You only get one brain: An exploratory retrospective study on life after adolescent traumatic brain injury

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Abstract

This research adds to the relatively scarce body of literature regarding adolescent experiences of traumatic brain injury (TBI). It uses a qualitative methodology to explore how sustaining a TBI at this unique stage of development might impact a young person as they navigate the challenges of adolescence and transition to adulthood, and what might support recovery. Thirteen young adults who sustained a mild-moderate TBI as an adolescent (aged 13 – 17 years), approximately 7.7 years (range = 6.7 – 8.0 years) prior, participated in the research. Semi-structured individual interviews were conducted to explore participants' experiences surrounding and following their TBIs. Thematic analysis of interview data produced five key categories of findings: (1) Following their TBIs, many participants experienced problems with cognitive (e.g., forgetfulness, concentration difficulties), physical (e.g., migraines, fatigue) and emotional (e.g., depression, anxiety) functioning, which were often endured into adulthood. (2) TBI-related problems often adversely affected important areas of life for the participant, including school, work and friendships. (3) Changes following TBI commonly impacted identity formation. (4) Recovery processes evolved over time as the participants coped initially by just 'getting on with it', before learning to accept new limitations and, ultimately, growing from their TBI experiences. (5) While the presence of friends and family assisted recovery, struggles were often exacerbated by a lack of emotional support from others, in addition to the absence of any assistance or information-provision from professionals regarding what to expect following TBI. In conclusion, even mild TBI sustained during adolescence can have consequences for an individual's functioning, engagement in life and identity development, whilst also giving rise to post-traumatic growth. Recovery following adolescent TBI might be maximised by facilitating greater understanding of the injury and acknowledging its impacts on important areas of life, as well as the provision of emotional support and facilitating self-reflection and meaning-making.

Contents

Glossary

The following abbreviations, listed in alphabetical order, are seen throughout this thesis

ACC	Accident Compensation Corporation
ADHD	Attention deficit hyperactivity disorder
BIONIC	Brain Injury Outcomes New Zealand in the Community
BIONIC4You	Brain Injury Outcomes New Zealand in the Community; 4 Year Outcomes
CDC	Centers for Disease Control and Prevention
COBIC	Child Outcomes of Brain Injury in the Community
DAI	Diffuse axonal injury
DSM-IV	Diagnostic and Statistical Manual; Fourth Edition
GCS	Glasgow Coma Scale
HRQoL	Health Related Quality of Life
mTBI	Mild traumatic brain injury
NZ	New Zealand
OI	Orthopaedic injury
PCS	Post-concussive symptoms
pTBI	Paediatric traumatic brain injury (TBI sustained up to the age of 18)
PTG	Post-traumatic growth
TBI	Traumatic brain injury
WHO	World Health Organization
YLL	Years of life lost

Chapter One: Introduction

The present study aims to explore qualitatively the adolescent experience of traumatic brain injury (TBI) and its potential long-term impacts. As such, this literature review examines the adolescent period, followed by a discussion of TBI in general, and finally what is known about TBI within the adolescent period in more detail. This includes a brief overview of quantitative findings, followed by an examination of available qualitative reports. The terms ‘adolescents’, ‘young people’ and ‘youth’ are often used interchangeably.

Adolescence

Defining adolescence. The World Health Organization (WHO) broadly defines adolescence as occurring between the ages of 10 and 19 years (Dick & Ferguson, 2015), a period generally viewed as a transitional phase between the relatively stable developmental stages of childhood and adulthood (Furlong, Woodman, & Wyn, 2011; Sawyer & Azzopardi, 2018). Although the onset of puberty, a biological event, typically marks the beginning of adolescence, its conclusion is largely defined socially (and thereby varies by cultural and historical circumstance), and is signalled by the full assumption of adult roles (Blakemore & Mills, 2014; Cotton Bronk, 2010; Inhelder & Piaget, 2013).

In order to prepare the young person for this assumption of adult roles, the adolescent period sees the considerable development of new skills, which are linked to cortical development and associated cognitive maturation, social development, and the formation of an identity. These are discussed, in turn, below, followed by a description of certain sociocultural influences that are relevant to youth in 21st century Western societies.

Adolescent cortical development. Adolescence is a critical period for brain development, with marked pruning of unused synapses, enhancements in connectivity amongst brain regions, and maturation of the prefrontal cortex. During the period surrounding adolescence, synaptic connections between neurons are overproduced, after which those receptors within networks that receive stimulation from the environment are reinforced and maintained, while those that are not stimulated are lost (Andersen, 2003; Cotton Bronk, 2010). This elimination of unnecessary connections (i.e., synaptic pruning) leads to more efficient neural communication, and a more integrated and differentiated brain (Andersen, 2003; Cotton Bronk, 2010). The progression of myelination throughout adolescence also contributes to improved communication within the brain (Imperati et al., 2011; Mabbott, Rovet, Noseworthy, Smith, & Rockel, 2009). This accelerated development of myelin sheaths paired with pruning of unused synapses during adolescence gives rise to increased cortical white matter and speeds up electrical impulse transmission (Giedd et al., 1999; Noggle, 2011; Sowell, Thompson, Colin, et al., 1999).

Cerebral changes during adolescence are most noteworthy in the prefrontal region (Cotton Bronk, 2010; Dumontheil, 2014; Giedd et al., 1999; Noggle, 2011; Sowell et al., 1999a; Sowell et al., 1999b), which neuropsychology identifies as essential for complex cognitive activities, including abstract thinking, decision-making, emotional regulation, working memory, divided attention and organising (Dumontheil, 2014; Lezak, 2012). This cortical development is not only implicated in enhancing these ‘executive functions’ (Dumontheil, 2014; Shaw et al., 2006), but also has implications for advanced language processing (Ashtari et al., 2007), visuospatial abilities (Fryer et al., 2008), memory recall (Dumontheil, 2014; Mabbott et al., 2009) and social skills (Nelson, Leibenluft, McClure, & Pine, 2005; Turkstra, Williams, Tonks, & Frampton, 2008; Yeates et al., 2004, 2013).

The cortical changes described co-occur with known advancements in adolescent thinking processes, as encapsulated in Piaget’s theory of cognitive development (Inhelder & Piaget, 2013; Piaget, 1968, 1972). Piaget described how, during the ‘formal operations’ stage, an adolescent progresses from thinking about concrete reality (i.e., ‘concrete operations’ stage of childhood), to engage in hypothetical reasoning and abstract thinking about matters beyond the immediate environment and everyday reality (Inhelder & Piaget, 2013; Piaget, 1968, 1972).

Together, the attainment of a more intricate cortical system and increasingly sophisticated cognitive operations have important implications for adolescent socioemotional development, enabling significant social development and the formation of identity.

Social development. Social skills are a particularly important area of proficiency to consolidate during adolescence, owing to the maturation of neuronal connections and prefrontal regions (Nelson et al., 2005; Turkstra et al., 2008; Yeates et al., 2013). Social interactions become especially important to the adolescent, not only for exchanging social knowledge, but as a vehicle to establishing and maintaining relationships, thereby preparing for intimate and supportive adult relationships (Turkstra et al., 2008). To successfully engage with others and negotiate their increasingly complex social world, the adolescent draws upon executive functions to perceive information, understand its explicit and implicit meanings, conceptualise the perspectives of others, and respond appropriately (Elkind & Bowen, 1979; Turkstra et al., 2008).

Elkind (1967) proposed that the young person's new social cognitive abilities give rise to two stereotypical belief systems that influence their social behaviour, which are still considered relevant to contemporary youth (Bluth & Blanton, 2015; Cingel & Krcmar, 2014; Cingel, Krcmar, & Olsen, 2015; Jowkar & Noorafshan, 2011). Firstly, the concept of a 'personal fable', an unrealistic belief that one is special or unique, has been linked to an adolescent's tendency to feel that no one could possibly understand them (Elkind, 1967; Elkind & Bowen, 1979). The second phenomenon, the 'imaginary audience', is a young person's belief that others are as concerned (and indeed as critical) with their thoughts, behaviour and appearance as they themselves are (Elkind, 1967; Elkind & Bowen, 1979).

Group membership and feeling connected to others is crucial for the adolescent (Baumeister & Leary, 1995), thus peer relationships at this stage often centre on competition for peer approval, social comparisons, and hypervigilance to rejection (Irons & Gilbert, 2005; Zimmer-Gembeck, 2015, 2016). Such peer processes can significantly impact the psychological wellbeing of adolescents, with young people who perceive themselves as inferior to their peers reporting greater depression and anxiety symptoms (Irons & Gilbert, 2005; Zimmer-Gembeck, 2015, 2016). With age, adolescents are seen to increasingly rely on peers as social influences and sources of support, although family remains an important supportive base (Baumeister & Leary, 1995; Blakemore & Mills, 2014; Bradford Brown & Bakken, 2011; Zimmer-Gembeck & Skinner, 2011).

Identity development. Identity development occurs in the context of this heightened sensitivity to sociocultural signals in the environment, as the young person seeks to discover who they are and where they fit in relation to others (Blakemore & Mills, 2014; Kroger, 2007). In his theory of psychosocial development, Erikson (1963, 1968) emphasised identity-formation as a key task of adolescence, where the young person reviews old self-conceptions, explores a range of possible identities, and integrates these. This process is enabled by developing cognitive abilities that facilitate more complex self-examination and increased interest in autobiographical events and personal continuity (Habermas & Bluck, 2000; Inhelder & Piaget, 2013; Klimstra, Hale, Raaijmakers, Branje, & Meeus, 2010).

With a foundation in Erikson’s theory, the identity status paradigm conceptualises the process of identity formation through adolescence and early adulthood in relation to the processes of exploration and commitment (Luyckx et al., 2006, 2008; Schwartz, Luyckx, Goossens, Beyers, & Missotten, 2011). Exploration relates to the degree to which multiple identity alternatives are considered, while commitment refers to choosing to adhere to one or more available alternatives. During the high school years, the young person might engage in in-depth exploration of commitments and evaluate how well they ‘fit’, before identifying with a commitment (Klimstra et al., 2010; Meeus, Van De Schoot, Keijsers, Schwartz, & Branje, 2010; Schwartz et al., 2011). A newly consolidated sense of identity emerges as a result of enacting identified commitments, and this contributes to a sense of personal continuity and a perception of security over time (Schwartz et al., 2011). Those who engage in insufficient exploration or commitment will remain undecided regarding identity, and tend to have higher rates of depression and lower self-esteem (Luyckx et al., 2008).

‘Emerging adulthood’ in the 21st century. Identity formation and transition to adulthood is shaped by the social, economic and political circumstances of the time (Erikson, 1968; White & Wyn, 2008). Considerable social change in recent decades has given rise to a very different experience of transition to adulthood for contemporary Western youth in comparison to previous generations (Chesters, Smith, & Laughland-booÿ, 2018). The youth cohort of the 1960s and 1970s enjoyed well-prescribed pathways from adolescence to adulthood, where one would finish high school and get married, with men entering the workforce and women becoming homemakers (Furlong et al., 2011; Schwartz, Tanner, & Sayed, 2016; White & Wyn, 2008; Wyn & Woodman, 2006). With recent global economic shifts and growing job insecurity (Furlong et al., 2017), this transition has become increasingly complex and precarious for 21st century youth (Chesters et al., 2018; Schwartz et al., 2016). With young people now leaving home, gaining stable employment, and entering long-term romantic relationships much later than previously, ‘emerging adulthood’ is proposed as a new phase between adolescence and the time when these adult roles are fully assumed (Arnett, 2000; Chesters et al., 2018; Furlong et al., 2011; Schwartz et al., 2016).

The increased unpredictability of outcomes in recent decades has required young people to take personal responsibility for their lives in a way that is different to previous generations (Furlong et al., 2011; Wyn, 2004; Wyn & Woodman, 2006). While the resulting growth of individualisation is considered positive and empowering in its facilitation of increased agency for young people (Wyn & Dwyer, 1999), uncertainty can be a source of stress (Chesters et al., 2018). With the dissolution of prescribed adult roles, young people feel increasingly pressured to extend their commitments across multiple life domains (e.g., work, study, leisure, relationships, personal development, parenthood) in order to become a successful adult (Wyn, 2004; Wyn & Woodman, 2006). Furthermore, the rise in the use of social media might contribute to perceived pressure to keep up with peers in all these areas (O'Keeffe et al., 2011). While most manage this balance fairly well, those who perceive that they have failed report negative implications for their mental health (Wyn, 2004).

Summary. Adolescence is a time of substantial development in many areas, with the emergence of more sophisticated cortical processes and cognitive abilities allowing for increased social competence and aiding what is believed to be the primary task of adolescence – to actively develop an independent social identity, and transition into adult roles. The social context of 21st century Western societies has seen the manifestation of an 'emerging adulthood' stage, characterised by delayed assumption of adult roles, increased uncertainty, and a need for autonomy and balance for contemporary youth.

Given the large amount of development and change expected during the adolescent period, particularly biological and brain development and their implications for social behaviour, it might be expected that experiencing a brain injury during this period could have particularly damaging outcomes. The general definitions and outcomes of TBI are reviewed below, followed by a more detailed exploration of TBI in adolescence.

Traumatic Brain Injury

This section defines TBI, discusses the mechanisms and pathophysiology of TBIs, and reviews the impact and epidemiology of TBI internationally and in New Zealand (NZ).

Classification of TBI in terms of injury severity is covered, followed by the cognitive, emotional, physiological and psychosocial outcomes.

Definition, mechanisms and pathophysiology of TBI. TBI is a heterogeneous condition, with significant variation in the definition, causes, pathology and prognosis of TBIs evident within the literature (Lingsma, Roozenbeek, Steyerberg, Murray, & Maas, 2010; Prins, Greco, Alexander, & Giza, 2013; Silver, McAllister, & Yudofsky, 2008). TBI is broadly defined as “an alteration in brain function, or other evidence of brain pathology, caused by an external force” (Menon, Schwab, Wright, & Maas, 2010, p. 1638). Such forces may produce ‘penetrating’ injuries, where the skull is punctured and brain tissue damaged; and ‘closed’ TBI, in which the brain is not penetrated but damaged by movement of the brain within the skull (McAllister, 2011; Menon et al., 2010; Prins, Greco, et al., 2013). Closed head injuries are substantially more common and are therefore discussed in further detail.

In closed TBI, two types of biomechanical forces, contact and inertia, can create focal and diffuse damage, as sudden acceleration-deceleration or rotation of the head causes the brain to move within the skull (McAllister, 2011; Prins, Greco, et al., 2013). Firstly, contact injuries can occur as the brain hits and rubs against the sharp bony interior ridges of the skull, with the sites most commonly exposed to such focal damage including the prefrontal cortex, orbitofrontal cortex, temporal poles, hippocampi, and ventral brain stem (Bigler, 2007; McAllister, 2011; Ogden, 2005a; Reddy, Rajeswaran, Devi, & Kandavel, 2017).

The primary cause of pathology is thought to be the tremendous inertial forces to which the brain is exposed as it moves within the skull (Giza & Hovda, 2001, 2014; Prins et al., 2013). This gives rise to a cascade of neurometabolic events, including bioenergetic challenges, axonal damage and impairments in neurotransmission, as the neurons and connective fibres that make up brain tissue are torn and stretched (Giza & Hovda, 2001, 2014; Prins et al., 2013).

Axons, which play a vital role in neurotransmission and inter-neuronal communication throughout the brain (Debanne, Campanac, Bialowas, Carlier, & Alcaraz, 2011), are particularly vulnerable to biomechanical stretching, given their inherent structural design and placement along different axes (Johnson, Stewart, & Smith, 2013). Diffuse axonal injury (DAI) can occur as axons become twisted, misaligned and even torn and degenerated, causing an indiscriminate release of neurotransmitters that initiates a multitude of intracellular reactions (Giza & Hovda, 2001, 2014; Johnson et al., 2013; McAllister, 2011; Zuckerbraun, King, & Berger, 2015). It is likely that DAI and impaired neurotransmission contribute to the post-concussive symptoms of TBI (Giza & Hovda, 2014), which are discussed in a later section, after a review of TBI epidemiology.

Epidemiology of TBI.

Incidence and prevalence. The frequency of TBIs reported worldwide vary considerably. Rates in Europe range from 47 to 453 per 100,000 (Koskinen & Alaranta, 2008; Peeters et al., 2015; Pérez et al., 2012; Tagliaferri, Compagnone, Korsic, Servadei, & Kraus, 2006; Yates, Williams, Harris, Round, & Jenkins, 2006), Australian population estimates vary between 219 and 345 per 100,000 per year (Crowe, Babl, Anderson, & Catroppa, 2009), and TBI incidence in the USA has been reported as 558 per 100,000 person-years in (Leibson et al., 2011). These studies are typically reliant on hospital and other health system admissions data.

Findings from the population-based incidence Brain Injury Outcomes New Zealand in the Community (BIONIC) study reported the total NZ incidence of TBI as 790 per 100,000 person-years (Feigin et al., 2013), a figure significantly greater than those of other high-income countries. BIONIC reported on community-based incidence, thereby capturing those who did not seek medical treatment and would have been missed by other studies. Approximately 36% of BIONIC cases were never seen by medical services (Feigin et al., 2013). With regard to prevalence, in 2010, approximately 527,400 New Zealanders (13% of the NZ population) had experienced at least one TBI event in their lives (Te Ao et al., 2015).

Burden. TBI is considered a major health and socioeconomic problem throughout the world (Peeters et al., 2015), affecting approximately 10 million people annually (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007). TBI is often considered a ‘silent epidemic’, a term reflecting the lack of awareness of the impact of TBI on society, the underestimation of its true incidence, and the invisibility of its consequences (Edge, 2010; Peeters et al., 2015).

One population study carried out across 16 European countries (Majdan et al., 2017) estimated 374,636 years of life lost (YLLs) to TBIs in 2013. The BIONIC research group reported 14,386 YLLs and 5,891 years lived with disability due to TBIs occurring in a 12-month period in NZ (Te Ao et al., 2015). Thus, the majority (71%) of health loss was due to TBI-related fatalities. Mild TBI made the greatest contribution (i.e., 56%) to the non-fatal burden. Health loss attributable to TBI in NZ was estimated to be over one-quarter (27%) of all losses of health attributable to injuries in 2010 (Ministry of Health, 2013). The total prevalence costs of all new TBI cases in NZ in 2010 was estimated to be US $101.4 million, with the total cost of treating of mild TBI cases was almost three times that of moderate/severe (Te Ao et al., 2014).

Demographic incidence and prevalence. TBI incidence worldwide appears to peak during early childhood, adolescence, and again in late life (Bener et al., 2010; Hyder et al., 2007; Langlois, Rutland-Brown, & Thomas, 2004; Taylor, Bell, Breiding, & Xu, 2017). In NZ, males, particularly young men, appear more affected by TBI than females (Barker-Collo, Wilde, & Feigin, 2008; Feigin et al., 2013). This is consistent with international findings that men and boys are 1.5 times as likely as women and girls to experience a TBI (Langlois et al., 2004). Crude prevalence estimates in NZ were 14.8% for males and 11.4% for females in

2010 (Te Ao et al., 2015). The burden of TBI (as captured by disability-adjusted life years/DALY) was estimated as twice as high in NZ males as in females, and higher in younger than in older age groups, peaking between 20 and 24 years (Te Ao et al., 2015).

Rates of TBI-related hospital appearances have been reported as much higher for Māori and Pacific peoples, than those for the remaining NZ population, with Māori males potentially twice as likely to experience a TBI (Barker-Collo et al., 2008). More recent figures show NZ Māori, specifically young Māori, are at particular risk of sustaining mild TBI compared to those of European descent with overall incidence in Māori males approximately 1000 per 100,000 (Feigin et al., 2013). That Māori feature disproportionately in TBI figures is consistent with patterns in other health statistics (Ministry of Health, 2015; Robson, Purdie, Simmonds, Waa, & Rameka, 2015). Māori children and young people are also shown to experience higher rates of almost all reported physical and mental health problems, compared to non-Māori non-Pacific people (Simpson et al., 2017).

Substantial ethnic disparities are shown in TBI incidence internationally (Corrigan, Selassie, & Orman, 2010; Hyder et al., 2007; Langlois, Rutland-Brown, & Thomas, 2005; Stålnacke, Elgh, & Sojka, 2007), and higher TBI rates have been observed in indigenous communities elsewhere (Rutland-Brown, Wallace, Faul, & Langlois, 2005). There are also reported differences in the impact of TBI according to race. For instance, African Americans experienced significantly lower social integration and greater loss of income following TBI than White Americans (Hart, Whyte, Polansky, Kersey-Matusiak, & Fidler-Sheppard, 2005).

Causes. The rise in motor vehicle use in recent decades brought about an increase in TBIs caused by road-traffic incidents in all parts of the world (Bener et al., 2010; Edge, 2010; Fagerholm, Hellyer, Scott, Leech, & Sharp, 2015; Hyder et al., 2007; Taylor et al., 2017). However, more recent improvements in traffic accident prevention has seen the number of traffic-related injuries superseded by an increased prevalence of fall-related TBI

(Heidenreich, 2017; Peeters et al., 2015; Taylor et al., 2017). This is consistent with the pattern in NZ, with most incidents due to falls (38%), followed by mechanical forces (21%), traffic incidents (20%), and assaults (17%; Feigin et al., 2013). Falls more often caused TBI in NZ children and the elderly, whereas assaults, transport accidents and exposure to mechanical forces were more common in young adults. This pattern is consistent with the international finding (Thurman, 2016) that, in children aged 5 to 14 years, falls are the most common cause of TBI, followed by sports and recreation-related incidents, and then motor vehicle accidents; while in youth 15 years and older, motor vehicle-related incidents were the most common cause, followed by assault, and sports-related incidents (Thurman, 2016). Māori people aged 15 to 64 years old had a greater incidence of assault-related TBI incidence compared to those of European origin (Feigin et al., 2013).

Classification of TBI. TBI is most commonly classified with regard to injury severity, with severities ranging from mild to moderate or severe (Vos & Diaz-Arrastia, 2015). Severity ratings are usually based on neurological examination, commonly operationalised via the Glasgow Coma Scale (GCS), a standardised assessment of the level of impairment in consciousness based on responses to defined stimuli (Teasdale & Jennett, 1974). A GCS score between 3 and 8 is suggestive of a severe TBI, moderate injuries fall between 9 and 12, and mild TBI (mTBI) are defined by a GCS of 13 to 15 (Vos & Diaz-Arrastia, 2015). However, this method of classification is often criticised, specifically for its inadequate sensitivity in capturing the nuances in signs occurring in mTBI (Grubenhoff, Kirkwood, Deakyne, & Wathen, 2011; Mayer, Quinn, & Master, 2017; Reith, Van den Brande, Synnot, Gruen, & Maas, 2016). Other information, such as the duration of unconsciousness and/or posttraumatic amnesia ("the transitory period of disorientation, confusion, and amnestic memory impairment following TBI, which leaves a gap in memory"; Rabinowitz & Levin, 2014, p.1), are often used concurrently to aid in classifying the severity of an injury (Menon et al., 2010; Vos & Diaz-Arrastia, 2015). The majority of injuries, from 70% to 90%, are reported as mTBI worldwide (Cassidy et al., 2004; Edge, 2010; McKinlay, 2010; Peeters et al., 2015; Tagliaferri et al., 2006), and 95% in NZ (Feigin et al., 2013).

Outcomes following TBI. There is broad heterogeneity in symptoms and recovery profiles following a TBI, even if injuries appear similar (Lingsma et al., 2010; McInnes, Friesen, Mackenzie, Westwood, & Boe, 2017), and outcomes can range from full recovery to permanent disability or death (Bener et al., 2010; Jones et al., 2016). The physiological, cognitive and emotional consequences of TBI are often clustered under the label ‘post-concussive symptoms’ (PCS). Below, those symptoms typically included in examinations of PCS are described, followed by a summary of their psychosocial implications.

Post-concussive symptoms. PCS are prevalent across all injury severities, and evolve in the initial minutes to days and weeks after the trauma (Heidenreich, 2017). PCS include a range of vestibular (e.g., dizziness, difficulty coordinating), physical/sensory (e.g., headaches, nausea, fatigue, light and noise sensitivity), cognitive (e.g., inattention, forgetfulness, slowed processing), and emotional (e.g., irritability, disinhibition, anxiety) symptoms (Hiploylee et al., 2016; Reddy et al., 2017; Vanderploeg et al., 2015). Although most PCS resolve within one to three months following TBI, evidence continues to emerge suggesting that recovery of symptoms may be prolonged beyond this period for 20% to 55% of patients (Heidenreich, 2017; Hiploylee et al., 2016; Johnson et al., 2013; McInnes et al., 2017). Hiploylee and colleagues (2016) reported that only 27% of their 110 participants fully recovered from PCS, with 67% of those doing so within one year, and indicated that PCS may be permanent if recovery has not occurred in the initial three years. Repeated TBIs are expected to trigger significantly more pronounced PCS than single injuries. The timing of the subsequent injury/injuries is the key determinant in consequential symptoms severity, with proximity to the index injury associated with worse outcomes (Giza & Hovda, 2014; Longhi et al., 2005;

Prins, Alexander, Giza, & Hovda, 2013; Theadom et al., 2015).

Cognitive symptoms. The cerebral regions particularly vulnerable to damage during TBI (i.e., prefrontal and temporal regions, subcortical white matter tracts) serve important cognitive and social functions. For instance, the prefrontal cortices are considered crucial for executive functions and intuitive reflexive social behaviours, circuits within temporal regions have critical involvement in episodic memory and learning, while speed of information processing is particularly dependent on white matter function (Lezak, 2012; McAllister, 2011; Rabinowitz & Levin, 2014). This understanding is oversimplified, however, and the responsibility for the true impact of TBI lies in the connections between various cortices. Damage to white matter due to DAI strongly correlates with burden of neurocognitive impairment (Babikian et al., 2010; Kraus et al., 2007). Diffusion magnetic resonance imaging has revealed the complex functional effects of TBI, by mapping disconnections in brain networks (e.g., intrinsic connectivity networks important for attentional control) brought about by DAI (Sharp, Gregory, & Leech, 2014).

The cognitive domains most often affected by mild to moderate TBI include memory, attention, processing speed, and executive functioning, with these deficits mostly resolving within three to six months of injury (Rabinowitz & Levin, 2014; Reddy et al., 2017). BIONIC study findings revealed forgetfulness, poor concentration and slowed thinking as the most common cognitive symptoms experienced up to 12-month following mTBI (Theadom, Parag, et al., 2016). At baseline and at 6 months post-mTBI, greater than 20% of individuals performed very poorly on tasks requiring executive ability, complex attention and cognitive flexibility (Barker-Collo et al., 2015)

Such functions are also impacted by moderate to severe TBI, while additional deficits may be observed in domains such as communication, visuospatial processing, intellectual ability, and insight (Rabinowitz & Levin, 2014). A roughly linear correlation exists between

TBI severity and cognitive sequelae, with longer duration of impaired consciousness at the time of injury predictive of greater cognitive dysfunction (Rabinowitz & Levin, 2014).

Emotional symptoms. Emotional symptoms were commonly reported in one study (Eisenberg, Meehan, & Mannix, 2014) that attempted to capture the duration of acute PCS in paediatric TBI patients (N = 235), with 27.7% reporting frustration, 25.5% irritability and 24.6% restlessness. TBI is also associated with increased risk of experiencing psychiatric disorders (Gould, Ponsford, Johnston, & Schönberger, 2011; McAllister, 2011). Clinical records of 279 NZ TBI patients indicated that 57.7% experienced significant psychological problems post-injury with 8.6% given a psychiatric diagnosis, including anxiety, schizophrenia, bipolar disorder, depression, post-traumatic stress disorder (PTSD; Gibson & Purdy, 2015).

Depression is the most commonly studied psychological disorder following TBI, and it appears particularly frequently in the first 12 months (Barker-Collo et al., 2015). Depression was reported as eight times more prevalent in the initial year post-injury than in the general population (Bombardier et al., 2010). Levels of injury severity, impairment, and functioning appear unrelated to developing major depression (Barker-Collo et al., 2015). Deciphering depression symptomology from those typical of TBI can affect the accuracy of research in this area (Corrigan & Deutschle Jr, 2008; Lin & Jorge, 2017). Barker-Collo and colleagues (2015) found depression to be related to self-reported pre-morbid anxiety and depression, as well as higher rates of depression immediately post-TBI using the Diagnostic and Statistical Manual, Fourth Edition (DSM-IV; 49%) than the Hospital Anxiety and Depression Scale (i.e., 21%). The latter removes more physiologically-based symptoms that could be result from the TBI itself. It remains unclear whether the increased prevalence of mental health disorders relates to brain changes following the injury or psychological responses to the injury, but it is assumed that there are some underlying organic mechanisms (Jorge & Arciniegas, 2014; Jorge & Starkstein, 2005).

Physiological/sensory symptoms. Most common acute physical and sensory symptoms reported amongst Eisenberg and colleagues' (2014) paediatric cohort (N = 235) included headaches (reported by 85.1%), nausea (seen in 41.6%), light sensitivity (42.5%), noise sensitivity (40.4%), dizziness (61.3%), blurred vision (32%), double vision (13.2%). Fatigue, however, is one of the most reported long-term physiological complaints, experienced by up to 70% of adult TBI patients (Ponsford et al., 2014; Theadom, Rowland, et al., 2016). Fatigue is thought to result from DAI and the increased mental effort required to think (Esbjörnsson, Skoglund, & Sunnerhagen, 2013; Johansson, Berglund, & Rönnbäck, 2009). With most improvement occurring in the first six months (Theadom, Parag, et al., 2016), fatigue seems to decrease only slightly from two to ten years (Ponsford et al., 2014). Headaches are another common chronic problem, with a prevalence rate reported as 57.8% (Nampiaparampil, 2008). Elsewhere, new or worse headaches or migraines, compared to pre-injury, occurred at a rate of 54% immediately after TBI, 69% six months later, and 58% at one year follow up (Lucas, Hoffman, Bell, & Dikmen, 2014).

Psychosocial implications. New difficulties arising from TBI can interfere with an individual's capacity to fulfil their social roles (Rabinowitz & Levin, 2014). Even in cases of mTBI, ongoing PCS can negatively impact a sufferer's confidence in their ability to work and maintain relationships, and disrupt family functioning (Ogden, 2005; Schönberger, Ponsford, Olver, & Ponsford, 2010). Only about half of patients with mild to severe TBI (N = 141) had returned to all previous activities two years post-injury (Ponsford et al., 2014). More than half of adults (N = 245) reported new challenges at work following a mTBI, with one in five struggling to meet the demands of their employment four years after their injury (Theadom et al., 2017). People report problems making and maintaining friendships following their injuries, and 41% to 47% report having lost friends or feeling more isolated (Ponsford et al., 2014).

Summary. TBI is a common condition that sees broad heterogeneity in terms of causes, symptoms, and recovery, and can significantly impact one's cognitive, emotional, physical and psychosocial functioning in both the short and long term. Having reviewed the literature on adolescence and TBI broadly, the section that follows discusses TBI in childhood and adolescence generally, followed by an examination of mTBI during the adolescent period more specifically.

