

Submitted in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology

February 2015

Doctoral Thesis

**Sleep Disturbances Following Traumatic Brain Injury:
Lived Experiences and the use of Psychological Interventions**

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Word Count

	Main Text	Appendices (including title page, figures, tables and references)	Total
Thesis Abstract	300	-	300
Literature Review	7,991	9,676	17,667
Research Paper	7,997	9,042	17,039
Critical Appraisal	3,976	1,145	5,121
Ethics Section	5,952	9,258	15,210
Total	26,216	29,121	55,337

Abstract

Sleep disturbances are common following traumatic brain injury (TBI). Biological, psychological and social aetiological factors have been identified, with consequences of sleep disturbances including mood disturbances and exacerbation of cognitive difficulties, with potential impacts on rehabilitation outcomes. Therefore, gaining a better understanding of sleep disturbances post-TBI is necessary to inform appropriate interventions and evaluate their efficacy. There is limited research into the efficacy of interventions for sleep disturbances post-TBI. However, the use of medications can be problematic due to their impacts on cognitive functioning, thus alternatives should be considered.

The first section of this work presents a narrative review which outlines the biological, psychological and social factors which influence the development and maintenance of sleep disturbance post-TBI and justifying the use of cognitive behavioural therapy for insomnia (CBT-I) in the management of sleep disturbances post-TBI. Limited but promising research exploring the efficacy of CBT-I post-TBI is reviewed, with therapy adaptations outlined and limitations of CBT-I post-TBI discussed.

Given the potential consequences of disrupted sleep for the individual, there is a lack of research on individual experiences of sleep post-TBI. Consequently, individuals' experiences of sleep disturbance post-TBI were explored. Interpretative phenomenological analysis was used to analyse data gathered from semi-structured interviews with nine participants. Three themes resulted: (1) "Why is that happening?": Making sense of sleep changes; (2) "Don't worry because it makes it worse": Finding a way to manage; (3) "Everyone's different": A unique and personal experience. Potential clinical implications of the findings are highlighted, with discussion of limitations and areas for future research.

The critical appraisal explores several considerations for conducting qualitative research with individuals post-TBI and provides further reflections on the research process.

Declaration

This thesis records research undertaken for the Doctorate in Clinical Psychology at the Division of Health Research at Lancaster University. The work presented is the author's own, except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

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Section One: Literature Review

The Feasibility of Cognitive Behavioural Therapy for Sleep Disturbance Following
Traumatic Brain Injury: A Narrative Review

Word count: 7991

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Prepared in accordance with 'Instructions to Authors on the Preparation of Manuscripts' for
the journal 'Neuro-Disability and Psychotherapy'

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Abstract

Sleep disturbances are common following traumatic brain injury (TBI), with varying causal factors and potential impacts upon recovery and rehabilitation. There is limited research into the efficacy of interventions, with identified risks that pharmacological interventions could exacerbate any cognitive impairments. This narrative review outlines the biological, psychological and social factors which influence the development and maintenance of sleep disturbance post-TBI. Cognitive behavioural therapy for insomnia (CBT-I) is outlined as the predominant psychological intervention for sleep difficulties. Limited but promising research exploring the efficacy of CBT-I post-TBI is reviewed. In providing support for its applicability, research is reviewed which considers evidence and adaptations for interventions for those with cognitive impairments and for other difficulties in a TBI population. Adaptations are outlined and limitations of CBT-I post-TBI are discussed, concluding that CBT-I appears to be a feasible intervention for sleep disturbance post-TBI and highlighting that future research is necessary to determine the impacts of cognitive impairments upon therapeutic outcomes.

Keywords: traumatic brain injury, sleep disturbance, review, CBT-I

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The Feasibility of Cognitive Behavioural Therapy for Sleep Disturbance Following Traumatic Brain Injury: A Narrative Review

Traumatic brain injury (TBI) is a worldwide public health concern with incidence rates of up to 790 per 100,000 each year (Feigin et al., 2013). Although survival rates are high, TBI frequently results in persistent sequelae with significant personal, social and economic costs (Corrigan, Selassie, & Orman, 2010; Olesen, Gustavsson, Svensson, Wittchen, & Jönsson, 2012). These wide-ranging outcomes include physical impairments (from TBI-related neurological damage or co-morbid injuries), chronic pain, epilepsy, fatigue, sleep disturbance, cognitive impairments, social difficulties (employment, financial, relationships) and emotional, behavioural and personality changes (Ouellet et al., 2012). Although some individuals post-TBI experience positive psychological growth (Hawley & Joseph, 2008) many of these sequelae can persist and deteriorate in the long term. As such, TBI can be considered a chronic health condition, rather than solely a traumatic ‘event’ (Corrigan & Hammond, 2013; Masel & DeWitt, 2010).

One commonly reported yet relatively under-studied consequence of TBI is sleep disturbance, with an estimated prevalence of 50%, significantly higher than in the general population (Mathias & Alvaro, 2012; Ponsford, Parcell, Sinclair, Roper, & Rajaratnam, 2013). However, actual prevalence rates could be higher due to an under-reporting of mild-TBIs and a lack of routine assessment for sleep disturbances post-TBI (Ouellet, Savard, & Morin, 2004; Viola-Saltzman & Watson, 2012). A greater incidence of sleep disturbances is frequently reported in mild-TBI populations compared to severe TBI (Beetar, Guilmette, & Sparadeo, 1996; Fichtenberg, Millis, Mann, Zafonte, & Millard, 2000; Mahmood, Rapport, Hanks, & Fichtenberg, 2004). Consequently, as study samples have frequently been recruited from rehabilitation units and as such consider more severe TBIs and complex difficulties

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(Wiseman-Hakes, Colantonio, & Gargaro, 2009), this sampling strategy may have led to under-estimated prevalence rates.

Despite inconclusive prevalence rates, it is nevertheless evident that sleep is commonly disrupted post-TBI. The most frequently experienced sleep disturbances post-TBI are reported to be insomnia (difficulties with initiation or maintenance of sleep resulting in inadequate sleep), hypersomnia (increased need for sleep) and sleep apnoea (breathing interruptions during sleep) (Mathias & Alvaro, 2012). Other reported disturbances include circadian rhythm sleep disorders (sleep-wake cycle disruptions), parasomnias (disorders of arousal affecting skeletal muscle and autonomic nervous system) and narcolepsy (excessive sleepiness with frequent, short periods of sleep), although these are less commonly reported (Castriotta & Murthy, 2011; Mathias & Alvaro, 2012). In addition to the diverse nature of sleep disturbances, individuals may experience the onset of sleep disturbances post-TBI at varying stages during recovery with disturbances differing in severity and duration (Wiseman-Hakes et al., 2009). Although some individuals show improvement over the course of rehabilitation (Nakase-Richardson et al., 2013), for others sleep disturbances persist for many years (Ouellet & Morin, 2006a). As such, there is a great degree of variability in the presentation and manifestation of sleep disturbances post-TBI.

In explaining this variability, several factors are hypothesised to contribute to the development and maintenance of sleep disturbances post-TBI. These differ between individuals and thus could account for the differences in presentation of sleep disturbances. These include biological factors (neurophysiological changes, co-morbid medical and physical difficulties, medication side-effects), psychological factors (anxiety, depression, trauma reactions, behavioural changes) and social factors (changes to independence, identity, employment, and relationships) which are all common consequences of TBI (Fichtenberg et al., 2000; Ouellet et al., 2012).

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However, understanding of the interplay between these factors and sleep remains limited at present, despite growing research interest. The majority of studies have been cross-sectional (e.g. Fichtenberg et al., 2000; Ponsford et al., 2013) and the few longitudinal studies conducted have explored different associated factors at differing time points since injury, using differing assessments with no pre-injury data for comparison (e.g. Cantor et al., 2012; Huang et al., 2013; Rao et al., 2008). As such, cause and effect relationships between factors are not well established. As studies in the general population conclude that sleep disturbances can have subsequent impacts upon emotional wellbeing (Jansson-Fröjmark & Lindblom, 2008; Johnson, Roth, & Breslau, 2006) and cognitive functioning (Fortier-Brochu & Morin, 2013; Szelenberger & Niemcewicz, 2000), these impacts are hypothesised to also occur in a TBI population, with deleterious effects on rehabilitation and recovery (Worthington & Melia, 2006).

Despite the complex interplay between factors in the aetiology of sleep disturbances, the current predominant treatment for sleep disturbance post-TBI involves medication. However within the United Kingdom, for example, the National Institute for Health and Clinical Excellence (NICE) recommends the use of 'hypnotic' medications (e.g. zopiclone) only as a short-term intervention for insomnia within the general population (NICE, 2004) as the evidence for efficacy of their long term use is limited (Riemann & Perlis, 2009). Instead, psychological interventions such as cognitive behavioural therapy for insomnia (CBT-I) are recommended for difficulties lasting four weeks or longer (NICE, 2014). While no guidance currently exists specifically for a TBI population, studies have highlighted potential negative impacts of pharmacological sleep interventions upon cognitive functioning and neuroplasticity, with implications for rehabilitation and recovery from TBI (Flanagan, Greenwald, & Wieber, 2007; Larson & Zollman, 2010; Thaxton & Myers, 2002). Although preliminary research with individuals with TBI supports the use of non-pharmacological

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interventions (Ouellet & Morin, 2004, 2007), sample sizes are small and, as such, generalised conclusions into their efficacies are limited. Given the potential impacts of untreated sleep disturbance in this population, it is imperative that alternative interventions to medications for sleep disturbances in this population are considered and researched. Aside from improving quality of life and outcomes for the individual, effective management of sleep disturbances could reduce consequential difficulties and thus reduce overall public health costs.

Despite longstanding recommendations for research to examine psychological intervention efficacies for sleep disturbances within this population (Ouellet et al., 2004; Wiseman-Hakes et al., 2009; Zeitzer, Friedman, & O'Hara, 2009), there remains a lack of published studies and conclusive findings. Therefore, the aims for this review are to consider the factors associated with sleep disturbance post-TBI and thus the appropriateness of CBT-I, to review research exploring efficacy of CBT-I post-TBI and to consider the challenges and limitations of this intervention, identifying areas which warrant further research. The review adopts a narrative methodology to provide a justification for using these psychological interventions while considering the challenges and limitations.

Justification for Review Methodology

Despite recommendations made over ten years ago (Ouellet & Morin, 2004; Ouellet et al., 2004), there remain only two published studies exploring CBT-I efficacy for sleep disturbances post-TBI, and none exploring other psychological interventions. There is therefore insufficient published empirical research to conduct a systematic review of efficacy. With the evidence base in its early stages of development, a stronger theoretical argument needs to be presented for researching and clinically utilising psychological interventions such as CBT-I for sleep post-TBI, which is not typically the aim of systematic reviews.

Therefore, a narrative review is considered the most appropriate methodology, given this permits the synthesis of evidence from a variety of sources (e.g. books, guidelines,

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research) in order to present an argument for the applicability of CBT-I for sleep post-TBI. Narrative reviews are a useful method to discuss theory and context (Green, Johnson, & Adams, 2006), giving scope to provide recommendations for researchers and clinicians for the design and implementation of CBT-I post-TBI. Although narrative reviews may not present strong evidence to influence clinical decision making directly (Green, Johnson, & Adams, 2006), nonetheless they allow the synthesis of evidence from a wide field of diverse areas. This is often not possible within the scope of systematic reviews due to strict search criteria which are not employed within narrative reviews. Thus a narrative review is a valuable method to provoke thought about interventions for sleep post-TBI and propose directions for future research.

Overview of this review

First, empirical studies which have explored factors associated with the development and maintenance of sleep disturbances post-TBI are reviewed. Although previous reviews have identified precipitating, predisposing and maintaining factors which can impact upon sleep post-TBI (e.g. Ouellet et al., 2004), the current review aims to advance this by reviewing more recent research and applying a biopsychosocial model to organise these factors, evaluating a role for psychological intervention to address underlying psychological factors. Subsequently, CBT-I, the predominant psychological intervention for sleep disturbances, is outlined with reference to the evidence-base for the general population. The empirical findings of the few studies exploring the efficacy of CBT-I in TBI populations are critically reviewed. Supporting evidence for the justification of this intervention is considered from populations with cognitive impairments, and for CBT for other difficulties in a TBI population. Finally, considerations and adaptations for utilising CBT-I for sleep disturbances within a TBI population are discussed, with limitations and alternative psychological interventions outlined.

Biopsychosocial Understandings of Sleep Disturbances Post-TBI

In justifying the use of psychological interventions such as CBT-I, it is crucial first to synthesise current understandings of the factors which are hypothesised to influence sleep disturbances post-TBI, therefore demonstrating the applicability of such interventions in targeting underlying factors. These can be understood within a biopsychosocial framework which illustrates the interactions between biological, psychological and social factors. The biopsychosocial model of illness was originally developed by Engel (Engel, 1977, 1980) and has subsequently been widely used as a person-centred model of understanding individual presentations and outcomes associated with illness and long-term health conditions. The model posits that biological, psychological and social factors are interrelated and influence the development, maintenance and outcomes of illness presentations and has been influential in collaborative working between professionals of different disciplines (Melchert, 2015; Wilson & Gracey, 2009).

A biopsychosocial model of the consequences of brain injury was described by Jon Evans (2006) and this is used clinically to structure assessment, collate information and develop a shared formulation between clients with TBI, relatives and professionals (Wilson & Gracey, 2009). Unfortunately, sleep disturbances are not explicitly outlined within the model, although sleep disorders can be considered to have underlying biopsychosocial determinants (Morin & Espie, 2003, pp. 2–7). Accordingly, a biopsychosocial model is applied in understanding the development, maintenance and outcomes of sleep disturbances post-TBI. As such, research and theory is described which demonstrates the complex interplay of factors following a TBI which can influence sleep disturbances and the impacts upon rehabilitation.

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Physical and Neurological Factors (Biological Factors)

TBI can result in neurological damage to the areas of the brain which have a known role in sleep-wake cycle regulation, including the brainstem and hypothalamus (Ouellet et al., 2012). While hypothesised, precise relationships are unclear as no studies have demonstrated the associations between sleep disturbance and localised regions of damage within the brain post-TBI, although TBI with multiple lobe contusion appears to be associated with insomnia (Jain, Mittal, Sharma, & Gupta, 2014). In addition, it has been discovered that post-TBI there is decreased production of hypocretin-1, a hypothalamic peptide associated with regulating sleep and promoting wakefulness (Baumann et al., 2005). Production levels were found to normalise six months after injury, correlating with a resolution in post-TBI sleepiness (Baumann, Werth, Stocker, Ludwig, & Bassetti, 2007). While this offers some explanation for hypersomnia post-TBI, it does not explain other sleep disturbances, such as insomnia, nor does it support the findings that sleep disturbances often persist beyond six months post-injury (Kempf, Werth, Kaiser, Bassetti, & Baumann, 2010). Furthermore, the frequent findings of higher prevalence rates in mild-TBI populations compared to severe TBI contradict the hypothesis that neurological damage directly causes sleep disturbance, as one would predict that greater injury severity would increase the likelihood of damage to structures which regulate sleep-wake cycles, thus disrupting sleep. Therefore, while it seems probable that neurological damage can affect the areas of the brain responsible for sleep regulation, the extent to which this hypothesis explains sleep disturbance post-TBI is unclear and it is evident that other factors are important.

Physical factors resulting from TBI such as pain, fatigue and epilepsy can also impact upon sleep. For example, chronic pain is common after TBI and known to disrupt sleep due to increased arousal (Jansson & Linton, 2007). Although pain is highlighted in the model as a physical factor, the psychological and behavioural processes underpinning the individual's

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tolerance, adjustment and management of pain can contribute to maintaining the experience of pain (Gatchel, Yuan Bo, Fuchs, Peters, & Turk, 2007). Beetar and colleagues (1996) found that pain can affect both the initiation and maintenance of sleep post-TBI, reporting that pain doubled the rate of insomnia. While these findings have not been replicated to the same extent in other studies (Cohen, Oksenberg, Snir, Stern, & Groswasser, 1992), a recent controlled study found that self-reported pain was associated with poorer subjective sleep quality and also greater anxiety (Ponsford et al., 2013), providing support for the associations between sleep, physical and psychological factors proposed by a biopsychosocial model.

Similar to pain, fatigue is a multidimensional construct encompassing both the physiological and psychological experience. Fatigue is a common co-morbidity of sleep disturbance post-TBI (Ponsford et al., 2012), with higher levels of fatigue considered a risk factor associated with the presence of insomnia (Ouellet et al., 2006). In a large sample of TBI patients, 38% of those experiencing fatigue also reported insomnia, and 87% of those with insomnia reported fatigue. Furthermore, those with both fatigue and insomnia also had significantly higher anxiety (Cantor et al., 2012), highlighting the potential interaction with psychological factors. Fatigue is also hypothesised to result in behavioural changes such as altered sleep routines which can perpetuate sleep disturbances (Ouellet et al., 2004), clearly indicating the complexity of the multi-factorial nature of sleep and fatigue.

Finally, epilepsy is a frequent consequence of TBI and is known to have a complex interaction with sleep. In people with epilepsy, sleep-wake activity and sleep deprivation have been found to induce epileptiform activity, while epilepsy can disrupt sleep structure and cause sleep disturbances (Bazil, 2003). Subsequently, sleep disturbance in epilepsy is associated with lower quality of life and increased anxiety (Piperidou et al., 2008). While one might expect these associations would be replicated in a TBI population, this has not yet been researched.

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Therefore, while physical and neurological factors may partially explain the development and maintenance of sleep disturbances post-TBI, they do not offer sufficient explanation for sleep disturbances post-TBI, as highlighted by the interactions with psychological factors.

Psychological Factors

Psychological factors include emotional and behavioural factors and cognitions about sleep, which can influence each other in the development and maintenance of sleep disturbance post-TBI. As already indicated, psychological factors may also interact with physical and neurological factors and may offer further explanation for the prevalence of sleep disturbance post-TBI.

Emotional factors.

A well-established association has been demonstrated between sleep disturbances and both anxiety and depression within the general population (Jansson-Fröjmark & Linton, 2008; Robotham, 2011), with sleep disturbance being a diagnostic feature of depression and anxiety disorders (American Psychiatric Association, 2013). This has also been documented within a TBI population, unsurprisingly given that individuals are at increased risk of depression and anxiety difficulties post-TBI (Deb & Burns, 2007). Across several studies employing subjective measures for sleep and mood assessment in TBI populations, depression and anxiety have both been associated with the presence of sleep disturbance, indicated by poorer quality of sleep, increased awakenings, reduced sleep duration and onset latency (Fogelberg, Hoffman, Dikmen, Temkin, & Bell, 2012; Ouellet et al., 2006; Parcell, Ponsford, Rajaratnam, & Redman, 2006; Rao et al., 2008). Although different measures were utilised across the studies to assess sleep, mood and anxiety, the findings consistently indicated associations between these factors. Fichtenberg and colleagues (2000) found that using the Beck Depression Inventory, 81% of participants with TBI and insomnia presented

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with depression and 68% of those with depression suffered from insomnia, suggesting a strong relationship between the two factors. Most recently, Ponsford and colleagues (2013) found that compared to a non-injured control group, self-reported anxiety and depression post-TBI was associated with poorer quality of sleep, greater daytime sleepiness and increased daytime napping. Furthermore, when sleep has been objectively assessed using polysomnography (biophysiological measurements of brain and muscle activity, heart rhythm and eye movements during sleep) associations with anxiety and depression were replicated (Parcell, Ponsford, Redman, & Rajaratnam, 2008).

Although the association between anxiety, mood and sleep disturbance appears robust, cause and effect relationships remain unclear. Indeed, it is likely that these are bi-directional, with anxiety and mood impacting upon sleep, and sleep disturbances causing and exacerbating anxiety and lowered mood (Fogelberg et al., 2012; Rao et al., 2008). This supports a biopsychosocial model, highlighting how anxiety and depression could be important in both the development and maintenance of sleep disturbances following brain injury, and therefore their potential treatment. These findings highlight that the interplay of these is an important consideration for selecting appropriate interventions.

In addition, TBI typically results from traumatic and life-threatening events. As a consequence, individuals can experience adverse psychological reactions to the traumatic event, with up to 18% experiencing moderate to severe post-traumatic stress disorder (PTSD) symptoms (Williams, Evans, Wilson, & Needham, 2002), including behavioural changes such as avoidance, anxiety and unpleasant intrusive thoughts, images or beliefs relating to the traumatic injury-causing event (McMillan, Williams, & Bryant, 2003). In addition, a defining feature of PTSD involves changes in relation to sleep and nightmares (American Psychiatric Association, 2013). In a PTSD population, as many as 70-91% of individuals subjectively report sleep disturbance, or experiencing nightmares and flashbacks relating to

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traumatic experiences which can result in frequent or early waking and difficulties in returning to sleep (Maher, Rego, & Asnis, 2006). In a TBI population, loss of memory for the injury-causing event is common and so doubts have been expressed whether such individuals can truly develop PTSD (Sbordone & Liter, 1995). However, others have argued that the "traumatic event" can include the secondary experiences beyond the initial injury-causing event for which the individual may have limited recall. Furthermore, the individual might experience recall of isolated memories for the event, or could have situationally accessible memories of particular aspects of their trauma (McMillan et al., 2003; McMillan, 2001; Williams, Evans, & Wilson, 2003). Where PTSD has been diagnosed post-TBI, sleep disturbances have often been reported and considered as a symptom of PTSD (McMillan, 1996). Therefore, sleep disturbance post-TBI could sometimes be an indicator of trauma reactions, however, research exploring this is lacking at present. Nevertheless, the possible impact of trauma is an important consideration for assessment of underlying factors which could contribute to sleep disturbances post-TBI.

Behavioural factors.

Sleep disturbances can result in behavioural changes which may in turn maintain the difficulties with sleep. For example, individuals may tend to stay in bed for longer or nap during the day to compensate for disturbed sleep at night. Ponsford and colleagues (2013) hypothesised that their finding of increased napping was linked to the experience of daytime sleepiness. These behaviours can create a cycle of inactivity and the maintenance of altered sleep-wake cycles (Jansson-Fröjmark & Linton, 2008; Ouellet et al., 2004). As discussed, sleep disturbance can also contribute to fatigue post-TBI with behavioural changes also contributing to the maintenance of fatigue (Ouellet et al., 2004; Ponsford et al., 2012).

A further behavioural factor which has been associated with sleep disturbance in the general population is substance misuse (Hasler, Smith, Cousins, & Bootzin, 2012). It is

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suggested that the rate of substance use post-TBI is around 50% (pre and post-injury), which is associated with elevated levels of anxiety, depression and risk of suicide (Parry-Jones, Vaughan, & Cox, 2006; West, 2011). Although this review process identified no research which explored the contribution of substance misuse to the development of sleep disturbances post-TBI, one can hypothesise that the stress and social changes of sustaining a TBI may lead to increased anxiety and depression, with substance use as a coping mechanism. While anxiety and depression are both identified factors associated with sleep disturbance, many drugs and alcohol are also known to disrupt sleep (Conroy & Arnedt, 2014). Furthermore, lifestyle factors associated with substance misuse may predispose individuals to irregular sleep patterns.

Cognitions about sleep.

According to Beck's (1970) cognitive-behavioural model, maladaptive cognitions include thoughts, beliefs, misconceptions and attitudes about the self, the world and the future. Cognitive-behavioural models of sleep disturbance propose that sleep-related cognitions (unrealistic expectations, faulty appraisals, misattributions of daytime impairments and misconceptions about the causes of sleep disturbances) result in heightened cognitive and physiological arousal, anxiety and behavioural changes, thus perpetuating sleep disturbances (Espie, 2007; Harvey, 2002; Jansson & Linton, 2007; Morin, 1993). Furthermore, individuals may experience cognitions specific to TBI, such as "If I don't sleep well, my brain will not recover" (Ouellet et al., 2004, p. 192). Although these types of cognitions have been documented post-TBI, they are not well-researched. As such, while a cognitive-behavioural model offers a plausible explanation, the role of cognitions in influencing sleep post-TBI remains unclear at present, with the potential for psychological and cognitive functioning to impact upon cognitions related to sleep.

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Social Factors

A traumatic brain injury is likely to result in a number of stressful life events or changes, such as loss of employment, threats to financial security, ongoing legal proceedings, disruption of daily routines and changes in familial and social roles and relationships, which could subsequently impact upon sleep (Ouellet et al., 2012). Individuals may experience hospitalisations, changes to residential circumstances or no longer sharing a bed with a partner. Therefore, their sleeping routines may be altered and the environmental changes in light and noise, for example, could also disrupt sleep.

Furthermore, within the general population there is longstanding evidence that stressful life events can impact upon psychological functioning and can be associated with the onset of anxiety, depression and sleep disturbances (Healey et al., 1981), mediated by cognitive processes such as rumination (Guastella & Moulds, 2007). One might hypothesise that this offers a good explanation for increased anxiety and depression post-TBI, which in turn is likely to influence sleep. The social factors associated with TBI are highly variable between individuals and could be successive or simultaneous. Indeed, such variability has been suggested as one explanation for the inconsistencies in onset of sleep difficulties (Fichtenberg et al., 2000; Ouellet et al., 2004). However, research exploring associations between social factors and sleep post-TBI is lacking, so despite the fact it is well documented in the general population that social changes can impact on psychological functioning (Brown, 1992; Kendler, Hettema, Butera, Gardner, & Prescott, 2003), further research is necessary to conclude the extent of these impacts post-TBI.

Cognitive Functioning

The neurological damage sustained in a TBI can result in changes to cognitive functioning, with varying impairments in memory, attention, perception, executive functions, communication and awareness; the degree and nature of impairment is dependent upon the

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severity of the injury and the brain structures which are affected (Lezak, Howieson, Bigler, & Tranel, 2012, pp. 180–218). However, cognitive impairments are often considered within a biopsychosocial framework (Wilson & Gracey, 2009), as it is well recognised that psychosocial factors can also impact upon cognitive functioning. Accordingly, one might hypothesise a relationship between sleep disturbance and cognitive functioning post-TBI.

As aforementioned, it is hypothesised that the association between increased sleep disturbance in mild-TBI compared with moderate and severe TBI reflects increased awareness of difficulties and thus these are more frequently reported (Ouellet et al., 2012). Mahmood and colleagues (2004) found that better performance on measures of executive functioning and speed of processing was associated with increased reports of sleep disturbance, more strongly so than performance on measures not associated with higher-order cognitive abilities. The authors suggest that these higher-order abilities, which are more likely to be preserved in mild-TBI, overlap with self-awareness and thus the ability to identify, recall and report sleep disturbances.

However, Mahmood and colleagues (2004) also argue that the less complex nature of mild-TBI may result in lower rehabilitation needs resulting in greater expectations for recovery or a perception of insufficient support. An increased awareness of these difficulties may increase psychological distress, which, as noted, is associated with sleep disturbance, thus supporting an interaction between cognitive functioning, psychological factors and social factors. As these hypotheses have not been comprehensively studied, it is difficult to establish the impact of psychological factors. In addition, disparities have been reported between objective and subjective measurements of sleep disturbance post-TBI, suggesting that the perception and recall of sleep disturbance may not correlate with the physiological experience. For example, Ouellet and Morin (2006b) found in a sample of 14 patients with TBI that the majority subjectively reported insomnia but this finding was not corroborated in

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objective measures of sleep. Although the small sample size limits the generalizability of the study, this disparity has been well documented in the general population suggesting that the objective, physiological experience of insomnia may represent a different construct than the subjective experience (Orff, Ayalon, & Drummond, 2009). This indicates that perceptual deficits could influence the experience of sleep disturbance post-TBI.

Sleep disturbance in the general population is known to impact upon cognitive functioning (Fortier-Brochu & Morin, 2013; Fulda & Schulz, 2001), with a positive correlation between severity of insomnia and degree of impairment (Szelenberger & Niemcewicz, 2000) and sleep deprivation resulting in deficits in working memory, attention and processing speed (Van Dongen, Maislin, Mullington, & Dinges, 2003). Similarly, within a TBI population, poor sleep and daytime sleepiness have been associated with slower reaction times and lapses in sustained attention (Bloomfield, Espie, & Evans, 2010; Castriotta et al., 2007) suggesting that sleep disturbance could exacerbate TBI-related cognitive impairment. Ziino and Ponsford (2006) found that subjectively reported fatigue post-TBI was associated with slower information processing, but also blood pressure measurements indicated increased effort post-TBI to maintain performance during the task. This indicates that cognitive impairments demand additional compensatory effort in tasks, thus resulting in fatigue. Ponsford and colleagues (2012) suggest that over time, this sustained effort results in stress, which consequently results in increased anxiety and depression, known to be associated with sleep disturbance. In line with a biopsychosocial model, this demonstrates the intricate relationships between sleep, fatigue, psychological factors and cognitive impairments, although the direction and extent of these associations remain uncertain.

Clinical Applications of a Biopsychosocial Model

Given the interplay between biopsychosocial factors in explaining sleep disturbances post-TBI, it is hypothesised that a change in any one factor may subsequently impact upon

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other factors. For example, effective management of pain could ease stress and associated anxiety and depression, enable re-engagement in social roles, improve quality of life and thus may also improve sleep. Undoubtedly, the complexity and variability of these factors has implications for the appropriateness and effectiveness of interventions, indicating that considerations and adaptations to traditional modes of therapy to target TBI-related factors may be beneficial. Thus, a biopsychosocial model offers a framework for comprehensive assessment of individual biopsychosocial factors, imperative for informing the design of effective interventions to address difficulties and needs in the short-term and also to make effective long-term changes, such as building resilience (Melchert, 2015).

As discussed, pharmacological interventions which target biological factors have limitations due to frequent unwanted side effects, including the potential to exacerbate cognitive impairments. In line with a biopsychosocial framework, these side effects could have negative consequences for social and psychological factors given their potential to impact upon rehabilitation and recovery. Furthermore, pharmacological interventions frequently target physical symptoms rather than resolving underlying causal factors, thus their use must be continued for benefits to be maintained. As such, where sleep difficulties are hypothesised to have underlying psychological factors, there is a clear argument to use psychological interventions as an alternative to pharmacological interventions. Psychological interventions can directly target sleep disturbances, which may also create beneficial secondary changes to biopsychosocial factors such as improving mood and fatigue, building resilience or reducing perceived pain or anxiety. Likewise, targeting depression or anxiety could also improve sleep.

CBT-I for Sleep Disturbances

The vast majority of empirical studies of psychological sleep interventions in the general population have explored the use of CBT programmes specifically adapted to target

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insomnia (CBT-I). Although other factors may influence sleep post-TBI, it is hypothesised that emotions, behaviours and cognitions could influence each other in the maintenance of sleep disturbance post-TBI, therefore indicating the potential for CBT-I. Furthermore, CBT-based interventions consider the individual's personal and social context which could influence psychological factors and thus would be expected to have clinical utility post-TBI, where these factors are highly variable.

CBT-I is a multi-component intervention, an adaptation of CBT specifically to target sleep. In line with a CBT approach, CBT-I aims to change the cycles which perpetuate difficulties by identifying, challenging and altering maladaptive cognitions about sleep and modifying behaviours in order to lead to symptomatic improvements in sleep, emotions and physiology (Espie & Kyle, 2009; Morin, 1993). As such, CBT-I consists of cognitive therapy to target cognitions, combined with one or more behavioural interventions. One such intervention is 'stimulus control', which involves restricting bed use to sleep, allowing associations to be created between bedroom stimuli and sleep onset. A further intervention, 'sleep restriction', involves limiting the time spent in bed to create a mild sleep deprivation which results in improved sleep quality. Finally, 'sleep hygiene' involves education of environmental and lifestyle factors such as diet, exercise and substance use which affect sleep. Relaxation strategies may also be incorporated into CBT-I, aiming to reduce physiological arousal in order to facilitate sleep onset (Espie & Kyle, 2009).

Evidence for the Effectiveness of CBT-I

As discussed, CBT-I is a recommended, evidence-based intervention for both primary and secondary insomnia in the general population (NICE, 2004), with up to 70-80% experiencing improvements in sleep following intervention (Murtagh & Greenwood, 1995). A recent meta-analytic review highlighted improvements in primary insomnia in both objective and subjective measures, with moderate to large effect sizes maintained over twelve

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months and secondary improvements in depression (Okajima, Komada, & Inoue, 2011).

