Reducing the Impact of Traumatic Brain Injury Related Fatigue on Paid Employment:

A Client Perspective.

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Abstract

Traumatic brain injury (TBI) is a common injury, which has a substantial effect on people's ability to return to their daily activities including work. Fatigue is one of the most prevalent TBI symptoms impacting on an individual's ability to return to work. There is no published evidence investigating fatigue-specific strategies that might be used to help people post-TBI manage their fatigue successfully at work to allow them to return to paid employment or the same number of pre-injury work hours. This research addresses the question 'How do people manage fatigue, which they attribute to TBI, to enable them to successfully return to and maintain paid work?'

A qualitative descriptive approach was taken to explore how people managed their post-TBI fatigue at work – including what they did and how it worked. Eight participants, 3 men and 5 women, participated in a semi-structured interview at their place of choice. Participants were aged between 24-66 years old, had sustained a TBI of any severity, returned to their pre-injury employment, and attributed fatigue symptoms to their TBI. The time from the participant's injury to interview was between 6 months and 22 months. The interviews were transcribed and analysed inductively using thematic analysis.

Participants learned through trial and error how to recognise the point at which their fatigue symptoms indicated that they needed to make a change to remain productive at work. At this change point, participants selected the appropriate strategy from a continuum of strategies ranging from those that minimally disrupted work productivity through to considerable disruption to work productivity. Least disruption resulted from strategies that reduced task intensity or demand, with increasing disruption as a participant chose one of three types of break. These ranged from 'super mini breaks' where activity was minimally disrupted, to 'mini breaks' consisting of a short removal from activity, to 'long breaks' which meant a prolonged interruption of the activity. Participants became increasingly skilled at anticipating fatigue and avoiding it and, when a change point was reached, choosing the strategy that worked best for the level of fatigue they experienced. Participants also altered activities outside work to manage fatigue at work as well as balancing their tasks over the week to ensure they could perform at work throughout the week.
Participants with TBI learned how to manage their fatigue at work. This fatigue management became increasingly sophisticated over time as participants developed an understanding of their fatigue symptoms and when and what type of fatigue management strategies to use to maximise their productivity at work. An infographic representing the participants learning about successful fatigue management at work was developed and further research could test how useful this is in the work setting.
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## Table of Contents

Abstract

Acknowledgements

Table of Contents

List of tables

List of figures

List of abbreviations

**Chapter 1: Introduction**

1.1. Traumatic brain injury and impact of fatigue

1.2. The research problem

1.3. Defining key terms

1.4. Research question

1.5. Research aims

1.6. Thesis structure

**Chapter 2: Background**

2.1. Overview

2.2. Traumatic brain injury (TBI)

2.2.1. Defining TBI.

2.2.2. Epidemiology of TBI.

2.3. Symptoms of TBI.

2.3.1. Impact of TBI on daily functioning.

2.3.2. TBI and RTW.

2.4. TBI and fatigue

2.4.1. Epidemiology.

2.4.2. The experience of TBI fatigue.

2.4.3. Impact of TBI fatigue.

2.5. TBI fatigue and RTW

2.6. Managing fatigue in the TBI population

2.6.1. TBI fatigue management evidence.

2.7. Therapists perspectives on fatigue management after TBI

2.8. Fatigue management in other conditions

2.8.1. Stroke.

2.8.2. Chronic fatigue syndrome (CFS).

2.8.3. Rheumatoid arthritis.

2.8.4. Multiple sclerosis (MS).

2.9. What we know about fatigue management

2.10. Fatigue management in context of TBI rehabilitation in NZ

2.11. Summary
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chapter 3: Methodology and Methods</strong></td>
<td>34</td>
</tr>
<tr>
<td>3.1. Overview</td>
<td>34</td>
</tr>
<tr>
<td>3.2. Choosing qualitative description</td>
<td>34</td>
</tr>
<tr>
<td>3.3. What I brought to the research</td>
<td>35</td>
</tr>
<tr>
<td>3.4. Qualitative Description</td>
<td>36</td>
</tr>
<tr>
<td>3.5. Methods</td>
<td>36</td>
</tr>
<tr>
<td>3.5.1. Sampling and participant recruitment</td>
<td>36</td>
</tr>
<tr>
<td>3.5.2. Interview</td>
<td>40</td>
</tr>
<tr>
<td>3.5.3. Data analysis</td>
<td>41</td>
</tr>
<tr>
<td>3.6. Research rigour</td>
<td>43</td>
</tr>
<tr>
<td>3.7. Ethical, Treaty, and other considerations in the research process</td>
<td>44</td>
</tr>
<tr>
<td>3.7.1. Ethical considerations specific to this research</td>
<td>45</td>
</tr>
<tr>
<td>3.7.2. Consideration of recruiting company's procedures</td>
<td>45</td>
</tr>
<tr>
<td>3.7.3. Emotional risks</td>
<td>45</td>
</tr>
<tr>
<td>3.7.4. Cultural considerations</td>
<td>46</td>
</tr>
<tr>
<td>3.7.5. Risk to the researcher</td>
<td>46</td>
</tr>
<tr>
<td>3.7.6. Confidentiality</td>
<td>46</td>
</tr>
<tr>
<td>3.8. Dissemination of findings</td>
<td>47</td>
</tr>
<tr>
<td>3.9. Summary</td>
<td>47</td>
</tr>
<tr>
<td><strong>Chapter 4: Results</strong></td>
<td>48</td>
</tr>
<tr>
<td>4.1. Overview</td>
<td>48</td>
</tr>
<tr>
<td>4.2. Recruitment</td>
<td>48</td>
</tr>
<tr>
<td>4.2.1. Study sample</td>
<td>49</td>
</tr>
<tr>
<td>4.3. Managing fatigue – the overall picture</td>
<td>49</td>
</tr>
<tr>
<td>4.4. Managing fatigue – detailed description</td>
<td>52</td>
</tr>
<tr>
<td>4.4.1. Productivity and drivers</td>
<td>52</td>
</tr>
<tr>
<td>4.4.2. Strategies for fatigue management at work</td>
<td>55</td>
</tr>
<tr>
<td>4.4.3. Strategies for fatigue management outside of work</td>
<td>63</td>
</tr>
<tr>
<td>4.4.4. Decision making and the learning process</td>
<td>67</td>
</tr>
<tr>
<td>4.4.5. The need to change (‘change point’).</td>
<td>68</td>
</tr>
<tr>
<td>4.4.6. Pushing through</td>
<td>71</td>
</tr>
<tr>
<td>4.4.7. Influences of self and others on decisions to change</td>
<td>73</td>
</tr>
<tr>
<td>4.5. Balancing system</td>
<td>75</td>
</tr>
<tr>
<td>4.6. Support</td>
<td>76</td>
</tr>
<tr>
<td>4.7. Summary</td>
<td>77</td>
</tr>
<tr>
<td><strong>Chapter 5: Discussion</strong></td>
<td>78</td>
</tr>
<tr>
<td>5.1. Overview</td>
<td>78</td>
</tr>
<tr>
<td>5.2. The fatigue experience</td>
<td>78</td>
</tr>
<tr>
<td>5.2.1. Fatigue</td>
<td>78</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
</tr>
<tr>
<td>----------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>5.2.2. Fatigue and work.</td>
<td>79</td>
</tr>
<tr>
<td>5.3. Learning how to manage fatigue at work</td>
<td>80</td>
</tr>
<tr>
<td>5.3.1. Trial and error learning.</td>
<td>80</td>
</tr>
<tr>
<td>5.3.2. Refining the learning.</td>
<td>83</td>
</tr>
<tr>
<td>5.4. Fatigue management strategies</td>
<td>84</td>
</tr>
<tr>
<td>5.4.1. Reducing task intensity.</td>
<td>84</td>
</tr>
<tr>
<td>5.4.2. Breaking it up.</td>
<td>87</td>
</tr>
<tr>
<td>5.4.3. Balancing and reducing non-work activities.</td>
<td>89</td>
</tr>
<tr>
<td>5.4.4. Sleep.</td>
<td>90</td>
</tr>
<tr>
<td>5.4.5. Exercise.</td>
<td>91</td>
</tr>
<tr>
<td>5.4.6. Relaxation.</td>
<td>91</td>
</tr>
<tr>
<td>5.5. Strengths and limitations of the study</td>
<td>92</td>
</tr>
<tr>
<td>5.5.1. A brief personal reflection.</td>
<td>95</td>
</tr>
<tr>
<td>5.6. Clinical implications</td>
<td>95</td>
</tr>
<tr>
<td>5.7. Recommendations for future research</td>
<td>99</td>
</tr>
<tr>
<td>5.8. Summary</td>
<td>101</td>
</tr>
<tr>
<td>5.9. Thesis summary</td>
<td>101</td>
</tr>
<tr>
<td>References</td>
<td>103</td>
</tr>
<tr>
<td>Appendix A: Advertisement</td>
<td>109</td>
</tr>
<tr>
<td>Appendix B: Recruiter Flow Chart</td>
<td>110</td>
</tr>
<tr>
<td>Appendix C: Cover Letter</td>
<td>111</td>
</tr>
<tr>
<td>Appendix D: Participant Information Sheet</td>
<td>112</td>
</tr>
<tr>
<td>Appendix E: Consent Form</td>
<td>116</td>
</tr>
<tr>
<td>Appendix F: Interview Schedule</td>
<td>118</td>
</tr>
<tr>
<td>Appendix G: Demographic Information Questionnaire</td>
<td>126</td>
</tr>
<tr>
<td>Appendix H: Ethics Committee Response Letter</td>
<td>127</td>
</tr>
<tr>
<td>Appendix I: Researcher Reply to Ethics Committee Response Letter</td>
<td>129</td>
</tr>
<tr>
<td>Appendix J: Māori Consultation Response</td>
<td>131</td>
</tr>
<tr>
<td>Appendix K: Possible Intervention Strategy</td>
<td>133</td>
</tr>
</tbody>
</table>
List of tables

Table 4.1. Recruiter Involvement 48
Table 4.2. Participants Demographic Information (Pooled) 50
List of figures

Figure 4.1: Fatigue management to enable a return to paid employment. 51

Figure 5.1. Clinical Application - Fatigue management to enable a return to paid employment. 97
List of abbreviations

TBI  Traumatic brain injury
NZ  New Zealand
RTW  Return to work
OT  Occupational therapist
PTA  Post-traumatic Amnesia
GCS  Glasgow Coma Scale
GP  General Practitioner
n  Number of participants
ACC  Accident Compensation Corporation
SMD  Standardised mean difference
CI  Confidence interval
RCT  Randomised controlled trial
CBT  Cognitive behavioural therapy
MBSR  Mindfulness-Based Stress Reduction
CFS  Chronic fatigue syndrome
MS  Multiple sclerosis
F  Fisher exact test
Chapter 1: Introduction

1.1. Traumatic brain injury and impact of fatigue

Traumatic brain injury (TBI) is a common injury, and is the leading cause of disability in people under 40 years of age (Bruns & Hauser, 2003; Feigin et al., 2013; World Health Organization, 2006). Fatigue is noted to be a common long-term symptom of TBI and has been found to have an incidence ranging between 16 – 80% for all TBI, depending on the research design. Fatigue has been found to impact long term with 50% of people continuing to have fatigue 10 years post-injury (Cantor, Gordon, & Gumber, 2013; Olver, Ponsford, & Curran, 1996; Ponsford et al., 2014).

There is a long-term impact on people's function post TBI with only 40% of previously employed individuals having returned to work (RTW) in some capacity 10 years after their TBI, and only 12% returning to their previous job (Ponsford et al., 2014). Fatigue has been identified as the most prevalent factor that limits an individual's ability to RTW after a brain injury (McCrimmon & Oddy, 2006; van Velzen, van Bennekom, van Dormolen, Sluiter, & Frings-Dresen, 2011; Waljas et al., 2014).

1.2. The research problem

While fatigue is a major contributor to problems with RTW, there is little research on the effectiveness of interventions for managing fatigue after TBI. A systematic review that investigated interventions to manage fatigue after TBI found that there was insufficient research to support any intervention for fatigue in this population in clinical practice (Cantor et al., 2014). These authors concluded that due to the prevalence of fatigue in the TBI population and the impact that fatigue has on someone's ability to return to their daily activities, and more so employment, it is essential that this area is explored more thoroughly (Cantor et al., 2014).

There is in contrast more evidence for the effectiveness of fatigue interventions in other populations, particularly multiple sclerosis (MS). A meta-analysis on the effectiveness of fatigue interventions for people with MS (including interventions such as aquatic exercise, vestibular rehabilitation, progressive
resistance training, teleconference on fatigue management, energy conservation course, mindfulness, and cognitive behavioural therapy (CBT) found significant treatment effects in all these interventions in this population (Asano & Finlayson, 2014). However, despite MS and TBI both being neurological conditions, there are important differences in these populations. For instance, MS has a higher incidence of sensory symptoms (40%) compared with TBI (none in a mixed severity TBI population) and MS is more often associated with greater limb weakness (12%) compared with TBI (none in a mixed severity TBI population) (Dikmen, Machamer, Fann, & Temkin, 2010; Lindsay & Bone, 2002). This means that the transferability of these findings from MS research to the TBI population may be limited.

My interest in research on fatigue management after TBI arose from my clinical practice. I am an occupational therapist (OT) who has worked with people with neurological conditions (including TBI, MS and stroke) for 20 years. Through working with all these conditions, I have noticed how prevalent fatigue is, and how frequently and substantially it impacts on people’s ability to fulfil their occupations. Occupation in occupational therapy is defined as “the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do” (World Federation of Occupational Therapists, n.d.). Furthermore, I noted that people would struggle to manage their fatigue, and would become entrenched in a cycle of good and bad days where fatigue controlled what they could and could not do. The lack of research to support clinical decision making in this area of practice was frustrating. I was therefore interested in gaining a better understanding of how people with TBI managed fatigue. Because fatigue has a particularly large impact on people’s ability to RTW, I decided to focus on how people managed their fatigue to allow a successful return to paid employment.

I thought that finding out what strategies people with TBI used to successfully manage their fatigue at work, would provide guidance for critically evaluating current understanding of fatigue management after TBI, and support the development of future evidence-based interventions. It is important to understand what people do to manage their fatigue and how they implement these strategies. A qualitative descriptive approach allowed the exploration of the what and how to
ensure an in-depth understanding of peoples experience of managing fatigue to enable a return to paid employment and remain productive.

1.3. Defining key terms

In this research, I have defined fatigue as ‘a conscious reduction of ability in a mental and/or physical activity as a result of depleting energy’. Work in this research has been defined by myself as ‘a job or activity that is carried out regularly in order to earn money’. Return to work has been defined as ‘successfully completing the job tasks that are expected’. With the use of the term successful this also includes work productivity.

1.4. Research question

The key question being addressed was “How do people manage fatigue that they attribute to TBI to enable them to successfully return to and maintain paid work?”

1.5. Research aims

The specific objectives for this study were:

1. Describe what fatigue management strategies people with TBI, who are successful in work, find useful to support activities of daily living and enable them to work.

2. Gain an understanding of what facilitates and impedes successful application of these strategies both in and outside of work.

1.6. Thesis structure

My thesis is divided into five chapters. The first chapter outlines the research problem, the clinical context from the researcher’s perspective and the research questions and objectives. The second chapter explores the background research on TBI and work in more depth. This includes research on the impact of TBI on returning to work, the importance of fatigue in relation to being able to RTW and be productive, and on the best current evidence regarding non-pharmacological management of fatigue after TBI or other neurological conditions. Chapter three is the methods section. This identifies the study design and sampling methods. It also
describes the inclusion criteria, data collection methods and other processes completed such as ethics approval, consultations and confidentiality procedures. The fourth chapter presents the main findings from this research. The final chapter draws together the new data collected and discusses how this links with past research. It also explores limitations of this research and possible future directions.
Chapter 2: Background

2.1. Overview

This chapter is a summary of what is known about TBI and fatigue, with a particular focus on the functional limitations of these conditions and especially in regards to people participating in work roles. Existing research in relation to managing fatigue after a TBI is also summarised, and because this is a small evidence base, the management of fatigue in some related populations is also considered.

2.2. Traumatic brain injury (TBI)

2.2.1. Defining TBI. The New Zealand Guidelines Group (2007, p. 22) defined a TBI as an “acute brain injury resulting from mechanical energy to the head from external physical forces”. The criteria for diagnosis of a TBI includes one or more of the following: confusion or disorientation, a loss of consciousness, a period of post-traumatic amnesia (PTA) and/or other neurological abnormalities (Carroll, Cassidy, Holm, Kraus, & Coronado, 2004; New Zealand Guidelines Group, 2007).

New Zealand Guidelines Group (2007) report that the severity of a TBI is determined by the level of coma as measured by the Glasgow Coma Scale (GCS), which has a score range of 3 - 15 with the lower scores indicating a more severe TBI. The length of time the individual is in post-traumatic amnesia (PTA) is measured in days. A TBI is deemed as severe when an individual has a GCS of 3 – 8 out of 15 and/or a PTA of 7 days or more. When a person’s GCS score is between 9 – 12 or their length of PTA is between 1 to 6 days, then this is classified as a moderate TBI. A mild TBI has a GCS of 13 or over and a PTA of no longer than 24 hours (New Zealand Guidelines Group, 2007).

2.2.2. Epidemiology of TBI. TBI is a common injury with a range in incidence from 600 – 900 per 100,000 population per year in the United States (Bruns & Hauser, 2003). In the Waikato region of New Zealand (NZ), where my study was undertaken, it was found that 95% of TBI’s studied sustained a mild TBI with the remaining 5% sustaining moderate or severe TBI’s (Feigin et al., 2013). They found the incidence of TBI in the Waikato region of NZ was 790 per 100,000
population per year, based on collecting reports of all TBIs presenting to emergency departments, General Practitioners (GP), and other community services over one year. Their study also found that the incidence of TBI in NZ is highest in two age groups, 0 - 4 years old and 15 – 34 years old. The majority of TBI’s in the adult population (15 - 64 years) were mostly as a result of transport accidents (25.2%), then falls (24.9%), assaults (24.0%) and lastly exposure to mechanical forces (21.5%), whereas falls were highest in the over 65-year-old group (Feigin et al., 2013).

Feigin et al. (2013) also found that the incidence of TBI in Māori was significantly higher than any other ethnicity, but Māori were more likely to sustain a mild TBI than Europeans. Also, men were two times more likely to sustain a mild TBI than women and three times more likely to sustain a moderate to severe TBI (Feigin et al., 2013).

2.3. Symptoms of TBI.

When sustaining a TBI individuals can experience a range of symptoms, as Dikmen et al. (2010) found when investigating TBI symptoms via four prospective longitudinal studies that utilised a self-reported Symptom Checklist for TBI symptoms. He also compared symptoms at one month and one year between a TBI group (n = 732) and a trauma control group without an injury to their head (n = 120). The one month assessment showed symptoms of memory, concentration, dizziness, headache, blurred vision, light sensitivity (all p=0.000), noise sensitivity (p<0.021) and fatigue (p=0.046), occurred at significantly higher rates than the trauma control group (Dikmen et al., 2010). They found that at one year, the above symptoms remained significantly different, but symptoms of anxiety (p=0.002), irritability, and temper (both p=0.002) that had not been significantly different to the trauma control group at one month became significantly different at one year. Noise sensitivity at one year was no longer significantly different between groups. This study also found that there was no significant differences in the correlation of reported fatigue and injury severity (Dikmen et al., 2010).

2.3.1. Impact of TBI on daily functioning. TBI has been found to have a substantial effect on people’s ability to return to their daily activities (Ponsford et
al., 2014) and has been reported to be the leading cause of disability in people under 40 years of age (World Health Organization, 2006). Ponsford et al. (2014) published a longitudinal study (n = 141) utilising the Structured Outcome Questionnaire, which was completed at two, five and 10 years after a TBI. Only 2.8% of their sample were people with mild TBI, with 23% having moderate TBIs, and the remaining 74% having severe to very severe TBI. The participants in this study had an average age of 35 years old (SD, 2.43) and 61% were men. Ponsford et al. (2014) identified that at 10 years, 5% of people were still having difficulties managing their personal cares, 30% required assistance for heavier domestic tasks and 20% needed help with shopping. Thirty percent of individuals required help with their financial management and were not able to return to driving (Ponsford et al., 2014). This study has a high likelihood of bias and also participants were recruited between 1985 and 2002 so some of the early participant results may not be as relevant in relation to current TBI management, as rehabilitation practice may have changed over this time.

2.3.2. TBI and RTW. In general, TBI impacts negatively on people’s long-term employment as found in Ponsford et al’s. (2014) longitudinal study where only 40% of previously employed individuals had returned to employment in some capacity, with only 12% returning to their previous job at 10 years. Yasuda, Wehman, Targett, Cifu, and West (2001) found via a literature review that depending on the study 10 – 70% of people entered the workforce after a TBI compared with 61 – 75% pre-injury employment rates.

Factors that impact on someone’s ability to RTW after an acquired brain injury were explored by van Velzen et al. (2011). They found via a qualitative study utilising interviews, that physical and cognitive tiredness were the most prevalent limiting factor for 10 out of the 12 participants, which included four people with TBI’s. Other physical limitations that they found included impaired vision or hearing, headaches, reduced muscle strength and reduced balance. Cognitive difficulties that limited RTW included aphasia, and reduced concentration. Being medically unable to drive a car was also identified as a substantial limitation to RTW (van Velzen et al., 2011). In contrast, other factors found via a systematic review (number of studies = 42), to be associated with unemployment after a TBI
included a low GCS score, longer time in PTA, behavioural changes, cognitive impairment, lower scores on the functional independence measure and polytrauma (Scaratti et al., 2017).

Saltychev, Eskola, Tenovuo, and Laimi (2013) found there is little evidence identifying interventions to support people with TBI in returning to work. They completed a robust systematic review with a narrative synthesis, on evaluating the evidence on predictors of vocational outcomes after TBI, including pre and post injury factors. Interventions that were shown to improve an outcome of a RTW after TBI, included resource facilitation programmes, intensive cognitive rehabilitation, comprehensive neurorehabilitation programmes and intensity of rehabilitation (four hours daily versus two hours daily) (Saltychev et al., 2013). They did conclude that all studies were of ‘modest’ quality and therefore there was no strong evidence supporting any type of rehabilitation to allow a successful RTW after TBI (Saltychev et al., 2013). There were no pooled results reported in this review and therefore no synthesis of the effect size of these interventions. Also, their focus was not on TBI related fatigue and RTW therefore there is fewer parallels with this research question, although it does highlight the lack of evidence in managing TBI at work. No research on work productivity once someone has returned to work after TBI have been found.

2.4. TBI and fatigue

2.4.1. Epidemiology. Fatigue is a common symptom after TBI. It is estimated to be in the range of 16 – 80% incidence for people with TBI, which is reported to be much higher than fatigue in the community dwelling general population of 10 – 18% (Cantor et al., 2013). Mollayeva et al. (2014) completed a robust systematic review on fatigue after a TBI. There were a number of variables that were statistically associated with more fatigue, these included an early fatigue severity, level of active mental health input, carrying the apolipoprotein E ε4 allele,
having a medical disability, being involved with litigation, being divorced, separated or widowed, and having depression (Mollayeva et al., 2014).

Factors that can contribute to the severity of peoples fatigue have been explored by Schnieders, Willemsen, and de Boer (2012). The contributors that they found included vitamin D deficiency, poor sleep and anxiety.

Hattori et al. (2009) identified that cognitive fatigue is a common symptom of mild TBI. They explored mechanisms of cognitive fatigue by comparing the brain activation of regional cerebral blood flow people with a mild TBI (n = 15) with a healthy control when completing the paced Auditory Serial Addition Test. They demonstrated that the TBI group had a different pattern of brain activation than the healthy control suggesting a pattern of compensation was occurring (Hattori et al., 2009).

The impact of TBI related fatigue on objective selective attention has also been explored by (Ziino & Ponsford, 2006) who found via a randomised controlled trial (RCT) of 46 participants with TBI and a control of 46 participants without TBI that there was a significant correlation (p<0.05), between greater levels of fatigue and poorer performance on the Complex Selective Attention Task. This correlation also remained after controlling for the effects of depression and anxiety (Ziino & Ponsford, 2006)

2.4.2. The experience of TBI fatigue. People’s experiences of fatigue were captured in a focus group carried out by Bushnik (as cited in Cantor et al., 2013) and a qualitative study by van Velzen et al. (2011). Participants identified a huge impact of fatigue on their cognitive ability with reports of needing to be alone with no more stimulation, feeling fatigue every time they needed to focus and feeling their brain was full. Participants also noted an impact on their physical ability - feeling like they could not lift their arms and just needing to sleep (Cantor et al., 2013).

Participants identified a need to think about their fatigue levels over a week, for example, when considering what they were doing on a Monday. They also needed to consider Tuesday, but on Wednesday they were still recovering from Tuesday (van Velzen et al., 2011). They also noted needing to consider where they
sat in a restaurant to reduce fatigue such as facing the wall (Cantor et al., 2013). Participants also reported that fatigue impacted hugely on their ability to participate in work roles which included an inability to finish projects (Cantor et al., 2013), and influencing everything including concentrating, calculating, and talking (van Velzen et al., 2011).

