldiers and their spouses. One spouse described her experience:

We didn’t have time [to prepare] and I was pregnant [when he came back unexpectedly] and we had to prepare for something completely different [than before]. (SP2)

A majority of families in this study indicated that their soldier's frequent deployment cycles created two separate lives and routines: one for the soldier and another for his/her family. An overwhelming majority of soldiers (all six soldiers with more than
two deployments) described their routine as a cycle of pre-deployment preparation, deployment, and re-deployment (homecoming), followed by preparation for another deployment. Thus, families had to maintain two separate routines: one for when the soldier was home and another for when the soldier was gone. As one soldier stated:

I’d say here’s the family [draws a separate circle and semi-circle] and you know, literally, since 9-11, the family’s moving [points at circle]. I deploy, I come back [pointing at semi-circle outside of circle] . . . I get all my stuff ready, we do laundry, we clean our gear, we get everything taken care of, and then we go away again. And that happens over, over and over. (SO5)

Families kept themselves busy with various activities while soldiers were gone, and many spouses reported having a greater involvement with their children’s extracurricular activities as a result. Therefore, it was an adjustment when the soldier came home unexpectedly with an injury which changed the family’s routine and responsibilities. All spouses who experienced an unexpected homecoming indicated a sense of uncertainty and bewilderment over the rapid change in their daily routine, from a well-planned and predictable daily routine to a much less predictable one that revolved around caring for an injured soldier. One spouse reported:

As far as activity within the first few weeks of coming home . . . It was all getting in the car, driving to a doctor’s appointment; I would say he probably had eight or nine doctors' appointments a week . . . with the kids, so it was difficult to try to juggle everything at once . . . it was constantly changing. There was never a consistent day. (SP1)

This spouse reported that at times, she felt that her family was living in a car. Her husband acknowledged as much when he said:
We were dragging the little one [daughter] around with us and the other one at school . . . if my wife couldn’t take me home then I would go find a spot and wait around all day at the hospital. (SO1)

### 3.3.1.2 Noticing changes in the soldier

A majority (seven out of nine) of spouses reported that they were not prepared for the post-mTBI changes in soldiers. These included changes in personality, physical appearance and ability, and emotional state. Personality changes ranged widely. For example, a soldier might go from being a person who is very assertive (before the mTBI) to one who avoids all situations that might involve personal confrontation. In one case, a soldier who was assertive before the mTBI suddenly found himself avoiding all situations that could involve confrontation, such as asking for a merchandise refund. Another soldier explained that she did not advocate for her cause when she experienced disagreement about her post-mTBI rehabilitation plan because she did not want conflict with her healthcare providers.

Some soldiers reported that physical changes caused by the injury (e.g., stitches on the face or a broken leg) contributed to initial family rejection and delayed bonding with their children. A majority of spouses talked about the post-mTBI soldier's emotional instability and were concerned by changes in the soldier’s behavior, such as sudden irritability and uncontrollable anger. This resulted in spouses feeling that they needed to "walk on eggshells" around the injured soldier. One spouse described her experience:

He’s a nice person and all of sudden it's just mean, just a meanness . . . and just [my] anxiety, I hate to use the word "cruel," a subtle cruelness . . . and then you
know he’s gone in waves and it’s really hard. It’s hard to figure out. I’ve cracked; I don’t know what’s happening here. (SP5)

Some soldiers and spouses also reported frustration over the inability of the injured soldier to resume his or her pre-mTBI family roles. This included roles such as paying bills or keeping finances in order. Soldiers who once took pride in their physical ability to perform yard work and other maintenance around the house could now no longer perform these tasks due to constant headaches, balance problems, and general functional limitations.

3.3.2 Managing Unexpected Change

All participants indicated they had to manage unexpected changes in returning soldiers in order to maintain a semblance of normalcy in their daily routine. They said that the pre-deployment education/briefing did not prepare them for a post-mTBI homecoming. This finding is worth noting in terms of the number of participants (17 of 18, or 94%) who found the pre-deployment briefing ineffective in preparing them for the actual post-injury reintegration. The one soldier who did have prior knowledge of mTBI was a combat medic; however, even he acknowledged a limited understanding of post-mTBI rehabilitation. Based on participant descriptions, there appeared to be a lack of connection between the pre-deployment education/briefing and the post-mTBI reality. Participants described their perception of the pre-deployment education/briefing in the following ways:

It’s difficult for a normal-thinking person that’s never sustained that particular injury to try and envision it. It’s like, what do you think it would be like to walk
around with a fake leg? You can’t imagine that because you have two real legs, so trying to anticipate an injury and trying to understand it before it actually happens to you is difficult. (SO6)

3.3.2.1 Assuming a caregiver role

Managing unexpected changes included assuming new roles, such as caregiver. Some spouses who had prior experiences of homecomings reported better adjustment and management. The majority of spouses had to assume a new role as caregivers, in addition to their existing role as spouses, and this created feelings of stress and burden. Often spouses had to assume responsibility of caring for the returning soldier, and this responsibility could range from acting as a case manager (filling out benefit applications, coordinating doctor appointments) to providing total care (bathing and feeding). One soldier described the extent to which he found himself depending on his wife:

She [has] to do everything from basic needs of feeding me and dressing me to helping me shower. My wife, from day one she has been my primary care giver . . . My profile says I can’t drive. I can’t do anything. But yet I am supposed to make formation [to report 3-4 times a day for military group meeting] and go to doctor’s appointments, and it’s all on us. But most of it goes back on her. (SO1)

Often, the participants had educated themselves about mTBI through online information. Spouses who provided caregiving eventually learned to recognize cues of when soldiers were experiencing symptoms in order to head off potential conflicts:

I’m almost like a trained dog now. He’ll start to do certain movements with his hands, with his head, and I’m like, Oh no, we need, I start positioning things around us. (SP5)

I just kind of play middleman . . . we’ve been together 15 years, so I can kind of tell his moods. When I see him getting frustrated or he’s had enough and he’s reaching that boiling point, I can redirect the kids somewhere else. Kind of step in
and say "Hey you know, hey babe. Won’t you go and watch some TV or go out to the workshop a little bit?" – telling him to take a break without letting the kids know there’s something wrong. (SP6)

3.3.2.2 Feeling caregiver stress

When a soldier sustains physical injuries along with mTBI, the spouse usually takes on the responsibility of caregiving, often with limited or no support from extended family or friends. Some spouses indicated that caring for soldiers over long periods without relief, combined with an overload of responsibilities, had caused them emotional and physical exhaustion, anger, and guilt (for feeling that way). Some participants had relocated to their current home shortly before the soldier’s deployment and had not had time to make friends with other military spouses or neighbors when the soldier came back unexpectedly with an injury. This left them with few support resources (e.g., respite care, child care, visits from friends) during the soldier’s recovery. Some spouses did not provide direct caregiving but still felt stressed about the soldier’s symptoms and actively sought ways to help with rehabilitation, for example, by advocating for care and learning about mTBI on the internet.

3.3.2.3 Managing post-mTBI changes within the context of the married relationship

Except for one participant, who was a medic, all indicated they had no previous knowledge of mTBI and did not know anything about managing its symptoms. There were two different levels of reintegration experience. Families with prior experiences of homecoming differed from those families without prior experience. Some spouses with prior experience of homecoming had learned the "do’s and don’ts" from their past
reintegration experiences, while their returning soldiers attempted to contribute to the family without getting in the way of the family’s established routine. Spouses with prior reintegration experience prepared their families for the soldier's return in order to make the soldier feel as welcome as possible. These families also knew how to include the returned soldier into their daily activities and routine gradually, so as to avoid causing the soldier to feel overwhelmed:

[When my children and I don’t ask for my husband’s help] it’s not excluding, but letting him integrate into the family routine at his own pace. Instead of, "Oh, you’re home now. I need you to take out the trash, do the dishes, do the laundry, help with the kids, do the yard work, all the stuff you used to do before you left now you can do it all again," it’s just slowly putting more in his court what he’s feel comfortable doing. (SP6)

The soldier elaborated further:

[This time] it seemed to take a little longer for me to reintegrate . . . I am more irritable and the thing that most bothers me is the inability to concentrate on our conversation, which frustrates me. (SO6)

Some spouses reported that post-mTBI reintegration was also influenced by the couple's pre-deployment marital relationship and family environment. Spouses who had seen other marriages break up were determined that their marriage would not end in divorce, and these spouses actively sought resources that would protect and enhance their marriage and family life. Of the nine couples in this study, eight couples took part in either marriage counseling or marriage retreats. The one couple that did not do counseling or retreats was prevented from doing so by child care issues and physical impairment.

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Families without prior reintegration experience faced a more difficult time during post-mTBI reintegration. Soldiers blamed themselves for problems or difficulties, especially couple relationship conflicts. Symptoms not related to any visible injury, such as headaches and cognitive impairment, exacerbated soldiers’ mood changes and irritability, contributing to problems of family conflict and avoidance:

We argue a lot, whether it be if I wake up not feeling good and she asks me to do something I don’t do or forget to do it. . . . Just the general inability to please your wife. That’s pretty bad, whether you don’t remember or not. She would tell me something and like it really never happened, a block of time of life was just missing. (SO2)

His spouse perceived their current relationship this way:

It has gotten better and the reason it’s ok now is because he’s more accepting that it may be him and not that I’m not listening. (SP2)

3.3.3 Experiencing Mismatched Expectations

A majority of spouses experienced mismatched expectations regarding the soldier’s functional capabilities. In some instances, soldiers themselves indicated having unrealistic expectations of their own about their functional capabilities, which resulted in frustration. Soldiers and spouses alike tended to believe that an injured soldier can eventually return to pre-injury level functioning, given time and patience. Many did not realize that expectations of performance would need to be adjusted, since post-injury symptoms would be likely to permanently impact the returning soldier's daily functioning. One spouse reported that “I ask him [the soldier] to give [our daughter] a bath . . . but he doesn’t like to do that.” Whereas, her soldier spouse reported that “Some
activities cause a lot of pain and I don’t like to [give bath] do that.” Mismatched expectations between soldiers and their spouses extended to roles and responsibilities in marriage, including the soldier's perception of the spouse's support during the reintegration process.

### 3.3.3.1 Coping with the shifting state of our relationship

A majority of soldier participants indicated that they were frustrated about marital conflict caused by the injury. For example, the soldier’s short-term memory loss was mistaken by the spouse for carelessness, which led to arguments. Some soldiers stated post-mTBI changes contributed to their feeling of being a burden to the family and an inability to make their spouses happy. Some spouses reported that it was difficult for them to be mindful of the soldier’s diminished functioning, since they did not have the expected visual cues to remind them of it, cues such as a visible wound or other physical impairment.

