The Impact of Continuity of Identity in Individuals with Acquired Brain Injury

by

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A Thesis Submitted in Partial Fulfilment to the University of Birmingham for the Degree of DOCTOR OF CLINICAL PSYCHOLOGY

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May 2023

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Overview

This thesis is submitted by Nandini Rajendran in partial fulfilment for the degree of Doctor of Clinical Psychology (ClinPsyD) at the university of Birmingham and is comprised of three chapters.

Chapter one of the thesis is a literature review and consists of a meta-ethnography study which explores the internal processes that contributes to positive adaptive reconstruction of identity in adults with a traumatic brain injury.

Chapter two of the thesis is a quantitative empirical study that investigated the impact of internal continuity in individuals with an acquired brain injury and how it influences wellbeing outcomes.

The final chapter is a press release consisting of a brief, executive summary of the two research components aimed for the general public.

Acknowledgement

I would like to first and foremost thank my research supervisor Dr. Gerard Riley for his immense support, guidance, expertise, and meticulous eye. I am very grateful to all your valuable suggestions and feedback during the completion of my thesis.

I am also very grateful to all my research participants who came forward to support my research. In particular, I would like to thank the participants from Headway as well as the manager for being so supportive and helpful with the recruitment.

I would like to also thank all my academic tutors, lecturers, and placement supervisors for sharing their knowledge, experience, wisdom, and my cohort for making this Doctorate journey a worthwhile experience. A special thanks to my appraisal tutor Dr. Michelle Fisher for her constant support, encouragement, and trust in my capabilities.

Finally, I can’t thank my family enough – my mom, dad and brother – for their unwavering love, support and for always being there for me. A special thanks to my brother for his help with my thesis, his inspiring academic rigor and my mom for being my constant source of support and inspiration.

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CHAPTER 1: A Review of the Internal Processes Contributing to Positive Adaptive Reconstruction of Identity in Individuals with Traumatic Brain Injury – A Meta-ethnography

1.1. Abstract

Background: Despite experiencing overwhelming challenges and life-altering changes following TBI, many individuals manage to overcome perceived threats to their self-identity and accomplish a positive and adaptive reconstruction of (self)-identity. Therefore, it is clinically relevant and important to investigate the internal psychological processes that facilitate and promote identity reconstruction in these individuals. However, there is a lack of qualitative studies that particularly focus on the internal processes of positive identity construction. This meta-synthesis aimed to address the question of how participants managed to sustain or develop a positive self-identity following TBI.

Method: A meta-ethnography approach was used to systematically explore existing qualitative studies to gain deep understanding of the internal processes that contribute to positive adaptive reconstruction of self-identity in TBI survivors. 30 qualitative research studies were located using a systematic search strategy. The quality of the research papers was critically appraised using an appraisal framework.

Findings: The main themes highlighted in the review include acceptance, valuing oneself as a better person, sense of pride, and the chosen one. In addition, the review highlighted three subthemes of re-evaluating values and beliefs, redefining roles and activities and being empathetic towards others.

Conclusion: The current study has identified various internal processes, including intrapersonal

and relational processes, that enable TBI survivors to rebuild their sense of self in a positive and meaningful way. Drawing from the findings of this study, it can be suggested that rehabilitation and psychotherapy goals aimed to help individuals re-evaluate and develop acceptance of their post-injury selves, meaningful social roles, and community participation can promote self-esteem and positive identity.

1.2. Introduction

Traumatic Brain injury (TBI) is defined as an injury to the brain as a result of an external mechanical force resulting in disruption of normal brain function (Menon et al., 2010). TBI affects approximately 1.4 million people annually in the UK (Lawrence et al., 2016). It is one of the leading causes of disabilities among people under the age of 40 and continues to remain a significant health concern globally in the past decade (Maas et al., 2022). TBI is considered a significant life event that can have a substantial effect not only on an individual’s quality of life but also impact their immediate family and community (Nalder et al., 2012). Several research studies have highlighted profound changes in physical, behavioural, affective, and neurocognitive functioning following TBI (Semple et al., 2019; Stocchetti & Zanier, 2016).

In particular, TBI can result in a broad range of difficulties including visible disabilities such as aphasia, dysarthria, problems with mobility (Pavlovic et al., 2019) and invisible disabilities such as attention and memory difficulties, fatigue, insomnia, and emotional dysregulation (Norman et al., 2020). Several clinical studies and extensive research have shown that these complex physical, emotional, and cognitive impairments can have a profound impact on an individual’s capacity to perform their daily activities, employability, social roles, recreational pursuits, and involvement in the community. (Godwin et al., 2014; Milders, 2019; Salas et al., 2018). Figure 1.1 illustrates the broader effects and challenges of TBI, and its profound impact on a survivor's life and identity.

