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Longitudinal qualitative study of the experience of sleep and fatigue after traumatic brain injury

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ABSTRACT

Objectives: To explore the experience of fatigue and sleep difficulties over the first two years after traumatic brain injury (TBI).

Design: Longitudinal qualitative descriptive analysis of interviews completed as part of a larger longitudinal study of recovery following TBI. Data relating to the experience of fatigue and/or sleep was extracted and coded by two independent researchers.

Setting: Community-based study in the Hamilton and Auckland regions of New Zealand

Participants: Thirty adult participants who had experienced mild, moderate or severe brain injury within last 6 months (>16 years of age). Fifteen participants also nominated significant others to take part. Interviews were completed at 6, 12 and 24 months post-injury.

Results: Participants described feeling unprepared for the intensity, impact and persistent nature of fatigue and sleep difficulties after injury. Participants struggled to learn how to manage their difficulties by themselves and to adapt strategies in response to changing circumstances over time. Four themes were identified: 1) Making sense of fatigue and sleep after TBI; 2) Accepting the need for rest; 3) Learning how to rest and; 4) Need for rest impacts on ability to engage in life.

Conclusion: Targeted support to understand, accept and manage the sleep and fatigue difficulties experienced may be crucial to improve recovery and facilitate engagement in everyday life. Advice needs to be timely and revised for relevance over the course of recovery.

Keywords: sleep, fatigue, brain injury, qualitative, longitudinal

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The use of qualitative methods facilitated an in-depth exploration of the experience of fatigue and sleep after brain injury
- The longitudinal design enabled exploration of changes over time and influence within the wider recovery journey
- As participants were sampled from a larger qualitative study on what helps or hinders recovery following TBI, data was participant led rather than being a response to direct questioning about sleep and fatigue.
- The study did not measure nor explore the cause of sleep or fatigue difficulties and it remains unclear as to the extent that difficulties were directly related to the injury.
- Whilst diversity in experience was captured through the sampling approach, findings may not be generalizable to TBI populations in other communities.

INTRODUCTION

Sleep difficulties and fatigue have been found to be highly prevalent following traumatic brain injury (TBI), with a meta-analysis revealing that 49% of people experience clinically significant sleep difficulties[1] and over 70% experience fatigue.[2] Sleep difficulties can include an increased sleep need,[3] reduced ability to sleep,[1] and waking during the night.[4] Most improvement in fatigue and sleep difficulties occurs in the first 6 months following injury, and while many difficulties do resolve spontaneously, problems with sleep and fatigue can persist over the longer term.[5] Sleep difficulties and fatigue have been linked to: longer stays in rehabilitation;[6] increased frequency and severity of symptoms; lower mood; poorer community integration;[5] increased cognitive impairments;[5,6] and reduced ability to undertake employment.[7] Understanding the difficulties people experience, how they adapt, and areas where intervention is needed is fundamental to inform the development of responsive treatment.

Sleep difficulties may arise directly as a result of injury (due to biochemical changes or neurotransmitter dysfunction) or as a secondary response to other effects of the injury including pain, lower mood, changes in lifestyle, side effects of medication and post-traumatic stress.[8,9] Fatigue may result from diffuse neuronal injury making it harder for the brain to complete previously simple neurological functions.[10] Pre-existing sleep difficulties are also likely to negatively impact on recovery, reducing the body's ability to rest and recuperate. Whilst sleep and fatigue are concepts which often overlap and should be studied concurrently, problems with sleep and fatigue do not always co-occur.[11]

Quantitative data has provided important information on the prevalence and nature of fatigue and sleep difficulties after brain injury. However, the nuances of how these difficulties impact on the person, their recovery and life after brain injury remain poorly understood.[12] The experience of fatigue and sleep difficulties on significant others also remains unexplored. To our knowledge no longitudinal qualitative investigation has specifically explored the experience of fatigue or sleep difficulties after TBI to provide a more detailed understanding of their nature and impact. Findings from qualitative studies involving people after stroke have suggested that fatigue can be a major barrier to returning to a normal life, and that individuals with stroke can struggle to manage both their own and other people's expectations of what they are capable of due to their fatigue.[13,14] However, the study did not explore sleep difficulties experienced and differences in pathophysiology, and patterns of impairment as well as the demographic features of the population affected, mean that it is difficult to generalise findings from stroke populations to TBI.

Many people experience fluctuations in their symptoms in response to new events and as they begin to increasingly challenge themselves to return to everyday life.[15] Longitudinal qualitative research allows exploration of these changes over time, to identify key periods in recovery when different types of services might have greatest impact. This study aimed to explore people's experiences of fatigue and sleep difficulties over a two year period following TBI, using a longitudinal qualitative descriptive approach.

METHOD

Participant recruitment

Participants were recruited from three sources: 1) an epidemiological study of TBI,[16,17] 2) community-based patient support organisations, and 3) TBI service providers in two New Zealand cities (Auckland and Hamilton). To be included participants needed to: have experienced a TBI within the past 6 months, be aged over 16 years, be able to provide informed consent, and report experiencing persistent difficulties. Severity of injury was not a reason for exclusion from this study. Eligible participants were telephoned by a member of the research team to briefly explain the study and to ask if they would like to receive further information in the post.

Injuries were verified from medical records or information from treating clinicians accessed with participants' permission. TBI severity was categorised as mild, moderate or severe based on the worst recorded Glasgow Coma Score (GCS)[18] and/or Westmead Post-Traumatic Amnesia (PTA) scale, which are routinely recorded in NZ for a suspected brain injury.[19] Mild TBI was defined as a GCS score of 13-15 and/or PTA<24 hours; moderate TBI as a GCS score of 9-12 and/or PTA 1-6 days; and severe TBI as a GCS score of 8 or less and/or PTA 7 or more days. If GCS and PTA severities differed, the more severe category was assigned. All participants who met the study's inclusion criteria but who did not have a recorded GCS or PTA score were classified as mild in severity.

Data collection

Semi-structured interviews with participants and significant others were conducted individually or as a dyad depending on participant preference. Interviews were conducted in the person's home, at the university or other private place such as a room in a general practitioners clinic. Written informed consent was obtained prior to commencing the interview with participants. Participants were asked to talk about their experiences after TBI, key outcomes of importance over time, the barriers and facilitators to their recovery and strategies used. Interviews were completed 6, 12 and 24 months after injury and lasted between 30 and 75 minutes. Key points raised in the 6 month interviews were discussed with participants at the subsequent time points to help people to recall what had changed or remained the same since the previous interview.

Interviews were conducted by a team of research assistants who each had several years' experience in conducting qualitative interviews. Interviews were audio-recorded and transcribed verbatim. Data was also collected on patient demographic characteristics including age, gender, ethnicity, mechanism and severity of injury. As the aim of this specific analysis was to explore how people experience sleep and fatigue after TBI over time, only data from participants who completed all three interviews were included.

Analytic approach

Given that a person's experience after injury results from an interaction of a number of factors (including the person's sense of self, the nature of the injury, social relationships and place in society) social constructivism[20] was selected as the most appropriate theoretical framework to underpin the study. Key themes influencing the experience of sleep and fatigue after TBI were identified using a qualitative descriptive approach[21]. This approach encourages researchers to remain close to the data and to extract descriptions that convey events in the correct sequence and the meanings participants attribute to them.[21] Transcripts were read in full to increase familiarity with the data and to observe the participants overarching story and key issues identified for them. Whilst complete interviews were analysed for the main study (pending publication) for this specific investigation, transcripts were analysed separately and extracts relating to issues with sleep and fatigue were independently coded by two researchers (AT and VR). The coders both had a background in health psychology and experience in working with people following a brain injury. Any disagreements or uncertain codes were discussed with the wider research team until a consensus decision was achieved. Interviewer notes were also used to guide interpretation of the data. Codes were initially developed based on the 6 month interview transcripts. Codes were then combined where applicable and the code names refined to reflect the data. Constant comparison was used to ensure that each interview was compared with other interviews and not just considered in isolation.

To capture changes over time, the three interview transcripts for each participant were then re-read and, the 12 and 24 month transcripts were coded based on what had changed or remained the same for the person since their last interview. New issues emerging at the later time-points were assigned new codes if there was no fit with existing codes. Alternatively code names were refined to reflect changes within the data over time. Overarching themes were identified from the final code list. To provide context for each quote whilst protecting anonymity, extracts from the interviews are presented with information on the participants' age, gender and TBI severity. To reflect how the themes presented over time, data extracts are presented in chronological order, with the time-point specific for each extract presented at the end of each quote.

RESULTS

In total, 52 participants were recruited to the main study and completed at least one interview. Thirty of these participants (58%) completed interviews at all three time-points (6, 12 and 24 months). Half of these participants (N=15) completed at least one interview with a significant other. A description of the 30 participants included in this analysis is provided in Table 1. Participants were aged between 16 and 85 years of age, with a mean age of 43.5 years. Significant others included spouses (wife N = 8, husband N=1), partners (N = 2), ex-partners (N=1) and daughters (N=3). Ten of the 15 significant others (66.7%) completed all three interviews alongside the participant, with three (20%) taking part in two interviews and two (13.3%) taking part in just one interview.

INSERT TABLE 1 HERE

Fatigue and sleep difficulties were described as being problematic for the majority of participants over the two years following injury. Only two participants (both with mild TBI) did not refer to fatigue or sleep difficulties at any time point. Four participants reported that their difficulties were resolved by 24 months. One participant had investigations for a sleep disorder (sleep apnea) during the study, but this was ruled out at 12 months, and no further investigations appeared to be undertaken.

Overall, participants reported that their recovery pathway had been a challenging, stressful process of self-learning and discovery. Four themes were identified that captured the participants' changing experiences of fatigue and sleep difficulties over the first two years post-injury: 1) Making sense of fatigue and sleep after TBI; 2) Accepting the need for rest; 3) Learning how to rest; and 4) Need for rest impacts on ability to engage in life. These themes reflected an on-going and variable experience. This occurred particularly during times when people tried to challenge themselves such as by increasing time at work or on physical activity. Changes to the participants' routines appeared to trigger a reevaluation of their limits, priorities, and what they needed to do to enable them to manage change in their symptoms.

Theme 1. Making sense of fatigue and sleep after TBI

Data from interviews at 6 months indicated that participants were only just coming to terms with the reality that their fatigue and sleep difficulties were going to be long term problems resulting from their injuries. This meant that they were no longer able to do what they used to do. Most participants reported not being prepared for the intensity and persistent nature of fatigue and daytime sleepiness. Their main issues included feeling tired more easily than usual, needing to sleep a lot both day and night, and experiencing interrupted sleep at night. There was considerable uncertainty as to how long these difficulties would persist.

> Like the fatigue, which is kind of bugging me a little bit, especially as there is a big question mark over the long-term prognosis, I've been doing some research online and there's not actually a lot of information. (Male, 27 years, severe TBI, 6 months).

At this stage, those who received advice from others, described benefitting most from encouragement to monitor their activities, sleep patterns and rest periods in order to understand what changes had occurred.

> Oh, it was really good… because she [occupational therapist] made me write in my rest periods and that sort of thing, so you'd look at the day before and think mmm, only had half an hour of rest yesterday and I'm pretty tired today now I should have a longer rest and that sort of thing so that was really, really good. (Male, 50 years, moderate TBI, 6 months).

At 12 months, some participants seemed to be more aware of factors that made their fatigue or sleep worse, including stress. At this point in their recovery, they reflected that at this time point additional advice would be useful in how to manage these triggers most effectively:

> There is definitely some things I'm finding a bit harder, that I wouldn't have felt in term four last year… a full teaching load again and it's been quite stressful you know? I find my fatigue level is getting a little bit... I'm getting very, very tired towards the end of this term... I probably need more support from [the insurance provider] around this timeframe than any other time really. (Male, 29 years, mild TBI, 12 month).

