“Who am I if my Brain Has Changed?”: Changes to Self-Identity after Severe Traumatic Brain Injury and the Relationship to Neurocognitive, Psychological and Social/Occupational Factors

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Traumatic brain injury (TBI) is a sudden, unexpected neurological event that can change an individual’s life course. Changes to self-identity or self-discrepancy between one’s pre-injury and post-injury selves is commonly reported. However, the mechanisms that underlie these subjectively experienced alterations after TBI are poorly understood. Comprised of four main studies, the broad objective of this thesis was to advance understanding of the impact of severe TBI on self-identity and the neurocognitive, psychological, and social/occupational factors associated with self-identity changes.

Study 1 consists of a systematic review of research on the impact of TBI on self-identity and the associations between self-identity change and neurocognitive and psychosocial functioning. Searches of four databases revealed fifteen studies that quantitatively examined changes in self-identity after TBI in adults using measures of self-concept, personality, or self-discrepancy. Despite methodological differences, these studies consistently identified evidence of negative changes to self-concept. However, stability in self-concept and positive changes in personal attributes were also reported. Negative changes in self-concept were associated with greater emotional distress in three of the studies. Key areas for further investigation related to understanding how neurocognitive functioning, psychological characteristics, and occupational engagement contribute to self-identity changes after TBI.

Guided by the findings of the systematic review, studies 2 to 4 used a validated measure of self-discrepancy (Head Injury Semantic Differential Scale [HISD] III) to examine the relationship between self-discrepancy and neurocognitive functions (study 2), psychological characteristics (study 3), and social/occupational factors (study 4). The participants were 59 adults with severe TBI (72.9% male, $M$ age $= 36.50$ years, $SD$
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= 12.54) recruited as part of a broader cognitive rehabilitation study. Participants were administered neuropsychological tests and questionnaires in the home.

Study 2 aimed to examine associations between self-discrepancy and measures of attention, memory, executive function, and self-awareness (i.e., Hopkins Verbal Learning Test, Trail Making Test, Zoo Map, Digit Span, Modified Stroop, Controlled Oral Word Association Test & Awareness Questionnaire). The results revealed that more negative self-discrepancy was significantly associated with better neurocognitive functions. Specifically, more negative self-discrepancy was associated with greater self-awareness and better performance on tests of immediate memory, working memory, and verbal fluency. Self-awareness was the only neurocognitive factor significantly and uniquely related to self-discrepancy, and was found to partially mediate the relationship between immediate memory and self-discrepancy. Overall, the findings highlighted that memory and self-awareness are central to updating self-identity after severe TBI.

Study 3 aimed to examine the relationship between personality characteristics (optimism and defensiveness), cognitive appraisals (threat appraisals, rumination, reflection, and perceived coping resources) and self-discrepancy. These constructs were assessed using the Life Orientation Test, Marlow Crowne Social Desirability Scale – short form, Appraisal of Threat and Avoidance Questionnaire, Reflection and Rumination Questionnaire, Coping Resource Questionnaire and HISD-III. Correlation analyses revealed that higher levels of optimism, defensiveness, and perceived coping resources were significantly associated with more positive self-discrepancy, whereas higher threat appraisals and rumination were significantly associated with more negative self-discrepancy. After controlling for personality characteristics, cognitive appraisals significantly accounted for self-discrepancy. Rumination significantly mediated the relationship between optimism and self-discrepancy. Overall, these findings suggest that
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individuals with certain personality characteristics and associated cognitive appraisals are more likely to experience negative self-discrepancy after severe TBI.

Study 4 examined the nature of occupational engagement after severe TBI, and the relationship between re-engagement in desired occupations, mood, psychosocial functioning and self-discrepancy. Participants with TBI completed the Occupational Gaps Questionnaire, Depression, Anxiety, and Stress Scales–21 and HISD-III and their relatives completed the Sydney Psychosocial Reintegration Scale. The results revealed that greater occupational re-engagement gaps were related to higher levels of anxiety and poorer psychosocial functioning. A mediation analysis revealed that re-engagement gaps were indirectly related to self-discrepancy through an association with anxiety. These results suggest that anxiety related to gaps in occupational functioning may contribute to negative comparisons between pre-injury and post-injury self.

Overall, this thesis advances understanding of changes to self-identity after TBI. Specifically, study 1 demonstrated that negative self-discrepancy is most commonly experienced and highlighted the need to further understand the role of neurocognitive and psychosocial factors. Studies 2 to 4 showed that individuals with better memory function, lower optimism, and greater occupational gaps (indirectly) are more likely to experience negative self-discrepancy. These associations were mediated by self-awareness, rumination, and anxiety symptoms (respectively), which represent potential targets for intervention to facilitate positive identity change after TBI. Collectively, the findings highlight the importance of integrated rehabilitation approaches that simultaneously address neurocognitive impairments, psychological adjustment, and activity re-engagement after severe TBI.
Statement of Originality

This work has not previously been submitted for a degree or diploma in any university.
To the best of my knowledge and belief, the thesis contains no material previously
published or written by another person except where due reference is made in the thesis
itself.

__________________________
Elizabeth Beadle
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<td>ABI</td>
<td>Acquired Brain Injury</td>
</tr>
<tr>
<td>ASSEI</td>
<td>Adult Source of Self-concept Inventory</td>
</tr>
<tr>
<td>ATAQ</td>
<td>Appraisal of Threat and Avoidance Questionnaire</td>
</tr>
<tr>
<td>AQ</td>
<td>Awareness Questionnaire</td>
</tr>
<tr>
<td>CAM</td>
<td>Cognitive Awareness Model</td>
</tr>
<tr>
<td>COWAT</td>
<td>Controlled Oral Word Association Test</td>
</tr>
<tr>
<td>CRQ</td>
<td>Coping Resources Questionnaire</td>
</tr>
<tr>
<td>DASS</td>
<td>Depression Anxiety and Stress Scale</td>
</tr>
<tr>
<td>GCS</td>
<td>Glasgow Coma Scale</td>
</tr>
<tr>
<td>HISD</td>
<td>Head Injury Semantic Differential Scale</td>
</tr>
<tr>
<td>HVLT</td>
<td>Hopkins Verbal Learning Test</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning</td>
</tr>
<tr>
<td>IQ</td>
<td>Intelligence Quotient</td>
</tr>
<tr>
<td>LOT</td>
<td>Life Orientation Test</td>
</tr>
<tr>
<td>MCSDS</td>
<td>Marlowe-Crowne Social Desirability Scale</td>
</tr>
<tr>
<td>MBA</td>
<td>Motor Bike Accident</td>
</tr>
<tr>
<td>MST</td>
<td>Modified Stroop Test</td>
</tr>
<tr>
<td>MVA</td>
<td>Motor Vehicle Accident</td>
</tr>
<tr>
<td>NEO-FFI</td>
<td>Neuroticism-Extraversion-Openness – Five-Factor Inventory</td>
</tr>
<tr>
<td>NEO-PI-R</td>
<td>Neuroticism-Extraversion-Openness – Personality Inventory - Revised</td>
</tr>
<tr>
<td>OGQ</td>
<td>Occupational Gaps Questionnaire</td>
</tr>
<tr>
<td>PTA</td>
<td>Post Traumatic Amnesia</td>
</tr>
<tr>
<td>RRQ</td>
<td>Reflection and Rumination Questionnaire</td>
</tr>
<tr>
<td>RSES</td>
<td>Rosenberg Self-Esteem Scale</td>
</tr>
<tr>
<td>SAC</td>
<td>Selves Adjective Checklist</td>
</tr>
</tbody>
</table>
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SEI  Self-Esteem Inventory
SI   Selves Interview
STROBE  Strengthening the Reporting of Observational Studies in Epidemiology
TBI  Traumatic Brain Injury
TSCS:2  Tennessee Self Concept Scale: Second Edition
TMT  Trail Making Test
WAIS  Wechsler Adult Intelligence Scale
WHO  World Health Organisation
WTAR  Wechsler Test of Adult Reading
Acknowledgments

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I would also like to thank my fellow HDR students met through the CRE, Griffith University, the Centre for Functioning and Health Research (CFHAR), and the Twittersphere. You are all the metaphorical glue binding this thesis, thank you for helping me maintain stability through words of support, coffee, long lunches, and companionship during the long work days and nights.

Lastly and by absolutely no means least, to my abandoned family and friends. I am looking forward to spending more time at the farm now Ma and Pa. Mark, I look forward to eating out at restaurants with you without my laptop being present. Friends, thank you for your patience and your reminders on what life is all about.
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Published Works by the Author and Acknowledgement of Published Papers

Included in this Thesis

Section 9.1 of the Griffith University Code for the Responsible Conduct of Research (“Criteria for Authorship”), in accordance with Section 5 of the Australian Code for the Responsible Conduct of Research, states:

To be named as an author, a researcher must have made a substantial scholarly contribution to the creative or scholarly work that constitutes the research output, and be able to take public responsibility for at least that part of the work they contributed. Attribution of authorship depends to some extent on the discipline and publisher policies, but in all cases, authorship must be based on substantial contributions in a combination of one or more of:

- conception and design of the research project
- analysis and interpretation of research data
- drafting or making significant parts of the creative or scholarly work or critically revising it so as to contribute significantly to the final output.

Section 9.3 of the Griffith University Code (“Responsibilities of Researchers”), in accordance with Section 5 of the Australian Code, states:

Researchers are expected to:

- Offer authorship to all people, including research trainees, who meet the criteria for authorship listed above, but only those people.
- accept or decline offers of authorship promptly in writing.
- Include in the list of authors only those who have accepted authorship
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- Appoint one author to be the executive author to record authorship and manage correspondence about the work with the publisher and other interested parties.

- Acknowledge all those who have contributed to the research, facilities or materials but who do not qualify as authors, such as research assistants, technical staff, and advisors on cultural or community knowledge. Obtain written consent to name individuals.

Included in this thesis are papers in Chapters 3, 5, 6, and 7 which are co-authored with other researchers. My contribution to each co-authored paper is outlined at the front of the relevant chapter. The bibliographic details/status for these papers including all authors, are:


Chapter 1: Introduction to Thesis and Background

Traumatic brain injury (TBI) is a major health condition that affects many Australians. In 2008, 1,493 Australians sustained a moderate TBI and approximately 1,000 sustained a severe TBI (Access Economics, 2009). This equates to 7.0 and 4.7 cases per 100,000 persons for moderate and severe TBI respectively.

The personal, social and economic costs associated with TBI are substantial. While survivors may have few physical signs of their injury, it can result in permanent changes in an individual’s life. Financially, the cost of TBI in Australia was estimated to be around $8.6 billion in 2008 (Access Economics, 2009). The lifetime cost per person has been estimated at $4.8 million for severe TBI. Most individuals who sustain a severe TBI will develop persisting neurocognitive and behavioural impairments following the injury. These impairments impact the individual’s ability to re-engage in previous activities and roles, including work, self-care, and social and community activities. Given the high incidence and costs of TBI and associated long-term functional consequences, there is a need to implement effective rehabilitation interventions to optimise quality of life and return to daily living activities.

The duration and nature of rehabilitation after TBI varies and is dependent on multiple factors including the physical, neurocognitive and psychosocial sequelae and social contextual factors. Traditionally, for more severe TBI, functional outcomes in the acute and early post-acute stages (i.e., during inpatient and outpatient rehabilitation) are well researched (Levin, Shum, & Chan, 2014; Ponsford, Sloan, & Snow, 2013). Rehabilitation outcomes in the more long-term phase of recovery have received less focus in research. In particular, there has been less focus on the impact of TBI on psychological adjustment and sense of self, and intervention approaches for supporting individuals to maintain or reconstruct a positive self-identity after TBI. A more advanced understanding of the impact of TBI on self-identity, or the unique and
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collective characteristics we perceive as our own, may inform early intervention approaches in rehabilitation.

Self-identity changes after TBI have received increased empirical attention over the past decade (Gracey & Ownsworth, 2008; Ownsworth, 2014; Ownsworth & Haslam, 2016; Wilson, 2011). Qualitative studies in particular have highlighted the multiple impacts of TBI on sense of self and the challenges of reconstructing one’s self-identity (Bryson-Campbell, Shaw, O’Brien, Holmes, & Magalhaes, 2013; Levack, Kayes, & Fadyl, 2010). Theoretical perspectives highlight the close links between self-identity and our emotions, memories, goal achievement, occupational engagement, community roles, and broader psychological wellbeing (e.g., Baumeister, 1987; Dweck, 1999; Erikson, 1968; Gagne & Deci, 2005; Higgins, Bond, Klein, & Strauman, 1986). After TBI, unfavourable comparisons between “pre-injury self” and “post-injury self”, often referred to as “self-discrepancy”, have been associated with psychological distress (Tyerman & Humphrey, 1984). Historically, self-discrepancy or changes to self-identity have been considered a core area of focus within holistic models of neuropsychological rehabilitation following brain injury (Ben-Yishay, 2000; Gracey & Ownsworth, 2008; Ylvisaker & Feeney, 2000).

Despite the recognised impact of TBI on self-perceptions, there is a paucity of research examining the impact of TBI on self-identity and the factors that contribute to or underlie self-discrepancy. The current dissertation seeks to address such gaps in the literature by investigating self-identity change after TBI and the relationship to neurocognitive, psychological, social and occupational factors. Self-identity change is operationalised by the discrepancy between ratings of one’s pre-injury self-concept and current (post-injury) self-concept. Broadly guided by a biological, psychological, and social/occupational framework, the aims of each study are summarized in Table 1.1.
Table 1.1

*Summary of the Aims of each Study and Factors Examined in Relation to Self-Discrepancy*

<table>
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<td>Neurocognitive functions and self-discrepancy</td>
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<tr>
<td>Neurocognitive Functions</td>
<td>- Identify studies examining impact of TBI on self-identity (self-concept/discrepancy) and biopsychosocial correlates</td>
<td>- Examine the relationship between self-discrepancy and measures of attention, memory, language, executive function, and self-awareness</td>
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<td>Psychological factors and self-discrepancy</td>
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<td>Memory</td>
<td>- Appraise methodology, synthesise findings, and identify gaps in literature to guide thesis, future research</td>
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<td>- Examine the relationship between personality characteristics, cognitive appraisals, and self-discrepancy</td>
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<td>Psychological factors and self-discrepancy</td>
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<td>Optimism</td>
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<td>- Examine the relationship between personality characteristics, cognitive appraisals, and self-discrepancy</td>
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<td>Occupation gaps (re-engagement)</td>
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<td>Occupational gaps and self-discrepancy</td>
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<td>Psychosocial functioning (living skills, work/leisure, relationships)</td>
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<td>- Examine the nature of occupational gaps</td>
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<td>Mood (depression, anxiety &amp; stress)</td>
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<td>- Investigate associations between occupational re-engagement, mood, psychosocial functioning and self-discrepancy</td>
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**Chapters and Aims of the Thesis**

This thesis is comprised of eight chapters: a brief introduction to the thesis (Chapter 1), general introduction to thesis and background (Chapter 2), a systematic review (Chapter 3), thesis methodology (Chapter 4), three empirical studies involving primary data collection (Chapters 5–7), and general discussion (Chapter 8). Three chapters (Chapters 3, 5, and 6) have been published, and one is currently under review (Chapter 7). For consistency, each chapter is formatted in accordance with the Publication Manual of the American Psychiatric Association Sixth edition (2009).

**Chapter 2: General Introduction to Thesis and Background**

Chapter 2 provides a general introduction to the key thesis concepts. This includes information on TBI such as definition, neuropathology and common sequelae. Further, the construct of self-identity is defined and conceptualized using theories relevant to understanding changes to self-identity after injury. This chapter also provides the rationale for investigating neurocognitive, psychological, and social/occupational factors that are potentially related to self-identity change after TBI.

**Chapter 3: The impact of TBI on self-identity: A systematic review of the evidence for self-concept changes (Study 1)**

Chapter 3 comprises a systematic review published in the *Journal of Head Trauma Rehabilitation* that aims to examine the evidence for self-identity change after TBI (Beadle, Ownsworth, Fleming, & Shum, 2016). This review appraised quantitative studies that either examined pre-post injury self-discrepancy or compared current levels of self-concept between people with TBI and matched controls (i.e., healthy controls and/or orthopaedic/trauma controls). A secondary aim was to investigate neurocognitive and psychosocial factors related to self-identity change. The findings of the review highlighted key gaps in the literature related to understanding of changes to self-identity after TBI. As relevant to the scope of this thesis, key areas for further investigation
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included 1) identifying how neurocognitive function influences changes to self-identity; 2) examining the role of psychological characteristics in self-identity changes; and 3) determining the impact of re-engagement in occupations on self-identity changes after TBI.

Chapter 4: Thesis Methodology

Chapter 4 outlines the methodology used for primary data collection relevant to chapters 5 – 7 of the thesis. As chapters 5 – 7 are presented in their journal manuscript format, and given different reporting requirements for different journals, this chapter provides a description of the entire thesis protocol. Specifically, it describes the eligibility criteria, participant characteristics, measures, procedure for recruitment and data collection, and the screening of data.

Chapter 5: The relationship between neurocognitive function and self-discrepancy after severe traumatic brain injury (Study 2)

Chapter 5 consists of an empirical study published in Journal of Head Trauma Rehabilitation (Beadle, Ownsworth, Fleming, & Shum, 2017). To understand how neurocognitive functions influence changes in self-identity, the key aim of chapter 5 was to investigate the relationship between self-discrepancy and measures of attention, memory, executive function, and self-awareness.

Chapter 6: Personality characteristics and cognitive appraisals associated with self-discrepancy after severe traumatic brain injury (Study 3)

Chapter 6 is comprised of an empirical paper that is currently in press in the journal Neuropsychological Rehabilitation (Beadle, Ownsworth, Fleming, & Shum, in press). The primary aims of study 3 were to examine the relationship between personality characteristics (optimism and defensiveness), cognitive appraisals (threat appraisals, rumination, reflection, and perceived coping resources) and self-discrepancy.
Chapter 7: The nature of occupational gaps and relationship with mood, psychosocial functioning and self-discrepancy after severe TBI (Study 4)

Chapter 7 presents the final empirical study which is currently under review. Study 4 aims to examine the nature of occupational gaps after severe TBI, and the relationship between re-engagement in desired occupations, mood, psychosocial functioning and self-discrepancy. Although mood is typically conceptualised as a psychological factor, the relationship between mood and self-discrepancy was investigated in this study instead of study 3 due to an interest in understanding the relationship between occupational re-engagement and mood.

Chapter 8: General thesis discussion

Chapter 8 synthesises the key findings of each study of the thesis and outlines the clinical implications arising from each study and the integrated findings. The methodological considerations and future research directions are also discussed.
Chapter 2: General Introduction to Thesis and Background

Definition of traumatic brain injury

Traumatic brain injury (TBI) refers to “an alteration in brain function, or other evidence of brain pathology, caused by an external force” (Menon, Schwab, Wright, & Maas, 2010, p. 1637). This could occur through rapid acceleration and deceleration, penetration, impact, or blast waves (Maas, Stocchetti, & Bullock, 2008). The severity of TBI varies broadly, from concussion with relatively temporary effects to persistent vegetative states. The leading causes of TBI in Australia include transport accidents, falls, assaults, collisions with objects, and water related accidents (Australian Institute of Health and Welfare, 2008).

This thesis focuses on individuals who have sustained a severe or very severe TBI. Severity is commonly classified using the Glasgow Coma Scale (GCS; Teasdale & Jennet, 1974). The GCS grades a patient’s level of consciousness, based on eye opening, motor response and verbal response. These indicators are scored on a 15-point scale, whereby a score of 3 to 8 constitutes severe TBI, 9 to 12 is moderate, and 13 and above is mild (Jennet, 1998; Saatman et al., 2008). Length of post-traumatic amnesia (PTA) is another leading index of TBI severity which refers to the state of confusion and rapid forgetting that occurs immediately after a TBI. It is characterized by disorientation and new learning deficits (Ponsford et al., 2013). Length of PTA after TBI is commonly assessed using validated scales such as the Westmead PTA Scale (Marosszeky, Ryan, Shores, Batchelor, & Marosszeky, 1997). A duration of PTA of less than 24 hours is considered a mild TBI; 1 – 7 days equates to a moderate injury; >1 – 4 weeks represents a severe injury; and over 4 weeks indicates a very severe injury (Arlinghaus, Shoaib, & Trevor, 2005; Ponsford et al., 2013). Both GCS and PTA duration are universally accepted indices of severity after TBI (Lezak, Howieson,
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Loring, Hannay, & Fischer, 2004), and were used to characterize injury severity in this thesis.

Neuropathology of severe TBI

The neuropathological consequences of severe TBI are generally classified as follows: a) focal brain damage due to a contact injury, resulting in contusion, laceration, and intracranial hemorrhage; and b) diffuse brain damage due to an acceleration/deceleration injury, resulting in widespread shearing, tearing, and lesioning in white matter tracts (Werner & Engelhard, 2007). Damage to the frontal and temporal lobes are common consequences of severe TBI as these regions are particularly vulnerable to diffuse axonal injury as well as focal damage. Such immediate consequences are termed the primary injury, and further complications can evolve over time, referred to as the secondary injury. Secondary injury is caused by numerous factors including loss of oxygen, swelling of the brain, and increased intracranial pressure. Further, mechanical changes from the injury have metabolic consequences, ultimately resulting in excitotoxic injury cascades which can have disproportionate effects on certain brain regions, including the hippocampus (Raghupathi, Graham, & McIntosh, 2000).

Recovery during the first weeks of injury is believed to signify early spontaneous physiological restoration of damaged pathways, such that neural pathways regenerate and resume some functioning (Werner & Engelhard, 2007). Other theories suggest that the neural pathways are reorganised or substituted around the damaged area, which assists in re-establishing functioning. Ongoing long-term recovery is hypothesised to be experience-dependent or occur through enriching environmental stimulation and engagement in meaningful activities (Ponsford et al., 2013). Thus, acute treatment of severe TBI usually focuses on stabilization of the initial insult to prevent further complications, while long-term rehabilitation involves activities to aid
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restoration of function or compensatory strategies to support re-engagement in meaningful activities.

The process of recovering after a severe TBI is highly complex and outcomes are difficult to predict. Research suggests that different domains (e.g., physical versus cognitive versus emotional/behavioural) recover at variable rates and to different degrees (Ponsford et al., 2013). It has been suggested that the greatest degree of recovery occurs within the first three to six months post-injury, although experience-dependent recovery facilitated by engagement in meaningful life experiences can occur over several years. Lack of improvement in functioning or functional decline over time can arise from maladaptive coping (e.g., activity avoidance) and associated psychological distress (Ownsworth, 2014).

The resulting physical and neurobehavioural sequelae following severe TBI are well documented (e.g., Levin et al., 2014; Maas et al., 2008; Ponsford et al., 2013). Common physical consequences include motor impairments, headaches, dizziness, sensory changes (e.g., changes to vision, hearing and smell), and sleep disorders. Self-awareness of physical changes typically develops earlier than self-awareness of changes to cognition and behaviour (Hart, Sherer, Whyte, Polansky, & Novack, 2004; Ownsworth et al., 2007). While such physical changes may impact individual’s capacity to independently perform day-to-day activities, longitudinal studies highlight that persisting cognitive and behavioural impairments have more significant impact on long-term psychosocial outcomes after TBI (Ponsford et al., 2013). The following sections briefly outline common neurocognitive and behavioural changes after TBI and their effect on rehabilitation and psychosocial outcomes. A more in-depth discussion on self-identity change after TBI will follow.
Neurocognitive and behavioural sequelae of severe TBI

The neurocognitive and behavioural effects of TBI and recovery patterns are highly variable (Lezak et al., 2004; Ponsford et al., 2013). Within the context of this thesis, the term “neurocognitive” refers to cognitive functions and the associated structures and processes of the brain (e.g., injury severity, lesion location, time since injury). These functional consequences are largely dependent on the site and mechanisms of injury. Generally speaking, given the high incidence of focal damage to the frontal and temporal lobes and diffuse axonal injury, deficits in attention, processing speed, memory, emotion regulation, and executive functioning are most common (Brown & Nell, 1992; Canty, Shum, Levin, & Chan, 2014; Huang, Shum, Chan, & Canty, 2014; Olver, Ponsford, & Curran, 1996; Wang, Chan, & Shum, 2014). Executive functioning deficits have been of particular focus in the literature and encompass a broad range of higher order neurocognitive functions that often have long-term social and psychological consequences. One of the most commonly reported concerns by the rehabilitation team and caregivers is lack of awareness of changes to self and abilities, which is often conceptualized as a metacognitive impairment (Fleming & Ownsworth, 2006; Prigatano, 2005; Sherer, Hart, & Nick, 2003). Other executive functions disrupted after severe TBI include planning and problem solving, reasoning, working memory, initiation, flexibility, and response inhibition (Busch, McBride, Curtiss, & Vanderploeg, 2005; Olver et al., 1996; Ponsford, Olver, & Curran, 1995). Social cognition and communication deficits are also frequently reported, which relate to emotion perception, perspective-taking and higher-order language functions such as verbal fluency and reasoning, and social discourse (Chapman & Cook, 2014; Snow, 2013). Discourse problems can include excessive talking, poor turn taking skills, and tangential conversation (Snow, Douglas, & Ponsford, 1998).
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Changes to behaviour and personality are common following TBI and are often considered the greatest source of stress for individuals with TBI and their support networks. For example, reduced behavioural control can lead to socially inappropriate reactions such as swearing, over-familiarity, or overly sexualized behaviour (McDonald, Rushby, Kelly, & Sousa, 2014; Olver et al., 1996). Ego-centrism, or self-centeredness, can contribute to insensitivity to the needs of others and a failure to see other people’s points of view (McDonald & Flanagan, 2004; Ponsford, Olver, & Curran, 1995).

Changes to emotion regulation and personality are frequently linked to orbito-frontal and fronto-limbic damage after TBI, and include disorders of control such as emotional lability, reduced anger control, and inability to learn from consequences (Grafman et al., 1996; Stuss & Benson, 1986). Disorders of drive on the other hand are associated with dorsolateral prefrontal lesions and characterized by reduced initiation, apathy, loss of interest, lethargy, and lack of emotional reactivity (Chan, Shum, Touloupoulo, & Chen, 2008; Stuss & Benson, 1986; Tate, 1999). Fatigue is also commonly reported as a more general consequence of TBI, although the causal mechanisms are poorly understood (Dikmen, Machamer, Powell, & Temkin, 2003; Ponsford, Schonberger, & Rajaratnam, 2015).

The psychosocial impact of neurocognitive and behavioural changes

The above-mentioned changes typically impact on the person’s engagement and progress in rehabilitation as well as resumption of premorbid occupations and social roles. For example, attention difficulties and excessive fatigue may reduce the individual’s ability to focus in therapy for extended periods of time, while memory deficits often affect retention of strategies learnt in therapy (Lezak et al., 2004; Ponsford et al., 2013). Changes to emotion and behaviour regulation can lead to difficulties in establishing and maintaining relationships, leading to social isolation and loss of opportunities to experience intimacy and social connection (Oddy, Coughlan, Tyerman,
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& Jenkins, 1985; Olver et al., 1996; Tate, Broe, Cameron, Hodgkinson, & Soo, 2005).
Lack of self-awareness can reduce motivation to engage in rehabilitation and pose
safety concerns regarding participation in daily activities (e.g., cooking, crossing roads).
Such changes can contribute to concern and frustration for caregivers and rehabilitation
professionals who are often required to provide a high level of supervision and support.

Individuals with severe TBI face many barriers to re-engaging in their previous
activities and lifestyle. However, there is significant variability in long-term
participation outcomes after severe TBI. For example, an Australian study on
reintegration outcomes after brain injury found that most individuals (89%) achieved
some level of independence in the home and community in the first 6 months after
discharge (Nalder et al., 2012). However, activities requiring high-level cognitive
functions, such as return to work and return to driving were less commonly achieved
(Fleming & Strong, 1999; Nalder et al., 2012). Family relationships and broader social
networks are also commonly affected after TBI, with socialisation often becoming
restricted to family members who provide long-term care and support (Ponsford &
Schonberger, 2010). Relationship strain and breakdown is common (Nalder et al.,
2012), with rates of 21% to 49% found to experience separation or divorce at 5-8 years
post-injury (Ponsford, 2007; Wood & Yurdakul, 1997).

Psychological problems including reduced self-esteem, grief, depression and
anxiety can arise from the loss of social roles and valued activities (Cooper-Evans,
Alderman, Knight, & Oddy, 2008; Goodinson, Ponsford, Johnston, & Grant, 2009;
Rogers & Read, 2007; Rosenthal, Christensen, & Ross, 1998; Williams & Evans, 2003).
In turn, psychological distress can impede functional recovery and progress in
rehabilitation, and adversely affect individuals’ quality of life (Jorge & Robinson, 2003;
Rosenthal et al., 1998). Studies have identified that 42-53% of individuals with TBI
experience a depressive disorder in the first year after injury (Bombardier et al., 2010;
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Gould, Ponsford, Johnson, & Schonberger, 2011; Whelan-Goodinson, Ponsford, Johnston, & Grant, 2009). While less research has investigated rates of anxiety after TBI, a prospective study found that 44% of individuals experienced an anxiety disorder over the first 12 month post injury (Gould et al., 2011).

Overall, the neurocognitive and behavioural changes after TBI and their psychosocial consequences have been well documented in the literature. What remains poorly understood is the impact of TBI and the associated neurocognitive and psychosocial consequences on self-identity or sense of self. The following sections review relevant background literature on the key topic of this thesis: changes to self-identity after TBI.

**Definition and conceptualisation of self-identity**

To understand how self-identity can change, it is important to understand what the concept of self-identity encompasses. Self-identity, a term often used interchangeably with sense of self and self-concept, is a complex personal construction. Historically, William James (1890) conceptualized the self as partially subjective (the “I”) and partially objective (the “me”), with the latter involving an interplay of social circumstances, material possessions, spirituality, and sense of one’s own continuity. Within the context of this thesis, self-identity is defined as the collective characteristics we perceive as our own, which endure over time and are continuously under construction (Ownsworth, 2014). It is the subjective, cognitive appraisal of “self” within one’s environmental context.

While the construct is nebulous, efforts have been made to operationalise self-identity for measurement (Leary & Tangney, 2012). In the developmental psychology literature, self-identity is typically inferred from self-report measures of self-concept and self-esteem (Harter, 2012; Marsh, 1989). Self-concept refers to the overarching thoughts and feelings a person has about him or herself, while self-esteem provides an
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evaluative component or judgments about one’s own worth or value (Rosenberg, 1965). It is also important to distinguish self-identity and its measurement from self-awareness, or accuracy of self-appraisal after brain injury. A person’s self-identity is entirely subjective and cannot be verified or contested by others, whereas external judgements are made about a person’s self-awareness, based on comparisons between his or her self-ratings and a presumably more objective standard such as a significant other’s ratings (Sherer, Bergloff, Boake, High, & Levin, 1998). Self-identity is also distinguishable from group-identity, such that group-identity refers to group expression and affiliation, while self-identity refers to personal conceptualisation and expression. Nonetheless, self-identity is considered intrinsically linked to one’s group memberships (e.g., age, gender, family, culture, work, leisure and other social groups). Social identity perspectives argue that an individual’s sense of who they are and what they stand for is closely tied to or derived from their social group memberships (Tajfel, 1979).

Developmental accounts propose that self-concept is hierarchical, and both unitary and multidimensional in nature with global and domain specific components (Harter, 2012; Marsh, Byrne, & Shavelson, 1992). Specifically, lower-level self-representations (e.g., situation specific appraisals) influence domain-specific areas (e.g., physical, cognitive, social), which are subjectively weighted in their importance according to personal values and contribute to higher level self-representations or global self-concept. While lower-level self-perceptions can be altered by situational influences (e.g., feedback), research suggests that global self-concept is relatively stable across the lifespan (Markus & Kunda, 1986; Orth, Trzesniewski, & Robins, 2010; Trzesniewski, Donnellan, & Robins, 2003). This degree of stability is similar to that observed for personality traits. Indeed, while not referred to as measures of self-concept per se, personality measures have also been used to examine self-perceived psychological characteristics (Lannoo, de Deyne, Colardyn, de Soete, & Jannes, 1997). One
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Distinction between these constructs is that personality characteristics are somewhat observable and can be reported on by others (Dwan, Ownsworth, Donovan, & Lo, 2017). Self-identity on the other hand, is inherently subjective and reflects broader characteristics of the self than personality (Ownsworth, 2014).

The formation of self-identity is influenced by diverse internal (biological, cognitive) and external (culture, social circumstances, life events/disruptions) factors (Jetten, Haslam, & Haslam, 2012; Legrand & Ruby, 2009). A person’s sense of self is closely linked to, and derived from their goals, achievements, relationships, occupational roles and psychological wellbeing (Baumeister, 1987; Dweck, 1999; Higgins, 1987). Self-identity guides personal choices and pursuits, which in turn strengthen who we are and shape who we become, thus encompassing one’s past, present and “possible selves” (Markus & Nurius, 1986). More recently, researchers have begun to elucidate the biological and social underpinnings of self-identity and their interaction (Jetten et al., 2012; Rathbone, Conway, & Moulin, 2011).

Theoretical perspectives on self-identity change

A stable self-identity across the lifespan is considered adaptive as it allows individuals to see the world and their own behaviour as predictable. However, self-identity changes are known to occur under certain circumstances. Such circumstances include neurological disorders, major life transitions (e.g., becoming a parent, changing professions), trauma, self-relevant situational feedback, and psychotherapy (Ownsworth, 2014). Positive or negative changes, or a combination of these can result from such experiences.

Of particular relevance to this thesis is understanding whether and how self-identity is altered by biological disruption (i.e., neurocognitive impairments) and social/occupational changes (e.g., changes in activity participation) associated with TBI, and the influence of premorbid personality characteristics. Consideration of theories
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relevant to understanding self-identity within the general population may provide insight into the key mechanisms that are important to examine within the TBI population. In particular, theoretical perspectives derived from social psychology may help to understand how changes between pre-injury and post-injury functioning contribute to self-identity change after TBI. For example, cognitive dissonance theory (Festinger, 1962) proposes that holding two or more conflicting beliefs, values, or emotions, or acting in a manner that is incongruent with personal beliefs or standards can result in emotional discomfort/distress. Similarly, balance theory (Heider, 1958) proposes that we are motivated to maintain our beliefs and live in accordance with our values to achieve psychological balance and self-coherence.

Self-discrepancy theory builds upon these theories by contending that conflicting beliefs about one’s self or self-discrepancy can elicit emotional distress (Higgins, 1987; Higgins et al., 1986; Higgins, Klein, & Strauman, 1985). When such inner conflicts arise, we are generally motivated to resolve these. The consequences of unresolved self-discrepancies are negative emotional states, such as anxiety and depression. Larger discrepancies between current self-concept (i.e., who I am) and “self-guides” (i.e., who I want to be or who I should be) lead to greater emotional distress. Our self-guides are argued to be important for self-regulation or the ability to control our behaviour, thoughts and emotions. Carver and Scheier (1998) argued that our approach system is activated when we are attempting to achieve a positive self-state, by reducing self-discrepancies. In contrast, our avoidance system is activated when we are attempting to avoid a negative self-state, which can inadvertently increase self-discrepancies. In the context of TBI, “pre-injury self” represents a salient standard for comparison with actual or current self (i.e., abilities, attributes and behaviour), whereby perceived negative changes between one’s pre-injury self and current self are proposed to contribute to emotional distress (Cantor et al., 2005).
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Neural mechanisms underlying self and identity

The neural mechanisms underpinning self and identity are largely an enigma for neuroscience. Nevertheless, a meta-analysis of neuroimaging results for both non-clinical and clinical populations by Legrand and Ruby (2009) identified the prefrontal cortex, precuneus, temporoparietal junction, and temporal poles as key structures involved in processing information about the self through their roles in memory and executive functioning. Research by Rathbone, Conway, and Moulin (2011) highlighted that memory processes are not only important for supporting personal episodic and semantic knowledge, but also imagining oneself in the future, collectively known as “autobiographical self” (Benedict, Schretlen, Groninger, & Brandt, 1998). Imaging studies have implicated the medial prefrontal cortex (MPFC) in reflecting on one’s past, present, and future selves (D’Argembeau et al., 2010). Such findings help to understand how self-identity develops in association with autobiographical memories, and is maintained by ongoing life experiences that reinforce existing notions of self. However, the mechanisms underlying changes to self-identity after TBI are less well understood.