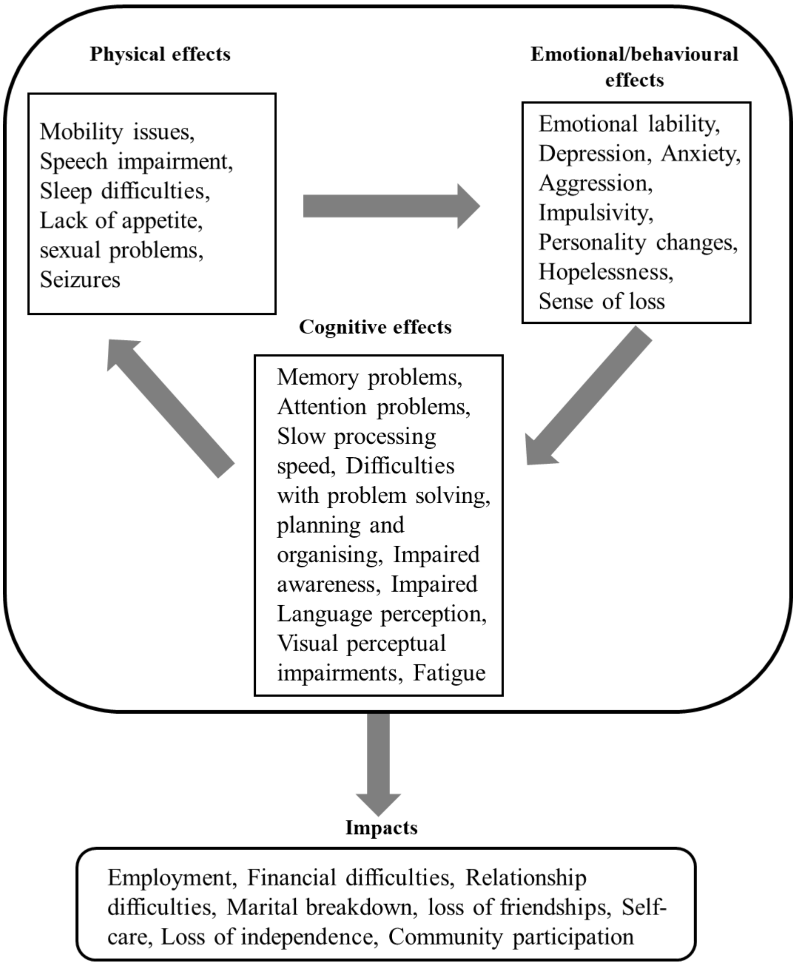

Figure 1.1 A diagram illustrating the effects of TBI on an individual's life based on Ponsford et al. (2014)

Impact of changes in Identity on Psychological Well-being

Previous studies emphasise that a subjective experience of loss of functions and roles after TBI may increase the vulnerability to develop mental health difficulties such as depressive disorders and suicidal tendencies (Coetzer, 2008; Fleminger et al., 2003). Several studies have documented a higher risk of developing mental health disorders in those with TBI (Haarbauer-Krupa et al., 2021; Ponsford et al., 2018). According to a study conducted by Juengst et al. (2017), the overall prevalence of depressive disorders and anxiety disorders in the participants were 14.1 % and 23.3 %, respectively, within the first year following TBI (Haarbauer-Krupa et al., 2021; Ponsford et al., 2018).

Negative changes in one's identity may be one of the major contributors for psychological distress following TBI. Evidence suggests that many individuals perceive that they are no longer the same person and can experience a range of feelings from discontinuity and discrepancy to complete estrangement from their pre-injury identity (Stephen, 2004). This concept of "loss of self" has been well documented in TBI literature and extensively researched in both quantitative (Beadle et al., 2018; Cantor et al., 2005; Ownsworth & Haslam, 2016) and qualitative literature (Douglas, 2013; Levack et al., 2010; Villa et al., 2021). For instance, Ponsford (2014) suggests that identity loss in TBI survivors results from an inability to resume their pre-injury roles and activities or functions on the same level. Furthermore, TBI survivors have a deep longing for their pre-injury self that can be compared to the process of mourning for the perceived losses after brain injury (Coetzer, 2008; Judd & Wilson, 1999). While emotional adjustment to grief and identity change can evoke strong responses such as sadness, despair, resentment, remorse, hopelessness and denial (Kreutzer et al., 2016). This may in turn increase susceptibility for developing mental health difficulties such as depression (Shields et al., 2016). As a result, such changes to their capabilities, personality, and lifestyle may impact individuals' self-perception, and results in experiencing a poor concept of self, identity, low self-worth, and reduced sense of control following a TBI (Ellis-Hill & Horn, 2000; Ownsworth, 2014).