At 24 months those experiencing difficulties were still struggling to make sense of the changes in their energy levels,

> I just get tired sometimes, I don't know why. Well like I know why but I don't know what really starts it too much, just doing stuff. (Male, 17 years, moderate TBI, 24 months).

Theme 2. Accepting the need for rest

Participants needed time to learn to accept the need for rest. The timeframe for this process differed across participants. At 6 months, many participants described pushing themselves too hard and reaching a breaking point before they accepted the need for rest. This was particularly observed by significant others. At this point, increases in fatigue and sleep difficulties occurred alongside an increase in other symptoms.

> That was really what broke the camel's back, at the end of last term when he was quite sick and just really got too fatigued, that's just how it was, and… the nausea and headaches and that stuff all came back again. (Significant other of male, 17years, moderate TBI, 6 months).

Participants described feeling like they needed permission to rest in the early stages of recovery and felt guilty about not completing everyday tasks in order to do so.

> Just having people there that are saying that it's ok to be able to cut your day out whenever you start feeling tired and have a sleep… You have half an hour and then you're up again and then you're away. It's because people are there on your side. It does make a difference. (Male, 51 years, mild TBI, 6 months).

A number of participants needed others to prompt them to take a rest or a nap when they started showing symptoms of tiredness until they became able to recognize for themselves that they needed a break.

> One of the guys came to me afterwards and said um do you... is fatigue an issue for you during the day, you know you are wearing yourself out during the day and crashing and burning? He said because I have noticed later in the day your color changes… and I said not that I'm aware of, I said everybody gets tired as the day goes on but I don't, haven't noticed any significant change in that, but that gave me the opportunity to ask him and a few more people what their perceptions of me were. (Male, 43 years, moderate TBI, 6months).

Over time, invariably life events occurred which meant participants sometimes needed to push themselves more than they would have liked. Participants described learning to manage this by allocating time to recover afterwards. This helped to prevent the negative trajectory of tiredness many experienced early in their recovery process.

> If I work myself too hard I've really got to go and have a sleep. Like on the weekend you know, I slept most of Sunday, that's because I worked a Saturday and I haven't worked a Saturday for a long time. (Male, 36 years, mild TBI, 12 months).

Even at 24 months, participants reported having to actively monitor their energy levels and activities to enable them to function most effectively. They also expressed concern or worry that if they failed to monitor their fatigue – overdoing it may lead to lasting or permanent problems.

> If I push too hard the body pushes back. The problem is I've got to be consciously aware if the body pushes back it might be pushing back permanently, or hard. So you got to sort of take notice then go for a lie down. (Male, 50 years, severe TBI, 24 months).

Theme 3. Learning how to rest

This theme first emerged at the 12 month time-point after participants became aware of the need to allow themselves to rest. Participants reported learning over time ways they could make their rest time more effective such as planning nap times, resting before becoming over-tired and reducing distractions (light and noise). This typically followed a process of trial and error, reflection and self-discovery.

> I'll give you an example, I had my sisters here on Wednesday, I give them lunch on a Wednesday, and I sometimes go and have a rest after a cook for them and feed them and that…but I didn't do it on Wednesday, and then I felt, I was really tired after I had had dinner, I was tired. I tried to go to bed, I said to [my spouse] I think I've got to go to bed, and I went to bed early but then I had to get up again, you know, I sort of dozed and listened to music and that, and dozed and then I was awake again. At half past six I went off to bed, that's how tired I was and I got up at half past nine and then I had to wait till 3am I think it was before I could actually get off to sleep. So I think it is related to um, you know getting overtired. (Female, 72 years, mild TBI, 12 months).

However, despite learning about resting, participants remained unsure about whether daytime naps specifically were a good thing for their recovery and wellbeing. Many were concerned that napping did not fit with their self-concept, that napping would become a bad habit, and were worried about the potential effect daytime napping would have on their nighttime sleep. Despite this the majority of participants described taking a nap if they became too tired or without planning to. There was uncertainty about when to nap, for how long and about how to best regulate nap times.

> Sit down, have a cup of tea and ah have a lie down or snooze, except trouble is that sometimes a snooze turns into a two or three hours sleep or partial sleep, not proper sleep, but then that's probably not good because you end up waking up half way during the middle of the night. (Male, 54 years, mild TBI, 12 months).

Over time, people described learning how long they needed to nap to achieve greatest benefit and to gradually extend the periods of activity before resting.

> I take longer lunch break. I usually have a lay down for 20 minutes. And that helps me a lot and then I know that I can work every day full time, that's all... but when I do big days like today, yeah I can feel it. And it takes a while to recover from it, but, sometimes you just have to. (Female, 32 years, mild TBI, 12 months).

By 24 months, participants perceived napping as increasingly beneficial and a necessary strategy to restore their energy levels. It became challenging to take a nap when they were outside of the home, although some participants described findings ways of adapting.

> So it was just being aware of where you were at the time and not to push it out or go flat out, and it was ok to slow down and have a bit of a nap in the afternoon, not a long one but if you had half an hour you felt real good. There was lots of times I'd be down town or something like that and I would think "gosh I can't handle this." So you go back to the car and maybe drive down under the tree by the river or something and just have a nap for half an hour and the whole afternoon would change. It would be so much easier. (Male, 51 years, mild TBI, 24 months).

Theme 4. Need for rest impacts on ability to engage in life

In most cases participants had not fully re-integrated back into normal life in the first few months after injury and there was little perceived impact of needing to nap or rest. However, in the longer term, participants described needing to re-evaluate their priorities and develop strategies to manage their own and others' expectations regarding their need for rest.

> You quickly realize that, that's not the way I would have reacted usually and so told me a lot about letting go, let other people do things for you, it's important letting go very quickly. When people are around and you start to feel tired you just say 'well that's me, you can stay here if you're happy but I am going to bed', whereas before I would never have done something like that I would have thought 'how rude'. (Female, 32 years, mild TBI, 6 months).

At 12 months, participants talked more about how the need to rest impacted on their ability to re-engage in everyday activities. The need to nap could become stressful, particularly if visitors arrived unexpectedly or other activities over ran. The need to rest a lot also restricted how much people could do in the day. Significant others were often shocked at how long people needed to rest so long after injury.

> He'll sleep for between like 12 hours at night, between 9 and 9 at night, and he'll sleep during 1 and 5 in the afternoon, all day every day. I mean every day's the same, so that a lot, so he's actually only up between 9 and 1 and 5 and 9, yeah so that in itself limits… limits his activity time. (Significant other of male, 65 years, severe TBI, 12 months).

Many participants talked about becoming isolated and losing social connections as they had not been able to invest the time or find ways to maintain relationships alongside managing their need for rest.

> Interviewer: So it's also had an impact on relationships with friends then?
> Participant: Yeah well I can't really do anything cause of my fatigue. I'd go to school and come home and be smashed. (Male, 17 years, moderate TBI, 24 months).

The impact of fatigue and sleep difficulties grew worse over time, even if the difficulties themselves were gradually improving or remaining stable. For example, the negative impact of needing to nap became most pronounced when participants tried to reengage more with normal life activities such as to getting back to employment. Participants described struggling to find ways of having a rest at work or saw it as a major barrier to seeking new employment.

> I believe that's what holds me down from being employable. Because I've got to stop and have a little nap. Even if it's only for 5 minutes, I have to sit back and just relax. (Female, 51 years, mild TBI, 24 months).

DISCUSSION

This study explored how people post TBI spontaneously described experiences of sleep and fatigue difficulties over the first two years post injury. Whilst many participants received services in the acute stage of recovery, analysis revealed they felt unprepared for the intensity and persistence of difficulties that they encountered in the longer term. Participants described struggling to understand, accept and manage their fatigue and sleep difficulties even many months or years after their injury. Initially participants reported pushing themselves too hard and reaching a breaking point before realizing the importance of needing to rest and pace themselves. Participants used trial and error to find ways of managing fatigue and sleep difficulties that worked for them. As their recovery progressed, participants found it increasingly difficult to balance the need for rest with the competing demands of everyday life particularly when returning to work. The findings highlight that a different approach is needed by practitioners to prevent set-backs and help people to better prepare for and manage sleep and fatigue over time.

This study confirms previous quantitative findings that fatigue and sleep difficulties are a common occurrence after TBI and have a substantial impact on recovery and community re-integration after TBI.[1,2,5,7] The findings also complement previous qualitative research on fatigue after stroke, highlighting the need for support to help people to understand the difficulties they are experiencing.[13] Indeed those supported with early information appeared to experience less of a struggle with accepting the need for rest compared to people who received no professional input. This study has also revealed specific ways support can be provided more effectively through facilitating acceptance of difficulties and emphasizing the need to allow people to rest early to prevent setbacks. Our analysis suggests that advice must be individually tailored to fit with the person, their life and circumstances. A summary of recommendations arising from the results are outlined in Table 2.

INSERT TABLE 2 HERE

Concerns were raised by participants specifically about daytime napping, despite its widespread use. Participants described napping for between 20 minutes and several hours. For the healthy population naps of up to 40 minutes have been found to be most beneficial in terms of improving alertness, performance and learning, whereas longer nap times appear to detrimental and linked to low mood and morbidity.[22] It remains unclear how much sleep is required after brain injury and while this is likely to vary considerably between individuals, our findings suggest that proactive monitoring of activity, fatigue, sleep and rest may help to identify the optimum rest times for individuals. Participants expressed concern about daytime naps not reflecting their true identity, making them lazy, and becoming habit forming. These issues should be explored with people after TBI when discussing strategies for managing fatigue and sleep difficulties. Ideally these strategies would focus on how to gradually increase activity and reduce rest periods giving people a greater sense of control and reducing some concerns about their long-term dependency on napping. Further research is needed to explore optimum nap times for people after brain injury, and to explore the notion of whether excessive rest can result in harm.

This study did not specifically explore the cause of the sleep and fatigue difficulties and yet the extent and similarity of difficulties is noteworthy. Whilst some participants compared their sleep quality after TBI to how they were before their injury, the study did not explore the extent that their difficulties were directly related to the injury. Only one participant described receiving investigations for a sleep disorder, sleep apnea. Therefore some participants may have been experiencing a specific sleep disorder that had not been identified.[23] Despite the open interview approach having some limitations, the study has enhanced our understanding that whatever the cause, sleep difficulties and fatigue disrupt recovery from TBI and reintegration back into the community and need to be identified and addressed as a core part of rehabilitation.

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CONTRIBUTORS

AT was a named investigator on the parent study. Led and conducted the design and analysis of the current study and drafted the manuscript

VR supported the data extraction and analysis on the current study and contributed to the writing of the manuscript

WL was a named investigator on the parent study. Supported the design and data analysis of the current study and contributed to the writing of the manuscript

LWM was a named investigator on the parent study. Supported the design and data analysis of the current study and contributed to the writing of the manuscript

NS was a named investigator on the parent study. Supported the design and data analysis of the current study and contributed to the writing of the manuscript

KM Was principal investigator on the parent study, contributed to the design and analysis of the findings and contributed to the writing of the manuscript.

JF provided support with data collection
AC was the study manager for the parent study and provided support with data collection
MH provided cultural advice on engaging with Maori communities
NK provided advice on the study design and data analysis
VF provided medical advice and facilitated recruitment of participants through a TBI incidence study conducted in the study region

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COMPETING INTERESTS

Subsequent to this research funding being awarded Kath McPherson has taken up the position of Chief Executive at the Health Research Council of NZ, but was not involved in the decision making process of grant funding. The other authors report no conflicts of interest.