Additionally, it has been shown that CBT-I can be more effective than some sleep medications for both short and long-term sleep outcomes (Sivertsen et al., 2006).

Furthermore, CBT-I is effective for primary insomnia when delivered in a variety of formats including individual, group and telephone (Bastien, Morin, Ouellet, Blais, & Bouchard, 2004) and computerised interventions (Espie et al., 2012).

However in a TBI population, co-morbid factors such as cognitive impairment, pain, physical injuries and fatigue could affect the ability to engage with the intervention, thus having implications for the implementation and efficacy of CBT-I for this population (Harb, Cook, Gehrman, Gamble, & Ross, 2009). Indeed, head injuries and cognitive impairments are frequently identified as exclusion criteria in studies of the general population, thus limiting the transferability of these robust findings to a TBI population. Although CBT-I is theoretically indicated for sleep disturbances post-TBI, without evidence for its effectiveness it could be argued that its use in clinical, evidence-based practise cannot reasonably be justified.

However to date, only two published studies have examined the use of CBT-I within TBI populations. Ouellet and Morin (2004) initially reported on a single case study of a male patient with moderate TBI and insomnia. Subsequently, they conducted a case-series study of 11 participants with mild to severe TBI, insomnia and identified cognitive impairments (Ouellet & Morin, 2007). All participants from both studies completed an eight session individual CBT-I intervention with a clinical psychologist over eight to ten weeks. The intervention was adapted for a TBI population from a manualised CBT-I protocol (Morin, 1993) which is typically used for primary insomnia. The intervention comprised cognitive therapy, stimulus control, sleep restriction and sleep hygiene education. Psycho-education also incorporated the specific factors which can affect sleep post-TBI, highlighting

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vulnerability to sleep disturbance post-TBI. As cognitive impairments were identified in all participants, adaptations included reducing the cognitive component via written aids, simplification of information and shorter sessions. Furthermore, sessions included fatigue management (self-monitoring, psycho-education and activity planning) and provided an opportunity to discuss return to work post-TBI. Sleep was assessed via clinical interview, a sleep diary and self-report measures pre- and post-intervention. Additionally, the initial case study completed polysomnography pre- and post-intervention which revealed that sleep onset latency decreased from 47 minutes pre-intervention to 18 minutes post-intervention and time spent awake after falling asleep decreased from 85 minutes to 28 minutes post-intervention. This corroborated the data reported in the diary indicating a reduction in the number of awakenings and an increase in sleep efficiency from 58% to 83%. Unfortunately, polysomnography was not repeated in the case series design, and so objective evidence for the efficacy of CBT-I post-TBI is limited to a single case study. Given that subjective and objective measurements of sleep do not always correlate (Ouellet et al., 2006), this evidence is insufficient to conclude that CBT-I leads to objective improvements in sleep. However, the case series revealed subjective improvements in sleep, with clinically and statistically significant improvements in sleep onset latency and sleep efficiency in 73% (eight) of participants, maintained over three months and with six no longer fulfilling criteria for insomnia. Furthermore, although not significant, the remaining three participants also increased their sleep efficiency post-treatment. Finally, the acceptability of CBT-I was also indicated as the case study participant initiated a discontinuation of zopiclone originally prescribed to manage sleep, due to symptomatic improvements with CBT-I.

In addition to these promising findings, the case-series indicated that CBT-I also led to a significant reduction in maladaptive cognitions, suggesting that cognitions influence sleep post-TBI and thus a cognitive-behavioural model is appropriate in understanding

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insomnia post-TBI, highlighting scope for intervention with CBT-I. Furthermore, CBT-I also resulted in a small reduction in scores on measures of anxiety and depression, although these were not significant. This suggests an interaction between sleep and anxiety and depression, thus offering support for the biopsychosocial framework

Although participants had cognitive impairments, these were not thoroughly assessed within the study, therefore limiting the conclusions which can be drawn for the efficacy of CBT-I for individuals with different kinds and severity of cognitive impairments. However, cognitive impairments did not emerge as a factor to explain intervention outcome and the authors conclude that cognitive impairments should not be a barrier to CBT-I. However, CBT-based interventions involve theoretical understanding, self-monitoring and insight into difficulties which require self-awareness, a prevalent difficulty in moderate and severe TBIs. Given this, severe impairments could potentially compromise the implementation of these interventions.

Case studies and case series designs present limitations for the conclusions which can be drawn due to the lack of a comparable control group and the varying individual factors associated with sleep disturbances post-TBI. Despite this, these preliminary findings are positive, mirroring the improvements documented within the strong evidence which indicates that CBT-I is clearly efficacious within the general population. Given evidence indicating an interaction between biopsychosocial factors in sleep disturbance post-TBI, with sleep post-TBI associated with maladaptive cognitions, this supports a CBT-I model, demonstrating that CBT-I is a theoretically appropriate, and potentially efficacious intervention for sleep disturbance post-TBI. Furthermore, limited evidence suggests CBT-I could be a more acceptable intervention for patients than medication, avoiding the associated side effects of medication use.

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Therefore, researchers are encouraged to further explore the efficacy of CBT-I for TBI. Randomised controlled trials and control group studies, drawing upon the intervention protocol employed by Ouellet and Morin (2004, 2007) and considering TBI of varying severity could significantly strengthen the evidence base. Furthermore, and as indicated by Ouellet and Morin (2007), rigorous measures of adherence and an exploration of participants self-efficacy may help to determine factors which can influence the efficacy of CBT-I post-TBI.

CBT-I in other populations with cognitive impairments.

Given the indication that cognitive impairments could affect the effectiveness of CBT-I post-TBI, research is considered which explores the use of psychological interventions with other populations with cognitive impairments. Ideally, survivors of stroke, haemorrhage, hypoxia or other neurological events would represent a good comparison population, given they have acquired brain injuries. While sleep disturbances are documented following such neurological events (Larson, 2012; Marquez-Romero, Morales-Ramírez, & Arauz, 2014), they have not received as much research consideration as TBI and unfortunately no studies were identified which examine the use of CBT-I or other psychological interventions to address sleep in these populations.

As such, research is considered for individuals with dementias, which are characterised by cognitive impairments such as difficulties with memory, executive functioning, self-awareness and communication. However, the use of CBT-I has not been explored within this population, but rather specific components of CBT-I such as sleep hygiene and behavioural strategies have been used. These are considered adaptations to a CBT-I intervention and have frequently been implemented via staff in residential care settings, often in conjunction with other components such as bright light therapy and physical exercise (Deschenes & McCurry, 2009). Although the interventions have demonstrated some

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effectiveness for improving sleep (Alessi et al., 2005; Martin, Marler, Harker, Josephson, & Alessi, 2007), outcomes have been mixed (Ouslander et al., 2006) and it is unclear whether this is due to individual factors affecting treatment, or challenges in implementing interventions in care settings (Deschenes & McCurry, 2009). Within a community setting, a trial combining sleep hygiene, physical exercise and light therapy was found to be effective at improving sleep for individuals with Alzheimer's disease. Although it is difficult to establish the relative efficacies of the individual components of this intervention, the active involvement of caregivers in assisting with implementation of the sleep hygiene programme resulted in improved outcomes compared to controls, thus suggesting that sleep hygiene was an important component of this intervention (McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2005). Therefore, the key effective adaptations for this population are assisted or indirect implementation of sleep hygiene and behavioural strategies, the incorporation of non-pharmacological interventions such as light therapy and the exclusion of the more cognitively demanding components of CBT-I.

However, while some impairments in dementia can be similar to those experienced post-TBI, dementias are progressive, neurodegenerative conditions, whereas TBI represents a more stable condition with greater potential for rehabilitation and new learning. As such, individuals with TBI may be more able to actively participate in CBT-I interventions, as indicated by Ouellet and Morin (2004, 2007). However, for individuals with more significant cognitive impairments which limit their ability to engage with CBT-I, these adaptations to CBT-I may be a more beneficial and effective approach.

CBT-Based Interventions for Other Difficulties Post-TBI

In justifying the appropriateness of CBT-I post-TBI, research is reviewed which has explored other CBT-based interventions for psychological difficulties post-TBI, such as anxiety and depression, to deduce the transferability of CBT to TBI populations by

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considering the efficacy, acceptability, variables associated with change and to examine any adaptations for a TBI population. Furthermore, as psychological factors may also impact upon sleep post-TBI, successful intervention targeting these factors could have beneficial secondary outcomes in improving sleep. Thus, considering this evidence has potential benefit for designing interventions and research for sleep disturbance post-TBI.

Again, empirical research is somewhat lacking, with a high proportion of single-case design studies and few randomised controlled trials, particularly for severe TBI (Soo & Tate, 2007). Nevertheless, a recent systematic review of 24 studies in acquired brain injury populations indicated CBT was effective for a number of psychological difficulties post-TBI including anxiety, depression, anger, PTSD, social skills and coping skills. Interestingly, while CBT for anxiety or depression resulted in large effect sizes, when CBT effectively targeted other factors such as coping skills or anger management, secondary improvements were noted for anxiety and depression, albeit with small effect sizes (Waldron, Casserly, & O'Sullivan, 2013). Although sleep outcomes were not measured, this finding shows potential for CBT to positively affect other factors in addition to the targeted factors.

Although these findings indicate effectiveness of CBT post-TBI, there is considerable methodological heterogeneity across studies, particularly with respect to intervention protocol and adaptations. As such, it is difficult to establish which variables could affect treatment adherence and effectiveness. However, Hsieh, Ponsford, Wong and McKay (2012) explored a number of variables hypothesised to affect outcomes of CBT for anxiety adapted for moderate-severe TBI. They discovered that greater injury severity, which was also related to memory functioning, may be predictive of poorer intervention outcomes, even within their adapted intervention. They conclude that further research is warranted to explore variables associated with change. Furthermore, exploration of additional adaptations is indicated, including longer therapy duration, shorter and more frequent sessions, additional post-

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treatment support and a need to target specific factors or symptoms rather than attempting to improve overall wellbeing.

Considerations and adaptations to CBT-I for TBI

Across the reviewed literature, adaptations to CBT post-TBI have primarily considered how cognitive impairments could impact upon the ability to engage with CBT and thus the outcomes. As such, adaptations have had several aims, including reducing cognitive demands of the intervention (simplified written and audio materials, prompts, cue cards and examples to aid recall, role play, session summary sheets, repetition), considering fatigue (shorter sessions, specific fatigue psycho-education) and facilitating engagement and adherence (motivational interviewing, involvement of a family member or caregiver) (Hsieh, Ponsford, Wong, Schönberger, et al., 2012). Furthermore, adaptations can be TBI-specific, such as psycho-education around aetiological factors for sleep disturbances post-TBI or fatigue management skills training (Ouellet & Morin, 2004, 2007)

Although there is no standardised protocol for CBT-I post-TBI, the intervention used by Ouellet and Morin (2004, 2007) appears thorough in considering a number of post-TBI difficulties, aiming to minimise their impacts upon therapy outcomes. Ouellet and colleagues (2012) provide a summary of potential clinical adaptations to CBT-I for TBI, informed by clinical experience, which offers an invaluable resource for researchers designing and implementing CBT-I interventions post-TBI. They consider how cognitive deficits, fatigue, inactivity, anxiety, depression, behaviour changes and physical difficulties can impact upon engagement with therapy offering suggestions to minimise these impacts. For example, assistance with the delivery of the intervention, such as implementation via carers or nursing staff, could be a useful way to adapt therapy for those whose difficulties limit their ability to engage with therapy or understand, implement or recall therapy details. Where mobility difficulties present challenges for engagement in therapy, alternative methods such as

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telephone or computer-based therapy may be helpful. These have been found to be efficacious for primary insomnia (Espie et al., 2012) and for depression following mild or moderate TBI (Topolovec-Vranic et al., 2010). However, despite their potential to overcome practical difficulties these methods still present the same theoretical challenges for those with severe cognitive impairments. Due to the variation in difficulties post-TBI, interventions are likely to be more effective when adapted and tailored to an individual's biopsychosocial factors. Therefore, while randomised controlled trials could strengthen the evidence-base, they are predicated on a manualised approach to interventions, based on diagnosis rather than a theory-driven individual assessment of difficulties (Persons & Silberschatz, 1998; Persons, 1991). Consequently, researchers may also consider small group and case-series designs which permit more individualised interventions, such that interventions are informed by a thorough biopsychosocial assessment.

Limitations and alternatives to CBT-I

Despite strong evidence for its use within the general population, and promising findings for a TBI population, CBT-I is not without limitations. Due to sleep restriction practices, individuals may initially experience decreased sleep and thus increased daytime sleepiness and fatigue. Given these factors are likely to result in subsequent impacts upon daytime functioning and sleep may not improve for the first three or four weeks of therapy, it is unsurprising that high drop-out rates are often found in the general population (Mitchell, Gehrman, Perlis, & Umscheid, 2012). As medication often results in much faster improvements, this could be considered as an adjunct to CBT-I as a short-term intervention to address the issue of high drop-out rates.

Furthermore, there are no clear guidelines on the 'dosage' of CBT-I, that is the optimum number of sessions required to be effective, with studies in the general population

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indicating improvements following two sessions, although six to eight is more typical (Edinger, Wohlgemuth, Radtke, Coffman, & Carney, 2007; Okajima et al., 2011).

Additionally, few professionals are trained sleep specialists or 'experts' in CBT-I, and so at present and despite strong evidence within the general population, CBT-I is not a particularly accessible intervention option. However, nurse-led CBT-I interventions in the general population have proved efficacious (Espie, Inglis, Tessier, & Harvey, 2001) and thus could improve accessibility of such interventions both generally and for a TBI population.

Despite promising findings for CBT-I post-TBI, and good scope for adaptations to consider cognitive difficulties, the presence of severe cognitive difficulties or communication difficulties could impact upon the potential for the approach to be used effectively (Ouellet & Morin, 2007) and further research is warranted to explore variables affecting treatment outcome for this population. Kangas and McDonald (2011) argue that 'cognitive restructuring', a central component of CBT interventions which involves identifying and replacing unhelpful thoughts with helpful and more adaptive thoughts, presents challenges for those with cognitive impairments due to its abstract nature. However, other research indicates that declining fluid intelligence in older adults does not affect ability to benefit from CBT-I (Doubleday, King, & Papageorgiou, 2002), so the impacts of cognitive impairments remain unclear. Furthermore, adaptations are made to CBT-I to consider these challenges and minimise their impacts.

Furthermore, Kangas and McDonald (2011) argue that cognitive restructuring could in fact be unhelpful in the early stages of recovery post-TBI as individuals are adjusting to limitations imposed by their TBI and this strategy could impact upon individual adjustment to these difficulties. They propose that alternative interventions, such as mindfulness may be more beneficial, which unlike CBT-I do not focus upon changing psychological processes including thoughts, emotions and behaviours, but aim to change the individual's relationship

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with the factors (Hayes, 2004; Kangas & McDonald, 2011). While these interventions have been found to be beneficial for improving sleep in the general population (Dalrymple, Fiorentino, Politi, & Posner, 2010; Gross et al., 2011; Winbush, Gross, & Kreitzer, 2007), at present there are no studies exploring these interventions for sleep disturbance post-TBI. Mindfulness-based cognitive approaches focus upon self-awareness and maintaining attention in the present moment, thus may be beneficial for individuals with memory impairments who struggle to recall previous thoughts, feelings and actions. However, impairments in self-awareness and attention are common post-TBI, which could suggest that mindfulness, and indeed other psychological interventions, may still present challenges for those with cognitive impairments. Indeed, a study which concluded that mindfulness improved fatigue post-TBI (Johansson, Bjuhr, & Rönnbäck, 2012) in fact excluded individuals with severe cognitive impairments. Therefore, while mindfulness may offer a promising alternative to CBT-I, cognitive impairments would likely still present challenges for implementation of the intervention.

Conclusions

A number of factors influence the development and maintenance of sleep disturbance post-TBI and these can be understood within a biopsychosocial framework. These factors vary between individuals, with potential implications for intervention outcomes, thus this framework can be utilised to facilitate a thorough assessment and to plan appropriate and tailored interventions. The risks of using pharmacological interventions in this population are not well understood, although the potential for side effects and impacts upon cognitive functioning can negatively affect recovery. Therefore, CBT-I provides a feasible approach for management of sleep disturbances post-TBI, given research highlights an interaction between biopsychosocial factors, and in particular cognitions, behavioural factors and emotions. However, evidence for the efficacy of such interventions remains sparse, although

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the limited findings to date indicate that CBT-I can be used effectively with some members of a TBI population. However it remains unclear how cognitive impairments could affect ability to engage with and benefit from intervention. As such, adaptations to the therapy procedure are warranted in order to consider TBI-specific factors and cognitive impairment. It remains unclear whether interventions which target other difficulties such as anxiety and depression could also have beneficial outcomes for sleep and further research on such interventions should include sleep as an outcome measure. Furthermore, proposed alternatives to CBT-I, such as mindfulness for sleep disturbance, have not yet been researched with a TBI population and outcomes may still be affected by cognitive impairments. In conclusion, CBT-I appears to be a feasible intervention for sleep disturbance post-TBI, with consideration to individual biopsychosocial factors. Therefore, researchers are encouraged to build upon the promising findings for CBT-I post-TBI, developing interventions which consider biopsychosocial factors and making adaptations to consider these accordingly. In addition, clinicians should be encouraged to utilise the suggested adaptations to CBT-I for sleep disturbance post-TBI in line with a thorough and holistic biopsychosocial assessment of individual difficulties post-TBI.

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Appendix A

Instructions to Authors on the Preparation of Manuscripts for the
Journal 'Neuro-Disability and Psychotherapy'

Instructions to Authors on the Preparation of Manuscripts

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1. Karnac books are edited according to the *Oxford English Dictionary* and Oxford editorial style with the exception of the use of “s” spelling (e.g., realise not realize / organisation not organization).
2. We use the serial comma ("Where more than two words or phrases or groupings occur together in a sequence a comma should precede the *and*: A great, wise, and beneficent measure." See *New Hart's Rules*, pp. 71-72).
3. We prefer to have *that* used in restrictive constructions and *which* in unrestrictive ones (see *Fowler's Modern English Usage*, pp. 625-630, 699-702).
4. Double quotation marks should be used throughout (with single quotes within the double).
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6. Please avoid terminology that might be construed as being sexist, racist, or discriminatory.
7. Numbers are spelled out in full up to one hundred, and from 100 onwards are given in numeric form, except when they begin a sentence (i.e., 'The study comprised 200 people', but 'Two hundred people took part in the study').
8. Centuries are to be spelt out in full: e.g., “nineteenth century” and not “19th century”. (Note: “a nineteenth-century novel” and “written in the nineteenth century”.)

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9. We prefer that “enquire” is used for general senses of “ask” and “inquire” is reserved for uses of meaning “make a formal investigation”.
10. Please use maximum number spans, e.g., 134–136, 112–113.
11. We prefer dates to be set out as 4 July 1998, but will accept other consistent methods (e.g., 4th July 1998; 4 July, 1998; July 4 1998, etc.).
12. Spell out simple fractions with a hyphen (e.g., three-quarters).
13. Insert a comma for thousands and tens of thousands in numbers, e.g., 1,000 and 10,000.
14. Use “first”, “second”, and “third”, not “firstly”, “secondly”, or “thirdly”.
15. When expressing a decade, use, for example, “1980s” (i.e., no apostrophe, 1980’s), except in colloquial usage, e.g., ‘swinging Sixties’.
16. Numbers in tables should always be numerals.
17. We use parentheses within parentheses, as per the British style. (As opposed to the American style of square brackets within parentheses.)
18. We use square brackets for interpolations only (e.g., to differentiate explanatory remarks made by an author within material published by another author, or to identify words added to make sense of elided material within extracts).
19. It is acceptable for compound adjectives to be hyphenated if this avoids ambiguity in the context: e.g., “best known example” – “best-known example”; “deep blue sea” – “deep-blue sea”; “little frequented place” – “little-frequented place”. But note there is no hyphen after an adverb, e.g., “a fully illustrated book”, “a widely known fact”, etc. For comprehensive guidelines, follow *Hart's Rules* pp. 76–77.
20. There should be no numbering with headings.
21. There should only be initial and essential capitals in all headings (including chapter titles)
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known, should be given in lower case. Only those that are vital should remain capitalized.

23. If a book is divided into parts, they should be called Part I, Part II, etc. using Roman numerals rather than Arabic and should be Part not Section.
24. Extracted text should not have quote marks around it, as by being extracted shows it is a quote.
25. The full stop at the end of extracted text should go at the end of the text, with the citation given in brackets after the full stop with no full stop after the end bracket.

ABBREVIATIONS

1. i.e. and e.g. (always followed by a comma) can be used within parentheses. Otherwise, they are given in full, again always followed by a comma. The punctuation that comes before “that is”, and “for example” varies according to the context and grammatical sense of the sentence; sometimes a comma is enough, but sometimes a semi-colon is more appropriate.
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6. The ampersand can be used between authors' names in citations provided these are in parentheses (e.g., “In *The Correspondence of Sigmund Freud and Sandor Ferenczi* (Falzeder & Brabant, 1996), it is stated that . . .”). If the citation is not in parentheses, “and” must be spelt out (e.g., “In Falzeder and Brabant's book, *The Correspondence of Sigmund Freud and Sandor Ferenczi* (1996), ...”).

Abbreviations for US States and Territories

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AK	Alaska	LA	Louisiana	OK	Oklahoma
AS	American Samoa	ME	Maine	OR	Oregon
AZ	Arizona	MD	Maryland	PW	Palau
AR	Arkansas	MH	Marshall Islands	PA	Pennsylvania
CA	California	MA	Massachusetts	PR	Puerto Rico
CO	Colorado	MI	Michigan	RI	Rhode Island
CT	Connecticut	MN	Minnesota	SC	South Carolina
DE	Delaware	MS	Mississippi	SD	South Dakota
DC	District of Columbia	MO	Missouri	TN	Tennessee
FM	Federated States of Micronesia	MT	Montana	TX	Texas
FL	Florida	NE	Nebraska	UT	Utah
GA	Georgia	NV	Nevada	VT	Vermont
GU	Guam	NH	New Hampshire	VA	Virginia
HI	Hawaii	NJ	New Jersey	VI	Virgin Islands
ID	Idaho	NM	New Mexico	WA	Washington
IL	Illinois	NY	New York	WV	West Virginia
IN	Indiana	NC	North Carolina	WI	Wisconsin
IA	Iowa	ND	North Dakota	WY	Wyoming
KS	Kansas	MP	Northern Mariana Islands		

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8. Explanatory notes should be avoided. Explanations should be given within the text, in parentheses.
9. Only acknowledgements of assistance or of information supplied for parts of chapters should appear as end-of-chapter notes; they are referred to with superscript numbers within the text, and the notes themselves listed at the end of the chapter.

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1. A biographical page, giving relevant biographical and professional data for each author and/or contributor.
2. A brief summary of the book, and its importance, relevance, and aims.

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Text citations should appear in the form of the surname of the author(s) and the year of publication in parentheses. For example: (Freud, 1931b).

If more than one work is cited, the works should be ordered alphabetically by authors' surnames.

In text citations in parentheses, an ampersand should be used with two authors (and serial comma and ampersand with more than two). List all authors' names, unless they number six or more, in which case abbreviate to first author's name, followed by et al. (in roman, and with no full point after "et").

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Please note that "ibid." should be in roman font with a full stop at the end. If it starts a sentence, the initial "i" should be upper case – Ibid.

References (for Bibliographies see page 10)

Complete references should be given in a single Reference section at the end of the manuscript, in the case of authored books, and, in the case of edited books where each chapter has been contributed by a different author, the references for each chapter should be placed at the end of the chapter. References in the reference list should be ordered alphabetically by the authors' surnames. Please repeat authors' names for each reference; do not replace with em rules or ditto marks.

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Text citations and reference list entries must agree, both in spelling and in date.

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Sigmund Freud

In the case of Sigmund Freud references only, citations should follow the *Standard Edition* Freud Bibliography, in terms of both date and identifying letter (e.g. "The unconscious" is always listed as 1915e, even if no other 1915 work is cited in the book). This means that Freud references can be changed without checking throughout the text for other references. Please note that where there is a discrepancy in the date in the *Standard Edition* between the alphabetical listing and the Freud Bibliography (for example, *Civilization and Its Discontents* is 1930a [1929] in the alphabetical listing, but only 1930a in the Bibliography), we take the date from the Bibliography.

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3. No full names, just initials. If more than one initial, there should be a space between them:
e.g. Alford, C. F.
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e.g. Benvenuto, B., & Kennedy, R.
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 - iii. The title of the work, styled as follows:
 - (a) book title (in italics), initial capitals on all main words, followed by a full point;
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 - (c) chapter in edited book (title of chapter, styled as for journal paper, followed by In: (name(s) of editor(s), presented with initials first, surnames second, followed by (Eds.), followed by a comma, and then the title of the book, in italics. This should be followed by the page numbers for the cited chapter in parentheses, followed by a full point.

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Presented as for journal paper.
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6. (a) If a book (including an edited book), the place of publication, followed by a colon, and then the name of the publisher.
- (b) If a journal, the name of the journal, in full, in italics, followed by a roman comma, then the volume number (just the number, the word 'volume' is not required) in italics, followed by either the issue number in roman, in parentheses closed up to the volume number and followed by a colon, or, if no issue number, a roman colon should follow the volume number. The page range numbers (in full, but no pp.) for the paper, followed by a full point should end the listing.
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Authored book**Include in the reference the following information in this order**

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Example:

Alexandris, A., & Vaslamatzis, G. (1993). *Countertransference: Theory, Technique, Teaching*. London: Karnac [not Karnac Books].

Note: when an entire edited book is cited, the names of the book's editor(s) should be in the author position, but with the abbreviation Ed. or Eds. in parentheses immediately after the last author's name, e.g.

Samuels, A. (Ed.) (1989). *Psychopathology: Contemporary Jungian Perspectives*. London: Karnac.

Detail for each element of the reference

Book authors (or editors, in the case of an edited book): Alexandris, A., & Vaslamatzis, G.

1. All authors' names should be surname followed by initials as in the example above; give surnames and initials for all authors, regardless of the number of authors. List all authors; do not use "et al." irrespective of number.

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Date of publication: (1993).

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Book title: *Countertransference: Theory, Technique, Teaching*.

1. Capitalise all main words.
2. Italicise the title. If the reference is to a volume (e.g., Volume 1), that should be placed in parentheses after the title, also in italics.
3. Enclose additional information necessary for identification and retrieval (e.g., 3rd edn) in parentheses immediately after the title. Do not use a full stop between the title and the parenthetical information.
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Example:

Frey-Wehrlin, C. T., Bosnak, R., Langegger, F., & Robinson, C. (1978). The treatment of chronic psychoses. In: A. Samuels (Ed.), *Psychopathology: Contemporary Jungian Perspectives* (pp. 205-212). London: Karnac, 1989.

Chapter authors: Frey-Wehrlin, C. T., Bosnak, R., Langegger, F., & Robinson, C.

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4. If a reference is to an entire edited book, see Note under "Example" in "Authored book", p. 8.

Date of publication: (1978).

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Article or chapter title: The treatment of chronic psychoses.

1. Capitalise only the first word of the title and any proper names; do not italicise the title or place quotation marks around it.
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4. Finish the element with a full stop.

Book editor: In: A. Samuels (Ed.),

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4. Identify the editor(s) by the abbreviation "Ed." or "Eds." in parentheses after the surname. To identify a translator, use "Trans." in parentheses after the surname.
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Book title and article or chapter page numbers: *Psychopathology: Contemporary Jungian Perspectives* (pp. 205-212).

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5. Give inclusive page numbers of the article or chapter in parentheses after the title.
6. Finish the element with a full stop.

Publication information: London: Karnac, 1989.

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2. Give the name of the publisher in as brief a form as is intelligible. Spell out the names of associations and university presses, but omit any superfluous terms such as Publishers, Co., Inc., or Ltd that are not required for easy identification of the publisher.
3. If two or more publisher locations are given, give the location listed first in the book or, if specified, the location of the publisher's home office.
4. Give date of publication of book in which chapter appears only if different from original publication date.
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Include in the reference the following information in this order

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Example:

Bernstein, I., & Glenn, J. (1988). The child and adolescent analyst's reaction to his patients and their parents. *International Review of Psycho-Analysis*, 15: 225–241.

Article authors: Bernstein, I., & Glenn, J.

1. Invert all authors' names; give surnames followed by initials for all authors, regardless of the number of authors.
2. Use commas to separate authors and to separate surnames and initials; with two or more authors, use an ampersand (&) before the last author.
3. Spell out the full name of a corporate author (e.g., World Health Organization not WHO).
4. In a reference to a work with no author, move the title to the author position, before the date of publication, and treat the title like a book title (see elements of a reference to an entire book).
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4. Finish the element with a full stop after the closing parenthesis.

Article title: The child and adolescent analyst's reaction to his patients and their parents.

1. Capitalise only the first word of the title and of the subtitle, if any, and any proper names; do not italicise the title or place quotation marks around it.

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2. Use Arabic numerals, not roman numerals, in two-part titles unless the roman numeral is part of the published title.
3. Enclose non-routine information that is important for identification and retrieval in brackets immediately after the article title (e.g., [Letter to the editor]). Brackets indicate a description of form, not a title.
4. Finish the element with a full stop.

Journal title and publication information: *International Review of Psycho-Analysis*, 15: 225–241.

1. Give the journal title in full, in Capital and lower-case letters; italicise the title.
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3. Give inclusive page numbers. Use pp. before the page numbers in references to newspapers and magazines, but not in references to journal articles.
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4. a short summary of the book (for our publicity and promotional material)
5. permissions summary (if no permissions required, please state this), and photocopies of all permissions (if relevant)
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Section Two: Research Paper

Experiences of Sleep and Dream Disturbances Following Traumatic Brain Injury

Word count: 7997

Joanne Bradley

Doctorate in Clinical Psychology

Lancaster University

Prepared in accordance with 'Instructions for Authors' for Neuropsychological Rehabilitation

(see Appendix 2-D)

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EXPERIENCES OF SLEEP DISTURBANCES POST-TBI

Abstract

Research indicates that sleep disturbances are common following traumatic brain injury (TBI), with hypothesised causes including neurological, psychological and social factors. Consequences of sleep disturbances following TBI include increased fatigue, impaired cognitive functioning, and decreased emotional wellbeing which can affect rehabilitation and recovery. Given these potential impacts, the lack of research on individual experiences of sleep disturbance post-TBI is notable. Consequently, this qualitative investigation aimed to explore individuals' experiences of sleep disturbance post-TBI. Data were collected via semi-structured interviews with nine participants who had sustained TBI. Interpretative phenomenological analysis of the data identified three themes: (1) "Why is that happening?": Making sense of sleep changes; (2) "Don't worry because it makes it worse": Finding a way to manage; (3) "Everyone's different": A unique and personal experience. Potential clinical implications of the findings are highlighted, with discussion of limitations and areas for future research.

Keywords: traumatic brain injury, sleep, qualitative, experiences, phenomenological

EXPERIENCES OF SLEEP DISTURBANCES POST-TBI

Experiences of Sleep and Dream Disturbances Following Traumatic Brain Injury

Traumatic brain injury (TBI) is a growing worldwide public health concern which results in a range of biopsychosocial sequelae (Deb & Burns, 2007). These include difficulties with memory, executive functioning and communication as well as increased aggression, anxiety and depression. Among the least researched consequences of TBI are sleep disturbances, despite up to 84% of individuals reporting difficulties including falling asleep, excessive daytime sleepiness and early awakening (Mathias & Alvaro, 2012; Rao et al., 2008).

