VALIDITY OF SYMPTOM REPORTING FOLLOWING MILD TRAUMATIC BRAIN INJURY

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ATTESTATION OF AUTHORSHIP

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

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Signature Date

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ABSTRACT

VALIDITY OF SYMPTOM REPORTING FOLLOWING MILD TRAUMATIC BRAIN INJURY

Objective: Recent evidence of persistent reporting of symptoms after mild Traumatic Brain Injury (mTBI) has come under question, with the suggestion that participants may be over-reporting symptoms more generally. This study set out to determine the proportion of people reporting atypical symptoms and to explore the relationship between acute (1 month) atypical symptom reporting and perceptions of recovery and experience of typical symptoms following mTBI.

Methodology: Data was drawn from the longitudinal population-based Brain Injury Incidence and Outcomes New Zealand (NZ) in the Community (BIONIC) study that was conducted in the Hamilton and Waikato districts. Cases included patients who had experienced a traumatic brain injury between the 1st March 2010 and 28th February 2011. Cases were identified from the ACC database, community healthcare services, such as general practitioners (GPs) and physiotherapists, hospital admissions and discharges, sports clubs, concussion clinics and self-referrals. Participants completed the Rivermead Post-Concussion Questionnaire (RPQ) assessment at one month (n = 261) and twelve months post-injury (n = 193), in addition to data on a series of distractor (atypical) symptoms. Typical symptoms generally relate to post-concussion symptoms, while atypical symptoms do not form part of a concussion clinical presentation. Characteristics of the sample were analysed and the proportion of participants reporting atypical and typical mTBI symptoms were explored at both timepoints. T-tests were used when data satisfied parametric assumptions; if not satisfied, the Chi square tests tested non-parametric equivalent statistics (for nominal/categorical variables). The significance level was set at $p < 0.05$. A regression

analysis determined whether increased atypical symptoms reported at one month predicted persistent symptoms and perceptions of recovery at twelve months.

Results: Data was available for n = 261 participants at one month and n = 193 at twelve months. Atypical symptoms were reportedly experienced by 25% of participants at one month and 16% of participants at twelve months. Atypical symptom reporting was higher in females than males. Sex, ethnicity, atypical symptoms and typical symptoms at one month following mTBI were significantly predictive of the one-year outcome, explaining 46% in the variance in typical post-concussion symptoms and 31 % of the variation in perceptions of recovery.

Conclusion: One in four people reported atypical symptoms in the acute phase (intense symptoms at one month) post-injury, which reduced over time (twelve months). However, the models did not explain all the variance in the outcome, and other factors are likely to influence outcomes from mTBI. Given links to symptom reporting and perceptions of recovery at twelve months post-injury, acute atypical symptom reporting could be a red flag to indicate those who may experience poorer long-term outcomes and require additional support to facilitate recovery.

Keywords: Symptom validity, symptom reporting, mild traumatic brain injury (mTBI), atypical symptoms, distractor symptoms, typical symptom reporting, mTBI symptom validity, concussion, post-concussion syndrome

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LIST OF ABBREVIATIONS

ACC	Accident Compensation Corporation
ADHD	Attention Deficit and Hyperactivity Disorder
ALS	Amyotrophic Lateral Sclerosis
APA	American Psychiatric Association
BIONIC	Brain Injury Incidence and Outcomes New Zealand in the Community
CDC	Centres for Disease Control and Prevention
CT	Computer Tomography
DSM 5	Diagnostic and Statistical Manual of Mental Disorders 5
GAD	Generalised Anxiety Disorder
GCS	Glasgow Coma Scale
GPs	General Practitioners
ICD 10	International Statistical Classification of Diseases, 10th Revision
ICF	International Classification of Functioning
LC	Locus of Control
LD	Learning Disability
LOW 6	Low Frequency 6
mBIAS	Mild Brain Injury Atypical Symptoms
MDD	Major Depressive Disorder
MRI	Magnetic Resonance Imaging
NIM 5	Negative Impression Management 5
NSI	Neurobehavioural Symptom Inventory
mTBI	Mild Traumatic Brain Injury
OCD	Obsessive Compulsive Disorder

PCD	Post-Concussion Disorder
PCS	Post-Concussion Symptoms
PRC	Perception of the level of Recovery
PTSD	Posttraumatic Stress Disorder
RPQ	Rivermead Post-Concussion Symptoms Questionnaire
SCAT	Sport Concussion Assessment Tool
SIS	Second Impact Syndrome
TBI	Traumatic Brain Injury

Chapter 1 - Introduction

The validity of symptom reporting after a concussion is not well studied. Mild traumatic brain injury (mTBI), also known as concussion, is brought on by an impact or force (blow) to the body not necessarily directly to the head (Accident Compensation Corporation, 2016; American Psychiatric Association, 2013). This affects approximately 35,000 New Zealanders each year (Accident Compensation Corporation, 2016; Feigin et al., 2013), with 95% of traumatic Brain Injury (TBI) cases being classified as mild (Forrest, Henry, McGarry, & Marshall, 2018). A concussion can lead to short term symptoms such as headache, dizziness, nausea, fatigue, ringing in the ears, blurred vision, loss of consciousness, brain fog and delayed response to questions and loss of balance (Ontario Neurotrauma Foundation, 2018). mTBI can also significantly decrease quality of life with long-term effects that include concentration and memory impairment, personality changes and cognition deficiencies (Kaufman, 2007). Overseas studies have reported that patients often exaggerate the effects of mTBI, typically in the US whose litigation-based healthcare regime motivates such over-reporting (Sreenivasan, Eth, Kirkish, & Garrick, 2003). One way of exploring over-reporting is to look at the proportion of people who report experiencing symptoms not related to TBI and that cannot be explained by associated comorbidities (such as broken bones). This study looks at the proportion of atypical symptom reporting and determines the relationships to perceptions of recovery and typical presentation.

Overview of Chapters

This overview provides a brief roadmap of the seven chapters discussed in this thesis:

1. Introduction:

Brief introduction of mTBI and defining the concept of concussion.

2. Literature review:

   The literature review includes current knowledge and findings as it relates to mTBI and symptom reporting.

3. Methods:

   This chapter explains the study procedures and methods used in more detail.

4. Results:

   Chapter Four is a quantitative analysis of the findings using the above methods.

5. Discussion:

   Chapter Five explores the findings and provides a more focussed discussion of the findings and implications for future practice.

6. Conclusion

Note: Terms used synonymously in this document include mTBI and concussion, European and Pākehā, gender and sex, atypical symptoms and distractor symptoms.

Chapter 2 - Literature Review

This chapter provides an overview of the prevalence of mTBI as discussed in the literature. Symptom reporting in mTBI will be described as it relates to sociodemographic factors, such as age, gender and ethnicity. This chapter also considers biopsychosocial considerations, mTBI risk factors pre- and comorbidity of concussion and ends by discussing the gap in the current literature, motivating the current research.

Mild brain injuries pose a significant financial cost to NZ, with Traumatic Brain Injuries (TBI) costing the Accident Compensation Corporation $83.5 million in 2015 (Accident Compensation Corporation, 2017). mTBI causes a disruption in brain function, which can result in loss of consciousness, causing the person to feel dazed and confused or not remembering what happened (Accident Compensation Corporation, 2016; Lezak, Howieson, Bigler, & Traniel, 2012). Concussion is a form of mTBI is a Latin derivative which means to shake violently, and mTBI comprises the mechanical impact and/or acceleration/deceleration processes of the brain (Gofton & Young, 2014; Lezak et al., 2012). mTBI has two main biomedical features: impulsive loading (a part of the body causes motion that leads to injury to the head such as in a car accident), and impact loading (the head is struck by a moving object) (Lezak et al., 2012). At a cellular level, during the mechanical force, the meninges (protective fluid surrounding the brain) is pushed to the skull, which stretches and tears nerve tissues, altering the chemicals and ion balance in the brain (McAllister, 2011). While some cells recover, others may be permanently damaged, and the injury could be exacerbated by inflammation in the brain's white matter (nerve fibres that speed up sending and receiving of messages between brain cells) (Chu et al., 2010; Lezak et al., 2012). When mTBI affects only one area in the brain, it is known as a focal (localised) injury (Andriessen, Jacobs, & Vos, 2010), whereas diffuse injuries are spread more widely across the brain (Browne, Chen,

Meaney, & Smith, 2011). Primary (both focal and diffuse) injuries resulting from mechanical damage lead to immediate trauma, whereas secondary mTBI develops over time due to a physiological response (Stern et al., 2010).

According to the American Psychiatric Association (2013), 1.7 million incidents of TBIs happen yearly in the United States of America (USA), which requires the services of 1.4 million emergency visits. Three times more people suffer mTBI in middle-income and low-income countries by comparison to high-income nations (Williams et al., 2018). This could be due to reduced health and safety legislation in middle and lower income countries, such as regulation on work safety, the use of seat-belts, helmets in contact sports and cycling, not promoting better design of private and public spaces, and lack of regulation around overconsumption of alcohol in public places (James et al., 2019; Suriyawongpaisa, Thakkinstian, Rangpueng, Jiwattanakulpaisarn, & Techakamolsuk, 2013). Research by Rockhill, Fann, Fan, Hollingworth, and Katon (2010) (n = 1470) in the US suggest that there have been significant increases in the healthcare costs for mTBI, especially in youth. Seabury et al. (2018) (n = 831) found that less than 50 % of patients treated for mTBI received follow-up services at three months, suggesting that persistent symptoms could go untreated. It is predicted that by 2020, TBI will become the third largest cause of illness globally and is known as the silent epidemic (Feigin et al., 2013; Forrest, Henry, McGarry, & Marshall, 2018; Williams et al., 2018).

The severity of TBI is classified as either mild, moderate or severe (American Psychiatric Association, 2013b). The majority of TBIs (70 % to 95 %), are classified as being of mild severity (Feigin et al., 2013; Theadom et al., 2018) and consist of non-fatal injuries (Te Ao et al., 2015). The severity of TBI refers to neurobehavioral outcomes following brain injury and is generally specific to closed head injuries, which exist on a continuum from no behavioural impact to a vegetative state (Lezak et al.,

2012). While many recover well following an mTBI, a proportion go on to experience long-term problems (Taylor, Bell, Breiding, & Xu, 2017). In 2010, an average of 13 % (14.8 % were male and 11.4 % female) of the NZ population had suffered at least one TBI incident in their lives (Te Ao et al., 2015). Only 10 % to 20 % of persons with concussion lose consciousness, and it may take hours or days for symptoms to emerge (Accident Compensation Corporation, 2016).

Research by Ruff (2005) confirms that most patients who sustain a concussion are asymptomatic (symptoms are not present) within weeks after injury. However, approximately 10 % to 20 % have symptoms which persevere with reports of adverse effects months or even years post-injury. In NZ, a 2010 study found that first time incidence of mTBI was higher among younger groups (43 % first ever in children 0-14 years) and men (57 %) (Te Ao et al., 2015). Te Ao et al. (2015) found that first ever concussion amounted to 281 incidents per 100,000, with males averaging 330 and females 233 per 100,000.

Brain injuries were found to affect the patient's competitiveness after returning to work (Lezak et al., 2012). An early study, which included 248 patients who experienced brain injury (94 % employed pre-injury), found that 50 % resumed competitive employment, following two years and six months of rehabilitation, whereas 11 % returned to non-competitive work and 39 % did not return to work at all (Evans & Ruff, 1992). A later study by Kahan et al. (2018), established that the majority of participants in a sample of employed adults returned to their places of work shortly after an injury, but younger workers delayed returning to their jobs. A delay in returning to work was linked to age and education level (Kahan et al., 2018).

Mild brain injuries relate to varying symptoms that have an impact on cognition and emotional health (Cole & Bailie, 2016). Physical symptoms of mTBI, also known

as post-concussion symptoms (PCS) (Theadom et al., 2018), may fluctuate in duration and persistence after a neurological event (Kay, Welch, & McLeod, 2014). Symptoms are generally viewed as transient (Kay et al., 2014). PCS includes cognitive, somatic, and emotional symptoms (Theadom et al., 2018). **Cognitive impairments** due to TBI includes attention, memory and executive functioning disturbances which are particularly problematic as they could disrupt communication and other complex cognitive activities (Arciniegas, Held, & Wagner, 2002). A study by Perrine and Gibaldi (2016) confirms that **somatisation** in post-concussion syndrome is relatively common and does not always involve loss of consciousness, retrograde amnesia or post-traumatic amnesia. Post-concussion syndrome refers to the persistence of mTBI symptoms after the injury. Somatic symptoms of concussion include a bad taste in the mouth, blurred vision, change in sleeping patterns, dizziness, headaches, nausea or vomiting, ringing in the ears and sensitivity to light or sound (Centers for Disease Control, 2013). Research found that headaches are more prevalent after mTBI than moderate or severe TBI (Jouzdani et al., 2014; NSW Goverment, 2012; Ruff & Blake, 2016). According to Tyerman, (2018), **emotional changes** may include loss of behavioural control (lability/disinhibition), anxiety, depression, irritability, frustration and aggression. Madey, Williams, Bodle, Williams, and Lehman (2013) suggest that mood disturbances, irritability and abulia (a disorder with a reduction in spontaneity and motivation) can present in mTBI, but it is less common (Cole & Bailie, 2016).

mTBI Symptom description

In the clinical setting, the most frequently used diagnostic tools to measure mTBI are the *Diagnostic and Statistical Manual of Mental Disorders* 5 (DSM 5) and the *International Statistical Classification of Diseases, 10th Revision* (ICD 10) (American Psychiatric Association, 2013a; World Health Organization, 1993). For brain injuries, the DSM 5 lists them as neurocognitive disorders rather than traumatic brain

injury (American Psychiatric Association, 2013a). The DSM 5 includes criteria that are required for the diagnosis of disorders (Regier, Kuhl, & Kupfer, 2013). DSM 5 Criterion A specifies that for a diagnosis, the major symptoms must be included; criterion B relates to the symptoms; and criterion C is the specifier for TBI (American Psychiatric Association, 2013a). Criterion C specifies that for the injury to be due to TBI it should present directly after the brain injury or shortly after regaining consciousness, and should persist beyond the acute post-injury timeframe (American Psychiatric Association, 2013a). Both neurocognitive disorders and TBI should include evidence of a traumatic brain injury. These criteria (B) include one or more of the following: (1) loss of consciousness, (2) posttraumatic amnesia, (3) confusion and disorientation, (4) or neurological indicators, such as loss of sense of smell, recent onset of seizures or worsening of a preceding seizure disorder, neuroimaging of injury, visual field cuts or weakening of one side of the body (American Psychiatric Association, 2013a).

The primary aetiologies of concussion include falls, vehicle-related injuries, unintentional blow by or against an object, assaults and sports (American Psychiatric Association, 2013; Centers for Disease Control, 2013). In terms of specifiers, TBI could be rated according to severity during the first assessment and can be mild, moderate, or severe (American Psychiatric Association, 2013a). Most severe symptoms are generally experienced during the acute stage, less than 72 hours post-injury (Cole & Bailie, 2016). The threshold for mTBI is less than 30 minutes of loss of consciousness, less than 24 hours post-traumatic amnesia, and 13-15 minutes of disorientation and confusion (American Psychiatric Association, 2013a). The ICD 10 includes codes specifically for brain injuries listed as with and without skull fractures, and with and without behavioural disturbance (World Health Organization, 1993).

Several models address PCS after mTBI. The “good old days” hypothesis refers to “expectations” as an aetiological factor (Gunstad & Suhr, 2001). The model suggests that a recovery bias occurs when patients underestimate prior concussions (Iverson, Lange, Brooks, & Rennison, 2010), leading to poor outcomes (Gunstad & Suhr, 2001; Iverson et al., 2010; Sullivan & Edmed, 2012). Furthermore, when patients do not believe in treatment and feel that the concussion is getting worse (nocebo effect), they can experience persistent post-concussion syndrome (Polich, Iaccarino, Kaptchuk, Morales-Quezada, & Zafonte, 2019). The expectation of good old days bias as aetiologies link the current concussion to previous mTBI (Gunstad & Suhr, 2001). Wood (2004) is of the opinion that the diathesis-stress model is useful when examining the interplay between psychological and physiological elements that perpetuate PCS. Turner et al. (2017) stress the importance of physiological and psychological responses to mTBI, especially in sports, to promote emotional and physical recovery. These approaches have been criticised concerning the substantiation of recovery of large groups and that it does not consider smaller groups with persistent symptoms (Iverson, 2010).