2.4.3. Impact of TBI fatigue. Many studies have been completed on the patterns of fatigue (Cantor et al., 2013; Hattori et al., 2009; Mollayeva et al., 2014; Ouellet & Morin, 2006; Schnieders et al., 2012) and impact on people’s lives (Borgaro, Baker, Wethe, Prigatano, & Kwasnica, 2005; Bushnik, Englander, & Wright, 2008a; Cantor et al., 2008; Goldin, Cantor, Tsaousides, Gordon, & Spielman, 2014; Juengst, Skidmore, Arenth, Niyonkuru, & Raina, 2013; Ponsford et al., 2014). Fatigue has a substantial effect on an individual's ability to carry out activities such as work, self-care, and other quality of life tasks. Individuals report that fatigue effects their ability to complete activities such as personal care, leisure activities social activities and work (Ouellet & Morin, 2006).

Fatigue has been found to have a lasting impact over years by Olver et al. (1996), who carried out a longitudinal study on individuals who had sustained a TBI. Through a structured questionnaire completed five years post injury, they found that 73% of participants (n = 103) felt their fatigue was greater than pre-injury (Olver et al., 1996). The same participants were then re-studied after 10 years and 50% were still experiencing fatigue (Ponsford et al., 2014). One issue when considering the findings from this study is that there was a high proportion of participants with severe TBI, i.e. 74% of the people in Ponsford et al.’s (2014) study in comparison to only 5% of moderate to severe in the total population in Waikato with TBI (Feigin et al., 2013). This could mean that a higher percentage of people have reported fatigue after 10 years due to them having sustained a more severe injury.

Similarly Dikmen et al. (2010) found fatigue has a lasting impact when they completed a prospective longitudinal study comparing post-traumatic symptoms of a TBI group and a group of people with traumatic injuries, but no brain injury. This studies sample severity was more closely aligned to the general population compared with Ponsford et al. (2014) above, with 63% having mild TBI, 19%
having moderate TBI and 18% having severe TBI. The participants Dikmen et al. (2010) investigated (n = 624) still showed difficulties with fatigue, but in comparison to Ponsford et al. (2014), fewer people had problems with fatigue at one month (66%) and one year (42%). However, these rates of fatigue were still higher than for the non-TBI population (Dikmen et al., 2010).

The severity of TBI does not appear to have any correlation with levels of fatigue. Dikmen et al. (2010) found there was no significant difference in the correlation of reported fatigue and injury severity. Similarly, Borgaro et al. (2005) found when comparing three groups of severity (mild, moderate and severe) that there was no significant differences in fatigue as measured by the Barrow Neurological Institute Fatigue Scale items (Borgaro et al., 2005) and when comparing severity with fatigue as measured on seven different fatigue measures (Cantor et al., 2008)

The impact fatigue has on people’s ability to function in their daily tasks is substantial. Bushnik, Englander, and Wright (2008b) identified through a prospective longitudinal study, that significant increases in fatigue were associated with poorer outcomes in areas such as cognitive ability, motor function and general functioning. Fatigue also impacts on people’s sexual activities with significant correlations found with high levels of fatigue and less sexual activity in a matched case control study of 223 participants (Cantor et al., 2008). Also high self-reported fatigue levels significantly predicted frequency of sexual activity, and importance of sex (Goldin et al., 2014). When considering everyday activities Ouellet and Morin (2006) found via a survey design (n = 452) that fatigue impacted in different functional areas including personal hygiene (25.5% of participants), mood, (44.3%), cognitive abilities (57.9%), social and leisure (43.3%), work (44.8%) and rehabilitation activities (32.9%). Similarly, Juengst et al. (2013) found via a cross sectional cohort study (n = 50) that fatigue in their community based participants was significantly correlated with disability as measured on the Mayo-Portland Adaptability Inventory (r=0.679, p<0.001). The importance of managing fatigue in this population is clear due to the impact on daily activities and the length of time that people are experiencing this symptom.
2.5. TBI fatigue and RTW

Fatigue as a symptom of TBI has also been identified as having a substantial impact on people's ability to RTW (McCrimmon & Oddy, 2006; Waljas et al., 2014). When McCrimmon and Oddy (2006) completed a group comparison design with non-workers and workers who had sustained a moderate to severe TBI (20 workers versus 13 non-workers) they found that there were statistically significantly greater levels of self-reported fatigue in the non-working group compared with the working group ($P = 0.0001$). Other factors that were also found in the non-working group included, spending more time in rehabilitation, more seeking of personal litigation, lower socioeconomic status (as determined from previous work roles) and relatives reporting more difficulties with depression, and physical, somatic, cognitive and communication difficulties (McCrimmon & Oddy, 2006). Due to these differences, the non-working groups fatigue scores cannot be solely attributed to their work status. Also, it was unclear whether fatigue was caused by not being in work or fatigue prevented participants from returning to work.

Similarly, Waljas et al. (2014) found that people reporting greater levels of fatigue RTW later. They found this via an inception cohort design study, which included a sample of 109 people with mild TBI. They found that 97.2% of the participants had RTW two months from their injury. When splitting these participants into two groups (utilising a cut-off score of 30 days to RTW) Waljas et al. (2014) found that people who RTW later reported significantly greater fatigue as measured on the Barrow Neurological Institute Fatigue Scale ($p<0.001$, Cohen $d = 0.98$). Although they did note that when they excluded participants who had multiple injuries there was no significant differences in these measures. Despite this, when looking at the first 30 days of recovery at points of 7, 14, 21 and 30 days post injury fatigue was a significant predictor of early RTW ($p<0.001$) (Waljas et al., 2014). Other predictors that they noted included younger age, and intracranial abnormalities detected on the day of the injury. They also noted that injury severity measures including GCS, duration of unconsciousness and PTA were not predictors of RTW. Waljas et al. (2014) reported that their findings were limited. They only located information about whether a person had RTW or not rather than
information about the capacity of their work such as reduced hours, change in responsibility or tasks, change in job, and work efficiency (Waljas et al., 2014). No research has been found on the impact of TBI related fatigue on work productivity once someone has returned to work after a TBI.

2.6. Managing fatigue in the TBI population

Fatigue management is a global term that covers any pharmacological or non-pharmacological treatments that aim to reduce fatigue and fatigue-related limitations. However, I am interested in non-pharmacological approaches to fatigue management therefore I have restricted my literature review to these types of treatments. Due to the nature of researching intervention, all studies investigating non-pharmacological strategies are limited by being unable to have blinded treatment providers due to the intervention being explicit.

The absence of guidance for managing fatigue after a TBI is evident such as in the New Zealand Guidelines Group (2007, p. 110) where guidance involves people with TBI getting advice from “a professional experienced in managing fatigue”. This may reflect the lack of available evidence in the literature for managing fatigue after a TBI. There was however, a clinical guideline for mild TBI found in Ontario, Canada, that described a variety of proposed non-pharmacological strategies/interventions that may be useful in managing fatigue after a TBI (Guidelines Development Team, n.d.). These included gradually increasing activity levels as energy allows, pacing of activities over the day, encouraging good sleep, scheduling rests, utilising a notebook to plan goals, recording activity achievement and identifying patterns of fatigue, and understanding the effects of fatigue on lowering mood (Guidelines Development Team, n.d.). This guideline was developed by an expert consensus group who also utilised the Guideline Adaptation Cycle Model (Guidelines Development Team, n.d.).

2.6.1. TBI fatigue management evidence. Despite the obvious importance of fatigue as a contributor to dysfunction, there is little high quality evidence regarding interventions that can improve fatigue management after TBI. Cantor et al. (2014) carried out a systematic review of 19 studies on intervention to manage fatigue after TBI. Within their review, the non-pharmacological approaches (11
studies in total) that were found and reported on included CBT (four studies), physical activity (four studies) and other interventions (three studies) (Cantor et al., 2014). Studies included in this review needed to be published in English, in peer reviewed journals, and at least 70% of a study’s population needed to have TBI or the results from the TBI participants needed to be reported separately. Cantor et al. (2014) identified the need for a fatigue measure as the primary or secondary outcome. Both pharmacological and non-pharmacological interventions were investigated.

Cantor et al.’s (2014) systematic review took a robust approach to identifying relevant studies, searching appropriate databases to capture TBI studies. They also checked references of the studies that met their criteria to determine further compatible studies, but they may have missed some studies due to only reviewing peer-reviewed journals and published studies in English. Two reviewers reviewed the suitability of articles against predetermined criteria and assessed the quality of each study using the 2011 American Academy of Neurology Classification of Evidence Scheme for therapeutic studies.

Cantor et al.’s (2014) review question was similar to the question posed in my study in that it investigated interventions to manage fatigue after TBI. However, the review included some studies where the participants were not working – which is not within the scope of my study – and the review was not focused specifically on the impact of fatigue on work. In fact, none of the included studies reported on any outcomes related to work status, work ability or other work-related functioning.

Cantor et al. (2014) found that few of the studies they reviewed researched fatigue as a primary outcome, and all studies looked at different interventions preventing any correlation of findings. The quality of the non-pharmacological interventions were all assessed as being poor. Cantor et al. (2014) concluded that due to there not being multiple studies for one intervention and as there was a high risk of bias in most studies there was not enough evidence to support any one intervention over another in clinical practice. All of Cantor et al.’s (2014) included studies, and other studies that were completed after their review, are further critiqued and discussed below.
(a) Cognitive Behavioural Therapy (CBT). CBT is based on a cognitive model that explores how someone comprehends a situation, as this is more closely associated with their reaction than the situation itself (Beck Institute for Cognitive Behavior Therapy, n.d.). CBT aims to change unhelpful or negative thinking and behaviour to allow an improvement in peoples mood and wellbeing (Beck Institute for Cognitive Behavior Therapy, n.d.) Five studies were found that measured the effect of CBT on fatigue after TBI.

Four of these were included in Cantor et al. (2014) (Hodgson, McDonald, Tate, & Gertler, 2005; Ouellet & Morin, 2004, 2007; Rees & Bellon, 2007) and the fifth was published later (Nguyen et al., 2017). Three investigated the effect of CBT on insomnia (Ouellet & Morin, 2004, 2007) and sleep (Nguyen et al., 2017) and one measured the effect of CBT on social anxiety (Hodgson et al., 2005), with all of these four measuring fatigue as a secondary outcome. The final study considered the effect of CBT on post-concussion symptoms that included fatigue (Rees & Bellon, 2007). The contribution these studies made to understanding the effectiveness of CBT in fatigue management post-TBI is very limited. Reasons for this include serious concerns about internal (study size and design) and external (population samples) validity, and the lack of data about fatigue. Synthesis is made more difficult by the heterogeneity of the CBT interventions.

Study design and methodological quality. Two studies were RCT’s (Hodgson et al., 2005; Nguyen et al., 2017), while the others were case series (Rees & Bellon, 2007), a single case study (Ouellet & Morin, 2004) and single case design with multiple baselines (Ouellet & Morin, 2007). The most noteworthy limitation of these studies was the small sample sizes. The sample sizes in the four studies with more than one participant (Hodgson et al., 2005; Nguyen et al., 2017; Ouellet & Morin, 2007; Rees & Bellon, 2007) ranged from 11 – 24 participants, which reduces both study power and precision with the increased chance of type II error. In the non-randomised studies, the lack of a randomisation process and comparison with controls also reduces the trustworthiness of the findings. Within the two RCT’s the control groups did not receive any intervention – one was a ‘waitlist’ control and the other ‘treatment as usual’ group – thereby increasing the risk of confounding because the treatment group received more therapeutic attention than the control
groups. All five studies were of poor quality due to the above-mentioned limitations – particularly the small sample sizes – and therefore the results did not contribute to any evidence in managing fatigue after TBI.

Further, fatigue was a secondary outcome in four studies where the primary outcomes were insomnia (Nguyen et al., 2017; Ouellet & Morin, 2004, 2007) or social anxiety (Hodgson et al., 2005). Fatigue measures included the Profile of Mood States (Hodgson et al., 2005), the Multidimensional Fatigue Inventory (Ouellet & Morin, 2004, 2007) and the Brief Fatigue Inventory and Fatigue Severity Scale (Nguyen et al., 2017). The fifth study investigated post-concussion symptoms and the measure contained two fatigue items out of 35 (Rees & Bellon, 2007). Thus, none of the studies was designed to investigate the effect of CBT on fatigue as the primary outcome of interest. All fatigue related outcomes, including the post-concussion symptoms schedule, were patient reported measures of fatigue.

**Populations.** The majority of participants in three studies sustained a moderate to severe TBI (Nguyen et al., 2017; Ouellet & Morin, 2004, 2007), one study included only those with mild TBI (Rees & Bellon, 2007), and severity of TBI was not reported in one (Hodgson et al., 2005). In addition, one study recruited participants with other neurological conditions although 10 of the 12 participants had a TBI (Rees & Bellon, 2007).

Employment or work status were either not measured (Hodgson et al., 2005; Nguyen et al., 2017), the participants had not RTW (Ouellet & Morin, 2004), or not all had RTW (Ouellet & Morin, 2007). In the remaining study no participant was working initially although 11 out of the 20 participants either returned to the same job or a different job after two years (Rees & Bellon, 2007).

**Interventions and outcomes.** While all five studies investigated CBT the interventions were heterogeneous, and none reported on fatigue as the primary outcome. There were some secondary fatigue-related data, or fatigue-related items within a broader measure, in each study.

The two studies with the same intervention were by the same authors (Ouellet & Morin, 2004, 2007). Their eight week CBT intervention included stimulus control, sleep restriction, cognitive therapy and sleep hygiene education.
Along with this, participants were offered TBI specific education on insomnia, cognitive limitations, and return to work issues, and fatigue management skills training. In their preliminary single case design Ouellet and Morin (2004) did not find CBT had an effect on fatigue, although in their later single case design with multiple baselines (Ouellet and Morin 2007), there was a statistically significant reduction in total fatigue score after treatment (p<0.012) and three months later (p<0.014). At three months, the domain scores showed the statistically significant reductions occurred for general (p=0.013) and physical fatigue (p=0.017), not mental fatigue (Ouellet & Morin, 2007).

A similar finding of changes in physical, but not cognitive, fatigue over a two-year period was made by Rees and Bellon’s (2007) study of post-concussion symptoms. Their CBT intervention, provided for two years with reduced frequency in the last 18 months, involved individualised psychoeducation to prioritise symptoms and develop compensatory strategies for them, discussion of mood states, identification of domestic, social and vocational goals, and development of strategies to improve concentration and daily activities.

The two remaining studies did not find statistically significant differences in fatigue-related measures. Hodgson et al. (2005) found no statistically significant improvement in fatigue inertia after CBT to reduce social anxiety. Their CBT intervention included relaxation, cognitive strategies, graded exposure and assertiveness training. Nguyen et al. (2017) found that the Brief Fatigue Inventory (which Nguyen et al. (2017) note was not validated for TBI) showed a significant effect in favour of CBT, although there was no statistically significant change in the Fatigue Severity Scale, which Nguyen et al. (2017) reported has been shown to be sensitive to TBI related fatigue. Specific details of this CBT intervention were difficult to discern from the report ‘in press’; components included psycho-education, behavioural activation, behaviour experiments, modification of unhelpful thinking styles, problem-solving, relaxation and relapse prevention. While I judged this to be the best quality out of the above studies due to a more robust study design, and it would have met the inclusion criteria for Cantor et al’s (2014) systematic review, the review findings were unlikely to change as Nguyen et al (2017) reported a null result for fatigue.
(b) Mindfulness-based stress reduction (MBSR). MBSR is a programme that uses mindfulness (awareness of body, mental states, and mental contents) to help people manage their health condition (Johansson, Bjuhr, Karlsson, Karlsson, & Rönnbäck, 2015). It consists of a combination of mindfulness meditation, body awareness and hatha yoga to allow people to become more mindful (Johansson et al., 2015; Ulrichsen et al., 2016). Two studies were found that measured the effect of MBSR on fatigue after TBI. These two studies were completed by essentially the same research team, and both investigated the effect of MBSR in populations of stroke and TBI (Johansson et al., 2015; Johansson, Bjuhr, & Rönnbäck, 2012). Both studies showed a significant reduction in fatigue after MBSR. The contribution of these studies to the effectiveness of MBSR in managing fatigue is again very limited. Reasons for this include internal (sample size and design) and external (population samples) validity. The first study was a RCT with MBSR given face-to-face and a waitlist control group (Johansson et al., 2012) and the second was a feasibility study comparing internet MBRS, face-to-face MBRS, and a walking control group (Johansson et al., 2015).

Study design and methodological quality. Both these studies were also considered to be of poor quality due to them both having small sample sizes of 26 (Johansson et al., 2012) and 34 (Johansson et al., 2015). Both these studies were determined to have high levels of bias due to a high risk of sample and selection bias as a result of recruitment occurring via advertisements (Johansson et al., 2015; Johansson et al., 2012) and the authors website (Johansson et al., 2015). One study had a waitlist control (Johansson et al., 2012) while the other was a walking group with a formal leader, but the duration of this contact time was one hour less a week in controls than the treatment groups (Johansson et al., 2015). Randomisation was not completed in the second due to the determined need to match computer literacy with the internet group study (Johansson et al., 2015). Both these studies included the use of a subjective fatigue measure, which focused on mental fatigue. Although when comparing this with the CBT studies above they did focus on a primary outcome of fatigue (Johansson et al., 2015; Johansson et al., 2012).

Populations. When considering these specifically to the population being explored in this research they had mixed populations of TBI and stroke therefore
the sample specific to TBI was even less with five (Johansson et al., 2012) and 13 (Johansson et al., 2015). Also the participant age range that was included in Johansson et al. (2012) was 30 - 65 year olds. The exclusion of 16 – 30 year olds is not useful considering the highest incidence of TBI is in 16 – 30 year olds (Bruns & Hauser, 2003). In relation to this study's aims, both these studies did not report on their participants work status or any work outcomes (Johansson et al., 2015; Johansson et al., 2012).

Interventions and outcomes. The MBSR was similar in both studies with both including Hatha yoga, body scan and sitting meditation. Sessions occurred weekly for 2.5 hours and at week six or seven there was a one day long ‘silent led’ retreat. Participants were also expected to practice at home six days a week (Johansson et al., 2015; Johansson et al., 2012).

The first study determined that the face-to-face MBSR reported a statistically significant reduction in fatigue on the subjective measure and the control did not (Johansson et al., 2012). Of interest in their next study, the internet group showed a statistically significant reduction in fatigue on their measure, but the face-to-face group and walking group did not (Johansson et al., 2015).

Both these studies only meet four of the five inclusion criteria that Cantor et al. (2014) set out so they were unlikely to be included. The criteria that they did not meet was that only 38% of the sample were TBI with the remaining being stroke. Cantor et al.’s (2014) criterion was that at least 70% of a study population had a TBI or the results of the TBI participants were reported separately; neither of the two studies reported TBI results separately (Johansson et al., 2015; Johansson et al., 2012).

However, both these studies (Johansson et al., 2015; Johansson et al., 2012) were included in a systematic review and meta-analysis to determine the effect of MBSR on fatigue after a neurological condition (Ulrichsen et al., 2016). This review synthesis also included two other studies that had samples of participants with MS. Their meta-analysis pooled the data from these studies (n = 257 participants) and found that the effect size, reported on the basis of a standard mean difference between the mindfulness training and control groups, was −0.37 (95% CI −0.58 to −0.17, p < 0.01). This indicated that MBSR may reduce fatigue after TBI, but they
reported that the effect size was moderate so further research is still required (Ulrichsen et al., 2016).

(c) Exercise/activity. There were four studies that investigated the effects of exercise on fatigue (Driver & Ede, 2009; Gemmell & Leathem, 2006; Hassett et al., 2009; Lundberg, Bennett, & Smith, 2011). The contribution of these studies to the effectiveness of exercise in managing fatigue is once again very limited. Reasons for this include internal (sample size and design) and external (population samples) validity. Synthesis is also made difficult due to the heterogeneity of the types of exercise or activities.

All the studies that investigated the effects of exercise or physical activity on fatigue were included in Cantor et al.’s (2014) systematic review, with no other studies found investigating effects on exercise and fatigue after TBI being found. These studies investigated the effects of; an aquatic exercise programme on mood (Driver & Ede, 2009) , Tai Chi on TBI symptoms (Gemmell & Leathem, 2006), a therapeutic recreational programme on quality of life and mood (Lundberg et al., 2011) and a comparison of a fitness centre-based exercise programme and a home based programme on cardiorespiratory fitness (Hassett et al., 2009).

Study design and methodological quality. There were three RCTs with the control being a vocational rehabilitation class of a similar time (Driver & Ede, 2009), a home based exercise programme (Hassett et al., 2009) and a waitlist control. The final study was a uncontrolled single group pre-test post-test design (Lundberg et al., 2011). All four studies were of poor quality and therefore the impact of exercise on TBI related fatigue is still largely unknown. The most substantial weakness was the small sample sizes of three of the studies. Two of these were RCT with n =16 (Driver & Ede, 2009), and n = 18 (Gemmell & Leathem, 2006), while the non RCT had a sample size of 18 (Lundberg et al., 2011). The fourth study had a larger sample size of 62, although the study authors said this was probably inadequately powered to detect a between group difference (Hassett et al., 2009).

All of the four studies utilised subjective fatigue measures and fatigue was considered a secondary outcome. Also the measurement of fatigue that did occur was part of a larger measure that assessed mood via the Profile of Mood States
(Driver & Ede, 2009; Hassett et al., 2009; Lundberg et al., 2011) and as part of the Medical Outcome Scale Short Form 36 and Visual Analogue Mood Scale (Gemmell & Leathem, 2006). Follow-up assessments were completed in two studies to determine if there were any lasting effects of the intervention. The length of time was short at three weeks (Gemmell & Leathem, 2006), and three months (Hassett et al., 2009). The other two studies did not complete any follow-up assessments (Driver & Ede, 2009; Lundberg et al., 2011).

**Populations.** All studies selected samples from the community, but only one study identified what proportion of their sample were working, 44% (Lundberg et al., 2011), but no RTW outcomes were reported in any of the four studies making it harder to link to this study on fatigue strategies at work (Driver & Ede, 2009; Gemmell & Leathem, 2006; Hassett et al., 2009; Lundberg et al., 2011). The severity of the TBI was only reported in one study which recruited only severe TBI (Hassett et al., 2009), whereas two studies recruited any severity with no breakdown of the severity in their sample and one study that recruited veterans with the sample consisting of 83% of TBI’s with some having multiple injuries (Lundberg et al., 2011).

**Interventions and outcomes.** When considering the effects of an aquatic exercise programme on mood, and fatigue as a secondary measure, there was a statistically significant reduction in fatigue in pre and post-tests. (p<0.05), although it was difficult to determine if fatigue was a core difficulty prior to treatment due to only the raw scores being reported (Driver & Ede, 2009).

In contrast, a centre based fitness programme failed to show any effects on fatigue when compared with a home exercise programme, although in this study the baseline fatigue assessments were not abnormal (Hassett et al., 2009). Similarly, there were no statistically significant effects of a six week, twice weekly, Tai Chi session on fatigue (Gemmell & Leathem, 2006). Also, Lundberg et al. (2011) found no improvements in fatigue after a five day recreational programme, which included activities such as skiing, fishing and kayaking (Lundberg et al., 2011).

**Use of rest.** Rest was identified as important in fatigue management in a recent study (Theadom et al., 2016). Their clear research focus explored peoples experience of sleep and fatigue and looked at factors that increase or decrease
fatigue and sleep disturbances. This longitudinal qualitative descriptive research carried out semi structured interviews on 30 individuals aged 16 – 85 years old and took a social constructivism approach (Theadom et al., 2016). They carried out interviews with participants at six, 12 and 24 months.

Theadom et al. (2016) identified four main themes in relation to sleep and fatigue after TBI. The first theme was ‘making sense of fatigue and sleep’, which initially involved people realising that sleep and fatigue were going to be long term problems (6 months), then starting to understand factors that made fatigue or sleep worse and making sense of their energy levels (12 and 24 months). The second, ‘accepting the need to rest’, participants were reporting a period of pushing too hard and having consequences of worsening symptoms and then realising they needed to rest (six months). Thirdly, ‘learning how to rest’, people learnt to avoid being overtired and reducing distractions (12 months). The final theme, ‘the need for rest impacting on people’s ability to engage in their daily life’, where the importance of evaluating both their own and other’s expectations was identified (12 months) and where participants identified difficulties with resting at work or the identified fatigue and sleep difficulties as a barrier to considering new work roles (Theadom et al., 2016). The main management of fatigue determined by people in this research appeared to be resting which involved ‘a nap’ although simply taking a rest was more complex with individuals finding it harder to understand, accept and manage their fatigue (Theadom et al., 2016).

Theadom et al.’s (2016) research was conducted over a two-year period with three points of a semi-structured interview being completed with both participants and their significant other. Their research had good credibility although it only uses one type of data collection (semi-structured interviews). Data saturation was reported to have occurred, but no member checking was completed. Their research was also considered to have good transferability (participants described well), good dependability (quotes being consistent with themes explored), as well as good confirmability (a team of researchers being involved in the interpretation of the data) (Theadom et al., 2016).