Self-identity change after TBI

The events that lead to and result from TBI are life changing. Subjective accounts of comparisons between individuals’ pre-injury and post-injury selves have been obtained from qualitative research. For example, a meta-synthesis of 23 qualitative studies on subjective experiences of recovery revealed that changes in self-identity, including loss of self, social disconnection and reconstruction of self-identity were dominant themes (Levack et al., 2010). More recently, Levack and colleagues conceptualised self-identity after TBI using focus groups involving 49 individuals with mild to severe TBI and a grounded theory approach (Levack et al., 2014). Their analysis revealed a central concept of “desiring to be or having lost a sense of being an integrated and valued person” (p. 4). This was underpinned by changes in the following
three core components: 1) self-coherence or having a complete, satisfying sense of self; 2) feeling respected, validated, and accepted by others; and 3) having a valued place in the world. Similarly, a scoping review of 19 qualitative studies highlighted common themes of loss of identity, stigmatised identity, and the challenging process of reconstructing sense of self in rehabilitation (Bryson-Campbell et al., 2013). Many individuals reported losing something of themselves that they valued but this was difficult to define (Jumisko, Lexell, & Soderberg, 2005).

While qualitative accounts provide valuable insights into the lived experience of self-identity change, the extent and nature of these changes and factors related to such changes are difficult to ascertain from these studies. A review of studies investigating the extent and nature of self-identity change after TBI through quantitative approaches may improve understanding of psychological adjustment and guide novel clinical interventions. This is the primary focus of study 1 (Chapter 3). As part of this systematic review, the approaches used to assess self-identity change after TBI are examined, to guide selection of the assessment approach in this thesis. Further, it is important to understand why some individuals are more likely to experience changes to self-identity than others, or the underlying factors contributing to these changes. Broadly guided by a biopsychosocial framework (Ownsworth, 2014), these factors include neurocognitive functions, psychological characteristics, and social/occupational factors, which are outlined in turn in the following sections.

**Neurocognitive functions related to self-discrepancy**

Drawing on a theoretical model developed to understand awareness deficits or “petrified self” in Alzheimer’s disease, Ownsworth (2014) applied the Cognitive Awareness Model (CAM; Agnew & Morris, 1998) to account for changes in self-identity after brain injury. This model proposes that self-perceptions of personal abilities and attributes are updated by experiences of relative success and failure in daily
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living (e.g., performance on occupational tasks and feedback during social interaction). Higher-order cognitive processes support people to identify a mismatch or discrepancy between stored self-representations (i.e., pre-injury self) and current self. This involves recalling past experiences and forming generalisations from patterns in one’s experiences (e.g., repeated instances of memory failure or anger outbursts). To experience self-identity change, these instances need to be attended to (i.e., noticed or recognised at the time), remembered (i.e., episodic memory) and compared with existing notions of self in order to modify self-schema (i.e., who I was and who I am now).

The CAM can help to understand why, despite marked functional impairments, individuals with severe memory and executive function impairments may not perceive changes to their personal abilities and attributes, thus maintaining their pre-injury notions of self (see also Naylor & Clare, 2008). Therefore, neurocognitive factors (cognitive and self-awareness deficits) are proposed to influence the extent to which individuals experience self-discrepancy after TBI and hence report self-identity change.

Psychological characteristics related to self-discrepancy

Psychological factors including personality style, cognitive appraisals, and coping resources are also likely to impact on how people make sense of their injury-related impairments and develop a sense of “who I am now” (Douglas, 2013; Ownsworth, 2014). In terms of personality style, longstanding dispositional characteristics serve as a lens through which stressful life experiences are perceived and reacted to (Carver & Connor-Smith, 2010). Unlike other dispositional factors (e.g., neuroticism and extraversion), optimism and defensiveness are considered relatively resistant to change in the context of TBI, and hence may reflect pre-injury personality style (Malia, Powell, & Torode, 1995; Ownsworth, 2005). Individuals who report higher dispositional optimism, or the general expectation or belief in positive
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psychological outcomes in the future, have been found to experience less psychological distress after TBI (Ramanathan, Wardecker, Slocomb, & Hillary, 2011). Similarly, individuals with high defensiveness who excessively try to present themselves in a favourable light have been found to underreport brain injury symptoms and experience better long-term emotional adjustment and psychosocial functioning (Ownsworth et al., 2007).

Given the associations between these personality characteristics and psychological distress, it is important to understand their influence on self-discrepancy. The experience of negative self-discrepancy may be less likely for individuals with high levels of optimism and defensiveness. Specifically, individuals with high levels of optimism may find positive meaning in their post-injury circumstances and perceive fewer negative changes to their self-concept after TBI. Individuals high on optimism are also more likely to believe they can achieve desired outcomes and strive towards their goals, even when progress is difficult (Carver & Connor-Smith, 2010). Similarly, individuals with high defensiveness are excessively motivated to maintain a positive self-image, and hence may be less likely to report negative self-discrepancy.

Understanding how personality characteristics relate to self-identity change is clinically important to help identify those at greater risk of experiencing negative self-discrepancy and psychological distress. However, within the context of psychotherapy, personality characteristics are considered relatively resistant to change, whereas cognitive appraisals are often targeted and considered modifiable (Anson & Ponsford, 2006b; Ownsworth, 2005). The cognitive appraisals that are considered particularly relevant to self-discrepancy after TBI include threat appraisals, self-focused attention (reflection and rumination) and perceived coping resources. These cognitive appraisals and their theorised relationship to self-discrepancy in the context of rehabilitation will now be discussed.
Gracey, Evans, and Malley (2009) developed a model of change processes in rehabilitation that highlights the role of self-discrepancy in the processes and outcomes in rehabilitation. Specifically, their “Y-shaped” model proposes that at the start of rehabilitation individuals commonly experience a discrepancy between their current self (i.e., who they are now with a brain injury) and their “aspired-to self” (i.e., pre-injury or ideal self). This self-discrepancy poses a threat to self and contributes to emotional distress and maladaptive coping (e.g., avoidance). Through participation in rehabilitation, individuals engage in a cyclical process of planning activities, making predictions about performance, experiential learning (i.e., testing beliefs through participation in activities), reflecting on outcomes, and exploring the meaning of post-injury changes. This cyclical process ultimately contributes to an updated and more realistic and adaptive self-identity.

Within the Y-shaped model, it is suggested that increased self-awareness of deficits and greater negative self-discrepancy may elicit threat appraisals and maladaptive coping reactions. In support of Gracey and colleagues’ model, Riley, Brennan, and Powell (2004) identified common threat appraisals related to valued roles and activities after TBI. Threat appraisals related to “doing things” (i.e., performing activities that they used to do before their injury), “dealing with people” (e.g., negative evaluations from others), and “personal safety” (e.g., getting hurt or reinjured). The “doing things” threat appraisal in particular suggests that the experience of task difficulty or failure triggers unfavourable comparisons between pre-injury and post-injury selves, or negative self-discrepancy (Riley et al., 2004).

Further, Anson and Ponsford (2006a) demonstrated that certain cognitive appraisals and coping styles such as worry, wishful thinking, self-blame and avoidance were associated with depression, anxiety and low self-esteem. Lack of perceived coping resources (i.e., low self-efficacy and inadequacy of social support) have been found to
be associated with higher activity avoidance and low self-esteem (Riley & Dennis, 2010). Further research is necessary to examine how threat appraisals and perceived coping resources are related to self-discrepancy after TBI.

Individuals may employ diverse ways of coping to adjust to the experience of TBI. For example, many people set goals that focus on resuming their former abilities and lifestyle in effort to maintain their continuity of self (Turner, Fleming, Ownsworth, & Cornwell, 2011). For others, TBI may propel them to search for meaning in, and adapt to their post-injury circumstances with modified goals and values (Silva, Ownsworth, Shields, & Fleming, 2011). Reflection is a form of self-focused attention that involves exploration of novel or alternative self-perceptions, motivated by curiosity and intrinsic interest in philosophical thinking (Trapnell & Campbell, 1999). Reflective practices can help people to recover from traumatic events, prepare and adapt to changes, and engage in health promoting behaviours (Feldman & Hayes, 2005; Watkins, 2008). Conversely, rumination is a form of self-focused attention characterised by repetitive negative thoughts related to perceived threats, losses, or injustices to the self. Ruminative tendencies have been found to lead to depression, anxiety, and physical health difficulties (Nolen-Hoeksema, Wisco, & Lyubomirsky, 2008; Papageorgiou & Wells, 2001). Along with threat appraisals and perceived coping resources, the relationship between self-focused attention and self-discrepancy after TBI is yet to be investigated.

**Social/occupational factors related to self-discrepancy**

Activity participation or occupation, which includes solo and shared activities and social roles, is an integral component of self-identity (Dumont, Gervais, Fougeyrollas, & Bertrand, 2004). Social roles and occupations provide meaning and opportunity to develop interests and to reflect on one’s abilities. Occupational activities are guided by our sense of self and values and, in turn, strengthen our sense of who we
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are and who we will become (Hammell, 2004). TBI often occurs during early adulthood, a pivotal time for developing independence, relationships and career; all of which are key to the formation of one’s sense of self. Severe TBI can therefore disrupt an individual’s life course and have major implications for self-identity (Yasuda, Wehman, Targett, Cifu, & West, 2001). Hence, individuals experiencing a loss of independence, challenges returning to work and leisure activities and difficulties maintaining relationships (i.e., poorer psychosocial functioning) may be at greater risk of self-discrepancy.

In studies by Eriksson and colleagues (Eriksson, Kottorp, Borg, & Tham, 2009; Eriksson, Tham, & Borg, 2006), individuals with ABI reported significant occupational “gaps” post injury (i.e., differences between actual and desired engagement in meaningful activities). Greater reported occupational “gaps” were associated with greater depressive symptoms and lower life satisfaction. Further, occupation-based interventions that aim to promote re-engagement in physical, social and leisure activities have been found to have a positive impact on mood and self-concept (e.g., Blake & Batson, 2009; Driver, Rees, O’Connor, & Lox, 2006; Fines & Nichols, 1994; Schwandt et al., 2012). However, the relationship between occupational gaps, mood and self-discrepancy has yet to be investigated. Overall, further research is needed to determine the relationship between occupational re-engagement, mood, psychosocial functioning and self-identity change after TBI.

Conclusions

A review of the literature highlights the need for a more advanced understanding of changes to self-identity after TBI and the factors that may underlie or contribute to these subjective alterations. Accordingly, Study 1 involves a systematic review of studies investigating the impact of TBI on self-identity and factors related to self-identity change or self-discrepancy. Guided by the findings of the systematic review,
the subsequent empirical studies aim to investigate the role of neurocognitive functions (Study 2), psychological characteristics (Study 3) and social/occupational factors (Study 4) in self-identity change. The theoretical and clinical implications arising from these studies are synthesised in the final General Discussion chapter.
Chapter 3: Statement of Contribution and Co-Authored Published Paper


This chapter includes a co-authored paper which has been published in an international peer reviewed journal. This has been included as published with the exception of changes to style and formatting of headings, tables and figures to maintain consistency throughout the thesis. The bibliographic details of the co-authored paper, including all authors, are: Dr Elizabeth Beadle, Professor Tamara Ownsworth, Professor Jennifer Fleming, and Professor David Shum. The candidate’s contribution to the paper involved conception of the study design, literature review, data collection and analyses, and writing of the manuscript. The co-authors contributed to the conception of the study, independently reviewed papers to determine suitability for inclusion in the systematic review (Prof Ownsworth and Prof Fleming), provided feedback on manuscript drafts/revisions and approved the final manuscript and revisions requested by the journal.

Name of student: Elizabeth Beadle

*Names of corresponding authors of paper:*
Professor Tamara Ownsworth (Primary Supervisor)

Professor Jennifer Fleming (External Supervisor)

Professor David Shum (Associate Supervisor)
Chapter 3: The impact of TBI on self-identity: A systematic review of the evidence for self-concept changes

Introduction

Self-identity is a nebulous term often used interchangeably with “sense of self” and self-concept. Philosopher William James (1890) conceptualized the self as a complex personal construction and “the most puzzling puzzle with which psychology has to deal” (James, 1890) due to the elusive nature of the term. Since James, diverse perspectives on self-identity have evolved within philosophy, sociology and neuroscience (Brinthaupt & Lipka, 1992; Mathews, Bok, & Rabins, 2009; Ownsworth, 2014). In the psychological literature self-identity is broadly defined as the collective characteristics we perceive as our own, which endure over time and are continuously under construction (Ownsworth, 2014). Self-identity research typically focuses either on individual characteristics (i.e., what makes us unique), or those shared with others based on common social memberships (Leary & Tangney, 2012). There is a general consensus that self-identity develops from and is shaped by an interplay of internal (biological, cognitive) and external (culture, social environment, life events) factors (Hogg & Terry, 2000; Jetten et al., 2012; Legrand & Ruby, 2009).

Although terminology differs (Leary & Tangney, 2012; Ownsworth, 2014), efforts have been made to operationalise the construct of self-identity for measurement. In developmental psychology measures of self-concept and self-esteem are commonly used to infer people’s sense of self or self-identity (Harter, 2012; Marsh, 1989; Ownsworth, 2014). Self-concept refers to the overarching thoughts and feelings a person has about him or herself, while self-esteem represents an evaluative component or judgments about one’s own worth or value (Schweitzer, Seth-Smith, & Callan, 1992). Developmental accounts propose that self-concept develops in a hierarchical manner with lower-level self-perceptions (e.g., situation-specific self-appraisals) having
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a bottom-up influence on domain-specific areas (e.g., physical, cognitive, social and behaviour), which are subjectively weighted in importance and contribute to higher-level self-representations or global self-concept (Marsh et al., 1992). Hence, self-concept is viewed by developmental theorists as both unitary and multi-dimensional with global and domain-specific components (Harter, 2012; Marsh et al., 1992). Although lower-level self-perceptions can be altered by situational influences to produce state-like variations (Markus & Kunda, 1986), research supports that global self-concept is relatively stable across the lifespan (Orth et al., 2010; Trzesniewski et al., 2003). Moreover, the degree of stability is similar to that observed for personality traits (Trzesniewski et al., 2003).

Researchers from diverse psychology fields have investigated the biological and social conditions for changes to self-identity and self-concept (Rathbone, Moulin, & Conway, 2009; Trzesniewski et al., 2003). Such changes have been attributed to many life experiences (Ownsworth, 2014), including: 1) a neurological event (Caddell & Clare, 2010; Feinberg, 2011) e.g., the onset of dementia or acquiring a brain injury; 2) major life transitions and stressful events (Orth et al., 2010) e.g., becoming a parent; 3) social evaluation (Higgins et al., 1986; Jetten et al., 2012) e.g., external feedback; and 4) psychotherapy and other interventions targeting self-schema (Beck, 2005; Ylvisaker, McPherson, Kayes, & Pellett, 2008).

Of particular relevance to this review, changes in self-concept and self-esteem have been investigated in the context of illness and trauma for many populations such as chronic pain (Harris, Morley, & Barton, 2003), spinal cord injury (Fitting, Salisbury, Davies, & Mayclin, 1978), stroke (Vickery, Evans, Lee, Sepehri, & Jabeen, 2009) and cancer (Munstedt, Manthey, Sachsee, & Vahrson, 1997). The domain of self-concept investigated in these studies has typically varied according to the functional consequences of the condition (e.g., body image and sexual self-concept after spinal
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cord injury). However, a consistent finding in the chronic illness literature is that global and domain-specific self-concepts can be altered by the experience of serious illness, which in turn influences emotional adjustment and quality of life (Harris et al., 2003).

The impact of TBI on self-identity and social identity has received greater attention in recent literature (Gracey & Ownsworth, 2008; Levack et al., 2014; Ownsworth, 2014; Ownsworth & Haslam, 2016; Wilson, 2011). A meta-synthesis (Levack et al., 2010) of 23 qualitative studies on subjective experiences of recovery after TBI found that changes in identity, including loss of self, social disconnection and reconstruction of self-identity were dominant themes. Similarly, a scoping review (Bryson-Campbell et al., 2013) of 19 qualitative studies highlighted the common experience of loss of identity and stigmatised identity, and the challenging process of reconstructing one’s sense of self in rehabilitation. Many individuals reported losing something of themselves that they valued but this was difficult to define (Jumisko et al., 2005). More recently, using grounded theory Levack and colleagues (2014) conceptualized self-identity after TBI according to three components: 1) self-coherence, or having a satisfying and complete sense of self; 2) feeling respected, validated and accepted by others, and 3) having a valued place in the world. Participants described a sense of loss in each of these aspects of self-identity. These insights into the lived experience of self-identity change highlight the importance of assessing changes to sense of self after TBI.

In research and clinical practice, the impact of TBI on self-identity is typically assessed using two main quantitative approaches. First, people’s responses on validated measures of current self-concept or self-esteem may be compared with relevant norms or matched controls to indicate people’s level of self-esteem or perceived competency across a range of domains (Downing, Stolwyk, & Ponsford, 2013; Ponsford, Kelly, & Couchman, 2014). Although not referred to as measures of self-concept per se,
personality inventories have also been used to examine self-perceived changes in characteristic patterns of emotions, behaviour and thinking (Lannoo et al., 1997). However, unless measures are conducted very early in recovery and re-administered over time (Vickery et al., 2009) it is not possible to determine changes in self-concept or personality arising from TBI. The second approach involves asking people to retrospectively rate their pre-injury self on a broad list of attributes and then rate their current self on the same attributes to indicate changes in self-concept since the injury (Tyerman & Humphrey, 1984). Various issues potentially influence retrospective ratings (e.g., memory impairment and overly positive views of pre-injury self (e.g., memory impairment and overly positive views of pre-injury self; Ownsworth, 2014); nonetheless, this approach seeks capture people’s own subjective understanding of changes to their sense of self. Related to this point, the construct of self-identity and its measurement needs to be distinguished from “self-awareness” or accuracy of self-appraisal after brain injury, for which self-ratings of functioning are compared with a presumably more objective standard such as significant others’ ratings (Sherer et al., 1998). Rather, the focus of the second approach is on assessing “self-discrepancy” or changes in self-concept since TBI, which has important implications for psychological adjustment and rehabilitation endeavours.

Informed by various social psychology theories e.g., Cognitive Dissonance theory (Festinger, 1962), Balance theory (Heider, 1958), self-discrepancy theory (Higgins et al., 1986) proposes that emotional distress is experienced when we hold two or more conflicting self-beliefs. This theory argues that discrepancy between one’s actual self (i.e., who I actually am) and ideal self (i.e., who I want to be) underlies depression while discrepancy between one’s actual self and ought self (i.e., who I should be) elicits anxiety. The concept of self-discrepancy has been applied to theories of adjustment in the TBI literature (Cantor et al., 2005; Gracey et al., 2009). In the
context of TBI, pre-injury self represents a salient standard for comparison with actual or current self (i.e., abilities, attributes and behaviour), whereby the perception of negative changes between one’s pre-injury self and current self are proposed to contribute to emotional distress (Gracey et al., 2009).

Self-discrepancy between one’s pre-injury and post-injury selves is also proposed to influence engagement and progress in rehabilitation (Gracey et al., 2009). Negative self-discrepancies may motivate people to set goals that focus on regaining their abilities and returning to their former self (Turner et al., 2011). Conversely, these may propel people to search for meaning in, and adapt to changes brought about by the injury (Silva et al., 2011). Over time, heightened distress associated with persisting negative self-discrepancies may produce a sense of hopelessness and lead to maladaptive coping and disengagement from rehabilitation (Gracey et al., 2009; Ownsworth, 2014). Conversely, lack of self-discrepancy may be related to neurologically-based awareness deficits and/or defensive coping (e.g., minimisation and denial), both of which pose a barrier to active participation in rehabilitation (Ownsworth & Clare, 2006). In a recent systematic review of intervention studies Ownsworth and Haslam (2016) found mixed support for the efficacy of rehabilitation for improving self-concept after TBI. They argued the need for improved assessment and intervention methodology to improve understanding of changes to sense of self in the context of rehabilitation.

Ownsworth (2014) presented a biopsychosocial conceptualization of factors contributing to self-identity change after brain injury. Drawing on the Cognitive Awareness Model (CAM; Agnew & Morris, 1998), which was developed to account for impaired self-awareness in Alzheimer’s disease, Ownsworth’s (2014) model asserts that self-perceptions of personal abilities and attributes are updated by experiences of relative success and failure in daily living (e.g., perceived performance on occupational
tasks and during social interaction). Higher order cognitive processes support people to identify a mismatch between stored self-representations (i.e., pre-injury self) and current self. This involves recalling past experiences, forming broader generalisations from patterns in one’s experiences and assimilating these with existing notions of self to produce modified self-schema (i.e., the old and new me). This account suggests that despite marked functional impairments, individuals with severe memory and executive dysfunction may perceive fewer changes to their personal abilities and attributes, thus maintaining pre-injury notions of self (Ownsworth, 2014). Ownsworth’s (2014) model proposes that psychosocial factors, including personality, coping style and the social environment (e.g., feedback) affect how people make sense of and respond to their injury-related impairments. Therefore, neurocognitive and psychosocial factors may influence the extent to which individuals experience self-discrepancy after TBI and hence report changes in self-identity.

**Study Rationale and Aims**

Qualitative studies highlight that people with TBI experience complex changes to their sense of self and find the process of reconstructing their self-identity challenging (Bryson-Campbell et al., 2013; Levack et al., 2010). In quantitative research the impact of TBI on self-identity is typically examined using psychometric measures of current self-concept or self-discrepancy (i.e., comparison of pre-injury vs. post-injury self-concept). However, it is unclear whether findings differ according to the approach to measurement or aspect of self-concept investigated (i.e., global vs. domain-specific areas). A review of assessment methods and research investigating self-identity changes after TBI may improve understanding of psychological adjustment and guide clinical interventions. Accordingly, the primary objective of this review was to examine the evidence for self-identity change after TBI by appraising quantitative studies that: a) examined pre-post injury self-discrepancies, or b) compared current levels of self-
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concept of people with TBI patients and matched controls (i.e., healthy controls and/or orthopedic/psychiatric controls). A secondary objective was to investigate factors related to self-identity change.

**Methods**

**Search strategy**

The following electronic databases were searched for the period of January 1983 to July 2014: Cochrane Systematic Review Database, CINAHL, PsycINFO, and PubMed. Bibliographies of included studies were manually searched for any further relevant studies. Two sets of keywords were entered to search each database:

1) Neurotrauma terms: Brain injur*; Head Injur*; Brain Damage; Head Trauma.
2) Identity change terms: Self Discrepancy; Self Concept; Self Esteem; Identity; Discontinuity; Continuity; Self Change*; Possible Sel*; Self Perception; Personhood; Personality change.

The search strategy was tailored for each specific database, according to search limit options. The full search strategy for each database is available from the first author on request. One of the authors (EB) screened all abstracts and titles for inclusion, while two of the authors (EB and TO) were involved in the review of the full texts for potentially eligible studies.

**Selection criteria**

The review included quantitative studies (i.e., those utilizing formal psychometric measures and statistical analyses) that investigated self-identity change, or compared levels of current self-esteem, self-concept or personality characteristics of adults with TBI to matched controls (healthy or orthopedic/trauma samples). For the purposes of this review, self-identity change was defined as subjective appraisal of post-injury changes in emotional, personality and behavioural attributes as compared to pre-injury functioning. Further eligibility criteria included: samples with mixed etiology of
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Brain injury were comprised of at least 70% with TBI and a validated approach to measuring self-esteem, self-concept, self-discrepancy or personality was employed. The exclusion criteria included: greater than 30% of participants had a brain injury from other causes (e.g. stroke), pediatric sample, qualitative data only, and publication in a language other than English.

**Data Extraction**

A 5-point scale was developed based on the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) guidelines (von Elm et al., 2007) to rate the methodological quality of the articles selected. Articles were scored 0 (does not meet criteria) or 1 (meets criteria) on the following criteria: 1) representative and adequate sampling (e.g., consecutive admissions and \( n \geq 30 \)); 2) longitudinal design and/or matched control sample; 3) employed a measure of self-concept, self-esteem or personality that has been validated for TBI and/or is well validated in the general population; 4) reporting of means and standard deviations in text, table or graph; and 5) adequate sample homogeneity, as indicated by TBI participant with similar chronicity (time since injury) or severity of injury. Higher scores represented stronger methodological quality. Two reviewers (EB and TO) independently appraised each study according to the five criteria. Discrepancies were resolved through discussion to determine a final score.

**Results**

As shown in Figure 3.1, a total of 1278 articles were initially identified from the search process across four databases. Of these, 288 duplicate articles were excluded. The title and abstract were reviewed for 990 articles, and a further 920 were removed for reasons including: not relevant to the population (e.g., not TBI, pediatric); not relevant to self-identity; and review article/opinion/editorial/book chapter. A full text review of the remaining 62 articles was conducted and 47 were excluded based on: lack
of measurement of current self-concept or self-identity change (or use of relative’s reports only); qualitative data only; non-validated or single item measures; and case study.

Figure 3.1 Flow diagram of search strategy and outcomes of systematic review
There was 100% agreement on the inclusion/exclusion of each study between the two reviewers; however, judgment of eligibility for one study was deemed “uncertain” by both reviewers, and therefore the opinion of the third author (JF) was sought and supported inclusion. Two papers were identified as using the same data set (Kelly, Ponsford, & Couchman, 2013; Ponsford et al., 2014), and so were considered as a single study (Ponsford et al., 2014). A final set of 15 studies was included for review. The characteristics and findings of these studies are summarized in Table 3.1.
### Table 3.1

*Participant Characteristics, Methodology and Key Findings of Included Studies*

<table>
<thead>
<tr>
<th>Authors/Country</th>
<th>TBI sample characteristics &amp; setting</th>
<th>Design</th>
<th>Self-identity, self-concept or personality measures</th>
<th>Key significant findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tyerman &amp; Humphrey, 1984 U.K.</td>
<td>25 severe TBI (aged 17 – 34 years); chronicity = 2-15 months; setting not specified</td>
<td>Cross-sectional</td>
<td>Self-concept (20-item Semantic Differential Scale)</td>
<td>Present self was rated as more negative than past self. Individuals expected to return to pre-injury self within one year. Present self was viewed less positively than a “typical” person, and more positively than a “typical head injured” person.</td>
</tr>
<tr>
<td>McWilliams, 1991 U.K.</td>
<td>8 severe (aged 16–57 years); chronicity = 6 months; community</td>
<td>Cross-sectional</td>
<td>Semantic Differential Scale</td>
<td>Current self-concept was viewed more negatively than pre-injury self. Return to pre-injury self was expected within 1 year.</td>
</tr>
<tr>
<td>Malia et al., 1995 U.K.</td>
<td>74 mild to severe (77% TBI; aged 16 – 54 years); chronicity = 6 – 30 months; community</td>
<td>Cross-sectional cohorts at 6, 12, 18, 24, and 30 months post injury</td>
<td>Personality (LOT; Easy going disposition)</td>
<td>Post-injury personality change was reported on all measures at 6 and 12 months; on “easy-going disposition” at 18 months; on all measures except optimism at 24 months post-injury changes. No personality changes were reported at 30 months.</td>
</tr>
<tr>
<td>Crisp, 1996 Australia</td>
<td>20 mixed brain injury (85% TBI; M age 32.45 years); chronicity M = 15.09 (SD = 13.66); community</td>
<td>Between-group: TBI vs. disability groups matched on age, education, unemployment</td>
<td>Self-esteem (SEI)</td>
<td>Individuals with chronic pain and other physical conditions reported higher self-esteem than those with brain injury or a psychiatric condition.</td>
</tr>
<tr>
<td>Wright &amp; Telford, 1996 U.K.</td>
<td>50 “minor” TBI (aged 17–86 years); chronicity = 6 months at time 1; community</td>
<td>Longitudinal: 36 complete HISD at time 1 21 at 3-years (n = 21) post injury</td>
<td>Self-concept change (HISD)</td>
<td>Present self was rated more negatively than pre-injury self. Return to past self was anticipated. Past/present and past/future self-discrepancies were related to</td>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Sample Characteristics</td>
<td>Study Design</td>
<td>Outcomes</td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>-----------</td>
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<td>--------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Lanoo et al., 1997</td>
<td>Belgium</td>
<td>68 moderate to severe (aged 15 – 65 years); chronicity: 6 months; setting not specified</td>
<td>Between group: TBI vs. 28 age, gender, and education matched trauma controls</td>
<td>Personality (NEO-FFI) No differences between the TBI and trauma control groups on personality dimensions.</td>
</tr>
<tr>
<td>Curran et al., 2000</td>
<td>Australia</td>
<td>88 severe (aged 14 – 75 years); chronicity = 1 – 5 years; community</td>
<td>Between-group: TBI vs. 40 gender and chronicity matched orthopedic controls</td>
<td>Self-esteem (RSES), No differences between TBI and orthopedic control groups. Lower self-esteem was associated with higher depression and anxiety.</td>
</tr>
<tr>
<td>Man et al., 2003</td>
<td>Hong Kong</td>
<td>120 mixed severity (aged 19–65 years); chronicity not reported; community</td>
<td>Between group: TBI vs. 146 healthy, non-matched controls</td>
<td>Self-concept (Chinese version of ASSEI) TBI participants were more satisfied than controls in their law-abidingness, spiritual convictions and sense of culture. They were less satisfied in their physical abilities, grooming, and appearance.</td>
</tr>
<tr>
<td>Cantor et al., 2005</td>
<td>U.S.A. (NY)</td>
<td>21 adults mild to severe (aged 22-77 years); chronicity: 2 – 33 yrs; community</td>
<td>Cross-sectional</td>
<td>Self-discrepancies (SI and SAC) On average, individuals reported negative changes to self after TBI. Negative associations between depression, anxiety and self-discrepancies on the SAC but not the SI.</td>
</tr>
<tr>
<td>Rush et al., 2006</td>
<td>U.S.A. (FL)</td>
<td>20 mild (mean age 37.21 years), 39 moderate/severe (M age 38.75); chronicity: “a few” months; setting not specified</td>
<td>Within and between group: TBI vs. 31 gender and race matched orthopedic controls; 1 – 2 year follow-up</td>
<td>Personality (NEO-PI-R) No differences between TBI and controls on personality scales. No consistent evidence of change in pre- and post-injury personality ratings for either TBI or control groups. No differences between premorbid personality and current personality.</td>
</tr>
<tr>
<td>Cooper-Evans et al., 2008</td>
<td></td>
<td>22 mixed brain injury (73% TBI; aged 18–70)</td>
<td>Cross-sectional with a repeated measures</td>
<td>Self-esteem (RSES) Current self-esteem was rated lower than pre-injury self-esteem. Higher current self-esteem was associated psychological distress and persisted at 2.5 years follow-up.</td>
</tr>
</tbody>
</table>
### Changes to Self after TBI

<table>
<thead>
<tr>
<th>Country</th>
<th>Sample Description</th>
<th>Setting</th>
<th>Assessment Method</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>U.K.</td>
<td>Mild to severe TBI (22–64 years); chronicity: 2–40 years; community</td>
<td>Cross-sectional</td>
<td>Self-concept change (HISD-III)</td>
<td>Current self was more negative than pre-injury self. Negative self-discrepancy was associated with depression, grief and low self-esteem. Higher current self-esteem was related to poorer awareness.</td>
</tr>
<tr>
<td>Carroll &amp; Coetzer, 2011</td>
<td>29 mild to severe (aged 22–64 years); chronicity: 2–40 years; community</td>
<td>Between group: TBI vs. 142 age and gender matched healthy controls</td>
<td>Self-esteem (RSES)</td>
<td>Individuals with TBI reported poorer global self-esteem than matched healthy controls.</td>
</tr>
<tr>
<td>Downing et al., 2013</td>
<td>865 mild to severe TBI (mean age 34.7 years); chronicity: 1–20 years; community</td>
<td>Between group: TBI vs. 142 age and gender matched healthy controls</td>
<td>Self-concept (TSCS: 2) and self-esteem (RSES)</td>
<td>Individuals with TBI reported poorer self-concept and global self-concept than matched controls. Lower self-concept and self-esteem was correlated with higher levels of anxiety and depression.</td>
</tr>
<tr>
<td>Kelly et al., 2013</td>
<td>Ponsford et al., 2014; Australia 41 mixed brain injury (83% TBI; 18 – 73 years); chronicity: 1–20 years; community</td>
<td>Between group: TBI vs. 41 age, gender, and education matched healthy controls</td>
<td>Self-esteem (RSES)</td>
<td>No difference between ratings of past, current, and future self.</td>
</tr>
<tr>
<td>Andrewes et al., 2014</td>
<td>10 severe (M age = 38.3); chronicity M = 4.2 years; outpatient</td>
<td>Within-group (pre-intervention data)</td>
<td>Self-concept change (HISD-II)</td>
<td>No difference between ratings of past, current, and future self.</td>
</tr>
</tbody>
</table>

Abbreviations: ASSEI = Adult Source of Self-concept Inventory; HISD = Head Injury Semantic Differential Scale; LOT = Life Orientation Test; NEO-FFI = NEO Five-Factor Inventory; NEO-PI-R = NEO Personality Inventory – Revised; RSES = Rosenberg Self-Esteem Scale; SAC = Selves Adjective Checklist; SEI = Self-esteem Inventory; SI = Selves Interview; TSCS:2 = Tennessee Self Concept Scale: Second Edition
Methodological Quality

There was substantial inter-rater agreement in ratings of methodology quality (Kappa = 0.90). As shown in Table 3.2, one study met 1/5 criteria (Cantor et al., 2005), seven studies met 2/5 criteria (Andrewes, Walker, & O’Neill, 2014; Carroll & Coetzee, 2011; Cooper-Evans et al., 2008; Malia et al., 1995; Man, Tam, & Li, 2003; McWilliams, 1991; Tyerman & Humphrey, 1984), two studies met 3/5 criteria (Crisp, 1996; Ponsford et al., 2014), three studies met 4/5 criteria (Downing et al., 2013; Lannoo et al., 1997; Rush, Malec, Brown, & Moessne, 2006), and two studies met 5/5 criteria (Curran, Ponsford, & Crowe, 2000; Wright & Telford, 1996). Five of the studies employed a representative sampling approach, such as consecutive hospital admissions or discharges (Curran et al., 2000; Downing et al., 2013; Malia et al., 1995; Rush et al., 2006; Wright & Telford, 1996). There was considerable heterogeneity in sample characteristics, with only six studies recruiting TBI participants that were similar in terms of chronicity or injury severity (Crisp, 1996; Curran et al., 2000; Downing et al., 2013; Lannoo et al., 1997; Malia et al., 1995; McWilliams, 1991). Chronicity ranged from 2 months to 40 years post-injury, while injury severity ranged from mild to very severe. One study (Wright & Telford, 1996) was noteworthy as the only one to measure self-identity change longitudinally. This study retained 21/36 (58%) of patients over a 2.5 year follow-up and found that negative self-discrepancies persisted long-term. Another study (Cooper-Evans et al., 2008) examined stability of ratings of current self-esteem over a two week period, but not pre- and post-injury self-discrepancy. Seven studies (Crisp, 1996; Curran et al., 2000; Downing et al., 2013; Lannoo et al., 1997; Malia et al., 1995; Ponsford et al., 2014; Rush et al., 2006) examined the impact of TBI on self-identity by comparing the current self-concept or personality characteristics of people with TBI with healthy
controls or orthopedic/trauma controls. Six of these studies employed a matched control sample, with matching on at least two characteristics such as age, gender, race, education and chronicity (Crisp, 1996; Curran et al., 2000; Downing et al., 2013; Lannoo et al., 1997; Ponsford et al., 2014; Rush et al., 2006).
## Table 3.2

<table>
<thead>
<tr>
<th>Study</th>
<th>Representative and adequate sampling (n &gt; 30)</th>
<th>Longitudinal and/or matched control design</th>
<th>Measure validated for TBI and/or well validated in general population</th>
<th>Reporting of mean and std deviation for self-concept in text, table or graph</th>
<th>Sample homogeneity: all TBI and similar chronicity or severity</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Man et al. (2003)</td>
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<td>McWilliams (1991)</td>
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<td>Ponsford et al. (2014)</td>
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<td>Rush et al. (2006)</td>
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<tr>
<td>Tyerman &amp; Humphrey (1984)</td>
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<td>Wright &amp; Telford (1996)</td>
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</table>

* Confirmed through correspondence with the authors
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Thirteen studies utilized measures that were either specifically developed or validated for TBI, or are well established in the general population (Andrewes et al., 2014; Carroll & Coetzer, 2011; Cooper-Evans et al., 2008; Crisp, 1996; Curran et al., 2000; Downing et al., 2013; Lannoo et al., 1997; Man et al., 2003; McWilliams, 1991; Ponsford et al., 2014; Rush et al., 2006; Tyerman & Humphrey, 1984; Wright & Telford, 1996). Four studies reported reliability coefficients for the measure of identity change in the study sample (Andrewes et al., 2014; Carroll & Coetzer, 2011; Cooper-Evans et al., 2008; Tyerman & Humphrey, 1984). As shown in Table 3.2, most studies (73%) reported descriptive data (means and standard deviations) on the measures of self-concept or personality. Other noteworthy strengths related to the analysis included adjusting for multiple comparisons (Carroll & Coetzer, 2011; Downing et al., 2013; Rush et al., 2006), careful matching of control samples (Crisp, 1996; Curran et al., 2000; Downing et al., 2013; Lannoo et al., 1997; Ponsford et al., 2014; Rush et al., 2006), and conducting a statistical comparison between participants retained and those lost to follow up (Wright & Telford, 1996).