Paediatric Traumatic Brain Injury

TBI is one of the most frequent accident types and a leading cause of death and disability for children and young people worldwide (Edge, 2010; Semrud-Clikeman & Bledsoe, 2010). While 30% to 60% of international TBI cases appear to be paediatric (Hyder et al., 2007; Rickels, von Wild, & Wenzlaff, 2010; Wu et al., 2008), much remains to be investigated regarding injuries at these life stages (Vos & Diaz-Arrastia, 2015). This section discusses literature concerning child and adolescent TBI, which will be referred to as paediatric TBI (pTBI), since most research has investigated both age groups together. Reference will be made to adolescent-specific research where possible. Literature regarding the role of neural plasticity and what is thought to be known about the impacts of pTBI are of particular interest.

The role of neural plasticity. Given the extent of neural plasticity and the maturation of neurological processes in children and adolescents (Andersen, 2003; Cotton Bronk, 2010; Giedd et al., 1999; Imperati et al., 2011; Sowell, Thompson, et al., 1999), it was once assumed that younger brains could adapt to the effects of head trauma, making youth more resilient to the impact of TBI than adults (Eslinger, Grattan, Damasio, & Damasio, 1992;

Kolb, 1989). On the contrary, subsequent investigations have uncovered the opposite pattern, suggesting that children and adolescents may actually suffer a worse prognosis (Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2005b; Keightley et al., 2014; McKinlay, Grace, Horwood, Fergusson, & MacFarlane, 2009).

Indeed, increased plasticity may enhance the brain's capacity to shift functions to preserved areas, thus boosting short-term recovery (Kade & Fletcher-Janzen, 2009). However, animal model studies suggest that axonal vulnerability (Prins, Hales, Reger, Giza, & Hovda, 2010; Reeves et al., 2005) and impairments in plasticity (Fineman, Giza, Nahed, Lee, & Hovda, 2000; Ip, Giza, Griesbach, & Hovda, 2002) may actually be more prominent in the young brain. Unmyelinated axons of white matter tracts in the corpus callosum of rats are more vulnerable to TBI, and show greater impairment of electrophysiological function, than myelinated fibres (Reeves et al., 2005). This finding has implications for humans, given the ongoing myelination of axonal tracts that occurs during adolescent development (Imperati et al., 2011; Mabbott et al., 2009).

Consistent with animal studies, human adolescents with mild, moderate and severe injuries present with persistent white matter abnormalities, particularly in the prefrontal and temporal regions (Adamson et al., 2013; Henry, Burkhart, Elbin, Agarwal, & Kontos, 2015; Königs et al., 2017). In addition, magnetic resonance imaging has revealed reduced cerebral blood flow in adolescents 12 months post-TBI (Wang et al., 2014) and significant volumetric loss in grey and white matter can be seen for years after moderate and severe pTBI (Wilde et al., 2005).

The true impact of TBI on the developing brain is prolonged and complex. Going beyond consideration of the loss of existing skills, the acquisition of new social and cognitive skills may be seen as the individual matures and more integrative neural processes become critical to functioning (Brenner et al., 2007; Di Battista, Soo, Catroppa, & Anderson, 2012;

Ewing-Cobbs et al., 2004; Savage, DePompei, Tyler, & Lash, 2005; Yeates et al., 2007). That is, young people may grow into their deficits as they age. Unfortunately, longer-term consequences of pTBI are often neglected in the research, and the impact of an injury, particularly on an older child or adolescent, beyond the acute phase, is poorly understood (Keightley, Côté, et al., 2014; Rennie, 2015; Savage et al., 2005).

Outcomes following pTBI. PTBI can culminate in a variety of adverse short- and long-term outcomes. Recent interest in pTBI has focussed on mild injuries, and this literature is discussed in detail below. Firstly, this section covers what is currently known about pTBI more generally, including the experience of PCS, followed by academic, behavioural, social and family-related outcomes following injuries across the severity spectrum.

Post-concussive symptoms. Children and adolescents present with similar PCS as those described for adults (Hawley, Ward, Magnay, & Long, 2004; Hooper et al., 2004). Figures regarding the prevalence rates of PCS in pTBI are unclear, given the reliance on parent report and the indication that parents are poor at recognising symptoms in their children following TBI (Stevens, Penprase, Kepros, & Dunneback, 2010). For instance, two studies that utilised parent report regarding paediatric cases have conflicting findings. One study (N = 681) reported that just 8.9% of children and adolescents experienced one or more symptoms one month and 2.8% ten months post-TBI (Hooper et al., 2004). Elsewhere, in a total of 526 cases, PCS were reported for one third of those with severe TBI, one quarter of youth with moderate injuries, and 10% to 18% of a mTBI group (Hawley et al., 2004).

Cognitive symptoms. Difficulties with attention, concentration and processing speed are amongst the most reported cognitive difficulties to emerge from reviews of pTBI outcomes, followed by memory, language and executive functioning deficits (Li & Liu, 2013; Savage et al., 2005; Savage, Pearson, McDonald, Potoczny-Gray, & Marchese, 2001). Parents reported that 9.5% of children and adolescents experience memory problems and

12.2% experience difficulties with attention 10 months post-TBI (Hooper et al., 2004).

Compared with children and adults, adolescents appear particularly vulnerable to the implications of TBI on executive functions (Baillargeon, Lassonde, Leclerc, & Ellemberg, 2012; Howell, Osternig, Van Donkelaar, Mayr, & Chou, 2013). Adolescents are shown to have particular trouble with working memory (Baillargeon et al., 2012; Keightley, Singh Saluja, et al., 2014), emotional lability (Henry et al., 2015), problem-solving (Wade et al., 2017), planning, obstacle-avoidance, and multitasking (Cossette et al., 2016) post-TBI. These findings are not surprising, considering the prevalence of disruption to white matter pathways and frontal cortices (Adamson et al., 2013; Henry et al., 2015; Königs et al., 2017), important for executive tasks (Lezak, 2012), and the concentrated period of maturation in these regions during adolescence (Cotton Bronk, 2010; Dumontheil, 2014).

Emotional symptoms. Adolescents who have experienced TBI are also at increased risk of developing emotional problems, including PTSD symptoms, anxiety and depression (Albicini & McKinlay, 2015; Emery et al., 2016; Laliberté Durish, Pereverseff, & Yeates, 2018; Max et al., 2012). Based on parent and self-report, 22% to 26% of adolescents demonstrated clinically elevated internalizing problems in the six months following TBI (Peterson, Connery, Baker, & Kirkwood, 2015). PTSD symptoms appear more commonly in milder injuries, supposedly since those with more severe injuries are less likely to recall their accidents (Albicini & McKinlay, 2015; O'Connor et al., 2012). Adolescents and older children appear more likely to experience depression post-TBI than younger children (Max et al., 2012), but may be less likely to present with anxiety than those who are younger at the time of the TBI (Albicini & McKinlay, 2015; Max et al., 2011). In their large sample spanning all injury severities, Max and colleagues (2012) attributed depressive symptoms to disrupted frontotemporolimbic connections, while anxiety after pTBI was reported to be indicative of a problem with affective dysregulation caused by disrupted frontal white matter systems (Max et al., 2011). Despite the discovery of structural brain changes related to depression, results are mixed regarding whether symptoms emerge due to the injury itself, were pre-existing, or evolve secondary to a young person's experiences following the TBI (Laliberté Durish et al., 2018; Max et al., 2012). Depression symptoms are associated with persistent pain in adolescents three years after sustaining TBIs of any severity (Tham et al., 2013).

Behaviour changes. Up to half of children and adolescents who sustain a TBI are at risk for developing specific behavioural problems, which may persist for several years following injury (Hawley et al., 2004; Hooper et al., 2004; Li & Liu, 2013). Problems reported include hyperactivity, impulsivity, low frustration tolerance, apathy, aggression and social disinhibition (Savage et al., 2005). Rates of behaviour related disorders, such as attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder and conduct disorder are higher for those who have sustained a pTBI (Lloyd, Wilson, Tenovuo, & Saarijärvi, 2015). Novel diagnoses of ADHD are reported as three times more common than in non-injured children (Li & Liu, 2013). However, youth with ADHD are also more likely to sustain a TBI, making it challenging to ascertain, post-injury, whether ADHD symptoms had been present prior (Alosco, Fedor, & Gunstad, 2014; Bonfield, Lam, Lin, & Greene, 2013). Research findings in this area are inconsistent, as other studies indicate that behaviour problems fall short of clinical ranges (Trenchard, Rust, & Bunton, 2013).

Academic and occupational outcomes. With deficits observed in cognitive skills so vital for learning new information, academic impairment is evident across ages following TBIs of all severities, but outcomes are poorer for more severe injuries (Ewing-Cobbs et al., 2004; Lloyd, Wilson, Tenovuo, & Saarijärvi, 2015; Savage et al., 2005; Taylor et al., 2002). Adolescents present with greater difficulty with reading comprehension and arithmetic post-TBI than children injured at earlier ages (Ewing-Cobbs et al., 2004). Learning problems may persist into adulthood (Anderson, Brown, Newitt, & Hoile, 2009), and those who sustained a TBI during adolescence are more likely to experience fluctuations in employment as young adults (Todis, Glang, Bullis, Ettel, & Hood, 2011). When compared to national census data, young adults who experienced pTBI are 3 times less likely to have completed high school; 2.3 times less likely to obtain a university qualification; 1.7 times more likely to be unemployed or in unskilled work; 2.1 times less likely to be in skilled positions; and 1.6 times less likely to have attained professional employment (Anderson et al., 2009).

Family distress. PTBI is associated with disrupted family interactions (Cattelani, Lombardi, Brianti, & Mazzucchi, 1998; Rashid et al., 2014; Wade et al., 2003), particularly in cases of poorer caregiver mental health and stress in reaction to the injury (Holland & Schmidt, 2015). Increased family distress can be associated with higher adolescent PCS (Ganesalingam et al., 2008), and differences in adolescents' and parents' appraisals of the nature and severity of the injury may cause conflict (Stancin et al., 2002). Family dysfunction and distress are associated with poorer long-term psychosocial adjustment following pTBI (McCarthy et al., 2006; Ryan et al., 2016; Taylor et al., 2002), while the availability of warm and responsive parenting is associated with fewer internalising and externalising problems in children with severe TBI (Wade et al., 2011).

Social outcomes. The past two decades have seen particular interest in the impact of pTBI on young peoples' social functioning, as measured by reduced social competence, the presence of social problems, number of friends and social cognition skills (Brenner et al., 2007; Rosema, Crowe, & Anderson, 2012; Ryan et al., 2016; Yeates et al., 2007).

Social competence, problems and friendships. Those aged 5 to 15 years display deterioration in social participation skills following TBI, as well as consistently higher rates of impairment in social outcomes than typically developing peers (Catroppa et al., 2015). Children and young adolescents who have sustained TBI are often found to have fewer friends than reference groups (Prigatano & Gupta, 2006; Yeates et al., 2013). Prigatano and Gupta (2006) reported that 75% of orthopaedic injury (OI) controls had four or more friends, compared with only 39% of those with mTBI and 20% of young people with moderate TBI. Long-term follow up following pTBI demonstrates that social difficulties can be pervasive and longstanding, continuing into adulthood, particularly for those with moderate and severe injuries (Brenner et al., 2007; Cattelani et al., 1998; Klonoff, Clark, & Klonoff, 1993; Muscara, Catroppa, Eren, & Anderson, 2009).

Social cognition. As described previously, the social interactions of ever-increasing complexity that occur during adolescence require increasingly sophisticated cognitive skills. New cognitive capacities are mediated by an integrated neural network that is established throughout childhood and adolescence (Nelson et al., 2005; Turkstra et al., 2008), with many components of this network susceptible to disruption by pTBI (Bigler, 2007; McAllister, 2011; Reddy et al., 2017). Long-term social outcomes following pTBI are predicted by neuropsychological abilities, social information-processing, and focal volumetric reductions in white matter within regions of the brain involved in social information-processing (Yeates et al., 2013, 2004).

Executive functions are central to this social information-processing network, and children and adolescents with better executive skills display better social adjustment and greater social self-awareness (Wolfe et al., 2015). Behavioural ratings of executive functions are also strongly related to social competence. Children with severe TBI display more negative outcomes than OI peers on ratings of executive functions and social competence (Ganesalingam et al., 2011). Theory of mind, emotional expression, and social problem-solving are more specific social cognition skills explored within the pTBI literature.

Theory of mind involves consideration of the mental states and intentions of others, in order to understand the perspectives of others and to predict how they will act (Dennis et al., 2012). Adolescents post-TBI have displayed an impaired capacity to recognise emotional and mental states in others 6 months to 10 years after sustaining mild to severe injuries, compared to OI controls (Dennis et al., 2012; Tousignant et al., 2016; Turkstra et al., 2008). This effect is magnified with increasing TBI severity (Dennis et al., 2012).

Emotional expressions serve important social communicative functions; not only do we use them to convey how we feel, but also to communicate to others what we want them to *think* we feel (Dennis et al., 2013). Dennis and colleagues suggest that young people with TBI have difficulty understanding the dual role of facial emotions in expressing feelings and communicating socially relevant but deceptive emotions, which may impact social outcomes. Up to four years post injury, older children and young adolescents who sustained TBIs of various severities performed more poorly on tasks involving emotional expression and emotional communication than OI controls (Dennis et al., 2013).

Children with TBI also demonstrate poorer social problem-solving skills (e.g., defining social problems, generating potential solutions to social problems, selecting problem-solving strategies, evaluating response outcomes) compared to OI controls, up to four years following their injuries (Ganesalingam et al., 2011; Janusz, Kirkwood, Yeates, & Taylor, 2002; Moran et al., 2015; Yeates et al., 2004). Social problem-solving abilities predicted the success of social reintegration post-pTBI (Muscara, Catroppa, Eren, & Anderson, 2009). However, much of the research in this area focuses on those with more severe injuries and those injured as children, as opposed to adolescents.

A model for social deficits following pTBI. Yeates and colleagues (2007) present a theoretical model illustrating how social information processing capabilities, and their neural substrates, interact with factors such as peer interactions and social adjustment, to determine how pTBI may impact a young person’s development of social competence post-injury. For example, deficits in social information processing may lead a young person to engage in behaviours that do not promote social affiliation (e.g., withdrawal), thus limiting social experiences and hindering peer interactions. Consequently, with increasing time since injury, social functioning may become more divergent from that of peers, and even if social information processing is entirely or partially restored, negative social outcomes might persist for the young person (Yeates et al., 2014, 2007).

Social dysfunction is reported to be the most debilitating problem for adolescent TBI sufferers (Rosema et al., 2012). Disruptions to social function at this critical period in development may contribute to loneliness, social isolation, reduced self-esteem, mood and anxiety disorders, with the potential to significantly reduce quality of life (Ganesalingam et al., 2011; Nelson et al., 2005; Rosema et al., 2012; Yeates et al., 2014).

Summary. This section has summarised the research on pTBI, including the inconsistent reports regarding the prevalence of PCS, ongoing cognitive, emotional and behavioural problems, impacts on academic and occupational outcomes, and family and social functioning. The literature reviewed demonstrates that, contrary to the previous perception of neural plasticity playing a protective role, experiencing a TBI during childhood or adolescence may adversely impact the maturation and integration of neural processes critical to functioning. Although literature regarding adolescent-specific social outcomes is limited, it can be assumed that pTBI may have particular implications for the development of complex social skills, given that many components of the ever-developing social cognitive network (e.g., executive functions) can become disrupted due to TBI at this stage.

Given the prevalence of milder injuries, the next section focuses more specifically on the impact of mTBI occurring during adolescence.

The Impact of Mild Traumatic Brain Injury on Adolescents

The outcomes of mTBI in particular are discussed briefly, since estimates show that 95% of TBI sustained by adolescents in NZ are classified as mild (Feigin et al., 2013).

Worldwide, mTBI are amongst the most prevalent injuries to occur during adolescence (McKinlay et al., 2008), thus given the overall number of young people affected, the burden is considered immensely significant even if only a proportion experience persistent problems (Keightley, Côté, et al., 2014; McKinlay, 2010; Yeates, 2010).

The controversy of mTBI. Understanding the true impact of mTBI is shrouded in controversy and confusion, especially in paediatric cases (McKinlay, 2010; Sharp & Jenkins, 2015; Voss, Connolly, Schwab, & Scher, 2015). With a history of polarisation within the literature (see Satz, 2001), even reviews incorporating many of the same studies (e.g., Emery et al., 2016; Keightley et al., 2014; Lloyd et al., 2015) have conflicting conclusions. Some authors suggest that the consequences of paediatric mTBI can be significant, and should receive serious evaluation (Keightley, Côté, et al., 2014; Lloyd et al., 2015; Sariaslan, Sharp, D’Onofrio, Larsson, & Fazel, 2016). Others insist that there is insufficient evidence that such problems persist beyond the initial couple of months (Carroll, Cassidy, Peloso, et al., 2004; Emery et al., 2016; Satz, 2001). Nevertheless, public recognition of mTBI as potentially serious has grown in recent years, with increased acknowledgement that all types of brain trauma, regardless of severity, can result in life-long difficulties (Heidenreich, 2017; Voss et al., 2015).

The study of adolescent mTBI is complex, as persisting methodological issues have created inconsistency in the literature (Carroll, Cassidy, Peloso, et al., 2004; Emery et al., 2016; Lloyd et al., 2015; McKinlay, 2010; Yeates, 2010). Firstly, the term ‘mild traumatic brain injury’ is often used interchangeably with ‘concussion’, and there is a lack of clarity regarding how these differ (McInnes et al., 2017; Radhakrishnan et al., 2016). However, recent discussions situate concussion as a form of mTBI (Mayer et al., 2017; McCrory et al., 2018). Secondly, there are no universal criteria being utilised for the clinical identification of paediatric mTBI (Davis et al., 2017; Mayer et al., 2017; McInnes et al., 2017), and the GCS is increasingly considered unreliable and lacking in sensitivity for classifying milder injuries (Mayer et al., 2017; Reith et al., 2016). Finally, research in the area is inconsistent in its definitions of adolescence, which makes comparisons between studies difficult.

With regard to research on the impact of mTBI, an emphasis on short-term outcomes means that the long-term psychosocial effects on adolescents remain misunderstood (Emery et al., 2016; Keightley et al., 2014; Limond, Dorris, & McMillan, 2009; McKinlay, 2010; Yeates, 2010). In addition, outcome measures are inconsistent (Davis et al., 2017) and are often based on cognitive testing or broad-based ratings of behavioural adjustment that may be insensitive to the true impact of mTBI (Lingsma et al., 2010; Petersen, Scherwath, Fink, & Koch, 2008; Satz, 2001). Furthermore, variations in the comparison groups used can contribute to inconsistent findings, as differences are often found between typically developing and OI controls (McCauley et al., 2013). Finally, little is known about cases who do not seek medical attention, which may be a large proportion of mTBI (Davis et al., 2017).

Outcomes following mTBI. Bearing in mind the above methodological issues, research pertaining to the various effects of mTBI during childhood and adolescence is now addressed, considering outcomes such as overall PCS, ongoing cognitive functional difficulties, psychological outcomes, behavioural sequelae, and academic impacts.

Post-concussive symptoms. Headaches, fatigue, dizziness and taking longer to think are the most common PCS reported by adolescents following mTBI (N = 235; Eisenberg, Meehan, & Mannix, 2014). The expected duration of symptoms for most children and adolescents is proposed to be four weeks (Barlow, Crawford, Brooks, Turley, & Mikrogianakis, 2015; Davis et al., 2017). However, growing evidence indicates that a large minority may remain symptomatic beyond this acute stage, with between 15% (Eisenberg et al., 2014) and 34% (N = 467; Barlow et al., 2015) of adolescents reporting ongoing PCS at 90 days post-injury. Adolescents seem to experience more symptoms, greater symptom severity and a longer duration of symptoms than children or college students (Carson et al., 2014; Corwin et al., 2014; Davis et al., 2017; Purcell, Harvey, & Seabrook, 2016). The most consistent predictors of prolonged PCS recovery in paediatric mTBI are presence of headache, migraine history, female sex, presence of dizziness, previous mTBI, and being aged 13 years or older (Davis et al., 2017; Zemek et al., 2016). Sleep disturbance, which is also common post-mTBI (Kostyun, Milewski, & Hafeez, 2015), and premature return to school (Makki et al., 2016) may exacerbate PCS for adolescents.

Cognitive symptoms. The methodological weaknesses described above, in addition to inconsistencies in assessments used and intervals between injury and cognitive testing, have contributed to considerable variation in findings regarding the impact of paediatric mTBI on cognitive functioning. Just 17.8% of studies in one review (Lloyd et al., 2015) indicated adverse neuropsychological outcomes, with findings based on various paediatric age ranges, testing measures and duration since injuries. In addition, one study (Babikian et al., 2011) reported no evidence of cognitive impairment for youth aged 8 to 17 years 12 months following mTBI (n = 124), relative to OI (n = 94) and non-injury (n = 106) controls.

On the other hand, studies show that neuropsychological deficits, including processing speed, memory and reaction time, are common in adolescents in the initial two weeks following a sports concussion (Davis et al., 2017; Sim, Terryberry-Spohr, & Wilson, 2008; Thomas et al., 2011). Ongoing working memory deficits have been observed in children and adolescents compared to OI controls 3 and 12 months post-TBI (Sesma, Slomine, Ding, & McCarthy, 2008). Working memory may be worse for adolescents than other age groups, since one study (N = 96) revealed working memory deficits in adolescents that were absent in children and adults six months post-injury (Baillargeon et al., 2012).

A small body of evidence indicates the presence of neurofunctional deficits that might go undetected by measures commonly used in research, particularly within regions involved in executive functions (Baillargeon et al., 2012; Virji-Babul et al., 2014). Functional changes in the right inferior frontal gyrus and right dorsolateral prefrontal cortex (involved in working memory, abstract reasoning, attention and other executive functions) were evident in adolescents an average of 26 days following concussion (Virji-Babul et al., 2014). Furthermore, Baillargeon and colleagues' (2012) investigation of event-related potentials revealed a reduction in the amplitude of the P3b in adolescents six months post-mTBI.

Emotional symptoms. Even mTBI can contribute to emotional problems for a young person. Positive associations are reported between paediatric mTBI and psychiatric diagnoses up to three years post-injury (AbdelMalik, Husted, Chow, & Bassett, 2003; Keightley, Côté, et al., 2014; Massagli et al., 2004). An increased risk of psychiatric problems is observed well into adulthood for adolescents exposed to mTBI, particularly for those injured after age 15 (Sariaslan et al., 2016).

In terms of specific problems, the greatest body of research is available for depression. Prevalence rates of depression in a cohort of 228 adolescents who sustained an mTBI aged between 14 and 17 years were reported as 6%, 4%, and 5% at 3, 12, and 24 months, respectively (O'Connor et al., 2012). Luis and Mittenberg (2002) reported that 21.4% of a small sample of 6 to 15 year olds (n = 42) met DSM-IV criteria for a novel mood disorder at six months post-mTBI, compared with 2.8% of an OI control group. Elsewhere, history of mTBI corresponded with a 3.2-fold greater risk for depression in comparison to adolescents who had never sustained a mTBI (Chrisman & Richardson, 2014). Chrisman and Richardson also reported the risk of depression as increased 1.5-fold for youth aged 15 to 17 years compared to those injured aged 12 to 14. Poorer sleep quality was found to be related to greater depressive symptoms in adolescents with mTBI (Tham, Fales, & Palermo, 2015). Rates of depression do not differ significantly amongst paediatric mTBI and injuries of greater severity (Max et al., 2012).

Comparatively less information is available regarding the presence of anxiety following youth mTBI. Over one third (35.7%) of Luis and Mittenberg's (2002) child and adolescent participants were reported to meet criteria for new anxiety disorders six months after an mTBI, compared with 11.4% of OI controls. Emery and colleagues' (2016) review concluded that youth (0 – 19 years old) who sustain a single mTBI are more likely to have elevated anxiety soon after their injury, but not necessarily in the long-term. Albicini and McKinlay (2015) indicated that anxiety is more problematic in cases of more severe injuries. It is thought that depression and anxiety may be organically based, but might also occur as secondary reactions to changes following mTBI, especially new restrictions to participation in school, sports or other activities important to a young person (Barlow et al., 2015; Emery et al., 2016; Keightley, Côté, et al., 2014).

Behaviour changes. Findings regarding the behavioural outcomes of paediatric mTBI are inconsistent, and research tends to span both children and adolescents. Some indicate that young people with mTBI are no more likely to demonstrate elevated behaviour problems than OI controls (Barker-Collo, 2007; Max et al., 2004; Peterson et al., 2013). On the contrary, one review found an increased risk for hyperactivity in children and adolescents compared to OI controls during the first year (Keightley, Côté, et al., 2014). Poorer behavioural outcomes following paediatric mTBI are associated with boys (Peterson et al., 2013; Segalowitz & Brown, 1991), as well as poor sleep quality (Theadom, Starkey, et al., 2016).

Academic and occupational outcomes. Although results are mixed, there is evidence that mTBI can lead to academic impairment. A comprehensive review indicated that between 35% and 73% of students experience school difficulty following a concussion (Davis et al., 2017). Further, just 4.4% of studies reviewed by Lloyd and colleagues (2015) indicated no adverse academic outcomes following mTBI in children and adolescents. Conversely, another review found no significant differences between the academic test scores of children and adolescents with mTBI and their peers (Rozbacher, Selci, Leiter, Ellis, & Russell, 2017).

Adolescents appear more concerned about their academic performance than children post-mTBI (Davis et al., 2017), and high school students reported significantly more adverse academic effects of mTBI than those who are injured when younger (Ransom et al., 2015). With regard to long-term outcomes, a population-based study of over 1.1 million Swedish people found associations between exposure to mTBI early in life and low educational attainment, welfare recipiency, and receiving a disability pension as adults (Sariaslan et al., 2016). The authors reported poorer outcomes for recurrent TBIs and those injured between the age of 15 to 25 years.

Summary. Overall, the study of adolescent mTBI is considered complex and controversial, with persisting methodological issues giving rise to inconsistent reports regarding the outcomes of an injury sustained at this stage in development. However, the available evidence suggests that most young people recover from PCS within four weeks, while about one third continue to experience ongoing difficulties in the form of cognitive, emotional and behavioural problems. In addition, sustaining a paediatric mTBI may adversely affect short and long-term academic and occupational functioning, and outcomes may be worse for those injured during adolescence than childhood.

The next session addresses another expanding area of literature, that of the impact that pTBI can have on a young person's quality of life.

Quality of Life following Paediatric TBI

In recent decades, research on pTBI has increasingly sought to quantify the psychosocial implications of TBI in terms of health-related quality of life (HRQoL; Di Battista, Godfrey, Soo, Catroppa, & Anderson, 2014b; Di Battista et al., 2012; Fineblit, Selci, Loewen, Ellis, & Russell, 2016). HRQoL is a multidimensional construct that encompasses the connection between an injury or illness and an individual's subjective appraisal of their subsequent physical, mental and social wellbeing (Di Battista et al., 2012; Dijkers, 2003, 2004; Theunissen et al., 1998).

Paediatric HRQoL findings. All of the research discussed refers to children and adolescents, as the literature addressing HRQoL specifically following adolescent TBI is lacking. A meta-analysis by Di Battista and colleagues (2012) reported that 56% of studies indicate an adverse impact of pTBI on HRQoL. More recent studies, including those with large cohorts (e.g., Rivara et al., 2011), multiple HRQoL measures (Di Battista, Godfrey, Soo, Catroppa, & Anderson, 2014a), OI controls with similar physical limitations (e.g., Stancin et al., 2002), and comparisons with normative populations (Limond et al., 2009), have shown that HRQoL is poor following pTBI. Cognitive, emotional and behavioural difficulties appear to impact the daily life of 40% to 43% of children and adolescents for one to five years following pTBI (Limond et al., 2009; McCarthy et al., 2006). Furthermore, longitudinal studies (Anderson, Brown, & Newitt, 2010; Anderson et al., 2009; Cattelani et al., 1998) demonstrate that adverse outcomes of pTBI may continue to impact HRQoL several years later, to affect and leisure functioning in adulthood.

HRQoL seems worse following more severe pTBI, particularly given the breadth of impact across multiple life domains (Di Battista et al., 2012). Nevertheless, a review of studies specific to HRQoL in paediatric mTBI reported that an important minority of youth experience diminished HRQoL in some domains one year following their injuries (Fineblit et al., 2016). Poorer outcomes related to older age at injury, lower socioeconomic status, worse cognitive symptoms and history of headaches or sleep problems (Fineblit et al., 2016).

Issues with HRQoL research. A number of factors, such as the timing of outcome assessments, how HRQoL is defined and measured, and the use of proxies, have created questions regarding the reliability of HRQoL and pTBI findings (Di Battista et al., 2012).

In terms of timing, studies that do not find HRQoL to be significantly affected by pTBI are often based on data gathered during the first six months following an injury (Di Battista et al., 2012). The authors of this review warn that early assessments are likely to exclude factors associated with ongoing life challenges for a child or adolescent, particularly reintegration into school and social networks. There are also multiple conceptualisations of HRQoL, ranging from measurement based on achievement, subjective wellbeing, or on utility (see Dijkers, 2003, 2004), and a young person's life quality can differ greatly depending on which definition is applied. For instance, HRQoL emerged as five times worse in studies that measured 'QoL as achievement' (Di Battista et al., 2012). In addition, quantifying HRQoL in this way potentially fails to capture the essence of what most would consider the quality of their lives (Di Battista et al., 2012; Dijkers, 2003). This matter may be particularly salient for adolescents, since measurement of paediatric HRQoL often involves downward extension of measures developed for adults (Armstrong et al., 1999).

Di Battista and colleagues (2015) demonstrated the relevance of this concern by asking their adolescent sample to rate the significance of domain scores on the Pediatric Quality of Life Inventory (PedsQL 4.0; Varni, Seid, & Kurtin, 2001) post-TBI. Although difficulty with concentration was the most endorsed life change following a TBI (reported by 7 of 10 participants), only two participants deemed this change as important to their quality of life. Likewise, no participant attributed significance to a common problem with memory. These findings highlight the limitations of assessments based on HRQoL measures, which may not provide much insight into anything more than the presence of a symptom or a functional change (Di Battista, Godfrey, Soo, Catroppa, & Anderson, 2015). Such data might be misinterpreted as detrimental to an adolescent, and fail to account for whether these changes are considered by the young person as impacting their lives (Di Battista et al., 2015).

The social implications of TBI were considered most important to the adolescents in Di Battista's (2015) study. Findings from group-based quantitative studies (Anderson et al., 2010; Di Battista et al., 2014a, 2012; Erickson, Montague, & Gerstle, 2010; Martin & Falcone, 2008; Rivara et al., 2011) also note the significance of disrupted social processes to HRQoL following all severities of adolescent TBI. However, the social sections included in HRQoL measures fall short in capturing the nuance of the adolescent social experience (Di Battista et al., 2015).

