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Sleep Following Traumatic Brain Injury: A Qualitative Descriptive Study

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SLEEP EXPERIENCES FOLLOWING TRAUMATIC BRAIN INJURY: A QUALITATIVE DESCRIPTIVE STUDY

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ABSTRACT

Introduction: Recent estimates suggest that as many as half of all survivors of Traumatic Brain Injury (TBI) may be experience sleep disturbances or disorders. Although quantitative research has resulted in a greater understanding of the prevalence, symptomology, and conditions associated with sleep, little is known regarding the sleep experiences of survivors of moderate-severe TBI, after their discharge from inpatient rehabilitation. The purpose of this qualitative descriptive study was to describe the sleep experiences of adults with moderate-severe TBI after rehabilitation.

Methods: Qualitative descriptive inquiry was used to explore and describe sleep experiences of survivors of moderate-severe traumatic brain injury TBI between one and 4 years post injury. Sixteen survivors (N = 16) were recruited from a previous TBI study at UAB. Demographic and injury data was obtained through Traumatic Brain Injury Module Systems (TBIMS) data. Interview data was analyzed using thematic analysis.

Results: The thematic analysis yielded five themes that cumulatively contribute to a description of sleep experiences following moderate-severe traumatic brain injury: 1) problems with sleep; 2) perceived impact of sleep and fatigue on relationships and work; 3) learning to manage; 4) coping; and 5) resources.

Conclusions: This study provides the first description of sleep experiences of survivors of moderate-severe TBI in a primarily non-veteran sample in the United States. Implications for research and practice are provided. The study confirms and extends

some elements of previous research of sleep in survivors of TBI but also adds new knowledge by highlighting previously unidentified sleep management strategies, coping strategies for impaired sleep, and preferences for sleep-related resources. Implications for practice include the need for a supportive transition from rehabilitation to community dwelling and continued education and screening throughout recovery following TBI. It is likely that a multitude of factors influence the sleep experiences and subsequent outcomes of survivors of moderate-severe TBI; future research should continue to explore the multifaceted nature of sleep in addition to the interplay between sleep and other comorbidities following TBI such as depression, Posttraumatic Stress Disorder (PTSD), or memory impairment.

Keywords: traumatic brain injury; sleep; experiences; qualitative; description

DEDICATION

This dissertation is dedicated to those who have suffered from TBI and the loving caregivers that provide for them. I am thankful for the opportunity to share their stories and experiences.

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Finally, and most importantly, I praise God for his provision and sustenance. He sparked my passion for research, led me to this program, and brought me any success that I have had. May all honor go to Him, and may my research findings improve the lives of TBI survivors and therefore bring Him glory.

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LIST OF ABBREVIATIONS

ADL	Activity of daily living
CDC	Centers for Disease Control
CSF	Cerebrospinal fluid
DMC	Decision making capacity
ED	Emergency department
EDS	excessive daytime sleepiness
EEG	electroencephalogram
GCS	Glasgow Coma Scale
IADL	Instrumental activity of daily living
IBIA	International Brain Injury Association
ICU	intensive care unit
IOM	Institute of Medicine
MAOI	monoamine oxidase inhibitors
MVC	motor vehicle crash
NREM	non-rapid eye movement
OEF	Operation Enduring Freedom
OIF	Operation Iraqi Freedom
OSA	Obstructive sleep apnea
PCS	Postconcussive syndrome
PhQ-2	Patient Health Questionnaire-2

PSG	polysomnography
PSQI	Pittsburgh Sleep Quality Index
PTA	Post traumatic amnesia
PTSD	Post traumatic stress disorder
REM	rapid eye movement
SCI	Spinal Cord Injury
SRC	Spain Rehabilitation Center
SSRI	selective serotonin uptake inhibitors
TBI	Traumatic brain injury
TBIMS	Traumatic Brain Injury Model Systems
TST	total sleep time
UAB	University of Alabama at Birmingham

CHAPTER 1

PROBLEM AND SIGNIFICANCE

Brain injury is estimated to be the leading cause of death and disability worldwide by 2020, and may impact persons of any age, race, or gender (Hyder et al., 2007). Disabilities following traumatic brain injury (TBI) may include cognitive, functional, and psychosocial deficits that negatively impact ability to return to work, interact in social environments, or maintain independence. An estimated 50% of individuals with TBI are impacted by sleep disturbances and 25-29% are diagnosed with sleep disorders (Mathias & Alvaro, 2012). Survivors already face a variety of underlying cognitive deficits which may be exacerbated by sleep disturbances or disorders. Additionally, bidirectional relationships exist between sleep problems and psychiatric diagnoses of depression or anxiety (Chaput et al., 2009; Fogelberg et al., 2012; Ponsford et al., 2013).

Although quantitative research has resulted in a greater understanding of the prevalence, symptomology, and conditions associated with sleep, little is known regarding the sleep experiences of community-dwelling survivors of moderate-severe TBI, after their rehabilitation experiences. Further investigation to describe the experiences of sleep following TBI could aid in the development of appropriate treatments or modification of existing treatments tailored to the needs of survivors of TBI. The purpose of this qualitative descriptive study was to describe the sleep experiences of adults with moderate-severe TBI after rehabilitation. This chapter will introduce the problem, background, significance, research questions, supporting

theoretical framework, and chosen research methodology. Relevant terminology will also be introduced.

Background

Traumatic Brain Injury

A TBI is an injury to brain tissue caused by a blast, penetrating wound, or blunt impact. It is estimated that over 3 million TBIs occur annually in the United States (Centers for Disease Control and Prevention [CDC], 2015). Nationally, across all levels of TBI severity, the most common causes from 2006-2010 included: falls (40.5%), blunt impact against or by an object (15.5%), motor vehicle crash (14.3%), assault (10.7%), and unknown cause (19%) (CDC, 2015). However, these calculations are suspected to be under-estimates due to barriers in seeking and receiving medical attention and lack of congruence between records at federal facilities (such as veterans or military hospitals) and civilian reporting agencies (CDC, 2015). In the Traumatic Brain Injury Model Systems (TBIMS) national database, an entity that collects longitudinal data specific to moderate-severe TBI in the United States, motor vehicle crash (52%) is the most common cause of moderate-severe TBI followed by falls (25%), violence (12%) and other causes (11%) (National Data and Statistical Center, 2016). Mortality rates are highest for individuals with severe TBI.

While the number of TBI-related emergency department (ED) visits and hospitalizations have increased each year, the number of TBI related-deaths have decreased from 1996-2009 (Coronado et al., 2012). Therefore, people with TBI are surviving longer and with comorbid cognitive and sleep conditions that are potentially

disruptive to their quality of life. Researchers suggest that decreases in TBI mortality may be due to improvements in emergency and neurological services over the past two decades (Coronado et al., 2012). Advances in screening and imaging techniques have enabled clinicians to better deal with diagnostic challenges associated with TBI; multi-modal imaging options have steadily increased since the mid-1990's (Irimia & Van Horn, 2015; Van Boven et al., 2009).

Increases in ED visits and hospitalizations may be attributed to increased public awareness generated by organizational campaigns and heightened media coverage of military and civilian TBI incidence. Blast-injury resulting in TBI has been identified as the hallmark injury of soldiers returning from Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF) (Bulson, 2012; CDC, 2015). Negative cognitive and functional outcomes in professional athletes as the result of repetitive TBIs have led to costly litigation against the National Football League (Belson, 2016), National Hockey League (Heitner, 2016), and multiple professional wrestling organizations (Firger, 2014). The public spotlight on TBI recognition, management, and prevention has trickled into collegiate (National Collegiate Athletic Association, 2014), high school, (CDC, 2015), and youth athletic organizations as well (Breslow, 2013).

National trends suggest that the number of survivors with TBI-related disabilities will continue to grow (Coronado et al., 2012). Over the past 2 decades, researchers have transitioned from perceptions of TBI as a singular event to consideration of TBI as a disease process with chronic health impacts (Masel & DeWitt, 2010). Of the many chronic symptoms experienced by survivors of TBI, problems with sleep appear to be

particularly important (Castriotta & Murthy, 2011; Verma et al., 2007; Wiseman-Hakes et al., 2013).

Traumatic Brain Injury and Sleep Disturbances and Disorders

As many as half of individuals who survive TBI are estimated to experience sleep disturbances or disorders (Mathias & Alvaro, 2012). This problem is considered to be an underestimate, due to a lack of consistent screening for sleep disturbances and disorders following TBI and the fact that some patients suffer from cognitive impairment which impacts self-awareness of symptoms (Mollayeva et al., 2013). Insomnia, hypersomnia, parasomnias, periodic limb movement disorders, and sleep apnea are among the sleep disturbances and disorders that may result from TBI (Viola-Saltzman & Musleh, 2016). Subsequent fatigue and excessive daytime sleepiness are commonly reported in survivors of TBI with sleep complaints. Repeated TBIs may increase the severity of sleep disturbances (Bryan, 2013).

Pilot data suggest that decreased cerebrospinal fluid levels of hypocretin, a neurotransmitter which helps stabilize the sleep-wake switch, may be related to the pathophysiology of TBI and development of sleep-wake disturbances (Baumann et al., 2007). Circadian rhythm changes may also play a role in sleep changes following TBI. In the general population, the timing of sleep is partly controlled by a circadian clock influenced by light exposure, melatonin levels, and external environmental cues (Steele, Rajaratnam, Redman, & Ponsford, 2005). Following TBI, circadian changes such as reversals in circadian rhythms and clock resets have been reported (Ayalon et al., 2007). Circadian rhythm changes are accompanied by altered patterns of melatonin secretion

and body temperature regulation (Culebras, 2011). Changes in melatonin levels have also been associated with sleep disturbance following TBI. Melatonin is a chemical produced by the pineal gland and sometimes in extrapineal tissues such as the kidneys, bone marrow, or pancreas; melatonin peaks during the night and is influenced by circadian and seasonal cycles (Naseem & Parvez, 2014). The most commonly reported circadian change following TBI is delayed sleep phase syndrome, a mismatch between the circadian clock and environment often misdiagnosed as general insomnia and characterized by later bed times and later rising times (Orff, Ayalon, & Drummond, 2009; Steele et al., 2005).

Significance

Multiple secondary conditions may result from TBI, leading to long-term functional deficits, disability, and decreased quality of life. Approximately 100,000 individuals in Alabama are living with a TBI related disability (Alabama Head Injury Foundation, n.d.). High rates of sleep disturbances and disorders following TBI are concerning because they may lead to chronic disability and a multitude of secondary conditions. In addition to worsening cognitive deficits (Bloomfield, Espie, & Evans, 2010; Wilde et al., 2007; Wiseman-Hakes et al., 2013), sleep disturbances post TBI have been associated with poorer functional outcome scores (Chan & Feinstien, 2015; Ettenhofer et al., 2012). Increased risk for psychiatric comorbidities has also been noted (Holster et al., 2016; Ponsford et al., 2013; Rao et al., 2014). Sleep disturbances and disorders may exacerbate secondary conditions associated with TBI and further both direct and indirect costs associated with TBI care (Mollayeva et al., 2013).

Survivors of TBI frequently present with deficits in executive function, attention, memory, and speed of processing (Cicerone et al., 2000; Wortzel & Arciniegas, 2012). Cognitive impairments following TBI may be worsened by sleep problems following TBI, negatively impacting activities of daily living for weeks to years after injury. Sleep problems are associated with difficulty maintaining attention and verbal and visual delayed recall following TBI (Bloomfield, Espie, & Evans, 2010; Wilde et al., 2007). These attention difficulties, in addition to slower speed of processing, impact reintegration to community settings following rehabilitation, including return to work and driving.

Pain, depression, and anxiety are commonly reported following TBI, but the literature suggests a complex relationship between these comorbidities and sleep problems (Chaput et al., 2009; Fogelberg et al., 2012; Ponsford et al., 2013). In a retrospective chart review (N = 443), TBI patients complaining of sleep alterations were more likely to experience depressive symptoms, irritability, and post-traumatic headache compared to patients without subjective sleep complaints (Chaput et al., 2009). Not only are pain, depression, and anxiety diagnoses more likely in the presence of sleep disturbances or disorders, but Fogelberg (2012) found that the severity of sleep problems following TBI significantly worsened with co-occurrence of one or more of the psychiatric comorbidities. Posttraumatic Stress Disorder (PTSD), another psychological comorbidity of TBI, is associated with disrupted sleep and reduced sleep quality; PTSD disrupts sleep more frequently in military populations (Gilbert, Kark, Gehrman, & Bogdanova, 2015; Powell et al., 2015), although it may also occur to any civilian who has experienced a traumatic situation (e.g., motor vehicle crash, violent crime).

Survivors of TBI with sleep problems may be more at risk for weight gain and subsequently at increased risk for cardiovascular disease and hypertension as well. In the general population, decreases in sleep duration are associated with diagnoses of obesity (Gangwisch et al., 2005). As a late onset complication, weight gain is much more common than weight loss following TBI (Verma, Anand, & Verma, 2007). Weight gain may impede mobility and functional independence, disrupting the rehabilitation process (Murphy & Carmine, 2012). A cyclical relationship between sleep disturbances and weight may exist following TBI; not only may sleep problems and metabolic changes following TBI contribute to weight gain, but higher body mass index (BMI) is associated with obstructive sleep apnea (OSA), a sleep disorder characterized by disrupted breathing, sleep fragmentation, and excessive daytime sleepiness (Wilde et al., 2007).

Cumulatively, secondary conditions occurring after TBI may decrease work productivity and raise concerns regarding safe performance upon returning to work (Little et al., 2015; Toyokura et al., 2012). Sleep deprivation in the general population has been linked to work-related injury and death (Uehli et al., 2014); sleep disturbances or disorders resulting exert a dangerous impact on survivors of TBI returning to work. Employment has multiple benefits, such as social engagement, routine establishment, and purposeful or meaningful activity. Employment may also provide cognitive stimulation, which may in turn augment cognitive functioning (Vance et al., 2015). The benefits of employment to cognition may be described as components of positive neuroplasticity, contributing to increased neurocognitive reserve. Failure to return to work, reciprocally, may generate psychological strain because of a lack of motivating activity or lack of purpose associated with unemployment (Little, Cook, Morissette, & Klocek, 2015). For

TBI patients experiencing cognitive impairment, therefore, unemployment may be particularly detrimental to their cognitive recovery. Productivity loss associated with TBI is 14 times greater than injury-related productivity loss associated with spinal cord injuries (Langlois et al., 2006). While some survivors may not be physically or cognitively capable of returning to work, some may be physically capable but unaware of their cognitive vulnerabilities; insomnia may play a role in the TBI survivor's perception of ability work following injury (Mollayeva, 2015).

The impact of sleep on cognition, increases in psychiatric disturbances, and difficulties regaining independence and productivity, may lead to a perceived decreased quality of life. Survivors of TBI with sleep disturbances also stay significantly longer in rehabilitation and trauma centers (Makley et al., 2009), potentially increasing costs for both patients and healthcare systems. Although financial estimates for sleep problems in the TBI population have not been calculated, the fiscal burden of TBI itself is substantial (Mollayeva et al., 2013); approximately 60 billion dollars was spent in the United States on both direct and indirect healthcare costs associated with TBI in 2000 (Finkelstein, Corso, & Miller, 2006).

The significance of the problem underscores the need to appropriately screen for and treat sleep disturbances and disorders following TBI to prevent negative outcomes. Early detection of sleep problems may be economically beneficial by reducing risk for secondary injuries, increasing the possibility that a survivor could return to productive employment, improving the overall recovery of survivors of TBI (Chan & Feinstein, 2015; Mollayeva et al., 2013). The proposed study could lead to a greater understanding of the individual experiences of sleep following TBI, and subsequently aid in the

modification of screening tools or treatment modalities. The potential contributions of this study to the development of screening tools is significant because many of the sleep disturbances and associated comorbidities are not visible to caregivers or health care professionals. The nature of sleep disturbances may contribute to difficulty screening and treating for them. Without knowledge of what these individuals are experiencing, both family caregivers and medical professionals may be unable to provide for physical or psychological needs—because they do not know what those needs are.

The ramifications of sleep disturbances after TBI may include a variety of deficits that impact rehabilitation, community reintegration, activities of daily living, employment, and cumulatively, quality of life. The lack of knowledge of the individual experiences of sleep after TBI is significant for not only for public knowledge, but also for individual patients, their loved ones and caregivers, and the medical professionals caring for them. By seeking to provide a comprehensive and holistic description of sleep experiences in survivors of TBI, this study aimed to fill a gap in scientific knowledge and provide future research questions. This study may aid healthcare providers and caregivers with the lens of their patients' perspectives, and potentially promote empathy for the survivors of TBI experiencing sleep disturbances. Given the prevalence of sleep problems in this population and potential effects on personal, functional, and financial outcomes, this problem requires attention.

Conceptual Framework

A modified version of a neuropsychological model for disability following TBI developed by Kay et al., (1992) was used as a conceptual framework for the development of this study (Figure 1). Kay's model is appropriate because it depicts the interplay of neurological, physical, psychosocial, and cognitive factors associated with functional outcomes following TBI. Sleep, considered a physical factor in the model, is interrelated with the neurological factors (e.g., level of injury severity), psychological factors (e.g., pain, depression, anxiety, or PTSD), and cognitive factors that impact function following TBI. Each element of the conceptual model may impact the descriptions of sleep provided by survivors of TBI. In addition, a better understanding of the patient experience of sleep could further knowledge regarding sleep's impact on neurological, psychological, cognitive, and functional outcomes.

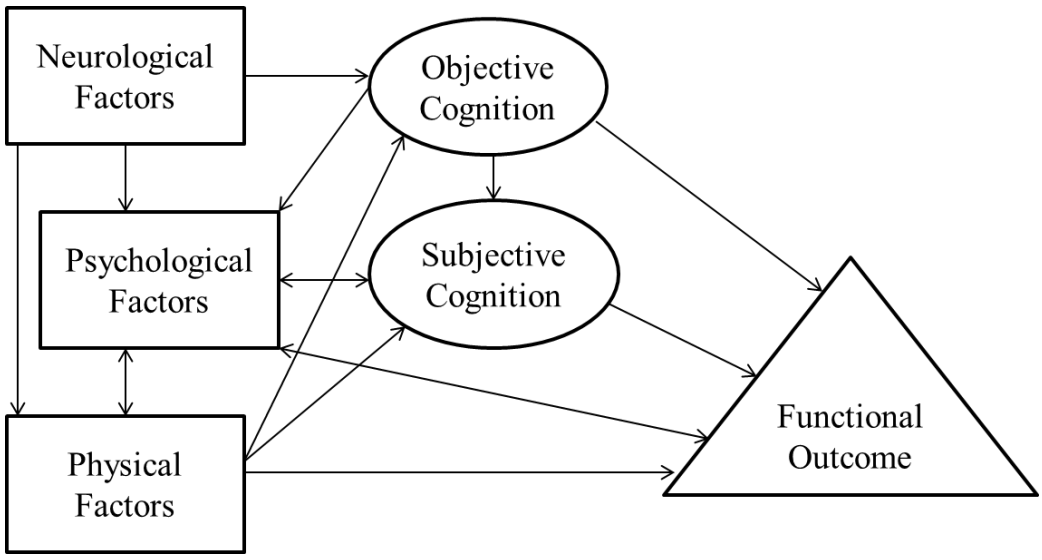

Figure 1. Kay et al. (1992) Neuropsychological Model of Functional Disability.

Research Questions

The study aimed to describe the experiences of moderate-severe, adult survivors of TBI using the following research questions:

1. How do survivors of a moderate-severe TBI describe their sleep before and after injury?
2. What factors do survivors of moderate-severe TBI describe as positively or negatively impacting their sleep experiences?
3. How do survivors of a moderate-severe TBI describe their social engagement in relation to their sleep experiences?
4. How do survivors of a moderate-severe TBI describe their occupational engagement in relation to their sleep experience?
5. What sleep-related education is provided to survivors of moderate-severe TBI?

Design and Methods

The qualitative approach is preferable to the quantitative approach in this study because the focus is on description of a phenomenon, sleep quality, from the perspective of survivors of TBI based on their personal experiences (Sandelowski, 2000). A quantitative approach is more appropriate in a study investigating relationships between sleep quality and other phenomenon or statistical descriptions of the phenomenon. Qualitative research is valuable for providing rich descriptions of phenomena such as sleep quality (Sofaer, 1999). Sleep is highly subjective in nature, and objective measures, such as polysomnography, that are frequently used in quantitative research may not

adequately reflect the experience of sleep by an individual (Buysse et al., 1989). The individual's perception of their own sleep quality, therefore, is integral for researchers seeking to develop a description of sleep quality that reflects its subjective nature. Therefore, the study was best investigated with a qualitative approach. Specifically, by using a qualitative descriptive approach to this study, a comprehensive summary of the experiences of sleep post TBI was generated (Sandelowski, 2000). Individual interviews were used to collect data from participants.

Philosophical Assumptions

A belief in multiple realities, a view of the constructivism-interpretivism paradigm, underlies the research approach to the study. Interpretivists interpret the world in the context of subjectively lived phenomena and seek to understand the experience of a phenomenon through the individual experiencing it (Nicholls, 2009; Ponterotto, 2005). Naturalistic methods are an appropriate fit for the constructivism-interpretivism paradigm, and qualitative description has been described as a naturalistic approach (Sandelowski, 2000). Naturalistic inquiry is appropriate for this qualitative descriptive study because it promotes the development of the description of the phenomenon "as it is" with little influence of an a priori theoretical view (Sandelowski, 2000, p. 337). Naturalism promotes the study of a phenomenon in its natural state with minimal to no manipulation of associated concepts or variables (Denzin & Lincoln, 2003).

Recruitment

The proposed study used purposive, convenience sampling to recruit moderate-severe survivors of TBI, 1-4 years post head injury. The investigator used a list of patients who participated in the TBIMS program at the University of Alabama at Birmingham (UAB) and agreed to be contacted for future research. TBIMS is an affiliated network of 16 rehabilitation centers in the United States, including UAB's Spain Rehabilitation Center (SRC) (National Data and Statistical Center, 2015). The TBIMS network collects longitudinal data to assess the rehabilitation of survivors of TBI. Potential participants were mailed an informational letter stating that they would be contacted within the next few weeks by phone to discuss their potential eligibility for the study. A follow-up call was conducted by the researcher and the potential participant received additional information about the proposed study. If interested, the participant was screened for eligibility. Enrollment was planned to continue until twenty participants were recruited or until saturation was met. Sixteen participants were enrolled in the study and completed interviews. The sample size ensured sufficient data were collected but feasibility maintained and were based on the recommended sample ranges of 3 to 20 (Magilvy & Thomas, 2009) and 6 to 25 (Sandelowski, 1995).

Inclusion/Exclusion Criteria

The following inclusion criteria were applied: 1) moderate-severe TBI; 2) appropriate cognition and ability to verbally communicate; 3) 18-50 years of age; and 4) 1-4 years post injury. The following exclusion criteria will be applied: 1) history of sleep

disturbance or disorder prior to TBI; 2) non-English speaking patient; and 3) current known pregnancy.

Data Collection

Participants meeting eligibility criteria who stated they would like to enroll were scheduled for an in-person interview to take place at UAB Medical Towers or UAB SRC. At the beginning of the appointment, the investigator described the research study and role of the participant. Consent was attained and each participant underwent an in-depth, semi-structured interview.

Data Analysis

After transcribing all interviews verbatim from audio files, the investigator conducted thematic analysis using NVivo 11™ software. Transcribing interviews allowed the investigator to gain familiarity with the data, a necessary component of qualitative analysis. Thematic analysis was used to identify concepts within individual interviews and group themes across interviews to generate descriptions of a phenomenon (Fereday & Muir-Cochrane, 2006). A codebook was generated to systematically guide analysis; adjustments to the codebook were made as analysis progressed to remove unnecessary codes, add new codes, and clarify existing codes. Transcripts were analyzed individually and collectively and then overarching themes were generated to describe the sleep experiences of the sample.

Definitions of Terms

Terms for the study were used in the following context:

Cognitive impairment refers to disruptions to brain function as the result of TBI, resulting in problems with executive function, attention, speed-of-processing, memory, or language (Arciniegas, Held, & Wagner, 2002).

Cognitive reserve refers to the neurological and structural support of cognitive functioning; more cognitive reserve supports recovery from neurological insult (Vance, Roberson, McGuinness, & Fazeli, 2010).

Fatigue is physical and/or mental tiredness; a persistent lack of energy that may or may not be related to sleep (Shen, Barbera, & Shapiro, 2006).

Level of injury severity is a range (mild, moderate, severe) used to classify survivors of TBI based on characteristics of injury and patient presentation. While definitions of TBI severity can vary, they are classically determined using Glasgow Coma Scale (GCS) upon admission to emergency department, presence of /length of posttraumatic amnesia, and diagnostic imaging (CDC, 2015; National Institute of Neurological Disorders and Stroke, 2016).

Mild level of severity (mild TBI) is used synonymously with ‘concussion’ and has varied criteria. For the purposes of the proposed study, the NINDS criteria will be applied: 1) GCS range of 13-15 associated with brief or no loss of consciousness (<15 minutes); 2) little or no post-traumatic amnesia; 3) mild TBI may or may not be visible on diagnostic imaging; and 4) mild TBI may or may not result in neurobehavioral symptoms (National Institute of Neurological Disorders and Stroke, 2016).

Moderate level of severity (moderate TBI) uses the following classification criteria: 1) GCS range of 9-12; 2) loss of consciousness (>15 minutes to several hours); 3) post traumatic amnesia lasting hours to days; and 4) likely visible on diagnostic imaging (National Institute of Neurological Disorders and Stroke, 2016).

Neuroplasticity refers to changes, positive and negative, in the brain and nervous system in reaction to environmental stimuli that influence cognitive reserve (Vance, Roberson, McGuinness, & Fazeli, 2010).

Qualitative description is a qualitative research methodology that aims to produce a comprehensive, descriptive summary of a phenomenon with little interpretation (Sandelowski, 2000).

Rehabilitation is an intensive, inpatient model of care for patients, following a TBI, with the goal of helping an individual return to their maximum of degree of pre-injury functioning (Model Systems Knowledge Translation Center, 2010).

Severe level of severity (severe TBI) uses the following classification criteria: 1) GCS range of 1-8; 2) loss of consciousness (>6 hours); 3) potential for coma or vegetative state following injury; and 4) likely visible on diagnostic imaging (National Institute of Neurological Disorders and Stroke, 2016).

Sleep disorders are disruptions to sleep caused by conditions with formally recognized diagnostic criteria (e.g., insomnia, hypersomnia, obstructive sleep apnea) (Mathias & Alvaro, 2012).

Sleep disturbances or sleep problems are disruptions to sleep caused by conditions without formally recognized diagnostic criteria; screening measures are sometimes used to capture sleep disturbances or problems but not a diagnosis (e.g.,

problems with sleep maintenance, efficiency, or initiation, daytime sleepiness, or parasomnias) (Mathias & Alvaro, 2012).

Sleep is a complex phenomenon that utilizes neurochemical systems to maintain balance between rest and wake states, a normal state in humans (American Sleep Association, 2007).

Traumatic brain injury (TBI) is a disruption in normal brain function resulting from a bump, jolt, penetrating injury, or close proximity to blast (Centers for Disease Control and Prevention, 2015).

Summary

As TBI mortality rates have declined over the last 2 decades, the number of TBI patients living with chronic comorbidities and disability has increased. Over half of survivors of TBI experience sleep disturbances and disorders; sleep changes may impact multiple facets of rehabilitation and long-term recovery. Although relationships have been investigated between sleep disturbances and disorders and physical, psychological, and cognitive sequelae following TBI, little is known regarding the sleep experiences of individual, adult survivors of moderate-severe TBI. A review of the literature yields very few qualitative research studies have been reported in adult TBI samples, and only one has investigated civilian experiences (Matthews et al., 2016; Theadom et al., 2016). This study addresses a significant and timely problem, lack of knowledge concerning the experiences of sleep in survivors of TBI, using qualitative descriptive methods.

CHAPTER 2

REVIEW OF LITERATURE

The purpose of this literature review is to communicate the contextual foundation of the study by presenting the relevant research surrounding the central concept (sleep after TBI and related concepts (fatigue, cognition, psychological correlates, and functional outcomes). Together, the epidemiology, literature review, framework, and methods provide rationale for the study in light of the problem. The study extends current knowledge of sleep following TBI, specifically, by providing descriptions of sleep experiences of adult community-dwelling survivors of TBI, which have not yet been investigated.

Epidemiology and Introduction of Concepts

An understanding of the epidemiology of TBI is essential in understanding the trends in incidence of sleep pathology in survivors of TBI. Traumatic brain injury is a concerning problem worldwide, nationally, and in the state of Alabama. Worldwide, TBI is the leading cause of death in the first 40 years of life and by 2020, the World Health Organization estimates that TBI will be the 3rd leading cause of death and disability in the world (Popescu et al., 2015). In the European Union, roughly one million hospital admissions each year are attributed to TBI (International Brain Injury Association [IBIA], 2015). Although the global incidence rate is estimated at 200 per 100,000 people yearly,

it is likely that this rate is underestimated (Bryan-Hancock & Harrison, Injury Prevention, 2010).

In the United States, 138 people die each day from TBI-related injuries. From 2001-2010, TBI-related death rates decreased by 7%, hospitalization rates increased by 11%, and ED visits increased by 70% (CDC, 2015). In 2010, 2.5 million ED visits in the United States were attributed to TBI, either alone or with concurrent injuries. Of those visits, 280,000 resulted in hospitalization. Increases in ED visits and hospitalizations may be attributed to increased public awareness due to organizational campaigns and heightened media coverage of military and civilian TBI incidence. The Alabama Department of Rehabilitation Services, the primary surveillance entity for TBI in the state, received reports of 9,095 moderate or severe TBIs from the beginning of 2013 through the end of 2015 (Alabama Head Injury Foundation, personal communication, July 1, 2016). Mechanisms associated with TBI in Alabama from 2013-2015 include a variety of blunt, penetrating, and blast injuries (e.g., motor vehicle crash [MVC], assault, firearm, fall, explosive) and reflect national civilian trends in mechanism of injury.

Unfortunately, there is a limited amount of data regarding TBI-related disability, only an extrapolated estimate suggesting that functional limitations and comorbidities associated with TBI contribute to 3-million to 5-million individuals living with TBI-related disability in the United States (CDC, 2016). No federal or state-level comparison data is available regarding TBI-related disability outcomes. However, projects advocating for TBI rehabilitation outcome measurement and tracking, such as the Common Data Elements Project and others, may lead to short and long-term assessment of outcomes of TBI (CDC, 2016). Moderate-severe TBI increases mortality risk across all age groups,

compared to the general population, but it remains unclear whether increased mortality risks are associated with the initial injury or rather a longitudinal result of a chronic disease process post-injury (Harrison-Felix et al., 2012).

Age and gender influence TBI epidemiological trends. Those very young and very old are more likely to experience TBI (CDC, 2015). Gender influence is significant; males are twice as likely to experience a TBI compared to females (CDC, 2015; IBIA, 2015; Popescu et al., 2015). Risk factors for increased mortality by age group include level of disability, mechanism of injury, time since injury, and gender (Harrison-Felix et al., 2012). The impact of age on TBI trends may be due to risk-taking behaviors in adolescents and young adults, ages 15-24 years, resulting in injury. Older adults most often experience fall-related TBI, particularly those adults over the age of 75 years (IBIA, 2015). While the epidemiological estimates of TBI are compelling, several methodological considerations may impact the estimates including lack of incidence tracking mechanisms, underreporting, and ambiguous definitions regarding concussion (CDC, 2015; Hancock & Harrison, Injury Prevention, 2010).

Sleep Disorders following TBI

The Institute of Medicine (IOM) (2006) reports an estimated 50-70 million of the 300 million adults in the United States have a chronic sleep disorder; approximately 15-20% (United States Census Bureau, 2015). The prevalence of sleep disturbance after TBI is much higher, at approximately 50% (Mathias & Alvaro, 2012). Cohen (1999) noted high incidence of sleep disturbances post-TBI in both acute (72.7%) and chronic phases on injury (51.9%, 2 years post-TBI). Despite the trend of improvements in sleep over

time, a high number of survivors suffer from sleep problems and require screening and intervention. Insomnia, hypersomnia, apnea, and circadian rhythm disorders are particularly prevalent post-TBI; insomnia incidence in mild TBI has been reported as triple that of the general population (Theadom et al., 2015), and meta-analysis suggests that sleep apnea incidence following TBI may be 12 times greater than that of the general population (Mathias & Alvaro, 2012). Some of the sleep disorders described may be prevalent during distinct time periods following TBI; Cohen (1999) found problems initiating and maintaining sleep more common during acute hospitalization for TBI (81.2%) and excessive sleepiness more common in survivors of TBI post-discharge (72.5%).

Fatigue, Sleep, and TBI

Fatigue is conceptually distinct from sleep, but is closely related, and impacts survivors of TBI with and without sleep disturbances. Some literature suggests that fatigue following TBI is a secondary consequence of sleep disturbance (secondary fatigue) and others assert that fatigue is a separate symptom (primary fatigue) (Cantor et al., 2012; Schonberger et al., 2012). It is especially difficult to clinically separate fatigue from sleep disturbances, attention problems, etc. Fatigue is frequently found in TBI patients with sleep disturbance, particularly insomnia (Cantor et al., 2008), and is also associated with concomitant psychological disturbances such as depression or pain (Bushnik, Englander & Wright, 2008).

Cognition, Sleep, and TBI

Sleep disturbances contribute to cognitive deficits in the general population and given the association between sleep and TBI, sleep problems associated with TBI may be particularly disruptive to cognition (Imogen, Bloomfield, Espie, & Evans, 2010; Duclos et al., 2014; Mahmood et al., 2004). Cognitive deficits such as impaired executive function, attention, memory, or speed of processing are frequently reported following TBI, even in TBI patients without sleep complaints (Cicerone et al., 2000). Cognitive reserve, the ability to maintain a functional level of cognition despite potential insults to cognition (e.g., injury, inflammation, aging) (Vance et al., 2014) is enhanced by positive neuroplasticity and depleted by negative neuroplasticity. Positive neuroplasticity involves changes to the brain that promote cognitive functioning by improving neuronal connections or stimulating production of neurotrophic factors. Conversely, negative plasticity refers to changes in the brain or nervous system that inhibit neuronal development and connections and decrease neurotrophic factors, thereby disrupting cognitive functioning. It is possible that sleep disturbances in survivors of TBI have negative neuroplastic effects, contributing to a broader negative impact on cognitive reserve (Gosselin & Baumann, 2016). The potential of sleep disturbance to disrupt cognitive reserve and therefore cognitive recovery is concerning, because rehabilitation is focused on learning new information and recall of past information to facilitate functional recovery (Cicerone et al., 2000).

Psychological Correlates of Sleep and TBI

In addition to cognitive deficits, concomitant psychological diagnoses are associated with sleep disturbance. Psychiatric comorbidities often consist of highly interrelated clusters, sometimes referred to as postconcussive syndrome (Fogelberg et al., 2012; Rao et al., 2014). Postconcussive syndrome often includes depression, anxiety, pain, or PTSD, which are each prevalent in TBI patients with sleep disturbances or disorders. Additionally, patients with sleep complaints are more likely to suffer from headaches, irritability, and depressive symptoms which may decrease perceived quality of life (Chaput et al., 2009).