In explaining the prevalence of sleep disturbances post-TBI, several aetiological factors are hypothesised. First, TBI can result in neurological damage to structures which regulate sleep, including the hypothalamus, causing abnormal neurotransmitter production which is linked to disruptions with the sleep-wake cycle (Baumann, Werth, Stocker, Ludwig, & Bassetti, 2007). However, mild TBI (and thus less severe damage to brain structures) has been associated with a greater incidence of sleep disturbances than more severe TBI (Fichtenberg, Millis, Mann, Zafonte, & Millard, 2000) a finding which has subsequently been evidenced via both objective and subjective measures (Mahmood, Rapport, Hanks, & Fichtenberg, 2004; Ouellet, Beaulieu-Bonneau, & Morin, 2006), suggesting a reliable finding. As this finding contradicts the hypothesis that neurological damage is the sole aetiological factor, other factors must also influence sleep post-TBI.

Indeed, within the general population, sleep disturbances often occur during or following stressful life events such as a bereavement, illness or work stress (Healey et al., 1981). Moreover, TBI-causing events are likely to be stressful and involve significant social changes such as loss of employment and changes in identity and roles in relationships (Bryson-Campbell, Shaw, O'Brien, Holmes, & Magalhaes, 2013; Ouellet, Savard, & Morin, 2004). Consequently, individuals may experience a sense of loss and grief, with perceived

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identity change associated with increased anxiety and depression (Carroll & Coetzer, 2011). In turn, anxiety and depression are associated with poorer sleep quality post-TBI (Ponsford, Parcell, Sinclair, Roper, & Rajaratnam, 2013), with several studies consistently finding these associations despite utilising a varied range of subjective (Fichtenberg et al., 2000; Fogelberg, Hoffman, Dikmen, Temkin, & Bell, 2012) and objective measures (Parcell, Ponsford, Redman, & Rajaratnam, 2008).

Furthermore, individuals who have sustained a TBI frequently experience physical difficulties and pain resulting from either neurological damage or co-morbid injuries. Pain can cause increased arousal, directly affecting sleep (Jansson & Linton, 2007; Ouellet & Morin, 2006). Medications routinely administered post-TBI such as sedatives, analgesics and anticonvulsants can also impact upon sleep (Ouellet, Beaulieu-Bonneau, & Morin, 2012; Rao, Rollings, & Spiro, 2005). Finally, fatigue is common post-TBI and often results in individuals engaging in behaviours such as napping, spending longer in bed and becoming less active. This can subsequently affect sleep routines, perpetuating sleep disturbances. Disrupted sleep can then lead to increased fatigue, maintaining sleep disturbance (Beaulieu-Bonneau & Morin, 2012).

Although research interest in sleep post-TBI is growing, research into changes in dreaming is more sparse, with mixed evidence. While two early studies indicated that dreaming decreases following head injury (Humphrey & Zangwill, 1951; George P Prigatano, Stahl, Orr, & Zeiner, 1982), a larger study contradicted this, finding similar rates of dreams pre- and post-injury (Benyakar, Tadir, Groswasser, & Stern, 1988), possibly reflecting the more thorough exploration via questionnaire, but nevertheless questions the reliability of the earlier findings. Furthermore, as these studies measured dreaming via self-reports, it is unclear whether findings reflect decreased dreams or poor recall due to cognitive impairments. Additionally, changes in the content of dreams have been documented, with

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more threatening dreams post-TBI (Benyakar et al., 1988) and increased nightmares, associated with post-traumatic stress disorder (Bryant, Marosszeky, Crooks, & Gurka, 2000; Kennedy, Leal, Lewis, Cullen, & Amador, 2010). However, dream content could affect recall, with implications for the validity of these studies, thus warranting further exploration of dreams post-TBI.

Sleep disturbances can significantly affect quality of life post-TBI. Disrupted sleep can cause and exacerbate existing cognitive impairments in speed of processing, attention and memory (Bloomfield, Espie, & Evans, 2010; Castriotta et al., 2007). As discussed, sleep disturbances are also associated with increased anxiety and depression (Ponsford et al., 2013). However, as this study was cross-sectional, exploring correlation between these variables, the cause-and-effect relationship remains unclear, although is hypothesised to be bi-directional. In addition, the impacts of sleep disturbance upon daytime functioning are likely to affect engagement with rehabilitation programmes and thus recovery (Worthington & Melia, 2006). While varying biopsychosocial causes and consequences of sleep post-TBI are hypothesised, conclusions remain limited despite their importance in informing future research, clinical understanding and treatment options. Further research is clearly needed to offer a greater understanding of TBI-related factors which influence sleep.

Recently, researchers have begun to use qualitative research to study experiences of recovery following TBI, providing valuable insight into individuals' subjective experiences (Conneeley, 2012; Levack, Kayes, & Fadyl, 2010; Shotton, Simpson, & Smith, 2007). However these studies have not examined individuals' experiences of sleep disturbances post-TBI and the subsequent perceived effects on daily life. The potentially significant presence of sleep disturbances, not only in their own right but also in respect of their impact upon other important areas of functioning, indicates a clinical, as well as a theoretical, need for further investigation.

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Furthermore, inconsistent findings between objective and subjective measurements of sleep (Gellis & Gehrman, 2011; Ouellet & Morin, 2006) indicate that subjective changes in sleep may not be objectively measureable, thus suggesting that objective and subjective sleep disturbances may represent different phenomena. Therefore, the subjective experience of sleep post-TBI is an area which would benefit from further exploration to understand better the key features, causal factors and impacts on the individual. Alongside improving accuracy of diagnoses and progressing research within the field, this understanding could have implications for the appropriateness and effectiveness of interventions, ultimately aiding clinical guidance for the management of sleep disturbances post-TBI.

There has been little exploration of the efficacy of interventions for sleep post-TBI. However, two studies have explored the effectiveness of cognitive behavioural therapy for insomnia (CBT -I) in people with TBI, a single case study and a case-series of eleven (Ouellet & Morin, 2004, 2007). While these highlighted the potential to use CBT-I post-TBI with notable subjective and objective improvements in sleep onset time and efficacy and success rates comparable to studies of the general population, the conclusions are limited due to small sample sizes and lack of control populations. Although there was no qualitative inquiry within the study, the authors hypothesised that "an exploration of the participants' self-efficacy toward their sleep problem might have helped to understand treatment outcome" (Ouellet & Morin, 2007, p.1591) and as yet, this has not been explored. Consequently, a qualitative exploration of the individual experience of sleep disturbance post-TBI may facilitate understanding of factors which influence the efficacy of interventions such as CBT, thus informing the development of such interventions.

Accordingly, the aim for this research was to capture individuals' perspectives of sleep post-TBI, to gain understanding of the subjective experience and inform future research and interventions. As the specific research question centred on exploring the experiences of

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sleep disturbance in individuals with a TBI, interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin 2009) was selected as an appropriate method of analysis.

Method

Participants

Participants were required to: (a) be aged 18 or over; (b) have capacity to consent to participate; (c) have sustained a TBI defined as “an alteration in brain function, or other evidence of brain pathology, caused by an external force” (Menon, Schwab, Wright, & Maas, 2010, p. 1638); (d) experience self-reported changes to sleep post-TBI and; (e) have sustained a TBI at least three months prior to data collection. This time frame: (i) minimised the likelihood that participants were experiencing post-traumatic amnesia which can impact upon ability to retain information and therefore capacity to consent to participate (Marshman, Jakabek, Hennessy, Quirk, & Guazzo, 2013); (ii) allowed opportunity for the individual to become aware of sleep disturbances post-TBI; (iii) ensured a more homogeneous sample of participants in a post-acute stage of recovery in order to understand this phenomenon. An upper time limit was not specified as this research was exploratory in understanding experiences of sleep disturbances post-TBI which have varying onsets and duration. Individuals were excluded where they did not have receptive and expressive verbal communication skills sufficient to engage in an hour-long interview.

Recruitment was carried out within four United Kingdom (UK) National Health Service (NHS) brain injury services and charitable organisations for neurological conditions within North West England. Nine self-selecting participants were recruited, all from NHS services although two also attended charity groups. All participants were males aged between 28 and 52 ($M = 45$, $SD = 8.40$). Six sustained TBIs from falls and three from road traffic accidents. Participants reported varying changes to their sleep post-TBI, including difficulty falling asleep, maintaining sleep, more frequent waking, early waking, falling

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asleep during the day, an overall reduced amount of sleep and changes to dreams.

Demographic information is displayed within Table 1.

INSERT TABLE 1

Design

An interpretative phenomenological analysis (IPA) approach was adopted, which has its groundings in phenomenology and symbolic interactionism. Consistent with the research question, IPA seeks to explore individuals' perspectives of lived experiences by elucidating an individual's understanding and meaning of particular phenomena in the context of their actions, interactions, perceptions and experiences. IPA adopts a double hermeneutic perspective, considering the individual's subjective understandings of their experience and the researcher's interpretation of the individual's understanding (Smith et al., 2009; Smith & Osborn, 2008; Smith & Shinebourne, 2012).

As an idiographic approach, IPA seeks to generate a rich and coherent understanding of the phenomenon being investigated while ensuring individuals' accounts of their experiences remain present within the themes (Smith et al., 2009; Smith & Osborn, 2008). As such, a homogenous sample is selected for whom the research question is relevant. In considering the question of sample size in IPA, Smith and Osborn (2008) state that there is "no right answer" (p. 56) and dependent upon the researcher, data obtained and analysis process. Published IPA study samples range from one to thirty (Brocki & Wearden, 2006), with a sample between four and ten considered appropriate for doctoral research (Smith et al., 2009). Hence, recruitment for this study ceased following nine interviews and no further participants opted into the study.

Whereas other qualitative approaches aim to achieve analytical saturation, the point at which no new relevant information is identified from interviews (Francis et al., 2010; Guest, Bunce, & Johnson, 2006), this is not typically a goal of IPA. The concept of data saturation

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can be criticised, as within an IPA approach it is argued that experiences are individual and thus subsequent interviews could generate new or conflicting evidence (Brocki & Wearden, 2006; Hale, Treharne, & Kitas, 2008). Therefore, the importance is for the researcher to ensure that the IPA generates a coherent and representative account of the experiences of this particular sample of participants.

Procedure

Ethical approval was obtained from a UK NHS Research Ethics Committee (Appendix 4-B, p.4-45) with research governance approval obtained from the NHS sites' Research and Development departments (Appendices 4-C to 4-F, p.4-47-55). Verbal and written permissions (via e-mail) to attend two charity sector organisation group meetings for recruitment were also obtained (Appendix 4-G, p.4-56).

Local collaborators at each NHS site identified potential participants and distributed recruitment information packs. The researcher attended two charity group meetings to distribute recruitment information packs (Appendices 4-I, J and K, p.4-67 to 4-71) via the co-ordinator. Individuals had the option to contact the researcher by telephone, e-mail or post to opt in or request further information, ensuring their anonymity remained preserved until they expressed an interest to participate. Additionally, poster advertisements (Appendix 4-L, p. 4-72) were provided to all recruitment sources for display in waiting areas and drop-in centres.

The researcher contacted individuals within two weeks of opting in to assess whether inclusion criteria were met and schedule the research interview. Participants were advised of limits to confidentiality and their rights to stop the interview or withdraw from the study. Participants completed a consent form (Appendix 4-M, p.4-73) prior to participation in the study. The researcher assessed participants' capacity to consent in accordance with the UK Mental Capacity Act 2005 and British Psychological Society (2006) guidelines for

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“Assessment of Capacity in Adults”. Thus, the participant was required to demonstrate their ability to understand and retain information about the study, their requirements as a participant and their actions should they have concerns following participation or wish to withdraw from the study. The researcher ensured that the participant was able to communicate their decision to take part (Appendix 4-G, p.4-60).

Eight interviews were conducted within single sessions and one over two sessions within a two-week period. The interviews lasted between 47 and 118 minutes ($M = 75$ minutes). A semi-structured interview schedule (Appendix 4-H, p.4-64) with open-ended questions was used to facilitate discussion, allowing for questions to be tailored according to participants' responses and enabled participants to lead the discussion of their experiences, consistent with an IPA approach. The interview schedule was developed through discussion with the research supervisor, field supervisor (a clinical neuropsychologist) and service-user members (with personal or familial experience of neurological conditions) of a public involvement network. Interviews were digitally audio-recorded and transcribed, with identifying information anonymised to maintain participant confidentiality.

Analysis

The analysis procedure followed the stages described by Smith and colleagues (2009). Each transcript was read and re-read initially while simultaneously listening to the audio-recording. This facilitated familiarity with the data, the participant's 'voice' and the feelings and thoughts conveyed by intonation and expression, information which is valuable in conducting a thorough analysis. The left margin of the transcript was used to record any initial notes on comments and language which captured experiences of sleep disturbances, observations, reflections and preliminary theme ideas. The right margin was used to record interpretations and emergent themes, primarily considering the initial notes with consideration to the original transcript (Appendix 2-A).

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In accordance with Smith et al. (2009), as the present study had a large sample size of greater than six, individual emergent themes were subsequently reviewed across all transcripts in order to establish the key themes for the entire sample (Appendices 2-B, C and D). Higher-level organisation of super-ordinate and sub-ordinate themes involved the processes of abstraction (putting like with like), polarization (searching for oppositional and conflicting relationships), contextualisation (identifying connections by attending to temporal, cultural and narrative themes), numeration (frequency with which themes appear) and function of the theme within the transcript (Smith et al., 2009).

Quality and Validity

Yardley (2000, 2007) proposed four principles to assess the quality of qualitative research: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. These were considered throughout the process of data analysis, utilising supervision and a reflective diary to facilitate awareness of the researcher's positioning, review interview techniques and discuss emergent themes. Supervision with a clinical neuropsychologist ensured the research remained sensitive to context and considered the impact and importance for a TBI population. In accordance with Smith and Osborn (2008), to ensure transparency and coherence of theme development to the reader, participant quotes are included in the theme description, and information detailing theme development within appendices 2-A to 2-D. This enables the reader to evaluate the fit of the data to the researcher's interpretation (Yardley, 2007).

Researcher's positioning

The researcher is a British female trainee clinical psychologist with experience working with individuals post-TBI, and interests in person-centred, systemic and collaborative therapeutic approaches. Her clinical psychology training and clinical experience have reinforced beliefs about the influences of psychological factors upon sleep,

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the utilisation of psychological interventions for sleep and awareness of psychological concepts. As such, the researcher had an interest in exploring these areas within the study and thus considered these factors to ensure these did not have undue influence. Therefore, the interview schedule was reviewed in supervision to ensure that questions were open, permitting the participants' perspectives to be elicited. Similarly, transcripts were reviewed to consider where the researcher had influenced the participant's response and these were accounted for in the analysis process. For example, one participant appeared to reconsider his understanding of his sleep difficulties via the process of the researcher's questioning and reflection, moving from a biological to a psychosocial viewpoint. In the analysis process this was considered to ensure it did not give additional weight to the development of the themes. Final themes were reviewed to check that mentions of psychological concepts did not represent overtranslations of participant experiences and thus remained grounded in the data.

The researcher adopted a critical realist stance to the research, with 'sleep' considered a feature of reality, existing independently of human experience. Therefore, IPA generates critical realist knowledge, an account of the researcher's experience and sense-making of the participants' understandings of their subjective experiences of real events, i.e. sleep post-TBI.

Findings

Through data analysis, three interconnected super-ordinate themes emerged: (1) "Why is that happening?": Making sense of sleep changes; (2) "Don't worry because it makes it worse": Finding a way to manage; (3) "Everyone's different": A unique and personal experience. The relationship between these themes is illustrated in Figure 1, highlighting how participants experienced fluidity of movement between themes (1) and (2), with potential for both processes to be experienced concurrently, influenced by the individual's unique experience of surviving TBI (theme 3).

INSERT FIGURE 1

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These themes are presented in detail below, incorporating the use of quotes as illustration. Where quotes have been shortened for clarity an ellipsis (...) replaces text without altering the meaning of the quote.

"Why is that happening?": Making sense of sleep changes

This theme comprises three subthemes which reflect a process of becoming aware of changes to sleep and trying to understand why these changes have occurred. In response to noticing change, participants attempted to establish patterns or regularities in these changes, thus gaining 'awareness and familiarity' with sleep post-TBI. As participants were 'wanting an explanation' for why changes had occurred, they subsequently began 'hypothesising', generating explanations to further their understanding.

Awareness and familiarity.

In becoming aware of changes in sleep, participants drew comparisons with their pre-injury sleep and their understanding of what is normal for sleep, highlighting their sense of sleep being different post-TBI. However, some made comparisons with other TBI survivors, acknowledging that it is "common to have irregular sleep patterns post brain injury" (Charlie), thus normalising their experience and facilitating sense-making of their experience as being typical post-TBI.

Upon becoming aware of changes to their sleep, participants attempted to become more familiar with these changes, with several participants describing predictable 'patterns'. For example, Simon woke up "at four o'clock every morning on the dot" and Ted had "a wake-up pattern of normally about two o'clock". However, other participants were unable to identify patterns and thus perceived their sleep as unpredictable, "very sporadic" (Charlie) and having "no set thing" (Melvin). Melvin described this unpredictability as unusual:

There's nothing that says that's how it's gonna be (...) I could go all week and I'd be lucky if I got an hour, or (...) I could have four hours a night. It's weird really!

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Melvin's reflection that his difficulties were "weird" suggests that this unpredictability is abnormal and unsettling. Thus, identifying patterns and becoming familiar with sleep could reflect attempts to predict and normalise sleep, potentially to ease the anxiety and frustration associated with uncertainty.

Wanting an explanation.

Subsequent to attempting to predict their sleep disturbances, participants described a desire to understand why changes had occurred. Simon asked: "Why is that happening? Why? I mean why?", indicating the frustration of not having an explanation and highlighting the importance of sense-making in easing this frustration. Although his question was somewhat rhetorical, Simon's repetition and tone of voice suggested he was eager for an answer. Similarly, Martin found it "frustrating" not having explanations, fuelling his desire to understand. Clearly 'not knowing' was unsettling and seeking an explanation appeared to reflect an attempt to normalise sleep difficulties as an understandable occurrence.

Hypothesising.

Unsurprisingly, this need to understand often manifested in participants actively searching for an explanation, identifying hypotheses for the sleep changes. They all described an awareness that the brain regulates sleep, positing that sleep difficulties were "due to damage in the brain" (Charlie). Interestingly none appeared to believe this was the sole cause, as all described additional factors which they believed impacted on sleep, suggesting their need for a multi-factorial understanding of sleep difficulties. As holding several hypotheses could provide a wider scope for intervention, this could reflect that sense-making is necessary for subsequently attempting to manage their difficulties.

Additional hypotheses included co-morbid physical problems, for example Martin "waking up with back pain", and Henry, Ted and Matthew noticing sleep disturbances following changes in medication prescribed for co-morbid difficulties. Some sought

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confirmation of these hypotheses to alleviate the uncertainty of sleep changes, for example via discussion with a doctor (Henry) or by independently researching medication side effects (Matthew).

In addition, participants hypothesised that sleep was affected by social and psychological factors. A change in social circumstances often meant a reduced level of activity post-TBI, with Robin positing: "I'm doing less in the day, so I burn off less energy, so I'm not tired", a hypothesis shared by others. While this suggests a belief that social factors influence physiology, Robin's hypothesis could indicate that he feels responsible for his disrupted sleep due to being less active. Ted identified that starting a new and stressful job role following his injury coincided with his sleep disturbances. Others observed that at bedtime their mind became active and occupied with racing, anxious thoughts that prevented them from sleeping. Stan described: "My mind starts racing and I start thinking about so much stuff". Sustaining a TBI appeared to bring anxieties such that bedtime was no longer associated with relaxation but instead a time for reflection and rumination on the daily impacts of TBI, thus affecting sleep.

Furthermore, several participants described how heightened 'alertness' affected sleep, feeling that they needed to maintain concentration and alertness post-TBI and thus awoke more easily. Melvin described being aware of potential "hazards" even during sleep, with noises waking him easily: "I can wake up and jump about! If I hear that [knocks] I'll wake up. I don't just wake up like "urrrr"[indicates grogginess], I'm wide awake!" This could reflect increased physiological arousal, a possible reaction to the trauma he had experienced. However, Melvin appeared to view his alertness as an advantageous ability despite its impacts upon sleep, which unsurprisingly appeared to affect how he coped.

As such, sense-making appeared to be aimed at reducing anxiety and uncertainty associated with sleep disturbances, informing coping and managing with difficulties (theme

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two) as Melvin highlighted: "If you don't understand it, you can't adapt to it". Finally, sense-making appeared to be influenced by the individual's circumstances and factors related to their 'unique' experience (theme three), which certainly reflected in their hypotheses.

"Don't worry because it makes it worse": Finding a way to manage

This theme encompasses three subthemes, reflecting a process of trying to manage with sleep difficulties, via implementing strategies and accepting difficulties. Participants described attempting to gain control of sleep difficulties by 'identifying strategies to improve sleep'. However, such interventions were rarely effective and hence participants also described 'acceptance of sleep difficulties' being part of life and 'managing the impacts', rather than trying to resolve difficulties. This theme is distinct from theme one yet closely related, representing a progression toward hypothesis testing, refuting and modifying by identifying strategies to manage sleep disturbances.

Identifying strategies to improve sleep.

Participants' understandings about their sleep (theme one) informed their choice of strategies. Where hypotheses suggested a degree of control over sleep, for example 'reduced activity affects sleep', strategies such as exercise were aimed at improving sleep (Matthew, Simon, Melvin). Those hypothesising that environmental factors influenced sleep implemented practical solutions including earplugs (Martin and Charlie), sleeping with music to block out noises (Henry) and purchasing a comfortable mattress (Martin). These appeared to be effective methods of gaining control over some factors despite having little control over other factors, such as neurological damage.

Some strategies were informed by knowledge of good sleep hygiene practices, acquired from books, television, or lifelong habits. Several described how "routine and regularity is imperative" in supporting better sleep (Charlie), implementing 'rules' in attempts to sleep better. Charlie had "always vowed not to take naps during the day. That's to avoid

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any sleeping irregularly during the night". Stan had a similar 'rule', describing how "all I wanna do is go to bed, but I'm scared to go to sleep because I won't sleep in the night time, so I will sort of force myself awake". Interestingly, while staying awake during the day requires immense effort, at night Stan has difficulty sleeping. Again, he reported effort in "trying" to sleep, indicating how anxiety appeared to affect to sleep at night. Indeed, several participants described a "battle" (Ted) to fall asleep, stay awake or get up in the morning, requiring effort and strength to overcome these challenges, mirroring many other aspects of life post-TBI. Other sleep hygiene practices included avoiding caffeine and alcohol (Matthew, Henry) and healthy eating (Ted, Matthew), thus modifying behaviour to gain control over sleep, and thus win the "battle".

Several participants believed relaxation was crucial for facilitating sleep, with Matthew requiring a period of time to "wind down" before falling asleep. Stan's longstanding strategy of occupying his mind with visual imagery prevented racing thoughts which would otherwise frustratingly keep him awake:

I get into bed and I always sort of imagine that I'm on a kind of ship (...) and I'm lying in the lifeboat like a stowaway with this cover over us and I can feel the rain all around and this cover is protecting us and that's the cover of my sheet (...) and that's one of me best ways of going to sleep

This represents an interesting metaphor for Stan's experience of relentless racing thoughts, like pounding rain. Stan seeks a 'cover' to shield him from these unwanted racing thoughts in order to fall asleep. As such, sleep represents a place of safety from these thoughts and an escape from the wider difficulties post-TBI.

Several participants used medications to manage their sleep, including over-the-counter, prescribed and illegal substances. Despite reporting benefits, participants indicated a wish to withdraw use of medications due to risks of side-effects and addiction, instead

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favouring other strategies. Robin explained that exercise had "worked effectively so I'd been able to reduce the zopiclone", but was a harder strategy to maintain. Therefore, medication was an easier but not preferred way to gain control, potentially resulting in less control of other factors, due to side effects or addiction. As such, the participant accounts collectively indicated that they adopted an evaluative approach to selecting strategies, considering various beliefs about the efficacy, safety and perceived control.

Although participants continued to use strategies, these had not resolved their difficulties, suggesting that some strategies are employed to prevent exacerbation, rather than resolve difficulties. Additionally, participants described as yet untried strategies, including exercise (Ted), not watching television before bed (Henry) and not smoking in the evening (Charlie). While participants thought that these strategies could be effective, it appeared they did not implement them due to perceiving more costs than benefits. Matthew acknowledged that watching films in bed was not "good practice" but was "trying to find a happy medium" as he enjoyed this activity. As such, some were not striving to find a solution, but instead gain a balance by not compromising enjoyable activities, thus maintaining quality of life. Therefore, the potential impacts upon quality of life appeared to influence the likelihood of the participant integrating the strategy into their lifestyle.

Acceptance of sleep difficulties.

All participants described hoping for improvements in their sleep disturbances yet often concurrently believing that sleep might not improve and they had to "learn to live with it" (Charlie). This appeared to facilitate acceptance of difficulties, enabling participants to accommodate rather than attempt to resolve their sleep difficulties and so was a helpful coping strategy. Matthew was no longer battling to resolve his difficulties and commented that this had actually helped his difficulties improve "I found as soon as you accepted

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something (...) it didn't seem to bother you as much, and then everything seemed to get better then. (...) Don't worry because it makes it worse!".

Managing the impacts.

When unable to resolve sleep difficulties, participants instead focused upon managing the consequences. Ted could not control waking at night, but acknowledged "there's nothing worse than being awake and not doing anything, I'd rather be doing something" and thus read or listened to music. While this did not help him return to sleep and indeed could prevent him sleeping, it eased his frustration of lying awake, therefore managing the impacts of not sleeping. Additionally, several participants tried to "keep busy" (Melvin) and "keep life as normal as possible" (Matthew), quite the converse of what might be expected when one is feeling tired, but was aimed at maintaining quality of life.

Melvin's outlook on life's challenges of "adapt and overcome" highlighted how accepting sleep difficulties allowed him to reappraise them and employ behavioural adaptations to minimise their consequences. He viewed being unable to sleep as an opportunity to "lay there and rest" or engage in a productive activity, reporting that not sleeping "doesn't bother me, I just adapt", seemingly overcoming his sleep difficulties by no longer viewing them as a 'problem'.

"Everyone's different": A unique and personal experience of sleep after TBI

This overarching super-ordinate theme encompasses and influences the processes described within themes one and two, yet extends beyond these themes. Three subthemes reflect how participants frequently discussed other difficulties besides sleep, highlighting their unique circumstances and indicating how sleep is a part of a wider, 'personal experience' of surviving TBI. Thus, participants considered 'sleep within the context of other difficulties'. Additionally, they described how surviving a TBI impacted upon their 'identity' and how sleep was considered a changed aspect of identity. As such these processes influenced and

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shaped the ways in which participants made sense of their difficulties (theme one) and attempted to manage them (theme two).

Sleep is a personal experience.

Participants frequently emphasised their sleep difficulties as personal, describing how sleep is "for me". Simon commented "every brain injury is different and everyone's different", highlighting how individual circumstances created a unique, personal experience of sleep post-TBI, with no universal experience, explanation or solution. While Charlie was aware that sleep disturbances can be common post-TBI, he added "Well, I know that is the case for me". Melvin exaggerated his difficulties, describing himself as exceptional: "I could go all year and not sleep one minute (...) which is not normal!", highlighting his feeling of being dramatically different from others. Clearly it was important for participants to acknowledge their unique context and personal situation.

Sleep within the context of other difficulties.

Participants freely discussed varied co-morbid difficulties including pain, cognitive changes, mood changes, physical injuries and disabilities, suggesting that they were perceived as closely connected to sleep as part of a holistic experience of surviving TBI. Participants assessed the relative importance of sleep difficulties in the context of their co-morbid circumstances in life post-TBI, considering the impact of sleep difficulties upon co-morbid difficulties. For example, Charlie experienced epilepsy post-TBI, "the bane of my life" and a clear priority for him. However, he knew that he frequently experienced seizures when he was tired, explaining "I need my sleep because of my epilepsy". As such, the interaction between these difficulties had placed a greater importance upon sleep. Similarly, sleep difficulties were a lesser concern to Ted than his current employment situation, but disrupted sleep "slows you down, you make more mistakes", so it was important for Ted to sleep well to minimise impacts upon work.

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Furthermore, the TBI experience appeared to be associated with specific beliefs relating to 'getting enough sleep'. Stan commented:

I need to get my sleep, you know, because sometimes I go for days without sleeping, and it'd be terrible towards my body. Because my body was recovering as well from the accident, you need a lot of rest, a lot of sleep.

This 'need' for sleep indicates a pressure to sleep more at a time when Stan was having considerably less sleep, likely resulting in anxiety that insufficient sleep could negatively affect recovery, which could indeed perpetuate sleep disturbances.

Identity and sleep changes.

Almost all participants described how TBI impacted upon the individual's lifestyle with losses and threats to the individual's identity including loss of employment (Ted, Melvin), driving licence (Simon, Henry), hobbies (Martin, Ted) and relationships with friends and partners (Charlie, Stan, Robin).

Robin explained "I'm like a different person" and although his identity change was observable to others, some participants described a discrepancy between their perceived identity and how others viewed them. Martin commented "[people said] 'you don't even look like you have been in an accident'. And I don't. But I do, if you can see inside", highlighting that changes can be subjective. These identity changes appeared to be associated with uncertainty about the self, with participants re-discovering themselves and re-establishing their identity. Identity changes frequently affected sleep, with Simon struggling to sleep due to thoughts of how TBI had threatened his identity: "I want to get back driving. I want to be a man. I want to get back working", as his circumstances post-TBI prevented him from fulfilling roles integral to his identity, indicating how this had threatened his sense of masculinity. Understandably, the grief and anxiety associated with these changes appeared to affect sleep. Ted observed how his dreams reflected identity changes post-TBI, with a

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recurring 'worst case scenario' theme: "a horse race, but a horse would fall over, and have to be put down." Ted had been made redundant and thus his work identity, the 'horse', had been 'put down'. However, his significant life changes post-TBI appeared to have left Ted questioning his usefulness, sense of purpose and ability to succeed and thus his dream metaphor appears to encompass the wider experience of changed identity post-TBI.

Participants described aspects of their identity specifically relating to sleep, consisting of individual, personal beliefs and requirements in relation to sleep such as sleeping positions (Martin), routines (Henry, Matthew), required amounts of sleep (Stan, Ted, Simon) beliefs about the functions of sleep (Stan, Robin, Ted, Matthew), individual perceptions and measurements of sleep quality. For example, Simon was now a "light sleeper", whereas Ted "can sleep for Britain in the morning". Participants observed that the TBI experience had changed aspects of their sleep identity post-TBI, with shifts in their perception of a 'good night's sleep', which for Robin was now "four and a half hours, that's a really good night!" It appeared that participants had often integrated the changes in sleep into their identity post-TBI, crucial for the acceptance of sleep difficulties and adjustment post-TBI.

Finally, several participants described how surviving a life-threatening accident can change one's outlook. The idea of being "fortunate" (Matthew, Charlie), "lucky to be alive" (Martin) or that "things could be worse" (Ted, Simon) was described by several participants and appeared to have resulted in a more positive appraisal of their current difficulties including sleep disturbances. Charlie commented: "I've got to learn to live with [sleep disturbances] but I could be a lot worse". Participants' appraisal of their sleep difficulties appeared to reflect their positive reframing of their difficulties as a whole, with the suggestion that sleep improves with recovery. Simon observed that: "the more I've felt better over time, the more I've relaxed and been able to sleep better". It appeared that sleep, as a

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significant part of life, was perceived to mirror one's waking life, as disruptions to aspects of one's lifestyle and identity were reflected in changes to sleep.

Influence upon other themes.

Themes one and two appeared to be influenced by theme three, with participants hypothesising suggesting that they looked to the factors which had changed in their life to inform their understanding of their own sleep difficulties. Considering sleep as part of the wider TBI experience appeared to influence acceptance of sleep difficulties, as those who seemed well-adjusted to a changed identity appeared to have also accepted and accommodated their sleep difficulties.

Furthermore, their circumstances appeared to influence participants' choice of interventions, with participants cautious about implementing strategies which could have side effects for other difficulties. Charlie was reluctant to take medication for his sleep disturbances as he worried that this could exacerbate his epilepsy thus affecting other aspects of his life. Matthew described how "[you start] worrying about everything, (...) start feeling depressed, and once you feel down everything hurts more, (...) so you sleep less" highlighting his hypothesis that emotional, physical and sleep difficulties were connected and cyclical. Matthew was reluctant to take medication, believing this could have wider impacts. In this respect, the participants' viewpoints that sleep is a part of their holistic experience post-TBI are aligned with those who would criticise the 'compartmentalisation' of difficulties associated with a medical model.