(e) Programmes (multiple active components). A fatigue management programme for acquired brain injury failed to show an effect on fatigue levels
The impact of an eight week programme on fatigue levels was completed by Cooper et al. (2009) using an exploratory approach. The majority of the programme involved education around brain injury, pacing, sleep, exercise, healthy eating, and mood. They found that there were no significant improvements in fatigue as measured on the self-reported Brain Injury Fatigue Scale. There were however significant improvements in the secondary outcome of participant’s quality of life as measured by the Short Form-36 quality of life measure (Cooper et al., 2009). In their study, there was likely a high rate of sample and selection bias due to the population being selected from only two clinics and volunteering to participate via a letter. Of the initial 35 individuals contacted only seven responded and consented to treatment, three of which had a TBI. Five of the participants were unemployed while one worked full time and one worked part time, although it was not reported what type of acquired brain injury the workers had. Fatigue as an outcome was assessed on the Brain Injury Fatigue Scale, which is unpublished and was reported to have ‘satisfactory’ reliability with no other validity or reliability information identified therefore adding a confounding factor. They also measured mood, sleep and quality of life. The risk of bias was high within their study due to the above design flaws and use of self-reported measures (Cooper et al., 2009).

(f) Alternative Treatments. Cantor et al. (2014) also found three further studies looking at other interventions that were less likely to be found in mainstream fatigue management treatment. These included a Flexyx Neurotherapy System, which is a type of electroencephalographic biofeedback. This RCT waitlist design included 12 participants with a mild to moderate TBI. The between group comparisons showed that the treatment group had a statistically significant improvement in general fatigue and mental fatigue post treatment compared with the control, as measure by the Multidimensional Fatigue Inventory. It was reported by Cantor et al. (2014) that this was not adequately powered and also there had been no corrections completed for multiple comparisons. They found no effect on physical fatigue and reduced activity between groups (Cantor et al., 2014).

The effect of Cranial Electrotherapy Stimulation on 10 participants with a TBI was also investigated via a small RCT. There was a placebo group as well as a
non-treatment group for comparison. This research demonstrated a statistically significant improvement in the fatigue inertia component of the subjective Profile of Mood States compared with the placebo and non-treatment groups (Cantor et al., 2014).

The effect of four weeks of daily 45 minutes sessions of bright blue light was also investigated compared with yellow light as placebo and no treatment. It was found via an RCT that subjects in the treatment group reported less fatigue than the comparison groups. The sample size and fatigue measurement were not reported by Cantor et al. (2014), but this was classified as a low quality study (Cantor et al., 2014).

Another study that came out after Cantor et al. (2014), but was completed by the same research team, found that blue light therapy had a statistically significant reduction in TBI fatigue when comparing to placebo and no treatment (Sinclair, Ponsford, Taffe, Lockley, & Rajaratnam, 2014). Their participants were randomised to three different groups: blue light, yellow light (placebo) and a no treatment control. There were 30 participants in total with the majority having a severe TBI and 97% of participants reporting clinically significant fatigue on the self-reported Fatigue Severity Scale. There was no indication of whether participants were working or not. After allocation, there were no reported significant differences in demographic or injury related characteristics. Sinclair et al.’s (2014) participants in the treatment and placebo group underwent four weeks of therapy for 45 minutes each morning. The results showed that people exposed to the high intensity blue light therapy had a statistically significant reduction in fatigue on the Fatigue Severity Scale at weeks two and four (during treatment (p<0.001) compared with the placebo and control group, but not at the eight week follow-up (Sinclair et al., 2014). There was a high risk of bias in this research due to group allocation not being blinded. Also with the combination of utilising a self-reported measure and the control group not receiving any treatment there was an increase of the placebo effect occurring on people being treated (Sinclair et al., 2014).
2.7. Therapists perspectives on fatigue management after TBI

Speech language pathologists were investigated by Hicks, Larkins, and Purdy (2011) to determine what interventions they used to manage fatigue via a qualitative study utilising semi-structured phone interviews. (Hicks et al., 2011) identified four themes that arose from the research. These were ‘intervention structure’, ‘client and family strategies’, ‘monitoring by both the client and therapist’ and ‘lifestyle and daily activities’. Intervention structure for physical fatigue included discussion with the client, compensation, scheduling, reducing physical exercise, rest, ending the session early, altering tasks and team liaison. It also included communication specific fatigue management such as altering communication styles, reducing stimuli and structuring sessions. Client and family strategies included education such as handouts, pictures, and diagrams. Monitoring included organisation of client’s daily schedule. Lifestyle and daily activities included rest/sleep, schedules, reducing activities, diet and meta-cognitive skills such as diaries. This study was identified to be of low quality. The theoretical approach of this research was not clear nor the reason for this study design. The sample was chosen via mail outs to hospitals and rehabilitation units, which likely missed community or independent speech language pathologists. Hicks et al. (2011) described all 13 participants and sampling was not completed until redundancy of data was reached although the sample was small. This study had low descriptive clarity, as it was hard to determine what sites the speech language pathologists worked in or what researchers study roles or participant relationships were. This research likely had moderate procedural rigor with an interview structure, recording of the interview, transcription of interviews and member validation. There was good analytical rigour as interviews were organized via a three-part procedure increasing familiarity of data. Authors and an independent assessor completed a thematic analysis and cross-referencing occurred (Hicks et al., 2011). There were no other studies found that explored strategies specific to any of the various registered health professions commonly involved in managing fatigue after TBI.
2.8. Fatigue management in other conditions

As there was little reliable evidence found on fatigue management in TBI, I explored other conditions similar to TBI that also report experiencing fatigue, to determine if there was any evidence supporting fatigue management in these conditions.

2.8.1. Stroke. The first condition I investigated was stroke or cerebrovascular accident as it is similar to TBI in that it is an injury to the brain (Lindsay & Bone, 2002). This injury differs from TBI in that it is acquired as a result of cerebrovascular disease. The clinical presentation of people with stroke also differs from TBI with the most common symptoms including hemiplegia/paresis, hemianopia, aphasia, dysarthria, and somatosensory deficits (Woodson, 2008), whereas the most common symptoms of TBI include issues with memory, concentration, fatigue, dizziness and headache (Dikmen et al., 2010).

Unfortunately, on a search for fatigue management in stroke it became apparent that there was also little evidence supporting any intervention in this condition. A robust systematic review was carried by McGeough et al. (2009), who aimed to look at whether any intervention reduced fatigue in people who have experienced a stroke, with the authors identifying 12 relevant studies (McGeough et al., 2009). It was determined that there was insufficient evidence to support any treatments of fatigue after stroke. The non-pharmacological treatments that were found included psychoeducation, Chinese medicine, MBSR, fatigue group education therapy, and a combination of CBT and graded activity training (Wu et al., 2015).

2.8.2. Chronic fatigue syndrome (CFS). I then examined literature on CFS thinking that perhaps the chronic nature of fatigue in this condition might be similar to the chronic nature of fatigue in the TBI population. CFS does however differ to TBI as it is not a neurological pathology and the primary symptom of CFS is fatigue (Price, Mitchell, Tidy, & Hunot, 2008). There is however a similarity aside from the chronic nature of the fatigue and that is that in both TBI and CFS there is
no ability to objectively measure fatigue or determine the impact on other areas such as physical or psychological disorders (Cantor et al., 2013; Price et al., 2008).

When comparing CBT with usual care and other psychological therapies on reducing CFS related fatigue, CBT was found to be significantly favoured (Price et al., 2008). This was found via a good quality Cochrane systematic review. They showed that when comparing CBT to usual care at post-treatment (five studies, 373 participants), the mean fatigue severity scores were significantly in favour of the CBT group (standardised mean difference (SMD) -0.39, 95% confidence interval (CI) -0.60 to -0.19). This also occurred at follow-up of 1 – 12 months (four studies, 330 participants) (SMD -0.47, 95%CI -0.69 to -0.25) (Price et al., 2008). When comparing CBT with other psychological treatments (such as relaxation, education and counselling), CBT was also significantly favoured post treatment (four studies, 313 participants) (SMD -0.43, 95% CI -0.65 to 0.20), and again at follow-up of 1 – 6 months (four studies, 294 participants) (SMD -0.47, 95% CI -0.83 to -0.11) (Price et al., 2008).

Exercise therapy was also found via a robust Cochrane systematic review, which found eight RCT’s (n = 1518) to reduce fatigue in CFS. Exercise therapy was compared with a passive control in eight trials (n = 971) where fatigue on a variety of measures was significantly reduced after treatment. When comparing exercise therapy to CBT, in two trials (n = 351) little or no difference in fatigue was noted. When comparing exercise therapy to adaptive pacing in one trial (n = 320) fatigue was significantly better at the end of treatment (Larun, Brurberg, Odgaard - Jensen, & Price, 2017).

2.8.3. Rheumatoid arthritis. Due to only exercise and CBT being found in CFS and no evidence in stroke, I began to investigate other conditions that were less similar to TBI. I considered rheumatoid arthritis due to the chronicity of this condition, although there are no other similarities with TBI except for rheumatoid arthritis having a common symptom of fatigue. Rheumatoid arthritis is a systemic inflammatory condition (Yasuda, 2008).

Cramp et al. (2013) found via a robust meta-analysis looking at what non-pharmacological interventions had an effect on rheumatoid arthritis related fatigue that physical and psychosocial interventions reduce fatigue. Within the 24 studies
that met their criteria they found that interventions that were statistically significant in reducing fatigue included physical activity and psychosocial interventions. The mean pre and post fatigue score from six physical activity studies were combined with a total of 219 treatment participants and 152 control participants. Physical activity was found to be statistically significantly more effective in reducing fatigue than the control group (SMD -0.36, 95% CI -0.62 to -0.10) (Cramp et al., 2013). Quality of these studies was moderate when using the GRADE approach. The physical activities included pool-based therapy, yoga, dynamic strength training, stationary cycling, low impact aerobics and Tai Chi. Thirteen psychosocial studies could be combined for analysis. These included 843 participants in the treatment arm and 713 participants that were in the control arm (Cramp et al., 2013). Psychosocial interventions included benefit finding, expressive writing, CBT, mindfulness, lifestyle management, energy conservation, self-management and group education. The quality of these studies was determined to be low, but when combining the mean change in fatigue scores, they found that psychosocial interventions were significantly more effective in reducing fatigue than the control (SMD -0.24, 95% CI -0.40 to -0.07) (Cramp et al., 2013).

2.8.4. Multiple sclerosis (MS). The MS population is different to the TBI population, but the interventions are still worth considering for the TBI population in absence of TBI specific studies. MS is similar to TBI in that it is a neurological condition and its common symptoms include fatigue, and cognitive changes, although it also has common symptoms of muscle weakness and pain that are less common in TBI. MS affects the myelin sheath of the central nervous system and is a progressive condition which TBI is not (Forwell, Copperman, & Hugos, 2008).

MS has a variety of interventions that have been found to have a significant effect on fatigue (Asano & Finlayson, 2014). Fatigue management was explored via a meta-analysis conducted by Asano and Finlayson (2014). They looked more specifically at four areas: exercise intervention, educational programmes, fatigue medications, and the comparison of MS fatigue interventions versus MS fatigue medications. Their Asano and Finlayson (2014) search was reasonable, but may not have captured all studies due to them only considering English peer reviewed RCT’s although they were conducting a meta-analysis. Criteria included adults with
MS and studies with fatigue outcomes. Articles were independently reviewed and quality assessed by two people. Collective data was taken from 1149 participants in 25 trials. The random-effects model was utilised to calculate the pooled effect sizes. Significant treatment effects were found in the following three studies (n = 233) on physical activity interventions; aquatic exercise, vestibular rehabilitation, and progressive resistance training, with a pooled effect size of 0.57 (95% CI 0.10 to 1.04, p=0.02) (Asano & Finlayson, 2014). When considering educational interventions Asano and Finlayson (2014) found that the following six studies (n = 662) had significant treatment effects; teleconference on fatigue management, energy conservation course, mindfulness, and CBT, with a pooled effect size of 0.54 (95% CI 0.30-0.77, p<0.001) (Asano & Finlayson, 2014).

The energy conservation course that was investigated with the meta-analysis above was considered separately to understand the components of this. This course took a psychoeducational approach and included concepts such as use of rest, body mechanics and ergonomics, environmental modifications, changing own standards and setting priorities, activity analysis and modification and living a balanced lifestyle (Mathiowetz, Finlayson, Matuska, Chen, & Luo, 2005).

The effects of exercise on fatigue in MS was also reinforced via a robust Cochrane systematic review by Heine, van de Port, Rietberg, van Wegen, and Kwakkel (2015). They investigated 45 trials with 69 interventions (n = 2250) that met their criteria. When considering the effect of different exercise therapies compared with non-exercise controls in reducing fatigue they found that endurance training (SMD -0.43, 95% CI -0.69 to -0.17), mixed training (SMD -0.33, 95% CI -1.23 to -0.23), and other training (SMD -0.54, 95% CI -0.69 to -0.29), had significant effects (Heine et al., 2015). Other training included Yoga, Tai Chi, hippotherapy, balance training, robot assisted gait training, motor learning, sports climbing and inspiratory muscle training (Heine et al., 2015).

2.9. What we know about fatigue management

Despite fatigue being a common symptom after someone has sustained a TBI and fatigue management being frequently used to treat fatigue, fatigue management is still a largely undefined intervention that has little evidence supporting it. There
are however some areas that have shown some evidence despite being of lower quality and are supported by stronger evidence in other conditions that have some similarities with TBI.

No studies looking at the effect of exercise on fatigue were found for the TBI population, but it has been found via a robust meta-analysis that exercise including aquatic exercise, vestibular rehabilitation, and progressive resistance training had a significant effect on self-reported fatigue in the MS population (Asano & Finlayson, 2014). Physical activities including pool-based therapy, yoga, cycling, aerobics and Tai Chi were also found to be significantly more effective in reducing self-reported fatigue than a control in a population with rheumatoid arthritis (Cramp et al., 2013) and exercise therapy had a significant effect on fatigue in people with CFS (Larun et al., 2017).

MBSR was shown to significantly reduce fatigue on a subjective measure in two studies although both these studies had a poor design and results are likely not clinically useful (Johansson et al., 2015; Johansson et al., 2012). There was however some strong evidence to say that mindfulness and CBT significantly reduces fatigue in the MS population (Asano & Finlayson, 2014) and CFS (Price et al., 2008). There was some evidence suggesting CBT and MBSR reduced fatigue in the rheumatoid arthritis population (Cramp et al., 2013), but no evidence supporting MBSR in stroke (Wu et al., 2015).

There were mixed results on the use of education on TBI with Cooper et al. (2009) in their low quality design finding no significant improvements in an eight week fatigue management programme consisting mostly of education. There was however some strong evidence looking at educational interventions with MS including teleconference on fatigue management, and an energy conservation course (Asano & Finlayson, 2014). Psychological and educational based interventions were grouped together by Cramp et al. (2013) for a meta-analysis and were found to have a significant effect on self-reported fatigue in a population with rheumatoid arthritis. Although a self-management programme showed no significant effect on fatigue for the stroke population (McGeough et al., 2009).

When investigating what therapist’s did to manage fatigue after a TBI, Hicks et al. (2011), found interventions included compensation, scheduling, reducing
physical exercise, rest, ending the session early, altering tasks, team liaison, altering communication styles, reducing stimuli, structuring therapy sessions, family education, organisation of a client’s daily schedule, rest/sleep schedules, reducing activities, diet and meta-cognitive skills such as diaries. While this is a list of what therapists provided there was no information, or other studies, on the effectiveness of these interventions. No other studies were found indicating what other types of therapies were used to help people after TBI manage fatigue.

2.10. Fatigue management in context of TBI rehabilitation in NZ

Within the NZ system TBI’s are covered under the Accident Compensation Corporation (ACC). This is a 24 hour ‘no-fault’ accidental injury insurance scheme. As a result of this the rehabilitation pathway is directed by ACC via case managers and service coordinators who will consider what a person requires in their rehabilitation and seek appropriate services to provide assessment or treatment to that person. ACC funds all treatment, assessments, and support services that an individual requires over the duration of their injury. ACC does not fund any condition that is not related to an injury. ACC acknowledges four distinct areas of rehabilitation. These include acute care, residential rehabilitation, non-residential rehabilitation, and longer-term community support. After someone has sustained a TBI they can come in contact with all or only one of these areas depending on their needs. For example, individuals who have sustained a severe TBI are more likely to experience all these areas where as an individual who sustains a mild TBI may not be seen by any service or only vocational services (New Zealand Guidelines Group, 2007).

Acute care is provided in the hospital and takes mostly a medical management focus. If some sustained a more severe TBI they are likely to require a period of residential rehabilitation where they stay at an inpatient facility and receive medical and therapy intervention. When someone with a TBI is in the community, either discharged from acute or residential services or referred by their GP, they will often receive non-residential rehabilitation (also known as outpatient or community rehabilitation). Therapy is mostly provided in people’s own homes and sometimes within clinics. Longer-term community support occurs either in a residential setting if the severity of injuries prevent people from returning home or
as case coordination by an ACC case manager (New Zealand Guidelines Group, 2007).

Once people are considering a return to work then they are provided with vocational rehabilitation through ACC. These include such options as having a stand-alone work assessment of specific work task demands to better inform GP's or other professionals of the job that individual is returning to. Some will have a vocational programme that involves completing a graduated RTW programme that is overseen by a vocational specialist such as an OT and medically cleared by a GP. People who have sustained a TBI and are unable to return to their pre-injury work or lose their job due to the length of time their rehabilitation has taken may be involved in a ‘work readiness’ programme which includes being assessed occupationally and medically to determine possible medically sustainable roles. This programme also includes assisting with job seeking skills such as preparing a curriculum vitae, and being interviewed (Accident Compensation Corporation, 2015).

Within the vocational rehabilitation and return to work process it is likely that if the client experiences fatigue – including fatigue at work – this will be treated by the therapists involved in their care. In the absence of any documented guidelines or process for fatigue management in NZ or for ACC client, the strategies that are used will depend on the experience and knowledge of the treating therapist.

2.11. Summary

The best evidence for fatigue management was found for MS. MS is similar to TBI in regard to them both having cognitive and physical limitations. They are different however in disease course with MS being progressive. Clients with TBI can have greater cognitive-behavioural difficulties than the MS population. Also more females experience MS (Asano & Finlayson, 2014) and more males sustain a TBI (Bruns & Hauser, 2003).

The research on the incidence of fatigue in TBI is substantial but this does not match the amount of evidence in strategies to manage or treat fatigue after TBI and there is no evidence on interventions for fatigue at work. Most of the research
that is available have poor quality designs and therefore the results cannot be relied on. There is some promising research in other conditions such as MS, stroke and cancer and it is likely that some of these approaches may benefit the TBI population although this is harder to correlate due to the combination of physical, sensory and cognitive behavioural difficulties that someone with a TBI experiences. Research would be beneficial in exploring fatigue management with the TBI population to determine the most effective treatments. Management of this needs to be looked at against outcomes of increased function, RTW, return to leisure and increased quality of life due to the lack of objective measures looking at fatigue specifically.

2.12. Aims of study

The specific objectives for this study were to:

1. Describe what fatigue management strategies people with TBI, who are successful in work, find useful to support activities of daily living and enable them to work.

2. Gain an understanding of what facilitates and impedes successful application of these strategies both in and outside work.
Chapter 3: Methodology and Methods

3.1. Overview

This research explored the strategies that people with TBI used to manage their fatigue that they felt had enabled them to return to paid employment. The research question was addressed using a qualitative descriptive design. This chapter provides an explanation for the choice of a qualitative descriptive approach followed by a detailed account of the recruitment and interview processes, data analysis and ethical and cultural considerations.

3.2. Choosing qualitative description

This study took a qualitative descriptive approach. The aim of qualitative description is to provide a rich description of a particular experience, and addresses questions about that experience such as what, who, how and when. In qualitative description, the intent is to stay ’close to the data’, draw on the researcher’s existing knowledge of practice and research literature in the field, to generate an output that informs clinical practice and implementation of interventions (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000).

This approach allows for a comprehensive description of events and experiences, such as those that facilitated a group of people with TBI to manage their fatigue and enable work productivity. Using this approach, I gathered detailed accounts of what my participants changed in their lives both in and out of work to minimise the impact of TBI related fatigue on their work roles, when they made those changes, and how those changes enabled them to work.

Further, I hoped the qualitative descriptive approach would give a comprehensive summary of fatigue management in everyday terms familiar to both clients and clinicians. As an OT working within the field of TBI in the community, I wanted to generate transferable information for use in clinical practice to reduce the burden that fatigue has in people’s lives after TBI. Qualitative description was congruent with this intent within the limits of generalisability that qualitative research in a small sample may have.
Qualitative description is the least theoretical of qualitative approaches (Neergaard et al., 2009; Sandelowski, 2000). However, it is recognised that there is inevitably a low level of interpretation and the researcher may influence that interpretation in the process of developing the research question, completing the data collection and analysis (Neergaard et al., 2009; Sandelowski, 2000). As the researcher, I cannot get a completely objective account of what the participants feel, think, and do; my perspective, formed by my personal and clinical experiences, will influence what I direct the participants attention toward and how I understand what they say. In qualitative description the recognition of these influences is crucial, but it is not problematic as qualitative descriptive was established by existing knowledge and clinical experience of the researcher (Neergaard et al., 2009)

3.3. What I brought to the research

In an effort to increase my awareness of how my existing experience and thinking about fatigue management directed my research, I reflected on and then discussed with one supervisor, prior to starting the research, the following influences:

• my 20 years of occupational therapy specialising in neurological conditions both in NZ and the United Kingdom, means I feel I have seen a lot in regard to fatigue and how people manage fatigue.

• the models of practice I use as an OT, including the Occupational Performance Model (Chapparo & Ranka, 2001), and the Model of Human Occupation (Kielhofner, 1995), which guide me on the importance of participation in occupations to ensure a healthy quality of life.

• the fatigue management strategies I recommend to clients with TBI believing them to be useful, including: fatigue diaries, sleep hygiene, ‘time outs’, using routines, daily exercise, prioritising daily and weekly tasks, utilising relaxation or meditation, altering between cognitive tasks and physical tasks, and reducing high stimulus. I thought
participants would probably describe these strategies, and that these were suggested to them by health professionals.

- a prior experience of substantial illness, and how this has shaped beliefs about the importance of work in distracting yourself from difficult times and also the healing achieved through the resumption of ‘normal’ routines.

The above reflections were important within the qualitative descriptive process to ensure that I had a good understanding of what I bought to the data analysis.

3.4. Qualitative Description

Qualitative description utilises purposeful sampling to ensure that the phenomenon of interest is explored with participants who draw on personal experience of the phenomenon leading to collection of information-rich data (Neergaard et al., 2009; Sandelowski, 2000). Sample sizes are usually small (Neergaard et al., 2009). Typically, data are collected via semi-structured interviews, with open-ended questions to prompt detailed description of the participant’s experience. The approach to data analysis is similar to other qualitative approaches with coding of data from interviews, recording insights and reflections, looking for patterns and themes in the data, then considering commonalities and differences (Sandelowski, 2000; Sullivan-Bolyai, Bova, & Harper, 2005). There is a low level of interpretation, with a straightforward description of the data. Findings are usually presented in a logical progression, such as chronology or key topics. The findings are then considered in relation to what is known by the researcher based on their clinical expertise and knowledge of existing research (Neergaard et al., 2009; Sandelowski, 2000; Sullivan-Bolyai et al., 2005).

3.5. Methods

3.5.1. Sampling and participant recruitment. The sample size was expected to range between 8-15 individuals to ensure that sufficient richness of data could be obtained. Purposive sampling was utilised, focusing on gender and
ethnicity. This was particularly important due to the higher rates of TBI in males and in Māori.

**Recruitment.** Initially the plan was to recruit from agencies, businesses, or health providers that came in contact with people with a TBI in the community. These included:

- Waikato treatment providers holding social and vocational contracts with ACC.
- GP’s in the Waikato region.
- Large companies in the Waikato such as Fonterra (employ more than 2,000 in the Waikato).
- General advertisement in health/medical centres, physiotherapy clinics and other places people with TBI may come in contact with (See Appendix A for advertisement).

In practice only the first of these were used to recruit all study participants. Over a 12-month period these treatment providers were introduced to the study via the following avenues:

- A specific research focused meeting that was added onto the end of general supervision meetings where people interested in helping with the study were asked to stay.
- Phone contact, after gaining permission to contact after the above meeting, to continue discussions on study criteria and potential participants throughout the year of recruitment.
- Initial email contact for people who did not attend supervision meetings or ongoing email and phone contact with treatment providers who were interested in recruiting and to continually engage them in the process and need for participants.

When the study was presented to potential recruiters the background and impact of fatigue after TBI was summarised, the lack of evidence on fatigue management in TBI was identified, and the study aims presented. Expectations of the recruiters were clearly outlined; a flow chart was provided summarising the
recruitment process and a ‘script’ explaining the study (see Appendix B for recruiter flow chart). Recruiters were also given copies of the participant cover letter and participant information sheet (see Appendix C for the participant cover letter and Appendix D for the participant information sheet). My contact details were confirmed in case recruiters wanted to ask further questions or check the eligibility of a potential participant. The treatment providers who were offered the opportunity to recruit included OTs, physiotherapists, speech and language therapists, psychologists and doctors.