ETHICS APPROVAL

Ethics approval was obtained from the National Health and Disability Ethics Committee (Ref: NTY/10/08/061) and the Auckland University of Technology ethics committee (Ref: 10/280).

DATA SHARING STATEMENT

No additional data are available

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562 **Table 1. Participant Characteristics**

	Participants who experienced a TBI (N= 30) Frequency (%)
Gender	
Male	20 (66.7)
Female	10 (33.3)
Ethnicity	
European	22 (73.3)
Maori	5 (16.7)
Other	3 (10.0)
Mechanism of Injury	
Fall	11 (36.7)
Motor Vehicle Accident	10 (33.3)
Assault	4 (13.3)
Hit by object	5 (16.7)
TBI Severity	
Mild	12 (40.0)
Moderate	8 (26.7)
Severe	10 (33.3)

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564 **Table 2. How people can be supported to manage sleep and fatigue after TBI**

Rationale	**Information needed or action required**
People at risk of persistent problems need to be identified early to enable provision of support to facilitate recovery	Routine screening in the acute phase for fatigue and sleep difficulties after TBI
People described being surprised and unprepared by the intensity and persistence of difficulties encountered and needing to understand. Knowledge was found to be empowering and facilitated the process of acceptance of difficulties encountered	Information is needed early about how many people are affected, the possible trajectories of recovery, why difficulties may occur after brain injury
Whilst common themes were identified, individual experiences of sleep and fatigue varied considerably and advice needs to address the specific challenges encountered	Discussion to determine how fatigue and sleep affects each person and to identify any known triggers is needed
Participants frequently talked about having to learn from pushing themselves too far and suffering the consequences before realizing the need to rest. Many were initially reluctant to allow themselves to rest due to expectations of others, self-perceptions and concerns about effecting night time sleep or becoming habit forming	Raise awareness of the importance of rest post-TBI and address any misconceptions about resting.
Many participants expressed that they were initially unable to tell when they needed a rest before they became too exhausted a needed a longer rest time that then impacted on nocturnal sleep	Initially some people may need others to help them to monitor their symptoms, and plan their rest periods.
Participants described having to learn by themselves over time about the best way to rest and having to try lots of different things before finding what worked for them. The theme related to learning to rest only became evident at 12 months suggesting support is needed much earlier to help people to manage and improve recovery	Advice on how to nap/rest most effectively is needed. For example; finding a dark quiet place; avoiding activities usually associated with resting but that stimulate the brain e.g.watching TV, helping people plan for if they need to rest outside the home and/or using an alarm clock to prevent people sleeping for too long if they do nap in the day.
Participants described finding it difficult to take a break outside of everyday routines and being setback following unexpected events. Participants learnt over time how to find ways of enabling themselves to have a rest outside the home and to give themselves time to recover after unexpected or demanding events.	People need help to identify ways that they can have a rest outside of the home e.g. at work. Contingency plans are needed to help people to cope when unexpected events occur and disrupt their routine.
Initially people described napping for several hours, several times a day and found that their naps hindered their ability to sleep at night. Over time participants described	If people need to sleep during the day, they need guidance to find what works for them to recharge their batteries to help them get through the day whilst not interfering with

learning by themselves as to what was the best time of day and duration they needed to take a nap without disrupting nighttime sleep or feeling unrefreshed afterwards.	sleep at night. Monitoring nap times, nocturnal sleep patterns and fatigue levels may help to identify the optimum nap time for each individual
As difficulties can arise or worsen at a later stage as people reintegrate back in everyday life, follow up is needed to monitor progress and to adapt advice accordingly	Follow up is needed to monitor progress
Participants described uncertainty about how and when to reduce their rest periods. Over time they reported learning to gradually increase activities and reduce nap/rest times but to return to previous levels if symptoms worsened before re-challenging themselves	Advice is needed on how and when to reduce nap and rest periods over time

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Exploring sleep and fatigue experiences of male and female adults over the two years following traumatic brain injury: a longitudinal qualitative study

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Exploring sleep and fatigue experiences of male and female adults over the two years following traumatic brain injury: a longitudinal qualitative study

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ABSTRACT

Objectives: To explore the experience of fatigue and sleep difficulties over the first two years after traumatic brain injury (TBI).

Design: Longitudinal qualitative descriptive analysis of interviews completed as part of a larger longitudinal study of recovery following TBI. Data relating to the experience of fatigue and/or sleep was extracted and coded by two independent researchers.

Setting: Community-based study in the Hamilton and Auckland regions of New Zealand

Participants: Thirty adult participants who had experienced mild, moderate or severe brain injury within last 6 months (>16 years of age). Fifteen participants also nominated significant others to take part. Interviews were completed at 6, 12 and 24 months post-injury.

Results: Participants described feeling unprepared for the intensity, impact and persistent nature of fatigue and sleep difficulties after injury. Participants struggled to learn how to manage their difficulties by themselves and to adapt strategies in response to changing circumstances over time. Four themes were identified: 1) Making sense of fatigue and sleep after TBI; 2) Accepting the need for rest; 3) Learning how to rest and; 4) Need for rest impacts on ability to engage in life.

Conclusion: Targeted support to understand, accept and manage the sleep and fatigue difficulties experienced may be crucial to improve recovery and facilitate engagement in everyday life. Advice needs to be timely and revised for relevance over the course of recovery.

Keywords: sleep, fatigue, brain injury, qualitative, longitudinal

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The use of qualitative methods facilitated an in-depth exploration of the experience of fatigue and sleep after brain injury
- The longitudinal design enabled exploration of changes over time and influence within the wider recovery journey
- As participants were sampled from a larger qualitative study on what helps or hinders recovery following TBI, data was participant led rather than being a response to direct questioning about sleep and fatigue.
- The study did not measure nor explore the cause of sleep or fatigue difficulties and it remains unclear as to the extent that difficulties were directly related to the injury.
- Whilst diversity in experience was captured through the sampling approach, findings may not be generalizable to TBI populations in other communities.

INTRODUCTION

Sleep difficulties and fatigue have been found to be highly prevalent following traumatic brain injury (TBI), with a meta-analysis revealing that 49% of people experience clinically significant sleep difficulties[1] and over 70% experience fatigue.[2] Sleep difficulties can include an increased sleep need,[3] reduced ability to sleep,[1] and waking during the night.[4] Most improvement in fatigue and sleep difficulties occurs in the first 6 months following injury, and while many difficulties do resolve spontaneously, problems with sleep and fatigue can persist over the longer term.[5] Sleep difficulties and fatigue have been linked to: longer stays in rehabilitation;[6] increased frequency and severity of symptoms; lower mood; poorer community integration;[5] increased cognitive impairments;[5,6] and reduced ability to undertake employment.[7] Understanding the difficulties people experience, how they adapt, and areas where intervention is needed is fundamental to inform the development of responsive treatment.

Sleep difficulties may arise directly as a result of injury (due to biochemical changes or neurotransmitter dysfunction) or as a secondary response to other effects of the injury including pain, lower mood, changes in lifestyle, side effects of medication and post-traumatic stress.[8,9] Fatigue may result from diffuse neuronal injury making it harder for the brain to complete previously simple neurological functions.[10] Pre-existing sleep difficulties are also likely to negatively impact on recovery, reducing the body's ability to rest and recuperate. Whilst sleep and fatigue are concepts which often overlap and should be studied concurrently, problems with sleep and fatigue do not always co-occur.[11]

Quantitative data has provided important information on the prevalence and nature of fatigue and sleep difficulties after brain injury. However, the nuances of how these difficulties impact on the person, their recovery and life after brain injury remain poorly understood.[12] The experience of fatigue and sleep difficulties on significant others also remains unexplored. To our knowledge no longitudinal qualitative investigation has specifically explored the experience of fatigue or sleep difficulties after TBI to provide a more detailed understanding of their nature and impact. Findings from qualitative studies involving people after stroke have suggested that fatigue can be a major barrier to returning to a normal life, and that individuals with stroke can struggle to manage both their own and other people's expectations of what they are capable of due to their fatigue.[13,14] However, the study did not explore sleep difficulties experienced and differences in pathophysiology, and patterns of impairment as well as the demographic features of the population affected, mean that it is difficult to generalise findings from stroke populations to TBI.

Many people experience fluctuations in their symptoms in response to new events and as they begin to increasingly challenge themselves to return to everyday life.[15] Longitudinal qualitative research allows exploration of these changes over time, to identify key periods in recovery when different types of services might have greatest impact. During analysis of a longitudinal study of people's experiences of recovery over two years following TBI, it became evident that sleep and fatigue formed a key part of the recovery process. Therefore this paper aimed to conduct a focused analysis of people's experiences of fatigue and sleep difficulties over a two year period following TBI, using a longitudinal qualitative descriptive approach.

METHOD

Research question

How do people experience poor sleep and fatigue over the two years following a TBI?

Participant recruitment

Participants were recruited from three sources: 1) an epidemiological study of TBI,[16,17] 2) community-based patient support organisations, and 3) TBI service providers in two New Zealand cities (Auckland and Hamilton). To be included participants needed to: have experienced a TBI within the past 6 months, be aged over 16 years, be able to provide informed consent, and report experiencing persistent difficulties. Severity of injury was not a reason for exclusion from this study. Eligible participants were telephoned by a member of the research team to briefly explain that the study was looking to explore people's experiences of recovering from a brain injury and to ask if they would like to receive further information in the post.

Injuries were verified from medical records or information from treating clinicians accessed with participants' permission. TBI severity was categorised as mild, moderate or severe based on the worst recorded Glasgow Coma Score (GCS)[18] and/or Westmead Post-Traumatic Amnesia (PTA) scale within two weeks, which are routinely recorded in NZ for a suspected brain injury.[19] Mild TBI was defined as a GCS score of 13-15 and/or PTA<24 hours; moderate TBI as a GCS score of 9-12 and/or PTA 1-6 days; and severe TBI as a GCS score of 8 or less and/or PTA 7 or more days. If GCS and PTA severities differed, the more severe category was assigned. All participants who met the study's inclusion criteria but who did not have a recorded GCS or PTA score were classified as mild in severity.

Data collection

Semi-structured interviews with participants and significant others were conducted individually or as a dyad depending on participant preference. Interviews were conducted in the person's home, at the university or other private place such as a room in a general practitioners clinic. Written informed consent was obtained prior to commencing the interview with participants. Interviews were completed 6, 12 and 24 months after injury and lasted between 30 and 75 minutes. The interviews were intended to be open to ensure a range of experiences and issues of importance could be identified. Questions focused on how the person felt they were recovering, the key things that were important to the participant at that time-point, any things that they found helpful or that they felt were hindering their recovery. Key points raised in the 6 month interviews were discussed with participants at the subsequent time points to help people to recall what had changed or remained the same since the previous interview.

Interviews were conducted by a team of male and female research assistants who each had several years' experience in conducting qualitative interviews. Interviews were audio-recorded and transcribed verbatim. Participants were allocated a unique study number and all identifying information was removed from the transcripts to ensure anonymity and confidentiality. Data was also collected on patient demographic characteristics including age, gender, ethnicity, mechanism and severity of injury. To enable the participation of people who were experiencing cognitive impairment, participants were able to have a support person with them during the interview. Interviewers also reflected back people's experiences to them to ensure understanding. As the aim of this specific analysis was to explore how people experience sleep and fatigue after TBI over time, only data from participants who completed all three interviews were included.