Little is known about the prognosis or the course of mTBI, and it is not well studied at a population level (Barker-Collo et al., 2016; Lagarde et al., 2014). Multiple concussions within twelve months of a current injury would have a negative effect on recovery (Biswas, Kabir, & King, 2017; Krishnan & Delivery, 2018). This could lead to Second Impact Syndrome (SIS), which occurs when someone experiences two head trauma events within weeks (Cobb & Battin, 2004). While rare, it can be deadly, and patients should be encouraged to recover fully before returning to work or sports activities (Bey & Ostick, 2009). Multiple concussions can also contribute to worse cognitive functioning and depression in young adults (n = 58) (Vynorius, Paquin, & Seichepine, 2016).

In an early study, Levin et al. (1987) reported that at the three month follow-up, nearly all the symptoms experienced by patients had resolved considerably. This was confirmed in a later population-based study (number [n] = 527) by Barker-Collo et al. (2016), who examined post-concussion syndrome symptoms and found reliable change in symptoms twelve months post-TBI, with most improvements happening between one and six months. Most patients recover within the first year (Carroll et al., (2004). However, a significant percentage remained the same or worsened (Barker-Collo et al., 2016). These findings were confirmed by Lagarde et al., (2014) (mTBI patients, n = 534; control group n = 827) who found that some individuals experience long-lasting symptoms after a concussion. Cole and Bailie (2016) also found that 20 % of the sample who reported persistent symptoms at two months got better at twelve months, whereas 17 % who did not report significant symptoms at two months showed persistent post-concussive symptoms at twelve months. Regardless of the incongruencies regarding the timeframes of concussion recovery, symptoms are mostly resolved within three months post-injury (McInnes, Friesen, MacKenzie, Westwood, & Boe, 2017).

Post-concussion syndrome refers to the prevalence of subjective, cluster symptoms after mTBI of any severity (Barker-Collo et al., 2016; Cassidy et al., 2004). Previously listed as post-concussive syndrome, the DSM 5 lists cerebral concussion, impairment in cognition (memory or attention) including apathy, affective disturbance, dizziness, irritability, fatigue, headache, personality change and sleep disturbance presenting shortly after mTBI as a differential diagnosis (American Psychiatric Association, 2013a). Directly after mTBI, patients usually describe one or more post-concussion symptoms (PCS) (Barker-Collo et al., 2016). These symptoms are not exclusive to mTBI and may occur concurrently with trauma and stressor related disorders, such as post-traumatic stress disorder (PTSD) (American Psychiatric Association, 2013a).

According to the APA (2013), neurocognitive disorders due to TBI have variable cognitive presentations, including domain difficulties in executive functioning, complex attention, memory and learning. Also common are information processing speed delays when it comes to social cognition and disturbances (American Psychiatric Association, 2013a). Barker-Collo et al. (2015) found that although neurological tests highlighted considerable improvements over time, a substantial number of patients still performed poorly twelve months after mTBI. The longer it takes to get specialised concussion assistance, the higher the chance of developing PCS (Forrest et al., 2018; Theadom et al., 2018).

2.1 Screening Tools in mTBI Diagnosis

Primary care workers and first responders are vital in the initial diagnosis of mTBI and often use screening tools as diagnostic aids (Bizon, 2017). Current diagnosis of TBI relies on self-reporting of symptoms (Flao, Hume, King, Zealand, & England, 2018), because biomarker imaging, neuropsychological screening, computer tomography (CT) and magnetic resonance imaging (MRI) scans are not effective TBI diagnostic tools (Tator, 2013). Research by Hellstrøm et al. (2017) confirms that the MRI imaging technique should be used with the clinical model since the MRI-based measures were slightly weaker than the clinical model in predicting short-term health-related mTBI outcomes. The clinical models used by Hellstrøm et al. (2017) included 14 preinjury elements such as preinjury work status, preinjury depression, preinjury anxiety, age, gender, education, marital status, and seven resilience factor scores; five injury-related components (mechanism of injury, Glasgow Coma Scale (GCS) on admission, posttraumatic amnesia (PTA), loss of consciousness, and alcohol influence), and four postinjury considerations (posttraumatic symptom scale (PTSS-10) total score, hospital anxiety and depression scale (HAD) total score, *expectation of a favourable outcome,*

and pain), assessments when admitted to hospital or during outpatient clinical appointment 8 weeks after the injury.

Currently, several screening tools for mTBI exist which are used internationally and in NZ. The *Rivermead Post-Concussion Symptoms Questionnaire* (RPQ) (King, Crawford, Wenden, Moss, & Wade, 1995), *Sport Concussion Assessment Tool (SCAT)* (Echemendia et al., 2006) and the *Glasgow Coma Scale (GCS)* (Teasdale, Knill-Jones, & Van Der Sande, 1978), are some of the more well-known measures. These screening tools measure the severity of symptoms, determine the presence of post-concussion syndrome and identify cognitive, emotional and somatic impairments post-injury (Echemendia et al., 2017; King et al., 1995; Kontos et al., 2012; Teasdale et al., 1978).

The RPQ questionnaire was designed to measure symptoms experienced specifically for concussion (King et al., 1995). The RPQ indexes 16 frequently-encountered symptoms post-mTBI, on a scale from zero (no more of a problem) to four (a severe problem) (King et al., 1995). A study, that still needs to be replicated to determine generalisability, conducted by Thompson et al. (2016) (healthy adult control: n = 46; mild to moderate TBI: n = 61) found a sensitivity of 97 % and specificity of 87% at their recommended cut off score at or above 16 for the RPC. The sensitivity of a scale measures the percentage of what was correctly identified and specificity correctly establishes the disease or infliction (Creighton, Davison, & Kissane, 2019). A cross-sectional study (n = 1689; age ≥ 18 years) reports that the RPQ as it is used at present does not conform to current psychometric standards. Some authors suggest that the RPQ should not tap into the same underlying construct for all 16 items as a single score, but be split into two separate scales; the RPQ-3 (headaches, dizziness, nausea) and RPQ-13 (later symptoms, such as cognitive, mood, sleep, and other physical symptoms) (Eyres et al., 2016; McMahon et al., 2014; Thompson et al., 2016) . This achieves acceptable external construct validity and provides good test/retest reliability (Eyres et al., 2016;

McMahon et al., 2014; Thompson et al., 2016). Furthermore, there is limited research on the RPQ's ability to assess dynamic symptoms over time, and further investigation is needed (Medvedev, Theadom, Barker-Collo, & Feigin, 2018).

That being said, the RPQ was found to be a useful tool for clinicians to arrive at a reasonably accurate prediction of outcomes in patients with concussion to target specific areas of intervention (De Guise et al., 2016). To allow better prediction of clinical trajectories, Maruta, Lumba-Brown, and Ghajar (2018) recommend further concussion subtypes with the RPQ. These subtypes include: (1) cognitive-fatigue: "fatigue, tiring more easily," "forgetfulness, poor memory," "poor concentration," and "taking longer to think," (2) vestibular: "feeling of dizziness" and "balance problems," (3) Oculomotor: "blurred vision" and "double vision," (4) Anxiety/Mood: "being irritable, easily angered," "feeling depressed or tearful," "feeling frustrated or impatient," and "restlessness," and (5) Migraine: "headaches," "noise sensitivity, easily upset by loud noise," "nausea and/or vomiting," and "light sensitivity, easily upset by bright light" (Maruta, Lumba-Brown, & Ghajar, 2018). Lannsjö et al., (2011) investigated the construct validity of the RPQ, and found that the questionnaire measured what it intended. King et al. (1995) tested the reliability of the RPQ; the questionnaire was administered twice in one week as a six-month post-injury follow up in a self-administration setting and carried out afterwards by a professional, and the scale was found to be reliable.

The SCAT 5 (latest version) is a commonly used screening tools to determine concussion in sports for those aged >13 years (Echemendia et al., 2017). The SCAT includes the GCS, Maddocks Score, Symptom Evaluation and the Standardised Assessment of Concussion (SAC) and Delayed Recall (Concussin in Sport Group, 2013; Davis et al. 2017). These focus on sports injuries and include balance (patients ability to balance) and gait (assessing the way patients walk and run) measures

(Echemendia et al., 2017). The main criticism of the latest version, SCAT 5, is that it examines reports on “typical feelings” (traits) and not “how do you feel right now” that tap into mTBI symptoms (Asken, Houck, Bauer, & Clugston, 2019). Due to the changes in SCAT 5, players may have obtained mTBI but present with normal scores, so therefore, assessment should include clinical judgement (Mistry & Rainer, 2018).

The GCS is termed the gold standard to determine the level of consciousness after a brain injury (Fischer & Mathieson, 2001; Jalali & Rezaei, 2014). The scoring parameters include best eye response (4 items), best verbal response (5 items) and best motor response (6 items) (Jain, Teasdale, & Iverson, 2019). However, the GCS has been criticised by Teasdale and Jennett (1978) (creators of the tool) stating that on its own, the measure was not intended to predict outcomes, monitor coma or assess brain injury severity. Some authors suggest finding strategies for greater consistency of the GCS (Braine & Cook, 2017), whereas others go as far as to recommend abandoning the measure due to reliability concerns (Green, 2011). The scale was further critiqued by Bhatty and Kapoor (1993) who found that out of the 120 possible eye, verbal and motor scores, only about 15 were valid and useful in assessing altered consciousness. Recent research by Reith, Van den Brande, Synnot, Gruen, and Maas (2016) identified 52 studies and found that the GCS reliability and validity (13% of studies) were only adequate in few good quality studies (with proper methodologies), but improvement was preferable. Even with these limitations, a study by Nik et al. (2018) (n = 125 with TBI) still found acceptable results using the GCS. Major benefits of the GCS are its ease of use (Jalali & Rezaei, 2014) and the fact that it is widely recognised (more than 75 countries) as a consciousness screening tool for mTBI (Jain et al., 2019).

Teasdale and Jennett (1978) stress the importance of using the GCS for its intended purpose. Likewise, the Maslow’s Hammer theory (1966) addresses the cognitive bias of over-reliance on familiar tools. Instead, he suggests using tools that are

fit for purpose (Maslow, 1966). Screening tools should ideally be used as part of the clinical interview and carefully selected for the correct purpose (Li & He, 2018). It should be kept in mind that participants who complete self-report scales can exaggerate symptoms, may be too embarrassed to give honest answers or may provide false feedback (Jupp, 2015). Therefore, screening measures should preferably form part of, but not replace, clinical diagnosis (Quittner et al., 2016).

The individual *Perception of the level of Recovery* (PRC) is a brief self-report questionnaire that measures the perception of recovery (Krishnamurthi et al., 2014). The PRS is often used to assess perceived overall recovery (Teasell, Mcclure, Salter, & Krugger, n.d.). Recovery is measured on a scale of 0-100, with zero representing no recovery, and 100 representing full recovery. This scale is easy to administer, consists of only one question, and tracks perception of improvement over time. Measuring perception of recovery is an essential factor to remember in rehabilitation intervention because negative perceptions of concussion itself could lead to persistent Post-Concussion Symptoms (PCS) (Snell, Siegert, Hay-Smith, & Surgenor, 2011).

To test for atypical or distractor symptoms, various scales were developed by and for the US military as a screening tool to test for overreporting of concussion complaints by combat veterans (Cooper, Nelson, Armistead-Jehle, & Bowles, 2011b; Lange, Brickell, Lippa, & French, 2015; Vanderploeg et al., 2014). The *Mild Brain Injury Atypical Symptoms* (mBIAS) scale is most reported on. This screening tool includes five items of instruction: being unable to hear anything (complete deafness) for periods of time, seeing only black and white, completely losing the voice for more than a minute, complete loss of feeling in both arms, and difficulty swallowing due to a lump in the throat (Cooper et al., 2011b). The mBIAS scale items were selected from a pool of symptoms not generally associated with mTBI by a panel made up of a two neurologists and a physiatrist (Cooper, Nelson, Armistead-Jehle, & Bowles, 2011a).

The response selection is from 1-5, with a minimum score of 5 and a maximum score of 25 (Cooper et al., 2011b). Elevated positive responses on the mBIAS self-report scale may represent over-reporting of symptoms (Cooper et al., 2011a). A study by authors Lange, Edmed, Sullivan, French, and Cooper, (2013) involving students with post-concussional disorder (PCD) (n = 29) and Post-traumatic Stress Disorder (PTSD) (n= 32) provided preliminary support for the mBIAS with a sensitivity score of 0.72 and specificity of 0.88.

The mBIAS was developed for use in a military context as a tool for screening out compensation seeking combat veterans (Armistead-Jehle et al., 2018; Cooper et al., 2011b; Jurick et al., 2016), but has also been applied in clinical settings to determine somatisation after mTBI (Stubbs et al., 2019). Research by Lange, Iverson, Brooks, and Ashton Rennison (2010) did not find the mBIAS a reliable tool to test mTBI in clinical settings. It could be due to the smaller number (n = 63) of military service members who participated (Lange et al., 2010). On the other hand, Cooper, Nelson, Armistead-Jehle & Bowles, 2011a (n = 403) found that the mBIAS was optimal in detecting bias in military veterans (specificity = 0.92 and sensitivity = 0.94). However, even though Lippa, Axelrod, and Lange (2016) (n = 117 veterans with mixed aetiologies) confirm good internal consistency, high specificity, moderate-high positive and negative predictive power, the sensitivity was low (0.31-0.57).

Other measures developed to test symptom overreporting include Negative Impression Management (NIM 5) and Low-Frequency items (LOW 6) (Lange et al., 2015). The NIM 5 tracks unlikely symptoms to determine exaggeration (Sullivan & King, 2008), the LOW 6 scale tracks low-frequency items. The combination of the NIM 5 and LOW 6 forms 10 nonoverlapping items (Validity-10) (Lippa, Lange, et al., 2016). As with the mBIAS, these scales were primarily developed for the US military to screen out compensation seeking veterans (DeViva & Bloem, 2003). Numerous often

contradictory studies discuss their validity (Cooper et al., 2011a; Lange et al., 2015; Lippa, Lange, et al., 2016; Vanderploeg et al., 2014), but little information is available on their origins[1].

2.2 Differential Diagnosis

There is an overlap of mTBI symptoms when it comes to generalised anxiety disorder (GAD), post-traumatic stress disorder (PTSD) and major depressive disorder (MDD) which could complicate the diagnosis for concussion. According to Lagarde et al. (2014), due to the subjective nature of the conditions and the similarity to other disorders, the question remains whether post-concussion syndrome deserves to be recognised as a diagnostic disorder. Table 1 highlights the similarities of mTBI symptoms as defined by the Centers for Disease Control and Prevention (Centers for Disease Control, 2013) which includes cognitive, physical, emotional and sleep disturbances (Centers for Disease Control, 2013) and links to the DSM 5 criteria for generalised anxiety disorder (GAD), major depressive disorder (MDD) depression and post-traumatic stress disorder (PTSD) to **highlight the similarities that could complicate** mTBI diagnosis.

Table 1

mTBI symptoms adapted from CDC links the DSM 5 symptoms for GAD, major depressive disorder (MDD) and posttraumatic stress disorder (PTSD)

Cognitive	Physical	Emotional	Sleep
Thinking difficulties feeling like "in a fog" (CDC) *GAD Criterion C ** MDD Criterion A ***PTSD Criterion D	Headache & vision problems (CDC) GAD Criterion E	Irritability (CDC) GAD Criterion C PTSD Criterion E	Sleeping difficulties (Sleeping more or less than usual) (CDC) GAD Criterion C MDD Criterion A PTSD Criterion E

[1] While numerous publications refer to these scales, it proved impossible to locate any of the original documents, and attempts to contact several of the authors of the studies proved fruitless. The references used here are of necessity indirect.

Cognitive	Physical	Emotional	Sleep
Feeling slowed down GAD Criterion D MDD Criterion A	Nausea or vomiting (early on), & dizziness (CDC) GAD Criterion E	Sadness (CDC) MDD Criterion A PTSD Criterion D	Drowsiness and trouble falling asleep (CDC) GAD Criterion C MDD Criterion A PTSD Criterion E
Poor concentration (CDC) GAD Criterion C MDD Criterion A PTSD Criterion D	Noise or light sensitivity & problems balancing (CDC) GAD Criterion E	More emotional (CDC) MDD Criterion A	
Struggling to remember new information and feeling confused (CDC) GAD Criterion C MDD Criterion A PTSD Criterion E	Fatigue, low energy (CDC) GAD Criterion C MDD Criterion A PTSD Criterion D	Nervousness or anxiety (CDC) GAD Criterion B MDD Criterion A PTSD Criterion E	

Note Symptoms table adapted from CDC (2013), which highlights the DSM 5 disorders associated with mTBI.