Post-mTBI emotional support from spouses varied from full support to a state of near indifference. Some spouses became the soldier’s advocate and case manager, while others provided sustained emotional support. In contrast, some spouses showed little interest in the soldier's post-mTBI symptoms and indicated that their soldier should stop making excuses and move on:

> When I’m sick, I can’t veer away from my responsibility. I have to get up and deal with things, and so I feel like sometimes he could just get up and do something and not like make excuses . . . all I do is get frustrated, and all I want to do is yell at him. (SP2)
Effective communication was reported as a significant mitigating factor in the ability of spouse and soldier to discuss post-injury expectations. Some soldiers described internal conflict between their need to confide in their spouse and a reluctance to share their combat or work experiences. This conflict, combined with the soldier’s short-term memory loss, impacted couples’ post-injury communication and intimacy, often resulting in misunderstanding and avoidance:

I’m getting angry because at first he wasn’t telling what was happening, so I’m over here in the corner [thinking], What’s wrong with me? (SP5)

You’ll have a conversation in your head and go to a totally wrong direction. And don’t you know, your mind will take you terrible places. And if you’re not speaking to each other, you’re thinking something in your head, and it’s probably not correct. (SO5)

The majority of participants described their post-mTBI conflicts as being similar to pre-mTBI conflicts in some ways, but increased in magnitude and frequency. This caused deliberate acts of self-isolating by soldiers and a sense of walking on eggshells among the spouses:

Before deployment, my wife and I, we would have you know, typical arguments. We would disagree on things, but never like it was – not like now. Now it’s, I don’t know, I get irate, I get mad, I get mad quick. (SO1)

At times, it was almost like walking on eggshells, you have to be cautious of what you say, what tone you use, because he’s already irritated. (SP1)

3.3.3.2 Losing my career/our future

Some soldiers with mTBI were ultimately forced to separate from the Army due to injury and related symptoms. All soldier participants who were going through the
Medical Evaluation Board (MEB) review indicated that they would have stayed in the Army for 20 years (or until they could retire) if they had a choice. These changes in career plans affected the couple’s future and retirement planning, which was a further source of conflict. All four soldiers who were going through MEB described how being a soldier had been their childhood dream. The injury had changed the course of their future, and for some soldiers, finding an after-Army career that would satisfy their professional needs and provide financial security was a difficult task. One soldier who held a leadership position in the Army prior to injury described her situation:

I used to cry a lot . . . I just have to deal with it. It’s financial for us too . . . [Education is] not something that can be offered because I already [have a master’s degree]. I could be retrained, but with my cognitive [deficits it will be difficult] . . . . I want to be able to identify what kind of work it is, and you know for me it also has to be [fulfilling], I’m not willing to go to work to be a Wal-Mart greeter. (SO4)

3.3.4 Adjusting to New Expectations

For both the soldiers and their spouses, adjusting to post-mTBI expectations and a new normal meant accepting post-injury changes, building new family routines, and incorporating new expectations into their family routine. One soldier described his experience this way:

I’m just taking the triaxodone for sleeping. . . TBI doctors gave me I think it’s celexa and I take that once a day and it’s supposed to help with those symptoms and the neurological orthopedic prescribed me some glasses I have to use when I’m working in the office on the computer or reading stuff, so I got to use those now. (SO8)
3.3.4.1 Accepting changes

Living with new expectations required the injured soldiers to accept changes in their lives. Most of the couples described this phase of their life as a constantly evolving process in which they had to reevaluate the injured soldier’s current functioning and limitations and their effects on the family. An overwhelming majority of participants accepted the changes in their lives as part of being in the military. Many dyads described the Army’s mTBI rehab program was inadequate or too fragmented. Nevertheless, they said they did not feel that it was the Army’s fault that the soldier had been injured; therefore, the Army was not obligated to provide future career plans.

3.3.4.2 Building a new family life

A majority of soldiers described building new family routines and a close relationship with family as an integral part of the new normal. This involved reintegrating the soldier back into the family without disrupting the family’s existing routine. Some soldiers reported a feeling of being ignored by their spouses and children during the reintegration process. Children were perceived as unintentionally excluding the soldier from their lives since during the soldier’s absence the children had established routines that involved only the other parent.

Providing “space” (time away from each other) was an important part of reintegration for some couples. Some spouses described how developing personal networks in the community provided effective support. These support networks included a variety of people, ranging from other military spouses to extended family members.
Often, couples consciously sought support from the individuals who provided the most positive influences. Almost all participants expressed the need for open communication and being patient.

3.3.4.3 Learning to live with new expectations

Often, soldiers were able to compensate for their memory loss with newer technologies such as the smart phone. In addition to these technologies the soldiers enlisted their spouse’s help in managing their daily activities. As one soldier stated:

Certain tasks I still can do . . . but it’s like I’m different with different things, so I compensate with my phone. [Spouse's name] has access and I have access, and I put it to where he gets reminders. As soon as I get appointments, right when they give it to me, I input it. If I don’t [it will be lost], because what they tend to do is to give you a piece of paper with all the appointments to do later. If I do it later I won’t do it. So what I do is I say, "Hold on a second, 'cause if I don’t put it in here I’ll forget." So I’ll set routines on what I’m going to do to help. (SO4)

Couples renegotiated their roles and responsibilities within the family. Some soldiers expressed difficulty in accepting the loss of their family roles but said that their spouse’s tolerance for changes and impairment provided support during this transition. A majority of couples identified "taking things one day at a time" as an important aspect of successful post-injury reintegration strategies they had employed. In addition, couples with longer marriages tended to have more flexible boundaries on household roles and responsibilities. Spouses in these longer marriages were more conscious about not overloading the soldier and letting the soldier take the lead on reintegrating:

Frustration about memory loss is big. There are still times where I’ll tell him things and, yeah, it’s like he never heard me or he doesn’t remember having the
conversation. And you know, I just attribute that to [the fact that] he’s still recovering, and I don’t even mention it to him anymore. (SP6)

There were a few things that he said since being back. One is he likes it when I touch him, because I felt for a while he didn’t want me, didn’t need me, he didn’t want our family. It was so, okay, I’m just here. Well now, he wants me to touch him and even sometimes I have to consciously tell myself to touch him when I pass by. (SP5)

3.3.4.4 Accepting the New Normal

None of the families indicated that they had fully embraced post-mTBI changes, but some families were working toward living a new normal family routine that incorporated the changes. One couple described the slow process of accepting the new normal this way:

And what I think also has helped me a lot is I have expressed my fears. I don’t think he’s quite there yet, but I have learned to speak up like, okay, I don’t know if fear's the right word, but if I tell him I am uncomfortable, I’m feeling uncomfortable when this is happening. And then he’ll explain to me why this is happening. (SP5)

How do I lead at the house without getting in the way? How can I contribute to the team and not pull the team down? Where I used to be able to come home from work and maybe do something around the house, now I come home from work, and I didn’t do much at work, but I’m spent, and I really can’t do much around the house even if I wanted to. It’s just tasking and it’s like you know, one, finding the energy and, two, just the strength to do it. So [it was a process of] finding a new normal and being able to recognize your limitation. (SO5)

All participants described their personal new normal as a constantly changing phenomenon. Some families reported that, while they could see a light at the end of the tunnel and would eventually emerge from the tunnel, they had not yet finished working out a new normal family routine. Other families indicated they did not need to accept the
mTBI-related changes, because they anticipated the soldier's full recovery. Some couples had different perspectives about their new normal. For example, the soldier might believe that the family was near to achieving a new normal, while the spouse believed the family was still far from that point:

We see the light at the end of the tunnel; that's what we are working towards, so we will get there. (SO1)

I realize every day is not going to be the same, but gosh it’s so far away from it, that I’m just angry. (SP1)

3.4 Discussion

Research suggests PTSD symptoms and emotional distress (i.e., anxiety and depression) affected soldiers’ reintegration and marital relationship (Bliese et al., 2008; Carlson et al., 2009; Carroll et al., 2004; Committee, 2010; Daggett et al., 2009; Defense, 2006). Quantitative findings from this study are consistent with existing literature that reported a high prevalence of clinically significant emotional distress and PTSD symptoms among soldiers with combat-related mTBI (Bliese et al., 2008; Daggett et al., 2009; Doyle & Peterson, 2005; Hoge et al., 2006; Johnson et al., 2007). A positive linear association between PTSD symptoms and anxiety symptom scores ($r_s = 0.74, r_s^2 = 0.55$) in the soldiers was noted. In addition, a strong negative linear association between marital satisfaction and anxiety ($r_s = -0.76, r_s^2 = 0.58$) and depression ($r_s = -0.65, r_s^2 = 0.42$) was noted in the spouses. In analyzing the quantitative data, Spearman correlation coefficients were used to capture the observed effect size for this small sample. The investigator
acknowledges that a larger sample would be needed in order to obtain a reliable estimate of effect size in the study population.

High number of participants in this study reported failure to manage post-mTBI symptoms which resulted in emotional distress and had a negative effect on couples’ marital satisfaction. Having to reintegrate following mTBI was an unexpected necessity for the injured soldiers and their families. Mood shifts and personality or behavior changes in post-mTBI soldiers were commonly observed by almost all spouse participants. A primary concern for couples during this period was the successful management of unexpected changes in their familiar routines and the gap between the soldier's functional capabilities and the spouse's understanding of those capabilities. Studies have found that families play an important role in assisting an injured individual’s post-injury adjustment (Ponsford & Schonberger, 2010; Zhang, 2009). The findings from this study suggest that, for these couples, achieving a post-mTBI new normal involved a series of social processes.

First, when the soldier returned home with an mTBI, the couples encountered unexpected changes from their normal family routines and often indicated that these changes were unlike any past experiences. This finding may be unique to these study participants since, unlike civilians with mTBI, these soldiers sustained their mTBI while they were separated from their families, thus presenting them and their spouses with a series of delayed (and unexpected) changes upon their return. Second, couples were required to manage the challenges of day-to-day life and somehow try to fit the injury-
related changes into their daily family routine. This finding was congruent with findings of both Naalt (2001) and Miles (2008), who suggest there is significant post-mTBI impact on the marital relationship as married couples go through a process of adjustment. Third, couples needed to resolve mismatched expectations of the soldiers’ post-mTBI functional capabilities, which created family conflict. Finally, couples who successfully negotiated household roles and responsibilities accepted post-mTBI changes and recognized limitations with the soldiers’ functional capabilities. These couples looked toward rebuilding a new normal for their family.

Almost all couples indicated that post-mTBI symptoms had impacted their marital relationship. This study supports findings from previous studies indicating that after mTBI, both partners have to adapt to new life situations and renegotiate their roles and responsibilities (Blais & Boisvert, 2005; Dawson, et al., 2006; Moore & Stambrook, 1995). In particular, this study shows how changes in a soldier’s mood and short-term memory loss can impact a couple’s communication and relationship. These findings support Blais and Boisvert’s research findings showing that spousal perceptions of the injured individual’s communication skills have significant effects on both psychological and marital satisfaction (Blais & Boisvert, 2005). In the present study, the post-injury alterations in couple communication resulted in the uninjured spouse avoiding communication and the soldier blaming him or her for the problems, which caused further deterioration in the relationship.
The way couples managed unexpected changes in the soldier and post-mTBI family reintegration appears to have been influenced by the spouse’s prior reintegration experiences and the soldier’s length of service in the military. Soldiers with more years of service and who were senior ranking appeared to accept the post-mTBI changes as being one of the risks or costs of serving in the military, whereas soldiers with fewer than 10 years of service viewed the post-injury changes as a loss of their career and of the lifelong dream of being a career soldier. All affected soldiers who were waiting for Medical Evaluation Board decisions had declined the Army’s offer of reclassification and offered essentially the same reason for their decision: “If I can't be an infantry soldier, why would I want to stay in the Army?”

Existing studies report that spouses were generally more distressed by the post-injury changes than were other family members (Gan et al., 2006; Kreutzer et al., 1994; Nabors et al., 2002; Wood & Yurdakul, 1997). In this study, the status of the relations within the family was influenced by many factors (including years of marriage and the length of service in the Army) rather than being influenced by symptom severity alone. In general, soldiers with more time in the Army and longer marriages adjusted to the new normal better than soldiers whose Army careers had just begun and/or who had newer marriages. Couples with more mature marriages (marriages of at least 10 years) adjusted to post-injury changes faster and better than couples with more recent marriages (less than 10 years). All spouses who had been married longer than 10 years indicated that they did not have clear boundaries about family roles or responsibilities; instead, these couples...
worked as a team and shared whatever tasks that needed to be done. These spouses appeared to be experienced homemakers who maintained their homes independently while their soldier spouses were gone. At the same time, they were willing to give up part of their independence upon the soldier's return.