When a potentially eligible participant was identified then the recruiter contacted the person and briefly introduced the study. If the potential participant was interested in taking part then they were asked for verbal consent to have the researcher contact them to discuss the study further. Recruiters sent an email to the researcher so this information was documented.

The potential participant was then contacted by the researcher to introduce the study further and address any questions the person had about the study. Study criteria were reviewed and eligibility confirmed. If the person remained interested in participation then verbal consent to participate was obtained. The researcher then confirmed postal or email details to send the information pack that included the participant information sheet, a consent form and contact details for the researcher (see Appendix E for the consent form). Finally, an interview time was made at least one week after the initial phone contact to allow time for the individuals to receive the information and to consider participation. The person was asked to read the information sheet. If they were happy to participate then they were invited to bring the signed consent form to the interview or to discuss it further at the interview. Participants were then contacted about one week later to confirm that they wanted to be involved in the study after reading the study information and if so then the interview appointment was confirmed. Participants brought the signed consent form to the interview. Due to the possibility that this study population could experience short-term memory, they were contacted in the week prior to the interview by phone, text or email according to their preference, and texted a reminder on the day of the interview.
Purposive sampling initially considered both gender and Māori but this proved difficult. None of the first four participants was male or Māori. Recruiters were then reminded regularly of the need to recruit from these client groups, and achieved some success with recruiting men.

**Eligible Participants.** The criteria used to select participants from the Waikato region were that they:

1. Had a TBI of any severity that occurred at least six months and less than three years prior. The researchers felt that people needed to have had their TBI for a period of time to gain insight into their fatigue and be involved in some level of trial of strategies to determine what worked for them to enable a successful RTW. Three years was also considered time enough to allow some reflection on strategies that did not work. Also, the severity of the persons TBI was not viewed as an essential criterion as the focus was on having returned to work despite their severity of injury.

2. Were aged between 18 and 65 years old. The research need to consider working aged individual’s due to the question being related to people who were working prior to their injury.

3. Participants attributed the primary cause of their fatigue as being their TBI. Due to this being research on someone’s experience of fatigue and managing this at work it is important that they attribute their fatigue to the TBI and are reporting on strategies that are related to this TBI. It was felt that any subjective measures of fatigue would not add to the depth of the data gathered from participants as it would confine what participants felt they could or should share and therefore impact on the true description of their fatigue strategies.

4. They had returned to employment (with the same employer as before their TBI). It was important for participants to be able to compare a job that they were participating in prior to their injury and the changes they had had to make post injury. This needed to be in the same job so that changes made could be largely associated with the injury and
related fatigue rather than changes to a job, and job responsibilities being the real reason that a need for change was required.

The exclusion criteria were:

1. An inability to communicate fluently in English, because the data collection method was interviews and the interpretation costs could not be met in this project.

3.5.2. Interview. A semi-structured face-to-face interview was carried out to gather information from participants about strategies that help them function in their daily activities. Semi-structured interviews were important to allow a flexible interviewing style to adapt to different individual’s cognitive levels and work environments. These also allowed the researcher to investigate strategies identified more thoroughly. Participants were offered their preference of interview environment such as their own home or work environment depending on their preference to maximise their ability to recall strategies and for their comfort whilst being interviewed.

An interview schedule was used with prompts to assist the interview flow (Appendix F for the interview schedule). The interview schedule was developed to move from broader to more specific content about work and fatigue management. Initial questions were focused on setting the scene (how the injury happened, if the participant had experience post-TBI fatigue) and then quickly moving into information specific to the research questions. These included injury history, TBI limitations, fatigue related limitations, work role, environment and tasks, fatigue management strategies at work, and fatigue strategies at home to allow work to occur. The interview schedule was peer reviewed by both supervisors, one of whom had experience in TBI research.

At the start of the interview participants were given further opportunity for questions to be answered. If they had not signed the consent form then they were invited to sign this prior to the interview beginning. Next, demographic information was collected via a pen and paper questionnaire (see Appendix G for questionnaire). Demographic information included age, gender, medical background, mental health background, ethnicity, living situation and household
income in categories used in the national census. Interviews were digitally recorded by the use of a dictaphone and participants were told when the dictaphone was being started, ended and paused if required.

All interviews were conducted by me. I have 20 years of experience working with people with TBI in clinical situations. Although I had a substantial amount of experience in clinical interviews, I had no experience with research interviews. I developed my research interview skills by debriefing after each interview with my supervisors, and peer coding of the interviews as the study progress also enabled feedback on interview technique. I also kept a reflective diary, which I updated after each interview, including any thoughts around the interview content, ways of altering research interview techniques, links to research question, any assumptions that I recognised, and what direction that interview took and new information that was presented.

3.5.3. Data analysis. After every interview, data was discussed with either one or both supervisors to summarise core concepts that came out of the interview, possible new codes or themes that had arisen and also reflections on the research interview techniques. I completed all the transcriptions from the recordings utilising a headphone set to avoid any accidental eavesdropping. Transcriptions were completed in a word document for ease of editing. An intelligent verbatim method was used when transcribing to eliminate unwanted ‘fillers’ such as conversational pauses, where the meaning of what the person was saying was unaltered. These included “umm’, “you know what I mean”, “and and”. Contractions and colloquialisms were not altered as it was felt that these were part of the data or emotional expression. Laughter or emotion within the interview was added in parentheses e.g. (laughing).

Transcriptions were checked for accuracy against the original recording, and proof read for spelling and grammar while listening to the original recording. At this point, interviews were de-identified to ensure participant confidentiality. This included removing names, proper nouns (e.g. place names, work organisations) and other identifiers replacing these with descriptors such as [partner’s name] or [workplace]. Also, if a participant had said there were particular things they did not
want in the public domain then these were highlighted, and while coded, were not paraphrased or quoted in the study findings.

After this process of familiarisation and checking the transcripts were imported into NVivo version 11.3.2 (QSR International) where all coding was completed. In the first stage of coding interviews were read sentence by sentence and a code assigned. Codes were specific to TBI and fatigue symptoms (such as headache, balance difficulties, cognitive difficulties), injury related information (such as time since injury, mechanism of injury, medical information), rehabilitation (such as therapy involvement, medical involvement, RTW programme). They also included impact of TBI or fatigue on life (such as work, domestic tasks, relationships), work information (such as job type, hours and work tasks), and possible overriding themes. And lastly fatigue management strategies (including what they were, when they were used, where they were used, whether they were an early strategy or late strategy in relation to injury, how helpful they were).

When a code was established a definition was drafted. Code definitions were revisited and altered if required, and revisions were dated to see the evolution of the code definition. Notes were added into transcriptions on researcher thoughts or reflections during the transcription and coding process.

As coding progressed, previously coded transcripts were checked to ensure accuracy and completeness of coding according to the coding schedule. Four transcripts were peer coded by a supervisor, and one transcript was peer coded by both, and the coding was discussed. Original codes were cross-checked with peer codes to determine if any data were coded differently by different coders, any new codes emerged, or any code definitions needed revisiting. The last two interviews did not produce any new codes, so it was decided at this point (eight participants) to cease recruitment.

At the end of initial coding each code was then considered in relation to other codes to determine whether codes could be merged. The grouping of codes was assisted by reference to the notes I had kept from the debrief with supervisors of each interview, where I had discussed core concepts that came out of each interview. Once this was completed then mind mapping occurred with pen and paper to consider how larger clusters linked together, considerations of themes and
how the findings could be presented in a way that stayed close to the data. A diagram was developed that encapsulated the data from all participants, from the broader context of fatigue management at work – such as needing to alter behaviour outside work – through to the specifics of what, how and when fatigue management strategies were used at work. Participant quotes were selected to represent the participant experience captured in each component of the diagram.

3.6. Research rigour

Qualitative descriptive designs have been criticised for their lack of rigour, particularly credibility, therefore it was important to consider maximising rigour in the study methods. Neergaard et al. (2009) suggested that the match between the goals of research and the qualitative descriptive approach needs to be carefully considered to maximise rigour. They also suggested use of strategies to increase rigour of a qualitative descriptive approach as identified by Milnes (as cited in Neergaard et al., 2009). Application of these strategies to this research thesis are considered below.

Authenticity. ‘Participants are free to speak’ - In the semi-structured interview, open questions were broad enough to allow participants to describe their own experience and own way of managing fatigue. Further clarification was encouraged, by prompting, when concepts or experiences shared by the participant seemed important to them as demonstrated by facial expression, or body language, or linguistic repetition or emphasis.

‘Purposeful, flexible sampling’ – with the purposeful sampling method the rigour of this design was increased. Also, rigour was increased with the continuous reassessment – in discussion between researcher and research supervisors – of whether enough participants had been recruited to yield sufficient, rich, data for analysis.

‘Accurate transcriptions’ – intelligent transcription methods were utilised, but this was not viewed as reducing the accuracy of the transcriptions. Transcription accuracy was ensured by checking the transcript against the recording up to three times.
‘Content analysis was data driven’ – Coding in NVivo allowed the researcher to stay close to the data and develop codes directly reflecting what the participants said. All transcripts were re-read once they were coded and again once the codes were grouped into larger concepts. This enabled repeated checking that all data were captured in codes.

**Credibility.** ‘Capturing and portraying an insider perspective’ – Recruitment of participants who had an experience of fatigue, and managing this at work, captured an insider’s perspective. Further, all but one participant was experiencing fatigue at the time of the interview; one was reflecting on the experience of fatigue that was now resolved.

**Critically.** ‘Reflecting on the application of critical appraisal of research decisions’ – All decisions throughout the research process were made in discussion with my supervisors, and an audit trail of all decisions was kept. Examples included the documentation of the evolution of the code descriptions, and peer coding.

**Integrity.** ‘Reflecting on researcher bias’ - Several strategies were used for reflection. As outlined previously, I discussed some influences on my research before the research began, used a research journal, especially for documenting pre and post-interview thoughts and feelings, and debriefing with supervisors during the data collection and data analysis processes.

‘Peer review and triangulation’ – Peer coding was completed with five of eight transcripts. Also, each interview was read by one or both supervisors, then verbally summarised by the researcher during discussion with my supervisors; the researcher identified possible codes for the content and this was compared with my supervisors’ thoughts about coding.

### 3.7. Ethical, Treaty, and other considerations in the research process

An ethics application was submitted and the proposal was approved prior to any participant being recruited (see Appendix H for ethics committee response letter and Appendix I for researcher response to ethics committee letter). A University of Otago Māori consultation form was submitted and a response letter was received (see Appendix J for Māori consultation response letter).
3.7.1. Ethical considerations specific to this research. The participants that fit the study criteria were in a similar geographical area to where I am employed. I am an OT who provides community rehabilitation under contracts to ACC and works with people who have had a TBI and are currently off work. A particular concern was the possibility of any ethical dilemmas that might arise if I was in a research role with a previous patient (Hay-Smith, Brown, Anderson, & Treharne, 2016). None of my current or past clients were approached to take part in the study. I included my name, clinical role, and area of work, on the participant information sheet so this was known to all those who were approached to take part. I also asked third party recruiters to approach potential participants, hoping this would reduce the chance of coercion to participate. Another way of keeping my research and clinical roles distinct was to tell participants that in the role of a researcher I would not offer or provide any rehabilitation advice other than to suggest they contact their existing or previous provider, or GP, if they had any questions or concerns.

3.7.2. Consideration of recruiting company’s procedures. The internal procedures governing research in the organisation that employed the recruiters were investigated. As there were none, there were no further ethical review or approval granted beyond that from the University of Otago. However, locality approval was sought from the company directors and I provided information about the study including the consent form, flow chart for recruiters, and the information sheet. Verbal agreement was given for their contracted treatment providers to act as recruiters for this study.

3.7.3. Emotional risks. Another risk was participant discomfort. While the interviews did not collect sensitive information, clients could have become upset when reflecting on their injury limitations or impact of their injury on their life. If a participant appeared distressed within the interview then the option of stopping the interview and/or withdrawing from the research was presented. If this occurred participants were provided with a list of services where support could be accessed.

There was also a risk to me that hearing participant experiences might have been upsetting, or that I might have been concerned about the care they received. I
used debriefing sessions with supervisors to review any concerns of this nature; if a participant was at all distressed, I tried to remain empathetic without becoming a ‘therapist’ (Hay-Smith et al., 2016).

3.7.4. Cultural considerations. It was hoped that people who identified as Māori would participate in this study. As outlined in the background, more Māori sustain a TBI compared with the general population. There was only one participant who identified as both Māori and NZ European. Principles of Mihimihī, Whakawhanaungatanga, Kaupapa and Poroporoaki were utilised as much as possible when interviewing this participant.

3.7.5. Risk to the researcher. All participants chose the environment in which they wished the interview to take place. Four interviews took place in the participant’s home. Basic safety strategies, familiar to me as a community OT, were implemented. These included:

- Checking likely risks prior to interview such as presence of a dog.
- Utilising Google Earth to check geographical environment.
- Parking the car without obstruction and outward facing.
- Sitting closest to the exit during the interview.
- Maintaining contact with mobile phone during the interview if concerned.
- Not entering the environment if at all concerned.
- Utilising a contact person to phone before and after interview.

3.7.6. Confidentiality. All information collected was kept strictly confidential. Participants names and any other identifying factors were only available to me, and my supervisors. I transcribed the interviews and utilised numbers for participants rather than their name. Any identifying information (e.g. names, place names, place of employment) was removed or anonymised during transcription. Electronic information, such as transcripts, were kept on a computer and backup drive with password protection and paper copies, such as consent forms and demographic information sheets, were scanned into the computer and checked. Once quality was confirmed the paper copy was disposed of in a cross
If participants were in a particularly sensitive job or were concerned about confidentiality, transcripts were sent to them to confirm that de-identifying was appropriate for their situation. Information will also be stored for 10 years and then confidentially destroyed.

3.8. Dissemination of findings

The following organisations were identified as possibly having an interest in using or disseminating findings from this research.

- ACC
- ACC Treatment providers including GP’s
- People who have experienced TBI and their family/whanau.

3.9. Summary

This chapter outlined why a qualitative descriptive approach was taken to investigate participant’s experience of managing fatigue at work after a TBI. Qualitative description was an appropriate methodology because it allowed a rich description of the participants experience and identification of fatigue management strategies that worked to enable a return to work after TBI related fatigue. The study methods were typical of qualitative description in using purposive sampling, semi-structured interviews, and thematic analysis. The study design, and the use of reflective activities, was carefully planned to support the conduct of rigorous and ethical research.
Chapter 4: Results

4.1. Overview

This chapter contains the analysis of the semi-structured interviews with eight individuals with TBI. The findings from the pooled demographic information is presented first. A figure illustrating the complexities of managing fatigue after TBI, which enables people to work is presented. Then the analytic focus was how participants managed their fatigue after a TBI to allow them to engage in paid employment.

4.2. Recruitment

Thirty-four health and medical professionals from Focus on Potential Ltd were contacted to recruit participants (17 OTs, 12 physiotherapists, three speech and language therapists and two medical doctors - a neurologist and an occupational physician), and four OTs recruited all the participants. These OT’s worked in either concussion type contracts or training for independence contracts (a community rehabilitation programme) and the participants were current or past patients. See Table 4.1 below for summary of recruiter outcomes.

Table 4.1. Recruiter Involvement

<table>
<thead>
<tr>
<th>OT</th>
<th>Participants</th>
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<tbody>
<tr>
<td></td>
<td>Agreed to be involved</td>
</tr>
<tr>
<td>A</td>
<td>3</td>
</tr>
<tr>
<td>B</td>
<td>3</td>
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<td>D</td>
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</table>

Eleven people were potentially eligible and eight consented to take part. Of the three that declined, one initially agreed, but reinjured and became un-contactable, one initially agreed to be involved and then cancelled the interview appointment and became un-contactable, and the third was un-contactable. All
three were presumed to be unwilling to be involved in the study after two attempted phone calls and one text message.

Interview times ranged from 47 minutes to 1 hour 17 minutes with an average time of 62 minutes. Four interviews were conducted within the participants home, three at their work and one was split between a café and work.

4.2.1. Study sample. The pooled demographic information of all eight participants is in Table 4.2 below. One participant was over the age range set in the criteria by one year (66 years old) but it was decided to accept him into the study as he was still working full time and had no reported age-related disorders that could be confused with brain injury related fatigue. All participants were estimated by the researcher via their self-reports in regard to their specific injury, loss of consciousness and duration of time not recalled at the time of injury (possible PTA) to be within the mild to moderate TBI severity range (see section 2.1).

The sample recruited were predominantly women who earned more than the NZ average wage, were professionals (major group on the ANZSCO) and lived with at least one other person. No participants identified as solely Māori, but one participant identified as both NZ European and Māori. All the participants had engaged in rehabilitation after TBI, consisting of a concussion service (including an OT with/without other health professional team members) and/or a specific vocational service with occupational therapy input. In addition, they all participated in a graduated RTW programme (varying format and duration, overseen by an OT) either via the concussion services or a specific vocational service. The recruitment method, via community based health professionals, meant it likely the participants were involved a graduated RTW programme as part of their rehabilitation because the current guideline for best practice in enabling return to work after TBI includes graduated RTW.

4.3. Managing fatigue – the overall picture

Figure 4.1 illustrates the strategies that participants used to manage their post-TBI fatigue after a brain injury to allow them to complete paid work. This figure illustrated all descriptive categories that was derived from the analysis.
<table>
<thead>
<tr>
<th>Table 4.2. Participants Demographic Information (Pooled).</th>
</tr>
</thead>
</table>
| **Sex** | Women: 5  
          Men: 3 |
| **Age range (years)** | Average: 42.88 (SD 16.38)  
                          Median: 41  
                          Interquartile Range: 30 – 54  
                          Range: 24 - 66 |
| **Time since injury (months)** | Average: 9.63 (SD 5.15)  
                                  Median: 7.5  
                                  Interquartile Range: 6 – 11.25  
                                  Range: 6 to 21 |
| **Ethnicity** | NZ European: 4  
                       NZ European/Māori: 1  
                       African: 1  
                       Irish: 1  
                       English: 1 |
| **Household income (NZ dollars)** | Above 75000: 5  
                                         55000 – 65000: 2  
                                         Less than 55 000: 1 |
| **Living situation** | Flatmates/Boarders: 3  
                           Partner/Spouse: 3  
                           Alone: 1  
                           Spouse and Adult child: 1 |
| **Mechanism of injury** | Mechanical Force (6 - sports injury): 7  
                             Assault: 1 |
| **Occupation¹** | Professionals: 5  
                         Labourer: 1  
                         Community and personal service workers: 1  
                         Clerical and administrative: 1 |
| **Work structure** | Employed: 7  
                           Self Employed Contractor: 1 |
| **Work environment** | Clinic/hospital: 2  
                           Office: 1  
                           Outside (primarily) and office: 1  
                           Office (primarily) and sports venue: 1  
                           Classroom (primarily) and office: 1  
                           Large shed/warehouse: 1 |

Figure 4.1: Fatigue management to enable a return to paid employment.

- **High “Intensity Tasks**
  - High Cognitive Demand
  - Computers.
  - Lots of thinking.
  - Lots of noise or light.
  - Multi-tasking
  - High social demands.

- **Low “Intensity Tasks**
  - Low Cognitive Demand
  - Implementing cognitive strategies.
  - Alter/move environment (noise/light/social).
  - Choose easier tasks.
  - Use equipment.

- **Super Mini Break**
  - Very short break (few minutes).
  - Occurs within the work task.
  - Occurs in the same environment.

- **Mini Break**
  - Obvious stop from task.
  - Away from core task
  - Often away from work environment.
  - From 2 to 10 minutes.

- **Long Break**
  - Obvious stop from task.
  - Away from core task
  - Often away from work environment.
  - From 15 minutes to 1 hour.
  - Often involved going for a walk.

- **Sleep (Outside work)**
  - Point of leaving work to sleep at home.
  - Increase sleep at night

- **Day Off**
  - When weekends aren’t enough to recover.
  - Occurs during a return to work programme.

- **Exercise**
  - Work / Outside Work
  - Light to moderate i.e a walk, bike, horse ride.
  - May be in long break or after work.
  - Avoid strenuous exercise
  - Preferably an outside environment.

- **Relaxation**
  - Outside Work
  - Short periods of relaxation.
  - Meditation techniques.

- **Non-Work Activities**
  - Outside Work
  - Reduce social, leisure and domestic tasks.
  - Avoiding computers.
  - Avoid alcohol.
  - Reduce coffee.

**Need to be productive (work)**

- Minimal interruption of Work Task – Higher Productivity

**OUTSIDE WORK**

- Pushing Through

**Need to recover (fatigue)**

- Interruption of Work Task – Lower Productivity

**Balancing**

- Work / Outside Work
  - Balance tasks over week.
  - Prioritising tasks over week (work and self-care tasks priority).
There were two core areas in which participants implemented strategies to ensure a successful RTW and work productivity – at work (large, horizontal, grey box) and in their home environment/non-work activities (large, blue L-shaped box). Most strategies were implemented at work. Strategies implemented outside work are used to allow them to work; this may be restorative - to recover from work - or to build reserves in anticipation of the energy level required to work. Participants identified balancing these two areas, work and non-work tasks, to implement strategies over the whole week. The balance of activities (circle) between home and work allowed work and also essential tasks at home to occur. This balance is constantly changing depending on the individual’s priorities each week. Points of change, where decisions about which strategies to use when are made, are represented by the arrows.

When fatigue management strategies are implemented well the participants successfully managed their workload and identified some of their personal life was managed as well. Despite this, almost all participants had not fully returned to their social and leisure activities outside work although the majority had returned to their pre-injury work hours. Work appeared to have priority in the participant's weekly activities. For example, Participant 7 said when discussing social evenings “Only on Friday nights. Otherwise I fall to pieces. Maybe one day I will get back to normality but right now I can’t”.

The concepts in figure 4.1 will now be broken down and discussed in more detail below following a graphic indicating the area being elaborated on.


4.4.1. Productivity and drivers.
Fatigue management strategies used at work formed a continuum – the green and purple region of figure 4.1 as above. Participants were pulled to be productive at work to fulfil their work role and achieve the appropriate outputs. This contrasted with the need to recover from fatigue so that they could continue to be productive. Productivity has been defined as “the ratio of output to input for a specific production situation” (Rogers, 1998, p. 5).

When the participants were at work they needed to be seen as productive. This seemed to reflect their descriptions of being seen as a high achiever, the ‘go to’ person, their own work expectations, and expectations of work colleagues including peers and managers. Participants expressed concern at being seen as incompetent; “fear’s so very real of just not being able to achieve what you used to be able to achieve and people judging you by that” (Participant 8). The ability to complete high intensity tasks (without fatiguing, or needing to take some sort of break to manage fatigue) signalled productivity and competence to them, their peers, and managers.

The closer the strategy is to the left of the continuum the less impact this strategy has on productivity. Equally the strategies closest to the right have the greatest impact on productivity. However, all of these strategies are required to maintain productivity overall. The detail of the strategies are covered elsewhere (see section 4.4.2), while movement within the continuum (and drivers of this movement) are explored here.

The continuum has two parts. On the left (green) is the area where participants were actually engaging in a work task (high and low intensity tasks) and on the right (purple) is recovery that enables them to later re-engage in work tasks. As soon as fatigue made work tasks harder and productivity reduced, “when I am just making mistakes on my data” (Participant 4) – the pull to recover began.
**Productivity and task intensity.**

Participants strive to do the highest intensity task they can. When the ‘pull’ to recover from fatigue begins they start to move away from productivity, further and further to the right towards recovery. However, the participants always tried, at work, to stay as far to the left of the continuum as their fatigue allowed to maximise their productivity. Therefore, if participants had full energy or were “fully recharged” (Participant 11) they engaged in the high intensity tasks that they were required to complete. These tasks, frequently encountered in the work environment included: computer work, tasks in multisensory environments, high demands on communication and cognitive processing, such as work meetings and other cognitively demanding tasks involving executive functioning.

If fatigue started to be experienced or if the participants were anticipating a highly demanding day, they made cognitively demanding tasks easier by reducing the demands of these tasks. Cognitive demand was reduced by reducing the light, noise and social components, such as colleague conversations off topic, if they were non-essential to the core task. If the work structure allowed, individuals chose to engage in an ‘easier’ task. Easier tasks were still part of their job role, but the reduction in cognitive processing was a way to manage fatigue and allow productivity to continue. Tasks may have been completed in a different sequence to that which would have occurred prior to their injury.

**Productivity and recovery.**

When determining what recovery strategy to take, the most productive rest was one where the participant stayed in the task environment and often within the task itself. These breaks (super mini breaks) had the least impact on the task,
which allowed the participants to maximise their productivity, yet have some recuperation. There was an obvious move away from the tasks in the next level of rest (mini breaks). This was still considered to have a small impact by most participants. Due to its short duration, and participants were able to return to the task and continue it within an acceptable timeframe, for example “People are allowed ten minutes smoke breaks” (Participant 11), where it was felt that this short break was justifiable in the work environment as it was similar to other workmates having a break for a cigarette.