The final issue with HRQoL measures is the use of proxy reporting. Assumptions that children and adolescents lack the appropriate language, cognitive capacity or insight to provide accurate self-reports have led to widespread use of parent proxy reports in paediatric research (Kirk, 2007; Theunissen et al., 1998). However, authors question if parents can comment accurately on a young person's internal difficulties (Barlow et al., 2015; Di Battista et al., 2012; Stevens et al., 2010; Theunissen et al., 1998). Studies commonly show little to no convergence between child and parent evaluations of difficulties following TBI (Erickson et al., 2010; Pieper & Garvan, 2015; Souza, Braga, Filho, & Dellatolas, 2007; Stancin et al., 2002), and parents' scores may reflect their own HRQoL or poor adjustment to the injury (Anderson et al., 2010; Brooks, 1991; Di Battista et al., 2014a; Eiser & Varni, 2013).

Summary. There is significant evidence to suggest that pTBI can impact HRQoL. However, limitations within the literature mean that many assumptions are made regarding what is important to adolescents and their recovery from TBI. Given the limited capacity for HRQoL measures to tap into the lived experiences of adolescents with TBI, the use of qualitative methodologies may represent a suitable alternative. The sections that follow address research that has employed qualitative methods to aid understanding of factors relating to the TBI experience that cannot be easily captured by quantitative measures.

Qualitative Research in TBI

Qualitative study of adult TBI. Since Tyerman and Humphrey (1984) highlighted the validity of subjective TBI experiences, personal accounts of TBI have been increasingly explored (Levack, Kayes, & Fadyl, 2010). Outcomes revealed as most important to adults in qualitative studies are often not captured by standardised measures commonly used (Levack et al., 2010; McPherson et al., 2018). Themes that commonly emerge from qualitative explorations of participant experiences of TBI include changes to one's identity or sense of self, impacts on social relationships and social identity, and recovery patterns.

The impact of TBI on the self. A sense of disconnection with one's identity (e.g., aspects of self, life, and prior aspirations) is common to many studies (e.g., Levack et al., 2010; McPherson et al., 2018; Nochi, 1998; Padilla, 2003). Struggles to keep up with life as before can impact post-injury adjustment and self-perception, as cognitive difficulties and fatigue place limitations on activities important for allowing individuals to live their lives (McPherson et al., 2018; Nochi, 1998; Paterson & Stewart, 2002; Theadom, Rowland, et al., 2016). Comparison of pre- and post-injury selves is common, and gives rise to a process of balancing the acceptance of aspects of the new self, and actively working to preserve or regain the old self (Levack et al., 2010; McPherson et al., 2018). Some anticipate a return to pre-injury selves, while others integrate changes into a modified identity (McPherson et al., 2018; Nochi, 2000; Shotton, Simpson, & Smith, 2007; Tyerman & Humphrey, 1984). Strong associations between affective distress and self-discrepancies have led to the suggestion that identity changes could account for psychological problems post-TBI (Cantor et al., 2005).

Impact on relationships. Individual narratives reveal that changes in social worlds up to 20 years post-TBI may vary from having few fulfilling relationships to enjoying mutually-satisfying relationships with co-workers, friends and family (Crisp, 1993). Paterson and Stewart (2002) discussed how cognitive and emotional problems gave rise to changed social worlds for their cohort over one year following mild to moderate TBI: Cognitive difficulties led to struggles with complex thinking, responding to multiple stimuli, and fatigue. This was associated with disrupted emotions (e.g., reduced tolerance for daily occurrences), reduced social enjoyment and motivation to participate in activities. The result was a redefinition of self, as manifested in changes in interactions with family, friends and acquaintances, strained friendships, and outward changes in personality and behaviour (Paterson & Stewart, 2002). A number of studies acknowledge how the invisibility of TBI-related struggles contribute to one's social relationships following brain injury (Levack et al., 2010; McPherson et al., 2018; Paterson & Stewart, 2002). While invisibility can be protective, allowing some to maintain a sense of 'normality' (McPherson et al., 2018), it may also lead the sufferer to feel judged, misunderstood or invalidated by loved ones and professionals (Paterson & Stewart, 2002).

Recovery. Identity reconstruction has been suggested as a fundamental recovery process for an adult post-TBI (Levack et al., 2010; Nochi, 2000; Thomas, Levack, & Taylor, 2014). Thomas and colleagues (2014) portray this reconstruction of self as 'self-reflective meaning making', a highly individualistic process which relates to one's sense of meaning in life and provides motivation for goal-setting and future behaviour. Similarly, Nochi (2000) described how individuals construct themselves within narratives in order to support post-TBI adjustment, with 'being worthwhile because of the TBI' as one narrative theme.

This fits with the recent emergence of interest in post-traumatic growth (PTG) following TBI (Grace, Kinsella, Muldoon, & Fortune, 2015). PTG is the conception that a traumatic event, such as TBI, can be a meaningful experience that might alter an individual's values (e.g., priorities regarding what is important in life), beliefs (e.g., perception of one's competence or resilience), and behaviour (e.g., development of new interests) in multiple areas of life (Rogan, Fortune, & Prentice, 2013). The concept of PTG goes beyond coping with the impact of an injury to emphasise changes "that cut to the very core of our way of being in the world" (Joseph, 2011, p. 147).

The process of identity redevelopment seems protracted and cyclical (Muenchberger, Kendall, & Neal, 2008; Padilla, 2003; Thomas et al., 2014), beginning immediately following the injury, to extend far beyond the period of functional recovery, and continuing indefinitely as the individual redefines themselves in the face of life's challenges (Muenchberger et al., 2008). Longer duration since sustaining TBI and milder disability are associated with more PTG experiences (McGrath & Linley, 2006; Powell, Gilson, & Collin, 2012).

Qualitative study of adolescent TBI. Qualitative exploration of the impact of TBI for adolescents is a relatively new field of study, with themes much less established than those within the adult research. This section addresses some of the emerging themes regarding processes that might occur for adolescents following TBI; namely, the persistence of PCS, the significance of social implications, impacts on family relationships and school, and recovery processes. Gaps in qualitative literature regarding adolescent experiences are then discussed.

The persistence of PCS. Interviews with adolescents, parents and professionals highlight the significance of persisting PCS for a young person one year after mTBI (Iadevaia, Roiger, & Zwart, 2015). The findings suggest that disruptions in cognitive abilities, sleep, fatigue, and emotional, behavioural and social functioning might adversely impact home and school life, and particularly emphasise the levels of frustration caused by an inability to participate in desired activities due to PCS.

The significance of social implications. Changes to social experiences are self-identified as the most important changes to adolescents following TBI (Di Battista et al., 2015; Mealings & Douglas, 2010; Rødset, 2008). Young people have reported that limitations placed on inclusion in activities due to PCS can cause them to feel left out, and adolescents are often eager to return to school and hobbies in order to resume friendships (Iadevaia et al., 2015; Mealings & Douglas, 2010; Rennie, 2015; Rosema et al., 2012; Sharp, Bye, Llewellyn, & Cusick, 2006).

Two-thirds of families observed a loss of friends for their adolescent post-TBI, and professionals suggest that young people lose friends because the TBI has changed them (Gauvin-Lepage & Lefebvre, 2010). Some young people also report increased difficulty with making friends after their injury, even for those with mTBI (Di Battista et al., 2015). Changes in behaviour (e.g., lack of impulse control, difficulties comprehending social cues) may act as barriers for inclusion in severe cases (Rødset, 2008). As noted for adults, some authors suggest that cognitive changes might make coping with social demands more challenging; for instance, slowed thinking may mean increased difficulty keeping up with conversations (Rennie, 2015; Rødset, 2008). Some adolescents have noticed a change in personality, such as a tendency to be more emotionally reactive, and increased anxiety or hesitance to engage in social behaviours (Di Battista et al., 2014b; Rennie, 2015).

Impacts on family relationships. The unexpected nature of TBIs, the resulting cognitive, physical and affective difficulties, and the uncertain prognosis can be very unsettling to the lives of adolescents and their families (Di Battista et al., 2014b; Gauvin-Lepage & Lefebvre, 2010). Parents report increased confrontation within the family, which may be intensified by the young person's frustration at restrictions on engagement in normal activities (Iadevaia et al., 2015). Other children in the family may also become frustrated by their sibling's ongoing symptoms, or sibling rivalries might be intensified as the injured one gains more attention (Iadevaia et al., 2015). The adolescent might perceive their role within the family as altered, particularly in terms of perceived independence, given increased post-TBI reliance on family members (Di Battista et al., 2014b; Ocampo & Dawson, 1997). Parents might be more protective after the accident or experience guilt, or the adolescent's injury may create stronger bonds in the family (Gauvin-Lepage & Lefebvre, 2010).

Impacts on school. Although academic outcomes have not emerged from qualitative data as priorities for those who have experienced mild or moderate TBI, young people with severe injuries report difficulty adjusting to imposed changes. These include acknowledging and accommodating for changed abilities or needing increased effort to achieve academic results, and loss of certainty regarding future opportunities (Mealings & Douglas, 2010; Rødset, 2008; Sharp et al., 2006).

Recovery processes. Common external (e.g., social inclusion and support) and internal (e.g., personal growth processes) factors for coping are touched upon in adolescent narratives. Firstly, there appears to be agreement amongst adolescents, parents, and healthcare professionals alike regarding the positive effect of friendships and social inclusion on recovery following brain injury (Gauvin-Lepage & Lefebvre, 2010; Iadevaia et al., 2015). Youth say that retaining meaningful social groups and teammate relationships provides a rich source of support (Di Battista et al., 2014a; Iadevaia et al., 2015; Mealings & Douglas, 2010).

Young participants often name ongoing support from family members (e.g., parents being present and motivating) as important for post-TBI adjustment (Di Battista et al., 2014a; Iadevaia et al., 2015; Mealings & Douglas, 2010; Rødset, 2008), which is consistent with quantitative evidence for the protective role of family support in recovery (Holland & Schmidt, 2015; Savage et al., 2005). Sibling relationships and similar-aged relatives can be helpful for adolescents who lack friends (Gauvin-Lepage & Lefebvre, 2010; Rennie, 2015).

PTG processes have been observed in young people’s narratives of TBI experiences. As with adults, reflecting on experiences might enable insight into the positive impact of TBI, despite the difficulties endured (Di Battista et al., 2014b). The experience of TBI contributed to a positive shift in some adolescents’ view of the world (Mealings & Douglas, 2010), and to a change in goals, aspirations and life trajectory for others (Di Battista et al., 2014b). Finding meaning in the injury, or developing belief in a higher purpose (Mealings & Douglas, 2010; Rennie, 2015; Rødset, 2008), maintaining optimism and getting on with life (Rødset, 2008) were all mentioned as important for coping. Integrating discrepancies between pre-injury pursuits and limitations posed by post-injury capabilities, young people have been seen to integrate both positive and negative aspects of sustaining a TBI, and tended to report a happy life, not wishing to be defined by their injuries (Di Battista et al., 2014b).

Gaps in qualitative literature regarding adolescent TBI. Levack and colleagues (2010) identified 23 qualitative studies of sufficient quality to meet criteria for their metasynthesis on adult TBI experiences. Indeed, the number of quality studies available on this matter has grown substantively in the subsequent ten years. In contrast, only seven studies could be identified which come close to addressing adolescent perspectives in a similar way (Di Battista et al., 2014b; Gauvin-Lepage & Lefebvre, 2010; Iadevaia et al., 2015; Mealings & Douglas, 2010; Rennie, 2015; Rødset, 2008; Sharp et al., 2006). These studies are limited by reasonably small samples (i.e., n = 3-10), and either report on short-term outcomes (i.e., <18 months post-TBI), or include a sample reflecting extremely broad variations in the interval between injury and research participation. No qualitative study was identified that considered long-term processes extending beyond the adolescent period.

Furthermore, three studies (Mealings & Douglas, 2010; Rødset, 2008; Sharp et al., 2006) limit their exploration to school return for adolescents with severe TBI, one focussed on social inclusion of those with moderate injuries (Gauvin-Lepage & Lefebvre, 2010), and another addressed only those with sports concussion (Iadevaia et al., 2015). The only study identified that broadly explored adolescent outcomes from various severities (Di Battista et al., 2014b) included participants injured during childhood and had vast variation in time since injury (i.e., 1-10 years). Three studies (Gauvin-Lepage & Lefebvre, 2010; Iadevaia et al., 2015; Rennie, 2015) also included the opinions of parents or professionals, which may have obscured information regarding what young people themselves considered most salient. Finally, two studies (Di Battista et al., 2014b; Rennie, 2015) used mixed methods, with the qualitative element discussed in the context of the quantitative data obtained. Thus, there is a clear need for broad qualitative research that explores the adolescent-specific experience of

TBI, and especially that considers long-term processes as the young person faces the challenges associated with transitioning to adulthood.

Conclusion and Overview of the Current Study

Adolescents are at particular risk of sustaining TBI, particularly in NZ. Findings from quantitative research indicate that despite youth and neuroplasticity, TBI can result in ongoing adverse outcomes with regard to cognition, behaviour, psychological wellbeing, academic and occupational performance, social participation and overall quality of life. However, reliance on traditional quantitative measurement may limit our understanding of the adolescent experience of TBI and its true impact on domains of life most important to a young person, and offers little insight into coping and recovery processes.

An ever-expanding body of qualitative research with adults has provided insights regarding matters relating to TBI that are difficult to measure quantitatively, such as the profound impact TBI can have on one’s sense of self. Unfortunately, there is little qualitative literature available for adolescents. The adolescent developmental stage sees increasingly complex social pressures as the young person strives to discover who they are and where they fit in society, to facilitate transitioning to adulthood. Sustaining a TBI during this critical period of development might impact upon these processes; particularly given that self-perception and identity seem central to recovery from an adult TBI. Little is known about how these identity processes play out during adolescence, when the young person’s identity is still forming. With little research focused on the adolescent period, the paucity of information available incorporating the transition to adulthood substantially limits our ability to support individuals to achieve optimum long-term outcomes post-TBI.

The present study. This exploratory study utilises a qualitative stance to gain an in-depth understanding of adolescent-specific experiences of TBI and recovery in the context of long-term (7–8 year) adjustment to adulthood. It focuses on the following broad questions:

1. What might it be like to experience a TBI as an adolescent?
2. How might sustaining a TBI during this critical stage of development impact upon a young person's life, long-term wellbeing and adjustment to adulthood, if at all?
3. What do young people perceive as helpful/unhelpful to recovery from an adolescent TBI?

At the time of writing, this was the first known study to explore the perspectives of young people who experienced a TBI specifically during the teenage years (i.e., aged 13–17 years), who have already entered early adulthood at the time of the research (i.e., aged 20–25 years), and for whom a consistent time period has lapsed (i.e., approximately 7–8 years) since injury. To the author's knowledge, this will also be the first study to explore experiences of young New Zealanders who have experienced a TBI from a qualitative perspective.

Chapter Two: Methodology and Methods

This study explores the individual perspectives of young people who experienced a traumatic brain injury (TBI) during early adolescence. This chapter will outline the study's methodology, by describing the value of a qualitative approach, the researcher's personal perspective entering the research, the research design, the sample, procedure, and steps taken to ensure quality and ethical practice throughout the study.

Qualitative Research

The methodological approach that is employed in a study, usually dichotomised into the categories of quantitative or qualitative research, can have a significant impact on the kind of information that is uncovered (Camic, Rhodes, & Yardley, 2003). Where quantitative research is nomothetic and seeks out generalisable behavioural patterns in large samples, qualitative research is idiographic and aims to make knowledge claims about very few individuals or groups (Marecek, 2004; Morrow, 2007; Ponterotto, 2005). Quantitative research takes an 'etic' perspective, such that findings are placed into categories that have been predetermined by the ‘outsider’ researcher (Morrow, 2007; Ponterotto, 2005). Conversely, qualitative research seeks to understand the holistic nature of human experiences (Chwalisz, Shah, & Hand, 2008), and derives categories from the data, which are based on the ‘insider’ or ‘emic’ perspective of participants (Hammersley, 2013; Morrow, 2007).

There is broad heterogeneity in how individuals recover following a TBI (Lingsma et al., 2010), and outcomes may be best improved if professionals seek to understand individual experiences and avoid making assumptions about what is considered most meaningful to a person’s recovery (McPherson et al., 2018; Snell, Macleod, & Anderson, 2016). Qualitative research regards participants as intentional agents, who are actively engaged in making sense of their lives (Marecek, 2004), and this approach is thus ideal for developing understanding of the subjective meanings individuals make from their experiences (Camic et al., 2003).

Researchers have sought to understand individual adult TBI experiences since the 1980s (Tyerman & Humphrey, 1984), with an extensive body of qualitative literature now available and adding tremendously to what is known regarding patient perspectives and adult priorities for recovery (e.g., Levack et al., 2010; Thomas et al., 2014; McPherson et al., 2017). Considering the specific developmental needs and challenges faced by adolescents, it cannot be assumed that the same themes apply to adolescent TBI experiences. Young people, overall, are afforded less opportunity than adults to have their opinions attended to (Hinshaw, 2005), and increased inclusion of adolescents in research is deemed crucial, so that their priorities are integrated into designs for support services (Dick & Ferguson, 2015; WHO, 2017). The dominance of quantitative research in child and adolescent TBI has meant that little is known about what young people themselves consider important following such an injury. Thus, seeking the reflections of young people regarding their experiences of adolescent TBI could provide a unique perspective on what may be important for recovery at this stage of life, thereby, aiding the provision of age-appropriate healthcare services.

The Perspective of the Researcher

Qualitative research is a 'stance' (Marecek, 2004) that incorporates the researcher's perspective on how best to study the world and on how humans construct and make sense of their world (Hammersley, 2013). In this section, I locate my research in a guiding paradigm, critical realism, before describing my personal orientation and the perspectives that have influenced how and why I have approached this research topic (Morrow, 2005).

Critical realist paradigm. A paradigm may be seen as a 'net' that reflects a researcher's assumptions in relation to ontology (which asks 'what is the nature of reality?'), epistemology (i.e., regarding how that reality can be known), and axiology (i.e., the role of values in the research process), and has an impact on how the research question is approached and the methodology employed (Chwalisz et al., 2008; Morrow, 2007; Ponterotto, 2005; Twining, Heller, Nussbaum, & Tsai, 2017). Here, a critical realist paradigm was applied. Critical realism falls between the extremes of essentialism (or realism) and constructionism. Essentialism might report on experiences and meanings of participants as reality or truth, whereas the constructionist approach perceives such experiences and meanings as products of the discourses that operate within society (Braun & Clarke, 2013; Twining et al., 2017). Critical realism "assumes an ultimate reality, but claims that the way reality is experienced and interpreted is shaped by culture, language and political interests" (Braun & Clarke, 2013, pp.329). It acknowledges a reality beyond individuals, without overestimating how much can be known about that reality (Porter, 2002).

Critical realism was considered an appropriate lens through which to explore the current research question, since this stance acknowledges that there are certain measurable 'truths' regarding sustaining a brain injury (e.g., neurological damage), whilst recognising the limitations of how we come to understand such truths. First engaging with the literature allowed me to formulate a picture of what is currently thought to be known about the experience of TBI during adolescence. Although prior findings and theories aided the development of broad areas of inquiry for this study, I could hold these theories amongst some of the possible ‘truths’ regarding the experience of adolescent TBI. In this way, critical realism allowed me to contemplate how participants ascribed meanings to their experiences of TBI and consider the influence of contextual factors on those meanings.

Personal orientation. Qualitative research has grown to embrace the role of the ‘researcher-self’, and takes advantage of the relationship that arises within the research setting, which sees both researcher and participant inevitably influencing the findings (Camic et al., 2003; Coffey, 2002; Hammersley, 2013). Taking a reflexive stance, acknowledging and disclosing one’s personal orientation (e.g., social position, experience with the chosen topic) is an important element in demonstrating researcher credibility, by enabling the reader to allow for the effects of such factors (Hammersley, 2013; Morrow, 2005; Patton, 1999).

I am a white Irish woman who moved to NZ at the age of 22, and was aged 28 to 30 years over the course of this research. I spent the eight years prior to commencing my Doctorate in Clinical Psychology working with children and young people in various roles within mental health, drug and alcohol treatment, and autism specialist services in the UK and NZ. This background enabled me to develop empathy for the unique position of young people, and to occupy a stance akin to that described in The World Health Organisation report, *Health for the World’s Adolescents (H4WA): A Second Chance in the Second Decade* (Dick & Ferguson, 2015; The WHO, 2017), that support at this stage of life could have significant and enduring implications for a young person, as well as for society.

The H4WA also endorses a positive youth perspective, viewing young people as resilient, with the potential to maximise the opportunities offered by the social circumstances of their generation. I entered this research with a similar youth empowerment stance. I felt disappointed by the prevalence of problem-focused themes within the broader literature regarding adolescent TBI and questioned whether such a discourse may serve more to stunt than empower a young person's development and recovery following TBI. With this research, I hoped to broaden the discussion to include themes of resilience and optimism amongst youth stories of TBI.

Power. Any research with people is inherently based on unequal power relationships (Guariento, 2010; Mero-Jaffe, 2011), and the concept of power has become increasingly prominent in youth research (Spencer & Doull, 2015). Most societies are perceived as adult-centred, and this unequal power distribution is replicated in the research setting (Kirk, 2007; Schelbe, Chanmugam, Moses, & Saltzburg, 2015). Throughout this research, I have reflected on how my position as a white, adult, trainee psychologist and doctoral student (all positions of relative power) might have impacted participants engagement with the research. Reflexivity practices also allowed me to monitor how my assumptions about young people might influence the interviews, my interpretation of data and reporting of findings. However, I recognise that reflexivity would not resolve the impact of power, privilege and perspective (Kirk, 2007; May & Skegg, 2012).

Power relationships with young people are more complex than the notion that the adult researcher 'has' power, and might empower a younger participant by 'giving' them a voice (Davidson, 2017). I have approached this research, not from the position that participant views were 'collected', but with an emphasis on power and 'voice' as a social, relational and interactive process (Davidson, 2017; Gallagher, 2008; Harden, Scott, Backett-Milburn, & Jackson, 2000; Komulainen, 2007). I sought to avoid telling participant stories in such a way that they have become *my* story (May & Skegg, 2012).

Reflexivity practices. My reflexivity practice involved keeping notebooks throughout the project, one in which to record field notes (i.e., observations and thoughts related directly to the research and data), and another to reflect on personal feelings and experiences. Such introspection allowed me to consider how factors such as my social position and values influenced the project, and particularly decisions made regarding the topic, procedures, and interpretation of data.

Research Design

This research involved semi-structured interviews, the most common method of collecting qualitative data (Doody & Noonan, 2013) and reportedly the most useful way to understand the meanings people make of their experiences (Morrow, 2007). Interview data were interpreted using thematic analysis, an uncomplicated, flexible, method of analysis which involves the search for themes across a dataset (Braun & Clarke, 2006).

Recruitment. All participants were recruited from the BIONIC (Brain Injury Outcomes New Zealand in the Community) study cohort. The BIONIC study investigated the incidence and 12-month outcomes of all cases of TBI occurring in the Hamilton and Waikato districts between 1st March 2010 and 28th February 2011 (Feigin et al., 2013). The sample region captured a general population of 173, 208 urban and rural residents considered to be representative of New Zealand as a whole (Statistics New Zealand, 2013). In total, 1,369 cases of TBI were identified, and consenting participants were assessed at baseline, and at 1, 6 and 12 months post-injury (Feigin et al., 2013). A comprehensive description of study methodology is available (Theadom et al., 2012).

BIONIC participants aged 1 to 15 years at the time of injury were then invited to join the COBIC study (Child Outcomes of Brain Injury in the Community; Jones et al., 2018, 2019; Starkey et al., 2018), which involved a longer term follow-up of children and younger adolescents within the BIONIC sample. COBIC replicated and supplemented the information gathered in the BIONIC study, collecting data at two- and four-years post-injury. In addition, BIONIC4You (Brain Injury Outcomes New Zealand in the Community: 4 Year Outcomes;

Theadom et al., 2017) followed-up consenting participants who were aged 16 and over at injury, examining the four-year outcomes of TBI in older adolescents and adults.

The present study sought to recruit those aged 13 to 17 at the time of their initial BIONIC injury, since participants in this group were attending high school at the time and thus might be considered most representative of the ‘typical’ adolescent. Demographic and contact details were obtained for participants within this age range from the COBIC (i.e., those aged ≤15 years at injury) and BIONIC4You (i.e., those aged ≥16 at injury) research cohorts. A total of 51 individuals aged 13 to 17 at injury were identified as consenting for participation in future research. It is acknowledged that recruiting participants in this way created inevitable sampling bias. For example, given the seven- to eight-year lapse since the initial BIONIC study, many participants would have dropped out of the research. Māori had a disproportionate drop-out rate, thus were underrepresented within the sample, which was unfortunate considering the relatively higher prevalence of TBI within the young NZ Māori population (Feigin et al., 2013). Purposeful sampling was used to select participants who varied with regard to ethnicity, age, gender, injury severity, and rural/urban location, so as to maximise the richness of data obtained (Chwalisz et al., 2008; Twining et al., 2017).

Letters of invitation to participate (Appendix A) and participant information sheets (PIS; Appendix C) were sent to potential participants. In order to promote recruitment of Māori participants, separate versions of the letter and PIS, incorporating Māori terminology, were developed (Appendices B and D, respectively). Ethnicity was self-reported within the BIONIC database from which participants were sourced. Invitation letters described the research, explained why the individual was being invited to participate and that they would be telephoned to inquire whether they were willing to take part in an interview regarding their TBI experience. An opt-out clause was included, allowing participants to contact the researcher first if they did not wish to be telephoned. The PIS contained further information regarding the study (i.e., the purpose of the research, the nature of participation, how data might be used, and how to withdraw data). A total of 35 invitations to participate were sent.

At least two weeks following postage of the letters, potential participants were contacted individually by telephone to inquire if they would like to participate. Telephone contact was made with 21 participants; the remaining 14 were uncontactable. When telephoned, participants were generally willing to participate in the research. Eight declined, offering reasons such as being busy with university or having moved overseas. Once participants agreed to engage in an interview, a time and location were arranged by telephone, text message or e-mail. Recruitment continued until ongoing analysis suggested that the study had reached theoretical saturation, that is, the point where themes appeared rich and fleshed out, and no new themes were evident (Nutt Williams, Morrow, Williams, & Morrow, 2009). A total of 13 individuals were recruited over a 12-month period.

Participants. The 13 participants recruited met the following inclusion criteria: (1) aged 13 – 17 years at the time of injury, (2) previously identified as willing to be contacted for future research, (3) were contactable, and (4) provided informed consent to participate. As seen in Table 1, 5 participants were female, and 8 were male. Participant ages ranged between 13 years 2 months and 17 years 11 months (mean = 15 years, 4 months) at the time of injury, and between 20 years 6 months and 25 years 8 months (mean = 23 years, 0 months) at interview. An average of 7 years 8 months (range = 6 years, 8 months – 8 years, 4 months) had passed since the TBI included in the initial BIONIC study had occurred. Almost half (n = 6) of the participants reported sustaining more than one TBI during adolescence. The age at which the index BIONIC injury occurred is underlined in these cases. While 1 of the BIONIC recorded injuries was classified as moderate, the remaining 12 were classified as mild. Two participants lived rurally, whilst eleven were from an urban centre. Eleven identified as New Zealand European, one as Māori, and one Samoan.

Table 1

Participant and injury details

"Name"	Gender	Age at injuries	Age at interview	Time since injury	Number of reported injuries	Injury Mechanism	Education level
Brandon	M	13y 2m	20y 6m	7y 5m	1, mild	Motor vehicle accident	Year 3 of bachelors (hons), engineering
Rachel	F	13y 6m	20y 11m	7y 5m	1, mild	Sport	Year 4 of bachelors (hons), engineering
Nick	M	11y; 13y 10m	20y 6m	6y 8m	2, mild	Cycling; sport	Year 3 of bachelors, healthcare
Danielle	F	14y, 6m	22y 5m	7y 11m	1, mild	Motor vehicle accident	Bachelors, healthcare
Adam	M	14y 9m; 17y	22y 7m	7y 10m	2, mild	Cycling; sport	Undergoing trade apprenticeship
Amy	F	14y, 9m	22y 3m	7y 6m	1, mild	Sport	Bachelors (hons), healthcare
Dylan	M	15y 2m; 15y; 16y; 17y	23y	7y 10m	4, mild	Sport; assault	Bachelors, healthcare
Samuel	M	15y 7m; 17y	23y 5m	7y 9m	2, mild	Sport	Trade qualification
Matthew	M	15y 10m; 19y	23y 10m	8y	2, mild	Motor vehicle vs. bicycle	Completed high school
Ethan	M	16y 6m	23y 11m	7y 5m	1, mild	Motor vehicle accident	Certificate (Level 3), trades
Ryan	M	17y 4m	24y 11m	7y 7m	1, moderate	Motor vehicle vs. bicycle	First year diploma, IT
Talia	F	17y 1m; 19y; 19y; 19y	25y 5m	8y 4m	4, mild	Assault; self-harm	Completed high school
Lauren	F	17y 11m	25y 8m	7y 9m	2, mild	Sport	Bachelors (hons), healthcare
Mean		15 y 4m	23y 0m	7y 8m			

Notes. Participant names have been changed to preserve anonymity and to make the reading of the findings more sensible. Underlined ages represent the age at the injury that prompted inclusion in the Brain Injury Outcomes New Zealand in the Community (BIONIC) study.

Data collection. All interviews were conducted by the primary researcher and were held at each participant's place of residence or at a local café or University, whichever was most convenient to the participant. Interviews began with informal rapport building, followed by a brief explanation of the research and interview framework, a discussion of the PIS, opportunities to ask questions, and signing of a consent form (Appendix E). Participants were given a copy of the PIS and consent form to keep. Participants were thanked with a koha/compensation, which was a choice of a movie or supermarket voucher valued at $20 at the conclusion of the interview. Interviews varied in duration (range = 35 – 100 minutes; mean = 58 minutes). All interviews were audio recorded. Interviews were carried out individually. Two of the participants' mothers were present for a small part of their interviews at the participants' request, and they made minor contributions. Family members were not considered participants themselves and their quotes were not included in the analysis, but important information was used indirectly via the researcher's field notes.

Data were collected following the recommended procedure for semi-structured interviews (Chwalisz et al., 2008; Doody & Noonan, 2013). An interview schedule (Appendix F) was devised surrounding several areas of inquiry elicited from the prior literature summarised in Chapter One. To provoke breadth and depth in responses, the interview schedule was deliberately wide-ranging and consisted of open-ended questions (Morrow, 2007). Interview questions were used flexibly, were omitted, adapted or elaborated upon according to the demands of each individual interview. The researcher usually began with an open comment, such as "tell me about the brain injury you had", before asking further open questions related to matters initiated by the participant. The 'naïve' inquirer position was assumed, where the interviewer presented as professional and knowledgeable, but less knowledgeable than the participant regarding the interview topic, and sought concrete examples from the participant's life rather than questioning theoretical ideas

(Hermanns, 2008; Leech, 2002). Further elaboration was encouraged with prompts, such as “can you tell me more about that?”, “what do you mean by …?”, and “can you give me an example?”.