Overall, due to the significant sample heterogeneity and variability in the study design and measurement of self-identity, meta-analysis was not used to synthesise the findings. The findings of each study are instead described qualitatively in Table 3.1. The following section describes the sample characteristics and assessment approaches used in the studies.

Sample Characteristics

The majority of studies were conducted within the U.K. (Andrewes et al., 2014; Carroll & Coetzer, 2011; Cooper-Evans et al., 2008; McWilliams, 1991; Tyerman & Humphrey, 1984). Other countries include Australia (Crisp, 1996; Curran et al., 2000; Downing et al., 2013; Ponsford et al., 2014), U.S.A. (Cantor et al., 2005;
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Rush et al., 2006), Hong Kong (Man et al., 2003), and Belgium (Lannoo et al., 1997). Eleven studies were conducted in a community outpatient setting, while the other four did not specify the setting (Cooper-Evans et al., 2008; Lannoo et al., 1997; Rush et al., 2006; Tyerman & Humphrey, 1984). Sample sizes varied from 8 to 865 participants, with most studies describing the use of convenience sampling (Andrewes et al., 2014; Cantor et al., 2005; Carroll & Coetzer, 2011; Cooper-Evans et al., 2008; Crisp, 1996; Lannoo et al., 1997; Man et al., 2003; McWilliams, 1991; Ponsford et al., 2014; Tyerman & Humphrey, 1984). Five studies used a more representative sampling approach such as consecutive hospital admissions (Curran et al., 2000; Downing et al., 2013; Malia et al., 1995; Tyerman & Humphrey, 1984; Wright & Telford, 1996).

Four studies included a brain injury sample with mixed etiology (Cooper-Evans et al., 2008; Crisp, 1996; Kelly et al., 2013; Malia et al., 1995). Severity of TBI varied within and between studies; two mainly recruited people with mild TBI (Rush et al., 2006; Wright & Telford, 1996), four predominantly included people with severe TBI (Andrewes et al., 2014; Curran et al., 2000; McWilliams, 1991; Tyerman & Humphrey, 1984), and five recruited people with mild to severe TBI (Cantor et al., 2005; Carroll & Coetzer, 2011; Cooper-Evans et al., 2008; Downing et al., 2013; Lannoo et al., 1997; Man et al., 2003). There was also considerable heterogeneity in chronicity within and between studies e.g., 2 – 15 months post injury (Tyerman & Humphrey, 1984); 2 – 40 years post injury (Carroll & Coetzer, 2011).

Measurement of Self-Identity Change

Table 3.3 summarizes the 10 measures used to investigate the impact of TBI on self-identity, including measures of self-concept change, current self-concept and personality characteristics. Information concerning reliability and validity is included where available.
Table 3.3  
**Quantitative Approaches to Measuring the Impact of TBI on Self-Identity**

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Items, domains</th>
<th>Scale</th>
<th>Administration (respondent’s task)</th>
<th>Reliability &amp; Validity in TBI Samples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Measures of self-concept change (self-discrepancy)</strong></td>
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<tr>
<td>HISD (I – III)</td>
<td>HISD-I &amp; - II: 20 items; HISD-III: 18 items</td>
<td>7-point semantic differential scale of bipolar adjective pairs</td>
<td>Rate each “self” (past/present/future) according to bipolar adjective pairs (e.g. “bored” to “interested”; “unhappy” to “happy”; “inactive” to “active”).</td>
<td>HISD-I &amp; - II: Internal consistency: $\alpha = .88-.93$; split half = .87-.93; Convergent validity with Frankfurt Self-Concept Scale. HISD-III: Internal consistency: $\alpha = .92-.93$; Convergent validity with RSES and Brain Injury Grief Inventory (BIGI; Coetzer, Vaughn, &amp; Ruddle, 2003)</td>
</tr>
<tr>
<td>Selves Interview (Cantor et al., 2005; Strauman, 1990)</td>
<td>At least 6 descriptors for “current actual self”, “current ideal self”, and “current ought self”</td>
<td>Open ended interview</td>
<td>Generate at least 6 descriptors for each self and rate the degree of applicability (1 = slightly true of me, to 5 = extremely true of me).</td>
<td>Reliability not examined in TBI. In general population: 3 year test-retest = .56; inter-rater = .86;</td>
</tr>
<tr>
<td>Selves Adjective Checklist (Cantor et al., 2005; Tangney, Niendenthal, Covert, &amp; Barlow, 1998)</td>
<td>38 items; Different versions for “current actual self”, “current ideal self”, and “current ought self”;</td>
<td>Forced choice bipolar adjective scale</td>
<td>Select from a list of adjectives and indicate which adjective is most descriptive of each self.</td>
<td>Reliability not examined. More negative self-discrepancy was associated with depression and anxiety (Cantor et al., 2005)</td>
</tr>
<tr>
<td><strong>Measures of current self-concept or self-esteem</strong></td>
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<tr>
<td>ASSEI (Elovson &amp; Fleming, 1989)</td>
<td>20 items; Importance of and satisfaction with various aspects of self esteem</td>
<td>11-point scale (0 – 10)</td>
<td>Rate the importance they attach to, and satisfaction with various aspects of self-concept. The scale covers physical, social, ethical, familial, and intellectual aspects of self-concept.</td>
<td>Reliability not examined in TBI. In general population: test-retest reliability = .67-.69 (Davis-Zinner, 1990); Total ASSEI satisfaction scores were related to the RSES ($r = .37$, $p&lt;.001$).</td>
</tr>
</tbody>
</table>
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<table>
<thead>
<tr>
<th>Measure</th>
<th>Description</th>
<th>Scale Type</th>
<th>Response Type</th>
<th>Reliability/Traits</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSEI (Coopersmith, 1989)</td>
<td>25 items</td>
<td>Dichotomous scale</td>
<td>Respond to statements by endorsing “Like Me” or “Unlike Me”. Scores range from 0 – 100.</td>
<td>Reliability not examined in TBI. In general population: split half reliabilities = .71-.74; test-retest reliability = .80-.82 (Bedian, Teague, &amp; Zmud, 1977)</td>
</tr>
<tr>
<td>RSES (Rosenberg, 1965)</td>
<td>10 items</td>
<td>4-point Likert scale</td>
<td>Respond to questions regarding feelings about self, from 1 = strongly disagree to 4 strongly agree.</td>
<td>High internal consistency (α = .89)(^5); convergent validity with HISD(^4); test-retest reliability = .86. Scores negatively associated with anxiety and depression (Cooper-Evans et al., 2008).</td>
</tr>
<tr>
<td>TSCS-2 (Fitts &amp; Warren, 1996)</td>
<td>82 items</td>
<td>5-point Likert scale</td>
<td>Rate how true each statement is about one’s self. The total summary score for self-concept is comprised of six domains: physical, moral, personal, family, social and academic/work. Items are rated from 1 (always false) to 5 (always true).</td>
<td>Reliability not examined in TBI. In general population: internal consistency = .73-.95; test-retest reliability = 0.47-.82; Convergent validity with RSES in TBI sample (Ponsford et al., 2014).</td>
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Measures of personality

<table>
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<tr>
<th>Measure</th>
<th>Description</th>
<th>Scale Type</th>
<th>Response Type</th>
<th>Reliability/Traits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life orientation Test (Scheier &amp; Carver, 1985b)</td>
<td>12 items; 4 filler, 4 optimistic, 4 pessimistic</td>
<td>5-point scale</td>
<td>Rate the extent to which they agree with each item, from 0 = strongly disagree to 4 = strongly agree. Higher values (0-24) indicate greater optimism.</td>
<td>In general population: internal consistency = .76 (Scheier &amp; Carver, 1985b); Internal consistency in TBI sample = .70 (Peleg, Barak, Harel, Rochberg, &amp; Hoofien, 2009)</td>
</tr>
<tr>
<td>NEO (PI-R &amp; FFI; Costa &amp; McCrae, 1992)</td>
<td>NEO PI-R: 240 items; NEO-FFI: 60 items</td>
<td>5-point scale</td>
<td>Rate on a 5-point scale (strongly disagree to strongly agree) their agreement with statements regarding the domains of: Extraversion, Agreeableness, Conscientiousness, Neuroticism, and Openness to Experience.</td>
<td>Reliability not examined in TBI. In general population: internal consistency of NEO-PI-R = .86-.92; NEO FFI = .79-.83 (Costa &amp; McCrae, 1992)</td>
</tr>
<tr>
<td>Health and Daily Living Form (Holahan &amp; Moos, 1985) – Easy going dimension</td>
<td>3-items</td>
<td>5-point scale</td>
<td>Rate how well each adjective (e.g., easy-going, calm, happy) describes one’s self on a 5-point scale (“not at all accurately” to “quite accurately”).</td>
<td>TBI: internal consistency = .53-.78 (Malia et al., 1995; authors did not differentiate between participant and relative rated versions)</td>
</tr>
</tbody>
</table>

Abbreviations: ASSEI = Adult Source of Self-concept Inventory; CSEI = Coopersmith Self-esteem Inventory; HISD = Head Injury Semantic Differential Scale; NEO-FFI = NEO Five-Factor Inventory; NEO-PI-R = NEO Personality Inventory - Revised; RSES = Rosenberg Self-Esteem Scale; TSCS:2 = Tennessee Self Concept Scale: Second Edition
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Measures of self-concept change

The most commonly used measure of pre-post injury self-discrepancy was the Head Injury Semantic Differential Scale (HISD; Tyerman & Humphrey, 1984). The original HISD was specifically designed to capture subjective changes to sense of self in individuals with brain injury. Three studies (McWilliams, 1991; Tyerman & Humphrey, 1984; Wright & Telford, 1996) utilized the original version of the HISD. Two revised versions of the HISD have subsequently been developed, which entailed minor wording changes (Ownsworth, 2014). Andrewes and colleagues (2014) utilized the second version (HISD-II), while the most recent version (HISD-III) was used by Carroll and Coetzer (2011). Cantor and colleagues (2005) developed a modified version of the Selves Interview (SI; Strauman, 1990) and Selves Adjective Checklist (SAC; Tangney et al., 1998). The adjective checklist had a forced-choice format, which was considered more suitable than open-ended questions for individuals with cognitive impairment.

Measures of current self-concept

Current global self-esteem was assessed using the Rosenberg Self Esteem Scale (Rosenberg, 1965; RSES) in four studies (Carroll & Coetzer, 2011; Curran et al., 2000; Downing et al., 2013; Ponsford et al., 2014). Cooper-Evans and colleagues (2008) also asked participants to provide retrospective ratings of self-esteem on the RSES prior to their TBI and calculated the degree of discrepancy between pre-injury and current self-esteem ratings. Two studies (Crisp, 1996; Downing et al., 2013) used other well-established measures to assess global self-esteem (i.e., Coopersmith Self-Esteem Inventory; Coopersmith, 1989) or multiple self-concept domains (Tennessee Self Concept Scale Second Edition (TSCS: 2; Fitts & Warren, 1996). Although the psychometric properties of these tools are well established in the general population, reliability and validity for the TBI population has only been investigated for the RSES (see Table 3.3).
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Measures of personality

Two studies (Lannoo et al., 1997; Rush et al., 2006) used different versions of the NEO personality inventory, which is based on the five-factor model of personality (Costa & McCrae, 1992). In contrast, Malia and colleagues (1995) utilized multiple measures of psychosocial functioning to assess perceived changes (i.e., pre- and post-injury ratings), two of which were measures of personality – the Life Orientation Test (Scheier & Carver, 1985b), and the Easy Going dimension of the Health and Daily Living Form (Holahan & Moos, 1985). These personality measures have not been validated for use in the TBI population, although internal consistency was reported by Malia and colleagues (1995) for their sample.

In summary, the impact of TBI on current self-concept and changes in self-concept was examined using 10 different self-report measures across the 15 studies, with the most common measure involving the HISD.

Evidence of Self-Identity Change after TBI

As summarized in Table 3.1, 11 of the 15 studies provided evidence of changes to self-concept after TBI (Cantor et al., 2005; Carroll & Coetzer, 2011; Cooper-Evans et al., 2008; Crisp, 1996; Downing et al., 2013; Malia et al., 1995; Man et al., 2003; McWilliams, 1991; Ponsford et al., 2014; Tyerman & Humphrey, 1984; Wright & Telford, 1996). Such studies demonstrated on at least one measure that individual’s current self-concept was viewed more negatively than their pre-injury self-concept (Andrewes et al., 2014; Cantor et al., 2005; Carroll & Coetzer, 2011; Cooper-Evans et al., 2008; Malia et al., 1995; McWilliams, 1991; Tyerman & Humphrey, 1984; Wright & Telford, 1996), or that self-concept was more negative for individuals with TBI in comparison to matched controls (Crisp, 1996; Downing et al., 2013; Man, Tam, & Li, 2003; Ponsford et al., 2014).

In the only study to examine both global and domain-specific self-concept, Ponsford and colleagues (Ponsford, et al., 2014) found that TBI participants rated their global self-concept and social, family, academic and personal self-concept as significantly lower than healthy
controls. There were no significant differences on physical or moral self-concept. However, the findings of three studies (Curran et al., 2000; Lannoo et al., 1997; Rush et al., 2006) with strong methodology (4-5/5, see Table 3.2) indicated that changes in self-concept or personality characteristics were not specific to TBI. Specifically, they reported no significant differences in personality or self-esteem ratings between their TBI and orthopedic/trauma control samples. Further, Rush et al. (2006) found no significant changes in pre- and post-injury personality ratings for either the TBI or orthopedic control sample. A study by Andrewes et al. (2014) also did not find significant differences between ratings of pre- and post-injury self-concept for their TBI sample; however this may have been due to the small sample size (n = 10).

The seven studies that examined the impact of TBI on different emotional, behavioural or personality attributes (i.e., on separate measures, subscales, or item-by-item analysis) revealed that not all changes were negative and that particular traits were stable (Carroll & Coetzer, 2011; Malia et al., 1995; Man et al., 2003; McWilliams, 1991; Ponsford et al., 2014; Rush et al., 2006; Tyerman & Humphrey, 1984). For example, Tyerman and Humphrey (1984) found that individuals perceived themselves as just as friendly as before their injury, and Malia et al. (1995) reported that ratings of optimism were similar to pre-injury levels for individuals with TBI at 18, 24 and 30 months post-injury. Additionally, positive changes were evident in some studies for particular attributes; for example, people with TBI rated themselves as more mature and appreciative since their injury (McWilliams, 1991), or were more satisfied than controls in their law-abidingness, spiritual convictions and sense of culture (Man et al., 2003).

In summary, despite methodological differences, a consistent finding across 11 studies is that people with TBI mainly reported negative changes in self-concept. The longitudinal study (Wright & Telford, 1996) found that negative self-discrepancies persisted at 2.5 years
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follow-up. Three studies with strong methodology found no significant differences in personality characteristics or self-esteem between TBI and orthopedic/traumatic control samples (Curran et al., 2000; Lannoo et al., 1997; Rush et al., 2006).

Factors Related to Self-Identity Change

Three studies investigated associations between self-concept change and measures of emotional adjustment (Cantar et al., 2005; Carroll & Coetzer, 2011; Wright & Telford, 1996). Two studies found that negative self-discrepancy was related to greater depressive symptoms (Cantar et al., 2005; Carroll & Coetzer, 2011). One study reported significant associations among measures of grief, adjustment, self-esteem and self-concept change, with negative self-discrepancy related to increased sense of loss and poorer adjustment and self-esteem (Carroll & Coetzer, 2011). Further, negative self-discrepancy was associated with increased anxiety, mental health concerns and psychological distress in two studies (Cantar et al., 2005; Wright & Telford, 1996).

Most studies did not examine neurocognitive correlates of current self-concept or self-discrepancy. However, two studies found that higher current self-esteem was related to lower IQ, poorer executive functioning and greater awareness deficits (Carroll & Coetzer, 2011; Cooper-Evans et al., 2008). Carroll and Coetzer (2011) found that self-concept change (i.e., self-discrepancy) was not significantly related to awareness of deficits (although there was a trend in the expected direction), which may have been partly due to the small sample size (n = 29) and associated power issues.

Discussion

The aims of this review were to examine the impact of TBI on self-identity and investigate factors related to changes in self-concept. Overall, 11 of the 15 studies indicated that TBI has a predominantly negative impact on self-identity (Cantar et al., 2005; Carroll & Coetzer, 2011; Cooper-Evans et al., 2008; Crisp, 1996; Downing et al., 2013; Malia et al.,
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1995; Man et al., 2003; McWilliams, 1991; Ponsford et al., 2014; Tyerman & Humphrey, 1984; Wright & Telford, 1996). Therefore, despite differences in sampling characteristics and approaches to measurement, the review yielded largely consistent findings. However, there was also evidence of stability in particular traits (e.g., friendliness and optimism) and positive psychological changes (e.g., more mature and appreciative) after TBI (Carroll & Coetzer, 2011; Malia et al., 1995; Man et al., 2003; McWilliams, 1991; Ponsford et al., 2014; Rush et al., 2006; Tyerman & Humphrey, 1984).

Importantly, three of the four studies that indicated no significant impact of TBI on self-identity were those that compared self-esteem or personality characteristics of participants with TBI with orthopedic/trauma (i.e., not neurological) controls (Curran et al., 2000; Lannoo et al., 1997; Rush et al., 2006). Such findings suggest that changes in self-identity after TBI do not arise from neurological damage per se, but are related to the broader psychosocial consequences of a traumatic event leading to hospitalisation, and adjustment to injury or loss of function. This explanation is further supported by the finding that personality characteristics did not differ between participants with mild and moderate/severe TBI (Rush et al., 2006). Nonetheless, firm conclusions about neurological influences on self-identity cannot be drawn from this review due to the lack of studies investigating neurocognitive factors related to self-concept changes. Intriguingly, higher levels of current self-esteem were related to lower IQ, poorer executive functioning and greater awareness deficits (Carroll & Coetzer, 2011; Cooper-Evans et al., 2008). These findings provide tentative support for Ownsworth’s (2014) theoretical proposition that people with more severe cognitive deficits and reduced self-awareness are less likely to make global negative self-evaluations. However, due to the methodological issues associated with these two studies (i.e., cross-sectional design and small and heterogeneous samples), caution is needed in interpreting these findings.
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Three studies identified that negative self-discrepancy was related to greater emotional distress and mental health problems (Cantor et al., 2005; Carroll & Coetzer, 2011; Wright & Telford, 1996). These findings support the “Y-shaped” model (Gracey et al., 2009) which proposes that discrepancies between people’s current self and aspired-to self (the top of the “Y”) pose threats to self and result in unhelpful coping reactions and emotional distress. According to this model, rehabilitation supports people to resolve negative self-discrepancies (convergence at the centre of the “Y”) by the therapist and client forming a strong alliance and engaging in experiential learning processes (e.g., goal setting, planning, performing activities, and reflecting on performance) which promote more adaptive and realistic self-representations (the vertical trunk of the “Y”). Positive identity transition after TBI is proposed to entail assimilation of both continuous and changed aspects of self (i.e., the “old” and “new” me), and consolidating the updated identity through regular participation in meaningful activities (Levack et al., 2010; Rathbone et al., 2009). This framework depicts self-identity change as process that occurs over time, and one that is strongly influenced by a person’s social environment.

This review identified that most studies employed a cross-sectional design with measures of self-concept change based upon retrospective ratings of pre-injury self, obtained many years post-injury. Two noteworthy studies reported retrospective ratings of pre-injury self within a month post-injury and compared these with ratings of post-injury self at 2-3 years post-injury (Rush et al., 2006; Wright & Telford, 1996). One of these studies (Wright & Telford, 1996) reported negative self-discrepancy on the HISD, whereas the other study (Strauman, 1990) reported no significant difference in pre- and post-injury personality ratings. In future research there is a need for prospective longitudinal studies to investigate changes in self-concept during the early phase of recovery (e.g., rehabilitation admission and discharge) and between the post-acute and long-term adjustment phases. Vickery and colleagues
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(Vickery et al., 2009) found significant improvements in self-esteem during acute stroke rehabilitation, with younger patients and those with higher levels of functional status at admission reporting greater improvement. A recent systematic review (Ownsworth & Haslam, 2016) identified largely mixed findings concerning the impact of rehabilitation on self-concept after TBI. Interestingly, despite minimal overlap with studies included in the present review, the same issue emerged in their review concerning lack of consistency in approaches to measuring self-concept change.

To achieve greater consistency in measurement of self-identity after TBI the use of common terminology would be beneficial. Ponsford et al. (2014) distinguished between global self-esteem and multi-dimensional aspects of self-concept and emphasized the need for clinicians to consider relevant domains of self-concept to address as a focus of intervention. Ownsworth and Haslam (2016) similarly recommended that clinicians and researchers be guided by developmental models of self-concept to select assessment and intervention approaches. In particular, they presented a hierarchical framework in which dynamic relationships were proposed between: a) lower level self-evaluations (i.e., self-perceptions of competency in specific situations), b) domain-specific self-concepts (e.g., physical attributes), and c) higher-level self-representations (i.e., global self-concept). Given that it is not practical to administer several tools to assess similar constructs, there is a need to consider both the level and domain/s of self-concept most relevant to assess in clinical practice or to address particular research questions.

There are a number of conceptual and methodological issues related to this review that may limit the conclusions drawn. In particular, self-identity was broadly defined in terms of self-perceived personal characteristics. Self-reported personality attributes were considered to fall within this general definition as both personality and self-identity refer to enduring characteristics within the individual. However, there is a distinction between these constructs:
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others can observe and describe someone else’s personality but not his or her self-identity, because this can only be subjectively construed (Ownsworth, 2014). Related to this definitional issue, studies investigating the impact of TBI on social identity were not included. Levack et al. (2014) emphasized the need to assess social and cultural aspects of identity. Development of validated measures of social identity after TBI represents a priority for future research.

Overall, the rigorous selection criteria identified a relatively small number of studies that were too heterogeneous to employ meta-analytic techniques. Despite this, the key findings largely concur with themes derived from qualitative research (Bryson-Campbell et al., 2013; Levack et al., 2010). The present review contributes to the literature by improving conceptual clarity regarding terminology and appraising approaches to measuring the impact of TBI on self-identity. Prospective longitudinal studies are recommended to investigate the process through which self-concept changes over time after TBI and in response to rehabilitation.

Conclusions

Overall, this review identified that people with TBI typically experience negative self-discrepancy and poorer self-concept than healthy controls. Levels of self-esteem and personality characteristics were similar between participants with TBI and orthopedic/trauma controls, thus suggesting that the neurological effects of TBI may not be as influential as the psychosocial consequences of a traumatic injury. Greater consistency in self-identity measurement and prospective longitudinal research would advance the field.
Chapter 4: Thesis methodology

Chapter 4 provides an overview of the methodology employed in empirical studies 2 – 4 of this thesis (i.e., chapters 5 – 7). Specifically, it describes the eligibility criteria, participant characteristics, measures, procedures for recruitment and data collection, and the screening of data. As chapters 5 – 7 are presented in their journal manuscript format, and given different reporting requirements and word limit constraints for journals, the following chapter provides a description of the entire thesis protocol.

Participants

Participants were recruited as part of the screening process for a larger in-home rehabilitation project targeting impairments in executive function and self-awareness after TBI. More information about this project can be found in the published protocol and RCT papers (Ownsworth et al., 2013; 2017). The larger in-home rehabilitation project was designed independently from the current dissertation. There was an overlap between some cognitive and psychosocial measures to be administered across both projects, and so to reduce burden on participants, as well as for efficiency of data collection, data for both projects were collected at the same time. Potential participants were identified by treating therapists or case managers in two metropolitan-based brain injury rehabilitation services in Brisbane, Australia, and one further rehabilitation service in Sydney, Australia. These services were: Brain Injury Rehabilitation Unit (BIRU) Day Hospital, Princess Alexandra Hospital – a public outpatient rehabilitation service; Acquired Brain Injury Outreach Service (ABIOS), Metro South Health – a public, community case management service; and Royal Rehab Private – a private community rehabilitation service (Sydney). Flyers and information sheets were also distributed through brain injury community organisations. Participants were recruited according to the following inclusion criteria:

- Aged between 18 and 65 years;
CHANGES TO SELF AFTER TBI

- Have a medical diagnosis of severe TBI within the last 15 years. TBI severity was determined by posttraumatic amnesia duration (>7 days) and/or Glasgow Coma Scale (<9/15) score;
- Live within a 100 km radius of each metropolitan centre where the study took place, to enable a face-to-face assessment; and

The exclusion criteria were as follows:

- Lacks the cognitive capacity to provide informed consent;
- Displays significant behavioural concerns (e.g., severe aggression);
- A severe sensory/perceptual/motor or language disorder (e.g., severe aphasia) that would limit their ability to partake in the study; and/or
- Major current psychiatric disorder not under effective management.

In total, 81 participants were referred to the broader study; of which 59 consented to participate in the PhD research. Figure 4.1 presents a flow diagram of participants and reasons for study exclusion. As shown, the sample sizes across the three empirical studies varied (i.e., n = 51 – 59), due to significant sensory/perceptual/language impairments impacting some participants’ ability to complete the neuropsychological assessment (Study 2), inability to collect certain data from participants at the Sydney site (Study 3) and significant fatigue preventing completion of the required questionnaires (Study 3).
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Assessed for eligibility \((n = 81)\)

Excluded \((n = 22)\)
- Mild-moderate TBI or sig. mental health condition not under effective management \((n = 9)\)
- Unable to be contacted after initial verbal consent \((n = 5)\)
- Did not consent \((n = 8)\)

Data available for Study 2 \((n = 54)\)
- Significant sensory/perceptual or language impairments, unable to complete tests \((n = 3)\)

Data available for Study 3 \((n = 51)\)
- Unable to collect these data from Sydney participants \((n = 6)\)
- Significant fatigue \((n = 2)\)

Data available for Study 4 \((n = 59)\)

Figure 4.1 Participant flow diagram

Measures

The selection of measures administered in studies 2 – 4 was based on several considerations, including: theoretical underpinning (i.e., measuring the construct of interest), adequate psychometric properties and demonstrated validity within the TBI population, and brevity and ease of administration to reduce fatigue/burden on participants. For example, for the psychological constructs questionnaire-based approaches that minimise reliance on verbal retrieval and fluency (e.g., open-ended questions) were considered to be most appropriate for individuals with severe TBI. Clinicians from the primary recruiting site (BIRU) were also consulted on measurement choice, to avoid overlap of commonly used measures. Based on the systematic literature review (Beadle et al., 2016) in Study 1, the measure of self-discrepancy that best matched these criteria was the HISD-III. Table 4.1 outlines the measures used to assess key constructs in chapters 5 – 7 and the reliability and validity of the measure.
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Please refer to Appendix B for full versions of the non-copyrighted self-report questionnaires.

The neuropsychological tests were administered first (in order indicated), followed by the questionnaires. Internal consistency of each questionnaire for the current TBI sample is reported in Table 4.1.
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Measures Administered in the Empirical Studies (Studies 2 – 4) of the Thesis

<table>
<thead>
<tr>
<th>Measure</th>
<th>Chapter</th>
<th>Construct assessed</th>
<th>Psychometric properties</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive assessment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Benedict et al., 1998)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trail Making Test (Army Individual Test Battery, 1944)</td>
<td>5</td>
<td>Executive functioning – cognitive flexibility</td>
<td>Reported reliability coefficients vary considerably, however most are above .60 and many in the .80s and .90s (Spreen &amp; Strauss, 1998). Both Trails A and B have been found to be sensitive to injury severity (Dikmen, Machamer, Winn, &amp; Temkin, 1995; Lange, Iverson, Zakrzewski, Ethel-King, &amp; Franzen, 2005)</td>
</tr>
<tr>
<td>Zoo Map (Wilson, Alderman, Burgess, Emslie, &amp; Evans, 1996)</td>
<td>5</td>
<td>Planning</td>
<td>The Zoo Map has shown reliability and validity for use in neurological populations, including TBI (Norris &amp; Tate, 2000).</td>
</tr>
<tr>
<td>Hopkins Verbal Learning Test – Revised. Delayed Trial</td>
<td>5</td>
<td>Verbal memory (delayed)</td>
<td></td>
</tr>
<tr>
<td>(Benedict et al., 1998)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Digit Span (Wechsler, 1997)</td>
<td>5</td>
<td>Working memory</td>
<td>The Digit Span subtest of the Wechsler Intelligence Scale, 3rd edition (WAIS-III) has demonstrated excellent internal consistency (.90+) and validity as a measure of working memory within the TBI population (Strauss, Sherman, &amp; Spreen, 2006)</td>
</tr>
<tr>
<td>Modified Stroop (Spreen &amp; Strauss, 1998)</td>
<td>5</td>
<td>Inhibitory control</td>
<td>Acceptable reliability and validity has been demonstrated (MacLeod, 1991), including sensitivity to the effects of TBI (Dodrill, 1978; Golden, 1976).</td>
</tr>
<tr>
<td>Controlled Oral Word Association Test (Benton &amp; Hamsher, 1978)</td>
<td>5</td>
<td>Verbal fluency</td>
<td>Test-retest reliability found to be adequate: ranging from .67 to .88 (Spreen &amp; Strauss, 1998). It has been validated as a measure of fluency with individuals with TBI (Henry &amp; Crawford, 2004).</td>
</tr>
<tr>
<td><strong>Psychosocial Questionnaires</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Head Injury Semantic Differential Scale – Version 3</td>
<td>5, 6, 7</td>
<td>Self-concept (past, present); self-discrepancy</td>
<td>Internal consistency has been reported as excellent (α = .92-.93; Carroll &amp; Coetzter, 2011); responsiveness to change has been reported (Vickery, Gontkovsky, Wallace, &amp; Caroselli, 2006); convergent validity demonstrated with the Rosenberg Self Esteem Scale (Rosenberg, 1965) and the Brain Injury Grief Inventory (Coetzter et al., 2003);</td>
</tr>
<tr>
<td>(Tyerman &amp; Humphrey, 1984); 18 items</td>
<td></td>
<td></td>
<td>Current sample: Internal consistency: past (α = 0.94) and present (α = 0.95) self-ratings;</td>
</tr>
<tr>
<td>Marlow Crowne Social Desirability Scale – short form</td>
<td>6</td>
<td>Personality; Defensiveness</td>
<td>The original scale has been used as a measure of defensiveness in brain injury research (Gisi &amp; D'Amato Carl, 2000; Ownsworth, 2005; Ownsworth et al., 2007; Ownsworth, McFarland, &amp; Young, 2002).</td>
</tr>
<tr>
<td>(Reynolds, 1982); 13 items</td>
<td></td>
<td></td>
<td>Current sample: Internal consistency: α = .71</td>
</tr>
</tbody>
</table>
## CHANGES TO SELF AFTER TBI

<table>
<thead>
<tr>
<th>Measure</th>
<th>Items</th>
<th>Subscale</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational Gaps Questionnaire (Eriksson, Tham, &amp; Borg, 2006); 30 items</td>
<td>7</td>
<td>Occupational gaps and re-engagement</td>
<td>Acceptable reliability (determined via Rasch analysis) and validity for different diagnostic groups, including acquired brain injury (Eriksson, Tham, &amp; Kottorp, 2013)</td>
</tr>
<tr>
<td>Current sample: Internal consistency: Current activity participation $\alpha = .88$; Desired activity participation $\alpha = .82$.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping Resources Questionnaire (Riley, Dennis, &amp; Powell, 2010); 24 items</td>
<td>6</td>
<td>Perceived coping resources</td>
<td>Excellent internal consistency ($\alpha = .91$) reported for the TBI population (Riley et al., 2010).</td>
</tr>
<tr>
<td>Current sample: Internal consistency: $\alpha = .90$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appraisal of Threat &amp; Avoidance Questionnaire (Riley et al., 2004); 36 items</td>
<td>6</td>
<td>Threat appraisals</td>
<td>Riley and colleagues (2004) reported excellent internal consistency for overall threat appraisals ($\alpha = .92$); evidence of construct validity (Shields, Ownsworth, O'Donovan, &amp; Fleming, 2015).</td>
</tr>
<tr>
<td>Current sample: Internal consistency: $\alpha = .90$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reflection and Rumination Questionnaire (Trapnell &amp; Campbell, 1999); 24 items</td>
<td>6</td>
<td>Reflection and rumination</td>
<td>The authors reported excellent internal consistency ($\alpha = .90$ for rumination; $\alpha = .91$ for reflection) and construct validity through factor analysis (Trapnell &amp; Campbell, 1999).</td>
</tr>
<tr>
<td>Current sample: Internal consistency: rumination $\alpha = .95$; reflection $\alpha = .86$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life Orientation Test (Scheier &amp; Carver, 1985b); 10 items</td>
<td>6</td>
<td>Personality: optimism</td>
<td>Adequate internal consistency reported in a TBI sample ($\alpha = .70$; Peleg et al., 2009).</td>
</tr>
<tr>
<td>Current sample: Internal consistency: $\alpha = .84$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression, Anxiety, and Stress Scales – 21 items (Lovibond &amp; Lovibond, 1995)</td>
<td>7</td>
<td>Depression, anxiety, and stress symptoms</td>
<td>Internal consistency: Depression $\alpha = .93$; Anxiety $\alpha = .85$; Stress $\alpha = .90$; construct validity supported by factor analysis and convergent validity with the Hospital Anxiety and Depression Scale (Dahm, Wong, &amp; Ponsford, 2013)</td>
</tr>
<tr>
<td>Current sample: Internal consistency: Depression $\alpha = .94$; Anxiety $\alpha = .85$; Stress $\alpha = .93$;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Awareness Questionnaire (Sherer et al., 1998); 17 items; self and relative rated</td>
<td>6</td>
<td>Intellectual awareness</td>
<td>Internal consistency: $\alpha = .88$ (Sherer et al., 1998); convergent validity demonstrated with the Patient Competency Rating Scale (Hellebrekers, Winkens, Kruiper, &amp; Van Heugten, 2017)</td>
</tr>
<tr>
<td>Current sample: Internal consistency: self-ratings $\alpha = 0.86$; caregiver $\alpha = 0.89$</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sydney Psychosocial Reintegration Scale – Relative form (Tate et al., 2012); 12 items</td>
<td>7</td>
<td>Psychosocial reintegration</td>
<td>Internal consistency: $\alpha = .87$; inter-rater reliability: ICC = .84; test-retest reliability: $r = .90$ (Tate et al., 2012); demonstrated concurrent validity with other re-integration questionnaires, including the Community Integration Questionnaire (Kuipers, Kendall, Fleming, &amp; Tate, 2004)</td>
</tr>
<tr>
<td>Current sample (caregivers): Internal consistency: $\alpha = .90$</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
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**Procedure**

Ethical clearance for this project was granted from the Metro South Human Research Ethics Committee (HREC/13/QPAH/096), Griffith University (PSY/55/13/HREC), and the University of Queensland (2013000598). A site specific assessment form was completed and granted for the Princess Alexandra Hospital/Metro South, Brisbane (SSA/13/QPAH/107) and Royal Rehab, Sydney (14SSA/03). The participant information sheet and original Metro South ethics approval letter can be viewed in Appendix A.