Functional Outcomes and TBI

Disability is an important clinical outcome, and typically refers to changes in an individual's capacity to interact socially or occupationally due to impairment (Mollayeva et al., 2016). Unfortunately, sleep difficulties may contribute to TBI-related disabilities. It is possible that the combined effects of sleep problems on cognition and psychological correlates contribute to the negative association between sleep problems and functional outcomes after TBI (Duclos et al., 2015). Functional outcomes are measured using instruments such as the Functional Independence Measure, Disability Rating Scale, Sheehan Disability Scale, Rachos Los Amigos Scale, Global Assessment of Functioning Score, Rivermead Follow-up Questionnaire, and other validated measures that typically combine cognitive and physical outcomes (Chan et al., 2015; Duclos et al., 2014; Ettenhofer et al., 2012; Holcomb et al., 2016; Mollayeva et al., 2016). The term functional outcomes is used frequently in TBI literature and often refers to the overall

scores from the measures listed above. However, functional outcomes may also refer to hospital disposition (e.g., discharged to home, rehabilitation facility, or long-term care facility) (Sandsmark et al., 2016).

Essentially, sleep problems may increase symptom burden and thereby impact outcomes. Sleep problems following TBI have been associated with poor functional outcomes (Fogelberg et al., 2012), lower perceived quality of life (Baumann 2007; Cantor et al., 2012; Zhang et al., 2009), and poor perceived health (Zhang et al., 2009). For survivors of TBI in rehabilitation, sleep disturbance has been associated with increased length of stay and higher costs; sleep disturbances cost each patient approximately $16,200 (Makley et al., 2008). Survivors of TBI who return to the workplace and have higher disability have greater insomnia severity in addition to multiple psychological correlates compared to those survivors of TBI with lower disability levels (Mollayeva et al., 2016).

Summary of Epidemiology and Introduction of Concepts

The high rates of TBI worldwide, nationally, and locally have fueled prevention efforts and prompted research in the development of effective rehabilitation approaches for survivors of TBI. Of the many comorbid conditions experienced by survivors of TBI, problems with sleep are highly prevalent and estimates suggest that as many as half of all survivors of TBI will suffer from sleep disturbances or disorders, in addition to cognitive, psychological, and functional deficits. Despite this large number of individuals who may suffer from sleep disturbance, little is known regarding the experiences of individuals with sleep disturbances or disorders following TBI. Given the prevalence of sleep

problems in this population and potential effects on personal, functional, and financial outcomes, this problem requires attention.

Search Strategy

A literature search was conducted in SCOPUS and PubMED for all articles published using the search criteria "traumatic brain injury AND sleep," "TBI AND sleep," and "brain injury AND sleep." Range of publication dates was not specified to avoid exclusion of seminal studies; using the analyze results feature of SCOPUS yielded relevant articles from as early as 1960. These searches yielded a total combination of 1,263 articles that was reduced to 879 after removing duplicates. Studies were included if published in English language, primary sources, included TBI participants in samples and sleep-related pathophysiology or characteristics as independent or dependent variables. Articles were excluded if duplicates, review articles and other secondary sources (with the exception of meta-analyses), or involving other neurological diseases such as stroke, multiple sclerosis, or Parkinson's. Pediatric and animal populations were also excluded, as were pharmaceutical trial studies. After review of abstracts for exclusion and inclusion criteria, 39 articles were selected for inclusion in the integrative review and 7 articles were added to the sample using the ancestry method. Therefore, a total of 100 articles were fully reviewed (Figure 2).

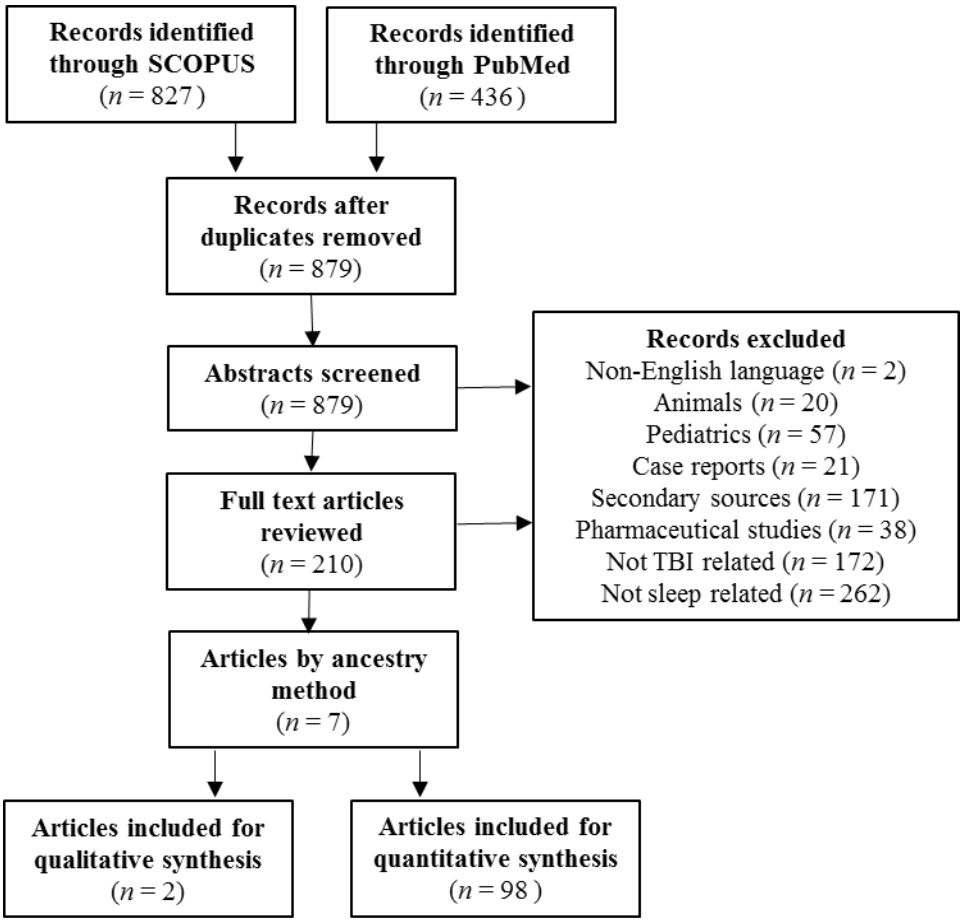

Figure 2. PRISMA chart of study selection for integrative review.

Review of Literature

Neurobiological Markers of Sleep Disturbance after TBI

Hypocretin. Decreased levels of hypocretin (orexin), a wake-promoting neurotransmitter found in cerebrospinal fluid (CSF), have been previously linked with narcolepsy cases in the general population (Nishino et al., 2000; Ripley, 2001). Basetti et al. (2003) first reported decreased levels of hypocretin in a single patient after head trauma as part of a larger sample with various neurological diagnoses. Baumann et al. (2005) explored the idea that hypocretin might be decreased following TBI in a focused study and reported that hypocretin levels were lower in 95% of patients with moderate or

severe TBI (n = 44) compared to controls. In 2007, Baumann's team linked hypocretin levels to the presence of sleep disturbances 6 months after TBI, reporting that low hypocretin levels were more common in the immediate days following TBI (25 of 27 patients) compared to 6 months (4 of 21 patients). Additionally, hypocretin was significantly lower in patients with excessive daytime sleepiness (EDS) compared to controls at 6 months after TBI (p = 0.05) (Baumann et al., 2007). It is possible that the decreased cortical excitability noted in survivors of TBI with EDS after transcranial magnetic stimulation is related to hypocretin deficiencies (Nardone et al., 2011). Although involvement of the hypocretin system in the pathophysiology of sleep disturbances following TBI is possible, particularly EDS, there is insufficient evidence linking decreased hypocretin levels to other common sleep disturbances and disorders post-TBI.

Melatonin. In addition to hypocretin deficiencies, decreased melatonin levels have been identified as potential biomarkers of sleep problems following severe TBI during both the acute (Paparrigopoulos et al, 2006) and chronic phases (Grima et al., 2016; Shekleton et al., 2010). Melatonin is a hormone released by the pineal gland that contributes to maintenance of the sleep-wake cycle. The specific timing of melatonin production may be disrupted in acute stages; although findings related to this phenomenon are inconsistent (Seifman et al., 2014; Steele, Rajaratnam, Redman, & Ponsford, 2005). Disruption of melatonin production may lead to circadian rhythm changes in addition to subjective sleep complaints (Grima et al. 2016, Shekleton et al., 2016). Patients post mild TBI produce significantly lower levels of evening melatonin,

compared to healthy controls (Shekleton et al., 2010). Most recently, Grima et al. (2016) conducted a comparison of TBI patients (n = 9) with healthy age and gender matched controls. Grima et al. reported that TBI patients produced 42% less melatonin overnight compared to controls (d = 0.87, p = 0.034), and as a result, dim light melatonin onset was delayed by an hour and a half more than controls (d = 1.23, p = 0.003). These results suggest that disruptions to circadian cycles, a feature of TBI, may be attributed to disruptions to melatonin production and timing.

Yaeger, Alhilali, and Fakhran (2013) hypothesized that decreased melatonin production post TBI may be attributed to damage to the pineal gland by a biomechanical factor: tentorial length and angle. The tentorium is a hard, dural structure perpendicularly attached to the inner surface of the skull at a boney area called the tentorial ridge. The pineal gland is positioned close to the tentorial ridge, and therefore is highly susceptible to impact on the tentorium. Using imaging and chart reviews, Yaeger et al. calculated tentorial angle and length in mild TBI participants with and without sleep disturbance and found three important findings: 1) tentorial length was longer in TBI patients with sleep disturbances compared to those without ($p < 0.01$); 2) tentorial angle was significantly smaller ($p < .01$); and 3) both tentorial length ($p = 0.002$) and angle ($p < 0.001$) were directly related to length of time to recovery. These findings suggest that longer tentorial length and more shallow tentorial angles increase the risk of physical damage to the pineal gland during TBI and may be associated with an elevated risk for sleep disturbances overall; it is unclear if specific sleep disorders or disturbances might be associated with tentorial length or angle.

Neuroendocrine changes. Studies of changes in neuroendocrine markers associated with TBI such as cortisol, growth hormone, and prolactin have shown mixed results (Friebos, 1999; Zhou et al. 2016). Decreases in nighttime peak growth hormone and increases in maximal prolactin secretion have been noted but not linked to sleep disturbances post TBI (Friebos, 1999). While Friebos (1999) reported no change in cortisol secretion in survivors of TBI, Zhou (2016) reported significantly lower peak cortisol levels in TBI patients with associated decreases in sleep efficiency and daytime dysfunction. However, the practice of administering steroids to acute TBI patients for increased intracranial pressure may have impacted the cortisol results in the Friebos investigation. While results have been inconclusive, the potential for underlying neuroendocrine changes in sleep disturbances after TBI cannot be excluded.

Sleep Architecture and Sleep Characteristics in TBI Samples

Sleep architecture. In addition to changes in neurochemistry, researchers have documented changes in sleep architecture following TBI. Sleep architecture refers to the basic organization or structure of normal sleep, and encompasses both macroarchitecture and microarchitecture. Typically, macroarchitecture refers to stages of sleep such as rapid eye movement (REM) and non-rapid eye movement (NREM) sleep seen during polysomnography (PSG). Microarchitecture refers to more detailed electrophysiological characteristics seen on electroencephalogram (EEG) or spectral analysis, such as the amplitude and frequency of alpha, beta, delta, or theta activity during sleep or wakefulness.

Studies of sleep macroarchitecture in survivors of TBI have noted potential changes to slow wave sleep and REM sleep, but results are highly varied (Lu et al., 2015; Parcell et al., 2008; Schreiber et al., 2008). Lower percentages of REM sleep have been noted across mild, moderate, or severe injuries and may be even less in mild TBI patients (Parcell et al., 2008; Schrieber et al, 2008). More time in slow wave sleep may be noted as well (Grima et al., 2016; Parcell et al., 2008; Schrieber et al, 2008). Ouellet and Morin (2006) did not find changes in slow wave sleep or REM sleep but found a higher percentage of stage one sleep in a mixed severity sample. Change in sleep microarchitecture have also been noted in TBI samples. Varying levels of alpha, beta, and delta power have been noted in NREM and REM states **(**Rao, 2011). Sigma, theta, and delta power changes have been noted during sleep onset (Williams, Lazic, & Olgivie, 2008). Additionally, sleep spindle frequency and amplitude may change during the first 80 days from injury and restore over time (Uramaki, 2012). Spindle restoration during the chronic stages of TBI recovery may indicate optimistic prognosis (Rumpl et al., 1983); however, Arbour et al. (2015) found no group differences in slow wave sleep or spindle characteristics. Overall, these results suggest that sleep in TBI patients is impacted by multiple components and electrophysiological outcomes on objective measures of sleep such as PSG and EEG show differences between TBI patients and controls. However, the relationships between macroarchitecture, microarchitecture, and patient outcomes remains unclear.

Sleep characteristics. The general sleep characteristics associated with TBI are also unclear due to mixed reports. Researchers comparing sleep in TBI patients to

controls have described fragmented sleep (Wiseman-Hakes et al., 2015), poorer sleep efficiency (i.e., time asleep divided by time in bed) (Chen et al., 2015; Chiu et al., 2013; Chiu, Lo, Chiang, & Tsai, 2014; Grima et al., 2016; Ponsford et al., 2013, Wiseman-Hakes et al., 2015), longer total sleep time (TST) (Chiu et al., 2013; Chiu et al., 2014), lower TST (Grima et al., 2016), longer wake time after onset (Chiu et al., 2014; Grima et al., 2016), longer sleep duration (Wisman-Hakes et al., 2015), shorter sleep duration (Grima et al., 2016), and earlier sleep onset (Wiseman-Hakes et al., 2015). In contrast, Sullivan et al. (2015) reported no significant differences between sleep quantity, timing, sleep efficiency, or daytime sleepiness when comparing patients with mild TBI to matched controls. While descriptions may differ with sample and with level of severity, it is apparent that many sleep characteristics are altered after TBI. Together, the many problems with sleep may contribute to a greater sleep need in the TBI population (Imbach et al., 2015), as suggested by higher levels of daytime sleepiness (Grima et al., 2016; Imbach et al., 2015; Sinclair, Ponsford, & Rajaratnam, 2014), more frequent daytime napping (Ponsford et al., 2013), and lower perceived sleep quality in this group, compared to controls (Grima et al., 2016; Ponsford et al., 2013; Sinclair et al., 2014).

Injury Severity and Sleep

A great divide exists in literature regarding the impact of severity of injury on sleep disturbances and disorders. Traditionally, researchers have reported that survivors of mild TBI experience sleep complaints more often than survivors of moderate-severe TBI and have targeted their investigations to include primarily mild TBI samples. The relationship between mild level of severity and sleep disturbances has been most

specifically linked with insomnia (Beetar et al., 1996; Fichtenberg et al., 2000, Sullivan et al., 2015). However, sleep problems appear throughout the severity continuum and contrasting evidence suggest that sleep disturbances and disorders should be identified and treated in moderate or severe TBI as well as mild TBI. Some investigators have failed to establish a significant relationship between severity of injury and presence of a sleep complaint (Huang et al., 2013; Kempf et al., 2010) and other researchers have found results suggesting that participants with moderate-severe TBI samples may experience just as many or more sleep complaints than those with mild TBI. In a mixed severity sample, Hou et al. (2013) found that participants with moderate-severe TBI had more sleep problems than those with mild TBI (53%, 57%, and 30%, respectively). Theadom et al. (2015) reported that sleep difficulties were equally problematic in mild TBI samples (41.4%) and moderate-severe samples (44%). Preliminary evidence in the ICU setting suggests that severity of injury may be related to melatonin levels and circadian rhythms underlying sleep changes (Paparrigopoulos, 2006). In a longitudinal qualitative investigation of sleep and fatigue in a mixed severity sample, Theadom et al. (2016) found no evidence of experiences differing by severity and proposed that sleep and fatigue were more related to the individual, their pre-injury factors, and context of their injury and recovery.

Sleep and Length of Time following TBI

Chen et al. (2015) found that injury severity could predict sleep changes acutely (first 7 days post-injury) but not past the first year after TBI. This finding highlights another important area of sleep and TBI research: trends associated with length of time

since injury and the development of sleep disturbances and disorders. A slow and gradual trend of improvement in sleep post-TBI, both acutely and post-rehabilitation, particularly within the first year following injury, has been noted (Chen et al., 2015; Duclos et al. 2014; Huang et al. 2013; Nakase-Richardson 2013). Sleep disturbances may persist throughout the first year, regardless of initial level of severity (Rao et al., 2014). Longitudinal studies past the first year following TBI show that sleep difficulties persist well after injury, as long as 2 years to 3 years after TBI (Kempf et al., 2010; Williams, Lazic, & Ogilvie, 2008).

Sleep, TBI, and Qualitative Inquiry

Much of the literature regarding sleep and TBI has been based on quantitative designs. Only two studies have investigated the sleep experiences of survivors of TBI using qualitative methods. Matthews et al. (2016) and Theadom et al. (2016) used qualitative descriptive methods to explore descriptions of sleep in the words of survivors of TBI with similar resulting themes; participants in both qualitative studies described concern for understanding their sleep disturbances and how to manage their subsequent sleepiness or fatigue. Theadom et al. studied community-dwelling survivors of TBI with sleep and/or fatigue problems within 2 years of initial injury, using in-depth interviews at 6 months, 12 months, and 24 months. Theadom et al. also incorporated the patient-caregiver dyad in a subset of interviews; inclusion of significant other depended on availability and participant preference. Matthews studied sleep disturbances in moderate-severe TBI in veterans after various lengths of time since initial injury using interviews and the participant's perspective, solely.

Participants in the Theadom et al. (2016) study reported feeling unprepared for the sleep difficulties they experienced after TBI and struggled with adapting to their circumstances. Theadom identified four central themes: 1) Understanding fatigue and sleep following TBI; 2) Accepting individual need for rest; 3) Learning ways to rest (including napping); and 4) Frustration with the impact of needing to rest on their participation in other life activities. In the context of learning how to rest and frustration with need to rest, napping was a source of confusion for participants; Theadom reported that participants were generally hesitant to nap because they were not sure if it was allowed or beneficial for their sleep. Juggling perceived need for naps and concerns for napping was most problematic when participants began to return to activities similar to before TBI, such as employment.

Matthews et al. (2016) reported two similar themes in their description of sleep disturbances in a sample of male U.S. military veterans: 1) "messed up sleep" (p. 3) and 2) surviving and managing sleep disturbances. Most often, participants described problems with initiating sleep, sleep maintenance, and sleep quality. Participants also described perceived impact of sleep disturbances on mood, cognitive functioning, and social interactions. Some veterans attributed their sleep problems to shift work and experiences during military service, describing flashbacks and nightmares that were intrusive to sleep. Matthews also asked participants to describe conversations with their healthcare providers related to sleep after TBI and reported that it was not consistently discussed, although the problem was described as having great impact on the lives of survivors of TBI. Participants also expressed willingness to try sleep interventions and strategies, but were generally unaware of potential treatment options.

Contributing Factors and Related Concepts

Underlying neurobiological mechanisms and changes in sleep architecture and characteristics may be exacerbated by additional factors that may contribute to the development of sleep disturbances and disorders after TBI, such as repetitive injury, medications, or environmental influences. Subsequent TBIs might occur due to repeated exposure to injury mechanisms (e.g., athletes returning to play or soldiers returning to combat) or impaired judgement resulting from initial injury. Multiple TBIs have been associated with higher risk for sleep disturbance and increased severity of sleep disturbance; when compared across groups by number of injuries, rates of insomnia increased in the following order: no TBI (5.6%), single TBI (20.4%), and repetitive TBIs (50%) even after controlling for confounding factors among all male, active-duty military personnel of unspecified severity (N = 150) (Bryan, 2013). However, Mollayeva (2016) found that repetitive TBIs were associated with lower insomnia severity among survivors of mild (N = 94). Both Bryan (2013) and Mollayeva (2016) used the Insomnia Severity Index as the primary measure of insomnia severity, although Bryan conducted a cross-sectional study and Mollayeva conducted a longitudinal study over 24 months. Further investigation is needed to explore the relationship between number of TBIs experienced and severity of sleep problems.

Medications impacting sleep. Antidepressants, antiepileptic drugs, and/or stimulants may impact sleep or wakefulness following TBI. Antidepressants, such as selective serotonin reuptake inhibitors (SSRIs), tricyclic antidepressants, or monoamine oxidase inhibitors (MAOIs), have varying effects on sleep architecture but most

significantly impact time in REM sleep (Wichniak, Wierzbicka, & Jernajczyk, 2012). Benzodiazepines may have hangover effects that cause drowsiness or effects similar to sedative-hypnotics; both benzodiazepines and hypnotics carry risk of chemical dependence and may have negative neuroplastic effects (Larson & Zollman, 2010). Stimulant medications sometimes used to treat attention problems following TBI may also impede sleep processes; methylphenidate, modafinal, and other stimulant drugs that promote wakefulness and vigilance are sometimes used as treatment for excessive daytime sleepiness or fatigue (Jha et al., 2008; Lee et al., 2005). Seizure medications, such as phenytoin, valproic acid, and gabapentin, have been found to increase drowsiness due to sedative effects and create changes to sleep architecture and sleep-wake cycles (Legros & Bazil, 2003; Placidi et al., 2000). Compared to controls, patients taking phenytoin display spend more time in stage one sleep and less time in slow wave sleep and REM sleep, patients taking valproic acid spend more time in stage one sleep, and patients taking gabapentin spend more time in slow wave sleep (Legros & Bazil, 2003).

Environmental factors. Beyond number of TBIs or medication effects, hospital environments, particularly in ICUs during acute care of TBI, are disruptive to sleep. Alarms from medically-necessary equipment, sedation, ventilation, and around-the-clock care are only a few of the factors contributing to poor sleep in the ICU. Non-TBI patients in ICU settings report poor sleep quality (Bihari et al., 2012) and may experience changes in their sleep-wake timing with more sleep during the day and lighter sleep at night (Hardin, 2009). In TBI patients in ICU settings, a lack of consolidation of rest-activity cycles has been noted using actigraphy (46.6% of days monitored) with a gradual,

significant trend of improvement over time and associations between poorer rest-activity cycles and longer lengths of stay in ICU and the hospital (Duclos et al., 2014). It is possible that inpatient rehabilitation may be less disruptive to patient sleep, but much of the research regarding sleep quality in general inpatient rehabilitation samples has been in older adults (Allen, Coon, Uriri-Glover, & Grando, 2013; Dzierzewski et al., 2015; Martin et al., 2011; Martin et al., 2012). Gardani et al. (2015) investigated the presence of sleep disturbances in severe TBI patients during inpatient rehabilitation and revealed high levels of sleep-wake cycle disturbances (67%, $n = 30$). More research is needed to determine the influence of the inpatient rehabilitation environment on patient sleep throughout the lifespan, including patients with TBI.

Another environment has been reported as highly associated with TBI and sleep disturbances post-TBI: the military environment. Although blast-mediated TBI may occur in variety of settings such as in occupational hazard, blast TBI has been extensively studied in soldiers and veterans of OEF and OIF. Much of the military research suggests that blast TBI, mild severity, sleep (particularly insomnia) and psychiatric comorbidities may be linked. While further investigation of the relationship between blast exposure, TBI, and sleep is needed, it is hypothesized that an increase in cerebral metabolic rate of glucose during REM sleep and wakefulness after mild TBI caused by blast may contribute to underlying neurobiological alterations (Stocker et al., 2014). In a sample of soldiers returning from combat, Collen et al. (2012) determined that blast TBI may be more highly associated with insomnia, while soldiers with blunt injuries may be more likely to develop sleep apnea. Veterans with blast exposure and mild TBI may be more likely to have subjective sleep disturbances if they lost consciousness following blast

exposure, compared to those who did not (Farrell-Carnahan et al., 2013). Current (soldier) or previous (veteran) exposure to military environments may contribute to the development of sleep disturbances prior to or following TBI; shift work is common and daytime napping habits may be carried over into everyday sleep routines (Wallace et al., 2011).

Related Concept: Fatigue

Fatigue is a common complaint that is found more frequently in TBI patients compared to matched controls (Beaulieu-Bonneau & Morin, 2012). The relationship between fatigue and sleep is complex; fatigue is difficult to accurately measure, is often confused with daytime sleepiness, and may be the result of factors outside of sleep pathology such as cognitive or physical exertion (Cantor et al., 2008; Cantor et al., 2012; Englander, Bushnik, Oggins, & Katznelson, 2010; Schnieders, Willemsen & de Boer, 2012). Different labels have been assigned to TBI-related fatigue, such as post-TBI fatigue (Cantor et al., 2012), or post-TBI chronic fatigue (Schnieders et al., 2012). Researchers are unsure of the primary vs. secondary nature of fatigue after TBI in conjunction with sleep disturbances. However, it is suspected that vitamin D deficiencies and anxiety in addition to poor sleep are contributing factors to fatigue development in TBI samples (Schneider et al., 2012). Furthermore, growth hormone deficiency, adrenal insuffiency, and hypothyroidism have been reported in TBI samples with fatigue (Englander et al., 2010). Although there was no significant correlation between pituitary function and fatigue, further research is needed to investigate the high prevalence of these hormone deficiencies. The relationship between fatigue after TBI and gender is also

unclear; Cantor et al. (2008) reported that women experience higher severity of fatigue compared to males, but Borgaro et al. (2005) found no relationship between fatigue and gender.

Specific sleep disorders may be highly correlated to fatigue, such as insomnia. Cantor et al. (2012) investigated insomnia and fatigue in a moderate-severe TBI sample and reported that anxiety, depression, and sleep quality mediated the relationship between insomnia and fatigue ($N = 334$). In a mixed sample, fatigue predicted sleepiness ($p < 0.05$) and depression ($p < 0.05$) but sleepiness did not predict fatigue (Schonberger et al., 2014). Naps are also highly correlated with fatigue; Borgaro et al. (2005) reported that managing a day without a nap was a sensitive indicator of fatigue in a TBI group of mixed severity.

Overall, fatigue appears to improve over the first and second years following TBI; those with stable or decreased fatigue displayed stable functional outcome scores but individuals with increased fatigue demonstrated declines in functional outcome scores (Bushnik, Englander, & Wright, 2008). Quality of life and perceived well-being are also negatively impacted by fatigue, suggesting that fatigue is problematic alone and in combination with sleep disturbances post-TBI (Cantor et al., 2008). Researchers have suggested that assessing and treating for sleep quality may improve fatigue symptoms; however, more research is needed to evaluate the impact of sleep interventions on fatigue-related outcomes (Bushnik et al., 2008). Although the proposed study will not specifically measure or address fatigue, a distinction between fatigue and sleepiness is necessary to adequately describe sleep experiences in survivors of TBI.

Related Concept: Cognition

Sleep problems associated with TBI may be particularly disruptive to cognition (Bloomfield, Espie, & Evans, 2010; Duclos et al., 2014; Gosselin & Baumann, 2016). Cognitive deficits are frequently reported following TBI, even without sleep complaints. Therefore, underlying cognitive problems may be worsened by sleep disturbances. The impact of sleep on cognition and therefore recovery following TBI may be best explained in the context of neuroplasticity and cognitive reserve.

Neuroplasticity and Cognitive Reserve. Cognitive reserve is defined as the neurological and structural support of cognitive functioning (Vance, Roberson, McGuinness, & Fazeli, 2010). More cognitive reserve translates to increased resistance and enhanced response to neurological insults. Essentially, individuals with better cognitive reserve may demonstrate better cognitive functioning following an insult to the brain, such as TBI. Cognitive reserve is an important component of cognitive rehabilitation following TBI and may be augmented to some extent; neuroplasticity refers to changes, positive and negative, in the brain and nervous system in reaction to environmental stimuli that influence cognitive reserve. Positive neuroplasticity involves changes to the brain that promote cognitive functioning by improving neuronal connections or stimulating production of neurotrophic factors. Conversely, negative plasticity refers to changes in the brain or nervous system that inhibit neuronal development and connections and decrease neurotrophic factors, thereby disrupting cognitive functioning.

Cognitive reserve and neuroplasticity play important roles in cognitive and functional recovery in patients with TBI. Cognitive and structural responses to TBI are dynamic and vary with mechanism of injury and pathophysiologic responses to injury. A combination of physical damage to tissues and disruption of functional circuits, as well as inflammatory responses and reductions in protein synthesis contribute to negative neuroplasticity after TBI (Griesbach & Hoyda, 2015). Both cognitive and functional recovery in patients with TBI are impacted by cognitive reserve and neuroplastic influences. Neuroplastic factors may impact cognitive recovery both before and after a TBI; greater cognitive reserve prior to TBI may lead to better recovery and a heavy negative neuroplastic influence on cognitive reserve post injury may contribute to slower or impaired rehabilitation.

Sleep deprivation contributes to negative neuroplasticity through inhibition of neurogenesis, particularly via inflammatory effects such as oxidative stress (Alkadhi et al., 2013). Decreases in sleep quantity, such as sleep deprivation, impact neuroplasticity and particularly memory and learning due to inflammatory effects on cellular correlates of those function. In a model suggesting the impact of neuroplasticity on cognitive reserve, Vance et al. (2010) present poor sleep hygiene, among other factors, as a concept promoting negative neuroplasticity and therefore less cognitive reserve. Frank and Cantera (2013) suggest that independent of sleep, circadian rhythms may impact plasticity; different vigilance states (i.e., sleep-wake states) attributed to increases in synaptic activity are in many cases driven by circadian timing.

Given the critical roles of neuroplasticity and cognitive reserve in TBI and the negative neuroplastic effects associated with injury, sleep disturbances, and even

circadian rhythm influence, it is possible that both sleep disturbances post TBI and circadian rhythm disorders in survivors of TBI have negative neuroplastic effects on cognitive reserve and therefore cognitive functioning. In survivors with TBI, sleep has been linked to general cognitive function (Chiu et al., 2014) and specific cognitive domains (e.g., attention, memory) (Bloomfield, Espie, & Evans, 2010; Wilde et al., 2007). Chiu et al. (2014) reported that total sleep time moderated the relationship between injury severity and cognitive function (t = -2.65, p = 0.004). Although the cognitive domains of executive function, attention, memory, and speed-of-processing are each commonly impaired following TBI, evidence suggests that sleep is associated with attention and memory deficits. It is likely that executive function and speed-of-processing are also impacted by sleep disturbance following TBI but there is a lack of evidence supporting this potential relationship.

Attention. Attention refers to components of cognition that maintain vigilance and focus on a particular task or necessary information and therefore directly influence performance (Duclos et al., 2014). In TBI, shortened attention span (length of time one is capable of focusing on a task) and divided attention (division of attention when faced with multiple operations) are particularly problematic and may be worse when combined with sleep disturbances or disorders (Bloomfield et al., 2010; Maruta et al., 2014; Wilde et al., 2007). In a comparison of TBI patients with good sleep or poor sleep (categorized by PSQI global score), Imogen, Bloomfield, Espie, and Evans (2010) reported that poor sleepers demonstrated worse performance in sustained attention compared to good sleepers, but no significant differences were noted in general attentional function. It is

possible that particular components of attention are impaired by sleep disturbance post-TBI, and the use of measures that can differentiate those components may be useful (Imogen et al., 2010).

Ability to focus attention post TBI may be impaired by sleep deprivation, as suggested in a comparison of sleep deprived subjects, controls, and individuals with mild TBI who underwent visual tracking (Maruta et al., 2014). The study reported that participants with 26 hours of sleep deprivation performed significantly worse in visual tracking than healthy controls and mild TBI subjects performed significantly worse than sleep deprived or control subjects. These results suggest that sleep deprivation post mTBI might lead to further declines in visual tracking performance. Visual tracking performance is dependent upon attention, suggesting that sleep deprivation as a result of sleep disorders may impact attention post-TBI.

Memory. Memory may also be impaired post-TBI. Memory includes encoding, storing, and retrieving information from short and long-term information storage systems (Velikonja et al., 2014). In a comparison of TBI patients without sleep disturbance (n = 16) to TBI patients with sleep apnea (n = 19), those with sleep apnea performed significantly worse on verbal and visual delayed recall measures, had more attention lapses, and slower reaction times (Wilde et al., 2007). Essentially, TBI participants with sleep disturbances displayed more impairment of memory and sustained attention.

Poor sleep efficiency, the ratio of time spent asleep to time spent in bed, may negatively impact memory return post-TBI (Makley et al., 2009). The potential negative impact of sleep on memory return is congruent with neuropsychological theories of

memory consolidation which suggest that the restorative nature of sleep is tied to the transfer of short term memory to long-term memory, or memory consolidation (Buzsaki, 1998). Based on a memory consolidation framework, researchers have suggested that disturbances to sleep interrupt restorative processes, yielding cognitive deficits such as problems with memory consolidation. Mantua et al. (2015) recently reported contrasting results—history of TBI did not affect sleep-dependent memory consolidation, despite significant differences in the sleep composition of TBI individuals vs. controls. The results of the Mantua study suggest that further research is warranted to establish the relevance of a memory consolidation framework in TBI patients with sleep disturbances or disorders.

Related Concept: Psychiatric Correlates

Anxiety (Chen et al., 2015; Parcell et al., 2008; Rao, 2008), depression (Chaput et al., 2009, Chen et al., 2015; Fichtenberg et al., 2000; Kempf et al., 2010), pain (Beetar et al., 1996; Fichtenberg et al., 2000; Mollayeva et al., 2016), and PTSD (Macera et al., 2012; Powell, 2015) are common psychological correlates associated with TBI and sleep disturbance. Compared to gender-matched controls, TBI patients reported higher levels of psychiatric disturbance and poorer sleep quality (Parcell et al., 2008). The relationship between psychiatric correlates and sleep disturbances in TBI patients may be bidirectional; sleep disturbances have contributed to increased risk for psychiatric complaints (Chaput et al., 2009; Rao et al., 2014) and psychological status has predicted changes in sleep patterns (Chen et al., 2015). The relationship between sleep and psychiatric disturbances has been attributed to common neuroanatomical and

neurotransmitter systems (reticular activating system, limbic system, basal ganglia) although specific underlying mechanisms for this possible bidirectional relationship are unclear (Rao et al., 2014).

Anxiety and depression. Anxiety alone is a risk factor for poor sleep after TBI (Rao, 2008), but is often found concurrently with depressive symptoms (Mollayeva et al., 2016; Rao et al., 2014). Both anxiety and depression are strongly linked to insomnia symptoms in TBI samples ($p = 0.003$) (Mollayeva et al., 2016), although reports suggest that depression and insomnia are more strongly associated (Fichtenberg et al., 2000, Kempf et al., 2010). Depression is associated with global sleep quality as well (Fogelberg et al., 2012). The presence of sleep disturbances at baseline is associated with more depression and anxiety symptoms a year post-injury, across levels of severity (Rao et al. 2014). Recovery of sleep quality is faster than recovery from anxiety or depression; in sample of participants with mild TBI ($n = 100$), sleep quality, depression, and anxiety scores each significantly improved at follow-up 6 weeks after a 1 month post-TBI baseline assessment but only sleep quality scores improved to the level of baseline (Ma et al., 2013). Depression and anxiety are also factors that may negatively impact neuroplasticity and therefore decrease cognitive reserve.

Pain. Headache and neck pain are common complaints after TBI. Pain was first linked to sleep disturbance after TBI by Beetar (1996) in a seminal study that reported pain was twice as likely to occur in survivors of TBI with insomnia compared to TBI patients without insomnia complaints. Since the Beetar investigation, other researchers

have reported strong associations between insomnia and pain in TBI samples of mixed severity (Fichtenberg et al., 2000) and mild severity (Mollayeva et al., 2016).

Postconcussive syndrome (PCS). Many of the psychiatric disturbances that occur post-TBI present in groups, especially in mTBI. PCS refers to the constellation of symptoms that present concurrently after TBI and may include cognitive impairment, sleep disturbance, pain, dizziness and/or psychiatric or emotional disturbance, although a standard definition for inclusion does not currently exist (Rathbone et al., 2015; Rose, Fischer, & Heyer, 2015). While some researchers have hypothesized that systemic inflammatory responses contribute to the wide range of symptoms possible after mTBI (Rathbone et al., 2015), it is likely that multiple pathophysiological factors contribute to PCS. Sleep quality predicted PCS variance beyond psychological distress or length of time since injury ($p < 0.001$) (Towns, Silva, & Belanger, 2015), and poor sleep quality at baseline predicted poorer post-concussive symptoms a year after injury (Theadom et al. 2015). Sleep may worsen with additional co-occurring conditions (e.g., pain, anxiety, and depression); Fogelberg et al. (2012) reported that sleep quality was worse in participants with co-occurring conditions compared to those without. Based on the complex relationship between sleep disturbance and PCS in survivors of TBI, it is possible that targeted screening and treatment of sleep difficulties might decrease PCS symptoms.