Once individuals moved past these two break levels, and they needed longer breaks, (Long breaks) the impact on productivity was greater. Often participants were only having long breaks once a day and if they needed more they went home “There’s nothing you can do and it’s like to the point where one day I actually had to get a staff member to drive me home” (Participant 8). What she described here was that the need to recover outweighed her ability to be productive. The choice of break depended on anticipating productivity over a whole week (Balancing). Participant 3 noted she had to be “more aware of what I had done the days before and what I was needing to do the days after so that I scheduled it a little better” (Participant 3). The specific strategies that are implemented at work are now discussed.

4.4.2. Strategies for fatigue management at work. In this section, the specific strategies that participants identified that they used to manage fatigue in the work environment are discussed. This is represented by the horizontal line of boxes on the continuum (see figure 4.1) The following section (4.4.3) then explores that strategies that are implemented outside of work to enable participants to function at their best in work.
Low intensity tasks.

With the onset of fatigue, most participants tried to do a task that was easier or less demanding. Participant 10 chose an easier task when he identified some fatigue occurring:

Something easier it didn’t need so much thinking I guess, where you had to process something and think about what you had to do and then several things going on around you, people asking questions and all that. Minimise that intensity if that’s the right word (Participant 10).

The choice to complete an easier task varied between individuals. Easier tasks were chosen when participants felt some level of fatigue in a task and they removed themselves from that task to complete an ‘easier’ or less demanding task. Participant 11 removed himself from the computer, which he reported was his hardest task, to an easier task such as light conversation:

It’s not often a conscious thing. What happens is I can’t sit on my computer. So I find something different that I can do, that doesn’t involve computer work so it may mean that it means going and talking to my manager about something that I am working on or that she wants me to do. (Participant 11).

Working on computers was often identified as the most challenging task. One participant implemented a variety of strategies that were used to help reduce the length of time on computers in a job that required a lot of computer time. Strategies included the use of a smaller screen such as a phone over a computer, increased computer fonts, reduced screen brightness, use of a screen filter, and
typing from notes on paper and avoiding looking at the screen until necessary “Write my note and then put it right here in front of me trying not to make contact with the screen” (Participant 11).

Some participants could not say why they chose an easier task, but when the work environment allowed a level of task choice, the individuals reported that they would make the choice to take an easier task to conserve their energy over the day. One participant who previously described looking at a computer screen as “really difficult” found that “if there was an opportunity to do something that wasn’t on a computer” she would take it (Participant 1). Another participant identified when having a choice of tasks, he chose “The easy one I suppose. The ones that I thought were the easiest” (Participant 7), to ensure that he would be confident in managing them. Harder tasks were reported as computer work or having work conversations with colleagues such as meetings or clients, for example, “because clearly the computer just drives me crazy, and the alternative task may not require so much, may not be taxing on my mind, my brain” (Participant 11).

Altering the work routine to allow more time to complete tasks was also identified as important to allow work productivity. One participant extended her allotted time to see clients and this reduced the pressure of the work and allowed her to think clearer “I guess having the extra time so I wasn’t under pressure between patients and stuff helped because you weren’t just running from one patient to another” (Participant 3). Another participant reported that knowing he could cope with the allocated work hours when he participated in a RTW programme allowed him to confidently complete his work tasks “When I came in I knew that I could cope with what I had to do so it was very easy and that’s the only way” (Participant 7).

At other times participants structured their workday, knowing that they needed to complete less demanding tasks after harder tasks. This involved short chunks of activity such as 45 minutes of interaction with a client and then 15 minutes of writing down the interaction. Or, over a whole day or week demanding tasks were schedule for a morning or afternoon and less demanding tasks were scheduled for the rest of the day, such as alternating tasks that required lots of concentration with low concentration tasks, “So I schedule it as well as I can and I
know that there’s low concentration stuff there or high concentration stuff in the morning and a low stuff in the afternoon usually” (Participant 4).

Participants also used a variety of cognitive strategies that would reduce the cognitive demands of a task, which reduced the task intensity. Memory and concentration were often identified as getting worse when they were fatigued and therefore reducing demands at this time was useful. When concentration was getting worse one participant identified using an internal strategy to prompt themselves to concentrate on a conversation “I got to actively remind myself just so my brain can focus on what they’re saying” (Participant 1). Participants also identified the need to write requests down or lists of what needed doing to help them manage their day and complete tasks “I was better at jotting quick notes down during my patient sessions because I would not always remember them after or that I would struggle to remember a couple of patients later” (Participant 3).

Another way to lower the tasks intensity was to make changes to the task environment, for instance a few participants closed the door to their office to reduce interruptions, reduce noise and to have a physical barrier between themselves and people. This would in turn reduce the possibility of colleagues socialising and as a result, participants energy was used on high priority work tasks:

*I think it was a way to just keep myself away from all the stuff really. It was quiet* “When I come out that’s when I am ready to be seen. When I am not out I don’t want to be seen (Participant 11).

Changing task environments was also essential in allowing individuals to manage their workday. These changes were made when individuals were becoming tired or prior to starting a challenging activity. The most common environmental change involved moving to a quieter environment to complete tasks such as computer work, for instance, "There was a computer in an area that’s kind of dark and closed off which I’d try to use if it was free just because it was quiet" (Participant 1). A few participants had difficulties with light and the need to move to an environment where lights could be turned off allowed them to reduce the task

demands, for instance, “If it’s just me I will leave the lights off in here still and just work”

If changing to a quieter environment was not achievable then individuals would find ways of making their current work environment quieter, for example, “If the radio was on in the gym I would have to go and ask them to turn it down or turn it off.” (Participant 3). One participant, with considerable job flexibility, chose to carry out some of their workday at home, “When I worked from home, I found I got more work done in some ways because you didn’t have lots of distractions and things” (Participant 9). Another participant said:

I couldn’t really keep up with that noise level so I wear my earmuffs even now. You can still hear people but the noise is cut down to quite a bit.........you can more get involved with the job you’re doing and get through it quicker easier and that’s what I was there to do (Participant 10).

If participants were unable to move to a darker or quieter environment then they utilised other strategies to alter the environment where they were. These included strategies such as lights being removed or turned off in their current environment to reduce the fatigue experienced from bright lights, for instance, “They had to take the light out over my desk” (Participant 9). One participant turned off half the lights in a classroom to reduce the light, “I first started working here we had to switch these lights off and I had to sit on this side of the classroom” (Participant 9). A few participants found that natural light was easier to tolerate than fluorescent light. This involved either choosing tasks outside over inside tasks, for instance, “I couldn’t handle the light, which is another reason we chose [outside sport] because I was out in the natural light, not so intensive for me” (Participant 4) or utilising time outside when the lights inside became too much. Another participant preferred light from a desk lamp rather than the fluorescent lights, “I have a desk lamp because we had fluoro lights, it doesn’t work. So I have a desk lamp” (Participant 8). One participant could not alter the lights or noise in a certain environment and therefore she wore a hat sunglasses and headphones to reduce the impact of the lights, “I came in and wore a hat, sunglasses and a singlet and headphones so I at least could watch it a bit” (Participant 4).
**Super mini break.**

**Super Mini Break**

- Very short break (few minutes).
- Occurs within the work task.
- Occurs in the same environment.

This was a very short break, which occurs within the work task that is being undertaken and in the same environment. It was often used when removal from the work task has a high impact on the task, such as supervising people, or teaching. It was also used when individuals felt more conscious of others seeing them as unproductive or feeling unproductive themselves. This break may not be seen by others as a break as it may be disguised as the individuals stays in the task, such as, “*When I was out on the jobs if I felt like I was quite tired I knew I would go and have a cold drink of water*” (Participant 7), where the participant was still in the task environment and the water was only a few steps away. Other examples were walking around rather than sitting this was possible, or having a pause within a task, for example, “*I just sit there and not look at the screen......... for a couple of minutes*” (Participant 1). Super minibreaks were also reported almost as part of a task such as when co-teaching handing the ‘stage’ to the other teacher, for example, “*I would often hand over to her or when she’d gone and they had another girl it was saying “so what’s your thought on that”*” (Participant 9). Or taking a short ‘brain break’ “*shall we have a brain break*” which was defined as doing “*different things to get your left brain and your right brain*” (Participant 9). Super mini breaks are differentiated from completing an easier task under low intensity tasks by the lack of disruption of the core task that is being completed.
Mini break.

Mini Break

- Obvious stop from task.
- Away from core task
- Still in work environment.
- From 2 to 10 minutes.

Mini break, constituted an obvious stop in the work task being completed. This break occurred in the general work environment, but took the person away from the core task itself or core task environment. It involved the participant taking anywhere from a two to ten minute break or ‘time out’. These breaks were, however viewed as being non-disruptive to core task “I had a few minutes between each patient as well. Just to kind of switch off” (Participant 3)

These breaks often involved going to get something from within the work environment such as a work tool or a drink of water a short walk away, for instance, “just get up and go and get some water” (Participant 4). Mini breaks could also involve a short social chat with a colleague, for example “go and talk to somebody for 5 – 10 minutes” (Participant 10). Mini breaks also involved participants removing themselves from noise and light, such as, “set my timer 10 minutes and then shut my eyes, dark room” (Participant 11).
Long break.

<table>
<thead>
<tr>
<th>Long Break</th>
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<tr>
<td>• Obvious stop from task.</td>
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<tr>
<td>• Away from core task</td>
</tr>
<tr>
<td>• Often away from work environment.</td>
</tr>
<tr>
<td>• From 15 minutes to 1 hour.</td>
</tr>
<tr>
<td>• Often involved going for a walk.</td>
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These breaks were also a definite stop in the task. Participants were taken away from the task, and often away from the work environment. What differentiates these from mini breaks is their duration and the complete removal from a task. These breaks were anywhere from 15 minutes to one hour away from the work task. These could be taken as usual work breaks such as lunch, but also could be additional breaks. The majority of long breaks involved going for a walk outside away from the work environment, for instance, “sometimes I could do a longer walk, sometimes I go for 30 40 minute’s walk” (Participant 11). Some consisted of sitting and having a social chat, for example, “I will go and have a hot chocolate or a catch up with someone in the café. And if that takes an hour that’s OK cause that’s what I needed to get back into my work” (Participant 4). Others involved just sitting in a quiet room within the work environment, but away from their own specific work environment, such as, “just go into a room or I would go and take my cereal and go and have my breakfast in another room and just sit there quietly with nothing not even my phone, just sitting” (Participant 8).
4.4.3. Strategies for fatigue management outside of work. Participants reported the need to change activities outside of their work to enable them to remain as productive as possible within work. These strategies are outlined below.

Sleep.

If participants identified that they needed sleep at work this would be the point at which they decided that they should go home and recover fully by sleeping, for instance Participant 8 identified that she got to a point where she could no longer work, so she went home to sleep.

Participants went to bed earlier to ensure that they had more sleep each night, for instance, "I am a bit more mindful of how much sleep I get. So I try to get as much as I can so eight hours so if I need to go to bed early I will and if I need to get up late I do that" (Participant 11). Improving their overnight sleep helped manage their fatigue the next day.

Participants slept at home after work if they were on reduced hours such as during a graduated RTW programme. Some reported this sleep enable them to manage their evening, for example,

Like even after work here, I would get back, say I would only work half a day I would get home and I'd fall asleep, and I would be asleep until I wake up and a couple of hours had gone by (Participant 7).

A few participants took alternative medications to help them fall asleep at night, or completed relaxing activities prior to bed to help them get to sleep more quickly, for instance, "using a meditation app to try and or sleep app to try relax my head when I was in bed" (Participant 3).
**Day off.**

Participants took occasional days off to help them manage their fatigue when they were not feeling in control of it, for instance,

*There was no recovery happening so I knew that I just had to stop. So I actually had to take a day off from work at one point as well, to add to the recovery time so that I could [recover] (Participant 11).*

Day’s off occurred in conjunction with participants choosing to ‘push through’ their change point when they felt they needed to get work done as a result of work pressure, their own internal expectations or other’s expectations, for example, “I was working weekends but often I would be quite tired after working weekends so I would need a day off in the week following just to catch up” (Participant 1).

These included days off that occurred in a RTW programme, which also involved increasing amounts of time at work, but at times these occurred after the completion of a RTW programme.

**Non-work activities.**

<table>
<thead>
<tr>
<th>Non-Work Activities</th>
<th>Outside Work</th>
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<tr>
<td>Reduce social, leisure and domestic tasks.</td>
<td></td>
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<tr>
<td>Avoiding computers.</td>
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<td>Avoid alcohol.</td>
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<td>Reduce coffee.</td>
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The majority of participants changed their non-work activities to enable them to function at their best within their allocated work hours. The most frequent reported change was a reduction in evening and weekends activities. Activities that were reduced included either sporting or social activities, for instance, “normally you would go home and do something you wanted to do, go and see your friends or go shopping or do what I don’t know. I couldn’t do any sort of like private life because I had to conserve my energy for going back into my job” (Participant 9), outside chores such as lawn mowing and gardening, or leisure such as fixing cars, and horse riding for example, “There’s a big area to mow lawns and do stuff and I’ve got quite a few cars to do and all that’s back burner stuff at the moment” (Participant 10).

Basic self-cares such as showering and dressing were never reported as being altered to manage fatigue. A few participants noted a reduction in some domestic tasks such as cooking meals and housework with additional support from their partner, for instance,

But when I got home in the evening I would usually help the wife do a bit of tea or something, but all I wanted to do was go home have a shower, sit down and have my dinner and gone” (Participant 7).

Some reduced or put study on hold, such as Participant 11 who stopped studying: “I was advised to stop [study] by my supervisor as well, and I couldn’t to be honest, [manage study] even though I tried it just wasn’t going to work” (Participant 11). Some participants also avoided technology, such as computer and their phone, or cognitively demanding tasks such as studying to conserve energy. For example, participant 1 reported that she: “avoided the computer and didn’t go on my phone very often” (Participant 1). Participants also noted that they would avoid coffee and alcohol, for example, “Just making sure I wasn’t having coffee because coffee made me significantly worse. Even if I had it in the morning of the day that night I would find it significantly worse” (Participant 3).
Relaxation.

A few participants used relaxation or meditation to help them regain energy. One utilised a previously learnt technique and found this helpful. Another participant attended a meditation class, for example, “And then started doing some weekly meditation things and I felt that that helped settle my head and the busy-ness that was in my head as well” (Participant 3).

Exercise.

A few participants said exercise helped to manage their fatigue over the day. It was noted that this was mostly light to moderate exercise such as walking, biking or rock climbing, for instance, “what often takes me back to baseline or whatever post concussion, is exercise. It’s so powerful, it’s just unbelievable really” (Participant 11). One participant avoided intense exercise as this fatigued them more and had an impact on the next day at work, for example, “if I did too much then I would fatigue out, so making sure that I wasn’t overdoing it” (Participant 3). One participant felt that exercise made no difference to managing fatigue. When asked if it helped fatigue or increased tiredness she stated: “no difference” (Participant 1).
Exercise such as walking was also used as a form of long break within work and was very useful to reduce fatigue at work, for instance, "Making sure that on the breaks that I didn’t sit at the computer and catch up with my notes, that I tried to go for a walk outside, not that I was very good at that" (Participant 3).

4.4.4. Decision making and the learning process.

There was a complex decision-making process in action when participants decided to change their task or activity to manage their fatigue. There were multiple influences on this decision to change from higher intensity task to a lower intensity task, or from a task to some type of break. The influences on the decision were individual, and often context specific. However, one consistent factor that was present in all decisions to change was having some self-defined fatigue symptom. The primary motivator to change was the concern of over-doing it and then experiencing severe fatigue, such as they had early on in their recovery process. They wanted to avoid severe fatigue because of the loss of control they experienced and the impact on their ability to complete any task presented.

Movement between high or low intensity tasks and breaks happened in either direction, and were not necessarily sequential. For instance, participants described moving from a high intensity task to a super mini break and back to a high intensity task before taking a long break (at lunch). They then might return to a low intensity task for the rest of the day. Choosing the direction of movement, and which point on the continuum to move to, was a balance between the pull to be productive and managing fatigue symptoms, therefore the pull towards recovery; participants learned this process, principally through trial and error, and recognised there were times when they deliberately chose to continue with a task even though it would be wiser to stop. Thus, the arrows in the figure 4.1 are bi-directional to represent the variation in movement between task and break, and
multi-coloured to reflect the individual convoluted process that occurs prior to a decision being made.

4.4.5. The need to change (‘change point’). Early on in their injury recovery participants noticed their fatigue related symptoms and that these symptoms were a signal of the point where they had to change what they were doing or their fatigue became debilitating, for instance,

And all it comes down to is fatigue because as soon as you get a slight sign which I wasn’t identifying back then, that I was tired then boom within ten minutes the world shut down for me it was like somebody just closed it off (Participant 8).

The participants also noted that while they learned that their symptoms were an indicator that change was needed, they were less sensitive to this earlier on in their recovery and learned to be more aware as time went on and the consequences of ignoring ‘the change point’ became clearer. The importance of paying attention to the ‘change point’, to better manage fatigue, was often realised after an event or incident where symptoms had taken control of the participants ability to function, for example,

I remember getting to the car and I didn’t know how to pick up my groceries. Didn’t know how to get them from the trolley into the car. So sat in the car and had an absolute melt down. Cried and cried and cried and cried. Thought I don’t know what I am doing; I don’t know how to do it; I don’t know where my home is. Complete and utter loss of everything (Participant 8).

One participant spent three months of engaging in a “boom and bust” approach before accepting they needed to make changes to allow a recovery. They accepted the need to change as other people encouraged them to accept help, “I often say I needed people to save me from myself” (Participant 11). Some participants experienced a different type of “bust” where they became “wired tired” (Participant 9) if they had not noticed their change point and had kept going. Being “wired tired” meant they had trouble resting because of their brain being overrun with thoughts, but despite the high level of cognitive activity they were not actually
able to function effectively, for instance, “Sometimes I was down to three two one even [on the fatigue analogue scale]. Real low where you were absolutely wired tired and you couldn’t come home and rest” (Participant 9).

Participants identified a variety of symptoms and/or behaviours that warned them that either their change point was approaching, or change was needed immediately. Such warnings were typically changes in cognition, emotion, or onset of physical symptoms. Cognitive changes included reduced concentration (“I am starting to loose concentration” (Participant 4), or “I would realise that I hadn’t listened to what they were saying” (Participant 1)), memory (“you would start forgetting things” (Participant 10)), problem solving (“I couldn’t think of other ways to explain it to them” (Participant 9)). Emotionally, participants noted irritability was a warning, (“I did notice that I was getting a little bit more irritable” (Participant 10). For others, the signal of a change point was physical, such as a headache (“It’s the headache, that is the first thing that gets triggered, my eyes as well get sore quite a lot” (Participant 11)) or heightened sensitivity to a point of noticing, background noise becoming louder:

so I learnt when the fridge that I can’t hear right now makes this ‘hua of a noise’ [deafening/annoying] when you’re in the thick of it when I could hear that really loudly then I knew things were tipping (Participant 8).

One participant found the use of a fatigue scale (analogue scale from 1 to 10 where 1 was extreme fatigue and 10 was full energy) helped her reflect on her fatigue levels to determine when she would change:

So it was just conscious of the fatigue levels and once I got into it, it was just making sure asking myself as well what kind of stage are you at. Gosh you’re a three that’s not good (Participant 9).

Over the course of the participants injury recovery the first thing participants learned was to identify when a change point was approaching “So it was just conscious, of the fatigue levels and once I got into it [work], it was just making sure, asking myself as well what kind of stage are you at?” (Participant 9). Once the concept of a ‘change point’ was realised, then the process of refining this
began such that participants chose actions congruent with the intensity of their symptoms:

*It’s not like every day I want to go for a walk, sometimes I’ve gotten really good at knowing “no I actually need to get up and do something because that will make me feel better” sometimes I know I just need to sleep for an hour. I don’t know how I know that. I seem to* (Participant 4).

One metaphor used by participants was that of their batteries being fully recharged (and therefore being able to cope with smaller rests such as super mini breaks or mini breaks) or being only partially charged (and therefore rests were longer and productivity time was shorter). Being fully recharged depended on the time of the week, time of the day, and what had happened outside of work, such as the level of sleep:

*It’s all dependent anyways. It depends on how much energy you’ve got or how much your brain, where it’s at.” “So when it’s fully recharged you could go an hour without having any symptoms, but when it’s not it could be ten minutes and you’re done* (Participant 11).

The process of learning and refining through trial and error, reflection and cueing into symptoms continued because change points shifted. For instance, one participant was successfully managing fatigue and increased their level of activity. However, they then reflected and identified that the weekend was insufficient recovery time, and even after stopping the extra activity and resuming previously successful fatigue management strategies at work, the reported still not being back to their baseline (prior to the extra activity):

*but I am not back to baseline yet [seven weeks later]. Prior to that boom and bust I could work on the computer for 30 – 40 minutes and I could recover quickly now it’s doesn’t happen so quickly and now I can only spend maybe five to ten minutes on the computer and I am done* (Participant 11).

Some participants appeared outwardly more confident in their fatigue management at work. They seemed to have a highly refined and seamless process
of moving between higher and lower intensity tasks, and incorporating short breaks within tasks or longer breaks with ‘usual’ breaks (such as lunch:

*do half an hour doing this then you go and process something or somewhere else or go and walk and catch something up, find some information out or whatever. As long as you broke up the intensity bit right the way through it made it easier* (Participant 10).

This refinement meant that the individuals were more productive at work and did not experience as much fluctuation in their symptoms.

Thus, a change point was the particular time within an activity that the participant identified the need to change what they were doing. Thus, avoiding further deterioration in their ability to function either within that task or over the rest of their day or week. Their action was to move further to the right in the continuum of tasks and breaks to gain some level of recovery (see Figure 4.1). The choice of where to move to was appropriate to the situation at the time the change was needed such as fatigue level, type of tasks, priority of task, and expectations. A further option was to push through and experience the consequences.

**4.4.6. Pushing through.**

At times a participant felt they had no choice, but to push through their fatigue due to the work demands:

*I obviously do things a lot different in an ideal world, but you know with work commitments and things like that it is different you know what I mean sometimes you just got to try and push on through* (Participant 9).
Making this choice had consequences, in relation to fatigue and other activities in and out of work. The resulting extreme fatigue might last for some days, but the decision to push through was made despite these consequences:

*I had to do seven days in a row. It was the first time doing seven days since I hit my head and I fell to bits on the, four days after that and I just slept the whole time* (Participant 4).

Pushing through differs from learning about the change point through trial and error, because pushing through is an active choice even though consequences are anticipated. It was a choice more often seen in the earlier stages of recovery when individuals were learning about their fatigue and how best to manage it: “*I used to push through and then I figured out that actually I am the only one that’s disadvantaged. So I just take a break.*” (Participant 4), or “*Well initially I didn’t take my breaks cause I just got so engrossed and thought God I’ve gotta get this done. And then I would tip over*” (Participant 8).

The pull to be productive was why participant’s initially experienced substantial crashes in ability as a result of their extreme fatigue when attempting to get back to work. The need to change what they were doing was then almost forced on them either physically or cognitively due to an inability to perform the task that they were completing. Participant 9 captured this well “*So sometimes when you’re trying to fight it then the next minute you’re just absolutely dead on your feet type of thing*” (Participant 9).

The experience of a substantial crash was viewed by participants as an important part of learning about the need to make a change prior to becoming too fatigued and non-productive. Participants would mostly find themselves in a position where they just had to suffer the consequences and continue to try work despite experiencing lower productivity as a result of their fatigue and recover at home with sleep or long breaks. This could also result in an additional need for days off. “*I had to do seven days in a row……I fell to bits on the…, four days after that and I just slept the whole time*” (Participant 4). Participant 8 would stop their work day early due to their perceived low productivity and go home for sleep or further long breaks.
There were some links between missing fatigue symptoms while continuing in higher or even lower demanding tasks, essentially ignoring the need for the change point and the need to take a long break or additional days off to recover. This was seen by participants as an occasional occurrence rather than a frequent one. The majority of participants reported that they experienced these mistiming’s of fatigue management or crashes in the earlier stages of their recovery, but these incidents were still discussed well into their recovery showing the substantial impact that these crashes had on the participants at that time.

Individuals also noted that a reason for choosing to push through was as a result of their own or others work colleague's expectations or the demands to finish a task.

4.4.7. Influences of self and others on decisions to change. The decision on what course of action to take after determining the change point was seen to be more complex in a work environment. Not only did the participant have to identify the intensity of their symptoms and the appropriate change to take as a result, but they also had to consider other external and personal (non-injury related) factors in this decision. These factors were the biggest influence on someone deciding to push through rather than choosing the appropriate change such as a type of break or change to the task intensity.

Participants noted that their own expectations of the level they achieved at work or the type of worker that they perceived themselves to be impacted on their choice, often opting for short breaks rather than the long break that they actually required, for instance, “fear’s so very real, of just not being able to achieve what you used to be able to achieve” (Participant 8). This sometimes linked into their perceived self-identity both pre and post injury, for example,

but I think sometimes you have to admit yourself that in the bigger picture who cares if you can’t do that task because in six weeks it’s not going to matter. But that’s been a really hard thing for me to try and get over (Participant 4).