Eligible participants were identified by treating therapists or case managers in one outpatient and two community brain injury rehabilitation services, from July 2013 – May 2016. These individuals were approached by their therapist or case manager who provided a brief summary of the study and asked them to provide initial verbal consent for the project coordinator (Elizabeth Beadle) to contact them about the study.

Following informed consent procedures, the researcher visited participants in their homes to conduct the assessment. The assessment involved completing the neuropsychological tests and questionnaires as outlined in Table 4.1. The participant’s primary caregiver completed the AQ and SPRS in person or over the telephone. The majority of participants completed all measures face-to-face, and the HISD-III was always administered face-to-face. However, due to time scheduling issues or fatigue some participants completed the remaining questionnaires at a later date (within one week) via telephone with the questions presented orally by the researcher. The assessments took between 2.5 and 5 hours to complete, including other measures given for the purposes of the larger rehabilitation project. Demographic information and medical history were collected from the treating clinician or case manager.

**Data screening**

All data were entered and analysed using SPSS Version 24. Data were screened for missing or incorrect values, univariate and multivariate outliers, violations of normality,
homogeneity of variance, linearity, multicollinearity and homoscedasticity. Five participants were unable to complete the neuropsychological tests due to significant sensory/perceptual impairments (see Figure 4.1). In relation to the self-report questionnaires, one participant did not complete the ATAQ and the RRQ due to experiencing significant distress (note: support and follow-up was provided); two participants did not complete the Marlow-Crowne due to time constraints. Mean replacement scores were utilized for these participants. One data entry error for an AQ score was identified. After checking the original questionnaire, this entry was corrected to reflect the true score. For correlation analyses, transformations (square root or logarithmic) were performed as necessary to address violations of normality, as per guidelines by Tabachnick and Fidell (2007). For the regression analyses, a multivariate outlier was identified in study 2. It was determined that this outlier’s removal did not affect significance and so it was retained in the analyses. Specific statistical analyses performed are discussed in detail for each of the studies in the chapters to follow.
Chapter 5: Statement of Contribution and Co-Authored Published Paper


This chapter includes a co-authored paper which has been published in an international peer reviewed journal. This has been included as published with the exception of changes to style and formatting of headings, tables and figures to maintain consistency throughout the thesis. The bibliographic details of the co-authored paper, including all authors, are: Dr Elizabeth Beadle, Professor Tamara Ownsworth, Professor Jennifer Fleming, and Professor David Shum. The candidate’s contribution to the paper involved conception of the study design, literature review, data collection and analyses, and writing of the manuscript. The co-authors contributed to the conception of the study, provided feedback on manuscript drafts/revisions and approved the final manuscript and revisions requested by the journal.

Name of student: Elizabeth Beadle

*Names of corresponding authors of paper:*

Professor Tamara Ownsworth (Primary Supervisor)

Professor Jennifer Fleming (External Supervisor)

Professor David Shum (Associate Supervisor)
Introduction

Traumatic brain injury (TBI) is particularly common in early adulthood, (Bryan-Hancock & Harrison, 2010; Helps, Henley, & Harrison, 2008) which is a pivotal life period for establishing one’s career, independence and relationships. Severe TBI can have a multitude of physical, cognitive, psychological, and social consequences. At a deeper level, TBI can alter people’s self-knowledge and understanding of their self-identity (Ben-Yishay, 1996; Ben-Yishay & Prigatano, 1990; Gracey & Ownsworth, 2012; Ownsworth, 2014). Individuals often view their post-injury selves in a more negative light compared to their pre-injury selves, a phenomenon referred to as “self-discrepancy” (Cantor et al., 2005). However, it is unclear how the neurocognitive consequences of TBI (e.g., impairments in attention, memory, executive functioning and self-awareness) influence this self-comparison process. Accordingly, this study aimed to examine the relationship between neurocognitive function and self-discrepancy following TBI.

Self-identity is a complex and nebulous term, which can be broadly defined as the collective bodily and internal psychological characteristics we perceive as our own, which endure over time and are continuously under construction (Ownsworth, 2014). Conceptually, self-identity is closely related to self-concept, or the overarching thoughts and feelings a person has about him or herself, and self-esteem which represents an evaluative component regarding one’s own worth or value (Rosenberg, 1965). Self-identity is related to but distinct from self-awareness which, in the context of TBI, refers to the accuracy of perceptions of one’s own abilities relative to a presumably more objective account (e.g., relative’s reports). Conversely, self-identity is an inherently subjective construction that cannot be reported or verified by others (Ownsworth, 2014). Changes to self-identity after TBI have been measured by comparing perception of self-concept before and after injury (Beadle et al., 2016).
CHANGES TO SELF AFTER TBI

A systematic review by Beadle and colleagues (2016) identified that changes in self-concept are commonly reported after TBI (see also Curvis, Simpson, & Hampson, 2016), and that negative self-discrepancy (i.e., past self-concept rated more positively than current self-concept) is associated with greater psychological distress (Cantor et al., 2005; Carroll & Coetzer, 2011; Wright & Telford, 1996). The review found that level of self-discrepancy was not significantly related to demographic factors or injury severity; however, the influence of neurocognitive function on self-discrepancy could not be determined due to a lack of research. In a subsequent study involving 50 individuals with mixed severity of TBI, Reddy and colleagues (Reddy, Ownsworth, King, & Shields, 2017) reported that poorer performance on a verbal fluency task was associated with more negative self-discrepancy. The authors surmised that impairments in language and executive function reduced people’s capacity to participate in personally meaningful activities, which in turn disrupted their sense of inner sameness or self-continuity after TBI.

According to social neuroscience perspectives, self-concept is influenced by a myriad of biological and social factors (Mograbi, Brown, & Morris, 2009). For instance, neural networks and associated cognitive processes support people’s self-reflective capacity and sense of inner sameness over time (Northoff, Qin, & Feinberg, 2011; Stuss & Alexander, 2007). The medial temporal and frontal lobes, posterior cingulate and retrosplenial cortex, and lateral parietal and temporal areas have been implicated in recollection of past and imagining one’s future (Schacter et al., 2012), while the medial prefrontal cortex has been consistently implicated in self-monitoring (Ham et al., 2013; Stuss & Alexander, 2007). Collectively, these brain regions support both lower-order (e.g., attention, memory, basic language) and higher-order (e.g., executive functions, self-awareness) neurocognitive processes (Gracey & Ownsworth, 2008; Ownsworth, 2014; Stuss, Picton, & Alexander, 2001). Thus, an integrated neural circuitry supports the stability of self-concept or continuity between one’s past, present and future selves.
Yet, changes in self-concept can occur in response to many life experiences, including neurological disorder and major life events and transitions. Severe TBI is associated with diverse neurocognitive impairments as well as changes to activity participation and social roles (e.g., inability to work). As self-awareness of such changes develops and consistent differences in abilities and behaviors are noticed, individuals begin to update their self-knowledge (Dirette, Plaisier, & Jones, 2008). This process can be distressing, and while individuals lacking this ability to self-reflect may be spared initial suffering, they are at risk of helplessness as they experience repeated goal failure without comprehension (Ben-Yishay, 1996, 2000).

It has been theorized that the development of self-awareness after TBI relies upon people noticing difficulties with their performance, retaining these experiences, recalling their pre-injury functioning in similar situations, and comparing their current performance with their pre-injury abilities (Ownsworth, 2014; Toglia & Kirk, 2000). Impairments in attention, memory and executive functioning can therefore affect the accuracy of people’s self-appraisal. Therefore, impaired self-awareness and other cognitive functions may reduce the likelihood of people experiencing a mismatch between their pre-injury and current self-concept (i.e., who I was and who I am now). Changes in self-schema reflects a deeper level of processing about one’s self whereby the meaning derived from everyday experiences challenges existing self-perceptions (Gracey & Ownsworth, 2012). This requires people to monitor, recall and reflect upon their performance across multiple situations. Neurocognitive impairments may disrupt or impede the higher-order processes that contribute to self-discrepancy; however, this has yet to be empirically investigated.

Models of adjustment to brain injury highlight how self-awareness and negative self-discrepancy can serve as a catalyst for change in rehabilitation, whereby people are more motivated to set appropriate goals and engage strategies to improve post-injury impairments (Gracey et al., 2009). An understanding of the neurocognitive basis of self-discrepancy has
implications for rehabilitation approaches that can support people to develop a realistic and adaptive self-identity after brain injury. Accordingly, this study aimed to examine the relationship between neurocognitive function and self-discrepancy in individuals with severe TBI. It was hypothesised that individuals with poorer self-awareness, attention, memory and executive function would experience less self-discrepancy or fewer negative changes in self-concept.

**Methods**

**Participants**

Participants were recruited as part of a broader research project evaluating the efficacy of a home-based cognitive rehabilitation program for individuals with TBI (Ownsworth et al., 2013). Participants were recruited from two metropolitan-based hospitals and a community service supporting people with TBI. They were screened by their treating team according to the following inclusion criteria: 1) aged 18-65 years; 2) have a medical diagnosis of severe TBI (Glasgow Coma Scale ≤9/15 and/or duration or posttraumatic amnesia >7 days); and 3) live within a 100km radius of the metropolitan center. The exclusion criteria were: unable to provide informed consent; displayed significant behavioral concerns (e.g., aggression) or a combination of severe sensory/perceptual/motor and language impairments that would preclude their participation in the study (i.e., completion of neuropsychological tests and questionnaires); and a major current psychiatric disorder (e.g., psychosis or substance abuse) not under effective management.

Of the 79 participants initially referred during the recruitment period (July 2013-2016), 54 were eligible and consented to participate in the study. Twenty-five participants did not participate for the following reasons: not eligible (too low in functioning = 7, severe mental health concerns not under effective management = 3, sustained a moderate TBI = 2), declined to participate (n = 7), and unable to contact following initial verbal consent (n = 6).
Table 5.1 presents the demographic and injury-related characteristics of the TBI sample. Participants were typically male (72%), aged between 18 and 64 years ($M = 36.87, SD = 13.40$), and had sustained a severe TBI on average 33.48 months ($SD = 42.20$) prior to the study. The main causes of TBI included traffic accidents (59%), falls (26%) and assaults (9%). Most participants (87%) had diffuse/multiple lesions as determined by CT or MRI scan at time of injury.

Table 5.1

**Demographic and Injury-Related Characteristics of the TBI Sample** ($n = 54$)

<table>
<thead>
<tr>
<th>Variable</th>
<th>M ($SD$), range; N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>36.87 (13.4), 18-64</td>
</tr>
<tr>
<td>Gender (male)</td>
<td>39 (72%)</td>
</tr>
<tr>
<td>Education (years)</td>
<td>12.87 (2.5), 8 – 18</td>
</tr>
<tr>
<td>Premorbid Intelligence (WTAR)</td>
<td>95.70 (13.8), 69 – 117</td>
</tr>
<tr>
<td>GCS</td>
<td>5.40 (3.1), 3 – 14</td>
</tr>
<tr>
<td>PTA duration (in days)</td>
<td>64.35 (64.4), 1 – 140</td>
</tr>
<tr>
<td>Relationship status (current)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>17 (32%)</td>
</tr>
<tr>
<td>In a relationship</td>
<td>4 (7%)</td>
</tr>
<tr>
<td>Single</td>
<td>33 (61%)</td>
</tr>
<tr>
<td>Previous psychological history (self-reported)</td>
<td>21 (39%)</td>
</tr>
<tr>
<td>Previous substance (drug and alcohol) abuse</td>
<td>13 (24%)</td>
</tr>
<tr>
<td>Time since injury (months)</td>
<td>33.48 (42.2), 2 – 204</td>
</tr>
<tr>
<td>Occupational status (prior to injury)</td>
<td></td>
</tr>
<tr>
<td>Full time work</td>
<td>37 (68%)</td>
</tr>
<tr>
<td>Part time/Casual</td>
<td>8 (15%)</td>
</tr>
<tr>
<td>Volunteer</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Student</td>
<td>8 (15%)</td>
</tr>
</tbody>
</table>
### CHANGES TO SELF AFTER TBI

<table>
<thead>
<tr>
<th>Occupational status (current)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Full time work</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Part time/Casual</td>
<td>3 (6%)</td>
</tr>
<tr>
<td>Volunteer</td>
<td>6 (11%)</td>
</tr>
<tr>
<td>Student</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>41 (76%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lesion location (CT/MRI)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Diffuse/multiple</td>
<td>47 (87%)</td>
</tr>
<tr>
<td>Frontal</td>
<td>5 (9%)</td>
</tr>
<tr>
<td>Temporal</td>
<td>2 (4%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cause of injury</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>MVA/MBA/Pushbike – driver</td>
<td>18 (33%)</td>
</tr>
<tr>
<td>MVA/MBA – passenger</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Assault</td>
<td>5 (9%)</td>
</tr>
<tr>
<td>Pedestrian/bike vs vehicle</td>
<td>12 (22%)</td>
</tr>
<tr>
<td>Fall</td>
<td>14 (26%)</td>
</tr>
<tr>
<td>Sports related</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Object falling</td>
<td>1 (2%)</td>
</tr>
</tbody>
</table>

GCS = Glasgow Coma Scale; PTA = Post Traumatic Amnesia; WTAR = Wechsler Test of Adult Reading

### Measures

All measures have been validated for use with individuals with TBI. The cognitive battery was designed to measure attention, memory, and executive functions, while the questionnaires assessed self-awareness and self-discrepancy. Scores were converted using age-based normative data for all cognitive tasks (excluding the AQ and the Zoo Map).
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Self-discrepancy

*Head Injury Semantic Differential Scale (HISD)-III*: The Head Injury Semantic Differential Scale (HISD)-III (Tyerman & Humphrey, 1984) utilizes a semantic differential rating method (Osgood, Suci, & Tannenbaum, 1957). It consists of 18 bipolar adjective pairs (e.g., bored – interested; unhappy – happy; inactive – active) rated on a 7-point scale from 1 to 7, where higher scores reflect more positive views of self. Total scores range from 18–126. For the purposes of this study, two self-views were examined: 1) past self (6 months prior to injury); and 2) present self (over the last few days). Discrepancy scores were calculated between total scores of past and present self-ratings. A negative self-discrepancy score is indicative of more positive ratings of past self than present self. The HISD is the most commonly used scale to measure self-discrepancy after TBI (Tyerman & Humphrey, 1984) and has demonstrated excellent internal consistency (Cronbach α = .92–.93) and convergent validity (Carroll & Coetzer, 2011). Internal consistency of the HISD-III for the current TBI sample was also excellent for past (α = .94) and present (α = .95) self-ratings.

Cognition

*Hopkins Verbal Learning Test-Revised (HVLT-R; Benedict et al., 1998)*: a list learning task (repeated twice, three trials in total), comprised of 12 semantically related words (e.g., gem stones, animals). For this study, two indices were used: 1) total immediate recall, as a measure of new verbal learning, and 2) delayed recall, as a measure of long-term verbal memory.

*Trail Making Test (TMT; Army Individual Test Battery, 1944)*: a timed pencil and paper test, measuring visual attention and processing speed (Trails A) and cognitive flexibility (Trails B). For this study, Trails B was utilized as a measure of executive functioning.

*Digit Span*: a measure of auditory attention and working memory. The version used in this study was drawn from the Wechsler Adult Intelligence Scale-Third Edition (Wechsler, 1997).
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*Modified Stroop Test:* a measure of selective attention, set shifting, and inhibitory control (Spreen & Strauss, 1998). The time taken on Trial 3 (seconds) was converted to an age-adjusted Z-score and utilized as an index of inhibitory control.


*Zoo Map:* a subtest from the Behavioral Assessment of the Dysexecutive Syndrome (BADS; Wilson et al., 1996). It investigates planning ability and rule following. A total raw score is converted to a profile score of 0 – 4.

*Awareness Questionnaire (AQ):* a 17-item scale designed to assess self-awareness of deficits across sensory, physical, cognitive, and behavioral domains (Sherer et al., 1998). Internal consistency of the AQ for the current sample was good (patient $\alpha = .86$; caregiver $\alpha = .89$).

**Procedure**

Ethical clearance for this study was gained from both hospital and university research ethics committees. Potential participants were identified by treating occupational therapists or case managers in two metropolitan-based brain injury rehabilitation services in Brisbane, Australia, and a rehabilitation service in Sydney, Australia. Demographic and injury-related information were collected via self-reports and medical reports. Data were collected across two sessions. Session one included the neuropsychological tests administered in the person’s home. Session two included self-report questionnaires completed over the telephone or face-to-face during a home visit. Caregivers (46% parent, 24% spouse, 19% other family/friend, and 11% paid caregiver) completed the AQ during the home visit, or over the telephone.

**Data analysis**

All data were entered into SPSS (version 23) and screened and managed for missing values and relevant assumptions of parametric analyses in accordance with Tabachnick and Fidell (2007). Previous research investigating associations between self-awareness or
executive function and self-concept in individuals with TBI (Anson & Ponsford, 2006a; Shields et al., 2015), yielded medium to large effect sizes ($r = .35-.50$). An a priori power calculation conducted using G*Power (Faul, Erdfelder, Buchner, & Lang, 2009), identified that a minimum sample size of approximately 44 participants was required ($r = .40$, power = .80 and alpha set at .05, two-tailed). Bivariate correlation analyses were used to investigate associations between the neurocognitive variables and self-discrepancy on the HISD.

Subsequently, a linear regression analysis was conducted to examine the relative contribution of neurocognitive variables in accounting for self-discrepancy. A minimum participant-to-variable ratio of 10:1 was adopted for the regression analysis.

**Results**

**Descriptive data on neurocognitive function and self-discrepancy**

Table 5.2 presents the descriptive data for the neurocognitive measures and HISD. On average, individuals rated their past self more positively than their current self ($t = 3.60, p<.001$), which produced a negative mean self-discrepancy score ($M = -13.06, SD = 26.6$). Participants’ average performance on the neurocognitive tests was well below the normative mean, although scores were highly variable. Furthermore, participants typically rated their functioning on the AQ as higher than their significant others, thus indicating impaired self-awareness ($M = -9.94, SD = 9.8$).
Table 5.2

Descriptive Data for Measures of Neuro-Cognitive Function and Self-Discrepancy

<table>
<thead>
<tr>
<th>Domain (Measure)</th>
<th>Raw scores</th>
<th>Age-adjusted/Standard scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td>Self-identity (HISD-III)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Past-self</td>
<td>97.35 (17.8)</td>
<td>-</td>
</tr>
<tr>
<td>Current-self</td>
<td>84.30 (22.8)</td>
<td>-</td>
</tr>
<tr>
<td>Self-discrepancy</td>
<td>-13.06 (26.6)</td>
<td>-</td>
</tr>
<tr>
<td>Verbal Memory (HVLT-R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Immediate new learning</td>
<td>19.81 (5.7)</td>
<td>Z = -2.39 (1.5)</td>
</tr>
<tr>
<td>Delayed recall</td>
<td>5.91 (3.2)</td>
<td>Z = -2.72 (1.9)</td>
</tr>
<tr>
<td>Executive functioning</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working memory (Digit span)</td>
<td>15.47 (4.2)</td>
<td>SS = 8.89 (3.0)</td>
</tr>
<tr>
<td>Planning (Zoo Map) a</td>
<td>-</td>
<td>1.37 (1.2)</td>
</tr>
<tr>
<td>Cognitive flexibility (TMT: B)</td>
<td>133.02 (85.6)</td>
<td>Z = -3.51 (4.4)</td>
</tr>
<tr>
<td>Inhibitory control (MST)</td>
<td>35.31 (19.7)</td>
<td>Z = -1.36 (2.2)</td>
</tr>
<tr>
<td>Verbal fluency (COWAT)</td>
<td>30.26 (12.7)</td>
<td>Z = -1.04 (1.2)</td>
</tr>
<tr>
<td>Awareness (AQ)</td>
<td>-9.94 (9.8)</td>
<td>-</td>
</tr>
</tbody>
</table>

*The profile score is reported for Zoo Map. AQ = Awareness Questionnaire; COWAT = Controlled Oral Word Association Test; HISD-III = Head Injury Semantic Differential Scale-III; HVLT-R = Hopkin Verbal Learning Test-Revised; MST = Modified Stroop Test; TMT: Trail Making Test; SS = scaled scores

Associations between neurocognitive function and self-discrepancy

There were no significant associations between age, gender, injury severity, time since injury, and estimated premorbid intelligence (WTAR) and the HISD, and so these variables were not included in subsequent analyses. As shown in Table 5.3, individuals reporting more negative self-discrepancy on the HISD had better immediate memory (r = -
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.43, p<.01), working memory (r = -.35, p<.05), verbal fluency (r = -.34, p<.05), and self-awareness (r = -.40, p<.01). A standard multiple regression analysis was conducted to determine the relative contribution of the four neurocognitive variables to self-discrepancy. The regression analysis revealed that together these variables accounted for 28.3% of the variance in HISD discrepancy scores $F(4,49) = 4.83, p<.01$. Only self-awareness was significantly related to self-discrepancy and accounted for unique variance in this model ($\beta = .31$, 95% CI [.15, 1.51], $r^2 = .086$, p<.05).

Table 5.3

*Correlations between Measures of Cognitive Functioning, Self-Awareness, and Self-Discrepancy*

<table>
<thead>
<tr>
<th>Measure of Cognitive Functioning</th>
<th>HISD (self-discrepancy)</th>
<th>HISD Past</th>
<th>HISD Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hopkins Verbal Learning Test – Revised (immediate)</td>
<td>-0.43**</td>
<td>0.30*</td>
<td>-0.26</td>
</tr>
<tr>
<td>Hopkins Verbal Learning Test – Revised (delayed)</td>
<td>-.26</td>
<td>.19</td>
<td>-.16</td>
</tr>
<tr>
<td>Trail Making Test – B</td>
<td>-.24</td>
<td>08</td>
<td>-.22</td>
</tr>
<tr>
<td>Zoo Map (Profile score)</td>
<td>-.16</td>
<td>.18</td>
<td>-.04</td>
</tr>
<tr>
<td>Digit Span</td>
<td>-.35*</td>
<td>0.22</td>
<td>-.24</td>
</tr>
<tr>
<td>Controlled Oral Word Association Test</td>
<td>-.34*</td>
<td>.25</td>
<td>-.21</td>
</tr>
<tr>
<td>Modified Stroop Test (interference score)</td>
<td>-.25</td>
<td>.41**</td>
<td>.02</td>
</tr>
<tr>
<td>Awareness Questionnaire discrepancy score</td>
<td>-.40**</td>
<td>.10</td>
<td>-.40**</td>
</tr>
</tbody>
</table>

HISD = Head Injury Semantic Differential Scale; *p < .05; **p < .01

Testing a mediating effect of self-awareness

Given the finding that immediate memory, working memory and verbal fluency were no longer significantly related to self-discrepancy with self-awareness in the model, the potential mediating effect of self-awareness was examined. Preliminary correlations
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identified a significant positive correlation between self-awareness and immediate memory ($r = .28, p < .05$), but not between self-awareness and working memory or verbal fluency ($p > .05$). A mediation model was tested with immediate memory as the independent variable, self-awareness as the mediator and self-discrepancy as the dependent variable. Preacher and Hayes’ (2004) bootstrapping method was utilized as this method is non-parametric and can be applied to smaller sample sizes. The PROCESS macro (A. Hayes, 2012) was employed with 1,000 bootstrap samples. In this analysis, mediation is deemed significant if the 95% confidence intervals for the indirect effect do not include 0. As shown in Figure 5.1, there was a significant total effect of immediate memory and self-awareness on self-discrepancy, $R^2 = .26, F = 9.17, p < .001$. Both the direct effect (DE) of immediate memory on self-discrepancy (DE = -5.92; lower CI = -10.25, upper CI = -1.60), and the indirect effect (IE) through the mediator of self-awareness (IE = -1.42; lower CI = -3.83, upper CI = -.11), were significant. These findings signify partial mediation, whereby individuals with poorer immediate memory experienced less self-discrepancy in part because they had lower self-awareness.

![Diagram of mediation model](image)

* $p < .05$
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Associations between neurocognitive function and past and current self-concept

A final exploratory analysis was conducted to understand factors influencing the self-perceptions that underlie self-discrepancy. Specifically, associations between the neurocognitive variables and ratings of past self and current self on the HISD were examined. More positive ratings of past self were related to better immediate memory ($r = .30, p < .05$) and inhibitory control ($r = .41, p < .01$). Self-awareness was negatively correlated with current self ($r = -.40, p < .01$), indicating that individuals who were more aware of their deficits had poorer self-concept. There were no other significant associations between the neurocognitive variables and ratings of past and current self ($p > .05$).

Discussion

Research indicates that individuals with TBI report negative changes in their self-concept which are associated with greater depression and anxiety (Beadle et al., 2016). To improve understanding of psychological adjustment to TBI, the present study aimed to investigate the impact of neurocognitive impairments on self-discrepancy. In support of the hypothesis, individuals with poorer immediate and working memory, verbal fluency and self-awareness reported less self-discrepancy or fewer negative changes to their self-concept. Self-awareness partially mediated the relationship between immediate memory and self-discrepancy, suggesting that better short-term recall of experiences supports the process of updating self-knowledge, which in turn contributes to self-discrepancy.

Consistent with previous TBI research (Cantor et al., 2005; Reddy et al., 2017), participants in the current study typically rated their post-injury self less favorably than their pre-injury self. Measures of self-discrepancy and self-awareness were significantly related ($r = -.40$); however, there was still considerable unique variance not accounted for by their relationship. The finding that negative self-discrepancy was associated with increased self-awareness and better memory (immediate and working memory) and executive function (verbal fluency) provides empirical support for Gracey and Ownsworth’s (2012) theoretical
account of self-identity change after brain injury. They theorized that neurocognitive impairments interfere with self-comparison processes (i.e., monitoring, reflecting and updating) that elicit a sense of discrepancy between one’s pre-injury and post-injury selves. These findings that immediate memory and self-awareness are central to updating self-knowledge following TBI also resonates with Conway’s account of the self-memory system whereby memories are considered the “database” of the self (Conway, 2005; Conway & Pleydell-Pearce, 2000).

Such findings also support theoretical perspectives on anosognosia and identity in the context of dementia (Agnew & Morris, 1998; Mograbi et al., 2009), which aim to account for people’s lack of recognition of changes in their abilities in the face of marked functional decline. Impaired self-awareness has been attributed to a failure to update self-knowledge, a phenomenon referred to as “the petrified self” (Stuss & Alexander, 2007). Naylor and Clare (2008) found that people with dementia who lacked awareness of their memory functioning had poorer autobiographical memory, yet they reported a more positive and definite sense of identity. They surmised that self-awareness and memory impairments buffer against the threats to sense of self posed by a progressive neurological condition. Considered alongside the present findings, more severe neurocognitive impairment may play a protective function in the adjustment to neurological disorder by limiting people’s awareness of distressing changes to their functioning.

Yet, theories on adjustment to brain injury highlight the importance of individuals developing self-awareness for coping effectively with their post-injury changes and setting achievable goals (Gracey et al., 2009; Ownsworth, 2014; Ylvisaker & Feeney, 2000). Indeed, a core aim of rehabilitation is to support people to make sense of and adapt to their impairments, activity limitations and lifestyle changes. Research indicates that better self-awareness is associated with greater gains in rehabilitation and more favorable long-term outcomes (Ownsworth & Clare, 2006). The process of becoming aware of new deficits and
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the eliciting of negative comparisons between pre-injury and post-injury self can play an integral role in supporting people to re-establish a positive and realistic identity after TBI. Although negative self-discrepancy is often associated with emotional distress initially, these perceptions can motivate people to engage in rehabilitation and develop effective ways to manage post-injury changes that over time help restore their self-esteem (Gracey et al., 2009). Conversely, denial of problems and avoidant coping is associated with poorer long-term psychological outcomes (Ownsworth, 2014).

Given the pivotal role of self-discrepancy in psychological adjustment to TBI, it is important to understand how neurocognitive impairments influence retrospective ratings of pre-injury self. The present findings indicated that better immediate memory and inhibitory control were conducive to more positive ratings of past self whereas positive ratings of current self were related to lower self-awareness. Retrospective ratings of one’s past requires access to and organization of self-knowledge, which is supported by memory and executive control processes (Conway, 2005). Coste and colleagues (Coste, Navarro, Vallat-Azouvi, & Brami, 2015) found that relative to controls, people with TBI had greater difficulty in both recalling their past (i.e., accessing personal semantic and episodic knowledge) and forming representations of themselves in the future. The ability to perform such mental “time-travel” has been linked to the left hippocampus and posterior visuospatial regions, which are often damaged by TBI (Canty et al., 2014; Huang et al., 2014). The present findings extend this view by suggesting that memory and inhibitory control deficits restrict access to past self-representations, requiring individuals with these impairments to draw upon their current self-perceptions to reconstruct who they were prior to their injury. This may account for their reduced self-discrepancy or greater consistency between ratings of past and current self.

In terms of clinical implications, the findings highlight the importance of supporting individuals with TBI who have better neurocognitive functions to make sense of discrepancies or perceived changes in their abilities and attributes. Psychotherapy can support
people to resolve self-discrepancies by developing effective ways to cope with post-injury changes that enable them to re-engage in meaningful everyday activities and form new expectations for the future (Gracey et al., 2009). This process promotes “self-integration” or the updating and consolidation of a positive and realistic self-identity (Ownsworth, 2014). For individuals with impaired self-awareness, it may be beneficial for training in compensatory strategies for memory impairment to be integrated with feedback interventions for self-awareness. Such approaches involve therapists providing structured feedback on performance on everyday tasks (e.g., meal preparation) to facilitate the development of self-awareness and use of compensatory strategies (Fleming et al., 2017; Ownsworth et al., 2013; Schmidt, Fleming, Ownsworth, & Lannin, 2013). Metacognitive approaches are not designed to elicit self-discrepancy, but rather aim to increase individuals’ acceptance of the need for strategies to enhance their performance which can foster more realistic goals. This approach has been found to improve self-awareness and self-regulation skills without eliciting emotional distress (Schmidt et al., 2013).

**Study limitations**

Several limitations of the present study may restrict the generalizability of the findings. First, participants with severe TBI were recruited as a part of a broader treatment study that screened for impaired self-awareness and executive dysfunction as inclusion criteria (Ownsworth et al., 2013); hence, the current sample may have more severe neurocognitive impairments than TBI samples recruited using more representative sampling approaches (e.g., consecutive admissions). Second, time since injury was quite variable (2–204 months post injury), which means that participants’ retrospective ratings of their pre-injury self-concept were made over a variable time interval. Although there was no significant association between time since injury and HISD ratings, differences in time since injury may obscure the interpretation of self-discrepancy data. Third, the HISD-III only assesses self-perceived emotional and behavioral attributes. While this tool was specifically
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developed for the TBI population and is well-validated, the HISD-III does not capture all domains relevant to self-understanding (e.g., physical, social, family, academic/work). The present findings need to be cross-validated in a more representative TBI sample using a multi-domain self-concept measure.

Overall, the current study advances understanding of the influence of neurocognitive impairment on self-discrepancy. In terms of future research, the role of psychological (e.g., personality and coping style) and social contextual factors in self-concept change after TBI is yet to be investigated. Research by Reddy et al. (2017) identified that cued recall of recent life events prior to completion of the HISD-III elicited positive self-discrepancies in healthy control participants. The effects of cued recall of salient personal information (e.g., functional impairments vs. personal strengths and achievements) on self-discrepancy is important to understand for individuals with TBI, and may guide therapy interventions for improving psychological adjustment.

Conclusion

In summary, this study identified that individuals with severe TBI who have better neurocognitive functions are more likely to experience negative self-discrepancy. Increased self-awareness was uniquely related to negative self-discrepancy and partially mediated the relationship between memory impairment and self-discrepancy. These findings highlight that memory and self-awareness are central to updating self-identity in the context of severe TBI. Further research investigating the role of psychological and social contextual factors in self-discrepancy is recommended.
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Chapter 6: Statement of Contribution and Co-authored Published Paper


doi: 10.1080/09602011.2018.1469416

This chapter includes a co-authored paper which has been published through an international peer reviewed journal. This has been inserted as published with the exception of changes to style and formatting of headings, tables and figures to maintain consistency throughout the thesis. The bibliographic details of the co-authored paper, including all authors, are: Dr Elizabeth Beadle, Professor Tamara Ownsworth, Professor Jennifer Fleming, and Professor David Shum. The candidate’s contribution to the paper involved conception of the study design, literature review, data collection and analyses, and writing of the manuscript. The co-authors contributed to the conception of the study, provided feedback on manuscript drafts/revisions and approved the final manuscript and revisions requested by the journal.