PTSD. Present and past members of the military are at higher risk for both blast TBI and PTSD which are each associated with sleep disturbances (Macera et al., 2012; Powell, 2015; Verfaellie et al., 2015; Wallace et al., 2011). Symptoms of PTSD,

particularly hyperarousal and re-experiencing traumatic moments, are disruptive to sleep and may contribute to the development of nightmares or insomnia (Wallace et al., 2011). Wallace and colleagues compared insomnia patients with PTSD to insomnia patients with both mTBI and PTSD and reported that those with TBI spent less time awake but experienced more subjective sleepiness. Macera et al. (2012) suggested that sleep difficulties may mediate the effect of TBI on PTSD and depression after observing that service members developed sleep problems acutely after deployment but several months later reported symptoms of PTSD and depression. Depression has been linked to sleep and PTSD after TBI, as well as pain (Powell, 2015) and impairment of multiple cognitive domains (Verfaellie, 2015). Powell (2015) noted that alcohol use, typically affiliated with both PTSD and mild TBI, might exacerbate the correlations between PTSD, pain, and sleep. The relationship between PTSD, Sleep, and TBI is complex, and factors such as alcohol use, pain, and psychiatric comorbidities further convolute the relationships between these concepts and make it difficult for researchers to identify causal mechanisms for treatment.

Related Concept: Functional and Rehabilitation Outcomes

Presence of sleep disturbance or changes in sleep microarchitecture may be important prognostic predictors of functional outcomes following TBI (Chan et al., 2015; Duclos et al., 2014; Mollayeva et al., 2016; Sandsmark et al., 2016). Functional outcomes are defined in the literature in various ways, including but not limited to discharge disposition (home, acute rehabilitation, long-term care, death) (Sandsmark et al., 2016), employment and disability status (i.e., perceived disability or disability scores)

(Duclos, 2014; Mollayeva et al., 2016), score on global functioning questionnaires or measurement tools (i.e., Glasgow Outcome Scale [GOS], Functional Independence Measure, Disability Rating Scale) (Cantor et. al., 2012; Makley et al., 2008; Urakami, 2012), driving performance (Beaulieu-Bonneau, Fortier-Brochu, Ivers, & Morin, 2015), or level of social engagement (Chan & Feinstein, 2015). The proposed study will focus on sleep experiences in relationship with functional outcomes associated with social engagement (i.e., relationships and participation in social events) and occupational status (i.e., return to work and work performance). The selection of these defining criteria are based on related questionnaire items in the Pittsburgh Sleep Quality Index (PSQI), GOS, and related interview questions in the two qualitative studies of sleep experiences in TBI to date, Matthews, Signoracci, Stearns-Yoder, and Brenner (2016) and Theadom et al., (2016).

Early presence of sleep disturbances and disorders have been linked with functional outcomes in the acute stages, while lack of sleep-wake cycle consolidation during acute stages has been noted to predict outcomes in the chronic stage of moderate and severe TBI (Duclos et al., 2014; Gosselin & Baumann, 2016). Chan et al. (2015) reported that high symptom burden ($p < 0.0001$) and persistent sleep disturbances ($p = 0.011$) predicted poor outcomes. EEG changes such as presence or absence of sleep architecture and the return of sleep spindles during acute hospitalization for TBI may inform clinicians of recovery prognosis (Evans & Bartlett, 1995; Sandsmark et al., 2016; Urakami, 2012); return of normal sleep features after TBI may be more accurate than the traditional use of GCS scores to predict discharge outcome (Evans & Bartlett, 1995).

Presence of sleep disturbances have predicted length of amnesia and rehabilitation length stay, in addition to GCS score and length of time since injury (Nakase-Richardson et al., 2013). The use of sleep medications may also be predictive of functional status (Ettenhofer et al., 2012). In addition to impact on functional outcomes and longer stays in rehabilitation, sleep disturbances have been linked to lower functional scores on admission to rehabilitation and higher rehabilitation costs (Makley et al., 2008). Poor sleep quality and sleep efficiency resulting sleep disturbances and disorders after TBI, fatigue, cognitive impairment, and psychiatric comorbidities are all barriers to participation during rehabilitation which is integral to achieving optimal functional outcomes and independence (Sandsmark et al., 2016).

Finally, although little is known regarding the impact of sleep on return to employment and disability status, Mollayeva et al. (2016) generated a work disability model in which the odds of higher disability were associated with insomnia and pain. Because employment status is a predictor of health-related quality of life after TBI, across levels of severity (Chiang, Guo, Huang, Lee, & Fan, 2015; Soberg et al., 2013), the impact of sleep on work-related disability warrants further investigation. Employment may promote positive neuroplasticity, as discussed in the context of other neurocognitive impairments (Vance et al., 2015), and barriers to employment due to TBI may therefore inhibit neurocognitive reserve.

Summary of Integrative Review

Studies investigating the many facets of sleep disturbance post-TBI have proliferated over the past two decades. Although there are needs for methodological

revision, gaps in what is known, and confounding factors to consider, researchers have a foundation on which to place future work: Sleep disorders are highly prevalent in TBI and are associated with a myriad of comorbid factors that collectively influence functional outcomes. Although estimates suggest sleep disturbances or disorders in as much as 50% of adult survivors of TBI (Mathias & Alvaro, 2012), the underlying pathophysiology and causal mechanisms are poorly understood (Gosselin & Baumann, 2016; Nikase-Richardson et al., 2013). Studies with varying measures, small samples, low statistical power, and varying results contribute to difficulty characterizing sleep post TBI. Currently, the role of injury severity in the development of sleep disturbances or disorders post TBI is unclear, although mild TBI appears to be integral to the development of sleep disturbance in military combat settings with blast exposure. Functional outcomes have been negatively associated with sleep disturbance in acute hospitalization and rehabilitation settings, highlighting the significance of sleep problems and the need for interventions. Yet, despite growing knowledge in this field, few studies have investigated the impact of sleep disturbance on individual survivors of TBI.

Methods. The widely varied and sometimes conflicting characteristics of sleep described following TBI may be due to the variety of samples and measures used throughout literature regarding TBI and sleep. Some researchers used only objective measures of sleep disturbances and disorders (e.g., actigraphy, PSG, EEG, transcranial magnetic stimulation, observation, serum and saliva biomarkers) (Duclos et al., 2014; Holcomb et al., 2016; Nikase-Richardson et al., 2013; Urakami, 2012; Wiseman-Hakes et al., 2015). Although polysomnography is considered the “gold standard” measure of

sleep in humans and was most frequently used, it is possible that those patients who underwent only one night of PSG exhibited 'first night effects,' or disruptions to sleep due to the new environment and equipment. Actigraphy was also a commonly used objective measure that provides information regarding sleep characteristics without the equipment required for PSG. Actigraphy also has limitations; actigraphy may not register appropriately when used in patients with motor impairment such as in TBI patients with concurrent spinal injuries (Sinclair, Ponsford, & Rajaratnam, 2014).

Other investigators used only subjective measures such as self-report questionnaires or sleep diaries with no objective followup (Cohen, 1999; Huang et al., 2013; Kempf et al., 2010; Wojcik; 2014). The purely subjective approach is problematic due to recall bias and high potential for over and under reporting of sleep propensity, sleep need, and daytime sleepiness documented in TBI samples (Imbach et al., 2015). Weak associations were noted between subjective and objective measures in TBI samples (Nazem et al., 2016; Sinclair et al., 2014). Accordingly, the literature suggests an ideal mix of subjective and objective measures in research of sleep after TBI is needed to adequately account for potential discrepancies.

Other methodological limitations impacting the research related to sleep and TBI include sample size, statistical power, appropriate inclusion and exclusion criteria, and design. Many studies acknowledged small samples with consequential impact on statistical power; few studies reported effect sizes (Oullet & Morin, 2006; Sullivan et al., 2015). Exclusion of participants with any sleep problems or disorders prior to injury is particularly important in research describing sleep in association with TBI. Yet, several studies either neglected to report excluding prior sleep disturbances or did not address the

potential confounding criteria. Finally, many of the studies utilized group comparisons between TBI participants and healthy controls, TBI participants with and without sleep problems, mTBI and moderate-severe TBI, etc. However, case-control and group comparison designs may not adequately address the multifactorial influence of sleep on TBI outcomes or the influence of other factors (psychological, cognitive) on sleep; nonlinear modeling approaches such as structural equation modeling may better address the complex network of associated factors (Durrant, 2015).

To align with the modern view of TBI as a chronic disease (Masel & DeWitt, 2010), researchers and clinicians will need a deeper understanding of the impact of TBI on the independence of survivors and the clinical impact on daily life. While poorer functional outcomes have been associated with sleep disturbances and sleep characteristics, there is a lack of research regarding the impact of sleep on specific activities of daily living (ADLs) and instrumental activities of daily living (IADLs) post-TBI. Although these may be incorporated into the overall functional outcome scores used in this population (FIM, DRS, Ranchos Los Amigos, etc.) there is not research pointing to exactly what activities sleep disturbance might impact or if it disrupts global functioning after TBI. Potential associations between ADLs, IADLS, and sleep disturbances post-TBI may have practical significance for nurses and other rehabilitation professionals caring for TBI patients and also provide more specific targets for intervention development (Duclos et al., 2015).

Experience of Sleep after TBI. The current body of literature lacks evidence pertaining to experiences of individual survivors of TBI. Although two qualitative studies

have contributed rich descriptions of sleep in veterans and community-dwelling citizens of New Zealand following TBI, there are still chasms in the literature suggesting the need for further investigation of this phenomenon (Matthews et al., 2016; Theadom et al., 2016). Participants in the two seminal qualitative works described difficulty grasping need for sleep and rest, confusion with regards to daytime napping, and feelings of being unprepared for the continued impact of sleep disturbances after rehabilitation. In light of these descriptions, research pertaining to sleep in the post-rehabilitation phase of TBI recovery, research investigating the efficacy of napping in TBI patients with sleep disturbances, and continued exploration of the relationships between poor sleep, sleepiness, and sleep need would be directly beneficial to survivors of TBI experiencing sleep disturbances or disorders. Researchers should acknowledge the variety of potential sleep experiences within TBI categories of severity and consider screening and intervention in all TBI cases. Therefore, this study addresses the need for description of sleep experiences in moderate-severe survivors of TBI post-rehabilitation in the United States.

Conceptual Framework

Kay, Newman, Cavallo, Ezrachi, and Resnick (1992) created a conceptual model of functional disability for TBI that depicts the interplay of neurological, physical, psychosocial, and cognitive factors on functional outcomes (Figure 3). An adapted version of this model (Figure 4) is presented to depict the relationships between related

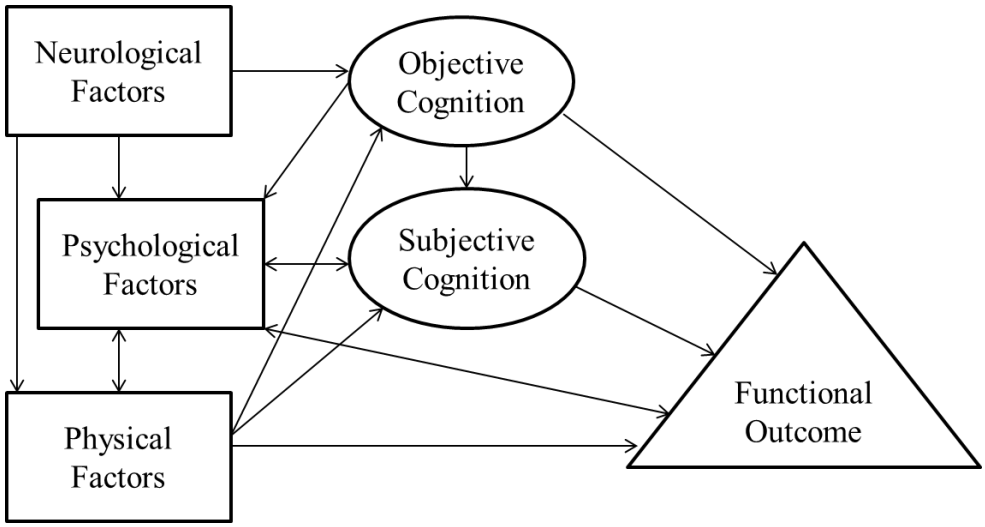

Figure 3. Kay et al. (1992) Neuropsychological Model of Functional Disability.

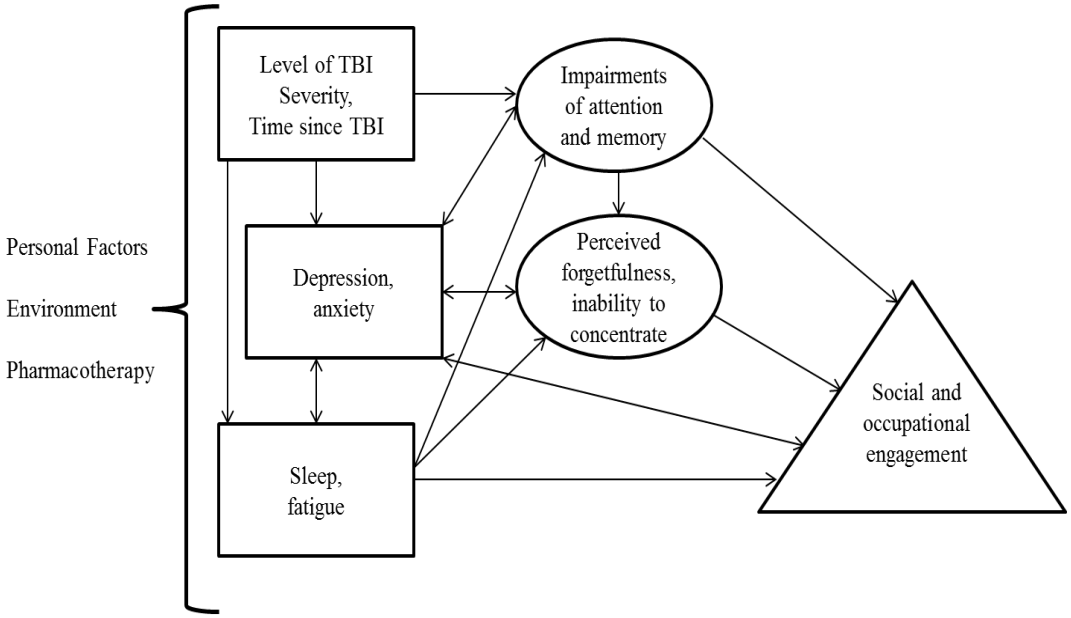

Figure 4. Adapted model for proposed study based on integrative review of literature.

concepts produced by the integrative literature review. The model was not tested, nor the relationships between the concepts in the model; the conceptual framework guided the development of the study and analysis. The modified conceptual model fit the hypothesized "domino effect" that takes place in patients with TBI and sleep disturbance. Differing levels of TBI severity and trajectories of recovery (upper left of model) are associated with different sleep disturbances and disorders (lower left of model) (Chen et al., 2015; Duclos et al., 2014; Huang et al., 2013; Nikase-Richardson, 2013). Sleep disturbances and disorders, in turn, impact psychological factors (Beetar et al., 1996; Chaput et al., Chen et al., 2015; Fichtenberg et al., 2000; Kempf et al., 2010; Parcell et al., 2008; Rao, 2008), cognition (Duclos et al., 2014; Gosselin & Baumann, 2016; Imogen et al., 2010; Maruta et al., 2014, Wilde et al., 2007), and functional outcomes (Chan et al., 2015; Duclos et al., 2014; Mollayeva et al., 2016; Sandsmark et al., 2016). Every piece of the model is impacted by sleep apart from initial TBI severity and time elapsed since injury.

This model highlights the results of the literature review—appropriate treatment of sleep disturbances and disorders following TBI may be pivotal in improving functional outcomes and may even improve cognitive and psychiatric symptoms associated with TBI. One main change was made to the modified conceptual model to reflect relevant literature. The relationship between psychiatric comorbidities and objective cognition was changed to reflect a bidirectional relationship (Mauri et al., 2014; Spitz, Shonberger, & Ponsford, 2013).

The relationships between sleep and cognition, both subjective and objective components, are represented by unidirectional arrows to reflect the impact of sleep on

cognition (Beaulieu-Bonneau et al., 2015; Bloomfield, Espie, & Evans, 2010; Wilde et al., 2007); while increased cognitive effort could lead to cognitive fatigue, this concept is distinct from sleep, which is the focus of this model. The relationship between sleep and psychological factors (depression, anxiety, pain, PTSD, etc.) is represented by a bidirectional arrow due to the potential cyclical relationship found between these concepts. Patients with insomnia often also present with pain, anxiety, or depression (Beetar et al., 1996; Fogelberg et al., 2012; Lang, Veazey-Morris, & Andrasik, 2014) and these conditions may subsequently disrupt sleep following TBI. The relationship between sleep and function is unidirectional, based on literature suggesting that sleep influences outcomes on follow up functional questionnaires (Chan et al., 2015), longer stays in trauma center and rehabilitation centers (Makley et al., 2008), higher levels of work disability (Mollayeva et al., 2016), and discharge outcome (home, long term care, assisted living, death, etc.) (Sandsmark et al., 2016).

The modified conceptual model suggests that sleep is a cornerstone of health and function and TBI patients. Therefore, clarifying experience of sleep after TBI may aid researchers and clinicians in developing targeted interventions for sleep post-TBI, with the potential to have secondary effects on psychological correlates (depression, anxiety, PTSD, pain), cognition (objective and subjective cognition), and functional outcomes. Additionally, unless sleep disturbances and disorders are more broadly understood and appropriate screenings and treatments take place, interventions targeting other areas of the model, such as depression or cognition, may not be as effective as they might be in conjunction with sleep-related intervention.

Design Selection and Methodology

Design Options

Qualitative or quantitative designs could be used to describe the sleep of survivors of TBI post-rehabilitation. A quantitative study might use subjective survey and/or objective observational methods to describe the sample, such as polysomnography or validated subjective measures of sleep quality (e.g., Pittsburgh Sleep Quality Index) or excessive daytime sleepiness (Epworth Sleepiness Scale). However, a quantitative design would be limited in the type and amount of data collected by the fixed design and closed-ended means of data collection. Many objective sleep measures such as polysomnograhy are expensive and require multiple nights to avoid 'first night' effects. A qualitative design using in-depth interviews might also be an option to address the problem and might allow the researcher to understand the nuances of patient experience and gather future research questions. Specifically, a qualitative design might gain contextual data otherwise uncaptured by validated sleep measures. Cognitive impairment could impair recall, a disadvantage to a qualitative design, but screening for patients with adequate cognitive and communicative ability could ensure that participants are able to share rich descriptions of their experiences. A qualitative design could potentially provide investigators with a broad range of contextual data through open-ended data collection (Sandelowski, 2010).

The problem, a lack of understanding of individual sleep experiences following TBI in the context of community-dwelling adults, post-rehabilitation, would be best addressed by a qualitative design in the proposed study. The qualitative approach is preferable to the quantitative approach in this study because the focus is on an analysis of

a single phenomenon, sleep quality, from the perspective of survivors of TBI post-rehabilitation. A quantitative approach would be more appropriate in a study investigating relationships between sleep and other phenomenon or statistical descriptions of the phenomenon (Polit & Beck, 2012). Since aspects of sleep such as sleep quality are highly subjective in nature, objective measures do not consistently corroborate self- report of perceived poor sleep quality (Buysse et al., 1989; Lu et al., 2015). Individual perception of sleep, therefore, is integral for researchers seeking to develop a description of sleep that reflects its subjective nature. A qualitative study could enhance understanding of poor sleep quality as experienced by survivors of TBI by elucidating a picture of what poor sleep quality is to these individuals, how it is experienced, and what words they would use to describe it (Sofaer, 1999).

Qualitative Design

This study was exploratory. Philosophical underpinnings of qualitative research guided this study, including the ontological assumption of multiple realities, or that individuals have different experiences and view their experiences uniquely. Also, the epistemological assumption that subjective descriptions of experiences are valuable knowledge was integral to this study and informed the use of quotes as evidence during analysis. The axiological assumption of qualitative research that biases are inherently present was also key in designing the study to promote trustworthiness and rigor and minimize bias to the extent possible. In general, naturalistic inquiry was an appropriate philosophical approach to the study because naturalism promotes the study of a

phenomenon in its natural state with minimal to no manipulation of associated concepts or variables (Denzin & Lincoln, 2003).

Methods

Two qualitative methodologies were considered for the study: Phenomenology and qualitative description. A phenomenological approach to this qualitative study might have allowed the investigator to focus on the meaning attributed to experiences of poor sleep quality that have been previously unreported. Individual interviews conducted by phenomenological design would have allowed the researchers to report and interpret experiences of sleep, and delve deeper into the essence of the phenomenon (McConnell-Henry, Chapman, & Francis, 2009). A benefit of a phenomenological approach would be that meanings ascribed to sleep experiences in survivors of TBI might highlight the personal impact of sleep disturbances and therefore contribute to the significance of problem and rationale for further research. However, individuals with TBI, depending on their cognitive ability, may be able to describe but not assign meaning to the phenomenon—which requires higher levels of cognition than simple description.

Qualitative description, or descriptive inquiry, is an approach to qualitative research that aims to create a "comprehensive summary of events in the everyday terms of those events" (Sandelowski, 2000, p. 334). A benefit of qualitative description is its straightforward and simple approach, such as the use of clear and concise research questions with little elaboration (Sandelowski, 2000). However, a drawback of qualitative description is that many misconceptions surround the terminology such as assuming surface-level analysis means no interpretation whatsoever. All forms of research involve

both description and interpretation of some kind; qualitative description involves interpretation but only minimally so, to ensure that interpretive validity is achievable with great transparency (Sandelowski, 2010).

Qualitative Description

Qualitative description is an appropriate fit for this study because it generates descriptions of a phenomenon as a starting point for further qualitative study such as phenomenological or grounded theory studies (Magilvy & Thomas, 2009; Sandelowski, 2000). Descriptive inquiry is considered a foundational method for other qualitative methods (Sandelowski et al., 2010) and therefore an ideal "first step" in understanding what patients experience, before moving on to interpretation and meaning. Considering the current trends in literature regarding sleep and TBI, as identified in the integrative review, a qualitative descriptive study of sleep in survivors of TBI post-rehabilitation in the United States would be both timely and appropriate. Additionally, qualitative description is appropriate for novice researchers learning to conduct qualitative research because of its clear and direct approach. Both Theadom et al. (2016) and Matthews et al. (2016) used qualitative description as initial qualitative investigations of sleep after TBI. Matthews focused on describing the experience of veterans, whose sleep experiences may differ from civilian survivors of TBI due to previous exposure to military environments and high comorbid prevalence of PTSD. Although Theadom et al. colleagues investigated sleep descriptions in civilian survivors of TBI, the study took place in New Zealand and included members of a local native group: Maori tribe members. While the inclusion of the Maori people was most likely aimed at increasing generalizability of study findings,

the experiences or rituals associated with Maori culture may have influenced the descriptions of sleep provided during the study. Altogether, a qualitative design, specifically qualitative descriptive methodology, is the most appropriate fit for investigation of the problem via this study.

Ethical Issues

Cognitive impairment after TBI is a significant problem and can impair ability to self-report symptoms or understand information necessary for informed consent. Survivors of TBI are specifically at risk for a category of vulnerability defined by the National Bioethics Advisory Commission (2001): cognitive or communicative vulnerability. Cognitive impairment may impact decision making capacity (DMC), a complex process that requires cognitive abilities that may be impaired after TBI (Johnson-Greene, 2010; Lynch, Kothari, & Kirschner, 2003). Aggarwal and Ford (2013) suggest that the ability of TBI patients to provide consent is not consistent during the recovery process, complicating attempts by investigators to appropriately time an approach for consent. Marson et al. (2005) conducted the first known empirical longitudinal study of DMC after TBI and reported intact simple decision abilities during acute care for participants but little or no intact ability to conduct formal reasoning. After 6 months, participants showed improvement and were able to perform the complex reasoning needed to provide consent (Marson et al., 2005). Dreer, DeVivo, Novack, Krzywanski, and Marson (2008) also investigated cognitive predictors of DMC during the acute phase of TBI treatment and 6 months after injury. They reported a significant impairment in short-term memory affecting DMC immediately after TBI that improved

with recovery time. The work by Marson et al. (2005) and Dreer et al. (2008) suggest that cognitive factors post TBI contributing to diminished DMC at the time of initial hospitalization may improve over a minimum 6-month recovery period and possibly longer.

A legally authorized representative (LAR) or surrogate for consent may be used for legal and ethical enrollment of TBI participants, alongside assent, if possible. A LAR is the designated surrogate decision maker for the potential research participant and may be a relative or trusted friend. Winslade and Tovino (2004) describe an important ethical benefit of surrogate consent in impaired DMC: it emphasizes the protection of a vulnerable population by ensuring that authority to enroll a participant in a study is not found solely within the research team. There is documented doubt regarding a surrogate's ability to choose the service members' participation preferences (Johnson-Greene, 2010). This doubt stems from the basis of LAR consent that assumes inherent accuracy of decision-making on the participant's behalf and the ability of the surrogate to adequately weigh the chances of biological survival, quality of life, and projected outcomes (Aggarwal & Ford, 2013). As an alternative strategy, a research team could align a study with a survivor's recovery and return of DMC so that LAR is no longer necessary. In this study, participants were approached post-rehabilitation and approximately 1-3 years after injury allowing some cognitive recovery prior to participation. Participants were also required to pass a cognitive screen with questions about the consent to be eligible for enrollment.

Chapter Summary

Worldwide, nationally, and locally, TBI remains a prevalent public health concern with heavy financial and personal impact. Although the underlying mechanisms are still unclear, many survivors of TBI suffer from sleep disturbances and disorders that increase risk for comorbidities and poor rehabilitation and functional outcomes. Despite exponential growth in publications related to sleep and TBI over the past two decades, much about sleep after TBI is still unknown; sleep disturbances and disorders have been statistically characterized and linked to related phenomena, but few researchers have characterized sleep after TBI using descriptions of survivors of TBI themselves. Therefore, the purpose of this study was to fill this gap in knowledge and produce a description of survivors of TBI post-rehabilitation that may inform intervention development and/or future studies of this phenomenon. A modified version of the Kay et al. (1992) Neuropsychological Model of Functional Disability was utilized as a guide for the proposed study. The use of qualitative inquiry is preferable for this endeavor, especially for a starting point in generating a description of the phenomenon that has not been previously produced.

CHAPTER 3

METHODS

Given the gaps in the literature presented in chapter 2, this study addressed the problem with a qualitative design, descriptive inquiry, to generate a description of sleep experiences from survivors of TBI. The purpose of this chapter is to discuss the methodological components of the study including the plans for sampling and recruitment, informed consent, procedures, and data analysis. Additionally, strategies for establishing trustworthiness of the data are identified and discussed. The proposed study aimed to describe the experiences of moderate-severe, adult survivors of TBI using the following research questions:

1. How do survivors of a moderate-severe TBI who are post-inpatient rehabilitation describe their sleep before injury?
2. What factors do survivors of moderate-severe TBI describe as positively or negatively impacting their sleep experiences?
3. How do survivors of a moderate-severe TBI describe their social engagement in relation to their sleep experiences?
4. How do survivors of moderate-severe TBI describe their occupational engagement in relation to their sleep experiences?
5. What sleep-related education is provided to survivors of moderate-severe TBI?

These questions were deemed appropriate for the study because the responses they aimed to generate would contribute to a holistic, comprehensive description of the sleep experiences of survivors of TBI. Although the research questions are simple, Sandelowski (2000) suggests that "straight and largely unadorned" research questions are best suited for qualitative descriptive research (p. 337).

Sampling

Purposive sampling was used to recruit participants for the proposed study. Purposive sampling is a non-probability sampling technique that aims to enroll participants who have experienced a specific phenomenon, and this element of eligibility is the objective of purposive sampling, more so than gender, race, or age. The participants' descriptions of experiences are of utmost interest in qualitative description. Therefore, purposive sampling is the most common and appropriate choice for qualitative descriptive research (Sandelowski, 2010). Permission was granted from the program director of TBIMS at UAB to access a list of participants who agreed to be contacted for future research (Appendix H). The list provided addresses and phone numbers of survivors of TBI who completed rehabilitation at SRC in Birmingham, participated in a TBIMS Study during their rehabilitation stay, and agreed to be contacted for future research. Inclusion in the TBIMS program requires that an individual must display all of the following characteristics: 1) admitted to an acute hospital affiliated with the Model System within 72 hours of injury; 2) at least 16 years of age; and 3) admitted for acute rehabilitation. In addition to meeting the first three criteria, individuals must also display one of the following: 1) post-traumatic amnesia greater than 24 hours; 2) trauma related intracranial neuroimaging abnormalities; 3) loss of consciousness exceeding 30 minutes

(unless due to sedation or intoxication); or 4) GCS in the emergency department of less than 13 minutes (unless due to intubation, sedation, or intoxication).

Inclusion and Exclusion Criteria for Proposed Study

The following additional inclusion criteria were applied: 1) moderate-severe TBI; 2) appropriate cognition and ability to verbally communicate; 3) 18-50 years of age; and 4) 1-4 years post injury. The following exclusion criteria were applied: 1) history of sleep disturbance or disorder prior to TBI; 2) non-English speaking patient; and 3) current known pregnancy.

Some of the cognitive requirements for capacity to consent (i.e., understanding purpose and risks/benefits before reasoning and making a choice) were similar to the cognition necessary for participation in the proposed study (i.e., understanding questions, remembering and sharing experiences). Because of this overlap, the proposed study used capacity to consent to determine the participant's cognitive eligibility for participation. While head trauma may result in cognitive impairment, it may not necessarily impact a participant's understanding of the consent document. Capacity to consent was determined by the PI's assessment of the individual's understanding of the following during the recruitment call: 1) purpose of study; 2) risks and benefits of study; and 3) voluntary nature of study and withdrawal. The PI assessed the appropriateness of responses to questions regarding the consent and study elements and the ability of the individual to answer, without the help of a caregiver, to determine capacity to consent. Assessment of these factors is consistent with the National Institute of Health's policy on questionable capacity to consent (2009)

Ability to verbally communicate experiences was assessed during the recruitment call and based on the clarity and appropriateness of the potential participant's verbal responses to questions without the help of a caregiver. Level of injury severity was determined by the TBIMS database. Moderate-severe TBI was an inclusion factor due to two main reasons. First, pragmatically, the list of TBIMS participants who agreed to be contacted for future research only includes moderate-severe TBI. Second, a review of the literature (see chapter 2) revealed that moderate-severe survivors of TBI are likely to suffer from sleep disturbances following injury. Additionally, the sleep experiences of moderate-severe survivors of TBI have not been extensively investigated or described. Age and time post-injury were determined by the TBIMS database and confirmed by self-report. The time range post-injury of 1-4 years allowed time for some cognitive recovery and completion of inpatient rehabilitation, but also prevented an excessively wide range of recovery trajectories. History of sleep disorder diagnosis prior to TBI (i.e., insomnia, hypersomnia, circadian rhythm sleep-wake disorders, sleep-related breathing disorders) were determined by self-report; the presence or absence of a premorbid sleep disturbance or disorder may impact the description of sleep experiences following TBI. Current known pregnancy was determined by self-report and excluded due to the hormonal changes accompanying pregnancy that might also impact sleep experiences following TBI.

The age range was identified to exclude adolescent participants due to circadian rhythm and developmental changes to sleep (Crowley, Acebo, & Carskadon, 2007), middle aged women due to poor sleep related to menopause and premenopause (Freeman, Sammel, Gross, & Pien, 2015), and older adults or geriatric participants due to

sleep changes associated with aging (Espiritu, 2008). Exclusion based on sleep disorder prior to TBI was determined by self-report. Although TBIMS data was, it did not include information about pre-existing sleep disorder(s). Exclusion of survivors of TBI with pre-existing disorders is essential to generate clear descriptions of sleep in reference to injury; descriptions from survivors of TBI with pre-existing sleep disorders might be clouded by their prior diagnosis or disturbance.

Present or premorbid mental illness, particularly depression or anxiety, may impact sleep experiences following TBI. However, depression and anxiety are also highly prevalent in TBI samples; estimates of anxiety prevalence reach as high as 70% and depression estimates range from 25-50% (Scholten et al., 2016). Exclusion based on depression or anxiety might limit the representativeness of the sample and transferability of results. Furthermore, exclusion based on depression or anxiety may hinder ability to reach recruitment targets (Maas et al., 2010; Trivedi & Humphreys, 2015). Given the concern for transferability and feasibility, premorbid or present mental illness was not added to the exclusion criteria of the proposed study. However, participants who appeared anxious during the interview were encouraged to take a break. Participants completed a screening instrument for depressive symptoms for referral to the TBIMS director. In the case of suicidal ideation, emergency services and the TBIMS director were notified. Many survivors of TBI take medications that may impact sleep or cognition. Because excluding participants based on medication would limit transferability, medication information was attained from participants but not used for exclusion criteria.

Sample Size

Research participants (N = 16) were recruited from January 2017 to April 2017. Data saturation (i.e., redundancy is noted in the data pertaining to key themes) was noted at interview 12 (Walker, 2012). The sample size was based on consideration of recommended sample sizes from a variety of sources. Magilvy and Thomas (2009) suggests that qualitative descriptive studies use 3 to 20 participants, depending on the research question and adequacy of collected data to generate description. While Sandelowski suggests that as few as one participant is necessary to explore a single aspect of an experience that is of interest, she also suggests a range as wide as 6 to 25 participants for generating descriptions (Sandelowski, 1995). This sample size is close to those published in other qualitative studies using TBI participants such as N = 19 (Matthews et al., 2016) and N = 30 (Theadom et al., 2016).

Recruitment and Informed Consent

Potential participants, identified through the TBIMS list of those who may be contacted for future research, had 2 weeks to 3 weeks from the mailing of the recruitment letter and consent document (Appendix I, J) to review the study information and consider participation. This provided ample time for the participant to consider involvement in the study and minimized coercion. The PI described the study and consent process during the recruitment call (Appendix K) and at the on campus interview, prior to written consent, to ensure a thorough understanding of the content. To prevent coercion from a family member, caregiver, friend, etc., surrogate consent was not accepted. Only potential participants capable of understanding the consent form and providing independent

informed consent were eligible. Written consent was obtained during the in-person interview. Capacity to consent was determined by the PI's assessment of the individual's understanding of the following during the recruitment call: 1) purpose of study; 2) risks and benefits of study; and 3) voluntary nature of study and withdrawal. The PI assessed the appropriateness of responses to questions regarding the consent and study elements and the ability of the individual to answer, without the help of a caregiver, to determine capacity to consent.

