

**LIFE WITH TRAUMATIC BRAIN INJURY: EXPERIENCES OF SOCIAL
PARTICIPATION, SELF-AWARENESS, AND SELF-IDENTITY**

by

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Life with traumatic brain injury: Experiences of social participation, self-awareness, and self-identity.

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Abstract

Background: Traumatic Brain Injury (TBI) affects a substantial number of Canadians every year, with individuals experiencing changes to their everyday life. **Objectives:** This thesis aimed to 1) explore perceived changes in social participation and self-identity post-injury, and 2) characterise individuals displaying higher and lower levels of posttraumatic growth, in terms of their social participation, self-awareness, and self-identity. **Methods:** Study 1 used a constructivist grounded theory methodology. In study 2, a sequential explanatory/exploratory mixed-methods design was followed. For study 1, qualitative data were obtained from a semi-structured interview, conducted to explore the participants' experiences of living with their TBI; for study 2, quantitative data were collected using questionnaires about social participation, self-awareness, and self-identity. **Results:** Participants were 16 adults with a moderate to severe TBI living in the community (average age= 49.8, male= 11). In study 1, an overarching theme 'living in a reshaped reality' was identified which comprised of three themes: 1) 'there's nothing that's the same' identified the daily challenges of living with a TBI, 2) 'rebuilding and restarting' described how participants navigated their post-injury life, and 3) 'embrace it and run with it' explored the participants' responses to life with TBI. An explanatory model of these themes was developed, which illustrated how changes in social participation and self-identity may impact an individual's post-injury life. In study 2, qualitative data were used to categorise individuals into two groups of higher (n=8) and lower (n=7) posttraumatic growth. The quantitative data were then used to characterise the two groups, indicating that participants portraying higher posttraumatic growth had greater social participation, more self-awareness, and fewer discrepancies in pre-and post-injury identities. **Significance:** This thesis builds understanding of the experience of life after TBI. Clinical rehabilitation could be framed to facilitate both social

participation and positive self-identity changes given the explanatory model. Using the findings of posttraumatic growth characterisation, future research could explore the experiences of the development of posttraumatic growth after TBI.

Lay Summary

Traumatic brain injury (TBI) occurs when there is damage to the brain due to an impact to the head. Sustaining a TBI can affect an individual's life in many ways, including changes to their daily activities, recognition of abilities (self-awareness), and sense of self (self-identity). The objective of this thesis was to develop an understanding of how individuals with TBI engage in life with regards to these changes. Data was co-constructed with people with TBI, by using a series of questionnaires and an interview. Overall, this thesis explores the experiences of life with TBI and the results may facilitate the development of new rehabilitative practices to help individuals navigate their life with TBI.

Preface

This project was reviewed and approved by the Research Ethics Board in the University of British Columbia (Certificate number: H19-03465). I developed the research question and study design and conducted the data collection and analysis under the guidance of my supervisor, Dr Julia Schmidt. The supervisory committee members, Dr Ben Mortenson and Prof Jennifer Fleming, were involved in the design of the studies and review of the thesis manuscript. Currently, chapter 3 has been submitted for publication and is under review.

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List of Abbreviations

AQ	Awareness Questionnaire
COREQ	COnsolidated REporting guidelines for Qualitative studies
GRAMMS	Good Reporting of a Mixed-Methods Study
HISDS-III	Head Injury Semantic Differential Scale-III
IPA	Impact of Participation and Autonomy
MPAI-4	Mayo Portland Adaptability Index-4
TBI	Traumatic Brain Injury

Glossary

Constructivist approach	This approach places ‘priority on the phenomena of study and sees both data and analysis as created from shared experiences and relationships with participants and other sources of data’. (Charmaz, 2006, p.130)
Epistemology	A study of knowledge that ‘embodies a certain understanding of what is entailed in knowing, that is, how we know what we know’. (Crotty, 2014, p.8)
Ontology	The study of being concerned with 'what is', with the nature of existence, with the structure of reality. (Crotty, 2014, p.10)
Relativist	A reality constructed within the human mind, such that no one true reality exists; instead, reality is relative according to each individual who experiences it at a given time and place. (Moon & Blackman, 2014, p.1170)
Self-awareness	Conceptualised as a person’s knowledge of their abilities and limitations. (Toglia & Kirk, 2000)
Self-identity	Broadly defined as a continuously constructed set of characteristics which a person chooses to identify with. (Ownsworth, 2014)
Social participation	‘A person’s (who) involvement (how) in activities that provided interactions (what) with others (with whom) in society or the community (where)’. (Levasseur et al., 2010, p.2144)

Traumatic brain injury	An alteration in brain function, or other evidence of brain pathology, caused by an external force. (Menon et al., 2010, p.1638)
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Chapter 1: Introduction

1.1 Traumatic brain injury

A traumatic brain injury¹ (TBI) falls under the umbrella term ‘acquired brain injury’, differing from non-traumatic injuries such as diffuse cerebrovascular events (e.g., stroke) and diffuse infectious disorders (e.g., encephalitis) (Teasell et al., 2007). A TBI can either be categorised as a closed-head (blunt impact that does not pierce the skull) or a penetrating injury, with the former being more common (Abdelmalik et al., 2019). The severity of a TBI (mild, moderate, severe) can be determined using measures such as the Glasgow Coma Scale, period of loss of consciousness, length of post-traumatic amnesia, and structural imaging findings (Brasure et al., 2012). The Glasgow Coma Scale is often measured in prehospital settings (e.g., ambulance, emergency room), and assesses an individual’s motor, verbal, and eye movement, with lower scores indicating a more severe injury (Faul & Coronado, 2015; Teasdale & Jennett, 1974). Post-traumatic amnesia is a period of confusion experienced by an individual, which is measured daily following the injury to determine mental status, alertness, and memory, with longer durations indicating higher severity of injury (Corrigan et al., 2010).

In Canada, approximately 170,000 individuals are affected by a TBI every year (Post et al., 2015). Data from the Canadian Community Health Survey showed an increase of incidence of TBI in the Canadian population from 1.4% in 2005 to 3.2% in 2014, portraying that the reported incidence of TBI has more than doubled in less than 10 years (Rao et al., 2017). Analysis of data on more than 133,000 TBI-related visits to the emergency departments in

¹ Defined in glossary

Ontario indicated that a total of \$945 million was spent on lifetime costs in this province alone. This included \$653 million in productivity costs due to potential loss of income following injury, as well as \$292 million spent on medical treatment (Fu et al., 2016). Falls and motor vehicle accidents were the most common causes of TBI, as represented by hospitalisations across Canada from 2006 to 2011, with the elderly being more susceptible to falls and young adults more prone to motor vehicle accidents (Fu et al., 2015).

Gender has been identified as a risk factor in sustaining a TBI, with men more susceptible to injury. Men are more likely to sustain TBIs at work, caused by injury in heavy labour jobs (e.g., machine-operators, construction), and in sports caused by collision and high contact (Chang et al., 2015; Mollayeva et al., 2018). However, as more women engage in fields traditionally dominated by men, such as military services, there have been an increase of TBIs reported by women working in these areas (Amoroso & Iverson, 2017; Mollayeva et al., 2018). Women sustain TBIs more frequently than men in educational and healthcare sectors, and women are more likely than men to sustain a TBI from intimate partner violence (Chang et al., 2014; Costello & Greenwald, 2022).

Sustaining a TBI can impact a person's daily life and function due to the impairments from the injury itself, as well as the limitations arising from barriers in society. An individual can experience various physical, cognitive, psychological, and behavioural issues which stem directly from the injury. Physical difficulties include decreased motor co-ordination and balance, affecting activities such as exercise or shopping (Perry et al., 2014). Cognitive issues consist of deficits in executive functioning, attention, and memory, impacting meaningful activities such as work and leisure interests (Beaulieu-Bonneau et al., 2017; Dunning et al., 2016). Psychological impacts following TBI can include negative changes to a person's sense of self and emotional

dysregulation hence affecting their mental health and impulse control (Shields et al., 2016). Lastly, behavioural changes may involve verbal or physical aggression, inappropriate social behaviour, and a lack of initiation (Kelly et al., 2008; Tam et al., 2015). An individual with TBI can encounter negative interactions in their surroundings due to physical and social barriers. Physical barriers include architectural (e.g., sidewalks, accessibility to buildings) and environmental (e.g., noise, crowds) factors, while social barriers include stigma, negative attitudes, or discrimination against an individual with an injury (Wong et al., 2017). Both types of barriers have been reported to reduce the community integration and participation of an individual with TBI (Fleming et al., 2014; Poritz et al., 2019).

While there is a substantial amount of literature that exists about the physical and psychosocial outcomes of a TBI, there are other areas of change in a person's life after TBI that are less understood. Issues of social participation², self-awareness³, and self-identity⁴ are the focus of this thesis and are discussed below.

1.2 Social participation

There is no clear definition for the term social participation, therefore this thesis will use the definitions postulated by Levasseur et al. (2010) and Piškur et al. (2014). Levasseur et al. (2010) described social participation as consisting of different types and levels of participation, which encompass varying proximities of involvement, such as activities done in preparation for social interaction and activities that involve direct interaction with others. Piškur et al. (2014)

² Defined in glossary

³ Defined in glossary

⁴ Defined in glossary

builds on this understanding, expanding the definition of social participation to include societal responsibilities to provide necessary conditions for an individual's participation to take place and the emphasis of a person's subjective experience of their participation.

Individuals with TBI often have difficulty participating in many activities due to issues arising from the injury and the environment. This can lead to a 'gap', which indicates the disparity in the desired activities individuals want to engage in and the activity they are limited to (Beadle et al., 2020). Individuals with TBI may regain some independence in their home and community (Nalder et al., 2012), however, gaps are identified in social activities that are more physically and cognitively challenging (e.g., return to work, travelling abroad) (Beadle et al., 2020). Another factor that can affect a person's social participation are the deficits in their self-awareness, which can be common after moderate to severe TBI.

1.3 Self-awareness

After sustaining a TBI, estimates of up to 97% of individuals display some degree of impaired self-awareness (Sherer et al., 1998). The severity of TBI is associated with the level of self-awareness, as individuals with longer periods of post-traumatic amnesia have a greater impairment of self-awareness (Richardson et al., 2015). Generally, levels of self-awareness improve overtime, with a prospective cohort study reporting a reduction in individuals with impaired self-awareness from 69.1% at discharge to 54.3% after six months (Geytenbeek et al., 2017).

Various aspects of life with TBI, such as employment, compliance in rehabilitation, and daily function, can be impacted by impaired self-awareness. Post-injury employment has been associated with having a high awareness of limitations, as these individuals are active in

addressing their problems by seeking out guidance and using strategies to help retain their employment (Kelley et al., 2014). Those with impaired self-awareness may overestimate their competency or fail to see the need to address their lack of capability. Hence, this can lead to poor motivation for treatment and ultimately contribute to challenges in acute and community settings (Robertson & Schmitter-Edgecombe, 2015). Engaging in rehabilitation is essential to improve daily function, as it develops an individual's knowledge about their personal abilities and reduces the errors made when engaging in everyday life (Schmidt et al., 2013).

There are many factors that contribute to the theories of self-awareness after TBI. A systematic review identified deficits in cognitive processing mechanisms, neurological foundations, and causal factors (Sansonetti et al., 2021). Cognitive processes include explicit and implicit knowledge as well as executive control systems. Neurological foundations consist of multiple brain regions (frontoparietal cortex, insula, ventromedial prefrontal cortex) as well as the motor cortex and central lesions. Causal factors include psychological (e.g., denial), neuropsychological (e.g., cognitive impairment), and neurological factors. These underlying factors can contribute to the understanding of impaired self-awareness after sustaining a TBI.

There are various models proposed to understand self-awareness after brain injury, such as neuroscientific (supporting frontal lobe involvement in self-awareness) (Stuss & Levine, 2002) and hierarchical models (pyramid model of awareness) (Crosson et al., 1989). The Dynamic Comprehensive Model of Awareness is a model that proposes a dynamic relationship of a person's knowledge, belief, recognition of task context and demand (Toglia & Kirk, 2000), and will be used in this thesis.

1.3.1 Dynamic Comprehensive Model of Awareness

The Dynamic Comprehensive Model of Awareness explains self-awareness as having two components: a person's prior knowledge about the characteristics of the task and the extent of their abilities (metacognitive knowledge) and a person's capability to monitor their performance during a task (online awareness) (Toglia & Kirk, 2000). Online awareness is described as comprising of: 1) anticipatory awareness (ability to predict their performance depending on their evaluation of the task), 2) emergent awareness (ability to self-monitor their performance to recognise limitations as they occur), 3) self-regulation (adjust behaviour accordingly to correct errors), and 4) self-evaluation (updating metacognitive knowledge after a task) (Toglia & Kirk, 2000). After a TBI, individuals may have impaired metacognitive knowledge, or attention and concentration problems that affect their ability to detect errors (Dockree et al., 2015; Robertson & Schmitter-Edgecombe, 2015). This can impact their participation in daily tasks (e.g., inaccurate assumptions about what a task entails), as well as cause safety issues. This model is introduced in this thesis, to inform the reasoning behind the development of questions, which ask participants with TBI to reflect about changes in their abilities. The biopsychosocial model of self-awareness will be explored to understand the different factors at play that contribute to an overall exhibition of impaired self-awareness after TBI.

1.3.2 Biopsychosocial model of self-awareness

The biopsychosocial model of self-awareness illustrates that there are interacting factors at the biological, psychological, and social levels that explains an individual's presentation of awareness deficits (Ownsworth et al., 2006). At the biological domain, the deficits in awareness

are neurologically based. The type of awareness is defined (e.g., domain-specific unawareness) and possible damage to the prefrontal cortex and neurocognitive mechanisms are assessed (e.g., conscious awareness system or executive functioning system). At the psychological domain, factors include denial, avoidant coping (a maladaptation of coping through avoidance thinking or discussing certain stressors), or minimisation strategies. These mechanisms are regarded as a protective measure instead of acknowledging the individual's changed reality, as this could result in distress. Some individuals may use non-defensive coping styles, where they continue to behave in their pre-injury ways, despite sensing that there is something wrong. At the socio-environmental domain, a person may feel the need to integrate themselves back into their pre-injury environments by concealing their deficits to maintain appearances in front of others to avoid stigma or exclusion (Ownsworth et al., 2006). Additionally, there may be lack of opportunities for a person to recognise the changes or they may be only surrounded by people who give positive feedback. The contribution of these factors from each domain differs according to the individual and adds to the exhibition of impaired self-awareness (Ownsworth, 2014). The biopsychosocial model of self-awareness is used in this thesis due to its holistic nature, which can facilitate the understanding of how other constructs, such as self-identity, can be impacted after TBI.

1.4 Self-identity

Developing self-identity is a life-long process, where identities are cultivated depending on the individual's life stage. However, a person's self-identity can be impacted by many life circumstances, such as postnatal depression (Abrams & Curran, 2011) or stroke (Musser et al., 2015). After sustaining a TBI, people can experience alterations in self-identity that may be due to biological or psychosocial factors (Yeates et al., 2008). For example, the direct impact to the

brain can affect regions involved in identity formation, such as autobiographical memories which rely on the frontal lobe (Thomas et al., 2014). Episodic memories consist of an individual's daily experiences and provides a sense of continuity. This may be disrupted after a TBI, making a person may feel at a loss with their current self, '... the history you've had gets you to the point that you're at now and then to become something totally different' (Muenchberger et al., 2008, p.985). A systematic review about self-identity and TBI reported that psychosocial factors, such as the traumatic incident of sustaining a TBI and the process of adjustment to the injury, may have greater impact on individuals than biological damage (Beadle et al., 2016). This is further supported by studies that showed no significant differences in self-esteem or personality between individuals with TBI and individuals with non-neurological (orthopedic) problems (Curran et al., 2000; Lannoo et al., 1997; Rush et al., 2006). It is recognised that adapting to a new post-injury identity can be a distressing time (Levack et al., 2014). A cross-sectional study reported associations of high levels of grief and depression, as well as a decrease in self-esteem, when adjusting to self-identity losses after TBI (Carroll & Coetzer, 2011).

As described above, the changes in self-identity after TBI are complex. Symbolic interactionism and identity theories can help provide an understanding on how these changes impact life with TBI.

1.4.1 Symbolic interactionism

Symbolic interactionism proposes that meaning, which is deemed to be the center of all human behaviour, are understood through social interactions and shared understanding of symbols (language) (Aksan et al., 2009). Individuals do not just react to one another but are

active agents, in that they respond depending on the meanings they attach to people's actions or behaviours (Carter & Fuller, 2015).

There are three basic premises of symbolic interactionism (Blumer, 1969; Handberg et al., 2015). The first premise states that an individual's actions depend on meanings they attach to objects or social situations (e.g., an individual may enjoy cross-country driving and attach a meaning of relaxation to this activity). The second premise indicates that meanings arise from social interactions (e.g., the individual's clinician may advise them to stop driving due to changes in their ability, hence the individual attaches a new meaning of danger to driving). The third premise states that meanings change as an individual interprets the situation differently at another point in time (e.g., as the individual's capabilities improves, the individual may attach a meaning of independence with driving). Therefore, symbolic interactionism can be used in this thesis to understand how interpretations of the meaning of social exchanges may shape a person's self-identity after TBI. Evolving from symbolic interactionism, is identity theory, which can be used to understand how the meanings individuals attach to themselves influence their behaviours and actions.