Name of student: Elizabeth Beadle

*Names of corresponding authors of paper:*

Professor Tamara Ownsworth (Primary Supervisor)

Professor Jennifer Fleming (External Supervisor)

Professor David Shum (Associate Supervisor)
Chapter 6: Personality characteristics and cognitive appraisals associated with self-discrepancy after severe traumatic brain injury

Introduction

Severe traumatic brain injury (TBI) can alter multiple facets of an individual’s functioning and lifestyle. Many individuals report changes to self-identity and perceive vast differences between their pre- and post-injury selves (Cantor et al., 2005; Levack et al., 2010; Nochi, 1998; Tyerman & Humphrey, 1984). This experience of “self-discrepancy” is often negative and anxiety provoking, and can lead to avoidance and self-imposed activity restrictions (Beadle et al., 2016). A complex interplay of premorbid, neurological, psychological and social factors is proposed to influence how individuals make sense of their injury-related changes and develop a perception of “who I am now” (Gracey & Ownsworth, 2012; Ownsworth, 2014). Of focus here is the role of personality characteristics and cognitive appraisals in self-identity change.

Conceptualisation and measurement of self-identity

Self-identity is a complex construct to define due to its broad and subjective nature. For consistency within the brain injury literature, self-identity is defined as the collective physical, cognitive, psychological and social characteristics that we perceive as our own (Beadle et al., 2016; Ownsworth, 2014). The term self-identity is often used interchangeably with “sense of self” and self-concept (Ownsworth & Haslam, 2016). In the developmental psychology literature, the construct of self-identity has been operationalised through self-report measurement of self-concept and self-esteem. Self-concept has been defined as the overarching thoughts and feelings a person has about him or herself (Rosenberg, 1965), whereas self-esteem is viewed as an evaluative component related to judgments about one’s own worth or value.

The impact of TBI on self-identity has frequently been investigated in qualitative research involving life history and narrative approaches (Douglas, 2013; Nochi, 2000). Quantitative approaches to assessing self-identity typically involve measures of self-concept
which assess specific attributes (e.g., physical, cognitive, social, emotional and behavioural). Changes in self-identity (i.e., self-discrepancy) have been assessed by comparing ratings of past (pre-injury) and current (post-injury) self-concept on measures such as the Head Injury Semantic Differential (HISD) Scale (Tyerman & Humphrey, 1984). Using this approach, both positive and negative changes in perceived attributes (e.g., more calm or less calm) can be represented, together with stable characteristics (no change) after TBI. In the current study the HISD was employed as a measure of self-discrepancy (past vs. current self-concept ratings) to operationalise the construct of self-identity change.

Self-identity is related to, although distinct from, personality, which refers to longstanding and characteristic ways of thinking, feeling, and behaving. These enduring cognitive, affective and behavioural patterns influence life goals, engagement in activities, roles and social connections with others, thus shaping who we are and who we become (Carver & Connor-Smith, 2010). Personality is like a lens through which we perceive and interpret daily experiences, and thus update our self-knowledge and beliefs. While personality characteristics are to some extent observable and can be reported on by others (Dwan et al., 2017), self-identity is inherently subjective (Ownsworth, 2014).

Evidence of self-identity change and associated factors

A systematic review on self-identity change after TBI identified that individuals typically report negative self-discrepancy (i.e., unfavourable comparisons between their current and pre-injury self), and poorer current self-concept than healthy controls (Beadle et al., 2016). Those experiencing negative self-discrepancy were found to report greater psychological distress (Carroll & Coetzer, 2011; Cooper-Evans et al., 2008; Wright & Telford, 1996). However, there was also evidence of stability in particular attributes (e.g., friendliness) and positive psychological changes (e.g., more mature, appreciative) after TBI (Malia et al., 1995; Man et al., 2003; Rush et al., 2006; Tyerman & Humphrey, 1984).

Previous research investigating the influence of neurocognitive factors on self-discrepancy found no consistent associations with severity of injury or time since injury.
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(Beadle et al., 2016). However, Beadle, Ownsworth, Fleming and Shum (2017) identified that individuals with severe TBI who had greater self-awareness of their deficits and better immediate memory were more likely to experience negative self-discrepancy. Further, self-awareness partially mediated the relationship between immediate memory and self-discrepancy, suggesting that better memory function supports the process of updating self-knowledge of impairments, which in turn contributes to self-discrepancy. Therefore, there is some evidence that neurocognitive processes influence people’s capacity to self-reflect on their post-injury changes and update their self-identity in the context of severe TBI.

Yet, other research highlights the likely influence of psychosocial factors in self-identity change. In particular, research comparing self-concept or experience of self-discrepancy in participants with TBI and orthopedic/trauma controls found no significant differences between these groups (Curran et al., 2000; Rush et al., 2006). Such findings suggest that self-discrepancy after TBI may not arise solely from neurological damage, but rather could be related to the broader consequences of a traumatic event leading to hospitalization and adjustment to injury or loss of function (Beadle et al., 2016). Accordingly, the psychosocial factors associated with self-identity change need to be better understood.

**Personality, cognitive appraisals and self-discrepancy**

Personality characteristics are proposed to influence psychological well-being and global self-views by shaping the manner in which people make sense of (i.e., cognitive appraisals) and cope with everyday situations (Carver & Connor-Smith, 2010). Following brain injury, changes in personality across the “Big Five” have been reported, that is, decreases in emotional stability, extraversion, conscientiousness, openness to experience and agreeableness (Jokela, Hakulinen, Singh-Manoux, & Kiyimaki, 2014; Stone et al., 2004). However, levels of optimism have been found to be relatively stable after TBI (Malia et al., 1995). Optimism refers to an enduring attributional style that influences how people come to terms with past, current and future life events (Scheier & Carver, 1985a). Highly optimistic individuals typically believe that they can achieve desired outcomes and strive towards their
goals, even when progress is difficult. They tend to appraise stressful situations as an opportunity for personal growth and are confident in their ability to cope with challenges (Carver & Connor-Smith, 2010). In line with this perspective, Ramanathan, Wardecker, Slocomb and Hillary (2011) found that people with higher optimism were less likely to experience psychological distress after TBI. Similarly, Ownsworth and Nash (2015) found that people with brain tumour who were higher on optimism perceived their illness as less threatening, had greater confidence in their coping abilities and reported better existential well-being. Therefore, individuals with TBI who have higher levels of optimism are expected to have more positive cognitive appraisals and experience less self-discrepancy than those who have lower levels of optimism.

Another personality characteristic considered important in the context of self-identity change is defensiveness or self-deception. Individuals high on defensiveness typically downplay or deny personal shortcomings and present themselves in an overly favourable light (Ownsworth, 2005). These individuals have been found to underreport brain injury symptoms and experience lower emotional distress. Despite denying difficulties to others, they may still develop effective compensatory strategies which help to maintain their independence, work and social functioning (Ownsworth et al., 2002). Accordingly, high defensiveness has been found to be associated with better long-term emotional adjustment and psychosocial functioning (Ownsworth et al., 2007). Although the relationship between defensiveness and self-identity change has yet to be investigated, it is theorised that due to excessive motivation to maintain a positive self-image, individuals with higher defensiveness would report less self-discrepancy than those with lower defensiveness.

Understanding the role of personality characteristics in self-identity change is clinically important for identifying those at greater risk of experiencing negative self-discrepancy and associated psychological distress. However, personality characteristics are relatively resistant to change, whereas cognitive appraisals are commonly targeted and found to be amenable to change in psychotherapy (Anson & Ponsford, 2006; Ownsworth, 2005).
Changes to Self After TBI

Cognitive appraisals that influence psychological adjustment after TBI which may also contribute to self-discrepancy include threat appraisals, self-focused attention and perceived coping resources.

Research by Riley, Brennan, and Powell (2004) identified that people with TBI commonly experience a sense of threat associated with valued roles and activities. These threat appraisals relate to “doing things” (i.e., performing activities that they used to do before their injury), “dealing with people” (e.g., negative evaluations from others), and “personal safety” (e.g. getting hurt or re-injured). Consistent with Goldstein’s notion of the “catastrophic reaction” (Goldstein, 1952), the experience of difficulties on tasks that were previously performed with ease may trigger comparisons between pre-injury and post-injury selves, thus eliciting self-discrepancy. Individuals with a heightened sense of threat are more likely to employ maladaptive coping strategies (e.g., avoidance and withdrawal) which interfere with the process of resuming valued activities and re-establishing a positive sense of self (Gracey et al., 2009). Consequently, it is expected that greater threat appraisals would be related to more negative self-discrepancy.

Rumination is a form of self-focused attention that is characterised by repetitive, negative and persistent thoughts regarding perceived threats, losses or injustices to the self (Trapnell & Campbell, 1999). Following a stressful or traumatic event, individuals may engage in rumination in an effort to solve problems, analyse and/or eliminate discrepancies between current and desired status, or to aid in goal attainment (Papageorgiou & Wells, 2001). Conceptualised as either a processing style or coping mechanism, rumination has consistently been found to contribute to mood symptoms and the development of a negative self-view (Nolen-Hoeksema et al., 2008). In the context of TBI, Curran et al. (2000) found that coping styles that involved worry, wishful thinking and self-blame were related to increased depression and anxiety.

As a contrasting form of self-focused attention, reflection involves exploration of novel, unique, or alternative self-perceptions, motivated by curiosity and openness to
Theoretically, reflection promotes greater knowledge of the self and can facilitate more positive adjustment to traumatic events, and restore self-esteem. In the context of TBI, greater self-reflective tendencies may support people to process their experiences in a way that promotes self-coherence and personal growth. Qualitative research by Nochi (2000) depicted reconstructed self-narratives that supported people to view themselves in a positive light, for example, by making comparisons with what could have been, focusing on their strengths and recognising the positive effects of their injury. Accordingly, it is expected that high levels of rumination would be associated with more negative self-discrepancy, and that high levels of reflection would be related to less self-discrepancy.

In line with theories on stress, appraisal and coping (see Folkman & Greer, 2000; Lazarus & Folkman, 1984), after individuals appraise a stressful event as personally significant or meaningful they evaluate their ability to cope. Those who perceive that they have fewer coping resources or less social support typically experience poorer mental health (Folkman & Greer, 2000). Consistent with this theory, Riley and Dennis (2010) identified a strong positive relationship between perceived coping resources and self-esteem following brain injury. They surmised that individuals who perceived themselves as more resourceful, resilient and supported by others were more likely to maintain their sense of self-worth. Conversely, feelings of dependency and lack of control have been related to negative changes in self-concept after stroke (Ellis-Hill & Horn, 2000). Therefore, lower perceived coping resources is expected to be related to more negative self-discrepancy.

Overall, it is theorized that the personality characteristics of optimism and defensiveness influence how people appraise and make sense of their post-injury changes after TBI, which in turn is proposed to influences their experience of self-discrepancy. Accordingly, it was hypothesised that lower levels of optimism and defensiveness would be related to maladaptive cognitive appraisals (i.e., greater threat appraisals and rumination, and lower self-reflection and perceived coping resources), and negative self-discrepancy. It was
further hypothesised that the relationship between personality characteristics and self-discrepancy would be mediated by cognitive appraisals.

Methods

Participants

Participants were recruited as part of a broader research project evaluating an in-home rehabilitation program for individuals with severe TBI (Ownsworth et al., 2013). Inclusion criteria were: 1) aged 18 – 65 years; 2) have a medical diagnosis of severe TBI within the last 15 years (severity was determined by posttraumatic amnesia duration [>7 days] and/or Glasgow Coma Scale [<9/15 score); and 3) live within a 100km radius of one of two metropolitan centres where the study took place. Individuals were excluded if they did not have the capacity to provide informed consent or displayed significant behavioural concerns (e.g., aggression) or a severe sensory, perceptual, or language disorder (e.g., severe aphasia) that would limit their ability to partake in the study. Further, those diagnosed with a major current psychiatric disorder (e.g., psychosis or substance abuse) that was not under effective management were excluded.

Of the 72 participants referred to the study, 51 were eligible and consented to participate in the current study. Twenty-one individuals did not participate for the following reasons: determined not eligible (n = 10), were unable to be contacted after initial verbal consent (n = 5), and did not consent (n = 6). Table 6.1 presents the demographic and injury related characteristics of the TBI sample. Participants were typically male (74%), aged 18 – 63 years (M = 36.22, SD = 12.65), and had sustained a severe TBI between 2 and 160 months prior to the study (M = 33.65; SD = 40.29).
### Table 6.1:

**Demographic and Injury-Related Characteristics of the Severe TBI Sample (n = 51)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>TBI group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD), range; N (%)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>36.22 (12.65), 18–63</td>
</tr>
<tr>
<td>Gender (male)</td>
<td>37 (74%)</td>
</tr>
<tr>
<td>Education (years)</td>
<td>12.92 (2.42), 9 – 18</td>
</tr>
<tr>
<td>GCS</td>
<td>5.39 (3.07), 3 – 14</td>
</tr>
<tr>
<td>PTA duration (in days)</td>
<td>71.92 (54.83), 1 – 218</td>
</tr>
<tr>
<td>Relationship status (current)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>17 (33%)</td>
</tr>
<tr>
<td>In a relationship</td>
<td>4 (8%)</td>
</tr>
<tr>
<td>Single</td>
<td>30 (59%)</td>
</tr>
<tr>
<td>Previous psychological history (self-reported)</td>
<td>17 (33%)</td>
</tr>
<tr>
<td>Previous substance (drug and alcohol) abuse</td>
<td>9 (18%)</td>
</tr>
<tr>
<td>Time since injury (months)</td>
<td>33.65 (40.29), 2 – 160</td>
</tr>
<tr>
<td>Occupational status (current)</td>
<td></td>
</tr>
<tr>
<td>Full time work</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Part time/Casual</td>
<td>3 (6%)</td>
</tr>
<tr>
<td>Volunteer</td>
<td>7 (14%)</td>
</tr>
<tr>
<td>Student</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>37 (73%)</td>
</tr>
<tr>
<td>Cause of injury</td>
<td></td>
</tr>
<tr>
<td>MVA/MBA/Pushbike – driver</td>
<td>18 (35%)</td>
</tr>
<tr>
<td>MVA/MBA – passenger</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Assault</td>
<td>5 (10%)</td>
</tr>
<tr>
<td>Pedestrian/bike vs vehicle</td>
<td>10 (20%)</td>
</tr>
<tr>
<td>Fall</td>
<td>13 (26%)</td>
</tr>
<tr>
<td>Sports related</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Object falling</td>
<td>1 (2%)</td>
</tr>
</tbody>
</table>
CHANGES TO SELF AFTER TBI

Measures

*Life Orientation Test – Revised*

The Life Orientation Test – Revised (LOT-R; Scheier, Carver, & Bridges, 1994) was designed to assess the traits of optimism and pessimism. It consists of 10 items (e.g., “In uncertain times, I usually expect the best”), four of which are “filler” items (i.e., items that were included to somewhat disguise the purpose of the test), and respondents answer each item on a 5-point scale (scored 0 – 4). Scores range from 0 to 24, with higher scores indicating greater optimism. Scheier et al. (1994) reported evidence of validity of the LOT-R, and adequate internal consistency has been previously demonstrated in a TBI sample (Cronbach α = .70; Peleg et al., 2009). Internal consistency for the current sample was good (α = .84).

*Marlowe-Crowne Social Desirability Scale – short form*

The Marlowe-Crowne Social Desirability Scale – Short Form (MCSDS-SF; Reynolds, 1982) is a 13-item scale that measures defensiveness or the tendency to downplay personal shortcomings due to an excessive desire to present oneself in an overly favourable light. An example item includes “No matter who I’m talking to I’m always a good listener”. The original MCSDS was initially developed to assess response style and the tendency to respond in a culturally sanctioned and desirable manner to gain approval. Accordingly, higher scores on this scale indicate a greater tendency to respond in a socially desirable manner. However, researchers have identified that the tool assesses more than a simple need for social approval, whereby high scores are considered to represent a repressive defence against a vulnerable self-esteem or self-deception (Evans, 1979). The MCSDS-SF has demonstrated adequate reliability and evidence of validity (Loo & Thorpe, 2000). The original MCSDS has been used as a measure of defensiveness in brain injury research (Gisi & D'Amato Carl, 2000; Ownsworth, 2005; Ownsworth et al., 2007; Ownsworth et al., 2002). In the current sample internal consistency of the MCSDS-SF was adequate (α = .71).
CHANGES TO SELF AFTER TBI

Appraisal of Threat and Avoidance Questionnaire

The Appraisal of Threat and Avoidance Questionnaire (ATAQ; Riley et al., 2004) is a 36-item questionnaire evaluating threat appraisals. It was specifically designed for individuals with TBI, and contains two indices: the appraisal index and the avoidance index. Only the appraisal index was used in this study. In the appraisal index, individuals were asked to indicate whether, in the past month, they have experienced threat appraisals relating to three situations: 1) Dealing with people, for example “I sometimes worry that people think there’s something wrong with me”; 2) Doing Things, for example “I sometimes get upset or frustrated if I do things wrong”; and 3) Personal Safety, for example “I sometimes worry that I might get another brain injury”. Affirmative answers are scored as “1” and negative responses are scored as “0”, with higher overall scores indicating greater negative appraisals. Riley and colleagues reported excellent internal consistency for overall threat appraisals (α = .92). Internal consistency for the appraisal index in the current sample was also excellent (α = .94).

Reflection and Rumination Questionnaire

The Reflection and Rumination Questionnaire (RRQ; Trapnell & Campbell, 1999) is a 24-item measure that distinguishes between “intellectual self-attentiveness” and “ruminative self-attention”. There are 12 items on the rumination scale (e.g., “My attention is often focused on aspects of myself I wish I’d stop thinking about”) and 12 items on the reflection scale (e.g., “I’m very self-inquisitive by nature”). Responses are made on a 5-point scale (1 = strongly disagree, to 5 = strongly agree) with higher scores indicating greater levels of rumination/reflection. The authors reported excellent internal consistency (α = .90 for rumination; α = .91 for reflection). Internal consistency for the current sample was excellent (α = .95) for the rumination scale, and good (α = .86) for the reflection scale.
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Coping Resources Questionnaire:

The Coping Resources Questionnaire (CRQ; Riley et al., 2010) is a 24-item measure of perceived coping resources in the context of TBI. The questionnaire is based on Lazarus and Folkman’s (1984) account of secondary appraisals. Example items include “My family has helped me a lot since the brain injury” and “I am confident I can get my life back on track”. The questionnaire includes four coping domains, namely, emotional resilience, resourcefulness, social support, and global appraisals, which each include six items and are rated as “true/false”. The present study used the total score as an overall index, with higher scores reflecting greater perceived coping resources. Excellent internal consistency (α = .91) has been previously reported for this measure (Riley et al., 2010). Internal consistency for the current sample was also excellent (α = .90).

Head Injury Semantic Differential Scale – version III

The Head Injury Semantic Differential Scale (HISD) was designed to assess subjective changes to self in individuals with brain injury (Tyerman & Humphrey, 1984). It utilizes a semantic differential rating method. The most recent version (HISD-III) consists of 18 bipolar adjective pairs (e.g., bored – interested; unhappy – happy; inactive – active) which are rated on a 7-point scale from 1 to 7. Total scores range from 18–126, with higher scores reflecting more positive views of self. Although the HISD can be administered in a number of contexts (e.g., past, present and future selves), views on past and present selves were of focus in this study. Self-discrepancy scores were calculated by comparing past and present self-ratings. A negative score is indicative of a more positively viewed past self than present self, and thus represents negative self-discrepancy. The HISD-III has demonstrated excellent internal consistency (α = .92 - .93) and convergent validity with the Rosenberg Self Esteem Scale and Brain Injury Grief Inventory (Carroll & Coetzer, 2011). In the present sample, internal consistency was excellent (α = .94 for past self; α = .95 for present self). In line with
the authors’ instructions for administration of the HISD-III, participants completed ratings for past self followed by present self ratings.

**Procedure**

Ethical clearance for this study was approved by hospital and university research committees. Participants were identified by treating therapists or case managers in two regional brain injury rehabilitation services in Brisbane, Australia, and a rehabilitation service in Sydney, Australia, from July 2013 – May 2016. Medical records were accessed to collect injury-related information. Data were collected in the context of a larger project, which also involved administration of neuropsychological tests (Beadle et al., 2017). The researcher went to participants’ homes to conduct the assessment. Participants completed the cognitive tests prior to the questionnaires. The majority of participants completed all measures face-to-face (n = 45/51), and the HISD was always presented face-to-face. However, due to time scheduling issues or fatigue six participants completed the remaining questionnaires via telephone with the questions presented orally by the researcher.

**Data analysis**

Data were entered into SPSS (version 24), screened for missing values, outliers, and violations of normality, and transformed via square root or logarithm transformations if necessary for parametric analyses (Tabachnick & Fidell, 2007). Data were missing for two participants on the MCSDS-SF, and for one participant on theATAQ and RRQ; mean score replacement was used to account for these. Previous research investigating associations between psychological factors and self-concept in individuals with TBI (Coetzer, 2008; Cooper-Evans et al., 2008; Ponsford et al., 2014) yielded medium to large effect sizes (i.e., r > .40). An a priori power calculation conducted using G*Power (Faul et al., 2009), identified that a minimum sample size of approximately 46 participants was required (power = .80 and alpha set at .05, two-tailed). Pearson product-moment correlation analyses were used to examine associations between personality characteristics, cognitive appraisals and self-
changes to self after TBI discrepancy. Hierarchical regression analyses were used to guide subsequent mediation analyses by determining which cognitive appraisal variables were significantly related to self-discrepancy when controlling for personality characteristics. Preacher and Hayes’ (2004) bootstrapping method was utilized to test mediation as this method is non-parametric and is appropriate for smaller sample sizes. The PROCESS macro (A. Hayes, 2012) was employed with 5,000 bootstrap samples. Mediation is deemed significant in this analysis if the 95% confidence intervals for the indirect effect do not include 0.

Results

Descriptive data

Table 6.2 presents the descriptive data for the personality and cognitive appraisal measures and HISD-III. On average, individuals rated their pre-injury self more positively than their current self \((t = 2.96, p < .01)\). Overall, 32 (63%) individuals reported a negative change in self-concept of some degree, while 19 (37%) individuals viewed their current self as the same or more positively compared to their pre-injury self. On examination of individual items, significant negative self-discrepancy was found on 10 out of the 18 items. The strongest effect sizes were evident for negative changes in the following attributes: incapable vs. capable \((d = 0.56)\), dependent vs. independent \((d = 0.69)\), and inactive vs. active \((d = 0.62)\). As shown in Table 6.2, mean scores on the HISD-III, LOT-R, ATAQ, and CRQ were generally comparable to other TBI samples. Although TBI data were not available for comparison on the MCSDS-SF and the RRQ, the TBI sample reported somewhat higher levels of defensiveness and lower levels of rumination than community samples.
Table 6.2: Descriptive Data for Personality, Cognitive Appraisal and Self-Concept Measures

<table>
<thead>
<tr>
<th>Domain</th>
<th>Measure</th>
<th>M (SD)</th>
<th>Range</th>
<th>Community/comparative data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-concept</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current-self</td>
<td></td>
<td>86.53 (22.96)</td>
<td>42 – 121</td>
<td>Past = 97.45 (20.92)</td>
</tr>
<tr>
<td>Self-discrepancy</td>
<td></td>
<td>-11.12 (26.80)</td>
<td>-67 – 78</td>
<td>Present = 74.79 (20.59)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>SD = -22.66 (26.46)</td>
</tr>
<tr>
<td><strong>Personality</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Optimism</td>
<td>LOT – R</td>
<td>16.69 (5.03)</td>
<td>5 – 24</td>
<td>Community (Scheier et al., 1994):</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>14.33 (4.28)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>TBI (Peleg et al., 2009):</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>12.6 (5.2)</td>
</tr>
<tr>
<td>Defensiveness</td>
<td>MCSDS – SF</td>
<td>8.06 (2.82)</td>
<td>1 – 13</td>
<td>Community (Loo &amp; Thorpe, 2000):</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5.76 (2.68)</td>
</tr>
<tr>
<td><strong>Cognitive appraisals</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Threat appraisal</td>
<td>ATAQ – appraisal</td>
<td>11.64 (9.43)</td>
<td>0 – 36</td>
<td>TBI (Riley et al., 2004):</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>18.0 (8.7)</td>
</tr>
<tr>
<td>Reflection</td>
<td>RRQ</td>
<td>36.76 (8.05)</td>
<td>19 – 50</td>
<td>Community (Trapnell &amp; Campbell, 1999):</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Item mean = 3.06 (0.67)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Item mean = 3.14 (0.76)</td>
</tr>
<tr>
<td>Rumination</td>
<td>RRQ</td>
<td>32.88 (12.69)</td>
<td>12 – 59</td>
<td>Community (Trapnell &amp; Campbell, 1999):</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Item mean = 2.74 (1.06)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Item mean = 3.46 (0.71)</td>
</tr>
<tr>
<td>Coping resources</td>
<td>CRQ</td>
<td>17.84 (5.61)</td>
<td>5 – 24</td>
<td>TBI (Riley et al., 2010):</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>16.51 (4.93)</td>
</tr>
</tbody>
</table>

ATAQ = Appraisal of Threat and Avoidance Questionnaire; CRQ = Coping Resources Questionnaire; HISD-III = Head Injury Semantic Differential Scale – Version III; LOT-R = Life Orientation Test – Revised; MCSDS – SF = Marlowe-Crowne Social Desirability Scale – Short Form; RRQ = Reflection and Rumination Questionnaire;
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As shown in Table 6.3, significant associations were found between optimism and cognitive appraisals. Specifically, individuals reporting higher optimism reported lower threat appraisals ($r = -0.60$, $p<0.001$) and rumination ($r = -0.60$, $p<0.001$), and perceived more coping resources ($r = 0.62$, $p<0.001$). However, optimism was not significantly associated with reflection and there were no significant associations between level of defensiveness and cognitive appraisals ($p>0.05$).

As hypothesised, more negative self-discrepancy on the HISD was significantly associated with less defensiveness ($r = 0.29$, $p<0.05$) and lower optimism ($r = 0.42$, $p<0.01$). Further, individuals reporting more negative self-discrepancy reported greater threat...
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appraisals \( (r = -.50, p < .001) \) and rumination \( (r = -.57, p < .001) \), and perceived fewer coping resources \( (r = .47, p < .01) \). Interestingly, levels of optimism and defensiveness were not significantly correlated \( (p > .05) \). However, the cognitive appraisals were significantly interrelated. Specifically, higher threat appraisals were associated with greater rumination \( (r = - .63, p < .001) \) and lower perceived coping resources \( (r = -.75, p < .001) \). Higher levels of rumination were associated with increased reflection \( (r = .42, p < .01) \) and lower perceived coping resources \( (r = - .68, p < .001) \). Reflection was not significantly associated with any other cognitive appraisals.

Supplementary correlation analyses were conducted to examine associations between past and current self-concept ratings on the HISD-III (i.e., ratings used to derive the self-discrepancy score) and personality and cognitive appraisals. More positive ratings of current self-concept were significantly related to higher optimism \( (r = .62, p < .001) \) and defensiveness \( (r = .34, p < .05) \), lower levels of threat appraisal \( (r = - .70, p < .001) \) and rumination \( (r = -.63, p < .001) \), and greater perceived coping resources \( (r = .70, p < .001) \). There were no significant associations between current self-concept and reflection \( (r = .08, p > .05) \), or between past self-concept and the personality and cognitive appraisal variables \( (r = .01-.19, p > .05) \).

A hierarchical multiple regression was conducted to determine whether cognitive appraisals were significantly related to self-discrepancy after controlling for levels of optimism and defensiveness. Demographic and injury-related variables were initially examined as potential covariates (note: these were not significantly related to self-discrepancy). In Step 1 the personality variables significantly accounted for 25.6\% of the variance in HISD-III discrepancy scores, \( F_{(2,49)} = 7.74, p < .01 \) (see Table 6.4). After entering the cognitive appraisal variables in Step 2, the variance in HISD-III discrepancy scores accounted for increased to 40.7\%, \( F_{(5,46)} = 5.76, p < .001 \). Thus, the cognitive appraisal variables contributed an additional 15.1\% of the variance in self-discrepancy, \( F_{\text{change}} = 3.57, \)
p<.05. Only rumination accounted for significant unique variance in self-discrepancy in Step 2, sr² = .08, p<.05.

Table 6.4:
Hierarchical Regression of the Relationship between Self-Concept Change and Personality Characteristics and Cognitive Appraisals (n = 51)

<table>
<thead>
<tr>
<th>Variable</th>
<th>R²</th>
<th>B</th>
<th>95% CI for B</th>
<th>β</th>
<th>T</th>
<th>sr²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td>0.25**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MCSDS-SF</td>
<td>2.42</td>
<td>[0.02 – 4.82]</td>
<td>.26</td>
<td>2.02*</td>
<td>.07</td>
<td></td>
</tr>
<tr>
<td>LOT-R</td>
<td>2.31</td>
<td>[0.88 – 3.74]</td>
<td>.42</td>
<td>3.23**</td>
<td>.17</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td>0.41***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MCSDS-SF</td>
<td>1.68</td>
<td>[-0.62 – 3.98]</td>
<td>.18</td>
<td>1.46</td>
<td>.03</td>
<td></td>
</tr>
<tr>
<td>LOT-R</td>
<td>.64</td>
<td>[-1.14 – 2.42]</td>
<td>.11</td>
<td>0.72</td>
<td>.01</td>
<td></td>
</tr>
<tr>
<td>ATAQ</td>
<td>-.28</td>
<td>[-1.32 – 0.76]</td>
<td>-.10</td>
<td>-0.53</td>
<td>.00</td>
<td></td>
</tr>
<tr>
<td>CRQ</td>
<td>.27</td>
<td>[-1.65 – 2.19]</td>
<td>.05</td>
<td>0.28</td>
<td>.00</td>
<td></td>
</tr>
<tr>
<td>RRQ –</td>
<td>-.85</td>
<td>[-1.57 – -0.13]</td>
<td>-.40</td>
<td>-2.41*</td>
<td>.08</td>
<td></td>
</tr>
</tbody>
</table>

*R < .05; **p < .01, ***p<.001

ATAQ = Appraisal of Threat and Avoidance Questionnaire; CRQ = Coping Resources Questionnaire; HISD = Head Injury Semantic Differential Scale; LOT – R = Life Orientation Test – Revised; MCSDS = Marlowe-Crowne Social Desirability Scale – Short Form; RRQ = Reflection and Ruminat Questionnaire;

Mediating effect of rumination on self-discrepancy

Given the findings that optimism was significantly related to rumination and that rumination was the only cognitive appraisal variable that contributed unique variance to self-discrepancy after controlling for personality characteristics, the potential mediating effect of rumination was examined. As shown in Figure 6.1, there was a significant total effect of
optimism and rumination on self-discrepancy, $R^2 = .33$, $F = 11.83$, $p < .001$. The direct effect (DE) of optimism on self-discrepancy was not significant (DE = .63; lower CI = -.96, upper CI = 2.22), whereas the indirect effect (IE) of optimism through the mediator of rumination was significant (IE = 1.16; lower CI = 0.62, upper CI = 2.99). These findings signify full mediation, indicating that lower optimism is related to more negative self-discrepancy through higher levels of rumination.

Figure 6.1. Mediating effect of rumination on the relationship between optimism and self-discrepancy ($\beta =$ the standardised beta coefficient)

** $p < .01$

**Discussion**

Overall, this study aimed to determine the role of personality characteristics and cognitive appraisals in self-identity change after severe TBI. As hypothesised, lower levels of optimism and defensiveness were related to more negative self-discrepancy. However, only optimism was found to be related to cognitive appraisals, with individuals lower on optimism reporting greater threat appraisals and rumination and lower coping resources. Further, the relationship between optimism and self-discrepancy was found to be mediated by rumination.

Consistent with previous research, individuals with TBI typically rated their post-injury (current) self less favourably than their pre-injury (past) self (Carroll & Coetzer, 2011; Shields et al., 2015; Tyerman & Humphrey, 1984; Wright & Telford, 1996). However, individuals with higher optimism and greater defensiveness were less likely to perceive
negative changes in their personal attributes. The supplementary correlation analyses indicated that these personality characteristics influence self-discrepancy by enhancing current notions of self, rather than affecting how people recall their past or pre-injury self-concept. Overall, these findings reinforce previous brain injury research linking higher dispositional optimism with greater hope for the future and lower psychological distress (e.g., Peleg et al., 2009; Ramanathan et al., 2011). Further, the results support theoretical perspectives that optimism shapes how people appraise stressful experiences, with greater optimism serving as a buffer to maintain or enhance self-esteem (Carver & Connor-Smith, 2010; Scheier & Carver, 1985a). The present findings extend the literature by demonstrating that after severe TBI, individuals with lower optimism were more likely to appraise everyday situations as threatening, experience negative repetitive thoughts and perceive that they possess fewer coping resources. Although these cognitive appraisals were closely inter-related, rumination had a unique influence on self-discrepancy and was found to mediate the relationship between optimism and self-discrepancy.

Rumination is a form of negative self-focused attention that is characterised by repetitive and persistent thoughts regarding perceived threats, losses or injustices to the self (Trapnell & Campbell, 1999). Individuals with lower optimism reported greater rumination which in turn was related to more negative self-discrepancy. In line with the findings for optimism, the tendency to ruminate was associated with more negative ratings of current self-concept, but did not appear to influence how people rated their past or pre-injury self-concept. This distinction is important, given empirical support for the “good-old-days” bias which has been found to inflate retrospective ratings of health and self-concept in TBI research (Gunstad & Suhr, 2001; Reddy et al., 2017). Specifically, the finding that ratings of past self-concept were not more positive for people experiencing high levels of rumination suggests that the “good-old-days” bias cannot account for the influence of rumination on self-discrepancy.
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Theoretical perspectives in the mental health literature propose that rumination is a misguided emotion regulation strategy associated with neuroticism and depression (Nolen-Hoeksema, 2000). Consistent with this view, previous TBI research found that coping styles related to rumination such as worry, wishful thinking, and self-blame were associated with increased depression and anxiety and lower self-esteem (Anson & Ponsford, 2006b; Curran et al., 2000). Theories on psychological adjustment to brain injury propose that efforts to reflect upon and make sense of post-injury changes are typically adaptive for developing a realistic and positive self-identity (Gracey et al., 2009; Ownsworth, 2014). However, repetitive thoughts about loss, threat and injustices to the self may develop into a negative perpetuating cycle without resolution. Everyday experiences after TBI such as memory failure, difficulty on tasks that were previously performed with ease and lack of goal attainment may serve to magnify self-discrepancy for individuals with ruminative processing styles (Cantor et al., 2005). The present findings indicate that individuals who are less optimistic are more likely to engage in rumination, which in turn contributes to negative self-discrepancy.

Conversely, individuals high on optimism are more likely to make active attempts to solve or accommodate challenges and find ways to construe positive meaning after adversity (Carver & Connor-Smith, 2010). Efforts to find meaning in everyday experiences after TBI can reduce self-discrepancy or promote positive changes in self-identity (Nochi, 2000). However, contrary to expectations, optimism and self-discrepancy were not significantly related to reflection. As measured by the RRQ, reflection refers to self-focused attention characterized by exploration of alternative self-views and openness to experience. Importantly, the RRQ has not been validated for use in the TBI population. Therefore, despite showing adequate reliability in the current TBI sample ($\alpha = .86$), it is possible that the reflection scale does not measure the same construct for this population. Nonetheless, the lack of significant associations between reflection and self-discrepancy is consistent with the mixed findings in the broader mental health literature (Luyckx et al., 2007). It has further
been proposed that the potentially adaptive function of reflection for mental health is offset by the maladaptive effect of rumination. In line with this view, Takano and Tanno (2009) found that people high on rumination also tended to have reflective processing styles, suggesting that “reflectors are likely to ruminate and reflect simultaneously” (p. 260). The significant positive association \( r = .42 \) between rumination and reflection in the current study reinforces this notion. Further research is needed to validate the use of the RRQ in the TBI population and determine whether individuals who engage in reflection in the absence of rumination are less likely to experience self-discrepancy.