The ability to adjust to a new normal or a new expectation appears to be influenced by a soldier's ability to accept post-injury impairment. This acceptance is in turn moderated by a soldier’s state of mind, rather than the simple passage of time. Interestingly, in this study, some soldiers whose injury had occurred almost 2 years prior to the interviews still worked toward pre-injury functioning and refused to accept that post-mTBI changes would be their new normal, while others whose injury had occurred less than a year prior to the interviews accepted the changes and planned for a different future than what they had envisioned before the injury.

Despite recently increased military support programs for family reintegration (e.g., marriage counseling, marriage retreats), there continues to be a lack of empirically tested data-driven family reintegration programs specifically designed to help with post-mTBI family reintegration. The findings from this study support those in the existing literature, which report that changes in injured individuals following mTBI affect family function and relationships. This study attempted to fill some of the gaps in the literature by examining the reactions of injured soldiers and their spouses to mTBI as well as by examining how the injury affects post-deployment family relationships. The findings suggest that soldiers recovering from mTBI and their families experience difficulties
maintaining the same relationships they had prior to the injury, largely due to changes in the soldiers’ emotional instability. Within the study sample, the most vulnerable population appears to be couples with shorter marriages and whose military careers had just begun.

The study findings suggest that the process of post-mTBI family reintegration—finding a new normal—is an evolving process that includes facing reality and accepting changes. This study provides a basic understanding of the needs of soldiers and their spouses following mTBI. Unlike other studies that focused exclusively on the view of the spouse, this study offers views of both injured individuals and their spouses, thus providing a more comprehensive understanding of how married couples manage the challenges of post-mTBI changes.

Future studies with longitudinal designs that examine mTBI symptoms as they evolve over time may provide a deeper understanding of how injured individuals and their uninjured spouses experience the variable nature of mTBI. These studies may illuminate how couples can achieve a successful recovery over time and can thus provide a basis for creating effective rehabilitation and support programs.

3.5 Conclusion

Mild TBI has not received sufficient attention from the nursing research community. For example, there is little in the published literature on caring for individuals with mTBI, symptom management, or family education programs. Although individuals with mTBI may be less cognitively impaired than those with moderate or
severe TBI, they are not spared from having to deal with household role changes and adjustment. In fact, they may experience even greater stress and family disruption due to mismatched expectations between themselves and other family members concerning their post-injury capabilities. Therefore, individuals with mTBI and their families may benefit greatly from interventions that directly address these mismatched expectations. Such interventions will go a long way toward improving awareness and acceptance of the residual effects of mTBI.
4. Chasing the Care: Soldiers Experience Following Combat-Related Mild Traumatic Brain Injury

I get right there on the thing [post deployment health screening] a doctor will contact you and no one ever contacts me, the only help I’ve received is help I’ve sought, help I’ve gone after (SO5)

4.1 Introduction

Mild traumatic brain injury (mTBI) is a growing concern for both military and civilian populations because of its treatment costs and potential long-term effects (Alexander, 1995; Binder et al., 1997; CDC, 2010; Daggett et al., 2009; Defense, 2006). A majority of existing studies define mTBI as an injury to the head as a result of blunt trauma or acceleration or deceleration forces that result in one or more of the following conditions: confusion, disorientation, impaired consciousness, memory dysfunction (around the time of injury), and/or loss of consciousness lasting less than 30 minutes (CDC, 2010; Daggett et al., 2009; Defense, 2006). Sosin and colleagues (1996) suggest as many as 75% of brain injuries are considered mild (CDC, 2010; Daggett et al., 2009; Defense, 2006; Sosin, Sniezek, & Thurman, 1996). It is widely accepted that the first year after brain injury is a critical time for recovery; therefore, early detection, appropriate treatment and effective rehabilitation for the individuals who are at risk for developing long-term sequelae post-mTBI is important to both patients and healthcare providers (Cassidy et al., 2004).

There has been little research on how individuals with mTBI access healthcare and receive rehabilitation following mTBI. Difficulty accessing a healthcare system after
injury may prevent injured individuals from making an optimal recovery. According to a report by the Center for Studying Health System Change (2008), access difficulties to healthcare have increased since 1996 across all income levels for people in the U.S (Cunningham & Felland, 2008). Some of the barriers reported by people with unmet medical needs included difficulty making appointments due to lack of providers, finding transportation to appointments, and coping with health care costs (Cunningham & Felland, 2008).

One segment of the population that has seen a drastic increase in mTBIs in recent years is military service members. More than 320,000 (20%) of the approximately 1.9 million service members who served in Iraq and Afghanistan meet the diagnostic criteria for mTBI, which is considered the most widespread and undertreated injury of both wars (Bradshaw, 2008; Terrio et al., 2009; Zoroya, 2006). Despite this increase in incidence, there are few published studies that have explored the challenges and the effect of early post-mTBI treatment for soldiers. While soldiers with mTBI may not have problems with lack of health insurance, they may face other barriers such as delays in seeking and receiving care and/or lack of availability of healthcare providers (Defense, 2006).

The report from the WHO Collaborating Centre Task Force on mTBI suggests that early diagnosis and treatment for individuals with mTBI may prevent later development of long-term sequelae of disabilities (Carroll et al., 2004). Due to the lack of objective findings, such as computed tomography (CT) or magnetic resonance imaging (MRI) tests, health care providers often fail to recognize mTBI (CDC, 2010; Cassidy et
Furthermore, many individuals with mTBI do not seek medical care at the time of the injury and may present to an emergency room later with complaints of persistent symptoms (Alexander, 1995; Kushner, 1998). This is a problem because providers may not be able to make the connection to the injury if the soldier waits too long.

Hoge and colleagues reported overall a high level of mental illness after deployment among soldiers with mTBI (Hoge et al., 2004). They found negative beliefs about mental health care increased perceptions of stigma and barriers to care among service members with mTBI (Hoge et al., 2004). However, little published research exists on rehabilitation, interventions, and health outcomes following mTBI. Therefore, the focus of this study was to answer three questions: (a) How do soldiers and their spouses describe post-mTBI recovery and/or rehabilitation? (b) What difficulties, challenges, or problems do they experience during post-mTBI recovery? and (c) What management strategies do they use to cope with the rehabilitation challenges?

4.2 Method

This study consisted of a series of interviews that explored the post-mTBI family reintegration process of soldiers with mTBI and their spouses. During the interviews, soldiers and their spouses indicated that receiving timely, appropriate education and rehabilitation was an integral part of their successful reintegration post-mTBI. Therefore, the interview data that described rehabilitation was examined across soldiers and their
spouse participants using Strauss and Corbin’s grounded theory methodology of constant comparison to analyze post-mTBI rehabilitation experiences (Strauss & Corbin, 1998).

4.2.1 Sampling

Research flyers/posters containing a description of the study were posted and distributed in the TBI clinic of a large Army Medical Center in the Southeastern United States. After viewing a recruitment flyer, interested volunteers left their contact information with their providers or contacted the researcher directly. The researcher also recruited participants directly from the TBI clinic waiting room. Once it was determined that the soldier met the study inclusion criteria and agreed to participate, the researcher contacted his/her spouse over the phone to obtain verbal consent and schedule a face-to-face meeting. The researcher discussed the purpose of the study and obtained informed consent during the initial in-person contact with both the soldier and his/her spouse.

Participants included active duty soldiers with deployment-related mTBI who were between 2 and 24 months post-deployment, and their civilian spouses. Sampling was guided by theoretical sampling methods (Pandit, 1996; Strauss & Corbin, 1998). Theoretical sampling decisions continued to evolve over the study data collection period, as guided by grounded theory methods (Strauss & Corbin, 1990).

4.2.2 Data Collection

The primary method for data collection was the face-to-face, semi-structured interview. All interviews were conducted either at the participant’s home or in a private
room at the TBI Clinic. Child care was provided if requested, and each participant received a $20 gift certificate after completion of an individual interview. Nine soldier-spouse dyads yielded 27 interviews (9 conjoint soldier-spouse interviews, 9 spouse interviews, and 9 soldier interviews). This study received approval from the Institutional Review Board of an Army Medical Center, a large Southeastern university, and a research grant organization.

The researcher used broad, open-ended queries during the conjoint interviews. These included questions such as: “Tell me about challenges or difficulties your family experienced receiving care after injury” or “Tell me about your experience of recovery after injury.” Separate interviews with the soldier and with the spouse were conducted approximately one week after the initial/joint interview. The open-ended questions for both joint and separate individual interviews were influenced by the ongoing analysis, and the direction of subsequent interviews was guided by the emerging theory (Strauss & Corbin, 1998).

Both joint and separate interviews averaged one hour in length and data was collected until saturation was achieved after completion of the 27th interview. This supports Guest and colleagues’ findings that suggested basic elements for meta-themes are present after six interviews and data saturation occurred within the first twelve interviews (Guest, Bunce, & Johnson, 2006). The investigator recorded field notes after each interview in order to capture the context surrounding the interview and the overall
impression of events relating to participants’ situations. These notes and analytic memos were used to illuminate interview data.

4.2.3 Data Analysis

Data collection and analysis occurred simultaneously during this study. After each round of analysis, the researcher went back and gathered more focused data on the rehabilitation process to answer emerging analytic questions (Charmaz, 2006). Digitally recorded interviews were transcribed verbatim and then analyzed using constant comparison across soldiers and marital dyads, Coding involved a process of examining interview data line-by-line, reassembling data based on relationships and patterns within and among the codes, and identifying core categories that were central to the phenomenon of the soldiers’ rehabilitation process (Strauss & Corbin, 1990). During the final phase of selective coding, the core category that best described the process of post-mTBI rehabilitation was defined as the phenomenon and analyzed systematically using the six c’s (causes, contexts, contingencies, consequences, covariances, and conditions), which are central to grounded theory methodology (Strauss & Corbin, 1990). Independent coding with colleagues as well as extensive guidance from two expert mentors promoted quality control (i.e., trustworthiness) and ensured rigor of data collection and analysis (Bloomberg & Volpe, 2008). Credibility of the data was achieved through summarizing and debriefing with participants after each interview.
4.3 Findings

Participants included 9 soldiers and their spouses. There were 5 White, 1 Black, 2 Hispanic, and 1 “other” race for soldiers, and 7 White, 1 Black and 1 Hispanic spouse. Soldiers’ ages ranged from 21 to 44 years old and their rank included 3 Officers, 4 Non-commissioned Officers, and 2 Enlisted soldiers. The number of deployments per soldier ranged from one to six. Soldier participants are identified as SO and spouse participants are identified as SP. Soldier characteristics are depicted in Table 9 to provide context for narratives. For example, SO1 was injured six months into his first deployment and reported a clinically significant PTSD symptom severity (54) and depression (11) as well as borderline abnormal anxiety (10). PCL-M scores 50 or greater, depression and anxiety scores 11 or greater are considered clinically significant.