Data Collection

Participants meeting eligibility criteria who stated they would like to enroll were scheduled for an in-person interview to take place at UAB Medical Towers (first 5 participants) or at UAB SRC (last 15 participants). The interview rooms were private to minimize distraction and protect confidentiality. At the beginning of each appointment, the investigator described the research study and role of participant. Consent was attained and each participant underwent an in depth, semi-structured interview, which lasted approximately 40-45 minutes (Appendix L)**.** The interview guide was developed based on the core concept of sleep and ancillary concepts of interest from the conceptual model, questions from related studies (Matthews et al., 2016), and similar items on the PSQI. The semi-structured interview guide was developed with oversight from a qualitative methods expert and was adapted based on a review of the first five interviews. Each interview was audio-recorded with a Sony ICDUX71 1GB Digital Voice Recorder. Participants completed the Pittsburgh Sleep Quality Index (PSQI), a validated instrument for determining "poor" or "good" sleep quality in survivors of TBI (Buysse et al., 1989; Fichtenberg et al., 2001, Lequerica et al., 2004) (Appendix L). Participants also

completed the Patient Health Questionnaire-2 (PHQ-2) (Appendix M), a two-item instrument for depressive symptoms used to make referrals. Although in-depth interviews typically last an hour or more, the interviews in the proposed study were aimed to be completed in 45 minutes or less to accommodate for shortened attention spans that are common in survivors of TBI (Paterson & Scott-Findlay, 2002). As discussed in the cognition section of chapter 2, survivors of TBI often struggle with shortened attention spans that can potentially hinder lengthy interviews. The direct and simple nature of qualitative description, in addition to a slightly shortened interview time of approximately 45 minutes, aimed to address these cognitive issues in interviewing (Paterson & Scott-Findlay, 2002). All procedures, including consent, questionnaire data, and PSQI took approximately 65 minutes**.**

The researcher recorded the overall time for each participant in individual field notes. All raw data, including audio files, field notes, and consent forms were stored in a locked space in Medical Towers at UAB and only accessible by the researcher or committee chair. The consent forms were stored separately from the data. Access to the TBIMS dataset occurred only at UAB SRC on a centrally-maintained computer under the supervision of the TBIMS director or data manager. At the end of the session, each participant was compensated $48 cash for their time, travel, and parking. The amount of compensation was determined based on previous amounts given during TBIMS studies to avoid coercion. The PI ensured that contact information for the participant was current. Each participant was provided with the PI's contact information for any questions that might arise.

Trustworthiness

Trustworthiness, described by Lincoln and Guba (1986), is an essential measure of rigor used to judge the quality of a qualitative research study. Lincoln and Guba discuss many strategies for achieving trustworthiness, although not every strategy is applicable to every qualitative study (Morse, 2015). For this study, transferability and credibility were addressed.

Transferability

Transferability, referred to as generalizability in quantitative literature, contributes to trustworthiness of qualitative work and was addressed in the proposed study to ensure utility of the collected data. The study sample may provide some transferability to adult survivors of moderate-severe TBI post-inpatient rehabilitation in the United States. The makeup of the list that will be used to recruit potential participants for the proposed study was very similar to the sample making up the TBIMS national database. The national database is suggested to be representative of U.S. admission of age 16 years and older survivors of moderate-severe TBI admitted for inpatient rehabilitation with two exceptions: patients over 65 years of age and those who stayed between 1 and 9 days in rehabilitation (Corrigan et al., 2012). The study did not include participants over age 50 years and the investigator had access to the TBIMS data reporting the length of time in rehabilitation.

Credibility

Several techniques were used in the proposed study to enhance credibility: 1) triangulation; 2) reflexivity; and 3) audit trail. Triangulation, the use of multiple sources of data to produce a comprehensive understanding of a phenomenon, was utilized to promote trustworthiness in the proposed study (Cresswell, 2013). A sleep measurement tool, the PSQI, was used in addition to interview data regarding sleep. The PSQI can be used to identify "good" vs. "poor" sleepers based on dichotomization of an overall score, the PSQI Global Score.

Reflexivity, attention to the researcher's perspective and position in relation to the investigation, is essential in minimizing bias. In this study, the researcher generated memos for self-exposure and self-awareness. Creating memos aided the researcher in differentiating between data-driven descriptions of the phenomenon and personal insights of the phenomenon. From a pragmatist perspective, the ability of the researcher to fully detach from their position may not be attainable. However, reflexivity is a useful tool in minimizing as much bias as possible, with an understanding that some amount of perspective is inherent in qualitative research due to the high level of investigator involvement.

Finally, an audit trail, consisting of raw data, field notes, memos, and any synthesis products were used to enhance transparency and therefore support credibility of the proposed study by providing a clear description of the research path for auditors to follow (Lincoln & Guba, 1986). Excerpts of the audit trail were shared with the committee chair to establish interpretive convergence (i.e., general consensus that the

given description(s) are grounded in the data and that credibility and trustworthiness are intact) (Saldana, 2015).

Data Analysis Plan

Transcription and analysis occurred as data became available and were ongoing during the course of the study. The audio interview data were transcribed verbatim by the PI to facilitate "closeness" to the data. Closeness refers to knowledge of and familiarity with the content of qualitative data (Gilbert, 2002). Any identifying information was removed from transcripts. Transcripts were uploaded to NVivo© qualitative analysis software on an encrypted computer. Together, field notes, memos, audio data, and transcripts made up the body of data analyzed.

A cyclical method of memoing and coding was utilized, followed by thematic analysis (Saldana, 2015). Thematic analysis was used to identify concepts within individual interviews and group themes across interviews to generate descriptions of a phenomenon (Fereday & Muir-Cochrane, 2006). The first step in analysis was thoroughly reading individual transcripts and writing a narrative memo for each to describe the overall thoughts of the researcher on how the participant might be describing his or her sleep experience. The second step in the analysis was initial coding, or first cycle coding. Preliminary codes were applied broadly and a tentative codebook with exemplar quotes was generated. Then, second cycle coding was used to further refine the codebook and identify relevant descriptions of sleep. Finally, refined codes were placed into categories and themes to facilitate succinct and synthesized description of participants' sleep experiences. As recruitment continued and subsequent transcripts

became available, the researcher applied the cyclical memo and coding process until all transcripts had been coded. Refinement of the codebook occurred throughout this process. Finally, the researcher looked at the transcripts as a collective body to determine if the coding, categorization, and theme development was applicable across the sample. Throughout the process, memoing on methodological choices, emerging codes and themes, and thoughts of the researcher applicable to the research question and data were documented. Coding was primarily descriptive, or aimed at topical indexing and description of the experiences, and in vivo coding (using the words of participant's to honor their word choices) dependent upon the interview data. Overall, the data itself and words of the participants drove the coding and analysis.

Chapter Summary

Given the problem and purpose of the proposed study, qualitative descriptive inquiry is the best suited approach for design, data collection, and analysis. Therefore, the researcher sought answers to the research questions by purposively recruiting individuals with TBI who were capable of describing their sleep experiences. After providing consent, participants shared sleep experiences during a semi-structured interview. Transcription and data analysis (coding and memos) occurred sequentially during the data collection period. The PI used safe and appropriate procedures throughout the processes of recruitment, data collection, and analysis to protect the confidentiality of participants.

CHAPTER 4

RESULTS

This chapter presents the final study results including central themes resulting from thematic analysis. Five themes, along with subthemes, that cumulatively contribute to a description of sleep experiences following moderate-severe traumatic brain injury are identified.

Sample Characteristics

A total of 16 survivors (N = 16) of moderate-severe TBI were recruited for participation. All required inpatient rehabilitation following injury, were previously part of a TBIMS study, and met study inclusion criteria. Data saturation, the point at which redundancy in themes was noted and no new codes were created during analysis, was reached after 12 interviews (Munhall, 2012). However, the four remaining scheduled interviews were completed. Recruitment and data collection took place over 4 months. A list of 153 potential participants was derived from TBIMS data by director Dr. Thomas Novack and his data manager. Each participant was mailed a copy of the consent form and information regarding the study. Sixteen informational packets were returned as undeliverable. Two survivors mailed back signed consent forms prior to recruitment calls but, when contacted by phone, said they couldn't participate at the time due to scheduling. During recruitment calls many potential participants did not answer. Of those who did answer, eight stated they were not interested and six stated that they were

interested but did not have transportation to the interview site. In total, 28 individuals completed the eligibility screening via phone or 18% of the 153 potential participants. Three participants were excluded based on self-reported previous diagnosis of sleep disorder (sleep apnea, narcolepsy, or circadian rhythm disorder) and two were not eligible based on cognitive status. Two participants were screened and scheduled but decided to cancel scheduled interview appointments during the reminder calls. Five participants did not come to scheduled interview appointments and did not answer follow-up calls (Figure 5).

All but one participant drove from within the state to the interview site; the individual who drove from a neighboring state shared that his eagerness to participate was due to his frustration with sleep and his desire to help future survivors. The first five interviews took place in a private interview space at UAB Medical Towers. The remaining 11 interviews took place in a private interview space at UAB SRC due to security and access to safety resources at that location after an early participant threatened suicide.

The final sample consisted of predominately Caucasian men (n = 14), which is consistent with national samples of survivors of TBI. The average age was 32.4 years (SD = 9.9); average length of years post-injury was 2.6 years (SD = .89). Most participants had sustained severe injuries (n = 12), and a fourth of the sample had sustained moderate injuries (n = 4). Most participants were civilians. Although three were veterans, none received care or resources from a VA facility. Participants completed the PhQ-2 as a screening tool for depression and to trigger referral as needed. Of the 16 participants, 5 were referred for follow-up with the TBIMS director based on PhQ-2 scores. Participants

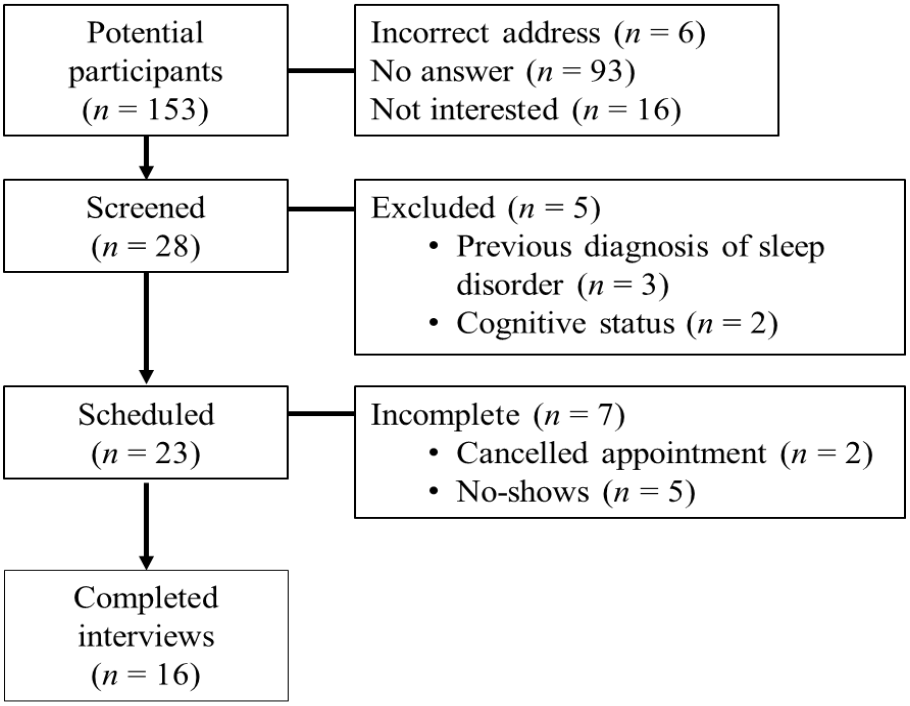

Figure 5. Recruitment flow chart.

also completed the PSQI as a measure of triangulation; each PSQI Global Score was dichotomized based on a cut-off score of 5 into poor sleep quality or good sleep quality. Each PSQI global score matched the description of sleep provided during the in-depth interviews and no major differences were noted. The average PSQI score was 8.44 (*SD* = 4.95), indicating that the sample had generally poor sleep quality, a finding consistent with the sleep described in participant interviews. Interview length ranged from 23 minutes to 1 hour and 56 minutes. The broad range may be attributed to the varying levels of cognitive function among participants, particularly attention span, and the addition of many stories and details from certain participants. Participants were offered breaks during longer interviews, although most refused.

Table 1. *Demographic and Clinical Description of Sample (N = 16)*

	n (%)	*Mean (SD)*	*Range*
Racial affiliation			
African American	2 (12.5)		
Caucasian	14 (87.5)		
Gender			
Female	5 (31.3)		
Male	11 (68.7)		
Level of Injury Severity			
Moderate	4 (25)		
Severe	12 (75)		
Mechanism of Injury			
Blunt trauma	3 (18.8)		
Motor vehicle crash	13 (81.3)		
GCS on admission		6.4 (4.40)	3-15
PTA duration		27.8 (17.60)	6-61
Age at injury		32.4 (9.90)	19-47
Years since injury		2.6 (0.90)	1-4
PSQI		8.44 (4.95)	1-18

Abbreviations. GCS, Glasgow Coma Scale on admission; PTA, posttraumatic amnesia; PSQI, Pittsburgh Sleep Quality Index Global Score.

.

Table 2. *Individual Participant Characteristics*

Label	GCS	PTA	Severity	Age at Injury	Years since Injury	Race	Gender	PSQI Global Score	PHQ-2 Score
Mr. A	14	20	Moderate	47	2	B	M	15	2
Mr. B	3	30	Severe	28	3	W	M	5	0
Ms. C	3	17	Severe	23	3	W	F	6	0
Mr. D	13	40	Moderate	37	2	W	M	11	4
Mr. E	6	7	Severe	43	1	W	M	9	0
Mr. F	6	8	Severe	42	3	B	M	8	1
Mr. G	3	37	Severe	44	3	W	M	1	0
Mr. H	4	61	Severe	43	2	W	M	6	3
Mr. I	15	6	Moderate	25	2	W	M	2	0
Ms. J	3	37	Severe	28	1	W	F	4	6
Mr. K	3	44	Severe	34	2	W	M	15	1
Ms. L	3	48	Severe	22	4	W	F	8	1
Mr. M	6	8	Severe	23	3	W	M	14	6
Ms. N	7	8	Severe	20	3	W	F	8	0
Ms. O	11	45	Moderate	41	4	W	F	5	0
Mr. P	3	29	Severe	19	3	W	M	18	4

Abbreviations. GCS, Glasgow Coma Scale from admission; PTA, posttraumatic amnesia duration; PSQI, Pittsburgh Sleep Quality Index; PHQ-2, Patient Health Questionnaire-2.

Themes

Five themes that cumulatively contribute to the description of survivors' sleep experiences following moderate-severe traumatic brain injury were identified: 1) problems with sleep; 2) perceived impact of sleep and fatigue on relationships and work; 3) learning to manage; 4) coping; and 5) resources. Themes one and two primarily describe sleep experiences of participants while themes three and four describe how participants respond to their experiences. The fifth theme describes the participants' desired resources to improve sleep experiences after moderate-severe TBI.

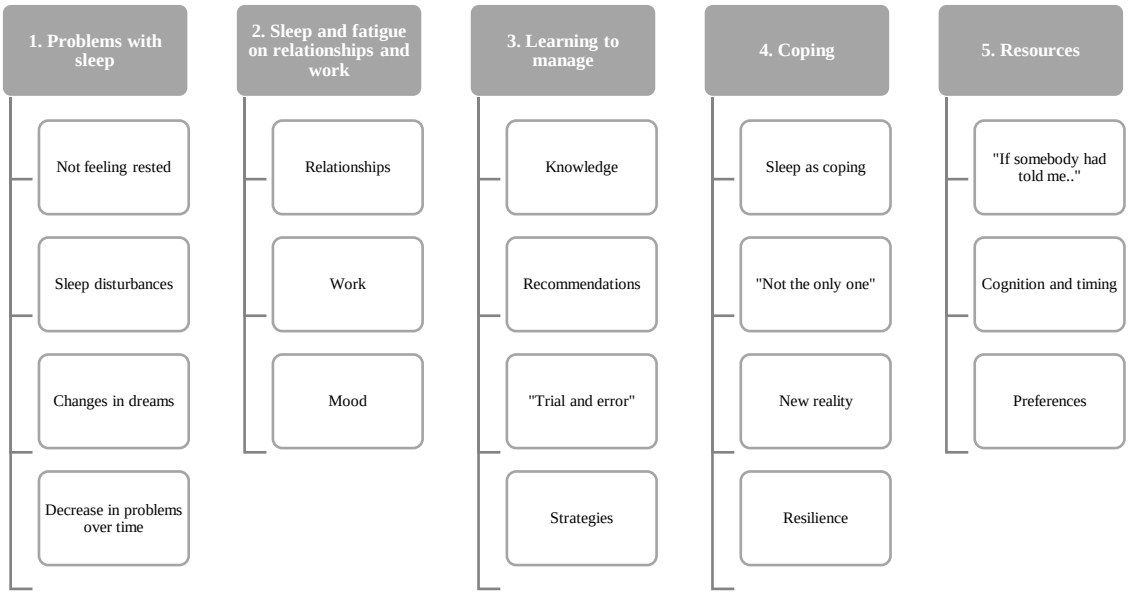

Figure 6. Central themes and subthemes.

Theme 1: Problems with Sleep

Survivors primarily described problems with sleep, both recent sleep experiences and sleep experiences close to the dates of their injuries. Changes to sleep quantity or

quality were often described. Participants described two extremes of sleep quantity, either sleeping very few hours per night or "sleeping my life away" (Mr. K). Some participants reported as few as two hours to three hours of sleep per night, others reported sleeping at least eight hours a night in addition to naps throughout the day. In terms of sleep quality, participants reported trouble falling asleep and/or trouble staying asleep (i.e., disruptions and frequent nighttime awakenings). Once sleep was achieved, awakenings were common. Survivors reacted to sleep problems with an increased appreciation for sleep, a desire to "get my sleep back" (Mr. B), and frustration with sleep problems after injury. Four subthemes emerged from the data related to problems with sleep: 1) not feeling rested; 2) sleep disturbances; 3) dreams; and 4) decrease in sleep problems over trajectory of recovery.

Not feeling rested. Participants reported difficulty achieving restful sleep regardless of the number of hours slept. They described poor sleep quality during nighttime sleep but improved sleep quality during daytime naps. Participants used "rest" or "restful" sleep as a label for sleep that resulted in a feeling of refreshment upon wakening or a feeling that their need for sleep had been met. Feeling rested or achieving restful sleep was described as illusive for participants:

> But I don't feel (pause) when I wake up in the morning (pause) I just don't feel restful. I still feel like I could sleep, like I need more sleep. I don't feel like, you know, how they tell you … if you go to bed and you get a good eight hours of sleep you're gonna wake up and feel rested …? NO. I don't ever feel that ever (Ms. J).

Similarly, another participant shared that he could fall asleep without difficulty "but…when I wake up, I feel like I ain't ever fell asleep…uh I get up tired, well uh I'll

fall asleep…and get up…but it feels like I never went to sleep. Which I probably have it just feels like I never have" (Ms. C). Some participants described their sleep during daytime naps as more restful than nighttime sleep: "when I get up from that nap though I do feel like I've slept and that it's been a restful sleep" (Ms. O). Another participant described nap sleep as "almost like a better quality sleep than my night sleep" (Ms. J).

Sleep disturbances. Participants described a variety of sleep disturbances contributing to problems with sleep following TBI. These range from excessive sleepiness to trouble falling asleep and trouble staying asleep (i.e., disruptions and frequent nighttime awakenings). For example, one participant shared "I'll be sleepy before I lay down but once I lay down I can't go to sleep" (Mr. D). Participants described not knowing why they were unable to fall asleep or attributed their difficulty falling asleep to thoughts or worries. Once sleep was achieved, awakenings were often described in relation to bedpartners, pain (including phantom pain), positioning, and nocturia. Less common reasons for nighttime awakenings included seizures, headaches, and night sweats. The frequency of nighttime awakenings varied, and many participants described waking up in the early morning hours, particularly between 2 am and 5 am, and were unable to go back to sleep. One participant described sleep as "…interrupted at least four to six times a night. Some nights I sleep better than others but for the most part, um, and it's sometimes I just wake up sometimes. I feel like I'm jolted awake" (Mr. B).

Dreams. Participants described their dreams or lack of dreams as a notable aspect of their sleep experiences. Although the original interview guide did not include

questions about dreaming, the topic was mentioned by participants so frequently that it was added in subsequent interviews. The most common complaint was a loss of dreams or inability to remember dreams, followed by dreams as returning memories after injury.

***Loss of dreams*.** The loss of dreams or inability to remember dreams was described as strange to one participant who shared "…It, it is (stammers), not dreaming (pause)…it…it's...it's kind of like (pause)…I don't want to say I feel a sense of loss, but I...it...it's weird to go to sleep suddenly and not ever dream!" (Ms. O). Another participant described the changes associated with a lack of dreams and their reaction:

> Post-accident I never dream…or I don't remember them. Very, very rarely do I remember a dream now. Which is a big change…I like dreams, so it's kinda sad! But I mean I guess you just go to sleep and there ain't nothing there. But it is, I mean, but that was a big difference (Ms. J).

Similarly, another participant noted an absence of dreams or the inability to remember dreams: "…before, I've noticed before that I'd dream and I'd kinda remember if I had a dream but, ever since the accident, I don't remember even if I dream I don't know anything about it" (Mr. K).

Memories in the form of dreams. Several participants described dreams after injury that seemed familiar and upon asking family members and friends they were determined to be memories of actual events, ranging from the distant past to events surrounding the mechanism of injury. For example, one participant described memories returning:

> kind of like faded dreams or whatever…basically like I said things are coming back in dream form and I might just ask myself like I have to people you know

> like, did this really happen or whatever? It's basically memories that come in the form of dreams or whatever (Mr. E).

Another participant described her dreams in the hospital as an amalgamation between dreaming and memories: "I think probably my dreams and reali—things that were really happening were getting…there was confusion, you know" (Ms. C). Another individual who could not remember details of his injury for months following his hospital admission described a dream he had that outlined his motorcycle accident and the moments following the injury. He then requested police records of the accident and noted that many of the details in the dream aligned with the reports.

> They were able to get the security camera video from the gas station. Like I said I've seen the pictures so I knew where I was laying but not until after I had this dream…after I had this dream I saw the pictures and it kinda made sense…it was kinda like in the dream, you know I'm laying there…people saying helps on the way, reaching up and grabbing the hand, uh, and then the way they had the scene marked off and where I was laying (Mr. G).

Decrease in sleep problems over trajectory of recovery. A prominent subtheme for problems with sleep is the description of sleep problems across the trajectory of injury; the majority of participants described the first six months following injury as the most problematic for sleep and they described progressive improvement, "getting better" (Ms. N) in the months and years following. Some described a faster transition to better sleep than others. Overall, problems with sleep and/or fatigue generally remained present after this period but:

> It gets better! Because it does! Because I mean, at first it was horrible. And I mean I just remember, I remember thinking like, I used to LOVE to be able to sleep…And then for three to six months I COULD NOT SLEEP! I COULD NOT SLEEP! IT WAS HORRIBLE (voice raised)! And I mean, it gets better…is it perfect no. I require more sleep now but I manage that, you know? So, I mean, but the sleep issue DOES get BETTER (Ms. C).

Similarly, another participant described struggling with sleep problems following injury but noting improvement over time:

> It has improved. Now I can sleep all night long without waking up, without any issues. No medicines, anything. It just took some time. I feel, good now. It was one of the biggest struggles after the injury. Uh, but now this many years later I'm fine. It's good now. It was a struggle (Mr. H).

Theme 2: Sleep and Fatigue on Relationships and Work

Participants described sleep problems including daytime sleepiness and fatigue as impactful to social and occupational engagement. Many participants stated it was difficult to "stay awake" and described falling asleep frequently—a factor that was highly influenced by sleep and impacted both relationships and work. Three subthemes comprised this theme: 1) mood; 2) relationships; and 3) work.

Mood. Mood is a subtheme that is highly related to relationships and work because participants describe their mood related to poor sleep as influential on relationships with coworkers and relationships at home; "Um, if I don't sleep, just in general, if I don't get enough sleep I'm really grumpy. I'm very grumpy and basically worthless" (Ms. O). One participant described a change in his social engagement in the workplace related to mood:

> I was very to myself, which is unlike me. I like to be helpful, if I see someone that I've never met before I talk to them just like right then I was talking to the people out in the lobby. I've always been like that but after my accident I would stay in my office and I was perfectly fine going the whole day without speaking to anyone (Mr. I).

Mood was described in terms of sleeping too much or too little and in context of daytime sleepiness. Mr. K described his mood in the following context,

> like if I might be sleepy during the day or uh, also I would uh, I guess my uh, my mental or emotions may not be as good as it was if I slept or if I slept too much. If I sleep too much, like I said, it does something to me.

Mood was also described as influential on temper, irritability, engagement with others, and communication: "And when I'm tired at times I really don't, I don't want to hear it. And I say, I convey it wrong. Word choices. I make poor choices in what I say at time when I'm tired" (Mr. B).

Relationships. Although some survivors described little impact of their sleep or fatigue on social engagement, most described some connection between sleep or fatigue and social engagement including attendance at social events, shame or embarrassment of sleep or fatigue problems, and mood. In terms of mood and social engagement, one participant described difficulty connecting with others due to "bad" nighttime sleep:

> You probably don't want to be around…I'm, I can be here but I'm not really gonna talk to you much, I'm not gonna be engaged. I'm not gonna obviously see I'm stumbling for words now and I didn't sleep bad last night but um…I'll be harder to connect with (Ms. J).

Participants described sleeping through or avoiding social events: "I'll go to see my mother or my daughter and uh I'll fall asleep. I just sleep right on or I forget" (Mr. K).

> I mean…I get up and go to church every Sunday. Social events? I don't like going anywhere with other people. If I don't know who you are, I don't want to be around you. That's changing slowly, but it's changing…but…other than going to church, I guess my brain is…trying to figure it out. If I want to get a good night's sleep I'll not go anywhere at night (Mr. P).

Survivors also described limiting others' knowledge of their problems with sleep. One participant described preventing his significant other from spending the night due to night sweats,

> Yeah, she can't sleep at my house. She can't stay. Because I don't want to put her through that. And I told her about it, but she just still doesn't like, there's not a way she can really understand until she knows (Mr. M).

Another participant described not telling friends when fatigue hit or a nap was needed, saying

> And I say hey yeah we can do that but I don't tell them, I need to be home for a nap, but I say I need to get home at this time or I can only be out this many hours (Ms. C).

Work. Survivors described a spectrum of occupational engagement, from applying for and receiving disability to returning back to work shortly after injury and maintaining a full-time job. For those who were on disability or not employed, sleep was not described as a factor in not working. For those who worked, poor sleep, daytime fatigue, and mood were described as hindrances to engagement at work, both social interactions with coworkers and job performance. In terms of work performance, participants expressed that daytime fatigue, coupled with trouble focusing prevented optimal production. Essentially, the relationship between work and sleep was best described as "good rest equals good production" (Mr. B). The same participant also summarized this relationship with the phrase, "if you get less sleep your craftsmanship is going to be less". Cognitive fatigue from exerting energy at work was also reported. A participant described work as a struggle due to cognitive fatigue, stating "I would come home from work and school and I had put forth so much effort using my brain that I'd be

so physically tired" (Mr. I). Similarly, another participant described her experience returning to work after injury,

> … I would literally, it was all I could do to stay awake and I got nothing, I would try to do. I would try to set myself just to do three things. What are three things I want to get done today. And um, I never got all three done there. Um, sometimes I could you know get one or two done if I like really focused in and did it but most of the time I just kind of sifted through and set around, put my head down on my desk a lot, it, you know, I was not functional. By any means. And I came home and went to sleep. I would say mentally and physically worn out. Like I've reached my limit of what I can (long pause) what I can do. (Ms. C)

Theme 3: Learning to Manage

Participants described either successes in learning to manage sleep difficulties or the ongoing struggle of learning to manage. One participant described learning to manage as necessary following injury, stating,

> So, it has changed, uh, it's still not like it was before the accident…if I had to guess I'd say it's never gonna be like it was before the accident. It's manageable, but it's manageable because I've learned how to manage it" (Ms. D).

Participants sought out information related to sleep after TBI, used prior knowledge, or listened to recommendations to manage sleep or fatigue. Participants used a variety of strategies, often discovered using "trial and error" methods. The following subthemes were identified related to learning to manage: 1) knowledge; 2) recommendations; 3) trial and error, and 4) strategies.

Knowledge. Participants described both using prior knowledge and seeking new knowledge as part of learning to manage. Some survivors had careers or prior knowledge related to sleep, such as a nurse, nursing assistant, and biology student, which gave them advanced knowledge of management strategies for sleep prior to their injury: "Going into

the accident I had a lot of knowledge so I didn't have to…I just had to pull from there" (Ms. D). Survivors also described a variety of information seeking strategies, particularly the use of online searches and the uses of chats or forums. The use of forums/chats were described as beneficial because survivors could relate to other survivors or medical professionals who posted on chats. One participant shared that reading the posts normalized the experiences, stating, "Hearing other people's opinion of how they thought things were, and seeing the doctors go back underneath [post] and be like yeah, that's exactly what is supposed to happen. That's exactly a thing that will happen." (Mr. M). Participants also sought experiential advice from others. A participant described reaching out to friends with a history of TBI, sharing, "When I see my friends are having the same problem, you know, I'll talk to them. What are you doing? …, So, but, I felt like well if its putting them to sleep its gonna put me to sleep" (Mr. I).

Recommendations. Survivors described using the recommendations of others when learning to manage sleep problems after injury. Recommendations were given by rehabilitation staff, family, or friends and in one case, a pastor. One participant recalled receiving information from a member of rehabilitation staff: "I think um, I wanna say that the girl who did, not physical but, um, speech, um occupation therapy? And… I feel like she gave me and my mom some websites and things…" (Ms. O). Similarly, another participant received information from a coordinator at his rehabilitation facility, describing his interactions with

> …the brain lady that works with me every week to…my memory and stuff? She was telling me about lavender…. I'm not sure if it really worked but I still do it. Cause she…told me it'd worked for her (Mr. K).

Recommendations included the use of resource websites and online chats, alternative therapies, and prayer: "… my preacher told me to pray more and that worked so I'm just gonna keep on doing it" (Mr. B).

"Trial and error". Survivors described trying out or testing strategies to manage sleep problems. Essentially, they described using "just trial and error" (Mr. I) in creating a sleep environment, finding optimal sleep positioning, learning limits of sleepiness and fatigue, using medications, and using alternative therapies. A participant described trial and error as a process, stating,

> Just trial and error? Um, mainly, you, (stammers) you just trial and error I mean at first I was like, went to bed, and I couldn't sleep in the bed with, in the room with other people so I took myself out of the room. So then slowly integrated back into the room. Not all at one time, you know what I mean…I just…I've tried to sleep on the couch for a while to see if that was a better position and I can sleep and be more comfortable on a couch than a bed…. (Mr. G)

Another participant shared that he "tried just about everything I could find. I tried…" and then went on to give an example of trying an over-the-counter medication, becoming addicted, and quitting cold turkey (Mr. I).

Strategies. Survivors described various strategies for managing sleep problems after injury. Strategies included the development of a good sleep/wake routine, engaging in physical activity during the day, using prescription medications or sleep aids, using alternative therapies, and managing the sleep environment by limiting light and sound disturbances. Establishing a good sleep/wake routine included timing of naps, as a participant shared in the following,

> … if I stay awake, if I can stay awake like make it all day long through and stay awake, not take any naps or something? I'll sleep good. Yeah, that right there. That makes a difference, definitely. I sleep better. If I can make it all day long without napping or nodding off, you know. It makes it better, you see. Lots better. Yeah when I lay down to go to sleep at night, it's a better sleep. (Mr. A)

Physical activity was a strategy to improve sleep and included work or occupation related duties: "I've worked my tail off all my life and always slept good so I knew I had to work, you know. You gotta make yourself tired to sleep good. If you don't make yourself tired, you won't sleep good" (Mr. B). Sleep aids were frequently utilized as well as illicit drugs such as pain killers or marijuana. A participant described using marijuana to fall asleep,

> Like I'll sit there and I'll smoke a joint about that big (holds up fingers indicating approximately 2 inches). I'll smoke half of it. I'll start feeling ya know (pause) the effects of it. I'll start getting drowsy I'll start feelin good. I'll go in there and play my video game for a little bit and then ya know I'll start getting drowsy and I'll go smoke the other half then I'll go pass out. But then ya know whenever that wears off I'll wake… I'll pop back up again...(Mr. P).

Last, minimizing sound and light in the sleep environment was a strategy frequently used by participants to manage sleep. Sensitivity to light and sound was common and participants often desired as little light exposure as possible. One participant described his ideal sleeping environment as "Total darkness. Total silence. To the point that I actually bought these headphones so my wife could listen to the television or whatever while I'm asleep" (Mr. E). Participants also used sleep masks or slept in rooms away from their bedpartner or spouse.

Theme 4: Coping

Participants described using sleep as an escape from pain or stress, coping with perceived isolation related to sleep problems, and coping with changes in identity and the

new self. Participants who described personal traits of resilience also described their personal ability to manage problems after injury and described a positive outlook on the new reality of post-injury life. Subthemes of coping included: 1) sleep as coping; 2) not the only one; 3) acknowledging new reality; and 4) resilience.

Sleep as coping. Some survivors described sleep as a method of dealing with other symptoms following TBI such as pain or stress because it separated the individual from the experience: "And uh, when I'm sleeping it helps my pain because I'm not uh, experiencing it I guess" (Mr. A). Sleep is also described as "an easy way out, I guess…if I go to sleep then I don't have to think about it…[pain]" (Ms. O). Sleep is also used as a means of getting away or "an escape…you don't have to worry" (Ms. C).

"Not the only one". Some participants described feeling isolated by their sleep issues after injury due to not knowing that other survivors had similar sleep problems. These participants sought out other TBI survivors via online forums, chats, social media, or internet searches—seeking a group identity related to sleep issues following TBI. Searches for group identity were prompted by questions such as the following: "Uh, is this sleeping problem, do people with brain injuries have this sleeping problem a lot? I didn't know if I was the only one or what" (Mr. K). The participant who asked this question also shared that the question was based in his desire to "be normal." The participant also asked "if it's normal for a brain injury person…trouble going to sleep" and described not wanting to be "the only one,"

> Knowing that I'm not the only one with a brain injury problem that has a sleeping problem. I mean, that would reassure me, that you're not the only one. It would

> make me more at ease if I knew it was the brain injury that was making me not fall asleep. I mean I don't wish it on nobody, but it would make me feel better that I'm not the only one. (Mr. K)

Another participant echoed this perspective:

> I think just realizing that I wasn't alone. That sleeping after brain injury was hard and made it easier to go okay. They are struggling too, I'm not a weirdo. I'm not weird right now. Because that's how I felt. And, because I had no real physical injuries, I looked great, but I wasn't' right. Couldn't get good sleep, memory sucked, couldn't remember what I ate the night before for dinner, so, I couldn't' relate with anyone else that I had physical communication with or anything like that but I could related with people posting stuff on the internet. Like yeah, this is a struggle. (Mr. I)

Acknowledging new reality—pre-injury self vs. postinjury self. Survivors described their own acknowledgement of the differences between the pre-injury version of themselves with a new, post-injury identity in the context of sleep problems and also in functional abilities post-injury:

> My aunts stay on me about not sleeping like they know that I used to. But it's like I tell them, I say there's a lot of things I used to do that I can't do now. Because it affects me two totally different ways. Then and now. It's like a whole different world. And here I used to get off work and I'd get to sleep no problem. Now it's…Trying to get my disability started and…its' like being two different people. I'm still trying to adjust to, I call it, the new me instead of the me I was before I got my head injured. It's a day by day deal, so…. (Mr. F)

The "whole different world" (Mr. M) was also described as "my new reality" (Ms. C) in the context of sleep. Mr. B stated "I don't like it! Because I like my sleep. I'm not happy about it, but it is, it is my new reality. And you can either deal with it, figure out ways to cope with it, or become a slave to it". The new changes in sleep and overall function led Ms. J to describe a new post-injury self: "I don't know…I feel like…it doesn't feel like who I was before…"

Resilience. Several survivors describe resilience--resolve or motivation to persist and move forward despite their injury and resulting symptoms, including problems with sleep and fatigue:

> So some of this, sleep issues, will vary by personality. You're gonna have people like me that are like, oh I'm fine. Because I'm just gonna power through and I'm gonna do it and I'll figure out a way and I'll make it work and it takes a lot for me to admit that I can't do something or I need help (Ms. C).