Definition of terms

For the purposes of this study sleep difficulties were defined as problems with initiating and/or maintaining nocturnal sleep. Fatigue is defined as the feeling of extreme tiredness. This may manifest as diminished energy, physical weakness or reduced mental capacity.

Fatigue overlaps with sleep difficulties as when people experience fatigue, they are likely to experience an increased desire to sleep. Sleeping during the day as a result of fatigue may impact on nocturnal sleep as the body experiences a reduced sleep need. Information relating to either or both of these distinct, but interrelated constructs, including strategies for managing them such as daytime napping and resting was coded as part of the analysis.

Analytic approach

Given that a person's experience after injury results from an interaction of a number of factors (including the person's sense of self, the nature of the injury, social relationships and place in society) social constructivism[20] was selected as the most appropriate theoretical framework to underpin the study. According to Crotty[20], people develop varied subjective interpretations of their experiences that are influenced by the wider context of the person, including other people around them. Prior to this research, it was assumed that participants would have developed interpretations of the changes in their sleep patterns and energy levels since experiencing a brain injury. The research design consequently aimed to provide the opportunity for participants to freely share their own personal interpretations through questioning of their overall recovery experience, rather than direct questioning about sleep and fatigue.

Key themes influencing the experience of sleep and fatigue after TBI were identified using a qualitative descriptive approach[21]. This approach encourages researchers to remain close to the data and to extract descriptions that convey events in the correct sequence and the meanings participants attribute to them.[21] Transcripts were read in full to increase familiarity with the data and to observe the participants overarching story and key issues identified for them. Extracts relating to issues with sleep and fatigue were independently coded using paper and pen by two researchers (AT and VR). There were no predetermined codes used to guide the data analysis. The coders both had a background in health psychology and experience in working with people following a brain injury. Any differences in interpretation or where there was uncertainty around coding were discussed with the wider research team until a consensus decision was achieved.

Interviewer notes were also used to guide interpretation of the data. Codes were initially developed based on the 6-9 month interview transcripts. Codes were then combined where applicable and the code names refined to reflect the data. Constant comparison was used to ensure that each interview was compared with other interviews and not just considered in isolation to elicit variation and conflicting experiences. Negative cases that challenged the emerging analysis resulted in changes to the coding, such that the final analysis presented in this paper incorporates any negative cases. To capture changes over time, the three interview transcripts for each participant were then re-read and, the 12-15 and 24 month transcripts coded based on what had changed or remained the same for the person since their last interview. New issues emerging at the later time-points were assigned new codes if there was no fit with existing codes. Alternatively code names were refined to reflect changes within the data over time. Overarching themes relating to sleep and fatigue were identified from the final code list (see coding tree in appendix 1). Few changes were required to the code list for the last proportion of interviews reflecting that data saturation was reached. To provide context for each quote whilst protecting anonymity, extracts from the interviews are presented with information on the participants' gender, age, and TBI severity. To reflect how the themes presented over time, data extracts within each theme are presented in chronological order. The time-point specific for each extract presented at the end of each quote.

RESULTS

In total, of those who were able to be contacted about the study (N=92) and who met the eligibility criteria (N= 71), 53 (75%) participants consented to participate in the main study and completed at least one interview. Thirty of these participants (58%) completed interviews at all three time-points (6-9, 12-15 and 24 months). Half of these participants (N=15) completed at least one interview with a significant other. A description of the 30 participants included in this analysis is provided in Table 1. Participants were aged between 16 and 85 years of age, with a mean age of 43.5 years. Significant others included spouses (wife N = 8, husband N=1), partners (N = 2), ex-partners (N=1) and daughters (N=3). Ten of the 15 significant others (66.7%) completed all three interviews alongside the participant, with three (20%) taking part in two interviews and two (13.3%) taking part in just one interview. There were no differences observed in age, gender, TBI severity or ethnicity between participants in the main study and current analysis.

INSERT TABLE 1 HERE

Fatigue and sleep difficulties were described as being problematic for the majority of participants over the two years following injury. Only two participants (both with mild TBI) did not refer to fatigue or sleep difficulties at any time point. The main issues experienced were feeling tired more easily than usual, needing to sleep a lot both day and night and having interrupted sleep at night. Four participants reported that their difficulties were resolved by 24 months. One participant had investigations for a sleep disorder (sleep apnea) during the study, but this was ruled out at 12 months, and no further investigations appeared to be undertaken.

Overall, participants reported that their recovery pathway had been a challenging, stressful process of self-learning and discovery. Four themes were identified that captured the participants' changing experiences of fatigue and sleep difficulties over the first two years post-injury: 1) Making sense of fatigue and sleep after TBI; 2) Accepting the need for rest; 3)

Learning how to rest; and 4) Need for rest impacts on ability to engage in life. These themes reflected an on-going and variable experience. This occurred particularly during times when people tried to challenge themselves such as by increasing time at work or on physical activity. Changes to the participants' routines appeared to trigger a reevaluation of their limits, priorities, and what they needed to do to enable them to manage change in their symptoms.

Theme 1. Making sense of fatigue and sleep after TBI

Data from interviews at 6 months indicated that participants were only just coming to terms with the reality that their fatigue and sleep difficulties were going to be long term problems resulting from their injuries. This meant that they were no longer able to do what they used to do. Most participants reported not being prepared for the intensity and persistent nature of fatigue and daytime sleepiness. There was considerable uncertainty as to how long these difficulties would persist.

> Like the fatigue, which is kind of bugging me a little bit, especially as there is a big question mark over the long-term prognosis, I've been doing some research online and there's not actually a lot of information. (Male, 27 years, severe TBI, 6 months).

At this stage, those who received advice from others, described benefitting most from encouragement to monitor their activities, sleep patterns and rest periods in order to understand what changes had occurred.

> Oh, it was really good… because she [occupational therapist] made me write in my rest periods and that sort of thing, so you'd look at the day before and think mmm, only had half an hour of rest yesterday and I'm pretty tired today now I should have a longer rest and that sort of thing so that was really, really good. (Male, 50 years, moderate TBI, 6 months).

At 12 months, some participants seemed to be more aware of factors that made their fatigue or sleep worse, including stress. At this point in their recovery, they reflected that at this time point additional advice would be useful in how to manage these triggers most effectively:

> There is definitely some things I'm finding a bit harder, that I wouldn't have felt in term four last year… a full teaching load again and it's been quite stressful you know? I find my fatigue level is getting a little bit... I'm getting very, very tired towards the end of this term... I probably need more support from [the insurance provider] around this timeframe than any other time really. (Male, 29 years, mild TBI, 12 month).

At 24 months those experiencing difficulties were still struggling to make sense of the changes in their energy levels,

> I just get tired sometimes, I don't know why. Well like I know why but I don't know what really starts it too much, just doing stuff. (Male, 17 years, moderate TBI, 24 months).

Theme 2. Accepting the need for rest

Participants needed time to learn to accept the need for rest. The timeframe for this process differed across participants. At 6 months, many participants described pushing themselves too hard and reaching a breaking point before they accepted the need for rest. This was particularly observed by significant others. At this point, increases in fatigue and sleep difficulties occurred alongside an increase in other symptoms.

> That was really what broke the camel's back, at the end of last term when he was quite sick and just really got too fatigued, that's just how it was, and… the nausea and headaches and that stuff all came back again. (Significant other of male, 17years, moderate TBI, 6 months).

Participants described feeling like they needed permission to rest in the early stages of recovery and felt guilty about not completing everyday tasks in order to do so.

> Just having people there that are saying that it's ok to be able to cut your day out whenever you start feeling tired and have a sleep… You have half an hour and then you're up again and then you're away. It's because people are there on your side. It does make a difference. (Male, 51 years, mild TBI, 6 months).

A number of participants needed others to prompt them to take a rest or a nap when they started showing symptoms of tiredness until they became able to recognize for themselves that they needed a break.

> One of the guys came to me afterwards and said um do you... is fatigue an issue for you during the day, you know you are wearing yourself out during the day and crashing and burning? He said because I have noticed later in the day your color changes… and I said not that I'm aware of, I said everybody gets tired as the day goes on but I don't, haven't noticed any significant change in that, but that gave me the opportunity to ask him and a few more people what their perceptions of me were. (Male, 43 years, moderate TBI, 6months).

Over time, invariably life events occurred which meant participants sometimes needed to push themselves more than they would have liked. Participants described learning to manage this by allocating time to recover afterwards. This helped to prevent the negative trajectory of tiredness many experienced early in their recovery process.

> If I work myself too hard I've really got to go and have a sleep. Like on the weekend you know, I slept most of Sunday, that's because I worked a Saturday and I haven't worked a Saturday for a long time. (Male, 36 years, mild TBI, 12 months).

Even at 24 months, participants reported having to actively monitor their energy levels and activities to enable them to function most effectively. They also expressed concern or worry that if they failed to monitor their fatigue – overdoing it may lead to lasting or permanent problems.

> If I push too hard the body pushes back. The problem is I've got to be consciously aware if the body pushes back it might be pushing back permanently, or hard. So you got to sort of take notice then go for a lie down. (Male, 50 years, severe TBI, 24 months).

Theme 3. Learning how to rest

This theme first emerged at the 12 month time-point after participants became aware of the need to allow themselves to rest. Participants reported learning over time ways they could make their rest time more effective such as planning nap times, resting before becoming over-tired and reducing distractions (light and noise). This typically followed a process of trial and error, reflection and self-discovery**.**

> I'll give you an example, I had my sisters here on Wednesday, I give them lunch on a Wednesday, and I sometimes go and have a rest after a cook for them and feed them and that…but I didn't do it on Wednesday, and then I felt, I was really tired after I had had dinner, I was tired. I tried to go to bed, I said to [my spouse] I think I've got to go to bed, and I went to bed early but then I had to get up again, you know, I sort of dozed and listened to music and that, and dozed and then I was awake again. At half past six I went off to bed, that's how tired I was and I got up at half past nine and then I had to wait till 3am I think it was before I could actually get off to sleep. So I think it is related to um, you know getting overtired. (Female, 72 years, mild TBI, 12 months).

However, despite learning about resting, participants remained unsure about whether daytime naps specifically were a good thing for their recovery and wellbeing. Many were concerned that napping did not fit with their self-concept, that napping would become a bad habit, and were worried about the potential effect daytime napping would have on their nighttime sleep. Despite this the majority of participants described taking a nap if they became too tired or without planning to. There was uncertainty about when to nap, for how long and about how to best regulate nap times.

> Sit down, have a cup of tea and ah have a lie down or snooze, except trouble is that sometimes a snooze turns into a two or three hours sleep or partial sleep, not proper sleep, but then that's probably not good because you end up waking up half way during the middle of the night. (Male, 54 years, mild TBI, 12 months).

Over time, people described learning how long they needed to nap to achieve greatest benefit and to gradually extend the periods of activity before resting.

> I take longer lunch break. I usually have a lay down for 20 minutes. And that helps me a lot and then I know that I can work every day full time, that's all... but when I do big days like today, yeah I can feel it. And it takes a while to recover from it, but, sometimes you just have to. (Female, 32 years, mild TBI, 12 months).

By 24 months, participants perceived napping as increasingly beneficial and a necessary strategy to restore their energy levels. It became challenging to take a nap when they were outside of the home, although some participants described findings ways of adapting.

> So it was just being aware of where you were at the time and not to push it out or go flat out, and it was ok to slow down and have a bit of a nap in the afternoon, not a long one but if you had half an hour you felt real good. There was lots of times I'd be down town or something like that and I would think "gosh I can't handle this." So you go back to the car and maybe drive down under the tree by the river or something and just have a nap for half an hour and the whole afternoon would change. It would be so much easier. (Male, 51 years, mild TBI, 24 months).