Table 9: Soldier Characteristics

<table>
<thead>
<tr>
<th>ID</th>
<th>Gender</th>
<th>Age</th>
<th>Race</th>
<th>Deployment</th>
<th>T injury</th>
<th>PCL-M</th>
<th>Dep</th>
<th>Anx</th>
</tr>
</thead>
<tbody>
<tr>
<td>SO1</td>
<td>M</td>
<td>31</td>
<td>H</td>
<td>1</td>
<td>6 mon</td>
<td>54</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>SO2</td>
<td>M</td>
<td>22</td>
<td>B</td>
<td>3+</td>
<td>16 mon</td>
<td>67</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td>SO3</td>
<td>M</td>
<td>39</td>
<td>W</td>
<td>2</td>
<td>6 mon</td>
<td>56</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>SO4</td>
<td>F</td>
<td>44</td>
<td>H</td>
<td>3+</td>
<td>23 mon</td>
<td>62</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>SO5</td>
<td>M</td>
<td>43</td>
<td>O</td>
<td>3+</td>
<td>18 mon</td>
<td>47</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td>SO6</td>
<td>M</td>
<td>30</td>
<td>W</td>
<td>3+</td>
<td>9 mon</td>
<td>56</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>SO7</td>
<td>M</td>
<td>21</td>
<td>W</td>
<td>1</td>
<td>7 mon</td>
<td>56</td>
<td>14</td>
<td>12</td>
</tr>
<tr>
<td>SO8</td>
<td>M</td>
<td>33</td>
<td>W</td>
<td>3+</td>
<td>8 mon</td>
<td>40</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>SO9</td>
<td>M</td>
<td>33</td>
<td>W</td>
<td>3+</td>
<td>4 mon</td>
<td>33</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>

Anx = Anxiety score from Hospital Anxiety and Depression Scale (HADS); B = Black; Dep = Depression score from HADS; Deployment = Number of deployments since 2001; F = Female; H = Hispanic-non White; M = Male; PCL-M = PTSD Checklist military version; O = Other race; T injury = Time since injury; W = White

*HADS sub scores = 11 or greater is clinically significant; MAT scores = less than 100 indicate maladjustment; PCL-M scores = 50 or greater is considered clinically significant
The core variable of this study’s finding was the overarching theme of *chasing the care*, which soldiers described as having to be persistent in order to receive adequate and appropriate care following mTBI. It is described with the following sub-themes: advocating for care for post-mTBI symptoms, getting the care for post-mTBI symptoms, and sharing the responsibility of care with healthcare providers. The relationship among sub-themes is shown in figure 1.

![Diagram](image)

**Figure 1: Chasing the Care**

**4.3 1 Advocating for Care**

A majority of soldiers and their spouses indicated a lack of understanding about mTBI and expressed frustration with the difficulty of receiving post-mTBI care. Participants reported that they had to demand/promote treatment for the soldier’s post-mTBI symptoms from healthcare providers. Often, this created perceived conflict with providers, which in turn affected soldiers’ satisfaction with their recovery. A majority of soldiers perceived a lack of empathy from providers for their post-mTBI symptoms and this resulted in a lack of trust in the military healthcare system.
4.3.1.1 Being aware of the injury

Almost all of the soldiers in this study reported that they were not aware they had sustained an mTBI. This lack of awareness contributed significantly to delays in receiving timely and appropriate care. In the interim (before they were correctly diagnosed and treated), soldiers often self-managed post-mTBI symptoms with over-the-counter medications or they lived with uncontrolled symptoms, such as headaches, memory loss, and balance problems. One soldier reported taking 30 aspirin a day for three days until he started feeling dizzy. Another described his pre-mTBI diagnosis experience in this way:

I wasn’t aware at the time . . . I just didn’t know I had a TBI incident until I actually got back. I just dealt with the symptoms downrange. Moodiness, headaches, sensitivity to the eyes, and I just dealt with those on a daily basis and my co-workers had to deal with it [my lash-outs] on a daily basis. . . . I just figured I’m not getting enough sleep or I’m just bored, tired, sick of the desert, that type of thing. You just get into ruts. I didn’t think it was a headache. I didn’t think it was my eyes, anything that was TBI related that was causing these lash outs. . . . I guess if you don’t lose a limb, or if you’re not bleeding out the ears or the eyes, you don’t think anything’s wrong. (SO3)

A majority of soldiers who were identified with an mTBI through post-deployment health screening indicated that they believed the symptoms experienced after exposure to an IED blast were a normal constellation of events that would gradually disappear. When symptoms continued, they were frustrated. Often, these post-mTBI symptoms impacted the soldier’s ability to perform pre-injury duties, resulting in feelings of betrayal and self-doubt. One soldier described his feelings of self-doubt this way:
They started pulling me off of flying, and that’s my job. My job is to fly, instead they put me on different details . . . They were punishing me. I kind of feel worthless. There’s not much I can do, you know. (SO7)

4.3.1.2 Proving the injury

Soldiers who did not have a visible injury often indicated that they had to convince providers of their post-mTBI symptoms before appropriate treatment and/or referral to a TBI specialist were provided. Furthermore, post-mTBI treatment was delayed for soldiers who had been medically evacuated for other physical injuries. Three soldiers who experienced mTBI along with at least one other visible physical injury described significant delays in mTBI screening and treatment despite their initial complaints of memory loss, cognitive deficit, and other mental health needs. Soldiers who sustained a visible physical injury reported they were immediately evacuated out of the combat zone, and from that point forward, the soldier’s rehabilitation focused exclusively on the physical injury. This appeared to cause a delay in appropriate post-mTBI care. One soldier, whose spouse’s advocacy for her reassessment resulted in her diagnosis of mTBI eight months after the injury, described her experience:

I was also on a [long] list of medications, so I didn’t know [the changes], but once I started getting better and started doing more stuff, like, around the house, becoming you know—I’m an independent person, and I want to do [things for myself] and my family are not enablers—that’s when I realized there is something wrong: I’m not tracking like I did before, I’m not remembering stuff. (SO4)

Soldiers often responded to their post-mTBI symptoms by isolating themselves from other family members and friends after returning home. This resulted in some spouses deciding to actively advocate with their soldiers for them to seek treatment. One
spouse described her experience of pressuring her husband to seek treatment in the emergency room for recurrent severe headaches:

The last straw was when we went to the emergency room and I basically said I’ve had [enough]. I’m taking matters into my own hands and I got in between him and the nurse and the doctor […] they asked “Have you been around a blast?” and he said, “Well—” And I stood in between them, and I said “Look, you really need to define [what you mean by being around a blast],” and that’s when, that is the moment everything changed. (SP5)

4.3.1.3 Perceiving conflict with healthcare providers

Over 50% of participants (six soldiers and three spouses) indicated that they had experienced conflict or disagreement about the soldier’s care plan. An overwhelming majority of spouses (seven out of nine) had not been included or felt that they were not welcome to participate in the soldier’s rehabilitation program. This resulted in the spouses perceiving a lack of empathy from healthcare providers or feeling that they were considered an “inconvenience.” This in turn impacted soldiers’ trust in providers, which resulted in them withholding information or not seeking treatment for their needs. It also led to an atmosphere of distrust in the military healthcare system among participants. One soldier described her feelings this way:

[The conflict was] not between my husband and I, [it was] more with the providers [who] take care of me. One of my biggest concerns were . . . [providers] think I was making it up. (SO4)

4.3.1.4 Perceiving lack of empathy from healthcare providers

Some soldiers indicated a perception that their post-mTBI symptoms were not being treated as a priority because providers could not see any visible injuries. One
explained his perceptions: “Their [providers’] big thing is amputees, internal organs, and TBI is not [important]. It seems more like a category than a diagnosis. Oh well, you have a TBI so you get to go to TBI PT [physical therapy].” He further elaborated his experiences:

Lack of empathy from providers, my biggest issue with mental health . . . I’ve actually had a mental health professional up there tell me to stop being a pussy and suck it up. It was his exact words to me, and after that, I kind of just stopped dealing with them. (SO2)

Another soldier described his experience:

Nobody has given me their time . . . everybody’s trying to get me in and out; nobody’s really taking the time to sit down with me . . . Everybody else is pushing me aside like I’m just another [injured] soldier. (SO7)

For some soldiers, having an objective finding of mTBI injury (for example, the results from a cognitive ability test) reassured them. They were concerned that in the absence of such evidence providers might perceive them as being malingerers, and this impacted the way they sought care after injury. One soldier discussed her concerns that providers would not believe her. Later, when an MRI result showed there was shrapnel lodged in her head/brain, she reported feeling relieved she had a diagnosis:

[I was worried that] people are going to start thinking I’m making it up. But luckily, there was objective data from my neuro-psych testing, which proved that I am not making it up. So once I find that out and they sent that to me, it’s been a lot easier to deal with, because I know that I’m not making it up. It’s something that I will have forever. (SO4)

Another soldier explained his reluctance to confide in providers:

We told [primary care providers that we had] some issues: anger issues and nightmares, and something like that. I’m scared to tell them about what happens. I
don’t want them to think I’m crazy. That’s really why I don’t talk to anybody about it. It’s like I’m scared to talk to somebody about it. (SO7)

4.3.2 Obtaining the Care

The majority of soldiers (7 out of 9) experienced difficulty in obtaining care for their post-mTBI symptoms. Often, the soldier’s lack of understanding about post-mTBI symptoms resulted in delayed care. Furthermore, frequent provider turnover resulted in lack of continuity and fragmented care. This, in combination with the lack of familiarity in navigating the healthcare system, resulted in further delays in getting care and resolving symptom management.

4.3.2.1 Seeking the care

A majority of soldiers reported that they had to actively seek appropriate treatment. They perceived that they had received care only after they and/or their spouses had asked repeatedly for it, or even demanded it. One soldier (SO5) described his experience of post-mTBI care this way: “The only help I’ve received is help I’ve sought, help I’ve gone after.” In many cases, the initial treatment was perceived as inappropriate or ineffective. As one spouse (SP5) put it: “They kept treating symptoms instead of investigating causes.” One soldier described his experience this way:

They [medics] did try, but for the most part you’re patched up and sent back out [into combat]. That’s just generally how it works and it’s acceptable, you know. You’re there [in combat] for a mission, it’s not about you, and I understand that and I accept that. And I keep pushing and you take whatever patches you can. They [combat medical support] will still keep you functional and then when you get back [from deployment] you expect to get care for all the stuff you were patched along the way. But, it kind of goes back to patching when you are back in the states and you still getting patched; that’s a bit frustrating. (SO6)
4.3.2.2 Receiving delayed care

Post-mTBI screening and evaluation by healthcare providers appears to have been significantly affected by the presence or absence of visible signs of injury, such as scars or amputations resulting from an IED exposure. Often, soldiers without visible injury did not seek immediate care because they did not understand or recognize mTBI symptoms. As one soldier put it, “I didn’t know [I had sustained an injury]. Well, nothing you can see” (SO6). This sentiment was echoed by all soldier participants. One had to be evacuated to the nearest Combat Support Hospital when he experienced mTBI symptoms just days after an IED exposure:

I didn’t have any physical injury you could see [at the time of IED exposure], so my medics went through treatments or whatever and I was at my firebase. . . . They medvacd [medically evacuated] me two days later because I was having problems. You know: getting dizzy, falling over, headaches, blurred vision, all that stuff, so they medvacd me . . . until I recovered. (SO8)

I wasn’t seeking any help until I was having some serious, serious balance issues. (SO2)

In some instances, the spouse noticed unusual symptoms well before the soldier returned home:

It was, Are you okay? [He said]: “No, I got this ringing in the ears all the time,” so that’s happening. He got the ringing in the ears, and he had to keep turning on the noisemaker (computer or music playing) [while he was deployed]. (SP5)