Data analysis. Interview recordings were listened to at least twice and then transcribed by the primary researcher, with support from a professional transcriptionist (who transcribed four interviews). The accuracy of all transcripts was checked back against the audio recordings at least twice. Transcriptions were then entered into a qualitative data analysis computer software package (NVivo; as described in Bazeley & Jackson, 2013; Silver & Lewins, 2014) in PDF format.

Analysis began inductively, deriving themes from the data themselves, rather than attempting to validate prior research or theory (Srivastava & Hopwood, 2009). A reflexive iterative approach was applied, which involved recursively moving back and forth through the dataset and the steps described below (Srivastava & Hopwood, 2009; Twining et al., 2017). Reading and rereading transcripts allowed continual checking of emerging insights against the data, thereby refining and progressively focussing the patterns. Thematic analysis was conducted using Braun and Clarke’s (2006, 2017) six-phase approach, as follows:

1. Familiarisation with the data. Analysis began with reading and rereading the entire dataset to familiarise myself with the depth of its content. Notes were taken on possible patterns within the data and an initial list of ideas regarding what seemed noteworthy was generated.

2. Coding. Based on the initial list, several potential categories/codes within NVivo were derived, each identifying an important feature of the data which might become relevant to answering the research questions. Sections of text within each interview transcript were collated within NVivo files that represented each code. Upon completion of this phase, there were 59 codes, and 88% of the data had been allocated to at least one category.

3. Searching for themes. Next, codes were printed, and different coloured highlighters were used to consider the relationship amongst the listed codes. Codes were sorted into potential themes and categories of themes based on broader patterns. Relevant data extracts were collated within each candidate theme.

4. Reviewing and refining themes. The significance of each theme was considered by checking candidate themes against the dataset and questioning if a theme captured the essence of a meaningful pattern in the data. In this way, themes were refined, combined, separated or discarded. A thematic map was developed and used to review and refine coding until the map seemed to accurately reflect meanings evident in the dataset. This phase resulted in 16 themes within 5 categories, as depicted in the thematic map in Appendix G.

5. Defining and naming themes. The focus of individual themes was considered, and themes were further refined as writing commenced. This resulted in 5 categories which looked somewhat different to the original, and now contained 20 themes. These final themes are listed in Table 2 at the beginning of Chapter Three. A detailed analytic narrative was then written for each theme, which sought to identify the story of each theme and how it fit within the broader story of the data.

6. Writing up the analysis. The analytic narrative was woven with data extracts in a way that would convey what was interesting about the data. Data extracts that most appropriately captured the essence of each theme were chosen. Extracts were cleaned by removing identifiers, repetitions and redundant discourse markers. Removed words in quotes were replaced by an ellipsis. Finally, a discussion section was composed, in which the analysis was contextualised in relation to existing literature.

Quality and Rigour

Striving for the highest possible quality is a crucial factor in conducting research (Cope, 2014). However, the divergent methodological, ontological and epistemological assumptions regarding how phenomena can be understood creates challenges for judging the quality of qualitative research (Hammersley, 2007; Twining et al., 2017). Rather than seeking reliability or validity statistics, concepts more suited to research situated in realist perspectives, rigour is often spoken about in qualitative research in terms of 'trustworthiness' (Twining et al., 2017). It is not reasonable to apply a single set of criteria for achieving trustworthiness across qualitative approaches (Braun & Clarke, 2006; Twining et al., 2017). Therefore, suggestions offered by a number of authors (Chwalisz et al., 2008; Nutt Williams et al., 2009; Twining et al., 2017) were used in designing and conducting this study, in an effort to demonstrate the integrity of the data and the credibility of the study.

Demonstrating the integrity of the data. A crucial element of allowing a reader to judge the trustworthiness of a study is making visible the details of data and how they were obtained (Nutt Williams et al., 2009; Santiago-Delefosse, Gavin, Bruchez, Roux, & Stephen, 2016). Thus, an attempt was made to demonstrate that data of sufficient quality and quantity have been gathered from a sample that was adequately diverse to offer a variety of viewpoints (Sandelowski, 1995). Trustworthiness may also be attained through thoroughly describing and referencing the research design, recruitment process, interview protocol, and any personal biases that might impact these (Nutt Williams et al., 2009; Twining et al., 2017). A rich description of the research setting and of participants was important for enabling the reader to ascertain the relevance of findings within other contexts (Chwalisz et al., 2008).

Credibility. The credibility or 'truth value' of research findings relates to how congruent reported findings are with participant experiences (Chwalisz et al., 2008). Nutt Williams and Morrow (2009) described this in terms of balancing "perspective and meaning", where research findings are deemed the product of a "mutual construction of meaning" (p. 579). I have acknowledged my consideration of the subjectivity of qualitative data collection and analysis, and attempted to verify credibility in several ways:

1. Reflexivity practices.

2. Clarifying participant meanings during interviews (Chwalisz et al., 2008) and offering participants the opportunity to review the transcribed data retrospectively.

3. Searching for alternative patterns helped me to challenge my own views and avoid overly simplistic interpretations of the data (Morrow, 2005; Patton, 1999).

4. I sought to broaden my interpretations by engaging in discussions with supervisors and members of a qualitative research peer group (Hill et al., 2005).

5. In forming the discussion, I applied theoretical triangulation (i.e., interpreting the findings from the perspectives of multiple theories) so as to examine how data and interpretations may be understood from various perspectives (Chwalisz et al., 2008; Patton, 1999).

Ethical considerations

Ethical approval for the study was obtained from the University of Auckland Human Participants Ethics Committee (Reference Number 019641). Ethical considerations included the preservation of confidentiality, power differentials in youth research, cultural responsivity, and the potential for participant distress.

Confidentiality. Participants' information was protected by the anonymisation of data, as each participant was assigned a unique codename to which they were referred throughout the analysis. While displaying participant quotes might increase the possibility of identification (Braun & Clarke, 2013), examples were selected in a way that would retain the richness and the meaning of the information, without revealing details regarding the participants (Guenther, 2009). There were also times where potentially identifying information (e.g., professions) was removed from a quotation.

Cultural responsivity. It was hoped that a participant sample could be recruited that reflected the diverse population of NZ (Statistics New Zealand, 2013). Thus, every attempt was made to devise a culturally appropriate research protocol, to minimise power differentials throughout the recruitment and data collection phases, and to ensure that interpretation of data remained true to various cultural perspectives as much as possible. Given the particular vulnerability of Māori in society and the prevalence of TBI amongst Māori, a Māori Clinical Neuropsychologist and TBI researcher within the University of Auckland was consulted, in addition to a Cultural Consultant at a service providing rehabilitation for individuals with TBI. A set of guidelines for Māori research ethics (Hudson, Milne, Reynolds, Russell, & Smith, 2010) were also consulted and followed.

Potential for distress. A response plan was devised in the unlikely event that a participant became distressed during their interview. This involved providing brochures and helplines regarding available support, or encouraging participants speak with family or a GP, and the researcher would be available to support with these discussions if the participant wished. The researcher also telephoned participants one week following the interviews to check their feelings regarding disclosures. In addition, it was hoped that the participants might gain from the opportunity to speak about their experiences. Interviews with adults from the BIONIC research cohort reported that engagement in research provided time for reflection, that answering questions about their experience of brain injury facilitated understanding of their injury and provided greater insight regarding how it affected them (Theadom, Fadyl, Hollands, Foster, & McPherson, 2014).

Conclusion

In summary, this research uses a qualitative approach to explore the experiences of 13 young adults who sustained a traumatic brain injury in during adolescence. Thematic analysis of semi-structured interviews was employed, and informed by the researcher’s critical realist paradigm and youth empowerment stance. The chapter that follows describes the findings from an analysis of the data obtained.

Chapter Three: Findings

In this chapter, the key themes that resulted from the thematic analysis of interview data are presented. As illustrated in Table 2, themes fell into five main categories, relating to the direct impact of the brain injury, impacts on important areas of life, impacts on identity, individual resources for coping and social resources for coping. The names referred to are not participants real names as these have been changed to preserve anonymity.

Table 2

Summary of key themes

Category	Themes
The direct impact of the brain injury	Waking up: ‘There’s a little chunk of time gone’ Feeling unwell and overwhelmed: ‘I was fairly concussed’ Headaches never quite went away: ‘I had migraines so severe’ Feeling exhausted: ‘I’m always tired’ Not being able to think: ‘Your brain’s no longer quite there’
Impacts on important areas of life	Schoolwork suffered: ‘It got pretty downhill at school’ Career opportunities changed: ‘Your options become limited’ Struggling with work: ‘What if I don’t have what they want?’ Things changed socially: ‘The most alone I had ever felt’
Impacts on identity	Changes to school identity: ‘I thought I was stupid’ Feeling self-conscious: ‘Being the weird kid’ Social identity was permanently altered: ‘Losing where I fit in’ Being dependent: Having to rely on family and friends
Individual resources for coping	Learning to cope with difficulties: ‘Just getting on with it’ Seeking acceptance and balance: ‘You can’t make your brain heal faster’ Finding Meaning: ‘You can either come out bitter or better’
Social resources for coping	Feeling included: ‘I had a really good friends’ network’ Relying on family: ‘I don’t know where I’d be without my parents’ Professionals didn’t get it: ‘Left in the dark to find your own way’ Lacking someone who understands: ‘Somebody to talk to might have helped’

Category One: The Direct Impact of the Brain Injury

This first category initially addresses the participants' descriptions of the immediate experience of 'waking up' or realising they had sustained a TBI. What follows is an exploration of participants' described experiences of 'concussion'. Three further themes convey the ways in which participants felt unwell and unable to function on a more long-term basis due to their injuries; specifically, the experience of migraines, fatigue and difficulties with thinking are explored.

Waking up: 'There's a little chunk of time gone'. The first impact of the TBI, for most participants, was felt in the immediate aftermath, as they were knocked out, woke up, and attempted to make sense of what had occurred. Some recalled waking up on the ground soon after being knocked out, and described a sense of exposure or vulnerability as they noticed people standing around them. For Nick, waking up having been *"knocked out for a couple of minutes"* was experienced as quite frightening:

> *Yeah, that was a very, very scary experience. I think because I was in Year 10 or Fourth Form, and I was surrounded by about 50 other people of my age, and I woke up in tears, because I was like, 'Oh I don't know what's going on' and everyone standing around me. Everyone is like, 'Woah, what's just happened?' you know. And, ah that was scary for me. Scary knowing that something had happened. Can't remember what happened. There's a little chunk of time gone, and I'm on the ground.*

For others, waking up was not so immediate and a few participants vividly recalled being 'out of it' during the hours or days following their injuries. They spoke about how, in this time, they had gradually regained full awareness of what was going on around them, whilst trying to recover some kind of memory of their injury. Matthew could not recall the incident but remembered his subsequent three- or four-day hospital stay, *"I just remember waking up in hospital with doctors all around me, and yeah, I can't remember that day at all"*. Other participants had pieced together what had happened, but continued to experience gaps in their memory of the period surrounding their injury, such as Talia, who said her *"memory is quite broken from that bit of time"*.

Ryan, who sustained the only 'moderate' injury of the sample, shared how he had woken up gradually across his one and a half week stay in hospital. He described being *"in a state they call like an awake coma or something, 'cause I'd be able to talk to people, but I had no idea what was going on"*. With gaps in their recollection of the events that caused their injuries, many participants depended on second-hand information to piece together what had happened to them. Ryan did not remember his bicycle accident at all, and therefore spoke in a rather matter-of-fact manner as he shared what he had been told about what had happened:

> *A car hit me on a roundabout, like didn't see me and drove into the side of me apparently, and sort of fractured my skull, and had like seizures and a few brains bleeds and stuff ... then in hospital my brain swelled up quite a bit, and then I had seizures again.*

For others, the injury was experienced as a significant event in their lives. Danielle, for instance, recalled her "*trauma*" response to the vehicle accident she was in. She described how she visualised the crash, *"have those memories in my head, thinking I was in that moment"*, in addition to recurring nightmares:

> *I think after the accident happened, I was wakening up every night just with the feeling of falling and then being in the whole crash again. I had quite a lot of trouble sleeping ... ages from when it happened ... probably over a year.*

However, the experience of a TBI itself did not loom so significantly in everyone's memory, and for some there was a sense of normalisation regarding hitting one's head. For example, Adam's recollection centred more on the inconvenience of having to wait around at hospital: *"I just hated going to the waiting room, because you end up sitting there for like two hours"*.

This theme captured two extremes. For some there was suddenness and shock of the initial injury that led to a diagnosis of TBI. It highlights the participants fear and confusion in the initial aftermath, whilst the patchiness of their memory of events during the incident and after seemed to have compounded the difficulties they experienced in grasping what had happened. For others, it was seen as a normal occurrence, which led to inconvenience.

Feeling unwell and overwhelmed: 'I was fairly concussed'. Most participants talked about the immediate aftermath of their TBIs as a time in which they felt unable to function as normal in the face of debilitating symptoms. This theme involves an exploration of how participants had felt impacted by 'concussion' symptoms in the initial days and weeks following their injuries.

Almost all participants described some combination of dizziness, nausea, vomiting, confusion, disturbed vision, noise and light sensitivity, tiredness and headaches in the immediate period following their injuries. The extract below illustrates Nick's experience of *"trouble thinking and functioning as normal"*:

> *I was fairly concussed, but I was very, very dazed. My vision was everywhere, I had a serious headache. I was very nauseous, so I think I vomited a couple of times.… I had a pretty bad headache. I think I was still a bit nauseous for a couple of days*.

A couple described *"just a concussion, it wasn't a big one"* [Rachel], with disturbances in functioning limited to a few days. Others recalled *"quite a severe concussion"* [Samuel], in which feeling often physically ill and tired significantly interrupted their normal routines:

> I *was just really, really tired for ages … I actually remember because our house is quite big, that just being downstairs, like, the rest of the family had the TV going and like everything going on, it was just too much and I'd just come up here and read a book or just watch one thing on TV on like low volume because there's just so much sensory stuff going on around.* [Amy]

It appeared that this feeling unwell and unable to function was often accompanied by difficulty managing overwhelming emotions. Many shared how they had struggled with irritability and frustration for a while, and found themselves becoming impatient and *"over the top emotional"* [Lauren] with *"little simple things"* [Adam]. Brandon recalled how becoming *"irritable"* and *"very grumpy"* was a change to his typical *"pretty easy-going"* personality. Some, like Ryan, remembered how difficulty managing new overwhelming irritability had constituted a significant and quite distressing change in their temperament:

> *I remember I broke my hand like probably six months after my head injury, which was something to do with irritability.… Yeah, I hit a wall.… I think what happened was, we had pizza I think the night before, and I was going to have it for lunch and my sister ate it all, and I got annoyed and hit the wall and broke my hand. I've never done something like that again. I think it was just 'cause I wasn't too used to like getting frustrated as quick as I did back then.*

This theme has explored what participants described as their experience of 'concussion' in the period immediately following their injuries that, for most, involved feeling physically unwell and unable to function. Struggling to cope with their symptoms was often accompanied by feeling unbearably overwhelmed, frustrated and quick to react to minor daily annoyances.

Headaches never quite went away: 'I had migraines so severe'. As the immediate aftermath of their injuries began to dissipate with passing days or weeks, many participants became aware of the more enduring effects of their injury. Although many had suffered with headaches in this initial stage, a subgroup spoke about this as ongoing, as frequent intense migraine headaches had seemed to arise following their injury.

Talia's account conveys the pain associated with her experience of migraines, and the extent to which this impeded her ability to function:

> *I've always suffered from some migraines, but after the injury they got a lot worse. I actually ended up having to go to the doctor for like heavy duty pain killers, I think it was codeine I had to take. Because they were so bad, I was having to sit in a dark room and take codeine for whole days. And this was for the couple of years after the*

> *head injury, and it's gone better over time, but yeah that was definitely made worse by it.… I just felt terrible.*

Participant narratives illustrated how migraines not only impacted them physically and functionally, but emotionally. Dylan talked about how migraines had become a source of fear and anxiety as he struggled to understand what was causing them:

> *I had migraines so severe, I used to get hospitalised for them. They used to call the ambulance to school to take me to hospital.… In Year 13 I would have probably had a major migraine at least once a week for the entire year. I think I went to hospital three times for them. Twice they did an MRI for brain haemorrhaging because, apparently, I was just that bad.… It's quite stressful at the same time 'cause you don't know what's happening, you know, people talking brain haemorrhages and you're like, "Oh my gosh, like, the rate of recovery from a brain haemorrhage is, like, pretty minimum", you know and I'm like 17 at the time to be told that you might be having a haemorrhage, it's quite scary, you know.*

Dylan also described how struggling to cope with debilitating pain and this fear of not knowing what was happening to him had caused him to feel depressed:

> *To be honest, I can remember crying, pretty much every week, every time I felt the headaches coming on I just burst into tears 'cause I just, like, I don't think I was coping very well, you know, there was definitely a lot of depression that went on with that.*

Talia shared that she had also been *"suffering from depression for like four years"* following her injury. She talked about how she had used the codeine prescribed for her migraines to help manage depressive symptoms. She recalled how ultimately *"everything had built up on top of each other"*, making it hard to cope, and this culminated in a suicide attempt:

> *The week before I tried to kill myself, I was taking about, probably about 12 to 16 codeine a day, like I was just taking three or four at a time, just to get through the day. 'Cause like there was the head injury, and then I had two of my grandparents pass away, and it just, I think all that just set it all in motion.*

Most participants who experienced migraines and headaches discussed them as something that still needed to be endured or managed with medication. Although much more infrequently than in the years immediately after his TBI, Brandon reported still experiencing migraines that *"just take over"*, cause him to *"feel really weak"* and to *"just need to go and lie down, go and have a sleep"*.

This theme has sought to capture the experience of debilitating migraines and accompanying low mood, which several participants had endured for years after their injuries. Extracts have conveyed how these participants had struggled to cope with the emotional impact of their migraines.

Feeling exhausted: 'I'm always tired'. Another enduring impact of the TBIs commonly spoken about was overwhelming tiredness. Lauren described: *"this would be like afternoon, like really falling asleep, like in class, sleeping very, very heavily, struggling to wake up, just no energy."* For many, this tiredness was most prominent in the initial months post-injury, but some participants described tiredness and fatigue as persisting for much longer. Brandon recalled needing sleep as one of the greatest challenges in the 18 months following his TBI:

> *'Cause I think it happened in October and then for all of that summer as well, I was really tired. Just slept at home. Probably only hung out with my friends maybe, like, twice, I was just sleeping the whole time, yeah, a lot of sleeping. And then as I started getting back into my first year of high school, I still was sort of sleeping, like, a lot.*

For a small proportion of participants, fatigue was still experienced as fairly debilitating at the time of the interview. Ryan provided two analogies to convey his experience of fatigue:

> *Have you ever done a really hard exam like, and been quite tired after that? So, it'd be sort of waking up in the morning and feeling like that, and then struggle for the rest of the day feeling like that. Then other times it's sort of like, if you wake up like a bad hangover or something, like, just your mental state and it's sort of just a mix*

> *between those two different levels. Like obviously sometimes would be pretty bad and other times it wouldn't be as bad.*

For Talia, ensuring a substantial amount of sleep was her only way of preventing exhaustion:

> *I'm always tired ... if I get anything less than about ten hours, I'm exhausted, just constantly exhausted. Like I slept till midday the last two days so I'm wide awake right now but usually I'd be half asleep if I hadn't. Yeah, and everyone's just like 'you sleep too much'. I usually sleep nine hours which is what they recommend, and exhaustion. And I've had this for years and it's a bit of a problem because it makes it difficult to get up in the morning for things.*

This theme has summarised participants' experience of tiredness and fatigue following their injuries. Some still, at the time of participation in the research, found themselves needing a substantial amount of sleep in order to manage everyday activities whilst continuing to suffer debilitating fatigue.

Not being able to think: 'Your brain's no longer quite there'. This theme discusses changes participants noticed in their thinking following their injuries. As with migraines and fatigue, thinking problems were most prominent in the immediate aftermath of TBI, but persisted for years for some.

A couple of participants had not noticed any changes in their thinking. Nick felt that any such changes may have gone undetected since he had not been very stimulated at the time:

> *I can't quite remember like cognitively if anything really changed. I think at that point I wasn't doing very well at school at all. So I probably didn't really notice that much change in regards to how, like, I was functioning as a person 'cause I wasn't very active. I wasn't, like, into sports or anything. I wasn't really doing anything after school apart from, sort of, sitting down watching TV, and I didn't really do a lot of schoolwork either.*

Unlike Nick, most participants noticed problems with 'zoning out', forgetfulness, or difficulties thinking straight. Although zoning out was frequently experienced acutely after their injuries, quite a few also talked about this as an ongoing difficulty. Talia expressed how she would *"get distracted very, very easily"*:

> *Somebody says something and I'd just be like staring at them, like full on staring, not realising I'm doing it and I could do it for like thirty seconds or so before I snap out of it. Like I do it at home sometimes, I just like stare at nothing and not realise I'm doing it. I just get completely distracted and then I'll just kind of snap back.*

A new tendency towards forgetfulness also appeared common amongst participant narratives. Ethan described a lengthy period following his TBI during which he had difficulty piecing together certain events and things that had happened:

> *Yeah, probably about two years of dazy patches where I get asked to remember things, and I'm like.… It'd probably be little patches, yeah very patchy. Like I wouldn't forget a whole day kind of thing, but it'd be like certain things that had happened.*

Whilst Ethan described his difficulties as limited to these couple of years following his injury, others identified forgetfulness as more permanent, and as continuing to impact them at the time of interview. Some made comparisons to their abilities prior to their TBI:

> *Mum always said when I was younger I was good 'cause she could tell me to go down the end room and in this drawer there's something or other and I'd come back with it, now I get halfway down the hallway and like, 'aw what did you want?' sort of thing … Yeah, I'd say it [the TBI] probably did have quite an impact on it.* [Adam]

Although participants, including Adam, mostly spoke about their forgetfulness as an inconvenience or source of annoyance, for others this was quite debilitating and impacted them every day. Dylan said about his memory: *"the whole thing is just a bit of a mess"*. He shared how he would frequently struggle when asked about his day: *"That's something that still happens, you know. People will be like you know, 'what did you do today?' and it's kind of like 'well I don't actually remember'."* Talia shared the following example of how her forgetting was more problematic than that of *"most people"*:

> *It really is a pain not being able to remember something, especially like, I know people walk into rooms to get, like, you go get something from the fridge and you forget what you're doing. I get up off the couch, look at the baby and then go, 'wait, what was I doing?', 'where was I going?' and I don't even get to the other room.*

Memory issues were experienced as overwhelming and anxiety-provoking. Talia described a sense of almost panic as she tried to remember something: *"It's like I see something and my brain is just running around in circles, going 'where's this information? Where's this information? It's nowhere here!'"*

Finally, some talked about a difficulty with processing and expressing thoughts. While some noted *"difficulty thinking"* [Nick] or being *"quite a bit slow just in processing things"* [Amy] in the immediate aftermath of their injuries, a couple reported these issues as ongoing. This manifested for Adam as *"a bit of trouble"* figuring out problems for his coursework, which although frustrating, were not too distressing day-to-day. Dylan, on the other hand, felt difficulties with thinking still impacted him substantially. His *"not being able to hold thoughts in my head"* and difficulty compiling his ideas in order to express himself was evident in the interview:

> *I think it's more like long thoughts, so like, ah, how do I put this? ... More complex thoughts is difficult, like sometimes having even just a general conversation, I'll get lost and what, like if somebody asks me a question I'll get lost as to how I'm answering it or what the question was and, kind of, have to go back to the start again and, you know, and repeat the conversation. And then sometimes when I'm just talking, it's almost like, I'm not aware that, I can hear myself talking but I'm not aware of what I'm talking about or saying. So sometimes you look back at a convers... you know, someone will recall a conversation to me and I am like, "oh I don't remember saying that and that's not what I meant" and, you know, so kind of, what goes on here (points to head) isn't always what comes out here (points to mouth). Yeah.*

Difficulty thinking clearly not only impacted his ability to express himself, but everything Dylan would try to do. The quote below illuminates the frustration and upset that resulted from feeling as though his brain was not functioning as he needed it to:

> *It is frustrating sometimes. You know, especially when you are halfway through doing something. Yeah, and it's something you do every day and then all of a sudden, it's like, you forget how to do it because your brain's no longer quite there and then it takes a minute or two and, you know, yeah, it's frustrating…. I find it extremely frustrating and upsetting, personally, not always being able to think clearly, I think I probably get upset in myself a lot more than I probably should but…. I mean it's still a struggle.*

The final theme in this category has addressed participants' described experiences of changes in their ability to focus, remember information and to think clearly following their injuries. Participants differed with regard to how much they felt impacted by these issues. While some found lapses in memory or focus to be frustrating or inconvenient, a small subgroup of participants seemed to suffer a great deal of distress, anxiety and upset day-to-day as they struggled with the impact of their brains not processing as clearly as they used to.

Summary. Themes in this category first summarised participants' immediate reactions to their injuries and their efforts to make sense of what had happened, before exploring participants' accounts of how they had been affected by subsequent physical unwellness and functioning difficulties. Overall, most talked about how they had endured some form of 'concussion' phase, which lasted days, weeks or months and featured symptoms such as confusion, light and noise sensitivity, difficulty focusing, tiredness and headaches. These symptoms made it challenging to function day-to-day and left many of the participants feeling emotionally overwhelmed, and struggling to cope with increased irritability, frustration and other temperamental alterations.

As the intense confusion that accompanied the immediate aftermath dissipated, many participants described how they gradually became aware of a range of more enduring effects of their injuries in the months after their TBI. For some, this meant having to endure ongoing migraines or fatigue, often in combination with new changes in their ability to think clearly. A surprising number of participants disclosed how they continued to suffer the effects of TBI-related changes long-term, at the time of their interview. Although such effects varied, it seemed that the emotional impact of these difficulties, which ranged from fleeting frustration to enduring anxiety and depression, added to the burden for many of the participants. The next category of themes explores how the difficulties described proceeded to impact important areas of the participants' lives throughout adolescence, and as they sought to adjust to early adulthood.

Category Two: Impacts on Important Areas of Life

Most of the participants talked about how lingering changes in their thinking, often combined with debilitating tiredness or migraines, impacted upon their participation in life. This category of themes explores the multitude of changes participants described in their school, work, and social lives following their TBIs.

Schoolwork suffered: 'It got pretty downhill at school'. For some participants, the greatest impact of their TBI was felt at school. Although a couple denied any noticeable changes in schoolwork at the time of injury, most participants reported some form of disruption to their academic performance. For some, this had mostly resolved in a couple of months, when the worst of their fatigue and noise sensitivity had resolved. The timing of injuries seemed to influence the degree of impact had on school for this group. A couple described how they had been able to recover from setbacks as their injuries had occurred at a time when they did not have major exam pressure:

> *I was really tired, like I wasn't as attentive in class as I probably could have been. But it wasn't at a time where there was, like, big exams or things going on, so by the time that I was better or felt better, I could catch up.* [Amy]

A larger group of participants described more enduring symptoms, which seemed associated with more ongoing problems at school. For the most part, changes in learning were attributed to new problems with thinking, with difficulty focussing and remembering information being the most common. Danielle described:

> *I'd just find it real hard, you know, sitting down and trying to study for this information, I'd probably do an hour and then go off and get distracted by something else 'cause I just couldn't focus and I just wasn't remembering that information.*

These difficulties had broad implications for many. Ethan described how *"it got pretty downhill at school in those years"* following his injury, as he felt his memory had *"deteriorated rapidly"*.

Difficulties with trying to think and remember were often most problematic when it came to examinations. Ethan recalled *"tests, always a low point"*. Exam time was remembered as *"scary and daunting"* and *"always stressful"* by Dylan. His description conveys the overwhelming experience of trying to think on the spot and produce a response in an exam:

> *It's almost [as though] there was no or very little connection from your brain down to your hand.... Sometimes you'd read a question ten times and it would still make no sense ... you're having so many ideas coming to head, you read a question and, it's like, you know, it does this and it does this and it does this, and then compiling it into an answer that makes sense. Again, just too many thoughts or not enough thoughts.*

The next extract highlights how these difficulties placed Dylan at an educational disadvantage, whilst illustrating how feeling unable to demonstrate his knowledge and skill through exams, understandably, created a great deal of frustration and sadness for him:

> *I feel like all my exam results were never a true reflection of what my actual classwork was like. I'd be just scraping, you know, C+, B in my exams but I could get A's in my assignments, and so there was always that struggle of, kinda, knowing just enough to get the exams. And then you review the exams later, and it's like "well, I*

> *know the answer. If you ask me the question verbally, I could probably give you the answer verbally".*

Some shared how problems with thinking had persisted to disrupt their ability to engage in professional training many years after their injury. Brandon described how, at the time of interview, difficulties with zoning out were affecting his ability to complete his degree:

> *With that getting distracted, paying attention, the long periods of paying attention. Yeah, sometimes I don't know whether that's just a normal, like everybody gets pretty bored in a lecture but then it just feels like, even if I try really hard to concentrate sometimes, yeah, zone out. I find I have to read everything twice to actually remember it.… When I'm having a bad day and I really can't pay attention, I'll probably be able to pay attention for about five minutes and then I'll zone out, five minutes, and then zone out.*

Adam attributed his being six months behind in completing his trade qualification to struggles with focusing on, comprehending and remembering written information, in particular *"reading and writing and shit.… Oh I don't remember f**k all if I read it!"*

This theme captured the participants' descriptions of how things had changed for them at school after their TBIs, and how ongoing problems with thinking continued to affect their ability to complete later professional training; which is reflected in the subsequent theme on changed career opportunities.