1.4.2 Identity theory

Identity theory explores the meanings and expectations attached to a person's self-identity (Serpe et al., 2020; Stryker, 1968). Identity theory is composed of various concepts such as identities, identity verification, identity salience, and identity prominence. However, for the purposes of this thesis, concepts of identities and identity verification will be described.

According to identity theory, there are three main bases which constitute identities: person, role, and group identities (Burke & Stets, 2009; Serpe et al., 2020). Person identity is

about the meanings associated with the personal characteristics one identifies with and uses to differentiate themselves from others. In response to the question, ‘Who am I?’, individuals may think of themselves as ambitious and optimistic (Ownsworth, 2014). However, after a TBI, some may feel a detachment to their pre-injury selves (Levack et al., 2010). For example, feelings of fragmentation have been expressed as individuals view their pre-injury and post-injury selves as two separate entities, ‘I’m probably like Dr Jekyll and Mr. Hyde. There’s two of us’ (Levack et al., 2014). After their injury, individuals may not be able to relate to the personal attributes that used to compose their pre-injury self.

Role identities are based on the meanings attached to roles that an individual occupies in society; hence one might think of oneself as a daughter and an educator (Burke & Stets, 2009; Serpe et al., 2020). An individual can have multiple roles with different meanings and expectations associated with each role. For example, when the role of a daughter is activated, they might perceive themselves to be caring, and when the role of an educator is assumed, there may be a different set of expectations such as being knowledgeable. After a TBI, difficulties may be encountered when trying to fulfill the expectations of their pre-injury roles. For example, an individual may see a shift from their previous familial role, ‘instead of say being, you know, the old-fashioned head of the household, it’s like I’m just a—well not quite a nothing, but just don’t have a lot of status’ (Levack et al., 2014, p.5). However, a person’s roles can be developed post-injury, shaping them to adapt to their current functional capabilities.

Finally, group identities are based on meanings attached to group memberships they occupy in society (e.g., member of a chess club) (Burke & Stets, 2009; Serpe et al., 2020). People may experience changes to their usual social interactions and community participation after a TBI. For example, individuals may feel isolated from their peers in a similar age group, as

they may be unable to participate in the activities commonly followed by their contemporaries (e.g., club culture among young adults) (MacQueen et al., 2020). However, new identities may be developed as individuals affiliate themselves with new group memberships such as brain injury communities or support networks.

Identity verification occurs when there is a congruency between the way individuals view their person, role, and group identities, and how others view them (Burke & Stets, 2009; Serpe et al., 2020). If there is a difference between the two viewpoints, identity non-verification occurs, and may cause the individual distress. In order to enable verification to happen, an individual might change their behaviour or look for other social settings where there is a compatibility in viewpoints (Burke & Stets, 2009). For example, an individual with TBI may not view themselves as a person with a disability, and hence feel at unease when their family or friends treat them as such. This can further highlight the discrepancies between their pre-and post-injury identities.

Overall, these changes in social participation, self-awareness, and self-identity can have a negative impact on a person after their TBI. However, these challenges may cause a person to undergo a process of change, where they develop a positive perspective as a result of these negative experiences.

1.5 Positive outcomes after TBI

People with TBI can experience positive long-term outcomes after injury, alongside challenges of decreased quality of life and life satisfaction (Andelic et al., 2010; Williams et al., 2014). Individuals with TBI can experience acceptance, positive outlook, and valued living (Allen et al., 2021; Pais et al., 2019).

Posttraumatic growth is defined as a ‘positive psychological change as a result of the struggle with traumatic or highly challenging life circumstances’ (Tedeschi et al., 2018, p.1). Posttraumatic growth is a transformative process after a trauma, whereby an individual may experience a development of personal strength, growing connections with others, pursuing new interests, greater appreciation of life, and having a spiritual or existential change. Factors such as employment, social support, and forming new group memberships can promote posttraumatic growth after TBI (Griffin et al., 2022; Grace et al., 2015; Powell et al., 2012). However, there is limited literature about self-awareness and self-identity in individuals with posttraumatic growth after sustaining a TBI.

1.6 Objectives

There is limited understanding of individuals’ experiences about life with TBI, specifically regarding their social participation, self-awareness, and self-identity. This thesis describes two studies to address the following research questions:

- 1) What are people’s experiences of social participation and self-identity after TBI?
- 2) How are individuals with higher and lower posttraumatic growth characterised based on their social participation, self-awareness, and self-identity?

1.7 Overview of thesis

This thesis consists of 5 chapters. Chapter 1 provides the reader with a foundational understanding of TBI, social participation, self-awareness, and self-identity. The following theories and models were introduced in this chapter: Dynamic Comprehensive Model of

Awareness, the biopsychosocial model of self-awareness, symbolic interactionism, and identity theory.

Chapter 2 presents the methods used to conduct the studies in chapter 3 (constructivist grounded theory study) and chapter 4 (mixed-methods study). Details on the study design, participant recruitment, ethical procedures, philosophical perspectives, and trustworthiness strategies are outlined.

Chapter 3 consists of a constructivist grounded theory study that is used to develop an explanatory model on the experiences of life with TBI. These findings explore the changes in an individual's social participation and self-identity post-injury.

Chapter 4 is a mixed-methods study that continues to broaden the understanding of the participants' experiences by characterising higher and lower levels of posttraumatic growth using quantitative data obtained on the constructs of social participation, self-awareness, and self-identity.

Finally, chapter 5 summarises and discusses the findings of chapter 3 and 4. The methodological and theoretical contributions are described as well as the limitations and potential areas for future research of this thesis.

Chapter 2: Methods

2.1 Study design

The studies in this thesis used two different designs. In study 1, qualitative data were analysed using the constructivist grounded theory approach (Charmaz, 2006). The data analysis procedure is provided in appendix A. The findings were reported using the COnsolidated REporting guidelines for Qualitative studies (COREQ) (Tong et al., 2007) (Appendix B). In study 2, a sequential explanatory/exploratory mixed-methods design was employed (Creswell et al., 2003). The study design and rationale are described in appendix C. This mixed-methods design was conducted and reported using the Good Reporting of a Mixed-Methods Study (GRAMMS) (O' Cathain et al., 2008) (Appendix D).

2.2 Participant recruitment

Convenience sampling was used to recruit participants by circulating notices that included information about the study and the participant criteria within GF Strong Rehabilitation Centre (Vancouver), British Columbia Brain Injury Association, and other community networks located in British Columbia. Participants were recruited until theoretical sufficiency, defined as the stage where a sufficient depth of understanding has been reached by the researcher to build a theory (Dey, 1999). This differs from data saturation, which is described as the point at which no new data can be found (Glaser & Strauss, 1967). The term 'saturation' may introduce the problematic assumption of 'a sense of completeness' regarding the data (Nelson, 2016), and has been aligned with postpositivist approaches, which differs from this study's ontological and epistemological perspectives. Therefore, for this study, recruitment was stopped after 16

participants as theoretical sufficiency was reached. The same individuals participated in both study 1 and study 2.

2.2.1 Inclusion criteria

The inclusion criteria for the participants were as follows: (1) between the ages of 18 to 65 years, (2) experienced a moderate to severe TBI, (3) sustained the injury at least a year ago, and (4) able to communicate in English. The rationale for the inclusion criteria is noted as follows. The participant ages of 18 to 65 were chosen as individuals older than 18 may have more autonomy in their social participation. Additionally, individuals below 65 were recruited to avoid age-related cognitive decline that might impact a person's self-awareness. However, as cognitive decline may not impact every person above 65, the experiences of older adults with TBI are not explored in this study. The severity of the injury was assessed by requesting participants to provide information regarding how they sustained their injury, their Glasgow Coma Score, and the duration of the loss of consciousness or coma. Individuals with moderate to severe TBI were recruited, excluding those with mild TBI, as a lower severity of TBI may differently impact social participation, self-awareness, and self-identity (Levack et al., 2014). A duration of at least one year of sustaining the injury was required as this was expected to be a sufficient length of time for the participants to experience the life changes associated with their injury. Communication in English was required due to the open-ended interview questions, as involving a translator was beyond the scope for this study.

2.3 Ethics and data management

Ethics was obtained through the Behaviour Research Ethics Board at the University of British Columbia (UBC) and approved under the certificate number H19-03465. The study was conducted either over an online video software (Zoom) or in-person, as regulated by the current provincial guidelines set out by the British Columbia Ministry of Health. All participants were provided with an overview of the study explaining the study purpose, study procedure, and the management of the data obtained. Before the study commenced, participants were informed that participation was voluntary, confidentiality and anonymity was assured, and they could choose to withdraw from the study at any point. Both verbal and oral consent were obtained from all participants before data collection. The digital documents containing participant data are stored in a secure UBC server while printed documents are kept in a locked UBC cabinet. All personal identifying information of the participants were removed during data analysis. Additionally, each participant was given a \$50 honorarium as a token of appreciation for their time.

2.4 Philosophical perspective

The philosophical perspectives for this thesis are a relativist ontology and constructivist epistemology. Ontology refers to the nature of reality, while epistemology refers to the relationship between the researcher and the research (Al-Ababneh, 2020). A relativist ontology acknowledges the notion of multiple realities, as each individual constructs their own reality (Moon & Blackman, 2014). This differs from the realism ontology which indicates that there is one single reality or ‘truth’, independent of human construction (Moon & Blackman, 2014). A constructivist epistemology states that the researcher co-constructs the data with the participant and is inseparable from it (Crotty, 2014). This contrasts with other types of epistemologies such

as objectivism (data are generated independent of the researcher) and subjectivism (data are solely generated from the researcher). The researcher is active in co-constructing the data with the participants through the researcher's interviewing style and interpretation of the data. This study consisted of a semi-structured interview, hence enabling the researcher to ask unplanned questions on areas that the participant introduced in the conversation. This allowed the researcher to contribute to the direction of the interview. In the data analysis stages, the researcher's interpretation of the data was influenced by prior experiences and their perspectives (Charmaz, 2006).

2.5 Trustworthiness

Trustworthiness was promoted in this study by using the transcendent criteria that includes social validity, subjectivity and reflexivity, adequacy of data, and adequacy of interpretation (Morrow, 2005). Below are descriptions of each criterion and how they were addressed in this thesis.

2.5.1 Social validity

The first criterion of social validity looked at the importance and significance of this study in the participant community and its social value. This is pursued as this study explores important post-injury changes and lays a foundation for future research. By exploring participant experiences, it is a source of information to widen the understanding about life after TBI. By examining the changes in an individual's social participation and self-identity, and the characteristics of higher and lower posttraumatic growth after TBI, this study can provide important insights that lead to the development of approaches in rehabilitation practices that address the challenges individuals with TBI encounter.

2.5.2 Subjectivity and reflexivity

In the second criterion of subjectivity and reflexivity, the researcher is considered dynamic throughout the duration of the process; hence the researcher's views need to be acknowledged (Berger, 2015). A reflexive practice was established in this study by the researcher maintaining a journal. A description of the environment, participant, and the researcher's perspective of the sessions with the participant were recorded in the journal. Additionally, analytic memos, consisting of the researcher's inferences during the coding stage, were documented.

2.5.3 Adequacy of data

Adequacy of data were analysed in five different ways: (1) adequate amounts of evidence, (2) adequate variety in kinds of evidence, (3) interpretive status of evidence, (4) adequate disconfirming evidence, and (5) adequate discrepant case analysis (Morrow, 2005). This thesis addresses each component in the following ways: (1) adequate amounts of evidence was met by recruiting participants until theoretical sufficiency, (2) adequate variety in kinds of evidence was pursued through use of various data sources, such as interviews, questionnaires, and member checking, (3) interpretative status of evidence was focused on by ensuring that a comfortable environment was created. Rapport was built by meeting with the participant twice for data collection. This allowed the participants to be acquainted with the researcher and develop a degree of trust. Additionally, the researcher used the following strategies: being responsive to the participants' demeanor throughout data collection, moving away from distressing topics if needed, and allowing the participant to set the pace of the session (Mitchell & Irvine, 2008). Finally, (4) adequate disconfirming evidence, and (5) adequate discrepant case

analysis involved the inspection of data to check if the obtained data disconfirmed any codes. Both criteria were met during the data analysis stage of constantly comparing the data obtained.

2.5.4 Adequacy of interpretation

Adequacy of interpretation explored the interpretation and translation of participant experiences by the researcher. This was pursued by addressing the memos documented as well as including various participant quotations throughout the written manuscript.

2.5.5 Positionality

When obtaining qualitative data, examining the subjectivity of the researcher is essential as subjectivity shapes the course of a study from the formation of a research question to the interpretation of data (Berger, 2015). The positioning statement below may provide understanding on how my subjectivity has influenced this thesis.

I am a female graduate student who has lived in five countries before travelling to Vancouver, Canada and undertaking my master's degree in rehabilitation sciences. I completed my undergraduate degree in psychology and cognitive neuroscience at the University of Nottingham. To transfer my knowledge into practice, I participated at a summer placement at a public hospital and volunteered at a rehabilitation centre. While this experience provided rich insights to the clinical duties of doctors and therapists, I still had limited experience interacting with people with brain injuries. Therefore, I had assumptions that people with TBI consistently experienced more negative changes after injury, and any positive outcomes were limited. Commencing my master's degree has not only expanded my knowledge about people with TBI, but also presented me with various opportunities to learn directly from those with TBI. Before

data collection commenced, I volunteered with a brain injury organisation and collaborated with a patient-partner for this study, developing insights about this community. As a researcher, I recognise that I play an instrumental role in shaping this study. I acknowledge that my perspectives, such as my previous postpositivist way of thinking, as well as my prior limited exposure to the brain injury population, may have impacted this thesis. I understand that my experience as a novice qualitative researcher may influence the interviews that I conducted. To consider my positioning on this thesis, I kept a reflexivity journal as a form of self-appraisal throughout the research study.

Chapter 3: Living in a reshaped reality: Exploring social participation and self-identity after TBI

3.1 Introduction

Traumatic brain injury (TBI) affects approximately 69 million individuals globally each year (Dewan et al., 2018). Individuals who sustain a moderate to severe TBI encounter many challenges as they resume life post-injury. These challenges may continue over the course of many years and include physical and cognitive issues, lack of resources, and problems with continued treatment and care (Downing, et al., 2021; Fadyl et al., 2019; Ponsford et al., 2014; Ruet et al., 2019). These issues can impact the way people with TBI participate in activities of daily life such as work and leisure (Klepo et al., 2020). Additionally, it may cause changes to their self-identity or sense of self (Ownsworth, 2014).

People with TBI experience changes in the ways they participate in the various activities of everyday life (Jourdan et al., 2016; Kersey et al., 2019). After a TBI, individuals report reduced participation compared to their pre-injury participation levels (Goverover et al., 2017). This can be related to factors associated to the injury itself or environmental and social constraints. For example, individuals with TBI may have cognitive problems, which include memory and attention impairments (Beaulieu-Bonneau et al., 2017; Dunning et al., 2016; Vakil et al., 2019) and decreased mobility and balance, affecting their capacity to perform household tasks, or resume pre-injury activities (Perry et al., 2014). Additionally, they may experience a reduction in social participation due to barriers in the institutional environment (e.g., limited programs and services) and the built environment (e.g., reduced physical access) (Fleming et al.,

2014; Heinemann et al., 2015; Wong et al., 2017). Individuals with TBI may encounter negative social attitudes such as stigma or marginalisation, which decreases their community participation (Poritz et al., 2019). This reduction in social participation may contribute to a ‘gap’, where individuals experience little or no participation in their valued roles (Beadle et al., 2020).

Changes with self-identity are commonly reported after TBI (Beadle et al., 2016; Ownsworth, 2014). Self-identity can be defined as a continuously constructed set of characteristics that a person chooses to identify with (Ownsworth, 2014), which is developed through social structures and self-verification processes (Stryker & Burke, 2000). As such, self-identity is linked to the roles that individuals occupy (Stets & Burke, 2000). The impact to self-identity after TBI can be the result of biological damage (e.g., loss of autobiographical memories) and psychosocial factors (e.g., adjustment to injury) (Beadle et al., 2016; Yeates et al., 2008). Some research indicates that as individuals return to pre-injury environments or try to resume prior roles, they may be prompted to examine and compare the differences in their pre- and post-injury selves (Villa et al., 2021). Hence, individuals with TBI may find the attributes that formed their pre-injury selves are no longer applicable to their current selves (Levack et al., 2014). For example, a qualitative study showed that men with TBI were unable to identify with pre-injury characteristics they considered masculine such as being self-reliant or a provider (MacQueen et al., 2020). As individuals find it difficult to resume meaningful roles after the TBI, they may experience feelings of fragmentation and distress (Levack et al., 2014).

There has been some research on the relationship between social participation and self-identity after TBI. The inability to resume pre-injury activities can result in a disruption of self-identity (Bryson-Campbell et al., 2013; Conneeley, 2012). For example, participating in an activity can contribute to defining self-identity, however, if participation is altered due to

changes in abilities and access after TBI, individuals may experience a loss of self-identity and have difficulties reconstructing a new identity (Bryson-Campbell et al., 2013). A meta-synthesis of TBI research on self-identity identified that if an individual with TBI occupies a new role that is attributed with a loss of status, they experience a less positive self-identity given their comparisons between their pre- and post-injury selves (Villa et al., 2021). However, much less is known about the lived experience and subjective relationship of social participation and self-identity in the TBI population. Therefore, the aim of this study is to explore the lived experience of TBI with respect to social participation and self-identity after TBI.