4.3.2.3 Receiving fragmented care

The majority of soldiers and their caregiving spouses indicated that they did not have any knowledge about mTBI prior to the injury. This resulted in complete reliance on
providers for the couple’s post-injury education and treatment. Once soldiers were referred for mTBI screening, they were subjected to a battery of cognitive tests and evaluation by multiple specialists before initiation of the post-mTBI treatment. In addition, high provider turnover resulted in soldiers being seen by different providers even within a single clinic. This required soldiers to reiterate for one provider after another the details of their medical histories:

You wish you could get all the doctors together because you go see this one. And the primary care providers will read things, but not gathering [not consolidating], so you really have to take your notes . . . If I didn’t have her [the spouse] or somebody in your life that’s helping with that [coordinating, remembering], you’re done. (SO5)

4.3.2.4 Navigating the healthcare system: Hard to find care

A majority of soldiers indicated that they had to navigate through multiple appointments with various specialists, and with minimal guidance. This resulted in extreme stress for both soldiers and their spouses, who were unfamiliar with the military healthcare system and found it difficult to coordinate all aspects of care, from making appointments to requesting referrals for specialty clinics. Soldiers often described their frustrations in terms like these:

For me, it was kind of upsetting. I thought I was coming here one time to talk to somebody, and I’d be good. And then it’s, I go to the one appointment and it’s like you need to do this, and you got to do this for the next 5 weeks, and you need to come here and do therapy for this for whatever. And I talk to somebody else and they’re like, we need you to set up this therapy to talk to this person. So for me, it’s draining. I’m not used to being at a hospital every day or every couple days doing some therapy or something. (SO8)
I started seeking help for [the mTBI symptoms] and called one of my primary care physicians before she [moved to another facility] to be tested for this and she was like, “No, everybody in the system wants to treat the symptom, not necessarily find out why.” So now, just now [after over a year] I’m just going to see Endocrinology to try to find out why. (SO5)

4.3.3 Sharing the Responsibility of Care

All soldiers and spouses indicated the soldier’s post-mTBI recovery should be a responsibility shared among providers, soldiers, and their families. Participants indicated this shared responsibility includes increasing the soldier’s awareness of the injury, acquiring knowledge about mTBI symptoms and treatment, and providing an appropriate recovery/rehabilitation plan. A majority of soldiers believed the best outcome following mTBI could be achieved by including their spouses in their rehabilitation plan at all levels.

4.3.3.1 Acquiring knowledge about mTBI

A majority of spouses (n = 7) reported not knowing how to help their soldier and felt excluded from the soldier’s rehabilitation plan. All spouses indicated that they had no knowledge of mTBI until their soldiers were diagnosed with it. They felt that they were often left in the dark regarding important details of the soldier’s rehabilitation plan. The majority of spouses resorted to self-education through online sources or secondhand information from their soldiers. Theses spouses reported the latter was not ideal because the soldiers were often not forthcoming about their recovery progress. A majority of soldiers indicated that they were reluctant to share their recovery progress because they did not want to burden their spouses. All participants reported that the pre-deployment
education offered on mTBI did not help them because they did not pay much attention to it at the time. One spouse described the challenges she faced in attempting to help her soldier husband:

He doesn’t share, because he doesn’t want to worry me. The only time [he shares] is when he’s in pain or something’s bothering him. He’ll get quiet and he’ll get distant. Or if his eyes are bothering him, you’ll find him wearing his sunglasses inside the house . . . So I just give him his space and let him have his time until he feels better. He doesn’t just say, “Hey, I’m having a bad day. Leave me alone.” It’s [that] you have to read between the lines sometimes and figure out what’s going on. I just come to accept [that] and he tells what he can. That’s how we do it. (SP3)

4.3.3.2 Working together for recovery

All participants expressed satisfaction with the TBI specialty care. They were relieved to have been assigned a nurse case manager who coordinated all aspects of their rehabilitation; this decreased their stress about navigating the healthcare system and helped them to keep track of their appointments. Almost all (n = 7) soldiers indicated that having a provider who was willing to listen to them and acknowledge their concerns motivated them to recover and adjust to post-injury changes. One spouse offered her view:

Now he’s actually in the [TBI] clinic I can actually say, things are better, much more under control now. (SP5)

4.4 Discussion

As noted above, the overarching theme for soldiers’ rehabilitation process following mTBI was “chasing the care.” A majority of soldiers (n = 7) indicated that they had to advocate for their post-mTBI care. Soldiers often received delayed screening for
mTBI due to fragmented care and high provider turnover. Lack of awareness after injury had a significant impact on soldiers’ likelihood of receiving timely interventions. Almost all participants (both soldiers and spouses) had difficulty recognizing mTBI symptoms as such, and often attributed these symptoms to the general stress of deployment or to the experience of combat, rather than to the injury.

Some soldiers did not seek timely healthcare either for post-mTBI symptom management or rehabilitation. The reason for the delay in seeking care varied from not recognizing changes as being related to mTBI (attributing them instead to after-effects of deployment) to thinking the symptoms were not serious enough to seek care and attempting to self-manage them. A majority of soldiers either sought care for their post-mTBI symptoms only at the urging of their spouses or were motivated to seek care because they simply could not manage the symptoms on their own.

The majority of soldier participants in this study reported receiving care for mood disorders and other mental health needs, which supports previous literature suggesting that a high number of soldiers with mTBI have co-existing psychiatric conditions, such as depression, post-traumatic stress disorder (PTSD), and other mental illnesses, in addition to symptoms resulting directly from the injury (Defense, 2006; Doyle & Peterson, 2005; Hoge et al., 2008). These study findings support those of Erez and colleagues who reported individuals with mTBI experience significant deficits in attention and emotional regulation (Erez et al., 2009). It also echoes Ponsford and colleagues’ research outcomes
showing that ongoing memory and concentration problems frequently follow an mTBI 
(Ponsford et al., 2011).

Perhaps the biggest contribution of this study is in filling gaps within the existing mTBI literature on rehabilitation. For example, existing literature suggests that behavioral healthcare (e.g., counseling) is considered stigmatizing among service members and keeps them from seeking needed treatment (Hoge et al., 2004; Pietrzak, Johnson, Goldstein, Malley, & Southwick, 2009). However, findings from this study suggest that the biggest barriers to the soldier’s care are the perceived lack of empathy from providers and inconsistency of care due to provider turnover. Only one soldier reported concerns about possible adverse effects on his career while receiving post-mTBI and mental health care. Meanwhile, the remaining eight soldiers indicated they were not as concerned about stigma as they were with the negative effect it would have on their marital relationship if they discontinued the rehabilitation process. These study findings suggest the Army’s efforts to reduce the stigma reportedly associated with psychological health issues have been at least somewhat successful.

Existing mTBI literature also suggests that the treatment of mTBI may be influenced by factors unrelated to the injury, such as pre-existing psychosocial difficulties (for example, depression and anxiety) and pre-injury coping behaviors (Carlson et al., 2009). While a majority of soldiers in this study reported no pre-injury psychosocial difficulties, they did report post-mTBI psychosocial difficulties. Findings from earlier studies indicate post-TBI depression is correlated with impairment awareness, rather than
injury severity (Kreutzer et al., 1994b; Yeates et al., 2007), thus placing the mTBI population who have intact awareness at a high risk for psychological distress. In this dissertation study, all soldier participants reported not being aware of impairment after injury which resulted in delayed psychosocial assessment and treatment. The majority of soldier participants (7 soldiers) were receiving psychological services at the time of the interviews. Further research is needed in this area to understand the psychological distress soldiers reported around their identity loss as combat soldiers after injury.

The majority of participants in this study expressed frustration over navigating the military healthcare system; several of them described this as “chasing the care.” This is one area where nurses and social workers may make a difference: as care advocates and coordinators of services. Moreover, these findings support the need for mTBI education programs that include early screening, standardized diagnosis, post-injury symptom recognition, and information about rehabilitation processes in general. A second urgent need is education for providers on how to interact with soldiers with mTBI to assure them they will be cared for. The findings from this study may lay the foundation for intervention programs that can assist thousands of service members who are affected by mTBI.

4.5 Limitations and Implication for Future Study

This study focused on soldiers recruited from a TBI clinic, where only injured individuals with residual symptoms were seen, thus excluding soldiers who recovered from an mTBI without symptoms or who were managing their symptoms successfully
without intervention. Nevertheless, it is clear that some soldiers experience post-mTBI symptoms that last beyond one year and that these symptoms contribute to marital and family relationship problems, anxiety, depression, and adjustment difficulties (Daggett et al., 2009; Hoge et al., 2008; Resnik et al., 2009). Future studies should explore the effects of mTBI on the marital relationship as well as the soldier’s post-injury adjustment.

4.6 Conclusion

While early diagnosis and treatment are important aspects of successful adjustment after mTBI, the absence of objective findings of impaired function at the time of the injury; the reluctance of soldiers to report their symptoms and face the loss of their identity as combat soldiers; the problems these soldiers face when they do report their post-mTBI symptoms; and the difficulty of navigating a maze of specialty providers to secure treatment for those symptoms, make early diagnosis and treatment of mTBI a challenge. Educating military families and providers about these challenges is the necessary first step in overcoming the aftermath of mTBI for the estimated 320,000 soldiers who have returned from war with this injury.
5. Discussion

This chapter summarizes the dissertation study and findings. The contributions as well as the limitations of the dissertation studies are included. Also included are recommendations for future research on post-mTBI family reintegration.

5.1 Summary of Study and Findings

This dissertation study consists of a literature review on post-mTBI adjustment, original data on the family reintegration experience, and original data on the recovery/rehabilitation experiences of soldiers following combat-related mTBI. Existing research on the post-mTBI soldier population is focused mostly on early diagnosis and treatment. The investigator hypothesized that post-deployment soldiers with mTBI may continue to experience emotional and physical adjustment as the recovery process continues; therefore, this dissertation study consists of three papers, each of which explores a different aspect of experiences that surround family reintegration following mTBI.

The first paper, titled “Individual and Family Adjustment After mTBI,” is a review of literature that examines commonly reported post-mTBI signs/symptoms and the impact of these signs/symptoms on the civilian injured individuals and their families. Due to the scarcity of military literature on family reintegration focus, the civilian literature was examined. Nineteen English language articles that were published from 2001 to 2011 and that described mTBI outcomes for individuals and/or their families
were analyzed to examine post-injury adjustment difficulties. Findings from this review suggest that psychological distress symptoms such as depression and anxiety are common in injured individuals and their families after mTBI. Additionally, the review found that post-mTBI changes in injured individuals affect marital and family relationships.

The second paper describes original data-based findings from a series of soldier and spouse interviews that were conducted by the author to explore the post-mTBI family reintegration processes. The core theme of this study was the “new normal.” Participants described finding their new normal as a process of post-mTBI adjustment that could be divided up into sub-processes, which are described by the following four themes: facing up to the soldier’s unexpected homecoming, managing unexpected changes in the family routine, experiencing mismatched expectations, and adjusting to new expectations for the family. The new normal encompassed a couple’s post-mTBI world and included changed expectations toward themselves and others. Adjusting to the new normal required the couple to realign their expectations based on a realistic assessment of the soldier's post-injury capabilities. The majority of soldier–spouse pairs indicated that symptoms such as irritability, memory loss, and cognitive deficits affected their family reintegration. Some participants reported that they had accepted the changes and were working toward a new normal; others indicated that these changes were unacceptable to them and their families, and they were continuing their efforts to resume their pre-injury level of functioning.

The third paper describes findings regarding the soldiers’ and spouses’ experiences around seeking treatment for mTBI-related symptoms. The core theme of
this study’s findings was “chasing the care,” which soldiers described as the need for them to be persistent in order to receive adequate care following mTBI. The theme of chasing the care is further defined by the three sub-themes: advocating for post-mTBI care, obtaining care for post-mTBI symptoms, and sharing the responsibility of care with healthcare providers. The majority of participants, both soldiers and their spouses, further indicated that delayed diagnosis, obstacles to mental health care access, and an unfamiliar military healthcare system were their biggest challenges.