Resilient survivors sometimes referenced spirituality and its influence on overcoming difficulty after TBI: "I think that God gave me a challenge to rise above (laughs). I mean, he's more powerful. God has played a big part of my life and I strongly think he's the reason I survived…" (Ms. L). Others described resilience as a trait carried all of their lives. For example, "the way I look at everything is it's just an obstacle that's been put in front of me. And I've gotta get over it. And I'm going to do everything in my power to get over it" (Mr. G). Another participant stated, "I've always gotten right back up. So. I ain't gonna quit yet". The same participant added "I'm one of those, you know, a lot of people call me stubborn. But, if I know there's a chance, yeah I'm gonna keep trying. I'm that strong, that strong-willed, that determined" (Mr. M).

Theme 5: Desire for Additional Sleep-Related Resources

Overall, survivors expressed a desire for resources regarding sleep after TBI. Survivors desired sleep-related information at varying time points after injury using varying methods of delivery. Survivors preferred to receive sleep or fatigue-related resources from knowledgeable healthcare workers, particularly individuals they have previously worked with and trust. Subthemes comprising a desire for resources included: 1) "If somebody had told me…"; 2) cognition and timing; and 3) preferred personnel.

"If somebody had told me…" The majority of participants expressed a desire for sleep-related resources above and beyond any resources they had already received, if any. Participants chiefly described a desire for information such as the background and mechanisms of sleep problems after TBI and strategies to promote healthy sleep after TBI: "I'd like to know what's going on! Like, WHY? Are there ways to fix it WITHOUT medication." (Mr. B). Participants often described a need for resources specific to their sleep problems (loss of dreams, falling asleep, staying asleep, night sweats, etc.). A participant stated, "It would have been interesting to realize that [loss of dreams] is going to happen" (Ms. O). Some participants expressed feeling isolated by their lack of resources. A participant expressed "I really wish somebody would help, or would offer to help, to do something, but, I have nobody. I don't know of anybody who can help" (Mr. K). The same participant yearned for any available information, stating "Anything to help me sleep better. If you have any ideas to help me sleep better. I'll try em out and see what happens" (Mr. K). Participants also described a need for follow-up evaluation of the effectiveness of sleep management strategies.

Cognition and Timing. Survivors described cognitive status as very important to the timing of resource delivery. Survivors expressed that grasping new information was most difficult during inpatient rehabilitation and the first few months immediately following discharge: "When I first came home from the hospital, if you was to try and tell me then what to do, what would help…*laughs*…. I'd forget it in 5 minutes" (Mr. K). Participants expressed that resources would be best delivered:

> When you're fully cognitive. That first month, you have really, I had no idea what was going on the first month…and then it was heavy sedation and pain

> medication. And…so…eh…probably at least maybe two months. Just, because I was really foggy. You need to fully process and think about it. (Mr. B)

Because of the varying cognitive changes and because sleep may change over the trajectory of recovery, participants suggested follow-up appointments across recovery and changes in sleep resources as sleep experiences change and cognition improves. A participant described sleep-related needs as "different at different times" and as changing throughout recovery (Ms. C). Because of the changing sleep needs, the participant shared that resources "may be needed to be repeated in different ways, in different avenues, at different time points" (Ms. C).

Delivery preferences. Many participants desired sleep-related resources via a face-to-face "conversation" because handouts were likely to be lost: "They give me a piece of paper and I stick it somewhere and I don't look at it …so…yeah *(Laughs)"* (Mr. P). Similarly, another participant shared that it was difficult to remember discharge instructions but handouts were cumbersome, stating

> It's hard to remember to go home and do all the things that they tell you to do. Then you have lists and you lose paper and lists are good but you have to keep up with them and they I mean, there is so much the first three months that are going on (Ms. J).

Another reason handouts were not preferred was due to visual deficits after injury and difficulty focusing. A participant described problems focusing, stating

> It's hard to read it…when I tried to read something…its hard focusing…uh video or talking on the phone both would probably…because it seems like I can remember it you know, I might watch the video…(Mr. K)

Most participants preferred a conversation about sleep-related resources via a phone call, video, or in-person follow-up visit. Survivors shared that their preferred healthcare

personnel to deliver sleep-related education and resources would be a familiar individual, knowledgeable about sleep and head injury, and trustworthy. Participants preferred to receive information from familiar healthcare providers who they've "learned to deal with" (Mr. D) or "who I interact with on a regular basis…because I feel like I have a better relationship with them" (Ms. T). Participants also described time with the familiar healthcare professional as important and often mentioned nurses or therapy staff in the context of extended patient contact. Trust was critical in determining preferences for sleep-related resources; one participant described a trustworthy neuropsychologist and shared "anything I heard from him I would definitely take to heart" (Mr. K). Similarly, another participant expressed a need for "someone I can talk to and I can trust them…Trust is enormous. Enormous" (Mr. D). Participants expressed that most rehabilitation staff, including nurses, nurse practitioners, doctors, neuropsychologists, speech therapists, and pharmacologists would be their preferred educational resource providers. Altogether, they had preferences to who shared sleep-related information and wanted any sleep-related information or resources possible: "Anyone who knows anything about sleep and why I ain't sleeping. I'd talk to any of them to give me some ideas, what to do and what not to do" (Mr. K).

Summary

Altogether, survivors described a variety of personal experiences with sleep following TBI including varying problems with sleep, impact of sleep on daily life, management of sleep, and reactions to sleep. Problems with sleep were described as troublesome and isolating. Participants described a variety of sleep management

techniques and coping mechanisms. Participants also described a lack of resources for sleep after TBI and described preferences for additional resources. The following chapter will discuss the central themes in the context of relevant literature and provide strengths, limitations, implications, and conclusions.

CHAPTER 5

DISCUSSION, IMPLICATIONS, AND CONCLUSION

The purpose of this study was to describe the sleep experiences of survivors of moderate-severe TBI. Thematic analysis was used to derive 5 central themes and 16 subthemes from rich semi-structured interview data: 1) problems with sleep; 2) perceived impact of sleep and fatigue on relationships and work; 3) learning to manage; 4) coping; and 5) resources. This chapter includes a discussion of central themes in context of relevant literature, strengths and limitations, implications for future research, and conclusion.

Discussion

The sleep experiences described in the current study enhance the findings of previous research. Daytime sleepiness (Grima et al., 2016; Imbach et al., 2015; Sinclair et al., 2014), more frequent daytime napping (Ponsford et al., 2013), and lower perceived sleep quality (Grima et al., 2016; Ponsford et al., 2013; Sinclair et al., 2014) have been previously reported in TBI samples. The frequent descriptions of sleep problems are also consistent with the qualitative descriptive work of Matthews et al. (2016) who noted a chief theme of "messed up sleep" in a sample of male U.S. military veterans, particularly sleep initiation, maintenance, and quality. "Satisfactory" or "good" sleep was described as rare. Nighttime awakenings were often described in relation to bedpartners, pain (including phantom pain), positioning, and nocturia. Less common reasons for nighttime

awakenings included seizures, headaches, and night sweats. Although bedpartners created noise or movement that occasionally disrupted sleep, another study noted that veteran survivors of TBI had difficulty sleeping due to fear of hurting a bedpartner or spouse—which was not described in the current study (Matthews et al., 2016). Overall, changes in sleep over time in the current study are consistent with published literature; gradual trends of improvement during the first year following injury have been noted (Chen et al., 2015; Duclos et al. 2014; Huang et al. 2013; Nakase-Richardson 2013) although problems persist for as long as 2 years to 3 years after TBI (Kempf et al., 2010; Williams et al., 2008).

Sleep plays an important role in learning and memory processing. Dreaming may be a reflection of the consolidation and processing of memories; exactly which memory systems are activated during dreaming and why is unclear (Stickgold, Hobson, Fosse, & Fosse, 2001). Dreams can occur in both REM and NREM, although REM dreams are "normally the longest, visually intense, bizarre, and emotional" and it is likely that dream production occurs more heavily in REM (Stickgold et al., 2001, p. 1056). The strong connection between memories and dreaming may contribute to the return of memories as dreams in the current study.

Because REM sleep may be heavily involved in dream production, it is possible that participants with dream cessation were not reaching REM sleep. However, in one of the few studies conducted in TBI patients specific to dreaming, time spent in REM sleep was not linked to dream cessation or a decrease in dreaming (Prigatano, Stahl, Orr, & Zeiner, 1982). The loss of dreams or ability to recall dreams following TBI has been reported in seminal work (Murri, Arena, Siciliano, Mazzotta, & Muratorio, 1984) and in a

recent case study (Nishida, Nariai, Hiura, Ishii, & Nishikawa, 2011) but has not been extensively investigated and more current studies are needed. It is possible that patients with focal injuries in certain areas of the brain would be more likely to lose dream recall, particularly if they experience visuoperceptive deficiencies (Murri et al., 1984). Cessation of dreaming has also been documented in other neurological injuries, such as stroke (Bischoff & Bassetti, 2004; Hobson, 2001).

Participants in the current study described sleep experiences and daytime fatigue as impactful to social and occupational engagement. Mood was described as highly influenced by sleep and often impaired temper, increased irritability, decreased engagement, and decreased communication with others. These findings are consistent with descriptions from veteran survivors who described poor communication, short temper, increased irritability, frustration, and feeling overwhelmed after a night of poor sleep (Matthews et al., 2016). It is possible that increased impulsivity and decreased inhibition, both of which are common behavioral problems following TBI and both of which are exacerbated by poor sleep (Anderson & Platten, 2011), contributed to poor communication and social engagement.

Social disconnect is a common theme across qualitative studies of recovery in survivors of TBI (Levack, Kayes, & Fadyl, 2010). Participants described the impact of sleep or fatigue on social engagement including attendance at social events, shame or embarrassment related to sleep or fatigue problems, and mood. Theadom et al. (2016) also noted feelings of shame in TBI survivors related to fatigue and increased sleep need and Matthews et al. (2016) noted that veterans often missed appointments due to sleep and fatigue.

Survivors described a spectrum of occupational engagement, from applying for and receiving disability to returning back to work shortly after injury and maintaining a full-time job. In terms of work performance, participants expressed that daytime fatigue coupled with trouble focusing prevented optimal production. Adams and Dahdah (2016) also reported that survivors expressed more difficulty and more effort for basic tasks. Matthews et al. (2016) also reported difficulty with occupational engagement specific to poor sleep, including cognition, limited attention span, forgetfulness, and in general being less "effective" (p.131). Benedictus et al. (2010) also noted that behavioral and cognitive impairment chronically influenced return to work in survivors of TBI. In a qualitative study of survivors who returned to work and their employers, both survivors and employers mentioned daytime fatigue, tiredness, cognitive problems, and sensory overload as barriers to occupational engagement (Donker-Cools, Schouten, Wind, & Frings-Dresen, 2016). Overall, findings from the current study were consistent descriptions of social and occupational engagement in preliminary qualitative work in survivors of TBI. However, much of the occupational literature described fatigue and not sleep; it is possible that fatigue played a more prevalent role in occupational engagement or that sleep was overlooked as a potential influence on daytime function in the workplace.

Learning to manage sleep after TBI was a central theme involving knowledge (seeking knowledge and knowledge prior to injury), recommendations from others, trial and error, and management strategies. Many participants utilized internet resources, especially search engines such as Google, to gain knowledge to manage sleep following TBI. Several used discussion boards or online support groups to gain knowledge and seek

recommendations from others. The frequent use of discussion boards by participants in this study differs from another study of health information preferences in which survivors reported that online discussion boards were the least commonly used online platform (Coffey et al., 2016). The recommendations of others were considered by participants to choose and implement management strategies, which is consistent with Theadom's (2016) findings. "Trial and error" methods were used in a similar fashion to those described by Matthews et al. (2016)—primarily for prescribed and over-the-counter sleep aids varying with perceived effectiveness and side effects.

Survivors describe varying strategies for sleep management, including general sleep hygiene strategies such as the development of a good sleep/wake routine, engaging in physical activity during the day, using prescription medications or sleep aids, using alternative therapies, and managing the sleep environment by limiting light and sound disturbances. The description of physical activity and work during daytime hours improving sleep latency and night time sleep quality is consistent with findings from Theadom et al. (2016) in which participants described pushing themselves followed by recovery sleep and Matthews et al. (2016), whose participants described using daily exercise to improve sleep. Although noise sensitivity has been previously reported in TBI samples (Landon et al., 2012), and light has been described as bothersome in the sleep environment (Matthews et al., 2016) the current study links noise sensitivity to sleep experiences following TBI. It is possible that hyperacusis or tinnitus, both of which are common following TBI (Attias, Azwecker-Lazar, Nageris, Keren, & Groswasser, 2005), contribute to lengthened sleep onset and frequent nighttime awakenings in survivors of TBI.

Participants who used lavender (in detergent to wash sheets or as essential oils) were unable to describe a difference in sleep experiences with or without lavender use. Lavender aromatherapy for sleep has not been previously studied in TBI samples, although results regarding lavender's impact on sleep are mixed in non-TBI samples (Karadaq, Samancioglu, Ozden, & Bakir, 2017; Lillehei, Halcon, Savic, & Reis, 2015; Lytle, Mwatha, & Davis, 2014). Several participants in the current study described smoking marijuana to aid sleep onset by "getting drowsy" and passing out. The substance was also mentioned for seizure prevention and pain relief. Cannabis is frequently used for pain control (Andreae et al., 2015; Martin-Sanchez, Furukawa, Taylor, & Martin, 2009) and for epilepsy and seizures (Katona, 2015; Reddy & Golub, 2016; Szaflarski & Bebin, 2014). Marijuana has not been extensively studied within TBI samples, particularly for seizure prevention. This description is a novel finding; while no other evidence is currently available discussing the use of marijuana specifically for sleep following TBI, Fogelberg et al. (2017) reported that survivors of another neurological population, individuals with spinal cord injury (SCI), used marijuana to induce sleep. In Fogelberg's qualitative study, participants described using marijuana for inducing sleep due to its effects on pain, spasms, and anxiety, very similar to the reasons for use in the current study. Marijuana use to facilitate sleep onset has also been noted in populations with PTSD; Bon-Miller, Babson, and Vandrey (2014) reported that individuals with higher PTSD scores were more likely to use marijuana to sleep and also found that cannabis was used more frequently in those who used it for sleep promotion compared to those who used it for other reasons. Although PTSD is often associated with active service members and veteran survivors of TBI, PTSD may also occur in cases of civilian TBI. The current

study did not measure or address PTSD, but PTSD should be considered in the design of future sleep-related studies in samples of TBI survivors, including civilians, and particularly when investigating cannaboid use.

Whether or not marijuana is specifically beneficial for sleep promotion after TBI is unknown. However, some recent work has suggested a potential neuroprotective effect on TBI outcomes, specifically decreased mortality among those who screened positive for cannaboid use (Nguyen, et al., 2014). Over 100 different cannaboids (active components) are found in a cannabis plant and it is likely that certain components are more beneficial to sleep (i.e., cannabidiol) than others (i.e., delta-9 tetrahydrocannabinol) (Babson, Sottile, & Morabito, 2017). It is also likely that certain components will facilitate sleep onset although the long-term use of cannaboids has been associated with decreased sleep quality and possible alterations in sleep architecture (Bon-Miller et al., 2014). Furthermore, withdrawal from cannabis is also associated with sleep disturbances which may further dependence on cannabis for sleep promotion (Gates, Albertella, & Copeland, 2016). The potential psychoactive effects of cannabis may hinder the clinical use of the substance.

Participants described several aspects of coping, including using sleep as an escape from pain or stress, coping with perceived isolation related to sleep problems, and coping with changes in identity and the new self. It is possible that the use of sleep as an escape is a form of avoidance coping; Littlewood, Gooding, Kyle, Pratt, and Peters (2016) conducted qualitative interviews with individuals with depression and noted a key theme of sleep as an escape from problems. Sleep was used to cope with negative thoughts, with the exceptions of individuals with nightmares. It is possible that the

participants in the current study that used sleep as an escape might have also had depressive symptoms. Many of the participants were on antidepressant medications. Sleep as an escape was not noted in the two qualitative works pertaining to sleep after TBI (Matthews et al., 2016; Theadom et al., 2016).

Survivors described acknowledgement of the differences between the pre-injury version of themselves with a new, post-injury identity in the context of sleep problems and also in functional abilities. References to survivors' new reality and pre-injury vs. post-injury self has been referenced in TBI literature (Adams & Dahdah, 2016; Theadom et al., 2016). Some participants described feeling isolated by their sleep issues after injury by not knowing that other survivors have similar sleep problems. These participants sought out other TBI survivors via online forums, chats, social media, or internet searches—seeking a group identity related to sleep issues following TBI. Although not specific to sleep, Levack et al. (2010) also noted the importance of relating to others with TBI, particularly the normalizing effect of peer experiences and importance of TBI support networks in addressing isolation after injury. The lack of knowledge regarding the prevalence of sleep disturbances following TBI and perception of isolation may allude to the lack of screening, diagnoses, and education related to sleep following TBI.

Several survivors describe resilience--resolve or motivation to persist and move forward despite their injury and resulting symptoms, including problems with sleep and fatigue. Having resilience may have enhanced or facilitated coping in some survivors--the survivors who described personal traits of resilience also described successfully learning to cope with changes since injury and managed their sleep problems at the time of the interview. Participants who described personal traits of resilience also described their

personal ability to manage problems after injury and described a positive outlook on the new reality of post-injury life. Levack et al. (2010) noted a similar theme, "internal resources," a theme in qualitative metasythesis of recovery after TBI included that "included their capacity for hope, and optimism and strength of will, spirituality, and having ability to appreciate success and the good things in life" (p. 995).

Participants strongly desired sleep-related resources to address their perceived sleep-related symptoms but expressed a lack of understanding of where to find such resources apart from internet searches and rehabilitation staff. However, most participants stated they did not receive screening or information related to sleep, or stated they did not remember, during rehabilitation stay, discharge, or after. Other qualitative studies have also noted that survivors and their caregivers do not remember or do not receive resources upon rehabilitation discharge (Adams & Dahdah, 2016l; Matthews et al., 2016). Survivors express that grasping new information was most difficult during inpatient rehabilitation and the first few months immediately following discharge. In addition to changing sleep needs over the first 6 months to 1-year post-injury, cognition improved and a desire for understanding of symptoms and management strategies increased.

Although not specific to sleep, these findings are consistent with Paterson, Kieloch, and Gmiterek (2001) who conducted a qualitative investigation of discharge instruction for survivors, families of survivors, and rehabilitation staff who provided discharge teaching. "Timing of content" was particularly important: "When they needed the resources, they had long forgotten about them" (p. 51). All but one family member in the Paterson et al. study had trouble recalling that information had been provided to them

regarding rehabilitation discharge and remained confused, although rehabilitation staff extensively documented teaching provided and sent written material to survivors' homes. Rehabilitation staff acknowledged the potential for information overload but believed the survivors and families would refer back to the written material. The findings of this study and others highlight the need for additional research regarding patient education during and after transition of care from inpatient to community settings. Given the use of typical sleep hygiene strategies to manage sleep in this sample, it is possible that participants found resources outlining sleep hygiene practices or received sleep-related resources and retained the information despite not remembering the events surrounding the receipt of the information. It is also possible that physical access to resources influenced sleep-related teaching; approximately half of the sample lived in the greater Birmingham area and approximately one fourth of the sample lived in rural areas.

Most participants preferred a conversation about sleep-related resources via a phone call, video, or in-person follow-up visit in addition to online resources such as discussion boards. Veteran survivors of TBI in the Matthews et al. (2016) study had varied preferences; some preferred individual in-person sessions and others preferred small groups with facilitators to discuss sleep difficulties. Interestingly, when a mixed sample of survivors of TBI, SCI, and burns were asked about preferences for health information, half of the TBI survivors preferred receiving information in-person and the other groups preferred online resources (Coffey et al., 2016). Survivors preferred trustworthy, familiar, and knowledgeable healthcare personnel to deliver sleep-related education and resources. The roles suggested were highly varied and consistent with findings by Levack et al. (2010) in a qualitative metasynthesis of recovery after TBI

although no one in the current study mentioned a preference for community organizations or advocacy groups for sleep-related resources. It is possible that the desire for face-to-face instruction is related to the perceived significance of trustworthiness and familiarity with the clinicians.

Reflection on Methods: Attention and Memory

Impaired memory was a barrier to recruitment and conduction of on-site interviews. Participants were sent reminder letters with appointment date and time and also received a call the day prior to the interview as a reminder and to confirm the appointment. Multiple interviews were rescheduled during the reminder calls due to the participants forgetting about the date and time, losing the appointment letter, or forgetting to ask a friend or family member for transportation. Several participants missed appointments despite confirmation the day prior.

During the interview process, participants were often easily distracted and the investigator used additional probing and reminders to guide the patient back to the topic of interest. Some distractions were external, such as the participant's cell phone ringing or buzzing, and more commonly the distractions were the participant's own thoughts. For example, some participants quickly jumped from topic to topic (often unrelated to the previously asked interview question) and after sharing detailed descriptions of non-sleep related experiences would ask to be reminded of the current topic. One participant self-described this behavior as "rambling." Despite impaired ability to focus, no follow-up calls for clarification were required and the interview guide was fully completed by each participant. Impaired recall was less frequently noted during interviews but often

associated with questions related to resources or patient education; participants often described not remembering if they had received any sleep related education or resources prior to discharge or if they had, could not recall where they had put resources such as handouts or discharge paperwork.

Survivor Experience of Participation

Participants frequently expressed during recruitment calls, appointment reminder calls, and at on-site appointments their eagerness to share stories and experiences related to sleep. Although participants expressed understanding that individuals participating would not directly benefit from the study, many participants stated they wanted to help future survivors with sleep; participants wanted to share their experiences so that other survivors or future survivors might relate and know they are not alone in their sleep-related struggles. Participants reported that any inquiry related to their sleep after injury was rare or absent and therefore they were all the more eager to discuss their sleep experiences. Participants often started telling their stories or sharing their difficulties with sleep as soon as introductions were made. As a result, some transcripts include referrals to those conversations that began prior to recording; the interviewer attempted to revisit as much of the initial conversation as possible. It is plausible that eagerness to share experiences was also lack of inhibition, however, the content of conversations uphold the impression that participants were eager to participate and help future survivors. Many participants also expressed unsolicited interest in participating in future sleep-related research.

Strengths and Limitations

A primary strength of this study was the use of qualitative descriptive inquiry which allowed for detailed description of sleep experiences in the voice of survivors. To my knowledge, this is the first qualitative descriptive study of sleep experiences in a primarily civilian sample of survivors of moderate-severe TBI in the United States. The use of a semi-structured interview guide facilitated the collection of data necessary to generate a description, but also allowed flexibility for the discussion of unanticipated details. Yet, due to the qualitative approach, this study could not investigate causal relationships associated with sleep after TBI. Another limitation is the potential for bias, which is inherent in any study. In the current study the researcher mitigated personal bias by writing reflective memos during data collection and analysis and an audit was conducted for oversight. It is also possible that participants gave socially desirable responses based on their perception of what might be important to the researcher, although, based on the rich and descriptive accounts provided during data collection, the data appear to be trustworthy.

Because the sample consisted largely of Caucasian men, consistent with national TBI incidence, the findings could be limited in application to females and minority groups. Although young teens and older adults were excluded to address the potential for age-related sleep disturbances, a wide age range could have influenced experiences. It is possible that the study topic appealed primarily to those with sleep disturbances and therefore the sample might not reflect the sleep experiences of TBI survivors without sleep disturbances. Participants were not screened for sleep disorders and it is possible that comorbid sleep disorders that were not self-reported might have influenced

participant experiences. Additionally, participants self-reported use of a variety of medications including sleep aids, antidepressants, or antiepileptics that might have influenced sleep experiences. Finally, the small sample was recruited from a single institution and as a result, generalizability may be limited. Research and practice implications should be considered in light of these limitations.

Implications

Research

The results of this study reveal the need for additional research on sleep among survivors of moderate-severe TBI. Given the complex nature of sleep, a mixed methods investigation of sleep following moderate-severe TBI in a larger sample may provide more comprehensive insight. A qualitative study of the survivor-bedpartner dyad would provide a more expansive view of sleep experiences following TBI. Given the variety of sleep disturbances or disorders that might arise following TBI, it may be beneficial to further explore the experiences associated with specific sleep disorders or disturbances (e.g., OSA, insomnia, hypersomnia, parasomnias etc.) following TBI. The results of this study also suggest the potential role of alternative therapies for sleep following TBI, particularly marijuana or lavender. The use of marijuana specifically for faster sleep onset following moderate-severe TBI has not been previously reported; this novel finding suggests the need for further investigation of the prevalence of this phenomenon and the impact of marijuana on sleep experiences, sleep architecture, fatigue, and other comorbidities in survivors of TBI. Further research is also needed to assess the utility and efficacy of lavender as an alternative or adjunct treatment for sleep disturbances

following TBI. The relationships between coping, resilience, and sleep outcomes also require further exploration to determine if personal characteristics, such as resilience, impact sleep symptom management. Sleep hygiene protocols typically address sleep habits such as those described in this study (e.g., delayed sleep onset, frequent daytime napping, stimulant use). Studies are needed to test sleep hygiene interventions in both inpatient rehabilitation and community settings following moderate-severe TBI. Finally, larger samples are needed to investigate survivor preferences for the delivery of sleep-related resources and screening to inform practice and policy. Given the frequent use of web-based resources in community-dwelling survivors of moderate-severe TBI, the development and testing of online sleep management resources may be beneficial. It is possible that telehealth technologies might also benefit rural survivors of TBI but pilot testing is needed to determine if telehealth appropriately matches the needs and preferences of survivors.

Practice

The results of this study suggest several implications for nursing practice, primarily the need for additional support for survivors transitioning from in-patient to community settings following moderate-severe TBI. Although rehabilitation facilities may have policies and mechanisms in place for discharge teaching, it may not be delivered in the format or mode that will be most successful in translating the knowledge to survivors for sleep management. The early and routine screening and treatment for sleep disturbances is needed. Information such as sleep management strategies, sleep hygiene recommendations, or contact information for resource persons is needed

throughout recovery and not solely at discharge. Sleep-related education is also necessary for rehabilitation professionals so that providers can encourage screening, treatment, and teaching for patients and families. The results of this study may aid healthcare providers and caregivers with the lens of their patients' perspectives, and potentially promote empathy for the survivors of TBI experiencing sleep disturbances.

Conclusion

This study addressed a significant and timely problem, lack of knowledge concerning the experiences of sleep in survivors of TBI. Using qualitative descriptive inquiry, this study provided the first comprehensive description of sleep experiences of survivors of moderate-severe TBI in a primarily civilian sample in the United States. Thematic analysis yielded five central themes: 1) problems with sleep; 2) perceived impact of sleep and fatigue on relationships and work; 3) learning to manage; 4) coping; and 5) resources. The study confirms and extends some elements of previous research of sleep in survivors of TBI but also adds new knowledge by highlighting previously unidentified sleep management strategies, coping strategies for impaired sleep, and preferences for sleep-related resources. Implications for practice include the need for a supportive transition from rehabilitation to community and continued education and screening throughout recovery following TBI. It is likely that a multitude of factors influence the sleep experiences and subsequent outcomes of survivors of moderate-severe TBI; future research should continue to explore the multifaceted nature of sleep in addition to the interplay between sleep and other comorbidities following TBI such as depression, PTSD, or memory impairment. Future research should also aim to confirm

and extend the findings of this study in a larger and more diverse sample, explore the sleep of the survivor and bedpartner dyad, and investigate the efficacy of sleep management strategies used by survivors.

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APPENDIX A

PRIMARY QUANTITATIVE REFERENCES TO SLEEP CHARACTERISTICS OR PREVALENCE OF SLEEP PROBLEMS IN TBI SAMPLES

Table 1.
Primary quantitative references to sleep characteristics or prevalence of sleep problems in TBI samples.

Author(s), Year, Title	Design	Sample and Inclusion (severity; time since injury)	Measures	Findings	Strengths and/or Limitations
Arbour et al. (2015) Are NREM sleep characteristics associated to subjective sleep complaints after mTBI?	Cross-sectional, case-control	*n* = 34 TBI (mild severity; time since injury not specified) *n* = 29 age-matched controls	Two nights of PSG PSQI BDI	Poorer sleep quality in mTBI patients compared to controls Increases in beta power during NREM in mTBI group No group differences on spindles or slow wave sleep	Strength: excluded for prior history of sleep problems Limitations: small sample; didn't match on gender, extensive exclusion criteria might limit generalizability
Ayalon et al. (2007) Circadian rhythm disorders following mTBI	Cross-sectional, cohort	*N* = 42 with insomnia and mTBI Israel	actigraphy, PSG, EEG, EMG, oral temperature, saliva melatonin MEQ	36% of sample diagnosed with CSRD (8 with delayed sleep phase and 7 with sleep-wake pattern irregularity)	Limitation: did not account for depression, anxiety, pain
Cantor et al. (2012) Insomnia, fatigue, and sleepiness in the first 2 years after traumatic brain injury: An NIDRR TBI Model System Module Study	Cross-sectional secondary analysis of a prospective longitudinal study	*n* = 334 (moderate-severe; one or two years after injury) One year followups: 213 Two year followups: 121 TBIMS participants	PSQI, ISI, SHI, Diagnostic Interview for Insomnia, ESS, GFI Patient Health Questionnaire and followup interview data DRS, FIM Satisfaction with Life Scale	More fatigue and sleep disturbance, lower sleep hygiene and life satisfaction in insomnia group vs. those without Sleep quality, anxiety, and depression mediated relationship between insomnia and fatigue Higher rates of anxiety, depression, panic disorders in insomnia group vs. those without Participants with fatigue had more disability and less satisfaction with life at followup	Limitations: not representative of all TBI survivors, did not use objective measures of sleep

Castriotta et al. (2007) Prevalence and consequences of sleep disorders after traumatic brain injury	Prospective cohort	*N* = 87 (mixed severity; < 3 months post injury)	PSG, MSLT, ESS, PVT FOSQ POMS	46% of sample had abnormal results from PSG. Sleep apnea, hypersomnia, narcolepsy, and periodic limb movements noted Objective daytime sleepiness in 25% of sample based on MSLT score (no difference between sleepy and non-sleepy participants in injury severity or time post injury)	Strength: one of few multisite studies in this domain of research Limitations: unclear if the study addressed role of sleep medications on sample
Castriotta & Lai (2001) Sleep disorders associated with traumatic brain injury	Prospective, cohort	*N* =10 TBI with subjective excessive daytime sleepiness (mild or severe; 1-552 months after injury)	PSG, MSLT ESS, clinical interview	10 of the 10 participants diagnosed with sleep disorder based on abnormal sleep studies. Sleep apnea, upper airway resistance syndrome, narcolepsy, hypersomnia noted.	Limitations: small sample size; broad range of time post injury; unable to comment on causality between TBI and sleep
Chen et al. (2015) Trajectories of sleep and its predictors in the first year following traumatic brain injury	Prospective, cohort	*n* = 53 TBI (mixed severity; within first year after injury) Taiwan	actigraphy BDI, BAI	Average sleep efficiency showed improvement during the first year after injury Slope of change in sleep efficiency was predicted by depression, anxiety, and use of analgesics Compared sleep efficiency to published normative data and found it significantly lower in TBI patients	Limitations: sample size; did not couple objective measure (actigraphy) with other subjective or objective sleep measures

Chiu et al. (2013) Trajectories of sleep changes during the acute phase of traumatic brain injury: A 7-day actigraphy study	Prospective, cohort	*N* = 52 TBI (mixed severity; 3.94 ± 2.68 days) Taiwan	Actigraphy (7 days) medical records	Initial GCS score (severe) predicted the slope of change of total sleep time Gender significantly predicted 24 hour sleep duration Comparison to published normal data yielded significantly lower sleep efficiency, longer wake time, longer 24 hr total sleep time in TBI sample	Limitations: small sample size; most patients had good prognosis (sample bias); did not account for pain or depression
Cohen (1992) Temporally related changes of sleep complaints in traumatic brain injury patients	Group comparison	*n* = 22 recent TBI (severity not specified; time since injury not specified) *n* = 77 chronic TBI (severity not specified; 2-3 years after injury)	38 item sleep questionnaire designed by investigators Rey-Osterrieth complex figure test, Weigel test. block design test, verbal logic test, transitive inductive-deductive and anologic thinking test, Raven-matrix test, trail-making test Rehabilitation outcome: occupational status of discharged patients	High incidence of sleep disturbances in both acute (72.7%) and chronic (51.9%) TBI groups Most common disorders in hospitalized patients: disorders initiating and maintaining sleep Most common disorder in discharged patients: excessive somnolence	Limitations: environmental influences of inpatient setting; sample size

Duclos (2014) Rest-activity cycle disturbances in the acute phase of moderate-severe traumatic brain injury	Prospective, cohort	*N* = 16 TBI (moderate-severe; time since injury not specified) Canada	Actigraphy Length of ICU stay, hospital length of stay Rancho Los Los Amigos Scale Galvestone Orientation and Amnesia Test	Lack of consolidation in rest-activity cycles for almost half of all days monitored (46.6%) with significant linear trend of improvement over time Poorer rest-activity cycle consolidation and trajectory associated with higher TBI severity and longer hospital and ICU lengths of stay Participants with faster return to consolidated rest-activity cycles were more likely at discharge to have cleared post traumatic amnesia and lower disability scores	Limitation: sample size
Duclos et al., (2016) Parallel recovery of consciousness and sleep in acute TBI	Prospective, cohort	*n* = 30 (moderate or severe, from 21 (± 13.7) days post injury to 233 days)	Actigraphy Rancho Los Amigos Scale of cognitive functioning (RLA)	Mixed model analysis at day 233 with RLA and sleep-wake variables and linear contrast analyses Correlations with scores on consciousness/cognitive functioning scale and: 1) sleep-wake cycle consolidation ($p < 0.001$); nighttime sleep duration ($p = 0.018$); and nighttime fragmentation index ($p < 0.01$). There was an improvement in cognition that paralleled with improvement of sleep quality	Strengths: controlled for quantity of sedatives and analgesics Limitations: small sample size, single site (potential for environmental influence)
Fichtenberg et al., (2000) Factors associated with insomnia among post-acute TBI survivors	Prospective, cohort	*n* = 91 TBI (mixed severity; 2 weeks-53 months after injury)	PSQI Sleep disturbance secondary to pain: PSQI pain item (frequency with which pain disrupts sleep) BDI	Insomnia associated with mild severity, negative CT findings, pain disturbance, and depression Strongest association between insomnia and depression (r=0.67, p<.001) 68% of depressed subjects with insomnia and 81% of those with insomnia with depression	Strengths: excluded those on sleep medications or with poor cognition Limitation: broad range of times since injury

Grima et al. (2016) Sleep disturbances in TBI: A Meta-Analysis	Meta-analysis	*N* = 16 Pooled polysomnography data from 16 studies with TBI samples and controls		Poorer sleep efficiency, shorter sleep duration, and less time in REM sleep in pooled TBI patients compared to pooled controls Greater subjective sleepiness and poor sleep quality in pooled TBI samples compared to pooled control samples	Strengths: focused on objective polysomnographic data; comparison of TBI individuals with controls; aggregated data Limitation: cannot imply causality between TBI event and sleep problems because no polysomnography from prior to injury
Holcomb et al. (2016) Incidence, characterization, and predictors of sleep apnea in consecutive brain injury rehabilitation admissions	Prospective, cohort	*n* = 86 (moderate-severe; time not specified) TBIMS sample	PSG FIM medical records	Half of sample diagnosed with sleep apnea Age and hypertension significantly predicted sleep apnea diagnosis after adjusting for demographics etc	Strengths: large cohort; objective sleep assessment; accounted for influence of sleep medications Limitations: potential for gender bias
Hou et al. (2013) Risk factors associated with sleep disturbance following traumatic brain injury: Clinical findings and questionnaire based study	Prospective, cohort	*n* = 98 (mixed severity; 33 ± 11 months) China	cranial CT PSQI, ESS HADS	GCS predicted hypersomnia Sleep disturbance associated with education, headache, severity of TBI (not associated with location of brain injury on imaging, age, gender, time since injury, or marital status) Moderate TBI most likely to have insomnia, severe TBI most likely to have hypersomnia Overall, higher frequencies in moderate and severe TBI compared to mild. Anxiety and depression symptoms more prevalent in TBI participants with insomnia	Limitations: potential for over or under reporting; small comparison groups when sorted by severity; several participants reported snoring but not followup objective measures