3.2 Methods

3.2.1 Study design

This study used constructivist grounded theory and aimed to use an inductive process to create a theory grounded in the data obtained through interviews (Charmaz, 2006). It supports the idea that the researcher is inseparable from the data and follows an ongoing iterative process (Charmaz & Belgrave, 2019). Ethics approval was obtained by the Research Ethics Board of the University of British Columbia. Data are reported using the COnsolidated criteria for REporting Qualitative research (COREQ) (Appendix B) (Tong et al., 2007).

3.2.2 Participant recruitment

Convenience sampling was used to recruit participants from British Columbia, Canada. Advertisements were circulated within GF Strong Rehabilitation Centre, BC Brain Injury Association, and other community networks. To be included in this study, participants had to: (1) be between the ages of 18 to 65 years, (2) experience a moderate to severe TBI, (3) sustain the

injury at least a year ago, and (4) be able to communicate in English. Individuals who sustained a mild TBI were excluded from the study. Written and oral consent were obtained from all individuals prior to data collection. Participant recruitment was stopped once theoretical sufficiency was deemed to have been reached (Dey, 1999).

3.2.3 Data collection

A semi-structured interview guide was developed and piloted with an individual with lived experience of a brain injury (e.g., patient-partner) (Appendix E). Participants were given a copy of the interview guide prior to the interview to aid with potential cognitive difficulties when answering questions. Each participant took part in an approximately 40-minute interview which was conducted either online, through a secured virtual platform, or in-person (at their place of residence), depending on the participants' preference. No relationships were established prior to the start of the study and all participants took part in the study. Participants were aware of the interviewers' backgrounds, as well as the of the goals of this master's thesis research project. Participants were encouraged to talk about their life experiences after sustaining their TBI and were asked questions specific to their social participation and self-identity. As these interviews were conducted during the COVID-19 pandemic, interviewers explained to all participants that their responses should be regarding their social participation and self-identity prior to the COVID-19 pandemic. Two participants requested their support workers to be present during the interviews. The interviews were conducted by first and fourth authors RM (master's student) and JS (assistant professor), along with two research assistants (master's and undergraduate students). All four interviewers were female and had previous experience interacting with people with brain injury. One interviewer was a researcher; the three other interviewers attended health or rehabilitation sciences educational programs at the University of British Columbia, Canada.

The three student interviewers were enrolled in a research graduate program, a clinical graduate program, and a bachelor's program respectively. Data collection was finalised when a sufficient depth of understanding was reached by the researcher to develop an explanatory model.

3.2.4 Data analysis

All interviews were audio recorded and transcribed verbatim with personal information replaced with pseudonyms. Data analysis occurred concurrently with data collection, in line with constructivist grounded theory. Data analysis followed three main stages: 1) initial coding, 2) focused coding, and 3) theoretical coding. These stages included line-by-line coding and constantly comparing the data to generate themes. Each participant transcript was coded using the software NVivo 12. As analysis progressed, three main themes were formed, and an overarching theme was generated.

The research team employed three main trustworthiness strategies: researcher reflexivity, member checking, and the involvement of multiple investigators in the data analysis process (Morrow, 2005). First, each interviewer maintained a reflexive journal after their interviews. After each interview, the interviewers gave their perspective on the overall content of the interview and how the participant responded to the questions. This journal was maintained to examine the influence of the interviewers' positionality during the research process, as the interviewers are considered to be active in the research process. Second, member checking was conducted to include complementary perspectives from the participants about the findings. A few participants responded when contacted and after the reviewal of the findings, they indicated that it supported their perspectives. Third, multiple researchers were included throughout the data analysis stages, hence acknowledging the different perspectives on the participants' data.

Following the first round of coding and generation of themes by the first author researcher RM, the other authors on this paper (WBM, JF, and JS) were invited to provide input and review the codes and themes. The themes were developed over various sessions, supporting an iterative process.

3.3 Results

Sixteen people with moderate to severe TBI participated in the study with an average time post-injury of 17 years (Table 3.1). The overarching theme of ‘living in a reshaped reality’ depicted how an individual experienced and grappled with a different world post-injury. Three themes were integrated in this post-injury experience: 1) ‘there’s nothing that’s the same’, identified the new challenges that individuals faced, 2) ‘rebuilding and restarting’, outlined how individuals navigated their new reality and acquired the necessary resources that were available to them, and 3) ‘embrace it and run with it’, described the responses to post-injury life. An explanatory model illustrating the findings and the relationships between social participation and self-identity was developed. Descriptions of themes with explanatory quotes are noted below.

Table 3.1 Participant demographics

Participants	Age bracket	Participant reported years since injury	Cause of injury	Living environment
Robert	51-55	23	MVA	Home with family
Marie	61-65	11	MVA	Assisted living
Jessica	31-35	7	MVA	Independent living
Ronald	61-65	25	Fall	Home with care aide
Paul	51-55	35	MVA	Independent living
John	51-55	2	Drug induced brain damage	Assisted living
Steven	51-55	10-15	Fall	Assisted living
David	61-65	26	MVA	Home with family
Susan	61-65	10-15	MVA	Home with family
Andrew	36-40	5	Assault	Assisted living
Matthew	26-30	9	MVA	Assisted living
William	56-60	14	Encephalomyelitis	Independent living
Michael	51-55	23	MVA	Home with family
Joshua	26-30	3	Fall	Independent living
Tammy	51-55	33	MVA	Independent living
Lisa	51-55	22	Fall	Independent living

Note. MVA= motor vehicle accident, participants 7 and 9 did not recall the year of their injury, but it is estimated to be 10 and 15 years prior to interview.

Explanatory model

The explanatory model (Figure 3.1) illustrates the continual nature of the process of negotiating life in a reshaped reality. William talked about his ongoing healing process, ‘it's like going up a hill with sand, three steps up and you slide one back’. Joshua echoed a similar notion, ‘I don’t think there’s ever an end to rehabilitation, I think it’ll be a lifelong journey’. As shown in the model, the participants’ social participation and self-identity are influenced as they live in their reshaped reality. For example, Susan described difficulties participating in work activities, as employers could not make accommodations for her abilities and limitations. This impacted her self-identity as she was not able to occupy the role of a driver. Michael discussed the support he received from the medical staff and his family, which facilitated acceptance of his new life. He described how his newfound self-acceptance enabled him to engage in pursuits that gave back to the TBI community, such as advocacy and the creation of activities to facilitate participation for other individuals with TBI. Additionally, Andrew spoke about how he felt his TBI had a positive impact on his life and self-identity, expressing his injury as a ‘clean slate’. He described that after his injury he became closer to his family, started to enjoy working, and developed new milestones he wanted to achieve. Overall, as depicted in this model, social participation and self-identity are constantly influenced by the participants’ new reality after TBI.

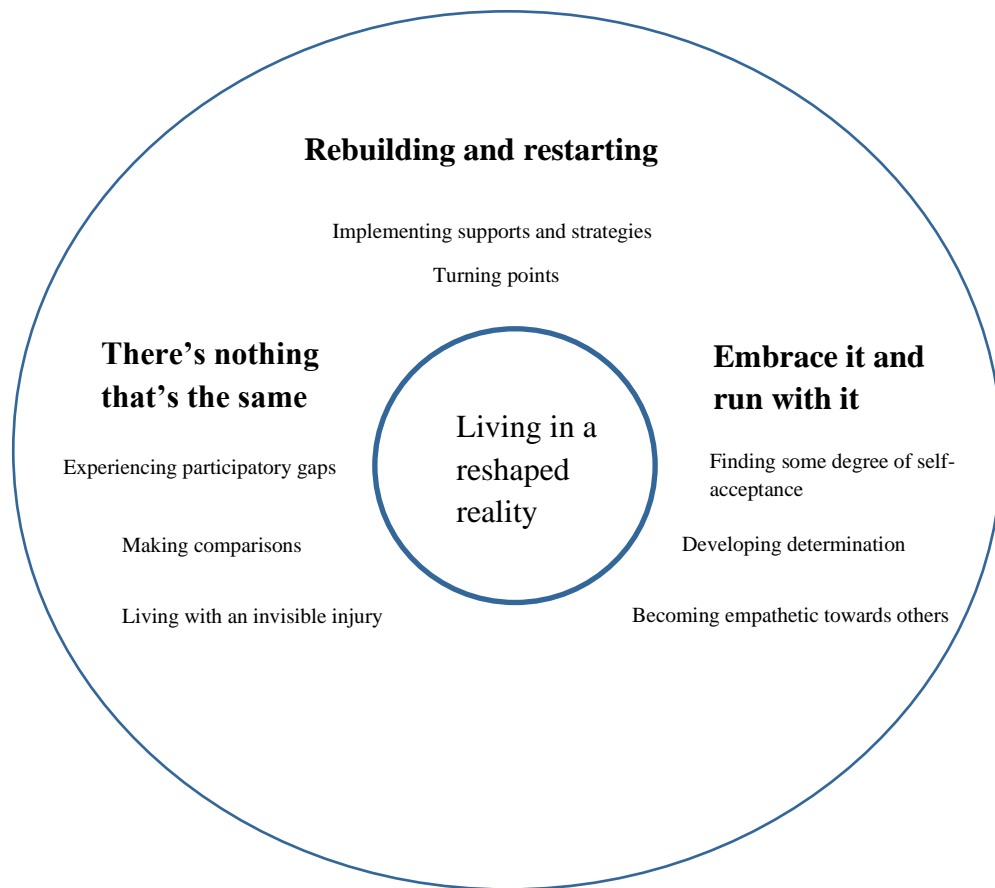


Figure 3.1 Explanatory model of participants' experiences of living in a reshaped reality since sustaining their TBI

There's nothing that's the same

In the first main theme, participants described new challenges they encountered after sustaining their TBI, with many indicating that adjusting to their new post-injury life was a difficult transition. As John stated:

There are so many changes. It's hard to describe really. Like being reborn at 33 years, at 40 years old. There's no one ready for that...You feel like you're the only person in the world to have some problems. You can't talk, you can't really do anything that you use to take for granted.

Michael expressed the troubles in acclimatising to his new life, 'very hard to lose, to lose everything that you love so much and to keep your life going, to have an even keel'.

Integrated in this theme are three sub-themes including (1) experiencing participatory gaps, (2) making comparisons, and (3) living with an invisible injury.

Experiencing participatory gaps

In this first sub-theme, participants described encountering 'gaps' or obstacles such as restrictions in activities. Participants highlighted new limitations they faced in their post-injury world, such as reduced participation in leisure and work-related activities. William spoke of the extra effort it took to analyse a task:

Every aspect of my life has changed, every aspect of me and it's really painful to be consciously aware of everything I do after that... if I want to do something I used to be able to do okay, I need to go through it, break it down piece by piece, and what problems am I going to run into anticipate... I don't have a choice.

Jessica talked about her desire to engage in sporting activities but perceived a constant sense of uncertainty as she explored the extent of her abilities:

My battle is, every single time I play a sport that I used to be able to play and I don't know when I pick something up, you know, am I going to be like the way I was before, or am I going to be completely 'I don't know how to play'.

Other participants emphasised the impact of losing their vocational role. For example, David stated, 'The hardest thing was his statement that you'll never be able to work again. Yeah, it's like if you are told you'll never get married. You'll never have children. How would you feel?'. Marie expressed that her profession contributed significantly to how she viewed herself:

Work, yeah that's where I felt, more important that I actually was. I was a somebody because of what I would actually do. I felt good when I worked. I did love my job, all my jobs. I was just so happy all the time... [Now that I'm not working, it] just knocks me down...I feel inadequate, frustrated because I know what has to be done, how to work. How to set up a filing system, how to set this up. But I can't do it.

However, new avenues were discovered to fill some gaps as described by Michael, 'I write my book and a screenplay and doing all these different films and ideas, and I got into art... Really, I didn't have that sense of creative need before my injury... It's wonderful, yeah, that's changed a lot'.

Making comparisons

In the second sub-theme, participants reported two types of comparisons they made, the first in which they compared their pre-and post-injury identities, and the second in which they compared their abilities to those of people without a TBI. In terms of comparing pre- and post-injury self, David expressed his thoughts on his pre-injury independence and how he struggled

with not being self-reliant anymore – a characteristic that he associated with his masculine identity:

It's mainly because when you're independent, and self-employed, and self-reliant, and energetic. And everything. And then after?... I suffered really, really, really bad. Because I lost a lot of pride. And that's really hard on a man. Pride is everything.

This change in pride was also experienced by William who had vision loss after TBI, 'But I didn't want to be blind. So that was one of the biggest obstacles, my own stubborn pride, I guess, male pride. So, I spent some time walking around with no cane'. He described eventually realising that he needed a cane to navigate through his surroundings safely. However, there were some participants who perceived themselves as becoming more involved in specific roles after the injury. Andrew reflected on how he was more engaged in his role as a father because of his injury, 'I also just had a kid, and I wasn't there and then this happened [the injury], and I was able to be there again...it's given me a life, and a chance to be a dad'.

Participants compared their capabilities to those without a TBI. For example, Michael said:

I read all the time, I'll try to better myself, and that's where I feel a little bit insignificant at times, because my wife is a very, very intelligent woman... we don't deal with work. I've become very sensitive I don't hear about what's happening, I mean, we're great team but a little bit I feel behind, I'm not as smart as she is.

Tammy reflected on how sustaining a TBI at a younger age meant she missed out on learning 'unwritten rules' that her peers were well versed with, 'But I just felt like there was this other

book that people were reading that knew how, I don't know, how you're supposed to respond to certain situations'.

Living with an invisible injury

In the third sub-theme, participants outlined how other individuals portrayed a lack of understanding about their TBI. Several participants recalled scenarios where they felt their disability was minimised by others due to the invisible nature of a TBI. Lisa talked about how she felt when others criticised her behavioural changes, 'Don't be so rough. When I just think well, if they only knew, like they're just judging. They mean well, but there are sometimes when they're doing more harm, because they forget I'm not like them'. Jessica expressed her discomfort when she encountered individuals who expected her to be the same person she was pre-injury:

Lots of people who knew me from before, they have expectations of who I'm supposed to be right, who they think I am... so when those people reach out, my first thing is to brace myself, there is always a, not expectation, but there is always a preconceived notion of who I am, and all of those things are fighting with you.

Feelings of frustration and resignation about the misunderstandings others had about their TBI were reported, as stated by Robert, 'Trying to explain to people sometimes was really hard for me, some people would understand, other people wouldn't. You look fine now, what's wrong with you'. Susan said, '[people don't understand brain injuries] And never will. Even doctors won't understand'.

Rebuilding and restarting

The second main theme highlighted the resources and measures taken by the participants to help them navigate life after TBI. Two sub-themes are incorporated in this theme. These consist of 1) implementing supports and strategies and 2) turning points.

Implementing supports and strategies

The need for support from both healthcare and social groups were highlighted in this first sub-theme, with participants emphasising support as an essential resource to navigate daily life. Andrew stated that even though he did not want to participate in his rehabilitation, his clinician's constant encouragement was essential in improving his capabilities:

I remember thinking, it's selfish for all of you to want me to keep going because this sucks. But it truly is awesome now... When you don't get results it's hard to want to keep trying new things. I had this lovely lady, the one that kept pushing me to do stuff and challenging me, and then I know that now, when I'm climbing on something, I think, oh good thing she pushed me actually.

The security and comfort of finding a place within the brain injury community was valued as Robert explained, 'The folks here are really supportive of my feeling down or having problems or something. Lots of folks here to talk too. Not entirely lost out in the world somewhere'. However, there were some participants who described the difficulties in navigating through their new life experience when they did not receive the necessary support. Tammy talked about how she wanted to meet with a counsellor, but did not feel her family recognised that she needed the support:

At one point, I finally said, I think I need to see someone. I think I need some help, like a counselor or something like that. And my dad's response was, oh, no, you're fine. So just the denial that there's anything wrong. And I mean, they don't deny that it happened, but it's like they just want to kind of move on... Well, it just pushed me further into depression.... because it's like, well, now I want help, but I can't get it.

A few participants spoke about situations in which they did not feel that they received adequate support from their medical staff. Marie indicated that she required more time in rehabilitation before being discharged, as she perceived her home as unfamiliar territory, 'Yeah, I still think I was released too soon. I, at least, should have been able to get out of bed by myself, go to the bathroom by myself. Make a bloody cup of tea by myself'.

In addition to the healthcare and social support needed, participants described the practices or strategies they cultivated that allowed them to engage in their post-injury life the way they desired. For example, Jessica reported:

And for me the strategy right now in the morning is to mentally prepare myself, not to have sudden things, surprises are not fun for me. Cause I want to mentally prepare, cognitively prepare. It's also one of my strategies for me, especially if I'm in a group surrounding. So, I knew I needed to take extra strength to listen to that, so before and after, you know, I was not doing anything, I was just going to rest and relax. And maybe the day before and the day after as well.

Conscious efforts were made to be immersed in everyday rehabilitative practices as elaborated by Michael, '[I'm] constantly bettering myself. Yeah, every day what I try to do, I try to do something cognitively, so it's reading or learning something, cognitively'.