*DSM 5 GAD: A GAD diagnosis includes excessive worry for at least six months in all areas of functioning. Compared to CDC symptoms, the following were present (see GAD Criterion A above): difficulty controlling worry (Criterion B), and at least three symptoms listed in Criterion C (listed above). TBI diagnosis could be complicated due to similarities to GAD.

** DSM5 MDD: In order to be diagnosed with depression, symptoms should be present for two weeks and represent a change from previous functioning. Most MDD symptoms are listed above (Criterion A). An MDD diagnosis should also include significant clinical distress (Criterion B). When diagnosing depressive mood, it should not be attributed to another medical condition (Criterion C).

***DSM5 PTSD. Patients diagnosed with mTBI could also experience PTSD resulting from the actual event (Criterion A). Duration of the symptoms should be more than one month (Criterion F) and cause significant clinical impairment in functioning (Criterion

G). The symptoms should also not be attributable to other conditions (Criterion H). Symptoms that are similar to mTBI are Criterion D and listed in Table 1.
More conditions: mTBI symptoms overlap, but are not limited to depression, anxiety or PTSD. Symptoms can also overlap with substance abuse, delirium and pathological crying/laughter (Jorge & Arciniegas, 2014).

Post-concussion symptoms are sometimes a reaction to distress due to injury or other health stressors, and also from whiplash after the concussion (Kristman et al., 2014). Depression, pain and stress often mimic post-concussion syndrome-like symptoms (Garden & Sullivan, 2010). Even healthy, non- injured groups often report symptoms identified with post-concussion syndrome (Garden & Sullivan, 2010). Chan (2001) explored PCS with participants of an extended neuropsychological performance study on people who did not experience neurological diseases, head injury or psychiatric diseases and found a high number reported concussion-like symptoms. These symptoms include low attention, poor working memory, poor strategy allocation and low mental fluency (Chan, 2001). This means that the mTBI injury may not necessarily drive the injury symptoms (called the nocebo effect) (Ferguson, Mittenberg, Barone, & Schneider, 1999; Glick, 2016). Clinical diagnosis and neuropsychological assessment, along with mTBI measures are therefore important (Hellstrøm et al., 2017).

2.3 Biopsychosocial Considerations in mTBI

Mild brain injury brings the disciplines of neurology and psychiatry together, and a clear understanding of that complex relationship is necessary to make a proper assessment and treatment plan (McAllister, 2011). A clinical diagnosis should not be formed purely based on assessment tools. The biopsychosocial model suggests the inclusion of biological, psychological and social processes to offer a more holistic perspective (Tomás-Aragones & Tomás-Aragones, 2017). Rather than mTBI viewed as

something within the individual, the International Classification of Functioning (ICF) stresses the importance of the person-task-environmental interaction by including activities a person can or cannot do by addressing bodily functions and structures, activities and participation within the environment (Kennedy, 2012).

2.4 Risk Factors

A concern with mTBI is the effects that it can have on personal and social competence as a result of changes in executive functioning (Hollands, 2014; Lezak et al., 2012). Recovery from mTBI varies, depending on specifics to the injury, such as age, history of brain injury or substance abuse (American Psychiatric Association, 2013a). After mTBI, dysregulation of behavioural functioning was found in the inhibition of behaviour in adolescents, and interventions are needed to reduce the risk of on-going social dysfunction (Hollands, 2014). According to the literature, those most at risk of concussions are athletes (Powell, 2001), especially female youths (Tsushima, Siu, Ahn, Chang, & Murata, 2019), and geriatrics (Papa, Mendes, & Braga, 2012). Listed below are some of the risk factors related to mTBI including age, gender, ethnicity, and pre- and comorbid factors.

2.4.1 Age

Research links poor mTBI outcomes to age (Biswas et al., 2017). Long-term outcomes of mTBI increase the risk of Alzheimer's-like dementia, Parkinson's disease, motor neuron disease and Amyotrophic Lateral Sclerosis (ALS) (Daneshvar et al., 2011; Nordström & Nordström, 2018; Shively, Scher, Perl, & Diaz-Arrastia, 2012). Furthermore, neuroimaging history results confirm onset at an earlier age (> 2 years) with significant risk factors of cognitive impairment in older adults with a history of mTBI (Li, Risacher, McAllister, & Saykin, 2016). TBI more than doubles the risk of dementia: 2.36 times higher risk without loss of consciousness, 2.51 with loss of

consciousness, and 3.77 higher risks linked to moderate to severe TBI (Barnes et al., 2018).

The effects of mTBI on young children may not be noticed immediately but could present long term problems in psychological and social functioning (McKinlay, Dalrymple-Alford, Horwood, & Fergusson, 2002). Schofield et al. (2015) suggest that people with a history of childhood TBI have an increased likelihood of adult imprisonment, with an early concussion resulting in aggravating violent behaviour in adults (Williams et al., 2018). Following an injury in children, on-going monitoring is needed to ensure enduring difficulties are addressed in order to reduce lasting adverse consequences (Jones et al., 2018)

A study by Hu, Hunt, and Ouchterlony (2017) (n = 167), confirmed that age impacts the severity and type of post-mTBI symptoms. Those aged over 66 years reported significantly more mTBI symptoms than the rest of the age groups. However, the middle-aged group (36-55) reported more severe symptoms, possibly due to additional stressors that come with being in that age group (Hu et al., 2017). This study is contrary to research by Papa, Mendes, and Braga (2012), who found that the effects of the mTBI increased with age and the injuries became more serious due to age-related conditions. The mortality rates due to the injuries were also higher in the older population when comparing three age groups: 18-39 (n = 971), 40-50 (n = 672), and 60-99 years (n = 684) (Papa et al., 2012). Recurring concussions can have lasting effects on executive functioning (behavioural control and goal attainment), short and long term memory, attention/concentration and language (McKee et al., 2013). A decline in memory and learning functions can cause difficulties when participating in programmes or developing new skills (Corrections, 2019).

Williams et al. (2018) provide reasons for the higher risk of violent offending as poor engagement during treatment and in-custody infractions leading to reconviction. An Australian study by Buckley and Chapman (2017) confirms the associations between concussion and later violence in a self-report survey. Clinicians should, therefore, take pre-injury mental health history seriously, including family, biology, and post-injury factors such as psychosocial stress, neurochemical changes in the brain, relational and family dynamics, and psychological response to injury when treating patients (Sandel, Reynolds, Cohen, Gillie, & Kontos, 2018).

2.4.2 Gender

According to Toninato et al. (2018), a predictor of concussion severity is associated with increased neck strength; women generally have weaker necks than men. Specifically, research links poor mTBI outcomes to older women who are more likely to have a worse prognosis than men (Biswas et al., 2017). Women also find it harder to recover from mTBI due to the brain's response to fluctuations in oestrogen levels during menstrual cycles (Arbogast, 2019). Furthermore, TBI risk in older women is linked to bone mineral density and bone strength associated with incident fracture risks across the menopause transition period (Takahiro et al., 2014, Cauley et al., 2012).

Kerr et al. (2016) found that athlete-based concussion risk was higher in females and Covassin, Moran, and Elbin (2016) confirmed that women had a 1.4 times higher overall concussion injury rate in sex-comparable sports than men. Mollayeva, El-Khechen-Richandi, and Colantonio (2018) suggest that women may report more symptoms, especially in sport but that the higher reporting of symptoms are due to reporting patterns (reporting bias) shown by females (Dick, 2009). Mollayeva et al. 2018 claim that more serious work-related injuries are far higher in men due to the nature of their duties, but that concussion due to intimate partner violence is extremely

high in women. Therefore they suggest that interventions be tailored to focus on specific gender needs (Mollayeva et al., 2018a).

2.4.3 Ethnicity

In NZ, mTBIs occur more frequently than in other developed countries, amounting to approximately 750 cases per 100 000 people per year (Feigin et al., 2013). Indigenous populations are also disproportionately represented in the incidence of concussion (Lagolago et al., 2015). In 2016, the TBI Strategy Action Plan was developed to prioritise prevention programmes to reduce risk-taking behaviours by targeting Māori and Pacific people (Accident Compensation Corporation, 2016). According to Lagolago et al. (2015), Pacific people (Samoan, Tongan, Fijian, Niuean, Cook Island, and Kiribati) are at the most significant risk of TBI (1242 cases per 100,000), which is considerably higher than NZ Europeans (842 per 100,000). Feigin et al. (2013) reported that the Māori population was 23% more likely to suffer from head injuries than Pākehā (NZ Europeans). In the 2017 ACC report *Traumatic Brain Injury Strategy and Action Plan 2017-2021*, a concern was that the Māori population showed higher accidental risk-taking behaviours which are listed as driving-related accidents (speeding), high-risk unregulated sports, falls, and intentional injuries such as shaking babies violently, alcohol and drug-related harm, and assaults. Historical trauma can have an impact on later behaviour which is passed on through generations (Wirihana & Smith, 2014) and Baxter (2014) argues that historical factors, such as colonisation, played a significant role in Māori health disparities. Wong, Wong, and Scott (2007) emphasise the importance of acknowledging the impact of Euro-American assessment methods and the effect it has on indigenous cultures. Durie (2011) condemns historical land alienation for creating a power imbalance that deprived indigenous groups globally, which contributes to their over-representation of multiple health disparities.

2.4.4 Pre- and Comorbid Factors

Pre-morbidity or premorbid conditions refer to afflictions that are present prior to a current injury (Bamvita, Bergeron, Lavoie, Ratte, & Clas, 2007). Comorbidity or comorbid conditions occur simultaneously (co-occur) with the concussion (Mollayeva et al., 2017). According to Toninato et al. (2018), a predictor of concussion severity is the existence of pre-injury symptoms (Flao et al., 2018). Patients tend to under-report premorbid conditions that overlap PCS (Kamins & Giza, 2016) and often describe PCS one month post-injury (Katz, 2014). Pre-existing susceptibilities to other conditions could be the cause of emotional and social inadequacy including personality adjustments (Joseph & Linley, 2012). Premorbid (pre-existing) conditions can complicate the treatment of mTBI (Joseph & Linley, 2012) and could contribute to the over-reporting of symptoms due to unresolved conditions (Iverson., 2012). Pre-existing conditions could also lead to exaggerating the severity of current concussion experiences or to fabricating of symptoms (Iverson, 2012). Premorbid conditions can contribute to personality changes after a TBI (Rieger, 2015). According to Barker-Collo et al. (2015), depression is not uncommon post-concussion and is often shown to be present for up to twelve months post-injury. Furthermore, post-concussion symptoms can unfold as anxiety/mood subtypes resulting from previous emotional sequelae (Gunstad & Suhr, 2002; Sandel et al., 2018).

Comorbid (co-occurring) conditions may further complicate the diagnosis of mTBI, especially since symptoms are not always visible (Kennedy, Cullen, Amador, Huey, & Leal, 2010; Kish & Koutures, 2016). When diagnosing depression, clinicians should be cautious concerning the significant overlap with mTBI symptoms (Barker-Collo et al., 2015). Due to the invisibility of mTBI symptoms, people often do not report concussion or ignore it, especially in sports (Clark & King, 2017; Kish & Koutures, 2016). Furthermore, self-reporting of persistent post-concussive symptoms

were linked to both mTBI or PTSD (Brenner et al., 2010). A concussion can be mistaken for overlapping symptoms from other disorders (including amnesia, concentration problems, PTSD, irritability and anxiety) (Real et al., 2017), and if left untreated, could exacerbate feelings of low mood, depression and anxiety (Sandel et al., 2018). When treating patients with mTBI it is essential to consider comorbid conditions such as PTSD, depression and anxiety (Barker-Collo et al., 2015; Lagarde et al., 2014). PTSD and post-concussion syndrome are strongly associated and share symptoms of hyperarousal (Lagarde et al., 2014). Research found that alcohol problems were associated with multiple (polytrauma) mTBIs (Lezak et al., 2012; Saunders et al., 2009) and could contribute to increased risk of substance use (pre-occurring) (Merkel et al., 2017). Alcohol abuse also frequently co-occurs with mTBI and, within the first six months after the injury, alcohol misuse intervention is imperative (Pagulayan, Temkin, Machamer, & Dikmen, 2016).

Social Appraisal

Environmental factors such as daily stressors, family and social support, and level of disability, will have an impact on rehabilitation outcomes (Koehler, Wilhelm, & Shoulson, 2012). External locus of control (LC) is an essential consideration in rehabilitation treatment (LaCaille et al., 2013). Patients who perceive that they receive high social support exhibit more significant progress in rehabilitation than those who feel they do not receive the needed environmental support (Izaute et al., 2008). External LC is when patients believe that they are not in control of their environments, which could lead to poorer outcomes (LaCaille et al., 2013). Perceptions of disability range from stoical beliefs, to being punished by God (Sherwin, 2012). According to Stuntzner and Hartley (2014), how patients respond to barriers (such as beliefs and emotions) will affect the level of resilience and outcomes (positive or negative). mTBI patients with weaker internal LC, attributed rehabilitation to chance and powerful others and reported

lower satisfaction in recovery than those who exhibited higher internal LC (Izaute et al., 2008). Patients showing a strong internal LC are more likely to look for solutions rather than relying on others for emotional encouragement (Buddelmeyer & Powdthavee, 2016).

Brown (2014) raised questions about the link between self and social appraisals, negative perceptions and experiences of discrimination, and how it affects recovery in rehabilitation. Broshek, De Marco and Freeman (2015) link illness perceptions to elevated reports of PCS. Rehabilitation resilience models focus on adjustment and coping (Fergus & Zimmerman, 2004) and have been linked to specific health outcomes (Petrie & Weinman, 2012). Patients with problem orientation target their immediate cognitive behavioural-emotions first, then reappraise thinking, including assumptions, beliefs, and expectations about real-life issues by focussing on solving problems (Rath & Elliott, 2012). Problem-focused strategies can be defined as a restorative function in illness that focuses on finding solutions to problems (Smith & Baum, 2009), whereas emotion-focused strategies are associated with psychological avoidance to stressors that contribute to feelings of being overwhelmed (Folkman & Moskowitz, 2000). By adopting a problem-focused orientation, patients recognise difficult issues as they happen and do not avoid, ignore or deny them (Rath & Elliott, 2012). Fergus and Zimmerman (2004) suggest that adverse outcomes develop in response to external and internal stressors which increase the risk of poor outcomes that could contribute to adjustment difficulties or maladaptive coping. When problems are perceived as challenges that can be solved (not as threatening or harmful), then it leads to effective coping solutions (Rath & Elliott, 2012). Cognitive rehabilitation for mTBI focuses on impairment, the ability in which physical activities can be carried out in the social and physical environment and the quality of life, which has an effect on how the condition is perceived (Koehler et al., 2012; Sherwin, 2012).

Litigation and Symptom Reporting

Internationally, litigation has been found to be an important predictor of recovery and it can lead to increased psychological distress (Bayen et al., 2019; Feinstein, Ouchterlony, Somerville, & Jardine, 2001; Kristman et al., 2014). Post-concussive symptoms can persist due to litigation involvement and could be more strongly linked to recovery than biomedical factors (Cassidy et al., 2014). Further stress is placed on patients because it is required that injuries be validated to be recognised (Pineau, Marchand, & Guay, 2015). According to Silver (2012), due to the litigation process, victims could report more mTBI symptoms out of fear of not being compensated for the injury. Hence, patients may exaggerate TBI symptoms to justify claims (Sreenivasan et al., 2003). This could be referred to as 'cheating,' where a patient consciously exaggerates symptoms to perform worse on evaluations for a financial incentive (Silver, 2012).

Perrine and Gibaldi (2016) suggest that clinicians examine the patient's entire history, including psychosocial factors and social influences to discover pre-existing conditions, stressors, family dynamics and complaints when considering the report of persistent post-concussion symptoms. Silver (2012) warns that the appearance of 'symptom magnification' or 'poor effort' could be 'incorrectly interpreted as a conscious process'. Measures should, therefore, include detecting exaggerated mTBI memory deficits, and symptoms (Perrine & Gibaldi, 2016) to determine the validity of post-concussion reporting.