Positive Psychological Experiences and Changes, and Developing a Positive Self-identity Following TBI

This review centres on the internal psychological processes that play a role in the development of a positive self-identity following a TBI, considering the specific challenges the injury presents to one's sense of self. Self-identity encompasses an individual's belief on their relatively enduring traits and characteristics, while self-esteem refers to evaluating oneself based on these beliefs (Ownsworth, 2014).

A concept that is closely related but encompasses a broader scope is the idea of post-traumatic growth (PTG). It suggests that individuals can respond to trauma with psychological improvements, drawing from their positive relationship with others, and by making appropriate life choices (Tedeschi & Calhoun, 1996, 2004). These changes aid in their ability to cope with and overcome the distress caused by the traumatic event (Linley & Joseph, 2004). While PTG is a distinct concept, it is plausible that various aspects of it could contribute to the development of a positive self-identity and heightened self-esteem (Seo & Kwon, 2018; Taku & McDiarmid, 2015). As a result, individuals may develop more positive self-perceptions and beliefs about themselves (Tedeschi & Calhoun, 2004). Another overlapping but distinct concept is the notion that positive experiences can emerge after trauma, potentially triggered by the traumatic event itself (Cadell et al., 2003). For instance, individuals may experience supportive relationships and care from their family or others who have undergone a similar trauma. While distinct from the notion of developing positive self-identity, these experiences may still contribute to the overall internal psychological processes.

Much of our self-identity and self-esteem is shaped by our interactions with others. How others respond to us plays a key role in in how we perceive and assess ourselves (Ownsworth, 2014). It is beneficial to differentiate between external events and circumstances that may contribute to the development of a positive self-identity (such as support from loved ones) and the internal psychological processes that involve appraising both external and internal events, circumstances, and experiences to foster a positive sense of identity. The focus of this review is to specifically examine these internal processes.

While the traditional focus of TBI literature has largely been on the negative psychological changes, there has been increasing research on individuals experiencing a positive self-identity, post-injury (Ownsworth et al., 2011; Powell et al., 2012; Walsh et al., 2014), and the clinical importance of positive identity change after TBI (Allen et al., 2022; Baseotto et al., 2022; Powell et al., 2012; Rogan et al., 2013). Qualitative works exploring the psychological and functional processes of positive identity change point to themes such as stronger interpersonal connections, a greater appreciation of life, re-evaluation of one's values and reconstructing a strong sense of self following TBI (Karagiorgou et al., 2018; Klinger, 2005; Nalder et al., 2013).

For instance, Gelech and Desjardins (2011) reviewed the dual facets of self that is involved in the reconstruction of self. The authors examined the public and private aspects of the post-injury self, highlighting that letting go of materialistic components of the public self and re-evaluating and giving precedence to the authentic aspects of one's private self, allowed for a positive identity change. From a theoretical perspective, the Y-shaped model for rehabilitation (Gracey et al., 2009) provides a biopsychosocial lens to understand these internal psychological processes. The authors postulate that minimising self-discrepancy, which entails the negative evaluation of the post-injury self in comparison to the pre-injury self, promotes positive identity change and post-injury growth. Employing concept analysis to synthesise existing theories on identity change following TBI, Levack and colleagues (2014) highlight several interconnected social factors such as feeling valued by others including family, social relationships, community members and health care professionals. These factors might reinforce or disrupt an individual’s sense of who they are (personal identity) and how valuable they are to the society (social identity).

In addition to the aforementioned clinical and theoretical studies, the concept of "post-traumatic growth (PGT)" has gained prominence in TBI literature recently for its exploration of psychosocial processes relating to positive construction of identity (Allen et al., 2022; Grace et al., 2015; Lyon et al., 2021; McGrath, 2011; McGrath & Linley, 2006). The notion that positive and adaptive psychological changes can emerge from a range of adverse life events and life-threatening conditions, including bereavement (Davis et al., 1998), physical and sexual assault (Burt & Katz, 1987; Thompson, 2000), cancer (Cormio et al., 2014), and cardiac diseases (Sheikh, 2004), has been documented and is a well-established phenomenon in the existential and philosophical (Frankl, 1962), religious (Linley & Joseph, 2004; Tedeschi & Calhoun, 1995; Tedeschi et al., 1998) and psychological literature (Park et al., 1996). Tedeschi and colleagues (Tedeschi et al., 2015) argue that this philosophy of growth through adversity underscores the importance of investigating the potential for PGT following TBI.