Turning points

In this second sub-theme, participants spoke of experiencing a turning point where they found a purpose in life which led them to embrace and improve their situation. Robert reported how he shifted his priorities and found meaning in raising his children, after realising that he will not be able to resume his vocational role:

That was the biggest push in my life. Just knowing that my children were okay... I had to keep telling myself that it's okay that you're not working, you still are, you're raising children here. That's a big job in itself. So that was the biggest push. If I couldn't have that, then I was going to raise my kids the best that I can. Without this strong motivation, I wouldn't be sitting here talking to you and we wouldn't be having all this right now.

David described the moment which led to his change in perspective, 'I'm like, what am I worth, what am I here for, on this planet? What do I do? I ended up in the hospital from drinking too much. And that's when I realized that I have to find something'. He expressed how his life transformed as he started to find a purpose after being involved in a meaningful activity, 'Cooking. Yes. So, I got involved. And right away, I just didn't drink. It all changed. Because I felt like I was worth something'.

Embrace it and run with it

In the third main theme, participants described the different ways in which they responded to their new reality of living with a TBI. Sub-themes included (1) finding some degree of self-acceptance, (2) developing determination, and (3) becoming empathetic towards others.

Finding some degree of self-acceptance

In the first sub-theme, most participants reported varying degrees of acceptance towards their TBI. These participants acknowledged the change in their abilities and showed compassion towards their post-injury selves. John said, ‘Just take everything as it comes. Take it slowly. Let yourself get used to it. Don't try and be like your old person. No, you just know you're never going back. Just accept it, it'll be okay’. Michael conveyed time as an important factor when living with a TBI:

Time is the most important thing in the world because you got to be patient because it's not going to happen tomorrow... For me too, it's been 23 years, I'll never ever be the same that I was. Acceptance and time are the two most important things in the world.

However, there were a few participants who indicated that they could not accept some experiences of their post-injury life. For example, Marie described a sense of grief when talking about her vision impairment, ‘But I still can't understand if they can do all that, keep them in a space capsule for how many months...and they can't fix the eye? You can get an artificial heart, why not work on the eye?’. In addition, there were participants who expressed avoiding post-injury activities after their TBI. For example, Jessica described how she didn't read for a long period of time:

I cried the first time I couldn't read. I couldn't pick a book up again. The first time I picked the book up was four years after... That is probably my biggest thing, the first time we tried was so devastating. And it took me months before we tried to read again. But it's like to pick up a book and to do it by myself. It's so scary.

For some, this avoidance behaviour extended to all parts of their life and roles after injury. For example, when asked about his injury, Steven said, 'Oh, holy cow, I don't want to. [Laughs.] Oh, forget this...Just don't even talk about it. I don't know...I don't know'.

Developing determination

The second sub-theme consisted of participants who talked about the determination and resilience they developed to overcome the daily issues that materialised post-injury. These participants conveyed positive personal traits and attitudes they adopted in the face of challenges, such as Michael, 'I remember looking out of the balcony and saying, what's gonna happen, I've lost everything. So, I said to myself, you know what to do, it's time to go, it's time to put my socks and get back into things'. Joshua gave another example, emphasising his self-efficacy to face the challenges ahead:

The doctors, the nurses, the therapist, they were saying, this isn't gonna happen, this is going to be this way. And I know the stubbornness or whatever, I just smiled and said, 'sure thank you I appreciate that', and then just not going to let that happen to me. Having that mindset is a big part of how I am today, the recovery I've been through.

There were also participants who opted for a more relaxed and hopeful approach to life, such as Matthew, ‘You have to understand life is hard for everyone...Take it all with a grain of salt. If you had a good day, it's going to get better’

Becoming empathetic towards others

There were participants in the third sub-theme who indicated that because of their injury they were able to empathise with others who had gone through similar experiences. Joshua expressed how he wanted to help others the way he was supported:

I think that I was in a bad place, but I was able to, I had people around me, I had people to help me. For me knowing that those people were there, changed my life, and changed the trajectory of my life...So, I think I’m in a position where I want to be able to help and I can say I was in your shoes, I was where you were a couple years ago, three years ago, I’m doing much better because of the people who were there.

Participants spoke to how they could identify with the challenges that other individuals with TBI encountered and felt a connection with those people, as conveyed by Tammy, ‘And I feel like I can relate to people who've gone through stuff I guess because I know what I've been through. And I know how I felt when people reacted in different ways to me’.

3.4 Discussion

This study identified an overarching theme of ‘living in a reshaped reality’ and three underpinning themes that depicted life after TBI: ‘there’s nothing that’s the same’, ‘rebuilding and restarting’, and ‘embrace it and run with it’, as shown in the explanatory model generated.

This study builds on previous research on social participation and self-identity after TBI to describe lived experience and perspectives on the relationship between social participation and self-identity. The following discussion considers these themes with a focus on social participation and self-identity.

3.4.1 Social participation

The first theme, ‘there’s nothing that’s the same’, indicated that individuals encountered difficulties in participating in meaningful activities (e.g., resuming employment or leisure activities) due to changes in their abilities as well as social and environmental constraints. As described by participants in the sub-theme ‘experiencing participatory gaps’, returning to work is a valued rehabilitation goal. This can be due to reasons such as increased financial security, as well as the means to socialise and develop positive self-identity after a brain injury (Lundqvist & Samuelsson, 2012; Moller et al., 2017). However, individuals who experienced greater injury severity and more cognitive impairments were less likely to be employed after their TBI (Chien et al., 2017; Ponsford & Spitz, 2015). This could be a result of lack of vocational rehabilitation, limited support from employers and colleagues, and decreased abilities and function (Matérne et al., 2017). Participants in this study have also identified the problems faced when they tried to engage in sports or exercise. Previous research has indicated that individuals with TBI may experience a change to more sedentary leisure activities post-injury, citing reasons such as fatigue, lack of transportation, and financial constraints (Wise et al., 2010). This shift can negatively impact an individual, as research findings have reported that individuals involved in physical activities after a TBI have portrayed an increase in mood and quality of life (Hoffman et

al., 2010; Wise et al., 2012). As such, individuals may be largely impacted when they find themselves unable to engage in their desired activities.

In the second theme ‘rebuilding and restarting’, participants described health care and social support as essential resources to help them participate in activities and navigate their post-injury life. This aligns with earlier work indicating that clinicians aid individuals with TBI to create patient-led solutions for facilitating engagement in meaningful activities (Knox et al., 2013). Receiving services during early rehabilitation is important as it influences long-term level of functioning and participation (Lefkovits et al., 2021). Participants in this study also described the benefits of long-term supports such as brain injury communities and peer-support. Participating in activities after TBI can be an ongoing process, and as such, long-term support services are essential in helping individuals through the new and unexpected problems that can arise (Fadyl et al., 2019). However, individuals in this study and others have acknowledged that it can be harder to access long-term medical support (Strandberg, 2009). This may reflect unawareness of resources available as well as the continuous struggle to obtain help from services (Fadyl et al., 2019; Stiekema et al., 2020). Similar to healthcare support, social and family support were especially viewed as helpful in promoting participation after TBI (Gagnon et al., 2016). Notably, previous qualitative investigations identified that most individuals indicate that social support also deteriorates after sustaining a brain injury (Fraas & Calvert, 2009; Lefkovits et al., 2021). There is a clear need for better healthcare and social support to facilitate participation in activities after TBI, particularly regarding the education and support for the caregivers of those with TBI (Lieshout et al., 2020; Powell et al., 2017).

In the second theme, participants reported the implementation of compensatory strategies as another key factor that helped increase participation in activities. Applying problem-focused strategies to daily life with TBI can help them cope with daily memory, stress, and aggression issues and provide a sense of independence (Downing et al., 2021). Additionally, as each brain injury is unique to the individual, tailoring compensatory strategies to help overcome individual problems can help facilitate engagement in meaningful activities (Dams-O'Connor et al., 2018).

Findings from the third theme, 'embrace it and run with it', highlighted participants' feelings of empathy and desire to help others with disabilities. Many participants acted on this outlook by engaging in roles that developed their new interest in helping others. This contrasts with some other studies indicating that people with TBI experience decreased empathy, due to damage in brain structures associated with cognitive and emotional empathy (de Sousa et al., 2010; Wearne et al., 2020). However, these quantitative studies did not explore lived experiences with TBI. Participants in the present study described how they reflected on their own challenges in life and were able to recognise the needs and vulnerability in others with disabilities, aligning to other studies on empathy after injury (Powell et al., 2007). Additionally, this reflected the volunteer nature of the participants in this study as these individuals wanted to share their experiences and help further research on TBI.

3.4.2 Self-identity

Findings from the first theme 'there's nothing that's the same', described the impacts to self-identity after TBI, which includes changes in the different roles they occupy (e.g., professional, leisure, familial). A systematic review indicated that individuals are more commonly reported to experience negative changes to their self-identity after TBI (Beadle et al.,

2016). While there were both positive and negative self-identity changes stated by the participants in this study, one of the main negative self-identity changes highlighted by men in the sub-theme ‘making comparisons’ were the perceived losses in masculine identity. This is consistent with other research studies in which the men described the changes they experienced after TBI conflicted with their pre-injury masculine ideals (e.g., switching roles from being the breadwinner to domestic roles) (MacQueen et al., 2020). This can be due to the influence of cultural and societal ideals where men are framed as the primary earners of a family. These influences can also impact women, as women with TBI may find it difficult to adjust to their change in roles from caregiver to receiving care and continue to engage in caregiving despite the possibility of health risks (Fabricius et al., 2020). However, individuals with TBI may accept these changes by reformulating their ideals of the characteristics that form their identity and finding positive meanings in new roles (e.g., men perceiving domestic roles as a way to support the family) (Jones & Curtin, 2011).

Participants in the first theme referred to their TBI as an ‘invisible injury’ as identified by participants in other studies (Lefkovits et al., 2021; Lorenz, 2010). This description of their TBI as ‘invisible’ describes an injury that is not obviously observable (e.g., memory impairment) compared to physical impairments (e.g., balance difficulty requiring the use of a cane). In other studies, individuals with TBI expressed that they preferred the invisible nature of their injury as it aligned with their desire to be perceived as ‘normal’ and able-bodied (Freeman et al., 2015). However, participants in the sub-theme, ‘living with an invisible injury’ expressed feelings of being misunderstood by others in their community and social circle because of incorrect assumptions about their physical well-being and behaviour. If an individual does not display

external indicators of an injury, others may not understand that an individual has a disability and hence, people may minimise the challenges individuals with TBI experience (Lowe et al., 2021; McClure, 2011).

Participants highlighted how they navigated through the challenges of life after TBI by creating a positive self-identity in the second theme, ‘rebuilding and restarting’. Participants talked about experiencing a ‘turning point’ in their life after TBI that caused a questioning and redefining of their values and goals. This aligns with a qualitative study, which reported a considerable shift in self as they recognised there were new opportunities that lay ahead post-injury, enabling them to take a positive next step (Muenchberger et al., 2008). In this theme, participants described experiences that provided a direction or purpose in life by engaging in meaningful activities, as well as achieving milestones or successes. This is consistent with the findings of a scoping review that stated the experience of having a positive perspective on life and achieving accomplishments can have further impetus of positive life experiences and promote resiliency after TBI (Nalder et al., 2022).

Resiliency was indicated by individuals in the third theme, ‘embrace it and run with it’, which depicted how they responded to life after their injury. Participants in the sub-theme ‘developing determination’ described characteristics such as hope and self-efficacy (the belief in their own capabilities) that helped protect them from the prolonged negativity after TBI. Perceived self-efficacy is associated with life satisfaction as it enables the individual to try and attain their desired outcomes (Cicerone & Azulay, 2007). Characteristics of hope and self-efficacy are theorised to facilitate resiliency after TBI, which in turn can promote acceptance of self and abilities (Nalder et al., 2019). Resiliency is conceptualised as a ‘group of

neurobiological and psychosocial processes by which individuals are able to reduce the potential negative impact of adversity' (King & Rothstein, 2010, p.369). Hence, the personal attributes of hope and self-efficacy may have helped participants to foster resiliency, which in turn led them to accept their new self after TBI. The TBI resiliency model also places importance on external resources, social support, and family resiliency to promote an individual's resiliency (Nalder et al., 2019).

Individuals in the third theme reported varying degrees of acceptance towards their TBI. A few participants reported feelings of grief and denial, as expressed in the sub-theme 'finding some degree of self-acceptance'. Grieving can be an important process of acceptance after TBI (Hooson et al., 2013). After a TBI, an individual may grieve for the loss of an anticipated future that an individual expected to experience, as well as the realisation that some aspects of life might never be the same as pre-injury, and represent a loss of future self (Ownsworth, 2014; Ruff, 2013). A few participants described instances where they previously avoided aspects of their injury or did not want to acknowledge the limitations and difficulties resulting from their TBI. This can be perceived as a self-protective mechanism and be indicative of impaired self-awareness. The biopsychosocial model of self-awareness explores this approach, where at the psychological level, individuals may use strategies such as avoidant coping or denial (Ownsworth et al., 2006). An exploratory study suggested that when individuals with TBI realised that their abilities had changed, denial helped them to cope better in the short-term (O'Callaghan et al., 2006). Hence, denial can be viewed as a protective mechanism for the individual, acting as a 'buffer' to the emotional distress felt when confronted with their post-injury change (Gainotti, 1993). However, the continuous use of these strategies overtime can

impact an individual negatively as they may fail to implement other essential coping strategies (Ownsworth, 2005).

Acceptance of self after TBI can be influenced by many factors, such as time since injury. The length of time living with a TBI can be important as described in the sub-theme of ‘finding some degree of self-acceptance’, as individuals may need opportunities over the course of time to obtain feedback from participating in different activities and thus readjust their expectations to life (Ellingsen & Aas, 2009). Additionally, a longitudinal study indicated that as time progressed, individuals adopted a more positive perspective on life and accepted their injury as they encountered more positive experiences (Lefkovits et al., 2021). However, in this case, individuals may be recalibrating their representation of a negative encounter, for example perceiving it as more positive due to the comparisons with newly encountered adverse events (Schwartz et al., 2007). Individuals may experience a re-prioritisation whereby they change what they consider positive, or re-conceptualisation where they re-define the meaning of a positive experience (Schwartz et al., 2007). Most participants in this current study sustained the TBI many years previous and as such may have had more opportunities to accept their re-shaped reality of life. Acceptance of TBI may also be influenced by the awareness of their impairments and understanding the extent of their capabilities (Fadyl et al., 2019). In acknowledging their limitations, it helps facilitate engagement in therapy, as well as contribute to positive growth (Allen et al., 2020; O’Callaghan et al., 2012). Notably, acceptance of injury is a key factor in reconstructing positive self-identity (Levack et al., 2014).

3.5 Limitations

This study has three main limitations. First, data collection occurred during the COVID-19 pandemic, hence when asked about their social participation after TBI, participants integrated COVID-19 related problems as well. However, the interviewers clarified the question by asking about the participants to answer according to their pre-COVID-19 participation. Second, some participants who had more severe impairments may not have been able to engage in the interview due to fatigue and cognitive processing difficulties. These participants were recruited to provide a wide level of abilities and experiences in life after TBI and were supported in the interview with support workers. Third, theoretical sampling, a process central to constructivist grounded theory, was not implemented due to recruitment difficulties and time constraints. As such, deeper insights into categories may not have been generated in this study.

3.6 Conclusion

This study describes the experience of living with a TBI, illustrating the new reality and individual experiences after a TBI. Findings indicate that individuals with TBI encounter new challenges, respond to these challenges with supports and strategies, and respond in various ways to their post-injury life. Future research and clinical practice may benefit from exploring how individuals can develop and strengthen their responses to the adverse encounters after TBI.

Bridging Statement

Chapter 3 focused on the findings from the qualitative data collected in this study and explored the lived experiences of changes in social participation and self-identity after TBI. Chapter 4 will explore the characteristics of individuals with TBI displaying higher and lower levels of posttraumatic growth, regarding their social participation, self-awareness, and self-identity. Chapter 4 is a secondary analysis of the study from chapter 3. Both studies in Chapter 3 and 4 consisted of the same participants with TBI and the same qualitative data collection methods.

Chapter 4: Characterising posttraumatic growth in individuals with TBI according to social participation, self-awareness, and self-identity

4.1 Introduction

In Canada, approximately 170,000 individuals are affected by a TBI annually (Post et al., 2015). After TBI, physical and cognitive problems are experienced, which affect everyday life, such as difficulties in walking and remembering information (Dunning et al., 2016; Perry et al., 2014). Additionally, there may be social and environmental challenges, such as difficulty obtaining employment due to cultural stigma of disability or inaccessibility to buildings (Fleming et al., 2014; Poritz et al., 2019). These issues impact how people with TBI participate and reintegrate in the community (Wong et al., 2017).

People with TBI may have remarkably different routines compared to before their injury, and engage in different types of activities in post-injury life. For example, due to the impairments associated with the injury (e.g., fatigue, memory impairments) and societal constraints (e.g., inaccessibility issues, marginalisation), an individual may experience a decrease in participation in their desired activities (Beadle et al., 2020). Additionally, there may be a change in the roles an individual occupies due to biological or psychosocial problems from their TBI, which can lead to disruptions in their self-identity (e.g., switching from a corporate job to a domestic role) (Beadle et al., 2016; Levack et al., 2014). While these experiences can negatively impact an individual, a positive perspective about life after injury can be developed (Tedeschi et al., 2018).