Research in the USA suggested that concussion symptoms may be fabricated or exaggerated for financial gain (Lange et al., 2017), but Marshall et al. (2018) are of the opinion that such cases are rare; nevertheless, comprehensive and evidence-based assessments are still required. The assessment by Marshall et al. (2018) is contrary to

the cognitive testing measures by Green, Rohling, Lees-Haley, and Allen (2001), that indicate in the USA that up to 40% of individuals who claim secondary financial incentives, such as disability or litigation settlements, and avoid obligations for fear of punishment (school or employment), are inclined to exaggerate symptoms. The study included 80 neurological patients and 470 with head injuries (Green et al., 2001). It seems that there is not a link between litigation and atypical symptoms. However, some patients would resort to litigation if they continued to experience symptoms or they received some compensation but were not improving (Wortzel & Granacher, 2015).

In NZ, the Accident Compensation Corporation (ACC) was instituted as a no-fault accidental injury scheme that provides citizens, residents, and temporary visitors of New Zealand with financial support and compensation (Accident Compensation Corporation, 2016). Having a no-fault scheme means that patients will be covered regardless of 'whose fault it was.' The ACC covers all accidental (1) physical injuries, (2) injuries caused by medical treatment, (3) conditions that happen over time due to work, (4) serious and long term disabilities, (5) mental injuries, (6) sexual violence, and (7) damage to prostheses, implants and dentures (ACC, n.d.).

Gaps in the Current Literature

In NZ, people sustaining an injury via an accident receive compensation and treatment from the Accident Compensation Provider. This contrasts with countries like the USA where healthcare received is dependent on the person's individual insurance cover. However, patients presenting with a genuine concussion may also give conflicting or exaggerated reports as a cry for help in order to obtain medical assistance if they have not received what they perceive as being sufficient support (Sreenivasan et al., 2003), or are not recovering to the extent that they believe they should.

Evaluation of such atypical symptom reporting for mTBI has been mainly conducted by and for the US military for the purposes of evaluating combat veterans (Armistead-Jehle et al., 2018; Cooper et al., 2011a; Stubbs et al.,2019). Studies focusing on the exaggeration of concussion included scales such as the mBIAS, NIM 5, LOW 6 and Validity-10 scales to detect over-reporting of concussion symptoms with military service members (Armistead-Jehle et al., 2018; Lange et al., 2015).

What remains unclear is the validity of symptom reporting following mTBI more generally, and in particular as it applies in a NZ context. The above review of the literature brings to light three main gaps in the existing literature: (1) the proportion of adults who reported atypical symptoms following a mild traumatic brain injury, (2) reports on the differences in those reporting atypical and typical symptoms in terms of age, gender and ethnicity, and (3) discovering if a link exists between atypical symptom reporting at one month and overreporting of typical post-concussion symptoms and perceptions of recovery in the longer term. This study aims to close this gap by looking at the proportion of atypical symptom reporting and to determine relationships to perceptions of recovery and typical presentation.

Chapter 3 - Methods

This chapter describes the research design, aim, sample selection and research procedures of this study. Ethical approval was obtained by the Auckland University of Technology (AUT) Ethics Committee (09/265) and from Northern Y Regional Ethics committee and Health and Disability Ethics Committee of New Zealand (NTY/09/09/095) for the *Brain Injury Incidence and Outcomes New Zealand in the Community,* (BIONIC) study.

Design

The data for this quantitative study was previously collected by the *Brain Injury Incidence and Outcomes New Zealand in the Community*, (BIONIC) study as discussed below. This quantitative study analysed the data using IBM's Statistical Package for the Social Sciences (SPSS) software for the statistical analysis.

Research Aim

The overall aim of this research was to determine symptom validity reporting, following a mild traumatic brain injury. Therefore, the objectives of this thesis were:

1) To determine what proportion of New Zealand adults (older than 16 years) reports atypical symptoms following a mild traumatic brain injury.
2) To examine if there are differences in those reporting atypical and typical symptoms at one month in terms of sociodemographic factors (age, gender, ethnicity) and comorbidities.
3) To identify if atypical symptom reporting at one month is linked to increased reporting of typical post-concussion symptoms and perceptions of recovery at one year (poorer outcome).

This study aimed to examine the validity of symptom reporting following mild traumatic brain injury. Based on the current evidence it was hypothesised that:

1) There will be a significant proportion of people reporting atypical symptoms.
2) There will be significantly higher reporting of atypical symptoms in those of older age, females and those with at least one comorbidity.
3) There will be a significant link between acute atypical symptom reporting and increased reporting of typical post-concussion symptoms and lower perceptions of recovery at one year.

Participants

For the purposes of this analysis, data was included for persons older than 16 at the time of concussion who consented to participate in the BIONIC study. The BIONIC study identified patients who had experienced a brain injury in the Hamilton and Waikato Districts (173,205 urban and rural residents) in NZ between 1 March 2010 to 28 February 2011 (12 month period) (Feigin et al., 2013; Theadom et al., 2018). Patients were identified from the ACC database, hospital admissions and discharges, community healthcare services such as general practitioners (GPs) and physiotherapists, sports clubs, concussion clinics and self-referrals (Barker-Collo et al., 2016; Theadom et al., 2018).

Data was obtained from participants who had completed the Rivermead post-concussion symptom (RPS) scale with four distractor items and perception of recovery scale (PRS) at one month and/or one-year post-injury. All participants sustained TBI and consisted of patients (all severities) who needed medical attention and self-referrals who did not seek treatment. Participants were invited to take part in the research if they reported at least one of the following; loss of consciousness for 30 minutes or less, dazed or confused after the accident, unable to remember details of the accident

(Theadom et al., 2012). The research participants were encouraged to engage in follow-up assessments, which included a baseline within two weeks of trauma, and again at one, six and twelve months after injury, to monitor recovery (Theadom et al., 2016a).

Procedure

The assessments were conducted in different ways to enable participation, 94.8% of assessments were completed in-person, and 3.8 % (the remainder) were delivered via the telephone. The way the assessments were delivered was decided based on participant preference (Theadom et al., 2018). The assessment as part of the BIONIC study included multi-domain assessments that took approximately 2-2.5 hours to complete. Assessments explored socio-demographic characteristics of participants, symptoms, perceptions of recovery, quality of life, mood, community participation, social support, fatigue, and sleep, as well as a neuropsychological assessment of cognitive functioning. The parent study aimed to determine trends in symptom recovery over time (Theadom et al., 2018; Theadom et al., 2016a). In addition to the assessment of post-concussion symptoms, four additional atypical symptom items were added to the assessment. The secondary analysis conducted as part of this study is a novel analysis because the data on the atypical symptoms has not yet been analysed.

3.1.1 Rivermead Post-Concussion Questionnaire (RPQ)

Data was collected using the Rivermead Post-Concussion Questionnaire (RPQ) one month and twelve months post-injury to determine the presence of post-concussion syndrome (PCS) and assess the severity of the mTBI.The RPQ is a self-assessment scale that rates experiences between 0-4 (subjective comparisons) on how patients felt before (within 24 hours of the accident) and after the injury. Higher scores imply more severe symptoms (Theadom et al., 2016a). A score of zero indicated “not experienced at all” and one “no more of a problem”. Severity ratings ≥ 2 indicated that symptoms

were experienced; two indicated “a mild problem”, three a “moderate problem” and four “severe problem”. Symptoms measured by the questionnaire include headaches, feeling dizzy, nausea/vomiting, noise sensitivity, sleep disturbances, fatigue, irritability/anger, depression/tearfulness, frustration/impatience, poor memory and concentration, longer thought processing, blurred/double vision and light sensitivity, and restlessness. Distractor (Atypical) Symptoms

Distractor items were added to the RPQ to test the proportion of adults who reported atypical symptoms following mTBI. An expert panel decided on symptoms that are not typically found in mTBI. Atypical (distractor) symptoms added to the RPQ included hemiplegia, difficulty swallowing, digestion, and difficulties with fine motor tasks. These symptoms are not commonly related to an mTBI and were selected to determine if sociodemographic factors and comorbidities contribute to symptom overreporting. A score equal or greater than two indicates that the symptoms pose a problem in daily functioning.

3.1.2 Perception of Recovery Scale (PRS)

The second scale, Perception of Recovery Scale (PRS), is a self-assessment that rates perceived recovery on a domain score ranging from 0 to 100, with 100 representing full recovery and 0 no recovery at all. The PRS provides an indication of perceived recovery and depending on the perception of the injury, rehabilitation outcomes could be effected (Cook & Beaven, 2013). Participants in the BIONIC study were asked*: On a scale of 0 to 100 with 100 representing full recovery and 0 representing no recovery how much have you recovered since your Injury?*

3.1.3 Comorbidities

Participants were also asked about comorbidities. Illnesses included were Alzheimer's disease, dementia, developmental disabilities, learning disability (LD), attention deficit and hyperactivity disorder (ADHD), psychosis, depression, anxiety, PTSD, schizophrenia, obsessive compulsive disorder (OCD) and other. Data was checked to see if there was higher reporting of atypical symptoms in those who reported at least one comorbidity.

Analysis

Descriptives of the sample in terms of age, gender and ethnicity distribution are presented to broadly determine the representativeness of this sample to the mTBI population. Descriptive statistics can be defined as a statistical analysis of data that describes and summarises information in an understandable way without drawing inferences (a general summary) (Kaliyadan & Kulkarni, 2019). For continuous variables, means and standard deviations were used. For categorical data, the frequency and percentage were reported.

The percentage of people reporting atypical symptoms at one and twelve-month timepoints was reported. The normality of the data was checked. Tests of difference were used to determine if there were any differences between those reporting atypical symptoms and typical symptoms in terms of sociodemographic factors, comorbidities.

The significance level was set at $p < 0.05$. If data met parametric assumptions, t-tests were used. If data did not meet parametric assumptions non-parametric equivalent statistics were used e.g. Chi square tests. A Chi-squared test tested nominal/categorical variable to determine the significance of the observed differences (p - values). Multiple

linear regression analysis tested whether symptoms at one month predicted persistent typical post-concussion symptoms and perception of recovery at twelve months.

Chapter 4 - Results

Participant Sample

Data on self-reported post-concussion symptoms were available for *n* = 261 at the one-month assessment and *n* = 193 cases at the twelve-month timepoint (see figure 1).

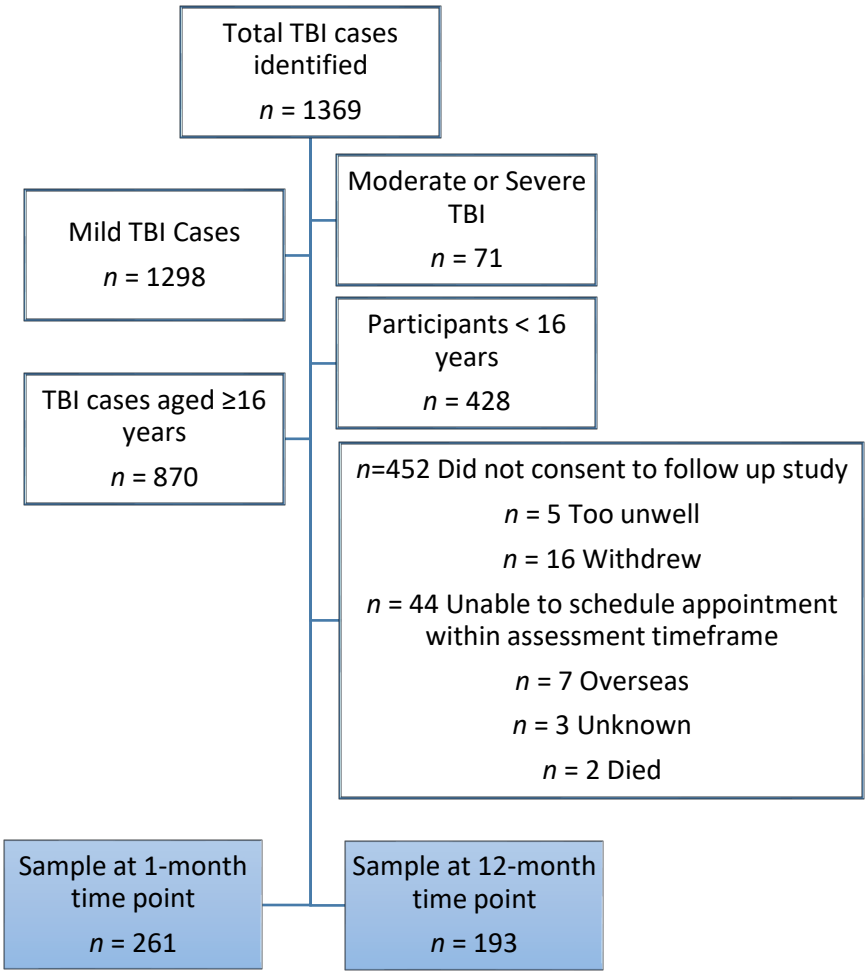

Figure 1. Participant flowchart (adapted from the BIONIC study)

Table 2 below describes the sample at one- and twelve-month timepoints. There were a higher proportion of male participants in the sample compared to females, reflecting the increased risk of TBI in men. A higher proportion of NZ Europeans and

Māori completed the outcome assessments. However, the proportion of participants identifying as Asian or Pasifika was low.

Table 2

Description of participants at one- and twelve-month timepoints

	One Month *n* = 261	Twelve Months *n* = 193
Mean age in years	37 (17.24)	38 (17.28)
Median age in years	33 (16-91)	33 (16-91)
Sex		
Female	106 (41 %)	75 (39 %)
Male	155 (59 %)	118 (61 %)
Ethnicity		
European	(65 %)	(68 %)
Māori	(28 %)	(26 %)
Asian	(3 %)	(2 %)
Pacifica	(3 %)	(3 %)
Other	(1 %)	(1 %)
Comorbidities		
None	220 (84 %)	165 (85 %)
At least one comorbidity	41 (16 %)	28 (15 %)

Note: Mean Age (ẋ); Standard Deviation (SD); number (*n*)

Males and females experienced mTBI at different ages. At the one-month timepoint, the average age at which women experienced mTBI was 39 years old (SD = 18.15) compared to males who experienced it three years younger at 36 years of age (SD =16.56). During the twelve-month timepoint males (*mean* = 37 ± 17.01) also averaged three years younger than females (*mean* = 40 ± 17.64).

Participants could select one or more comorbid (co-occurring) conditions. These are listed in Table 3 below. The number of selected comorbidities were reported at the one-month assessment and related to medical conditions diagnosed pre-injury.

Table 3

Comorbidities indicated by participants

Comorbid conditions	One Month *n* = 41	Twelve Months *n* = 28
Typical	29 (71 %)	20 (71 %)
Atypical	12 (29 %)	6 (29 %)
Any psychiatric illness (such as depression, anxiety disorder, schizophrenia, paranoia)	32 (78 %)	19 (68 %)
Attention deficit	8 (18 %)	5 (18 %)
Learning disability	3 (7 %)	2 (7 %)
Alzheimer's disease	2 (5 %)	2 (7 %)
Dementia other than Alzheimer's disease	2 (5 %)	2 (7 %)
Developmental disability/handicap	2 (5 %)	2 (7 %)

Table 3 also summarises the comorbidities by typical and atypical symptoms. At the one-month timepoint, 20 comorbid selections were made by females and 21 by men. At the twelve-month interval, 13 comorbidity symptoms were reported by women and 15 by men.

Due to the small number of participants who reported comorbidities, this research examined individual cases to establish a connection between the comorbidities and the atypical symptoms reported.

No comorbidities for the atypical symptom 'hemiplegia' were reported at the one or twelve-month timepoints. Participants who reported the atypical symptom 'difficulty swallowing' included one case of depression at one month. At the twelve-month timepoint, there was one case of anxiety and one case for depression for participants reporting difficulty swallowing.

The atypical symptom 'digestion' included one case of each of the following; anxiety, attention deficit disorder, and two cases of depression at one month. Further

linking atypical symptoms to comorbid conditions, at the twelve-month timepoint one person reported attention deficit disorder and two reported depression. Another person with Alzheimer's disease reported 'difficulties with fine motor tasks at month one.' Persons who reported difficulties with fine motor tasks also reported developmental disability (one case), and learning disability (one case). Two people reported anxiety, and five participants reported depression. Multiple comorbidities selected included attention deficit and bipolar disorder (one case), depression and anxiety (one case) at the one-month timepoint. At twelve months people reported attention deficit (one case), and depression (two cases).