Or
I have to get this done” cause I was already starting to feel detached from work and I was letting people down and I wanted to prove that I could still be who I was before. Which clearly I was never going to be (Participant 8).

Participant’s also reflected on the level of support they felt at work and noted that this would impact on what choice they made in relation to their fatigue management, for instance, “I couldn’t finish it and that gets really frustrating. And she’s [manager] really good at saying “don’t worry [participants name], it’s not the end of the world, don’t worry” (Participant 4).

The importance or priority of the task that the participant puts on a task also influenced their decision on managing their fatigue at work, for instance, “you can’t just sort of get up and walk away cause they are looking to you for guidance and support” (Participant 9). This was also seen when time pressures were noted by participants, for example needing to prepare for a class that occurs after a scheduled break:

often you don’t have morning tea because you’re supposed to have it but your still maybe prepping for the next bit [class]. And again because I was only doing a couple of hours there’s no time to say prep your last one beforehand (Participant 9).

Participants often reported on what others expected of them and what they perceived others thought they should be doing at work, especially in relation to being productive at work, for example,

Oh but [participant’s name] this is urgent. I get that. I totally get the urgency or my job, I have nothing left to give. How many times have I said that. I have nothing left to give you. The tank is empty. Crap, it’s crap (Participant 8).
4.5. Balancing system

The majority of participants identified strategies for balancing activities over a day and/or over a week to manage their fatigue as effectively as possible. Three types of balancing was identified – pacing, prioritisation, and planning.

Pacing such as breaking a task up into smaller parts, for instance "you could do bite size chunks so you could sort of do 20 minutes then take a little bit of a rest even if you went and had a cup of tea" (Participant 9), or timing their tasks over the week, such as “being more aware of what I had done the days before and what I was needing to do the days after so that I scheduled it a little” (Participant 3).

Utilising a system of prioritisation of tasks that their energy was used on each week, eliminating low priority tasks from their week such as overtime, secondary jobs, for instance, “Because I did get offered a sports position job, a physio position for a sports team but I decided to turn it down so it wouldn’t be affecting my fatigue and stuff” (Participant 3). Often leisure and social activities were seen as lower priority tasks and reduced or eliminated from the week, for example, “I’ve got a mate doing my horses for me so I am only doing them on a Sunday, Monday and Tuesday when I am not working I will go and do them” (Participant 7).

Being mindful of the order of tasks and alternating between high demand tasks and low demand tasks within a day, for example, “So I schedule it as well as I can and I know that there’s low concentration stuff there or high concentration stuff in the morning and a low stuff in the afternoon usually” (Participant 4).
4.6. Support

Support does not appear as an element of figure 4.1. It was, nevertheless, a concept that permeated the context in which the participants managed their fatigue. Support was essential to the participant’s effective fatigue management at work, and outside work.

Where other people’s expectations and the priority of tasks could lead the participant to a negative fatigue experience with pressure to push through, support was seen as a positive impact on fatigue where there was less pressure to push through and greater ability to make an appropriate choice in relation to only their fatigue levels. A lot of participants identified reduced pressure at work helped them to manage their fatigue and implement strategies more effectively. This reduced pressure was identified as either employers reducing the demands of work or colleagues helping participants with more complex jobs “But you know we’ve got a good bunch of guys here and they sort of always have your back covered. So if you were struggling to do something they would do it for you” (Participant 7).

A couple of participants identified the benefits of talking to someone else, in their work environment, who had sustained a TBI especially if they were in a similar job to them. They noted that this provided them with reassurance about their progress and validated symptoms they were experiencing, for instance,

he’d had a lot of head injuries because he got bashed a bit you know and he said to me “I’ve had some really bad concussions and it takes a long time to get right, it’s not going to happen overnight” he said “it’s taken me months to get through things”, you know people come back like that you think well there is a way through this (Participant 10).

There were also a lot of participants who mentioned a negative impact of unsupportive colleagues or employers, or colleagues who had little understanding of their TBI:

but his managers who I work for have not been and have given me so much grief which has made things ten times worse. I don’t feel supported, I don’t feel understood. It’s hideous. I’ve joked and said I need to put a bandage on my
head every day I get up to go in so when I go to leave work and I’ve done my hours they don’t make me feel guilty by saying “oh but I’ve pencilled you in for a meeting this afternoon”, um my hours have been the same for the last month you know what I work and what I don’t work put them in the mornings I am here every morning, afternoons are not good for me (Participant 8).

Participants support at home were also identified as essential and often included support helping with practical things at home, or giving emotional support when required, for instance, “he’s been the best thing. He’s the one that deals with me every day when I am balling my eyes out” (Participant 4).

4.7. Summary

In this chapter I have described how participants managed their TBI related fatigue at work in two core strategy areas (strategies in work and out of work). When the strategies at work were explored a continuum has been proposed from the highest productivity to the least productivity. It has been identified that individuals at work want to be productive, but when experiencing TBI related fatigue they also want to recover. A variety of breaks have been identified as being implemented at work to reduce their impact on the work tasks and hence productivity at work. Also, strategies outside of work have been developed to allow maximal productivity in work.
5.1. Overview

This chapter relates the findings from this study back to previous research carried out on managing fatigue after a TBI to enable a work productivity and a RTW. Chapter 2, looking at the background of fatigue management after TBI, ended with several key points. These were that: a) TBI is common especially amongst people of working age; b) people who have sustained a TBI can experience a range of difficulties that impact on their ability to return to their roles including the role of a worker; c) fatigue is common in people who have sustained a TBI; and d) TBI has a considerable impact on people’s ability to return to paid employment. There is, however, very little research on how people can best manage their fatigue after a TBI. My review of the literature did not identify any study that offered clear evidence regarding strategies for fatigue management after TBI. It did however identify some evidence based fatigue management after other conditions, in particular MS, which included CBT, mindfulness training, educational based interventions and exercise. Exercise was also found to help fatigue in populations experiencing CFS, MS and rheumatoid arthritis. The aim of my study was to help address this gap in knowledge by answering the question: “How do people manage fatigue that they attribute to TBI to enable them to complete paid work?”. To my knowledge this study is the first study to look explicitly at how people manage their fatigue after TBI in the workforce to enable them to participate in paid work.

5.2. The fatigue experience

5.2.1. Fatigue. Participants in this study described TBI-related fatigue symptoms at work such as reduced cognition, irritability, and headaches. They also recognised the debilitating aspects of these symptoms on their ability to be productive at work. Similar symptoms are reported in other samples of people with TBI, and while no other studies have directly asked about fatigue symptoms at work it is possible that similar symptoms are experience outside work. For instance, Ouellet and Morin (2006), in their survey of 302 significantly fatigued participants found that self-reported fatigue, an average of 7.9 years after TBI, impacted on mental abilities, including memory and concentration, in 58% of participants, and
on mood in 44% of participants TBI fatigue management evidence. (see section 2.5.1).

Measures of fatigue symptoms developed from clinical observations and patient input and used in TBI research – such as in the Fatigue Symptom Inventory (Hann et al., 1998) and the Multidimensional Fatigue Symptoms Inventory (Stein, Martin, Hann, & Jacobsen, 1998) – also reflect symptoms expressed by participants in my study. Items in these questionnaires ask about symptoms such as impact of fatigue on concentration, relations with people, and mood as well as feelings of bewilderment, frustration, forgetfulness, difficulty talking, irritability, trouble doing simple tasks, trouble concentrating, making mistakes and being distressed.

Despite participant-reported links between fatigue and reduced productivity or functioning, establishing a correlation between these variables has been hard to achieve. Ashman et al. (2008) in their study of 202 community dwelling participants, 14 years post injury, found a correlation between greater subjective fatigue and a slower response speed, but they found no correlation between subjective fatigue and accuracy or executive functioning. While it may be useful to establish the relationship between fatigue and function, in clinical practice the priority is helping a client manage fatigue symptoms that they perceive negatively impact their function and quality of life.

Going beyond documentation of fatigue symptoms, my research suggests the importance for the person with fatigue of being able to ‘read’ the symptom and severity of symptoms in order to choose an appropriate fatigue management strategy. Participants learnt to recognise the signals of fatigue specific to them, and the level of their fatigue, how much reserve capacity they had left before a break was needed, and which strategy was likely to help most.

5.2.2. Fatigue and work. All participants in this research thesis described fatigue as the primary difficulty preventing them from returning to work full-time, and the most frequent symptom to interfere with their work tasks and work productivity. The impact of fatigue on RTW after TBI was explored in the background section (see section 2.4). There was consistent evidence that fatigue adversely affected RTW. For instance, in a comparison of those who had and had not RTW after moderate to severe TBI, McCrimmon and Oddy (2006) found that
self-reported fatigue was significantly higher in the group who had not RTW. A similar finding was made by Waljas et al. (2014) in a cohort of participants with mild TBI; participants with fatigue were more likely to have a slower or no RTW compared with participants who did not report any fatigue.

While participants were not required to have experienced negative effects from fatigue at work in order to participate in this study, all participants nevertheless described such negative effects in their interviews. The participants identified the experience of fatigue symptoms such as reduced concentration, headaches and becoming distracted, with these impacting on their ability to perform within work tasks compared with how they performed prior to their TBI. Thus, the impact of fatigue on work productivity and RTW reported by participants in this study is consistent with previous research on predictors of RTW after TBI (see section 2.4).

5.3. Learning how to manage fatigue at work

Participants in this study found that if they did not acknowledge their early fatigue symptoms and make changes (such as taking a break), then they eventually became unable to complete their job tasks. Participants learned how to ‘read’ the intensity of their fatigue symptoms and identify a change point at which they implemented a fatigue management strategy to sustain their productivity at work. However, gaining this knowledge took time and all participants described a learning process of trial and error, with refinements in response to contextual changes at work and home, to finally achieve a semblance of ‘mastery’ in managing their fatigue in the work place.

5.3.1. Trial and error learning. This trial and error learning usually began with one or two experiences of extreme fatigue that were described as scary, before going on to experience ongoing ‘boom bust’ cycles as the participants learnt about their fatigue triggers and task limits. These experiences were then followed by phases of acceptance that a change in an overall approach to fatigue management was needed because ‘pushing through’ fatigue ultimately (see section 4.4.6) had negative consequences. Another acceptance was required in identifying the onset of
fatigue and then choosing a strategy to manage it; that is identifying the 'change point' and then selecting a strategy to implement (see Figure 4.1).

Theadom et al. (2016) (see section 2.5.1), in an analysis of people’s experience of fatigue and sleep after TBI, derived a theme called “accepting the need for rest”. Theadom et al’s (2016) participants described pushing themselves too hard and reaching a ‘breaking point’. This breaking point was a precursor to them identifying the ongoing need for better use and management of rest. Thus, their theme captured content similar to what was reported by participants in my study when they were experiencing a boom bust cycle.

‘Boom bust’ type experiences have also been referred to in a review on rheumatoid arthritis (Hewlett, Nicklin, & Treharne, 2008). Boom bust was discussed in the context of the clinical application of fatigue management; Hewlett et al. (2008) noted that existing evidence was limited and then described some possible approaches that could be followed. These included utilising daily diaries to identify boom bust behaviours or excessive rest, and then supporting individuals to change these behaviours.

Theadom et al. (2016) also found that their participants went through a learning process about when to rest, sometimes needing others to prompt them and finally allocating time to recover after finding pushing through fatigue did not help. In their study ‘rest’ was not well operationalised, but it did include reference to ‘napping’ and through participant accounts it appeared to be similar to strategies such as a long break or sleep in my study.

Utilising a trial and error approach with rehabilitation of people with TBI is currently not recommended ‘best’ practice, with emphasis instead placed on errorless learning (New Zealand Guidelines Group, 2007). Errorless learning aims to eliminate errors from the learning phase, and is recommended for individuals with memory impairments (Middleton & Schwartz, 2012). Errorless learning is theorised as being best for people with amnesia (such as in TBI) due to the impairment of explicit memory rendering these individuals more susceptible to learning errors (Middleton & Schwartz, 2012). In comparison, trial and error strategies accept and even encourage errors as part of the learning process (Landis et al., 2006).
However, the evidence to support the importance of errorless learning post-TBI is contradictory. Landis et al. (2006) had mixed results when they compared trial and error learning and errorless learning in children and adolescents with TBI related memory impairments. The sample of 33 children aged between 6 – 18 years, had mild, moderate or severe TBI. In a within-subject design each child learned social studies or science facts in one hour sessions twice a week for seven weeks. Learning order – trial and error, and errorless – was counterbalanced. Trial and error learning was better for initial learning. However, Landis et al. (2006) found that for younger children with mild TBI errorless learning was superior for retention of facts at two days (p=0.014) and seven days (p=0.008) retention. There were no differences found for 21 and 49-day retention, although 77-day retention was better with errorless learning in younger children with severe TBI (p=0.036). Due to this disconnect between longer term retention and initial retention and errorless learning only being advantageous with selected groups, Landis et al. (2006) concluded that errorless learning was unlikely to be clinically useful.

Such variable findings were also noted in the critical review completed by Middleton and Schwartz (2012) who collated findings from research comparing errorless and trial and error learning (or errorful learning) in people with amnesia and aphasia. They found the effect depended on the type of patient and the training task. It seemed trial and error learning was more advantageous to mild to moderate memory impairments – perhaps similar to my study participants who had mild TBI – whereas errorless learning was more advantageous to severe memory impairments. However, trial and error learning appeared more advantageous for long term retention (Middleton & Schwartz, 2012). The authors concluded that more robust comparisons were needed.

Similar to Landis et al’s (2006) observation that errorless learning may lack clinical utility, it is hard to see how errorless learning could be applied in the case of fatigue management at work. Errorless learning relies on an explicit task where the target response is known and practice is pre-empted (Middleton & Schwartz, 2012). For my participants this would have meant that the clinicians working with them could tell them when a change point was approaching, and which strategy to select. However, fatigue symptoms are difficult to observe objectively and so a clinician is
unlikely to know a change point is approaching. Further, strategy selection was highly complex – including fatigue level, work priorities, and a range of contextual factors – and it is hard to see how a clinician could definitively instruct which strategy to use when. Therefore, it seems trial and error learning is necessary for successful implementation of fatigue management strategies at work.

When considering these findings it must be acknowledged that all the participants had some form of return to work programme. It is unclear how much this programme influenced the participants’ awareness of their fatigue and how much they learnt from it about implementing fatigue strategies. It could be argued that therapy input – focused on fatigue management – would allow participants to learn quicker as they were provided with more information rather than seeking it themselves. Equally, therapy intervention may impede the trial and error learning process by providing a ‘template’ of how to return to work, therefore eliminating the occurrence of errors during the return to work process and delaying the learning in these situations.

Nevertheless, findings such as those from my study, may assist clinicians in educating people on change points and types of strategies. This may optimise the trial and error learning process by reducing the amount of errors or failures. This would in turn reduce the possibility of a reduction in self-efficacy in fatigue management, and adverse impacts on return to work.

5.3.2. Refining the learning. ‘Refinement’ was subtler than trial and error learning. Rather than learning about change points through trial and error, refinement focused more on ways my participants increased the effectiveness of their fatigue management strategies. Theadom et al. (2016) also found that learning included a process of refining fatigue management strategies; their participants refined their rest strategy to increase its effectiveness. This included resting before becoming overtired, planning their nap times, and adjusting the length of naps as recovery progressed. Parallels in my research were the participants’ responding to their earliest fatigue symptoms, planning a longer break over a lunchtime, and selecting the most appropriate type of break to match their level of fatigue. Although the refinement in my study continued with even shorter,
less disruptive rests being incorporated (super mini and mini breaks) and considering changing the intensity of tasks to reduce the need for breaks or rests.

The participants in my study refined the implementation of their fatigue management strategies to the point that there was almost a seamless change from work task to strategy and back to work task. This level of mastery may have been gained through repeated cycles of work task exposure and increasing success in managing fatigue. This bears some similarity to Bandura’s description of mastery experiences, and its contribution to self-efficacy (Bandura, 1977).

The level of self-monitoring and self-reflection required for successfully learning to manage fatigue after brain injury is complex, particularly when higher executive functioning skills have also been impaired. For instance, problems with insight and memory can impact on a person’s ability to identifying their own limitations, reflect and learn about these limitations and then implement appropriate changes. This research mostly recruited people who had sustained a milder TBI and had a level of capacity to be able to consider and ultimately engage in paid employment. It is likely that the participants’ level of insight, memory retention and related ability to learn was mostly retained, allowing this refinement and successful outcome to occur. This is likely to have been quite different if the participants had been towards the more severe end of the TBI spectrum and had executive functioning impairments. The level of refinement that occurred may not have been possible with executive functioning impairments. It is postulated that the more severe the executive functioning impairment the less easy it would be to learn how to manage fatigue, engage in paid employment, and maintain work productivity.

5.4. Fatigue management strategies

5.4.1. Reducing task intensity. This research identified a variety of strategies that participants used to reduce the intensity of tasks and, as a result, enabled them to engage in work tasks for longer, with less fatigue. These strategies included reducing background noise, reducing light, reducing the number of tasks being completed at one time, implementing cognitive compensating (such as writing things down that need to be recalled), and reducing distractions. All of
these strategies are similar in the way they reduce the cognitive demands of a task. This in turn likely reduces the cognitive effort that people require to complete a task. The cognitive components that are being eliminated in the strategies above are mostly unrelated to the core tasks, but often a result of what is occurring in the task environment. Participants identified what a task consisted of, drew out the most important components required to complete the task, and eliminated the non-essential often aggravating components. Participants often identified the aggravating components in the midst of fatigue symptoms when they were more aware of the components that were interfering most with their ability to complete the core task. From the perspective of the participant, this manifested in experiences such as noises becoming louder and more distracting, light becoming overbearing and struggling to cope with unrelated distractions. This learning contributed to the trial and error learning described above (see section 5.3.1). This process was crucial in allowing participants to achieve the highest levels of productivity and reduce the impact of fatigue and related recovery.

The impact of cognitive tasks on fatigue has been explored and it has been found that when people with TBI engage in some cognitive tasks that involve divided attention or a cognitive process that requires more effort they experience an increase in cognitive fatigue (Hattori et al., 2009). Through investigating cerebral regional blood flow while completing an attention test (see section 2.3.1), it was found that individuals with mild TBI had significantly more cerebral blood flow in their inferior frontal and superior temporal cortices compared with the cerebellar cortex of the healthy control group. Hattori et al. (2009) concluded that this was due to a compensatory process occurring as a result of cognitive impairment and explain why cognitive fatigue occurred. This goes some way to explain the cognitive fatigue experienced by the participants in my study. It also explains why tasks that were not a problem pre-injury can cause an increase in cognitive fatigue post-injury and therefore require the cognitive demands to be reduced to manage them again.

The impact of attention-based tasks on subjective fatigue after TBI has also been investigated by Ziino and Ponsford (2006). This research compared selective attention abilities in a group of people with TBI to a matched group (by age and
education) of people without TBI. Ziino and Ponsford (2006) found that there was a significant correlation between subjective higher levels of fatigue and lower performance on the Complex Selective Attention Task even after controlling for effects of depression and anxiety. In my research, the majority (if not all) of the strategies utilised by participants to reduce the task intensity or the tasks cognitive demands involved reducing demand for divided or selective attention required in a task. It could be hypothesised therefore that reducing attentional demands within a task could result in a reduction in cognitive fatigue; this effect was reported by participants in my study. Future research could potentially explore these ideas further by more explicitly examining the relationship between task intensity and severity of cognitive fatigue. This could involve research looking at comparing task performance for high and low intensity tasks from the perspective of factors such as task tolerance (length of time), task success and levels of cognitive fatigue before and after the task. Such future research could potentially see a development of new strategies for managing fatigue after TBI.

Cognitive strategies as seen in my study when considering a reduction in task intensity is similar to what is considered when people received cognitive strategy training where strategies are developed to overcome a cognitive impairment. Cognitive strategy training can include the learning of internal strategies such as rhymes or visualisations or external strategies such as writing lists, diary use, alarms and calendars (Malia & Brannagan, 2005). The alterations that participants made to a task in this study to reduce the intensity of the tasks were similar to the external strategies described above. The evidence supporting cognitive strategy training is limited, but there has been some low quality studies showing improvements in functional tasks via a pre-and posttreatment test study of 21 war veterans who had TBI (Huckans, 2010) and Parkinson’s disease via a case series of seven participants (Foster, Spence, & Toglia, 2017). My study suggests that when participants start to manage their fatigue they tend to adopt techniques that reduce the cognitive demands of tasks. These techniques were similar to techniques used in cognitive strategy training.

Theadom et al. (2016) also identified that participants learnt how to make rest more effective by using cognitive strategies such as reducing distractions. The
concept of reducing distractions was an important part of what participants in this study considered when they reduced the task intensity, but continued with the task. In Theadom et al.’s (2016) study, the reduction of distractions appears to be in relation to when the participant is resting as opposed to engaging in an activity.

5.4.2. **Breaking it up.** When participants in this study refined their strategies to fit into a work routine, they developed different types of rest to accommodate different intensities of fatigue. These included super mini breaks, mini breaks, and long breaks. These differed in length, location, and impact on core task and therefore also differed in terms of work productivity (see section 4.4.2).

Within this study, rests were considered to be a stop point where participants did not engage in any other task or activity, whereas a break was considered an interruption of a work task for the purpose of recovery. Participants did sometimes choose to rest within their break, but at times they were also choosing physical non-work tasks such as walking, social chatting or similar.

Rest has been identified as a fatigue management strategy in research conducted by Theadom et al. (2016) where rest was referred to as ‘rest’, ‘lying down’, ‘going to bed’, or ‘sleep’. Although the definition of rest was not specified, it appeared distinct from what they described as daytime napping. This was the main strategy they explored over their two-year research period, but the intricacies of what this actually consisted of was not explored due to their focus being on the experience of fatigue and sleep (Theadom et al., 2016). In Ouellet and Morin (2007) study, their CBT programme also explored “dysfunctional” attitudes towards rest with rest being documented as the only strategy for managing fatigue, however there was no further exploration into what rest consisted of or how it was incorporated (see section 2.5.1). Use of rest has also been considered within an energy conservation programme for MS (see section 2.7.2) (Mathiowetz et al., 2005). Rest has been suggested as a component within fatigue management programme for people with MS (Harrison, 2007). Rest within this programme is described as ‘doing nothing at all’ although this is then followed by references to utilising relaxation methods while resting (Harrison, 2007).

The effect of rest was explored within a non-TBI population by investigating rest/work schedules in a directory assistant operator task (Kopardekar & Mital,
When comparing three schedules (30 minutes work and 5 minutes break, 60 minutes work with 10 minutes break and 2 hours without breaks) it was found that the two schedules with breaks had significantly fewer errors than the schedule with no break (Kopardekar & Mital, 1994). This research reinforces the findings in my study that breaks from work tasks are beneficial.

Rest is commonly prescribed as the primary way to manage fatigue (Ponsford, n.d.). This was also suggested as a strategy by speech and language pathologists when they were treating TBI related fatigue (see section 2.6) (Hicks et al., 2011). Both the clinical observations and the research on speech and language pathologists were similar where rest is considered within a client’s fatigue management education as well as being incorporated into a client’s daily schedule as a structured approach to rest, such as resting every day at 1pm. This contrasts with my study where participants recognised the importance of taking a break, but noted that this was a more complex process where they utilised their fatigue symptoms and considered their external work demands to determine the type and timeliness of a break.

In my study, participants gained mastery over their use of breaks and incorporating them almost seamlessly into their working routine to maximise productivity. Participants appeared confident in determining when they should and should not take breaks and the impact of their choice to manage fatigue symptoms early or to continue with a work task for longer. This confidence of managing breaks has not been seen in any other research to date. Theadom et al. (2016) did note that participants were starting to utilise their rests more effectively, but they also noted under their theme of ‘learning how to rest’ that their participants did express being unsure about taking rests during the day and whether this was positive in relation to their recovery and well-being. They also reported a mismatch with day time napping and their own self-concept. It is unclear whether Theadom et al. (2016) participants were working or not although in quotes published there was only two references to work, so it is unclear how comparable Theadom et al.’s (2016) participants might be to the participants in this study in regards to work commitments. Also, Theadom et al.’s (2016) study contained a higher percentage of participants with severe TBI (33%) compared
with this study (estimated from subjective accounts to be 0). However, the participants in my study appeared to have a higher level of acceptance of the need for breaks within their day. This may be because they were better able to reflect on their ability to complete work tasks and remain productive, and therefore used this outcome to reflect on the success and future implementation of different types of breaks.

The background literature refers to rest as a strategy to recover from fatigue (Mathiowetz et al., 2005; Ouellet & Morin, 2006; Theadom et al., 2016). The impact of rests on the potential for productivity was explored by Ouellet and Morin (2006) who found that their participants increased their rests when they experienced TBI related fatigue with participants having to stop activities to take a rest or sleep during the day, and half of them resting more than seven times a week. This author felt that the high amount of rests would be a significant barrier to individuals returning to work. This perspective was also found in Theadom et al.’s (2016) final theme: ‘Need for rest impacts on ability to engage in life’ where the need for napping interfered with people’s ability to return to work or gain new employment. Similarly, in my study participants also cited the impact of rest on work, but this saw an evolution of rest and what a rest consisted of to allow it to fit into a work context and allow productivity to occur. This evolution of how rest (or breaks) are defined and used is seen as an extension on the work of Theadom et al. (2016) when exploring the utility of rests specifically in the work environment.