Posttraumatic growth is defined as a ‘positive psychological change as a result of the struggle with traumatic or highly challenging life circumstances’ (Tedeschi et al., 2018, p.1). After a traumatic

event, individuals may engage in rumination, which becomes more deliberate overtime. As a traumatic experience may challenge a person's prior existing views about the world, deliberate rumination facilitates individuals in making sense of the trauma and incorporating new information about themselves to rebuild their belief system, leading to psychological growth (Ramos et al., 2018). Five key domains from the Posttraumatic Growth Inventory are considered components of posttraumatic growth (Tedeschi & Calhoun, 1996; Tedeschi et al., 2018). These include personal strength, relating to others, new possibilities, appreciation of life, and spiritual and existential change. 'Personal strength' indicates an individual stepping into a survivor mindset with increased confidence and self-reliance. 'Relating to others' reflects the subsequent positive changes in relationships, such as a greater sense of compassion and connection towards others. 'New possibilities' refers to the development of interests or opportunities identified by the individual in the aftermath of the trauma. 'Appreciation of life' and 'spiritual and existential change' describes the changes in an individual's philosophy of life with new perspectives of religious/existential beliefs (Tedeschi et al., 2018).

People with TBI may experience posttraumatic growth as early as 6 months post-discharge (Silva et al., 2011). Employment and productive occupations are associated with greater levels of posttraumatic growth after TBI, as individuals experience more social contact and autonomy (Grace et al., 2015). In particular, paid employment is a key factor that differentiates individuals with higher posttraumatic growth from those with lower degrees of growth (Powell et al., 2012). Self-awareness can impact posttraumatic growth after TBI as individuals with low posttraumatic growth can display avoidance coping, a behaviour associated with impaired self-awareness, and prevent deliberate rumination (Allen et al., 2020). Additionally, acknowledging limitations after TBI facilitates adaptation, re-integration in society, and acceptance of new strategies to participate in meaningful activities, and

consequently, psychological growth (Gracey et al., 2009). Posttraumatic growth may be related to self-identity after TBI, as individuals continue to experience new roles and engage in valued activities, they strengthen and consolidate a new positive self-identity (Tedeschi et al., 2018).

There is established research on the factors that influence posttraumatic growth after TBI using quantitative data (Powell et al., 2012; Rogan et al., 2013), as well as qualitative data (Allen et al., 2020; Lyon et al., 2021). However, no research has used a mixed-methods approach to examine the characteristics of social participation, self-awareness, and self-identity in individuals with TBI who have experienced posttraumatic growth. Hence, this study aims to describe the characteristics of people with TBI displaying higher and lower posttraumatic growth, with a focus on social participation, self-awareness, and self-identity.

4.2 Methods

4.2.1 Study design

This study used a sequential explanatory/exploratory mixed-methods design (Appendix C), with the data collection following an explanatory design, and data analysis adhering to the exploratory design (Creswell et al., 2003; Zhang et al., 2013). The qualitative data used in this study is part of another research project exploring the experiences of life after TBI and the changes to social participation and self-identity (Mamman et al., 2022). Ethics approval was obtained by the Research Ethics Board of the University of British Columbia. The data are reported using the Good Reporting of a Mixed-Methods Study (GRAMMS) (Appendix D) (O' Cathain et al., 2008).

4.2.2 Participant recruitment

Convenience sampling was used to recruit participants from British Columbia, Canada. One participant could not complete the questionnaires as they could not comprehend the questions, due to the severity of their cognitive impairments. Advertisements were circulated within GF Strong Rehabilitation Centre, British Columbia Brain Injury Association, and other community networks in British Columbia. Participants had to: (1) be between the ages of 18 to 65 years, (2) have experienced a moderate to severe TBI, (3) sustained the injury at least a year ago, and (4) be able to communicate in English. Individuals who sustained a mild TBI were excluded from the study. Written and oral consent were obtained from all individuals prior to data collection.

4.2.3 Data collection

Two sessions were conducted for each participant. The sessions took place either through a secure virtual platform or in-person, depending on the participants' preference. Support workers for two participants were present during both sessions. In the first session, quantitative data were collected, in line with the explanatory design. Participants provided information on demographics (date of birth, date of injury, cause of injury, and living environment) (Appendix F) and on global functioning using the Mayo-Portland Adaptability Inventory-4 (MPAI-4) (Appendix G). Participants then completed questionnaires on social participation, self-awareness, and self-identity (Table 4.1). To generate a discrepancy score to measure the participant's self-awareness, an additional form was completed by either a family member or the participant's clinician using a secure online link, administered through email. In the second session, the qualitative data were collected through a semi-structured interview, either through a secured virtual platform or in-person at their place of residence. Participants were

provided with the interview guide prior to the session as a way to help any cognitive difficulties they may have when answering questions. Participants were asked questions pertaining to their social participation, self-awareness, and self-identity (e.g., ‘What does a typical day for you look like?’, ‘What, if any, changes have you noticed since your injury?’, ‘How would you describe yourself?’) (Appendix E). The interviews were conducted by the first and fourth author (RM, JS), as well as two research assistants (masters’ and undergraduate students). All four interviewers were female and had experience conducting research studies with individuals with brain injuries. The first author and the two research assistants were enrolled in health and rehabilitation sciences educational programs at the University of British Columbia, Canada, while the fourth author is an academic researcher with clinical experience in brain injury rehabilitation. No relationship was established prior to the start of the study. All participants were aware that the study was part of a master’s thesis project and was informed of the interviewer’s academic backgrounds. Each interview lasted approximately 40 minutes.

Table 4.1 Description of outcome measures

Construct	Questionnaire	Description	Scoring
Social participation	Impact of Participation and Autonomy (IPA) (Cardol et al., 2001)	The IPA consists of 39 questions which assesses an individual's participation and autonomy (Appendix H). Internal consistency is high for all subscales, ranging from Cronbach's $\alpha = .81$ to $\alpha = .96$.	A total score is calculated. Higher scores indicate decreased participation.
Self-awareness	Awareness Questionnaire (AQ) (Sherer et al., 1998)	The AQ compares an individual's current abilities with their pre-injury abilities. It consists of 17 questions. This measure consists of both a self-report questionnaire by the participant (Appendix I.1) as well as a similar informant questionnaire completed by a family member (Appendix I.2) or clinician (Appendix I.3). Scores can range from -68 to 68. The participant and informant form has an internal consistency of Cronbach's $\alpha = .80$ and $\alpha = .82$ (Hellebrekers et al., 2017). Additionally, it has a well-established use in	The scores obtained on the family or clinician form are subtracted from the participant form. The larger the difference in scores, the greater the deficits in self-awareness.

the TBI inpatient, outpatient, and community population (Tate, 2010).

Self-Identity	Head Injury Semantic Differential Scale-III (HISDS-III) (Tyerman & Humphrey, 1984)	The HISDS-III includes 18 questions which assess the discrepancy between pre-and post-injury personality attributes (Appendix J). Each question is answered on a 7-point scale situated between two dichotomous adjectives that address personality aspects. While there are three versions of the scale available (past, present, and future), only the past and present scales were utilised. This scale has shown construct validity with the Frankfurt Self-Concept Scale, Rosenberg Self-Esteem inventory, and the Brain Injury Grief Inventory as well as a good internal consistency with Cronbach's $\alpha = .92$ for the present scale and $\alpha = .93$ for the past scale (Carroll & Coetzer, 2011).	The total score from the post-injury scale is subtracted from the total score from the pre-injury scale. Higher scores indicate positive changes, and lower scores indicate negative changes.
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4.2.4 Data analysis

An exploratory method was followed to analyse the qualitative and quantitative data. First, qualitative interview data were transcribed verbatim with personal information replaced with pseudonyms. Data were coded using an inductive content analysis approach, with the software NVivo (Hsieh and Shannon, 2005). As codes were generated, the inductive findings started to align with the four domains of posttraumatic growth: personal strength, growing connections, engaging in new ventures, and greater appreciation of life post-TBI. Hence, posttraumatic growth was identified as a key concept in this study. Second, Posttraumatic Growth Inventory (Appendix K) (Tedeschi & Calhoun, 1996), a commonly used measure for posttraumatic growth, was selected to categorise the participants into two groups using their qualitative data. One group consisted of participants who portrayed higher levels of posttraumatic growth, and the other group included of participants who indicated lower levels of posttraumatic growth. Participants whose qualitative data aligned with the higher scores on the items provided in the Posttraumatic Growth Inventory were catergorised as higher posttraumatic growth (Appendix L). Alternatively, participants who had qualitative data that had minimal or no correspondence with the inventory were identified as portraying lower posttraumatic growth (Appendix L). The categorisation was performed based on researcher RM's subjective scoring of the participant's qualitative data using the items from the posttraumatic growth inventory. Last, the quantitative data were used to characterise the two groups based on the constructs of social participation, self-awareness, and self-identity.

The research team employed two main trustworthiness strategies: researcher reflexivity and the input of multiple researchers in the data analysis process (Morrow, 2005). Each interviewer maintained a reflexive journal, which was used to record the interviewer's experiences and thoughts. Following the

first round of coding by the first author researcher RM, the other interviewers were invited to provide their perspectives and review the codes generated, hence acknowledging the complementary perspectives on the data. Additionally, after researcher RM categorised participants into higher and lower posttraumatic growth groups, author JS provided input and reviewed the groupings.

4.3 Results

Fifteen people with moderate to severe TBI participated in the study (Table 4.2). Two groups were identified, 1) ‘I have changed and every aspect has changed’ described 8 participants who indicated higher degrees of posttraumatic growth and 2) ‘it’s hard everyday and it doesn’t go away’ described 7 participants who conveyed lower degrees of posttraumatic growth.

Mean age of each group was similar (46.3 for higher posttraumatic growth, 53 for lower posttraumatic growth). The sexes in each group were quite different (88% male for higher posttraumatic growth, 57% male for lower posttraumatic growth). Mean age of injury was similar between each group (17 years) as was cause of injury and living environment.

Table 4.2 Participant demographic (N=15)

	Higher posttraumatic growth (n=8)	Lower posttraumatic growth (n=7)
Age, mean (SD)	46.3 (14.3)	53 (10.2)
Male, n (%)	7 (88)	4 (57)
Years since injury (n=8,6), mean (SD)	17 (10)	17 (12.4)
Cause of injury, n (%)		
Motor Vehicle Accidents	5 (63)	4 (50)

Fall	1 (13)	3 (38)
Other	2 (25)	1 (13)
Living Environment, n (%)		
Home with family	3 (38)	1 (13)
Home with care aide	0	1 (13)
Assisted living	2 (25)	3 (38)
Independent	3 (38)	3 (38)
Global functioning score, MPAI-4	48 (14.3)	59.9 (23.8)

Note. 2 participants from the low posttraumatic growth group did not recall the year of their injury, but they estimated 10 and 15 years since their injury.

Descriptions of each group are illustrated below with supplementary quotes as well as descriptive data about the participants' social participation, self-awareness, and self-identity.

I have changed and every aspect has changed (higher posttraumatic growth)

Participants with higher levels of posttraumatic growth described post-injury experiences that led to discovering new opportunities in life, increased appreciation of life, developing personal strength, and positive changes in relationships. These participants had mild to moderate limitations in functioning as per the MPAI-4 (Table 4.2). Quantitative data on social participation, self-awareness, and self-identity are described below along with supporting quotes.

Social participation

Participants within this group had moderate participation as indicated by the IPA scores (Table 4.3). Participants conveyed discovering new possibilities in life, such as exploring different facets of

their abilities, and engaging in more everyday activities. Participant 13 (male, age 54) talked about how his creative side was amplified after his accident, facilitated by the support and resources available to him:

I became wildly creative, wrote my book, and wrote a screenplay, I got into art, I love to go to art classes...really, I didn't have that sense of creative need when I was before my injury and afterwards, this is overtaken, my wife's said how have you done this, like your training license and your book, it's nonstop when I get creating, I can't stop.

Participant 10 (male, age 38) stated that his injury provided him the opportunity for a new start, 'I'm guessing there's some people live life before and have goals. I didn't live life before and now I have goals and do stuff'.

Self-awareness

Participants with higher posttraumatic growth demonstrated fairly intact self-awareness as portrayed by their AQ scores (Table 4.3), indicating small discrepancies between the ratings of the participant and the ratings of the clinicians/family members regarding the participants' recognition of abilities. Participants who displayed higher levels of posttraumatic growth were aware of the changes in their abilities post-injury. Participant 1 (male, age 55) described how the healthcare system, through a conversation with the doctor, helped him understand his post-injury capabilities:

And for about two to three years, it was rough, it became not easier, but it became a better place and time. As time went by the doctors, I had a really good doctor, a neurologist, that was explaining things to me and was really trying to figure things out. With that knowledge and his understanding, it was really easy. And it brought me out of this dark place.

Participant 12 (male, age 59) acknowledged that his life was different post-injury and wanted to obtain a degree to help other individuals: ‘I was doing ok, I was providing and then suddenly nope, I can't do that anymore...My limitations, I knew what I had to do. I had to go to school...and now I want to help people with brain injuries’.

Self-identity

Participants portrayed moderate discrepancies between their pre-and post- injury identities as described by the HISDS-III, indicating a negative change in self-identity (Table 4.3). Participants with higher posttraumatic growth described the efforts taken to rebuild their self-identity. This came through development of personal strength and self-reliance, as some individuals had limited access to professional support, as communicated by participant 1 (male, age 55):

I worked on it by myself...I couldn't afford to go to a counsellor. I've had to do things for myself, I've had to adjust to what's going around me. I knew there were supports and lots of help out there for me, but I had to do this for myself too right.

Additionally, participants conveyed how they persevered when faced with challenges, as indicated by participant 8 (male, age 61) and his battle with depression post-injury: ‘You know how many times I've been to the rodeo? This is not my first rodeo...You gotta get back up. And brush yourself off. You don't hang on to the pain. You gotta pushed through it’. Participant 12 (male, age 59) talked about his children being the purpose behind his perserverance, ‘you got to turn a negative into a positive and I'm not ready to die yet. My boys are counting on me. So, I got to keep on going’.

Some participants who portrayed higher posttraumatic injury highlighted how their self-identity had changed since their injury and there was a positive impact on life because of their injury. For

example, participant 10 (male, age 38) talked about how his behaviour changed which enabled him to be more present for his daughter, ‘I was fully self-indulgent on everyone before and now I just have a kid and it's awesome and I play dad’. Additionally, there was an increase in compassion toward other individuals with disabilities as expressed by participant 15 (female, age 51), ‘I think I'm compassionate and I even recognize that after my accident, that probably because of it, I would have more empathy towards others’.

It's hard everyday and it doesn't go away (lower posttraumatic growth)

Participants in this group conveyed lower levels of posttraumatic growth by indicating an increased sense of frustration when they were unable to resume meaningful activities. Participants also displayed avoidance coping strategies where they refused to talk about their injury and felt alone when confronting challenges. These participants had moderate to severe limitations in functioning as per the MPAI-4 (Table 4.2). Quantitative data on social participation, self-awareness, and self-identity are described below accompanied with explanatory quotes.

Social participation

Participants within this group had lowered levels of participation as depicted by their IPA scores (Table 4.3). Participants expressed their sense of frustration when they felt there were limitations to the opportunities to pursue. An overall sense of restriction was perceived by participants, in part due to their physical but also as a result of the lack of resources in the environment when comparing their pre- and post-injury lives. Participant 3 (female, age 33) recalled:

I'm used to being able to accomplish and achieve the things that I wanted to before. Now, it's like, no I can't do that, or oh I have limitations. So, before it was more about possibility. And now it's more about limitations.

Participants spoke of their distress when their employment was affected. For example, participant 2 (female, age 61) said, 'I'm a moocher. Not paying my own way, I feel inadequate, frustrated because I know what has to be done, how to work... But I can't do it'.

Self-awareness

Participants with lower posttraumatic growth demonstrated low levels of self-awareness, indicated by their AQ scores with larger discrepancy between clinicians/support workers and participants (Table 4.3). This was described through the avoidance coping and denial strategies, in which participants indicated as not wanting to acknowledge their injury. When asked about cognitive changes experienced, participant 7 (male, age 52) said, 'Well, I'll just put it at the back of my head. Just don't even talk about it'. Participant 6 (male, age 53) reflected on the restrictions placed on his driving, even though he felt that there were no changes in his abilities, 'I used to like driving, but they took my driver's license away... you know you can but they don't allow it'.

Self-identity

Participants with lower posttraumatic growth had high discrepancies between pre-and post-injury self-identities, as indicated by the HISDS-III scores, reflecting negative changes in their self-identity (Table 4.3). Participants talked about how the injury affected who they were as a person, such as participant 2 (female, age 61), 'I'm not the same person who I was before the accident. I'm pathetic, I am useless, and I can't do anything by myself much. I'm not independent anymore'. Participants

experienced a transition to feeling more alone when confronting their challenges, as explained by participant 16 (female, age 52), ‘I just feel like I got the weight of the world on my shoulders. You know, and it's just me against the world’. She also felt misunderstood by her friends, as she experienced the different changes from her injury. For example, she said, ‘On the rough days, it's really hard. And it's discouraging. And so I think my friends have noticed...I can tell when they see changes in me. I don't think they always understand that, oh, today's not such a good day.’