Management strategies during reintegration included building a positive network of informal support and seeking care for post-mTBI symptoms. The reviewed literature suggests that a higher incidence of depression may be associated with mTBI due to the injured person’s intact awareness of their post-injury functional deficits. However, in spite of the depression, the soldier’s increased awareness of deficits can be a good thing, since it may assist healthcare providers in planning the most effective (and collaborative) rehabilitation plan. The reviewed literature also suggests that soldiers and spouses have to adapt to a new life situation and renegotiate their roles and responsibilities after mTBI. Unfortunately, spouses are often not considered in the formal rehabilitation plan, and the spouse’s needs are thus frequently neglected. Subtle cognitive impairment following mTBI, combined with a family’s mismatched expectations of the injured individual’s functioning, has the potential to engender conflict and misunderstanding; therefore, spouses should be included in the injured person’s rehabilitation plan.
5.2 Discussion of Study and Findings

This dissertation study contained several important findings. First, the literature suggests that, while individuals with moderate to severe TBI are usually unaware of their post-injury cognitive impairment, individuals with mild TBI (mTBI) typically are aware of their cognitive deficits and functional limitations (Erez et al., 2009; Malec et al., 2007; Yeates et al., 2007). The findings from the present study show that soldiers often do not recognize post-injury cognitive impairments in relation to mTBI. For example, almost all participants (both soldiers and spouses) had difficulty recognizing mTBI symptoms as such and often attributed the symptoms they did recognize to the general stress of deployment or to the experience of combat, rather than to the injury. This lack of injury awareness often resulted in significant delays in seeking healthcare and receiving timely intervention. Some soldiers were aware of their symptoms but believed that these symptoms were not serious enough to seek care and attempted to self-manage them. A majority of soldiers either sought care for their post-mTBI symptoms because someone else (their spouses) had urged them to or because they realized that their symptoms had become unmanageable.

One conclusion that emerged from this study is the importance of the nurse’s role in the care of soldiers with mTBI and their families. Current practice in the military for post-mTBI soldier care relies almost exclusively on physician providers. However, nurses are at the forefront in identifying mTBI when post-deployment soldiers present to the emergency room or other clinical settings. It is also nurses who, as case managers,
advocate for post-mTBI care, and it is nurses who provide much of that care and who educate soldiers and their family members about mTBI. Often, primary providers focused only on treating the visible physical injury when soldiers are evacuated stateside, and this results in lost opportunities for early assessment and treatment for mTBI. During this crucial period, nurses could be assessing for mTBI during soldiers’ initial admission following medical evacuation, providing post-mTBI education for identified soldiers and their families, and providing referral to social worker and case managers as needed in collaboration with other providers (i.e., physician, physical therapist, occupational therapist).

Nurses could also provide or reinforce education regarding mTBI and its course and recovery to soldiers, family, and unit leaders. Early education can help soldiers and their families manage expectations and can prevent conflict between soldiers and their chain of command over duty assignments. Moreover, a better system of education will keep unit leaders supporting the soldiers’ recovery, thus reducing the injured soldier’s perception of worthlessness and anxiety over being considered as “broken” or not contributing to the mission of the organization.

Some soldiers in this study indicated that post-mTBI symptoms didn’t appear until days or weeks after the injury, which caused them to misinterpret the symptoms in relation to their injury. Therefore, it is vital to get field nurses to proactively screen for mTBI with every soldier who has experienced a potential mTBI event. This also means
soldiers have to be taught to report these events and proactively seek screening. One-on-one mTBI education should be provided for identified soldiers and their spouses.

Second, two areas that soldiers in this study identified as being important aspects of soldier care was the difficulty in making a follow-up appointment and the role of unit leadership in supporting time away from work for proactive screening and treatment. There is a need for a policy revision that reorganizes the existing schedule and establishes a system of soldier-care priorities in a military facility. Soldiers reported that one of the main difficulties in receiving post-mTBI specialty care is that the mission of the unit takes priority over some medical appointments and can even dictate the soldiers’ treatment course. For example, soldiers often had to wait 2 to 3 months for specialty care (e.g., mental health, occupational therapy, etc.) only to discover they had to reschedule their care due to conflict with mandatory training. Then, when training is over and the soldier is available again, there sometimes were no appointments available and the appointment has to be pushed out even further. This system might be acceptable when static or non-life threatening health conditions are involved, but for emergent conditions like mTBI, where time is of the essence in diagnosing and treating, it is not. Creating evening clinic hours or allowing soldiers to see civilian providers if the needed care is not readily available at the military healthcare system can greatly improve post-mTBI soldier care.

Turnover among military providers is another aspect of post-mTBI soldier care that needs a policy change. To insure continuity of care, injured soldiers may need to see
civilian providers. Under the current active duty care system this is usually not allowed. Soldiers in this study expressed that building rapport with military providers was one of their biggest challenges. Providers would change frequently due to moves or redeployments, and injured soldiers were required to repeat the history of their injury for each new provider. This made the soldiers feel like they were being forced to relive their injuries over and over, which naturally caused them stress. As noted earlier, soldiers with mTBI often have other mental health needs; therefore, providing continuity in their care is one way to ensure effective recovery and reduce unnecessary anxiety and delayed care for this population.

Third, the findings from this dissertation study confirm findings from previous research by Erez and colleagues, who reported that individuals with mTBI experience significant deficits in attention and emotional regulation (Erez et al, 2009). The findings also echo Ponsford and colleagues’ research outcomes showing that ongoing memory and concentration problems frequently follow an mTBI (Ponsford et al., 2011). The majority of soldier participants in this study reported receiving care for mood disorders and other mental health issues, which supports previous literature suggesting that a high number of soldiers with mTBI have co-existing psychiatric conditions (Hoge et al., 2004; Hoge et al., 2006; Hoge et al., 2008; Johnson et al., 2007).

All but one soldier reported either borderline or abnormal depression symptoms and/or anxiety symptoms with the HADS test. These findings indicate the need for changes in the current policy on administration timing of the Post Deployment Health
Screening (PDHS). Currently, the PDHS is performed either the same day or the day after the soldier returns from deployment. The current timing schedule for the screening does not take into account the soldier’s desire to return home as soon as possible. Soldiers in this study and at the TBI clinic admitted that they did not provide honest answers on the PDHS because they did not want to risk being referred for further testing or treatment, which would have delayed them in rejoining their loved ones. Therefore, a company-level PDHS screening for all soldiers sometime after their block leave (30 days post-deployment) may provide a better way of identifying soldiers who need post-mTBI healthcare intervention.

Fourth, another area in need of policy change is the Family Readiness Group (FRG). FRG was established to provide support for family members of soldiers who have been deployed. However, spouses in the study reported that this program was ineffective in providing support for them, and the most frequently cited reason for that ineffectiveness was the inexperience of the FRG leader. Most often the FRG leader position was held by the company commander’s spouse (most often a woman), and these spouses tend to be young and inexperienced in the hardships of military life. Therefore, appointing paid professionals such as nurses and social workers to FRG roles would be a great improvement.

Fifth, a special challenge for couples during the post-mTBI family reintegration period was managing unexpected changes in their familiar routines and negotiating mismatched expectations between the soldier's functional capabilities and the spouse's
understanding of those capabilities. When the soldier returned home with an mTBI, couples encountered unexpected changes from their normal family routines and indicated that these changes were unlike any they had experienced after previous homecomings. These unexpected changes in the family routine forced couples to manage the challenges of day-to-day life and somehow try to fit the changes into their daily family routine. This finding was consistent with findings from previous studies, such as those conducted by Naalt (2001) and Resnick (1993), which suggest that mTBI has a significant impact on the marital relationship, as a returning soldier can no longer assume his/her pre-mTBI roles and needs assistance with effects of the injury (Blais & Boisvert, 2005; Naalt, 2001; Resnick, 1993).

Dissertation study findings revealed almost all couples (8 of 9) received marriage counseling and found it to be helpful. This finding is significant since the couples’ marital adjustment scores indicated a lack of satisfaction with their marital relationship. These results indicate the need for marital relationship enhancement intervention during post-mTBI reintegration. A policy that incorporates optional counseling and marital assistance with child care may greatly assist couples as they adapt to post-mTBI expectations.

In summary, in order to achieve successful family reintegration, couples need to resolve mismatched expectations of the soldiers’ post-mTBI functional capabilities. The findings from this dissertation study indicate that couples who accepted post-mTBI changes and recognized that there would be limitations on the soldier’s functional
capabilities successfully renegotiated household roles and responsibilities and looked toward rebuilding a new normal for their family.

5.3 Limitations

The participants for this study were recruited from a single Army post; thus, findings from this sample setting may not be generalizable across service settings. Nevertheless, it is clear that, for the Army as a whole, some soldiers with mTBI experience symptoms that last beyond 1 year and that these symptoms contribute to post-injury marital and family reintegration challenges.

5.4 Study Contributions

This study makes several contributions to the current science on post-mTBI family reintegration. Two of the main themes identified in the present study (mismatched expectations and finding a new normal) have not been addressed in previously published research. Therefore, this study contributes to the existing knowledge of the field. Perhaps the biggest contribution this study makes, however, is to fill in the gaps in the existing mTBI literature on family reintegration, since the literature tends to focus on either the perspectives of injured individuals or the perspectives of their uninjured spouses, but seldom both. This study also contributes to the knowledge on post-mTBI family reintegration by identifying the unique needs of mTBI-affected families, as well as introducing new perspectives that counter long-held assumptions about stigma and soldiers’ mental healthcare-seeking behavior.
As shown in Chapter 2, mTBI is often missed and thus often goes untreated. For individuals with mTBIs and their families, this results in puzzling, often incapacitating symptoms that have an adverse effect on individual and family functioning. Chapter 3 demonstrates how soldiers with mTBI and their families can struggle with the aftermath of an undiagnosed and untreated mTBI. These difficulties are in turn complicated by lack of understanding of mTBI symptoms and by the soldiers’ reluctance to report symptoms for fear that doing so could affect their military career. When mTBI goes undiagnosed and untreated, the spouse must take on the main responsibility for mTBI symptom management. And when this approach becomes unmanageable, as it inevitably does, the spouse must then advocate with military healthcare providers for the soldier to get the needed medical treatment.

Chapter 4 illuminates the difficulties soldiers and their families often confront when “chasing the care” in a medical system characterized by high provider turnover and fragmentation of services. Taken as a whole, the information soldiers and their spouses provided in this study makes a strong case for a new policy of educating the medical community around combat-related mTBI and creating a system of reintegration support programs. This study also identifies several areas in which healthcare providers can assist uninjured spouses in dealing with both the practical (role change) and emotional (relationship perception) aspects of adjustment during family reintegration. This includes providing education on mTBI as well as support groups for family members.
Contrary to some research showing that soldiers view mental healthcare as stigmatizing and will therefore avoid it (Hoge et al., 2004; Pietrzak, Johnson, Goldstein, Malley, & Southwick, 2009), this study found that soldiers did not find mental healthcare stigmatizing if the diagnosis is related to mTBI and will seek care if they feel it is necessary for their physical recovery or to improve their marital relationship. The study findings also suggest that the Army’s efforts to reduce the stigma associated with psychological health issues have been at least somewhat successful. Finally, the study found that injured soldiers’ perceptions of the provider’s attitude toward them was one of the biggest barriers to seeking post-mTBI care. Soldiers expressed a sense of betrayal and feeling let down because the quality and kinds of care available to them upon their return from deployment were not up to the level they had expected. Some soldiers also reported being fearful of being categorized as malingerers or fakers by their peers, superiors, and healthcare providers.