Consistent with the findings for optimism, defensive personality characteristics were positively associated with self-discrepancy, albeit modestly. Hence, individuals excessively motivated to present themselves in an overly favourable light were less likely to make unfavourable comparisons between their pre-injury and post-injury attributes. Defensiveness was positively associated with ratings of current self-concept, but did not influence individuals’ ratings of their past or pre-injury attributes. Further, defensiveness was not related to threat appraisals, rumination and reflection or perceived coping resources. Previous TBI research has identified that although individuals with high defensiveness may deny or downplay their impairments in certain contexts, they can still develop adaptive coping strategies to accommodate the effects of their injury in order to maintain a positive self-image (Ownsworth et al., 2007; Ownsworth & McFarland, 2004).

Clinical implications

The present finding that individuals with a greater tendency to ruminate experienced more negative self-discrepancy has important implications for clinical practice. Brain injury rehabilitation broadly aims to support individuals to re-establish their sense of self and place in the world. This may occur through multi-disciplinary therapies that address functional impairments and enable people to resume valued activities and social roles that are closely tied to their self-identity (Ownsworth & Haslam, 2016). However, most individuals with
severe TBI experience long-term functional impairments that limit their activity participation and affect relationships. Indeed, in the present study participants most commonly reported feeling less capable, more dependent and less active. Therefore, therapy approaches that support individuals to adapt to changes in their personal abilities, develop modified goals and re-engage in meaningful activities can help to address negative self-discrepancies. The current findings suggest that individuals with a greater tendency to ruminate on perceived losses, threats and injustices may find the identity reconstruction process more challenging. Such individuals may particularly benefit from an integration of psychotherapy, cognitive rehabilitation and occupation-based approaches (Ownsworth & Haslam, 2016).

In particular, psychotherapy can support individuals to identify their ruminative thinking styles and unhelpful coping reactions and to explore the subjective meaning of post-injury changes for their self-identity (Ownsworth, 2005). In the broader clinical literature changes in cognitive appraisals have been found to predict or mediate the effects of psychotherapy on treatment outcomes for individuals with major depression (Velden et al., 2015). Use of behavioural experiments can test assumptions about perceived threat or failure, and involve trialing alternative ways of coping and modified self-views (Ownsworth & Gracey, 2017). Group psychotherapy programs can also help to update self-identity through peer learning exercises that support individuals to recognise and accept changed aspects of self alongside stable attributes (Vickery et al., 2006). In addition to cognitive behavioural therapy (CBT; see Ownsworth & Gracey, 2017), third wave therapies are increasingly being used in brain injury rehabilitation to enhance emotion regulation skills and foster behaviour change (see Ashworth, Evans, & McLeod, 2017). For example, Acceptance and Commitment Therapy seeks to support people with brain injury to accept their changed life situation and commit to living a meaningful life by being guided by personal values and taking effective action (Kangas & McDonald, 2011).
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Cognitive rehabilitation interventions can teach individuals compensatory strategies that increase their independence and self-efficacy on everyday tasks. Use of technological aids can support prospective remembering and goal-directed behaviour (e.g., alerting devices to cue timely actions), and recall of salient life experiences (e.g., Instagram, video recordings), thus supporting autobiographical memory and self-coherence (Ownsworth, 2014). Occupation-based approaches that support skill development and activity participation are essential to create regular opportunities for people to experience a sense of achievement and mastery (Ownsworth & Haslam, 2016). Developing avenues for supportive social interaction (e.g., joining support groups, volunteering, involvement in advocacy) can enhance feelings of belonging and reciprocity (i.e., benefiting from support and contributing to other’s welfare), which can challenge longstanding maladaptive self-appraisals (e.g., “I have nothing to offer”) and coping reactions that feed into negative self-concept. It is also important to involve family and other natural supports to reinforce and consolidate an individual’s renewed sense of identity (Klonoff, 2010). Notably, there is only preliminary evidence supporting identity-orientated therapy for people with TBI (Ownsworth & Haslam, 2016); therefore, further intervention research guided by these principles is recommended.

Limitations and future directions

Several limitations in the current study are important to acknowledge. Due to the modest sample size the findings of the mediation analysis should be considered preliminary, and requires validation in a larger TBI sample. Further, the cross-sectional design and lack of experimental manipulation does not allow inferences to be drawn regarding causal relationships between personality characteristics, cognitive appraisals, and self-discrepancy. In addition, the participants were recruited as a part of a broader research project (Ownsworth et al., 2013), which used a convenience sampling approach. This sample may not be representative of the broader TBI population and hence caution is needed in generalising the findings. Further, given the reliance on self-report measures it is important to recognise the
potential for method variance, or covariance related to the measurement approach rather than the constructs that tools are purported to measure (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003). Hence, method variance may have resulted in inflation of correlation coefficients between the common scale formats (i.e., HISD-III, RRQ, LOT-R, MCSDS, ATAQ, CRQ).

However, as noted by Spector (2006), if common scale format is a concern, then significant correlations should be observed among all variables assessed using self-report measures. This was not the case for the current findings, particularly for measures of defensiveness and reflection (see Table 6.3).

It is also important to recognise that the HISD-III assesses specific emotional and behavioural attributes and thus does not capture all domains that may be relevant to self-identity (e.g., physical attributes and family/social roles). Future research could examine self-discrepancy using a multi-domain measure such as the Tennessee Self-Concept Scale (TSCS:2; Fitts & Warren, 1996). Further, although optimism and defensiveness were selected for examination in the current study on the basis that these characteristics appear relatively resistant to change after TBI (Malia et al., 1995), the role of other personality traits (e.g., neuroticism, extraversion and openness to experience) in self-discrepancy could be examined. It is important to recognise that appraisal and coping variables may be related to self-discrepancy because they are common manifestations of premorbid traits such as neuroticism. Nonetheless, consistent with the present findings, research has found that cognitive appraisals and coping behaviours are related to psychological well-being independent of personality traits, including neuroticism (see van Mierlo, van Heugten, Post, de Kort, & Visser-Meily, 2015). In addition to investigating other personality traits, research investigating the relationship between re-engagement in occupational activities and self-discrepancy would provide a more comprehensive understanding of processes underlying self-identity change.

Finally, due to the lack of control group in the present study, it is uncertain if the present findings are relevant only to individuals with severe TBI. As previously discussed,
self-discrepancy can be experienced by individuals after other traumatic events that involve adjustment to injury or loss (Beadle et al., 2016). Further research is needed to determine whether the observed relationship between optimism, rumination, and self-discrepancy exists for other clinical populations (e.g., orthopaedic injury or trauma groups) as well as the general population.

Conclusions

Overall, this study provides preliminary support that personality characteristics and cognitive appraisals contribute to self-discrepancy after severe TBI. Specifically, lower levels of optimism and defensiveness were related to negative self-discrepancy. Further, maladaptive cognitive appraisals (i.e., increased threat appraisals and rumination, and lower perceived coping resources) were associated with negative self-discrepancy. The relationship between optimism and self-discrepancy was mediated by rumination. These findings may assist clinicians in conceptualising factors involved in the development and maintenance of negative self-discrepancy following TBI and guide the focus of interventions. Further research is required to understand how other personality traits and re-engagement in occupational activities influence self-discrepancy after TBI.
Chapter 7: Statement of Contribution and Co-Authored Published Paper

This chapter includes a co-authored paper. The bibliographic details of the co-authored paper, including all authors, are:


This manuscript has been accepted for publication and is currently in preparation for publication. It is included in its original form, with modifications to the formatting, referencing and the Table and Figure numberings in order to be consistent with the thesis formatting. The candidate’s contribution to the paper involved conception of the study design, literature review, data collection and analyses, and writing of the manuscript. The co-authors contributed to the conception of the study, provided feedback on manuscript drafts and approved the final manuscript.

Name of student: Elizabeth Beadle

Names of corresponding authors of paper:

Professor Tamara Ownsworth (Primary Supervisor)

Professor Jennifer Fleming (External Supervisor)

Professor David Shum (Associate Supervisor)
Chapter 7: The nature of occupational gaps and relationship with mood, psychosocial functioning and self-discrepancy after severe traumatic brain injury

Occupations refer to groups of everyday activities that people engage in as individuals within their homes and communities to occupy themselves and bring a sense of purpose, structure and meaning to life. Such activities include those that people need to do, want to do and are expected to do (Townend & Polatajko, 2013). The notion that occupational activities contribute to wellbeing and self-identity can be traced back to early philosophical doctrine. Greek philosopher Aristotle argued that what we do informs who we are and what we become, stating that “every art and inquiry, and similarly every action and pursuit is thought to aim at some good” (Nicomachean Ethics, I:1, W. D. Ross translation, 1998). Maslow identified occupations, supportive relationships, and positive learning experiences as essential for the fulfilment of self-esteem and self-actualization (Maslow, 1943). Major life events and health conditions such as severe traumatic brain injury (TBI) can alter individuals’ ability to engage in valued occupations (Turner, Ownsworth, Cornwell, & Fleming, 2009), which in turn potentially affects their emotional wellbeing and self-identity. However, the psychological impact of occupational “gaps” or the mismatch between individuals’ past, actual (current) and desired occupations after TBI has received little attention in research.

The integral relationship between occupation and health and wellbeing is universally recognised. The World Health Organization’s (WHO) framework for health and disability – the International Classification of Functioning, Disability and Health (ICF; WHO, 2001) – emphasises that activity and participation are core components of health. Similarly, a central tenant of the Model of Human Occupation (MOHO; Kielhofner, 2008) is that one’s sense of capacity, effectiveness, values, and interests are related to participation in, and the choice of everyday activities. Occupational therapy as a discipline seeks to promote wellbeing and a meaningful existence through the dimensions of doing (purposeful action), being (living in the moment), belonging (affiliation and affirmation), and becoming (self-actualisation; Hammell, 2004; Wilcock, 1998). Occupation-based interventions aim to support individuals...
to achieve goals related to these dimensions through enabling participation in valued activities (Christiansen, 1999).

In psychology, there is a similar consensus that the activities and roles we choose in life are guided by our sense of self (i.e., values, beliefs, and motivations), and in turn strengthen who we are and what we become (Ownsworth, 2014). Third wave cognitive behavioural therapy (CBT) approaches such as acceptance and commitment therapy (ACT) aim to identify personal values in order to “move toward valued behavior” (S. Hayes, Strosahl, & Wilson, 2012; p 240). Client-centred therapy approaches link occupation and self-identity through values, goals, behaviour and mood, which form the basis of assessment, formulation and intervention approaches. Specifically, occupational participation contributes to wellbeing and self-identity by providing the means to develop personal competencies and to learn about one’s strengths and limitations from others and the environment (Ownsworth, 2014). Participation in meaningful activities can improve mood and self-concept and through interpersonal interaction, can enhance feelings of belonging and reduce loneliness (Dumont, Gervais, Fougeyrollas, & Bertrand, 2005). More generally, occupations can provide structure and consistency in life which promotes self-coherence or continuity between one’s past, present and future selves. However, the meaning of occupation is subjectively derived, and changes in occupational participation can affect people differently (Hammell, 2004).

Severe TBI often leads to major changes in participation in everyday life activities. TBI commonly occurs during young adulthood which is a pivotal time for forging one’s independence, career, relationships and self-identity. Research on psychosocial reintegration after brain injury highlights that most individuals (i.e., 89%) achieve some level of independence in the home and community in the first 6 months after hospital discharge (Nalder et al., 2012). Further, a majority (i.e., 78%) regain their ability to access the community independently in the first 6 months (Nalder et al., 2012). However, occupations requiring high-level cognitive functions, such as return to work or study, and return to driving
are less commonly achieved after TBI (Fleming & Strong, 1999; Nalder et al., 2012). Specifically, estimates have reported between 40 – 62% (Culthbert et al., 2015; Nalder et al., 2012) of individuals with TBI returned to work or study and 55% returned to driving in the first 6 months after discharge. Individuals’ social networks are also found to diminish after TBI, with most socialisation occurring through family members who provide long-term care and support (Degeneffe, 2001). Nearly 1 in 5 people with brain injury experience a relationship breakdown with a family member or partner in the first 6 months post-discharge (Nalder et al., 2012); however, in the longer term much higher rates have been reported, with 49% found to experience separation or divorce at 5-8 years post-injury (Wood & Yurdakul, 1997).

Eriksson and colleagues (Eriksson, Kottorp, Borg, & Tham, 2009; Eriksson et al., 2006) developed the Occupational Gaps Questionnaire to measure people’s actual occupational engagement and desired participation in everyday activities after brain injury. This enables the identification of two types of occupational gaps: namely, activities they are doing but do not want to do, and activities that they want to do but are not currently doing. Their initial study, which focused on the number and nature of both types of occupational gaps between 1-4 years after TBI or stroke (n = 116), reported that occupational gaps increased from 46% (pre-injury) to 71% (post-injury). Gaps were present across a broad range of instrumental activities of daily living, leisure activities, social activities, and work-related activities. Occupational gaps were most strongly related to executive function impairments, motor impairments, and somatic complaints (e.g., headaches, dizziness). In another study involving the same sample, Eriksson and colleagues (2009) found that individuals who perceived greater occupational gaps (actual vs. desired) reported lower life satisfaction ($r = -.63$). Further, there was a positive association between occupational gaps and depressive symptoms ($r = .35$). Overall, this research highlights that the perception of greater occupational gaps was associated with lower life satisfaction and greater depressive symptoms.
Some further research highlights the links between occupational participation and mood and self-concept. In a study on social participation after TBI, Dumont (2005) found that engagement in meaningful activities enhanced mood and self-worth, and was an important avenue for interpersonal interaction. However, Turner and colleagues (2007) found that re-engagement in activities during the first three months post-discharge after brain injury was a mixed blessing. Specifically, although activity re-engagement was perceived to facilitate functional recovery, this process also contributed to feelings of frustration when efforts to resume pre-injury activities were not successful. In terms of interventions targeting occupational participation, a systematic review (Ownsworth & Haslam, 2016) found that there was mixed support concerning the efficacy of occupation-based rehabilitation for improving self-concept.

Given that participation in valued activities and social roles is typically reduced after TBI, it is not surprising that many individuals report changes in self-concept. Individuals with TBI often make unfavourable comparisons between their pre-injury and post-injury selves, which is commonly referred to as “negative self-discrepancy” (Cantor et al., 2005). Using the Head Injury Semantic Differential (HISD) Scale III (Tyerman & Humphrey, 1984), Reddy and colleagues (2017) found that participants with TBI rated their current (post-injury) selves as less interested, independent, and active than their past (pre-injury) selves. A systematic review identified that negative self-discrepancy after TBI was typically associated with greater anxiety and depression (Beadle et al., 2016). Although greater occupational gaps are found to be related to poorer mental health (i.e., lower life satisfaction and depression; Eriksson et al., 2009), the relationship between occupational re-engagement, mood and self-discrepancy has yet to be investigated. Due to the subjective nature of desired occupational engagement (i.e., activities the person wants to participate in), it is also unclear whether occupational gaps correspond with individuals’ psychosocial functioning, or their levels of independence, relationship functioning and work and leisure skills as rated by relatives.
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Aims and hypotheses

The first aim of this study was to characterise the nature of occupational gaps after severe TBI. The primary focus was on occupational re-engagement gaps, or those related to activities that individuals want to do but are not currently doing. It was hypothesised that individuals would report engaging in significantly fewer occupations than desired, and significantly fewer occupations than they engaged in prior to their injury. Further, it was expected that individuals’ desired participation would reflect their past occupational participation (i.e., endorsement of desired activities would be consistent with pre-injury occupational participation). The second aim was to examine the associations between occupational re-engagement gaps, mood, psychosocial reintegration and self-discrepancy after TBI. It was hypothesised that greater re-engagement gaps would be significantly associated with greater symptoms of depression, anxiety and stress, poorer psychosocial functioning and negative self-discrepancy.

Method

Participants

Participants were recruited from outpatient and community-based rehabilitation services as part of a screening process for a larger in-home rehabilitation research project (Ownsworth et al., 2013; 2017). The inclusion criteria for the current project were: 1) aged 18 – 65 years; 2) have a medical diagnosis of severe TBI within the last 15 years (severity was determined by post-traumatic amnesia duration [>7 days], loss of consciousness [+6 hours], and/or Glasgow Coma Scale [<9/15] score); and 3) live within a 100Km radius of the two metropolitan centres where the study took place. Exclusion criteria were: 1) lack of capacity to provide informed consent; 2) significant behavioural concerns (e.g., severe aggression); 3) a severe sensory, perceptual, or language disorder (e.g., aphasia) that would limit their ability to partake in the study; and/or 4) diagnosis of a current psychiatric disorder (e.g., psychosis or substance abuse) that was not under effective management.

Of the 81 participants referred to the broader study, 59 participated in the current
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study. Twenty-two individuals did not participate for the following reasons: were not eligible \((n = 9)\), were unable to be contacted after initial verbal consent \((n = 5)\), and did not consent \((n = 8)\). Table 7.1 presents the demographic and injury-related characteristics of the severe TBI sample. Participants were typically male \((73\%)\), aged 18 – 63 years \((M = 36.50, SD = 12.54)\), and had sustained a TBI between 2 and 204 months prior to the study \((M = 35.71; SD = 45.48)\). Traffic-related accident were the most common cause of TBI \((54.2\%)\).

Table 7.1:

*Demographic and Injury-Related Characteristics of the Severe TBI Sample \((n = 59)\)*

<table>
<thead>
<tr>
<th>Variable</th>
<th>(M (SD)), range; (N(%))</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>36.50 (12.54), 18-63</td>
</tr>
<tr>
<td>Gender (male)</td>
<td>43 (72.9%)</td>
</tr>
<tr>
<td>Education (years)</td>
<td>12.96 (2.40), 9 – 18</td>
</tr>
<tr>
<td>GCS</td>
<td>5.91 (3.61), 3 – 15</td>
</tr>
<tr>
<td>PTA duration (in days)</td>
<td>67.73 (53.52), 1 – 218</td>
</tr>
<tr>
<td>Relationship status (current)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>18 (30.5%)</td>
</tr>
<tr>
<td>In a relationship</td>
<td>5 (8.5%)</td>
</tr>
<tr>
<td>Single</td>
<td>36 (61%)</td>
</tr>
<tr>
<td>Previous psychological history (self-reported)</td>
<td>23 (39%)</td>
</tr>
<tr>
<td>Previous substance (drug and alcohol) abuse</td>
<td>14 (23.7%)</td>
</tr>
<tr>
<td>Time since injury (months)</td>
<td>35.71 (45.48), 2 – 204</td>
</tr>
<tr>
<td>Cause of injury</td>
<td></td>
</tr>
<tr>
<td>Traffic-related accident</td>
<td>32 (54.2%)</td>
</tr>
<tr>
<td>Assault</td>
<td>6 (10.2%)</td>
</tr>
<tr>
<td>Fall</td>
<td>18 (30.5%)</td>
</tr>
</tbody>
</table>
## CHANGES TO SELF AFTER TBI

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Sports related</td>
<td>2 (3.4%)</td>
</tr>
<tr>
<td>Object falling</td>
<td>1 (1.7%)</td>
</tr>
</tbody>
</table>
Measures

**Occupational Gaps Questionnaire.** The Occupational Gaps Questionnaire (OGQ) was designed to measure the extent to which an individual engages in desired daily activities (Eriksson et al., 2006). Gaps between desired and actual participation are examined for 30 occupations, which relate to instrumental activities of daily living (IADL; e.g., cooking, managing finances), leisure (e.g., listening to radio/watching TV, participating in hobbies), social activities (e.g., supporting others, involvement in societies, clubs, unions) and work (e.g., working, studying). There are two questions posed for each item: “Do you perform the activity?” and “Do you want to perform the activity?” In the OGQ, answering “no” to the first question and “yes” to the other is considered a gap, and vice versa. Thus, two types of occupational gap may be present: 1) the person does an activity that he or she does not want to do (i.e., desire to disengage); and 2) the person does not do an activity that he or she wants to do (i.e., desire to re-engage). This study was primarily interested in desired activity re-engagement (i.e., the latter gap), although both gaps will be reported. Total scores for current and desired activities and occupational gaps range from 0 to 30, whereby higher scores indicate greater participation or number of gaps (respectively).

To explore potential links between past and desired occupational participation, a third question was added for each activity, which asked participants whether or not they participated in this activity prior to their injury. This series of questions was asked after completing the original OGQ. The OGQ has demonstrated acceptable reliability and evidence of validity in both stroke and TBI research (Eriksson et al., 2009). In the current sample internal consistency was satisfactory for the current ($\alpha = .88$), desired ($\alpha = .82$) and past ($\alpha = .79$) domains.

**Depression, Anxiety, and Stress Scales.** The Depression, Anxiety, and Stress Scales – 21 (DASS-21; Lovibond & Lovibond, 1995) is a 21 item self-report measure designed to assess various symptoms associated with depression, anxiety, and stress. Based on the original 42-item version, the DASS-21 contains three, 7-item scales. Participants are asked to
rate on a 4-point Likert scale the extent to which each item has applied to them over the past week. Scores for each item are summed and doubled to create a total scale score (range = 0 – 42). There are recommended cut-off scores for severity categories (normal, mild, moderate, severe, and very severe). For example, on the depression scale, scores of 9 or less are ‘normal’, while scores greater than 28 are ‘extremely severe’. Scores that are less than 7 on the anxiety scale are ‘normal’, while those above 20 are ‘extremely severe’. For the stress scale, scores less than 14 are ‘normal’, while scores greater than 34 are considered ‘extremely severe’. The DASS-21 has demonstrated adequate reliability and validity within the TBI population (Depression subscale α = .93; Anxiety subscale α = .85; Stress subscale α = .90) (Dahm et al., 2013; Ownsworth, Little, Turner, Hawkes, & Shum, 2008). The internal consistency in the current TBI sample ranged from good to excellent (α = .85-.94).

**Head Injury Semantic Differential Scale – version III.** The Head Injury Semantic Differential Scale (HISD) – version III was designed to assess self-discrepancy in individuals with brain injury (Tyerman & Humphrey, 1984). It consists of 18 bipolar adjective pairs (e.g., friendly vs unfriendly; active vs inactive; calm vs irritable) which are rated on a 7-point scale from 1 to 7. Total scores range from 18–126, with higher scores reflecting more positive views of self. The HISD can be administered in a number of contexts (e.g., past, current and future selves), and views on past and current selves were of focus in this study. In accordance with administration guidelines, participants completed the 18 HISD items twice, initially rating their past self (prior to TBI), and then rating their current self (Ownsworth, 2014). Self-discrepancy scores were calculated by comparing past and current self ratings. A negative total discrepancy score is indicative of a more positively viewed past self than current self, and thus represents negative changes in self-concept. The HISD-III has demonstrated excellent internal consistency (α = .92 - .93) and convergent validity in brain injury research (Carroll & Coetzer, 2011). Internal consistency was excellent in the present sample (α = .94 for past self; α = .95 for current self).

**Sydney Psychosocial Reintegration Scale (SPRS) – 2.** The Sydney Psychosocial
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Reintegration Scale (SPRS) – version 2 (Tate et al., 2012) is a 12-item questionnaire that assesses level of psychosocial reintegration, or the ability to resume valued societal roles after brain injury. The scale comprises three domains, with four questions for each domain. The three domains are: Occupational Activities, Interpersonal Relationships, and Independent Living Skills. The relative rated Form B was utilised in this study, which examines current level of functioning in each domain. Excellent psychometric properties have been reported for the SPRS-2 Form B, including internal consistency (α = .87), inter-rater reliability (ICC = .84) and test-retest reliability ( r = .90). Further, the SPRS has demonstrated construct validity and sensitivity to change (Tate, Hodgkinson, Veerabangsa, & Maggioto, 1999). Internal consistency for the current sample was excellent (α = .90).

Procedure

Ethical clearance was approved by hospital and university research committees. Prospective participants were identified by treating therapists or case managers in two metropolitan based brain injury rehabilitation services in Brisbane, Australia, and a rehabilitation service in Sydney, Australia, during July 2013–2016. Medical records were accessed to collect injury-related information. Data were collected as part of a pre-intervention assessment in the context of a larger intervention study (Ownsworth et al., 2013; 2017). Questionnaires were administered either over the telephone or in person at individuals’ homes.

Data analysis

Data were entered into SPSS (version 24) and screened for missing values, outliers, and violations of normality. Transformations via square root or logarithm were performed as necessary for parametric analyses (Tabachnick & Fidell, 2007). In line with previous research (Eriksson et al., 2009), a medium to large effect size (r = .40) was anticipated for associations between occupational gaps and psychological variables. An a priori power calculation conducted using G*Power (Faul et al., 2009), identified that with alpha set at .05 (two-tailed) and power of .80, a minimum sample size of approximately 46 participants was required to
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detect significant associations. Paired sample $t$-tests were used to compare overall levels of activity engagement for the current, desired, and past activity domains. McNemar’s test was performed to compare the proportion of participants endorsing “yes” versus “no” on each activity (past, current, desired). Due to the large number of comparisons a more conservative alpha ($p<.01$) was adopted. Pearson product-moment correlations were used to examine associations between occupational participation and the psychosocial variables.

Results

Descriptive data

Table 7.2 presents the descriptive data for the activities, occupational gaps, mood, self-discrepancy and psychosocial functioning. As hypothesised, there was a significant difference between current and past activity engagement ($t = -11.07, p < .001$), such that individuals reported engaging in fewer current activities than prior to their injury. There was also a significant difference between current and desired activities ($t = -10.66, p < .001$), whereby individuals reported that they participated in fewer current activities than desired. However, there was no significant difference between their overall levels of past and desired activity participation ($t = -.20, p = .84$). In terms of the type of occupational gaps, individuals reported a significantly higher number of re-engagement gaps ($M = 7.29, SD = 4.8$) than disengagement gaps ($M = 0.37, SD = 0.76; t = 10.54, p < .001$). The mean scores for the DASS fell within the mild, moderate, and normal ranges for depression, anxiety, and stress, respectively. Individuals rated their pre-injury self significantly more positively than their current self ($t = 3.94, p <.001$). Overall, 40 (67.8%) individuals reported a negative self-discrepancy of some degree, while 19 (32.2%) individuals viewed their current self as the same or more positively compared to their pre-injury self. In terms of psychosocial reintegration on the SPRS-2, relatives rated participants’ independent living skills and interpersonal relationships as higher than their occupational activities i.e., work/study and leisure skills ($t = 11.85, p <.001$ and $t = 11.86, p <.001$, respectively).
Table 7.2:

Descriptive Data for Occupational Gaps, Mood, Self-Concept and Psychosocial Functioning

<table>
<thead>
<tr>
<th>Measure/Domain</th>
<th>M (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>OGQ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Past activities (pre-injury)</td>
<td>22.03 (4.23)</td>
<td>10-30</td>
</tr>
<tr>
<td>Current activities</td>
<td>14.86 (6.30)</td>
<td>2 – 28</td>
</tr>
<tr>
<td>Desired activities</td>
<td>21.93 (4.93)</td>
<td>9 – 30</td>
</tr>
<tr>
<td>Gaps, desired re-engagement</td>
<td>7.29 (4.80)</td>
<td>0 – 21</td>
</tr>
<tr>
<td>Gaps, desired disengagement</td>
<td>0.37 (0.76)</td>
<td>0 – 3</td>
</tr>
<tr>
<td>DASS-21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>10.85 (11.86)</td>
<td>0 – 40</td>
</tr>
<tr>
<td>Anxiety</td>
<td>12.17 (11.92)</td>
<td>0 – 38</td>
</tr>
<tr>
<td>Stress</td>
<td>5.83 (8.59)</td>
<td>0 – 28</td>
</tr>
<tr>
<td>HISD-III</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Past-self</td>
<td>97.97 (17.63)</td>
<td>43 – 126</td>
</tr>
<tr>
<td>Current-self</td>
<td>84.59 (22.63)</td>
<td>42 – 121</td>
</tr>
<tr>
<td>Self-discrepancy</td>
<td>-13.37 (26.07)</td>
<td>-67 – 78</td>
</tr>
<tr>
<td>SPRS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total psychosocial functioning</td>
<td>27.36 (9.99)</td>
<td>7 – 48</td>
</tr>
<tr>
<td>Occupational activities</td>
<td>5.93 (3.96)</td>
<td>0 – 16</td>
</tr>
<tr>
<td>Interpersonal Relationships</td>
<td>11.03 (3.86)</td>
<td>1 – 16</td>
</tr>
<tr>
<td>Independent Living Skills</td>
<td>10.31 (3.68)</td>
<td>4 – 16</td>
</tr>
</tbody>
</table>

DASS-21 = Depression, Anxiety, and Stress Scale – 21 items; HISD-III = Head Injury Semantic Differential Scale – Version III; OGQ = Occupational Gaps Questionnaire; SPRS = Sydney Psychosocial Reintegration Scale.

The nature of activities and occupational gaps

Table 7.3 presents the proportion of participants endorsing past, current, and desired engagement in the 30 activities on the OGQ. An examination of endorsement rates on the OGQ indicated that the majority of participants with TBI currently participate in the following activities: listening to radio/watching television (93.2%), seeing relatives and
friends (86.4%), and playing computer games and surfing the internet (78%). Participants reported the lowest engagement in: heavy-duty maintenance (15.3%), working (15.3%) and studying (18.6%). In terms of desired activities, the majority of individuals reported wanting to engage in the following activities: listening to radio/watching television (94.9%), travelling for pleasure (93.3%), managing personal finances (91.5%) and transporting oneself (91.5%).

Using McNemar’s test, a comparison between current and desired engagement indicated a significant difference on 18 of the 30 activities ($p<.01$). The direction of this difference was the same regardless of activity, such that a higher proportion of participants wanted to participate in these activities as compared to current activity participation. Significant re-engagement gaps were present for 5/8 activities of the IADL domain, 5/11 of the leisure activity domain, 4/7 of the social activity domain, and 4/4 of the work or work-related activity domain.

A comparison between past and current activity participation indicated a significant difference for 21 of the 30 activities ($p<.01$), with the proportion of participants endorsing current participation on these activities being lower than past participation. This was significant ($p<.01$) for all activities (8/8) of the IADL domain, 7/11 of the leisure activity domain, 4/7 of the social activity domain, and 2/4 of the work or work-related activity domain.

In terms of past and desired activities, there was a significant difference for 5 of the 30 activities ($p<.01$). Specifically, for three IADLs (doing laundry, cleaning and light maintenance) a lower proportion of participants indicated that they wanted to do these activities as compared to past participation. Conversely, for two activities in the social activities (supporting others) and work or work related (volunteering) domains, a higher proportion wanted to do these activities as compared to past participation. Aside from these activities, the proportion of participants endorsing past and desired activities was similar, suggesting that individuals’ desired occupational engagement was largely consistent with their pre-injury engagement.
## CHANGES TO SELF AFTER TBI

Table 7.3:

*Proportion of TBI Participants (n = 59) Endorsing Past, Current and Desired Activity Participation*

<table>
<thead>
<tr>
<th>Activity (Domain)</th>
<th>% Doing prior</th>
<th>% Current Activities</th>
<th>% Wanting to do (desired participation)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Instrumental ADLs</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grocery shopping</td>
<td>93.2***</td>
<td>&gt; 71.2</td>
<td>= 84.7</td>
</tr>
<tr>
<td>Cooking</td>
<td>88.1***</td>
<td>&gt; 62.7</td>
<td>&lt; 88.1***</td>
</tr>
<tr>
<td>Doing laundry</td>
<td>89.8***</td>
<td>&gt; 57.6</td>
<td>= 62.7</td>
</tr>
<tr>
<td>Cleaning</td>
<td>89.8***</td>
<td>&gt; 66.1</td>
<td>= 67.8</td>
</tr>
<tr>
<td>Light maintenance (garden, car)</td>
<td>86.4***</td>
<td>&gt; 45.8</td>
<td>&lt; 71.2***</td>
</tr>
<tr>
<td>Heavy-duty maintenance</td>
<td>44.1***</td>
<td>&gt; 15.3</td>
<td>&lt; 42.4***</td>
</tr>
<tr>
<td>Managing personal finances</td>
<td>96.6***</td>
<td>&gt; 52.5</td>
<td>&lt; 91.5***</td>
</tr>
<tr>
<td>Transporting oneself</td>
<td>98.3***</td>
<td>&gt; 49.2</td>
<td>&lt; 91.5***</td>
</tr>
<tr>
<td><strong>Leisure activities</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shopping</td>
<td>98.3***</td>
<td>&gt; 69.5</td>
<td>&lt; 89.8**</td>
</tr>
<tr>
<td>Participating in sports</td>
<td>76.3***</td>
<td>&gt; 40.7</td>
<td>&lt; 83.1***</td>
</tr>
<tr>
<td>Participating in outdoor activities</td>
<td>88.1***</td>
<td>&gt; 57.6</td>
<td>&lt; 89.8</td>
</tr>
<tr>
<td>Participating in hobbies</td>
<td>83.1***</td>
<td>&gt; 47.5</td>
<td>&lt; 88.1</td>
</tr>
<tr>
<td>Participating in cultural activities</td>
<td>94.9***</td>
<td>&gt; 64.4</td>
<td>&lt; 89.8</td>
</tr>
<tr>
<td>Listening to radio/watching TV</td>
<td>100</td>
<td>= 93.2</td>
<td>= 94.9</td>
</tr>
<tr>
<td>Reading newspapers/magazines</td>
<td>67.8**</td>
<td>&gt; 50.8</td>
<td>&lt; 62.7**</td>
</tr>
<tr>
<td>Reading literature/periodicals</td>
<td>72.9**</td>
<td>&gt; 54.2</td>
<td>&lt; 69.5**</td>
</tr>
<tr>
<td>Writing</td>
<td>42.4</td>
<td>= 30.5</td>
<td>&lt; 47.5**</td>
</tr>
<tr>
<td>Playing the lottery, crosswords</td>
<td>44.1</td>
<td>= 49.2</td>
<td>= 54.2</td>
</tr>
<tr>
<td>Computer games &amp; surfing Internet</td>
<td>88.1</td>
<td>= 78</td>
<td>= 86.4</td>
</tr>
<tr>
<td><strong>Social activities</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeing partner/children</td>
<td>69.5</td>
<td>= 62.7</td>
<td>= 71.2</td>
</tr>
<tr>
<td>Seeing relatives/friends/neighbours</td>
<td>94.9</td>
<td>= 86.4</td>
<td>= 89.8</td>
</tr>
<tr>
<td>Supporting others</td>
<td>54.2**</td>
<td>&gt; 35.6</td>
<td>&lt; 71.2***</td>
</tr>
<tr>
<td>Activities in societies, clubs, unions</td>
<td>54.2***</td>
<td>&gt; 32.2</td>
<td>&lt; 49.2***</td>
</tr>
<tr>
<td>Practicing religion</td>
<td>18.6</td>
<td>= 25.5</td>
<td>= 32.2</td>
</tr>
<tr>
<td>Visiting restaurants and cafes</td>
<td>94.9***</td>
<td>&gt; 57.6</td>
<td>&lt; 86.4***</td>
</tr>
</tbody>
</table>
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<table>
<thead>
<tr>
<th></th>
<th>83.1***</th>
<th>&gt;</th>
<th>47.5</th>
<th>&lt;</th>
<th>93.2***</th>
</tr>
</thead>
<tbody>
<tr>
<td>Travelling for pleasure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work or work related activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>89.8***</td>
<td>&gt;</td>
<td>15.3</td>
<td>&lt;</td>
<td>83.1***</td>
</tr>
<tr>
<td>Studying</td>
<td>44.1***</td>
<td>&gt;</td>
<td>18.6</td>
<td>&lt;</td>
<td>54.2***</td>
</tr>
<tr>
<td>Taking care of children</td>
<td>39.0</td>
<td>=</td>
<td>28.8</td>
<td>&lt;</td>
<td>50.8***</td>
</tr>
<tr>
<td>Volunteering</td>
<td>18.6</td>
<td>=</td>
<td>20.3</td>
<td>&lt;</td>
<td>55.9***</td>
</tr>
</tbody>
</table>

Note. Significant differences are based on McNemar’s test

**p < .01; ***p < .001

Associations between occupational re-engagement gaps, mood, psychosocial functioning and self-discrepancy

Correlational analyses indicated that there were no significant associations between demographic and injury-related variables (time since injury, age, gender, GCS, PTA) and occupational gaps or self-discrepancy (p > .05). As shown in Table 7.4, greater occupational re-engagement gaps were associated with higher levels of anxiety (r = .30, p < .05), and lower psychosocial functioning (r = -.29, p < .05). There was no significant association between gaps and self-discrepancy (r = -.05, p = .70). Higher levels of depression, anxiety and stress were significantly related to more negative self-discrepancy (r = -.36-.49, p < .01) and lower psychosocial functioning (r = -.31-.39, p < .05). Overall, these correlation coefficients were typically in the moderate effect size range.
A noteworthy finding was that anxiety was significantly related to both re-engagement gaps and self-discrepancy. This raised the possibility that occupational gaps were indirectly related to self-discrepancy through an association with anxiety (Shrout & Bolger, 2002). Therefore, this potential indirect effect was examined through mediation analysis. Preacher and Hayes’ (2004) bootstrapping method was utilized to test mediation as this method is non-parametric and is appropriate for smaller sample sizes. The PROCESS macro (A. Hayes, 2012) was employed with 5,000 bootstrap samples. Mediation is deemed significant in this analysis if the 95% confidence intervals for the indirect effect do not include 0.