5.4.3. Balancing and reducing non-work activities. The importance of considering the energy consumption of activities over the whole day and the whole week was highlighted in my study. This also involved reducing what participants viewed as lower priority tasks such as leisure and social activities, so they could achieve a successful return to work and be productive at work (higher priority task). This was seen as crucial to ensure the success of managing fatigue at work and ensure productivity. This balance was achieved through pacing, prioritising and considering the order in which tasks were completed. The evidence explored in chapter 2 (see section 2.7.2) included two studies showing some effect of an energy conservation programme and a fatigue management programme in reducing fatigue with MS related fatigue. Both of these programmes were similar and
included concepts such as banking and budgeting of energy, working on a balance of activities and rests, prioritising of tasks, planning a day, analysing and modifying a day, and planning a week (Finlayson, Preissner, Cho, & Plow, 2011; Mathiowetz et al., 2005). These concepts were similar to that discussed in my study, although mine differed in that participants in my study acquired the skills of balancing through their own learning and refinement of strategies, achieving a level of mastery rather than being involved in an education based treatment. Educational based treatment does not feature in Banduras social model theory as a way of achieving mastery (Bandura, 1977).

These components of balancing are also commonly included in fatigue management or energy conservation programmes within clinical settings. Although no formal fatigue management programmes for TBI appear in the research literature, there is a programme designed for MS that was published by the College of OTs in the United Kingdom. This programme includes these concepts in their energy conservation section where they look specifically at prioritisation and planning ahead, which includes making use of daily and weekly timetables, breaking down tasks into smaller stages to allow them to be spread over the day and spreading light and heavy tasks throughout the day (Harrison, 2007). The background section also highlighted that speech and language pathologists utilised scheduling as an intervention for TBI related fatigue (Hicks et al., 2011).

The use of task prioritisation to retain energy for the highest priority tasks was a common thread throughout my study. Prioritising was also discovered in Theadom et al.'s (2016) final theme: “need for rest impacts on ability to engage in life” (p.6) where participants were describing a need to re-evaluate their priorities and expectations for their own activity level. The evolution of this need to prioritise was very similar to that of the participants in my study. Both sets of participants learnt about the need to implement a strategy of prioritisation due to them starting to return to a variety of activities within their day and week, and realising through trial and error that they did not have the energy to complete all tasks.

5.4.4. Sleep. My study highlighted the need for sleep as an important recovery tool when fatigue was becoming overwhelming. This meant that at times participants would sleep within the day to help manage their fatigue and cope over
the week. The idea of sleeping during the day can cause conflict amongst therapy and medical professionals clinically. For example, counter to the reported experience of participants in this study (some of whom valued daytime napping to maintain activity levels), Ouellet and Morin (2007) recommended restricting daytime napping in their intervention for insomnia and fatigue. Ouellet and Morin (2007) showed that after the participants (n = 12) received CBT their total fatigue scores significantly improved post treatment (p<0.012) and at three months (p<0.014). The intervention in this study included stimulus control (bed and bedroom is for sleep with no daytime napping), sleep restriction (with specific bedtimes and wake times), sleep hygiene, cognitive therapy for insomnia and fatigue management skills. Another difference between Ouellet and Morin’s (2007) fatigue management intervention and the findings from my study were that the participants would go to bed at a predetermined time which was earlier than pre-injury, whereas Ouellet and Morin (2007) intervention included going to bed whenever participants felt sleepy.

5.4.5. Exercise. Exercise was found to be beneficial in managing fatigue in my study. This closely links with previous research that has been completed by Driver and Ede (2009) who found that aquatic exercise in the moderate range (50–70% of maximum heart rate) improved scores in fatigue inertia with TBI (see section 2.5.1). Also exercise has been found to have a significant effect on fatigue in populations with rheumatoid arthritis, CFS and MS (see section 2.7.1 and 2.7.2) (Asano & Finlayson, 2014; Cramp et al., 2013; Larun et al., 2017). In contrast to this fatigue was not improved by a six week course of Tai Chi (Gemmell & Leathem, 2006), a five day recreational programme (Lundberg et al., 2011) or a 12 week cardiorespiratory fitness programme (Hassett et al., 2009).

5.4.6. Relaxation. Several participants identified relaxation or meditation-type activities were beneficial at points in the day during breaks or to help with sleep at night. The specifics of what participants were doing in regard to relaxation was not explored in this research. Relaxation has not been found to have an impact on fatigue after TBI (see section 2.5.1) (Hodgson et al. (2005), although MBRS (which has similarities to relaxation) has been found to reduce fatigue after TBI (Johansson et al., 2015; Johansson et al., 2012; Juengst et al., 2013). This small RCT
found that in their intervention, which included Hatha yoga, body scan and sitting meditation, participants reported a significant reduction in self-reported fatigue (see section 2.5.12.6.1.), which is similar to what participants reported in my research.

5.5. Strengths and limitations of the study

There were a number of strengths to the methodology employed in this study. A reflective diary was kept with reflections being considered prior to an interview, within the interview and afterwards. This was referred to when considering the analysis of the data and formation of the codes and end concepts. In order to enhance the trustworthiness of the analysis, data were peer coded by two supervisors and regular (mostly fortnightly) meetings occurring to reflect on progress, reflect on interviews and discuss the emerging themes and concepts. No member checking was completed within this research.

I am an OT who has many years of experience in neurological rehabilitation and rehabilitation of people with TBI. Care was taken when interviewing to maintain a researcher role rather than becoming a clinician. The separation of these roles was made more possible by not interviewing people that I had had a previous or current therapy-client relationship. There were very few ethical dilemmas in regard to clinician versus researcher role. The majority of dilemmas were around clinical queries similar to theme one in Hay-Smith et al. (2016) systematic review on dual role experiences. All clinical queries that were asked were simple queries, often reaffirming what the participant had already been discussing. The responses from myself were kept very short, but still ensured some reciprocity was given, with the plan that if further questioning arose then they would be referred to their current health professional or GP, although this did not occur. This approach along with reflection of the clinician versus researcher role with supervisors was considered a strength of this study.

My experience as an OT can help this research and the direction that it has taken in regard to linking what was found in the data to what has been observed clinically. Equally this will have influenced the data collection and analysis with preconceived ideas. The impact was minimised by having peer coding completed
with five of the eight participants (63%). One of my supervisors had minimal knowledge of working with a TBI population but had a health professional background. The second supervisor was a well-established researcher in TBI and was a health professional, but was not an OT. Themes identified by my supervisors were considered in the final analysis as well as consistency of coding over all the participants.

All participants were aware that I was an OT. This may have influenced what information was shared and how, especially considering that all of the participants had received occupational therapy input in the past, so they may have had a preconceived idea of what an OT would be looking for. Furthermore, all participants were recruited by OT’s contracting to a rehabilitation service and would have all experienced occupational therapy interventions, which may have influenced their perspectives on fatigue and fatigue management.

Quotes from the data have been used to demonstrate the link between the data gathered and the findings that have been presented. As per above, the findings were discussed with supervisors regularly, peer coding was completed and the whole data collection process was made explicit in the methods section above.

Trustworthiness was maximised by keeping a reflective diary before during and after data collection. The findings and reflections on the process were discussed regularly with my supervisors. The findings were also tested with colleagues working in the area of fatigue management to determine if they were consistent with what was seen clinically.

This study would have been strengthened if it had been possible to formally assess insight, memory retention and learning ability – although this would have required a neuropsychological assessment, which was outside the scope of this particular project. The ability to assess these areas would have given information on cognitive difficulties and whether there were particular difficulties that this approach worked for. It would have also provided more information about the cognitive strengths that enabled the trial and error approach to be successful.

The demographic characteristics of the participants recruited for this research did not match the demographics for the general TBI population in NZ,
particularly with regard to gender and ethnicity. When considering someone of working age (15 – 64 years old) in the Waikato, 65% of TBI’s are sustained by males compared with 35% of females. In this research, women were more inclined to take up the offer to participate in the study and only 38% (3/8) of the participants were males. Ideally this figure should have been five males to represent this population better. In fact, I had to focus on getting more male participants in the final stages of the research because of low recruitment of men. The final two interviews were completed on males.

In regard to ethnicity within this study there was a very poor representation of Māori. I had hoped that there would be a higher percentage of Māori recruited due to there being a greater representation of working age Māori experiencing TBI (43% of the total TBI population) compared with the local and national statistics (22% of Māori in the Waikato and 15% in NZ). Also, this was viewed as important due to the cultural environment of NZ and the need to represent both NZ European and NZ Māori.

In regard to the variety of areas of work recruited from when considering the ANZCos grouping, there was a high proportion of professionals recruited, who worked in higher than average income brackets (63%). The challenges that people working in ‘professional’ roles experience may not be the same as those experienced by those working in physically demanding jobs in sectors such as farming, fishing, forestry, or manufacturing.

The majority of the participants had sustained their injury via a mechanical force, which included sporting accident’s (86%), with one being as a result of an assault. The TBI population in the Waikato was found to have a higher incidence of traffic accidents (25%) and falls (25%) in adults of working age. Of note is the substantial lower percentage of mechanical force injuries in the Waikato of working age adults compared with this research’s sample. The mechanism of injury is not thought to be of any importance at this stage when considering how people manage their fatigue. Although, the six injuries occurring as a result of mechanical forces, were sporting injuries and therefore this may have seen a greater level of exercise being used as a strategy in the findings. Also, all of the TBI’s sustained were towards the mild to moderate level of severity. The strategies that people returning
to work with a severe TBI utilise to manage fatigue may be quite different to the people with a mild TBI due to greater difficulties with cognitive functioning.

Another limitation of this study was that this population was only selected from the geographical area of the Waikato in NZ. All of this reducing the transferability of study findings.

5.5.1. A brief personal reflection. I felt my professional training, and clinical expertise in supporting a return to work with post-TBI clients, influenced the analysis. When interpreting the data, I noticed that the models that I use as an OT were reflected in patterns I saw in the data. For instance, Australian Occupational Performance Model (Chapparo & Ranka, 2001) where internal constructs such as self-care, productivity, leisure and rest and external constructs including the social, physical, cultural and sensory environments, time and space are considered. I feel these concepts came through in my data analysis, but this model’s influence did not make any of these concepts greater than what participants themselves identified.

I had to work hard to avoid imposing preconceived ideas on the data; I felt my clinical and professional expertise in the field helped me frame the model in a way that made sense clinically while honouring what the participants said and creating a model that represented their experience of fatigue management at work. For example, the fatigue management strategies the participants identified are strategies I have observed clients use, and have recommended to clients in the past. What I had not considered before was that these might form a continuum of strategies, or how clients learned to select strategies and how sophisticated their selection became over time.

5.6. Clinical implications

One of the primary themes that emerged from my study was the trial and error process that individuals applied to learn about their own fatigue, when they could tell they reached point where a change in task strategies was required (i.e. a change point), when they needed to alter what they were doing, and what the variety of strategies were that they incorporated at these change points.
This information is potentially useful as a guide to other people recovering from TBI and attempting RTW or wanting to increase their work productivity after returning to work. Figure 5.1 provides an overview of change points and change strategies reported by people with TBI, which could be useful for helping make the trial and error process of learning to manage fatigue more explicit. Specifically, Figure 5.1 presents the fatigue/activity continuum previously discussed in the form of a battery. This battery shows full energy (and highest productivity) at one end, with diminishing energy and need for different types of rests depending on the energy levels. The use of a 'battery' as a metaphor for fatigue management after TBI was derived from one participant’s description of having to rest to recharge. As such, this metaphor might better help people understand fatigue and the options they can consider when fatigued.
Figure 5.1. Clinical Application – Fatigue management to enable a return to paid employment.

- **High “Intensity” Tasks**
  - High Cognitive Demand
  - Computers
  - Lots of thinking
  - Lots of noise or light
  - Multi-tasking
  - High social demands

- **Low “Intensity” Tasks**
  - Low Cognitive Demand
  - Choose easier tasks
  - Cognitive strategies
  - Reduce noise/light in environment
  - Change environment (Quieter, better light, no social contact)
  - Use equipment

- **Super Mini Break**
  - Very short break (few minutes)
  - Stay in task
  - Stay in the same environment

- **Mini Break**
  - Stop task
  - Move away from task
  - Stay in work environment
  - 2 to 10 minutes

- **Long Break**
  - Stop task
  - Move away from task
  - Away from work environment
  - 15 minutes to 1 hour
  - May involve going for a walk

- **Sleep (Outside work)**
  - Point of leaving work to sleep at home
  - Increase sleep at night

- **Day Off**
  - When weekends aren’t enough to recover

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**Work**

- **Home**
- **Balancing Work/Old Outside Work**
  - Balance tasks over week
  - Prioritising tasks over week

- **Exercise**
  - Light to moderate i.e. a walk, bike, horse ride
  - Either in long break at work or after work
  - Avoid intense exercise
  - Ideally an outside

- **Relaxation**
  - Short periods of relaxation
  - Relaxation Apps
  - Meditation techniques

- **Non-Work Activities**
  - Reduce social, leisure and domestic tasks
  - Avoid computers
  - Avoid alcohol
  - Reduce coffee
The house in Figure 5.1 represents home and what people can also consider changing at home to allow them to function at their best at work. Of note, sleep and days off are still within the home concepts (on the chimney) as these are highly unlikely to be able to occur at work, but are what are needed when the battery is ‘flat’. Then hands represent the balance that is needed between work and home and how both these areas are brought together over the day and week to allow success in what each individual considers as the priority tasks.

One possibility that required future clinical study is that presenting this diagram to clients with mild to moderate level brain injuries, prior to RTW, might help support the learning process and increase the speed at which they learn to identify these concepts and apply them to their own life. It is essential that the process of learning is supported, which also includes supported failures. The majority of individuals identified failures in managing their fatigue highlighting the need to change their routines and approaches to life to get back to the activities that they wanted to do. These limits also appeared to be tested at various points in their recovery as another reality check that they still needed to utilise their learnt strategies.

To simplify this process, it may be beneficial for individuals to initially think about what their change point looks like. A clinician could work with individuals to consider what symptoms and/or behaviours are occurring that are telling them that they are reaching their change point. The client would need to consider this over a period of time such as two weeks. This approach is also supported by Theadom et al. (2016) when considering their first theme: “making sense of fatigue and sleep after TBI”. Participants noted in the early stages (first six months) the advice they benefited from included advice around monitoring their activities and rest to understand the changes that had occurred since their injury (Theadom et al., 2016, p. 4). This allows the client to experience these symptoms and then make a note of them. At this stage of experimentation, it may be beneficial to advise the client to implement basic fatigue management principles such as a regular breaks each day, as they need to develop their own awareness of fatigue and what it is like to experience different levels of fatigue. Sessions could focus on reflecting and discussing symptoms that have been experienced.
Once an individual has identified symptoms that occur then the next focus would be for them to be able to rank these symptoms from the earliest experiences (low levels of fatigue) to the latest (high levels of fatigue) – identifying change points. This also would need to occur over a period of time such as a week to allow individuals to reflect and learn from their own experiences. Clinician input would be around brainstorming and reflecting on the week and the way that symptoms are being ranked.

The next stage would be to return to the battery concept and look at matching the strategy at the change point (such as type of rest, or change to task). This could be done with the client referring to the battery and jotting down possible strategies in pencil next to their ranked symptoms. Then this could be put into practice and refined. Clinician support would be particularly important to brainstorm possible alterations to the activities to reduce the intensity or ways that types of rests could be implemented in different situations. The ‘What is My Change Point’ process provides a starting point for formalising this learning process, and could be the subject of future research (see Appendix K for the ‘What is My Change Point’ process).

5.7. Recommendations for future research

It would be useful to consider some important groups that were absent from this research and explore these groups more in relation to how they manage their fatigue at work. These include Māori, lower socioeconomic groups and different occupational groups, for instance those from primary industries.

It is important to capture the views and practices in relation to fatigue management for Māori with TBI. Due to the lack of Māori participants in this study the perspectives and challenges that face this ethnic group have not been explored. It is unclear whether the results of this study are applicable to this ethnicity. It is important that Māori are considered within fatigue management after TBI due to the higher rate of Māori sustaining a TBI. To gain a better understanding of how Māori manage their fatigue, further research targeting the recruitment of Māori who have sustained a TBI and have successfully RTW, is required. Strategies to increase the participation of Māori in this research could include support of a
Kaumatua to target Māori health providers and other Māori community groups, involving Māori in the development of the participant information sheet and consent form, and working in partnership with a Māori co-investigator. Also, data could be collected via a focus group where the Māori co-investigator could be utilised to lead the focus groups (hui’s) to ensure that customs and protocols are accommodated such as sharing food, and waiata. The hui’s could be carried out at a wharenui and there would be additional time allowed for hui’s to integrate customs (Farmer, Gage, Kirk, & Edgar, 2016).

In regard to the lower social economic groups that were not represented well in this research, it would be important to explore this group further as there may be other factors that need to be consider when managing their TBI related fatigue to allow them to manage at work. The motivation and pressure to work and earn money may be different in this group and this may impact on their consideration of implementing strategies at work. Also, the type of work that they participate in may be less conducive to self-management as discussed below. To do this, future researchers could more explicitly aim to recruit people from manual labouring jobs or primary industry.

It is likely that with different industries such as technicians and trades workers, sales workers, and machinery operators and drivers, they may have developed different fatigue management strategies due to them being less autonomous in their occupation. This would also be true to the occupational groups of community and personal service workers, labourers and clerical and administrative workers who had lower representation in this research with no ability to compare due to there only being one participant recruited in each occupational group. To target these occupational groups the recruiter could target specific companies that have a higher rate of these occupational types or industry associations or groups such as Master Builders Association or a company like Fonterra (dairy company).

Also, the occupational group of managers was not represented at all. This group also may have some other challenges around being responsible for other workers and this may mean alternative strategies are incorporated to manage their fatigue at work.
It would also be important to explore how people manage fatigue after TBI in unpaid roles such as parenting, study, or other primary roles. It is likely that fatigue in these roles would be managed very differently due to the changes in demands and different motivations to succeeding. This would also include how people who have been unable to RTW particularly at the severe end of the TBI scale where cognitive and behavioural impairments would limit people’s ability to learn and refine their fatigue management and it may fall more on their significant others and/or support workers to guide their fatigue management.

To capture a more heterogenic sample and to better track the learning process around fatigue management it may be beneficial to consider a longitudinal prospective study. This would allow recruitment from an early stage of the TBI such as after hospital admission, or contact with GP or emergency departments. This would also allow investigations into why people have not been successful in their return to work after injury or have difficulties with work productivity, providing further information from this perspective.

The fatigue management framework that is hypothesised above (see section 5.6) could be developed further into a fatigue management programme. This could then be included in a clinical trial to test this approach and determine its impact on fatigue after TBI and its clinical usefulness. (see Appendix K for the ‘What is My Change Point’ process).

5.8. Summary

This chapter presents reflects on the results of this research and how this compares and contrast to other research in this area. Possible future research directions have been explored and the clinical implications of this research and possible application to clinical situations have been pondered, but with considerations for the strengths and limitations of this study.

5.9. Thesis summary

This research explored how people manage their TBI related fatigue at work to successfully engage in work tasks. Participants went through a process of trial and error learning about identifying and managing their fatigue symptoms. They mastered fatigue management through awareness of their ‘change point’, and
selection and implementation of a strategy to manage the symptoms and remain productive at work. There was a continuum of fatigue management strategies that had low to high impact on work productivity. Low intensity activities and super-mini breaks had minimal impact on productivity. Mini breaks and long breaks had greater impacts on productivity at work, but needed to be incorporated to allow recovery from fatigue and ensure future productivity. The decision to implement a strategy, and choice of strategy, was influenced by level of fatigue, self-expectations and work identity, colleagues’ expectations, and task priority. Balancing tasks over the day and week, and adapting activities outside work, also contributed to the success of managing fatigue at work.

This research highlighted the essential need to understand the intensity of fatigue symptoms, awareness of a ‘change point’ to avoid a boom and bust cycle, and judicious selection of a fatigue management strategy that address fatigue symptoms while enabling work productivity. The individual’s in-depth knowledge of fatigue symptoms was crucial in ensuring a greater level of success in managing fatigue at work to allow greater productivity.

The relationship between awareness of the intensity of fatigue symptoms – or ‘change points’ – and implementation of an appropriate strategy has not been identified in any other studies. An infographic, developed from the study findings, captures the sophisticated process that participants used to manage fatigue at work. Further research could investigate the usefulness, for clinicians and people post-TBI, of the infographic as a resource for fatigue management within the return to work process.
References


female adults over the 2 years following traumatic brain injury: a qualitative descriptive study. BMJ Open, 6(4).


Appendix A: Advertisement

Research Study


What is the purpose of this project? This project will explore what helps people who have had a brain injury manage their fatigue to enable them to work. This new knowledge will help health professionals and people with a brain injury, plan a more effective return to work.

This project is part of a Master’s thesis and is being carried out by a research student from the University of Otago. The project team is independent from your health providers and ACC.

Who can be involved? - We are looking for people, aged 18 to 65 years, living in the Waikato region who had a brain injury between 1 and 3 years ago. You need to be in paid work (with the same employer as before your brain injury), and experience fatigue as a result of your brain injury.

Benefits – There are no direct benefits to individuals being involved in this study.

What is involved? - If you agree to take part, you will be interviewed about your brain injury, and what has helped you manage your fatigue to enable you to work. This interview will probably not take any longer than one hour of your time.

Sarah Lillas, Student Researcher, Phone: 021 868 312 Email: liis273@student.otago.ac.nz

This project has been reviewed and approved by the University of Otago Human Ethics Committee, (Health). Reference: H15/123
Appendix B: Recruiter Flow Chart

Process for Initial Recruiters

Do you have a client that has experienced fatigue post TBI, and has returned to work?

**YES**

Do they meet all the following criteria?
- Have a TBI that occurred over 6 months and under 3 years ago.
- Aged between 18 - 65 years old.
- Participants attribute the primary cause of their fatigue as being their TBI
- Returned to employment with the same employer as before their TBI.
- Can communicate fluently in English

**NO**

**UNSURE**

Keep searching 😊

**NO**

**YES**

Contact client - Discuss the aims of the study

*The study aims to explore fatigue management strategies used by people with a TBI to manage their daily activities. Specifically, the study will investigate how fatigue is managed to enable you to work.*

And the expectations of the person

*You will be interviewed by the researcher, Sarah Lillas, at a venue of your choice about your brain injury, your fatigue, and what has helped you manage your fatigue to enable you to work. This interview will probably not take any longer than one hour of your time. With your consent you may be contacted again by phone or email if there is anything you said in the interview that needs clarifying. Sarah is a health professional and works with people with TBI. She is doing this research for her master of health sciences thesis.*

Ask the potential participant whether they are interested in being contacted by the researcher to discuss this research further and the possibility of them participating. Confirm they are happy for their phone number to be given to the researcher

Email researcher (sarah.lillas@xtra.co.nz) with potential participants name and phone number and identify that they have consented to researcher contacting them to give them more information.

Researcher – Sarah Lillas
Phone: 021 868 312 Email: sarah.lillas@xtra.co.nz
Appendix C: Cover Letter

First Name  Last Name
Street Name/Number
Town
Postcode

Date 21/3/18

Dear First Name


Thank you for considering being involved in the above study, which is being completed as part of a Master’s Thesis by Sarah Lillas (Student Researcher).

Please see the enclosed for the Participant Information Sheet for this study for more information. I will contact you in a few days to confirm whether you are still interested in being involved in this study. Remember, at any time you can change your mind about taking part in this study.

If, after reading the Participant Information Sheet, you are still interested in taking part in the study I have enclosed a consent form for you to sign. You can give this to me on the day of the interview, or you can bring it with you and sign it at the interview if you prefer.

Please do not hesitate to contact myself if you have any questions/concerns, or require more information.

Thank you for your time.

Kind regards,

Sarah Lillas
Student Researcher
Phone: 021 868312
sarah.lillas@xtra.co.nz
Appendix D: Participant Information Sheet

Participant Information Sheet

|----------------|----------------------------------------------------------------------------------|
| Principal investigator: | Name: Jean Hay-Smith  
Department: Rehabilitation Teaching & Research Unit (RTRU)  
Position: Associate Professor |
| Contact phone number: | 021 029 63623 |

Introduction

Thank you for showing an interest in this project about fatigue after brain injury. Please read this information sheet carefully, discuss it with friends or family, and take time to consider whether or not you wish to participate.

If you decide to take part, we thank you. If you decide not to take part, there will be no disadvantage to you and we thank you for considering our invitation.

What is the purpose of this project?

This project will explore what helps people who have had a brain injury manage their fatigue to enable them to work. We cannot find any existing research on how people successfully manage their fatigue when they are returning to work after a brain injury. This new knowledge will help health professionals and people with a brain injury, plan a more effective return to work. Fatigue is a very common problem after a brain injury and it does make it harder to return to work.