Discussion

The aims of this research were to explore the subjective experience of sleep disturbances post-TBI, to facilitate theoretical understanding and inform future research and interventions. Three themes were identified, reflecting processes of sense-making, implementation of strategies, making adaptations and acceptance, influenced by the

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individual's personal circumstances of sleep disturbance as a part of the wider experience of surviving TBI.

Interestingly, the sample recruited was entirely male. While there is a higher incidence of TBI for men than women, this is approximately a 2:1 ratio (Frost, Farrer, Primosch, & Hedges, 2013). As such, this sample could suggest that sleep disturbances are more prevalent within males post-TBI. Research exploring gender differences in sleep disturbance post-TBI has not been adequately researched, although Mahmood and colleagues (2004) found that male gender was predictive of sleep disturbance. However, in the general population, meta-analysis data indicates a higher incidence of insomnia in females (Zhang & Wing, 2006). However, Colantonio and colleagues (2010) found that men perceived sleep disturbances to have a greater impact upon daily living than women did, and thus could suggest that men may report sleep disturbances more and may have been more likely to participate in the current study. Further exploration of gender differences in sleep post-TBI is warranted, primarily to examine prevalence and perceived impacts.

Participants identified varied hypotheses for their sleep disturbances and described the consequences of disrupted sleep. These factors were in line with biopsychosocial factors identified in the evidence base (Ouellet et al., 2012; Zeitzer, Friedman, & O'Hara, 2009), highlighting the importance of individualised formulation of difficulties. Several participants hypothesised a role of psychological factors such as anxiety and depression, both as a cause and consequence of their sleep difficulties, a relationship which is well-documented (Ouellet et al., 2004; Parcell et al., 2008; Ponsford et al., 2013).

Participants also described specific beliefs about the importance of getting sufficient sleep, thus placing additional pressure on themselves to sleep. Such beliefs are common in the general population (Roane, Dolan, Bramoweth, Rosenthal, & Taylor, 2012) and are documented, but not well-researched post-TBI (Ouellet & Morin, 2007; Ouellet et al., 2004).

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The current study highlights that post-TBI some individuals do experience cognitions specifically relating to the impact of sleep upon recovery and other difficulties. As such, these findings support a cognitive-behavioural model of sleep disturbance post-TBI. This model purports that such cognitions are associated with increased anxiety and arousal, thus disrupting sleep (Espie, 2007; Harvey, 2002; Morin, 1993). Indeed, participants described experiencing 'racing thoughts' at bedtime and increased arousal, being more easily awoken. These factors are amenable to therapeutic intervention using cognitive behavioural therapy for insomnia (CBT-I). By formulating individuals' sleep disturbances, identifying cognitions, beliefs and maladaptive behavioural coping strategies, CBT-I provides an appropriate intervention targeted at modifying thoughts and associated behaviours to improve sleep (Ouellet & Morin, 2007; Roane et al., 2012). Indeed, CBT-I post-TBI has been examined using a series of case studies (Ouellet & Morin, 2004, 2007) which demonstrate its potential efficacy for this population, albeit large-scale research is lacking. As such, the current evidence supporting a cognitive model of sleep disturbance post-TBI provides some justification for the appropriateness of CBT-I by illustrating that individuals may experience increased arousal and maladaptive cognitions about sleep post-TBI. However, future research should utilise measures to explore these cognitions and illness beliefs in order to inform the development of interventions.

Participants engaged in behaviours which reflect proactive coping strategies, including normalising their experience, gaining familiarity and hypothesising. These all appeared to ease anxiety or uncertainty, or give greater perception of control of difficulties. Greater perceived controllability has been associated with adaptive coping and positive outcomes in adjustment and recovery post-TBI (Moore, Stambrook, & Wilson, 1991; Shotton et al., 2007). As such, beliefs of low controllability may lead to the processes identified within themes one and two, as a means to increase perception of control of sleep difficulties,

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reflecting problem-focused coping strategies (Pearlin & Schooler, 1978). Likewise, holding multi-factorial hypotheses for the sleep disturbances could lead to a greater perception of control over the difficulties, by allowing for a greater variety of strategies and potential solutions to be explored. Snyder and colleagues (2000) describe how 'hope' for an outcome is associated with generating a pathway to an end point, in this instance resolution of sleep difficulties. Multiple pathways, or strategies are generated when barriers are encountered in getting to the end point. Therefore when a hypothesis does not permit a pathway to the end point of gaining control over sleep, other hypotheses and strategies were identified.

Furthermore, the 'Goodness-of-Fit' coping hypothesis (Lazarus & Folkman, 1984) suggests that perceived controllability of an event is low and thus generates more anxiety, the most adaptive coping strategies are perception-focused. These involve individuals managing the negative impacts of factors which cannot be controlled, by positive appraisal or perception of the impacts (Pearlin & Schooler, 1978). Shotton et al. (2007) conducted a qualitative exploration of psychological adjustment post-TBI, highlighting a relationship between positive appraisal and adaptive coping, although this did not consider sleep. However, the current study indicates that coping with sleep disturbances post-TBI follows a similar process, as when participants were unable to gain control over sleep difficulties, they adopted perception-focused strategies by reappraising and reframing their difficulties. Thus, as hypothesised by Ouellet and Morin (2007), self-efficacy or perceived control of sleep does appear to influence behavioural coping strategies, however, further research is needed to determine whether perceived control affects engagement with interventions.

Indeed, acceptance of difficulties post-TBI has been associated with increased readiness to engage with therapy (Medley, Powell, Worthington, Chohan, & Jones, 2010; O'Callaghan, McAllister, & Wilson, 2012). Therefore as the current study highlights how acceptance appears to be associated with reappraisal of difficulties, promoting this reappraisal

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could influence therapy engagement. For example within narrative therapy, "re-authoring" can help individuals shift focus from the dominant, problem-focused narrative of their experience to a preferred narrative which incorporates values and exceptions to the problem, thus facilitating adaptive coping (Hogan, 1999; Weatherhead & Todd, 2014).

Furthermore, these findings suggest scope for Acceptance and Commitment Therapy (ACT) to promote acceptance of sleep disturbances post-TBI. ACT aims to change the individual's relationship with their difficulties, facilitating functional change via meditation, guided visualisation and developing self-awareness (Hayes, 2004; Kangas & McDonald, 2011). As indicated in theme two, acceptance resulted in a shift in participants relationships with sleep difficulties, as they accommodated these rather than 'battling' against them. For one participant, acceptance led to perceived improvements in sleep. Similarly, a recent study of ten participants with insomnia found improvements in subjective sleep quality after a six-week ACT intervention (Hertenstein et al., 2014), although to date this is the only study exploring ACT for insomnia.

Likewise, there is a lack of published research exploring the efficacy of ACT post-TBI. However, awareness of the importance of acceptance post-TBI is longstanding, with Prigatano et al. (1984) finding that acceptance of impairments post-TBI was associated with greater benefit from a rehabilitation programme. Furthermore, acceptance toward one's difficulties post-TBI has also been associated with better quality of life and community integration (Snead & Davis, 2002). As such, the feasibility of ACT post-TBI has been considered, highlighting potential challenges for implementing ACT where individuals have impaired self-awareness and cognitive flexibility (Kangas & McDonald, 2011; Soo, Tate, & Lane-Brown, 2011).

The identified processes within the current study relating to experiences of sleep post-TBI mirror the findings of TBI experiences more widely, with similar processes of trying to

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understand, manage with and accept difficulties. There were striking similarities with the findings of Howes et al. (2005) who interviewed women about their experience of TBI, although did not explore sleep. The authors described themes relating to gaining awareness of changes, struggling to make sense of difficulties, and finally adaptation and acceptance. Similarly, the experience of gaining awareness of deficits post-TBI was explored by O'Callaghan, Powell and Oyebode (2006), who described that personal circumstances affect the process of acceptance of deficits post-TBI. Interestingly, they too reported changed outlooks and identities, with personal discovery forming an important part of gaining knowledge, awareness and acceptance. Finally, Conneeley (2012) explored transitions post-TBI and found that familiarity and understanding of difficulties was associated with acceptance, with participants identifying strategies to manage consequences. This suggests that the processes described within the current research mirror the experiences of living with TBI more generally, and may indeed be important strategies for managing and adjusting to the entire experience of TBI of which sleep can be a significant aspect.

Limitations

As this study utilised an IPA methodology, the findings reflect the experiences of the nine participants and do not purport to be representative of all individuals with sleep disturbances post-TBI. As all participants had engaged with services which offered rehabilitation and psychological interventions, this sample may over-represent those who are coping well with difficulties. Although none reported receiving psychological input for sleep difficulties, previous interventions could have influenced methods of appraising and coping with brain injuries. Furthermore, information was not obtained for severity of TBI, however research indicates that sleep disturbances in mild TBI may differ in their nature and impact compared with more severe TBI (Orff, Ayalon, & Drummond, 2009). As such further research exploring the impact of severity on sleep experiences is warranted.

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Given the entirely white male sample, research with a female population would provide a useful gender comparison. However, the similarity between the themes identified in this study and those for experiences of TBI in a female population (Howes et al., 2005) indicates that similar processes occur irrespective of gender, suggesting the findings of the current study are a reliable interpretation of post-TBI experiences.

Conclusion

Individuals who experienced sleep disturbances post-TBI reported a unique, personal experience affected by their individual circumstances, difficulties and losses post-TBI. Making sense of sleep difficulties appeared to be an important process to ease anxieties, gain familiarity and facilitate adjustment by integrating difficulties into their post-TBI identity. Participants implemented strategies to manage, accept and adapt to living with sleep difficulties reflecting a process of adaptive coping. This sample represented a population who were coping well with their difficulties, demonstrating the importance of gaining an individualised understanding, accepting, reappraising and accommodating difficulties into one's life post-TBI. As such, these findings provide useful insights for therapeutic consideration for individuals post-TBI who may not be coping as well as this sample.

These findings suggest that professionals can help support individuals with TBI via holistic assessment of the individual's difficulties, considering their individual circumstances and developing formulations which consider the individual's unique, personal experience and their beliefs, facilitating an individualised comprehension of one's difficulties. Several factors which participants hypothesised to affect sleep post-TBI appear amenable to psychological intervention. The current study highlights the potential for a number of psychological interventions for addressing sleep difficulties post-TBI, namely CBT-I, narrative therapy and acceptance and commitment therapy, which should ideally be individualised and formulation-driven. To date, only two studies have explored the use of

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CBT-I, and while findings were promising, clearly more research is necessary to determine the most appropriate and effective methods of delivering interventions for sleep disturbances post-TBI.

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Table 1

Participant demographic information

Participant Pseudonym	Gender	Age	Nature of TBI	Time since injury (months)	Nature of predominant sleep difficulty/difficulties	Onset of difficulties
Charlie	Male	39	Fall	69	<ul style="list-style-type: none"> – difficulty falling asleep – early waking – more frequent waking/easily disturbed – fewer dreams, but had a dream-like flashback memory 	1-2 years post injury
Simon	Male	35	Fall	16	<ul style="list-style-type: none"> – disruptions to sleep wake cycle – sleeping more and then sleeping less – recent improvements - change over time – initially hallucinations, then no dreams, but now similar to pre-injury 	Immediately after injury - noticed when discharged home
Ted	Male	52	Fall	18	<ul style="list-style-type: none"> – waking in the middle of the night – struggling to get back to sleep – changes to content of dreams - nightmares 	When started epilepsy medication and returned to work
Melvin	Male	51	Fall	18	<ul style="list-style-type: none"> – difficulty falling asleep at night – falling asleep before going to bed – waking early/frequent waking/easily woken – no longer remembering dreams 	Immediately after injury

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Participant Pseudonym	Gender	Age	Nature of TBI	Time since injury (months)	Nature of predominant sleep difficulty/difficulties	Onset of difficulties
Robin	Male	49	Fall	33	<ul style="list-style-type: none"> – difficult falling asleep – sleeping more in the day – experiencing more meaningful and positive dreams and thought about dreams more post-injury 	Immediately
Stan	Male	50	Road traffic accident.	242	<ul style="list-style-type: none"> – difficulty falling asleep – more frequent waking 	Immediately
			Subsequent TBI from object hitting head.	72	<ul style="list-style-type: none"> – dream-like out of body experience after injury, now more aware of dreams and their interpretation 	
Henry	Male	52	Fall	202	<ul style="list-style-type: none"> – difficulty falling asleep – more frequent waking/easily disturbed – dream content changes 	When changing epilepsy medication
Matthew	Male	28	Road traffic accident	8	<ul style="list-style-type: none"> – difficulty falling asleep – falling asleep during the day – initially more frequent waking - now improved – experiencing more dreams 	Immediately - noticed in hospital
Martin	Male	51	Road traffic accident	7	<ul style="list-style-type: none"> – initially irregular sleep wake cycle – more frequent waking – recent improvements – experiencing fewer dreams 	Immediately

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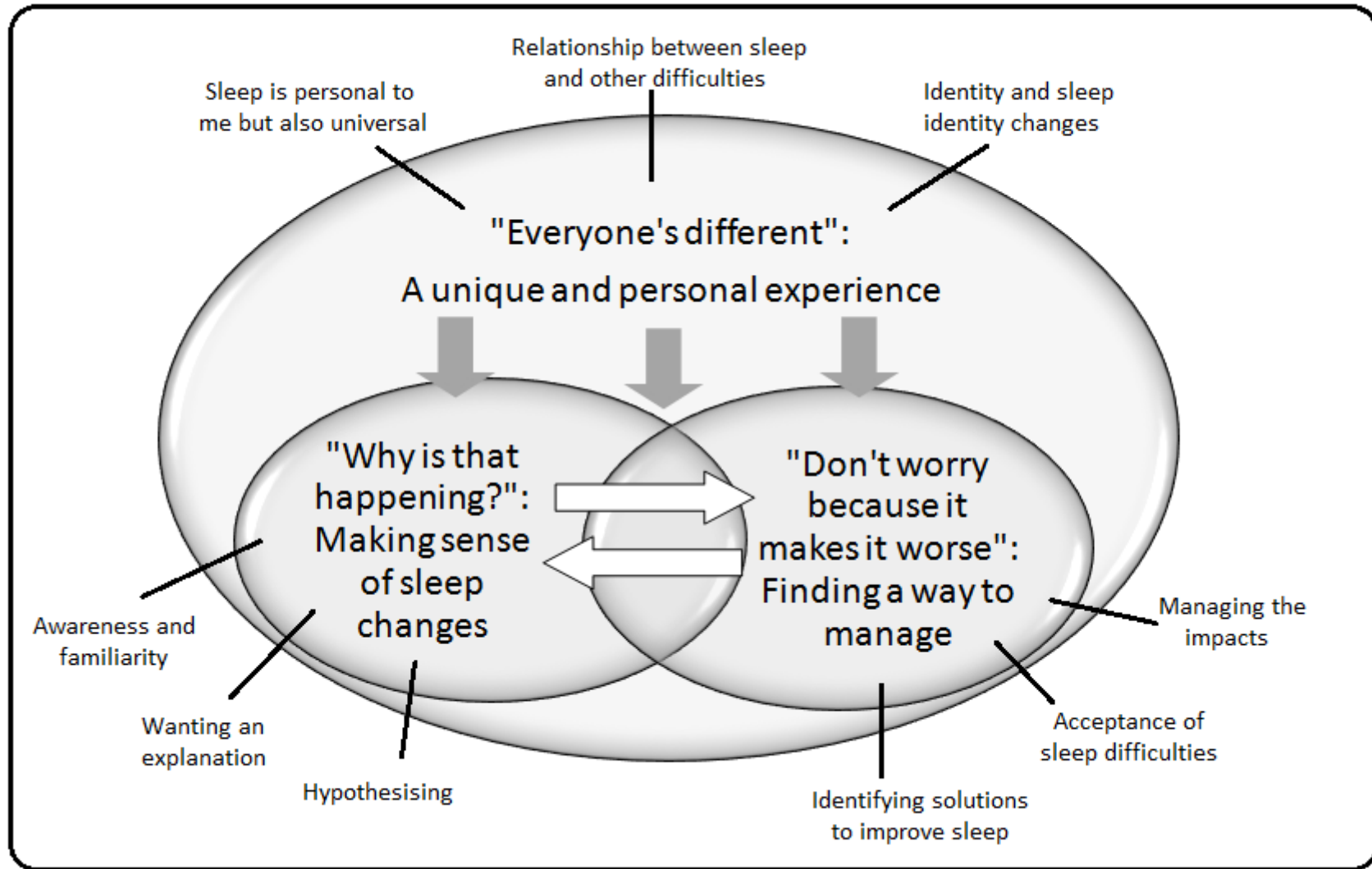


Figure 1. Diagrammatic representation illustrating the relationship between themes for experiences of sleep disturbances post-TBI

EXPERIENCES OF SLEEP DISTURBANCES POST-TBI

Appendix 2-A

Excerpt from Transcript (Matthew) with Initial Codes and Interpretations.

Initial notes	Transcription	Interpretation
	I: How does that feel more generally, you know, kinda having this thing that's difficult about sleep, how does it leave you feeling?	
Thoughts on my mind	R: Things sort of play on your mind, you seem to wonder how long you are going to be	Mind is occupied
It's a struggle	struggling with it for, erm, you try to change	It's difficult
Changing things	the way you do things, you try to change what	
Changing lots of things – really searching for something that works	time you go to sleep, what time you get up, see if that changes anything, and you just think about whether it is affecting you, erm, but in	Trying multiple solutions
Not tired in the middle of the day	the middle of the day I don't seem to feel tired.	
Feeling tired in the evening	[I: okay] erm I seem to feel tired earlier at night, so I might be tired at 8 or 9 o'clockish,	Patterns to tiredness
	erm, but obviously I won't go to sleep, and I	Sleep impacts on the daytime
Wasting the day	worry then about if I go to sleep early, I'm just wasting my day then, because I'll be asleep for	Not letting sleep change you
	say 12 hours and just you've got things to do	
Doing it at the same time	haven't you, so I just try to, I try to do everything at the same time really to try and	Keeping routines
Settle in	get my body to settle in.	Adjusting

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	I: Okay, so it sounds like you've tried a few	
Doesn't make a difference to sleep	things, but they haven't made a difference?	
Might wake up before alarm	R: No, because I can set, even if I set my clock for 9 o'clock sometimes I might wake up at	Solutions didn't work
Sometimes want to stay in bed	half past 8 or sometimes the alarm will go off and I'll feel like I want to stay in bed again, it's...	Things are variable
	I: So it can be a bit variable in the mornings?	
	R: Yeah.	
	I: Okay, and you feel tired first thing in the morning, and then also this bit of time at night	
Being active stops feeling tired	that's kinda 8, 9 o'clock, you start to feel...	
Feel tired when relaxing	R: Yeah, similar sort of, feeling.	Active and awake
Falling asleep in the chair	I: Does the tiredness go on until you go to bed, or do you wake up?	Strategies for sleep
Waking up soon after	R: Erm, once, 'cause that'll be like, say I was	Sleep patterns in napping
Takes the same time to relax before you can sleep	sat down and if I was wandering about I wouldn't feel tired, sat down relaxing, feel	Needing relaxation for sleep – strategies
Can't sleep when you try to	tired, fall asleep in the chair but I wake up every 20 minutes, then if I get up and go to bed, I'm awake again, and then it takes like the same length of time to, to like relax before you feel like you could go to sleep. [I: Okay] and then when you try and go to sleep you just....	Trying to sleep and can't

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Appendix 2-B

Example of Theme Development for Theme One "Why is that happening?": Making sense of sleep changes

Quote	Initial Thoughts	Emergent Themes	Subtheme	Individual theme
"I don't know why, I think, me, me body clock, I don't know, if its just set to me medication or not, I don't know" (Charlie, line 437)	Guessing why he always wakes up at this time, but seems uncertain	Finding an explanation to ease uncertainty	Hypothesising	"Why is that happening?": Making sense of sleep changes
"I presume medication is a key factor in all that. I don't know. Beginning, like I say, I had half an head, so I was very conscious of touching on it, you know, on the pillow and everything, and trying to keep one way when I was asleep, erm, probably just relaxing, I don't know" (Simon, line 502)	Exploring different hypotheses for sleep changes, linked to other difficulties Not settled on one explanation	Exploring different explanations		
"I wake up because I got, my brain has already kicked in, and its thinking about some...so when I wake up I could be thinking about me job, about finding another job, so my brain has already kicked in and its already..." (Ted, line 325)	Believes that his brain is active which affects his sleep, racing frantic thoughts wake him up Frantic, hurried speech describing this	An active brain stops sleep		
"I found that my sleep pattern went, not back to what it was, but not far off, away from everything, away from work" (Ted, line 777)	Being away on holiday affected his sleep, helped him to realise work stress could be a factor	Noticing what affects sleep shapes hypotheses		

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"Work all day, sleep all night, that's how it used to be! But I think because I'm not burning no energy off now, you know, because I'm not doing nothing" (Melvin, line 310)	Believes that sleep is linked to work and activity, he can't sleep because he isn't being active anymore	A relationship between sleep and lack of activity	Hypothesising	"Why is that happening?": Making sense of sleep changes
"I don't know whether that's to do with the temazepam, or because I used to think it was, but then I don't know, maybe now is the stopping smoking and I've been wearing patches. I'm always aware of things, looking for answers" (Stan, line 830)	Having a few different possible explanations Looking for explanations	Considering hypotheses Figuring it out		
"Err now whether it's because of the tablets or what I don't know" (Henry, line 278)	Being uncertain about explanation	Hypotheses not facts		
"I thought that was just the hospital originally, erm, and then it just didn't really get any better, the sleep" (Matthew, line 16)	Hospital initially affected his sleep but then the difficulties maintained	An external trigger and internal factor which maintains		
"The other thing that's affected my sleep, or the way I sleep, is I broke my arm..." (Martin, line 281)	Having an alternative explanation - more than one thing affected sleep	Having multiple hypotheses		

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Appendix 2-C

The Development of the Theme "Why is that happening?": Making sense of sleep changes

Clustering of Participant Emergent Themes into a Super-ordinate Theme

Participant	Emergent Themes	Summary Paragraph
Charlie	<p>Noticing patterns</p> <p>Information seeking</p> <p>Normalising my experience</p> <p>Understanding the patterns</p> <p>Finding an understanding</p>	<p>Charlie was keen to seek out more information to try to understand patterns in his sleep disturbances</p> <p>Charlie had a regular pattern for waking up too early before his alarm which he thought was because of the time he had medication. Charlie also noticed that he was no longer dreaming as much.</p> <p>Charlie's sleep was very sporadic, there didn't seem to be a pattern to it.</p> <p>Charlie didn't know why his sleep disturbances had started, but thought it was probably because of the damage to his brain. He sought confirmation in the interview that these changes were common following traumatic brain injury, normalising his experience.</p> <p>Charlie hypothesised that several other factors might be influencing his sleep, such as his epilepsy and noise caused by traffic.</p>
Simon	<p>Noticing change</p> <p>Awareness</p> <p>Finding a pattern</p> <p>Seeking an explanation</p> <p>An understanding helps acceptance</p> <p>Making sense of changes</p> <p>Exploring different explanations</p> <p>External factors cause internal changes</p>	<p>Simon's sleep has fluctuated since his injury, initially being much worse than it is now. Simon thought this was due to medication, sweating and hallucinating when he was in hospital and the fact that he was conscious of sleeping on one side whilst he awaiting a plate in his skull.</p> <p>Simon felt his sleep disturbances were linked to fatigue and to the amount he was doing, feeling that doing less in the day means he probably needs less sleep.</p> <p>Simon noticed that every day he would wake up at 4 o'clock in the morning, and wondered if this was the time that doctors did their medication rounds when he was in hospital.</p> <p>Simon said that he is easily woken by noises. Simon described how he wanted to get a good night's sleep but that this was always being broken and he found this frustrating.</p>

EXPERIENCES OF SLEEP DISTURBANCES POST-TBI

Ted	<p>Noticing patterns Becoming more aware Searching for an explanation Finding out why Noticing what affects sleep shapes hypotheses External impacts on internal processes An active brain stops sleep</p>	<p>Ted noticed patterns in his sleep and dreams, most notably that he had a wake up pattern each night at 2 o'clock, which was aggravating because this made him feel tired during the daytime. He was keen to discover why this had happened and explored a number of hypotheses.</p> <p>Ted noticed his sleep changes started when he stopped medication for epilepsy but he also started back at work in a new job role at the same time, and wasn't sure whether this might have affected sleep too. He finds that his brain refuses to close down, waking him up with thoughts about work. He noticed that being on holiday helped his sleep, and hypothesised that perhaps stress at work was affecting his sleep.</p>
Melvin	<p>A heightened awareness Sleep is unpredictable There's no set pattern Changes without an explanation are strange Seeking understanding Reaching a personal explanation Understanding helps me adapt Making links between sleep and other factors post-TBI A relationship between sleep and lack of activity</p>	<p>This theme reflects how Melvin's sleep disturbances were quite variable and unpredictable and he had good nights and bad nights. This was strange to him and didn't make sense. He felt it was normal to sleep for a period of time in the night, but yet he often found himself unable to. Melvin tried to tire himself out, thinking that the reason he was unable to sleep was because he wasn't burning enough energy, but he found that exercise didn't seem to help him sleep. Melvin said that he had changed his normal way of life because of his injury and so this seemed to have affected sleep, but he didn't know if his understanding was right or not. Melvin wondered if 'always thinking' could be affecting his sleep, as he felt more alert to things like noises, but nothing seemed to make a difference to his sleep.</p>

EXPERIENCES OF SLEEP DISTURBANCES POST-TBI

Robin	<p>Becoming more aware of sleep and dreams</p> <p>A desire to understand</p> <p>Need an understanding in order to search for strategies</p> <p>Understanding and learning helps coping</p> <p>Finding a hypothesis for sleep</p> <p>Hypothesising about factors which influence sleep</p> <p>Being more overactive and vigilant impacts on sleep</p> <p>Relationship between the brain and sleep</p>	<p>Robin struggled to relax and felt this is why he couldn't sleep. He felt that his sleep disturbances were because his brain was thinking too much, but that because he wasn't now as physically active he wasn't tired enough to stop his brain from being overactive. Robin was using zopiclone to manage his sleep, and without it he would be awake for most of the night, every night. Robin found that working or being very active in the day helped him to sleep better, but found it frustrating not being able to get his brain to switch off. He felt that he needed more stimulation to occupy his mind so that he would not be kept awake by thoughts.</p> <p>Robin also commented that he was more vigilant and observant to information particularly in relation to his dreams.</p>
Stan	<p>Becoming aware of difficulties</p> <p>Predictable patterns</p> <p>Things happen for a reason which will become clear</p> <p>Considering hypotheses</p> <p>Making sense of sleep changes</p> <p>Figuring it out</p> <p>Active, racing mind prevents sleep</p>	<p>Stan regularly struggled to get to sleep, noticing a pattern that each night at 9 o'clock his mind would start racing, occupied by thoughts from the day. Stan's understanding was that his mind was too busy, so he couldn't switch it off in order to fall asleep. Stan had noticed changes in his dreams too, in that he didn't dream as often and his dreams were boring, but this didn't bother him. Stan described how he was often reading and studying about his sleep and dreams, trying to find answers and understanding and figure it out. He wondered whether it was partly due to the damage in his brain, but also he was taking temazepam and felt this was now stopping him from seeing how things really were, so he was keen to stop this so he could 'examine his own mind' and understand his difficulties better.</p>

EXPERIENCES OF SLEEP DISTURBANCES POST-TBI

Henry	<p>Becoming aware of a predictable pattern</p> <p>Noticing what affects sleep</p> <p>Finding familiarity in an unusual situation</p> <p>Wondering why</p> <p>Seeking understanding</p> <p>TBI = many changes = many hypotheses</p> <p>More sensitive to external factors</p> <p>My beliefs about sleep</p> <p>Identifying factors which don't help sleep</p> <p>Hypotheses not facts</p>	<p>Henry has found that in the last few years his sleep pattern has changed. He now finds that he gets tired much earlier in the evening, every night at about 8pm and then falls asleep in the chair. He then wakes up and gets ready for bed, but struggles to fall asleep then. Henry thought this was because of a change in his epilepsy medication, but also felt that a number of other factors affected sleep, such as being more sensitive to noise, and worrying about things he has to do the next day. He felt that it was hard to establish a reason why because having a TBI changed his life in many ways. This left him feeling frustrated by his difficulties, and keen to resolve them.</p>
Matthew	<p>Discovering a pattern</p> <p>Noticing change</p> <p>Active searching for an explanation</p> <p>Taking an interest and wanting to learn</p> <p>Establishing cause and effect</p> <p>Identifying explanations</p> <p>An external trigger and internal factor which maintains</p> <p>Making sense of sleep disturbances</p>	<p>This theme reflects Matthew trying to make sense of which factors were affecting his sleep. He noticed a pattern in how long it took him to get to sleep - two hours. He identified a number of factors which were around at the time of the onset of his difficulties whilst he was in hospital, and he described wanting to know more about medications and their impacts, trying to understand more about what was happening.</p> <p>Matthew explained that environmental factors affected sleep such as hospital beds and noise, being awoken by staff. Medication was also affecting his sleep, causing him to itch and wake up. He obtained a copy of the BNF because he was interested in knowing more. Matthew was suffering neck pain that also affected his sleep. However, Matthew's difficulties persisted when he returned home after these factors were resolved/no longer an issue. Matthew continued to try to make sense of his difficulty, hypothesising that perhaps less sleep was needed because he was now less active. He felt like his brain was active and thinking which was keeping him awake.</p>

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Martin	<p>Becoming more aware, noticing change</p> <p>Need an explanation to help processing difficulties</p> <p>Need for understanding to ease frustration</p> <p>Having multiple hypotheses</p> <p>Considering hypotheses</p>	<p>Martin felt he had become more aware of his sleep since his injury. It was important to have an understanding of things, it was important to him, eased anxiety and was just the way he's always been, so he was keen to find answers for the changes in his sleep. Martin found his sleep was disrupted by his back pain after his injury, and by being uncomfortable due to restricted movement in his shoulder. He hypothesised that this was due to his mattress, and spent a thousand pounds on a new mattress to ease his back pain. Martin wondered whether worry and reacting to the trauma of the accident had affected his sleep straight after the accident. Martin noticed he had stopped dreaming, and he was not sure whether this was due to him not now being as stressed with work, or whether this was because of the damage to his brain.</p>
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Appendix 2-D

The Contribution of Participant Emergent Themes to Final Subthemes and Super-ordinate Themes

Theme:	"Why is that happening?": Making sense of sleep changes		
Subtheme:	Awareness and familiarity	Wanting an explanation	Hypothesising
Charlie Emergent Themes	Noticing patterns	Information seeking Normalising my experience	Understanding the patterns Finding an explanation to ease uncertainty
Simon Emergent Themes	Noticing change Awareness Finding a pattern	Seeking an explanation why An understanding helps acceptance	Making sense of changes Exploring different explanations External factors cause internal changes
Ted Emergent Themes	Noticing predictable patterns Becoming more aware of sleep difficulties	Need an understanding to make difficulties feel more 'normal' Searching for an explanation Finding out why sleep pattern changed	Noticing what affects sleep shapes hypotheses External impacts on internal processes An active brain stops sleep
Melvin Emergent Themes	A heightened awareness Sleep is unpredictable There's no set pattern	Changes without an explanation are strange Seeking understanding Reaching a personal explanation Understanding helps me adapt	Making links between sleep and other factors post-TBI A relationship between sleep and lack of activity