Figure 7.1 displays the standardised beta coefficients for each path in the mediation analysis. There was a significant total effect of occupational re-engagement gaps and anxiety on self-discrepancy, $R^2 = .25$, $F = 9.27$, $p < .001$. The direct effect (DE) of re-engagement gaps on self-discrepancy was not significant (DE = -.65; lower CI = -1.65, upper CI = 0.35), whereas the indirect effect (IE) of re-engagement gaps through the mediator of anxiety was significant (IE = .60; lower CI = 0.05, upper CI = 1.45). These findings signify full mediation, indicating that greater occupational re-engagement gaps are related to more
negative self-discrepancy through higher levels of anxiety.

Figure 7.1. Mediating effect of anxiety on the relationship between occupational re-engagement gaps and self-discrepancy ($\beta =$ the standardised beta coefficient; $\beta_d =$ the standardised beta coefficient for the indirect relationship between occupational gaps and self-discrepancy, through the mediator of anxiety)

* $p<.05$, ** $p<.01$

Discussion

Consistent with previous research (Eriksson et al., 2009; Eriksson et al., 2006), this study identified that occupational gaps are commonly experienced after severe TBI. As hypothesised, individuals reported that they currently engage in fewer activities than prior to their injury. Rates of current activity participation were significantly lower than pre-injury participation rates for 21 activities. Additionally, there were 18 activities that individuals wanted to engage in, but were not. Participants’ desired activities were largely consistent with their past or pre-injury activities. As hypothesised, greater occupational re-engagement gaps were found to be related to higher levels of anxiety and lower psychosocial functioning. Although there was no direct association between gaps and self-discrepancy, re-engagement gaps were indirectly related to self-discrepancy through an association with anxiety. The implications of these findings for client-centred rehabilitation will be discussed.

TBI participants reported high rates of current participation (>75%) for visiting
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relatives/friends, listening to the radio or watching television, and playing computer games/surfing the internet. Conversely, low rates of participation (<25%) were reported for working, studying, and completing heavy-duty maintenance. The activities most commonly engaged in after TBI appear to be more sedentary and less physically and cognitively demanding, whereas occupational gaps tended to relate to more active and social occupations (e.g., sports, visiting restaurants, and travelling for pleasure). These findings are broadly consistent with qualitative research on the hospital to home transition after brain injury which identified a key theme of “desired versus actual participation” (Turner et al., 2009). Desired activities included returning to driving, sport, work and education, whereas the activities that individuals were actually engaged in related to self-care, general domestic activities, household maintenance tasks and lower-risk hobbies.

In the present study, although the nature of desired activity engagement tended to reflect pre-injury engagement, there were some noteworthy exceptions. Specifically, relative to pre-injury participation data, fewer participants wanted to do laundry, cleaning and light maintenance, whereas more participants wanted to support others and volunteer. The focus of brain injury rehabilitation is often on supporting individuals to resume their independence with activities of daily living (Nalder et al., 2012). Having resumed these personal care and instrumental activities, participants often strive to achieve goals related to social participation (Turner, Ownsworth, Fleming, & Turpin, 2008). The desired focus on supporting others and volunteering may reflect a shift in values or reconsideration of what is most meaningful or important in a person’s life, a phenomenon that has been well documented previously in the TBI literature (Ownsworth & Fleming, 2011; Silva et al., 2011; Bellon et al., 2015; Pais, Ponsford, Gould, and Wong, 2017). The change in desired activities may also reflect a re-adjustment of one’s social and work-related goals due to lack of opportunities or inability to maintain paid employment (Ownsworth & McKenna, 2004; Ponsford, Olver, Curran, & Ng, 1995; Sloan, Winkler, & Callaway, 2004).
Previous research highlighted that executive function impairments, activity limitations and somatic concerns arising from brain injury were associated with greater occupational gaps (Eriksson et al., 2009). In the current study individuals’ level of psychosocial reintegration, as rated by relatives, was significantly related to re-engagement gaps, although the association was relatively modest ($r = -.29$). Therefore, individuals who achieve lower levels of independence, interpersonal relationships and work and leisure functioning are more likely to experience re-engagement occupational gaps. Greater occupational re-engagement gaps were found to be significantly related to anxiety, but not depression or stress. Notably, the relationship between these gaps and self-discrepancy was mediated by anxiety, such that individuals who were not engaging in desired activities experienced more anxiety, which in turn was related to negative self-discrepancy.

Such findings are consistent with a theoretical account by Goldstein (1942, 1952), who proposed that individuals with TBI can experience a “catastrophic reaction” of extreme anxiety, triggered by situations in which they struggle to complete tasks that were previously performed with ease. The experience of difficulty in completing familiar activities can elicit threat appraisals and negative comparisons between one’s pre-injury and post-injury abilities (Riley et al., 2004). For example, an appraisal such as “I used to confidently shop in large shopping centres but now I feel overwhelmed” may elicit anxiety and lead to avoidance of the activity and busy social settings despite wanting to resume one’s former lifestyle. While activity avoidance may reduce anxiety in the short-term, in the longer term individuals can experience heightened anxiety and negative self-discrepancy (Ownsworth, 2014). Although the direction of these relationships cannot be determined from the cross-sectional data, the finding that re-engagement gaps were related to self-discrepancy through anxiety highlights the need for longitudinal research to investigate whether anxiety is a precursor to, or consequence of occupational gaps, and whether there are bi-directional or reciprocal effects.
Limitations

In addition to the cross-sectional design, limitations of this study relate to sampling and the information captured by the OGQ. The sample size was relatively small for mediation analysis and thus the results should be considered preliminary. Participants were recruited as a part of a broader research project with specific inclusion criteria (Ownsworth et al., 2017). The convenience sample may not be representative of the broader TBI population; hence, caution is needed in generalising the findings. Further, time since injury for the sample was quite variable (2-204 months), which may have impacted on the opportunities that participants had to re-engage in particular activities and experience occupational gaps. Although time since injury was not significantly related to occupational gaps, longitudinal research involving ongoing assessments between hospital discharge and 12 months post-discharge would improve understanding of changes in occupational participation, and the emergence of gaps and their psychological consequences.

As a further limitation, the OGQ does not capture the relative importance of each occupation to the individual. In future research, involving the OGQ it may be beneficial to additionally gain information on the personal importance of each activity to the individual, his or her efforts and success in resuming activities since the TBI and perceived reasons for not engaging in activities. Related to this point, the relationship between awareness of deficits and re-engagement gaps is of interest to determine how self-awareness may contribute to gaps through expectations of occupational engagement. Other factors potentially related to re-engagement gaps, such as family support, access to rehabilitation, and financial resources could also be examined. Although less frequently reported than re-engagement gaps (see Table 7.2), future research could also explore the reasons for individuals not wanting to re-engage in particular occupations (i.e., desired disengagement).

Clinical implications

The finding that greater occupational re-engagement gaps were associated with
anxiety, and indirectly with negative self-discrepancy, highlights the likely benefits of exploring the personal meaning of changes in occupation after TBI as well as monitoring emotional status. Cognitive behavioural therapy has been found to be effective for reducing anxiety and improving psychosocial functioning after TBI (Ponsford et al., 2016). A specific focus on re-engagement in meaningful activities through client-centred occupation-based interventions (e.g., Doig, Fleming, Kuipers, Cornwell, & Khan, 2011; Ownsworth, Fleming, Shum, Kuipers, & Strong, 2008) may also help to reduce occupational gaps and enhance emotional functioning and continuity of self.

Integrated rehabilitation and psychotherapy approaches that simultaneously address functional impairments, activity re-engagement and psychological adjustment have long been advocated to facilitate a positive and realistic self-identity after brain injury (Ben-Yishay, 1996; Ownsworth & Haslam, 2016; Prigatano, 1986). Yet, a systematic review (Ownsworth & Haslam, 2016) that included some occupation-based interventions (Blake & Batson, 2009; Driver et al., 2006; Fines & Nichols, 1994; Schwandt et al., 2012), identified only preliminary evidence that brain injury rehabilitation improves self-concept. Notably, most interventions were designed to improve particular functional skills and mood, rather than self-concept. Ownsworth and Haslam (2016) advocated the need for goals in rehabilitation to be guided by higher level self-representations (i.e., who I am and who I want to be). An assessment of occupational gaps and their personal meaning (e.g., via ratings of importance or relationship with personal values) may help to understand how certain activities are tied to an individual’s sense of self, and thus guide the focus of client-centred rehabilitation.

Conclusion

Greater occupational re-engagement gaps were found to be related to higher levels of anxiety and poorer psychosocial functioning after severe TBI. Re-engagement gaps were related to negative self-discrepancy through an association with anxiety. Further research on the personal meaning of occupational gaps and the relationship to mood and self-discrepancy
changes to self after TBI during community reintegration is recommended.
Chapter 8: General Thesis Discussion

Sustaining a TBI is a life changing event with profound implications for one’s self-identity. A wealth of qualitative studies have highlighted that individuals with TBI experience complex changes to their self-identity and that many find the process of re-establishing their sense of self challenging (Bryson-Campbell et al., 2013; Levack et al., 2010). However, there is a lack of systematic research on the evidence of changes to self-identity as well as the factors that contribute to self-discrepancies between one’s pre-injury and post-injury selves after severe TBI. This thesis aimed to address these knowledge gaps through four studies that investigated changes in self-identity after severe TBI and the relationship of this construct to neurocognitive functioning, psychological characteristics and social/occupational factors. Within the systematic review (Chapter 3) and empirical studies of this thesis (Chapters 5 – 7), the construct of self-identity change was operationalised as the global difference between individuals’ ratings of their pre-injury self-concept and current self-concept, namely, self-discrepancy. This final thesis chapter summarises the key findings of each study, discusses the overarching clinical and theoretical implications, and outlines the methodological limitations and directions for future research. Table 8.1 provides a summary of these key findings and the clinical implications for each study of the PhD.
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#### Table 8.1

**Summary of Key Findings and Theoretical and Clinical Implications for each Study of the PhD**

<table>
<thead>
<tr>
<th>Chapter/Study</th>
<th>Key significant findings</th>
<th>Theoretical Implications</th>
<th>Clinical Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chapter 3: Study 1</strong>&lt;br&gt;Aims: 1) to systematically appraise evidence for changes to self-identity after TBI in adults; 2) to investigate factors related to self-identity change.</td>
<td>15 studies were selected and reviewed. Most studies provided evidence of negative changes to self-concept. However, stability in self-concept and positive changes were also reported for some attributes. Levels of self-esteem and personality characteristics did not differ between participants with TBI and orthopaedic/trauma controls. Negative self-concept change was associated with emotional distress in three studies.</td>
<td>Changes in self-identity after TBI may not arise solely from neurological damage, but rather from the broader psychosocial consequences of a traumatic event. Findings also support the “Y-shaped” model, which links negative self-discrepancy to increased emotional distress.</td>
<td>People with TBI commonly experience negative changes in self-identity; although continuity of self and positive changes may also be experienced. The neurocognitive and psychosocial factors that contribute to such perceptions are largely unknown.</td>
</tr>
<tr>
<td><strong>Chapter 5: Study 2</strong>&lt;br&gt;Aims: to investigate the relationship between neurocognitive function (attention, memory, executive)</td>
<td>Negative self-discrepancy was associated with greater self-awareness, and better performance on tests of immediate memory, working memory, and verbal fluency. Self-awareness partially</td>
<td>Better memory function may support the process of updating self-knowledge of impairments, which in turn contributes to self-discrepancy. More severe neurocognitive impairment may</td>
<td>Individuals with severe TBI who have better neurocognitive functioning may benefit from psychotherapy to make sense of changes in their abilities and attributes and develop effective</td>
</tr>
<tr>
<td>Chapter 6: Study 3</td>
<td>Aims: to examine the influence of personality characteristics (optimism and defensiveness) and cognitive appraisals (rumination; reflection; threat appraisal; coping resources) on self-discrepancy.</td>
<td>Higher levels of optimism, defensiveness and perceived coping resources were associated with more positive self-discrepancy, whereas higher threat appraisals and rumination were related to more negative self-discrepancy. Ruminaton significantly mediated the relationship between optimism and self-discrepancy.</td>
<td>People low on optimism are more likely to experience negative recurrent thinking styles, which in turn contribute to unfavourable comparisons between one’s current and pre-injury selves. High optimism and defensiveness reduce self-discrepancy by enhancing current notions of self, rather than affecting the recall of one’s past or pre-injury self-concept.</td>
</tr>
<tr>
<td>Chapter 7: Study 4</td>
<td>Aims: to examine the nature of occupational gaps following severe TBI and the relationship between occupational re-engagement, mood, psychosocial functioning and self-discrepancy.</td>
<td>Participants reported lower current occupational engagement than prior to their injury and their desired re-engagement. Gaps between current and desired participation were identified for 18 of the 30 occupations. A higher number of occupational re-engagement gaps were related to</td>
<td>Gaps in occupational re-engagement are commonly experienced after severe TBI. Desired re-engagement gaps are associated with greater anxiety and poorer psychosocial functioning. Anxiety regarding these gaps may contribute to changes to sense of self.</td>
</tr>
</tbody>
</table>
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<table>
<thead>
<tr>
<th>Combined findings</th>
<th>greater anxiety and lower psychosocial functioning. Gaps in occupational re-engagement were indirectly related to self-discrepancy through an association with anxiety. The key constructs found to be associated with more negative self-discrepancy include better memory, reduced optimism, and greater desired re-engagement gaps (indirectly). These relationships were mediated by higher levels of self-awareness, rumination, and anxiety symptoms, respectively.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Considered together, the findings support existing literature advocating a holistic rehabilitation approach, integrating cognitive rehabilitation, psychotherapy and occupation-based approaches to promote a positive and realistic self-identity after brain injury.</td>
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<td>Mediating variables including self-awareness, rumination, and anxiety represent potential targets for intervention to facilitate positive identity change after TBI.</td>
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Study 1: The impact of traumatic brain injury on self-identity: a systematic review of the evidence for self-concept changes

To identify the existing research on changes to self-identity and the associated factors after TBI, a systematic review was conducted in Study 1 (refer to Table 8.1). This review investigated the evidence for self-identity change after TBI by appraising quantitative studies that examined either pre-injury vs. post-injury self-discrepancy or compared current levels of self-concept between people with TBI patients and matched controls (i.e., healthy controls and/or orthopaedic/trauma controls). A secondary objective was to investigate neurocognitive and psychosocial factors related to self-identity change. Fifteen studies met the review criteria, and methodological quality was rated as per relevant indicators from the STROBE guidelines (von Elm et al., 2007).

The construct of self-identity change was inferred by comparing self-ratings of pre-injury and post-injury self-concept, self-esteem, or personality attributes (i.e., self-discrepancy) or through comparison of current ratings of self-esteem, self-concept, or personality characteristics with matched controls. The Head Injury Semantic Differential scale (HISD; Tyerman & Humphrey, 1984) was the most commonly utilised measure (5/15 studies), followed by the Rosenberg Self Esteem Scale (Rosenberg, 1965) (4/15 studies). Despite variability in methodological quality, sampling characteristics and approaches to measurement, the review yielded largely consistent findings.

Overall, 11 of the 15 studies indicated that TBI has a predominantly negative impact on self-identity. However, there was also evidence of stability on particular attributes (e.g., friendliness and optimism) as well as positive psychological changes (e.g., more mature and appreciative) after TBI. Interestingly, although individuals with TBI were found to report more negative self-concept and lower self-esteem than healthy
controls (Downing et al., 2013; Man et al., 2003; Ponsford et al., 2014), several studies indicated that their self-concept or self-esteem was comparable to orthopaedic/trauma (i.e., non-neurological) controls (Curran et al., 2000; Lannoo et al., 1997; Rush et al., 2006). Such findings suggest that changes in self-identity after TBI do not necessarily result from neurological damage per se, but instead reflect the broader psychosocial consequences of a traumatic event that leads to hospitalisation and results in changes in one’s functioning, activities and life roles. This is in align with social psychology theories which propose that self-identity is influenced by external (e.g., culture, social groups, life events/disruptions) factors (Jetten, Haslam & Haslam, 2012).

Further, an examination of factors related to changes in self-identity highlighted that individuals experiencing more negative self-discrepancy reported greater psychological distress (Carroll & Coetzer, 2011; Cooper-Evans et al., 2008; Wright & Telford, 1996). These findings provide empirical support for the “Y-shaped model” (Gracey et al., 2009) of change processes in rehabilitation, which depicts how self-discrepancies can pose a threat to self and elicit emotional distress. There were no clear findings regarding the influence of neuro-cognitive factors on self-identity change due to insufficient research. Nonetheless, some interesting preliminary findings from two small studies ($n <30$) indicated that higher levels of current self-esteem were related to lower IQ and executive functioning, and poorer self-awareness (Carroll & Coetzer, 2011; Cooper-Evans et al., 2008). This suggests that individuals with more severe cognitive deficits and reduced self-awareness are less likely to make negative self-evaluations.

In summary, this systematic review highlighted numerous gaps in our understanding of changes to self-identity after TBI. As relevant to the scope of this thesis, a key area for further investigation related to how neurocognitive functions
influence people’s experience of changes to self-identity. By appraising existing
approaches to measuring the impact of TBI on self-identity, along with identifying gaps
in knowledge regarding factors associated with self-identity changes, this review guided
the focus and methodology of the three subsequent empirical studies. Spanning all three
empirical studies (studies 2 – 4), the HISD version III – a measure of pre-injury and
current self-concept focused on emotional and behavioural attributes – was used to
assess changes to self-identity after TBI.

**Study 2: Relationship between neurocognitive function and self-discrepancy after
severe TBI**

The systematic review (study 1) identified preliminary evidence that higher self-
esteeem after TBI is related to lower IQ and executive functioning, and poorer self-
awareness. A subsequent study published after the review identified that poorer
performance on a verbal fluency task was associated with more negative self-
discrepancy on the HISD-III (Reddy et al., 2017). These researchers proposed that
impairments in language and executive function may reduce people’s capacity to
participate in personally meaningful activities, which in turn may disrupt their sense of
self-continuity. Importantly, their study mainly focused on executive functioning and
included individuals with TBI of mixed severity (mild to severe). Given the diversity of
neurocognitive impairments after severe TBI, a broader range of cognitive functions
were assessed in study 2, including self-awareness. To understand how neurocognitive
functions contribute to changes in self-identity, the key aim of study 2 was to
investigate the relationship between self-discrepancy on the HISD-III and measures of
attention, memory, executive function, and self-awareness.

Overall, a main finding of study 2 was that individuals with severe TBI who had
better neurocognitive functions were more likely to experience negative self-
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discrepancy. Specifically, individuals with better immediate and working memory, verbal fluency, and self-awareness reported more negative self-discrepancy. Another novel finding was that increased self-awareness partially mediated the relationship between memory impairment and self-discrepancy. These findings broadly support Gracey and Ownsworth’s (2012) theoretical account of self-identity change after brain injury. Their theory suggests that neurocognitive impairments interfere with self-comparison processes (i.e., monitoring, reflecting, and updating self-knowledge) that contribute to a mismatch between one’s pre-injury and post-injury selves. The findings were also consistent with Conway’s account of the self-memory system, whereby memories are considered the “database” of the self (Conway, 2005; Conway & Pleydell-Pearce, 2000). Hence, intact immediate memory and accurate self-appraisal of post-injury deficits may support the process of updating self-knowledge of emotional and behavioural attributes following TBI.

To further understand the relationship between neurocognitive factors and self-discrepancy, the associations between neurocognitive functions and ratings of past and current self on the HISD (i.e., self-perceptions underlying self-discrepancy) were examined. Interestingly, better immediate memory and inhibitory control were associated with more positive ratings of past self-concept, whereas better self-awareness was related to more negative ratings of current self-concept. Prior research has suggested that retrospective recall of one’s past requires access to and organization of self-knowledge, which is supported by memory and executive control processes (Conway, 2005). The current findings extend the literature by suggesting that deficits in memory and inhibitory control restrict access to past self-representations, and so individuals are required to draw upon their current self-perceptions to reconstruct who they were before their injury. This explanation could account for the reduced self-
discrepancy or greater consistency between ratings of past and current selves for individuals with more severe neurocognitive impairments.

This improved understanding of the neurocognitive processes that contribute to self-discrepancy has implications for rehabilitation approaches that help support people to develop a realistic and adaptive self-identity after brain injury. A key clinical consideration arising from these findings relates to the importance of supporting individuals with TBI who have better neurocognitive function to make sense of self-discrepancies or perceived changes in their abilities and attributes. This could be achieved through psychotherapy interventions that explore self-discrepancies and their meaning and support individuals to cope with post-injury changes and re-engage in meaningful everyday activities (Ownsworth & Gracey, 2017). For individuals with poorer neurocognitive functioning and impaired self-awareness, cognitive rehabilitation approaches that facilitate more realistic self-appraisals without triggering emotional distress are needed. For example, metacognitive approaches that incorporate feedback on performance and training in compensatory strategies have been found to improve self-awareness and task performance without eliciting emotional distress (Schmidt et al., 2013). Further recommendations for rehabilitation that are informed by the current findings are outlined in a later section entitled “Implications of integrated thesis findings”.

Study 3: Personality characteristics and cognitive appraisals associated with self-discrepancy after severe TBI

The primary aims of study 3 were to examine the relationship between personality characteristics (optimism and defensiveness), cognitive appraisals (threat appraisals, rumination, reflection, and perceived coping resources) and self-discrepancy. The personality characteristics of optimism and defensiveness were proposed to
influence self-identity change by shaping the manner in which people make sense of and cope with everyday situations after injury. Cognitive appraisals such as threat appraisals, self-focused attention (rumination and reflection) and perceived coping resources are manifestations of personality that are potentially amenable to change in response to enriching life experiences such as psychotherapy (Velden et al., 2015).

As hypothesised, lower levels of optimism and defensiveness were related to more negative self-discrepancy. These personality attributes were found to contribute to self-discrepancy by influencing individuals’ current self-concept, rather than affecting how they recalled their past or pre-injury self-concept. Further, lower optimism was related to more negative cognitive appraisals (greater threat appraisals and rumination and lower coping resources). Another key finding was that individuals with lower optimism reported greater rumination, which in turn was related to more negative self-discrepancy. These results support the theoretical perspective that optimism shapes how people appraise stressful experiences (Carver & Connor-Smith, 2010), and also reinforce prior TBI research linking higher optimism to greater hope and lower psychological distress (Peleg et al., 2009; Ramanathan et al., 2011). The current findings extend the literature by demonstrating that after severe TBI, individuals with higher optimism are less likely to appraise everyday situations as threatening, and experience negative repetitive thoughts. Further, they are more likely to perceive that they possess greater coping resources. While higher defensiveness was associated with lower self-discrepancy and more positive current self-concept, defensive characteristics were not significantly related to threat appraisals, rumination and reflection or perceived coping resources. Consistent with previous TBI research, it is apparent that individuals with high defensiveness strive to maintain a positive self-image after brain injury (Ownsworth et al., 2007; Ownsworth & McFarland, 2004).
Overall, as per Study 1, these findings reinforce the “Y-shaped” model, which proposes that negative cognitive appraisals and maladaptive coping efforts may serve to magnify perceived differences between one’s pre-injury and post-injury selves (Gracey et al., 2009; Ownsworth, 2014). Thus, everyday experiences after TBI such as difficulty on tasks previously performed with ease and lack of goal attainment are likely to contribute to self-discrepancy regarding personal attributes for individuals with ruminative processing styles. Conversely, individuals high on optimism are less likely to experience threat appraisals or engage in negative repetitive thinking, and more likely to find ways to accommodate their challenges and maintain coherence between their pre-injury and post-injury selves. Contrary to expectations, optimism and self-discrepancy were not related to reflective processing. Further research is needed to identify cognitive appraisals and coping strategies (e.g., benefit finding or meaning-based coping) that support self-continuity for people high on optimism.

Clinically, these findings underscore the need for therapy approaches that support individuals to adapt to changes in their personal abilities, develop modified goals and re-engage in meaningful activities to reduce negative self-discrepancies. Individuals with a greater tendency to ruminate on perceived losses, threats, and injustices to the self may find the process of identity reconstruction more challenging and are more likely to experience psychological distress (Curran et al., 2000). Psychotherapy may support individuals to identify their ruminative thinking styles and unhelpful coping reactions and to explore the subjective meaning of post-injury changes for their self-identity (Ownsworth & Gracey, 2017). Behavioural experiments can help test assumptions about perceived task failure and trial alternative ways of coping, which in turn can lead to modified self-views (Ownsworth & Gracey, 2017). There is evidence from randomised controlled trials supporting the efficacy of CBT for reducing mood
symptoms and improving psychosocial functioning after TBI (Fann et al., 2015; Ponsford et al., 2016); yet, the impact on self-identity has been largely overlooked in psychotherapy research (see review by Ownsworth & Haslam, 2016). Third wave CBT approaches are increasingly being used in brain injury rehabilitation to enhance emotion regulation skills and foster behaviour change (Ashworth et al., 2017). For example, Acceptance and Commitment Therapy seeks to support individuals to adapt and commit to living a meaningful life by being guided by personal values and taking effective action (Kangas & McDonald, 2011). Clinical trials evaluating the efficacy of CBT for addressing negative self-discrepancy and associated emotional distress after TBI are a priority for future research.

Study 4: The nature of occupational gaps and relationship to mood and self-discrepancy after severe TBI

Study 4 sought to understand the nature of occupational gaps after severe TBI and examine the associations between desired occupational re-engagement, mood, psychosocial functioning and self-discrepancy. Reduced participation in everyday activities is commonly reported after TBI. Re-engagement in meaningful activities is proposed to improve mood and self-concept (Dumont et al., 2005). Consistent with this view, gaps between actual participation and desired participation have been found to be associated with lower life satisfaction and greater depressive symptoms (Eriksson et al., 2009). However, the process occupational re-engagement after injury can be mixed, such that feelings of frustration and despair can develop when attempts to resume pre-injury activities are not successful (Turner et al., 2007). However, the effects of gaps in desired occupation re-engagement on self-identity are unclear.

As hypothesised, individuals reported that they were currently engaged in fewer activities compared to before their injury. Activity engagement after TBI appeared to be
more sedentary, and individuals reported a desire to be involved in more cognitive, physically active and social occupations. While participants’ desired activities were largely consistent with their past or pre-injury participation, there were some exceptions, for example, more participants wanted to support others and volunteer after their injury compared to before the injury. The focus of rehabilitation after TBI is often on supporting individuals to resume their independence with activities of daily living (Turner et al., 2008). The results suggest that having resumed these activities, individuals may set new goals related to social and community participation. This shift in desired activity engagement may reflect changes in personal values after injury, or alternatively a re-adjustment of one’s occupational goals due to lack of opportunity or failure to maintain employment (Ownsworth & McKenna, 2004; Sloan et al., 2004).

Also consistent with the hypotheses, greater occupational gaps were found to be related to higher levels of anxiety and lower psychosocial functioning. Notably, the relationship between occupational gaps and self-discrepancy was mediated by anxiety, such that individuals who were engaging in fewer desired activities experienced more anxiety, which in turn was related to negative changes in self-discrepancy. These findings are consistent with Goldstein’s (1942, 1952) classic account of a “catastrophic reaction” of extreme anxiety after TBI, triggered by unsuccessful attempts to complete or resume tasks previously performed with ease. Further, these findings provide some support for self-discrepancy theory (Higgins, 1987; Higgins et al., 1986), which predicts that conflicting beliefs about one’s self elicit emotional distress. As demonstrated in study 3, threat appraisals regarding difficulty in completing familiar activities are associated with negative comparisons between one’s pre-injury and post-injury abilities. While activity avoidance may reduce anxiety in the short-term, in the longer term individuals can experience heightened anxiety and negative self-discrepancy
Collectively, the findings of studies 2 to 4 highlight the importance of integrated rehabilitation approaches that simultaneously address neurocognitive impairments, psychological adjustment, and activity re-engagement. The following section outlines key clinical implications arising from the combined thesis findings.

**Implications of integrated thesis findings**

Considered together, the findings from this thesis have some key implications for rehabilitation of people with severe TBI. Based on studies 2 to 4, Figure 8.1 represents the factors empirically related to self-discrepancy. The key constructs found to be associated with more negative self-discrepancy include better memory, reduced optimism, and greater desired re-engagement gaps (indirectly). These relationships were mediated by higher levels of self-awareness, rumination, and anxiety symptoms (respectively). As such, the latter factors represent potential targets for intervention to facilitate positive identity change after TBI.

*Figure 8.1. Diagrammatic representation of key thesis findings*

It has long been advocated that an integration of cognitive rehabilitation, psychotherapy and occupation-based approaches is essential to support a positive and
realistic self-identity after brain injury (Ben-Yishay, 1996; Ownsworth & Haslam, 2016; Prigatano, 1986; Ylvisaker & Feeney, 2000). As supported by the current findings, it is clinically important to assess changes to self-concept, anxiety, rumination, self-awareness and occupational gaps. Ongoing supported, collaborative formulation of changes with the client (e.g., using diagrams and words reflecting personal attributes) may assist with insight and making meaning processes, as well as development of strategies to support the achievement of personally relevant goals (e.g., targeting re-engagement in desired occupations). Initial consideration of positive therapeutic alliance, or the relationship between the therapist and client, has also been identified as a key factor in the development of self-awareness as well as enhancing self-efficacy (Klonoff, Lamb, & Henderson, 2000).

Driving rehabilitation is the identification of personal values and goals. Ownsworth and Haslam (Ownsworth & Haslam, 2016) argued that goals in rehabilitation should be guided by higher level self-representations (i.e., who I am and who I want to be). Examination of occupational gaps and their personal meaning and relevance to self-identity could be used to guide client-centred rehabilitation. For those with more severe neurocognitive impairment, use of technological aids may support recall of one’s goals (e.g., reminders, online calendars) and prompt goal-directed behaviour. Other technological aids such as video recordings and Instagram may support recollection of salient life experiences both prior to and after TBI and that enhance self-coherence (Ownsworth, 2014).

Cognitive rehabilitation interventions aim to teach compensatory strategies that increase independence and self-efficacy on everyday tasks. Occupation-based approaches that support skill development and activity participation may create regular opportunities for individuals to experience task mastery and success, which in turn may
reduce self-discrepancy and associated emotional distress (Ownsworth & Haslam, 2016). Through planned activities and behavioural experiments individuals can gently test perceptions regarding their abilities and “new self” and reflect on these in therapy. Metacognitive approaches that systematically teach individuals to anticipate, check and correct errors may increase acceptance of the need for strategies to improve performance. Further, such metacognitive approaches have been found to improve self-awareness without eliciting distress (Ownsworth et al., 2017). Teaching strategies to manage cognitive deficits may also alleviate anxiety, by reducing cognitive load and equipping individuals with the practical tools to manage unexpected demands.

Targeted psychotherapy approaches that address anxiety and rumination and support individuals to develop effective coping strategies to manage post-injury changes may also help to resolve self-discrepancies. As discussed previously, there is some support for the efficacy of adapted CBT for reducing mood symptoms and improving psychosocial functioning after TBI (Ownsworth & Gracey, 2017; Ponsford et al., 2016). With regards to anxiety, psychoeducation, behavioural experiments, cognitive restructuring, relaxation strategies, and graded exposure to anxiety provoking situations have been identified as important components of these programs (Ownsworth & Gracey, 2017). Further research is needed to determine whether such interventions promote a more positive and realistic identity after TBI.

Finally, reconstruction of self-identity is facilitated by positive feedback provided within a social context (Ylvisaker & Feeney, 2000). Avenues for increasing social interaction opportunities (e.g., through peer support groups, volunteering, advocacy) may increase a person’s sense of belonging and value to others and decrease loneliness, which in turn can challenge negative self-appraisals. People may develop new interests and priorities after TBI which support them to positively redefine
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themselves. Involvement of family members and other naturalistic supports in activity planning is vital to positively reinforce strategy use and rehabilitation progress, and to consolidate an individual’s renewed sense of identity (Klonoff, 2010).

Methodological considerations

There are some key conceptual and methodological limitations related to this thesis that need to be acknowledged, which may limit the conclusions drawn and the generalisability of the results. First, due to the convenience sampling approach used in the context of a rehabilitation intervention, the participants may not be representative of the broader severe TBI population. Nevertheless, the gender ratio of 2.7 males to 1 female was consistent with that reported for Australian population data of approximately 3.1:1 (Fortune & Wen, 1999). Further, it is known that younger adults are more vulnerable to TBI, which was reflected in the current sample’s age characteristics (median age at injury = 32 years). However, given that the participants were recruited as a part of a broader study (Ownsworth et al., 2017) which had inclusion criteria related to impaired self-awareness and executive dysfunction, the sample may have more severe neurocognitive impairments than the broader TBI population. Time since injury was also highly variable, (2-204 months post injury), which could have impacted on self-report measures that required participants to reflect on their pre-injury functioning (AQ) and self-concept (HISD). While there was no significant association between time since injury and HISD ratings, these differences may obscure the interpretation of the self-discrepancy data. Further, due to varying time post-onset, individuals may have had different opportunities to engage or re-engage in particular life roles and activities post-injury. Thus, it is recommended that future research employ longitudinal designs along with representative sampling approaches such as recruitment based on consecutive hospital admissions.
An additional limitation of the present research relates to the approach to measurement selected to infer changes to self-identity. The HISD was specifically developed for the TBI population, is well validated and was identified as the most commonly used measure of changes to self-identity after TBI in study 1. However, the tool only has 18-items regarding emotional and behavioural attributes and hence does not capture all domains relevant to self-understanding (e.g., physical, social, family, and academic/work). Future research could examine self-discrepancy using a multi-domain measure such as the Tennessee Self-Concept Scale (TSCS:2; Fitts & Warren, 1996). As identified in study 1, the development of validated measures of social and cultural identity after TBI represents a priority for future research.