Huang et al. (2015) Sleep duration and sleep quality following acute mTBI: A propensity score analysis	Case-control	n = 171 mTBI (mild; < 1 month) n = 145 healthy controls	PSQI, ESS BDI, BAI	Shortened sleep duration and poor subjective sleep quality most frequently reported within 1 month after mTBI	Limitation: no matching of controls; no objective sleep data
Imbach et al. (2016) Sleep-wake disorders persist 18 months after TBI but remain underrecognized	Case-control	*n = 60 TBI* (mixed severity; 18 months after) *n = 42* controls matched on age, sex, sleep satiation	PSG Actigraphy ESS	Compared to controls (7.1 ± 0.7 hours), sleep need per 24 hours was increased (8.1 ± 0.5 hours). Chronic objective excessive daytime sleepiness was 19% in controls and 67% in individuals with brain trauma.	Strengths: Excluded for other neurologic diseases, prior sleep disorders, drug or alcohol abuse, psychiatric comorbidities Limitations: sample size
Imbach et al. (2015) Increased sleep need and daytime sleepiness 6 months after TBI: A prospective controlled clinical trial	Case-control	n = 46 TBI age and gender matched control group (number not specified) Switzerland	CT, GCS, biomarkers actigraphy (2 weeks), PSG (2 nights), MSLT ESS, Sleep Apnea Scale of Sleep Disorders Questionnaire, Ullanlinna Narcolepsy Scale, Fatigue Severity Scale	Average sleep need per 24 hours increased at 6 months compared to controls (8.3±1.1h vs. 7.1 ± 0.8h, p <.0001) however, sleep latency was reduced (p = 0.0009) Daytime sleepiness was found in 57% of TBI participants Sleep need and excessive daytime sleepiness where underestimated by TBI patients using subjective measures	Limitation: did not specify number of control subjects; did not exclude for prior sleep problems
Jain et al. (2014) Study of insomnia and associated factors in traumatic brain injury	Cross-sectional, cohort	N = 204 TBI (mild and moderate; up to 1 year after injury)	GCS ISI PHQ-9	Just under half of the sample had symptoms of insomnia (42.4%) Insomnia associated with severity and duration of TBI, neuroanatomical localization (not associated with depression	Limitation: no objective data; did not exclude prior history of sleep problems (only prior neurological problems)

				although depression was present in insomnia cases 32.84%) Moderate TBI was more likely to have insomnia compared to mild TBI ($p = 0.0000$) and if insomnia developed, it was more likely to develop within first three months of injury	
Kempf et al. (2010) Sleep-wake disturbances 3 years after traumatic brain injury	Prospective, longitudinal, cohort	$n = 51$ (mixed severity; 6 months to 3 years after injury) Switzerland	GCS HADS, BDI	67% screened for sleep disturbances, 27% for hypersomnia and 35% for fatigue, and 10% for insomnia Insomnia associated to depression (not severity, location of injury, or duration of injury) Fatigue moderately associated with depression and anxiety (not associated with TBI severity, location of injury, outcome, age, gender, or sleep duration) 10% with insomnia at 3 years, 5% at 5 months post injury; 35% met fatigue criteria at 3 years, 17% at six months EDS-12% at 3yrs, 28% at 6 months; 2 patients were involved in car accidents due to daytime sleepiness	Strengths: excluded for previous sleep disorders and psychiatric or neurologic disorders Limitations: no objective sleep measures; lost 14 patients (22%) to followup
Khoury et al. (2013) Rapid EEG activity during sleep dominates in mild TBI patients with acute pain	Case-control	$n = 24$ mTBI (8 with pain, 16 with no pain) (mild; 45 ± 22.7 days) $n = 18$ healthy controls (no sleep problems, no pain)	EEG, PSG PSQI BDI, BAI, Pain Catastrophizing Scale	mTBI group had triple the incidence of poor sleep quality compared to controls Lower delta and higher gamma/beta in arousal in mTBI pts compared to controls ($p < 0.04$) Those with pain had greater increase in rapid EEG frequency bands during REM	Strength: excluded prior history of sleep disorders Limitation: small sample; did not match for age or gender; did not include group of chronic pain without mTBI

Lu et al. (2015) Relationship between self-reported sleep disturbance and polysomnography in TBI	Cross-sectional, cohort	*N* = 44 TBI (mixed severity; time post injury not specified) community dwelling	PSG (2 nights) PSQI, ESS, MAF	Poor sleep quality associated with poor sleep efficiency, short stage 2 sleep duration, and long REM duration No association between fatigue and daytime sleepiness	Strength: did 2 nights of PSG to address potential for first night effect Limitation: used cut-off score of 10 in PSQI but only justified use of >8
Mathias & Alvaro (2012) Prevalence of sleep disturbances, disorders, and problems following TBI: A meta-analysis	Meta-analysis	*N* = 21 articles with following criteria: 1) sleep disturbances, regardless of type or severity 2) diagnosed sleep disorders 3) specific sleep problems following TBI, were analyzed and compared to data from general population.		50% of TBI survivors are estimated to have sleep disturbances and 25-29% are estimated to have a sleep disorder (insomnia, hypersomnia, apnea) with higher rates than the general public. TBI survivors twice to four times as likely to have problems with sleep maintenance and efficiency, nightmares, excessive sleepiness, early wakenings, or sleep walking	
Mollayeva et al. (2016) Insomnia in workers with delayed recovery from mild traumatic brain injury	Cross-sectional, cohort	*N* = 94 (mild, 197 mean days post injury)	ISI, Restless Leg Questionnaire, Swiss Narcolepsy Scale PHQ HADS, Pain Visual Analog Scale (P-VAS), STOP-BANG questionnaire	69.2% of sample met criteria for insomnia Stepwise multivariate regression model: 55% of insomnia variance (justified for age and sex) including predictors of depression severity, previous head trauma, age, use of tricyclic antidepressants, wake-up time instability Insomnia score positively correlated with age, anxiety, and depression	Limitation: cross-sectional so no causality assumptions, need more psychometric data in TBI for some of the chosen measures (ISI, VAS-P); unclear if multiple testing was accounted for

				Those with depression or anxiety had higher insomnia scores ($p = 0.003$) Significant differences in insomnia scores between workers with pain vs. those without pain ($p = 0.009$)	
Nardone et al. (2011) Cortical excitability changes in patients with sleep-wake disturbances after TBI	Group comparison	For all TBI subjects (mild and moderate; time not specified) $n = 11$ TBI with subjective EDS $n = 12$ TBI with objective EDS $n = 11$ with TBI subjective fatigue $n = 10$ with TBI hypersomnia $n = 14$ control subjects	transcranial magnetic stimulation (TMS) PSG, MSLT ESS, Sleep Apnea Scale of the Sleep Disorders Questionnaire, Ullanlinna Narcolepsy Scale MMSE, BDI	More pronounced resting motor threshold and short-latency intracortical inhibition in patients with TBI and EDS compared to controls ($p = 0.001$ and $p = 0.009$). Cortical hypoexcitability may be an underlying factor in sleep problems after TBI	Strength: excluded history of prior TBI
Nazem et al. (2016) Actigraphy and sleep diary measures in veterans with traumatic brain injury: Discrepancy in sleep parameters	Cross-sectional, cohort	$n = 19$ (moderate-severe; time not specified)	Sleep diary, actigraphy ISI HADS, Beck Scale for Suicide Ideation (BSS) Cognitive Failures Questionnaire	Actigraphy and sleep diary did not agree on total sleep time , wake after sleep onset, or sleep onset latency (actigraphy generally measured higher on all of these areas) Notable mismatch between objective and subjective sleep measures in this TBI sample	Limitation: did not account for PTSD or pain; small sample size

Nakase-Richardson et al. (2013) Prospective evaluation of the nature, course, and impact of acute sleep abnormality after traumatic brain injury	Prospective, cross-sectional cohort	*n* = 205 TBI (moderate-severe) TBIMS	Actigraphy chart review Family and nursing reports of sleep to rate DelRS-R98 sleep disturbance items into gross categories	84% met criteria for sleep disturbance on admission; 66% at 1 month after TBI Initial GCS score, days postinjury, presence of moderate-severe sleep disturbance predicted duration of post-traumatic amnesia ($p < 0.01$) and rehabilitation hospital length stay ($p < 0.01$) after adjusting for age	Strength: prospective evaluation of large sample Limitations: use of only one item on an instrument that is not validated for sleep disturbance; lack of objective sleep data; did not account for influence of medications; did not establish causal relationship
Oullet, Beaulieu-Bonneau, & Moring (2006)	Cross-sectional, cohort	*N* = 452 (mixed severity; time since injury 94.18 ± 90.30) Canada	Sleep and Fatigue Questionnaire, ISI, MAF Psychiatric Symptom Index Significant Other's Evaluation Questionnaire	29.4% met criteria for insomnia, 50.2% reported insomnia symptoms Mild TBI severity, fatigue, depression, and pain were risk factors for insomnia	Limitation: no objective sleep data, possible sample bias if TBI survivors with insomnia were more likely to participate
Oullet & Morin (2006) Subjective and objective measures of insomnia in context of traumatic brain injury: A preliminary study	Cross-sectional, case-control	*n* = 14 TBI (mixed severity; time not specified) *n* = 14 healthy controls Canada community dwelling	PSG, sleep diary, diagnostic interview for insomnia ISI,MAF BDI, BAI	Subjective insomnia measures tended to overestimate compared to objective PSG Large effect sizes suggesting sleep fragmentation No differences were found in percentage of stage 2, 3, 4, or REM sleep but did note a higher percentage of stage 1 sleep in TBI sample	Strength: two nights of PSG to address potential for first night effect Limitation: did not account for pain; sample size

Parcell et al. (2006) Self-reported changes to nighttime sleep after traumatic brain injury	Cross-sectional, case-control	*n* = 63 TBI (mixed severity; mean 230 days since injury) *n* = 53 age, sex matched controls community-dwelling Australia	sleep-wake diary ESS, General Sleep Questionnaire HADS	Factors identified by participants as restricting sleep: pain, work or chores, noise, worries TBI group had longer sleep onset and more awakenings with changes more common in mild TBI severity More sleep changes in TBI group (80%) compared to controls (23%)	Strength: excluded preinjury sleep disorder Limitations: only used PTA for severity of injury and used odd labeling: mild, moderate, severe, very severe
Parcell et al. (2008) Poor sleep quality and changes in objectively recorded sleep after TBI: A preliminary study	Case-control	*n* = 10 TBI (moderate-severe; 516 ± 124.04 days) *n* = 10 sex matched controls community dwelling Australia	PSG PSQI, ESS, MEQ HADS	Higher levels of depression and anxiety poorer sleep quality in TBI group. More slow wave sleep, less REM sleep, and more awakenings in TBI. No relationship between these sleep findings and injury severity or time since injury.	Strengths: excluded prior sleep disturbances, excluded if taking meds that would interfere with sleep (ex: Benzodiazepines), and those traveling across time zones Limitations: some sleep disturbances may still have been unaccounted for prior to recruitment
Ponsford et al., (2013) Changes in sleep patterns following traumatic brain injury: A controlled study.	Case-control	*n* = 153 TBI (mixed severity; 9.9 ± 6.7 months after injury) *n* = 128 noninjured controls	Clinical interview, medical records Westmead Posttraumatic Amnesia Scale sleep-wake diary (7 days) PSQI, ESS, General Sleep Questionnaire	Poorer sleep quality was associated with anxiety, depression, and pain Longer sleep time need in higher injury severity Poorer sleep quality and daytime sleepiness in TBI group along with longer sleep onset latency, poorer sleep efficiency, daytime napping, early bedtimes, and longer total sleep duration	Strengths: excluded those on meds impacting sleep; excluded preinjury sleep disorders Limitations: potential for recall bias

			HADS, Brief Pain Inventory		
Rao (2011) Sleep disturbance after mild traumatic brain injury: An indicator of injury?	Case-control	*n* = 7 mTBI *n* = 7 age and race matched mTBI controls	PSG, EEG GCS	Didn't differ from controls on macroarchitecture, however on microarchitecture the following changes were noted: Lower delta power and higher alpha power in first NREM period; lower beta in third REM and higher delta in first REM	Limitations: excluded subjects with prior history of sleep problems; small sample
Schrieber (2008) Long-lasting sleep patterns of adult patients with mTBI and non-TBI	Case-control	*n* = 26 mTBI (mild, time since injury not specified) Israel	PSG, MSLT	Compared to controls, mTBI subjects had. more NREM sleep ($p < 0.05$), lower REM sleep ($p = 0.05$), and lower total sleep time ($p < 0.05$)	Limitations: spent two nights in PSG but data from second night was not used therefore potential for first night effects
Sinclair, Ponsford, & Rajaratnam (2014) Actigraphic assessment of sleep disturbance following traumatic brain injury	Case-control	*n* = 21 TBI *n* = 21 controls Australia	Actigraphy (7 days), sleep diary (7 days) ESS,PSQI, Berlin Sleep Questionnaire Westmead PTA Scale BDI-II	A weak association noted between subjective and objective measurements in TBI group TBI group had poor sleep quality, more daytime sleepiness, and more fatigue compared to controls ($p < 0.01$) No sleep outcomes were associated with depression.	Limitations: excluded for prior history of sleep problems; small sample

Steele, Rajaratnam, Redman, & Ponsford (2005) The effect of traumatic brain injury on the timing of sleep	Case-control	*n* = 10 post acute TBI (severity and exact time since injury not specified) *n* = 10 age and gender matched controls Australia	sleep diary (1 week) salivary melatonin MEQ, General Sleep Questionnaire HADS	Variability noted in TBI groups pre-injury to followup MEQ score. No difference in timing of melatonin onset between groups	Limitations: cognitive impairment may have impacted the protocol (eating before salivary melatonin collection, etc.); sample size
Sullivan et al. (2015) Characterizing self-reported sleep disturbance after mTBI	Cross-sectional, case-control	*n* = 33 mTBI (mild, time since injury not specified) *n* = 33 controls matched on age, sex, ethnicity Australia	PROMIS Sleep Disturbance Short-Form 8b, Version 1, PROMIS Sleep Disturbance Short-Form 8a, ISI, STQ, ESS	All medium to large effect sizes for mTBI group having more sleep disturbance, more severe insomnia, longer wake after sleep onset, and greater sleep impairment No differences noted in sleep quantity, timing, sleep onset latency, sleep efficiency, or daytime sleepiness between groups	Strength: reported effect sizes; excluded for previous history of sleep disorder
Theadom et al. (2015)	Prospective, longitudinal; repeated measures	*n* = 346 TBI (mild; up to 1 year post injury)	PSQI, ESS RPQ CNS Vital Signs HADS CIQ	Poor sleep quality at baseline was not correlated to home integration but was predictive of post-concussion symptoms, mood, community integration, and cognitive ability at one year The insomnia rate for the sample was more than three times the rate of the general public 44.9% showed improvements in sleep quality at 12 months, 16.2% remained stable, and 38.9% worsened	Strength: sample size Limitation: lack of objective data, potential for over or underreporting

Tkachenko et al. (2016) Sleep disorders associated with mTBI using Sport Concussion Assessment Tool 3	Retrospective, cross-sectional	*N* = 93 mTBI (mild, mean 135 days post injury)	GCS Sport Concussion Assessment Tool Balance Error Scoring System Standardized Assessment of Concussion King-Devick Test	Positive correlation between dizziness, headache, psychiatric problems, and sleep problems Increased time since injury was associated with increase in severity of sleep related symptoms A significant association noted between moderate-severe psychiatric symptoms and moderate-severe sleep symptoms	Limitation: included fatigue as a sleep problem; no objective sleep data; did not correlate imaging with sleep disturbance
Urakami (2012) Relationship between sleep spindles and clinical recovery in patients with TBI: Simultaneous EEG and MEG study	Prospective, cohort	*N* = 8 TBI (mixed severity; time not specified)	EEG,MEG GCS GOS WAIS-III	Significant decreases in frequency , amplitude, and cortical activation source were noted during the sub-acute stage but recovered later post injury, along with cognitive function	Limitation: patients had good prognosis (potential for sample bias)
Verma, Anand, & Verma (2007) Sleep disorders in chronic traumatic brain injury	Retrospective, cohort	*N* = 60 TBI (mixed severity; 3 months to 2 years range post injury)	PSG ESS, MSLT BDI,HAS GAF	50% complained of hypersomnia, 25% with insomnia, 25% with parasomnias (particularly REM behavior disorder) Sleep disruption associated with some GAF scores ($p < 0.05$) (stage 1, sleep efficiency, and wake during sleep)	Strength: excluded for prior sleep disturbance Limitations: potential for first-night effect; did not account for possible effects of medications or pain; HAS and BDI were not attained in all patients; Ranchos Los Amigos Scale may have been a better option than GAF
Watson et al. (2007) Hypersomnia following traumatic brain injury	Prospective, cohort	*n* = 514 with TBI (1 month post injury and 1 year post injury)	GCS SIP	55% of TBI group reported sleepiness at 1 month after injury. 27% of the TBI group reported sleepiness at 1 year after injury. Over time, almost all TBI subjects (84%-	Strength: large sample size Limitation: unable to control for sedating-med exposure; injury severity confounder,

		n = 132 non-cranial trauma controls *n* = 102 trauma free controls		100%) reported improved sleepiness and only 78% of non cranial trauma group improved	not objective sleep data
Webster (2001) Sleep apnea in adults with TBI: A preliminary investigation	Prospective, cohort	*n* = 28 TBI with Rancho level 3 or greater (severity not specified, mean 35.4 days post injury)	GCS PSG Main outcome: Respiratory disturbance index (RDI) (number of apneic and hypopneic episodes per hour of sleep)	Sleep apnea criteria met in 36% of sample, determined by RDI of 5 or greater, slightly higher than general population Many of the sleep-related breathing disorders were central in nature, although cases of obstructive apnea were noted No relationship between BMI and RDI noted (unexpected)	Strength: excluded for previous sleep problems Limitations: half of sample were on medications that could impact central nervous system; small sample size; no ability to infer causality
Williams, Lazic, Ogilvie (2008) PSG and EEG analysis in long-term insomnia complaints after mild traumatic brain injury	case-control	*n* = 9 mTBI *n* = 9 controls	PSG, sleep log PAI, Brock Adaptive Functioning Inventory (BAFQ) PSQI, Sleep Disorders Questionnaire (SDQ), Brock Sleep and Insomnia Questionnaire (BSIQ)	mTBI group had cognitive and affect-related problems Compared to controls, mTBI group had 4% less efficient sleep ($p = 0.019$), shorter REM onset latency ($p = 0.011$), and longer sleep onset latencies. In mTBI group, changes in sleep microarchitecture were also noted in sigma, delta, and theta powers during sleep onset	Strength: accounted for pain impact on sleep Limitation: small sample; limited generalizability
Wiseman-Hakes et al., (2015) Sleep in the acute phase of severe TBI:	Cross-sectional, case-control	*n* = 7 TBI (severe, acute stage of injury) *n* = 6 patients	PSG, actigraphy GCS hospital length of	TBI group had longer sleep duration and early sleep onset; sleep was fragmented; poor sleep quality In both groups, sleep efficiency was low and	Strength: excluded prior history of sleep disorders Limitations: small sample; ortho and SCI group had

A snapshot of polysomnography		with ortho or spinal injuries Rationale for using ortho patients as control group: both groups include young adults who were healthy prior to injury, which is not case for most critically ill	stay Rancho Los Amigos (RLA) scale Galveston Orientation and Amnesia Test (GOAT)	sleep stages met expected proportions appropriate for age No correlations found between clinical characteristics and sleep variables	different pain medications during PSG; pain could have been a confounder for either group

APPENDIX B

PRIMARY QUANTITATIVE REFERENCES FOR FATIGUE AND SLEEP IN TBI SAMPLES

Table 2.
Primary quantitative references for fatigue and sleep in TBI samples.

Author(s),Year, Title	Design	Sample (severity; time since injury)	Measures	Findings	Strengths and/or Limitations
Beaulieu-Bonneau, S., & Morin, C. M. (2012) Sleepiness and fatigue following traumatic brain injury	Prospective, case-control	*n* = 22 TBI (moderate-severe; > 1 year since injury) *n* = 22 matched controls	PSG, MWT, Sleep diary ESS, MFI, VAS, ISI FOSQ BDI-II, State-Trait Anxiety Inventory	TBI group had greater impact of sleep on daytime functioning (more time in bed, more frequent and longer naps)	Limitations: small sample size; reduced power
Borgaro et al. (2005) Subjective reports of fatigue during early recovery from traumatic brain injury	Prospective, case-control	*n* = 45 TBI (mixed severity; 24.37 ± 17.01 months after injury) *n* =30 controls convienence sample	Barrow Neurological Institute (BNI) Fatigue Scale BNI Screen for Higher Cerebral Functions	TBI group reported more fatigue than normal controls. Fatigue was not associated with injury severity, cognition, gender, or time since injury. The most sensitive item associated with fatigue was "Being able to last the day without taking a nap"	Limitations: did not exclude for prior history of sleep problems or medications; no general medical group to account for hospital/environmental variables

Busnik, Englander, & Wright (2008) Patterns of fatigue and its correlates over first two years after traumatic brain injury	Prospective, longitudinal, repeated measures	*N* = 51 (moderate-severe; 6 months, 12 months, and 18-24 months post TBI)	GCS Barroso Fatigue Scale (BFS), VAS, BDI-II, Craig Handicap Assessment Reporting Technqiue, NFI	Over the first year, the following aspects improved: fatigue, pain, sleep quality, cognition, and participation Those with fatigue increases over the two years had worse cognition, motor symptoms, and worse general function compared to those whose fatigue scores stabilized or decreased	Limitation: large potential for symptom overlap
Busnik, Englander, & Wright (2008) The experience of fatigue in first 2 years after mod-severe traumatic brain injury: A preliminary report	Prospective, longitudinal	*N* = 38 moderate-severe first 2 years post injury	GCS (severity) Orientation Log (PTA) Barroso Fatigue Scale Global Fatigue Index Multidimensional Assessment of Fatigue Scale PSQI, DRS, Craig Handicap Assessment and Reporting Technqiue, Neurobehavioral Functioning Inventory	Between the first and second year, fatigue did not change Sleep quality most prevalent concurrent disturbance (then depression, then pain)	Limitations: small sample; normative data not appropriate for TBI scores comparison

Cantor et al. (2008). Fatigue after traumatic brain injury and its impact on participation and quality of life	Case-control	*n* = 223 TBI (mixed severity; 15.0 ± 13.2 years post injury) n= 85 non injured controls community dwelling	GFI, PSQI BDI-II, PSQI, MpQ, Participation Objective Participation Subjective (POPS), SF-36, Life-3	Among women and among individuals with TBI, fatigue was more prevalent and more severe. Health related quality of life and overall quality of life were correlated with fatigue but participation was not. 23% of variance in fatigue of TBI group was explained by depression, pain, and sleep problems; 58% of variance in control group explained by same factors	Limitation: potential for sample bias (if only those with fatigue registered)
Englander, Bushnik, Oggins, & Katznelson (2010)	Cross-sectional, cohort	*N* =119 (mixed severity ; 9 ± 7.6 years post injury) community hospital based rehabilitation centers	Neuroendocrine assessments: GH reserve, thyroid, cortisol and testosterone levels MAF, FSS, PSQI BDI II NFI, DRS, Craig Handicap Assessment and Reporting Technique	Predictors of fatigue scores: gender (female), depression, pain, and self-report memory deficits 53% of sample reported fatigue Despite 65% of sample having growth hormone deficiency and 65% having adrenal insufficiency, pituitary dysfunction was not associated with fatigue or any other factors.	Limitations: not able to independently verify injury severity, assessment measures (apart from blood samples) were self-report; did not exclude for prior sleep disorders but other conditions that could contribute to fatigue minimum 1 year post injury

Schneiders, Willemsen, de Boer (2012) Factors contributing to chronic fatigue after traumatic brain injury	Cross-sectional, between-groups, partially randomized	*N* = 166 (moderate-severe; minimum 1 year post injury) 2 groups: with fatigue (n=84) and without fatigue (n=82). From each group, 50 randomized.	Checklist Individual Strain (CIS-20R) PSQI cognition: "2 computerized tests" HADS, Acceptance and Action Questionnaire QoliBri 1 and 2 Frenchay Activity Index	Severity of fatigue correlated with poor sleep, Vitamin D serum levels, and anxiety (not correlated with growth hormone deficiency or gonadal hormone deficiency) The most important factors associated with fatigue were poor sleep quality, anxiety, and low serum levels of Vitamin D.	Limitations: very vague on computerized testing for cognition and did not discuss validity/reliablity of computer evaluations
Schonberger et al. (2014) Fatigue as a cause, not a consequence of depression and daytime sleepiness: Cross-lagged analysis	Prospective, cohort	*N* = 88 (mixed severity; time since injury not specified)	FSS, ESS HADS	Suggests that fatigue is "primary" Using structural equation modeling, fatigue predicted depression and sleepiness, but neither depression nor sleepiness predicted fatigue.	Limitations: small sample, lacking potential predictors

APPENDIX C

PRIMARY QUANTITATIVE REFERENCES TO COGNITION AND SLEEP IN TBI SAMPLES

Table 3.

Primary quantitative references to cognition and sleep in TBI samples.

Author(s), Year, Title	Design	Sample (severity; time since injury)	Measures	Results	Strengths and Limitations
Beaulieu-Bonneau, Fortier-Brochu, Ivers, Morin (2015) Attention following TBI: Neuropsychological and driving simulator data, and associated with sleep, sleepiness, fatigue	Case-control	*n* = TBI (moderate-severe; 53 ± 37.08 months post injury) *n* = 22 age and gender matched controls	GCS PSG 1 nighttime; 1 daytime measure of sleepiness Maintenance of Wakefulness Test (MWT) driving simulator task visual analogue scales (VAS) Delis-Kaplan Executive Fucntion System Trail Making Test (D-KEFS TMT) (including visual scanning, number sequencing, letter sequencing, nubmer-letter switching, motor speed, Auditory Consonant Trigrams (ACT), Continuous Performance Test II (CPT-II)	In TBI group, worse performance on tap speed of processing and sustained attention; no difference in selective attention Poor sleep associated with poor performance on some neuropsych tests TBI group had greater variability in lane position compared to controls during simulated driving task Attention seems to be associated with sleep continuity and daytime sleepiness but needs to be explored further; speed of processing seems to be impacted	Strengths: effect sizes; interventions were conducted during same time frames for each subject to accommodate impact of circadian rhythm; excluded for previous history of sleep problems Limitations: small sample; underpowered; driving simulator session may not have been demanding enough; only 1 night in PSG therefore potential for first night effects

Bloomfield, Espie, Evans (2010) Do sleep difficulties exacerbate deficits in sustained attention following TBI?	Prospective; group comparison	*N* = 44 TBI (mixed severity; 71.5 post injury-- unit of time not specified) United Kingdom Divided into good sleepers vs. poor sleepers	GCS Actigraphy, sleep diary PSQI, ISI HADS WASI, WTAR, Paced Auditory Serial Attention Test (PASAT); Digit Symbol Substitution (DSS) and Letter Number Sequencing (LNS) from WAIS-III; Cognitive Failures Questionnaire	Worse sustained attention in those with poor sleep vs. those with good sleep; no differences noted on other measures of attention	Limitations: offered "Good sleep Guide" instead of referring them for followup if they had sleep complaints; cutoff score of 6 for PSQI used to split group into good sleep vs. poor sleep for comparison; clinicians were also data collectors
Chiu, Lo, Chiang, Tsai (2014) The effect of sleep on the relationship between brain injury severity and the recovery of cognitive function: A prospective study	secondary data analysis of a prospective longitudinal study	*N* = 52 (mixed severity; within 24 hours of admission post injury) neurosurgical ward Taiwan		Daytime total sleep time mediated the relationship between TBI severity and cognitive function (t = -2.65, p = 0.004) Compared to normative values, TBI patients in this sample had worse sleep effiency, longer total sleep time, and longer waking time after onset ($p < 0.05$)	Strength: excluded for prior history of sleep disturbances Limitations: sample size; limited observation period of 7 days, only applicable to acute phase; factors that interfere with sleep in hospital settings; anxiety and depression were not accounted for
Holcomb et al. (2016) Relationship between sleep wake disturbance and trajectory of cognitive recovery during acute TBI	prospective	*N* = 106 (moderate, severe, first days post injury) inpatient rehabilitation	Sleep-wake cycle disturbance rating (item 1) on Delirium Rating Scale-Revised 98; DelRS-R98 Cognitive Test for Delirium Medical records	Ratings of sleep-wake cycle disturbance on later exams were significantly associated (using IGC modeling)	L:imitations: only used 1 item from DRS-98 scale, which represents confusion does not conceptually fit with cognition

Mahmood, Rapport, Hanks, Fichtenberg, (2004) Neuropsychological performance and sleep disturbance following TBI	Prospective	*n* = 87 (mixed severity) 97.7% within first year 89.7% in 6 months 70.1% within 3 months Outpatient Neurorehabilitation program	PSQI GCS BDI-II Digit Span, Grooved Pegboard Test, Block Design, Memory Assessment Scales (MAS), Trail Making Test part B, Controlled Oral Word Association (COWAT), and Digit Symbol, Wide-Range Achievement Test-3rd Revision (WRAT-3)	Some cognitive function measures may predict the occurrence of sleep disturbance, beyond injury severity and gender. 31% of PSQI score variance was accounted for in total model More sleep disturbance ($p < 0.01$) reported in mild TBI compared to severe 37% reported sleep disturbance PSQI scores was related to gender (0.21, $P = 0.046$) Higher order cognition measures (SOP, executive function) showed positive relationship with PSQI scores, compared to nonexecutive cognition measures (avg. correlation between higher-order functions, PSQI and SOP was 0.37 vs. avg. correlation for other cognitive domain 0.16)	Strength: did not include patients that were on sleep medications Limitations: awareness of deficits (or lack) may have influence results
Makley (2009) Return of memory and sleep efficiency following moderate to severe closed head injury	Prospective; observational	*N* = 14 TBI (moderate-severe; timing not specified)	Actigraphy PSQI Orientation Log FIM, DRS, Supervision Rating Scale, Satisfaction with Life Scale	Disrupted sleep most often occurred acutely; 78% had low mean sleep efficiency Step-wise increases in sleep efficiency score were associated with step-wise increases on measure of PTA ($p = 0.032$); improved sleep efficiency was related to improvement of PTA (resolution)	Strength: excluded for previous history of sleep disorders and neurological problems Limitations: small sample size; results may not be generalizable

Mantua et al (2015) Altered sleep composition after TBI does not affect declarative sleep-dependent memory consolidation.	Prospective, between groups	$N = 58$ (severity not specified, 4.35 ± 3.14 years) $n = 14$ TBI sleep $n = 12$ TBI wake $n = 15$ non-TBI sleep $n = 15$ non TBI wake	PSG ESS, SSS, MEQ Word-pair learning task, Forward Digit Spain task from WAIS- IV	Sleep after TBI did not impact sleep-dependent memory consolidation TBI group sleep architecture: greater proportion in slow wave sleep slightly lower delta power during slow wave sleep (central region)	Limitation: did not verify TBI data with records; could have used varied means of testing memory consolidation
Maruta et al. (2014) Predictive visual tracking: Specificity in mild TBI and sleep deprivation	Group comparison	$n = 13$ TBI (mild, time not specified) $n = 127$ controls $n = 42$ sleep deprived for 26 hours	Eye visual tracking using EyeLink CL; infrared video-oculography while head was stabilized with head and chin rest	Compared to normal subjects, TBI subjects had sig. worse visual tracking performance ($p < 0.001$) Compared to group sleep deprived for 26 hours (who was sig. worse than healthy controls on tracking performance), mTBI group still had worse visual tracking	Limitations: used mixed groups; civilians with TBI, military members for sleep deprivation; small sample size; couldn't exclude possibility of fatigue or sleep problems in mTBI group

Wilde et al. (2007) Cognitive impairment in patients with TBI and Obstructive Sleep Apnea	Case-control	*N* = 35 TBI patients (mixed severity; 94.3 ± 152.1 months postinjury) n = 19 with OSA n = 16 without OSA matched on age, education, severity of injury, time postinjury, and GCS	PSG ESS, MSLT Psychomotor Vigilance Test (PVT), Rey Complex Figure Test, Rey Auditory Verbal Learning Test, digit span test from Wechsler Memory Scale-Revised, and finger-tapping test	No sig. differences in groups on age, education, TBI severity, or ethnicity Compared to TBI without sleep problems, TBI with OSA performed sig. worse on recall measures (both visual and verbal) OSA and TBI group had more attention lapses but similar reaction times	Strengths: even with small sample size, effect sizes ranged from medium to large
Wiseman-Hakes et al. (2013) Evaluating the impact of treatment for sleep wake disturbance on recovery of cognition and communication in adults with chronic TBI		*N* = 10 TBI (mixed severity)	ISI BDI, BAI Latrobe Communication Questionnaire, Speed and Capacity and Language Processing, Test of Everyday Attention, Repeatable Battery for Assessment of Neuropsych status Daily cognitive communication and sleep profile	Insomnia severity, (0.0003), depression severity (0.03), language (0.01), speed of language processing (0.007) all statistically improved	Limitations: small sample; no control group, no cognitive behavioral therapy which might have improved the intervention

APPENDIX D

PRIMARY QUANTITATIVE REFERENCES TO BOTH SLEEP AND PSYCHIATRIC CORRELATES IN TBI SAMPLES; MILITARY STUDIES INCLUDED BECAUSE OF PTSD COMPONENT

Table 4.

Primary quantitative references to both sleep and psychiatric correlates in TBI samples; military studies included because of PTSD component.