Three cases reported multiple atypical symptoms and comorbidities, including difficulty swallowing, digestion and difficulties with fine motor tasks. At the one-month timepoint one participant reported depression and panic attacks. At the twelve-month timepoint, another participant reported learning disability, developmental disability, schizophrenia, depression, anxiety and PTSD. The third participant reported attention deficit disorder and depression at the one- and twelve-month points.

Experience of Perception of Recovery Scale

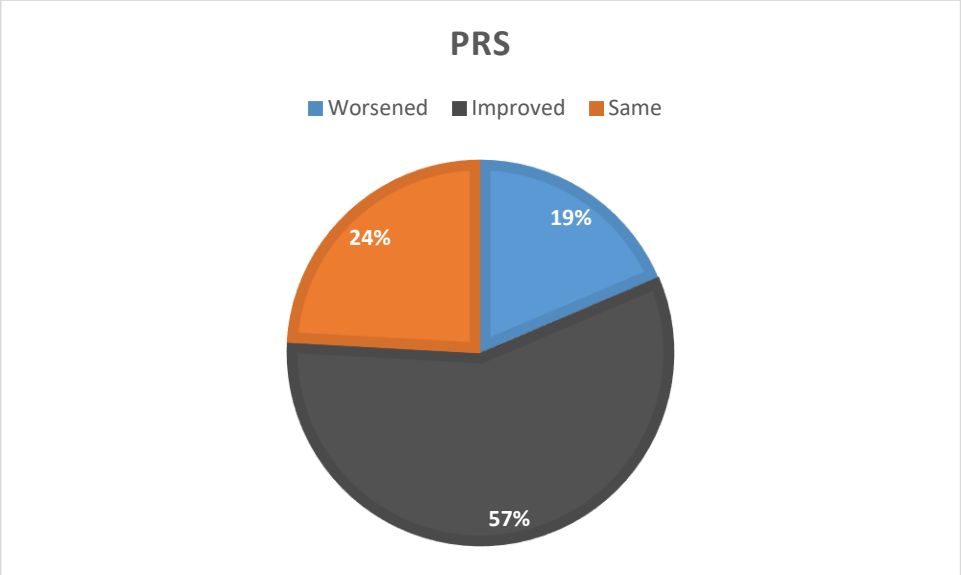

Figure 2. Perception of recovery scale outcome at the twelve-month timepoint

Figure 2 is a summary of the PRS outcome 12 months postinjury. Participants who completed the PRC questionnaire at both the one- and twelve-month timepoints were compared. More than half of the participants reported that their symptoms had improved (57%) twelve months after injury. However, 24 % felt their symptoms had remained the same, and 19 % reported that their symptoms worsened.

Experience of Typical Post-Concussion Symptoms

Figure 3 below shows the percentage of participants reporting the typical symptoms reported one month after injury. By considering the severity rating ≥ 2, the most selected symptoms were "fatigue and tiring more easily," "taking longer to think," "forgetfulness and poor memory" and "headaches." The least rated symptoms were double vision and nausea.

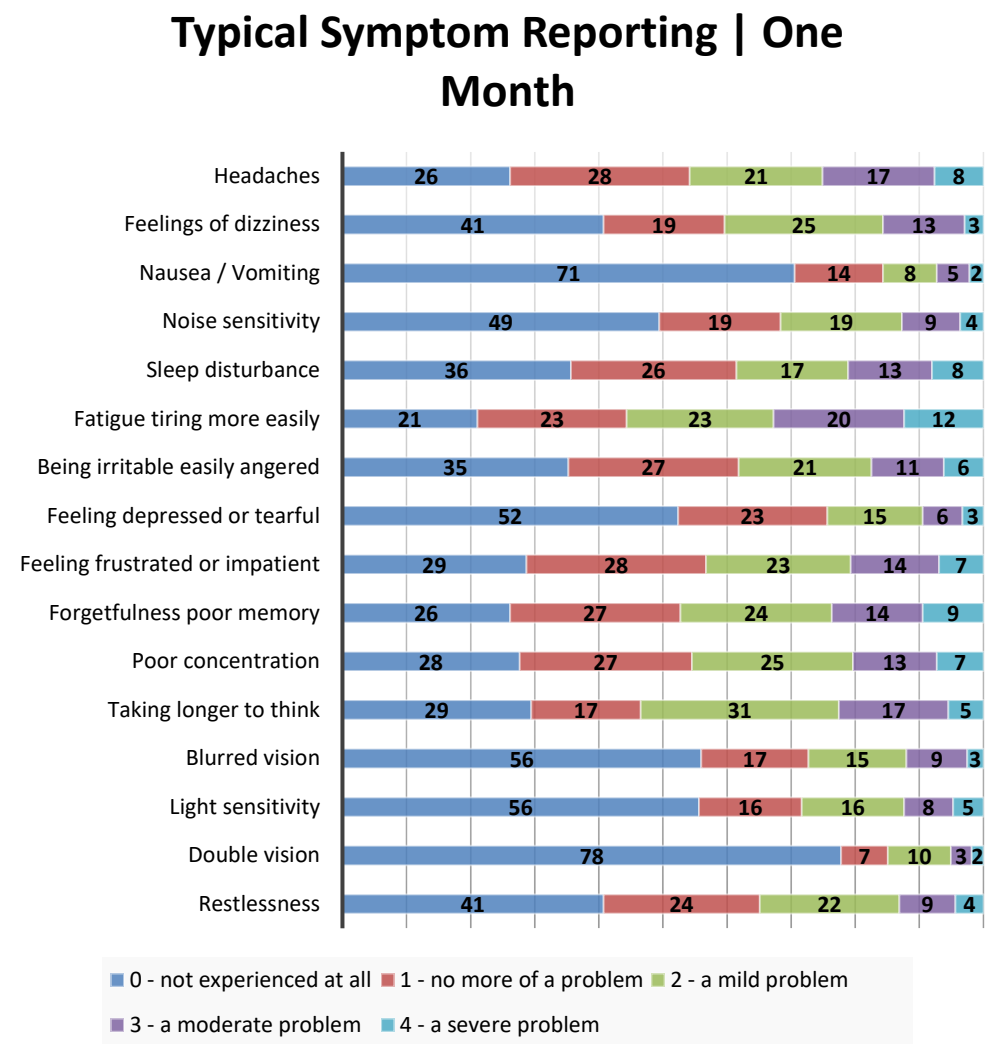

Figure 3. Typical symptom reporting one month after TBI

At the twelve-month timepoint, the most common symptoms were consistent with the one-month timepoint. “Fatigue and tiring more easily,” “taking longer to think,” “forgetfulness and poor memory,” and “headaches” remained the most common symptoms. Double vision and nausea were also less frequent at the twelve-month timepoint.

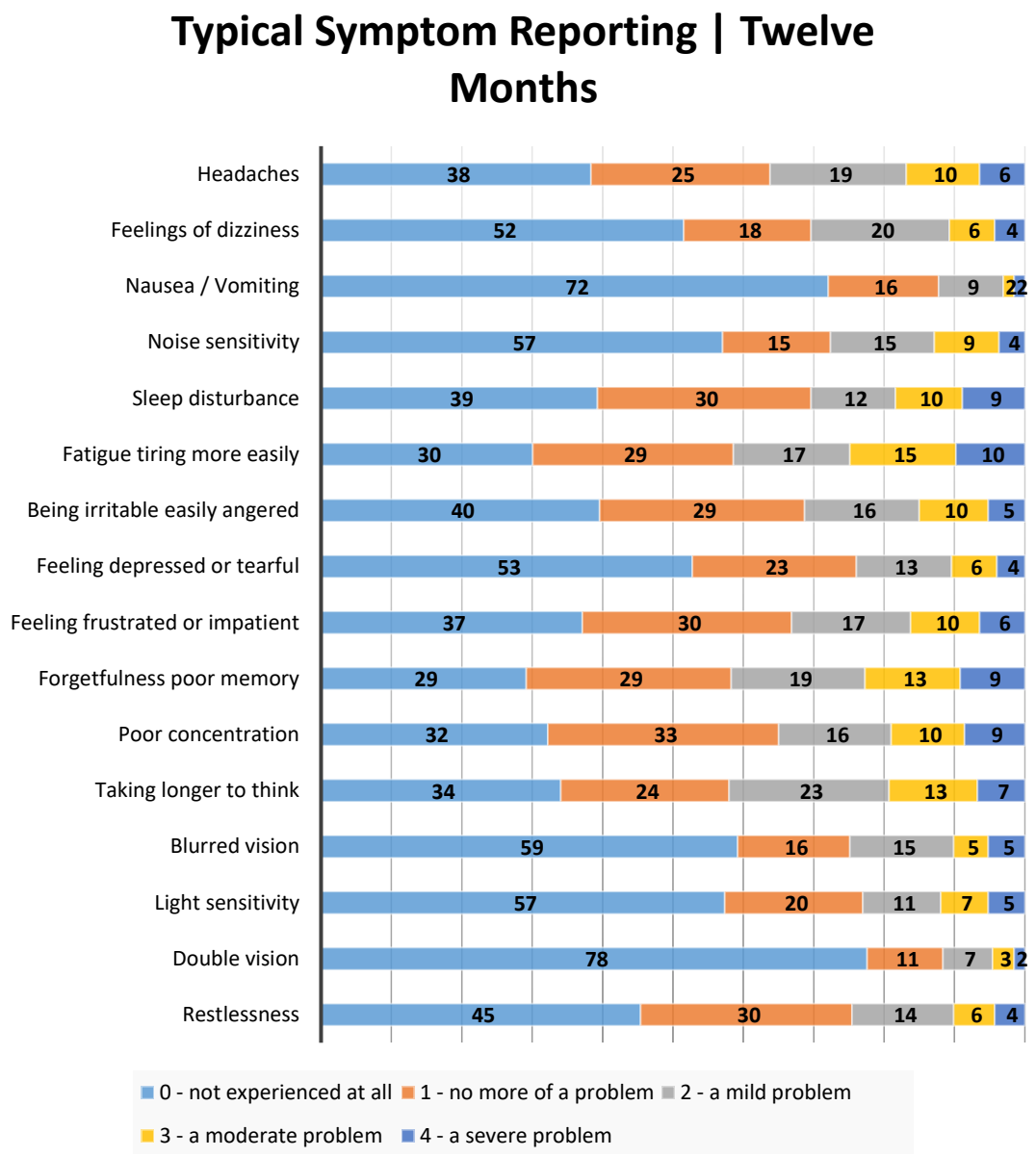

Figure 4. Typical symptom reporting twelve months after TBI

Proportion of Sample Reporting Atypical Symptoms

A quarter of the sample reported at least one atypical symptom at the one-month timepoint. This proportion reduced over time to 16 % at twelve months. Of all the atypical symptoms reported, 69 % were European and 31 % non-European at the one-month timepoint, and 67 % European at the twelve-month timepoint.

Table 4

Symptom reporting at one- and twelve-month timepoints

Frequencies	One Month *n* = 261	Twelve Months *n* = 193
Typical Symptoms	196 (75 %)	161 (84 %)
Atypical Symptoms	65 (25 %)	31 (16 %)

The most commonly selected distractor items at one month were “difficulties with fine motor tasks” and “digestion,” followed by “difficulty swallowing” and “hemiplegia.”

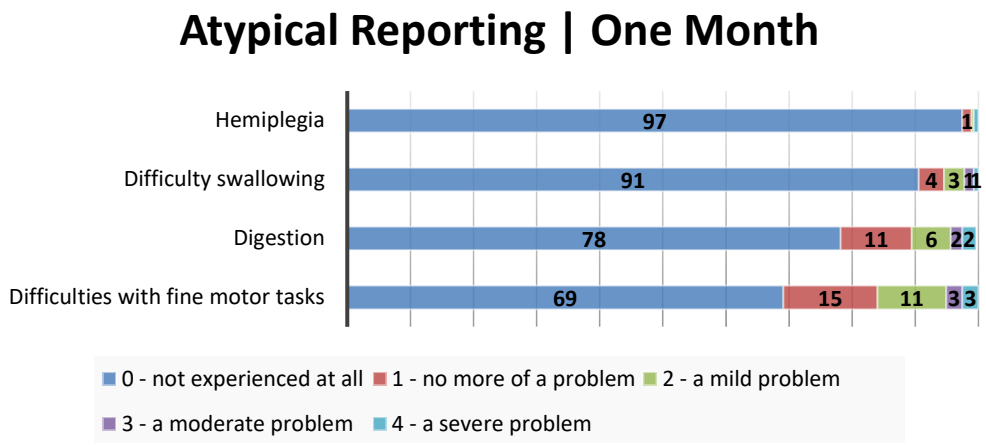

Figure 5. Atypical symptom reporting one month after TBI

The distractor questions at the twelve-month timepoint were in line with the one-month data and identified “difficulties with fine motor tasks” and “digestion” as most commonly selected distractors followed by “difficulty swallowing” and “hemiplegia.”

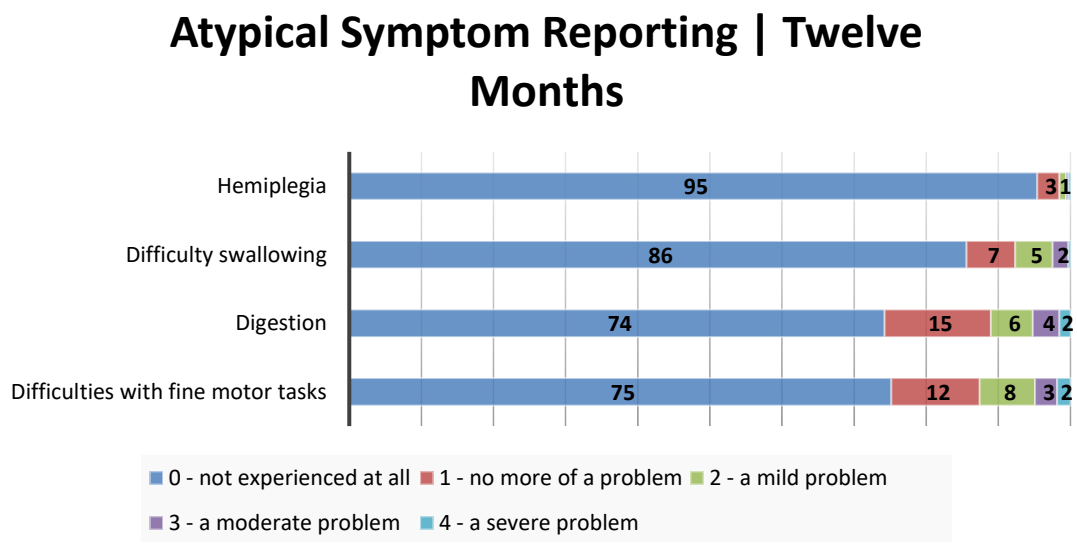

Figure 6. Atypical symptom reporting one month after TBI

Factors Linked to Atypical Symptom Reporting

Table 5 outlines differences in characteristics of participants reporting atypical symptoms and those who do not at the one-month timepoint. A t-test or chi square test was used to test if there were differences in age, sex, ethnicity, other comorbidities and perception of recovery. In this study, females were more likely to report atypical symptoms than males.

Table 5

Symptom reporting one month after TBI

	Atypical *n* = 65	Typical *n* = 196	Test of difference
Average Age (SD)	45 (11.42)	35 (10.93)	t = 1.35 p = 0.16
Sex			
Female	36 (55.4 %)	70 (35.7 %)	X^2 = 7.83 p = 0.005
Male	29 (45.6 %)	126 (64.3 %)	
Ethnicity			
European	45 (69.2 %)	124 (63.3 %)	X^2 = 0.76 p = 0.38
Other	20 (30.8 %)	72 (36.7 %)	
Comorbidities:			
No comorbidities	53 (81.5 %)	167 (85.2 %)	X^2 = 0.50 p = 0.48
With comorbidity	12 (18.5 %)	29 (14.8 %)	

Regression Analysis (determining relationships between two or more variables)

The regression analysis aimed to explore whether there was a link between acute atypical symptom reporting at one month and longer-term outcomes (typical post-concussion symptoms and perceptions of recovery) while accounting for age, sex, comorbidities (at one month), and ethnicity. This model demonstrates a simple correlation between the independent variables and the dependent variable (Field, 2018).

Table 6 presents the results of the regression model for typical post-concussion symptoms. The R Square is 0.46, which means that 46% of the variance in typical post-concussion symptoms was explained by the model. Acute atypical symptom reporting, age, sex, and ethnicity and comorbidities, did not significantly predict typical symptoms at twelve months reporting at the $p < 0.05$ level. However, long term symptoms are best predicted by acute symptoms.