EXPERIENCES OF SLEEP DISTURBANCES POST-TBI

Robin Emergent Themes	Becoming more aware of sleep and dreams	A desire to understand Need an understanding in order to search for strategies Understanding and learning helps coping	Finding a hypothesis for sleep Hypothesising about factors which influence sleep Being more overactive and vigilant impacts on sleep Relationship between the brain and sleep
Stan Emergent Themes	Becoming aware of difficulties Predictable patterns	Things happen for a reason which will become clear	Considering hypotheses Making sense of sleep changes Figuring it out Active, racing mind prevents sleep
Henry Emergent Themes	Becoming aware of a predictable pattern Noticing what affects sleep Finding familiarity in an unusual situation	Wondering why Seeking understanding	TBI = many changes = many hypotheses More sensitive to external factors My beliefs about sleep Identifying factors which don't help sleep Hypotheses not facts
Matthew Emergent Themes	Discovering a pattern Noticing change	Active searching for an explanation Taking an interest and wanting to learn	Establishing cause and effect Identifying explanations An external trigger and internal factor which maintains Making sense of sleep disturbances
Martin Emergent Themes	Becoming more aware, noticing change	Need an explanation to help processing difficulties Need for understanding to ease frustration	Having multiple hypotheses Considering hypotheses

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Theme:	"Don't worry because it makes it worse": Finding a way to manage		
Subthemes:	Identifying strategies to improve sleep	Acceptance	Managing the impacts
Charlie Emergent Themes	Testing solutions Evaluating pros and cons Being in control	Accepting difficulties won't change Hoping for improvement Coming to terms with it	Finding a way to cope Not making sacrifices A challenge I need to manage Minimising the impacts
Simon Emergent Themes	Getting into good habits to help sleep Making it work for you	Getting used to it	Being flexible in managing difficulties Solutions to manage the impacts Working around commitments
Ted Emergent Themes	Testing out strategies and solutions Reshaping hypotheses Having control Pros and cons	Accepting things might not improve Learning to live with it Fluctuating between accepting and wanting change Acceptance facilitates readiness to take advice	Finding a way to manage the impacts Adjusting to difficulties Keeping things as normal as possible Accommodating difficulties
Melvin Emergent Themes	Trying out solutions based on hypotheses Solutions don't work Weighing up solutions	Winning and losing a battle	Adapting in order to overcome Keeping busy
Robin Emergent Themes	Evaluating solutions based on risk Solution choice based on severity of impacts Belief in strategies influences choice Pro's and con's of strategies		Needing time to adjust Making adaptations Making lifestyle changes indirectly affects sleep

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Stan Emergent Themes	Making active changes to directly and indirectly affect sleep Evaluate treatments based on risk and side effects Solutions match hypotheses Finding a strategy to mask the problem Forcing myself	Accepting things which don't make sense Accepting that there is no cure, but still hoping for one	Unable to control sleep Surviving sleep difficulties Strategies to avoid exacerbating or worsening difficulties Stopping my active mind
Henry Emergent Themes	Eager to make changes to sleep Noticing what affects sleep Beliefs influence interventions Trying out strategies which fit with me Don't make sacrifices Contemplating making changes	Accepting the things I am unable to change	Establishing a routine Avoiding the impacts of sleep difficulties
Matthew Emergent Themes	Testing out hypotheses via strategies - refute and modify Noticing improvements Choosing solutions which don't bring a sacrifice Need to work strategies around commitments	Hoping for change and stability Importance of acceptance	Strategies to maintain not improve Establishing a routine Minimising the impacts
Martin Emergent Themes	Gaining control Evaluating strategies Understanding why strategies work Having multiple strategies Testing hypotheses		Balancing difficulties Maintaining normal life

EXPERIENCES OF SLEEP DISTURBANCES POST-TBI

Theme: "Everyone's different": A unique and personal experience of sleep after TBI			
Subtheme:	Sleep is a personal experience	Identity	Relationship between sleep and other difficulties
Charlie Emergent Themes	A personal experience but universal phenomenon	Highlighting difference from pre-injury My changed identity affects sleep Uncertainty of self Changed perception of sleep	Linking sleep to other difficulties post-TBI Sleep impacts affect me because of my circumstances Prioritising difficulties
Simon Emergent Themes	A personal experiences which needs a personal approach Experience different from others	Making comparisons with pre-TBI sleep Identity changes post-TBI affect sleep My sleep identity has changed Being a survivor - new positive outlook Reshaping myself, taking positives from experience	Putting sleep into context of life events My injury impacts upon sleep Other difficulties impact on sleep and your ability to manage Sleep improvements reflect recovery Sleep and TBI affect how I manage Life is disrupted, so sleep is disrupted Difficulties interlinked - snowball effect
Ted Emergent Themes	Sleep difficulties are a personal experience My beliefs and circumstances affect my coping Need a personal and unique way to address difficulties	Who I am as a 'sleeper' has changed - a trait/identity My identity has changed - impact on sleep Rediscovering/reinventing myself A new norm Loss of who I was A new relationship with sleep Changing your perspective and attitude	TBI impacts upon your internal resources affecting ability to cope with sleep Maintaining temporary control of tiredness to avoid exacerbating other difficulties Finding relationships between sleep and other factors

EXPERIENCES OF SLEEP DISTURBANCES POST-TBI

Melvin Emergent Themes	Being unique, a unique situation, unique understanding and unique solutions Sleep is not 'normal'	Comparing to others and my 'norm' Feeling uncertain about myself A change in my identity Sleep is a part of my identity and linked to working hard Being exceptional Changed perception of sleep	Prioritising difficulties Impacts of TBI affect sleep Poor recall affects perception of sleep Importance of sleep not impacting upon commitments
Robin Emergent Themes	A personal experience How it is for me	Drawing comparisons post-TBI for myself and sleep A changed relationship with sleep Establishing a new identity/sleep identity Change how I view sleep - what is "good sleep"	TBI increases the importance of sleep Lack of sleep affects ability to have control TBI increases impacts of not sleeping TBI created a void in my life Influence of other factors, commitments, circumstances
Stan Emergent Themes	What is normal or expected A personal sleep difficulty which others cannot understand The importance of sleep to me	Sleep is a part of my identity Feeling different from others Proving my qualities to myself Being exceptional Gaining something from this experience Shifting perception of a good night's sleep	Connection between sleep and life Sleep protects me, a sanctuary from other difficulties Cyclical impacts with difficulties Greater importance of sleep for recovery Impacts on mood impacts on ability to deal with it
Henry Emergent Themes	Finding what fits for me	Comparing to pre-injury Wanting to be who I used to be Being a different person Sleep identity - desired amount, position, quality	Life disrupted by TBI, sleep disrupted too, sleep disrupts life Sleep impacts on other difficulties Sleep impacts on my mood and motivation Prioritising other difficulties

EXPERIENCES OF SLEEP DISTURBANCES POST-TBI

Matthew Emergent Themes	<p>Sleep criteria are personal and influenced by lifestyle, identity, personality</p> <p>Sleep needs unique, ideal situation in order to happen</p> <p>Personal way of understanding and measuring sleep</p> <p>Considering the individual</p>	<p>Comparing to pre-injury sleep</p> <p>Changed relationship with sleep and views about sleep</p> <p>How we perceive the problem</p> <p>Changed outlook helps coping</p> <p>A positive outlook</p>	<p>Putting sleep difficulties into perspective with other difficulties</p> <p>Cyclical impacts of sleep, other difficulties and mood</p>
Martin Emergent Themes	<p>Personal situation, beliefs, circumstances affects coping</p> <p>My own personal requirements for sleep</p>	<p>Learning who I am</p> <p>Gaining new insights, outlooks about myself and life</p> <p>A relationship with sleep and with my bed</p> <p>Changes in identity influence sleep</p>	<p>If one thing changes other things will be impacted on</p> <p>Comparing sleep to other difficulties, prioritising importance based on impact</p> <p>Sleep in the context of other difficulties</p>

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Appendix 2-E

Instructions for Authors

Instructions for authors

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Section Three: Critical Appraisal

A Critical Appraisal of the Research Study:

'Experiences of Sleep and Dream Disturbances following Traumatic Brain Injury'

Word count: 3976

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A Critical Appraisal of the Research Study:

'Experiences of Sleep and Dream Disturbances following Traumatic Brain Injury'

This critical appraisal presents further consideration and reflection on issues which arose during the process of conducting the research presented within the research paper (section two). In keeping with phenomenological methodology, this critical appraisal presents my own experience of conducting this piece of research, providing reflections upon the factors which have influenced my decisions throughout the process. The structure of this critical appraisal follows that of the research process beginning with choosing a research topic and appropriate methodology, and progressing to reflect on my experiences of conducting the research, highlighting challenges and considerations in collecting and analysing the data. In addition, the therapeutic benefits for research participation are discussed and theoretical implications for the study are highlighted.

Choosing a Thesis Topic

My professional interest in neuropsychology is longstanding, beginning with the theoretical knowledge gained during my undergraduate degree and developing throughout clinical psychology training via placements within neuropsychological settings. In addition, my interest in the psychological impacts of neurological events has been stimulated by several personal experiences: my grandmother's suffering with vascular dementia, my auntie's disability resulting from multiple sclerosis and the loss of my uncle following a subarachnoid haemorrhage. These experiences have given me insight into the importance of considering the individual's perspective and experience of neurological events, as well as the wider impacts for the individual and also their family.

Within my clinical work I strive to use person-centred and systemic approaches to assessment, therapy and rehabilitation. Naturally, I was eager to extend to my approach to conducting research. Neuropsychology literature is dominated by quantitative research,

aimed at researching objectively measurable outcomes for individuals with traumatic brain injury TBI. In addition, data are often collected from families and carers due to the cognitive impairments experienced by individuals post-TBI which can compromise the ability and capacity to participate in research. Consequently, the individual's experience of TBI has been largely neglected within the literature (Howes, Benton, & Edwards, 2005). However, more recently studies are beginning to explore the lived experiences of surviving and recovering from TBI (Chamberlain, 2006; Howes et al., 2005; Levack, Kayes, & Fadyl, 2010; Shotton, Simpson, & Smith, 2007). As such, I was keen to conduct a study which could contribute to the developing body of qualitative research within this field and inform future person-centred practice. Due to medical advances, a greater proportion of individuals are now surviving TBI-causing events (Flaada et al., 2007; Harrison-Felix et al., 2009) and gaining an understanding of experiences of surviving TBI and living with difficulties post-TBI is important in informing effective rehabilitation and psychological therapy.

The thesis topic of exploring experiences of sleep disturbances post-TBI was developed through discussions with my research and field supervisor and via literature searching. Literature revealed that sleep disturbances were commonly experienced sequelae of TBI (Mathias & Alvaro, 2012), yet one which had not been researched from a qualitative perspective.

I was enthused by this research topic due to my own interests in sleep and dreaming. Considering theories relating to the functions of sleep and dreaming, I have a longstanding interest in the roles of sleep and dreams in information processing, consolidating emotional memories and problem-solving (Vandekerckhove & Cluydts, 2010; Walker, 2010; Walker & van der Helm, 2009). I wished to discover how these processes might be disrupted as a result of neurological damage sustained as a result of TBI and how experiencing a traumatic event could impact upon sleep. As such, when developing a research question, I considered the

wider implications of this research, for its potential to contribute to the literature on theories of sleep and dreaming.

In addition to literature on sleep and dreaming, I was also interested in how this research might contribute to understanding the experience of post-traumatic stress disorder (PTSD) post-TBI. Sleep and dreaming difficulties are noted as potential diagnostic criteria for PTSD in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association (APA); 2013). In particular, two criteria relate to sleep; “recurrent distressing dreams of the event” and “sleep disturbance (APA, 2013, p.271). Within the literature, there has been controversy associated with diagnosing PTSD in TBI. Individuals often experience post-traumatic amnesia (PTA) immediately following TBI, experiencing difficulties recalling memories of the TBI-causing event, memories preceding the event, or subsequent new memories (Kosch, Browne, King, Fitzgerald, & Cameron, 2010; Nakase-Richardson et al., 2011). PTA therefore can hinder the recollection of the traumatic event, which is key in meeting DSM-5 diagnostic criteria (Feinstein, Hershkop, Ouchterlony, Jardine, & McCullagh, 2002; Bryant et al., 2009). However, a review by McMillan et al. (2003) concluded that individuals can meet diagnostic criteria for PTSD, despite having limited or no memory of the injury-causing event itself, arguing that individuals can have ‘islands of memory’ which can be traumatic, or that secondary events such as waking up in hospital can also be traumatic (Harvey, Kopelman, & Brewin, 2005). In addition, diagnosis of PTSD in TBI is complicated by the overlap in many of the symptoms and difficulties experienced in both PTSD and TBI, such as changes in mood, sleep and appetite (Flor, 2011; Sumpter & McMillan, 2005). Nonetheless, the intrusive recollections stated as part of the diagnostic criteria for PTSD are not thought to overlap with TBI, indicating that PTSD may exist as a phenomenon following TBI (Harvey et al., 2005; McMillan et al., 2003). As the literature on dreaming post-TBI is relatively sparse, with no qualitative analysis, I was eager

to discover whether individuals' dreams held emotional content which could relate to the injury-causing event, and whether this could be useful in understanding trauma reactions post-TBI.

Choosing an Appropriate Methodology

From a young age, I was often absorbed in philosophical and phenomenological thoughts regarding perception and individual experience. I was intrigued as to whether the sounds, colours and tastes which I experienced were the same as other people's experiences of these phenomena. I considered how one might test or explore these hypotheses, pondering whether a science of phenomena could involve language-based descriptions to identify common, shared experiences. However, I acknowledged the limitation that this method could assume a universal experience of language, contrasting with my belief that the words we use and the meanings they hold can be subjective, based upon our experiences and interactions. Unsurprisingly given these phenomenological beliefs, interpretative phenomenological analysis (IPA) appealed to me as a method of exploring phenomena while acknowledging my own experiences and positioning as a researcher as part of the process of analysis (Smith, Flowers, & Larkin, 2009). As such, I felt that IPA was an appropriate methodological approach to explore common meanings and interpretations which individuals ascribe to their experiences of sleep and dream phenomena post-TBI.

Conducting the Research: Data Collection and Analysis

Subsequent to identifying a research question, I began the task of selecting appropriate inclusion and exclusion criteria in order to generate a homogeneous sample in accordance with IPA methodology (Smith et al., 2009). This created some challenges and issues for the homogeneity of the sample and ultimately for the validity of the data. These limitations are discussed below.

I considered how PTA could impact upon memory immediately after TBI, and this could have implications for the individual's capacity to take part in the research and their ability to attribute meaning to their experience (Dean, O'Neill, & Sterr, 2012; King, 2003). As such, I opted for an inclusion criterion of 'at least three months post-TBI'. This influenced the choice of services which I approached for recruitment services, in that these were post-acute, community-based and outpatient services. Consequently, my sample represented a group who were all currently receiving rehabilitative and therapeutic input and support post-TBI. I contemplated how this could have influenced the meanings they ascribed to their experiences and ultimately the themes which were identified. The sample seemed to represent a group who had already gone through a process of psychological adjustment post-TBI and this appeared to influence their appraisal of their sleep difficulties.

As the study was exploratory, I did not identify an upper time-limit criterion. This decision was based upon research indicating that the development of sleep disorders post-TBI can be variable in time of onset (Ouellet, Savard, & Morin, 2004; Wiseman-Hakes, Colantonio, & Gargaro, 2009). This however had implications for the homogeneity of the sample, as both onset of sleep difficulties and duration of sleep difficulties differed between participants.

Furthermore, I opted to include participants who were 'currently experiencing sleep disturbances such as changes in sleeping patterns and duration, frequent waking, or experiences of disturbing or upsetting dreams or nightmares, with onset post brain injury'. This decision was based on several factors. Firstly, literature indicated that sleep disturbances post-TBI can vary in their nature (Ouellet et al., 2004). Secondly, research suggests that in individuals with sleep disturbances post-TBI, approximately half are diagnosed with sleep disorders, with the remaining half undiagnosed or not meeting diagnostic criteria (Mathias & Alvaro, 2012). My aim for this research was to capture the

individual experience of changes to sleep post-TBI. Therefore, as diagnosable sleep disorders are not TBI-specific, I felt it was more appropriate to recruit individuals who were self-reporting changes in their sleep, as opposed to meeting diagnostic criteria. However, the criteria of "sleep disturbances" somewhat compromised the homogeneity of the sample as participants reported experiences which were markedly different. For example, some reported struggling to fall asleep whereas some reported unwanted early awakenings. This has potential implications for the validity of the research, as the IPA approach aims to create understanding of a specific phenomenon, whereas the individuals within the sample recruited could be experiencing different phenomena.

Considerations for Conducting Qualitative Research with a TBI Population

As part of the process of conducting this research study a reflective diary was written. This diary allowed for documentation of reflections, thoughts and emotions relating to the process of conducting research. In particular, diary entries represented initial thoughts which arose during the process of conducting research interviews. These reflections and thoughts were acknowledged during the process of analysing the data. Several of these reflections represented challenges for conducting research with individuals with TBI and are discussed below.

I had commented that several interviews were much longer than anticipated, but that this seemed to be a result of participants drifting 'off topic'. My reflections highlighted my hypotheses for these occurrences, and also my dilemma of how to address this in subsequent interviews. Drawing upon my clinical experience and expertise, I hypothesised that drifting 'off topic' could be a consequence of cognitive difficulties resulting from TBI. Individuals with TBI often present with executive function difficulties as a result of damage to the frontal lobes. Executive function difficulties include disinhibition, attention difficulties and perseveration, which can impact upon social interactions. Individuals with executive

function difficulties find it difficult to stay on topic and follow conversations, struggling to inhibit urges to discuss other topics. In addition, individuals can perseverate with one particular conversation topic (Damasio & Anderson, 2003; Lezak, Howieson, Bigler, & Tranel, 2012). This presented a challenge for conducting research in accordance with an IPA approach, as semi-structured interviews with open-ended questions are indicated as the exemplary method for data collection, as this allows for the participant to take a lead in the discussion of their experience and permits questions to be tailored to facilitate the collection of rich, detailed data of individual experiences (Smith et al., 2009; Smith & Osborn, 2003). However, this also allows for the possibility of drifting from the topic which is being investigated. This represented a challenge in conducting the research, in deciding whether to modify the interview schedule in order to create a more structured interview, limiting the opportunities for participants to drift off topic. While my proposed hypothesis offered one explanation, I also considered whether any of the 'off topic information, although seemingly unrelated to sleep, might be of importance to consider as part of my analysis. In deciding this I felt it was more appropriate to continue to conduct interviews using a semi-structured interview schedule, but provided more direction to participants. This was in line with Smith's (2004) suggestion for carrying out research with individuals with intellectual disabilities, who may have cognitive and communication difficulties, similar to a TBI population. In the analysis, I considered my reflections and my hypotheses in conjunction with the data which represented topics other than sleep. This information was utilised in the development of the third theme within the research paper. This theme reflected how the interviews were often long, but that whilst the majority of the time was spent discussing sleep, a considerable amount of time was spent with the participants sharing their stories of other difficulties. Therefore, this indicated the significance of other difficulties alongside sleep, placing the

experience of sleep disturbances as often existing within the context of the wider experience of living with TBI.

A further challenge in conducting research with individuals post-TBI is considering capacity to consent and ability to engage with the research process (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007; Paterson & Scott-Findlay, 2002). As such, the individuals capacity was considered throughout the process, with capacity to consent to take part in research assessed prior to commencing the research interview. The researcher read the information sheet aloud to participants as part of capacity assessment, providing the opportunity to discuss information. Consideration was given to the individual's ability to engage with the research interview, with participants excluded if they 'did not have receptive and expressive verbal communication skills sufficient to engage in a one hour interview'. Research materials including the interview schedule were written in an accessible format, drawing upon consultation from service-users within a public involvement network. Short, simple words and sentences were used, avoiding the use of complex language. In conducting the research, my previous and ongoing clinical experience with individuals with TBI and other neurological impairments enabled me to communicate effectively with participants. In addition to communication difficulties, individuals may have memory difficulties post-TBI, which may impact upon their abilities to recall details of their experiences, thus affecting the validity of the data obtained. However, it was felt that although individuals may be experiencing difficulties in recalling accurate details of their experiences, the data collected was considered to be useful as it represented their personal experience, and how a TBI had impacted upon their own understandings of this experience.

Furthermore, by using IPA, there was a requirement for participants to ascribe meaning to their experiences, a process which relies upon cognitive processes and this might be problematic for individuals post-TBI (Paterson & Scott-Findlay, 2002). This was

considered during the research interviews, and it was felt that all the participants had the abilities to ascribe meaning and understanding to their experiences, as they demonstrated this as part of the interview dialogue.

Fatigue is a commonly experienced difficulty post-TBI (Beaulieu-Bonneau & Morin, 2012; Englander, Bushnik, Oggins, & Katznelson, 2010), and represents another challenge in conducting research with this population (Carlsson et al., 2007). The length of interview was a particular factor for consideration, and as discussed above, several of the interviews were quite lengthy, extending beyond an hour in duration with the longest interview one hour and fifty minutes. As a researcher, this required consideration of the participants' fatigue and cognition during the interview process, with breaks encouraged, and questions asked in an economical manner. The interview schedule was piloted, with subsequent supervision to adapt questions which were ambiguous or easily misunderstood (Paterson & Scott-Findlay, 2002).

As individuals with TBI have experienced a traumatic event or events, it was of importance to remain sensitive to this throughout the interview process. This was ensured by holding discussions prior to commencing the interview outlining the participant's right to withdraw, postpone, stop or break from the interview. Participants were provided with an information sheet with contact details of support services for individuals with TBI and debriefed post-interview.

Benefits and Challenges of a Dual-Role of Researcher and Clinician

As a trainee clinical psychologist, I hold a dual-role as a scientist-practitioner, being a clinician alongside my role as a researcher. Within my reflective diary, I had documented on several occasions information relating to both the benefits of holding this dual position, but also the challenges which this presented in conducting research as an effective, competent and skilled researcher. Throughout a significant proportion of the research process I have

been working directly with individuals post-TBI within a community setting. As described, this has been invaluable as the skills developed through my clinical experience have allowed me to gain insight into the difficulties individuals may experience post-TBI, considering the implications of these difficulties for the data collected and for the individual during the research interview (Carlsson et al., 2007). In particular, my clinical experiences allowed me to better understand the potential risk issues associated with recreational drug use post-TBI which were identified within one interview. My clinical experiences and skills equipped me with the confidence and competence to address and manage these issues both within the interview and in taking appropriate action subsequent to the interview. Yanos & Ziedonis (2006) described how holding a dual role of scientist-practitioner can "bridge" the gap between the research and practice-based communities, helping to promote clinically and ethically sound and relevant research, and disseminate findings directly and practically within clinical services.

However, my experience of conducting the research also highlighted challenges of holding a dual role. One such challenge that holding a dual-role can present is that of blurring or confusion of these roles, and the potential impacts upon the research. The scientist-practitioner can experience an "internal role confusion", a conflict representing a "clash in agendas, tasks and 'ways of being' that create practical and ethical conflicts" (Yanos & Ziedonis, 2006, pp. 250-251). This can result in the research becoming compromised as the clinician role dominates, prioritising the participant's needs. I had documented this experience within my reflections, both during interviews and through the process of listening to and transcribing interviews. Within my clinical role, I have developed skills such as offering reflection, validation and empathy and highlighting the participant's strengths and positives. These skills are in conflict with the skills required of a researcher in gaining information (Thompson & Russo, 2012). In addition, I also documented two instances of an

"external role confusion" defined as the research participant's confusion over the role of the researcher (Yanos & Ziedonis, 2006). Although steps were taken to outline my role and duties as a researcher and ensure the participants understanding prior to the start of the interview, two participants made comments indicating they may have perceived me to also have clinical duties. One participant asked me after the interview when his next appointment with me would be, and another participant asked whether I could provide him with psycho-education materials about sleep disturbances and their management. As highlighted by Yanos and Ziedonis (2006), these instances of role confusion could represent practical and ethical challenges for the research. In response to both participants' comments, information was reiterated regarding my roles and duties as a researcher ensuring that the participant understood these roles and the purposes of the research and how the data collected would be used. In both instances, participants subsequently demonstrated an understanding and capacity to consent. If it was judged that the participant did not show an understanding of the roles or was assessed to lack capacity, the appropriate action would be to destroy the data collected, in line with the conditions of ethical approval. As participants were able to demonstrate an understanding, I considered possible reasons for the external role confusion. I hypothesised as to whether the participants cognitive functioning could lead to confusion over my roles and duties, as a number of individuals discussed the impacts of having a TBI upon their memory. In addition, I hypothesised whether the choice of location for the research interview may have facilitated confusion over my role. Interviews were arranged at a location convenient for the participant, which was usually a clinic venue. My clinical experience has allowed me to understand that familiarity and convenience of an appointment location can create a safe environment to discuss sensitive information. This is particularly important for a TBI population, whose cognitive difficulties can mean that orientating to unfamiliar locations is challenging (Lezak et al., 2012). However, the participant may

associate the familiar clinic venue with clinical appointments, thus having implications for conducting research within this setting, creating confusion as to the purpose of the interview appointment.

Therapeutic Benefits of Research Participation

Within my reflective diary I had documented a number of instances whereby I observed a shift in the thinking of participants, which I hypothesised as representing therapeutic change occurring as a result of the process of participating in the interview. This was observed most clearly for Ted, whose interview was conducted over two sessions within a two week period. When initially asked about his understanding of the sleep disturbances, Ted hypothesised that he had noticed the onset coincided with a change in medications. Ted also commented how his sleep had been much improved whilst he was on holiday, but did not give an explanation for why this may have occurred. However, in the second interview, Ted spontaneously discussed an alternative hypothesis that his sleep disturbances may be related to his current work stresses, identifying both an understanding and also the potential for intervention. In addition, within this interview Ted also discussed more information relating to acceptance of these disturbances. Ted commented that he had previously not discussed his sleep disturbances in the way he had within the interview. This led me to consider whether providing the opportunity to discuss and reflect upon such difficulties may allow for therapeutic change and adjustment, with the individual making meaning of their experience through the process of the interview. Similar psychotherapeutic benefits have been documented within the literature, indicating that individuals find it beneficial to discuss phenomena and stories (Lakeman, McAndrew, MacGabhann, & Warne, 2013).

Theoretical Implications

Despite explicit questioning regarding both sleep and dreaming experiences, the data collected was largely relating to experiences of sleep, with little information pertaining to

dreams. However, two participants described near-death experiences during their hospitalisation period, described as dream-like, yet a very different experience. In line with findings from a recent study, these participants described vivid, euphoric and supernatural experiences, which seemed to be linked to spiritual beliefs (Hou, Huang, Prakash, & Chaudhury, 2013). This has implications for considering spirituality and faith in assessment for TBI, and may indeed be an effective coping strategy, as faith, religion and spirituality have been associated with post-traumatic growth subsequent to TBI (Powell, Gilson, & Collin, 2012).

As discussed, I was keen to explore whether the experience of dreaming post-TBI could be related to trauma reactions including PTSD. However as noted, dreaming was not salient within the themes. As such, this study did not draw any conclusions in relation to the significance of sleep and dream disturbances post-TBI for trauma reactions and PTSD. Furthermore, no information was collected regarding PTSD diagnoses. One participant did disclose that they had PTSD, although didn't report experiencing any nightmares. In order to further explore this, future research could recruit individuals either with a diagnosis of PTSD, or administer a PTSD assessment measure such as the Impact of Event Scale (Horowitz, Wilner, & Alvarez, 1979) as part of the research procedure.

Conclusion

Conducting an IPA study with individuals with traumatic brain injuries represents challenges for the researcher due to cognitive impairments, communication difficulties and fatigue experienced by participants. Due consideration to these factors is a necessary part of conducting ethically sound research including the use of reflective diaries and supervision. Considerations for scientist-practitioners include ensuring that researcher roles are clearly explained to participants, that capacity is assessed and the opportunity for debrief is provided.

The clinical experience of a scientist-practitioner is however invaluable in conducting research with a TBI population.

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Section Four: Ethics Section

Word count: 5952

Joanne Bradley

Doctorate in Clinical Psychology

Lancaster University

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NHS Research Ethics Committee (REC) Application Form

NHS REC Form

Reference:

IRAS Version 3.4

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)

Experiences of sleep and dream disturbances following TBI

1. Is your project research?

☒ Yes ☐ No

2. Select one category from the list below:

- ☐ Clinical trial of an investigational medicinal product
- ☐ Clinical investigation or other study of a medical device
- ☐ Combined trial of an investigational medicinal product and an investigational medical device
- ☐ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- ☐ Basic science study involving procedures with human participants
- ☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ☒ Study involving qualitative methods only
- ☐ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- ☐ Study limited to working with data (specific project only)
- ☐ Research tissue bank
- ☐ Research database

If your work does not fit any of these categories, select the option below:

☐ Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

3. In which countries of the UK will the research sites be located? (Tick all that apply)

- ☒ England
- ☐ Scotland
- ☐ Wales
- ☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

Date: 04/12/2012

NHS REC Form

Reference:
[REDACTED]

IRAS Version 3.4

- ☒ England
☐ Scotland
☐ Wales
☐ Northern Ireland
☐ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☒ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☒ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☐ Ministry of Justice (MoJ)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- ☒ Yes ☐ No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

- ☐ Yes ☒ No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

- ☐ Yes ☒ No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

- ☐ Yes ☒ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- ☐ Yes ☒ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or

NHS REC Form

Reference:
[REDACTED]

IRAS Version 3.4

who are offenders supervised by the probation service in England or Wales?☐ Yes ☒ No**9. Is the study or any part of it being undertaken as an educational project?**☒ Yes ☐ No

Please describe briefly the involvement of the student(s):

The student is the chief investigator of the project, and the project forms part of the thesis submitted as part of the Doctorate in Clinical Psychology (DClinPsy).

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?☒ Yes ☐ No**10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?**☐ Yes ☒ No**11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?**☐ Yes ☒ No

Integrated Research Application System
Application Form for Research involving qualitative methods only**Application to NHS/HSC Research Ethics Committee**

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Experiences of sleep and dream disturbances following TBI

Please complete these details after you have booked the REC application for review.

REC Name:

[REDACTED]

REC Reference Number:

[REDACTED]

Submission date:

04/12/2012

PART A: Core study information**1. ADMINISTRATIVE DETAILS****A1. Full title of the research:**

Experiences of sleep and dream disturbances following traumatic brain injury

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Miss	Joanne	Bradley
Address	[REDACTED]		
	[REDACTED]		
	[REDACTED]		
Post Code	[REDACTED]		
E-mail	[REDACTED]		
Telephone	[REDACTED]		
Fax			

NHS REC Form

Reference:

IRAS Version 3.4

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

Doctorate in Clinical Psychology

Name of educational establishment:

Lancaster University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
Address			
Post Code			
E-mail			
Telephone			
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):

Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)**Academic supervisor(s)**

Student 1 Miss Joanne Bradley



A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- ☒ Student
☐ Academic supervisor
☐ Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Miss	Joanne	Bradley
Post			
Qualifications			
Employer			
Work Address			
Post Code			
Work E-mail			

NHS REC Form

Reference:

IRAS Version 3.4

* Personal E-mail

Work Telephone

* Personal Telephone/Mobile

Fax

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*

A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?

This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
Address			
Post Code			
E-mail			
Telephone			
Fax			

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):

N/A

Sponsor's/protocol number:

N/A

Protocol Version:

1.0

Protocol Date:

28/10/2012

Funder's reference number:

N/A

Project website: N/A

Additional reference number(s):

Ref.Number	Description	Reference Number
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Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

☐ Yes ☒ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

This is a qualitative study, which aims to recruit 8-10 individuals from brain injury services (NHS and community based organisations/networks) within the [REDACTED]. Participants will have sustained a traumatic brain injury (defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force, such as rapid acceleration or deceleration or an impact (Menon, Schwab, Wright & Maas, 2010)), and the study aims to explore their experiences of sleep disturbances or changes subsequent to their injury. These changes may include; sleeping more or less frequently, for longer or shorter periods of time, difficulty falling asleep or waking, or waking frequently. There may also be reported changes to dreams, such as experiencing upsetting or disturbing dreams, or noticing changes in the content or perception of dreams. The study aims to explore individuals' understanding of the causes of these symptoms, the impacts of these symptoms, and how the individual manages, copes with or controls these symptoms. These perceptions will be explored via a semi-structured individual interview with participants, which will be analysed using interpretative phenomenological analysis. It is hoped that this study will help inform therapeutic work with individuals who have experienced traumatic brain injury and subsequently present with changes or difficulties related to sleeping and dreaming. These difficulties also form part of the diagnostic criteria for post traumatic stress disorder, and so it is hoped that by exploring individual experiences of these difficulties, it can contribute to understanding of the development and experience of trauma related reactions in individuals post brain injury.