Author(s) and Year	Design	Sample (severity; time since injury)	Measures	Results	Strengths and Limitations
Beetar et al., (1996) Sleep and pain complaints in symptomatic traumatic brain injury and neurologic populations	Case-control	*n* = 127 mild (23.9 ± 21.2 months post injury) *n* = 75 moderate-severe (23.9 ± 21.2 months post injury) *n* =123 non-TBI "general neurologic group"	Sleep problem: determined present if it was mentioned in the chart as a concern reported by patient. No mention was coded as no sleep complaints Insomnia: complaints in chart of problems with difficulty falling asleep, sleep maintenance, and early morning wakening were grouped as insomnia Pain: determined present if mentioned in chart; regardless of severity or location	Over half of TBI patients had insomnia complaints (56%), most common problem was poor sleep maintenance; TBI patients reported more sleep problems in those without pain Presence of pain double in those with insomnia compared to those without insomnia Pain in either group associated with a 100% increase in sleep complaints ; More sleep complaints in mild TBI compared to moderate or severe; Pain most common in head and neck, particularly in mild TBI In mTBI insomnia improved over time; in moderate-severe TBI the insomnia symptoms persisted over 2-4 years	Strengths: seminal work in pain with sleep and TBI Limitations: Sleep diagnosis was determine by patient complain in medical records; some TBI patients may not realize they have sleep difficulty
Bryan et al. (2012) Repetitive traumatic brain injury (or concussion) increases severity of sleep disturbance among deployed military personnel	Group comparison	*n* = 150 male military patients 3 groups *n* = 18 zero TBIs *n* = 54 single TBI *n* = 78 multiple TBIs	Clinical interviews	Insomnia rates increased across groups (no TBIs 5.6%; single TBIs 20.4%, multiple TBIs 50%) ($p < 0.001$) even after controlling for TBI severity, PTSD, and depression	

Chaput et al. Relationship among subjective sleep complaints, headaches, and mood alterations following mild TBI	Retrospective descriptive	*N* = 443 (mild; 10 days or 6 weeks post injury) Canada	Rivermead Post Concussion Symptom Assessment CT chart review	Subjective sleep complaints 13.3% (10 days) vs. 33.5% (6 wks); headaches 46.8% (10days) vs. 39.3 (6 wks); depressed 9.5% (10days) and 20.4% (6 wks); and irritability 5.6% (10 days) and 20.2% (6 wks). Sleep complaints at 6 weeks 2.9 times as likely ($p = 0.004$) if reported at day 10 post injury Sleep complaints at day 10 associated with headaches, depression, and irritability	Limitation: no objective sleep data

Collen et al. (2012) Sleep disturbances among soldiers with combat-related TBI	Retrospective cohort	*N* = 116 (mild, moderate severity; 16.1 ± 11.5 months)	DVBIC TBI Screening Tool aka Brief TBI Screen for mTBI; moderate or severe were given a diagnosis based on evaluation in TBI clinic Consultation with certified sleep medicine physician EMR pulled for: initial sleep consultation, follow-up evaluations, polysomnographic testing, age, sex, BMI, subjective assessment of ESS, VAS If suspicion for snoring, sleep fragmentation, apnea, or daytime somnolence, underwent overnight PSG	97.4% of sample complained of sleep problems; 85.2% hypersomnia, 54.3% sleep fragmentation, 34.5% obstructive sleep apnea (OSA), 55.2% insomnia Blast injuries were more likely to have anxiety and insomnia (63% vs. 40%, p = 0.02) and patients with blunt trauma were more likely to have OSA (54.3% vs. 25.9%, p = 0.003). Blunt trauma was a predictor of OSA (OR 3.09, 95% CI, 1.02-9.38; p = 0.047) 56.9% had PTSD, 85.3% had depression, and 41.4% had an anxiety disorder. Majority of cohort on psychiatric medications (94.0%)	Limitations: did not account for multiple testing; most were on medications so limited ability to assess impact of meds; potential for selection bias; limited applicability to civilians; narrow definition of insomnia may have contributed to underestimation

Farrell-Carnahan et al. (2013) Subjective sleep disturbance in veterans receiving care in the veterans affairs polytrauama system following blast-related mTBI	Cross-sectional secondary analysis	*N* = 114 TBI (blast; mild; 1,044 ± 538 days) Parent study: the DVBIC's Prospective TBI Tracking Protocol Study	Clinical Tracking Form and Chart review NSI PLC-C; Subjective Sleep Disturbance (SSD)-response on item 13 of PLC-C: "Please indicate how much you have been bothered by trouble falling and staying asleep in the past month."	PTSD in 78.10%, sleep disturbance in 77% (91% of those with sleep disturbance also had PTSD) Sleep disturbance not associated with time since injury, age, or marital status; more likely to have sleep disturbance with initial loss of consciousness at time of injury (compared to those who did not lose consciousness) Sleep disturbance associated with more nightmares, depression, and headaches	Limitations: only used 1 Likert scale item regarding sleep from the PLC-C to estimate sleep problems; did not capture data on number of blast exposures
Fogelberg et al., (2012) Association of sleep and co-occuring psychological conditions at 1 year after traumatic brain injury	Prospective longitudinal with non-equivalent comparison group	*n* = 174 (moderate-severe; up to 1 year post injury) TBIMS	Sleep: PSQI Depression: Patient Health Questionnaire 9 Anxiety: Generalized Anxiety Disorder-7 Scale Pain: Analog pain scale Functional status: Disability Rating Scale (DRS); Functional Independence Measure (FIM); Satisfaction with Life Scale (SWLS)	Subjects reported the worst sleep with 2-3 comorbid conditions 44% of TBI group had sleep disturbances and significantly worse depression, anxiety, or pain and worse on all functional outcome measures Association between sleep, depression, anxiety ($r = 0.72$, 0.39, and 0.56 respectively) ($p < 0.001$)	"level of sleep disturbance in TBI may be underestimated" More specific level of severity in this study only inpatient rehab participants "We did not measure sleep characteristics or parameters during inpatient rehabilitation early after injury"

King et al., (2017) The natural history of sleep disturbance among OEF/OIF vets with TBI and PTSD and the role of proxy variables in its measurement	Secondary analysis of longitudinal data	*N* = 291 (no severity or time since injury specified))	Structured diagnostic interview for TBI Alcohol Use Disorder Identification Test-Consumption questions (AUD-C) BDI-II Neurobehavioral Symptom Inventory (NSI) Pain intensity numeric rating scale PTSD Checklist-Military version (PCI-M) ISI, 3 and 4 item sleep disturbance scales	23-28% average reduction in sleep symptoms with bulk of change during first 6 month followup. TBI history best predictor of worse sleep symptoms. Worse sleep symptoms also associated with PTSD baseline and pain status. Identified four core items for future screening: trouble sleeping, changes in sleep, fatigue, and nightmares	Strength: large sample Limitations: original study wasn't designed to explore sleep as a primary outcome; few sleep measures available, no data on sleep-related interventions for these individuals
Lang, Veazey-Morris, Andrasik (2014) Exploring the role of insomnia in relationship between PTSD and Pain in Veterans with polytrauama injuries	Retrospective	*N* = 137	PTSD Checklist-Civilian Version (PCL-C) Insomnia Severity Index Brief Pain Inventory-Short Form (BPI)	51.8% of sample had co-occurrence of PTSD, insomnia, and pain Increased PTSD associated with insomnia (r = 0.67), pain interference (r = 0.61), and pain severity (r = 0.53) Relationship between PTSD and pain severity and pain interference partially mediated by insomnia	Limitations: cross-sectional; limited inference from mediation models; screening interview from medical records that has a 40% false negative rate

Ma et al (2013) Recovery from sleep disturbance precedes that of depression and anxiety following mTBI: A 6 week followup study	Case-control	*n* = 100 TBI (mild, one month or six weeks post injury) *n* = 137 non-TBI controls Taiwan	ESS, PSQI BDI, BAI	Anxiety, depression, and sleep quality scores were significantly different in TBI group vs. controls at baseline. Only sleep quality improved to the level of no sig. difference at the followup 6 week visit. No differences in subjective sleepiness scores	Limitations: medications could have influenced scores; could have diseases or preinjury conditions not specified; only subacute stages not chronic

Macera et al., (2012) Do sleep problems mediate the relationship between TBI and development of mental health symptoms after deployment?	Prospective, repeated measures	*n* = 29650 Navy and Marine Corp men mixed severity; time since injury not specified	Post-Deployment Health Assessment (PDHA) and Post-Deployment Health Reassessment---in 2008, TBI portion was added to this; a modified 3 item Brief TBI Screen (BTBIS): identify current health, deployment-related occupational and environmental exposures, and provide service members with the opportunity to discuss health concerns with a trained HCP THe Primary Care PTSD Screen or (PC-PTSD) is on the PDHA and PDHRA (includes sleep items and depression items)	Sleep problems mediated 26% of impact of TBI on PTSD development. Odds of being positive for depression decreased after controlling for sleep problems; sleep mediated 41% of TBI impact on depression development	Limitations: no objective sleep measures, unknown if sleep problems existed prior to injury; did not account for pain or sleep medications

Powell, 2015 Sleep quality and reexperienceing symptoms of PTSD are associated with current pain in U.S. OEF/OIF veterans with and without traumatic brain injury	Prospective ; exploratory	*N* = 171 TBI (mild; time not specified)	Boston Assessment of TBI-Lifetime (BAT-L) PSQI Clinician-Administered PTSD Scale (CAPS), Structured Clinical Interview for DSM Disorders, combat experiences module of Deployment Risk and Resilience Inventory (DRRI), Alcohol: total lifetime drinks, McGill Short Form Pain Questionnaire, Chronic pain-Centralized patient record system	Pain was associated with PTSD severity, sleep quality, and alcohol use (R^2 = 0.24) Re-experiencing symptoms of PTSD was associated with PTSD severity, sleep quality, and alcohol use (R^2 = 0.25) Only PTSD associated with chronic pain; current pain associated with PTSD severity, poor sleep quality, and alcohol use	Limitations: unable to confirm history of chronic pain in each participant; duration of chronic pain not known; did not specify time since injury; did not use cutoff score for sleep categories, used as a continuous variable
Rao (2008) Prevalence and types of sleep disturbance acutely after TBI	Longitudinal, observational	*N* = 54 TBI (< 3 months post injury)	Medical Outcome Scale for Sleep GCS, CT Structured Clinical Interview for Axis 1 disorders General Medical Health Rating	Anxiety disorder was the most consistent risk factor for worsening sleep scores	Limitations: called three e months post TBI "chronic;" did not account for pain or sleep medications

Rao et al. (2014) Does acute TBI-related sleep disturbance predict subsequent neuropsychiatric disturbances?	Longitudinal, observational	*n* = 101 TBI (mixed severity, 6 and 12 months post injury)	Medical Outcome Scale for Sleep (MOS) HAM-D, CAS, Apathy Evaluation Scale General Medical Health Rating (GMHR) Social Ties Checklist, Social Functioning Checklist, personal and instrumental activities of daily living via Lawton and Brody scale MMSE; National Adult Reading Test; Verbal Fluency Subtest; Category Subtest; Hopkins Verbal Learning Test, Brief Visuospatial Memory Test-Revised, Trail Making Test, Stroop Color and Word Test, Brief test of Attention, and the Wisconsin Card Sorting Test	Increases in symptoms of depression and anxiety were associated with sleep disturbances during a acute phase; apathy was associated with sleep disturbance during chronic phase Cognitive function was not related to sleep disturbance at either time point	Limitations: no objective measures of sleep disturbances; those with pre-morbid sleep disturbances were not excluded; did not account for pain or medications

Ruff, Want, & Ruff (2009) Improving sleep: Initial headache treatment in OIF/OEF veterans with blast mTBI	Intervention	*N* = 126 veterans of OIF/OEF (blast; mild; time not specified) seen 1 month from reported symptoms to clinic	ESS (specific questions below) 1) Is your sleep impaired due to nightmares for any other reason? 2) When you awake from sleep at the end of your sleeping period, do you feel rested? MOCA	Reduction in daytime sleepiness in entire group seen at end of intervention period; those who took prazosin did not improve at follow-up; those with sleep hygiene counseling but not prazosin did not improve MOCA scores and had persistent headaches Possible that sleep hygiene and prazosin were synergistic, but unable to conclude	Limitations: data collector was a care provider; history of TBI based on self-report; concurrent treatment for mood disorders; selected certain questions from ESS
Russo & Fingerhut (2017) Consistency of self-reported neurocognitive symptoms, post-traumatic stress disorder symptoms, and concussive events from end of first deployment to VHA comprehensive TBI evaluation by OEF/OIF/New Dawn veterans	Retrospective chart review	*N* = 140 (mixed severity)	DOD Post Deployment Health Assessment VHA Comprehensive TBI Evaluations (CTBIE)	Subjects reported more impairment in the areas of concentration, decision making, memory, headache, and sleep compared to their self-reported symptoms post-deployment.	Strengths: excluded for multiple deployments and head injuries post deployment; excluded participants from previous pilot study Limitations: missing data, didn't report time since injury; only includes those who sought VHA services

Stocker et al. (2014) Combat-related blast exposure and TBI influence brain glucose metabolism during REM sleep in military veterans	Cross-sectional, case-control	*n* = 14 mTBI (blast; mild; 42.64 ± 26.88 months after injury) *n* = 11 with no history of TBI	PSG PET imaging data Structured Clinical Interview for DSM-IV Axis I Disorders, CAPS, CES, MACE PSQI Life Events Checklist	Lower cerebral rate of glucose metabolism noted in veterans with mTBI, particularly during wakefulness and REM sleep	Limitation: small sample; underpowered
Towns, Silva, & Belanger (2015) Subjective sleep quality and post concussion symptoms following mild traumatic brain injury	Cross-sectional, cohort	*N* = 158 (mild) *n* = 58 (< 1 month post injury) *n* = 50 (1 month-1 year post injury) *n* = 50 (> 1 year post injury)	PSQI BSI-18, GSI,NSI	Poor sleep quality in 92% of those with mTBI; sleep quality, above and beyond demographics, time since injury, and psychological distress, accounted for a small amount of the variance in post concussive symptoms	Strength: excluded for prior sleep disturbance; used cut-off score of 7/8 in PSQI (more strict) and gave rationale Limitations: only self-report sleep measures; did not account for sleep aids or medications

Verfaellie (2015) Self-reported sleep disturbance mediates the relationship between PTSD and cognitive outcome in blast-exposed OEF/OIF veterans	Group comparison	*N* = 160 (blast, mild, 49.33 ± 28.99 months post injury) assigned to 1 of 3 groups: 1) no TBI 2) mTBI no LOC 3) mTBI LOC	Processing speed: Wechsler Adult Intelligence Test-III (WAIS III) Digit Symbol Coding D-KEFS Trail Making Test , DKEFS Color-Word Interference Test, WAIS-III Digit Span Backwards, Auditory Consonant Trigrams, D-KEFS Verbal Fluency Test, number-letter switching subtest of the DKEFS Trail Making Test, DKEFS Color-Word Interference Test, California Verbal Learning Test, Brief Visual Memory Test-Revised, Finger Tapping Test, Grooved Pegboard Test	Worse performance in cognitive domains associated with increased PTSD (mediated by sleep disturbance) Lower manual dexterity associated with mTBI with loss of consciousness (not mediated by sleep disturbance) Characteristics of those with mTBI without loss of consciousness: more severe PTSD, more sleep disturbance, worse manual dexterity (trend, not significant) Characteristics of those with TBI with loss of consciousness: more severe PTSD, more sleep disturbance, slower processing speed, and worse manual dexterity Effect of sleep disturbance on cognitive factors: processing speed (*B* = -0.04, *SE* = 0.02) verbal memory(*B* = -0.06, *SE* = 0.02) visual memory (*B* = -0.06, *SE3* = 0.02) motor speed (*B* = -0.04, *SE4* = 0.02 cognitive control (*B* = -0.04, *SE6* = 0.02) Sleep disturbance accounted for 48.2% of the variance in the final model(11.8% processing speed, 9.3% verbal memory, 8.2% visual memory, 6.3% motor speed, 4.9% manual dexterity, 9.7% cognitive control)	Limitation: Used cut off score of 8 on PSQI. Limitations: "other mental health outcomes may also contribute to cognitive outcome " (other than PTSD)

Wallace et al. (2011) Insomnia characteristics and clinical correlates in OEF/OIF veterans with post-traumatic stress disorder and mTBI: An exploratory study	Group comparison	*N* = 38 (mostly blast; mild; time not specified) *n* = 6 healthy subjects (HS) *n* = 9 PTSD *n* = 15 PTSD-mTBI Ethnicity was primarily Hispanic (63%)	Clinical interview PSG, Actigraphy (2 weeks), sleep diaries	Compared to HS and PTSD groups, daytime sleepiness was significantly greater in PTSD-mTBI group Insomnia patients had significant percentage of co-morbid sleep disturbances and disorders; insomnia in PTSD-mTBI had higher subjective sleepiness, spent less time awake at night Compared to PTSD patients, PTSD-mTBI group had shorter wake after sleep onset on PSG and actigraphy 38% of total sample had REM or NREM parasomnias	Limitations: recall bias; did not validate history of each TBI case; woke patients earlier than their normal waking time in PSG; allowed patients to take medications which may have influenced PSG

APPENDIX E

PRIMARY QUANTITATIVE REFERENCES TO FUNCTIONAL OUTCOMES RELATED TO SLEEP AND TBI

Table 5.
Primary quantitative references to functional outcomes related to sleep and TBI.

Author(s),Year, Title	Design	Sample (severity; time since injury)	Measures	Findings	Strengths and/or Limitations
Chan et al. (2015) Persistent sleep disturbances independently predict poorer functional and social outcomes 1 year after mild TBI	Longitudinal, repeated measures	*N* = 374 TBI (mild; 3 months-1 yr post injury)	Injury Severity Score (ISS) Rivermead Postconcussion Questionnaire (RPQ), Rivermead Head injury follow-up Questionnaire 28 item General Health Questionnaire	Poor outcomes predicted by sleep disturbance and higher symptom burden at 6 months 71.9% of sample reported sleep disturbance at 3 months; 57.2% at 6 months Late-onset of sleep disturbance was uncommon Females more likely to have sleep disturbance Sleep disturbance associated with gender (female), symptom burden, psychological distress, and worse functional and social outcomes.	Strength: power analysis Limitation: lack of objective evidence; sleep from a handful of selected items in RPQ
Ettenhofer et al (2012) Correlates of Functional Status among OEF/OIF Vets with a history of TBI	Retrospective, cross-sectional	*n* = 57 (mixed severity; mean 44.98 months post injury)	Clinical interview; medical records NSI, GAF Battery of neuropsychological tests	Lower levels of functioning after TBI associated with increased symptom severity, lower education levels, ongoing medication for treatment of sleep and psychiatric symptoms Low functional status associated with poor cognition, especially speed of processing and executive function Higher cognition associated with level of involvement in work and school activities (particularly domains of fine motor skills, processing speed, executive function, working memory)	Limitations: do not clarify what test composed the neuropsych battery, only that they were converted to a Global Cognition Score from merged scores

Evans and Bartlett (1995) Prediction of outcome in severe head injury based on recognition of sleep related activity in the polygraphic electroencephalogram	Between groups, consecutive sampling	*N* = 138 (within 7 days post injury) Split into 5 groups based on EEG/EEGP characteristics United Kingdom	EEG GCS Outcomes graded by Jennett and Bond criteria (1) good recoveries with no disability 2) mild disability 3) severe disability 4) persistent vegetative state 5) death.	Group 2, the "sleep-like group," had strong associations with positive functional outcomes, despite varying GCS scores Speaks to applicability of EEG results for prognosis, compared to GCS	
Makley et al (2008) Prevalence of sleep disturbance in closed head injury on a rehabilitation unit	Prospective, cohort	*N* = 31 TBI (moderate-severe; time not specified) inpatient rehabilitation unit	FIM Montebello Rehab Factors Score (MRFS); Montebellow Effiency Score (MRFS) LOS (acute and rehab) GCS nursing observation of sleep; received training; high interrater reliability	No differences noted in GCS or age 68% of the sample reported nighttime sleep disturbances Significantly longer stays in the trauma center ($p < 0.003$) and in rehabilitation center ($p < 0.03$) were noted in patients with sleep wake disturbances	Strength: excluded for prior history of sleep problems Limitations: did not address potential confounders such as sleep medications or obesity or BMI

Mollayeva et a. (2016) The relationship between insomnia and disability in workers with mTBI/concussion, insomnia an d disability in chronic mTBI	Cross-sectional	*N* = 92 (mild, 196 days post-injury) Canada	ISI LOC at injury, PTA, history of prior head trauma P-VAS, HADS, substance abuse, DSM-IV primary outcome: perceived disability level by Sheehan disability scale (SDS)	Workers with higher disability had more severe insomnia in addition to depression, anxiety, and pain; higher global disability increased with insomnia and pain In an adjusted model of work disability, insomnia was the only significant covariate	Limitation: did not exclude for prior history of sleep disturbance' no criterion for measurement work-related disability in TBI; mostly self-report measures; cross-sectional so can't infer causality
Sandsmark et al (2016) Sleep features on continuous EEG predict rehabilitation outcomes after severe TBI	Retrospective, cross-sectional	*N* = 64 TBI (severe, 14 days post injury)	Review of medical records EEG GCS outcome: 1) location of hospital disposition (home, acute rehab, long-term acute care facility, death) and 2) modified Rankin Scale (mRS) at discharge.	Seizures on EEG associated with poor outcomes (death or being discharged to a skilled nursing facility). Sleep characteristics present on EEG were associated with better outcome (89% discharged home or to rehabilitation facility). Lack of sleep elements on EEG associated with poor outcome at hospital discharge. Sleep features, independent of GCS, predicted functional outcomes.	Limitations: retrospective; did not control for use of medications
Zhang et al. (2009) Factors influencing self-rated health in traffic-related mild TBI	Retrospective, cross-sectional	*N* = 929 TBI (mild; median 11 days post injury) Canada	insurance claim reports	Poor post-TBi health associated with sleep problems and dizziness Patients without sleep problems reported better quality of life	Limitations: not validated items; no objective sleep measure; retrospective

APPENDIX F

PRIMARY REFERENCES TO BIOLOGICAL MARKERS AND POTENTIAL UNDERLYING MECHANISMS RELATED TO SLEEP IN TBI SAMPLES

Table 6.

Primary references to biological markers and potential underlying mechanisms related to sleep in TBI samples.

Author(s), Year, Title	Design	Sample (severity; time since injury)	Measures	Findings	Strengths and/or Limitations
Baumann et al., (2005) Hypocretin-1 (orexin-A) deficiency in acute TBI	Prospective, cohort	*N* = 44 acute TBI (mixed severity; 1-4 days)	hypocretin: assessed via intraventricular catheters (n=37) or lumbar puncture (n=8) GCS (severity) CT brain, Marshall criteria	Hypocretin 1 levels were lower in 95% of moderate-severe TBI patients	Limitation: sample size

Baumann et al., (2007) Sleep-wake disturbances 6 months after traumatic brain injury: A prospective study	Prospective, cohort	*n* = 96 (mixed severity; 6 months post TBI) Switzerland	PSG, MWT Blood draw: cerebrospinal fluid (CSF) for hypocretin, serum tests for hemoglobin, thyroid, iron metabolism; HLA typing ESS, MSLT, Sleep Apnea Scale of the Sleep Disorders Questionnaire, Ullanilinna Narcolepsy Scale, Swiss Narcolepsy Scale MMSE BDI GOS, SF-36	72% reported new onset sleep disturbances (28% subjective daytime sleepiness, 25% objective daytime sleepiness, 17% fatigue, 22% hypersomnia) Low CSF levels found in 25 of the 27 patients during first few days after TBI but 6 months later only found in 4 of 21 patients At 6 months after TBI, subjects with daytime sleepiness had sig. lower levels of hypocretin Lower quality of life associated with sleep disturbance post-TBI No relationships between sleep disturbances and gender, clinical outcome, TBI severity, or location of injury	Strength: excluded prior sleep-wake or psychiatric disorders Limitation: Didn't factor in psychiatric evaluations so cannot rule out the influence of psych disturbances on post traumatic sleep wake disturbances
Friebos (1999) Nocturnal hormone secretion and the sleep EEG I patients several months after TB	Case-control	*n* = 13 non depressed pts post TBI *n* = 13 age-matched controls post TBI (severe; mean 15.5 months post injury)	sleep EEG nocturnal hormone secretion: GH, prolactin, and cortisol GCS HAM-D	Increase in second REM stage and decrease in first cycle of stage 2 sleep noted ($p < 0.05$) (not other sig. changes in sleep architecture); sleep effiency unchanged No change in cortisol secretion; maximal prolactin secretion and decrease of peak production of GH noted	Strength: excluded for prior history of depression

Grima et al. (2016) Circadian melatonin rhythm following TBI	Case-control	*n* = 9 TBI (severe; 79.6 ± 75.5 months post injury) *n* = 9 age and gender matched controls	Salivary melatonin samples to determine salivary dim light melatonin onset (DLMO) as well as melatonin synthesis (SynOn) and offset (SynOff)	42% less nighttime melatonin secretion in TBI patients compared with controls ($d = 0.87$, $p = 0.034$) Delayed dim light melatonin onset (DLMO) by over an hour compared to controls ($d = 1.23$, $p = 0.003$)	Limitation: cannot infer causation because melatonin levels were not taken before and after TBI; did not measure association of other confounders with melatonin levels
Hong et al. (2015) PERIOD3 polymorphism is associated with sleep quality recovery after mild TBI	Cohort; repeated measures	*N* = 96 mTBI (mild; 1 week post TBI baseline; 6 week followup) Taiwan	Genomic DNA PSQI BAI, BDI	Only PER3-5 carriers significantly improved on PSQI scores at followup The allele was sig. related to short sleep duration and improvement in sleep quality	Limitations: high drop out rate; no objective sleep data
Paparrigopoulos et al. (2006) Melatonin secretion after head injury: Pilot study	Cohort, descriptive	*N* = 8 (severe, day 1 and 2 post injury) Greece	GCS Acute Physiology and Chronic Health Evaluation (APACHE II) score serum melatonin	Compared to normative values, melatonin concentrations were lower in sample GCS score was related to diurnal variation; low GCS did not have consistent variation compared to high GCS	Limitations: small sample; lack of control group; potential for environmental and other confounders
Shekleton et al. (2010) Sleep disturbance and melatonin levels following TBI	Case control	*n* = 23 TBI (moderate-severe; 429.7 ± 287.6 days) *n* = 23 age and gender matched controls Australia	PSG salivary dim light melatonin	Higher anxiety and depression in TBI patients as well as lower sleep effiency and higher wake after sleep onset Dim light melatonin onset was not sig. different between groups Lower levels of evening melatonin in TBI group; lower melatonin level associated with REM sleep	Strength: objective measures Limitations: small sample

Siefman et al. (2014) Measurement of serum melatonin in ICU patients, changes in TBI, trauma, and medical conditions	Between groups	*N* = 45 TBI (severe; first 8 days post injury) group 1: TBI group 2: trauma but no TBI group 3: ICU with no trauma or TBI	Serum melatonin	No sig. difference between groups for melatonin production over the 7 days Timing of melatonin disrupted in ICU patients although melatonin production levels not impacted	Limitations: small sample size; short length of time for evaluation (1 week)
Valko et al., (2016) Damage to arousal-promoting brainstem neurons with TBI	Post mortem, controlled	*n* = 8 TBI (severe, 11-36 days after) *n* = 10 controls	Post mortem analysis of brain stem tissue following fatal TBI; counts of hypothalamic cells	17% less serotonergic neurons in dorsal raphe nucleus (effect size 1.25) but no difference in number in median raphe nucleus. 29% fewer noradrenergic neurons in locus coeruleus (effect size 0.96).	Limitations: sample size; potential for inclusion bias (stated by authors); focus on neuronal loss alone and not axonal injury; no correlation with subjective complaints or sleep physiology
Yaeger, Alhiilali, & Fakhran (2013) Evaluation of Tentorial length and angle in sleep wake disturbance after mild traumatic brain injury	Retrospective, group comparison	*n* = 34 mTBI with sleep disturbance *n*=30 mTBI without sleep disturbance	Length of tentorium and angle formed between tentorium and line through foramen magnum (tentorial angle) were measured.	Longer tentorial length ($p < 0.01$) and small tentorial angle ($p < 0.01$) in TBI subjects with sleep disturbance compared to those without sleep disturbance Inverse relationship between tentorial angle and recovery time ($p = 0.002$) Tentorial length directly related to recovery time ($p < 0.001$) Tentorium may impact the pineal gland during impact	Limitations: did not record the direction of initial injury (often unavailable); large delay between injury and seeking medical attention (mean 70.7 days)

Zhou et al. (2016) Neuroendocrine dysfunction and insomnia in mild traumatic brain injury	Case-control;	*n* = 59 mTBI *n* = 50 healthy controls CHINA	GCS PSG PSQI-Chinese version low-dose short synacthen test (LDSST)	Higher subscores on PSQI in mTBI patients, but only sleep efficiency and daytime dysfunction associated with peak cortisol On PSG, TBI patients had lower sleep efficiency was lower and longer wake after sleep onset (both related to peak cortisol	Limitations: only assessed cortisol and ACTH

APPENDIX G

PRIMARY QUALITATIVE REFERENCES TO SLEEP IN TBI SAMPLES

Table 7.
Primary qualitative references to sleep in TBI samples.

Author(s), Year, Title	Design	Sample	Data collection and analysis	Findings	Strengths and Limitations
Matthews, Signoracci, Stearns-Yoder, Brenner (2016) A qualitative study of sleep-wake disturbance among veterans with post-acute moderate-severe TBI	Qualitative description	*n* = 19 TBI male veterans (mixed severity) with sleep-wake disturbances Convienence sample; purposeful recruitment	ISI Ohio State University TBI-Identification Method In depth interviews with probing Thematic analysis and content analysis using constant comparative method	Two main dimensions: "Messed up sleep" and surviving and managing sleep problems after TBI Many of the dimensions and themes are overlapping Potential for habits related to military environment to carry over into sleep during chronic stages of TBI (shift work, nightmares, etc)	Strengths: documentation of biases by each team member; team meetings before each analysis session; team consensus on coding form
Theadom et al. (2016) Exploring the experience of sleep and fatigue in male and female adults over the 2 years following TBI: A qualitative descriptive study	longitudinal qualitative description (as part of a larger longitudinal study) community-dwelling New Zealand	*n* = 30 TBI (mixed severity) (53 completed at least one interview but only 30 completed all 3 time points). *n* = 15 completed at least 1 interview with a significant other	Interviews at 6, 12, and 24 months postinjury Individual or dyad interviews, depending on participant preference Setting: at home OR university or private room at clinic 30min to 75 minutes each interview Analytic approach underpinned by social constructivism Constant comparative method	4 Themes were identified: 1) Making sense of fatigue and sleep after TBI, 2) accepting the need for rest, 3) learning how to rest, 4) need for rest impacts on ability to engage in life Napping was a large source of confusion for patients Significant others were surprised by the increased need for rest into chronic stages after injury	Strengths: trained interviewers Limitations: inconsistent methods (different settings, different interviews such as single vs. dyad); included people of different culture (Maori) group and did not acknowledge the impact this could have had on their descriptions of experiences .

APPENDIX H

LETTER OF SUPPORT

UAB SCHOOL OF MEDICINE

Department of Physical Medicine and Rehabilitation

November 16, 2016

UAB Internal Review Board

Rachael Mumbower is working with me on a study entitled Descriptions of Sleep Experiences following Traumatic Brain Injury. Her recruitment will come from people who are already enrolled in the UAB TBI Model System program who have provided consent to be contacted concerning future studies focusing on TBI. I will be monitoring Ms. Mumbower's access to the participants and data from the TBI Model System database. I will be available if any problems arise with the participants.

Thomas A. Novack, Ph.D., ABCN
Director, UAB TBI Model System

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APPENDIX I

RECRUITMENT LETTER

Sleep Experiences Following Traumatic Brain Injury: A Qualitative Descriptive Study

Dear [Mr. / Ms. LAST NAME],

As a participant in the Traumatic Brain Injury Model System program at UAB, you have provided permission to be contacted about new studies focusing on TBI. I am writing to tell you about a study starting at UAB under the direction of Rachael Mumbower from the UAB School of Nursing.

The study, entitled "Descriptions of Sleep Experiences following Traumatic Brain Injury," will be conducted through an in-person interview, on campus at UAB, with Rachael Mumbower. If you choose to participate, the process will take approximately an hour and 15 minutes of your time (consent paperwork, brief questionnaire, interview). If you choose to participate, you will be reimbursed $48 at the end of the session for your time and travel.

This study will enroll participants 18-50 years of age, with moderate-severe traumatic brain injury who did not have a diagnosed sleep disorder before injury. If you agree to participate, your identity will be protected and all of your information held confidential. Any information or for publications resulting from the study will not include identifiers.

Your participation in the study would be greatly appreciated. Your personal experiences with sleep after TBI may help to develop support and education materials for future brain injury survivors with similar experiences. Please expect a call from Rachael Mumbower within the next two-three weeks to discuss your interest, if any, in participating in the study. If you choose not to participate it will not affect your care at UAB, but I hope you will consider participating. If you wish to contact Rachael Mumbower, please call her at 601-608-8187.

Thank you for your consideration,

Thomas A. Novack, Ph.D., ABCN
Director, UAB TBI Model System

APPENDIX J

INFROMED CONSENT DOCUMENT

Informed Consent Document

TITLE OF RESEARCH:	Sleep Experiences Following Traumatic Brain Injury: A Qualitative Descriptive Study
IRB PROTOCOL NO.:	X161107001
INVESTIGATOR:	Rachael Mumbower, BSN, RN; Karen Heaton, PhD
SPONSOR:	UAB School of Nursing

Purpose of the Research

We are asking you to take part in a research study about sleep after traumatic brain injury. The purpose of the study is to learn more about what happens to sleep after traumatic brain injury. It is hoped that the information gained from this study will help us understand how to support traumatic brain injury survivors with resources and materials regarding sleep. If you enter this study, you will be one of up to 20 people asked to participate in an interview about what your sleep and your traumatic brain injury.

Explanation of Procedures

You will be asked questions about how your sleep before and after the injury and what information you have been given about sleep. The interview will take around 45 minutes to complete. The interview will be audio recorded. Following the interview you will be asked to complete a brief sleep questionnaire, the Pittsburgh Sleep Quality Index (PSQI), which will take approximately 10 minutes. The PSQI will also provide information about your sleep quality. You will also take the Patient Health Questionnaire 2 (PHQ-2) to provide information on depressive symptoms, which will take approximately 5 minutes. You may receive a follow up phone call from the investigator to clarify information from the interview.

Risks and Discomforts

In this study, you will not have any more risks than you would in a normal day of life. You may experience anxiety, stress, or sadness during the interview; however, you may stop the interview at any time or not answer questions that you do not feel comfortable answering. There is a potential risk of loss of confidentiality of the information obtained about you, but we believe this risk is small, and we will do everything we can to prevent your loss of confidentiality.

Benefits

You may not benefit directly from taking part in this study. However, this study may help us better understand the sleep of traumatic brain injury survivors and develop interventions for future clinical use.

Alternatives

The only alternative to participating in the study is to not participate in the study.

Confidentiality

Information obtained about you for this study will be kept confidential to the extent allowed by law. However, research information that identifies you may be shared with the UAB Institutional Review Board (IRB) and others who are responsible for ensuring compliance with laws and regulations related to research, including people on behalf of UAB School of Nursing and the Office for Human Research Protections (OHRP). The information from the research may be published for scientific purposes; however, your identity will not be given out.

Voluntary Participation and Withdrawal

Whether or not you take part in this study is your choice. There will be no penalty if you decide not to be in the study. If you decide to enter the study and change your mind, you have the right to stop at any time. You may be removed from the study without your consent if you are not following the study rules.

Cost of Participation

There is a possible cost for parking in Birmingham for the interview. There is metered street parking in addition to deck parking at Medical Towers (rate $2.00 for first hour and $1 every following hour).

Payment for Participation in Research

You will receive $48 cash at the end of your in-person interview to compensate for your time, participation, and parking.

Questions

If you have any questions, concerns, or complaints about the research please contact Rachael Mumbower, BSN, RN. She will be glad to answer any of your questions. Rachael Mumbower's number is 601-608-8187. You may also contact her faculty mentor, Dr. Karen Heaton. Her telephone number is 205-996-9467.

If you have questions about your rights as a research participant, or concerns or complaints about the research, you may contact the UAB Office of the IRB (OIRB) at (205) 934-3789 or toll free at 1-855-860-3789. Regular hours for the OIRB are 8:00 a.m. to 5:00 p.m. CT, Monday through Friday. You may also call this number in the event the research staff cannot be reached or you wish to talk to someone else.

Legal Rights

You are not waiving any of your legal rights by signing this informed consent document.

Signatures

Your signature below indicates that you have read (or been read) the information provided above and agree to participate in this study. You will receive a copy of this signed consent form.