Career opportunities changed: 'Your options become limited'. While many of the participants felt that, whether through the passage of time or working hard, they were able to regain their previous performance capacities at school, this seemed unattainable for some. Matthew described how, despite trying hard, he was unable to re-establish his educational achievement standard after his injuries, concluding, *"it was quite clear for me academically after that"*:

> *It was a little bit harder, because when I first started high school it was good, my grades were pretty good, and then it kind of just went backwards a little bit. But I really did try and work at it more, like harder than everyone else because of what had happened.*

Matthew expressed disappointment and loss as he felt his efforts ultimately did not pay off:

> *Yeah, when I was at high school I was really trying and doing it, and then it didn't really work out in the end which did feel, I didn't feel happy at the time because I put all this time and effort in, even after school and during school. I just feel like it wasn't worth it.*

Matthew believed his TBIs had prevented him from going to university, where he *"probably would have done like mechanical engineering or something"*: *"If I didn't have it, I would have gone to university. But then since it has, I couldn't keep myself going, to be able to get into university".*

Similarly, Dylan recalled questioning, *"Where is my life?! What's happened?!"* as he had felt his world of opportunities become much smaller due to his multiple injuries:

> *I felt, you know at about 15, 16, I knew where I wanted to go, I knew what I wanted to do, I kind of, I had a general direction, a purpose to what I was doing and then it changes.… even academics you can no longer think clearly in part, you can't do things anymore. You know, so it's, kind of, all of a sudden, your options in terms of study outside of school become quite limited in what you can do.*

Whilst Matthew and Dylan had attributed their disrupted educational goals to changes in thinking, Ryan shared how his debilitating fatigue had caused him to drop out of school:

> *I didn't finish high school. Like the year afterwards I went back and did two classes and that's all I could do really like. I tried doing three classes when I first went back to high school afterwards, and I kept getting really sick and run down, so I just did two classes and that's all I could do.… it was a bit of a waste of time.… was just the fatigue really.*

Not everyone felt that changes in their ability to perform had drastically impacted their career trajectory in this way. Adam reflected that he would still have chosen his current profession:

"I definitely would have been a tradie, aye. I don't think I could sit down all day at a computer ... Yeah, wouldn't be my thing".

This theme has addressed how some participants had felt their injuries disrupted their career trajectories. Some had tried hard to re-establish their intended pathways, but with time discovered that changes in their thinking or ongoing fatigue had meant their career prospects had suddenly become limited. This leads directly to the next theme on struggles at work.

Struggling with work: 'What if I don't have what they want?' This theme explores how, almost eight years later, the TBIs still had consequences that impacted some participants as they sought to establish themselves in their careers. Lingering thinking difficulties appeared to make learning on the job difficult for some. Matthew, for example, described struggling to adjust to his new labouring job, and felt that he *"just got chucked in the deep end and sink or swim kind of thing".* He expressed frustration and confusion as he felt his needs for time to learn the ropes and to be shown clearly what was expected of him often were not met, causing tension with his workmates:

> *If it's at work and I don't get it, I usually ask once, and then if they don't answer it does get annoying.... sometimes it's like 'well now you know how to do it, you can do it', and then they tell me off.... If I have asked, then sometimes if I ask [again] they don't like it, and it does make it quite hard, a lot harder on me. And then I'm trying to do it the way they showed me how to do it, and then they're saying, 'aw you've done this wrong'.*

Other participants described the emotional impact of adjusting to their professional environment when they could no longer trust their brains to function properly. Dylan shared how he would worry a great deal about having to think on the spot in high-pressure situations:

> *There's always a lot of fear of "what if I don't have what they want?", "what if I don't know?", you know, "what if they ask for something by its different name and I don't know what it is?" and I guess there's always a lot of anxiety in that sense.*

Danielle expressed similar anxiety regarding her healthcare role. The extract below illustrates how she would find herself lying awake at night, ruminating over whether she had completed every step in a procedure, even though she would *"usually triple check"* that she had:

> *Yeah, 'cause like if I've had a bad day at work or something, I can't just go to sleep, like I always have it. Even just like the small stuff, I just I'm constantly thinking about it when I go to, trying to go to sleep.*

Both Danielle and Dylan described how these work-related worries impacted their mood. Dylan had once found himself unable to recover for some time upon making an error at work:

> *I can remember for probably about two months just being so depressed, and I felt like I'd failed, you know and it didn't matter how much you talked with your colleagues about it, there was just that feeling of 'I've absolutely failed, I've messed up', you know, just, kind of, impending doom.*

Danielle wondered if her worrying tended to build up to cause her to feel depressed:

> *Now I get a bit of anxiety and depression.... I sort of go through phases so, you know, some days it might be, or weeks it might be really good and I won't have that feeling but as soon as I just hit something then, yeah ... it just will happen ... all the time, even just like the littlest, smallest things, I worry about.*

Not everyone with persisting challenges related to thinking found these impacted their work. Ethan described how his career choice provided opportunity to retrain his memory, thereby enabling recovery from the significant problems he had experienced throughout school:

> *Oh working at my job now my memory has to be pristine, so I kind of just retrained myself to remember every little detail of everything ... I've got to remember part numbers, people, lots of stuff like that.... But even now, I'm pretty sure to this day my memory's pretty good after, obviously since work I've had to really put my mind to things to be able to do it.*

For some participants, fatigue and migraines continued to impact their ability to perform at work, or in Brandon's case, trying to balance work and study: *"I could do, like, half a day at uni' then half a day at work and I'll be so tired, just mentally fatigued"*. Brandon shared his frustration over having to miss work when a migraine would come on:

> *I just got a new job at the beginning of this summer, and I started getting them, like, a couple of them and it was really frustrating. 'Cause I'd only just started the job and it's taken me out of work already.*

Fatigue meant that rest had to be prioritised for a couple of participants, causing them to make sacrifices in areas of their lives, such as work. Ryan recounted how a recent attempted return to starting upon a career path had impacted his wellbeing, which prompted him to quit:

> *I was working like 20 or 24 hours a week or something … I was working like Monday, Tuesday and Thursday, Friday and I was working probably six hours a day on the days I was working. And like I'd just get really worn out during the days, and on the days off I'd be having to recover and then I'd go back to work and I would do it again, and on the weekend I'd recover and wouldn't be able to do much after work and stuff, and doing all that I still wasn't doing like full time work.*

Talia reported a tendency to feel overwhelmed, which was unaided by fatigue and migraines. She spoke about considerable distress and emotional problems experienced in the past, and attributed a suicide attempt to pressure to get a job, whilst already struggling to cope:

> *It was just everything had built up on top of each other, and then there was WINZ. And at the time [the migraines] were quite bad, and at this point they were trying to make me get a job, and sending me to seminars every week, and they were getting me to come in and see them every week. So I was spending two days a week on the bus, one-hour bus ride travelling to these places back and forth, and that was just wearing me down and making me worse.*

Although not engaging in paid employment at the time of the research, Talia described feeling overwhelmed in her role as a single mother with a toddler: *"feelings like, sometimes* *it's just everything and it's overwhelming. Even when it's, you're like it shouldn't be overwhelming 'cause there's nothing stressful happening that is so overwhelming."*

This theme illustrates how TBI-related challenges continued to impact participants' jobs in many ways. Thinking problems meant that learning on the job was difficult for some, others felt anxious and depressed due to problems trusting their brain to function at work, whilst others struggled with frustration, exhaustion and feeling overwhelmed as fatigue and migraines formed ongoing barriers to working. In addition to its impact on academic and employment spheres, TBI also had both immediate and ongoing impacts on social interactions.

Things changed socially: 'The most alone I had ever felt'. Another prominent pattern noted throughout participant narratives was how their social involvement was impacted by the brain injuries, both through the teenage years and, for some, as adults. Social changes were most commonly felt initially via missing sports involvement. For many of the participants, sustaining a TBI meant giving up sports, either in the short-term as they underwent physical recovery, or permanently because the implications of potentially sustaining another TBI could be devastating. Standing down from sports for a few weeks or months was *"really pretty rubbish"* [Lauren]. Amy recalled:

> *I think I had to stand down from sports for a while. Yeah, that was pretty bad like. I was pretty into it, and I played for quite a few different water polo teams at the time and I had netball and things going on as well, so that was a bit of a bummer.*

The social implications of missing out on sports seemed to loom most prominently in participants' memories. Not feeling included on their teams was spoken about as almost painful: *"'cause like my brother was playing, and so it was kind of gutting like, I'd go watch his games and then knowing that I couldn't jump on"* [Samuel]. Although missing out on sports was short-lived for most, those who were never able to return to their teams found their social lives permanently altered. Dylan described a great deal of grief and loneliness having lost the sense of belonging he had once enjoyed through sports:

> *I can remember going and watching one of their rugby games, and then afterwards being in the changing room and just being absolutely ignored by everyone 'cause I wasn't playing in the team. They had won the game, they had a good game, they were all excited, you know, whatever, but in that moment I probably felt the most alone I had ever felt just because it's like, I can no longer relate to, you know, there's still the euphoria from winning but knowing that I was just on the sideline watching your team mates do it without you and then being happy and excited without you, you know, it was, yeah quite difficult.*

Missing out socially was not just felt in relation to sports. Not having the energy even to 'hang out' was an issue for those with enduring problems, such as Brandon:

> *I think the biggest thing was just how I was so tired all the time. Like, my friends would ask me out and I'd just want to lie in bed and do nothing all day. That was pretty much it. Just getting out and hanging out all the time, yeah, just missed out on a lot of that ... Probably only hung out with my friends maybe like twice, I was just sleeping the whole time, yeah, a lot of sleeping.*

Brandon and Ryan explained how debilitating fatigue and migraines had been all they could care about, which meant they had not noticed how much they were missing out on at the time: *"Yeah, it doesn't feel like you're missing out on doing stuff when you're always that tired, 'cause you don't feel like doing stuff, if that makes sense".* [Ryan]. Nevertheless, the feeling of having missed out on something important was noted in retrospect, and this would be accompanied by frustration as fatigue or migraines continued to impact years after the injury. For instance, Brandon expressed how his attempts to re-establish himself in his social world were impeded:

> *It would be really annoying, like I'd go out on the weekend with my friends, we'd go and play rugby or something down at the rugby club and I'd start getting a migraine and then I'd just have to go home. You know, and it happened often, so just having to leave and go home was a bit frustrating sometimes, yeah.*

Participants' accounts varied with regard to how they felt their injuries impacted their sense of social inclusion. Amy, who had sustained her TBI at age 14, wondered if the age at an injury occurred might be a factor in this:

> *It was way before I started going to parties and driving and drinking and that kind of thing. So, if I was a bit older when it happened, that would have been really hard 'cause that's kind of when a lot of those like pressures and things would come on. Like, when all the friends would go out partying and if you had to stay at home, you weren't very cool and then you wouldn't have anything to talk about the whole week at school, 'cause that's what they would be talking about … I think it probably would have had more of an impact on my relationships at school, definitely, if I was a little bit older.*

Whilst a sense of missing out socially was more prominent in the time immediately following the injuries, several participants expressed how their problems with memory, focus, and expressing their thoughts had contributed to more ongoing social changes. Talia, for instance, talked at length about how a new difficulty remembering faces impacted her socially:

> *No it doesn't [help], it doesn't…. It's hard but you just pretend you know who they are. Like the amount of times people come up to me and are like, "hi, how are you?" and in my head I'm just like, "who the hell is this?"*

Difficulty recognising people could be a source of embarrassment for Talia, while also forming a barrier to her ability to make and maintain connections with others: *"I think that's the biggest thing and it's really embarrassing when it's someone you, especially someone you've known for years and years and you don't recognise them".*

Participants most commonly noted problems with *"drifting off"* [Adam] as contributing to difficulties in social interaction. Talia said about her *"terrible"* concentration:

> *People would be talking to me and I'll get distracted by a car or TV or I don't even like cars, but I could be like "oh look at the colour of that car" and people would be*

> *like "you're not paying attention, are you?" And I'll be like "um no?" But no, I just like get distracted very, very easily.*

New thinking problems seemed, at times, to contribute to conflict between the participants and the people in their lives. Adam said about his new difficulty expressing his thoughts:

> *I get my words and that mixed up.… That's caused a lot of issues with exes and that in the past, 'cause they always want to talk about things, but I don't know how to actually say it. I can think about it easy enough, but I have trouble saying it. Yeah so I f**k a lot of people off.*

A few described how thinking difficulties meant reduced confidence engaging with others. Adam shared *"I get sort of uncomfortable around people quite easily … I can't really keep a conversation with someone I don't really know".* Dylan described how changes in his thinking created anxiety during conversations:

> *There's always anxiety … I just don't like lots of thoughts, trying to conversate lots of thoughts. But if I'm just purely thinking, it's alright because I can keep, you can kind of, you know, you're thinking about something and you're bringing thoughts together, it sticks in the head but when you're trying to get it out, that's when the issue is, I find.*

This theme has explored how changes related to their TBIs had impacted the participants' social relationships. Most acknowledged how they had somehow missed out on feeling included due to their injuries and this was often experienced as frustrating and *"gutting".* Another area addressed was a change in social performance as thinking difficulties seemed to impede some participants' abilities to interact and connect with others. This had the potential to result in anxiety and reduced social confidence.

Summary. Overall, themes explored in this category have further explored the emotional burden of the participants' TBIs as they sought to move forward in many important areas of their lives, whilst coming to terms with ongoing symptoms. The first theme captured how problems with thinking, fatigue and/or migraines had disrupted the participants' educational performance, which resulted in a great deal of stress and anxiety, particularly around exam time. These new difficulties caused many participants to feel that school had gone ‘downhill’, leading to limited career prospects for some, as explored in the second theme. The third theme addressed how ongoing physical or thinking problems had continued to create difficulties for some as they sought to set themselves up in jobs and careers as young adults. Again, some experienced anxiety and upset as they struggled to adapt to the new challenges faced during the workday, particularly as they felt they could no longer trust their brain. The final theme in this category explored how participants had felt their injuries impacted them socially, as many recalled the pain of missing out on feeling included, whilst others found their ability to connect impeded by thinking problems. The next category of themes expands upon the impact of TBI from specific areas of life to the way in which participants viewed themselves within these important areas.

Category Three: Impacts on Identity

This category of themes conveys the ways in which changes in important areas of life, as explored in the previous category, altered the participants’ self-perception. Specifically, themes address how participants began to question themselves academically, how some had felt like the ‘weird kid’, how some experienced permanent changes in their social identity, and how some felt a sense of lost independence.

Changes to school identity: ‘I thought I was stupid’. This theme captures a common pattern observed amongst the participants’ responses to new changes in their school performance, namely, a tendency to locate issues within themselves, rather than attributing them to their injuries. The extracts below illustrate the frustration, anxiety and upset that resulted from this propensity for TBI-related changes to impact how many of the participants viewed themselves academically.

Lauren spoke about her shock as she recognised that something about her had changed, and her devastation as she felt that she may not be intellectually on par with her family:

> *I honestly thought I was stupid, I just thought it was all downhill … for me it was a shock that I couldn't understand, well I could understand but the information that I was hearing and seeing, like I couldn't process so well, and that was a real shock to me. And I was very like 'I must be a [intended profession]', right through from high school, so the idea that my brain wasn't going to function so well was like, yeah. It got me down quite a lot, 'cause my whole family is very intellectual, and the thought that I might not be intellectually able with them was devastating!*

It seemed that Lauren, like some others, had difficulty understanding what was happening, and responded by turning on themselves and, assuming there must have been something inherently wrong with them, assigning themselves harsh labels, like 'stupid'. Understandably, this altered viewing of oneself was accompanied by a great deal of distress and upset for those who might have once considered themselves competent at school:

> *I felt really stupid, cause from what I'd read and everything I thought 'well this shouldn't affect me, maybe it's just all in my head and I should just get over it' and all of that. And really just like, I was very emotional, like over the top emotional about a lot of things…. I wouldn't say mood swings, but things that shouldn't have upset me did. I got frustrated, I was frustrated all the time anyway, angry, didn't really get sad, just frustration.* [Lauren]

Brandon described how he had *felt "quite sad, like when my grades were really bad, like I think for Year 9 science I averaged 26% or something like that. That was really frustrating, got me quite down, yeah".* Brandon recalled how his view of himself had changed suddenly from feeling at the top of his class through primary and intermediate school, to the bottom of the class in any new subjects introduced at high school following his injury:

> *I wasn't sure if it actually was just me that was struggling or if it was because of that [the TBI]. So yeah, I guess so. I thought, because we didn't really do science at*

> *intermediate or anything like that, so I thought, you know, it's something I'm bad at, which I would not really, I don't know, I'd usually been really good at everything at school. And then I found something that I struggled with a lot, yeah.*

Even those who had not cared so much about school seemed to experience changes in how they viewed themselves. Adam had ascribed his need to put time and effort into reading and writing to *"a reading, writing, learning disability thing"*, as opposed to his TBIs. However, upon reflection in the interview, he recalled how this had been a new change since his injuries, as his mother told him that he had always liked reading. Also, he remembered his primary school teachers always telling him to slow down as he rushed through his work. Unfortunately, it seemed that a couple of participants had teachers who had only served to reinforce these new unhelpful assumptions. Danielle, for instance, reported: *"I did get told I was too dumb to go to uni' by a teacher."*

This theme has demonstrated participants' tendency to interpret new difficulties with learning at school as something that was wrong with them, as opposed to viewing changes in the context of their injuries. For some, this meant feeling stupid, feeling sad, and feeling anxious about the consequences of what these changes might have for their future identities.

Feeling self-conscious: 'Being the weird kid'. This theme captures how some participants described feeling different or weird following their TBIs. Nick recalled feeling *"very self-conscious"* as others reacted to his facial injuries:

> *The hardest part was probably the recovery, going back to school after it, 'cause I had to go back to school within a few days, and it's hard, you're sitting there and you have like a massive injury to your face and stitches, and like and everyone looks at you quite weirdly and strangely.... So, I just remember walking through school and like a complete, feeling very weird, and obviously looking very weird too, so it wasn't quite that ideal, I guess.*

Nick believed that the effects of his TBI, sustained in his first year of high school, had served to exacerbate the self-consciousness he already experienced as a young teenager:

> *It's a relationship, definitely, to how you look and having, I guess the brain injury or the accident doesn't help, because, you know, you're already feeling quite bad about yourself and at the time also I had severe acne. So huge things about being self-conscious and not liking the way you look and that side of things.*

Nick's experience aligns with Amy's perspective below regarding the social vulnerability of participants entering high school, and the potential for injuries sustained at this age to incur ripple effects in terms of social standing:

> *That year like where you're just getting into high school, like that transition phase ... when you're already kind of vulnerable ... and everything is all new, and then if you had a brain injury or concussion or something on top of that, then, I don't know, you might be that weird kid and then you wouldn't have friends for the whole of high school and it would be really isolating.*

Nick disclosed being bullied in high school, which was helped by the visibility of his injury. Matthew had described a similar experience:

> *I have had a bit of trouble since the injury at school. I was bullied quite a lot from it. People just taking the micky out of me and not making it very nice. Just any chance they could get, the bullying ... I think it was because of the accident that I had.... It was mainly about the appearance ... the scars.*

Participants' comments indicated that teenagers were perceived as harsh or *"ruthless"* [Ryan], and not just young adolescents. Ryan described feeling a sense of *"prejudice"* from peers during his later teen years and early 20s:

> *Over the years I've just told people less and less about my head injury as well, just 'cause there is always quite a bit of prejudice around like, having a brain injury ... I guess people just thinking you're slower at stuff, and people are less likely to want to be friends with you I guess as well if they know like you've had a big head injury.*

This theme has addressed how some participants had felt prejudiced from others due to their TBIs, and how many had begun to perceive themselves as 'the weird kid' in relation to their peers. Other teenagers were considered ruthless in their reactions to an injured participant, a position which seemed to reinforce this negative self-perception of the participants.

Social identity was permanently altered: 'Losing where I fit in'. Participants talked about how things had changed in their perception of themselves with regard to group membership following their injuries. This theme includes how some experienced longstanding changes their perception of where they 'fit' socially. Some continued to feel socially disconnected and as though they did not fit.

Dylan who, as discussed previously, had struggled with the impact of having to permanently stand down from sports due to his multiple TBIs, spoke at length regarding the grief he experienced over the loss of his position on various sports teams. The two excerpts below convey how this loss had permanently disrupted his sense of who he was socially:

> *Through primary school I can remember winning our division four or five years in a row and being the best player on the team. You know, everyone's excited towards you and then to suddenly having that all ripped away is, I don't know, it's just like having an open, bleeding wound that no one's stitching closed. No, it really hurts.... You know, it goes from that feeling of isolation and hopelessness to just anger. It's almost, you know, like the stages of grief that you go through.*

Below, Dylan further articulates how he had not just lost his sports, but also an important source of confidence, social recognition and confirmation of who he was. He felt he had never recovered from these losses and described still struggling with *"that feeling of isolation".*

> *There's probably a lot of, you know, lost a lot of confidence and that, and then not being able to, you know having to give up contact sports, which as a young teenager, who, I was quite good at rugby to the point where I had reps coming in and watching me play and then to have all that taken away, you know, it does a lot to your confidence.... It kind of took away, you know, my identity, part of who I viewed myself as, which definitely was a struggle for a long time to re-find something to be passionate about, something to care about. Your whole world changes in a heartbeat.*

Ethan described a different set of social changes, as his school performance declined due to memory problems, and he found himself placed amongst a different group of peers:

> *Because you know, you're not really up there with the schoolwork, 'cause I always failed tests and stuff like that, so you get put down. And then you're hanging out with people that are down, at a lower grade because they don't care as such.... Yeah, so I would have been focusing and not being able to remember, and then getting put with people who just don't care. And then I started hanging out with that group.*

Friends were talked about as those peers who are in the same situation as you, who do the same things, and with whom you 'fit in'. For Ethan, no longer being in the same situation as his old classmates meant that he no longer felt like he fit in. He reflected on how this led to a change in how he viewed himself socially, and a cascade of social decisions followed, as he *"found the wrong crowd"*, *"the crowd that used to just wag school, drugs, smoking"*, the crowd with whom Ethan felt he *"just kind of fitted in"*. Ethan's experience illustrates how his social identity impacted various life decisions. He shared how he remained with this friend group for the subsequent couple of years before considering, *"maybe I am different to these guys"*, which prompted *"a complete just turnaround of who I hung out with, probably saved me really. I wouldn't be where I am at the moment if I'd stuck around with that group"*.

Others described more permanent changes to how they fit in due to their injuries. Ryan recounted how his friends had moved on without him as he had spent years focussing on managing his fatigue following his injury:

> *When I was really bad and stuff, like, all my friends obviously like disappeared basically, just 'cause it's like who wants to hang out with someone who can't do much at all you know? ... People definitely did try and be around me like when it first happened, just 'cause it takes so long to recover it's quite hard to understand and people just move on.*

Ryan reflected on how he had changed socially following this experience: *"I'm definitely not a really popular person or anything, but it's okay. I'm not very, a bit less outgoing and all now, just 'cause of not having as much energy as I did."* Ryan was one of several participants who viewed themselves as less popular due to their injuries. Matthew recounted his struggles to maintain friendships, and his subsequent sense of social disconnection:

> *I have had trouble with the social side of it, and it's just like trying to keep mates, kind of thing. That's always been quite hard ... I do find it quite hard for me, that I don't really have a social life as such.*

Talia talked about how she would go into shops to alleviate her sense of social isolation:

> *It's just the talking to someone, that interaction. Like on shopping day I feel very bad for the shops I go into because like I know I go into a lot of places just to talk to the people… I come out and you go like, "why did I go into that shop? I probably just went in there just to talk that person, didn't I?"*

This theme has captured some of the considerable changes that many of the participants perceived to occur in their social identities following their injuries. Participants talked about their social position, or how they viewed themselves amongst their peers, as central to their lives. Feeling as though they had lost their social standing due to, for example, having to quit sports or changes in academic performance, forced the participants to consider who they were in relation to their peers. It seemed that those who endured multiple injuries or more severe fatigue had suffered the most significant losses related to their social identities. Attempts to recover these losses remain ongoing eight years following their injuries.

Being dependent: Having to rely on family and friends. Many participants shared how their injuries created a need for increased support from others for a time, which resulted in a feeling of reduced independence. For most participants, this seemed to resolve once the most severe aspects of the TBIs had resolved. Amy, for instance, described how she needed support during the period immediately following her injury, which mostly involved her family *"reminding me of the things I needed to do"*.

Another minority of participants described an ongoing need for significant practical support from parents, and this seemed to create more ongoing challenges to their sense of autonomy. Samuel, who sustained significant physical injuries in addition to his TBI, described his *"quite humbling"* experience:

> *Couldn't do the things I was used to doing, I didn't really change what I was, I just had to change the things I did day-to-day and that was just difficult. Even just things like showering and that was difficult, like, so I had to get help.... So it's just little things like that, that you take for granted.*

Participant narratives tended to imply that young people develop independence and a sense of identity through a diversity of experiences, making decisions without parental input, being able to drive, and moving out of home. Amy expressed her thoughts regarding these vital aspects of growing up, which she believed help participants to develop confidence:

> *I think it's through experiences, for me, like just doing a lot of different stuff and trying lots of different stuff out and kind of figuring who you are as a person. Like I was pretty lucky too, I had lots of different opportunities to, like, play different sports and go different places. When we got our licenses too, like, me and my friends would go to the beaches and things and be a little bit independent, which was cool. So, all that kind of stuff where you go out on your own and come back and learn who you are is really cool.*

The extract from Samuel's interview below indicates how sustaining a second injury at age 17 had implications for the sense of independence awarded by being able to drive:

> *That was kind of gutting. Yeah, I think I just got my full [driver's license], I think. I was just about to get my full. So yeah, that was a bit of a pain like, yeah actually, yeah good point. I wasn't allowed to drive, I wasn't really allowed to bike; I just had to be driven around everywhere. I could walk but, yeah, I couldn't really transport myself places very easily so I was having to rely on my family and friends, and that was a bit of a pain. ... Having to ask, "Mum can you drop me off?" You know, just*

> *things like that, when there was events on, I had to make sure I had to organise rides and that, where usually I'd just go myself. So that was part the worst.*

Ryan considered how his injury had meant missing out on the many things that he associated with learning to become an independent adult: *"It was just the age I was, you know I was in high school, going into like University and stuff, and I'm stuck twiddling my thumbs really."* Missing these experiences, for Ryan, was equated to missing out on *"just living basically"*. At the time of the interview, turning 25 soon, he reported still living with his parents: *"I didn't really have many options to be like independent or anything just 'cause it was enough of a struggle just to do little things, let alone like do all the things and look after myself."* With this perception that he had not been able to do many of the things that would be conducive to living as an adult, Ryan reflected: *"I guess I lived just like a teenager for quite a few years"*.

A few participants talked about how their parents had become more protective after their injuries, which did not align with their perceived need for increased independence. Matthew attributed struggles in living independently to parental protectiveness. Having *"been in and out [of home] a few times",* he had returned to live with his parents because, he believed, his father worried about his ability to be self-sufficient.

> *I'm not allowed to go out, like go out and drink with mates and stuff. And it just kind of feels like I'm confined in [hometown] and I'm not allowed to go to [other NZ city] or something if I have to have work, or somewhere else.*

Similarly, Ethan recalled how his parents *"were trying to keep hold of me better afterwards"* and *"trying to keep a bubble around me"*. He shared his thoughts regarding how teenagers might rebel against any sense of being restricted, and he had done everything he could to escape feeling *"overprotected"*: *"If the parents try and hold you back, you just go out"*. Rachel shared a similar opinion that parental protectiveness could form a barrier to living independently, and recalled of her transition to university:

> *So, you went from being kind of sheltered, overprotective dad, to then being in a University hall. And that was a big jump and, like, all of that social learning that I had to do and that. I probably did a lot of social learning in that year alone versus most of my high school experience, because suddenly there was no "be home by this time" and "you can't go there".*

Those who were older at the time of injury seemed to speak more about ongoing issues with gaining a sense of independence, whilst those who were injured before the age of 14 did not mention any struggles with this.

This theme has addressed how some participants experienced a sense of reduced independence, either due to a heightened need for support or increased protectiveness from parents. While for most this was brief, spanning the weeks after the TBI, some participant narratives presented increased support or protectiveness from family as more ongoing. This contributed to feelings of frustration and sadness, especially for those who felt they had not been able to achieve the milestones perceived as necessary for becoming an independent adult.

Summary. Themes within this category drew together underlying references within participant narratives about how injury-related changes had caused the participants to view themselves differently; summarising the main ways in which participant identities were altered by the impacts of their injures. Firstly, struggling to comprehend why things had changed in one's ability to achieve at school had created shock and devastation as some participants no longer felt intellectually able, and therefore began to view themselves as 'stupid'. Second, participants recounted how normal self-consciousness had been exacerbated by certain aspects of their injuries, both visible and cognitive. This seemed to cause some to feel like the 'weird kid' amongst their peers. This self-consciousness seemed compounded by the perception of other teenagers as cruel and, for some, the experience of bullying at the hands of their peers. The third theme addressed how participants seemed to undergo a process of questioning where they fit socially. For some, the impacts of their TBIs meant drastic changes to their group identity or, at times, a total loss of group identity and, ultimately, for a few, an ongoing feeling of social disconnection. Finally, the experience of needing a greater degree of support from families for a while, and/or increased protectiveness from parents following their injuries, had left a couple of participants feeling as though they had missed out on the necessary experiences to be able to view oneself as an independent adult. The final two categories of themes, described below, explore how participants managed to navigate these challenges following their TBIs, firstly those individual resources for coping and secondly through social resources/supports.

Category Four: Individual Resources for Coping

Participant narratives were rich with descriptions of what had helped them to navigate a way through the challenges described thus far. This category of themes captures the participants' resourcefulness in getting themselves through difficulties that followed their injuries. The first theme summarises how participants managed by 'getting on with it'. This was often followed by the second theme, learning to 'accept' their limitations and subsequently seeking a 'balance' in their lives. Finally, the third theme represents endeavours to move on and to decipher some sense of 'meaning' from the injury experience.

Learning to cope with difficulties: 'Just getting on with it'. The perception of the TBI as a minor event or 'just a concussion' was common amongst participants in the initial aftermath of their injuries. Adam considered his TBIs as like any other injury: *"At the time, I didn't really link it to anything. I thought a concussion was like, when I broke my arm, all that sort of stuff, a week later, I'm sweet, sort of thing"*. Like others, Adam *"just thought it was normal, that high school thing to have a couple of concussions"*.

This attitude seemed to prompt participants to respond to the struggles that accompanied their injuries by 'just getting on with it'. Some talked about how this meant not complaining or seeking help: *"I again just thought 'oh, it's just a concussion, it'll go away, I'll be fine'. And even when I was realising I was having difficulty studying I didn't say anything, 'cause I just assumed that's how it was."* [Lauren].

'Just getting on with it' sometimes meant 'not stressing'. This was spoken about, particularly by the young men in the sample, as the ideal response to an event like a TBI, and seemed related to a self-perception as someone who was 'easy-going'. Ethan stated: *"Yeah, there's no point in crying about it, that's my theory anyway"*, and Ryan said: *"I've always been the sort of person not to complain about too much. It's probably a good thing for this sort of injury."* Brandon's comparison to friends revealed his thoughts about how 'stressing' could increase one's vulnerability to depression:

> *Like for me, like I'm pretty easy-going and stuff like that, but I've got friends who get really stressed about school. Like, if it was them who was in my position, it would be a lot, you know, they'd probably get depression and stuff like that.*

'Just getting on with it' involved drawing on an internal sense of determination in order to get back on track following the injuries. Again, this coping stance seemed connected to how the participants viewed themselves. For instance, Ethan stated that *"I just put my mind to something and stick to it"*, and Samuel reflected, *"I've always been quite focused on what I'm doing, so if I've got a goal, I'll try and achieve it and just try to not let anything hold me back."* One way in which participants utilised their determination was by 'knuckling down' and working hard to find new approaches to studying, and this enabled some to regain a sense of control at school and university following setbacks.