Table 4.3 Participants’ scores on outcome measures (N=15)

	Higher posttraumatic growth (n=8), mean (SD)	Lower posttraumatic growth (n=7), mean (SD)
IPA	34 (22)	51.4 (27.6)
AQ*	-2.88 (22.6)	5.5 (23.4)
HISDS-III	-20.63 (21.9)	-31.86 (35.6)

AQ= Awareness Questionnaire; HISDS-III = Head Injury Semantic Differential Scale-III; IPA= Impact of Participation and Autonomy

*AQ was completed for 8 participants with higher PTG and 6 participants with lower PTG

4.4 Discussion

This study found that people with higher posttraumatic growth had moderate levels of participation, relatively intact self-awareness, and experienced more negative change in their identity, in comparison to participants with lower posttraumatic growth.

Participants in the higher and lower posttraumatic growth groups were similar on most demographic data. The ages of both groups were similar, with the higher posttraumatic group having a slightly younger mean age than the lower posttraumatic growth group. A meta-analysis on the development of posttraumatic growth in individuals with life-threatening illnesses, such as cancer, indicated that younger individuals are more likely to show higher post-traumatic growth than older individuals (Sawyer et al., 2010). The meta-analysis postulated that younger individuals may have core beliefs of a fair and just world, however after experiencing a trauma, this could be disrupted. The challenges to their core beliefs may cause individuals to undergo more conscious efforts in order to understand the reasoning of why the trauma happened, and hence facilitate posttraumatic growth by integrating these experiences into their life narrative. There were more males in the higher posttraumatic growth group than the lower posttraumatic growth. This contrasts with previous studies, as females with TBI have been reported to experience more posttraumatic growth than males (Akbar et al., 2016; Vishnevksy et al., 2010). The reasoning behind the higher representation of males in the higher posttraumatic group in this study could be given that there are more males who sustain TBI compared to females, there may be more social support, peer-mentoring programs, and resources available for them (Mollayeva et al., 2018).

All participants in this study had a moderate to severe TBI, however, some participants had a higher severity in their global functioning. Participants with worse global functioning were more represented in the lower posttraumatic growth group. This is consistent with other studies, as the impacts of a more severe injury, such as more deficits in cognitive and physical impairments, may restrict the individual from engaging in processes that facilitate posttraumatic growth such as participation in work and leisure activities, accepting limitations, and forming new positive identities (Powell et al., 2012).

Hence, ensuring that adequate social support and resources are provided can give individuals an opportunity to find new positive ways to engage in life post-injury. However, it has been shown that those with severe brain injuries have higher or similar posttraumatic growth levels compared to those with less severe injuries (Hawley & Joseph, 2008; Powell et al., 2007). This reiterates the notion that high levels of distress and trauma are needed to initiate posttraumatic growth (Grace et al., 2015).

In this study's sample, participants in the higher posttraumatic growth group indicated a greater level of perceived social participation. This finding aligns with other studies that indicate participation in physical, leisure, and vocational activities are indicators of posttraumatic growth (Chun & Lee, 2010; Powell et al., 2012). These activities promote posttraumatic growth through meaning making, finding purpose, and a sense of independence (Kampman et al., 2015). Participants in this study described pursuing new interests after their injury, relating to the posttraumatic growth domain of 'new possibilities'. This could be reflective of the changes in life narratives where individuals develop new perspectives on what they want in life. Additionally, when engaging in newly meaningful activities, individuals with TBI have shown to experience positive emotions (e.g., enjoyment, laughter), recognition of new talents, and building relationships (Chun & Lee, 2008). Strengthening social connections are an instrumental source which has been reported to facilitate posttraumatic growth in individuals with TBI (Powell et al., 2012). This includes the development of relationships with support workers and TBI community groups (Griffin et al., 2022). Building these relationships are an indicator of the posttraumatic growth domain 'relating to others'. Being able to connect with others who have gone through similar challenges are important, as those individuals can share their experiences and provide examples of the positive outcomes that can materialise (Morris et al., 2011).

Self-awareness may be an important component in posttraumatic growth. In our study, participants in the higher posttraumatic growth group reported increased self-awareness, while participants in the lower posttraumatic growth group displayed denial or avoidance coping strategies. The findings from the higher posttraumatic growth group are congruent with the results of a multi-method design study, where an accurate self-assessment of abilities after a TBI was an indicator of higher posttraumatic growth (Allen et al., 2020). Additionally, acceptance of a person's injury, a predictor for posttraumatic growth, can develop from understanding the extent of their capabilities (Allen et al., 2020; Lyon et al., 2021). Participants in the lower posttraumatic growth group in this study expressed denial or avoidance coping strategies and displayed lower self-awareness. While some research indicates the protective nature of denial behaviours contributed to posttraumatic growth (Gangstad et al., 2009), other research indicates the long-term maladaptive aspects of denial behaviours and impaired self-awareness (Ownsworth, 2005). For example, individuals who do not acknowledge the challenges and limitations resulting from a TBI may not be able to reflect and generate the meaning behind their struggles, a critical process in the development of posttraumatic growth (Tedeschi et al., 2018). Additionally, this may contribute to the lack of the posttraumatic growth domain 'appreciation of life', as individuals may report being restricted in activities they feel they should be able to engage in.

Self-identity may have an impact on a person's posttraumatic growth, as shown in this study's findings, as the participants in the lower posttraumatic growth group reported larger discrepancies between their pre-and post-injury identities than the higher posttraumatic growth group. This difference in discrepancies between the two groups could be due to the reports of the participants in the higher posttraumatic group gaining new personal attributes through the strengthening of former roles and the cultivation of new roles. This can be related to the posttraumatic growth domain of 'personal strength'

and ‘new possibilities’. These findings are consistent with the ‘Y-shaped’ model, which states that as the discrepancies in pre-and post-injury identities are resolved, positive adjustment and psychological growth occurs (Gracey et al., 2009). Individuals who show higher posttraumatic growth may view the traumatic event as central to their identity (Boals et al., 2010). This event could become turning point in an individual’s life, with an individual assuming a new role of a survivor.

4.5 Limitations

This study has three main limitations. First, the AQ required a family member or clinician who could address the pre- to post-injury changes, however, not all the participants were in contact with family members or medical professionals who knew them from before the injury. Hence, some participants’ current family members or clinicians were asked to answer the questionnaire based on their knowledge of the participant post-injury. This may have affected the AQ scores obtained. Second, the groupings of participants were based solely on qualitative data and hence may have been inadequately grouped. However, the method of qualitatively grouping participants was guided by the posttraumatic growth domains, as well as the questions in the posttraumatic growth inventory. Finally, as this is a cross-sectional study with a small number of participants in each group, a between group analysis was not included (e.g., effect size). This limits the understanding of how the constructs relate to each other and which factor may be more strongly associated to the development of posttraumatic growth. However, this study provides important first-step data for the design of a longitudinal quantitative investigation of posttraumatic growth development in people with chronic TBI.

4.6 Conclusion

This study explored social participation, self-awareness, and self-identity, in individuals with higher and lower posttraumatic growth after TBI. Findings indicate that individuals with higher posttraumatic growth have greater levels of social participation, more self-awareness, and fewer discrepancies between their pre-and post-injury identities. These findings can facilitate further research and provide a better understanding of posttraumatic growth after TBI. By using the participants' qualitative data to group them, and not through the use of a quantitative data measure such as the Posttraumatic Growth Inventory, it provides a more comprehensive understanding of their experiences of higher and lower posttraumatic growth. Hence, this can extend the use and understanding of the Posttraumatic Growth Inventory and the posttraumatic growth domains.

Chapter 5: Synthesis

This thesis used a qualitative methodology and a sequential explanatory/exploratory mixed-methods design to understand the experiences of life after TBI. The first study followed constructivist grounded theory. Qualitative data were analysed to develop an explanatory model, which provided important insights into the changes of an individual's social participation and self-identity. In the second study, a sequential explanatory/exploratory mixed-methods design was used. This study suggested that individuals with higher levels of posttraumatic growth portrayed moderate levels of social participation, intact self-awareness, and experienced fewer negative changes in self-identity. Individuals with lower levels of posttraumatic growth indicated less social participation, impaired self-awareness, and greater negative changes in self-identity.

The studies had some commonalities and differences in the findings. First, the importance of support was evident in both studies, as participants expressed the positive impact of support from health and social groups in their navigation of life post-injury. This was reported in the first study in the themes 'rebuilding and restarting' and 'embrace it and run with it', as well as in the second study with participants in the higher posttraumatic group. This could indicate that the support is essential for an individual's social participation and self-identity, which in turn can be an indicator for posttraumatic growth. Second, a common factor of personal strength and determination was expressed by participants in the higher posttraumatic group in study two, as well as in the themes 'embrace it and run with it' in study one. The development of this attribute could be a key indicator in helping an individual overcome the challenges they encounter with their TBI. Another commonality could be the low social participation scores in study two, mirrored in the theme 'there's nothing that's the same' in study one, where participants talked about the participatory gaps they experienced. This could show the impact that social

participation has in post-injury life and an individual's posttraumatic growth. There were a few differences in the findings between the two studies, such as the overall self-identity changes. While there were positive self-identity changes perceived in study one, this contrasted with the results of the self-identity measure in study two, which shows participants in both higher and lower posttraumatic growth groups displaying overall negative changes to their self-identity after TBI. This highlights the complexities of self-identity and the comprehensive understanding that is brought by using both qualitative and quantitative findings. Another difference was the two contrasting views adopted in each study, study 1 used a constructivist and person-centered approach while study 2 followed a postpositivist and deficit-based view. This was due to the use of questionnaires as outcome measures in study 2. For example, the AQ scoring scale requires two questionnaire forms to be filled out by the participant as well as a family member or clinician. The bigger the discrepancy between the forms, the more deficits in self-awareness. However, this overlooks the subjective views of the participant about their own abilities. Hence, the extent of the participant's abilities is based on the perspectives of the clinician or their family member, supporting a more ableist view.

5.1 Methodological contributions

This thesis provides two main novel methodological contributions in TBI research: the integrative method of the mixed-methods study and the use of a model to group participants qualitatively.

The second study used a mixed-methods approach, combining an explanatory/exploratory design. While typically mixed-methods designs usually follow either an explanatory or exploratory design (Riley et al, 2020; Rutz Voumard et al., 2021), this study integrated both designs, connecting the

qualitative and quantitative phases in both the data collection and data analysis stages (Appendix C). Data collection followed an explanatory design with quantitative data (questionnaires) informing the qualitative data collection (interview); data analysis followed the exploratory design with qualitative data analysis (coding and categorising) informing the quantitative data analysis (describing and characterising posttraumatic growth) (Appendix C). By using this novel method, insights were gained in the questionnaire session that informed the subsequent interview (e.g., the specific prompts that were used by interviewers). In this way, rapport was built so that participants were more at ease when answering interview questions that might be personal or emotional for them. The sequential design was helpful for data collection with the population of moderate to severe TBI as the data were collected at different times to mitigate potential fatigue and attention problems (Paterson & Stewart, 2002). Additionally, to compensate for potential cognitive difficulties after TBI, participants were given the interview questions prior to the interview, providing extra time for the participants to read and comprehend the questions. Overall, integrating these methods in this particularly novel way, which has not been conducted in prior posttraumatic growth and TBI literature, is suitable when investigating research that may be sensitive to the participants as well as when recruiting populations with more severe impairments.

The second novel methodological contribution of this thesis was to use the Posttraumatic Growth Inventory (Appendix K) in the second study to group participants qualitatively, contributing to the development of the posttraumatic growth theory. In this study, the participants were asked about their experiences of TBI and were not asked to quantify their experiences with the Posttraumatic Growth Inventory. Instead, the inventory was used after data collection and analysis, with codes mapped on the

domains of the interview, in order to group participants. Hence, this method extends the use and understanding of the Posttraumatic Growth Inventory and the theory of posttraumatic growth.

5.2 Theoretical application

Symbolic interactionism has been applied to this thesis as a way to understand how the actions of individuals depend on the meanings they attach to their experiences from social interactions (Blumer, 1969). In the first study, in the theme ‘there’s nothing that’s the same’, participants attached a meaning of frustration to the invisible nature of their injury due to interactions with other individuals who minimised their experience of a brain injury. This may have been due to the different experiences and meanings that were related to their life after injury. In the theme, of the first study, ‘rebuilding and restarting’, participants described assigning a meaning of confidence in navigating post-injury life due to the positive encounters they experienced with the healthcare and brain injury community. Alternatively, participants who indicated they had a lack of support from their clinicians or families, described feelings of helplessness and vulnerability when adjusting to their post-injury life. Through the symbolic interactionism theory, it is understood individuals act according to the meanings gained from social interactions. Therefore, it is essential for the community and clinicians to provide a supportive environment for individuals with TBI, as this can help provide meanings of security and confidence in facing post-injury life.

Identity theory was used in this thesis to explore the changes in pre- and post-injury self (Stryker, 1968). In study one, participants described developing personal attributes such as determination and empathy after their TBI. Positive and negative changes to roles were expressed as well, with participants talking about the strengthening of familial roles or the impact of not being able to return to their

vocational roles post-injury. In study two, all the participants in the higher posttraumatic growth group described experiencing positive new personal attributes or roles, relating to the posttraumatic domains, such as becoming stronger, more compassionate, appreciative, and pursuing new interests. Identity theory provides insight as to how pre-injury attributes and roles may have changed since sustaining a TBI. Non verification was highlighted in the theme ‘there’s nothing that’s the same’, in which participants reflected about the discrepancy they experienced, between how others perceived them and the way they perceived themselves. Participants talked about the expectations placed on them to behave in the same manner they used to before their injury. Identity theory helps in understanding the enactment of roles that are consistent with the internal identity standards of an individual with TBI.

The Dynamic Comprehensive Model of Awareness and the biopsychosocial model of self-awareness informed the understanding of impaired self-awareness in participants in the lower posttraumatic growth group in study two (Ownsworth et al., 2006; Toglia & Kirk, 2000). These participants had a lower-self-awareness score and expressed denial and avoidance coping strategies. Both models contribute to the understanding of how deficits in self-awareness in the psychological domain and inabilities to self-detect errors or self-evaluate everyday performances can affect an individual in engaging in the domains of posttraumatic growth.

The models used in this thesis can be related to each other. For example, after sustaining their TBI, individuals with TBI may have impairments in error detection or self-regulation (Dynamic Comprehensive Model of Awareness), which leads to problems when engaging in prior roles or social activities (social participation). As a result, individuals may perceive a discrepancy between their pre- and post-injury selves (identity theory), in terms of roles or social activities (social participation). By

attaching a meaning of denial (symbolic interactionism), individuals may use strategies such as avoidant coping or minimisation (biopsychosocial model of self-awareness).

5.3 Empirical contributions

This thesis provides two empirical contributions. First, an explanatory model was developed that contributed important insights into the changes of social participation and self-identity in life after TBI. This expands previous literature linking social participation and self-identity, such as changes in occupational identity after TBI (Bryson-Campbell et al., 2016) which aligns to the qualitative data's sub-theme of 'experiencing participatory gaps', as well as the engagement in activities to consolidate positive new identities (Gracey et al., 2009), as stated in the sub-theme of this thesis' qualitative data, 'turning points'. Additionally, the explanatory model can be further developed to inform clinical rehabilitative practices by obtaining clinician perspectives. As this model emphasises the challenges individuals face post-TBI and the importance of healthcare support, clinicians could develop a framework that addresses both social participation and positive self-identity changes. Second, the sequential explanatory/exploratory mixed-methods study added to the understanding of how social participation, self-awareness, and self-identity relates to the Posttraumatic Growth Inventory. While previous studies have identified the importance of participation to promote posttraumatic growth (Grace et al., 2015; Powell et al., 2012), literature that focuses on the changes in self-awareness and self-identity in the TBI population is relatively limited (Grace et al., 2015; Silva et al., 2011). Hence, this thesis provides data on the characterisation of higher and lower posttraumatic growth in terms of all three constructs of social participation, self-awareness, and self-identity.

5.4 Limitations

There were limitations in both studies of this thesis. First, data collection was conducted during the COVID-19 pandemic, so the effects of the pandemic (e.g., socially isolating, transition to virtual activities) may have influenced the participants' responses about their engagement in different activities, their social life, and the roles they occupy. To reduce this issue, participants were reminded that the interview and questionnaires inquired about all experiences, particularly those prior to the COVID-19 pandemic. Second, participants with moderate to severe TBI were recruited, with all participants reporting cognitive or physical impairments. Some participants had greater degrees of impairments that affected their ability to understand and answer some questions in the interview and the questionnaires. These participants were intentionally included in this study as they represent the TBI population who have more complex impairments and their experiences are essential in providing a wider perspective of life after TBI. For some of these participants, support workers were involved to add further explanations and help participants answer questions. However, one participant was not able to understand quantitative questionnaires and was thus not included in the second study. Third, participants in this study were recruited from community settings with an average of 17 years since the injury. These findings may not be representative of participants with a shorter timeframe since their injury, as participants in these studies had years to experience daily challenges and differences after their TBI. However, these findings provide unique insights into the population with chronic TBI; clinicians, support workers, and researchers may gain further understanding of this population.