Signature of Participant Date

Signature of Principal Investigator Date

University of Alabama at Birmingham
AUTHORIZATION FOR USE/DISCLOSURE OF PROTECTED HEALTH INFORMATION (PHI) FOR RESEARCH

Participant Name: _____ **UAB IRB Protocol Number:** X161107001
Research Protocol: Sleep Experiences Following Traumatic Brain Injury: A Qualitative Descriptive Study **Principal Investigator:** Rachael Mumbower
Sponsor: UAB School of Nursing

What is the purpose of this form? You are being asked to sign this form so that UAB may use and release your protected health information for research. Participation in research is voluntary. If you choose to participate in the research, you must sign this form so that your protected health information may be used for the research.

Why do the researchers want my protected health information? The researchers want to use your protected health information as part of the research protocol listed above and as described to you in the informed consent.

What protected health information do the researchers want to use? All medical information, including but not limited to information and/or records of any diagnosis or treatment of disease or condition, which may include sexually transmitted diseases (e.g., HIV, etc.) or communicable diseases, drug/alcohol dependency, etc.; all personal identifiers, including but not limited to your name, social security number, medical record number, date of birth, dates of service, etc.; any past, present, and future history, examinations, laboratory results, imaging studies and reports and treatments of whatever kind, including but not limited to drug/alcohol treatment, psychiatric/psychological treatment; financial/billing information, including but not limited to copies of your medical bills, and any other information related to or collected for use in the research protocol, regardless of whether the information was collected for research or non-research (e.g., treatment) purposes.

Who will disclose, use and/or receive my protected health information? All Individuals/entities listed in the informed consent documents, including but not limited to, the physicians, nurses and staff and others performing services related to the research (whether at UAB or elsewhere); other operating units of UAB, HSF, UAB Highlands, Children's of Alabama, Eye Foundation Hospital, and the Jefferson County Department of Health, as necessary for their operations; the IRB and its staff; the sponsor of the research and its employees and agents, including any CRO; and any outside regulatory agencies, such as the Food and Drug Administration, providing oversight or performing other legal and/or regulatory functions for which access to participant information is required.

How will my protected health information be protected once it is given to others? Your protected health information that is given to the study sponsor will remain private to the extent possible, even though the study sponsor is not required to follow the federal privacy laws. However, once your information is given to other organizations that are not required to follow federal privacy laws, we cannot assure that the information will remain protected.

How long will this Authorization last? Your authorization for the uses and disclosures described in this Authorization does not have an expiration date.

Can I cancel this Authorization? You may cancel this Authorization at any time by notifying the Principal Investigator, in writing, referencing the research protocol and IRB Protocol Number. If you cancel this Authorization, the study doctor and staff will not use any new health information for research. However,

researchers may continue to use the protected health information that was provided before you cancelled your authorization.

Can I see my protected health information? You have a right to request to see your protected health information. However, to ensure the scientific integrity of the research, you will not be able to review the research information until after the research protocol has been completed.

Signature of participant: _____ Date: _____

or participant's legally authorized representative: _____ Date: _____

Printed Name of participant's representative: _____

Relationship to the participant: _____

APPENDIX K

SCRIPT FOR RECRUITMENT CALL

Script for Recruitment Call

INTRODUCTION

Hello, my name is Rachael Mumbower and I am a PhD student at the University of Alabama at Birmingham's School of Nursing. Is this <*name of participant*>?

I am calling to talk with you about my research study. I recently mailed some information regarding the study to your home address. Did you receive the letter?

> **If NO:** May I send you the letter with information about the study? May I confirm your mailing address?
>
> **If YES:** Is this a good time to talk?

The purpose of this research study is to describe the sleep experiences of traumatic brain injury survivors. Specifically, we want to ask about your sleep since the traumatic brain injury and what information you have received about your sleep so that we can develop resources and/or interventions for other survivors.

We will be asking participants to come to UAB for an interview about their sleep and ask them to complete a brief sleep questionnaire. It will only require one visit to complete the study. The interview would last around 45 minutes and with the consent process and questionnaire, the total time would be approximately 65-70 minutes. Participants will be compensated $45.

Do you have any questions about this study? Would you be interested in participating?

> **If NO:** Thank you for your time and have a great day [*end call*].
>
> **If YES:** Thank you for your interest. Before enrolling participants in the study, we need to ask a few questions to determine eligibility. I would like to ask you a few questions. It will take around 10-15 minutes of your time. You do not have to answer questions that you do not feel comfortable answering. Any information I receive today will be kept confidential.

SCREENING

Do I have your permission to ask you a few questions?

> **If NO**: Ok, thank you for your time and have a great day [*end call*].
>
> **If YES**: [*move forward with questions*]

1. Have you ever been diagnosed with a sleep disorder? (Sleep apnea, narcolepsy, insomnia, etc.). If YES: Was this diagnosis received before or after your head injury?

2. Are you able to complete an interview and questionnaire on the UAB campus that will last a total of approximately 65-70 minutes? Breaks will be provided as needed.

CAPACITY TO CONSENT*: during the screening process, the PI will assess the potential participant's ability to clearly communicate verbally and appropriately answer questions without assistance through the interactions that take place. By understanding and appropriately answering questions, the potential participant will demonstrate capacity to consent and ability to provide oral descriptions during the interview.*

If ELIGIBLE: Based on your answers to these questions, it appears you may be eligible to participate in the research study. Would you like to schedule a time to meet at UAB to receive more details about the study and complete the interview?

IF YES: [*Move forward to scheduling.*]

If NOT ELIGIBLE: Unfortunately, you are not eligible to participate in this study. Thank you for your time and interest [*end call*].

SCHEDULING

CAMPUS: [*Provide different time/date options for the participant. Instruct them to pick a time that does not interfere with daily naps or immediately follow rehabilitation appointments to prevent fatigue.*]

Please look over the blank consent form that was mailed with the recruitment letter and we will complete it together at the appointment. The interview appointment will take place at Spain Rehabilitation. We ask that you park in the lot directly in front of the building and we will reimburse you $3 for parking. You may bring a significant other or friend with you, if you wish, but we ask that you complete the interview alone with the research for your privacy. Do you have any questions at this time?

TELEPHONE:

The recruitment letter that was mailed to you also included a blank copy of the informed consent to participate in the study. Please think about what we have discussed today and call me if you have any questions about your participation in the study and any risks. Remember that you do not have to participate and may stop participation at any time. Please complete the consent form and mail it back to me at the address listed. Once I have received your completed consent form, I will call you to schedule a time for a telephone interview.

To validate your identify for the interview call, please tell me a password that you and I can use to ensure that you are the person I'm talking to. This will also protect your confidentiality.

CONCLUSION

Thank you for talking with me today. I look forward to meeting you for the on campus interview. I will call you the day before you appointment to remind you of the time and location. If you have any questions or concerns, please feel free to contact me. Again, my name is Rachael Mumbower and you can reach me by phone at 601-608-8187 (cell) or 205-975-6194 (office) or by email at mumbower@uab.edu [*end call*].

APPENDIX L

SEMI-STRUCTURED INTERVIEW GUIDE

Sleep Experiences Following Traumatic Brain Injury: A Qualitative Descriptive Study

Individual Interview Guide

Welcome, and thank you for your participation. During this interview, I am going to ask you several questions about yourself, your head injury, and your sleep. Please describe your experiences as much as you can. You are free to stop at any time. Please feel free to use as much detail as you need to tell your story. I'm happy to repeat a question. This should take around 30-45 minutes. I may take a few notes as we talk, but only so that I can remember details later. This interview will be recorded.

Research Question	**Interview Question**
Opening/Icebreaker	Please tell me about your head injury.
1. How do survivors of moderate-severe TBI describe their sleep since injury?	Tell me about your sleep BEFORE the head injury. • *What was the quality of your sleep before your head injury?* • *Did you experience any problems with your sleep before your head injury? If so, please describe them.* Tell me about your experiences with sleep SINCE the head injury. By experiences, I mean any aspects of your sleep that stand out to you such as memorable or important; any incident that stands out in your mind. • *Has your sleep changed since before your injury? If so, how?* • *What is your sleep environment like? (Where? Lighting? Bed partner?)* • *What do you do normally do when getting ready for bed? (nighttime routine)* • *Tell me about how much you sleep (duration).* • *Tell me about when you sleep (When do you normally go to sleep or wake up? Do you normally sleep during the night or during the day?)* • *Have you received any treatment or intervention for your sleep?* • *Tell me about your dreams and your sleep after head injury.*

	• *Have you tried any alternative therapies or treatments for your sleep? Such as over the counter medicines, essential oils, etc.* How do you feel about your sleep since the head injury?
2. What factors do TBI survivors describe as positively or negatively impacting their sleep experiences?	Tell me what seems to help your sleep. Tell me what seems to make your sleep worse. • What about pain and your sleep?
3. How do TBI survivors describe their social engagement in relation to their sleep experiences?	Think about your interactions with family and friends. How does your sleep affect those relationships? How does your sleep affect your involvement in church and social events?
4. How do TBI survivors describe their occupational engagement in relation to their sleep experiences?	How does your night time sleep affect you during the day? Tell me how your sleep affects your job or work.

5. What sleep-related education is provided to TBI survivors post-rehabilitation?	Tell me about any information you have received about your sleep since injury.
	• *Where did you receive the information from?*
	• *This could be from any source (health care provider, home health nurse, rehabilitation facility, internet, book, family member, etc).*
	• *What type of information was it?*
	• *Was it helpful?*
	  ○ *If so, why?*
	  ○ *If not, why?*
	
	What information do you wish you had received regarding your sleep.
	• *What would be helpful?*
	• *When would be the best time to receive the information?*
	• *Who would you prefer to give you the*

	information?
Conclusion	Think about your sleep experiences since your head injury. If you had to write a book about those experiences, what would be the title of the book? Is there anything else you would like to share with me about your sleep?

Thank you very much for your participation. You may receive a follow-up call to clarify a response, if necessary.

APPENDIX M

PITTSBURGH SLEEP QUALITY INDEX (PSQI)

PITTSBURGH SLEEP QUALITY INDEX (PSQI)

INSTRUCTIONS: The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions.

1. During the past month, when have you usually gone to bed at night?

   USUAL BED TIME _____

2. During the past month, how long (in minutes) has it usually take you to fall asleep each night?

   NUMBER OF MINUTES _____

3. During the past month, when have you usually gotten up in the morning?

   USUAL GETTING UP TIME _____

4. During the past month, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spend in bed.)

   HOURS OF SLEEP PER NIGHT _____

INSTRUCTIONS: For each of the remaining questions, check the one best response. Please answer all questions.

5. During the past month, how often have you had trouble sleeping because you...

	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
(a) ...cannot get to sleep within 30 minutes	☐	☐	☐	☐
(b) ...wake up in the middle of the night or early morning	☐	☐	☐	☐
(c) ...have to get up to use the bathroom	☐	☐	☐	☐
(d ...cannot breathe comfortably	☐	☐	☐	☐
(e) ...cough or snore loudly	☐	☐	☐	☐
(f) ...feel too cold	☐	☐	☐	☐
(g) ...feel too hot	☐	☐	☐	☐
(h) ...had bad dreams	☐	☐	☐	☐
(i) ...have pain	☐	☐	☐	☐
(j) Other reason(s), please describe _____ _____				
How often during the past month have you had trouble sleeping because of this?	☐	☐	☐	☐

	Very good	Fairly good	Fairly bad	very bad
6. During the past month, how would you rate your sleep quality overall?	☐	☐	☐	☐

	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
7. During the past month, how often have you taken medicine (prescribed or "over the counter") to help you sleep?	☐	☐	☐	☐
8. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?	☐	☐	☐	☐

	No problem at all	Only a very slight problem	Somewhat of a problem	A very big problem
9. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?	☐	☐	☐	☐

	No bed partner or roommate	Partner/ roommate in other room	Partner in same room, but not same bed	Partner in same bed
10. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?	☐	☐	☐	☐

If you have a roommate or bed partner, ask him/her how often in the past month you have had...

	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
(a) ...loud snoring	☐	☐	☐	☐
(b) ...long pauses between breaths while asleep	☐	☐	☐	☐
(c) ...legs twitching or jerking while you sleep	☐	☐	☐	☐
(d) ...episodes of disorientation or confusion during sleep	☐	☐	☐	☐
(e) Other restlessness while you sleep; please describe	☐	☐	☐	☐

SCORING INSTRUCTIONS FOR THE PITTSBURGH SLEEP QUALITY INDEX:

The Pittsburgh Sleep Quality Index (PSQI) contains 19 self-rated questions and 5 questions rated by the bed partner or roommate (if one is available). Only self-rated questions are included in the scoring. The 19 self-rated items are combined to form seven "component" scores, each of which has a range of 0-3 points. In all cases, a score of "0" indicates no difficulty, while a score of "3" indicates severe difficulty. The seven component scores are then added to yield one "global" score, with a range of 0-21 points, "0" indicating no difficulty and "21 " indicating severe difficulties in all areas.

Scoring proceeds as follows:

Component 1: Subjective sleep quality

Examine question #6, and assign scores as follows:

Response	Component 1 score
"Very good"	0
"Fairly good"	1
"Fairly bad"	2
"Very bad"	3

Component 1 score: _____

Component 2: Sleep latency

1. Examine question #2, and assign scores as follows:

Respo\nse	Score
≤15 minutes	0
16-30 minutes	1
31-60 minutes	2
> 60 minutes	3

Question #2 score: _____

2. Examine question #5a, and assign scores as follows:

Response	Score
Not during the past month	0
Less than once a week	1
Once or twice a week	2
Three or more times a week	3

Question #5a score: _____

3. Add #2 score and #5a score

Sum of #2 and #5a: _____

4. Assign component 2 score as follows:

Sum of #2 and #5a	Component 2 score
0	0
1-2	1
3-4	2
5-6	3

Component 3: Sleep duration

Examine question #4, and assign scores as follows:

Response	Component 3 score
> 7 hours	0
6-7 hours	1
5-6 hours	2
< 5 hours	3

Component 3 score: _____

Component 4: Habitual sleep efficiency

1. Write the number of hours slept (question #4) here: _____
2. Calculate the number of hours spent in bed:

   Getting up time (question #3): _____

   Bedtime (question #1): _____

   _____

   Number of hours spent in bed: _____

3. Calculate habitual sleep efficiency as follows:

   (Number of hours slept/Number of hours spent in bed) X 100 = Habitual sleep efficiency (%)

   (_____/_____) X 100 = %

4. Assign component 4 score as follows:

Habitual sleep efficiency %	Component 4 score
> 85%	0
75-84%	1
65-74%	2
< 65%	3

Component 4 score: _____

Component 5: Step disturbances

1. Examine questions #5b-5j, and assign scores for each question as follows:

Response	Score
Not during the past month	0
Less than once a week	1
Once or twice a week	2
Three or more times a week	3

5b score: _____

5c score: _____

5d score: _____

5e score: _____

5f score: _____

5g score: _____

5h score: _____

5i score: _____

5j score: _____

2. Add the scores for questions #5b-5j:

Sum of #5b-5j: _____

3. Assign component 5 score as follows:

Sum of #5b-5j	Component 5 score
0	0
1-9	1
10-18-4	2
19-27	3

Component 5 score: _____

Component 6: Use of sleeping medication

Examine question #7 and assign scores as follows:

Response	Component 6 score
Not during the past month	0
Less than once a week	1
Once or twice a week	2
Three or more times a week	3

Component 6 score: _____

Component 7: Daytime dysfunction

1. Examine question #8, and assign scores as follows:

Response	Score
Never	0
Once or twice	1
Once or twice each week	2
Three or more times each week	3

Question#8 score: _____

2. Examine question #9, and assign scores as follows:

Response	Score
No problem at all	0
Only a very slight problem	1
Somewhat of a problem	2
A very big problem	3

Question #9 score: _____

3. Add the scores for question #8 and #9:

Sum of #8 and #9: _____

4. Assign component 7 score as follows:

Sum of #8 and #9	Component 7 score
0	0
1-2	1
3-4	2
5-6	3

Component 7 score: _____

Global PSQI Score

Add the seven component scores together:

Global PSQI Score: _____

APPENDIX N

PATIENT HEALTH QUESTIONNAIRE-2 (PHQ-2)

The Patient Health Questionnaire-2 (PHQ-2) - Overview

The PHQ-2 inquires about the frequency of depressed mood and anhedonia over the past two weeks. The PHQ-2 includes the first two items of the PHQ-9.

- The purpose of the PHQ-2 is not to establish final a diagnosis or to monitor depression severity, but rather to screen for depression in a "first step" approach.
- Patients who screen positive should be further evaluated with the PHQ-9 to determine whether they meet criteria for a depressive disorder.

Clinical Utility

Reducing depression evaluation to two screening questions enhances routine inquiry about the most prevalent and treatable mental disorder in primary care.

Scoring

A PHQ-2 score ranges from 0-6. The authors[1] identified a PHQ-2 cutoff score of 3 as the optimal cut point for screening purposes and stated that a cut point of 2 would enhance sensitivity, whereas a cut point of 4 would improve specificity.

Psychometric Properties[1]

Major Depressive Disorder (7% prevalence)				Any Depressive Disorder (18% prevalence)			
PHQ-2 Score	Sensitivity	Specificity	Positive Predictive Value (PPV*)	PHQ-2 Score	Sensitivity	Specificity	Positive Predictive Value (PPV*)
1	97.6	59.2	15.4	1	90.6	65.4	36.9
2	92.7	73.7	21.1	2	82.1	80.4	48.3
3	**82.9**	**90.0**	**38.4**	**3**	**62.3**	**95.4**	**75.0**
4	73.2	93.3	45.5	4	50.9	97.9	81.2
5	53.7	96.8	56.4	5	31.1	98.7	84.6
6	26.8	99.4	78.6	6	12.3	99.8	92.9

** Because the PPV varies with the prevalence of depression, the PPV will be higher in settings with a higher prevalence of depression and lower in settings with a lower prevalence.*

The Patient Health Questionnaire-2 (PHQ-2)

Patient Name _____ Date of Visit _____

Over the past 2 weeks, how often have you been bothered by any of the following problems?	Not At all	Several Days	More Than Half the Days	Nearly Every Day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed or hopeless	0	1	2	3

APPENDIX O

IRB APPROVAL FORMS

THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

Institutional Review Board for Human Use

Form 4: IRB Approval Form
Identification and Certification of Research
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on November 8, 2021. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator:	MUMBOWER, RACHAEL MARIE
Co-Investigator(s):	CHILDS, GWENDOLYN DENICE DREER, LAURA E NOVACK, THOMAS A VANCE, DAVID E
Protocol Number:	**X161107001**
Protocol Title:	*Sleep Experiences Following Traumatic Brain Injury: A Qualitative Descriptive Study*

The IRB reviewed and approved the above named project on 12/9/16. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 12-9-16

Date IRB Approval Issued: 12/9/16

IRB Approval No Longer Valid On: 12/9/17

Partial HIPAA Waiver Approved?: Yes

Marian Doe

Expedited Reviewer
Member - Institutional Review Board
for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

470 Administration Building
701 20th Street South
205.934.3789
Fax 205.934.1301
irb@uab.edu

The University of
Alabama at Birmingham
Mailing Address:
AB 470
1720 2ND AVE S
BIRMINGHAM AL 35294-0104

UAB IRB Approval of Partial Waiver of HIPAA Authorization to Use PHI in Screening for Research

☐ **Patient Authorization: Approval of Partial HIPAA Waiver to Use PHI in Screening for Research.** The IRB reviewed the proposed research and granted the request for a "partial HIPAA waiver," to allow the proposed use of protected health information (PHI) in screening for research, based on the following findings:

1. The use/disclosure of PHI to screen candidates for research involves no more than minimal risk to the privacy of individuals
   a. There is an adequate plan to protect the identifiers from improper use and disclosure.
   b. There is an adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers or such retention is otherwise required by law.
   c. The PHI will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research study, or for other research for which the use or disclosure of PHI would be permitted.
2. The screening cannot practicably be conducted without the waiver or alteration.
3. The screening cannot practicably be conducted without access to and use of the PHI.

—OR—

☐ **Full Review**

The IRB reviewed the proposed research at a **convened meeting** at which a majority of the IRB was present, including one member who is not affiliated with any entity conducting or sponsoring the research, and not related to any person who is affiliated with any of such entities. The partial waiver of authorization for screening was approved by the majority of the IRB members present at the meeting.

_____
Date of Meeting

_____
Signature of Chair, Vice-Chair or Designee

_____
Date

☐ **Expedited Review**

The IRB used an **expedited review procedure** because the research involves no more than minimal risk to the privacy of the individuals who are the subject of the PHI for which use or disclosure is being sought. The review and approval of the partial waiver of authorization for screening was carried out by the Chair of the IRB, or by one of the Vice-Chairs of the IRB as designated by the Chair of the IRB.

12-9-14
Date of Expedited Review

Marilyn Dass
Signature of Chair, Vice-Chair or Designee

12-9-14
Date

470 Administration Building
701 20th Street South
205.934.3789
Fax 205.934.1301
irb@uab.edu

The University of
Alabama at Birmingham
Mailing Address:
AB 470
1720 2ND AVE S
BIRMINGHAM AL 35294-0104

Project Revision/Amendment Form

Form version: June 26, 2012

In MS Word, click in the white boxes and type your text; double-click checkboxes to check/uncheck.

- **Federal regulations require IRB approval before implementing proposed changes. See Section 14 of the IRB Guidebook for Investigators for additional information.**
- **Change means any change, in content or form, to the protocol, consent form, or any supportive materials (such as the Investigator's Brochure, questionnaires, surveys, advertisements, etc.). See Item 4 for more examples.**

1. Today's Date	2/2/17

2. Principal Investigator (PI)

Name (with degree)	Rachael Mumbower	**Blazer ID**	11161349
Department	School of Nursing	**Division (if applicable)**	Nursing Research
Office Address	1717 11th Ave. S.	**Office Phone**	205-996-0090
E-mail	mumbower@uab.edu	**Fax Number**	

Contact person who should receive copies of IRB correspondence (Optional)

Name		**E-Mail**	
Phone		**Fax Number**	
Office Address (if different from PI)			

3. UAB IRB Protocol Identification

3.a. Protocol Number	X161107001
3.b. Protocol Title	Sleep Experiences Following Traumatic Brain Injury: A Qualitative Descriptive Study

3.c. Current Status of Protocol—Check ONE box at left; provide numbers and dates where applicable

- ☐ **Study has not yet begun** — **No participants, data, or specimens have been entered.**
- ☒ **In progress, open to accrual** — **Number of participants, data, or specimens entered:** 5
- ☐ **Enrollment temporarily suspended by sponsor**
- ☐ **Closed to accrual, but procedures continue as defined in the protocol (therapy, intervention, follow-up visits, etc.)**
  - **Date closed:**
  - **Number of participants receiving interventions:**
  - **Number of participants in long-term follow-up only:**
- ☐ **Closed to accrual, and only data analysis continues**
  - **Date closed:**
  - **Total number of participants entered:**

4. Types of Change

Check all types of change that apply, and describe the changes in Item 5.c. or 5.d. as applicable. To help avoid delay in IRB review, please ensure that you provide the required materials and/or information for each type of change checked.

- ☐ **Protocol revision (change in the IRB-approved protocol)**
  In Item 5.c., if applicable, provide sponsor's protocol version number, amendment number, update number, etc.
- ☒ **Protocol amendment (addition to the IRB-approved protocol)**
  In Item 5.c., if applicable, provide funding application document from sponsor, as well as sponsor's protocol version number, amendment number, update number, etc.
- ☐ **Add or remove personnel**
  In Item 5.c., include name, title/degree, department/division, institutional affiliation, and role(s) in research, and address whether new personnel have any conflict of interest. See "Change in Principal Investigator" in the IRB Guidebook if the principal investigator is being changed.
  - ☐ **Add graduate student(s) or postdoctoral fellow(s) working toward thesis, dissertation, or publication**
    In Item 5.c., (a) identify these individuals by name; (b) provide the working title of the thesis, dissertation, or publication; and (c) indicate whether or not the student's analysis differs in any way from the purpose of the research described in the IRB-approved HSP (e.g., a secondary analysis of data obtained under this HSP).
- ☐ **Change in source of funding; change or add funding**
  In Item 5.c., describe the change or addition in detail, include the applicable OSP proposal number(s), and provide a copy of the application as funded (or as submitted to the sponsor if pending). Note that some changes in funding may require a new IRB application.

☒ **Add or remove performance sites**
In Item 5.c., identify the site and location, and describe the research-related procedures performed there. If adding site(s), attach notification of permission or IRB approval to perform research there. Also include copy of subcontract, if applicable. If this protocol includes acting as the Coordinating Center for a study, attach IRB approval from any non-UAB site added.

☐ **Add or change a genetic component or storage of samples and/or data component—this could include data submissions for Genome-Wide Association Studies (GWAS)**
To assist you in revising or preparing your submission, please see the IRB Guidebook for Investigators or call the IRB office at 934-3789.

☐ **Suspend, re-open, or permanently close protocol to accrual of individuals, data, or samples (IRB approval to remain active)**
In Item 5.c., indicate the action, provide applicable dates and reasons for action; attach supporting documentation.

☐ **Report being forwarded to IRB (e.g., DSMB, sponsor or other monitor)**
In Item 5.c., include date and source of report, summarize findings, and indicate any recommendations.

☐ **Revise or amend consent, assent form(s)**
Complete Item 5.d.

☐ **Addendum (new) consent form**
Complete Item 5.d.

☒ **Add or revise recruitment materials**
Complete Item 5.d.

☐ **Other (e.g., investigator brochure)**
Indicate the type of change in the space below, and provide details in Item 5.c. or 5.d. as applicable.
Include a copy of all affected documents, with revisions highlighted as applicable.

5. Description and Rationale

In Item 5.a. and 5.b, check Yes **or** No **and see instructions for** Yes **responses.**
In Item 5.c. and 5.d, describe—and explain the reason for—the change(s) noted in Item 4.

☐Yes ☒No **5.a. Are any of the participants enrolled as normal, healthy controls?**
If yes, describe in detail in Item 5.c. how this change will affect those participants.

☒Yes ☐No **5.b. Does the change affect subject participation, such as procedures, risks, costs, location of services, etc.?**
If yes, FAP-designated units complete a FAP submission and send to fap@uab.edu. Identify the FAP-designated unit in Item 5.c.
For more details on the UAB FAP, see www.uab.edu/cto.

5.c. Protocol Changes: In the space below, briefly describe—and explain the reason for—all change(s) to the protocol.

Following an unanticipated safety event and due to a change in policy for the interview rooms at Medical Towers, the interviews will take place in a private interview room on the 5th floor of Spain Rehabilitation Center. The change will increase safety for the participants and the PI by having closer access to neuropsychology staff and emergency services. Parking will be available to participants directly in front of Spain Rehabilitation.

There will be **no changes to the protocol** with the exception of this location change.

5.d. Consent and Recruitment Changes: In the space below,
(a) describe all changes to IRB-approved forms or recruitment materials and the reasons for them;
(b) describe the reasons for the addition of any materials (e.g., addendum consent, recruitment); and
(c) indicate either how and when you will reconsent enrolled participants or why reconsenting is not necessary (not applicable for recruitment materials).

Also, indicate the number of forms changed or added. For new forms, provide 1 copy. For revised documents, provide 3 copies:
- **a copy of the currently approved document (showing the IRB approval stamp, if applicable)**
- **a revised copy highlighting all proposed changes with "tracked" changes**
- **a revised copy for the IRB approval stamp.**

(A, B.) The appointment reminder letter mailed to participants is modified to change the location and parking information from Medical Towers to Spain Rehabilitation Center. The map on the second page now directs participants to Spain Rehabilitation rather than Medical Towers.

(C.) Reconsenting will not be necessary because the informed consent process takes place at the visit.

Participants scheduled for interviews that have not yet come to their appointments will be notified of the change via modified recruitment letter.

The following documents are attached:

1) Consent form with track changes
2) Clean copy consent form
3) Appointment reminder letter with track changes
4) Clean copy appointment reminder letter
5) HSP with track changes
6) Clean copy HSP

Signature of Principal Investigator Rachael Muntaner Date 2-2-17

FOR IRB USE ONLY

☐ Received & Noted ☑ Approved Expedited* ☐ To Convened IRB

Sally Blake Headley, CIP Feb 2, 2017

Signature (Chair, Vice-Chair, Designee) Date

DOLA 12/9/16

Change to Expedited Category Y / (N) / NA

*No change to IRB's previous determination of approval criteria at 45 CFR 46.111 or 21 CFR 56.111

Project Revision/Amendment Form

Form version: June 26, 2012

In MS Word, click in the white boxes and type your text; double-click checkboxes to check/uncheck.

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- **Change means any change, in content or form, to the protocol, consent form, or any supportive materials (such as the Investigator's Brochure, questionnaires, surveys, advertisements, etc.). See Item 4 for more examples.**

1. Today's Date	3/13/17	31947

2. Principal Investigator (PI)

Name (with degree)	Rachael Mumbower	**Blazer ID**	11161349
Department	School of Nursing	**Division (if applicable)**	Nursing Research
Office Address	1717 11th Ave. S.	**Office Phone**	205-996-0090 or 601-608-8187
E-mail	mumbower@uab.edu	**Fax Number**	

Contact person who should receive copies of IRB correspondence (Optional)

Name		**E-Mail**	
Phone		**Fax Number**	
Office Address (if different from PI)			

3. UAB IRB Protocol Identification

3.a. Protocol Number	X161107001
3.b. Protocol Title	Sleep Experiences Following Traumatic Brain Injury: A Qualitative Descriptive Study

3.c. Current Status of Protocol—Check ONE box at left; provide numbers and dates where applicable

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- ☒ **In progress, open to accrual** — **Number of participants, data, or specimens entered:** 10
- ☐ **Enrollment temporarily suspended by sponsor**
- ☐ **Closed to accrual, but procedures continue as defined in the protocol (therapy, intervention, follow-up visits, etc.)**
  - **Date closed:**
  - **Number of participants receiving interventions:**
  - **Number of participants in long-term follow-up only:**
- ☐ **Closed to accrual, and only data analysis continues**
  - **Date closed:**
  - **Total number of participants entered:**

4. Types of Change

Check all types of change that apply, and describe the changes in Item 5.c. or 5.d. as applicable. To help avoid delay in IRB review, please ensure that you provide the required materials and/or information for each type of change checked.

- ☒ **Protocol revision (change in the IRB-approved protocol)**
  In Item 5.c., if applicable, provide sponsor's protocol version number, amendment number, update number, etc.
- ☐ **Protocol amendment (addition to the IRB-approved protocol)**
  In Item 5.c., if applicable, provide funding application document from sponsor, as well as sponsor's protocol version number, amendment number, update number, etc.
- ☐ **Add or remove personnel**
  In Item 5.c., include name, title/degree, department/division, institutional affiliation, and role(s) in research, and address whether new personnel have any conflict of interest. See "Change in Principal Investigator" in the IRB Guidebook if the principal investigator is being changed.
  - ☐ **Add graduate student(s) or postdoctoral fellow(s) working toward thesis, dissertation, or publication**
    In Item 5.c., (a) identify these individuals by name; (b) provide the working title of the thesis, dissertation, or publication; and (c) indicate whether or not the student's analysis differs in any way from the purpose of the research described in the IRB-approved HSP (e.g., a secondary analysis of data obtained under this HSP).
- ☐ **Change in source of funding; change or add funding**
  In Item 5.c., describe the change or addition in detail, include the applicable OSP proposal number(s), and provide a copy of the application as funded (or as submitted to the sponsor if pending). Note that some changes in funding may require a new IRB application.

☐	**Add or remove performance sites** In Item 5.c., identify the site and location, and describe the research-related procedures performed there. If adding site(s), attach notification of permission or IRB approval to perform research there. Also include copy of subcontract, if applicable. If this protocol includes acting as the Coordinating Center for a study, attach IRB approval from any non-UAB site added.
☐	**Add or change a genetic component or storage of samples and/or data component—this could include data submissions for Genome-Wide Association Studies (GWAS)** To assist you in revising or preparing your submission, please see the IRB Guidebook for Investigators or call the IRB office at 934-3789.
☐	**Suspend, re-open, or permanently close protocol to accrual of individuals, data, or samples (IRB approval to remain active)** In Item 5.c., indicate the action, provide applicable dates and reasons for action; attach supporting documentation.
☐	**Report being forwarded to IRB (e.g., DSMB, sponsor or other monitor)** In Item 5.c., include date and source of report, summarize findings, and indicate any recommendations.
☐	**Revise or amend consent, assent form(s)** Complete Item 5.d.
☐	**Addendum (new) consent form** Complete Item 5.d.
☐	**Add or revise recruitment materials** Complete Item 5.d.
☐	**Other (e.g., investigator brochure)** Indicate the type of change in the space below, and provide details in Item 5.c. or 5.d. as applicable. Include a copy of all affected documents, with revisions highlighted as applicable.

▶

5. Description and Rationale

In Item 5.a. and 5.b, check Yes **or** No **and see instructions for** Yes **responses.**
In Item 5.c. and 5.d, describe—and explain the reason for—the change(s) noted in Item 4.

☐Yes ☒No	**5.a. Are any of the participants enrolled as normal, healthy controls?** If yes, describe in detail in Item 5.c. how this change will affect those participants.
☒Yes ☐No	**5.b. Does the change affect subject participation, such as procedures, risks, costs, location of services, etc.?** If yes, FAP-designated units complete a FAP submission and send to fap@uab.edu. Identify the FAP-designated unit in Item 5.c. For more details on the UAB FAP, see www.uab.edu/cto.

5.c. Protocol Changes: In the space below, briefly describe—and explain the reason for—all change(s) to the protocol.

▶ The changes will be specific to the interview guide that will be used in directing participant interviews about sleep. One question will be altered and several will be added. These changes are based on findings from the first five transcribed, completed interviews.

- **Change opening question** to "Please tell me about your head injury."
  - *The broad "tell me about yourself" has resulted in some very long stories or details that aren't pertinent to the study. Many of the participants have transitioned into telling about the head injury, though, and that allows me to transition to the questions about sleep and head injury more easily.*
- **Add question**: "Tell me about your dreams and your sleep after head injury."
  - *Dreams have been brought up in several interviews already, without prompting, particularly changes in dreams or lack of dreaming after injury and appears to be important to the participants.*
- **Add question**: "Have you tried any alternative therapies or treatments for your sleep? Such as over the counter medicines, essential oils, etc."
  - *Participants have mentioned using lavender essential oils and over the counter medications to help with their sleep.*

- **Add question**: "What about pain and your sleep? after "Tell me about what seems to make your sleep worse."
  - *Pain seems to be particularly problematic to sleep and has been mentioned by more than one participant.*

▶ No other protocol changes will be made.

5.d. Consent and Recruitment Changes: In the space below,
(a) describe all changes to IRB-approved forms or recruitment materials and the reasons for them;
(b) describe the reasons for the addition of any materials (e.g., addendum consent, recruitment); and
(c) indicate either how and when you will reconsent enrolled participants or why reconsenting is not necessary (not applicable for recruitment materials).

Also, indicate the number of forms changed or added. For new forms, provide 1 copy. For revised documents, provide 3 copies:
• a copy of the currently approved document (showing the IRB approval stamp, if applicable)
• a revised copy highlighting all proposed changes with "tracked" changes
• a revised copy for the IRB approval stamp.

▶ A) No changes to recruitment materials will be necessary. Revised version of the interview guide will be submitted in this package.
▶ B) See rationale for changes in 5c.
▶ C) Reconsenting will not be necessary because the added questions to the consent form will not change the content of the consent form.

10 participants have been interviewed in this study. The proposed changes will impact future participants but will not impact those who have already completed interviews. The desired sample for this study is $N = 20$.

Signature of Principal Investigator Rachael Mumbower Date 3-13-17

FOR IRB USE ONLY

☐ Received & Noted ☑ Approved Expedited* ☐ To Convened IRB

Signature (Chair, Vice-Chair, Designee) 3/15/17 Date

DOLA 12/9/16

Change to Expedited Category Y / (N) / NA

*No change to IRB's previous determination of approval criteria at 45 CFR 46.111 or 21 CFR 56.111