> *I knuckled down; I was like 'I have to learn as much as I can just to get through this'.… I even took an online quiz about what sort of learner you are, to sort of see what's going on. 'Cause yeah, usually I'd just listen to it or see it and that's it, got it, but it wasn't happening.… so, it was a big learning curve for me having to actually process things a bit differently, yeah.* [Lauren]

Participants also reflected that it could take some time and effort to figure out new ways of doing things. Danielle, who was injured aged 14, reflected on how she finally learned this important lesson at university:

> *I found it real hard studying for exams throughout my high school years, but it was when I went to Uni', I found a way to, sort of, go around and trying to remember, my exams and stuff, and like I did really well at Uni'.*

Knuckling down thus could be *"massively time consuming"* [Lauren], and some found their fatigue become exacerbated by their desire to work hard in the interest of progressing at school or university. Lauren recalled how *"there were definitely times when fatigue hit me pretty hard, mostly around the exam period"*, while Danielle described her fatigue and migraines as being at their worst *"mainly at uni"*. Lauren's quote about what she had learned about herself following her TBI experience demonstrates some of the pros and cons of 'just getting on with it': *"Definitely that I'm quite determined. I don't know, I guess that I wasn't stupid, I just needed to do things differently. Probably should have looked after myself a bit better, yeah."*

In summary, participants tended to respond to their initial injuries by 'just getting on with it' and working hard to quickly re-establish themselves in their lives. This could be a double-edged sword, however, as participants found themselves at risk of overdoing it and exacerbating their symptoms at the same time. Some of the young men in the sample expressed the importance of not 'stressing' in helping them through these challenges.

Seeking acceptance and balance: 'You can't make your brain heal faster'. This theme explores how many participants had gradually learned to accept the ongoing effects of their TBIs, and how 'just getting on with it' gave way to a search for balance in life.

The concept of acceptance was interwoven throughout participant narratives of how they had moved forward in the face of the difficulties that arose following their injuries. Matthew shared: *"I just started just getting over it and getting on with it, kind of thing.… Just* *getting over what had happened, and just realising I've got to put up with this, and getting used to it."* Although acceptance was rarely immediate, its eventual emergence seemed to support the participants to cope with the upset of some of their losses. Samuel's initial *"gutted"* reaction to having to quit playing sports evolved into *"it wasn't too bad, it just didn't mean the world to me. It was fun, but it wasn't a matter of life and death."*

For many of the participants, acceptance seemed aided by reflecting on how things could be much worse. This generally involved making comparisons to others who seemed worse off: *"there's always kind of like 'why me?' but then there's always someone worse"* [Samuel]. Otherwise participants, like Dylan, reflected on how their own situation *"could be a lot worse"*:

> *I think I've definitely come out of it probably, I don't know, I'd say, a lot stronger and a better person than what I was and what I would have been, you know. I think if maybe I'd gone into professional sports and I'd done an injury a lot later on where I was actually at that level, you know like, doing a knee or something and having it taken away when you know that you're there, probably would have been a bigger loss. Having put in so much time and effort into it already and all of a sudden then stuck, as an adult not knowing what I was going to do, you know, for fifty more years.*

As time went on, those who had been knuckling down and working hard to get back on track began to accept this approach as counterproductive. Ryan reflected on how he had learned to accept the slow pace of recovery and to feel grateful to be *"gradually"* getting better: *"Yeah you can't make your brain heal faster, I guess.... I'm always getting better slowly. It just takes a very long time to get better."* Others discussed coming to the realisation and acceptance that brain injuries may be worse than generally believed: *"I had a boss and he said, 'you're young, you can bounce back quite a bit quicker'. That's actually not the case, it doesn't matter how old you are, the way I see it, it takes ages to recover."* [Matthew].

These processes of acceptance allowed participants to approach their difficulties in a new way. This generally meant learning to balance their determination to move forward with rest and recovery, which they had begun to view as important for maintaining wellbeing. Samuel recounted how he had come to realise the importance of *"making sure that you rest up when you have an injury like that, 'cause you only get one head and one brain, so you might as well look after it"*. Similarly, Ryan wished to advise other participants experiencing TBI of the significance of balance:

> *I think just the biggest thing's like time, and making sure that you're pushing yourself and not overdoing it basically, like 'cause you got to keep trying, but you can't overdo it. It takes a while to get used to that, 'cause it's quite easy to overdo it and everything changes 'cause you just want to be normal obviously."*

Many of the migraine sufferers noted managing stress levels and ensuring regular sleep as important for staying well even years following their injuries. Brandon, for example, learned, *"I think I can usually pretty much avoid them [migraines] if I just have, like it's not really about the lack of sleep, it's about how regular my sleeping pattern is…like, if I get out of whack, yeah."*

Despite their efforts, some expressed how it was not always possible to maintain the perfect balance or to pre-empt *"burn out"* [Amy]. Brandon noted: *"but it's hard, you get caught up in life and you've already run yourself down by the time you realise."* As with the immediate aftermath of their TBIs, motivation to remain involved in life continued to present dilemmas for the participants as they wanted to stay involved in everything that they valued. Amy shared how she had learned to recognise her limitations, prioritise the things considered most important to her, and to practise saying 'no':

> *It was hard to say no to some people because you're so used to like, I don't know, spending so much time with them and doing stuff with them. But like once I'd said "no" once, it was really empowering, right. So once I was like "okay like it doesn't actually ruin the world, I can say 'no' to people and that's fine"…. Definitely in*

> *talking to you now like thinking back to how insecure and teenager-like I was in that time, like, I've definitely come a long way to be like reflecting on what's happened and actually knowing what I like and being confident in myself, and saying 'no'.*

All the participants talked, in some way, about the importance of having a hobby or passion, and this seemed to provide another means of achieving balance in their lives. Most expressed the opinion that life is better when one can do the things they are passionate about. Nick spoke about how having *"found something that I'm really passionate about, something that I really love and enjoy"* had been central to multiple changes that improved his life:

> *I struggled with my mental health for a few years so, until I was about, probably about 16. So, at that point things kind of changed a bit, so when I was 16, I started picking up sport, became more active and a little bit more social, kind of, stopped doing some of the odd stuff that I used to do. ... So that I was actually out doing something, doing something productive, something that was actually, sort of, changing my life. And I think that was really important for me as a young, you know, as a bit of kid, yeah.*

It seemed that having balance between a range of interests was best. Still carrying lingering grief over losing his sports, Dylan felt that balancing one's identity across multiple areas might protect against any single loss: *"If you throw your whole identity into that, and then, some people do it with work as well as you say, and then if you lose that thing it can be devastating."*

In summary, this theme captured how participants began to gradually recognise that their injury had impacted them more than they had initially believed. As time went on, it became apparent to some that 'knuckling down' was counterproductive to their ability to stay involved and well in the long term. Most talked about reaching a point of acceptance that their injuries had changed them in some way. For many, this was followed by a change in priorities, and learning to balance working hard and engaging in enjoyable interests and passions, as well as having sufficient rest.

Finding meaning: 'You can either come out bitter or better'. This theme explores how, through time, the participants seemed to engage in a process of finding meaning in what had happened to them. Interestingly, none of the participants said that they would take away what happened – this only emerged once, in a comment made by a family member. Although parents' perspectives were not the focus of this study, a comment from Brandon's mother, *"you do definitely still wish it never happened",* provided an interesting contrast to the narratives presented by the participants themselves. Rather than wishing their injuries had not happened, participants sought meaning from them, mostly by reflecting on how they had become stronger or more resilient, and how they could use their experience to help others.

For some, taking part in the research had provided an opportunity to reflect on what they had been through, and how they had responded:

> *Funny how this [interview] makes me realise and makes me think, kind of double think what reasons make sense.… A bit of an eye opener this one. This is probably the most adult conversation I've had about this stuff, it's definitely eye-opening. Especially looking back at it now, 'cause I never talked about it at all.* [Ethan]

Upon these reflections, many participants seemed to consider that going through difficult experiences, like their TBIs, had been necessary for developing strength and growing into a better person. This point was aptly articulated by Samuel:

> *Definitely, if you don't go through trials then you don't become stronger, you just become, you're just weak, I guess. The more things you go through, the better you come out. You can either come out of it bitter or better. So it's just a personal choice you have to make.*

Samuel's comment implies that there is an element of choice in how one responds to their adversities. In a similar vein, Amy hinted that finding the empowering lesson from a challenging event was a conscious process:

> *I think that, yeah, it really helps to, I don't know, kind of like empower yourself and be like, "I can get through this, I've done this and the world didn't end, like it's fine, I'm a better person at the end of it"*

Focusing on the positives was not straightforward, however, and certainly seemed to require fully acknowledging just how hard the experience had been (and continued to be) to endure. Looking back and reflecting appeared to help participants look forward and trust that they possessed the skills to deal with future difficulties. Some emphasised acknowledging the ongoing sense of loss and suffering that might come from sustaining a TBI, whilst also holding onto the learning gained:

> *You are almost able to look back and be like, you know, "I've been through this, it's been terrible. Sure, I'm going to go through hard stuff again, but look at what I do know. Look at where I've come, where I've been".... And I don't think any of that happens without, you know, the brain injuries. But at the same time, having that, it is, it's difficult, you know?* [Dylan]

Dylan's words exemplify the emotion and inner conflict felt as he has endeavoured to accept the impacts of his TBIs and to have gratitude for having survived and grown from them whilst, at the same time, allowing himself to feel sad over what was lost:

> *I find trying to think about it, you know, there are some parts where I just want to break down and cry. Yeah that's probably the biggest part, I just, you know, it's almost, it's not, tears of sadness ... part of it's, you know, this overwhelming emotion, like "I can't believe I've been through that, and it happened to me, and I've got out the other side" and then part of it's, you know, like, "I wonder what it could have been like, if it had been different?"* [Dylan]

Similarly, Ryan's words have a flavour of the conflict between acknowledging how one's injury has shaped them, and not wishing to be defined by it:

> *I guess it has been quite a big chunk of my life so far, so I try to make sure it doesn't define me, 'cause I don't want it to, because it's not a good thing to be defined by. Yeah, it's definitely affected who I am.*

Difficult events happening during adolescence were perceived as having the potential to change you as a person, to shape who you are, and help you learn to be an adult: *"Oh yeah, I've had numerous pressures and, you know, everything really. I've had it all. Now I'm kind of, it's pretty much made me who I am."* [Ethan]. This, in turn, provides the confidence to keep going, to know that you are 'okay', despite things happening that are hard to deal with:

> *Yeah and that's probably where they find, or I found, my confidence was in like the going through some big events, you know things that happen in your life and then being able to bounce back from that, and being like "I'm a better person than this" or "this happened but it wasn't my fault, like, I'm okay" and keep going with life.* [Amy]

Another common source of meaning for the participants emerged from the use of their TBI experiences to help others. Interestingly, a large proportion of the participants were either training or working in healthcare at the time of their participation in the research. Many felt their experiences provided them with inside knowledge, which enabled them to develop a deeper empathy for the position of their patients than they may otherwise have had:

> *I've almost been able to flip it back the other way now that I work in [healthcare], you know flipping it back round when you're talking to patients and relating to them, you know and they go through, I mean they may not have had a head injury but they've got that anxiety, that stress, you know…. Being able to get alongside them and say, "I understand this is what it's like for you, I'm here to support you", which I think is what I would have liked. So, kind of, my negative experience has pretty much become a positive change for the way I would try to relate to people in my job.* [Dylan]

Being able to offer this kind of support through work was perceived as not only helpful for their patients, but also for the participant. Dylan spoke about how this offered a sort of meaning to what had happened to him:

> *In all the years that I've been struggling, you know with everything, that probably helped the most … just being able to turn it back round. I think, "Okay, it was a negative experience that sucked while it was happening, it still sucks because you are*

> *still going through it, but you can benefit others because of it”…. I wonder if there’s that sense of isolation and almost abandonment, and wanting to help others so that they don’t have to, you know, share your experience.*

Some participants found that their personal TBI experience gave them a unique position from which to advocate for patients with similar injuries, particularly when colleagues underestimated the extent of symptoms experienced by patients, as Lauren reflected:

> *It’s totally, well, it’s changed my practice. I guess like if we ever get someone on the ward with a concussion or TBI … I think if I hadn’t had had a concussion, I wouldn’t have been as understanding, ‘cause I know a lot of [my colleagues] are just like “oh, could be a TBI, could be a concussion, they’ll be right, they’re walking, they’re fine”. … Like I had a patient a wee while ago … she didn’t have any physical deficits, but she was just so hugely fatigued and just super dizzy all the time. To the fact where she needed help to get out of bed. Physically she was fine, but everything else wasn’t. And the [staff member] on the ward was like “oh, she just needs to get over it”, and I was like “hang on!”*

This theme explored how many participants had reflected on and discovered some sense of meaning from their injury. Participants shared powerful narratives depicting how the experience of challenges like a TBI could ‘empower’ a person, and/or shape you into a ‘better’ person. Some expressed gratitude for how their own experiences enabled them to have a deeper level of empathy for others who are struggling, with this providing a great deal of meaning for the participant.

Summary. This category of themes has explored the participants’ resourcefulness in coping with the challenges that accompanied their injuries. The ways in which the participants had responded to their TBIs tended to be shaped by their general perception of the injury, perceptions which seemed to gradually change over time. Initially minimising their suffering to ‘it’s just a concussion’, most had sought to ‘just get on with it’ and proceeded to ‘knuckle down’ and work hard to try and get back on track with life. Counter to their intentions, this approach seemed to exacerbate difficulties that participants had been trying to overcome, particularly as their efforts caused them to feel more ‘worn out’. What followed was a gradual shift in perspective towards recognising that the injuries had perhaps impacted the participants more than initially considered. The participants learned to accept their losses and limitations and sought to gain a sense of balance in life, mostly in the form of prioritising rest and developing their interests. Finally, participants told of how they had been able to attribute some kind of meaning to what had happened to them. This seemed to occur through a mostly conscious process of reflecting on how the experience of adversities is crucial for the development of strength. Some also found meaning by using their experiences to help others. The next category of themes covers participant descriptions of how friends, family and professionals helped, or could have helped, them through their difficulties.

Category Five: Social Resources for Coping

When discussing the factors that were most important for recovery from TBI, almost all participants talked about the significance of support from three sources; friends, family, and professionals. This final category explores the role of each of these groups in the participants’ journey of recovery by capturing the ways in which the participants felt that others had helped, or could have helped, them through their difficulties.

Feeling included: ‘I had a really good friends’ network’. Most participants talked about the role of peers as prominent in their lives. Whilst previous sections have highlighted the pain associated with lost friendships following TBI for some, another line of narrative was how helpful friends had been, not only for recovery from a head injury, but for helping navigate the typical challenges of growing up.

One important way in which friends had been supportive was by simply carrying on as normal and continuing to hang out with the participant following their injury. Danielle recalled the significance of being able to return to her previous friendship groups:

> *I guess I had quite a really good friends' network, like I had quite a lot of friends, different friends, so like I had all my riding friends, I had my school friends and I had, you know, friends from sports and I guess spending quite a lot of time with them… Yeah it did make quite a bit of difference I guess.*

Similarly, Brandon had shared how his friends *"always still kept inviting me out and stuff like that ... I suppose just going to school and carrying on like it's a normal day, yeah, just going back to normal, that helped."*

Participants' stories suggested that things were better for them when they felt a sense of belonging. Continuity of friendships was less available for some participants due to moving schools or disrupted belongingness to a sports team. For these youth, there was often a process of seeking a new group to which to belong. Nick reflected on how finding a new sense of this belonging had helped him overcome a period of anxiety, depression and loneliness:

> *Definitely for me as a kid, like camaraderie. So, I was part of a rowing team and within that we became like family ... they became like brothers to me, and so did about another fifteen other guys. And so you form like a family and it's a really tight bond and especially when you're, like, when you're with each other, we were doing like twice a day, six days a week, you know. So it was quite intense, and it was really good 'cause it really kind of groups you together, keeps you on a good track, on a path upwards, you know.*

Group belonging did not cease to be important after the teenage years. Dylan's description of finding a work team indicates how regaining a sense of camaraderie, even years later, served as a powerful antidote to the isolation he felt after giving up sports:

> *To be honest, it probably wouldn't have been until my last year of Uni ... just instantly suddenly overnight, just fell in love and I was like, "this is where I'm supposed to be". You know, you're working in a team, and it might not be on a sports field but there's always that sense of accomplishment…. We've done it as a team, everyone is excited and happy, you know. Even the whole meeting up after work and stuff, you know like, that hasn't happened to me since high school. So coming into*

> *this team as a brand-new person and being so accepted and so welcomed straight away, having everyone wanting to get to know you, I think was when the whole isolation bit, I kind of started living.*

Matthew described similar experiences when he started his new job. Having someone to joke with seemed to add a sense of quality to his day, and an element of this belonging:

> *We're just kind of, like if I give someone crap at work, they just give it straight back, just like joking around kind of thing … like that's usually just like sometimes during the day, just to try and make the day go a bit better.*

Generally, friends were discussed as critical for survival. Ethan spoke at length about how, through his teenage years and up to now, *"definitely friends"* had been the most important presence for helping him with all kinds of life difficulties:

> *Oh yeah, even to this day if I wasn't hanging out with the people I am today, like the reason I'm moving out is 'cause I've broken up with my ex of numerous years, and if my friends weren't there for me, I'd be falling into a bottomless pit.*

Overall, this theme has depicted the centrality of friendships to participants' recovery. Friends helped by providing a sense of belonging, which made the participants feel less alone as they navigated the challenges related to, not just their TBIs, but life in general. For some, continuity of group-belonging had helped, while others had found this support through new friendship connections.

Relying on family: 'I don't know where I'd be without my parents'. This theme details how, in addition to friends being there, feeling cared for by family was portrayed in participant narratives as essential for recovery from a TBI.

Many spoke appreciatively of their families for continuing to look after them following their injuries. This seemed particularly important for Ryan, who named family as the single most crucial factor in his recovery, *"I mean if I didn't have my parents supporting me as much as I did, I have no idea where I would be now"*. In addition to providing support with daily needs as he was consumed by fatigue, Ryan noted the importance of his parents' advocacy and assistance with navigating the medical system:

> *Aw just everything, like letting me live here no problem. Just, like Mum definitely helped with all the ACC stuff 'cause I had none of that basically, I wasn't, it was hard enough to deal with other stuff. Yeah, they just generally helped with everything like. I guess I lived just like a teenager for quite a few years you know.*

Brandon's mother had continued to help him navigate the medical system at the time of interview: *"She's probably just been like a manager really, organising, taking the lead"*.

Parents, it seemed, were also there to remind participants to take care of themselves. Samuel's mother's knowledge of brain injury, and her insistence that he follow her guidelines for looking after his body, was appreciated retrospectively, as he reflected, *"It was nice to have someone that cares, I guess, even though we don't always appreciate it when we're young"*. In describing his mother's input, Samuel stated:

> *Yeah probably family I guess, definitely and yeah 'cause my mum used to work in a head injury place, where they did rehabilitation, so she knew all about it. So she made sure I had enough rest and you know, I ate and drank properly, and didn't do anything too rough for a while. So, that's kind of cool I guess, yeah. Us guys can be a little bit ignorant, and just want to do things and don't care about the consequences.*

When considering family support, participants mostly talked about their parents, but there were times where siblings had filled the 'looking after' role, as opposed to their parents. Lauren recalled how her sister helped her out in the initial stages after her TBI:

> *Well I think my sister did the extra looking after for a little while. She was the one that was there telling me, like waking me up when I'd sleep too long, and making sure I wasn't reading too much and all of that, yeah.... It was really nice to be honest, because I love being looked after and I loved the attention I was getting from my sister, like I thrived on it.*

Lauren explained how this was special for her as she and her sister had not previously had a very close relationship: *"At that stage were not friends at all, in the slightest. She's three* *years older than me, very difficult relationship, and then when I got my concussion, she just changed and was loving, caring. It was really nice."* Rachel described her older sister as taking a similar position following her injury: *"When I'm injured, she gets very protective older sister"*.

This theme has captured the ways in which the participants had felt supported by their families following their injuries. That parents provided practical support with daily needs and with navigating medical systems seemed particularly appreciated and necessary as participants struggled to manage their symptoms.

Professionals didn't get it: 'Left in the dark to find your own way'. This theme discusses participant descriptions of the kinds of professional support that they felt might have been helpful to their recovery. Almost all participants talked about the absence of professional input throughout their recovery journey. Brandon, for instance, reflected that he *"probably didn't actually have a lot of support from any doctors or anything like that, well it didn't really feel like it anyway"*.

One of the most common difficulties mentioned was the absence of someone with specialised TBI knowledge who could provide participants with an idea of how their injury might impact them. No one recalled receiving any information regarding what to expect during recovery. Lauren stated, *"I got nothing"*, and Ryan reflected, *"I remember at the time no one would ever like tell you how long it's going to take to recover, and that sort of thing"*. Difficulty understanding what was happening to them was described amongst the most challenging and anxiety-provoking aspects of the injury: "*It's given me a lot of fear and anxiety just from not knowing what was going on or what was going to happen*" [Dylan]. Many felt that being given some information regarding what to expect would have made it easier to cope:

> *I think just knowing that there was the potential that it could have lasted longer I think would have helped me cope better. Like, I like timelines and I know you can't*

> *give definitive timelines in something like this, but the possibility that this could be a longstanding thing would have been nice to know.* [Lauren]

Participants believed that the professionals they had contact with also did not know what was happening. Brandon reflected: *"I think part of the issue was that no one really knew what was happening or, kind of, why I was getting a lot of the headaches and stuff that I was getting"*. Ryan had accepted how this lack of certainty on the professionals' part made it difficult for them to provide the answers he sought:

> *No one would really give you like a sort of straight answer about it, because they probably don't know if you're ever going to recover or not, and they don't want to tell you that you're not going to recover, or they don't want to tell you that it's going to take a long time, because it might not be the most positive news, but without telling you it sort of leaves you a bit like not knowing what's going on. And 'cause you don't really hear too much about how other people with similar injuries are going, or what sort of things they do, so you're sort of left in the dark, to find your own way, basically.*

Many participants also noted a lack of rehabilitation or treatment, akin to what they had received for other injuries, which targeted their TBI-related symptoms:

> *Yeah well, it's just the same if you break your arm or whatever, then you go to physio' after you get your cast off, to rehabilitate it. There should be rehabilitation afterwards. ... Yeah, well I mean I was going to physio' for my neck and stuff like that, to get better, but then I wasn't going to anything for the concussion, so yeah.* [Brandon]

Ryan, the only participant to have sustained a moderate injury, described his follow-up professional input as mainly a lot of assessment, which had not really helped:

> *A lot of work I guess like. Just 'cause you'd have to go see, you have to do a bunch of different things that weren't actually much help, I guess. I mean there was not a lot they can do, I guess they're just trying to help so.*

Ryan expressed a great deal of resignation regarding the limitations to what could have been done to help him, since *"they can't change my brain, I guess"*. Samuel, whose mother had professional experience with TBI, was the only participant to report receiving rehabilitative input specific to his TBI, and he described feeling satisfied with this support:

> *No, it was all fairly good, like. I think I had regular check-ups with the doctors and that and then like, physio' and that, that was all pretty good. Like, you know, I had a pretty good physio' program for memory. So that was there, and then you had check-ups with the doctor.*

This theme has captured how participants reported a lack of specialist input during their recovery, and how they may have benefitted from such support. Most participants explained how some of the uncertainty and anxiety surrounding their injuries may have been alleviated had they been given information about what to expect. Furthermore, some others expressed how they might have benefitted from some form of rehabilitation for their symptoms, which only one member of the sample had received.

Lacking someone who understands: 'Somebody to talk to might have helped'. Finally, participants commonly reflected on how they would have greatly benefited from having access to others who understood what they were going through and with whom they could speak about their difficulties.

Many participants had found initial understanding from those around them to be short-lived, particularly as others struggled with maintaining patience for the participant's persisting headaches, fatigue and irritability. Lauren shared how, *"when it just carried on and I kept being frustrated and angry, it just all fell apart again"*. Participants often interpreted their family's general attitude to injuries as *"Oh, you'll be fine"* [Rachel] or *"you'll be right"* [Lauren], and recalled feeling as though they had been expected to "get back on the horse" [Danielle] and to *"just kind of get on with it and try to get on with life, put it back to normal"* [Matthew]. Feeling as though others could not comprehend their ongoing suffering was spoken about as upsetting and frustrating:

> *It kind of got to the point, too, where friends and even mum and dad, because they're not going through the same thing, they are not experiencing what you're experiencing, they get quite frustrated at you too, and then it's kind of frustrating that they are getting frustrated at you because they don't understand. And they just think, you know, "oh my goodness, get over yourself, it's just a headache!"* [Dylan]

Some, like Ryan, shared how hard it had been to cope with the invisibility of their injuries:

> *It's something they can't really see or anything as well like. I remember I broke my hand like probably six months after my head injury ... I remember people like asking me about my hand a lot more than my head, and it's like my hand was nothing you know ... they think you're healed. But yeah, it's quite hard.*

Ryan described the disillusionment he felt as people did not seem to recognise just how hard he was trying in the face of considerable fatigue:

> *It's always pretty de-motivating as well like, 'cause like you're working your ass off but nobody else can see it basically. Yeah, 'cause you're doing as much as, like I'd be like really working as hard as I can and the rest of my life would suffer, and everyone else would just take it for granted that you should be doing more than that.*

The perception that others would not understand seemed to contribute to a tendency to *"hold everything in"* [Danielle]. It seemed that holding things in had served to prevent the sense of vulnerability that might result from openly sharing one's struggles with others who did not understand, as told by Dylan:

> *I think there are just still some things that, you know, I'd just rather keep to myself about, kind of, what's going on and how I'm feeling, you know? Yeah, it's kind of, you know, something happens and you tell someone, and then the negative experience that you got from them and I'm just, I'll close that part off. Which I think, is probably why as well sometimes when things get a little bit too much, I think I kind of retreat to, maybe, a lot more of a darker place than I probably could have if I let some of it go. But I just, I'm just not ready to let out all that emotion to people.*

Keeping everything to oneself, whilst feeling misunderstood by the people around them, had been quite a lonely experience for participants: "*I very much felt like I was on my* *own"* [Dylan]. On reflection, many participants considered how they would have appreciated *"somebody to talk to"* [Brandon]. Rachel felt that parents should position themselves as available for their participants to talk to, and considered *"not just knowing they're there"* as important *"but actually being able to talk to them"*. Rachel believed that parents, being in the relative position of power, should approach the participant and ask them how they are:

> *I feel like, it's almost on the parent to approach them more cause, like, it's really easy, 'cause, like, they've set the rules your whole life.... I feel like you almost need the parent to come to you and be like "Are you okay? Is this going okay? Is that going okay? Do you need anything?" kind of thing.*

Some related their loneliness to feeling as though they were the only one to experience this kind of suffering. Some predicted that others could not possibly understand them, as they had not been through a similar experience. Matthew said: *"Just not having the support from people, just that's quite hard 'cause it just feels like I'm the only one who's had it and I only know what it's like to go through it."* Matthew was one of a couple of participants to note how it may have helped to talk to peers with similar injuries: *"If they had gone through the same thing it would have given me, I would have been able to learn from their experience of what they learnt, rather than going into it alone"*. Indeed, those who had access to peers who had experienced similar injuries, such as Samuel, described how they had not felt so alone:

> *I know heaps of people who had concussions ... So that helped. And I'm not the only one to go through injuries, my older brother's had a few so, it's like, "I kind of know how you feel". He's had concussions, but not quite as bad, but he's like "Yeah, I know how you feel, kind of". So it's kind of cool.... He's sort of been through a similar thing.*

In addition to these suggestions regarding how having understanding family and peers to talk to may have helped, many shared how they also would have liked a professional to talk to. It seemed that having access to someone with specialist knowledge of TBI might have helped normalise the participant's experience, as expressed by Dylan:

> *Aw yeah, you know, yeah, just having someone tell me, you know, telling you, "this is normal, this is what we see", not "Oh we don't really know what's going on, we don't know how we can help you, you're just going to have to sit and ride it out".*

Brandon reflected on how such a professional may have recognised that he was still struggling, *"like, how my grades at school were bad, like have somebody, like obviously they will see from that that I'm not back to normal."* Participants highlighted the importance of having an ongoing relationship with such a professional, as this may have aided a sense of feeling understood, thereby enabling the participant to share their struggles as they emerged. Amy indicated the potential implications of having such a relationship available for a participant's mental health and wellbeing following a TBI:

> *And even like the kind of mental health stuff that goes with it, like anxiety around doing things, or depression around like, I don't know, the isolation and the fatigue that you feel. Like it could evolve into more if you didn't have that support, in my opinion. Not like labelling things, but yeah, I think that it's really important to have that and even just have somebody to talk to like some kind of counsellor or support or something so that you have somebody reliable to get that off your chest and try and move past it.*

In summary, a sense of feeling misunderstood by the people around them permeated the narratives told regarding the roles of friends, family and professionals. The participants found themselves avoiding talking about their ongoing issues, as the perceived invisibility of these meant that others seemed to expect them to quickly return to how they had been before. Participants reflected on how having someone to talk to about their difficulties might have alleviated the loneliness that accompanied this experience of feeling misunderstood, and may have increased their sense that their experiences were normal. It seemed that a combination of having an approachable parent who asks how they are going, access to peers who have been through something similar, and an ongoing relationship with, or at least some access to, a professional who knows about TBI might have been beneficial in alleviating some of the suffering and loneliness experienced in the months and years following their TBIs.

Summary. Overall, themes in this final category have demonstrated participants' descriptions of how other people had been there to help them following their injuries, as well as the ways in which they would have liked people to be there. All participants, in some way, discussed the real or hypothetical role of support from three sources; friends, family and TBI professionals. It seemed that, in general, the ideal support scenario would have provided the participants with a sense of belonging, someone to take care of them and tend to practical needs, someone with professional knowledge of TBI, and someone to talk to who was perceived to understand.

Participants discussed how friends had helped them by just being there, continuing to involve the participant as they had always done. Some who had lost this sense of continuity in friendships talked about how things were better for them when they later found a new source of belonging. Families, particularly parents, were crucial to providing care, practical support and helping navigate health systems, whilst the participants focused on managing their symptoms. Thirdly, this category has highlighted the absence of meaningful professional input throughout the TBI recoveries. Participants reflected on how they might have benefited from being provided with information about what to expect following a TBI, from having their experiences normalised, and from having some kind of rehabilitation for their symptoms. The one participant to have received this input had a family member who had worked professionally with TBI, which seemed to have increased access to this support. Finally, throughout participant narratives was a strong sense that having someone to talk to (be it friends, family or professionals), and to show they understood, would have made the biggest difference to recovery and coping with the challenges that followed sustaining a TBI.