5.5 Personal reflection

Throughout the completion of my thesis, I was given the opportunity to learn and understand the experiences of life with TBI directly from this population. While I had previously volunteered with individuals with disabilities, I had little experience as an interviewer, especially with individuals with TBI. Overtime, I have grown from a novice interviewer into an individual who can build rapport and trust with participants while eliciting insightful conversations. During the data collection stage, I was continuously discovering the “dos and don’ts” on how to effectively interview individuals with moderate to severe TBI, which helped me build my confidence as an interviewer. In research prior to my masters training, I worked mainly with quantitative data, and as such, I had embodied a postpositivist approach. However, as I explored the methodology of constructivist grounded theory for this thesis, I embraced the constructivist perspective. I recognise that knowledge is subjective, and my history and past experiences impact the way I make sense of the world. As such, my existing values have influenced the formation of this study, from the development of the research question to the analysis of data and writing of the manuscript. I have expanded my knowledge about the many facets of qualitative research, and the need for this type of research in the academic world. While my master’s journey was not always linear in the making, I am grateful for and appreciate the growth I have been able to achieve in both my academic and personal life throughout this degree. I am conscious that there is still a long way to go in the development of my research skills, but I know I have taken the necessary steps in order to continue this journey in research.

5.6 Future Research

The thesis highlights potential areas of future research. First, there is limited conceptual understanding of the relationship of self-awareness and self-identity. Further research may explore the relationship theoretically and empirically. Additionally, the thesis suggested that high social participation and self-awareness may be characteristics of higher posttraumatic growth, however experimental studies are needed to understand the relationships among these constructs. As these constructs are modifiable factors, further research on individualised programs and services to support improvement may be beneficial. An optimal timeframe can be identified to apply interventions targeting a person's social participation, self-awareness, and construction of positive self-identity.

5.7 Conclusion

This thesis provides insights about life with TBI by examining the challenges encountered, the navigation and responses of post-injury life, and the subsequent growth that may take place overtime. Using constructivist grounded theory and a sequential explanatory/exploratory mixed-methods design, a comprehensive understanding of life after TBI was illustrated.

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Appendices

Appendix A : Constructivist grounded theory data analysis procedure

As data collection and analysis were concurrent processes, analysis took place after the first few interviews and the software NVivo was used to aid the coding process. In-vivo codes were used to interpret the data, with codes in the form of actual phrases used by the participant and considered as ‘symbolic markers’ of the participants’ speech (Charmaz, 2006). Gerunds (words ending with ‘-ing’) were used to capture the sense of action in the data.

The constructivist grounded theory analysis process was followed (Figure A.1). Throughout data analysis, constant comparisons took place, comparing data from different interviews throughout the three coding stages: initial coding, focused coding, and theoretical coding. In this study, the first stage of initial coding was achieved through coding line by line. This allowed the researcher to look at the data more critically and reduce the possibility of not detecting a potential category. In the next stage of focused coding, large amounts of initial codes were compared. Prior initial codes were then selected, or a new code determined, which interpreted the context of the compared codes. Theoretical coding occurred next and formed themes that explained the relationships between the codes formed in the previous coding stage. Throughout the coding stages, memos were developed which aimed to capture the essence or meanings about the codes.

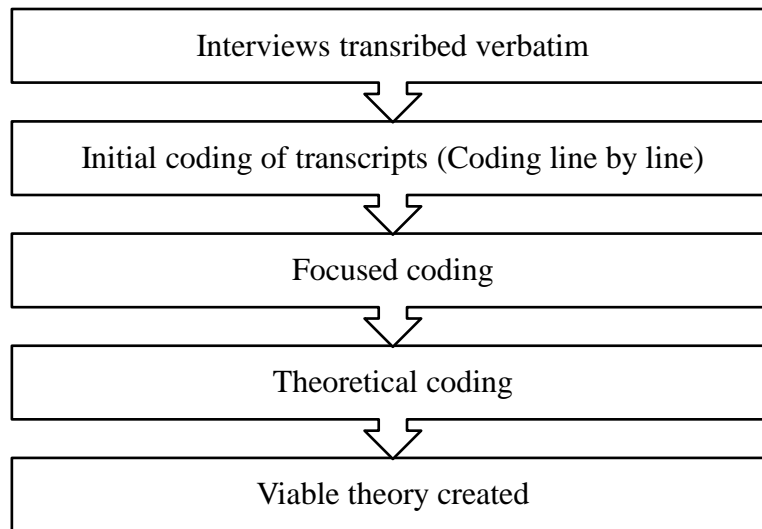


Figure A.1 Constructivist grounded theory analysis process

Appendix B : COREQ checklist

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	24
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	24
Occupation	3	What was their occupation at the time of the study?	24
Gender	4	Was the researcher male or female?	24
Experience and training	5	What experience or training did the researcher have?	24
<i>Relationship with Participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	24
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	24
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	24
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	23
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	23
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	23
Sample size	12	How many participants were in the study?	26
Non-participation	13	How many people refused to participate or dropped out? Reasons?	24
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	24
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	24
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	27
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	24
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	24

Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	25
Field notes	20	Were field notes made during and/or after the inter view or focus group?	25
Duration	21	What was the duration of the inter views or focus group?	24
Data saturation	22	Was data saturation discussed?	25
Transcripts returned	23	Were transcripts returned to participants for comment and/or corrections?	25

Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	26
Description of the coding tree	25	Did authors provide a description of the coding tree?	29
Derivation of themes	26	Were themes identified in advance or derived from the data?	26
Software	27	What software, if applicable, was used to manage the data?	25
Participant checking	28	Did participants provide feedback on the findings?	25
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	29-39
Data and findings consistent	30	Was there consistency between the data presented and the findings?	29-39
Clarity of major themes	31	Were major themes clearly presented in the findings?	29-39
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	29-39

Appendix C : Mixed-methods design and rationale

A sequential explanatory/exploratory design (Figure C.1) was applied. This enabled the merging of the explanatory design used for data collection (where the quantitative data were collected to inform the qualitative data) and the exploratory design used for data analysis (where the qualitative data were analysed to inform the quantitative data) (Zhang et al., 2013). The sequential design was chosen for three main reasons. First, reviewing the responses obtained in the questionnaire session allowed the development of planned prompts for the interview session. Second, incorporating a break between the two data collection sessions was essential to alleviate the participants' fatigue levels. Last, the first session of quantitative data collection provided an opportunity to build rapport between the researcher and the participant before engaging in the interview.

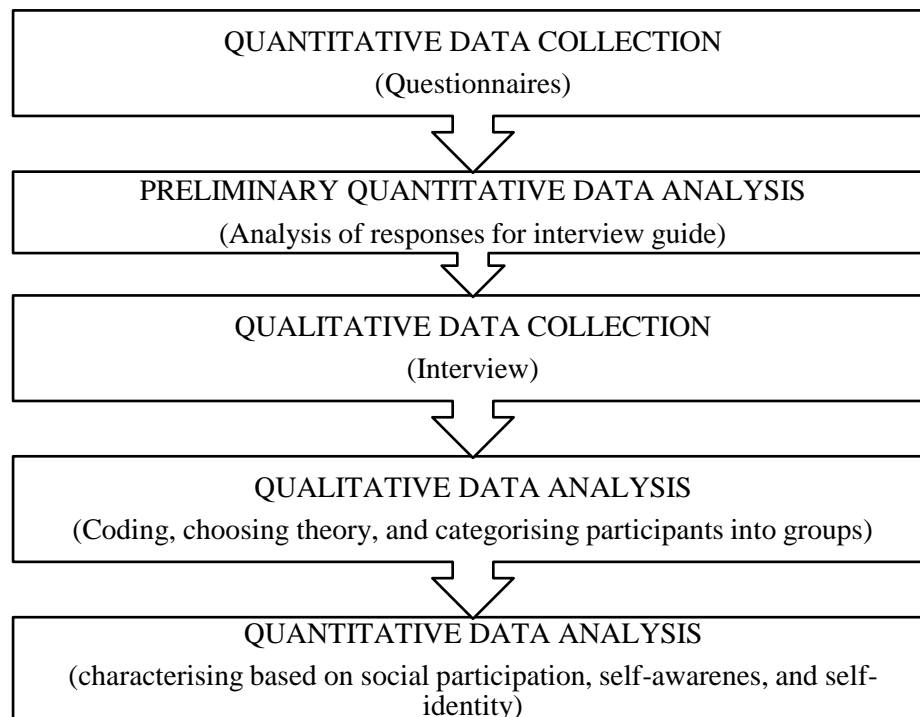


Figure C.1 Sequential explanatory/exploratory mixed-methods design

Appendix D : GRAMMS checklist

Guideline	Section: page
Describe the justification for using a mixed methods approach to the research question	Appendix C, 109
Describe the design in terms of the purpose, priority and sequence of methods	51
Describe each method in terms of sampling, data collection and analysis	51-57
Describe where integration has occurred, how it has occurred and who has participated in it	51-57
Describe any limitation of one method associated with the present of the other method	67
Describe any insights gained from mixing or integrating methods	Appendix C, 68

Appendix E : Interview guide

General Questions

1. Tell me about your brain injury.
2. What has your journey of rehabilitation been like?

Prompt: Are you currently receiving rehabilitation?

Social participation Questions

1. What does a typical day for you look like?
2. How if at all has your daily activities changed since your injury?

*Prompt: What do you do now, what did you do before the injury? How has your injury
i. changed your daily activities?*

Self-Awareness Questions

1. How would you describe your abilities after the injury?
2. What, if any, changes have you noticed after your injury?
3. What, if any, limitations did you experience after your injury?

*Prompt: Was there a particular time in your recovery that you realised you had these
limitations? If so, can you describe this?*

4. What, if any, improvements have you noticed to those limitations?

Self-Identity Questions

1. How would you describe yourself?

*Prompt: Who are you, what are you like, what makes you 'you'? Any examples of how
you think about yourself, your personality. What roles are important to you?*

2. How if at all has your brain injury changed the way you think about yourself?

Prompt: What have you learnt about yourself? What have you discovered about yourself since your injury?

3. What do you think is important for students, clinicians, and the community to know about the experience of having a brain injury?

Appendix F : Demographic questionnaire

1. Date of Birth: dd/mm/yyyy
2. Year of Injury: dd/mm/yyyy
3. Cause of Injury:
 - A. Motor Vehicle Accident
 - B. Fall
 - C. Sports Injury
 - D. Other _____
4. Living environment:
 - A. Family
 - B. Care aide
 - C. Assisted Living Community
 - D. Other _____

Appendix G : MPAI-4

Below each item, circle the number that best describes the level at which the person being evaluated experiences problems. Mark the greatest level of problem that is appropriate. Problems that interfere rarely with daily or valued activities, that is, less than 5% of the time, should be considered not to interfere. Write comments about specific items at the end of the rating scale. *For Items 1-20, please use the rating scale below.*

0 None	1 Mild problem but does <u>not</u> interfere with activities; may use assistive device or medication	2 Mild problem; interferes with activities 5-24% of the time	3 Moderate problem; interferes with activities 25-75% of the time	4 Severe problem; interferes with activities more than 75% of the time
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Part A. Abilities					
1. Mobility: Problems walking or moving; balance problems that interfere with moving about	0	1	2	3	4
2. Use of hands: Impaired strength or coordination in one or both hands	0	1	2	3	4
3. Vision: Problems seeing; double vision; eye, brain, or nerve injuries that interfere with seeing	0	1	2	3	4
4. *Audition: Problems hearing; ringing in the ears	0	1	2	3	4
5. Dizziness: Feeling unsteady, dizzy, light-headed	0	1	2	3	4
6. Motor speech: Abnormal clearness or rate of speech; stuttering	0	1	2	3	4
7A. Verbal communication: Problems expressing or understanding language	0	1	2	3	4
7B. Nonverbal communication: Restricted or unusual gestures or facial expressions; talking too much or not enough; missing nonverbal cues from others	0	1	2	3	4
8. Attention/Concentration: Problems ignoring distractions, shifting attention, keeping more than one thing in mind at a time	0	1	2	3	4
9. Memory: Problems learning and recalling new information	0	1	2	3	4
10. Fund of Information: Problems remembering information learned in school or on the job; difficulty remembering information about self and family from years ago	0	1	2	3	4
11. Novel problem-solving: Problems thinking up solutions or picking the best solution to new problems	0	1	2	3	4
12. Visuospatial abilities: Problems drawing, assembling things, route-finding, being visually aware on both the left and right sides	0	1	2	3	4

Part B. Adjustment					
13. Anxiety: Tense, nervous, fearful, phobias, nightmares, flashbacks of stressful events	0	1	2	3	4
14. Depression: Sad, blue, hopeless, poor appetite, poor sleep, worry, self-criticism	0	1	2	3	4
15. Irritability, anger, aggression: Verbal or physical expressions of anger	0	1	2	3	4
16. *Pain and headache: Verbal and nonverbal expressions of pain; activities limited by pain	0	1	2	3	4
17. Fatigue: Feeling tired; lack of energy; tiring easily	0	1	2	3	4
18. Sensitivity to mild symptoms: Focusing on thinking, physical or emotional problems attributed to brain injury; rate only how concern or worry about these symptoms affects current functioning over and above the effects of the symptoms themselves	0	1	2	3	4
19. Inappropriate social interaction: Acting childish, silly, rude, behavior not fitting for time and place	0	1	2	3	4
20. Impaired self-awareness: Lack of recognition of personal limitations and disabilities and how they interfere with everyday activities and work or school	0	1	2	3	4

21. Family/significant relationships: Interactions with close others; describe stress within the family or those closest to the person with brain injury; “family functioning” means cooperating to accomplish those tasks that need to be done to keep the household

0 Normal stress within family or other close network of relationships	1 Mild stress that does <u>not</u> interfere with family functioning	2 Mild stress that interferes with family functioning 5-24% of the time	3 Moderate stress that interferes with family functioning 25-75% of the time	4 Severe stress that interferes with family functioning more than 75% of the time
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Part C. Participation

22. Initiation: Problems getting started on activities without prompting

0 None	1 Mild problem but does <u>not</u> interfere with activities; may use assistive device or medication	2 Mild problem; interferes with activities 5-24% of the time	3 Moderate problem; interferes with activities 25-75% of the time	4 Severe problem; interferes with activities more than 75% of the time
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23. Social contact with friends, work associates, and other people who are not family, significant others, or professionals

0 Normal involvement with others	1 Mild difficulty in social situations but maintains normal involvement with others	2 Mildly limited involvement with others (75-95% of normal interaction for age)	3 Moderately limited involvement with others (25-74% of normal interaction for age)	4 No or rare involvement with others (less than 25% of normal interaction for age)
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24. Leisure and recreational activities

0 Normal participation in leisure activities for age	1 Mild difficulty in these activities but maintains normal participation	2 Mildly limited participation (75-95% of normal participation for age)	3 Moderately limited participation (25-74% of normal participation for age)	4 No or rare participation (less than 25% of normal participation for age)
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25. Self-care: Eating, dressing, bathing, hygiene

0 Independent completion of self-care activities	1 Mild difficulty, occasional omissions or mildly slowed completion of self-care; may use assistive device or require occasional prompting	2 Requires a little assistance or supervision from others (5-24% of the time) including frequent prompting	3 Requires moderate assistance or supervision from others (25-75% of the time)	4 Requires extensive assistance or supervision from others (more than 75% of the time)
--	--	--	--	--

26. Residence: Responsibilities of independent living and homemaking (such as, meal preparation, home repairs and maintenance, personal health maintenance beyond basic hygiene including medication management) but not including managing money (see #29)

0 Independent; living without supervision or concern from others	1 Living without supervision but others have concerns about safety or managing responsibilities	2 Requires a little assistance or supervision from others (5-24% of the time)	3 Requires moderate assistance or supervision from others (25-75% of the time)	4 Requires extensive assistance or supervision from others (more than 75% of the time)
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27. *Transportation

0 Independent in all modes of transportation including independent ability to operate a personal motor vehicle	1 Independent in all modes of transportation, but others have concerns about safety	2 Requires a little assistance or supervision from others (5-24% of the time); cannot drive	3 Requires moderate assistance or supervision from others (25-75% of the time); cannot drive	4 Requires extensive assistance or supervision from others (more than 75% of the time); cannot drive
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28A. *Paid Employment: Rate either item 28A or 28B to reflect the primary desired social role. Do not rate both. Rate 28A if the primary social role is paid employment. If another social role is primary, rate only 28B. For both 28A and 28B, “support” means special help from another person with responsibilities (such as, a job coach or shadow, tutor, helper) or reduced responsibilities. Modifications to the physical environment that facilitate employment are not considered as support.

0 Full-time (more than 30 hrs/wk) without support	1 Part-time (3 to 30 hrs/wk) without support	2 Full-time or part-time with support	3 Sheltered work	4 Unemployed; employed less than 3 hours per week
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28B. *Other employment: Involved in constructive, role-appropriate activity other than paid employment. Check only one to indicate primary desired social role: Childrearing/care-giving, Homemaker, no childrearing or care-giving, Student Volunteer, Retired (Check retired only if over age 60; if unemployed, retired as disabled and under age 60, indicate “Unemployed” for item 28A.

0 Full-time (more than 30 hrs/wk) without support; full-time course load for students	1 Part-time (3 to 30 hrs/wk) without support	2 Full-time or part-time with support	3 Activities in a supervised environment other than a sheltered workshop	4 Inactive; involved in role-appropriate activities less than 3 hours per week
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29. Managing money and finances: Shopping, keeping a check book or other bank account, managing personal income and investments; if independent with small purchases but not able to manage larger personal finances or investments, rate 3 or 4.