Theme 4. Need for rest impacts on ability to engage in life

In most cases participants had not fully re-integrated back into normal life in the first few months after injury and there was little perceived impact of needing to nap or rest. However, in the longer term, participants described needing to re-evaluate their priorities and develop strategies to manage their own and others' expectations regarding their need for rest.

> You quickly realize that, that's not the way I would have reacted usually and so told me a lot about letting go, let other people do things for you, it's important letting go very quickly. When people are around and you start to feel tired you just say 'well that's me, you can stay here if you're happy but I am going to bed', whereas before I would never have done something like that I would have thought 'how rude'. (Female, 32 years, mild TBI, 6 months).

At 12 months, participants talked more about how the need to rest impacted on their ability to re-engage in everyday activities. The need to nap could become stressful, particularly if visitors arrived unexpectedly or other activities over ran. The need to rest a lot also restricted how much people could do in the day. Significant others were often shocked at how long people needed to rest so long after injury.

> He'll sleep for between like 12 hours at night, between 9 and 9 at night, and he'll sleep during 1 and 5 in the afternoon, all day every day. I mean every day's the same, so that a lot, so he's actually only up between 9 and 1 and 5 and 9, yeah so that in itself limits… limits his activity time. (Significant other of male, 65 years, severe TBI, 12 months).

Many participants talked about becoming isolated and losing social connections as they had not been able to invest the time or find ways to maintain relationships alongside managing their need for rest.

> Interviewer: So it's also had an impact on relationships with friends then?
> Participant: Yeah well I can't really do anything cause of my fatigue. I'd go to school and come home and be smashed. (Male, 17 years, moderate TBI, 24 months).

The impact of fatigue and sleep difficulties grew worse over time, even if the difficulties themselves were gradually improving or remaining stable. For example, the negative impact of needing to nap became most pronounced when participants tried to reengage more with normal life activities such as to getting back to employment. Participants described struggling to find ways of having a rest at work or saw it as a major barrier to seeking new employment.

> I believe that's what holds me down from being employable. Because I've got to stop and have a little nap. Even if it's only for 5 minutes, I have to sit back and just relax. (Female, 51 years, mild TBI, 24 months).

DISCUSSION

This paper presents analysis of how people post TBI spontaneously described experiences of sleep and fatigue difficulties over the first two years post injury. Whilst many participants received services in the acute stage of recovery, analysis revealed they felt unprepared for the intensity and persistence of difficulties that they encountered in the longer term. Participants described struggling to understand, accept and manage their fatigue and sleep difficulties even many months or years after their injury. Initially participants reported pushing themselves too hard and reaching a breaking point before realizing the importance of needing to rest and pace themselves. Participants used trial and error to find ways of managing fatigue and sleep difficulties that worked for them. As their recovery progressed, participants found it increasingly difficult to balance the need for rest with the competing demands of everyday life particularly when returning to work. The findings highlight that a different approach is needed by practitioners to prevent set-backs and help people to better prepare for and manage sleep and fatigue over time.

This study confirms previous quantitative findings that fatigue and sleep difficulties are a common occurrence after TBI and have a substantial impact on recovery and community re-integration after TBI.[1,2,5,7] The findings also complement previous qualitative research on fatigue after stroke, highlighting the need for support to help people to understand the difficulties they are experiencing.[13] Indeed those supported with early information appeared to experience less of a struggle with accepting the need for rest compared to people who received no professional input. This study has also revealed specific ways support can be provided more effectively through facilitating acceptance of difficulties and emphasizing the need to allow people to rest early to prevent setbacks. Our analysis suggests that advice must be individually tailored to fit with the person, their life and circumstances. A summary of recommendations arising from the results of this study are outlined in Table 2. It should be noted that this advice should not be considered in isolation from other research evidence on the management of sleep disorders/ insomnia and that further research is needed to test the effectiveness of these recommendations.

INSERT TABLE 2 HERE

Concerns were raised by participants specifically about daytime napping, despite its widespread use. Participants described napping for between 20 minutes and several hours. For the healthy population naps of up to 40 minutes have been found to be most beneficial in terms of improving alertness, performance and learning, whereas longer nap times appear to detrimental and linked to low mood and morbidity.[22] It remains unclear how much sleep is required after brain injury and while this is likely to vary considerably between individuals, our findings suggest that proactive monitoring of activity, fatigue, sleep and rest may help to identify the optimum rest times for individuals. Participants expressed concern about daytime naps not reflecting their true identity, making them lazy, and becoming habit forming. These issues should be explored with people after TBI when discussing strategies for managing fatigue and sleep difficulties. Ideally these strategies would focus on how to gradually increase activity and reduce rest periods giving people a greater sense of control and reducing some concerns about their long-term dependency on napping. Further research is needed to explore optimum nap times for people after brain injury, and to explore the notion of whether excessive rest can result in harm.

This study did not set out to specifically explore the cause of the sleep and fatigue difficulties and yet the extent and similarity of difficulties is noteworthy. Whilst some participants compared their sleep quality after TBI to how they were before their injury, the study did not explore the extent that their difficulties were directly related to the injury. Only one participant described receiving investigations for a sleep disorder, sleep apnea. Therefore some participants may have been experiencing a specific sleep disorder that had not been identified.[23] Approximately two thirds of participants had received services in the acute phase of their injury. In many cases fatigue was discussed and pacing and planning strategies discussed. However, no participants reported discussing their sleep and daytime napping patterns with rehabilitation practitioners. This suggests that sleep and napping need to be routinely screened for and addressed as part of service provision to assist in the recovery process. Despite the open interview approach having some limitations, the study has enhanced our understanding that whatever the cause, sleep difficulties and fatigue disrupt recovery from TBI and reintegration back into the community and need to be identified and addressed as a core part of rehabilitation.

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CONTRIBUTORS

AT was a named investigator on the parent study. Led and conducted the design and analysis of the current study and drafted the manuscript
VR supported the data extraction and analysis on the current study and contributed to the writing of the manuscript
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LWM was a named investigator on the parent study. Supported the design and data analysis of the current study and contributed to the writing of the manuscript
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KM Was principal investigator on the parent study, contributed to the design and analysis of the findings and contributed to the writing of the manuscript.
JF provided support with data collection

AC was the study manager for the parent study and provided support with data collection
MH provided cultural advice on engaging with Maori communities
NK provided advice on the study design and data analysis
VF provided medical advice and facilitated recruitment of participants through a TBI incidence study conducted in the study region

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COMPETING INTERESTS

Subsequent to this research funding being awarded Kath McPherson has taken up the position of Chief Executive at the Health Research Council of NZ, but was not involved in the decision making process of grant funding. The other authors report no conflicts of interest.

ETHICS APPROVAL

Ethics approval was obtained from the National Health and Disability Ethics Committee (Ref: NTY/10/08/061) and the Auckland University of Technology ethics committee (Ref: 10/280).

DATA SHARING STATEMENT

No additional data are available

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615 **Table 1. Participant Characteristics**

	Participants who experienced a TBI (N= 30) Frequency (%)
Gender	
Male	20 (66.7)
Female	10 (33.3)
Ethnicity	
European	22 (73.3)
Maori	5 (16.7)
Other	3 (10.0)
Mechanism of Injury	
Fall	11 (36.7)
Motor Vehicle Accident	10 (33.3)
Assault	4 (13.3)
Hit by object	5 (16.7)
TBI Severity	
Mild	12 (40.0)
Moderate	8 (26.7)
Severe	10 (33.3)
Mode of Referral	
Previous research study	11 (36.6)
Service provider	19 (63.3)

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617 **Table 2. How people can be supported to manage sleep and fatigue after TBI**

Rationale	Information needed or action required
People at risk of persistent problems need to be identified early to enable provision of support to facilitate recovery	Routine screening in the acute phase for fatigue and sleep difficulties after TBI
People described being surprised and unprepared by the intensity and persistence of difficulties encountered and needing to understand. Knowledge was found to be empowering and facilitated the process of acceptance of difficulties encountered	Information is needed early about how many people are affected, the possible trajectories of recovery, why difficulties may occur after brain injury
Whilst common themes were identified, individual experiences of sleep and fatigue varied considerably and advice needs to address the specific challenges encountered	Discussion to determine how fatigue and sleep affects each person and to identify any known triggers is needed
Participants frequently talked about having to learn from pushing themselves too far and suffering the consequences before realizing the need to rest. Many were initially reluctant to allow themselves to rest due to expectations of others, self-perceptions and concerns about effecting night time sleep or becoming habit forming	Raise awareness of the importance of rest post-TBI and address any misconceptions about resting.
Many participants expressed that they were initially unable to tell when they needed a rest before they became too exhausted a needed a longer rest time that then impacted on nocturnal sleep	Initially some people may need others to help them to monitor their symptoms, and plan their rest periods.
Participants described having to learn by themselves over time about the best way to rest and having to try lots of different things before finding what worked for them. The theme related to learning to rest only became evident at 12 months suggesting support is needed much earlier to help people to manage and improve recovery	Advice on how to nap/rest most effectively is needed. For example; finding a dark quiet place; avoiding activities usually associated with resting but that stimulate the brain e.g. watching TV, helping people plan for if they need to rest outside the home and/or using an alarm clock to prevent people sleeping for too long if they do nap in the day.
Participants described finding it difficult to take a break outside of everyday routines and being setback following unexpected events. Participants learnt over time how to find ways of enabling themselves to have a rest outside the home and to give themselves time to recover after unexpected or demanding events.	People need help to identify ways that they can have a rest outside of the home e.g. at work. Contingency plans are needed to help people to cope when unexpected events occur and disrupt their routine.
Initially people described napping for several hours, several times a day and found that their naps hindered their ability to sleep at night. Over time participants described learning by themselves as to what was the	If people need to sleep during the day, they need guidance to find what works for them to recharge their batteries to help them get through the day whilst not interfering with sleep at night. Monitoring nap times,

best time of day and duration they needed to take a nap without disrupting nighttime sleep or feeling unrefreshed afterwards.	nocturnal sleep patterns and fatigue levels may help to identify the optimum nap time for each individual
As difficulties can arise or worsen at a later stage as people reintegrate back in everyday life, follow up is needed to monitor progress and to adapt advice accordingly	Follow up is needed to monitor progress
Participants described uncertainty about how and when to reduce their rest periods. Over time they reported learning to gradually increase activities and reduce nap/rest times but to return to previous levels if symptoms worsened before re-challenging themselves	Advice is needed on how and when to reduce nap and rest periods over time

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Coding Tree

Themes	Sub themes
Making sense of fatigue and sleep after TBI	Feeling unprepared Persistent and enduring nature confusing Understanding triggers Early advice is helpful
Accepting the need for rest	Reaching a crisis point Needing permission to rest Needing others to monitor and prompt Continuous monitoring
Learning how to rest	Knowing how to rest Are naps a good or bad thing? Knowing how and when to push self Allowing self to recover
Need for rest impacts on ability to engage in life	Re-evaluating priorities Restriction in participation Managing unexpected events

COREQ Checklist

Domain 1: Research team and reflexivity	Page Number
1. Which author/s conducted the interview or focus group?	4
2. What were the researcher's credentials? E.g. PhD, MD	1
3. What was their occupation at the time of the study	4
4. Was the researcher male or female?	4
5. What experience or training did the researcher have?	4
6. Was a relationship established prior to study commencement?	4
7. What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
8. What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4
Domain 2: study design	
9. What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5
10. How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
11. How were participants approached? e.g. face-to-face, telephone, mail, email	4
12. How many participants were in the study?	6
13. How many people refused to participate or dropped out? Reasons?	6
14. Where was the data collected? e.g. home, clinic, workplace	4
15. Was anyone else present besides the participants and researchers?	4
16. What are the important characteristics of the sample? e.g. demographic data, date	Table 1
17. Were questions, prompts, guides provided by the authors? Was it pilot tested?	4
18. Were repeat interviews carried out? If yes, how many?	4
19. Did the research use audio or visual recording to collect the data?	4
20. Were field notes made during and/or after the interview or focus group?	5
21. What was the duration of the interviews or focus group?	4
22. Was data saturation discussed?	6
23. Were transcripts returned to participants for comment and/or correction?	6
Domain 3: analysis and findings	
24. How many data coders coded the data?	5
25. Did authors provide a description of the coding tree?	Appendix 1
26. Were themes identified in advance or	5

derived from the data?	
27. What software, if applicable, was used to manage the data?	5
28. Did participants provide feedback on the findings?	6
29. Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	7-11
30. Was there consistency between the data presented and the findings?	7-11
31. Were major themes clearly presented in the findings?	7-11
32. Is there a description of diverse cases or discussion of minor themes?	6

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Exploring the experience of sleep and fatigue in male and female adults over the two years following traumatic brain injury: A qualitative descriptive study

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Exploring the experience of sleep and fatigue in male and female adults over the two years following traumatic brain injury: A qualitative descriptive study

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ABSTRACT

Objectives: To explore the experience of fatigue and sleep difficulties over the first two years after traumatic brain injury (TBI).