Chapter Four: Discussion

This study used a qualitative methodology to gain an improved understanding of the adolescent experience of sustaining a TBI, and how this might impact a participant's long-term psychological wellbeing and adjustment to adulthood. It also sought the perspectives of participants who had sustained a TBI during adolescence regarding recovery processes and support they would have liked. This study adds to the growing body of literature regarding adolescent TBI to inform and enhance age-appropriate rehabilitative interventions.

This chapter begins with a brief commentary on the demographic and injury characteristics of the sample. This is followed by a discussion of the key findings in relation to the literature regarding TBI overall, and adolescent TBI specifically. Potential implications of these findings for clinical practice and future research are addressed, and the primary strengths and inevitable limitations of the study are discussed.

Participant Demographics and Injury Features

The proportion of the sample who had sustained a mTBI (n=12 or 92.31%) is reasonable, given that 95% of the overall BIONIC cohort had mTBI (Feigin et al., 2013). The proportion of young men to young women is close to the overall finding of increased incidence in young males in NZ (Barker-Collo et al., 2008; Feigin et al., 2013), and internationally (Langlois et al., 2004). With just one Māori participant (7.69%), Māori were underrepresented based on overall population (14.9%; Statistics New Zealand, 2013) and the finding that TBI is substantially more common amongst Māori (Feigin et al., 2013); whereas one Pacific participant (7.69%) is representative of the overall population (7.4%; Statistics New Zealand, 2013). Māori are commonly underrepresented in research, as their indigenous status and history of colonisation present barriers to participation (Health Research Council of New Zealand, 2010; Sporle & Koea, 2004). Māori were less likely than NZ Europeans to consent to participate in the original BIONIC study and were also harder to contact for follow ups. For instance, in the BIONIC adult cohort, 33.6% and 65.7% of Māori declined follow up or could not be contacted at one and four years, respectively, compared with 26.6% and 50.9% of NZ Europeans, respectively (Barker-Collo et al., 2015; Theadom et al., 2017).

Injury causes included motor vehicle accidents (n=5), sporting injuries (n=7), and assault (n=1), which aligns roughly with recent international figures on the common causes of TBI in youth (Thurman et al., 2016). BIONIC findings also reported motor accidents and assaults as common causes of TBI in young people, but unfortunately did not include sporting injuries as a separate category (Feigin et al., 2013).

Key Findings

Thematic analysis of data from semi-structured interviews with participants who sustained a TBI between the ages of 13 and 17 produced five categories of themes. The key findings from these themes are discussed in turn below in relation to the existing research. Firstly, the experience of enduring post-concussive symptoms (PCS) is discussed. Secondly, the ways in which injuries impacted important areas of the participants' lives (i.e., school, employment, peer relationships), are addressed. The subsequent section discusses how experiencing a TBI during adolescence might impact identity-formation and adjustment to adulthood. Finally, recovery processes following TBI are discussed, specifically in relation to findings regarding individual and social resources for coping.

The enduring nature of post-concussive symptoms. Participants' descriptions of symptoms such as migraine headaches, tiredness, thinking problems and emotional difficulties are consistent with most reports of common PCS amongst adolescents (Babcock et al., 2013; Starkey et al., 2018). While a couple of members of the current sample noted these symptoms abating within days or weeks, problems more commonly endured for years, even until the time of the interview. This is contradictory to previous indications that PCS resolve quickly following paediatric TBI (Carroll, Cassidy, Peloso, et al., 2004; Emery et al., 2016; Hooper et al., 2004), particularly the ‘persuasive’ evidence reported by the WHO (Carroll, Cassidy, Peloso, et al., 2004), which maintained that mTBI has little impact on children and adolescents. The current pattern is more consistent with later suggestions that 30% to 32% of children and adolescents continue to experience PCS beyond the initial month following even mTBI (Davis et al., 2017; Eisenberg et al., 2014; Zemek et al., 2016). Inconsistent findings might be due to over-reliance on quantitative measures and proxy reports (Di Battista et al., 2015, 2012). Variations in the age ranges may also have contributed to differences, since less than half of the studies included in the WHO report investigated outcomes for participants injured over the age of 14, whereas Davis and colleagues (2017) mostly reviewed studies favouring the adolescent period. The latter review concluded that those aged over 13 were more likely to experience persisting symptoms. Recent papers from the BIONIC cohort provide figures for longer-term outcomes, indicating that 28% of children and adolescents (aged <16 years; N = 208) continued to present with four or more PCS two years following mTBI (Starkey et al., 2018), with little improvement observable two years later (Jones et al., 2019).

Cognitive, physical and emotional symptoms seemed more prolonged and debilitating for those who were older when injured, and particularly those who reported additional TBIs as older adolescents. The latter finding is unsurprising, given the association between more severe and enduring PCS and recurrent TBIs in adolescents (Davis et al., 2017; Zemek et al., 2016). Whilst research regarding age-related patterns of PCS recovery within the adolescent period itself is lacking, there is evidence for an increased risk of psychological problems (e.g., depression) for adolescents who are injured after the age of 15 years (Chrisman & Richardson, 2014; Sariaslan et al., 2016). It is possible that the older participants observed a greater impact of symptoms due to the increasing pressures associated with later adolescence. For instance, Amy expressed that the impact of her injury may have been greater had she been older at the time and facing important exams as well as greater pressure to keep up socially. Many of those injured later found PCS were exacerbated by exam stress. Adolescents elsewhere have indicated that PCS were worse when school expectations and general pressures of growing up increased (Di Battista et al., 2014b), and there is evidence that work and study can exacerbate PCS (Mayer et al., 2017). Another factor that seemed to exacerbate PCS was a general eagerness to quickly return to school and activities, as has been observed in other adolescents post-TBI (Iadevaia et al., 2015). A correlation has been found between increased hours of school attendance and exacerbated PCS in adolescents (14 – 19 years old) shortly following a concussion (Makki et al, 2016). Finally, a tendency for the participants to deal with problems themselves, without seeking support may have also contributed to difficulties (a coping pattern discussed further below).

Powerful descriptions provided by the participants in this study regarding their emotional functioning added a particularly striking contribution to the growing literature on the adolescent experience of PCS. Emotional symptoms ranged from bouts of frustration and irritability to more enduring anxiety and depression, still experienced by some participants seven to eight years after their injury. Anecdotes, such as Ryan’s about breaking his hand, add richness to the quantitative evidence for ongoing irritability and frustration following child and adolescent TBI (Starkey et al., 2018). Furthermore, the extraordinary accounts of the fear, anxiety and depression felt by participants may help explain the higher rates of psychological problems found in youth who experienced TBI (Albicini & McKinlay, 2015; Chrisman & Richardson, 2014; Laliberté Durish et al., 2018). The broader literature is unclear regarding whether emotional problems emerge as a direct result of TBI or secondary to other TBI-related changes (Laliberté Durish et al., 2018; Max et al., 2012). Narrative patterns from the current study would trace anxiety to uncertainty regarding what other symptoms (e.g., slowed thinking) might mean for the participants’ health or their futures, as well as to difficulty trusting their brain to function properly as they tried to carry on with life. Depressive symptoms appeared to arise from struggling to cope with other overwhelming PCS, such as migraines, fatigue, and cognitive impairments. This is in agreement with the finding of an association between depression and pain in adolescents three years after sustaining a TBI (Tham et al., 2013).

In summary, the initial category of themes from this study highlighted that some youth may continue to struggle with the impact of PCS following an adolescent mTBI for longer than was once thought. Those injured when older face particular life pressures that could result in increased difficulty coping, which prolongs symptoms, and this might have an especially adverse effect on the emotional functioning of older adolescents. The next section explores the impacts of PCS on the areas of life considered important to the participants.

Impacts on life.

Impacts on school and work. New performance problems at school were common amongst the current participants. Narratives were laden with descriptions of how cognitive problems, such as zoning out, forgetfulness, difficulty putting thoughts together, and physical issues, such as fatigue and migraines, had caused them to feel as though their school performance had deteriorated. These findings add some context to previous evidence for academic impairments following adolescent TBI (Ewing-Cobbs et al., 2004; Lloyd et al., 2015; Savage et al., 2005).

Findings from the current study might also inform our understanding of even longer term poor educational and occupational outcomes for those who sustained TBI as children or adolescents, particularly after age 15 (Sariaslan et al., 2016). Thinking problems carried on, impacting some participants’ transition to new professions as adults, whilst fatigue and/or migraines created barriers for others as they sought to establish themselves in a career. These patterns may help explain why young adults (aged 19 – 25 years) experience relatively high fluctuations in employment after sustaining a paediatric TBI (Todis et al., 2011; N = 89). Other findings, such as associations between recurrent TBIs and poor concentration and slowed thinking at one month post-injury and work problems years later (Theadom et al., 2017), are in agreement with many of the narratives shared here.

Impacts on peer connections. Almost all participants experienced some sense of feeling left out by peers as they had to focus on recovering from PCS, and this was described as frustrating and upsetting. Some completely lost touch with former peer groups as they had to cease playing sports, move classes at school or simply because friends moved on without them. In addition, changes in thinking appeared to make engaging socially more difficult, which could lead to embarrassment, anxiety, reduced confidence and conflict in relationships. Quantitative researchers (Nelson et al., 2005; Rosema et al., 2012; Ryan et al., 2018; Yeates et al., 2014, 2007) tend to emphasise social information processing deficits as the basis for social changes, which is reasonable given the vulnerability of white matter (critical to the increasingly sophisticated social skills developed during adolescence) to TBI-related damage (Andersen, 2003; Henry et al., 2015; Turkstra et al., 2008). However, the current findings imply that feeling excluded by one's peers may be a more immediate culprit.

Whilst social changes have emerged from qualitative research regarding adult TBI, they are not generally reported as prominent themes or a key source of distress for participants. Adult papers (Levack et al., 2010; McPherson et al., 2018; Paterson & Stewart, 2002) tend to emphasise the impact of complex thinking difficulties, fatigue, irritability and the invisibility of TBI on participants' social behaviours, quality of interactions and motivation to engage socially. The current pattern of findings is more akin to limited qualitative research with adolescents (Di Battista et al., 2014b; Iadevaia et al., 2015; Mealings & Douglas, 2010; Rennie, 2015; Rødset, 2008); which places social changes, particularly a changed sense of 'fitting in', amongst the most distressing impacts of their injuries. This difference may be attributed to life-stage factors, with developmental research highlighting the importance of constant positive connection to peers and a sense of belonging for a young person's wellbeing (Baumeister & Leary, 1995; Zimmer-Gembeck, 2016).

In the current study, those who sustained more severe (e.g., Ryan) or multiple (e.g., Talia, Dylan, Matthew) injuries seemed to report the most ongoing changes to their social lives and social identity. These young people described a degree of ongoing isolation, a lost sense of where they 'fit' socially, reduced social confidence and a sense that they were no longer as sociable as they had once been. Members of Di Battista and colleagues' (2014b) cohort mentioned a similar sense of lost social confidence. Those participants who experienced a greater degree of disruption to their social lives were also older members of the current sample, with all sustaining their index injury over the age of 15.

Summary. The current research provides rich descriptions regarding changes that occurred within important areas of participants' lives post-TBI. Such findings inform possible mechanisms underlying reduced quality of life reports following adolescent TBI (Di Battista et al., 2012; Fineblit et al., 2016). The ongoing distress triggered by participants' struggles to regain momentum in life might explain the significant deterioration in quality of life (particularly in school and social domains) observed in the BIONIC youth cohort between one and four years post-TBI (Jones et al., 2019).

Impacts on identity. The finding that TBI impacted how young people viewed themselves is not unexpected, given recurring reports of how adult TBI causes identity disruptions (Beadle, Ownsworth, Fleming, & Shum, 2016; Levack et al., 2010; Thomas et al., 2014). While themes within the adult literature emphasise the rediscovery of one's self post-TBI, the patterns observed in this study's data would indicate that TBI sustained during adolescence is more disruptive to the process of identity-formation. This fits with decades' worth of literature emphasising identity formation as a key task of adolescence (Erikson, 1968; Kroger, 2007; Luyckx et al., 2008; Schwartz et al., 2011). The current participants shared a belief that identity is formed through social engagements and partaking in a variety of activities, akin to trying on different available identities before committing to a particular identity, as described in identity formation theories (Erikson, 1968; Luyckx et al., 2006; Schwartz et al., 2011).

As adolescents, the present study participants seemed highly sensitive to what changes following their injuries meant about *them* (e.g., the assumption that changes at school meant one must be 'stupid'). Other authors have observed that, where individuals lack visible signs of TBI, struggles associated with the injury may be misattributed to the person themselves (Krahn, 2015; McClure, Patel, & Wade, 2011). On the other hand, visible injuries gave rise to a separate range of challenges, by creating an undesirable sense that there was something weird or different about the participant, as has been observed in adolescents with TBI elsewhere (Gauvin-Lepage & Lefebvre, 2010; Rødset, 2008). Adolescents with chronic illnesses and disabilities also concern themselves with such difference and value being perceived as 'normal' or 'just like everyone else' (Gibson et al., 2014; Yates et al., 2010). At a developmental time where one perceives an 'imaginary audience' (Elkind, 1967; Elkind & Bowen, 1979), where one's assessment of one's standing amongst peers is a priority (Irons & Gilbert, 2005), and where peer rejection can shape one's developing personality (Zimmer-Gembeck, 2016), it is evident that feeling different to one's peers following a TBI might impact a young person's social self-perception.

Participants who were older at the time of injury seemed to struggle with the loss, or threatened loss, of certain identities. Considering the concepts of exploration and commitment within the identity status paradigm (Luyckx et al., 2006), it seemed that those who had already 'committed' to a specific identity experienced distress when this identity was no longer available following a TBI. For instance, Lauren felt anxious and upset as she believed she might no longer be ‘intellectual’ like her family; and Dylan expressed ongoing grief over the loss of his sporting identity. In contrast, Adam lacked distress regarding cognitive changes because he had never imagined a cognitively-taxing career for himself. Such a range of responses would suggest that a TBI may impact an adolescent differently depending on their prior degree of identity commitment, the degree of perceived disruption to that identity, and the permanence of that disruption following injury.

An adolescent TBI might form a barrier to the exploration of potential identities, particularly as symptoms such as fatigue, migraines or thinking problems prevent a young person from taking part in a multitude of experiences (i.e., ‘trying on’ various identities). Difficulty keeping up with life is a common problem impacting adults’ self-perception post-TBI (McPherson et al., 2018; Nochi, 1998; Paterson & Stewart, 2002; Theadom et al., 2016). This may be a particular challenge for adolescents who, as Amy highlighted, feel pressured to be involved in ‘everything’. Sociological literature indicates that the transition to adulthood has become more complex for the current cohort of young people, given sociocultural and political changes in recent decades. The decline of prescribed pathways to adulthood and increased economic precarity has brought about greater pressure on youth to extend their commitments across multiple life domains (e.g., work, study, leisure, relationships, personal development, parenthood) in order to become a successful adult (Schwartz et al., 2016; Wyn & Woodman, 2006). The present study patterns suggest that sustaining a TBI during later adolescence might be disruptive to a young person’s ability to engage in these commitments.

The current findings have also shown that TBI may be disruptive to attaining many of the perceived symbols of gaining ‘independence’ (i.e., the primary marker of adulthood; Sawyer & Azzopardi, 2018), including being able to drive, going out with friends, living away from home and attending university. Previous research has indicated a positive correlation between the severity of a TBI sustained during adolescence and longer time till independent living is attained (Todis et al., 2011), which is consistent with the current research where Ryan, the only participant with a moderate injury, had described the greatest felt sense of delayed independence. For the current participants, it seemed that perceived parental overprotectiveness also formed a barrier to attaining independence.

Participants' stories also contained evidence of positive identity growth experiences, as will be discussed in the next section. As has been observed in adult TBI experiences (Levack et al., 2010; Nochi, 2000; Thomas et al., 2014), the participants in this study engaged in a process of self-reflective meaning-making, which saw their injuries contributing to a sense of having grown from the experience of TBI and culminated in a more resilient self-perception.

Overall, this research has shown how certain features of the adolescent TBI experience may disrupt or influence the process of identity-formation and create barriers to attaining certain markers of independence, thereby affecting the transition to adulthood.

Coping and recovery processes. This study sought to broaden the literature regarding recovery processes following adolescent TBI, and to understand what adolescents themselves considered helpful or unhelpful following such an injury.

Individual resources for coping. Participants in this study showed a clear preference for self-reliance and problem-solving when faced with TBI-related challenges. This is consistent with the developmental literature, which proposes that adolescents become more autonomous in their coping with age, and begin to approach problems as challenges that can be mastered through self-efficacy and problem-solving (Cicognani, 2011; Gulliver, Griffiths, & Christensen, 2010; Zimmer-Gembeck & Skinner, 2011). This approach provided the young people with some sense of control as they found themselves in seemingly uncontrollable situations following their TBIs. Although it has been suggested that male adolescents display more self-efficacy than females (Cicognani, 2011), such gender differences were not apparent in the current sample.

The broader literature on coping (Folkman, 1997; Thomsen, Fritz, Mößle, & Greve, 2015) suggests that when stressful situations cannot be resolved through problem-solving, accommodative strategies, which involve changing one's perspective of a problem, are used. Participants in the current study gradually accepted problems that could not be solved (e.g., enduring difficulties with learning) or issues over which they had no perceived control (e.g., migraines, fatigue). In doing so, they made downward comparisons (e.g., 'it could be worse'), altered their view of the problem to a more positive one, and/or changed their focus to new interests and achieving rest and balance. These efforts are consistent with Thomsen and colleagues' (2015) descriptions of accommodative coping.

Participants' responses to their injuries went beyond simply coping as, through time, many underwent what appeared to be post-traumatic growth (PTG) experiences (Rogan et al., 2013). Many seemed to conclude that experiencing their TBIs had helped them grow into stronger or 'better' people. Some also had found meaning from their injuries through serving patients with other healthcare concerns. PTG has frequently been observed in adults following TBI (Grace et al., 2015; Graff, Christensen, Poulsen, & Egerod, 2018; McGrath & Linley, 2006; Powell et al., 2012). Adolescents in other qualitative studies have been seen to draw meaning from TBIs, integrate their limitations to develop new priorities in life, and report being 'happy' in their lives post-TBI (Di Battista et al., 2014b; Mealings & Douglas, 2010; Rennie, 2015; Rødset, 2008).

Given the dearth of research on youth experiences of TBI, and especially the lack of longer-term studies, there is limited literature regarding youth recovery processes. However, research regarding youth experiences of physical illness (Jones, Parker-Raley, & Barczyk, 2011; Manning, Hemingway, & Redsell, 2014; Yates et al., 2010) and mental health issues

(Corrigan, Druss, & Perlick, 2014; Kerrisk, 2014; Lam, 2013; Lam et al., 2011) reveal parallel recovery patterns to the current study, and highlight PTG as central to recovery at this stage of life. Specifically, qualitative research indicates that young people recovering from an episode of psychosis face very similar challenges to those described by participants in the current study. In particular, both samples noted that the unpredictable course of the illness and fear of exacerbating symptoms can create uncertainty for youth as they face developmental tasks associated with adjusting to adulthood (Corrigan et al., 2014). Youth and young adults recovering from psychosis spoke about their illness as life-enhancing and as having improved them in some way (e.g., increased maturity, confidence, awareness of their values). Recovery was spoken about as an ongoing process involving finding balance and reducing commitments, learning about oneself and finding ways to ‘give back’ by helping others (Corrigan et al., 2014; Lam, 2013; Lam et al., 2011); much the same as the present sample.

Participants in this research displayed developmentally appropriate use of independent coping responses, as the patterns described are observed increasingly in children and adolescents as they age. This is enabled by cognitive development, and can buffer against the negative effects of stress, and predict wellbeing and social and emotional functioning in youth in the general population and adolescent brain tumour survivors (Thomsen et al., 2015; Zimmer-Gembeck & Skinner, 2011).

Overall, participants made great attempts to utilise independent coping mechanisms to manage a large and unexpected stressor that had altered their sense of self. Coming to grips with the consequences of their injuries was not immediate, but an extended process that continues to the present.

Social resources for coping. The literature indicates that, while adolescent coping styles tend to centre on individual efforts, social supports also play an important role as a ‘back up system’ in the event of stress (Compas et al., 2017). That is, peers become more prominent in the young person’s support system with age, while adolescents continue to seek support from family, if to a lesser degree (Cicognani, 2011; Compas et al., 2017; Zimmer-Gembeck & Skinner, 2011). Almost all participants described how friends, family and professionals had helped or could have helped their recovery.

The presence of friends. Participants in the current study saw friendships as important to providing a sense of belonging and continuity. Being able to return to their peers helped the young people maintain some normality. It was evident that some participants (e.g., Amy, Brandon, Danielle) felt better able to cope with the ups-and-downs of post-injury life when they had an established and available friendship group. Others described stress related to the unavailability of steady friendships. For example, Nick had started a new school, and Dylan had lost his sense of belonging to his sports teams. This finding may be understood in the context of the ‘general benefits’ and ‘stress-buffering’ models of social support, which together convey the importance of peer availability for bolstering self-worth, purpose and positive affect more generally, whilst also offering protection against the negative effects of stress (Cohen & Wills, 1985; Rueger, Malecki, Pyun, Aycock, & Coyle, 2016). The association between social support and wellbeing is stronger for older youth (Rueger et al., 2016) and adolescents are thought to become increasingly dependent on their peers for support with age (Cicognani, 2011; Compas et al., 2017). Such a pattern was not evident in the current study. Although girls are also thought to rely on social support more than boys (Cicognani, 2011), there were no obvious differences relating to gender in how the current sample of participants spoke about the role of friends in their recovery.

Support from family. Emotional support and caring from family were critical for helping the participants through challenges related to their injuries. It seemed important that family were available to ‘look after’ the participant as they struggled to manage symptoms, and to provide practical support by allowing the participant to remain living at home. Parents were also important advocates who helped navigate the healthcare system. Adults who have experienced TBI (Graff et al., 2018; McPherson et al., 2018) and young people experiencing a psychotic episode (Corrigan et al., 2014; Windell & Norman, 2013) have reported similar forms of support from family as helpful in their recoveries.

The unavailability of professionals. Overwhelmingly, participant narratives denoted an absence of any specialised brain injury support. Participants felt that the professionals available (e.g., GPs, assessing psychologists) were unable to provide the answers they sought regarding what to expect from TBI recovery. Participants expressed that feeling more informed might have alleviated some of their anxiety regarding ongoing symptoms. Feeling validated and reassured by practitioners, as well as being supported to develop a coherent understanding of their injuries, are considered by other TBI sufferers as important for enabling recovery (Levack et al., 2010; Snell, Martin, Surgenor, Siegert, & Hay-Smith, 2017).

Adult participants in NZ and internationally have expressed similar feelings of confusion, dissatisfaction and perceived lack of rehabilitation and information from professionals (Graff et al., 2018; McPherson et al., 2018; Snell et al., 2017). Whilst specialist TBI services are available in NZ via the Accident Compensation Corporation (ACC; i.e., the government funded no-fault system that funds all injury-related health care), it seemed that many were unaware of this or of how services could be accessed. Only Ryan (who had sustained the more severe TBI) and Samuel (whose mother could advocate for him as she had previously worked in TBI rehabilitation) had reported receiving any engagement with specialist TBI services. TBI sufferers elsewhere have identified a lack of transparency regarding support available as a barrier to treatment, and individuals with milder injuries seem to experience particular difficulty in this regard (Graff et al., 2018). These authors also noted the absence of services equipped to meet the specific needs of young people.

The absence of validation. The current participants' descriptions of what they would have liked to receive as part of their recovery indicated an overall lack of validation and emotional support. Many wished they had had a trustworthy other to talk to about their TBI-related problems. Similarly, young people elsewhere have shared the importance of feeling understood, believed and listened to non-judgementally in their journeys of recovering from a mental illness episode (Wallcraft, 2005). Likewise, interviews with adults following a mTBI indicated that feeling validated and reassured by others could have a buffering effect on the stress experienced (Snell et al., 2017). The current study revealed a combination of factors (e.g., developmental, injury-related, societal) that seemed to contribute to the participants' difficulty with accessing this validation and support.

Firstly, literature regarding adolescent help-seeking behaviours indicates that a preference for autonomous coping forms a key barrier to overall help-seeking, while mistrust in health professionals further limits willingness to approach services (Berridge, McCann, Cheetham, & Lubman, 2018; Gulliver et al., 2010; Rickwood, Deane, Wilson, & Ciarrochi, 2005). In addition, the developmental perception that no one could possibly understand the young person (Elkind, 1967; Lapsley, 1993; Stallard, 2007; Vasa et al., 2002) seemed active in this sample and was perhaps exacerbated by the invisibility of TBI. Those around a young person might be likely to misattribute features of the TBI (e.g., irritability) to their life stage (McClure et al., 2011; Starkey et al., 2018), increasing a sense that no one understands them. Qualitative research with adults indicates that, whilst invisibility may enable a degree of 'normality' to be preserved, it might also exacerbate suffering and loneliness (McPherson et al., 2018; Paterson & Stewart, 2002). The concept of the 'identity paradox', which has been addressed by research with young people with chronic illnesses and disability (Jones et al., 2011; Yates et al., 2010), appears relevant to the current sample. This concept emphasises how motivation to appear ‘just like everyone else’ and not wanting to be defined by one’s illness/injury could lead an adolescent’s need for support to go unrecognised.

Societal factors may also have played a role in the youth’s difficulty obtaining emotional support. Attempts by the participants to elicit care from others were met with a feeling of being stigmatised, as well as messages such as ‘you’ll be right’ and ‘get back on the horse’. In the NZ context, stigmatisation of TBI occurs as there is a perception that people look down upon those who have sustained a TBI (McLellan et al., 2010). Participants’ reported responses from others also reflect a cultural view common within NZ that promotes stoicism and a ‘she’ll be right’ approach to life (Braun, 2008; Catley, Blackwood, Forsyth, & Tappin, 2015; Cupples, Guyatt, & Pearce, 2007; Peter, Losekoot, & Poulston, 2013). It seems that this attitude has created a tendency for people to respond to expressions of emotional distress from family and friends (particularly men) with messages to ‘harden up’ and ‘deal with it’ (King, 2019). In the current sample, these sentiments were especially evident in young men’s tendency to identify as someone who does not ‘stress’.

The current participants offered suggestions regarding how they might have felt more emotionally supported. With regard to peers, the participants thought they might have felt more understood if they were able to talk to someone who had been through a similar experience. Research with young people recovering from a serious mental illness indicates that group identification and connecting with similar others might contribute to better recovery, personal wellbeing and social integration (Corrigan et al., 2014; Naslund, Aschbrenner, & Bartels, 2016; Windell & Norman, 2013). The current sample also felt that the onus is on the parents to approach the adolescent to check how they are going, and that having an ongoing relationship with a trustworthy professional may have helped. Young people have indicated that the availability of a professional who demonstrates trustworthiness and approachability, and who prioritises rapport might reduce the barriers to help-seeking and disclosure (Berridge et al., 2018; Corry & Leavey, 2017; Lindsay et al., 2016).

Summary. The current study has revealed insights from young adults regarding how recovery following an adolescent TBI may be better supported by others. The findings have shown that recovery was smoother for those with a continued sense of belonging and continuity amongst their peers, when parents were present and offered practical support and 'looked after' the young person, and when TBI professionals were available to provide information regarding what to expect from TBI recovery. In addition, developmental and cultural factors regarding barriers to support-seeking in this group have been discussed.

The clinical implications of the key findings discussed above are addressed below, followed by examination of the study's strengths and limitations and, finally, some conclusions are drawn.

Clinical Implications

Findings from this study have multiple potential implications for clinical practice, both in supporting a young person through the acute stage following adolescent TBI and for facilitating recovery and growth in the longer term. Many recommendations parallel those that have recently been described in the guidelines for mTBI management in children and adolescents by The Centers for Disease Control and Prevention (CDC; Lumba-Brown et al., 2018). However, there are no specific protocols available in NZ for meeting the unique needs of adolescents post-TBI (Accident Compensation Corporation, 2017).

Acute management. That many participants in this study experienced symptom exacerbation upon return to their activities adds support for cognitive rest. Cognitive rest (i.e., refraining from all cognitive and physical activity), in addition to a carefully-considered plan for gradual return to activity, is increasingly recommended as most crucial for managing the impact of PCS (Lumba-Brown et al., 2018; Mayer et al., 2017). The current research findings also add to a growing discussion regarding the benefits of education about TBI (Lumba-Brown et al., 2018; Snell et al., 2017). The CDC specifically recommends providing information to youth and their families regarding PCS features, the expected course of recovery, signs of more serious injury, instructions for monitoring PCS, rest and careful return to activity (Lumba-Brown et al., 2018). Whilst there is no definitive evidence for providing information to families in paediatric cases, systematic reviews demonstrate the effectiveness of educational interventions for adult mTBI in reducing negative outcomes (Nygren-De Boussard et al., 2014; Snell et al., 2016).

The present findings also support the CDC recommendation for ongoing monitoring of PCS and a plan for follow up with a multidisciplinary team in the event of persisting symptoms (Lumba-Brown et al., 2018). There is preliminary evidence for the benefits of multidisciplinary case management in treating PCS (McCarty et al., 2016; Vikane et al., 2017). One study with adolescents (McCarty et al., 2016; N = 49) showed promise for the role of a case manager who would advocate for patients and coordinate with professionals in school, psychiatry, GP, and other specialist areas to ensure that participants' physical, psychological, and other needs were addressed. Those who experience ongoing difficulties due to mild or moderate TBI sustained in NZ are entitled to access the ACC Concussion Service, which provides multidisciplinary assessment and intervention coordinated by a case manager (Accident Compensation Corporation, 2019; Provost, 2014). However, the current participants' experiences would indicate the presence of considerable problematic gaps in accessing this service. Adult participants in NZ reported a need to be proactive and assertive to have their problems recognised and to access the necessary support (McPherson et al., 2018; Snell et al., 2017). TBI symptoms often make advocating for oneself more challenging (McPherson et al., 2018) and problems with accessing services, understandably, can exacerbate symptoms and prolong recovery (Snell et al., 2017). Work needs to be done to reduce these barriers to accessing services.

Facilitating longer-term recovery. Beyond coordination of care and PCS-management, the current study has highlighted the importance of facilitating social and emotional support for adolescents post-TBI, and this also aligns with CDC recommendations (Lumba-Brown et al., 2018). The participants in this study indicated that having family members ask how they are going might have alleviated their distress. Perhaps educating parents regarding TBI might also prompt them to initiate conversations with their young person regarding their symptoms and the resulting emotional impact.