Menon, D.K., Schwab, K., Wright, D.W. and, Maas, A.I. (2010). Position statement: definition of traumatic brain injury. Archives of Physical Medicine and Rehabilitation. 91(11):1637-40

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Consent:

Each participant's capacity to consent to participating in the research study will be assessed. If the potential participant expresses a wish to take part in the research, the researcher will assess the person's capacity to consent, as follows:

1. Researcher will provide the potential participant with an information sheet, and will also offer to read out this information to the client. This will inform of the objectives of the study, outline any potential risks and procedures which will be followed, outline what will be required of anyone participating in the study and outline what options individuals have should they have any concerns following their participation in the study.
2. Researcher will ask the potential participant to tell them, using their own words, what will be required of them if they decide to participate.
3. Researcher will ask the potential participant why they decided to take part in the study.
4. Researcher will ask the potential participant to tell them in, using their own words, what their options are if they have concerns following participation in the study.
5. Researcher will ask the potential participant whether they would like to participate in the study. The participant will then be required to complete a consent form.

If the participant is deemed to lose capacity during the data collection process, they will be withdrawn from the study and any collected data will be destroyed.

Risks to participants:

Participants may be at risk of experiencing distress during the interview, given the personal nature of the topic discussed. Should the researcher observe the participant experiencing distress, they will be asked whether they would like to take a break, stop or postpone the interview. At the end of the interview they will be given the opportunity to discuss anything which distressed them. At this time, a list of services will be provided which may be of potential benefit to the participants and they will be encouraged to seek support via Lancaster University secure network, and all audio files and transcripts will be encrypted and password protected.

If anything is disclosed during the interview which indicates the participant or another is at risk of harm this information will be shared with the field/research supervisor in the first instance and with other agencies where appropriate. Participants will be informed of this before consenting to participate.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there*

are ethical issues that require consideration at a full REC meeting.

☐ Yes - proportionate review ☒ No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply.

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☒ Qualitative research
- ☒ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

This study aims to investigate and explore experiences of sleep and dream disturbances or changes in individuals who have sustained a traumatic brain injury.

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

The study aims to explore the impacts of changes to sleep and dreaming, and how individuals perceive themselves to cope, manage or control the changes they experience.
The study aims to contribute to understanding of assessment, care and therapy following traumatic brain injury.
As sleep and dreaming difficulties form part of the diagnostic criteria for post traumatic stress disorder, a secondary objective of the study is to contribute to understanding of the possible development and presentation of post traumatic stress disorder and trauma reactions following brain injury.

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

Traumatic brain injuries (TBI) result from specific traumatic events involving external factors such as an accident (e.g. a fall or road traffic accident) or an attack or assault. Traumatic brain injury can be defined as "an alteration in brain function, or other evidence of brain pathology, caused by an external force" such as a rapid acceleration or deceleration, or an impact (Menon, Schwab, Wright & Maas, 2010).

A number of identified psychological and cognitive sequelae are associated with traumatic brain injury. Commonly, individuals may experience a post traumatic amnesia immediately after the event, experiencing difficulties recalling memories of the injury causing event, memories preceding the event, or memories following the event. Individuals may also experience 'post concussional syndrome' (PCS) which is a term given to a cluster of neurobehavioural and

psychological symptoms including difficulties in memory, attention and executive functioning, changes in mood, headaches, dizziness, sleep disturbances and changes in mood and anxiety (Whittaker, Kemp & House, 2007). Literature has also explored a relationship between post traumatic stress disorder (PTSD) and traumatic brain injury, with some studies finding a link between PTSD symptoms and earlier TBI (Bryant, 1996; Creamer, O'Donnell & Pattinson, 2005). These symptoms include distressing recollections of traumatic events (such as images, hallucinations, memories, dreams and flashbacks), changes in sleep, appetite and mood, and elevated levels of anxiety and arousal.

Literature indicates that sleep disturbances are commonly reported following TBI. Gosselin and Tellier (2010) found a prevalence of 50% of sleep-wake disturbances such as insomnia and hypersomnia in individuals with a traumatic brain injury. A review by Castriotta and Murthy (2011) indicated a range of sleep-related disturbances or changes following TBI, including hypersomnia, insomnia, excessive waking, fatigue and sleepiness, circadian rhythm disorders and changes to the content of dreams, with more threatening dreams reported, and fewer dreams with sexual content. Clinically, individuals often report having disturbing dreams or nightmares after a TBI. Much of the literature examining sleep and dreaming following TBI has looked at prevalence rates of symptoms experienced. However, there is little exploration of individuals' experiences of these symptoms, changes or difficulties. Literature has indicated correlations between sleep disturbances and mental health sequelae such as anxiety and depression (Kempf, Werth, Kaiser, Bassetti & Baumann, 2010; Rao et al, 2008), but again does not explore individuals' experiences of any possible impacts of sleep disturbances upon mental health, emotional wellbeing and quality of daily life.

Therefore, this research study aims to explore individual experiences and perspectives of sleep and dream disturbances and changes following a traumatic brain injury. The aims of the research are to explore the nature of these changes or experiences, the impacts of these experiences, and explore means by which individuals cope with or manage these experiences. The research aims to generate a greater understanding of the lived experience following a traumatic brain injury, and may have clinical relevance in terms of improving methods of assessment of distress and interventions following a traumatic brain injury.

Furthermore, sleep and dreaming difficulties are noted as potential diagnostic criteria for PTSD in the American Psychiatric Association's (1994) Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). In particular, there are two criteria of relevance; "recurrent distressing dreams of the event" and "difficulty falling or staying asleep". Within the literature, there has been controversy associated with the possibility of diagnosing PTSD in TBI, given that post traumatic amnesia is frequently experienced. In post traumatic amnesia, the individual is likely to have an impaired memory for the TBI causing event. This has been thought to impact upon the individual's ability to recall memories of the event, which is key in meeting DSM-IV diagnostic criteria. However, a review by McMillan, Williams and Bryant (2003) which has explored literature examining PTSD and TBI indicates that individuals can meet diagnostic criteria for PTSD, despite having limited or no memory of the injury causing event itself. It is acknowledged that diagnosis of PTSD in TBI is complex, and complicated by the overlap in many of the symptoms and difficulties experienced in both, such as changes in mood, sleep and appetite. However, the intrusive recollections stated as part of the diagnostic criteria for PTSD do not overlap with TBI.

Therefore, an exploration of the experience of dreaming following TBI may help us to explore the nature of distressing dreams following a TBI. This may help to understand the process of adjustment following a TBI and better understand how dreaming phenomena may be related to post traumatic stress disorder and trauma reactions following TBI. The research aims to develop understanding of the experience of distress following a TBI, and contribute to understanding and developing the process of therapy and rehabilitation with people who have experienced traumatic brain injuries.

American Psychiatric Association. (1994). Diagnostic and statistical manual of mental disorders (4th ed.). Washington, DC: Author

British Psychological Society. (2006). Assessment of capacity in adults: Interim guidance for psychologists. London: Assessment of Capacity Guidelines Group.

Bryant, R.A. (1996). A comparison of traumatic memories and pseudomemories in close head injury. *Journal of traumatic stress*, 9: 621-629

Castriotta, R. J., & Murthy, J. N. (2011). Sleep disorders in patients with traumatic brain injury. *CNS Drugs*, 25(3), 175-185. doi:10.2165/11584870-000000000-00000

Creamer, M., O'Donnell, M. L., & Pattison, P. (2005). Amnesia, traumatic brain injury, and posttraumatic stress disorder: A methodological inquiry. *Behaviour Research And Therapy*, 43(10), 1383-1389. doi:10.1016/j.brat.2004.11.001

Gosselin, N., & Tellier, M. (2010). Patients with traumatic brain injury are at high risk of developing chronic sleep-wake disturbances. *Journal of neurology, neurosurgery and psychiatry with practical neurology*, 81: 1297
doi:10.1136/jnnp.2010.222471

Kempf, J., Werth, E., Kaiser, P.R., Bassetti, C.L., & Baumann, C.R. (2010). Sleep-wake disturbances 3 years after traumatic brain injury. *Journal of neurology, neurosurgery and psychiatry with practical neurology*, 81:1402 -1405
doi:10.1136/jnnp.2009.201913

McMillan, T. M., Williams, W., & Bryant, R. (2003). Post-traumatic stress disorder and traumatic brain injury: A review of causal mechanisms, assessment, and treatment. *Neuropsychological Rehabilitation*, 13(1/2), 149.

Menon, D.K., Schwab, K., Wright, D.W. and, Maas, A.I. (2010). Position statement: definition of traumatic brain injury.

Archives of Physical Medicine and Rehabilitation. 91(11):1637-40 doi:10.1016/j.apmr.2010.05.017

Rao, V., Spiro, J., Vaishnavi, S., Rastogi, P., Mielke, M., Noll, K., & ... Makley, M. (2008). Prevalence and types of sleep disturbances acutely after traumatic brain injury. *Brain Injury*, 22(5), 381-386. doi:10.1080/02699050801935260

Whittaker, R., Kemp, S., & House, A. (2007). Illness perceptions and outcome in mild head injury: A longitudinal study. *Journal Of Neurology, Neurosurgery & Psychiatry*, 78(6), 644-646. doi:10.1136/jnnp.2006.101105

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

The study is a qualitative study, aiming to recruit 8-10 participants to take part in interviews to explore their experiences

NHS services will be approached by the researcher who will request that potential participants be identified by the service. Clinicians will be asked to identify potential participants who are felt to meet the inclusion criteria (although the researcher will ultimately decide if the participant meets this criteria before entry into the study). Information packs (containing an invitation letter, participant information sheet, opt in form and stamped addressed envelope) will be provided to the NHS services to be distributed to identified potential participants, maintaining the anonymity of service users to the researcher.

The researcher will also attend local [REDACTED]

branch meetings, in order to provide more information about the study, the chance for individuals to ask questions, and to provide information packs (containing participant information sheet, opt in form and stamped addressed envelope) to interested parties.

Posters will also be provided to NHS, [REDACTED], to allow participants to contact the researcher by telephone or e-mail if they wish to participate. A participant information sheet will then be posted or e-mailed directly to the participant.

Within two weeks of initial contact with the participant (either via receipt of the opt in form or initial telephone call from the participant after seeing the poster) the researcher will contact the participant to provide an opportunity to ask questions and further discuss the study. The researcher will ask questions to determine if the individual meets inclusion criteria of; age 18 or over, sustained a traumatic brain injury, time since injury of at least 3 months and current experience of sleep disturbances (capacity will be assessed at the time of the interview). The researcher will give the participant the option of being contacted again one week later in order to give them the chance to consider the information thoroughly and decide whether they wish to take part, or they may decide at this stage.

If participants decide to take part, they will be given a choice of location (either community based location, or local NHS trust site) and a convenient date and time will be arranged for interview.

At the interview, the study will be explained again to the participant, with the participant given an information sheet for their reference. Confidentiality principles and procedures will be outlined. The participant will also be requested to complete a written consent form to take part in the study, and their capacity to consent will be assessed. If the participant is not felt to have capacity to consent, they will not be included in the study. Likewise, if the potential participant is felt to lose capacity during the interview, the interview will be stopped and any collected data for that participant will be destroyed.

Interviews will follow the interview schedule (attached to protocol) but will give participants the chance to discuss any aspect of their experience they feel to be relevant. Interviews will be audio recorded and will be transcribed within one week of the interview.

Transcripts will be analysed using interpretative phenomenological analysis.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- ☒ Design of the research
- ☐ Management of the research
- ☐ Undertaking the research
- ☐ Analysis of results

- ☐ Dissemination of findings
- ☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.

Lancaster University Public Involvement Network (LUPIN) is a network of service users of clinical psychology services, carers, clinical psychology doctoral programme staff and trainee clinical psychologists. LUPIN aims to increase public involvement in the Lancaster University clinical psychology doctoral programme. In designing the research, service user members of LUPIN were consulted. LUPIN members reviewed research materials which are to be distributed to participants (posters and information packs) and provided a service user perspective on the materials. Materials were subsequently amended following LUPIN feedback.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

- Participants will be aged 18 or over and will be assessed to have capacity to consent to participating in this research.
- Participants will be individuals who have sustained a traumatic brain injury, defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force, such as rapid acceleration or deceleration or an impact (Menon, Schwab, Wright & Maas, 2010)
- Participants will be currently experiencing sleep disturbances such as changes in sleeping patterns and duration, frequent waking, or experiences of disturbing or upsetting dreams or nightmares. The onset of these disturbances will be post TBI.
- Length of time since traumatic brain injury will be at least 3 months.

Reference:

Menon, D.K., Schwab, K., Wright, D.W. and, Maas, A.I. (2010). Demographics and Clinical Assessment Working Group of the International and Interagency Initiative toward Common Data Elements for Research on Traumatic Brain Injury and Psychological Health. Position statement: definition of traumatic brain injury. Arch Phys Med Rehabil. 91(11):1637-40 doi:10.1016/j.apmr.2010.05.017

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

- The study will not include participants who have sustained damage to the brain arising primarily from any event or disease other than a traumatic brain injury, as defined above.
- The study will not include participants who report experiencing other trauma reactions but with no reported changes or disturbances related to sleep or dreaming.
- Participants will be excluded if they are unable to provide informed consent. The potential participant's capacity to provide informed consent will be assessed by the potential participant demonstrating to the investigator that they understand what would be asked of them should they consent to participate in the research, and demonstrating that they understand their options should they have any concerns following their participation in the study.
- Participants will be excluded if they do not have receptive and expressive verbal communication skills sufficient to engage in an interview. This will be assessed by the investigator prior to the interview by assessing the potential participant's ability to respond appropriately and verbally when their ability to give informed consent is assessed.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Reference:

NHS REC Form

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Intervention or procedure	1	2	3	4	
Receiving information pack and 'opting in'	1	0	20 minutes		Researcher will give participants an information pack containing an invitation letter, participant information sheet (detailing the purpose of the study and requirements), and an opt in form. Participants will be required to complete and return the opt in form.
Telephone call to participants (upon receipt of opt in form)	1	0	15 minutes		Telephone contact will be made within two weeks of receiving the opt in form. This provides potential participants with the opportunity to ask further questions, and arrange a time to meet if interested in taking part.
Gaining consent	1	0	10 minutes		The researcher will provide the participant with a copy of the information sheet for them to read, and will offer to read this to the participant. Participants' capacity to consent will be assessed. Participants will be asked to sign a consent form if they wish to take part.
Semi structured interview	1	0	60 minutes		Interview led by chief investigator guided via semi-structured interview schedule
Participant posted summary of themes	1	0	30 minutes		Participant will be sent a summary of the themes found in the research study. This summary will be brief and so the time of 30 minutes reflects the time for participants to read the summary.

A21. How long do you expect each participant to be in the study in total?

Interviews are expected to last around 60 minutes in total.

Participants will be included in the study from the time of opting in, until the study feedback is provided, which is anticipated to be in April-May 2013. Recruitment is expected to commence in January 2013, therefore participants are expected to be in the study for up to 5 months.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

One potential burden to participants is that of giving up their time to take part in interviews. This would be minimised by the researcher by offering participants a choice of convenient location (either community venue or local NHS trust), date and time. Any travel experiences incurred to the participant will be reimbursed.

Given the discussion topic of personal traumatic experiences, it is possible that participants may experience some distress in taking part. Should the researcher observe the participant becoming distressed, they will be offered the chance to take a break, stop or postpone the interview. At the end of the interview, the participant will be given the opportunity to discuss anything they found distressing or difficult, and will be provided with information (on the participant information sheet) of services and helplines which they may find of benefit. Opportunities for further support from professionals will be discussed if necessary, and participants will also be encouraged to contact their GP in these instances.

It is possible that the participant may disclose information which indicates risk of harm to themselves or others. Prior to the interview, the researcher will outline the limits to confidentiality and explain that disclosures may need to be shared with other professionals or agencies. Any issues of confidentiality will be addressed by the researcher with their field and research supervisors in the first instance.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

☒ Yes ☐ No

If Yes, please give details of procedures in place to deal with these issues:

Given the discussion topic of the individual's personal traumatic experiences, it is possible that participants may experience some distress in taking part. Should the researcher observe the participant becoming distressed, they will be offered the chance to take a break, stop or postpone the interview. At the end of the interview, the participant will be given the opportunity to discuss anything they found distressing or difficult, and will be provided with

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Reference:

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information (on the participant information sheet) of services and helplines which they may find of benefit. Opportunities for further support from professionals will be discussed if necessary, and participants will also be encouraged to contact their GP, or an appropriate member of a brain injury support team (if available) in these instances.

If the participant has been recruited via an NHS service, the researcher may also seek permission from the participant to contact the NHS service.

Limits to confidentiality will be discussed with participants prior to consenting to participate. Should any disclosures occur which require action, the field or research supervisor will be informed in the first instance. If appropriate, this will be discussed with the participant.

A24. What is the potential for benefit to research participants?

There are no direct benefits for research participants. However, it does give participants the opportunity to express their views on their experiences after having a traumatic brain injury. Results from this research may contribute towards the understanding of trauma reactions following brain injury and may also contribute toward improvement of services offered to individuals experiencing these reactions.

A26. What are the potential risks for the researchers themselves? (if any)

There are potential risks to the researcher of carrying out interviews in community locations during the research. The "Lancaster DClinPsy course procedure relating to home visits in order to carry out research interviews" will be adhered to, alongside [REDACTED] "Lone Working Policy" and Lancaster University's "Guidance on Safety in Fieldwork"

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).

The researcher will approach NHS services for brain injury and explain the study to an identified clinician. If the service/clinician agrees to their service being used for recruitment purposes, they will be asked to identify any clients who potentially meet inclusion criteria for the study. The service/clinician will be provided with information packs to distribute to these participants, maintaining the participant's anonymity to the researcher until they opt in to take part in the study.

The researcher will also approach [REDACTED] services, and attend meetings to provide individuals with study information. The researcher will provide information packs to interested parties and will provide the branch co-ordinator with additional information packs. Again, participants will be required to opt in to the study.

Posters will be provided to NHS, [REDACTED] services for display in waiting rooms/at meetings, to allow participants the chance to opt in by contacting the researcher directly and the researcher will then e-mail or post an information sheet to the participant and answer any questions they may have about the study

The researcher will telephone individuals no later than two weeks after receiving the opt in form. During this telephone call the researcher will ascertain whether the individual meets the inclusion criteria for the study by asking them brief questions corresponding to the inclusion and exclusion criteria.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

☐ Yes ☒ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

☒ Yes ☐ No

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).

Posters will be provided to all identified services for display in areas used by potential participants such as waiting areas and [REDACTED] meeting locations, with the service's consent. The posters will contain the researcher's contact details, to allow individuals to contact the researcher directly for more information regarding the study.

A29. How and by whom will potential participants first be approached?

Potential participants identified through NHS trusts will be sent an information pack from the researcher via the NHS trust to maintain anonymity to the researcher. Potential participants attending [REDACTED] services will be approached by the researcher distributing information packs at branch meetings (or by the branch co-ordinator) Upon completion and return of an opt in form, the researcher will contact the participant by telephone.

A30-1. Will you obtain informed consent from or on behalf of research participants?

☒ Yes ☐ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Participants are required to opt in to the study by completing an opt in form.

At the start of the interview, the researcher will assess the participant's capacity to consent as follows;

1. Researcher will provide the potential participant with an information sheet, and will also offer to read out this information to the potential participant. This will inform of the objectives of the study, outline any potential risks and procedures which will be followed, outline what will be required of anyone participating in the study and outline what options individuals have should they have any concerns following their participation in the study.
2. Researcher will ask the potential participant to tell them, using their own words, what will be required of them if they decide to participate.
3. Researcher will ask the potential participant why they decided to take part in the study.
4. Researcher will ask the potential participant to tell them in, using their own words, what their options are if they have concerns following participation in the study.
5. Researcher will ask the potential participant whether they would like to participate in the study.

If the individual is assessed to have capacity to consent, informed consent will be obtained by the researcher prior to beginning the interviews, via completion of a written consent form. The researcher has experience of obtaining informed consent in both a research and a clinical setting.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

☒ Yes ☐ No

A31. How long will you allow potential participants to decide whether or not to take part?

Participants are required to sign an opt in form or contact the researcher by telephone or e-mail to indicate their potential interest in taking part in the study. They will then be telephoned within two weeks and given further information and the offer of a follow up telephone call one week later in order to give them chance to make a decision to take part. Participants may withdraw from the study at any point up to the interview taking place, and up to two weeks following the interview. After this point analysis will have commenced, and so removal of the data would not be possible.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters)

If individuals are accessing services and using interpreters, this will also be offered for the purposes of the research.

The chief investigator has experience of working with individuals with receptive and expressive communication difficulties, and will tailor the information to the participant's needs wherever possible.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

- ☒ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ☐ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ☐ The participant would continue to be included in the study.
- ☐ Not applicable – informed consent will not be sought from any participants in this research.
- ☐ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

Should any participant lose capacity to consent during the study, they will be withdrawn from the study and any data collected will be destroyed.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study**A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)**

- ☐ Access to medical records by those outside the direct healthcare team
- ☒ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☒ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☒ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☒ Use of audio/visual recording devices
- ☒ Storage of personal data on any of the following:
- ☒ Manual files including X-rays
 - ☐ NHS computers
 - ☐ Home or other personal computers
 - ☒ University computers
 - ☐ Private company computers
 - ☐ Laptop computers

Further details:

Encrypted electronic transcripts of data may be transferred between the researcher and research supervisor, via e-mail, and e-mails will be deleted immediately after use. Files will be saved on the secure Lancaster University network, on the accounts of the researcher and the research supervisor.

Potential participants' addresses and telephone contact numbers will be used in the identification of participants. No unnecessary contact information will be recorded.

All personal information will remain in a locked filing cabinet separate from other raw data, and only the Chief Investigator will have access to personal contact information.

Direct quotations from respondents may be published in the research, and consent will be obtained to do this. Any identifiable information will be removed or changed to ensure anonymity.

Interviews will be recorded using a dictaphone. Consent will be obtained to record discussions. The audio recordings will be transferred to the Lancaster University secure network and files will be encrypted. Data will subsequently be deleted from the dictaphone hard drive. Any electronic transcripts will be encrypted and stored on the Lancaster University secure network.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

Each participant will be allocated a pseudonym and only this name will be used for reference during the data analysis.

Transcribed data will be anonymised and any identifiable information such as patient or participant names or personal details will be removed or pseudonymised in the transcript.

Any personal identifiable information such as telephone numbers and addresses will be kept in a locked cabinet in accordance with the Data Protection Act 1998. No identifiable data will be published or disseminated following collection of the data.

It is possible that participants may disclose information which may suggest to the interviewer that any individual or group of individuals may be at risk of being hurt or harmed. Under these circumstances confidentiality would be breached, and participants will be informed of these conditions prior to giving consent to participate. Should this occur, this would be discussed in the first instance with either the field or research supervisor. If the confidentiality of the participant was in question, the use of their data will be discussed with the participant.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

Once an individual has opted into the study, only the chief researcher/investigator will have access to the participants' personal details. These will be kept separate from transcripts and will not be shared with either field or research supervisor.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- ☐ Less than 3 months
- ☒ 3 – 6 months
- ☐ 6 – 12 months
- ☐ 12 months – 3 years
- ☐ Over 3 years

INCENTIVES AND PAYMENTS

Reference: [REDACTED]

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A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

☒ Yes ☐ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined. Reimbursement of any travel expenses incurred for travelling to and from the interview location.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

☐ Yes ☒ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

☐ Yes ☒ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

☐ Yes ☒ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

☐ Yes ☒ No

Please give details, or justify if not registering the research.

The study is not a clinical trial, and it does not appear that there is a suitable database for registry.

Registration of research studies is encouraged wherever possible.

You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- ☒ Peer reviewed scientific journals
- ☒ Internal report
- ☒ Conference presentation
- ☐ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

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- ☐ No plans to report or disseminate the results
- ☒ Other (please specify)

The results of the study will be presented at a "Thesis presentation day" at Lancaster University attended by students, staff and stakeholders of the Doctorate in Clinical Psychology Programme.

A53. Will you inform participants of the results?

- ☒ Yes ☐ No

Please give details of how you will inform participants or justify if not doing so.

Participants will be sent a summary of the results.

5. Scientific and Statistical Review
A54. How has the scientific quality of the research been assessed? Tick as appropriate:

- ☐ Independent external review
- ☐ Review within a company
- ☐ Review within a multi-centre research group
- ☒ Review within the Chief Investigator's institution or host organisation
- ☐ Review within the research team
- ☒ Review by educational supervisor
- ☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

Research has been assessed by presentation of proposal at a peer review and review by educational supervisor with refinement following this.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.

Total UK sample size: 10

Total international sample size (including UK):

Total in European Economic Area:

Further details:

Proposed sample size of 8-10 participants

A60. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.

The proposed sample size is based upon research indicating that data saturation occurs after 6-12 interviews (Guest, Bunce & Johnson, 2006)

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82. doi:10.1177/1525822X05279903

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Reference:

NHS REC Form

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Interviews will be transcribed within two weeks of the interview. The transcripts will then be analysed using interpretative phenomenological analysis (IPA), which aims to explore the individuals' perspectives of their experiences. This analysis will follow the process described by Smith et al (2009). The researcher will firstly read the transcripts several times, and initial notes will be made. The researcher will then identify emergent themes, and develop these themes by searching for connections. This process will be repeated with each participant's transcript. The researcher will finalise these themes by searching for connections or patterns between themes across the transcripts.

Smith, J.A., Larkin, M., & Flowers, P. (2009). Interpretative phenomenological analysis: Understanding method and application. London: Sage

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

	Title	Forename/Initials	Surname
Post			
Qualifications			
Employer			
Work Address			
Post Code			
Telephone			
Fax			
Mobile			
Work Email			
Post			
Qualifications			
Employer			
Work Address			
Post Code			
Telephone			
Fax			
Mobile			
Work Email			

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

NHS REC Form

Reference:
[REDACTED]

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- Status: ☐ NHS or HSC care organisation
☒ Academic
☐ Pharmaceutical industry
☐ Medical device industry
☐ Local Authority
☐ Other social care provider (including voluntary sector or private organisation)
☐ Other

If Other, please specify:

Contact person

Name of organisation Lancaster University

Given name [REDACTED]

Family name [REDACTED]

Address [REDACTED]

Town/city [REDACTED]

Post code [REDACTED]

Country [REDACTED]

Telephone [REDACTED]

Fax [REDACTED]

E-mail [REDACTED]

Is the sponsor based outside the UK?

- ☐ Yes ☒ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- ☐ Funding secured from one or more funders
☐ External funding application to one or more funders in progress
☒ No application for external funding will be made

What type of research project is this?

- ☒ Standalone project
☐ Project that is part of a programme grant
☐ Project that is part of a Centre grant
☐ Project that is part of a fellowship/ personal award/ research training award
☐ Other

Other – please state:

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

- ☐ Yes ☒ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
Organisation			
Address			
Post Code			
Work Email			
Telephone			
Fax			
Mobile			

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/01/2013

Planned end date: 31/05/2013

Total duration:

Years: 0 Months: 4 Days: 30

A71-2. Where will the research take place? (Tick as appropriate)

- ☒ England
☐ Scotland
☐ Wales
☐ Northern Ireland
☐ Other countries in European Economic Area

Total UK sites in study

Does this trial involve countries outside the EU?

☐ Yes ☒ No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:

- | | |
|--|---|
| <input checked="" type="checkbox"/> NHS organisations in England | 3 |
| <input type="checkbox"/> NHS organisations in Wales | |
| <input type="checkbox"/> NHS organisations in Scotland | |
| <input type="checkbox"/> HSC organisations in Northern Ireland | |
| <input type="checkbox"/> GP practices in England | |
| <input type="checkbox"/> GP practices in Wales | |
| <input type="checkbox"/> GP practices in Scotland | |

NHS REC Form

Reference:

IRAS Version 3.4

- ☐ GP practices in Northern Ireland
☐ Social care organisations
☐ Phase 1 trial units
☐ Prison establishments
☐ Probation areas
☒ Independent hospitals
☐ Educational establishments
☐ Independent research units
☐ Other (give details)

2

Total UK sites in study:

5

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- ☐ NHS indemnity scheme will apply (NHS sponsors only)
☒ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- ☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)
☒ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- ☒ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

Reference:

NHS REC Form

IRAS Version 3.4

☒ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site		Investigator/ Collaborator/ Contact	
Institution name		Title	
Department name		First name/ Initials	
Street address		Surname	
Town/city			
Post Code			
Institution name		Title	
Department name		First name/ Initials	
Street address		Surname	
Town/city			
Post Code			
Institution name		Title	
Department name		First name/ Initials	
Street address		Surname	
Town/city			
Post Code			
Institution name		Title	
Department name		First name/ Initials	
Street address		Surname	
Town/city			
Post Code			
Institution name		Title	
Department name		First name/ Initials	
Street address		Surname	
Town/city			
Post Code			
Institution name		Title	
Department name		First name/ Initials	
Street address		Surname	
Town/city			
Post Code			
Institution name		Title	
Department name		First name/ Initials	
Street address		Surname	
Town/city			
Post Code			

Reference:

NHS REC Form

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Post Code

Institution name

Department name

Street address

Town/city

Post Code

Title

First name/
Initials

Surname

Institution name

Department name

Street address

Town/city

Post Code

Title

First name/
Initials

Surname

PART D: Declarations**D1. Declaration by Chief Investigator**

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
 - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
 - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
 - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
 - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication *(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

- ☐ Chief Investigator
- ☐ Sponsor

NHS REC Form

Reference:
[REDACTED]

IRAS Version 3.4

- ☐ Study co-ordinator
☒ Student
☐ Other – please give details
☐ None

Access to application for training purposes (*Not applicable for R&D Forms*)*Optional – please tick as appropriate:*

☒ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

Signature:

Print Name: Joanne Bradley

Date: 03/12/2012 (dd/mm/yyyy)

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Signature:

[REDACTED]

Print Name:

[REDACTED]

Post:

[REDACTED]

Organisation:

[REDACTED]

Date:

3/12/12

(dd/mm/yyyy)

NHS SSI

IRAS Version 3.4

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

Signature: 

Print Name: 

Post: 

Organisation: 

Date: 05/12/2013 (dd/mm/yyyy)

NHS Site-Specific Information (SSI) Form

NHS SSI

IRAS Version 3.4

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)
Experiences of sleep and dream disturbances following TBI

1. Is your project research?

☒ Yes ☐ No

2. Select one category from the list below:

- ☐ Clinical trial of an investigational medicinal product
- ☐ Clinical investigation or other study of a medical device
- ☐ Combined trial of an investigational medicinal product and an investigational medical device
- ☐ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- ☐ Basic science study involving procedures with human participants
- ☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ☒ Study involving qualitative methods only
- ☐ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- ☐ Study limited to working with data (specific project only)
- ☐ Research tissue bank
- ☐ Research database

If your work does not fit any of these categories, select the option below:

☐ Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

3. In which countries of the UK will the research sites be located? (Tick all that apply)

- ☒ England
- ☐ Scotland
- ☐ Wales
- ☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ☒ England
☒ Scotland
☐ Wales
☐ Northern Ireland
☐ This study does not involve the NHS

4. Which review bodies are you applying to?

- ☒ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☒ Research Ethics Committee
☐ National Information Governance Board for Health and Social Care (NIGB)
☐ Ministry of Justice (MoJ)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- ☒ Yes ☐ No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

- ☐ Yes ☒ No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

- ☐ Yes ☒ No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

- ☐ Yes ☒ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

- ☐ Yes ☒ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or

who are offenders supervised by the probation service in England or Wales?

☐ Yes ☒ No

IRAS Version 3.4

9. Is the study or any part of it being undertaken as an educational project?

☒ Yes ☐ No

Please describe briefly the involvement of the student(s):

The student is the chief investigator of the project, and the project forms part of the thesis submitted as part of the Doctorate in Clinical Psychology (DClinPsy).