Design: Longitudinal qualitative descriptive analysis of interviews completed as part of a larger longitudinal study of recovery following TBI. Data relating to the experience of fatigue and/or sleep was extracted and coded by two independent researchers.

Setting: Community-based study in the Hamilton and Auckland regions of New Zealand

Participants: Thirty adult participants who had experienced mild, moderate or severe brain injury within last 6 months (>16 years of age). Fifteen participants also nominated significant others to take part. Interviews were completed at 6, 12 and 24 months post-injury.

Results: Participants described feeling unprepared for the intensity, impact and persistent nature of fatigue and sleep difficulties after injury. Participants struggled to learn how to manage their difficulties by themselves and to adapt strategies in response to changing circumstances over time. Four themes were identified: 1) Making sense of fatigue and sleep after TBI; 2) Accepting the need for rest; 3) Learning how to rest and; 4) Need for rest impacts on ability to engage in life.

Conclusion: Targeted support to understand, accept and manage the sleep and fatigue difficulties experienced may be crucial to improve recovery and facilitate engagement in everyday life. Advice needs to be timely and revised for relevance over the course of recovery.

Keywords: sleep, fatigue, brain injury, qualitative, longitudinal

STRENGTHS AND LIMITATIONS OF THIS STUDY

- The use of qualitative methods facilitated an in-depth exploration of the experience of fatigue and sleep after brain injury
- The longitudinal design enabled exploration of changes over time and influence within the wider recovery journey
- As participants were sampled from a larger qualitative study on what helps or hinders recovery following TBI, data was participant led rather than being a response to direct questioning about sleep and fatigue.
- The study did not measure nor explore the cause of sleep or fatigue difficulties and it remains unclear as to the extent that difficulties were directly related to the injury.
- Whilst diversity in experience was captured through the sampling approach, findings may not be generalizable to TBI populations in other communities.

INTRODUCTION

Sleep difficulties and fatigue have been found to be highly prevalent following traumatic brain injury (TBI), with a meta-analysis revealing that 49% of people experience clinically significant sleep difficulties[1] and over 70% experience fatigue.[2] Sleep difficulties can include an increased sleep need,[3] reduced ability to sleep,[1] and waking during the night.[4] Most improvement in fatigue and sleep difficulties occurs in the first 6 months following injury, and while many difficulties do resolve spontaneously, problems with sleep and fatigue can persist over the longer term.[5] Sleep difficulties and fatigue have been linked to: longer stays in rehabilitation;[6] increased frequency and severity of symptoms; lower mood; poorer community integration;[5] increased cognitive impairments;[5,6] and reduced ability to undertake employment.[7] Understanding the difficulties people experience, how they adapt, and areas where intervention is needed is fundamental to inform the development of responsive treatment.

Sleep difficulties may arise directly as a result of injury (due to biochemical changes or neurotransmitter dysfunction) or as a secondary response to other effects of the injury including pain, lower mood, changes in lifestyle, side effects of medication and post-traumatic stress.[8,9] Fatigue may result from diffuse neuronal injury making it harder for the brain to complete previously simple neurological functions.[10] Pre-existing sleep difficulties are also likely to negatively impact on recovery, reducing the body's ability to rest and recuperate. Whilst sleep and fatigue are concepts which often overlap and should be studied concurrently, problems with sleep and fatigue do not always co-occur.[11]

Quantitative data has provided important information on the prevalence and nature of fatigue and sleep difficulties after brain injury. However, the nuances of how these difficulties impact on the person, their recovery and life after brain injury remain poorly understood.[12] The experience of fatigue and sleep difficulties on significant others also remains unexplored. To our knowledge no longitudinal qualitative investigation has specifically explored the experience of fatigue or sleep difficulties after TBI to provide a more detailed understanding of their nature and impact. Findings from qualitative studies involving people after stroke have suggested that fatigue can be a major barrier to returning to a normal life, and that individuals with stroke can struggle to manage both their own and other people's expectations of what they are capable of due to their fatigue.[13,14] However, the study did not explore sleep difficulties experienced and differences in pathophysiology, and patterns of impairment as well as the demographic features of the population affected, mean that it is difficult to generalise findings from stroke populations to TBI.

Many people experience fluctuations in their symptoms in response to new events and as they begin to increasingly challenge themselves to return to everyday life.[15] Longitudinal qualitative research allows exploration of these changes over time, to identify key periods in recovery when different types of services might have greatest impact. During analysis of a longitudinal study of people's experiences of recovery over two years following TBI, it became evident that sleep and fatigue formed a key part of the recovery process. Therefore this paper aimed to conduct a focused analysis of people's experiences of fatigue and sleep difficulties over a two year period following TBI, using a longitudinal qualitative descriptive approach.

METHOD

Research question

This research aimed to explore how people experienced poor sleep and fatigue over the two years following a TBI and identify any factors that increased or decreased fatigue and sleep difficulties over time.

Participant recruitment

Participants were recruited from three sources: 1) an epidemiological study of TBI,[16,17] 2) community-based patient support organisations, and 3) TBI service providers in two New Zealand cities (Auckland and Hamilton). To be included participants needed to: have experienced a TBI within the past 6 months, be aged over 16 years, be able to provide informed consent, and report experiencing persistent difficulties. Severity of injury was not a reason for exclusion from this study. Eligible participants were telephoned by a member of the research team to briefly explain that the study was looking to explore people's experiences of recovering from a brain injury and to ask if they would like to receive further information in the post.

Injuries were verified from medical records or information from treating clinicians accessed with participants' permission. TBI severity was categorised as mild, moderate or severe based on the worst recorded Glasgow Coma Score (GCS)[18] and/or Westmead Post-Traumatic Amnesia (PTA) scale within two weeks, which are routinely recorded in NZ for a suspected brain injury.[19] Mild TBI was defined as a GCS score of 13-15 and/or PTA<24 hours; moderate TBI as a GCS score of 9-12 and/or PTA 1-6 days; and severe TBI as a GCS score of 8 or less and/or PTA 7 or more days. If GCS and PTA severities differed, the more severe category was assigned. All participants who met the study's inclusion criteria but who did not have a recorded GCS or PTA score were classified as mild in severity.

Data collection

Semi-structured interviews with participants and significant others were conducted individually or as a dyad depending on participant preference. Interviews were conducted in the person's home, at the university or other private place such as a room in a general practitioners clinic. Written informed consent was obtained prior to commencing the interview with participants. Interviews were completed 6, 12 and 24 months after injury and lasted between 30 and 75 minutes. The interview questions were intended to be open to ensure a range of experiences and issues of importance to participants could be identified. Questions focused on how the person felt they were recovering, the key things that were important to the participant at that time-point, any things that they found helpful or that they felt were hindering their recovery. Key points raised in the 6 month interviews were discussed with participants at the subsequent time points to help people to recall what had changed or remained the same since the previous interview. Participants were not directly questioned about sleep and fatigue but when these issues were raised, the participants were prompted to talk about their experience and the impact on their recovery.

Interviews were conducted by a team of male and female research assistants who each had several years' experience in conducting qualitative interviews. Interviews were audio-recorded and transcribed verbatim. Participants were allocated a unique study number and all identifying information was removed from the transcripts to ensure anonymity and confidentiality. Data was also collected on patient demographic characteristics including age, sex, ethnicity, mechanism and severity of injury. To enable the participation of people who were experiencing cognitive impairment, participants were able to have a support person with them during the interview. Interviewers also reflected back people's experiences to them to ensure understanding. As the aim of this specific analysis was to explore how people experience sleep and fatigue after TBI over time, only data from participants who completed all three interviews were included.

Definition of terms

For the purposes of this study sleep difficulties were defined as problems with initiating and/or maintaining nocturnal sleep. Fatigue was defined as the feeling of extreme tiredness, which may manifest as diminished energy, physical weakness or reduced mental capacity.

Fatigue overlaps with sleep difficulties as when people experience fatigue, they are likely to experience an increased desire to sleep. Sleeping during the day as a result of fatigue may impact on nocturnal sleep as the body experiences a reduced sleep need. Information relating to either or both of these distinct, but interrelated constructs, including strategies for managing them such as daytime napping and resting was coded as part of the analysis.

Analytic approach

Given that a person's experience after injury results from an interaction of a number of factors (including the person's sense of self, the nature of the injury, social relationships and place in society) social constructivism[20] was selected as the most appropriate theoretical framework to underpin the study. According to Crotty[20], people develop varied subjective interpretations of their experiences that are influenced by the wider context of the person, including other people around them. Prior to this research, it was assumed that participants would have developed interpretations of the changes in their sleep patterns and energy levels since experiencing a brain injury. The research design consequently aimed to provide the opportunity for participants to freely share their own personal interpretations through questioning of their overall recovery experience, rather than direct questioning about sleep and fatigue.

Key themes influencing the experience of sleep and fatigue after TBI were identified using a qualitative descriptive approach[21]. This approach encourages researchers to remain close to the data and to extract descriptions that convey events in the correct sequence and the meanings participants attribute to them.[21] Transcripts were read in full to increase familiarity with the data and to observe the participants overarching story and key issues identified for them. Extracts relating to issues with sleep and fatigue were independently coded using paper and pen by two researchers (AT and VR). There were no predetermined codes used to guide the data analysis. The coders both had a background in health psychology and experience in working with people following a brain injury. Any differences in interpretation or where there was uncertainty around coding were discussed with the wider research team until a consensus decision was achieved. For example, the initial proposed codes of 'managing fatigue with rest' was taken for discussion with the wider research team as data coded here seemed to reflect a more complex process than was reflected by the initial code name. After reviewing extracts from this code, ‘knowing how to rest’ was agreed upon as a more accurate code name to reflect the underlying process of trial and error that participants went through in understanding how to rest in a way that worked for them, their family and their lifestyle.