A further limitation of the study relates to the modest sample size for conducting mediation analysis. The mediation findings should therefore be considered preliminary and require validation in a larger TBI sample. A larger sample size (i.e., >100) would also permit the use of more complex modelling approaches such as path analysis to understand the interplay between the variables examined. For example, the relationship between better neurocognitive function and negative self-discrepancy may be mediated and/or moderated by multiple factors including other variables examined in studies 3 and 4.

It is important to also recognise that the cross-sectional design and lack of experimental manipulation does not allow inferences to be drawn regarding the direction of relationships between the neurocognitive, psychological and social/occupational variables and self-discrepancy. As noted in study 1, changes in self-concept can be experienced by individuals after other traumatic events that involve adjustment to injury or loss (Beadle et al., 2016). Further research is warranted to compare the impact of different types of trauma related conditions on self-identity. For
example, an orthopaedic sample matched on age, gender, time since injury, and injury severity may provide a useful comparison group for understanding the unique effects of TBI on sense of self.

As noted in study 3, the reliance on self-report measures in studies 3 and 4 is important to recognise. In particular, consideration must be taken regarding the possible impact of method variance, or covariance related to the measurement approach rather than the constructs that the tools claim to measure (Podsakoff et al., 2003). In studies 2, 3, and 4, it is possible that there was inflation of correlation coefficients for variables assessed using self-report measures (i.e., HISD-III, OGQ, DASS-21, AQ, RRQ, LOT-R, MCSDS, ATAQ, CRQ). However, as identified by Spector (2006), common scale format is considered a concern when significant correlations are observed among all variables assessed by measures that use the same self-report format, which was not the case in the present research. Further, self-report measures were considered most appropriate for measuring subjective or internal states such as self-identity. Additionally, all self-report measures used demonstrated sound reliability in the present sample (refer to chapter 3). Further research examining other psychometric properties (e.g., test-retest reliability and validity) of measures less commonly used in the TBI population (e.g., RRQ) is recommended.

As a final important consideration, it was beyond the scope of this thesis to include a broader range of social and cultural variables that may influence self-discrepancy. While the OGQ assessed engagement in particular social roles, the impact of family dynamics and relationships, social networks and group memberships more broadly on self-identity change would be beneficial to understand. Theoretical accounts highlight that self-identity is influenced by our social interactions, roles and group memberships (Jetten et al., 2012). Social networks and group identification has been
linked to health and well-being via health-related social capital, health-related norms, coping, and social support (Haslam, Jetten, Postmes, & Haslam, 2009). Social interaction opportunities and groups memberships are known to change and often diminish after TBI (Douglas, 2012). In a meta-synthesis exploring experience of recovery after TBI, Levack et al. (2010) reported that individuals perceived a “social disconnection”, whereby they experienced a loss of intimate relationships, friends and employment. As noted by Klonoff (2010), family members also undergo identity changes and their reactions to and support of the person as they begin to recognise changes to their sense of self are crucial. Due to the neuropsychological consequences of TBI, it is more challenging for individuals to form new relationships and access social opportunities. One such common neuropsychological consequence of TBI that was not examined within this dissertation was social cognition. An important component of social cognition involves theory of mind, namely, recognising and attributing mental states (i.e., thoughts, beliefs and intensions) to oneself, as well as other people. Understanding “who am I compared to everyone else” warrants further exploration. Therefore, important gaps in the literature relate to understanding a) how impairments in social cognition impact self-identity; b) how family and other social groups can serve as barriers to, or facilitators of the identity reconstruction process; and c) the interplay between self-identity, social cognition, and social networks.

**Recommendations for Future Research**

Bearing in mind the limitations outlined, the current research has advanced knowledge of the impact of TBI on self-identity and the neurocognitive, psychological and social/occupational factors related to self-discrepancy. Such findings have stimulated some key directions for future research in this field. As identified in the preceding sections, a prospective longitudinal study involving early assessment during
hospitalisation and ongoing assessments at discharge, 1 – 3 months post-discharge, and 12 months post-discharge would improve understanding of the timing of changes to self-identity and the neurocognitive, psychosocial and environmental factors that predict or account for these changes. A larger sample size would permit the use of more advanced modelling approaches (e.g., multiple mediation, moderated mediation) to better understand the interplay of neurocognitive and psychosocial factors, as identified in Figure 8.1. More representative sampling approaches (e.g., consecutive admissions) would also reduce potential selection bias and enhance the generalisability of findings. Inclusion of other clinical populations (e.g., orthopaedic injury or trauma groups) would also contribute to understanding of changes in self-identity that are unique to TBI.

There is also greater scope for research into other neurocognitive, psychological and social/environmental factors. For example, in addition to family and social groups, the role of social cognition, language and narrative in making sense of changes and updating self-identity is important to explore. Consideration of other personality traits (e.g., neuroticism, extraversion and openness to experience) and their influence on self-discrepancy could also be examined. Understanding the factors that may contribute to positive self-discrepancy and potential role of post-traumatic growth in positive self-identity change would also be beneficial. Further, it would be beneficial to identify the personal importance of roles and activities and how efforts to re-engage may impact self-representations. There is only preliminary evidence supporting the positive effects of brain injury rehabilitation on self-concept (Ownsworth & Haslam, 2016). The development and evaluation of identity-oriented interventions after TBI is recommended, guided by the thesis findings.
Conclusion

Overall, this thesis extends the TBI literature in several important ways. Initially, the systematic review (study 1) demonstrated that changes to self-identity after TBI are commonly experienced, and that these may not arise solely from neurological damage; rather, the broader psychosocial consequences of a traumatic event or injury should also be taken into consideration. This review also highlighted the need for consistency in the measurement of self-identity change, as well as the need to understand the role of neurocognitive and psychosocial factors in shaping sense of self after TBI. These findings informed the development of studies 2 to 4. Study 2 demonstrated that more negative self-discrepancy was significantly associated with greater self-awareness and better performance on tests of immediate and delayed memory, working memory, and verbal fluency. These findings highlight the need to support individuals with better neurocognitive function to make sense of “who am I now after brain injury”.

Study 3 highlighted the role of optimism and associated cognitive appraisals such as rumination in shaping sense of self after TBI. Therefore, it may be beneficial for psychological interventions to target ruminative thinking styles to explore and address self-discrepancy post-injury. Finally, a novel finding of study 4 was that greater occupational re-engagement gaps were related to increased anxiety, which in turn was associated with negative self-discrepancy. Anxiety regarding changes in occupational functioning may be important to address in rehabilitation. Overall, this thesis provides conceptual advances in understanding changes to self-identity after TBI and has important implications for rehabilitation practices and future research. Ultimately, furthering and sharing this understanding of how survivors navigate complex changes to
self and reconstruct their self-identity has the potential to assist individuals to live meaningful lives after TBI.
Complete thesis reference list


doi:10.1076/clin.12.1.43.1726


doi:10.1177/0269215508101736

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doi:10.1080/09602010701860266


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CHANGES TO SELF AFTER TBI


Changes to Self after TBI


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doi: http://dx.doi.org/10.3109/02699059509008226


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CHANGES TO SELF AFTER TBI


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CHANGES TO SELF AFTER TBI

doi:10.1080/09602011.2015.1037772


doi:10.1136/jnnp.2004.037887


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stroke. *Archives of Physical Medicine and Rehabilitation, 96*(6), 1064–1070. doi:10.1016/j.apmr.2015.01.022


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Appendix A: Ethics approval and participant information sheet

Enquiries to: Metro South
Human Research Ethics Committee
Phone: 07 3443 8049
Fax: 07 3443 8003
HREC Ref: HREC/13/QPAH/096
E-mail: PAH.ETHICS.Research@health.qld.gov.au

A/Prof Ownsworth
School of Psychology
Griffith University
Mount Gravatt Campus
Mount Gravatt QLD 4122

Dear A/Prof Ownsworth

HREC Reference number: HREC/13/QPAH/096
Project Title: A Comparison of errorless learning and error-based learning for improving functional performance following traumatic brain injury

Thank you for submitting the above research protocol to the Metro South Human Research Ethics Committee for ethical and scientific review. This protocol was first considered by the Human Research Ethics Committee (HREC) at the meeting held on 5th March 2013.

You are reminded that this letter constitutes ethical approval only. You must not commence this research protocol at a site until separate authorisation from the Metro South Chief Executive or Delegate of that site has been obtained.

A copy of this approval must be submitted to the Research Governance Office(ies)/Delegate of the relevant institution with a completed Site Specific Assessment (SSA) Form for authorisation from the Chief Executive or Delegate to conduct this research at the Princess Alexandra Hospital.

I am pleased to advise that the HREC has granted approval of this research protocol. The documents reviewed and approved include:

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<td>Sydney Psychological Reintegration Scale</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please note the following conditions of approval:
1. The Principal Investigator will immediately report anything which might warrant review of ethical approval of the protocol in the specified format, including unforeseen events that might affect continued ethical acceptability of the protocol. Serious Adverse Events must be notified to the HREC as soon as possible. In addition the Investigator must provide a summary of the adverse events, in the specified format, including a comment as to suspected causality and whether changes are required to the Patient Information and Consent Form. In the case of Serious Adverse Events occurring at the local site, a full report is required from the Principal Investigator, including duration of treatment and outcome of the event.

2. Amendments to the research protocol which may affect the ongoing ethical acceptability of a protocol must be submitted to the HREC for review. Amendments should be accompanied by all relevant updated documentation and a cover letter from the principal investigator, providing a brief description of the changes, the rationale for the changes, and their implications for the ongoing conduct of the study. Hard copies of the cover letter and all relevant updated documents, with tracked changes, must be submitted to the HREC office as per standard HREC SOP. (Further advice on submitting amendments is available at [http://www.health.qld.gov.au/ojhr/documents/researcher_userguide.pdf](http://www.health.qld.gov.au/ojhr/documents/researcher_userguide.pdf).)

3. Amendments to the research protocol which only affect the ongoing site acceptability of the protocol are not required to be submitted to the HREC for review. These amendment requests should be submitted directly to the Research Governance Office.

4. Proposed amendments to the research protocol which may affect both the ethical acceptability and site suitability of the protocol must be submitted firstly to the HREC for review and, once HREC approval has been granted, then submitted to the Research Governance Office.

5. Amendments which do not affect either the ethical acceptability or site acceptability of the protocol (e.g. typographical errors) should be submitted electronically (track changes) and in hard copy (final clean copy) to the HREC Coordinator. These should include a cover letter from the Principal Investigator or Study Co-ordinator providing a brief description of the changes and the rationale for the changes, and accompanied by all relevant updated documents with tracked changes.

6. The HREC will be notified, giving reasons, if the protocol is discontinued at a site before the expected date of completion.

7. The Coordinating Principal Investigator will provide at least, an annual report to the HREC on the anniversary of the approval and at completion of the study in the specified format.

8. If you require an extension for your study, please submit a request for an extension in writing outlining the reasons. Note: One of the criteria for granting an extension is the compliance with the approval’s conditions including submission of progress reports.

9. Any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes ([WHO / ICMJE 2008 definition](http://www.anzctr.org.au/)) should be registered, including early phase and late phase clinical trials (phases I-III) in patients or healthy volunteers ([WHO Recommendation / ICMJE policy](http://www.anzctr.org.au/)). If in doubt, registration is recommended. All studies must be registered prior to the study’s inception, i.e. prospectively.

This HREC approval is valid for 3 years from the date of this letter.

Should you have any queries about the HREC’s consideration of your protocol please contact the Metro South HREC Office on 07 3443 8049.

Please note that the Metro South HREC is constituted and operates in accordance with the National Health and Medical Research Council’s (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPM/ICH Note for Guidance on Good Clinical Practice. Attached is the HREC Composition with specialty and affiliation with the Hospital (Attachment I).
The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the following websites:

Once authorisation to conduct the research has been granted, please complete the Commencement Form (Attached) and return to the Metro South Human Research Ethics Committee.

The Metro South HREC wishes you every success in your research.

Yours sincerely,

Professor Maher Gandhi
Chair
Metro South Hospital and Health Service
Human Research Ethics Committee (EC00167)
Centres for Health Research
Princess Alexandra Hospital

Office
Centres for Health Research
Level 7 Translational Research Institute
Postal
37 Kent Street
Woolloongabba Q 4102
Phone
61 7 3443 8049
Fax
61 7 3443 8003
Participant Information and Consent Form (Person with TBI)

The Princess Alexandra Hospital and Griffith University

**Project Title:** Comparison of home based neuro-rehabilitation programs for improving functional performance following traumatic brain injury

**HREC Reference number:** HREC/13/QPAH/096

**Principal Researchers:** A/Prof Tamara Ownsworth, School of Applied Psychology, Griffith University; Associate Professor Jennifer Fleming, Department of Occupational Therapy, the University of Queensland and Princess Alexandra Hospital; Professor David Shum, School of Applied Psychology, Griffith University.

**Associate Researchers:** Janelle Griffin, Brain Injury Rehabilitation Unit, Princess Alexandra Hospital; Dr Melissa Kendall, Acquired Brain Injury Outreach Service; Dr Elizabeth Beadle, School of Applied Psychology, Griffith University; Julia Schmidt, School of Allied and Public Health, Australian Catholic University; and Iain Irving, Brain Injury Community Rehabilitation Team, Royal Rehabilitation Centre.

*This Participant Information and Consent Form is 7 pages long. Please make sure you have all the pages.*

**Part 1. What does my participation involve?**

1. **Information**

You are invited to take part in this research project. This is because you are currently receiving rehabilitation and support from the Brain Injury Rehabilitation Unit (BIRU) at the Princess Alexandra Hospital or the Acquired Brain Injury Outreach Service (ABIOS). This research project aims to investigate the effectiveness of different approaches for improving performance on everyday tasks following traumatic brain injury.

This Participant Information and Consent form tells you about the research project. It explains the procedures involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Feel free to ask questions about any information that you don’t understand or want to know more about. Before deciding whether or not to take part, you may wish to talk about it with a relative, friend or healthcare worker.

Participation in this project is voluntary: if you don’t want to take part, you don’t have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing this you are telling us that you:

- Understand what you have read;
- Consent to take part in the research project;
- Consent to participate in the research process as described;

Version 6; 19 February 2014
CHANGES TO SELF AFTER TBI

- Consent to the use of your personal information as described
You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. **What is the Purpose of this research?**
The purpose of this project is to examine different approaches for training new skills and routines following traumatic brain injury (TBI).

This study aims to understand how we can best teach people new skills in their own home environment after TBI.

It is important for therapists in brain injury rehabilitation to know the most effective techniques for promoting recovery and adjustment after TBI. This study will help the therapists improve their skills in providing rehabilitation.

We also invite a member of your family or a caregiver to participate in this project.

3. **What does participation in the research project involve?**
You will be participating in a randomised controlled research project. Sometimes we do not know which treatment is best for treating a condition. To find out we need to compare different treatments. We put people into groups and give each group a different treatment. The results are compared to see if one is better. To try to make sure the groups are the same, each participant is put into a group by chance (random).

4. **What do I have to do?**
The project coordinator (Dr Elizabeth Beadle) will contact either your treating occupational therapist at BIRU, and/or case manager at ABIOS, and/or neuropsychologist at BIRU to access medical information that is relevant to this study (i.e., severity and location of injury, discharge functional summary and other medical information such as history of seizures and medication).

You will then do a **pre-program assessment** with Elizabeth Beadle in your own home and on the telephone. These assessments will take approximately **2.5 – 3 hours** in total and include the following:
- Several brief cognitive tasks (e.g., that assess your ability to pronounce words, remember a list of words, plan a task).
- A functional skills assessment involving a cooking task (note: all ingredients and recipes will be provided by Elizabeth). An audiovisual recording will be made of this functional skills assessment for later viewing and coding by Elizabeth.
- Questionnaires regarding your thinking abilities, emotional well-being, self-concept, coping resources, social skills and independence on daily tasks. Your family member will also be asked by Elizabeth to complete the same questionnaires about you, in addition to answering questions about your support needs in daily living.

You will then complete **eight sessions (90 mins)** of a home-based program conducted by a research therapist (a qualified psychologist or occupational therapist). These sessions will be recorded on an audio device, though you can ask for the sessions not to be recorded (your choice to not have the sessions recorded will not influence your involvement in the study).

Version 6; 19 February 2014
The first four rehabilitation sessions will focus on training new skills in meal preparation. The second four sessions will be tailored according to a home-based functional activity or routine of your own choosing.

You will then do a post-program assessment with Elizabeth one week after the final rehabilitation session. This will involve the same cognitive tasks, the functional skills assessment and completing the same questionnaires as the pre-program assessment (you and your family member). Once again, an audiovisual recording will be made of the functional skills assessment for later scoring by Elizabeth.

There will be a six month post-program follow-up assessment over the telephone. This will involve a brief interview (20-30 minutes) regarding your home and community functioning (involving you and your family member).

5. What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this project. But, as the programs have previously been found to lead to improvements in functioning, it is expected that you will experience some direct benefits from participation in terms of skill development. It is also expected that your participation in this study will help our understanding of the usefulness of particular strategies for rehabilitation.

6. What are the possible risks of taking part?

Participation in the project is not seen to be associated with any possible risks or discomfort. However, some people might find it distressing to answer questions about the effects of their brain injury in daily living; or they may find that completing the assessments increases their understanding of changes in their abilities since the injury. For some people this may produce feelings of distress or frustration.

If you become distressed during the study Elizabeth or the research therapists will provide immediate emotional support and also discuss other options for psychological support in the hospital or community. They can also contact your treating occupational therapist at BIRU or case manager at ABIOS and support you to access psychological support. You may prefer to suspend or end your participation in the research.

7. Do I have to take part in the research project?

Participation in any research project is voluntary. If you do not wish to take part you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

Your decision to take part, or to take part and withdraw, will not affect your relationship with the Princess Alexandra Hospital, Acquired Brain Injury Outreach Service or Griffith University.

8. What if I withdraw from this research project?

If you decide to withdraw please let a member of the research team know (please find these contact details on page 5 of this form, under “who can I contact?”). If you wish to withdraw and do not want your information in the study, the researcher will provide a form for you to sign. Your data will then be removed from the data set and destroyed. Otherwise, if you are
happy for us to use the information, but no longer want to take part in the study; we can note your withdrawal and make no further contact with you regarding participation.

9. What if my caregiver chooses to withdraw from this research project?

The decision of your caregiver/family member to take part in, or withdraw from the research project will in no way effect your ability to take part in the project should you wish to participate or continue participating in the study.

10. How will I be informed of the results of this research project?

A 1-2 page summary of the results of the study can be mailed to you on your request at the end of the study.

Part 2 How is the research project being conducted?

1. What will happen to the information about me?

By signing the consent form you consent to the research staff collecting and using personal information about you for the research project. Any information obtaining in connection with this project that can identify you will remain confidential. The audio recorded sessions are being used to ensure the therapists deliver your intervention correctly, and this information will be deleted once the session has been checked. It will be checked by a member of the research team. The audio files will be stored on a computer with a password protected file until reviewed by a member of the research team and then deleted. You will be assigned an ID code with which all data relating to you will be labelled. Only members of the research team will have access to the data you have provided. Your identifying information will be removed from all data records and stored in a de-identified form on completion of the study. Files will be kept locked in a filing cabinet in the School of Applied Psychology at Griffith University for a period of 7 years, then destroyed.

By signing the consent form you agree to the study team accessing health records if they are relevant to your participation in this research project.

The findings from this study will only be presented as group data. It is anticipated that this will be published/presented in a variety of forums. In any publication/presentation, information will be provided in such a way that you cannot be identified.

Any information obtained within this research project that can identify you will remain confidential and will only be used in this research project. It will only be disclosed with your permission, except as required by law.

2. How can I access my information?

In accordance with relevant Australian and/or Queensland privacy and other relevant laws, you have the right to access the information collected and stored by the researchers about you. You also have the right to request that any information, with which you disagree, be corrected. Please contact one of the researchers if you would like to access your information.

3. Is this research project approved?

The ethical aspects of this research project have been approved by the Human Research Ethics Committees (HREC) of Metro South (of which the Princess Alexandra Hospital is a part of), Griffith University, and the University of Queensland.

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interest of people who agree to participate in human research studies. If you would like any further information on the approval of this study, contact details for the HREC Metro South are:

Version 6; 19 February 2014
Metro South Human Research Ethics Committee (EC00167) HREC Coordinator
Centres for Health Research
Level 7 TRI
37 Kent Street WOOLLOONGABBA QLD 4102
Ph: (07) 3443 8049 or 3443 8047
Fax: (07) 3176 7667

4. Reimbursement for your costs
You will not be paid for your participation in this project.

5. Who can I contact?
Regarding further information, problems with involvement, or withdrawal from study:
Please contact Dr Elizabeth Beadle
On Ph. 3735 3304

At address:
School of Applied Psychology
Griffith University
Mt Gravatt 4122

Regarding concerns or complaints about the ethical conduct of the research project:
The Senior Manager, Research Ethics and Integrity on 3735 5585
Or email: research-ethics@griffith.edu.au.

Metro South Human Research Ethics Committee (EC00167) HREC Coordinator
Contact details can be found at the bottom of page 4.
I have read, or have had read to me in a language that I understand, this document dated 19/02/2014 and I understand the purposes, procedures and risks of this research project as described within it.

1. I give permission for my treating occupational therapist at BIRU and/or my case manager at ABiOS and/or my neuropsychologist from BIRU to release relevant medical information to the members of the research team from Griffith University, the Princess Alexandra Hospital and the Acquired Brain Injury Outreach Service as needed for this project. I understand that such information will remain confidential.

2. I have had an opportunity to ask questions and I am satisfied with the answers that I have received.

3. I freely agree to participate in this project according to the conditions in the Participant Information.

4. I understand that I will be given a signed copy of the Participant Information and Consent Form to keep.

5. The researchers have agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant’s Name (printed) ...............................................

Signature .............................................................. Date

Declaration by project clinician*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Project Coordinator’s Name (printed) .................................

Signature .............................................................. Date

* A member of the research team must provide the explanation and provision of information concerning the research project.

Note: All parties signing the Consent Form must date their own signature.
The Princess Alexandra Hospital
Griffith University

Revocation of Consent Form

Full Project Title: Comparison of home based neuro-rehabilitation programs for improving functional performance following traumatic brain injury

If you wish to withdraw, prior to your withdrawal please contact:
Dr Elizabeth Beadie
On Ph: 3735 3304
At address: School of Applied Psychology
Griffith University
Mt Gravatt 4122

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise my relationship with the Princess Alexandra Hospital, Acquired Brain Injury Outreach Service or Griffith University.

Participant's Name (printed) ..............................................................

Signature Date
**Appendix B: List of Self Report Measures**

**Head Injury Semantic Differential Scale – Version 3**

**HEAD INJURY SEMANTIC DIFFERENTIAL III**

<table>
<thead>
<tr>
<th>Scale Description</th>
<th>Directions</th>
</tr>
</thead>
</table>

(1) Emotionally  (2) As a Person
Marlow Crowne Social Desirability Scale – Short Form

**Personal Reactions Inventory (MCSDS-SF)**
Listed below are a number of statements concerning personal attitudes and traits. Reach each item and decide whether the statement is **true** or **false** as it pertains to you personally.

**Answer: T/F**

1. It is sometimes hard for me to go on with my work if I am not encouraged.

2. I sometimes feel resentful when I don’t get my way.

3. On a few occasions, I have given up doing something because I thought too little of my ability.

4. There have been times when I felt like rebelling against people in authority even though I knew they were right.

5. No matter who I’m talking to, I’m always a good listener.

6. There have been occasions when I took advantage of someone.

7. I’m always willing to admit it when I make a mistake.

8. I sometimes try to get even rather than forgive and forget.

9. I am always courteous, even to people who are disagreeable.

10. I have never been irked when people expressed ideas very different from my own.

11. There have times when I was quite jealous of the good fortune of others.

12. I am sometimes irritated by people who ask favours of me.

13. I have never deliberately said something that hurt someone’s feelings.
Coping Resources Questionnaire (CRQ)

**COPING RESOURCES QUESTIONNAIRE**

A brain injury can cause problems which affect your ability to do things, your work, your relationships with family and friends and so on. These are some questions about what helps you to cope with these problems, and how well you think you do cope with them. Please answer all the questions by circling **true** or **false**.

<table>
<thead>
<tr>
<th>Question</th>
<th>True/False</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My family has helped me a lot since the brain injury.</td>
<td>True/False</td>
</tr>
<tr>
<td>2. I usually manage to stay calm in difficult situations.</td>
<td>True/False</td>
</tr>
<tr>
<td>3. I'm not very good at asking for help when I need it.</td>
<td>True/False</td>
</tr>
<tr>
<td>4. I don't feel I've had the support I needed.</td>
<td>True/False</td>
</tr>
<tr>
<td>5. I've been quite successful in overcoming some of the problems that the brain injury left me with.</td>
<td>True/False</td>
</tr>
<tr>
<td>6. It doesn't take much to get me feeling stressed.</td>
<td>True/False</td>
</tr>
<tr>
<td>7. It takes a lot to get me down.</td>
<td>True/False</td>
</tr>
<tr>
<td>8. When I think about some of my problems, I just don't know what to do for the best.</td>
<td>True/False</td>
</tr>
<tr>
<td>9. I am confident I can get my life back on track.</td>
<td>True/False</td>
</tr>
<tr>
<td>10. I get upset easily when things go wrong.</td>
<td>True/False</td>
</tr>
<tr>
<td>11. I don't think there's much that I personally can do to improve my situation.</td>
<td>True/False</td>
</tr>
<tr>
<td>12. Sometimes I feel like I've just been left to cope with it all by myself.</td>
<td>True/False</td>
</tr>
<tr>
<td>13. I think I'm fairly good at thinking my problems through and coming up with a plan for dealing with them.</td>
<td>True/False</td>
</tr>
<tr>
<td>14. Most people cope better than me when it comes to dealing with life.</td>
<td>True/False</td>
</tr>
<tr>
<td>15. I know people I can rely on to boost my confidence when it's low.</td>
<td>True/False</td>
</tr>
<tr>
<td>16. I've lost confidence in my ability to decide on the best way of dealing with problems.</td>
<td>True/False</td>
</tr>
<tr>
<td>17. I think I've coped well with what's happened to me since my brain injury.</td>
<td>True/False</td>
</tr>
<tr>
<td>18. If my mood gets low, I find it hard to snap out of it.</td>
<td>True/False</td>
</tr>
<tr>
<td>19. I can deal with most things that life throws at me.</td>
<td>True/False</td>
</tr>
</tbody>
</table>

Please turn over the page for more questions
(Remember, these are some questions about what helps you to cope with problems, and how well you think you do cope with them. You’re answering all the questions by circling true or false)

20. Some of my problems just don’t have a solution.  
21. I think I’m mentally quite tough.  
22. I’ve had good support from my friends in coping with what’s happened.  
23. I’m fairly confident in my ability to tackle difficult situations.  
24. Sometimes I feel it’s just all too much for me to cope with.  

<table>
<thead>
<tr>
<th></th>
<th>True/ False</th>
<th>True/ False</th>
<th>True/ False</th>
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</tbody>
</table>
Appraisal of Threat & Avoidance Questionnaire

ATAQ

The follow set of questions are about times when you may have felt worried. I want you to consider the situation, and answer:

a) Consider the previous month, is this statement true? Y / N

b) Because of this concern, have you avoided this situation? Y / N

1. Sometimes I worry I might get attacked and injured while I’m out.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

2. Sometimes I worry I might fall and injure myself while I’m out.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

3. Sometimes I feel home is the only place where I’m safe.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

4. Sometimes I worry that, if I’m attacked, I won’t be able to stick up for myself.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

5. With regards to electrical appliances, or sharp knives or tools, I sometimes worry that I’m not safe to use them.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

6. When crossing the road, I sometimes worry about getting knocked over.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

7. When I am out, I sometimes worry that I might walk into someone, or that they might bump into me.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

8. I sometimes worry that I might get another brain injury.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

9. I some times worry that people will patronise me, or talk down to me.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

10. I sometimes worry about getting tearful or upset in front of others.
    a) is this statement true? Y / N
    b) Because of this concern, have you avoided this situation? Y / N
11. I sometimes get fed up of people asking me about my brain injury.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N

12. I sometimes worry that people will get annoyed if I make mistakes, or take too long to do things.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N

13. I sometimes think that people will laugh at me.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N

14. I sometimes worry about losing my temper with other people.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N

15. Sometimes I don’t like people seeing me using aids such as diaries, walking sticks or wheelchairs, etc.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N

16. I sometimes worry that people think there’s something wrong with me.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N

17. I sometimes feel less sexually attractive since the brain injury.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N

18. I sometimes think that people don’t tell me things because they think I can’t understand.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N

19. I sometimes think that people prefer talking to others I’m with, rather than me.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N

20. I sometimes feel that people treat me differently because of the injury.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N

21. I sometimes feel that other people look down upon me.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N

22. I sometimes feel my injury makes people feel sorry for me.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N

23. I sometimes feel that other people are watching me.
   a) is this statement true?  Y / N
   b) Because of this concern, have you avoided this situation?  Y / N
24. I sometimes feel that I’m not very good company.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

25. Sometimes when I’m with people, I feel like I don’t fit in.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

26. I sometimes think that people are comparing me to how I was before the brain injury.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

27. I sometimes think that people fuss over me because of my brain injury.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

28. I sometimes worry that people think I’m stupid.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

29. I sometimes feel I would be uncomfortable meeting people I haven’t seen since my injury.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

30. I sometimes feel I make more mistakes now than I used to before the injury.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

31. I sometimes get upset or frustrated if do things wrong.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

32. Sometimes when things go wrong, it reminds me of the brain injury and all the problems it’s caused me.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

33. It sometimes bothers me that I can’t do things like I used to.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

34. If things go wrong when I’m doing something, I sometimes feel useless and stupid.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

35. I sometimes get frustrated because it takes me too long to do things.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N

36. Doing some things sometimes reminds me of how different I have become since the injury.
   a) is this statement true? Y / N
   b) Because of this concern, have you avoided this situation? Y / N
Reflection and Rumination Questionnaire

RRQ

Instructions:
For each of the statements located on the next two pages, please indicate your level of agreement or disagreement by circling one of the scale categories to the right of each statement. Use the scale as shown below:

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

1. My attention is often focused on aspects of myself I wish I’d stop thinking about. ................................................................. 1 2 3 4 5

2. I always seem to be “re-hashing” in my mind recent things I’ve said or done. ................................................................. 1 2 3 4 5

3. Sometimes it is hard for me to shut off thoughts about myself. ................................................................. 1 2 3 4 5

4. Long after an argument or disagreement is over with, my thoughts keep going back to what happened. ................................................................. 1 2 3 4 5

5. I tend to "ruminating" or dwell over things that happen to me for a really long time afterward. ................................................................. 1 2 3 4 5

6. I don’t waste time re-thinking things that are over and done with. ................................................................. 1 2 3 4 5

7. Often I’m playing back over in my mind how I acted in a past situation. ................................................................. 1 2 3 4 5

8. I often find myself re-evaluating something I’ve done. ................................................................. 1 2 3 4 5

9. I never ruminate or dwell on myself for very long. ................................................................. 1 2 3 4 5

10. It is easy for me to put unwanted thoughts out of my mind. ................................................................. 1 2 3 4 5

11. I often reflect on episodes in my life that I should no longer concern myself with. ................................................................. 1 2 3 4 5

12. I spend a great deal of time thinking back over my embarrassing or disappointing moments. ................................................................. 1 2 3 4 5

PLEASE CONTINUE ON THE NEXT PAGE...
<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>Philosophical or abstract thinking doesn't appeal to me that much.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>I'm not really a meditative type of person.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>I love exploring my &quot;inner&quot; self.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>My attitudes and feelings about things fascinate me.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>I don't really care for introspective or self-reflective thinking.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>I love analyzing why I do things.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>People often say I'm a &quot;deep&quot;, introspective type of person.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>I don't care much for self-analysis.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>I'm very self-inquisitive by nature.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>I love to meditate on the nature and meaning of things.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>I often love to look at my life in philosophical ways.</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Contemplating myself isn't my idea of fun.</td>
<td>1 2 3 4 5</td>
<td></td>
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</tr>
</tbody>
</table>
Life Orientation Test

LOT-R

This questionnaire asked about how you cope with general situations. Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

A = I agree a lot
B = I agree a little
C = I neither agree nor disagree
D = I DISagree a little
E = I DISSagree a lot

<table>
<thead>
<tr>
<th></th>
<th>A, B, C, D, or E</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In uncertain times, I usually expect the best.</td>
<td></td>
</tr>
<tr>
<td>2. It's easy for me to relax.</td>
<td></td>
</tr>
<tr>
<td>3. If something can go wrong for me, it will.</td>
<td></td>
</tr>
<tr>
<td>4. I'm always optimistic about my future.</td>
<td></td>
</tr>
<tr>
<td>5. I enjoy my friends a lot.</td>
<td></td>
</tr>
<tr>
<td>6. It's important for me to keep busy.</td>
<td></td>
</tr>
<tr>
<td>7. I hardly ever expect things to go my way.</td>
<td></td>
</tr>
<tr>
<td>8. I don't get upset too easily.</td>
<td></td>
</tr>
<tr>
<td>9. I rarely count on good things happening to me.</td>
<td></td>
</tr>
<tr>
<td>10. Overall, I expect more good things to happen to me than bad.</td>
<td></td>
</tr>
</tbody>
</table>
## Depression, Anxiety, and Stress Scale – 21 items

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I found it hard to wind down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>I was aware of dryness of my mouth</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>I couldn't seem to experience any positive feeling at all</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>I found it difficult to work up the initiative to do things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>I tended to over-react to situations</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>I experienced trembling (eg, in the hands)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8</td>
<td>I felt that I was using a lot of nervous energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>I was worried about situations in which I might panic and make a fool of myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10</td>
<td>I felt that I had nothing to look forward to</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11</td>
<td>I found myself getting agitated</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12</td>
<td>I found it difficult to relax</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13</td>
<td>I felt down-hearted and blue</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14</td>
<td>I was intolerant of anything that kept me from getting on with what I was doing</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15</td>
<td>I felt I was close to panic</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16</td>
<td>I was unable to become enthusiastic about anything</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17</td>
<td>I felt I wasn't worth much as a person</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18</td>
<td>I felt that I was rather touchy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19</td>
<td>I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20</td>
<td>I felt scared without any good reason</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21</td>
<td>I felt that life was meaningless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Awareness Questionnaire

<table>
<thead>
<tr>
<th>Name: ___________________</th>
<th>Patient #: ________</th>
<th>Date: __________</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>much worse</td>
<td>a little worse</td>
<td>about the same</td>
</tr>
</tbody>
</table>

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?
<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>much worse</td>
<td>a little worse</td>
<td>about the same</td>
<td>a little better</td>
<td>much better</td>
</tr>
</tbody>
</table>

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?**