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

☒ Yes ☐ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

☐ Yes ☒ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

☐ Yes ☒ No

Site-Specific Information Form (NHS sites)

NHS SSI

IRAS Version 3.4

Is the site hosting this research a NHS site or a non-NHS site? NHS sites include Health and Social Care organisations in Northern Ireland. The sites hosting the research are the sites in which or through which research procedures are conducted. For NHS sites, this includes sites where NHS staff are participants.

- ☒ NHS site
☐ Non-NHS site

This question must be completed before proceeding. The filter will customise the form, disabling questions which are not relevant to this application.

One Site-Specific Information Form should be completed for each research site and submitted to the relevant R&D office with the documents in the checklist. See guidance notes.

The data in this box is populated from Part A:

Title of research:
 Experiences of sleep and dream disturbances following traumatic brain injury

Short title: Experiences of sleep and dream disturbances following TBI

Chief Investigator: Title Forename/Initials Surname
 Miss Joanne Bradley

Name of NHS Research Ethics Committee to which application for ethical review is being made:

[REDACTED]

Project reference number from above REC:

[REDACTED]

1-1. Give the name of the NHS organisation responsible for this research site

[REDACTED]

1-2. In which country is the research site located?

- ☒ England
☐ Wales
☐ Scotland
☐ Northern Ireland

1-3. Is the research site a GP practice or other Primary Care Organisation?

- ☐ Yes ☒ No

2. Who is the Principal Investigator or Local Collaborator for this research at this site?

Select the appropriate title: ☐ Principal Investigator

NHS SSI

☒ Local Collaborator

IRAS Version 3.4

Title Forename/Initials Surname
 [REDACTED]
 Post [REDACTED]
 Qualifications [REDACTED]
 Organisation [REDACTED]
 Work Address [REDACTED]
 [REDACTED]
 PostCode [REDACTED]
 Work E-mail [REDACTED]
 Work Telephone [REDACTED]
 Mobil [REDACTED]
 e Fax [REDACTED]

a) Approximately how much time will this person allocate to conducting this research? *Please provide your response in terms of Whole Time Equivalents (WTE).*

The input from the local collaborator will be on a one-off basis. They will be identifying potential participants from their caseload/service and distributing information packs. This activity is not expected to take longer than 6 hours in total.

b) Does this person hold a current substantive employment contract, Honorary Clinical Contract or Honorary Research Contract with the NHS organisation or accepted by the NHS organisation?

☒ Yes ☐ No

A copy of a current CV for the Principal Investigator (maximum 2 pages of A4) must be submitted with this form.

3. Please give details of all locations, departments, groups or units at which or through which research procedures will be conducted at this site and describe the activity that will take place.

Please list all locations/departments etc where research procedures will be conducted within the NHS organisation, describing the involvement in a few words. Where access to specific facilities will be required these should also be listed for each location.

Name the main location/department first. Give details of any research procedures to be carried out off site, for example in participants' homes.

	Location	Activity/facilities
1	[REDACTED] [REDACTED]	Identification of potentially suitable participants Distribution of information packs to identified potential participants Use of rooms for research interviews where this is most convenient for the participant

5. Please give details of all other members of the research team at this site.

6. Does the Principal Investigator or any other member of the site research team have any direct personal involvement (e.g. financial, share-holding, personal relationship etc) in the organisation sponsoring or funding the research that may give rise to a possible conflict of interest?

☐ Yes ☒ No

NHS SSI

IRAS Version 3.4

7. What is the proposed local start and end date for the research at this site?

Start date: 01/01/2013
 End date: 31/05/2013
 Duration (Months): 5

8-1. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. (These include seeking consent, interviews, non-clinical observations and use of questionnaires.)

Columns 1-4 have been completed with information from A18 as below:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention would have been routinely given to participants as part of their care, how many of the total would have been routine?
3. Average time taken per intervention (minutes, hours or days)
4. Details of who will conduct the procedure, and where it will take place

Please complete Column 5 with details of the names of individuals or names of staff groups who will conduct the procedure at this site.

Intervention or procedure	1	2	3	4	5
Receiving information pack and 'opting in'	1	0	20 minutes	Researcher will give participants an information pack containing an invitation letter, participant information sheet (detailing the purpose of the study and requirements), and an opt in form. Participants will be required to complete and return the opt in form.	Chief Investigator will provide local collaborator with information packs. Local collaborator will distribute packs to identified participants
Telephone call to participants (upon receipt of opt in form)	1	0	15 minutes	Telephone contact will be made within two weeks of receiving the opt in form. This provides potential participants with the opportunity to ask further questions, and arrange a time to meet if interested in taking part.	Chief Investigator will make contact with potential participants.
Gaining consent	1	0	10 minutes	The researcher will provide the participant with a copy of the information sheet for them to read, and will offer to read this to the participant. Participants' capacity to consent will be assessed. Participants will be asked to sign a consent form if they wish to take part.	Chief investigator will conduct these procedures relating to gaining consent
Semi structured interview	1	0	60 minutes	Interview led by chief investigator guided via semi-structured interview schedule	Interview led by Chief Investigator
Participant posted summary of themes	1	0	30 minutes	Participant will be sent a summary of the themes found in the research study. This summary will be brief and so the time of 30 minutes reflects the time for participants to read the summary.	Chief Investigator will send participants a summary of the themes found.

8-2. Will any aspects of the research at this site be conducted in a different way to that described in Part A or the protocol?

☐ Yes ☒ No

If Yes, please note any relevant changes to the information in the above table.

Are there any changes other than those noted in the table?

10.5.5.1 How many research participants/samples is it expected will be recruited/obtained from this site? IRAS Version 3.4

Up to a maximum of 10.

In total, it is expected that 8-10 participants will be recruited across all sites, therefore it is not expected there will be more than around 4 participants per site.

11. Give details of how potential participants will be identified locally and who will be making the first approach to them to take part in the study.

Potential participants will be identified by local collaborator from caseloads, patient databases, files, or discussion with colleagues.

Posters will be provided for display in waiting areas.

12. Who will be responsible for obtaining informed consent at this site? What expertise and training do these persons have in obtaining consent for research purposes?

Name	Expertise/training
Joanne	Chief Investigator is responsible for obtaining informed consent at all sites.
Bradley	The chief investigator has experience of obtaining informed consent as part of both clinical and research activity as a trainee clinical psychologist. Training is provided by Lancaster University Doctorate in Clinical Psychology Programme.

15-1. Is there an independent contact point where potential participants can seek general advice about taking part in research?

General contact details are provided on the information sheet

15-2. Is there a contact point where potential participants can seek further details about this specific research project?

General contact details are provided on the information sheet. These include the chief investigator's contact details and both the field and research supervisors' contact details.

16. Are there any changes that should be made to the generic content of the information sheet to reflect site-specific issues in the conduct of the study? A substantial amendment may need to be discussed with the Chief Investigator and submitted to the main REC.

No changes are made to the information sheet as procedures are uniform across sites.

Please provide a copy on headed paper of the participant information sheet and consent form that will be used locally. Unless indicated above, this must be the same generic version submitted to/approved by the main REC for the study while including relevant local information about the site, investigator and contact points for participants (see guidance notes).

17. What local arrangements have been made for participants who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters etc.)

If individuals are accessing services and using interpreters, this will also be offered for the purposes of the research.

The chief investigator has experience of working with individuals with receptive and expressive communication difficulties, and will tailor the information to the participants needs wherever possible.

18. What local arrangements will be made to inform the GP or other health care professionals responsible for the care of the participants?

As participation in the research will not involve any medical interventions, the GP and/or healthcare professionals will

not be informed of the participant's involvement in the study, to protect the participant's anonymity.

NHS SSI

IRAS Version 3.4

19. What arrangements (e.g. facilities, staffing, psychosocial support, emergency procedures) will be in place at the site, where appropriate, to minimise the risks to participants and staff and deal with the consequences of any harm?

It is possible that the participants may experience some distress in taking part, given the topic of individual's experience of traumatic brain injury and subsequent changes. Should the researcher observe the participant becoming distressed they will be offered the chance to take a break, stop or postpone the interview. At the end of the interview, the participant will be given the opportunity to discuss anything they found distressing or difficult and will be provided with information (via the information sheet) of services and helplines which they may find of benefit.

Opportunities for further support from professionals will be discussed if necessary, and participants will also be encouraged to contact their GP, or an appropriate member of a brain injury support team (if available) in these instances.

If the participant has been recruited via an NHS service, the researcher may also seek permission from the participant to contact the NHS service.

20. What are the arrangements for the supervision of the conduct of the research at this site? Please give the name and contact details of any supervisor not already listed in the application.

The chief investigator will receive regular supervision from [REDACTED] (research supervisor) and [REDACTED] (field supervisor) in relation to conducting the research at the sites. No additional/local supervisors are identified.

21. What external funding will be provided for the research at this site?

- ☐ Funded by commercial sponsor
- ☐ Other funding
- ☒ No external funding

How will the costs of the research be covered?

The costs at this site are minimal, any costs e.g. postage/printing of materials will be covered by Lancaster University.

23. Authorisations required prior to R&D approval

This section deals with authorisations by managers within the NHS organisation. It should be signed in accordance with the guidance provided by the NHS organisation. This may include authorisation by clinical supervisors, line managers, service managers, support department managers, pharmacy, data protection officers or finance managers, depending on the nature of the research. Managers completing this section should confirm in the text what the authorisation means, in accordance with the guidance provided by the NHS organisation.

This section may also be used by university employers or research support staff to provide authorisation to NHS organisations, in accordance with guidance from the university.

1. Type of authorisation:

Title Forename/Initials Surname

Post

Qualifications

Organisation

Work Address

PostCode

Work E-mail

Work Telephone

Mobile
NHS SSI
Fax

IRAS Version 3.4

Signature:

Date:

Declaration by Principal Investigator or Local Collaborator

1. The information in this form is accurate to the best of my knowledge and I take full responsibility for it.
2. I undertake to abide by the ethical principles underpinning the World Medical Association's Declaration of Helsinki and relevant good practice guidelines in the conduct of research.
3. If the research is approved by the main REC and NHS organisation, I undertake to adhere to the study protocol, the terms of the application of which the main REC has given a favourable opinion and the conditions requested by the NHS organisation, and to inform the NHS organisation within local timelines of any subsequent amendments to the protocol.
4. If the research is approved, I undertake to abide by the principles of the Research Governance Framework for Health and Social Care.
5. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to the conduct of research.
6. I undertake to disclose any conflicts of interest that may arise during the course of this research, and take responsibility for ensuring that all staff involved in the research are aware of their responsibilities to disclose conflicts of interest.
7. I understand and agree that study files, documents, research records and data may be subject to inspection by the NHS organisation, the sponsor or an independent body for monitoring, audit and inspection purposes.
8. I take responsibility for ensuring that staff involved in the research at this site hold appropriate contracts for the duration of the research, are familiar with the Research Governance Framework, the NHS organisation's Data Protection Policy and all other relevant policies and guidelines, and are appropriately trained and experienced.
9. I undertake to complete any progress and/or final reports as requested by the NHS organisation and understand that continuation of permission to conduct research within the NHS organisation is dependent on satisfactory completion of such reports.
10. I undertake to maintain a project file for this research in accordance with the NHS organisation's policy.
11. I take responsibility for ensuring that all serious adverse events are handled within the NHS organisation's policy for reporting and handling of adverse events.
12. I understand that information relating to this research, including the contact details on this application, will be held by the R&D office and may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
13. I understand that the information contained in this application, any supporting documentation and all correspondence with the R&D office and/or the REC system relating to the application will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.

Signature of Principal Investigator
or Local Collaborator

Print Name: Joanne Bradley

NHS SSI

IRAS Version 3.4

Date:

12/12/2012



Appendix 4-A

NHS REC Favourable Opinion Letter



[REDACTED]

20 December 2012

Miss Joanne Bradley, Trainee Clinical Psychologist

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Dear Miss Bradley

Study title: Experiences of sleep and dream disturbances following traumatic brain injury

REC reference:

IRAS project ID:

The Research Ethics Committee reviewed the above application at the meeting held on 18 December 2012. Thank you for attending to discuss the application. You were commended on your study and on the involvement of the public in its design

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator, [REDACTED]

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, **subject to** the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study. Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

1. Information sheet

- a. This should include a sentence to say 'You will be sent a summary of the result of the study and asked to comment on the themes that emerge'.
- b. A statement about the payment of expenses provided receipts are supplied where applicable.
- c. Please clarify the level of involvement which Dr Craig Murray may have in your study. If he may have some involvement, please provide details in the information sheet of a contact fully independent of the study, such as the research governance office for the University.

2. Consent form

- a. Please rephrase the term 'anonymised' in the consent form to ensure that it is understood by lay people.
 - b. The form needs to include the following standard research governance paragraph, adapted to your study:
 - c. There needs to be a place for the researcher to sign and date the form. Suggestions
- The poster and invitation letter could provide a work telephone number for people to use in the event of queries about the study.
 - Under the heading in the information sheet 'What will happen to the results?', the first sentence could be amended to read '.....might be published in a PhD thesis and a psychology journal'.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Advertisement	Appendix E: v 1.0	28 October 2012
Covering Letter		03 December 2012
Interview Schedules/Topic Guides	Appendix A: Interview Schedule v 1.0	28 October 2012
Investigator CV	Miss J Bradley	03 December 2012
Investigator CV	Dr F Eccles	10 September 2012
Letter of invitation to participant	Appendix B: Invitation Letter	01 December 2010
Other: Letter confirming peer review details		03 December 2012
Other: Appendix D: Opt-in form	1.0	28 October 2012
Participant Consent Form: Appendix F: Consent Form	1.0	28 October 2012
Participant Information Sheet: Appendix C: PIS	1.0	28 October 2012
Protocol	1.0	28 October 2012
REC application	1.0	03 December 2012

Membership of the Committee

The members of the Ethics Committee present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely

[Redacted signature]

Chair

Email: [Redacted]

Enclosures: List of names and professions of members who were present at the meeting

"After ethical review – guidance for researchers"

Copy to:

[Redacted]
[Redacted]

Appendix 4-B

NHS REC Final Approval Letter



[REDACTED]

12 February 2013

Miss Joanne Bradley, Trainee Clinical Psychologist

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Dear Miss Bradley

Study title: Experiences of sleep and dream disturbances following traumatic brain injury

REC reference:

Protocol number: N/A

IRAS project ID:

Thank you for your e-mail earlier today. I confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 20 December 2012

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Advertisement	Poster - v1.1	10 January 2013
Participant Consent Form	1.1	10 January 2013
Participant Information Sheet	1.1	10 January 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Advertisement	Poster - v1.1	10 January 2013
Covering Letter		03 December 2012
Interview Schedules/Topic Guides	Appendix A: Interview	28 October 2012

	Schedule v 1.0	
Investigator CV	Miss J Bradley	03 December 2012
Investigator CV	Dr F Eccles	10 September 2012
Letter of invitation to participant	Appendix B: Invitation Letter	01 December 2010
Other: Letter confirming peer review details		03 December 2012
Other: Appendix D: Opt-in form	1.0	28 October 2012
Participant Consent Form	1.1	10 January 2013
Participant Information Sheet	1.1	10 January 2013
Protocol	1.0	28 October 2012
REC application	1.0	03 December 2012

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

[REDACTED]	Please quote this number on all correspondence
------------	---

Yours sincerely

[REDACTED]

[REDACTED]

Committee Co-ordinator

[REDACTED]

Copy to:

[REDACTED]

[REDACTED]

Appendix 4-C

NHS Trust R&D Approval Letter: Service One

[REDACTED]

[REDACTED]

[REDACTED]

22nd January 2013

Miss Joanne Bradley
Trainee Clinical Psychologist

[REDACTED]

Dear Miss Bradley

R&D: [REDACTED]
REC Number: [REDACTED]
Lead Researcher: Miss Joanne Bradley
Project Title: Experiences of sleep and dream disturbances following TBI

I am pleased to inform you that the research approval administration process for your project has been completed successfully. The Trust grants approval for this research project to take place and is satisfied it passes site assessment requirements. The table in appendix 1 details the documents approved. Approval however is based upon the following conditions:

- Details of your research project will be entered onto the database maintained by the R&D Office.

[REDACTED]

[REDACTED]

- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]
- All research carried out within the [REDACTED] Trust should be in accordance with the principles set out in the Research Governance Framework for Health and Social Care (Second Edition, DH 2005).
 - In accordance with ICH/GCP (Good Clinical Practice) you are required to retain a study site file holding key documents that serve to demonstrate compliance with Research Governance.
 - Under the terms of the Research Governance Framework, you are obliged to report any adverse events to the R&D Department in line with your protocol.
 - The R&D Department must be informed of any amendments to the project.
 - As PI representing the Trust you must keep the R&D Department informed in the first instance of any issues you have in running the project or a change in circumstances.
 - Likewise, if you feel the internal arrangements for this project need to be changed, the R&D Department will facilitate these discussions.
 - The R&D Office will send out a short questionnaire for monitoring purposes. If your project is for less than one year, monitoring will occur at the end of the project. We will also contact you at the predicted closure date of your research to follow up on your progress.
 - The R&D Department should be informed of the outcome of the research, in particular any presentation of the results at scientific or professional meetings, papers published or direct and indirect impacts on patient care.
- [REDACTED]
- [REDACTED]
- [REDACTED]
- [REDACTED]

May I also draw your attention to the need to comply with the Health & Safety at Work Act, the Data Protection Act and the Human Tissue Act 2004

Please contact us if you require any further guidance or information on any matter mentioned above. We wish you every success in your research.

Yours sincerely

[REDACTED]

[REDACTED]

Research & Development Manager

Copy to:

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Appendix 1

Document	Version	Date
Advertisement: Appendix E	V1	28/10/12
Interview Schedules/Topic guides: Appendix A	V1	28/10/12
Letter of invitation to Participant	V1	01/12/10
Other: Opt-in form: Appendix D	V1	28/10/12
Participant Consent Form: Appendix F	V1	28/10/12
Participant Information Sheet: Appendix C	V1	28/10/12
Protocol	V1	28/10/12

[REDACTED]
[REDACTED]
[REDACTED]

[REDACTED]

Appendix 4-D**NHS Trust R&D Approval Letter: Service Two**

[REDACTED]

[REDACTED]

[REDACTED]

23rd January 2013

Miss Joanne Bradley
Trainee Clinical Psychologist

[REDACTED]

Dear Joanne,

Study Title: Experiences of sleep and dream disturbances following traumatic brain injury

REC Reference: [REDACTED]

R&D Reference: [REDACTED]

Thank you for forwarding all the required documentation for your study as above. I am pleased to inform you that your study has been registered with [REDACTED] and has gained NHS R&D approval from the following NHS Trusts:

- [REDACTED]
- [REDACTED]

All clinical research must comply with the Health and Safety at Work Act, www.hse.gov.uk and the Data Protection Act. <http://www.hmsa.gov.uk/acts>

It is a legal requirement for Principal Investigators involved in Clinical Trials to have completed accredited ICH GCP training within the last 2 years. Please ensure that you provide the R&D Department with evidence of this (certificate for completing the course). A list of GCP training courses can be obtained from the R&D Office.

All researchers who do not hold a substantive contract with the Trust must hold an honorary research contract before commencing any study activities related to this approval. The 'Research Passport Application Form'. This can be obtained from web addresses:

[REDACTED] and [REDACTED]

This form should be completed and returned, with a summary C.V and recent (within 6 months) CRB to the address shown above.

It is a condition of both NRES and NHS R&D approval that participant recruitment data should be forwarded on a regular basis. Therefore, progress reports must be submitted annually to the main REC and copied to the R&D office until the end of the study. <http://www.nres.npsa.nhs.uk/applications/after-ethical-review/annual-progress-reports/>

[REDACTED]

Where clinical trials of investigational medicinal products are sponsored by [REDACTED] it is a condition of Trust approval that Chief Investigators submit quarterly progress reports (to include Annual Safety Reports at the appropriate time) to R&D. For clinical trials of investigational medicinal products hosted within [REDACTED] the local PI will be expected to submit bi-annual progress reports to R&D. It is also a condition of approval that delegated duties (as agreed within clinical trial agreements and trial delegation logs) are fulfilled by only those delegated to undertake a specific duty. This will be monitored by the Sponsor's Representative during routine monitoring of the trial. Persistent non-compliance with these requirements may result in removal of Sponsorship or Trust R&D Approval.

Any amendments to the study should also be notified and approval sought by Ethics Committee and R&D Department. **Where [REDACTED] is acting as Sponsor then amendments or changes MUST be discussed with the Sponsor prior to REC submission.** On completion of the study you are required to submit a 'Declaration of End of Study' form to the main REC, which should also be copied and forwarded to the R&D office at the address shown above.

Any serious adverse events or governance issues related to the research must be notified to the R&D office.

Yours sincerely,

[REDACTED]

[REDACTED]
R&D Manager

[REDACTED]

Appendix 4-E

NHS Trust R&D Approval Letter: Service Three

Our Ref: [REDACTED]

Your Ref: [REDACTED]

Date: 15 February 2013

Miss Joanne Bradley,
Trainee Clinical Psychologist[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Tel: [REDACTED]

Fax: [REDACTED]

Email: [REDACTED]

Dear Joanne,

Re: Research Governance Decision Letter**Project Reference:** [REDACTED]**Project Title:** Experiences of sleep and dream disturbances following traumatic brain injury

Further to your request for research governance approval, we are pleased to inform you that this Trust has approved the study. Thank you for providing copies of the Ethics committee letter, dated 12 February 2013 confirming your approved document list. With regard to your study, we would like you to note that it is required to acknowledge the Trust when publishing your work and this also applies to any posters that maybe produced. The form of acknowledgement should be as described on the [REDACTED] website. Please note when contacting the Research Office about your study you must always provide the project reference numbers provided above.

Trust research approval covers all locations within the Trust; however, you should ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing your research.

Please take the time to read the attached 'Information for Researchers – Conditions of Research Governance Approval' leaflet, which give the conditions that apply when research governance approval has been granted. Please contact the Research Office should you require any further information. You may need this letter as proof of your approval.

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

We would like to point out that hosting research studies incurs costs for the Trust such as: staff time, usage of rooms, arrangements for governance of research. We can confirm that in this instance we will not charge for these. However we would like to remind you that Trust costs should be considered and costed at the earliest stage in the development of any future proposals.

May I wish you every success with your research.

Yours sincerely

[Redacted signature]

[Redacted name]

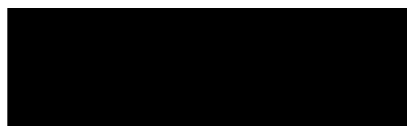
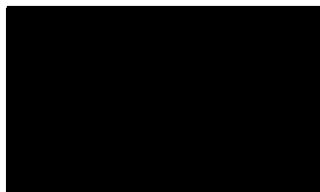
Head of Research

cc : Research Governance Sponsor
Employing Organisation

Enc: Approval Conditions Leaflet V3 11
Induction & ID Badge Information 13

[Redacted footer text]



Appendix 4-F**NHS Trust R&D Approval Letter: Service Four**

28/02/2013

Miss Joanne Bradley



Dear Miss Bradley,

Re: NHS Permission for Research

Project Reference: [REDACTED]
IRAS/REC Reference Number: [REDACTED]
Sponsor: Lancaster University
Protocol Version and Date: Version 1.1, 10/01/13
Project Title: Experiences of sleep and dream disturbances following traumatic brain injury
Date of Permission: 28/02/2013

Further to your request for permission to conduct the above research study at this Trust, we are pleased to inform you that this Trust has given NHS permission for the research.

Please take the time to read the attached conditions for NHS permission. Please contact the R&D Office should you require any further information. You will need this letter as proof of NHS permission. Please note when contacting the R&D office about your study you must always provide the project reference numbers provided above.

NHS permission for the above research has been granted on the basis described in the IRAS application form, Protocol and supporting documentation.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP (if applicable), and NHS Trust policies and procedures. Permission is only granted for the activities for which a favourable opinion has been given by the Ethics Committee [and which have been authorised by the MHRA].

Permission covers all locations within the Trust, however, you should ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing your research.

May I wish you every success with your research.

Yours sincerely

A black rectangular box redacting the signature of the R&D Lead.


R&D Lead

Enc: Approval Conditions Leaflet

Appendix 4-G**Evidence and details of process for gaining permissions
to recruit from charity sector organisation.**

a) E-mail correspondence between researcher (myself) and group regional co-ordinator

From: [REDACTED]
Sent: 29 October 2012 14:25
To: Bradley, Joanne
Subject: RE: research

Hi Joanne,
Sorry didn't get back to you I have had some time off for personal reasons and your email fell through the net. I am more than happy for you to contact groups direct and I hope that they are able to support you with your research and wish you every success.

Kind regards
[REDACTED]

From: Bradley, Joanne [REDACTED]
Sent: 19 October 2012 15:53
To: [REDACTED]
Subject: RE: research

Hi [REDACTED],

I'm writing regarding my research project, which I got in touch with you about a little while ago. Just to update you, the focus of the project has changed slightly since my initial discussion with you.

The proposed project title is now "Experiences of sleep and dream disturbances following traumatic brain injury" and I plan to interview participants who are experiencing changes to their sleep and dreaming. I am keen to find out what changes people have experienced, what impacts these changes have had in their daily living, and how people make sense of these changes.

I had originally sent you my planned interview schedule, however this now looks considerably different, and is no longer focused on post traumatic stress disorder. I didn't hear anything further back from you after this, however I have attached my new interview schedule. I am keen to submit my proposal to the ethics committee within the next two weeks, and so I require permissions from potential recruitment sources prior to this in order to list them on my application. I will hope to start recruitment by January 2013.

I understand there are a number of [REDACTED] services. My supervisor and I discussed my recruitment and he suggested that I approach services directly as he has liaised with them previously for research and recruitment purposes. I thought this might speed things up in time for the ethics submission? Would you be happy for me to contact groups directly at this stage?

Do let me know if there is anything further you wish to discuss or need from me at this stage.

Kind regards,
Joanne Bradley

From: [REDACTED]
Sent: 10 September 2012 09:54
To: Bradley, Joanne
Subject: RE: research

Hi Joanne,

I have been away from the office for some time so just catching up. I will not be at the 19th meeting so suggest we make alternative arrangements.

I would like to see information of the proposed interview schedule/ questions before we agree to you using [REDACTED] as potential recruitment in your ethics application so please send through and then I will ring to discuss, hope that's ok.

Kind regards
[REDACTED]

From: Bradley, Joanne [REDACTED]
Sent: 09 September 2012 21:48
To: [REDACTED]
Subject: RE: research

Hi [REDACTED]

Further to this, I am happy to attend the meeting on September 19th in the evening. Would you be able to give me details of times and location? Would it be at all possible to have a brief chat beforehand, as I am hoping to submit my ethics application shortly for the project and so would be keen to know whether it might be OK to list your service as a potential recruitment source in the interim to our discussion?

If it is helpful I can send you information of the proposed interview schedule/questions?

I am happy for you to contact me on [REDACTED] to discuss further, or if you want me to contact you at a time you are free we can arrange this?

Kind regards,
Joanne Bradley
Trainee Clinical Psychologist

From: [REDACTED]
Sent: 13 August 2012 10:34
To: Bradley, Joanne
Subject: RE: research

Hi Joanne,

I would be happy to meet with you at one of the [REDACTED] to discuss this further. I would need to look at the type of questions you are asking before I would ask any members as sometimes these things can cause some distress revisiting the original

trauma...but happy to discuss and see if it is workable.

We are meeting in September on the 19th in the evening or October the 3rd in the day if this is any good to you. If you let me know which date is best I will give you further details. I have to say it is not a guarantee that the candidates will be drawn from our groups as I would have to assess risk to their wellbeing but hope that we can work something out.

Kind Regards

[REDACTED]

From: Bradley, Joanne [mailto:j.bradley2@lancaster.ac.uk]

Sent: 09 August 2012 15:29

To: [REDACTED]

Subject: research

Hello,

I am writing regarding a research project I am hoping to run within the North West over the next few months. The project forms part of my thesis for a Doctorate in Clinical Psychology at Lancaster University.

I aim to recruit around 10 participants who have sustained a traumatic brain injury and are experiencing symptoms of trauma/trauma reactions following their brain injury. The project aims to explore individual's understandings of the causes of the development of the trauma symptoms. This hopes to inform future services and support offered to individuals who have sustained brain injuries.

I was wondering whether you would be happy for me to possibly recruit participants from your [REDACTED] service/groups within the North West. I am currently in the stages of designing the project and gaining ethical approval, prior to commencing recruitment, but hope to begin recruiting around October/November. My suggestion would be to possibly attend meetings in order to provide accessible information about the study and hand out recruitment packs, however I am willing to consider other recruitment suggestions such as providing posters for display if this would be more appropriate?

Kind regards,

Joanne Bradley
Trainee Clinical Psychologist
Lancaster University

b) E-mail correspondence between researcher (myself) and group chair detailing process of gaining permission to recruit from individual group 1.

From: Chair Person [REDACTED]
Sent: 05 November 2012 17:02
To: Bradley, Joanne
Cc: [REDACTED]
Subject: Re: sleep and brain injury research

Dear Joanne

We discussed your proposal at our committee meeting this week and agreed that we would like you to come and discuss your project and that we have members who are interested in contributing.

My contact details are as follows and we look forward to hearing that you have been granted ethics approval.

Kind regards

[REDACTED]

[REDACTED]

[REDACTED]

On 5 Nov 2012, at 15:05, "Bradley, Joanne" [REDACTED] > wrote:

Dear [REDACTED],

Many thanks for your quick reply, and apologies it has taken a couple of weeks to get back in touch with you.

I'd certainly be keen to attend a meeting and provide some information about the study. At this stage I will need to wait until I gain ethical approval, and then I am able to attend meetings and begin the recruitment process, so I could contact you again at this time to find out when your meeting dates are?

For the purposes of my ethics form I need to list contact details for a named contact for each organisation which I intend to recruit from. Would it be possible to take a contact address for you, as I am required to provide the details for each organisation.

Kind regards,

Joanne Bradley
Trainee Clinical Psychologist
Lancaster University

From: Chair Person [REDACTED]

Sent: 22 October 2012 16:11

To: Bradley, Joanne

Cc: [REDACTED]
[REDACTED]

Subject: Re: sleep and brain injury research

Dear Joanne

Many thanks for contacting [REDACTED]

I am circulating your message to other members of the committee, and I feel sure that they will be most interested to support your research.

On that basis I am happy for you to name us as a partner, and it would be really good if you could come to one of our meetings and meet our members, to allow them to understand more how they can help you.

I have copied in our regional coordinator and a couple of our local ABI team who are members of our committee who may have other opportunities for you to pursue.

With best wishes

[REDACTED]

On 22 Oct 2012, at 13:58, "Bradley, Joanne" <[\[REDACTED\]](#)> wrote:

Hi,

I am writing regarding a research project I am currently undertaking as part of my doctorate in clinical psychology at Lancaster University.

My project is looking at individuals experiences of sleep/dreaming changes or disturbances following traumatic brain injury. My understanding is that changes in sleep patterns and dreams are commonly reported following brain injury, yet peoples experiences of this aren't very well researched. I am hoping that by discovering more about peoples experiences we can broaden the knowledge around people's well being after brain injury and hopefully this can contribute to literature and lead to advances in assessment and care.

I am hoping to recruit from north west NHS services for brain injury, but I'd also really like to capture the views of individuals in the wider community and thought that [REDACTED] might be a great service for this. My ideas for recruitment would be to provide posters which could be displayed at meeting locations or places frequented by [REDACTED] service users. I'd also be happy to attend meetings and

give a short presentation about the study and hand out information packs to interested individuals. I'd be really interested to hear your views or the views of any [REDACTED] members around the project idea and recruitment plans.

I am hoping to submit a proposal for ethical approval within the next couple of weeks, and on this proposal I need to list the names of services who would be happy for me to recruit from. If as a service you felt that you would be happy for me to recruit [REDACTED] service users, all I would need at this stage would be the permission for me to name your service on my proposal form. Once I then receive ethical approval, I could contact you again and agree a time to perhaps attend a meeting or distribute posters/information packs?