Table 6

Regression analysis for typical post-concussion symptom reporting total score at twelve months (Dependent variable)

Model	B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound
(Constant)	3.67	4.61		0.79	0.43	88.55	120.84
Age at time of injury	0.07	0.04	0.11	1.90	0.06	- 0.39	- 0.14
Acute symptoms	0.57	0.07	0.58	8.67	0.00	- 0- 94	- 0.47
Atypical symptoms	0.86	1.59	0.03	0.54	0.59	- 4.42	6.76
Sex	- 1.96	1.29	- 0.09	- 1.53	0.13	- 4.69	4.31
Comorbidities	- 0.40	1.77	- 0.01	- 0.22	0.82	- 3.91	8.52
Ethnicity	3.65	1.26	0.16	2.89	0.00	1.56	6.13

Table 7 summarises the regression model for perceptions of recovery twelve months after the mTBI. Age at the time of injury and acute typical symptoms atone month was predictive of perceptions of recovery at twelve months.. Sex, comorbidities and ethnicity were not individually predictive of perceptions of recovery in the longer term. The R Square value is 0.31, which means that 31% of the variance in perceptions of recovery was explained by the model.

Table 7

Regression analysis for PCS recovery at twelve-month interval

Model	B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound
(Constant)	104.69	8.18		12.79	0.00	- 5.42	12.76
Age at time of injury	- 0.27	0.06	- 0.27	- 4.26	0.00	- 0.00	0.14
Acute symptoms	- 0.70	0.12	- 0.44	- 5.90	0.00	- 0.45	0.71
Atypical symptoms	1.17	2.83	0.03	0.41	0.68	- 2.28	3.99
Sex	- 0.194	2.281	- 0.01	- 0.09	0.93	- 4.50	0.57
Comorbidities	2.31	3.15	0.05	0.73	0.47	- 3.90	3.09
Ethnicity	- 4.05	2.27	- 0.11	- 1.78	0.07	- 8.54	0.44

Chapter 5 - Discussion

It has been suggested that patients reporting persistent symptoms following a mTBI may be over-reporting (Vasterling, Bryant, & Keane, 2012). The aim of this study was to determine the validity of symptom reporting following mTBI. Participants were asked to complete the Rivermead Post-Concussion Questionnaire (RPQ) as well as a series of atypical (distractor) items, rating their perceived level of recovery on a 0 to 100 scale. A quarter of participants reported distractor symptoms at the one-month timepoint post-injury, but reporting of atypical symptoms reduced over twelve months. There was also an association between the reporting of acute atypical symptoms and perceptions of recovery at one year. Acute atypical symptom reporting could be an indicator of poorer long-term outcomes that may help identify those in need of extra support. The models, however, only explained 31 % of the variation in perceptions of recovery and 46 % of the variations in typical post-concussion symptoms at one year, hinting at scope for future research as discussed below.

Proportions Reporting Atypical (Distractor) Symptoms

It was hypothesised that a significant proportion of participants would report atypical symptoms. A quarter of the sample reported distractor symptoms at one month and 16 % at one year. Participants reported difficulties with fine motor tasks approximately 11 % of the time, digestion 8 %, difficulty swallowing 2 % and hemiplegia less than 2 % of the time. Excessive symptom reporting which is inconsistent with neuropsychological impairment is often interpreted as malingering (Denning & Shura, 2017). Malingering is when people pretend to have mTBI (or a psychosomatic complaint) for personal gain or more generally some form of affliction (Mayer, Quinn, & Master, 2017). In the US, exaggeration of symptoms is often due to the litigation process of healthcare settlements as a way to support claims (Sreenivasan

et al., 2003; Silver, 2012). Green, Rohling, Lees-Haley and Allen (2001) found that up to 40 % of people are open to exaggerating symptoms to cheat the system or to avoid punishment.

Analysis of the research results does not seem to confirm an intentional exaggeration of symptoms by the participants. Only three cases reported atypical and comorbid conditions greater than three conditions. From a New Zealand (NZ) perspective, the Accident Compensation Corporation (ACC) covers all accidental injuries which remove the issue of litigation effects on symptom reporting (Accident Compensation Corporation, 2016). This means that litigation is far less likely to be an issue in New Zealand than it is in the US, leaving lesser factors such as use of over-reporting in order to obtain more support. While some degree of over-reporting is present in virtually all studies, the incidence of this in the New Zealand study is far less than in the US with its litigation-focused healthcare settlement system (Forster, Barraclough, & Mijatov, 2017). This may reflect ACC's no-fault system, which does not motivate over-reporting as it does in the US.

Forster, Barraclough, and Mijatov (2017), however, are critical of the term ‘no-fault system’ because the medicolegal requirements for ACC now insist on proving causation to qualify for cover. In the absence of research, Acclaim Otago, which is a support group for injured New Zealanders and their families, has criticised the ACC as becoming part of the problem (Acclaim Otago (Inc), 2015). It is unclear however whether this constitutes any kind of genuine issue with ACC or is merely an indication of a few patients unsatisfied with the treatment obtained resorting to alternative methods to gain attention and support, or even just expressing dissatisfaction with the treatment received. In the foreword of the Acclaim Otago report, the Honourable Justice Winkelmann explains that there has been an increase in patients turning to the courts and tribunals for assistance in enforcing their human rights to get compensated for

injuries (Acclaim Otago (Inc), 2015). Following the report, research by Forster, Barraclough, and Mijatov (2017) suggested solving the problem by looking at the causes, being transparent and utilising access to the justice system for personal injury if it is necessary. They recommend a reassessment of the requirement of causation for entitlement of cover; however, they believe that the intention of the assessors is generally to be fair (Forster et al., 2017) so that the occasional exaggeration of symptoms is more likely to represent a cry for extra support than a basic means of obtaining treatment, as it is in more litiginous healthcare regimes.

Should the ACC include litigation as part of proving the cause of injury, it would be prudent to look at the implications internationally. Litigation was established as a predictor of poorer recovery and increased stress (Bayen et al., 2019; Kristman et al., 2014; Silver, 2012). The litigation process is also linked to persistent post-concussive symptoms leading to poorer outcomes (Cassidy et al., 2014) and an exaggeration of symptoms to prove causation for fear of not being assisted (Silver, 2012). It seems that in these cases, the results were poorer than with the ACC's no-fault system, indicating that the NZ way of addressing claims is by and large an effective means of facilitating recovery.

Comorbidities

Typical and atypical symptoms in this research were not significantly predicted by comorbidities, this contrasts with previous studies that revealed that symptom reporting was affected by comorbid conditions (Chan, Mollayeva, Ottenbacher, & Colantonio, 2017; Mollayeva et al., 2018b, 2017). Several studies found a link between atypical symptom reporting and pre- and comorbid conditions (Flao et al., 2018; Joseph & Linley, 2012; Kamins & Giza, 2016; Katz, 2014; Toninato et al., 2018). Atypical symptom reporting in mTBI can be complicated, especially when patients report

somatisation disorder symptoms, such as gastrointestinal upset after concussion (Stubbs et al., 2019). Gastrointestinal conditions are linked to digestion (Liao, Zhao, & Gregersen, 2009) which was one of the atypical symptoms listed in this research. A cohort study (n = 4,076) by Gradus et al. (2017) links PTSD to gastrointestinal disorders amongst US veterans to varying degrees. Atypical symptom reporting can also be as a result of iatrogenesis (effects of incorrect products or treatments) and secondary gain (Edmed, 2014; Schoenberg & Glenn Scott, 2011).

Age

In this study, increased age significantly predicted persistent concussion symptoms. Biswas et al. (2017) specifically found that older age at an mTBI predicted poor outcomes. More generally, many older adults perceive ageing negatively (Warmoth, Tarrant, Abraham, & Lang, 2016). As a result, older people who perceive their health poorly were also more prone to be using more pharmaceuticals, had poorer nutrition, and participated in less social or cognitive stimulating activities (Machón, Vergara, Dorronsoro, Vrotsou, & Larrañaga, 2016).

Poor outcomes regarding the perception of symptoms can also be explained by the "good old days" hypothesis when people compare current symptoms to the past and believe that the present symptoms are worse (Lange et al., 2017). A negative perception of an injury is linked to elevated experiences of post-concussion symptoms (PCS) (Broshek & De Marco, 2015) and can lead to enduring PCS (Snell et al., 2011). Chen et al. (2012) used fMRI technology to examine young adults aged 21-30 years (n = 13) and older adults aged 51-68 years (n = 13) with a control group of 26 year old participants (gender match), and found that older people found it more challenging to recover from mTBI. Not only do older people report more concussion symptoms (Hu et al., 2017), they also report more severe conditions, possibly as a result of diseases that

go with age (Papa et al., 2012). Furthermore, the mortality rate is also higher in older adults (Peters & Gardner, 2018). However, not all studies found age to be a significant predictor of persistent post-concussion symptoms (PPCS). A study by Tator et al. (2016), who studied the demographics and predictors of post-concussion syndrome in 221 patients, did not find age a significant predictor. Machón et al. (2016) stress the importance of self-perceived health in older adults and the need to develop programmes to encourage health in ageing.

Gender

Females were more likely to report atypical symptoms than males. However, men reported more typical symptoms. According to Mollayeva et al., (2019), sex and gender policy frameworks have been under-addressed in the literature. The research found that it is not unusual for women to be affected more strongly by mTBI, which some have attributed to reporting bias (women being more likely to report concussion) (Dick, 2009). Female mTBI is often affected by physiological factors such as neck strength (Toninato et al., 2018), and older women find it hard to recover due to a reduction in oestrogen levels (Arbogast, 2019) and mineral density (Cauley et al., 2012). According to Esopenko, Simonds, and Anderson (2018), these factors can have a negative impact on the recovery of women. However, there are contradictory findings on post-concussion symptoms and how it relates to women. The literature often reports that post-concussion symptoms were higher in women (Garber, Rusu, & Zamorski, 2014; Preiss-Farzanegan, Chapman, Wong, Wu, & Bazarian, 2009) while others found no differences (Brickell et al., 2017). Various research studies also link higher athlete-based concussion outcomes to women (Covassin et al., 2016). This difference in reporting between males and females suggests the use of gender-specific treatment when considering recovery programmes (Mollayeva et al., 2018b). Gender considerations need to be accounted for not only in concussion research but also in

treatment programmes once relevant research results become available (Mollayeva et al., 2018a).

Ethnicity

Although findings by Feigin et al. (2013) found that the Māori population were 23 % more likely to suffer a concussion, in this research, Europeans seem to be more likely to have a negative perspective on recovery than the other ethnicities. There is limited research on the perception of recovery and the long-term effects on ethnicity. In the literature, research on perception and ethnicity is covered by topics such as bias of cultural competence in healthcare (Johnson, Saha, Arbelaez, Beach, & Cooper, 2004), perception of concussion in sports (Bloodgood et al., 2013) and perceived disparities of mTBI in healthcare (Wallace, Covassin, Nogle, Gould, & Kovan, 2017). A US study found that race predicted persistent post-concussion symptoms (PPCS) (Houck, Asken, Clugston, Perlstein, & Bauer, 2018) since it can be linked to socio-ethnic factors and disparities in healthcare (Gao, Kumar, Wisniewski, & Fabio, 2018; Heffernan et al., 2011). PPCS refers to mTBI symptoms persisting way beyond the injury (Satz et al., 1999). Minorities are also less likely to make use of rehabilitation services than Europeans (Gao et al., 2018) and have poorer health outcomes because they cannot afford treatment (Heffernan et al., 2011). In NZ, even though males within the Pacific communities were up to three times more likely to sustain TBI than females, PPCS are difficult to predict (Lagolago et al., 2015). The perception and reporting behaviour of concussion is often informed by cultural narratives (Corman et al., 2019) because this is how people make sense of their worlds (Branigan, 1992). Lagolago et al. (2015) recommend targeted prevention efforts to address the higher risk of TBI in Pacific communities.

Recovery and Symptom Reporting

Hypothesis three posited that there would be a significant link between acute atypical symptom reporting and increased reporting of persistent typical post-concussion symptoms at one year. Acute symptom reporting not only predicted the perception of recovery at one year, but also PPCS. The predictors of PPCS are poorly understood; however, Rabinowitz et al. (2015) found early symptom reporting to be a predictor of longer-term outcomes. This study found that 57 % of those who completed the Perception Recovery Scale (PRS) at both timepoints improved, 24 % remained the same and 18 % worsened. This research corroborates findings by other authors that found participants who reported typical symptoms, mostly resolved symptoms within the first year (Lagarde et al., 2014; Levin et al., 1987; McInnes et al., 2017; Theadom et al., 2016). Although this study also found that persons who reported atypical symptoms had worse outcomes, there was an improvement of 22 % over a year with participants who selected distractor symptoms. According to Carroll et al. (2004), most patients recover from typical concussion symptoms within one year.

One issue not shown in the current study due to the fact that data was gathered only at one-month and twelve-month timepoints, is that recovery from mTBI is often nonlinear, presenting many ups and downs on the way to recovery (Fadyl, Theadom, Channon, & McPherson, 2019; McPherson et al., 2018). It is vital to "make room" for recovery and to build on meaningful resources as seen from a longitudinal qualitative study (Fadyl et al., 2019). The best outcomes result when people are listened to and believed (McPherson et al., 2018). McPherson et al. (2018) highlight the importance of personal context in recovery, especially as it relates to acknowledging an individual's story through the helper's actions and by avoiding assumptions. In the context of this research, the fact that the process is nonlinear supports the use of discrete rather than

continuous sampling in order to capture the final outcomes of the recovery process rather than potentially anomalous readings along the way.

Several theories exist on the perception of recovery. Theories on how perception affects psychological outcomes are not new. Lazarus and Folkman, (1984) were some of the forerunners linking stress and coping with how people appraise their situation. Fadyl et al. (2019) found that participants and their significant others at times became consumed and exhausted from adapting and coping with TBI. Strom and Kosciulek, (2007) conducted a study with mTBI patients (n = 94) using the stress appraisal coping model and found that higher levels of perceived stress predicted poorer outcomes. Perception of an injury is intrinsically linked to coping styles and the perceived control of the stressful event (Dijkstra & Homan, 2016). Individuals who look for solutions have a stronger internal locus of control and believe in their ability to overcome adversity (Buddelmeyer & Powdthavee, 2016). Therefore, those who feel that they are more in control of their situation have better health outcomes (Izaute et al., 2008).

Resilient people generally adjust better to their environments after an injury (Fergus & Zimmerman, 2004). Resilience refers to a person's ability to bounce back from stressful situations, which is linked to the way they appraise their situation (Luthar, Lyman, & Crossman, 2015). In their rehabilitation model, Stuntzner and Hartley (2014) link resilience and positive outcomes to individual perceptions and the way patients respond to injuries. When patients believe that they have no control over their environments, a perception that they are victims of circumstance (external locus of control) can lead to poorer outcomes (LaCaille et al., 2013). In practice, patients can be assisted to develop problem-focused strategies that will help shift negative perceptions to find solutions (Smith & Baum, 2009). This can be done by targeting cognitive behavioural emotions, reassessing perceptions of their injury, and working through expectations in order to solve problems (Rath & Elliott, 2012).

Although acute symptoms may be transient, this research is consistent with studies that found that acute perception and symptom reporting can lead to post-concussion syndrome and complications in dealing with mTBI in the long term (Iverson, 2012; McCrea, 2008). Findings by McCrea (2008) and Rabinowitz et al. (2015) confirm that the onset of delayed symptoms is unusual and often due to injuries related to other factors. In their research, Vargas et al. (2015) attribute the continued PCS to depression, and Polinder et al. (2018) to subset conditions such as behavioural issues, enduring cognitive, emotional and somatic presentations. It is important to address PPCS in the clinical setting early on to facilitate the recovery process (McCrory et al., 2013). Treating PCS early on is crucial in assisting patients to deal with the symptoms before working with the underlying pathologies in order to enhance the recovery process (Real et al., 2017).