In addition, access to peers who have been through a similar experience should be facilitated. Whilst the current ACC strategic plan indicates an intention to establish peer support groups, these are also likely to focus on adult cases (Accident Compensation Corporation, 2017). Young people recovering from mental illness have expressed a preference for sourcing peer support online (Alvarez-Jimenez, Gleeson, Rice, Gonzalez-Blanch, & Bendall, 2016; Highton-Williamson, Priebe, & Giacco, 2015; Lal, Nguyen, & Theriault, 2018), and there is emerging interest in the literature in the use of social media for support following TBI (Brunner, Hemsley, Palmer, Dann, & Togher, 2015). Social media can offer a psychological sense of community (Reich, 2010), and reduce social isolation and a feeling of missing out following TBI (Brunner et al., 2015). A brief search of social media sites has revealed multiple available TBI support groups, including those specific to NZ. With social media use now a part of everyday life, particularly for young people (Greenwood, Perrin, & Duggan, 2016), adolescents may already be seeking information and support from this source. Thus, it might be important for TBI professionals to be informed regarding accurate websites and online support groups, given the potential for misinformation online (Frish & Greenbaum, 2017; Lal et al., 2018).

Psychotherapy may be a helpful resource in supporting young people in their recovery in many ways. Firstly, clinicians might promote the use of adaptive coping strategies, such as positive cognitive re-appraisal, which could help reduce distress in the short-term and, with time, activate PTG processes (Rogan et al., 2013). Psychotherapy may also facilitate meaning-making and identity formation with young people (Kerrisk, 2014). There is a dearth of quality evidence for the effectiveness of psychotherapeutic interventions following TBI, even in adults (Bergersen, Halvorsen, Tryti, Taylor, & Olsen, 2017). However, there is some support for cognitive behaviour therapy in adults targeted at anxiety and depression symptoms post-TBI, even years after injury (Bédard et al., 2014; Ponsford et al., 2016). McCarty and colleagues (2016) found significant improvements in PCS and functioning following six months of modular cognitive behaviour therapy, in addition to case management, in 11 to 17-year-olds who sustained a concussion. Treatment targeted anxiety and depressive symptoms via teaching coping skills, relaxation and positive reappraisal of symptoms.

The findings from this study indicate that assistance following an adolescent TBI should extend beyond the acute phase and management of PCS, and clinicians should be aware of the broad range of impacts that a TBI might have on a young person’s life. Furthermore, in the years following a TBI, youth may continue to require support with completing high school exams, transitions to university, employment, and other steps on the pathway to adulthood. For those with more enduring issues, transfer to adult services may be required (Lindsay et al., 2016). This study has also highlighted the need to address the difficulty that people experience in accessing supports that are available via ACC.

Strengths and Limitations

This research adds considerably to the growing body of literature regarding the impacts of adolescent TBI. To the writer’s knowledge, this is the first study to qualitatively explore longer term experiences and recovery processes following adolescent TBI, spanning the period into early adulthood. That all participants in the sample had sustained their TBI between the ages of 13 and 17 years and were in their early 20s at interview, and with a similar time period between injury and research participation add to the strength of this study. This was also the first study to qualitatively present the experiences of NZ youth following an adolescent TBI, with some inclusion of members from Māori and Pacific communities.

The qualitative design presented the ideal stance from which to explore the research topic. With the majority of existing research on adolescent TBI dependent on quantitative measures and parent reports, by seeking the perspectives of young people themselves, this study offers a unique insight into adolescent experiences and their definitions of recovery and wellbeing. A critical realist epistemology enabled the research to locate participants' accounts within the reality of sustaining a TBI, whilst also acknowledging that such an experience is shaped by multiple individual and sociocultural factors. Rather than pursuing an objective 'truth', this research sought to uncover the range of subjective experiences that might occur for a young person following a TBI. In addition, a positive youth empowerment stance allowed this study to draw out the strengths that young people possess as they face challenges that commonly result from TBI. This study has thereby broadened the discussion within the somewhat deficits-focused body of existing literature to incorporate themes of resilience and growth following an adolescent TBI.

The findings of this study are, however, limited by selection bias, which inevitably arose due to the nature of the recruitment process. Those who continued to consent to involvement in the BIONIC research, and who were willing to partake in the current study, were possibly more likely to fall in the minority of adolescents who experience enduring PCS (Davis et al., 2017; Starkey et al., 2018). The sample may also have been biased towards those with a particular interest in healthcare and/or those who were more educated, as most participants were at least working towards third level qualifications. This is not insignificant, given that socioeconomic status can affect outcomes following adolescent TBI (e.g., Fineblit et al., 2016). In addition, given the longitudinal nature of the BIONIC research, the sample was impacted by attrition over time. This seemed to account for the low number of Māori and participants of other ethnicities, since retention rates have been reported as significantly lower for members of ethnic minority groups in longitudinal research on TBI (Sander et al., 2018). Despite attempts to reduce these barriers in the current study, it was also important to be respectful of the young people’s right to decline participation.

Other research limitations relate to the nature of the qualitative methodology. With regard to participant numbers, in a field of study that values quantitative investigations, large samples and generalisability, a sample size of 13 is small. Yet in qualitative work, approximately 12 participants is considered sufficient for achieving saturation in a study with a homogenous sample (Guest, Bunce, & Johnson, 2006; Morrow, 2005). With no new significant themes evident in the final interview, saturation was considered achieved with the current sample; that is, sufficient data had been gathered to tell a rich story, but not too much that would preclude a deep engagement with the data. Generalisability is not the intention of qualitative research, so much as providing a snapshot of certain common elements of a phenomenon, in order to deepen the overall understanding of that phenomenon. Findings should be read with consideration of the effects of recall bias; that is, the patterns reported reflect how participants *remembered* their experiences. This research sought to capture the perspectives of those young people who were willing to tell their stories, and therefore cannot be taken to represent any single ‘truth’ or the experiences of all young people who sustain an adolescent TBI. In particular, given that the majority of participants had sustained mTBI, these findings cannot be considered representative of the experiences of youth who endured moderate or severe injuries.

Finally, it is important to reiterate the role of the researcher in shaping the current findings. Although reflexivity allowed the researcher to monitor the influence of power differentials and researcher biases, the directions taken during interviews, the interpretation of data and the shaping of themes were all influenced by the researcher. Thus, the present findings are to be viewed as collaborative and interactional productions, rather than as uninfluenced by the researcher. In keeping with this stance, input from a second coder was not sought during analysis, as this would align more with the (realist) assumption that the data hold an accurate reality that could be uncovered through coding (Braun & Clarke, 2017).

Directions for Future Research

This study has uncovered many gaps that exist in the literature pertaining to adolescent TBI. Certainly, there has been an upsurge in quantitative research regarding certain direct impacts of adolescent TBI (e.g., the prevalence of persisting PCS) since the commencement of the current study. However, this picture remains rather vague. For instance, despite the growing indication that PCS are likely more debilitating for adolescents than children or adults, a suggestion of poorer outcomes for those injured during later adolescence is much less substantiated. Further establishing a possible connection between the increased pressures of the later teenage years and greater impacts of TBI could inform more targeted treatment for this age group.

In addition, our understanding of the potential secondary effects on young people's lives, particularly into adulthood, remains significantly lacking and requires further attention. The broad focus of this exploratory study meant that many matters raised by the participants could not be explored in depth. Most significantly, given the centrality of identity formation processes to youth development, it seems imperative that these areas be further explored through quantitative and/or qualitative research, as has been done within the adult literature (Beadle et al., 2016; Levack et al., 2010; Thomas et al., 2014).

Furthermore, more specific investigation into the adult phase after adolescent TBI should prove to be informative. For instance, the current sample included just one parent, who reported an ongoing sense of feeling overwhelmed and exhausted. Unfortunately, one participant is insufficient to identify any parenting-related patterns following adolescent TBI. Further studies should investigate how young adults adjust to new pressures that accompany becoming a parent, particularly in the event of enduring fatigue or memory problems.

Finally, with the bulk of the literature directed at problem identification, there is a strong need for empirical investigation regarding interventions. Rigorous evidence for the effectiveness of case management, multi-disciplinary team involvement, and psychotherapy is significantly lacking in both adult and adolescent literature.

Conclusion

In conclusion, adolescents are at a particular risk of sustaining a TBI, and even mild TBI can have consequences for a young person’s functioning, engagement in life and developing sense of self. Injury impacts and recovery processes following adolescent TBI differ to those seen in research with adults, as the young person faces unique developmental challenges, particularly as they must learn to navigate their increasingly complex social worlds whilst discovering who they are and where they fit in the world. Recovery following adolescent TBI might be maximised by facilitating greater understanding of the injury and acknowledging its impacts on important areas of life, as well as the provision of emotional support and encouraging post-traumatic growth.

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Appendix A: Letter of Invitation to Participate

School of Psychology
Level 2, Building 302, Science Centre
23 Symonds Street
Auckland Central
Phone: +64 9 373 7599 ext 88413

INVITATION TO PARTICIPATE IN RESEARCH

Project Title: An exploration of young people's experiences following traumatic brain injury during adolescence

Dear

Thank you for your valued contribution to studies previously carried out by the BIONIC research group, and for agreeing to be contacted again for future research.

My name is Therese, and I am a student in the Clinical Psychology training programme at the University of Auckland. I am interested in learning more about what it is like to have a head injury as a teenager, and how this might affect someone's life as they go through the teenage years and transition to adulthood.

I am contacting you to offer you the opportunity to take part in an interview to talk about your experience of having a head injury during, or just before, your teenage years. This discussion would last about an hour, and we can do it at your home, or somewhere else close to you (like the local library or a café) if you would prefer.

Participation in this research is entirely your choice, so you do not have to say yes to an interview. If you do decide to take part, you would be free to pull out at any time, without having to give a reason. You would be given a koha of a cinema voucher or supermarket voucher as a thank you for your time. You may wish to talk about the study with whanau, friends or family members before deciding whether to participate. I have included a Participant Information Sheet with more information about the study.

I have been given your details by fellow-researchers in the BIONIC group. This letter is to let you know that I will be contacting you by telephone in the next few weeks to see if you would like to take part in this study. If you do not wish to be telephoned, please contact me by phone, text or e-mail (my details are below), letting me know how you would like us to communicate, or that you do not wish to take part in the interview.

I am looking forward to speaking with you soon.

Kind regards,

Therese Mulligan
School of Psychology, The University of Auckland
E-mail: tmul981@aucklanduni.ac.nz Phone/text: 022 313 9854

Approved by the University of Auckland Human Participants Ethics Committee on 31st July 2017 for three years, Reference Number 019641

Appendix B: Letter of Invitation to Participate

(Māori version)

School of Psychology
Level 2, Building 302, Science Centre
23 Symonds Street
Auckland Central
Phone: +64 9 373 7599 ext 88413

INVITATION TO PARTICIPATE IN RESEARCH

Project Title: An exploration of young people's experiences following traumatic brain injury during early adolescence

Tēnā koe,

Thank you for your valued contribution to research studies previously carried out by the BIONIC research group, and for agreeing to be contacted again for future research.

My name is Therese, and I am a student in the Clinical Psychology training programme at the University of Auckland. I am interested in learning more about what it is like to have a head injury as a teenager (or just before becoming a teenager), and how this might affect someone's life as they go through their teenage years.

I am contacting you to offer you the opportunity to take part in an interview to talk about your experience of having a head injury during, or just before, your teenage years. This discussion would last about an hour, and we can do it at your home, or somewhere else close to you (like the local library or a café) if you would prefer.

Participation in this research is entirely your choice, so you do not have to say yes to an interview. If you do decide to take part, you would be free to pull out at any time, without having to give a reason. You would be given a koha of a cinema voucher or supermarket voucher as a thank you for your time. You may wish to talk about the study with your family or whanau before deciding whether to participate. I have included a Participant Information Sheet with more information about the study.

I have been given your details by fellow-researchers in the BIONIC group. This letter is to let you know that I will be contacting you by telephone in the next few weeks to see if you would like to take part in this study. If you do not wish to be telephoned, please contact me by phone, text or e-mail (my details are below), letting me know how you would like us to communicate, or that you do not wish to take part in the interview.

I am looking forward to a kōrero with you soon.

Nāku noa, nā,

Therese Mulligan
School of Psychology, The University of Auckland
E-mail: tmul981@aucklanduni.ac.nz Phone/text: 022 313 9854

Approved by the University of Auckland Human Participants Ethics Committee on 31st July 2017 for three years, Reference Number 019641

Appendix C: Participant Information Sheet

School of Psychology
Level 2, Building 302, Science Centre
23 Symonds Street
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Phone: +64 9 373 7599 ext 88413

PARTICIPANT INFORMATION SHEET

Project Title: An exploration of young people's experiences following traumatic brain injury during adolescence

Researcher: Therese Mulligan **Research Supervisor:** Professor Suzanne Barker-Collo

Researcher Introduction
My name is Therese, and I am a student in the Doctorate of Clinical Psychology at the University of Auckland. I am working with a supervisor, Professor Suzanne Barker-Collo, who is a Clinical Neuropsychologist in the School of Psychology.

This Document
This document is five pages long, please make sure you have read and understood all the pages, and feel free to ask me any questions if you need to (my contact details are on the final page). This information sheet is for you to keep.

This Project
Rationale: I am doing this research to find out more about what it is like to have a traumatic brain injury (TBI) during the teenage years. There is a lot that we (researchers, psychologists and people in general) know about the kinds of things that happen during the years that we call 'adolescence'. This is considered the time between being a child and an adult, when a young person is trying to find their place in the world (maybe finding out the kinds of friends they want to have, or what to do for a job). Unfortunately, we don't know quite so much about what going through this search for a 'self-identity' is like if you have had even a mild brain injury, and if it has any effect at all.

Aims: This study is going to explore the individual life experiences of 12 to 15 young people who had a TBI during adolescence, to see if there are any common themes or patterns of experiences.

Duration: This project will continue for about two years.

Benefits: I hope that the results from this study will increase our knowledge of the longer term effects of having a TBI during adolescence, and that this will improve our understanding of the kinds of supports that might be helpful for a young person as they go through life after an injury.

Risks: I do not expect there to be much risk for you in taking part in this research. However, there is a slight chance that you will become upset talking about some of the experiences that might have been difficult for you. You are invited to talk about whatever is comfortable for you. If you like, I can give you some information about what might be helpful if you need more support after our discussion.

People in this research: The only person that you will encounter while you are participating in this research will be me. Other people who might be able to see the information you give to me will be my supervisor, Suzanne, and a transcriber (I will explain this later).

Invitation to Participate

Why me: You are invited to participate in this research because you have been involved in the BIONIC research studies in the past, and have agreed to be contacted regarding participation in future research.

How: My supervisor, Suzanne, has been involved with the BIONIC studies since they started, and she has helped me to access your details, and those of other young people like you.

Voluntary participation: Participation in this research is entirely your choice. If you do decide to take part, you would be free to pull out at any time, without having to give a reason.

Compensation: If you choose to participate, you will be given a koha, which will be your choice of a voucher for one cinema trip or for $20 to spend in Countdown.

Project Procedure

What you will do: Participation will involve engaging in an interview with me, which will take about an hour depending on how much you would like to share. This will mainly involve talking about your life over the past few years. I will try not to ask too many questions, and I hope that you will feel comfortable talking about your experiences, and it should not feel like an interrogation.

Where: I will come to meet you at your home, or somewhere in the community (like a library or café) if you prefer.

Recording: Your interview will be recorded on an audio-recording device (sound only), as this will ensure that important information is not lost. If you require a break from recording during the interview, you can ask for the recording device to be turned off without giving a reason. The recorder can be turned back on when you feel comfortable. Should you wish for the recording device remain turned off, this would equate to withdrawal from the study.

Withdrawal: You can change your mind about participating or stop the interview at any time. You can withdraw yourself from the study at any time, even after the interview has been completed.

Data Storage, Destruction and Future use

How: Your interview recording will be listened to and transcribed (typed out so that it can be read). I will do some of this transcribing, but I will also need some help from someone else, known as a transcriber. Afterwards, you will be given the option to review the transcription of your interview if you wish.

Where: This interview information or ‘data’ will be stored on my supervisor, Suzanne’s, computer at the university. It will be password protected, and only Suzanne and I will have the password.

How long: The data will be stored for a minimum of 10 years.

Destruction: After these 10 years, all data will be permanently deleted from the computer.

Right to Withdraw from Participation
As noted above, you have the right to withdraw from the interview at any time without giving a reason, and you can withdraw your interview data up to two months from the day of the interview. You may still stay on the list for future research with the BIONIC group, or let me know if you would prefer not to be contacted again.

Confidentiality
Preserving the confidentiality of the information you share with me is very important to us. Your information will only be shared between me and Suzanne, and possibly a transcriber. The transcriber will sign a confidentiality agreement, saying that they will not share your information, and will delete it when they are finished. The audios that the transcriber will use will also not have your name attached to them or allow you to be identified in any way.

After the interview, your name will not be associated with the data, in order to preserve your confidentiality. A codename will be written on your consent form, and only this codename will be used to identify your data later on. The consent forms and codenames will be stored separately to all information relating to your interview. Consent forms and all paper data will be stored in a locked drawer in a locked office in a locked building at the University of Auckland, and shredded after 10 years.

If the information you provide is published or presented, this will be done in a way that does not identify that it has come from you.

A copy of the research findings will be made available to you, if you wish. Please tick ‘yes’ on the Consent Form if you would like to receive this summary, and provide your e-mail or postal address.

Consent
If you agree to take part in this study, you will be asked to sign a Consent Form and return it to the researcher. You may keep this Participant Information Sheet and a copy of the Consent Form.

Questions
If you have any questions or concerns about this study, you may contact me (the researcher), my supervisor or the Director of the Clinical Psychology programme. The relevant contact details are as follows.

Researcher
Therese Mulligan
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The University of Auckland, Private Bag 92019
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Research Supervisor
Prof Suzanne Barker-Collo
Clinical Psychology Training Programme
The University of Auckland, Private Bag 92019
Auckland 1142
Email: s.barker-collo@auckland.ac.nz
Phone: 021 969 464

Ethics
For any queries regarding ethical concerns:
The Chair, The University of Auckland Human Participants Ethics Committee,
The University of Auckland, Research Office,
Private Bag 92019, Auckland 1142.
Telephone 09 373-7599 ext. 83711.
Email: ro-ethics@auckland.ac.nz

Approved by the University of Auckland Human Participants Ethics Committee on 31st July 2017 for three years, Reference Number 019641

Appendix D: Participant Information Sheet

(Māori version)

School of Psychology
Level 2, Building 302, Science Centre
23 Symonds Street
Auckland Central
Phone: +64 9 373 7599 ext 88413

PARTICIPANT INFORMATION SHEET

Project Title: An exploration of young people's experiences following traumatic brain injury during adolescence

Researcher: Therese Mulligan

Supervisor: Professor Suzanne Barker-Collo

Researcher Introduction

Tēnā koe. My name is Therese, and I am from Ireland. I am a student in the Doctorate of Clinical Psychology at the University of Auckland, and I am working with Professor Suzanne Barker-Collo, who is a Clinical Neuropsychologist in the School of Psychology.

This Document

This information sheet is five pages long, please make sure you have read all the pages, and feel free to ask me any questions if something does not make sense (my contact details are on the final page). This information sheet is for you to keep.

This Project

Rationale: I am doing this research to find out more about what it is like to have a traumatic brain injury during the teenage years. There is a lot that we (researchers, psychologists and people in general) know about the kinds of things that usually happen as rangatahi go through the years that we call 'adolescence'. Adolescence is thought of as that time between being tamariki/children and becoming adults, when rangatahi/young people are trying to find their place in the world (maybe finding out the kinds of friends they want to have, or what to do for a job). Unfortunately, we don't know quite so much about what going through this search for a 'self' is like if you have had even a mild brain injury, and if it has any effect at all.

Aims: This study is going to explore the individual life experiences of about 12 to 15 rangatahi/young people who had a brain injury during their teenage years, to see if there are any similarities in their experiences.

Duration: This project will continue for about two years.

Benefits: I hope that the results from this study will grow our kete of knowledge about having a brain injury as a young person, and that this will help us better understand the kinds of tautoko/support that might help rangatahi as they go through life after an injury.

Risks: I do not expect there to be much risk for you in taking part in this research. However, there is a slight chance that you will become upset talking about some of the experiences that might have been difficult for you. You are invited to talk about whatever is comfortable for you. If you like, I can give you some information about what might be helpful if you need more tautoko after our kōrero.

People in this research: The only person that you will encounter while you are participating in this research will be me. Other people who might be able to see the information you give to me will be my supervisor, Suzanne, and a transcriber (I will explain this later).

Invitation to Participate

Why me: You are invited to participate in this research because you have been involved in the BIONIC research studies in the past, and have agreed to be contacted regarding participation in future research.

How: My supervisor, Suzanne, has been involved with the BIONIC studies since they started, and she has helped me to access your details, and those of other rangatahi like you.

Voluntary participation: Taking part in this research is entirely your choice. If you do decide to take part, you would be free to pull out at any time, without having to give a reason.

Compensation: If you choose to participate, you will be given a koha, which will be your choice of either a cinema or supermarket voucher to the value of $20.

Project Procedure

What you will do: Participation will involve engaging in a kōrero/interview with me, which will take about an hour depending on how much you would like to share. This will mainly involve talking about your life over the past few years. I will try not to ask too many questions, and I hope that you will feel comfortable talking about your experiences, and it should not feel like an interrogation.

Where: I will come to meet you at your home, or somewhere in the community (like a library or café) if you prefer.

Recording: Your interview will be recorded on an audio-recording device (sound only), as this will ensure that important information is not lost. If you require a break from recording during the interview, you can ask for the recording device to be turned off without giving a reason. The recorder can be turned back on when you feel comfortable. Should you wish for the recording device remain turned off, this would equate to withdrawal from the study.

Withdrawal: You can change your mind about participating or stop the interview at any time. You can withdraw yourself from the study at any time, even after the interview has been completed.

Data Storage, Destruction and Future use

How: Your interview recording will be listened to and transcribed (typed out so that it can be read). I will do some of this transcribing, but I will also need some help from someone else, known as a transcriber. Afterwards, you will be given the option to review the transcription of your interview if you wish.

Where: This interview information or 'data' will be stored on my supervisor, Suzanne's, computer at the university. It will be password protected, and only Suzanne and I will have the password.

How long: The data will be stored for a minimum of 10 years.

Destruction: After these 10 years, all data will be permanently deleted from the computer.

Right to Withdraw from Participation

As noted above, you have the right to pull out/withdraw from the interview at any time without giving a reason, you can withdraw your interview data up to two months from the day of the interview. You may still stay on the list for future research with the BIONIC group, or let me know if you would prefer not to be contacted again.

Anonymity and Confidentiality

Preserving the confidentiality of the information you share with me is very important to us. Your information will only be shared between me and Suzanne, and possibly another person whose job will be simply to help type out the interviews (a transcriber). This person will sign a confidentiality agreement, saying that they will not share your information and delete it when they are finished. The audios that the transcriber will use will also not have your name attached to them or allow you to be identified in any way.

After the interview, your name will not be associated with the data, in order to preserve your confidentiality. A codename will be written on your consent form, and only this codename will be used to identify your data later on. The consent forms and codenames will be stored separately to all information relating to your interview. Consent forms and all paper data will be stored in a locked drawer in a locked office in a locked building at the University of Auckland, and shredded after 10 years.

If the information you provide is published or presented, this will be done in a way that does not identify that it has come from you.

A copy of the research findings will be made available to you, if you wish. Please tick 'yes' on the Consent Form if you would like to receive this summary, and provide your e-mail or postal address.

Consent

If you agree to take part in this study, you will be asked to sign a Consent Form and return it to the researcher. You may keep this Participant Information Sheet and a copy of the Consent Form.

Questions

If you have any questions or concerns about this study, you may contact me (the researcher), my supervisor or the Director of the Clinical Psychology programme. The relevant contact details are as follows.

Researcher
Therese Mulligan
School of Psychology
Clinical Training Programme
The University of Auckland
Private Bag 92019
Auckland 1142

E-mail: tmul981@aucklanduni.ac.nz
Phone: 022 313 9854
Text: 022 313 9854

Supervisor
Prof Suzanne Barker-Collo
School of Psychology
Clinical Training Programme
The University of Auckland
Private Bag 92019
Auckland 1142

Email: s.barker-collo@auckland.ac.nz
Phone: 021 969 464

Clinical Psychology Programme Director

Associate Professor Kerry Gibson
School of Psychology
Clinical Training Programme
The University of Auckland
Private Bag 92019
Auckland 1142

Phone: +64 9 923 8556
Email: kl.gibson@auckland.ac.nz

Ethics For any queries regarding ethical concerns you may contact:
The Chair, The University of Auckland Human Participants Ethics Committee,
The University of Auckland,
Research Office,
Private Bag 92019,
Auckland 1142.
Telephone 09 373-7599 ext. 83711.
Email: ro-ethics@auckland.ac.nz

"Ka tō te rā, ka ara anō te rā"

"The sun sets, but always rises again. Though darkness descends, the shine of light surpasses it."

(Today is a new day to overcome tribulations.)

Approved by the University of Auckland Human Participants Ethics Committee on 31st July 2017 for three years, Reference Number 019641

Appendix E: Consent Form

Participant codename:

School of Psychology
Level 2, Building 302
Science Centre
23 Symonds Street
Auckland Central
Phone: +64 9 373 7599 ext 88413

CONSENT FORM

THIS FORM WILL BE HELD FOR A PERIOD OF 10 YEARS

Project Title: An exploration of young people's experiences following traumatic brain injury during adolescence

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Supervisor: Professor Suzanne Barker-Collo

I have read the Participant Information Sheet, and I have understood the nature of the research and why I have been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

- I agree to take part in this research.
- I understand that participation is voluntary.
- I understand that I will take part in an interview which will last about an hour.
- I recognise that this kōrero/interview will be audio-recorded.
- I understand that the audio-recording will be transcribed, and the researcher will use my data to look for themes in the experience of other participants like me.
- I understand that I am free to withdraw participation at any time without giving a reason, and to withdraw any data traceable to me up to __________________ (two months from today).
- I understand that data will be kept for 10 years, after which time any data will be destroyed.
- I understand that my identity will be kept confidential, as described in the Participant Information Sheet.
- I would like to review my interview transcript: Yes ☐ No ☐
- I would like to receive a summary of findings: Yes ☐ No ☐
- My e-mail or postal address for correspondence relating to transcript feedback and/or summary of research findings: __________________________________

  ____

Name: ____________________________

Signature: ____________________________ Date: ___________________

Appendix F: Semi-structured Interview Schedule

THE UNIVERSITY OF AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

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SEMI-STRUCTURED INTERVIEW SCHEDULE

The aim of the interview is to elicit from participants the key influences on their lives and life trajectory since they experienced their TBI. The researcher wishes to avoid leading the participant to discussing specific topics that may not be of relevance to them. The following schedule of questions is to be used as a broad guideline. Prompting phrases or questions, such as “can you tell me more about that?”; “can you give an example?”; “Some things that other young people have found are…” will be used.

General opening

- “Thank you for agreeing to speak with me about your experiences. I am very interested in hearing about what the past few years have been like for you….”
- Can you tell me about what you/your life were/was like before your injury?
- Perhaps we could draw a timeline of some of the main things that have gone on for you over the past ten years?

Injury-specific questions

- Tell me about the head injury you had…
- How did you feel about your injury at the time?
- How did you come to understand your injury?
- Did anything change for you after your injury?
- How do you feel about those changes?
- Can you tell me about any challenges you have had in the years since your injury?
- Do you feel those changes have something to do with the injury, or just part of growing up?
- Can you think of anything good about having your injury?

Specific areas of inquiry

- School:
    - Did you have to take any time off school?
    - How did you feel about missing school?
    - How was it going back to school?
    - Do you think your injury affected your ability to do your schoolwork?

- Social relationships and participation:
    - Do you think your injury affected your ability to participate in your social world?
    - Can you think of an example where this might have happened? Were you able to continue to play sports, or to partake in other extra-curricular activities?
    - Did your injury affect your ability to go out or to drink alcohol as much as your mates?

- Family dynamics or roles:
    - Did anything change in your family after your injury?
    - Were your parents any different with you? (e.g., maybe they were more protective?)
    - Did anything change with siblings? (e.g., perhaps they were jealous over the attention you got from your parents?)

- Identity:
    - Did you feel different about yourself after your injury?
    - Have you ever felt different because of your injury?
    - Did you feel any different to your friends?
    - Did you feel your ability to do things for yourself changed after your injury?
    - Did it affect your sense of independence?

- Resilience and coping:
    - What was helpful during the time after the injury? (This can be related back to what they had described as difficulties)
    - Who was important in helping you recover? (e.g., family, friends, school, sports team/coach, rehabilitation services, religious community)
    - What kind of help could you have done with?
    - Is there any kind of help that you feel would have been beneficial, but not available or offered to you?

- Life trajectory:
    - Did you have to make any life-changing decisions because of your injury?
    - Did you have to rethink the kind of lifestyle, or career, you had planned on having before the effects of your injury?

- Questions relating to other factors which the participant considers important in their lives

Closing

I think that's basically everything I had to ask you to talk about, have you got anything else you'd like to say, any final thoughts or anything you'd like to follow up that I haven't asked you?

Appendix G: Initial Thematic Map

Category	**Theme**	**Patterns captured within each theme**	**What is interesting about patterns**
Description of symptoms	Immediate symptoms	Post-concussive symptoms and trouble comprehending what happened	The severity of symptoms and their enduring nature
	Ongoing symptoms	Experiences of cognitive, physical and emotional symptoms as enduring	
Ongoing impact on the adolescent	Disrupted school performance	For some, working hard to get back to where they were	How each of these come together to influence identity formation The impact on development and how the young person saw themselves
		For others this meant re-thinking their possibilities/doing something else	
		The impact of age - worst at big exams and during Uni.	
	Impact on social life	Loss of sense of belonging	
		Social skills	
		Self-consciousness, stigma	
		Impacts differently depending on age/stage	
	Impact on leisure activities	Having to give up something in the short (acute recovery) or long (giving up all together) term	
	Emotional responses	Anxiety; Grief; Depression	
The enduring impact of TBI into adulthood	Work impacts	How physical symptoms (fatigue, migraines) impact adjustment to adult job	The impact of these factors on becoming an independent adult The impact on quality of life
		How cognitive symptoms (memory, concentration) impact adjustment to adult job.	
	Social and leisure	Reduced social confidence and skills Still having fewer friends	
		The need for balance – not able to do as much as prior	

	Independence	Couple of participants – reduced independence	
	Emotional responses	Anxiety; Depression; Grief	
Internal supports	Personality	Determination – doing what is needed to get back to where I was/somewhere new Acceptance – of the injury, the need for recovery time, ‘could be worse’	Young people as struggling but also resilient – developing an identity and personality an ongoing process, not having lost anything that was fully formed
	‘Resilience’	Need to go through hard times to develop strength	
	Hobbies and passions	Crucial for identity Trumps parental advice re safety Life is better when you have things to do/balance Recovering from the loss of old interests Helpful for grounding/emotional management	
External supports	Peers	Sense of belonging and acceptance	Young people as situated within a social environment – all described the importance of these three levels
		Peers with similar experiences – feeling understood Unlikely to attend support groups though	
	Family	Family as over or more protective	
		Family as under or less supportive	
	Professionals	Need for information and to feel understood	