I'd be really keen to hear your thoughts!

Kind regards,

Joanne Bradley
Trainee Clinical Psychologist
Lancaster University

c) E-mail correspondence between researcher (myself) and group named contact detailing process of gaining permission to recruit from individual group 2.

From: [REDACTED]
Sent: 06 March 2013 13:52
To: Bradley, Joanne
Subject: RE: research

Hi I will attach our meeting dates for you if you are coming to any will you email and let me know
Regards [REDACTED]

From: [REDACTED]
To: [REDACTED]
Subject: RE: research
Date: Tue, 19 Feb 2013 11:24:13 +0000

Dear [REDACTED],

I contacted you toward the end of last year regarding my research project, which I was in the process of gaining ethical approval for. Unfortunately there have been some delays with the process, however I have finally now received confirmation from the ethics committee of approval for the project, so I can now begin recruiting participants.

As a reminder, the project is looking at recruiting individuals who have sustained a traumatic brain injury and are experiencing changes to their sleep and dreams. I am hoping to recruit individuals to attend a one-to-one interview.

When we last spoke, we discussed whether I might attend a meeting where I could briefly discuss my project and provide information for anyone who might be interested in taking part. Would this still be a possibility, and if so could you provide details of when would be the most convenient time for me to attend? I understand that you have a meeting coming up next Tuesday, and wondered whether this might be a good time for me to come along?

If you would like to discuss further I can be contacted on [REDACTED]

Joanne Bradley
Trainee Clinical Psychologist
Lancaster University

From: [REDACTED]
To: [REDACTED]
Subject: RE: research
Date: Tue, 5 Nov 2012 15:02:25 +0000

Hi [REDACTED],

I spoke to you a couple of weeks ago regarding my research project and you explained that you would be happy for me to name your service on my ethics application form in order to then hopefully attend one of your meetings for recruitment for my research.

Would it be possible to have a contact address or telephone number which I can put on my application form, as I need to provide this information in order to gain ethical approval.

Kind regards,

Joanne Bradley
Trainee Clinical Psychologist
Lancaster University

From: [REDACTED]
To: [REDACTED]
Subject: RE: research
Date: Thu, 2 Aug 2012 14:00:15 +0000

Hi [REDACTED],

Thanks for your quick reply and info regarding dates. I am currently in the process of finalising study details and seeking ethical approval - and I need to wait for this approval before I am able to attend a meeting. However, I can add your service to my study protocol, if this is okay? I can then contact you once I have ethical approval so you know which meeting I am able to attend.

Thanks,

Joanne

Joanne Bradley
Trainee Clinical Psychologist
Lancaster University

From: [REDACTED]
Sent: 02 August 2012 09:46
To: Bradley, Joanne
Subject: RE: research

Hi Joanne, Yes that would be fine our next meeting is on 13th Aug but is an evening one, or

28th Aug 2-4 pm I will attach our dates for you please come and find me first before asking anyone at the drop in.

Regard [REDACTED]

From: [REDACTED]

To: [REDACTED]

Subject: research

Date: Wed, 1 Aug 2012 15:07:17 +0000

Hi,

I am writing regarding a research project I am hoping to run over the next few months. The project forms part of my thesis for a Doctorate in Clinical Psychology at Lancaster University.

I aim to recruit around 10 participants who have sustained a traumatic brain injury and are experiencing symptoms of trauma/trauma reactions following their brain injury. The project aims to explore individual's understandings and attributions of the causes of the development of the trauma symptoms.

I was wondering whether you would be happy for me to possibly recruit participants from your [REDACTED]? I am currently designing the project, but would be happy to attend meetings to provide further information about the study and hand out recruitment packs.

Kind regards,

Joanne Bradley
Trainee Clinical Psychologist
Lancaster University

The researcher had subsequent discussions via telephone (group 1) and in person (group 2) prior to approaching participants to ensure that the organisation did not have any group specific ethics or research approval processes, and was informed that there were no specific processes, and that decisions were made within individual groups. Named contacts were provided with details of my procedure, protocol and ethics approval for research. At this stage the researcher was granted permission verbally to distribute research materials allowing participants to contact the researcher directly should they wish to take part in the research.

Appendix 4-H
Research Protocol

(Version 1.1 created 10.01.13)

Experiences of sleep and dream disturbances following traumatic brain injury

Chief Investigator: **Joanne Bradley**
Trainee Clinical Psychologist
Furness College
Lancaster University
Lancaster
LA1 4YG

Telephone: 01524 592971
Email: j.bradley2@lancaster.ac.uk

Academic Supervisor:

[REDACTED]

Telephone: [REDACTED]
Email: [REDACTED]

Field Supervisor:

[REDACTED]

Telephone: [REDACTED]
Email: [REDACTED]

Introduction

Traumatic brain injuries (TBI) result from specific traumatic events involving external factors such as an accident (e.g. a fall or road traffic accident) or an attack or assault. Traumatic brain injury can be defined as “an alteration in brain function, or other evidence of brain pathology, caused by an external force” such as a rapid acceleration or deceleration, or an impact (Menon, Schwab, Wright & Maas, 2010).

A number of identified psychological and cognitive sequelae are associated with traumatic brain injury. Commonly, individuals may experience a post traumatic amnesia immediately after the event, experiencing difficulties recalling memories of the injury causing event, memories preceding the event, or memories following the event. Individuals

may also experience ‘post concussional syndrome’ (PCS) which is a term given to a cluster of neurobehavioural and psychological symptoms including difficulties in memory, attention and executive functioning, changes in mood, headaches, dizziness, sleep disturbances and changes in mood and anxiety (Whittaker, Kemp & House, 2007). Literature has also explored a relationship between post-traumatic stress disorder (PTSD) and traumatic brain injury, with some studies finding a link between PTSD symptoms and earlier TBI (Bryant, 1996; Creamer, O’Donnell & Pattinson, 2005). These symptoms include distressing recollections of traumatic events (such as images, hallucinations, memories, dreams and flashbacks), changes in sleep, appetite and mood, and elevated levels of anxiety and arousal.

Literature indicates that sleep disturbances are commonly reported following TBI. Gosselin and Tellier (2010) found a prevalence of 50% of sleep-wake disturbances such as insomnia and hypersomnia in individuals with a traumatic brain injury. A review by Castriotta and Murthy (2011) indicated a range of sleep-related disturbances or changes following TBI, including hypersomnia, insomnia, excessive waking, fatigue and sleepiness, circadian rhythm disorders and changes to the content of dreams, with more threatening dreams reported, and fewer dreams with sexual content. Clinically, individuals often report having disturbing dreams or nightmares after a TBI. Much of the literature examining sleep and dreaming following TBI has looked at prevalence rates of symptoms experienced. However, there is little exploration of individuals’ experiences of these symptoms, changes or difficulties. Literature has indicated correlations between sleep disturbances and mental health sequelae such as anxiety and depression (Kempf, Werth, Kaiser, Bassetti & Baumann, 2010; Rao et al, 2008), but again does not explore individuals’ experiences of any possible impacts of sleep disturbances upon mental health, emotional wellbeing and quality of daily life.

Therefore, this research study aims to explore individual experiences and perspectives of sleep and dream disturbances and changes following a traumatic brain injury. The aims of the research are to explore the nature of these changes or experiences, the impacts of these experiences, and explore means by which individuals cope with or manage these experiences. The research aims to generate a greater understanding of the lived experience following a traumatic brain injury, and may have clinical relevance in terms of improving methods of assessment of distress and interventions following a traumatic brain injury.

Furthermore, sleep and dreaming difficulties are noted as potential diagnostic criteria for PTSD in the American Psychiatric Association’s (1994) Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). In particular, there are two criteria of relevance; “recurrent distressing dreams of the event” and “difficulty falling or staying asleep”. Within the literature, there has been controversy associated with the possibility of diagnosing PTSD in TBI, given that post traumatic amnesia is frequently experienced. In post-traumatic amnesia, the individual is likely to have an impaired memory for the TBI causing event. This has been thought to impact upon the individual’s ability to recall memories of the event, which is key in meeting DSM-IV diagnostic criteria. However, a review by McMillan, Williams and Bryant (2003) which has explored literature examining PTSD and TBI indicates that individuals can meet diagnostic criteria for PTSD, despite having limited or no memory of the injury causing event itself. It is acknowledged that diagnosis of PTSD in TBI is complex, and complicated by the overlap in many of the symptoms and difficulties experienced in both, such as changes in mood, sleep and appetite. However, the intrusive recollections stated as part of the diagnostic criteria for PTSD do not overlap with TBI.

Therefore, an exploration of the experience of dreaming following TBI may help us to explore the nature of distressing dreams following a TBI. This may help to understand the process of adjustment following a TBI and better understand how dreaming phenomena may be related to post traumatic stress disorder and trauma reactions following TBI. The research aims to develop understanding of the experience of distress following a TBI, and contribute to understanding and developing the process of therapy and rehabilitation with people who have experienced traumatic brain injuries.

Method

Design.

A qualitative methodology is appropriate for this study, which aims to collect data and develop knowledge of individuals' understanding and perceptions of their experiences following brain injury. Qualitative research aims to produce understandings of experiences by the collection and analysis of rich, detailed data (Mason, 1996). Interpretative phenomenological analysis (IPA) has been identified as an appropriate qualitative method of data collection and analysis. IPA has its groundings in phenomenological psychology and symbolic interactionism, and aims to explore the meanings and understandings of individuals' experiences of particular phenomena, and the subsequent influences of these phenomena on actions, interactions, perceptions and experiences. IPA uses an interview method of data collection, whereby the researcher collects data that represent the individuals' perceptions of their experience. The researcher then analyses the data by developing themes which incorporate the researcher's interpretation of the individuals' experiences. IPA therefore considers both the individual's understanding of the experience and the researcher's role in these understandings (Smith, Flowers & Larkin, 2009; Smith & Osborn, 2008). This study will utilise semi-structured interviews to collect data which will subsequently be transcribed and analysed.

Participants.

It is anticipated that between 8 and 10 participants will be recruited for the study. This is thought to be an appropriate sample size for an IPA research study to provide a reasonably homogeneous, well defined sample. A maximum sample size of 10 ensures that the sample is not so large that the richness of the understandings in the data becomes diluted (Smith, Jarman, & Osborn, 1999). Participants will be recruited from NHS services for brain injury situated in [REDACTED]. In addition, participants will also be recruited from [REDACTED]

[REDACTED] are charity sector organisations who help and support people affected by brain injury and other neurological conditions and have a number of local branches [REDACTED] [REDACTED] is a charity sector organisation providing support for people affected by a neurological condition.

Inclusion Criteria.

- Participants will be aged 18 or over and will be assessed to have capacity to consent to participate in this research.
- Participants will be individuals who have sustained a traumatic brain injury, defined as an alteration in brain function, or other evidence of brain pathology, caused by an external force, such as rapid acceleration or deceleration or an impact (Menon, Schwab, Wright & Maas, 2010).

- Participants will be currently experiencing sleep disturbances such as changes in sleeping patterns and duration, frequent waking, or experiences of disturbing or upsetting dreams or nightmares. The onset of these disturbances will be post TBI.
- Length of time since traumatic brain injury will be at least 3 months.
This time frame reduces the likelihood of the individual being in 'post traumatic amnesia' (PTA). Individuals who are still experiencing PTA would be unlikely to retain information relating to the study details in order to be assessed to have capacity to consent to the research. This time frame also allows time for the individual to become aware of impairments following the injury and the potential impacts of these impairments. There is no defined upper limit on time since injury as part of inclusion/exclusion criteria, as this research is exploratory in understanding experiences, and these may occur at different times since injury or be ongoing for varying durations.

Exclusion Criteria.

- The study will not include participants who have sustained damage to the brain arising primarily from any event or disease other than a traumatic brain injury, as defined above.
- The study will not include participants who report experiencing other trauma reactions but with no reported changes or disturbances related to sleep or dreaming.
- Participants will be excluded if they are unable to provide informed consent. The potential participant's capacity to provide informed consent will be assessed by the potential participant demonstrating to the investigator that they understand what would be asked of them should they consent to participate in the research, and demonstrating that they understand their options should they have any concerns following their participation in the study.
- Participants will be excluded if they do not have receptive and expressive verbal communication skills sufficient to engage in an interview. This will be assessed by the investigator prior to the interview by assessing the potential participant's ability to respond appropriately and verbally when their ability to give informed consent is assessed.

Materials.

A semi-structured interview schedule with open-ended questions will be used as a guide to facilitate discussion, with scope for the addition or removal of questions dependent upon participants' responses. The interview schedule was developed by the researcher in conjunction with the field supervisor and service users from a local service user and carer group which provides consultancy to the Lancaster Doctoral Course in Clinical Psychology. A copy of the proposed interview schedule for the study can be found in Appendix 4-H.

Procedure.

The researcher will approach several [REDACTED] NHS Services for brain injury [REDACTED] and request that potential participants be identified by an identified clinician. The researcher will request that information packs (which will be provided and will contain an invitation letter (Appendix 4-I), participant information sheet (Appendix 4-J), opt in form (Appendix 4-K) and a stamped addressed envelope) will be distributed to potential participants (by post or during

appointment). This ensures the anonymity of potential participants to the researcher until individuals opt-in to being contacted via return of the opt-in form.

The researcher will also attend [REDACTED] in order to provide the groups with more information about the study, and to provide information packs for potential participants.

Posters (Appendix 4-L) will be provided for [REDACTED] and NHS services, for display in waiting areas/meeting locations with consent, to allow participants to contact the researcher by telephone if they wish to participate. A participant information sheet will then be posted or e-mailed directly to the participant.

Within two weeks of initial contact with the participant (either via receipt of the opt-in form or initial telephone call from the participant after seeing the poster) the researcher will contact the participant to provide an opportunity to ask questions and further discuss the study. The researcher will also ask questions to determine if the individual meets inclusion criteria of; age 18 or over, sustained a traumatic brain injury, time since injury of at least 3 months and current experience of sleep disturbances. If at this stage the participant would like further time to decide if they wish to take part, they will be offered a follow up telephone call in one week's time, or they may decide to take part at this stage. If they decide they would like to take part, an interview time and location will be arranged.

Participants will be asked whether they would like to complete the interview at a local NHS trust site (for participants recruited through NHS trusts), or a community venue convenient for them. In these instances the Trust risk procedures, lone working policies and Lancaster University and Doctorate in Clinical Psychology lone working policies will be adhered to.

At the start of the interview appointment, the researcher will explain confidentiality and any limits and procedures surrounding this. Participants will then be asked to complete a consent form in order to take part in the study (see Appendix 4-M). The researcher will discuss the issue of obtaining informed consent with participants. The researcher will assess the participants' capacity to consent in accordance with the Mental Health Act (2005) and as per the British Psychological Society (2006) guidelines for the "Assessment of Capacity in Adults", in order to determine whether potential participants are deemed to have capacity to consent as per the inclusion criteria for the study.

The Mental Capacity Act (2005) emphasises that all adults should be assumed to have the capacity to consent for themselves, unless evidence is presented which indicates they lack capacity. A person may be considered to lack capacity to make a decision (such as the decision to consent to participant in research) if they are unable to demonstrate that they can understand information, retain information, use information in decision making and communicate their choice.

Capacity to consent will therefore be assessed as follows:

1. Researcher will provide the potential participant with an information sheet, and will also offer to read out this information to the client. This will inform of the objectives of the study, outline any potential risks and procedures which will be followed, outline what will be required of anyone participating in the study and outline what

options individuals have should they have any concerns following their participation in the study.

2. Researcher will ask the potential participant to tell them, using their own words, what will be required of them if they decide to participate.
3. Researcher will ask the potential participant why they decided to take part in the study.
4. Researcher will ask the potential participant to tell them in, using their own words, what their options are if they have concerns following participation in the study.
5. Researcher will ask the potential participant whether they would like to participate in the study.

All decisions regarding assessment of a person's capacity to consent will be discussed with both field and research supervisors. If the potential participant is felt to lack capacity to consent, they will not be included in the study.

It is anticipated that the interview will last approximately 45-60 minutes. Additional time will be provided to give the opportunity for breaks or to discuss any issues arising from the interview.

Proposed analysis.

Interviews will be transcribed within two weeks of the interview. The transcripts will be analysed using interpretative phenomenological analysis (IPA), which aims to explore individuals' perspectives of their experiences. This analysis will follow the process described by Smith et al (2009). The researcher will firstly read the transcripts several times, and initial notes will be made. The researcher will then identify emergent themes, and develop these themes by searching for connections. This process will be repeated with each participant's transcript. The researcher will finalise these themes by searching for connections or patterns between themes across the transcripts.

Practical Issues.

Inconvenience to participants will be minimised where possible by arranging the interview at a convenient time and location for the participant. Participants will be asked whether they would like to complete the interview at a local NHS trust site or a community venue convenient to them. Trust risk procedures, lone working policies and Lancaster University and Doctorate in Clinical Psychology lone working policies will be adhered to. If participants opt to complete interviews on NHS trust sites or community location, travel expenses will be reimbursed by the Lancaster Doctorate in Clinical Psychology course.

Any photocopying, printing and postage costs will be covered by the Lancaster University Doctorate in Clinical Psychology.

Interviews will be audio-recorded using a Dictaphone. Digital recordings will be transferred from the Dictaphone to an encrypted, password protected file on the Lancaster University secure network. The recordings will subsequently be deleted from the hard drive of the Dictaphone. Encrypted digital recordings will be deleted from the secure network once the project has been completed and submitted. Transcribed data will be anonymised, with identifiable information changed or removed. Anonymised transcripts will be stored as electronic encrypted files on the Lancaster University secure network. Any hard copies of transcripts, consent forms or personal information will be kept in a locked drawer during the conduction of the study.

The field supervisor will not have access to any electronic or hard copies of personal data collected during the study. Both the researcher and the research supervisor will have access to audio recordings and electronic and hard copies of transcripts, for the purposes of reviewing the interview schedule, and supervision of the analysis process. The researcher will be the only person who has access to personal information such as contact details, names, addresses and/or telephone numbers of recruited participants in the study. Each participant will be allocated an individual identification number upon entry to the study, to be used on all collected data, and only the researcher will be aware which participant relates to which transcript.

Hard copies of data transcripts will be stored securely at Lancaster University for five years after completion of the research, in accordance with the Data Protection Act 1998. If the research is published, the data will be stored for five years following publication. After five years, the data will be destroyed.

Ethical Considerations.

Whilst it is hoped that participants will not find the interview distressing, there is the potential for distress to occur given the discussion topic. Participants will be informed that they may pause for a break or stop the interview at any point if they become distressed. If the researcher observes the participant becoming distressed, the researcher will ask whether the participant would like to continue, take a break or stop the interview. Additional time will be set aside to provide the opportunity for breaks or to discuss any issues which may have been distressing for the participant. The researcher is a trainee clinical psychologist. As the researcher, they are not positioned to provide therapy for the participant, but will use therapeutic skills to contain any distress during the interview, and will provide suggestions for appropriate support services. Contact details for support services will also be provided on the participant information sheets. If the participant has been recruited via an NHS service, the researcher may also seek permission from the participant to contact the NHS service.

Prior to the commencement of the interview, the researcher will explain confidentiality and its limits. Participants will be informed that should they disclose any information indicating a risk of harm to themselves or others, then the researcher may need to inform supervisors or other agencies including the NHS team involved in their care if recruited via the NHS. The researcher will approach either the academic or field supervisor in the first instance to discuss any risk issues.

Timescale

Following ethical approval, it is hoped that the data collection will commence in December 2012. It is envisaged that the project will be submitted to Lancaster University in May 2013.

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Appendix 4-I

Interview Schedule

This interview schedule will be used as a guide during interviews to help facilitate discussion of participants' experiences of sleep and dream disturbances following brain injury. The interview schedule is not intended that all questions are asked of all participants, but acts as a guide to the types of questions which may be asked, under the topic areas indicated. The questions in italics are intended as prompts to the main questions, which may help to facilitate conversation where appropriate. Questions may be adapted, removed or added based upon participants' responses.

Introduction/Background

- Introductions.
- Provide/read participant information sheet and allow time to answer any questions participants may have.
- Assess for clients capacity to consent via the following questions:
 - Can you tell me what you will be asked to do if you take part in the study
 - Have you decided whether you want to take part? What is your decision?
 - How did you decide you wanted to take part?
- Explain that participation will remain confidential and participants will remain anonymous, with any identifiable information changed or removed. Explain that should anything be discussed which raises concerns that the participant or anyone else may be at risk of harm, that this will be discussed in the first instance with either supervisor ([REDACTED]).
- Explain that the interview will last between 45-60 minutes and will be audio recorded. The opportunity for breaks will be given if necessary, and the participant may have a break or terminate the interview at any point if they wish.
- Ask the participant to sign a consent form.

Experiences and changes post injury and current difficulties

- Can you tell me about your injury/accident?
 - *What happened? How long ago was this? Time spent in hospital?*
 - *What do you remember about the experience? What is the last thing you remember before, and the first memory you have after?*
- Can you tell me about yourself and your family?
 - *Age, family/partner, living arrangements, work/job, lifestyle, friends, support)*
 - *Any changes for you since injury?*
 - *When did you first notice these changes?*
 - *Who first noticed them? Did you notice or did someone else?*

Sleep/dreaming experiences and changes

- Tell me about how you sleep?
 - *What changes have you noticed in relation to your sleep? How have things changed?*
 - *When did you first notice the changes?*
 - *What impact have these changes had – how do they make you feel?*
- Are there any changes to your dreams? Any unusual dreams? Can you tell me about the dreams?

- *How did/do the dreams make you feel? At the time/During the dream? When you woke up? Now?*
- *When did these dreams start? How often do they happen?*

Understanding of experiences/changes

- Do you feel you understand these experiences/changes in your sleep/dreams?
 - *Why did/do these changes happen? Why did/do these dreams happen? What is your understanding of why people dream?*
 - *Is it important to understand these experiences? Why?*
 - *Have you been given enough information about your experiences?*
 - *Have you discussed your understanding of these experiences with anyone?*

Impact of changes

- How do you feel about these changes/experiences?
 - *How do these experiences affect you on a day to day basis? Does it impact on social life, work, what you are able to do? Have you had to make any changes in your life because of these symptoms?*
 - *Have you noticed any other changes as a result of these experiences? What?*
 - *Are there good/bad days and good/bad times? What is a good day/bad day like?*

What helps?

- What helps you cope with these symptoms/difficulties?
 - *Is there anything you do to try and reduce these symptoms/difficulties? Medication, exercise, diet?*
 - *Do they help? How do you think they work?*
 - *Is there anything you do which changes the dreams?*
 - *How much control do you feel you have over these symptoms? What would have to be different for you to have more/less control?*
- Who do you find helpful in managing your symptoms/difficulties?
 - *How do they help?*
 - *Do they understand your difficulties/experience?*
- What treatments/therapies/support have you been offered?
 - *What have you tried?*
 - *Do you feel you have a say in the treatment you receive?*
 - *Is there any other treatment you feel you would like to receive? Would this be helpful? How?*

General support/treatment

- Can you think of any ways that the treatment or support of people with these symptoms/their families could be improved?
- What do you think people need to know about how to manage these symptoms?
- Do you have any advice to others in your position? Would this advice have helped you when you first began experiencing symptoms?

Close of interview

- Is there anything else you would like me to know before we finish the interview?

- Ensure that the participant is not distressed. If the participant appears distressed, the researcher will discuss with the participant and where appropriate will advise them of support services which they can access.
- If any risk issues have been disclosed, researcher will again discuss confidentiality issues and will discuss with the participant that advice will be sought from supervisors in the first instance. A decision will also be made including the participant as to whether the data collected can continue to be used within the study. If it is deemed unsuitable (or the participant cannot be contacted if this is done at a later date), the data will be destroyed.
- Thank participant for taking part in the interview.

Appendix 4-J**Invitation Letter**

Dear Participant,

Re: Experiences of sleep and dream disturbances following traumatic brain injury

My name is Joanne Bradley. I am a trainee clinical psychologist and I am doing a research project as part of my degree at Lancaster University.

I am asking you to take part in my research project looking at changes in sleep and dreaming following a brain injury. [Name of service] is sending this letter to you on my behalf, and I do not have access to any of your personal information.

I have included a “participant information sheet” which explains the research in more detail. If you are interested in taking part in the research, I have enclosed an “opt in form” for you to sign and send back to me in the stamped envelope or you can contact me by e-mail.

Thank you for taking the time to read this letter.

Yours sincerely,

Joanne Bradley
Trainee Clinical Psychologist
Lancaster University

Email: j.bradley2@lancaster.ac.uk

Appendix 4-K**Participant Information Sheet****EXPERIENCES OF SLEEP AND DREAM DISTURBANCES FOLLOWING TRAUMATIC BRAIN INJURY**

You are being invited to take part in this research study. Before you decide whether to take part it is important to understand why the research is being done and what it involves.

Please take time to read the following information carefully and discuss with other people if you wish to. Please ask if there is anything that is not clear, or if you would like more information. Contact details are given at the end of this information sheet.

WHAT IS THE STUDY ABOUT?

After experiencing traumatic brain injuries (resulting from falls, accidents or assaults) people often experience changes in their sleep, such as sleeping for longer, waking up a lot, or not being able to get to sleep as easily. People often experience changes in their dreams too, such as having unwanted or upsetting dreams. This research aims to find out more about what people experience, how this affects them and how they manage with these changes. It is hoped that this research will contribute to understanding on how to support people following traumatic brain injuries.

WHY CAN I TAKE PART?

You are invited to take part in the study if you have experienced a traumatic brain injury, and are experiencing changes or difficulties in your sleeping or dreaming that started after your injury. I am recruiting participants from NHS trusts and support groups for people with brain injuries [REDACTED]

[REDACTED] I am recruiting up to 10 people to take part in the study.

WHAT WILL I BE ASKED TO DO?

If you decide you would like to take part, please complete the 'opt-in form' and send it in the stamped addressed envelope provided or you can contact me by email. I will contact you within two weeks of receiving your 'opt-in form' to discuss the study further with you. I may ask you some questions to make sure it is suitable for you to take part. I will then arrange a time to complete an

interview. If I have already recruited enough participants I will telephone you to inform you of this.

The interview will involve me asking you some questions about your experience of the event which caused your traumatic brain injury and any changes to your sleep and dreaming which you believe may be linked to your experience.

The interview will be arranged at a place convenient for you. This can be at a local NHS trust or a local community venue, and any travel expenses incurred will be reimbursed where mileage or receipts are supplied. The interview will take around one hour to complete and will be tape recorded and typed up.

DO I HAVE TO TAKE PART?

No, it is up to you to decide if you wish to take part. If you decide to take part, you will be asked to sign a consent form agreeing to take part in the research. You can stop the interview at any time and do not have to give a reason. After the interview you can change your mind up to two weeks after the interview has been completed, and any data will then be destroyed. Your decisions will not impact upon any current or future treatment you receive in any way.

WILL MY INFORMATION BE KEPT CONFIDENTIAL?

What we talk about in the interview will be kept confidential. However, if you tell me anything which indicates you or someone else may be at risk, I have to report this to an appropriate professional.

WHAT WILL HAPPEN TO THE DATA?

The interview will be tape recorded and typed up. The recordings will be destroyed at the end of the research. Some of the things you say might be put into a report to help explain the results of the research. All the data in the report will be anonymous and your name will not be used in the report.

WHAT WILL HAPPEN TO THE RESULTS?

The results will be written up as a report which will be submitted as part of a thesis for a Doctorate in Clinical Psychology programme. The report may also be published in a psychology journal. Quotes from the interview may be included in the report, but participants will not be identifiable in the text. You will be sent a summary of the main results of the study, and asked to comment on the themes that emerge. A summary of the final study results will also be provided to the services which assisted with recruitment, either in written form or via a presentation.

ARE THERE ANY BENEFITS OR RISKS TO TAKING PART?

There are no direct benefits to taking part in the research. However it does give participants an opportunity to express their views on their experiences after having a traumatic brain injury. It is hoped that this study will help to

improve the support that is offered to people sustain brain injuries.

Talking about changes in our lives can sometimes be upsetting. It is hoped that this interview will not cause any distress. If you experience any distress in the interview you will be asked if you would like to break or stop the interview. If you experience any distress there are a number of people you can contact, including your keyworker or GP, or one of the following organisations:

Headway

Website: www.headway.org.uk
Helpline: 0808 800 2244

BASIC

(Brain and Spinal Injury Centre)
Website: www.basiccharity.org.uk
Helpline: 0870 750 0000

WHAT IF I WANT ANY FURTHER INFORMATION?

If you have any questions about the study, please contact any of the following

Main researcher:

Joanne Bradley

Email: j.bradley2@lancaster.ac.uk

Tel: [REDACTED]

Field supervisor:

[REDACTED]

Research supervisor:

[REDACTED]

To voice any concerns or complaints about this study, you may also contact:

Dr Craig Murray,

Acting Research Director,
Department of Clinical Psychology,
Lancaster University,
Lancaster
LA1 4YG
E-mail: c.murray@lancaster.ac.uk
Telephone: 01524 592858

Professor Susan Cartwright

Head of Division of Health Research
C04, Furness College
Lancaster University
Lancaster
LA14YG
Email: s.cartwright@lancaster.ac.uk
Telephone: 01524 592430

Thank you for taking the time to read the information sheet.

Joanne Bradley

(October 2012)

Appendix 4-L**Opt-in Form****Experiences of sleep and dream disturbances following traumatic brain injury**

I am interested hearing more about the above research project. I agree to the researcher contacting me by telephone.

Name_____

Address_____

E-mail address _____

Telephone Number_____

Signed_____

Date_____

Appendix 4-M

Recruitment Poster



HAVE YOU EXPERIENCED A BRAIN INJURY as a result of a car accident, a fall, or violence?

Are you experiencing changes to your sleep or dreams?

These changes might include:

- Sleeping more often or for longer
- Sleeping less often or for less time
- Waking up a lot
- Sleeping at different times of the day
- Not being able to get to sleep
- Changes in your dreams e.g. unusual or upsetting dreams



**I am inviting people to take part in a research study
which will involve one interview.**

**I will be exploring people's experiences of changes to sleeping
and dreams after having a brain injury.**

**The study aims to help understand these experiences so that
professionals can find better ways to treat and work with patients.**

If you would like to know more information please contact:

Joanne Bradley,

Trainee Clinical Psychologist, Lancaster University

e-mail: j.bradley2@lancaster.ac.uk

telephone: [REDACTED]

Appendix 4-N**Consent Form****Study Title: Experiences of sleep and dream disturbances following traumatic brain injury**

Researcher: Joanne Bradley

Supervisors: [REDACTED]

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the chief investigator, Joanne Bradley.

**Please initial
box after each
statement**

- | | |
|--|--------------------------|
| 1. I confirm that I have read the information sheet and fully understand what is expected of me within this study | <input type="checkbox"/> |
| 2. I confirm that I have had the opportunity to ask any questions and to have them answered | <input type="checkbox"/> |
| 3. I understand that the interview will be audio recorded and then typed up. Alternative names will be used so participants' identities remain confidential | <input type="checkbox"/> |
| 4. I understand that audio recordings will be kept until the data has been analysed and then destroyed. | <input type="checkbox"/> |
| 5. I understand that I am not obliged to take part in the study and can withdraw my participation up to two weeks after the interview has taken place | <input type="checkbox"/> |
| 6. I understand that the information from the interview will be pooled with other participants' responses, and may be published | <input type="checkbox"/> |
| 7. I consent to information and quotes from the interview being used in reports, conferences and training events. Participants will not be identified in the research by using alternative names. | <input type="checkbox"/> |
| 8. I understand that any information I give will remain strictly confidential unless it is thought that there is a risk of harm to myself or others, in which case the chief investigator may need to share this information with their research or field supervisor or other appropriate agencies. | <input type="checkbox"/> |
| 9. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from Lancaster University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. | <input type="checkbox"/> |

10. I consent to Lancaster University keeping written transcriptions of the interview for 5 years after the study has been published

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11. I consent to take part in the above study

☐

Name of Participant _____ **Signature** _____ **Date** _____

Name of Researcher _____ **Signature** _____ **Date** _____