Often patients distrust treatment due to misinformation or negative experiences and beliefs (nocebo effect), which could contribute to worsening effects after a concussion (Polich et al., 2019). Hence, subjective symptom reporting and resolving post-concussive symptoms are linked to the way people persistently perceive or misattribute their injuries (Gunstad & Suhr, 2002; McCrea, 2008). Acute symptoms are usually tested by using self-report questionnaires (WHO, 2001). In this research, the RPQ survey measured the acute symptoms and the PRS just after the injury and again at twelve months. Cole and Bailie (2016) found that even by using the term “mild traumatic brain injury” instead of “concussion,” perceptions were negatively affected and can lead to weaker recovery. Fergus and Zimmerman(2004) link negative outcomes and inadequate thought responses to external and internal stressors, and they suggest that poor adjustment is as a result of maladaptive coping. Perception of recovery is crucial to the healing process (Iverson et al., 2010).

Assessment

Assessment practices are important to consider because they could potentially influence symptom reporting (Edmed, 2014). The measures used in this research to test PPCS were the RPQ and the Perception of the level of recovery scale (PRC) at both timepoints. Edmed (2014) suggest that the severity of symptom reporting is greater when elicited by a checklist as opposed to spontaneous reporting because participants found it more challenging to remember PCS symptoms when not prompted. Acute symptoms are subjective and assessed based on self-reporting (McCrea, 2008). For this reason, screening tools were developed such as the Rivermead Post-Concussion Questionnaire (RPQ) (King et al., 1995), the Glasgow Coma Scale (GCS) (Jain et al., 2019) and the Sports Concussion Assessment Tool (SCAT) to test mTBI symptoms (Echemendia et al., 2017).

The understanding of symptom reporting should consider multifactorial influences from a neurocognitive perspective and biopsychosocial framework (Cole & Bailie, 2016; Edmed, 2014). The DSM 5 and biopsychosocial frameworks are some of the most well-known assessment measures in the treatment of mTBI (McCrea, 2008). The biopsychosocial framework is an integrated health model that considers social, psychological and biological factors during assessment and treatment (Havelka, Lučanin, & Lučanin, 2009). One means of addressing atypical symptoms is through a multimethod, multi-systems approach, which works on a systematic exclusion of symptoms to get to an alternative diagnosis. This includes examining documents, history, internal and external factors that can have an influence on symptom reporting (Edmed, 2014). Acute symptom reporting after concussion and exaggeration of symptoms may be a cry for help to receive medical assistance when patients believe their recovery process is too slow or when they perceive they do not get enough support.

Other Factors that could affect Atypical Symptom Reporting

The regression models only explained 46% of the variance. Research beyond the scope of this study that could explain the rest includes maintaining factors such as misattributing symptoms or errors in the understanding of concussion that could lead to lengthy recovery periods (Broshek & De Marco, 2015). Financial struggles can also exacerbate perceived stress and can lead to psychological symptoms (Adams, Meyers, & Beidas, 2016; Fröjd, Marttunen, Pelkonen, Von Der Pahlen, & Kaltiala-Heino, 2006). Accumulation of life stressors sometimes leads to feelings of helplessness, feeling like a failure, low self-esteem and self-blame that exacerbate and prolong PCS (Vargas et al., 2015). Furthermore, socio-demographic factors such as lack of social support, lifestyle choices and lower education level can have an impact on concussion recovery (Polinder et al., 2018; Silverberg et al., 2015).

Schoenberg and Scott (2011) highlighted multiple factors that can have an influence on symptom reporting. Postinjury symptom presentation can include factors such as assessment methods, social support, early treatment and education, preinjury factors, injury characteristics, neurological and biological sequelae, psychiatric and medical comorbidities, biases and expectations (Schoenberg & Glenn Scott, 2011).

Strengths and Limitations of the Study

A strength of this research is that data was drawn from a cohort study that spanned over one year. Initially, the data was collected as a baseline, hence, providing reliable information on participants who experienced a concussion shortly before the research. The sample was also large, therefore it is fairly safe to generalise findings to the greater population of Hamilton and Waikato who experienced mTBI.

One issue that arose during the study was that there was a reduction in sample size of 14% from the one month to twelve month timepoints. This dropout rate, however, was lower than the rate reported for general clinical trials (Bell, Kenward, Fairclough, & Horton, 2013), and even with the marginally reduced sample size at the twelve-month timepoint the total still provided the required confidence level, since provision for dropouts had been built into the study (Overall, Shobaki, Shivakumar, & Steele, 1998).

One of the challenges of mTBI research is that symptoms are subjective and can only be elicited from self-reporting and so are difficult to verify. Self-report studies are also subjective and open to response bias (Rosenman, Tennekoon, & Hill, 2011). This research was only able to highlight links between variables and was not able to determine cause and effect (Schneider & Schneider, 2017). Furthermore, the sample was selected from the Hamilton and Waikato population which may not necessarily represent the wider NZ population. The TBI participants were directly approached by the research team or responded to advertisements which could have introduced selection bias (Theadom et.al., 2018). It remains unclear if some types of injuries, such as those who were assaulted or those who had multiple injuries sustained at the time of the accident, are linked with atypical symptom reporting. It should also be kept in mind that the data was drawn from a study that was conducted between 2010 and 2011. Conditions may have changed since then.

There is limited work on distractor symptoms, such that some values chosen as atypical symptoms for mTBI in this research may be genuine comorbidities via one level of indirection. For example, in the context of mTBI, digestion is a genuine distractor, but for comorbid conditions such as PTSD, digestive problems could be a genuine symptom (Gradus et al., 2017). Limited research exists on the measurement of atypical symptoms and works in this field mostly relate to the mBIAS, Validity-10,

NIM 5 and LOW 6 scales that have principally been created and evaluated in the US military context for use on US combat veterans to screen for compensation seeking overreporting (Armistead-Jehle et al., 2018; Lange et al., 2013). These scales do not cover any of the distractor symptoms used in this research.

This research did not cover personal and social competence after mTBI. The impact of emotion focused and problem-focused thinking and how it relates to atypical symptoms, was also not covered. This research did not explore the participants' understanding of concussion, nor the services they have received after the injury. Furthermore, this research did not investigate social or family support. Daily stressors affect people's worldview, but this research did not investigate how social or family support affects symptom reporting following a concussion. From a NZ cultural perspective, further research is needed to determine how land alienation and power imbalance influence the validity of symptom reporting following concussion in the Māori population.

Implications for Future Practice

In the NZ context, people do not seem to overreport mTBI symptoms. Studies in the US showed patients often overreport mTBI symptoms due to the litigation-based healthcare system that encourages symptom exaggeration (Sreenivasan et al., 2003). An important contribution of this research is that it balances the US-centric understanding of symptom exaggeration, showing that within the NZ-context, symptom reporting is not impacted by a litiginous regime and therefore participants were less likely to over-report concussion symptoms. Worldwide mTBI symptom exaggeration patterns compared to incidence of atypical symptom reporting in NZ and its relationship with demographics and overall mTBI recovery are topics that could be further explored.One in four participants reported atypical symptoms at one-month post-concussion, which

reduced at one year. However, men reported more typical symptoms and females more atypical symptoms. Symptom reporting and perceptions of recovery one year after the concussion showed that acute atypical symptom reporting may be a red flag to highlight individuals who experience persistent mTBI symptoms and require support to assist in the process of recovery, highlighting the importance of individualised intervention programmes.

Chapter 6 - Conclusion

This study investigated the validity of symptom reporting following mTBI of a population 16 years and older one- and twelve-months post-injury. One in four persons reported atypical symptoms; however, symptoms reduced over time. Compared to the US where patients frequently overreport concussion symptoms as a result of the litigation-based healthcare system, in NZ mTBI symptom reporting is not as heavily influenced by the healthcare regime, hence participants tend to be less likely to over-report concussion symptoms for personal gain. In NZ, symptom reporting patterns could serve as a red flag in that in the few cases where people did overreport symptoms it seems to be more typically an attempt to gain additional support to facilitate recovery.

Overreporting of symptoms could also be due to other underlying issues (not covered by this research). Long term outcomes were best predicted by acute symptoms and perceptions of recovery. Women and older persons were also more likely to report atypical symptoms. Perception has an influence on overreporting and the way people report symptoms at one month will have an impact on their outcomes at twelve months. Since atypical symptom reporting at one month and poor perception of recovery predicts worse outcomes at one-year, clinical intervention strategies should focus on early symptom reporting patterns.

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Appendices

Appendix A: Ethics Approval

Health and Disability Ethics Committees

Northern Y Regional Ethics Committee
Ministry of Health
3rd Floor, BNZ Building
354 Victoria Street
PO Box 1031
Hamilton
Phone (07) 858 7021
Fax (07) 858 7070
Email: northerny_ethicscommittee@moh.govt.nz

19 October 2009

Prof Valery Feigin
AUT North Shore Campus
AA254, 90 Akoranga Drive
Northcote 0627
Private Bag 92006, Auckland 1142

Dear Prof Feigin

Traumatic brain injury burden in New Zealand: a population-based incidence & outcomes study.
Investigators: **Prof Valery Feigin, Dr Suzanne Barker-Collo, Prof Kathryn McPherson, Prof Robert Kydd, Prof Alan Barber, Varsha Parag, Dr Paul Brown, Dr Nicola Starkey, Prof Tony Dowell, Dr Michael Kahan.**
Ethics ref: **NTY/09/09/095**
Locations: **WDHB, ADHB.**

The above study has been given ethical approval by the **Northern Y Regional** Ethics Committee.

Approved Documents
-Study protocol version 6 dated 28/08/09.
-Information Sheets version 6 dated 25/08/09 for adult participants, child participants, parent/child proxy, adult participant proxy, and nominated family members.
-Consent Form version 6 dated 25/08/09 for adult participants, child participants, parents proxy, adult participant proxy, and nominated family members.
-GP information Sheet version 2 dated August 09.
-Advertisement and letter of invitation version 2 dated 25/08/09.
-Description of case record forms.
-Participant questionnaires.
-Assessment delivery tables.

Certification
The Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out.

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports
The study is approved until **1 November 2012**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **19 October 2010**. The report form is available on http://www.ethicscommittees.health.govt.nz. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Requirements for SAE Reporting
The Principal Investigator will inform the Committee as soon as possible of the following:
- Any related study in another country that has stopped due to serious or unexpected adverse events
- withdrawal from the market for any reason

Appendix B: Adult Participation Information Sheet

Adult Participant Information Sheet

An invitation

You are invited to take part in a research study because you have recently had a head injury (brain injury). This study is coordinated by the National Research Centre for Head injury, Applied Neurosciences and Neurorehabilitation, AUT University in Auckland in collaboration with Waikato University in Hamilton.

Your participation is entirely voluntary (your choice). You do not have to take part in this study. If you choose not to take part, any care or treatment that you are currently receiving will not be affected. If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason. Withdrawing at any time will in no way affect your future health care. To help you make your decision please read this information brochure. You may take as much time as you like to consider whether or not to take part. If you require an interpreter this may be arranged.

What are the aims of this study?

The main aim of the study is to determine the broad impact of head injury in New Zealand. We will be looking at the frequency, characteristics and effects on all

people who suffer a new head injury who live in Hamilton and Waikato District over a 12 month period, from March 2010 to February 2011.

The study also aims to find out what the effects of the head injury (if any) are on:

- Physical activity
- Memory and other cognitive functioning
- Mood and feelings
- Quality of life
- The families of people with head injury

We hope this study will be of long term benefit to New Zealanders in identifying incidence, mechanisms and outcomes of TBI, and eventually lead to an improved care and reduction in the number of TBI patients in New Zealand.

What types of people can be in the study?

All people who are resident in Hamilton or Waikato District who suffer a head injury between 1 March 2010 to 28 February 2011 are able to participate in the study.

We would also like to ask a family member or carer of people who have had a brain injury, so that we can ask them some questions about how your injury may have affected them. We will ask you if you would like to nominate someone to answer these questions

How many people will be in the study?

We estimate about 1040 people will be involved in this study.

What happens if I do decide to take part?

Participant's medical records will be checked to identify participants eligible for the study and to find out information about the type and nature of their injury. If you decide you would like to take part, your participation would be for twelve months only. In total there will be four assessments. These assessments will take place at the start of the study and then at one month and 6 months and 12 months after your head injury.

Each assessment will include answering some questions about your injury. This will take about 60 minutes and can be conducted over the telephone or in person. All researchers who will be asking you some questions will have been specifically trained for this project. You will be asked questions about your recovery, mood, treatments, care and services that you have received after the onset of your head injury.

The researcher will then arrange a suitable time to visit you at home. You will also be asked to complete some activities on a computer (the computer will be provided for you). These activities will look at your attention span, memory and the way you process information. This will help us to see if your injury may have affected your skills and to monitor your recovery. The computer activities will last for 60 minutes and there will be opportunities for you to take a break. These activities can also be done over several sessions if you prefer. In previous studies people have often said that they find these activities enjoyable.

In total the four study interviews should take about 8 hours of your time over twelve months.

What is the time-span for the study?

The study is expected to start on 1 March 2010 and will continue until 30 October 2012.

How will the study affect me?

Taking part in this study will take some of your time and require you to answer a series of questions. There are no known risks caused by this study. Your usual medical care will not be affected in any way by participating in the study, or by declining to participate or withdrawing from the study at any stage. Your participation in this study will be stopped should any harmful effects appear or if the doctor feels it is not in your best interests to continue. Similarly, your doctor may at any time provide you with any other treatment he/she considers necessary.

This study will be of benefit to the wider population. There is no guarantee that you will benefit directly from being involved in this study. However, you will be given an opportunity to discuss your injury with someone who is an expert in head injury. The results obtained from your participation may help others with this condition in the future.

Compensation

A $20 food/fuel voucher will be provided to you after completion of Interviews 2,3 and 4 ($60 in total).

If someone involved in the study experiences a further head injury during the study, they will be asked to continue with the scheduled follow up assessments for their initial injury as planned. Participants will only be eligible for these vouchers for one head injury occurring between 1 March 2010 to 28 February 2011, not including previous or further injury.

Confidentiality

The study files and all other information that you provide will remain strictly confidential. No material that could personally identify you will be used in any reports on this study. Upon completion of the study your records will be stored for 16 years in a secure place at the central coordinating centre in Auckland. All computer records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

Your rights

If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Advocate at the Health Advocates Trust,

Telephone 0800 555 050, or email: advocacy@hdc.org.nz

Or Te Puna Oranga (Waikato DHB Māori Health Unit), Hockin Building, Level 1, Pembroke St, P.O.Box 934, Hamilton. Ph: (07) 834 3644. Fax: (07) 834 3619.

Finally

This study has received Ethical Approval from the Northern Region Y Ethics Committee 19th October, 2009.

If you would like some more information about the study please feel free to contact the BIONIC Study Manager:

Study Manager on 0508 BIONIC (0508 246642) or email bionic@aut.ac.nz
Waikato University and National Research Centre for Stroke, Applied Neurosciences and Neurorehabilitation (NRC-SANN), AUT University

Alternatively, you can contact;
Dr Nicola Starkey, Senior Lecturer, Department of Psychology, University of Waikato, Hamilton, on 07 8384466 ext 6472 or email: nstarkey@waikato.ac.nz

or Ms Alice Theadom, Senior Research Fellow, NRC-SANN, AUT University on 09-921-9999 ext. 7805 or email: alice.theadom@aut.ac.nz

Study Investigators

The principal investigator for this study is: Professor Valery Feigin Tel: (09) 921 9166
National Research Centre for Stroke, Applied Neurosciences and Neurorehabilitation (NRC-SANN), AUT University, Private Bag 92006, Auckland 1142

Please keep this brochure for your information.

Thank you for reading about this study

Appendix C: Baseline assessment, to be completed within 10 days of date of injury

Form B1: Baseline (Telephone/Face to face)

Adults (aged 16 +)

Registration number: ☐☐☐☐☐☐

Participant initials: ☐☐☐☐

Date of birth: ☐☐ ☐☐ ☐☐

d d m m y y

To be completed within 10 days of date of injury

Check the participant has signed and dated the consent form and that the details on form C are correct and not likely to change before the next assessment.

Co morbidities

Now I am going to ask you about any medical conditions. Has a doctor or medical person ever told you that you have any of the following:

Q#	Label	Field Format
4.8	Alzheimer's disease	Present Not present
4.9	Dementia other than Alzheimer's disease (Includes diagnoses of organic brain syndrome (OBS) or chronic brain syndrome (CBS), senility, senile dementia, multi-infarct dementia, and dementia related to neurological diseases other than Alzheimer's (eg: Picks, Creutzfield-Jacob, Huntingtons disease etc.)	Present Not present
4.10	Developmental Disability/Handicap	Present Not present
4.11	Learning disability	Present Not present
4.12	Attention deficit	Present Not present
4.15	Any mental health difficulty (psychiatric illness such as depression, anxiety disorder, schizophrenia, paranoia)	Present Not present
4.15.1	If yes, diagnosis (tick as many as apply)	Depression Anxiety disorder PT Schizophrenia Obsessive Compulsive Disorder Other

Signature of Study Researcher

Label	Field format
Signature	Text
Printed name	Text
Date	ddmm20yy

Once this form is complete, and the data has been entered, give the original to the BIONIC Study Manager.