Interviewer notes were also used to guide interpretation of the data. Codes were initially developed based on the 6-9 month interview transcripts. Codes were then combined where applicable and the code names refined to reflect the data. Constant comparison was used to ensure that each interview was compared with other interviews and not just considered in isolation to elicit variation and conflicting experiences. Negative cases that challenged the emerging analysis resulted in changes to the coding, such that the final analysis presented in this paper incorporates any negative cases. To capture changes over time, the three interview transcripts for each participant were then re-read and, the 12-15 and 24 month transcripts coded based on what had changed or remained the same for the person since their last interview. New issues emerging at the later time-points were assigned new codes if there was no fit with existing codes. Alternatively code names were refined to reflect changes within the data over time. Overarching themes relating to sleep and fatigue were identified from the final code list (see coding tree in appendix 1). Few changes were required to the code list for the last proportion of interviews reflecting that data saturation was reached. To provide context for each quote whilst protecting anonymity, extracts from the interviews are presented with information on the participants’ sex, age, and TBI severity. To reflect how the themes presented over time, data extracts within each theme are presented in chronological order. The time-point specific for each extract presented at the end of each quote.

RESULTS

In total, of those who were able to be contacted about the study (N=92) and who met the eligibility criteria (N= 71), 53 (75%) participants and/or their significant others consented to participate in the main study and completed at least one interview and 18 participants declined. Thirty of these participants (58%) completed interviews at all three time-points (6-9, 12-15 and 24 months). Half of these participants (N=15) completed at least one interview with a significant other. A description of the 30 participants included in this analysis is provided in Table 1. Participants were aged between 16 and 85 years of age, with a mean age of 43.5 years. Significant others included spouses (wife N = 8, husband N=1), partners (N = 2), ex-partners (N=1) and daughters (N=3). Ten of the 15 significant others (66.7%) completed all three interviews alongside the participant, with three (20%) taking part in two interviews and two (13.3%) taking part in just one interview. There were no differences observed in age, sex, TBI severity or ethnicity between participants in the main study and current analysis.

INSERT TABLE 1 HERE

Fatigue and sleep difficulties were described as being problematic for the majority of participants over the two years following injury. Only two participants (both with mild TBI) did not refer to fatigue or sleep difficulties at any time point. The main issues experienced were feeling tired more easily than usual, needing to sleep a lot both day and night and having interrupted sleep at night. Four participants reported that their difficulties were resolved by 24 months. One participant had investigations for a sleep disorder (sleep apnea) during the study, but this was ruled out at 12 months, and no further investigations appeared to be undertaken.

Overall, participants reported that their recovery pathway had been a challenging, stressful process of self-learning and discovery. Four themes were identified that captured the participants' changing experiences of fatigue and sleep difficulties over the first two years post-injury: 1) Making sense of fatigue and sleep after TBI; 2) Accepting the need for rest; 3) Learning how to rest; and 4) Need for rest impacts on ability to engage in life. These themes reflected an on-going and variable experience. This occurred particularly during times when people tried to challenge themselves such as by increasing time at work or on physical activity. Changes to the participants' routines appeared to trigger a reevaluation of their limits, priorities, and what they needed to do to enable them to manage change in their symptoms.

Theme 1. Making sense of fatigue and sleep after TBI

Data from interviews at 6 months indicated that participants were only just coming to terms with the reality that their fatigue and sleep difficulties were going to be long term problems resulting from their injuries. This meant that they were no longer able to do what they used to do. Most participants reported not being prepared for the intensity and persistent nature of fatigue and daytime sleepiness. There was considerable uncertainty as to how long these difficulties would persist.

> Like the fatigue, which is kind of bugging me a little bit, especially as there is a big question mark over the long-term prognosis, I've been doing some research online and there's not actually a lot of information. (Male, 27 years, severe TBI, 6 months).

At this stage, those who received advice from others, described benefitting most from encouragement to monitor their activities, sleep patterns and rest periods in order to understand what changes had occurred.

> Oh, it was really good… because she [occupational therapist] made me write in my rest periods and that sort of thing, so you'd look at the day before and think mmm, only had half an hour of rest yesterday and I'm pretty tired today now I should have a longer rest and that sort of thing so that was really, really good. (Male, 50 years, moderate TBI, 6 months).

At 12 months, some participants seemed to be more aware of factors that made their fatigue or sleep worse, including stress. At this point in their recovery, they reflected that at this time point additional advice would be useful in how to manage these triggers most effectively:

> There is definitely some things I'm finding a bit harder, that I wouldn't have felt in term four last year… a full teaching load again and it's been quite stressful you know? I find my fatigue level is getting a little bit... I'm getting very, very tired towards the end of this term... I probably need more support from [the insurance

> provider] around this timeframe than any other time really. (Male, 29 years, mild TBI, 12 month).

At 24 months those experiencing difficulties were still struggling to make sense of the changes in their energy levels,

> I just get tired sometimes, I don't know why. Well like I know why but I don't know what really starts it too much, just doing stuff. (Male, 17 years, moderate TBI, 24 months).

Theme 2. Accepting the need for rest

Participants needed time to learn to accept the need for rest. The timeframe for this process differed across participants. At 6 months, many participants described pushing themselves too hard and reaching a breaking point before they accepted the need for rest. This was particularly observed by significant others. At this point, increases in fatigue and sleep difficulties occurred alongside an increase in other symptoms.

> That was really what broke the camel's back, at the end of last term when he was quite sick and just really got too fatigued, that's just how it was, and… the nausea and headaches and that stuff all came back again. (Significant other of male, 17years, moderate TBI, 6 months).

Participants described feeling like they needed permission to rest in the early stages of recovery and felt guilty about not completing everyday tasks in order to do so.

> Just having people there that are saying that it's ok to be able to cut your day out whenever you start feeling tired and have a sleep… You have half an hour and then you're up again and then you're away. It's because people are there on your side. It does make a difference. (Male, 51 years, mild TBI, 6 months).

A number of participants needed others to prompt them to take a rest or a nap when they started showing symptoms of tiredness until they became able to recognize for themselves that they needed a break.

> One of the guys came to me afterwards and said um do you... is fatigue an issue for you during the day, you know you are wearing yourself out during the day and crashing and burning? He said because I have noticed later in the day your color changes… and I said not that I'm aware of, I said everybody gets tired as the day goes on but I don't, haven't noticed any significant change in that, but that gave me the opportunity to ask him and a few more people what their perceptions of me were. (Male, 43 years, moderate TBI, 6months).

Over time, invariably life events occurred which meant participants sometimes needed to push themselves more than they would have liked. Participants described learning to manage this by allocating time to recover afterwards. This helped to prevent the negative trajectory of tiredness many experienced early in their recovery process.

> If I work myself too hard I've really got to go and have a sleep. Like on the weekend you know, I slept most of Sunday, that's because I worked a Saturday and I haven't worked a Saturday for a long time. (Male, 36 years, mild TBI, 12 months).

Even at 24 months, participants reported having to actively monitor their energy levels and activities to enable them to function most effectively. They also expressed concern or worry that if they failed to monitor their fatigue – overdoing it may lead to lasting or permanent problems.

> If I push too hard the body pushes back. The problem is I've got to be consciously aware if the body pushes back it might be pushing back permanently, or hard. So you got to sort of take notice then go for a lie down. (Male, 50 years, severe TBI, 24 months).

Theme 3. Learning how to rest

This theme first emerged at the 12 month time-point after participants became aware of the need to allow themselves to rest. Participants reported learning over time ways they could make their rest time more effective such as planning nap times, resting before becoming over-tired and reducing distractions (light and noise). This typically followed a process of trial and error, reflection and self-discovery.

> I'll give you an example, I had my sisters here on Wednesday, I give them lunch on a Wednesday, and I sometimes go and have a rest after a cook for them and feed them and that…but I didn't do it on Wednesday, and then I felt, I was really tired after I had had dinner, I was tired. I tried to go to bed, I said to [my spouse] I think I've got to go to bed, and I went to bed early but then I had to get up again, you know, I sort of dozed and listened to music and that, and dozed and then I was awake again. At half past six I went off to bed, that's how tired I was and I got up at half past nine and then I had to wait till 3am I think it was before I could actually get off to sleep. So I think it is related to um, you know getting overtired. (Female, 72 years, mild TBI, 12 months).

However, despite learning about resting, participants remained unsure about whether daytime naps specifically were a good thing for their recovery and wellbeing. Many were concerned that napping did not fit with their self-concept, that napping would become a bad habit, and were worried about the potential effect daytime napping would have on their nighttime sleep. Despite this the majority of participants described taking a nap if they became too tired or without planning to. There was uncertainty about when to nap, for how long and about how to best regulate nap times.

> Sit down, have a cup of tea and ah have a lie down or snooze, except trouble is that sometimes a snooze turns into a two or three hours sleep or partial sleep, not proper sleep, but then that's probably not good because you end up waking up half way during the middle of the night. (Male, 54 years, mild TBI, 12 months).

Over time, people described learning how long they needed to nap to achieve greatest benefit and to gradually extend the periods of activity before resting.

> I take longer lunch break. I usually have a lay down for 20 minutes. And that helps me a lot and then I know that I can work every day full time, that's all... but when I do big days like today, yeah I can feel it. And it takes a while to recover from it, but, sometimes you just have to. (Female, 32 years, mild TBI, 12 months).

By 24 months, participants perceived napping as increasingly beneficial and a necessary strategy to restore their energy levels. It became challenging to take a nap when they were outside of the home, although some participants described findings ways of adapting.

> So it was just being aware of where you were at the time and not to push it out or go flat out, and it was ok to slow down and have a bit of a nap in the afternoon, not a long one but if you had half an hour you felt real good. There was lots of times I'd be down town or something like that and I would think "gosh I can't handle this." So you go back to the car and maybe drive down under the tree by the river or something and just have a nap for half an hour and the whole afternoon would change. It would be so much easier. (Male, 51 years, mild TBI, 24 months).

Theme 4. Need for rest impacts on ability to engage in life

In most cases participants had not fully re-integrated back into normal life in the first few months after injury and there was little perceived impact of needing to nap or rest. However, in the longer term, participants described needing to re-evaluate their priorities and develop strategies to manage their own and others' expectations regarding their need for rest.

> You quickly realize that, that's not the way I would have reacted usually and so told me a lot about letting go, let other people do things for you, it's important letting go very quickly. When people are around and you start to feel tired you just say 'well that's me, you can stay here if you're happy but I am going to bed', whereas before I would never have done something like that I would have thought 'how rude'. (Female, 32 years, mild TBI, 6 months).

At 12 months, participants talked more about how the need to rest impacted on their ability to re-engage in everyday activities. The need to nap could become stressful, particularly if visitors arrived unexpectedly or other activities over ran. The need to rest a lot also restricted how much people could do in the day. Significant others were often shocked at how long people needed to rest so long after injury.

> He'll sleep for between like 12 hours at night, between 9 and 9 at night, and he'll sleep during 1 and 5 in the afternoon, all day every day. I mean every day's the same, so that a lot, so he's actually only up between 9 and 1 and 5 and 9, yeah so that in itself limits… limits his activity time. (Significant other of male, 65 years, severe TBI, 12 months).

Many participants talked about becoming isolated and losing social connections as they had not been able to invest the time or find ways to maintain relationships alongside managing their need for rest.

> Interviewer: So it's also had an impact on relationships with friends then?
> Participant: Yeah well I can't really do anything cause of my fatigue. I'd go to school and come home and be smashed. (Male, 17 years, moderate TBI, 24 months).

The impact of fatigue and sleep difficulties grew worse over time, even if the difficulties themselves were gradually improving or remaining stable. For example, the negative impact of needing to nap became most pronounced when participants tried to reengage more with normal life activities such as to getting back to employment. Participants described struggling to find ways of having a rest at work or saw it as a major barrier to seeking new employment.