Primary care physicians are certainly not the only source of care available to the families of soldiers affected by mTBI. Nurses and social workers may also contribute as care advocates and coordinators of services. Education programs that include early screening, standardized diagnosis, post-injury symptom recognition, and information about the rehabilitation process in general can also provide support for injured soldiers and their families.

Providers must be educated on how to build rapport with soldiers diagnosed with mTBI, as this will ultimately enhance treatment. The findings from this study support
previous studies showing that a treatment plan oriented toward problem-solving and acknowledgement of the injury were associated with a better quality of post-injury adjustment and marital satisfaction (Blais & Boisvert, 2005; Ponsford & Schonberger, 2010; Rappaport & Herero, 1989).

5.5 Recommendations for Future Study

Many factors may prevent a soldier who sustains an mTBI in combat from seeking immediate care. Often, soldiers who have been exposed to IEDs remain at their stations, far from a major medical center that can provide comprehensive screening and treatment. In other cases, injured soldiers may be engaged in sustained combat, making immediate evacuation impossible. In addition, the variable nature of post-mTBI symptoms and mTBI’s uncertain trajectory sometimes makes it difficult for providers to diagnose and treat affected soldiers in a timely and effective manner; therefore, longitudinal studies of mTBI symptoms as they evolve over time are needed.

Traumatic brain injury research to date has focused almost exclusively on the views and responses of the uninjured spouse (who is often also the primary caregiver). The unexamined assumption of providers and investigators is that the spouse with the brain injury is incapable of providing independent responses that would allow the couple to recover after a TBI. Future research should focus on understanding how injured individuals and their uninjured spouses together experience the variable nature of mTBI and collaborate to achieve a successful recovery over time. As this study shows, family function is impacted as families react to an injured soldier’s symptoms and behavioral
changes. However, healthcare professionals still need a better understanding of the complicated dynamic between the family and injured individual under these conditions.

Existing rehabilitation services focus on moderate and severe TBI. There are few formal programs designed to help individuals and their families manage the variable and unpredictable symptoms of mild TBI. Furthermore, while families are commonly considered to be a major source of support and care for injured individuals, there are few rehabilitation programs that specifically include the family unit -- the marital dyad, partners, children, and any others who may be living with the injured individual -- in their treatment plans. Trials of rehabilitation services designed to help both injured individuals and with their families are therefore needed.

Last, a major gap in the current literature on family adjustment following mTBI is the absence of an empirically tested framework for understanding post-mTBI family experiences and coping processes. In reviewing the literature, the investigator found that the concept of “family” was not defined consistently, and therefore it was difficult to determine family composition from one study to the next. Without a standard definition, it will be difficult to design effective interventions for the “family.” Future studies should therefore focus on generating and testing theories of individual and family adjustment after mild TBI.

Soldiers face a variety of challenges when they report their post-mTBI symptoms, including (a) the absence of objective findings, (b) potential impacts on their military career, and (c) unfamiliarity with the military healthcare system. These challenges make
early diagnosis and treatment difficult. Educating military families and providers about these challenges is the necessary first step in dealing with the aftermath of mTBI for the estimated 320,000 soldiers who have returned from war with this injury. Therefore, studies that explore the many dimensions of post-mTBI family adjustment may identify successful family adaptation strategies following mTBI. In addition, explorations of how psychological distress is related to post-injury family function can provide a basis for creating effective rehabilitation and support programs.

As noted above, injured soldiers and their spouses often have difficulty recognizing symptoms of mTBI. This is at least partly due to the fact that mTBI is not well-known among the public. In this study, all of the participants reported that they did not have a good understanding of what mTBI was and were therefore required to educate themselves on the subject through information available on the Internet. Since they did not fully understand mTBI, many families -- even the ones who had some knowledge of the injury -- experienced significant disruption due to mismatched expectations of the soldier’s post-mTBI capabilities. More research is needed to understand how this mismatch impacts the soldier’s recovery and reintegration. When the results from that research become available, mTBI researchers and clinicians will be able to develop effective post-injury rehabilitation programs for soldiers and their families.

While the war in Iraq has ended and the war in Afghanistan has begun winding down, challenges remain for the soldiers returned and returning from these wars. Thousands of service members with mTBI are still struggling to transition back into their
communities, so especially now there is a need need for data-driven intervention programs that can help them do that. These programs can lay the foundation for wounded soldiers and family support programs in the coming decades.

5.6 Conclusion

This dissertation study explored family reintegration of soldiers with mTBI and their spouses. Readjustment into the family following mTBI can be a highly complex task for post-mTBI soldiers. The literature suggests that a wide range of personality changes and symptoms can disrupt relationships and trigger marital difficulties. The study produced three manuscripts: (a) the literature review, which explored current empirical knowledge regarding family readjustment after mTBI; (b) an original data-based paper, which described the process by which soldiers with mTBI and their spouses achieve family reintegration; and (c) an original data-based paper that explored soldiers’ recovery and/or rehabilitation experiences, including their perceptions of barriers and facilitators. Findings from this study may help address critical health issues in the Army by improving the overall health and welfare of the soldiers and their families.
Appendix A

Participant Demographic Data Sheet (Soldier)

Case Number: ______

Instructions: Please answer each item below.

Gender: ___________ (1=Male, 2=Female)

Race/Ethnicity: ___________ (1=Caucasian, 2=AA, 3=Asian, 4=Hispanic, 5=Other)

Age at last birthday: __________

Education (highest grade completed): __________

Occupation: __________

Rank: __________

Years of marriage to current spouse __________

Number of children living in your home: ________ Ages: ________

Closeness of relationship with your spouse before deployment: ___________ (1=Very close, 2=moderately close, 3=somewhat close, 4=not close)

Length of deployment: __________

Number of times deployed since 2003: ______ (1=one time; 2=twice; 3=>3 or more times)
Appendix B

Participant Demographic Data Sheet (Spouse)

Case Number: _______

Instructions: Please answer each item below.

Gender: ___________ (1=Male, 2=Female)

Race/Ethnicity: ___________ (1=Caucasian, 2=AA, 3=Asian, 4=Hispanic, 5=Other)

Age: _______

Education (highest grade completed): ___________

Occupation: ___________

Closeness of relationship with your spouse before deployment: ___________ (1=Very close, 2=moderately close, 3=somewhat close, 4=not close)
Appendix C

Interview Guide (Joint)

Interview #1 (Joint interview)

Main Questions:

- Tell me about your family’s experience of reuniting after deployment, especially the process that the two of you experienced to re-connect? (i.e., challenges, coping strategies used)

(Areas to cover)

- Describe your family’s activity the first few weeks after reuniting with returning soldier?
- How was your family’s daily routine before deployment?
- Describe your family’s daily routine now? How is that different from pre-deployment?
- How would you describe your family’s experience of reconnecting after deployment? Some families reported reconnecting after deployment was difficult; did your family have a similar experience? If so, what was most difficult?
- How did your family handle the reconnecting?
- How would you describe your family’s behavior toward each other after deployment?
• Is this behavior different from before deployment?

• How has this behavior affected your relationship with your spouse, family, and other relations?

• Can you share a difficult situation experienced by your family before deployment?

• How did your family deal with it then?

• Have there been difficult situations experienced by your family since soldier’s return from deployment?

• How did your family deal with it?

• What have you learned about post-deployment family reintegration from your experience?

• What has been the most helpful?

• What has been the most difficult?

• How did both of you handle that difficulty?

• Do you still have these difficulties that you described?

• Has anything or anyone been helpful for your family during reconnecting after deployment?

• What can you suggest to help in during family reintegration after deployment?
Appendix D

Individual Interview Guide (Spouse)

Interview #2 (individual interview)

Directions: This interview will be conducted within 1 week of enrollment into the study.

Focus: Gain an understanding of family reintegration experience from the spouse’s perspective

Main Questions:

- Tell me about your experience with your spouse’s returning home from deployment, specifically your experience on re-connecting with your spouse after deployment. (i.e., challenges, coping strategies used)

Prompts:

- Can you describe your first week after your spouse’s returning home?
- How would you describe what your relationship was like with your spouse before his/her deployment?
- How would you describe your relationship with your spouse since his/her return?
- Is this relationship different from prior to his/her deployment? If different, in what way?
- After the first couple of weeks of your spouse’s return, how would you describe his/her involvement with your family routine?
- Can you tell me about your daily routine now?
How would you describe your experience of reconnecting with your spouse? Some spouses reported that reconnecting with their returning soldier was difficult; did you have a similar experience? If so, what was most difficult? How did you handle the difficulty?

How would you describe your behavior toward your spouse since his/her return? Is this behavior different from before your spouse’s deployment?

Have there been difficulties experienced by you and your spouse before deployment?

If there was a difficult situation, what was it?

How did you deal with it then?

Have there been difficulties experienced by you and your spouse since his/her return from deployment?

If there were difficulties, what were they?

How did you deal with it?

What do you know about military resources that can assist you with reconnecting with your spouse?

What available military resources have you used? How did you find out about these resources?

How do you feel about using military and/or community resources? (availability, stigma, perceptions, and other issues)
• Has anything or anyone been helpful in dealing with reconnecting with your spouse?

• What concerns do you have either about your job or your family relationship?

• What have you learned about post-deployment reintegration from your experience?

• What are your current feelings of your family and marital situation?

• Anything you would like to add that was not asked about your reintegration experience that you think is important for us to know?
Appendix E

Individual Interview Guide (Soldier)

Interview #2 (individual interview)

Directions: This interview will be conducted within 1 week of enrollment into the study and joint interview (#1).

Focus: To gain an understanding of the family reintegration experience from the soldier’s perspective

Main Questions:

- Tell me about your experience of coming home, specifically family reintegration, meaning the process that you experienced to re-connect with your family? (i.e., challenges, coping strategies used)

(Areas to cover)

- Can you describe your first week after returning home?
- How would you describe what your relationship was like with your spouse before deployment?
- How would you describe your relationship with your spouse since your return? Is this relationship different from prior to deployment? If different, in what way?
- After the first couple of weeks of returning home, how would you describe your involvement with your family routine?
- Can you tell me about your daily routine now?
How would you describe your experience of reconnecting with your family? Some soldiers reported reconnecting with family was difficult; did you have a similar experience? If so, what was most difficult? How did you handle the difficulty?

How would you describe your behavior toward your family since your return? Is this behavior different from pre-deployment?

Have there been difficulties experienced by you and your spouse before deployment?

If there was a difficult situation, what was it?

How did you deal with it then?

Have there been difficulties experienced by you and your spouse since your return from deployment?

If there were difficulties, what were they?

How did you deal with it?

What do you know about military resources that can assist you with reconnecting with your family?

What available military resources have you used? How did you find out about these resources?

How do you feel about using military and/or community resources? (availability, stigma, perceptions, and other issues)
• Has anything or anyone been helpful in dealing with reuniting with your family?
• What concerns do you have either about your job or your family relationship?
• What have you learned about post-deployment reintegration from your experience?
• What are your current feelings of your family and marital situation?
• Anything you would like to add that was not asked about your reintegration experience that you think is important for us to know?
Appendix F

Hospital Anxiety and Depression Scale (HADS)

Please circle one response from each question. Please do not think too long about your answers. The answers should reflect your current feelings.