Appendix D: Follow-up Assessments (face-to-face), completed within 10 days of injury

Form B2: Follow-up Assessments (face to face)

Adults (aged 16 years +)

Registration number: ☐☐☐☐☐☐

Participant initials: ☐☐☐☐

Date of birth: ☐☐ ☐☐ ☐☐

d d m m y y

TO BE COMPLETED WITHIN 10 DAYS OF DATE OF INJURY

General Questions

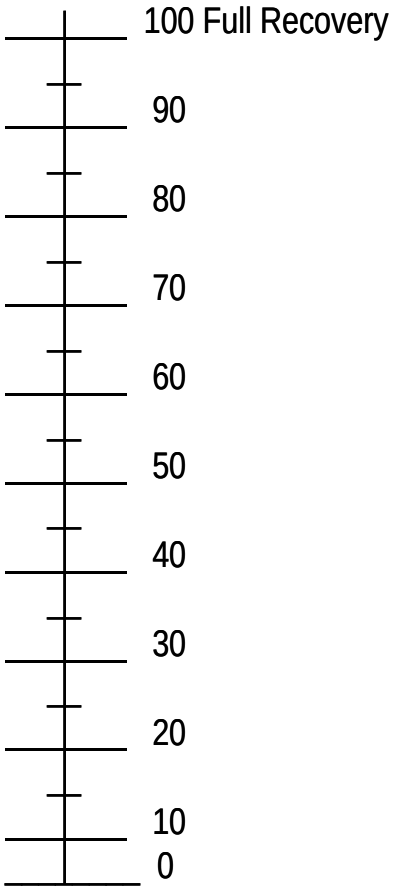
G.1	Date of assessment	Dd/mm/20yy
G.2	Participant is alive on scheduled assessment date	Yes/No/Unknown
G.2.1	If unknown, date last definitely known to be alive	dd/mm/20yy
G.2.2	If no, date of death (Ensure death is reported on Form D, Stop here, YYYY must be 2010, 2011)	dd/mm/20yy
G.3	Is further data to be collected for this assessment?	Yes No
G.3.1	If no, reason for not doing assessment (tick one only)	Declines/refuses Cannot be contacted Overseas Too unwell Out of timeframe Other
G.3.2	If other, please specify	Text

G.3.3	If no, is data to be collected from a proxy? If yes, stop here, sign and date form, go to proxy form R	Yes No

Note to researcher: Please give this sheet to the participant to complete or provide assistance if required

Individual perception of the level of recovery

On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you recovered since your Injury?



Rivermead Post-concussion Symptoms

Questionnaire (PCS)

After a head injury or accident some people experience symptoms that can cause worry or nuisance. We would like to know if you now suffer any of the symptoms given below. Because many of these symptoms occur normally, we would like you to compare yourself now with before the accident. For each symptom listed below please circle the number that most closely represents your answer.

Compared with **before** the accident, do you **now** (i.e., over the last 24 hours) suffer from:

Q#	**Label**	**Field Format**				
		not experienced	no more of a problem	mild problem	moderate problem	severe problem
10.1	Headaches	0	1	2	3	4
10.2	Feelings of dizziness	0	1	2	3	4
10.3	Nausea and/or vomiting	0	1	2	3	4
10.4	Noise sensitivity (easily upset by loud noise)	0	1	2	3	4
10.5	Sleep disturbance	0	1	2	3	4
10.6	Fatigue, tiring more easily	0	1	2	3	4
10.7	Being irritable, easily angered	0	1	2	3	4
10.8	Feeling depressed or tearful	0	1	2	3	4

10.9	Feeling frustrated or impatient	0	1	2	3	4
10.10	Forgetfulness, poor memory	0	1	2	3	4
10.11	Poor concentration	0	1	2	3	4
10.12	Taking longer to think	0	1	2	3	4
10.13	Blurred vision	0	1	2	3	4
10.14	Light sensitivity (easily upset by bright light)	0	1	2	3	4
10.15	Double vision	0	1	2	3	4
10.16	Restlessness	0	1	2	3	4
10.17	Paralysis of half of the body (Hemiplegia)	0	1	2	3	4
10.19	Difficulty swallowing	0	1	2	3	4
10.24	Digestion	0	1	2	3	4
10.25	Difficulties with fine motor tasks (e.g. picking things up)	0	1	2	3	4

Signature of Study Researcher

Label	**Field format**
Signature	Text
Printed name	Text
Date	ddmm20yy

Once this form is complete, and the data has been entered, give the original to the BIONIC Study Manager. Keep copies in the participant's Case Record Folder.

Appendix E: One Month Assessment

Form O1: Follow-ups (Telephone)

Adults (aged 16 +)

Registration number: ☐☐☐☐☐☐

Participant initials: ☐☐☐☐

Date of birth: ☐☐ ☐☐ ☐☐

d d m m y y

One month assessment: To be completed after a minimum of 2 weeks post baseline assessment and within 2 calendar months of date of injury

Six & twelve month assessment: To be completed within 2 weeks either side of 6 or 12 calendar months of participants date of injury

Check the participant has signed and dated the consent form and that the details on form C are correct and are not likely to change before the next assessment

General Questions *(Collect data for all assessments)*

Q#	Label	Field Format
G.0	Assessment (tick one only)	1 month 6 months 12 months
G.1	Date of assessment	Dd/mm/20yy

G.2	Participant is alive on scheduled assessment date	Yes No Unknown
G.2.1	If unknown, date last definitely known to be alive (Stop here, YYYY must be 2010, 2011)	Dd/mm/20yy
G.2.2	If no, date of death (Ensure death is reported on Form D, Stop here, YYYY must be 2010, 2011)	Dd/mm/20yy
G.3	Is further data to be collected for this assessment? (If participant was still in PTA at last assessment but is no longer in PTA, record duration of PTA on form A)	Yes No
G.3.1	If no, reason for not doing assessment (tick one only)	Declines/refuses Cannot be contacted Overseas Too unwell Out of timeframe Other
G.3.2	If other, please specify	Text
G.3.3	If no, is data to be collected from a proxy? If yes, stop here, date and sign form, go to proxy form L	Yes No
G.5	Has participant entered permanent residential care since last assessment?	Yes No
G.5.1	If yes, date of entry into permanent residential care	Dd/mm/20yy
G.6	Has participant been admitted to hospital since the last assessment?	Yes No
G.6.1	If yes, date last admitted to hospital	Dd/mm/20yy
G.7	Has the participant had a serious fall since the last assessment?	
G.7.1	If yes, date of fall/injury	Dd/mm/20yy
G.13	Has the participant had a traumatic brain injury since the last assessment? If yes, complete new Form A	Yes No

GS.4	What is the most disabling issue for you now (Physical, cognitive or mental)? (Write none, if they do not feel they have a disabling issue)	Text
GS.4.1	Are you receiving any benefit for your main disability (such as injury compensation, disability allowance or support)?	Yes No

GS.4.2	If yes, when did you start receiving this benefit?	yyyy

Co morbidities

Since their head injury has the participant been diagnosed with any of the following conditions?

Q#	Label	Field Format
4.8	Alzheimer's disease	Present Not present
4.9	Dementia other than Alzheimer's disease (Includes diagnoses of organic brain syndrome (OBS) or chronic brain syndrome (CBS), senility, senile dementia, multi-infarct dementia, and dementia related to neurological diseases other than Alzheimer's (eg: Picks, Creutzfield-Jacob, Huntingtons disease etc.)	Present Not present
4.10	Developmental Disability/Handicap	Present Not present
4.11	Learning disability	Present Not present
4.12	Attention deficit	Present Not present
4.15	Any mental health difficulty (psychiatric illness such as depression, anxiety disorder, schizophrenia, paranoia)	Present Not present
4.15.1	If yes, diagnosis (tick all that apply)	Depression Anxiety disorder PT Schizophrenia Obsessive Compulsive Disorder Other

Signature of Study Researcher

Label	Field format
Signature	Text
Printed name	Text
Date	ddmm20yy

Once this form is complete, and the data has been entered, give the original

to the BIONIC Study Manager.

Appendix F: Six and Twelve Month Assessment

Form O2: Follow-up Assessment (face to face)

Adults (aged 16 years +)

Registration number: ☐☐☐☐☐☐

Participant initials: ☐☐☐

Date of birth: ☐☐ ☐☐ ☐☐

d d m m y y

One month assessment: To be completed after a minimum of 2 weeks post baseline assessment and within 2 calendar months of date of injury6 & 12 month assessment: To be completed within 2 weeks either side of 6 or 12 **calendar months of participants date of injury**

General Questions

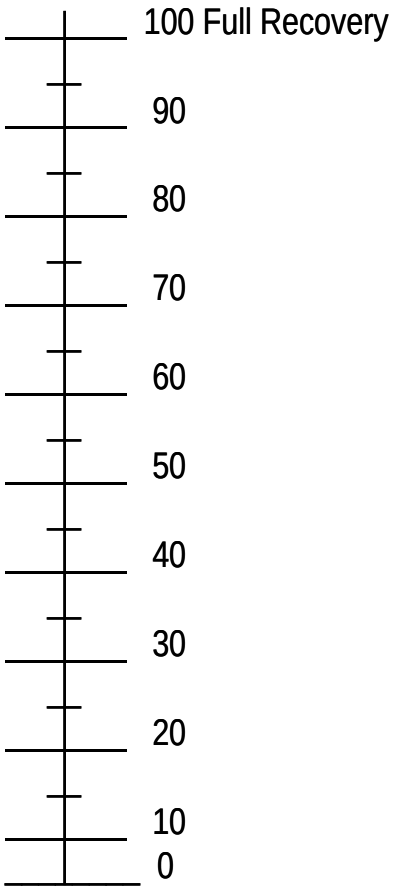
G.0	Assessment: (tick one only)	1 month 6 months 12 months
G.1	Date of Assessment	Dd/mm/20yy
G.2	Participant is alive on scheduled assessment date	Yes/No/Unknown
G.2.1	If unknown, date last definitely known to be alive	dd/mm/20yy

G.2.2	If no, date of death (Ensure death is reported on Form D, Stop here, YYYY must be 2010, 2011)	dd/mm/20yy
G.3	Is further data to be collected for this assessment? If yes, go to question G.5	Yes No
G.3.1	If no, reason for not doing assessment	Declines/ refuses Cannot be contacted Overseas Too unwell Out of timeframe Other
G.3.2	If other, please specify	Text
G.3.3	If no, is data to be collected from a proxy? If yes stop here (sign and date form), go to proxy form L	Yes No

Note to researcher: Please give this sheet to the participant to complete or provide assistance if required

Individual perception of the level of recovery

On a scale of 0 to 100, with 100 representing full recovery and 0 representing no recovery, how much have you recovered since your Injury?



Note to researcher: Please give this sheet to the participant to complete or provide assistance if required

Rivermead Post-concussion Symptoms Questionnaire (PCS)

After a head injury or accident some people experience symptoms that can cause worry or nuisance. We would like to know if you now suffer any of the symptoms given below. Because many of these symptoms occur normally, we would like you to compare yourself

now with before the accident. For each symptom listed below please circle the number that most closely represents your answer on each line.

Compared with **before** the accident, do you **now** (i.e., over the last 24 hours) suffer from:

Q#	**Label**	**Field Format**				
		not experienced	no more of a problem	mild problem	moderate problem	severe problem
10.1	Headaches	0	1	2	3	4
10.2	Feelings of dizziness	0	1	2	3	4
10.3	Nausea and/or vomiting	0	1	2	3	4
10.4	Noise sensitivity (easily upset by loud noise)	0	1	2	3	4
10.5	Sleep disturbance	0	1	2	3	4
10.6	Fatigue, tiring more easily	0	1	2	3	4
10.7	Being irritable, easily angered	0	1	2	3	4
10.8	Feeling depressed or tearful	0	1	2	3	4
10.9	Feeling frustrated or impatient	0	1	2	3	4
10.10	Forgetfulness, poor memory	0	1	2	3	4
10.11	Poor concentration	0	1	2	3	4
10.12	Taking longer to think	0	1	2	3	4

10.13	Blurred vision	0	1	2	3	4
10.14	Light sensitivity (easily upset by bright light)	0	1	2	3	4
10.15	Double vision	0	1	2	3	4
10.16	Restlessness	0	1	2	3	4
10.17	Paralysis of half of the body (Hemiplegia)	0	1	2	3	4
10.19	Difficulty swallowing	0	1	2	3	4
10.24	Digestion	0	1	2	3	4
10.25	Difficulties with fine motor tasks (e.g. picking things up)	0	1	2	3	4

Future Contact (To be completed at 12 month assessment only)

Q#	Label	Field Format
GE.2	Would you be willing to be contacted again in the future for a further follow up assessment?	Yes No

Signature of Study Researcher

	Label	**Field format**
	Signature	Text
	Printed name	Text
	Date	ddmm20yy

Once this form is complete, and the data has been entered, give the original

to the BIONIC Study Manager.

Appendix G: Consent Form

Registration Number:	Participant Initials:	Date of Birth:

CONSENT FORM

REQUEST FOR INTERPRETER			
English	I wish to have an interpreter.	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhakaMāori /kaiwhaka pakeha korero.	Ae	Kao
Samoan	Oute mana'o ia iai se fa'amatala upu.	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea.	Io	Ikai
Cook Island	Ka inangaro au i tetai tangata uri reo.	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu.	E	Nakai

1. I have read/had explained to me, and understand, the Information Sheet (Version 6, dated 25/08/2009) for adult participants taking part in the BIONIC study. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
2. I understand that taking part in this study is voluntary (my choice). I realise the study involves an interview with medical and lifestyle questions, that I may choose not to answer any questions or withdraw from the study at any time and this will in no way affect my future health care.

3. I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.
4. I agree to an approved auditor appointed by either the ethics committee, or the regulatory authority or their approved representative, and approved by the Northern Region Y Ethics Committee reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.
5. I give my approval for information regarding my present illness to be obtained from medical records.
6. I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
7. I understand the compensation provisions for this study.
8. I have had time to consider whether to take part.
9. I know whom to contact if I have any questions about the study.

I understand that my GP will be contacted about my participation in this study. I am indicating my approval (or otherwise) for the following:

I wish to receive a copy of the results. I understand that there may be a significant delay between data collection and the publication of the study results.	Yes / No

I _____ hereby consent to take part in this research.

OR

I am a representative of _____ (the participant), being a person who is lawfully acting on the participant's behalf or in his or her interests. My relationship to the participant is _____. I agree to health information about the participant being disclosed for the purposes of this research. I also agree to participate in this research.

(Please draw a line through the statement above that is not relevant).

Signature

(or representative) Signature of witness…….

Date: Name of witness……...

Project explained by Project role

……..……

Signature Date

……..……

Note: A copy of the consent form to be retained by participant and a copy to be placed in the Case Record File

Approved by the Northern Region Y Ethics Committee

Appendix H: Letter Requesting Access

FORM A: Case Notification

(For ALL Participants)

Information to be obtained from medical notes and/or interview

(Data to be collected at next assessment, if information not available from medical records)

Registration number: ☐☐☐☐☐☐

Participant initials: ☐☐☐☐

Date of birth: ☐☐ ☐☐ ☐☐

d d m m y y

General Questions – Section 1

Q#	Label	Field format
1.1	NIH Number	
1.2	Gender	Male Female
1.3.1	TBI between 1 March 2010 and 28 Feb 2011	Yes No
1.3.2	Are they a resident of Hamilton /Waikato District	Yes No
(If answer no to 1.3.1 or 1.3.2, the person is not eligible for the study, stop here sign and date form)		
1.3.3	Area of Residence	Resident of Hamilton Resident of Waikato
1.4	Ethnicity (tick one on each line) New Zealand European Māori Samoan Cook Island Māori Tongan Niuean Chinese Indian Other (such as Dutch, Japanese, Tokelauan)	 Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No Yes/No
1.4.1	If other, please specify	Text
1.5	Date of Birth	ddmmyyyy