0 Independent, manages small purchases and personal finances without supervision or concern from others	1 Manages money independently but others have concerns about larger financial decisions	2 Requires a little help or supervision (5-24% of the time) with large finances; independent with small purchases	3 Requires moderate help or supervision (25-75% of the time) with large finances; some help with small purchases	4 Requires extensive help or supervision (more than 75% of the time) with large finances; frequent help with small purchases
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Appendix H : IPA

Mobility: getting around where and when you want (with or without aids or assistance)

First we would like to ask some questions about your mobility: your chances of getting around where and when you want. We are interested in whether you can decide yourself where and when you want to go somewhere

1a. My chances of getting around in my house *where* I want to are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

1b. My chances of getting around in my house *when* I want to are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

1c. My chances of visiting relatives and friends *when* I want to are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

1d. My chances of going on the sort of trips and holidays I want to are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

1e. If your health or your disability affect your chances of getting around where and when you want, to what extent does this cause you problems?

No problems	<input type="checkbox"/>	0
Minor problems	<input type="checkbox"/>	1
Major problems	<input type="checkbox"/>	2

Space for further comments on your mobility (optional):

Self care (with or without aids or assistance)

The next questions concern your personal care. When answering these questions, think about whether you can decide yourself when and how you want things done, even when you are assisted by someone else.

2a. My chances of getting washed and dressed *the way* I wish are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

2b. My chances of getting washed and dressed *when* I want to are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

2c. My chances of getting up and going to bed *when* I want to are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

2d. My chances of going to the toilet *when* I wish and need to are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

2e. My chances of eating and drinking *when* I want to are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

2f. If your health or your disability affect your self care, to what extent does this cause you problems?

No problems	<input type="checkbox"/>	0
Minor problems	<input type="checkbox"/>	1
Major problems	<input type="checkbox"/>	2

Space for further comments on your self-care (optional):

Activities in and around the house (with or without aids or assistance)

The next questions are about the tasks and responsibilities you have at home, and the way your health or disability influences these. We would like to know whether you can decide when and how something is done, even if you don't do it yourself.

3a. My chances of contributing to looking after my home *the way* I want to are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

3b. My chances of getting light tasks done around the house (e.g. making tea or coffee), either by myself or by others, *the way* I want them done are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

3c. My chances of getting heavy tasks done around the house (e.g. cleaning), either by myself or by others, *the way* I want them done are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

3d. My chances of getting housework done, either by myself or by others, *when I want* them done are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

3e. My chances of getting minor repairs and maintenance work done in my house and garden, either by myself or by others, *the way I want* them done are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

3f. My chances of fulfilling my role at home *as I would like* are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

3f. If your health or your disability affect your activities in and around your home, to what extent does this cause you problems?

No problems	<input type="checkbox"/>	0
Minor problems	<input type="checkbox"/>	1
Major problems	<input type="checkbox"/>	2

Space for further comments on activities in and around the house (optional):

Looking after your money (with or without aids or assistance)

The next questions deal with the effect of your health or disability on the control you have over spending your own money.

4a. My chances of choosing how I spend my own money are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

4f. If your health or your disability affect the opportunities you have over spending your own money, to what extent does this cause you problems?

No problems	<input type="checkbox"/>	0
Minor problems	<input type="checkbox"/>	1
Major problems	<input type="checkbox"/>	2

Space for further comments on your control over your financial situation (optional):

Leisure (with or without aids or assistance)

The next questions are about whether you can decide how you use your leisure time.

5a..My chances of using leisure time *the way* I want to are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

5b. If your health or your disability affect how you use your leisure time, to what extent does this cause you problems?

- | | | |
|----------------|--------------------------|---|
| No problems | <input type="checkbox"/> | 0 |
| Minor problems | <input type="checkbox"/> | 1 |
| Major problems | <input type="checkbox"/> | 2 |

Space for further comments on your leisure time (optional):

Social life and relationships

The next questions are about the quality and frequency of your social relationships. We would like to know whether your health problems or disabilities affect your relationships.

6a. My chances of talking to people close to me on equal terms are

- | | | |
|-----------|--------------------------|---|
| Very Good | <input type="checkbox"/> | 0 |
| Good | <input type="checkbox"/> | 1 |
| Fair | <input type="checkbox"/> | 2 |
| Poor | <input type="checkbox"/> | 3 |
| Very Poor | <input type="checkbox"/> | 4 |

6b. The quality of my relationships with people who are close to me

- | | | |
|-----------|--------------------------|---|
| Very Good | <input type="checkbox"/> | 0 |
| Good | <input type="checkbox"/> | 1 |
| Fair | <input type="checkbox"/> | 2 |
| Poor | <input type="checkbox"/> | 3 |
| Very Poor | <input type="checkbox"/> | 4 |

6c. The respect I receive from people who are close to me is

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

6d. My relationships with acquaintances are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

6e. The respect I receive from acquaintances is.

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

6f. My chances of having an intimate relationship are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

6g. My chances of seeing people as often as I want are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

6h. If your health or your disability affect your social life and relationships, to what extent does this cause you problems?

- | | | |
|----------------|--------------------------|---|
| No problems | <input type="checkbox"/> | 0 |
| Minor problems | <input type="checkbox"/> | 1 |
| Major problems | <input type="checkbox"/> | 2 |

Space for further comments on your social life and relationships (optional):

Helping and supporting other people (with or without aids or assistance)

The next questions are about your opportunities to help and support other people such as family, neighbours, friends or members of a club.

7a. My chances of helping or supporting people in any way are,

- | | | |
|-----------|--------------------------|---|
| Very Good | <input type="checkbox"/> | 0 |
| Good | <input type="checkbox"/> | 1 |
| Fair | <input type="checkbox"/> | 2 |
| Poor | <input type="checkbox"/> | 3 |
| Very Poor | <input type="checkbox"/> | 4 |

7b. If your health problems or disability affect your opportunities to help other people, to what extent does this cause you problems?

- | | | |
|----------------|--------------------------|---|
| No problems | <input type="checkbox"/> | 0 |
| Minor problems | <input type="checkbox"/> | 1 |
| Major problems | <input type="checkbox"/> | 2 |

Space for further comments on helping and supporting other people (optional)

Paid or voluntary work (with or without aids or assistance)

The next questions are about paid or voluntary work. We would like to know what your chances are of finding or keeping a paid or voluntary job, even if this does not seem relevant to you at present.

8a. My chances of getting or keeping a paid or voluntary job that I would like to do are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

Please only answer questions 8b to 8f if you do have some form of paid or voluntary work, even if you are not working at the moment due to illness. Otherwise please proceed to question 9.

8b. My chances of doing my paid or voluntary work *the way* I want to are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

8c. My contacts with other people at my paid or voluntary work are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

8d. My chances of achieving or keeping the position that I want, in my paid or voluntary work are,

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

8e. My chances of getting different paid or voluntary work are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

8f. If your health or your disability affect your paid or voluntary work, to what extent does this cause you problems?

No problems	<input type="checkbox"/>	0
Minor problems	<input type="checkbox"/>	1
Major problems	<input type="checkbox"/>	2

Space for further comments on paid or voluntary work (optional):

Education and Training (with or without aids or assistance)

The next questions are about the way your health condition or disability affect your chances of getting the education or training you want. If you do not wish to have further education or to follow a course, you may tick the box 'not applicable'.

9a. My chances of getting the education or training I want are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4
Not applicable	<input type="checkbox"/>	

9b. If your health problems or disability affect your opportunities in education or training, to what extent does this cause you problems?

No problems	<input type="checkbox"/>	0
Minor problems	<input type="checkbox"/>	1
Major problems	<input type="checkbox"/>	2

Space for further explanation regarding your chances of education or training (optional):

In this questionnaire you have answered questions that deal with the effect of your health or disability on your personal and social life. Considering all things, could you say whether, in general, you have sufficient control over your own life?

10. My chances of living life the way I want to are

Very Good	<input type="checkbox"/>	0
Good	<input type="checkbox"/>	1
Fair	<input type="checkbox"/>	2
Poor	<input type="checkbox"/>	3
Very Poor	<input type="checkbox"/>	4

Space for further comment about the control you have over your life (optional):

Appendix I : Awareness questionnaire

I.1 Participant form

	1	2	3	4	5
	much worse	a little worse	about the same	a little better	much better
___	1.	How good is your ability to live independently now as compared to before your injury?			
___	2.	How good is your ability to manage your money now as compared to before your injury?			
___	3.	How well do you get along with people now as compared to before your injury?			
___	4.	How well can you do on tests that measure thinking and memory skills now as compared to before your injury?			
___	5.	How well can you do the things you want to do in life now as compared to before your injury?			
___	6.	How well are you able to see now as compared to before your injury?			
___	7.	How well can you hear now as compared to before your injury?			
___	8.	How well can you move your arms and legs now as compared to before your injury?			
___	9.	How good is your coordination now as compared to before your injury?			
___	10.	How good are you at keeping up with the time and date and where you are now as compared to before your injury?			
___	11.	How well can you concentrate now as compared to before your injury?			
___	12.	How well can you express your thoughts to others now as compared to before your injury?			
___	13.	How good is your memory for recent events now as compared to before your injury?			

- ____ 14. How good are you at planning things now as compared to before your injury?
- ____ 15. How well organized are you now as compared to before your injury?
- ____ 16. How well can you keep your feelings in control now as compared to before your injury?
- ____ 17. How well adjusted emotionally are you now as compared to before your injury?

I.2 Family form

	1	2	3	4	5
	much worse	a little worse	about the same	a little better	much better
___	1.	How good is the participant's ability to live independently now as compared to before injury?			
___	2.	How good is the participant's ability to manage your money now as compared to before injury?			
___	3.	How well does the participant get along with people now as compared to before their injury?			
___	4.	How well can the participant do on tests that measure thinking and memory skills now compared to before injury?			
___	5.	How well can the participant do the things you want to do in life now as compared to before injury?			
___	6.	How well is the participant able to see now as compared to before injury?			
___	7.	How well can the participant hear now as compared to before injury?			
___	8.	How well can the participant move their arms and legs now as compared to before injury?			
___	9.	How good is the participant's coordination now as compared to before injury?			
___	10.	How good is the participant at keeping up with the time and date and where they are now as compared to before injury?			
___	11.	How well can the participant concentrate now as compared to before injury?			
___	12.	How well can the participant express their thoughts to others now as compared to before injury?			
___	13.	How good is the participant's memory for recent events now as compared to before injury?			

- _____ 14. How good is the participant at planning things now as compared to before injury?
- _____ 15. How well organized is the participant now as compared to before injury?
- _____ 16. How well can the participant keep their feelings in control now as compared to before injury?
- _____ 17. How well adjusted emotionally is the participant now as compared to before injury?

I.3 Clinician form

1	2	3	4	5
much worse	a little worse	about the same	a little better	much better

- _____ 1. How good is the participant's ability to live independently now as compared to before injury?
- _____ 2. How good is the participant's ability to manage your money now as compared to before injury?
- _____ 3. How well does the participant get along with people now as compared to before their injury?
- _____ 4. How well can the participant do on tests that measure thinking and memory skills now compared to before injury?
- _____ 5. How well can the participant do the things you want to do in life now as compared to before injury?
- _____ 6. How well is the participant able to see now as compared to before injury?
- _____ 7. How well can the participant hear now as compared to before injury?
- _____ 8. How well can the participant move their arms and legs now as compared to before injury?
- _____ 9. How good is the participant's coordination now as compared to before injury?
- _____ 10. How good is the participant at keeping up with the time and date and where they are now as compared to before injury?
- _____ 11. How well can the participant concentrate now as compared to before injury?
- _____ 12. How well can the participant express their thoughts to others now as compared to before injury?
- _____ 13. How good is the participant's memory for recent events now as compared to before injury?

- ____ 14. How good is the participant at planning things now as compared to before injury?
- ____ 15. How well organized is the participant now as compared to before injury?
- ____ 16. How well can the participant keep their feelings in control now as compared to before injury?
- ____ 17. How well adjusted emotionally is the participant now as compared to before injury?

1	2	3	4	5
completely	severely	moderately	minimally	not at all

- ____ 18. To what extent is the client's accurate self-awareness impaired by their injury.

Appendix J : HISDS III Pre/post injury scale

Choose a point on this scale closest to the term you identify with pre-injury (past) and post-injury (present).

	1	2	3	4	5	6	7	
Bored								Interested
Unhappy								Happy
In control								Helpless
Worried								Relaxed
Satisfied								Dissatisfied
Despondent								Hopeful
Self-confident								Lacks confidence
Unstable (emotionally)								Stable (emotionally)
Attractive (as a person)								Unattractive (as a person)
Of value								Worthless
Aggressive								Unaggressive
Calm								Irritable
Capable								Incapable
Dependent								Independent
Inactive								Active
Withdrawn								Talkative
Friendly								Unfriendly
Patient								Impatient

Appendix K : Posttraumatic Growth Inventory

Indicate for each of the statements below the degree to which this change occurred in your life as a result of the crisis/disaster, using the following scale.

0 = I did not experience this change as a result of my crisis.

1 = I experienced this change to a very small degree as a result of my crisis.

2 = I experienced this change to a small degree as a result of my crisis.

3 = I experienced this change to a moderate degree as a result of my crisis.

4 = I experienced this change to a great degree as a result of my crisis.

5 = I experienced this change to a very great degree as a result of my crisis.

Possible Areas of Growth and Change	0	1	2	3	4	5
1. I changed my priorities about what is important in life.						
2. I have a greater appreciation for the value of my own life.						
3. I developed new interests.						
4. I have a greater feeling of self-reliance.						
5. I have a better understanding of spiritual matters.						
6. I more clearly see that I can count on people in times of trouble.						
7. I established a new path for my life.						
8. I have a greater sense of closeness with others.						
9. I am more willing to express my emotions.						
10. I know better that I can handle difficulties.						
11. I am able to do better things with my life.						
12. I am better able to accept the way things work out.						
13. I can better appreciate each day.						
14. New opportunities are available which wouldn't have been otherwise.						
15. I have more compassion for others.						
16. I put more effort into my relationships.						
17. I am more likely to try to change things which need changing.						
18. I have a stronger religious faith.						
19. I discovered that I'm stronger than I thought I was.						
20. I learned a great deal about how wonderful people are.						
21. I better accept needing others.						

The Post Traumatic Growth Inventory (PTGI) is scored by adding all the responses. Individual factors are scored by adding responses to items on each factor. Factors are indicated by the Roman numerals after each item below. Items to which factors belong are not listed on the form administered to clients.

PTGI Factors

Factor I: Relating to Others

Factor II: New Possibilities

Factor III: Personal Strength

Factor IV: Spiritual Change

Factor V: Appreciation of Life

1. I changed my priorities about what is important in life. (V)
2. I have a greater appreciation for the value of my own life. (V)
3. I developed new interests. (II)
4. I have a greater feeling of self-reliance. (III)
5. I have a better understanding of spiritual matters. (IV)
6. I more clearly see that I can count on people in times of trouble. (I)
7. I established a new path for my life. (II)
8. I have a greater sense of closeness with others. (I)
9. I am more willing to express my emotions. (I)
10. I know better that I can handle difficulties. (III)
11. I am able to do better things with my life. (II)
12. I am better able to accept the way things work out. (III)
13. I can better appreciate each day. (V)
14. New opportunities are available which wouldn't have been otherwise. (II)
15. I have more compassion for others. (I)
16. I put more effort into my relationships. (I)
17. I am more likely to try to change things which need changing. (II)
18. I have a stronger religious faith. (IV)
19. I discovered that I'm stronger than I thought I was. (III)
20. I learned a great deal about how wonderful people are. (I)
21. I better accept needing others. (I)

Appendix L : Sample of participant categorisation for posttraumatic growth

Posttraumatic Growth Inventory Domains	Higher posttraumatic group (n=8)	Lower posttraumatic group (n=7)
Appreciation of life	This car accident I have no recollection of it. But in a mere amount of seconds, my life was gone. So you've got to really appreciate the simple things. And take your time and enjoy the beautiful surroundings and your family and just enjoy. (P13)	I used to like driving, but they took my driver's license away...As I said before, you take everything for granted. And it's all taken away from you. (P6)
Relating to others	I think I'm compassionate and I even recognize that after my accident, that probably because of it, I would have more empathy towards others. (P15)	But it just feels like I'm always I just feel like I got the weight of the world on my shoulders. You know, and it's and it's just me against the world. (P16)
Personal strength	I'm way much stronger than I was. When I was in the hospital, there was a lot of negativity...I just smiled and said, sure thank you I appreciate that and then just not going to let that happen to me. Having that mindset is a big part of how I am today, the recovery I've been through. (P14)	I'm not the same person who I was before the accident. I'm pathetic, I am useless, and I can't do anything by myself much. (P2)
New possibilities	And because of the accident... there was a big adjustment there from not having a job to having a different job in my life and that was looking after my children right...So that was the biggest push. If I couldn't have this, then I was going to raise my kids the best that I can. (P1)	I'm used to being able to accomplish and achieve the things that I wanted to before. Now, it's like, no I can't do that, or oh I have limitations. So, before it was more about possibility. And now it's more about limitations. (P3)