1. I feel tense or 'wound up' (A):

   Most of the time (3)
   A lot of the time (2)
   From time to time, occasionally (1)
   Not at all (0)

2. I still enjoy the things I used to enjoy (D):

   Definitely as much (0)
   Not quite so much (1)
   Only a little (2)
   Hardly at all (3)

3. I get a sort of frightened feeling as if something awful is about to happen (A):

   Very definitely and quite badly (3)
   Yes, but not too badly (2)
   A little, but it doesn't worry me (1)
   Not at all (0)

4. I can laugh and see the funny side of things (D):

   As much as I always could (0)
   Not quite so much now (1)
   Definitely not so much now (2)
   Not at all (3)

5. Worrying thoughts go through my mind (A):

   A great deal of the time (3)
   A lot of the time (2)
   From time to time, but not too often (1)
   Only occasionally (0)
6. I feel cheerful (D):
   Not at all (3)
   Not often (2)
   Sometimes (1)
   Most of the time (0)

7. I can sit at ease and feel relaxed (A):
   Definitely (0)
   Usually (1)
   Not Often (2)
   Not at all (3)

8. I feel as if I am slowed down (D):
   Nearly all the time (3)
   Very often (2)
   Sometimes (1)
   Not at all (0)

9. I get a sort of frightened feeling like 'butterflies' in the stomach (A):
   Not at all (0)
   Occasionally (1)
   Quite Often (2)
   Very Often (3)

10. I have lost interest in my appearance (D):
    Definitely (3)
    I don't take as much care as I should (2)
    I may not take quite as much care (1)
    I take just as much care as ever (0)

11. I feel restless as I have to be on the move (A):
    Very much indeed (3)
    Quite a lot (2)
    Not very much (1)
    Not at all (0)
12. I look forward with enjoyment to things (D):

   As much as I ever did (0)
   Rather less than I used to (1)
   Definitely less than I used to (2)
   Hardly at all (3)

13. I get sudden feelings of panic (A):

   Very often indeed (3)
   Quite often (2)
   Not very often (1)
   Not at all (0)

14. I can enjoy a good book or radio or TV program (D):

   Often (0)
   Sometimes (1)
   Not often (2)
   Very seldom (3)

Reference: Zigmond & Snaith (1983)
Appendix G

Marital Adjustment Test

On the test below are 15 questions. Read each one and determine the answer that best describes your current relationship with your spouse.

1. Circle the rating on the scale below which best describes the degree of happiness, everything considered, of your present marriage. The middle point, ”happy,” represents the degree of happiness which most people get from marriage, and the scale gradually ranges to those few who are very unhappy in marriage and to those few who experience extreme joy or felicity in marriage.

|___________|___________|___________|___________|___________|____________|

a. ----------- b. ------------ c. ------------ d. ------------ e. ############ f. ------------ g. 

(a. Very Unhappy) (d. Happy) (g. Perfectly Happy)

2. To what extent do you and your mate agree on the following item? (Handling family finances)

   a. Always Agree
   b. Almost Always Agree
   c. Occasionally Disagree
   d. Frequently Disagree
   e. Almost Always Disagree
   f. Always Disagree

3. To what extent do you and your mate agree on the following item? (Matters of recreation)

   a. Always Agree
   b. Almost Always Agree
   c. Occasionally Disagree
   d. Frequently Disagree
   e. Almost Always Disagree
   f. Always Disagree

4. To what extent do you and your mate agree on the following item? (Demonstrations of affection)
a. Always Agree
b. Almost Always Agree
c. Occasionally Disagree
d. Frequently Disagree
e. Almost Always Disagree
f. Always Disagree

5. To what extent do you and your mate agree on the following item? (Friends)

a. Always Agree
b. Almost Always Agree
c. Occasionally Disagree
d. Frequently Disagree
e. Almost Always Disagree
f. Always Disagree

6. To what extent do you and your mate agree on the following item? (Sex relations)

a. Always Agree
b. Almost Always Agree
c. Occasionally Disagree
d. Frequently Disagree
e. Almost Always Disagree
f. Always Disagree

7. To what extent do you and your mate agree on the following item? (Conventionality - right, good, or proper conduct)

a. Always Agree
b. Almost Always Agree
c. Occasionally Disagree
d. Frequently Disagree
e. Almost Always Disagree
f. Always Disagree

8. To what extent do you and your mate agree on the following item? (Philosophy of life)

a. Always Agree
b. Almost Always Agree
c. Occasionally Disagree
d. Frequently Disagree
e. Almost Always Disagree
f. Always Disagree

9. To what extent do you and your mate agree on the following item? (Ways of dealing with in-laws)

   a. Always Agree
   b. Almost Always Agree
   c. Occasionally Disagree
d. Frequently Disagree
e. Almost Always Disagree
f. Always Disagree

10. When disagreements arise, they usually result in:

   a. Husband Giving in
   b. Wife Giving in
c. Agreement by Mutual Give and Take

11. Do you and your mate engage in outside interests together?

   a. All of Them
   b. Some of Them
c. Very Few of Them
d. None of Them

12. In leisure time, do you generally prefer to be on the go or to stay at home? Does your mate generally prefer to be on the go or to stay at home?

   a. We prefer Opposite Activities
   b. We Both prefer to be On the Go
c. We Both prefer to Stay at Home

13. Do you ever wish you had not married?

   a. Frequently
   b. Occasionally
c. Rarely
d. Never
14. If you had your life to live over, do you think you would:
   a. Marry the Same Person
   b. Marry a Different Person
   c. Not Marry at all

15. Do you confide in your mate?
   a. Almost Never
   b. Rarely
   c. In Most Things
   d. In Everything

By: Harvey J. Locke & Karl M. Wallace
## Appendix H

**PCL-M**

INSTRUCTIONS: Below is a list of response to stressful military experiences. Please read each one carefully, then circle one of the numbers to the right to indicate how much you have been bothered by that problem in the past month.

<table>
<thead>
<tr>
<th>Not at all (1)</th>
<th>A little bit (2)</th>
<th>Moderately (3)</th>
<th>Quite a bit (4)</th>
<th>Extremely (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Repeated, disturbing <em>memories, thoughts, or images</em> of a stressful military experience?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Repeated, disturbing <em>dreams</em> of a stressful military experience?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Suddenly <em>acting or feeling</em> as if a stressful military experience <em>were happening again</em> (as if you were reliving it)?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Feeling <em>very upset</em> when <em>something reminded you</em> of a stressful military experience?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Having <em>physical reactions</em> (e.g., heart pounding, trouble breathing, sweating) when <em>something reminded you</em> of a stressful military experience?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Avoiding <em>thinking about</em> or <em>talking about</em> a stressful military experience or avoiding <em>having feelings</em> related to it?</td>
<td>1 2 3 4 5</td>
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<td>7. Avoiding <em>activities</em> or <em>situations</em> because <em>they reminded you</em> of a stressful military experience?</td>
<td>1 2 3 4 5</td>
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<td>8. Trouble <em>remembering important parts</em> of a stressful military experience?</td>
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<td>Question</td>
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<td>9</td>
<td>Loss of interest in activities that you used to enjoy?</td>
<td>1 2 3 4 5</td>
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<tr>
<td>10</td>
<td>Feeling distant or cut off from other people?</td>
<td>1 2 3 4 5</td>
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<td>11</td>
<td>Feeling emotionally numb or being unable to have loving feelings for those close to you?</td>
<td>1 2 3 4 5</td>
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<td>12</td>
<td>Feeling as if your future will somehow be cut short?</td>
<td>1 2 3 4 5</td>
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<td>13</td>
<td>Trouble falling or staying asleep?</td>
<td>1 2 3 4 5</td>
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<td>14</td>
<td>Feeling irritable or having angry outbursts?</td>
<td>1 2 3 4 5</td>
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<td>15</td>
<td>Having difficulty concentrating?</td>
<td>1 2 3 4 5</td>
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<tr>
<td>16</td>
<td>Being &quot;super-alert&quot; or watchful or on guard?</td>
<td>1 2 3 4 5</td>
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<tr>
<td>17</td>
<td>Feeling jumpy or easily startled?</td>
<td>1 2 3 4 5</td>
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Appendix I

Glossary of Military Terms

**Army** - the ground fighting component of the US military.

**Battalion Aid Station (BAS)** - echelon II level of health care services provided to soldiers, usually includes one provider and several medics. These elements are located in close proximity to where soldiers work and live when in garrison or deployed.

**Combat Zone** - location where service members are deployed in support of combat operations.

**Department of Defense (DOD)** - the organization within the United States government, responsible for planning, funding, and training of defense-related personnel that fall under the joint services: Army, Air Force, Navy, and Marine Corps.

**Deployment** - term given to military organizations that are operating away from their home garrison, either for training or in combat zones (e.g. Joint Readiness Training Center, Ft Polk, LA or Operation Iraqi Freedom (OIF), Camp Anaconda, Iraq).

**Garrison** - location where most service members live and work, which may be located in the United States or overseas (e.g. forts, post, camp, or base).

**Medic** - a term used for any Army soldier with training equivalent to basic emergency medical technicians, usually first line (echelon I) of healthcare for soldiers in combat zone.
Military - an organization made up of personnel who are trained to conduct operations to defend a nation or state.

Military Occupational Specialty (MOS) - designated code for the name of the occupational (job) skill members of the Army (e.g. 66P- Family Nurse Practitioner, 11B-infantry soldier, 88M- truck driver).

Military Treatment Facility (MTF) - any facility in the DOD which provides health care to service members, their families, and retirees. Examples include fixed facilities located in the United States (Walter Reed Medical Center), clinics, and tents located in combat zones (28th Combat Support Hospital).

Primary Care Manager (PCM) - includes (military and civilian) personnel that are licensed to provide primary health care services (e.g. nurse, nurse practitioners, PA’s, physicians, midwives, podiatrist, optometrist, and physical therapist.)

Rear Detachment - provide administrative support for the deployed unit (i.e., pick up the daily workload of the deployed unit) and home-station support (i.e., liaison for family members of the deployed service members).

Service Member - term used in the United States military to describe a man or women who serves in uniform within the joint services.

Soldier - term used to describe a man or woman who serves in the Army.
References


Biography

Kyong Suk Hyatt was born in Busan, South Korea in 1961. She graduated from the Medical College of Georgia in Augusta, GA in 2005 with a Master’s in Nursing and a BSN from the University of Alabama in Huntsville in 2001. She worked as a Medical-Surgical unit Clinical Nurse Specialist and Headnurse/Nurse Manager in Pediatric and OB/GYN clinics. She was selected as one of the podium presenters at the 15th Biennial Phyllis J. Verhonick Nursing Research Symposium in 2008 for two research abstracts that she authored and co-authored, “Patient Discharge Education: Medical Surgical Clinical Nurse Specialist Role;” “Hourly Nursing Rounds: Decreasing Fall Incidents, Frequency of Nurse Call and Increase Patient Satisfaction?” She has received numerous awards, including TriService Nursing Research Program Graduate Award, Army Meritorious Service Medal, Army Commendation Medal, Army Achievement Medal, Korean Defense Service Medal, and the UAH Clinical Excellence Award. She is a member of Phi Theta Kappa, Sigma Theta Tau, International Honor Society of Nursing, Beta Phi Chapter, and Military Officers Association of America. As an active duty member of the Army Nurse Corps, Kyong’s research interests are to explore and expand on the impact of mild traumatic brain injury (mTBI) post deployment screening process to improve outcomes in the provision of patient care for Soldier and civilian populations with concussion injury that impair neurological functions. She is currently assigned to the Walter Reed National Military Medical Center Research Department.