> I believe that's what holds me down from being employable. Because I've got to stop and have a little nap. Even if it's only for 5 minutes, I have to sit back and just relax. (Female, 51 years, mild TBI, 24 months).

Across the time-points there was no evidence of sex differences or differences in experience by TBI severity. The experience of sleep and fatigue was more a factor of the person, what they brought to the injury and their context.

DISCUSSION

This paper presents analysis of how people post TBI spontaneously described experiences of sleep and fatigue difficulties over the first two years post injury. Whilst many participants received services in the acute stage of recovery, analysis revealed they felt unprepared for the intensity and persistence of difficulties that they encountered in the longer term. Participants described struggling to understand, accept and manage their fatigue and sleep difficulties even many months or years after their injury. Initially participants reported pushing themselves too hard and reaching a breaking point before realizing the importance of needing to rest and pace themselves. Participants used trial and error to find ways of managing fatigue and sleep difficulties that worked for them. As their recovery progressed, participants found it increasingly difficult to balance the need for rest with the competing demands of everyday life particularly when returning to work. The findings highlight that a different approach is needed by practitioners to prevent set-backs and help people to better prepare for and manage sleep and fatigue over time.

Previous quantitative findings have proposed that people who have experienced a mild TBI have more difficulties initiating or maintaining sleep (insomnia) and those with moderate to severe injuries are more likely to experience hypersomnia.[22] The findings from this study highlight that given the wide variation in experience within TBI severity categories observed, it is important that each case is individually assessed. The extracts from participants, highlight that pre-injury factors (such as prior sleep quality), how they understand and manage their difficulties after injury and the contextual demands placed on them (such as work and family commitments) all influence their experience of sleep and fatigue and need to be considered and addressed within treatment.

This study confirms previous quantitative findings that fatigue and sleep difficulties are a common occurrence after TBI and have a substantial impact on recovery and community re-integration after TBI.[1,2,5,7] The findings also complement previous qualitative research on fatigue after stroke, highlighting the need for support to help people to understand the difficulties they are experiencing.[13] Indeed those supported with early information appeared to experience less of a struggle with accepting the need for rest compared to people who received no professional input. This study has also revealed specific ways support can be provided more effectively through facilitating acceptance of difficulties and emphasizing the need to allow people to rest early to prevent setbacks. Our analysis suggests that advice must be individually tailored to fit with the person, their life and circumstances. A summary of recommendations arising from the results of this study are outlined in Table 2. It should be noted that this advice should not be considered in isolation from other research evidence on the management of sleep disorders/ insomnia and that further research is needed to test the effectiveness of these recommendations.

INSERT TABLE 2 HERE

Concerns were raised by participants specifically about daytime napping, despite its widespread use. Participants described napping for between 20 minutes and several hours. For the healthy population naps of up to 40 minutes have been found to be most beneficial in terms of improving alertness, performance and learning, whereas longer nap times appear to detrimental and linked to low mood and morbidity.[23] It remains unclear how much sleep is required after brain injury and while this is likely to vary considerably between individuals, our findings suggest that proactive monitoring of activity, fatigue, sleep and rest may help to identify the optimum rest times for individuals. Participants expressed concern about daytime naps not reflecting their true identity, making them lazy, and becoming habit forming. These issues should be explored with people after TBI when discussing strategies for managing fatigue and sleep difficulties. Ideally these strategies would focus on how to gradually increase activity and reduce rest periods giving people a greater sense of control and reducing some concerns about their long-term dependency on napping. Further research is needed to explore optimum nap times for people after brain injury, and to explore the notion of whether excessive rest can result in harm.

This study did not set out to specifically explore the cause of the sleep and fatigue difficulties and yet the extent and similarity of difficulties is noteworthy. Whilst some participants compared their sleep quality after TBI to how they were before their injury, the study did not explore the extent that their difficulties were directly related to the injury. Only one participant described receiving investigations for a sleep disorder, sleep apnea. Therefore some participants may have been experiencing a specific sleep disorder that had not been identified.[24] Approximately two thirds of participants had received services in the acute phase of their injury. In many cases fatigue was discussed and pacing and planning strategies discussed. However, no participants reported discussing their sleep and daytime napping patterns with rehabilitation practitioners. This suggests that sleep and napping need to be routinely screened for and addressed as part of service provision to assist in the recovery process. Despite the open interview approach having some limitations, the study has enhanced our understanding that whatever the cause, sleep difficulties and fatigue disrupt recovery from TBI and reintegration back into the community and need to be identified and addressed as a core part of rehabilitation.

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CONTRIBUTORS

AT was a named investigator on the parent study. Led and conducted the design and analysis of the current study and drafted the manuscript
VR supported the data extraction and analysis on the current study and contributed to the writing of the manuscript
WL was a named investigator on the parent study. Supported the design and data analysis of the current study and contributed to the writing of the manuscript
LWM was a named investigator on the parent study. Supported the design and data analysis of the current study and contributed to the writing of the manuscript
NS was a named investigator on the parent study. Supported the design and data analysis of the current study and contributed to the writing of the manuscript
KM Was principal investigator on the parent study, contributed to the design and analysis of the findings and contributed to the writing of the manuscript.
JF provided support with data collection
AC was the study manager for the parent study and provided support with data collection
MH provided cultural advice on engaging with Maori communities
NK provided advice on the study design and data analysis
VF provided medical advice and facilitated recruitment of participants through a TBI incidence study conducted in the study region

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COMPETING INTERESTS

Subsequent to this research funding being awarded Kath McPherson has taken up the position of Chief Executive at the Health Research Council of NZ, but was not involved in the decision making process of grant funding. The other authors report no conflicts of interest.

ETHICS APPROVAL

Ethics approval was obtained from the National Health and Disability Ethics Committee (Ref: NTY/10/08/061) and the Auckland University of Technology ethics committee (Ref: 10/280).

DATA SHARING STATEMENT

No additional data are available

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Table 1. Participant Characteristics

	Participants who experienced a TBI (N= 30) Frequency (%)
Sex	
Male	20 (66.7)
Female	10 (33.3)
Ethnicity	
European	22 (73.3)
Maori	5 (16.7)
Other	3 (10.0)
Mechanism of Injury	
Fall	11 (36.7)
Motor Vehicle Accident	10 (33.3)
Assault	4 (13.3)
Hit by object	5 (16.7)
TBI Severity	
Mild	12 (40.0)
Moderate	8 (26.7)
Severe	10 (33.3)
Mode of Referral	
Previous research study	11 (36.6)
Service provider	19 (63.3)

643 **Table 2. How people can be supported to manage sleep and fatigue after TBI**

Rationale	**Information needed or action required**
People at risk of persistent problems need to be identified early to enable provision of support to facilitate recovery	Routine screening in the acute phase for fatigue and sleep difficulties after TBI
People described being surprised and unprepared by the intensity and persistence of difficulties encountered and needing to understand. Knowledge was found to be empowering and facilitated the process of acceptance of difficulties encountered	Information is needed early about how many people are affected, the possible trajectories of recovery, why difficulties may occur after brain injury
Whilst common themes were identified, individual experiences of sleep and fatigue varied considerably and advice needs to address the specific challenges encountered	Discussion to determine how fatigue and sleep affects each person and to identify any known triggers is needed
Participants frequently talked about having to learn from pushing themselves too far and suffering the consequences before realizing the need to rest. Many were initially reluctant to allow themselves to rest due to expectations of others, self-perceptions and concerns about effecting night time sleep or becoming habit forming	Raise awareness of the importance of rest post-TBI and address any misconceptions about resting.
Many participants expressed that they were initially unable to tell when they needed a rest before they became too exhausted a needed a longer rest time that then impacted on nocturnal sleep	Initially some people may need others to help them to monitor their symptoms, and plan their rest periods.
Participants described having to learn by themselves over time about the best way to rest and having to try lots of different things before finding what worked for them. The theme related to learning to rest only became evident at 12 months suggesting support is needed much earlier to help people to manage and improve recovery	Advice on how to nap/rest most effectively is needed. For example; finding a dark quiet place; avoiding activities usually associated with resting but that stimulate the brain e.g. watching TV, helping people plan for if they need to rest outside the home and/or using an alarm clock to prevent people sleeping for too long if they do nap in the day.
Participants described finding it difficult to take a break outside of everyday routines and being setback following unexpected events. Participants learnt over time how to find ways of enabling themselves to have a rest outside the home and to give themselves time to recover after unexpected or demanding events.	People need help to identify ways that they can have a rest outside of the home e.g. at work. Contingency plans are needed to help people to cope when unexpected events occur and disrupt their routine.
Initially people described napping for several hours, several times a day and found that their naps hindered their ability to sleep at night. Over time participants described learning by themselves as to what was the	If people need to sleep during the day, they need guidance to find what works for them to recharge their batteries to help them get through the day whilst not interfering with sleep at night. Monitoring nap times,

best time of day and duration they needed to take a nap without disrupting nighttime sleep or feeling unrefreshed afterwards.	nocturnal sleep patterns and fatigue levels may help to identify the optimum nap time for each individual
As difficulties can arise or worsen at a later stage as people reintegrate back in everyday life, follow up is needed to monitor progress and to adapt advice accordingly	Follow up is needed to monitor progress
Participants described uncertainty about how and when to reduce their rest periods. Over time they reported learning to gradually increase activities and reduce nap/rest times but to return to previous levels if symptoms worsened before re-challenging themselves	Advice is needed on how and when to reduce nap and rest periods over time

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Appendix 1. Coding Tree

Themes	**Sub themes**
Making sense of fatigue and sleep after TBI	Feeling unprepared Persistent and enduring nature confusing Understanding triggers Early advice is helpful
Accepting the need for rest	Reaching a crisis point Needing permission to rest Needing others to monitor and prompt Continuous monitoring
Learning how to rest	Knowing how to rest Are naps a good or bad thing? Knowing how and when to push self Allowing self to recover
Need for rest impacts on ability to engage in life	Re-evaluating priorities Restriction in participation Managing unexpected events

COREQ Checklist

Domain 1: Research team and reflexivity	Page Number
1. Which author/s conducted the interview or focus group?	4
2. What were the researcher's credentials? E.g. PhD, MD	1
3. What was their occupation at the time of the study	4
4. Was the researcher male or female?	4
5. What experience or training did the researcher have?	4
6. Was a relationship established prior to study commencement?	4
7. What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
8. What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4
Domain 2: study design	
9. What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	5
10. How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
11. How were participants approached? e.g. face-to-face, telephone, mail, email	4
12. How many participants were in the study?	6
13. How many people refused to participate or dropped out? Reasons?	6
14. Where was the data collected? e.g. home, clinic, workplace	4
15. Was anyone else present besides the participants and researchers?	4
16. What are the important characteristics of the sample? e.g. demographic data, date	Table 1
17. Were questions, prompts, guides provided by the authors? Was it pilot tested?	4
18. Were repeat interviews carried out? If yes, how many?	4
19. Did the research use audio or visual recording to collect the data?	4
20. Were field notes made during and/or after the interview or focus group?	5
21. What was the duration of the interviews or focus group?	4
22. Was data saturation discussed?	6
23. Were transcripts returned to participants for comment and/or correction?	6
Domain 3: analysis and findings	
24. How many data coders coded the data?	5
25. Did authors provide a description of the coding tree?	Appendix 1
26. Were themes identified in advance or	5

derived from the data?	
27. What software, if applicable, was used to manage the data?	5
28. Did participants provide feedback on the findings?	6
29. Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	7-11
30. Was there consistency between the data presented and the findings?	7-11
31. Were major themes clearly presented in the findings?	7-11
32. Is there a description of diverse cases or discussion of minor themes?	6