Who is funding this project?

This project is part of a Master’s thesis and is being carried out by a research student from the University of Otago. The project team is independent from your health providers and ACC.
Who is being invited to take part in the project?

We are looking for people who live in the Waikato region and have had a brain injury more than six months, and less than three years ago. In addition, you need to be between 18 and 65 years old, currently working in paid employment (with the same employer as before your brain injury), and you experience fatigue as a result of your brain injury. You cannot be a past or current patient of Sarah Lillas. Sarah is the student researcher and also an occupational therapist working with people with a brain injury in the Waikato region.

If you take part in the project, what will you be asked to do?

If you agree to take part in this project, and sign the consent form, then Sarah Lillas (the student researcher) will interview you about your brain injury, your fatigue, and what has helped you manage your fatigue to enable you to work. This interview will probably not take any longer than one hour of your time. We will also ask your permission to contact you again by phone or email if there is anything you said in the interview we would like to check to make sure we have understood correctly.

Is there any risk of discomfort or harm in this project?

The interview will be focused on your brain injury and the impact this has had on your life. It might be upsetting to talk about some parts of this experience. If the researcher notices you are upset she will offer to stop the interview. All participants will also be given some information about support services they can access if they require this.

What are the costs of being involved in this project?

The cost is your time. You will not receive any financial incentive to take part in this project. The interview will take place at your home or work, unless you prefer to be interviewed somewhere else, so this will not involve any extra travel.

What will happen with the results and will I be able to see them?

The information from all the interviews will be analysed to find out how people with brain injury successfully manage fatigue to enable them to work. If you would like a copy of the results, then a summary can be sent to you at the conclusion of the project. There will be delay of up to 2 years between the interviews and when the results are available.
How will my privacy be protected?

All information collected from you will be kept strictly confidential and is available only to the researchers involved in this project. Each interview will be given a number. Only Sarah will have access to the file that matches your name with the number of your interview. When Sarah transcribes the interview she will take out your name and any other information that might identify you (such as the names of workmates, or where you live). All this information will be kept on a computer with password protection, a backup drive with password protection or paper copies that will be kept in a locked filing cabinet. All of these will be in a locked office. After the project, to comply with the Health (Retention of Health Information) Regulations 1996, your consent form and transcribed interview and the file that matches your name with your interview will be kept for a minimum of 10 years at the Rehabilitation Teaching and Research Unit, University of Otago. After this it will be confidentially destroyed.

Do I have to take part and can I withdraw later?

Taking part in this project is voluntary (your choice). If you decide not to be part of this project there will be no disadvantage to you of any kind.

If you choose to participate you will sign a consent form. You can withdraw at any time during the project without giving a reason if you do not wish to. Once all the people in the project have been interviewed, the information from everyone has been put together in the project report, you cannot withdraw.

Who should I contact if I have further questions?

If you require further information in relation to this project and your possible participation you can contact the primary researcher (see first page), or contact:

<table>
<thead>
<tr>
<th>Name: William Levack</th>
<th>Contact phone number:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position: Associate Dean – Research &amp; Postgraduate Studies; Senior Lecturer in Rehabilitation</td>
<td>04 385 5591 ext 6279</td>
</tr>
<tr>
<td>Department: Rehabilitation Teaching &amp; Research Unit (RTRU)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name: Sarah Lillas</th>
<th>Contact phone number:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position: Student Researcher</td>
<td>021 868 312</td>
</tr>
<tr>
<td>Department: Rehabilitation Teaching &amp; Research Unit (RTRU)</td>
<td></td>
</tr>
<tr>
<td>Also an Occupational Therapist for Focus on Potential Ltd.</td>
<td></td>
</tr>
</tbody>
</table>
You can contact the Health and Disability Advocate if you have any questions or concerns in regards to your rights as a participant in this project (Phone: 0800 555 050)

Thank you for taking the time to read this information sheet.

This project has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.c.nz). Any issues you raise will be treated in confidence and investigated, and you will be informed of the outcome.
Appendix E: Consent Form


Student Researcher: Sarah Lillas  Phone: 021 86 8312  Email: sarah.lillas@xtra.co.nz

Consent form for participants

Following signature and return to Sarah Lillas this form will be stored in a secure place for 10 years.

1. I have read, or had read to me, the Information Sheet (Version 2, dated 28th April 2016) about this research. I understand the aims of the research.

2. I have had enough time to talk to other people of my choice about taking part in this research.

3. I confirm that I meet the criteria for participation, which have been explained by Sarah and in the Information Sheet (Version 2, dated 28th April 2016).

4. All my questions about the research have been answered to my satisfaction. I know that I can ask for more information at any stage.

5. I understand that taking part in this research is voluntary (my choice) and I can withdraw at any time without disadvantage.

6. I understand that in this research I will take part in an interview with Sarah. I know that the interview will explore the effects of my brain injury on my everyday life, my experience of fatigue, and how I manage fatigue to enable
me to work. I understand that if any question(s) make me feel uncomfortable I do not have to answer.

7. I agree to my interview being audio-taped.

8. I know that during the research all information about me will be kept confidential and shared only with the other researchers of this study.

9. At the end of the research I understand that the information collected from me will be held in secure storage for a minimum of 10 years to comply with the Health (Retention of Health Information) Regulations 1996.

10. I understand the results of the study may be published, and held in the University of Otago Library as a research thesis. There will be no personal information identifying me in any publications.

11. I understand that there is no remuneration (reward) offered for this study.

12. I wish to receive a summary of the results of this study.
   Yes / No

13. I know who to contact if I have any further questions or concerns

I ......................................................... (print full name) agree to take part in this study.

**Participant Signature:** ..........................................................

**Name:** ..................................................................................  **Date:** ...............  

**Participant Contact Details:** ..............................................

**Alternative Phone Contact:** ..............................................

**Student Researcher Signature:** ............................................

**Name:** ..................................................................................  **Date:** ...............
Appendix F: Interview Schedule

Interview Schedule

Reducing the Impact of Fatigue after a Traumatic Brain Injury: A Client Perspective.

Aim:

To explore fatigue management strategies, enabling participation in paid employment after a traumatic brain injury, from the perspective of the person with the injury.

Objectives

1. Describe what fatigue management strategies people with TBI find useful to allow them to function at work.
2. Determine the common elements of successful fatigue management practice.
3. Gain an understanding of what facilitates and impedes successful application of these strategies both in and out of work.

Introduction

Fatigue affects up to 80% of individuals who have sustained a brain injury. Fatigue frequently limits people’s ability to return to work. There is little evidence supporting any type of treatment to reduce the impact of fatigue with people who have sustained a brain injury. This study will explore what helps people manage their fatigue to enable them to work. Fatigue will be explored in greater depth to gain an accurate understanding of what people have done to manage their fatigue when they are successfully completing work tasks.

<table>
<thead>
<tr>
<th>Stem questions/prompts</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Will you describe what happened when your injury occurred?</td>
<td>Aims/Objectives Being Addressed</td>
</tr>
<tr>
<td>o When did this occur?</td>
<td>Background information for Aim and all 3 Objectives. Also specific information around severity, and presence of other injuries when considering objective 3.</td>
</tr>
<tr>
<td>o What caused the injury</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Checking eligibility criteria with time since injury</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------</td>
</tr>
<tr>
<td>What do you recall doing before you were injured?</td>
<td>Reason for question</td>
</tr>
<tr>
<td>Who was there?</td>
<td>For background information. To gage the severity of injury and whether there is any patterns with more severe injuries versus very mild injuries. Questioning on the injury and recall of the incident</td>
</tr>
<tr>
<td>What do you first recall after the injury?</td>
<td>This will also alert me to any possible post-traumatic stress that may exclude someone from the study. Possibly if I were concerned about this at this stage I would stop the interview due to likelihood that they don’t fit the criteria. It is likely that this wouldn’t come out in initial questioning on eligibility criteria.</td>
</tr>
<tr>
<td>What happened after your injury?</td>
<td>This is to get some gage on the severity of the injury. This may be useful when analysing the data.</td>
</tr>
<tr>
<td>Did you go to hospital?</td>
<td>Rapport - This is also allowing some story telling of the injury to help develop rapport in these early stages.</td>
</tr>
<tr>
<td>Did you sustain any other injuries?</td>
<td>Information wanted</td>
</tr>
<tr>
<td></td>
<td>What the accident was, rough idea of loss memories to gage post-traumatic amnesia, list of other injuries.</td>
</tr>
</tbody>
</table>

2. **What effects has the brain injury had on your day-to-day living?**

<table>
<thead>
<tr>
<th>Question</th>
<th>Aims/Objectives Being Addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Describe any difficulties you had with…. (thinking / moving / sensing / mood)?</td>
<td>Background information for Aim and all 3 Objectives. Also specific information around other limitations and degree these impact on function when considering objective 3.</td>
</tr>
<tr>
<td>Describe any changes in your roles….. (e.g. mother / worker / friend)?</td>
<td>Reason for question</td>
</tr>
<tr>
<td></td>
<td>To get a clear idea of what their limitations are will help determine what strategies may be required do</td>
</tr>
<tr>
<td>Question</td>
<td>Aims/Objectives Being Addressed</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Describe any changes in your ability to ..... (complete personal care / sleep / complete household tasks / drive / access the community / socialise / complete recreational tasks / work)?</td>
<td>Background information for Aim and all 3 Objectives. Also to allow more specific prompting in questions 6, 7 and 8.</td>
</tr>
<tr>
<td>to other limitations such as reduced memory or motor weakness.</td>
<td>Reason for question</td>
</tr>
<tr>
<td>Also this may allow a gage of the severity of their fatigue in the initial stages.</td>
<td>To establish impact over all activities. If I only focused on work I may miss that fatigue is still substantially impacting on home tasks. This could be a consideration when consider what works at work (prioritising work tasks over home task may be a strategy).</td>
</tr>
<tr>
<td>Determine the impact of multiple deficits and success of fatigue management strategies or need for alternative strategies to people who have just fatigue as a symptom.</td>
<td>Information wanted</td>
</tr>
<tr>
<td>Determine limitations in other task outside of work will also allow some insight into complexity of limitations at home and possible impact on work fatigue levels.</td>
<td>Where fatigue effects them in the day.</td>
</tr>
<tr>
<td>Information wanted</td>
<td></td>
</tr>
<tr>
<td>List of limitations, list of activities that were hard and list of role changes.</td>
<td></td>
</tr>
</tbody>
</table>

3. As you know, I'm particularly interested in what effect fatigue has had on your day-to-day living. What have the effects of fatigue been for you after the brain injury?

- Describe any changes in your ability to manage.....(personal care / sleep / household tasks / driving / accessing the community / socialising / recreational tasks / work / maintaining relationships)?
4. **I’d like to talk about your work now.**
*Please describe your job. What do you do at work?*
- What is your job title/position?
- Describe a typical workday
- What are you responsible for?
- Who do you work with?
- Who are you responsible for?
- What does the environment that you work in look like?

**Aims/Objectives Being Addressed**

*Background information for Aim and all 3 Objectives.*

*Allow more specific prompting in questions 6, 7 and 8.*

**Reason for question**

*This is to get a good idea of their work demands, work type, mental versus physical demands, work environment and support at work. This will also allow some context to the strategies that are discussed later in interview. Knowing the work tasks and environment will also allow for further prompts when asking questions about fatigue management, limitations and what changes have been made post-injury.*

*Rapport - These questions on work are also low intimacy questions to start developing rapport in these early stages.*

**Information wanted**

*A clear picture of what the individuals does on a daily basis including what and who they are responsible for and what environment they are functioning in.*

5. **How did you go about getting back to work after your brain injury?**
- Are you or were you involved in a return to work programme or gradual increase in hours to get back into your work roles?

**Aims/Objectives Being Addressed**

*Background information for Aim and all 3 Objectives.*

*Also looking at strategy of return to work programme for objective 1 and 2.*

*Also will allow more specific prompting in questions 6, 7 and 8.*
- How long have you been back at work including the return to work programme?
- How many hours a week are you currently working?
- Have you returned to your pre-injury work hours?
- How long have you been completing these hours for now?

**Reason for question**

This is to establish where in their rehabilitation they are. Have they completed their rehabilitation and strategies are refined and proved to be successful or are strategies in the preliminary stages and possibly still being trialled. This may help me to determine some of the areas that are not working in this early stage.

Determining whether they were involved in a graduated return to work also adds to strategies around return to work due to this being a fatigue management strategy in itself and possibly one that can be overlook retrospectively.

Also it will allow me to determine if strategies discussed later have been maintained long term.

**Rapport** - These questions on work are also low intimacy questions to start developing rapport in these early stages.

**Information wanted**

What hours the person works and how this compares to pre-injury. Whether they had return to work rehabilitation. Length of time they have been working.

---

6. **When you first started back at work what tasks did you find difficult as a result of your fatigue?**

- How did your fatigue affect your core work tasks?
- How did your fatigue affect your work relationships?

**Aims/Objectives Being Addressed**

Objective 1 and 2 to look at what is successful at work.

Will also allow some specific prompting for question 7 and 8

**Reason for question**

To get a baseline of what they were struggling with. This will allow me to determine if the strategies implemented were successful and made
Note. Utilised responses in question 4 for further prompting on work roles affected.

7. **As you spent more time at work what did you do to manage your fatigue better?**
   - How did you overcome or minimise ……………
   - **Note:** Work through difficulties listed above in Question 3
   - What strategies would you recommend to someone else in your situation?
   - What did you find didn’t work

**Aims/Objectives Being Addressed**

**Aim and Objective 1 and 2.**

**Reason for question**

This is looking at the development of strategies. So it may give me an idea of what initial strategies were used either by trial and error or by what they were told to do, but then seeing the development into what strategies actually worked and is being implemented long term due to effectiveness. This will also allow some insight into what has not worked.

**Information wanted**

Strategies that were being implemented

8. **When you think about you work week last week, what has changed in the way your week looked compared with a work week before you had you brain injury.**
   - How has your approach to your day changed?
   - What has changed in how long it takes to do tasks?

**Aims/Objectives Being Addressed**

**Aim and Objective 1 and 2.**

**Reason for question**

This is just identifying what strategies are being implemented long term and are sustainable. This will allow a comparison with strategies determined above and also bring in a different angle to determine whether there are any other strategies that have been missed.
<table>
<thead>
<tr>
<th>Describe any environmental changes that you have had to incorporate? (using different rooms, changing workspace.)&lt;br&gt;Described any equipment or devices you use now that you didn’t previously?&lt;br&gt;Describe any changes to organising your tasks or daily routine?</th>
<th>This will tap into recent memory as well if there are any memory difficulties or if the individuals are having difficulties recalling what they did initially.&lt;br&gt;<strong>Information wanted</strong>&lt;br&gt;Strategies that were being implemented or practices that changed post injury</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>9.</strong> What things do you do outside of work to manage fatigue so you have enough energy to work?&lt;br&gt;Describe any increased rest you need?&lt;br&gt;How have your home activities changed?&lt;br&gt;How have your evenings changed?&lt;br&gt;How have your leisure and social activities changed?&lt;br&gt;How have your relationships changed?</td>
<td><strong>Aims/Objectives Being Addressed</strong>&lt;br&gt;This is specifically looking at Objective 3.&lt;br&gt;<strong>Reason for question</strong>&lt;br&gt;This will help to determine if they have to do anything different at home to enable them to work. Have they prioritised their energy for work tasks and then crash at home due to exhaustion.&lt;br&gt;<strong>Information wanted</strong>&lt;br&gt;Strategies that are being implemented at home to enable work.</td>
</tr>
<tr>
<td><strong>Now check:</strong>&lt;br&gt;<strong>Age:</strong>&lt;br&gt;<strong>Other Medical Background:</strong></td>
<td><strong>Aims/Objectives Being Addressed</strong>&lt;br&gt;<strong>Eligibility Criteria and Sampling</strong>&lt;br&gt;<strong>Reason for question</strong>&lt;br&gt;This is more the information that would be asked on the phone and maybe recording here to confirm</td>
</tr>
<tr>
<td>Ethnicity using standard census question:</td>
<td>eligibility so this may be pre-documented and then identifying removed in transcription.</td>
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<td>-----------------------------------------</td>
<td>--------------------------------------------------------------------------------------</td>
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<tr>
<td></td>
<td>Cultural identity and gender is for any quota sampling.</td>
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</tbody>
</table>

Thank you for taking the time to participate in this interview. Do you have any further questions or things that you want to add that we haven’t covered?
Appendix G: Demographic Information Questionnaire


Demographic Information

This form helps us collect demographic information about you so we get a good idea of who is involved in this research. Any information specifically identifying you will not be included in the write up of this research.

Current Age:

Gender (circle): Male/Female

Medical Background (include all diagnosed conditions you have):

Mental Health Background (include all diagnosed conditions you have):

Ethnicity (circle):

- NZ European
- Māori
- Asian
- Pacific peoples
- Middle Eastern, Latin American, African
- Other

Who do you live with:

Household Income (circle)

- Less than 55 000
- 55 000 – 65 000
- 65 001 – 75 000
- above 75 000
Appendix H: Ethics Committee Response Letter

14 December 2015

Assoc. Prof. J Hay-Smith
Department of Rehabilitation Teaching and Research Unit (Wtn)
School of Medicine
University of Otago, Wellington

Dear Assoc. Prof. Hay-Smith,

I am writing to let you know that, at its recent meeting, the Ethics Committee considered your proposal entitled "Managing fatigue after a traumatic brain injury: A client perspective".

As a result of that consideration, the current status of your proposal is:- Approved

For your future reference, the Ethics Committee's reference code for this project is:- H15/123.

The comments and views expressed by the Ethics Committee concerning your proposal are as follows:-

Please address the following comments before proceeding with the research:

While approving the application, the Committee would be grateful if you would respond to the following:

Screening of treatment providers

The Committee seeks clarification in respect of how potential participants will be identified. To question 11.1 "Will your study involve reviewing or screening health information, for example in order to identify potential participants" you responded "no". However, in question 13.3, you indicate that Waikato treatment providers will be used to identify potential participants.

Advertisement

The Committee suggests that in addition to the recruitment method outlined that you may also wish put up advertisements to seek interest from potential participants.

Consultation with Maori
In relation to question 14.1, and the response indicating that in Waikato 31% of those who sustained Traumatic Brain Injury are Maori, the Committee suggests that you might wish to attempt to purposively sample Maori participants if this has not already been considered.

Please provide the Committee with copies of the updated documents, if changes have been necessary.

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Yours sincerely,

[Signature]

Mr Gary Witte  
Manager, Academic Committees  
Tel: 479 8258  
Email: gary.witte@otago.ac.nz

c.c. Assoc. Prof. W Taylor  Department of Rehabilitation Teaching and Research Unit (Wtn)
Appendix I: Researcher Reply to Ethics Committee Response Letter

Mr Gary Witte,  
Manager, Academic Committees,  
Room G22, Clocktower Building,  
University of Otago,  
362 Leith St,  
North Dunedin,  
Dunedin 9016.  
Email: gary.witte@otago.ac.nz

Dear Gary

Thank you for your letter dated 14th December 2015 in regards to my proposal entitled "Managing fatigue after a traumatic brain injury: A client perspective" (Reference code: H15/123).

We are writing to respond to the points raised by the Ethics Committee. Our response is as follows:

Screening of treatment providers

As per your letter you stated:

The Committee seeks clarification in respect of how potential participants will be identified. To question 11.1 “Will your study involve reviewing or screening health information, for example in order to identify potential participants” you responded “no”. However, in question 13.3, you indicate that Waikato treatment providers will be used to identify potential participants.

Thank you for pointing out this inconsistency. We are recruiting through treatment providers. The treatment providers will utilise the health information they hold in order to identify potential participants. However, we will therefore not be seeing any health information related to the participants.

Advertisement

As per your letter you stated:

The Committee suggests that in addition to the recruitment method outlined that you may also wish put up advertisements to seek interest from potential participants.

The committee has offered a very useful suggestion here. We do not anticipate the need for an advertisement when we approach treatment providers, but if we do not recruit enough participants via treatment providers and we will need to use GPs or large companies; in those instances an advertisement is a logical way to bring the study to the attention of potential participants. Therefore we have attached the proposed advertisement to be used, only if required.
Consultation with Māori

As per your letter you stated:

In relation to question 14.1, and the response indicating that in Waikato 31% of those who sustained Traumatic Brain Injury are Māori, the Committee suggests that you might wish to attempt to purposively sample Māori participants if this has not already been considered.

We agree with the point that you raise here. Ideally we would like to purposively sample in order to achieve representativeness for Māori, especially as the rate of traumatic brain injury is higher for Māori in the Waikato. In the event that we have sufficient potential participants we will purposively sample for representativeness, but will not be able to do this if insufficient potential participants are identified. We will bring this study to the attention of Te Ora Māori GP practices in the Waikato.

We hope this has clarified the above queries.

Yours sincerely,

Sarah Lillas
Student Researcher

Jean Hay-Smith PhD
Associate Professor
Department of Rehabilitation Teaching and Research Unit (Wtn)
School of Medicine
University of Otago, Wellington
Appendix J: Māori Consultation Response

Tuesday, 17 November 2015.

Associate Professor Elizabeth Hay-Smith,
Rehabilitation Teaching and Research Unit,
WSM&HS.

Tēnā Koe Associate Professor Elizabeth Hay-Smith,

Reducing the impact of fatigue after a traumatic brain injury: A client perspective

The Ngāi Tahu Research Consultation Committee (the committee) met on Tuesday, 17 November 2015 to discuss your research proposition.

By way of introduction, this response from The Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum it states "Ngāi Tahu acknowledges that the consultation process outline in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago". As such, this response is not "approval" or "mandate" for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."

The Committee considers the research to be of importance to Māori health.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project. That is the questions on self-identified ethnicity and descent, these questions are contained in the latest census.

The Committee strongly recommends contact with iwi in the area where this research is to be conducted. This may be best done through the Waikato District Health Board Te Puna Oranga Māori Health Service.

Book 2010. Another Publication, Hauora: Māori Standards of Health IV (2000-2005), has its own website, http://www.hauora.maori.nz/. These publications provide information on a range of Māori health issues and will assist in ensuring your research has an appropriate Māori health focus.

The Committee suggests researchers consider the Southern District Health Board's Tikaka Best Practice document, in particular patient engagement. The document also covers the collection, storage and disposal of blood and tissue samples. This document is available on the Southern District Health Board website.

The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

We wish you every success in your research and the committee also requests a copy of the research findings.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 17 November 2015 to 17 May 2017.

Nāhaku noa, nā

Mark Brunton
Kaiwhakahaere Rangahau Māori
Research Manager Māori
Research Division
Te Whare Wānanga o Otāgo
Ph: +64 3 479 8738
Email: mark.brunton@otago.ac.nz
Web: www.otago.ac.nz
Appendix K: Possible Intervention Strategy

What is My Change Point?

It has been found that people describe symptoms when they are experiencing fatigue after TBI. It is important to learn what these symptoms are so that we can master how we manage our fatigue and maximise our ability to do the activities that we want to do.

Once we understand these symptoms we can then learn more specifically when they occur and what strategy we need to implement at the time they are occurring. The implementation of a strategy is considered a change point. This is the point when you need to change what you are doing to recharge your batteries before they become flat and you can’t do anything.

**Week 1-2 Fatigue Symptoms**

Consider symptoms you experience when you are starting to become tired e.g. headaches, reduced concentration, reduced memory, irritability or anything else you notice.

It may be that you have experienced a situation where you ‘crashed’ or could no longer function. What was happening at that time?

Do you notice any changes around you with people, or the environment e.g. noticing a noise, lights, people are more annoying.

Write all these symptoms below in any order. Even if they seem minor.

---

**Week 3-4 – Reading Fatigue Symptoms**

It is now important to determine what your symptoms are telling you. Some symptoms will occur earlier when you are only beginning to fatigue and others will occur much later when you are already exhausted. You may not notice the early symptoms if you are completely engaged in an activity.

Once you are sure that you have considered all of your fatigue symptoms, (Week 1-2), you need to look at all these symptoms and consider ranking these below.

The order you are ranking them in is from the very first symptoms that you experience through to the symptoms you experience when you really can’t do anything anymore such as, when you are exhausted.
<table>
<thead>
<tr>
<th>Symptom ranking (see above)</th>
<th>Change points (see below)</th>
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</thead>
<tbody>
<tr>
<td>1.</td>
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<td>10.</td>
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**Week 5-6 – Implementation of Change Points.**

When you are experiencing your symptoms above you need to consider what to do next. Use the battery in the handout to see possible options that you could consider. These could include reducing the intensity of the activity, taking a super mini break, a short break, a long break or having a sleep. Try implementing these over the next few weeks. When you experience your first few symptoms listed above attempt to change the activity to something that is not as mentally demanding.

Note: Discuss this with your Occupational Therapist for some examples in your specific situation.

If you are experiencing symptoms at the bottom of your ranking (high levels of fatigue) consider a long break or a sleep.

Brainstorm these over the next few weeks in the right-hand column above. Refer to the battery to consider what worked and what didn’t and possible changes to the strategy next time this symptom occurs.