Tedeschi and Calhoun (2006) postulate PGT as a process of reconstructing oneself after a traumatic event, achieved through cognitive reappraisal of one's self-perceptions, social schemas, and the external world. This process of meaning-making enables people to successfully transform and grow in comparison to their premorbid selves (Brand et al., 2016). Drawing on positive psychological perspectives, Tedeschi and Calhoun (2004), highlight the centrality of interpersonal connections, perceived changes to sense of self, meaning, and an appreciation towards life in the process of self-reconstruction. In particular, they emphasise a number of psychological processes, including: (1) reassessing life priorities and values; (2) discovering new possibilities and pursuits; (3) developing stronger sense of autonomy and self-sufficiency; (4) embracing vulnerabilities and negative emotions; (5) experiencing enhanced sense of connection and relationships with other people; and (6) demonstrating care and compassion. They argue that these processes facilitate positive adjustments after life-changing events (Tedeschi & Calhoun, 2004).

McGrath (2011) argue that the process of challenging and reconstructing one’s internal belief system post-TBI might cause some level of emotional distress. Experiencing emotional distress may be intrinsic to the concept of PTG and can act as a catalyst for reframing one’s cognitive schemas in an intricate and sophisticated manner, in response to the challenging event (Helgeson et al., 2006; McGrath, 2011; Sawyer et al., 2010). For McGrath (2011), these aforementioned internal processes distinguishes PTG from existing discourses in TBI literature. Positive psychological change may not be an expression of genuine psychological transformation brought about by trauma, but rather a means of "sense-making" of the event to match our pre-existing worldview so that it no longer poses a challenge to one’s sense of self (Davis et al., 1998). Finally, positive identity changes may also be accomplished by a range of psychological processes including denial or maintaining "positive illusion" of the event to minimise emotional distress (Taylor & Armor, 1996) and "benefit-finding" or emphasising the positives from the experienced adversity (Davis et al., 1998).

1.3. Study Rationale

Despite experiencing overwhelming challenges and life-altering changes following TBI, many individuals manage to overcome perceived threats to their self-identity and accomplish a positive and adaptive reconstruction of (self)-identity (Gelech et al., 2019; Gelech & Desjardins, 2011; Grace et al., 2015). It is evident from the preceding section that developing a strong positive identity greatly enhances the quality of life and life satisfaction among TBI survivors. Therefore, investigating the internal psychological processes that facilitate and promote identity reconstruction in these individuals is of clinical relevance and importance.

The qualitative literature provides a unique opportunity to examine subjective experiences and provide valuable insights to facilitate better understanding of these internal processes (Nassaji, 2020), particularly in the context of TBI (George & Apter, 2004). In recent years, there has been a growing focus in qualitative studies to investigate subjective experiences of identity reconstruction following TBI (Gelech et al., 2019; Mamman et al., 2022). However, there is a lack of qualitative studies that particularly focus on the internal processes of positive identity construction. Hence, the findings on this subject are scattered throughout the literature. Some valuable papers concerning identity change after TBI were published in recent times, including a scoping review of 72 qualitative studies that identified several positive subjective experiences among TBI survivors (Gelech et al., 2019). While this scoping review provides commendable information on the indicators of successful living from the perspective of TBI survivors, it does not systematically synthesise data relating to processes contributing to positive identity construction. A better comprehension of how TBI survivors develop positive self-identity may suggest some interventions that could facilitate this process, increasing the likelihood of supporting those individuals who might find it difficult to overcome the challenges of negative self-identity and low self-esteem that are often associated with TBI.

Therefore, the aim of this current review is to provide a meta-synthesis of 30 qualitative studies that have, at least in part, addressed the question of how participants managed to sustain or develop a positive self-identity following TBI. As described earlier, the review primarily focuses on self-identity rather than PTG or positive experiences resulting from TBI. The review confines to the internal psychological processes through which external and internal events, circumstances and experiences are evaluated to develop a positive sense of identity. The emphasis is placed on these internal processes rather than solely on external events and circumstances.

1.4. Method

Meta-ethnography Following Noblit and Hare (1988)

Meta-ethnography is an interpretative methodology that is frequently adopted for the synthesis of qualitative research studies (Britten et al., 2002). Originally developed by sociologists Noblit and Hare (1997), this method uses the distinctive process of "translation" for identifying, comparing, connecting and re-interpreting concepts and themes across qualitative literature to produce higher-order interpretations, overarching conceptual models and theories (France et al., 2016). This method conserves the original meaning and context of the primary studies and goes beyond the consolidation of findings in individual studies, which distinguishes it from other literature review methods (Dixon-Woods, 2004). Noblit and Hare (1997) outline seven phases to enable systematic comparison and translation of qualitative studies (see Table 1.1).

Table 1.1 Noblit and Hare's seven guiding stages for conducting a meta-ethnography (1997, pp. 110–112)

Stage	Purpose
1. Getting started	This stage entails selecting an area of intellectual interest that could be explored by qualitative research. This is accomplished by searching for and identifying qualitative studies
2. Deciding what is relevant to the initial interest	This stage involves determining which of the identified studies are pertinent to the initial area of interest
3. Reading the studies	This stage entails careful and repeated reading of the identified relevant studies
4. Determining how the studies are related	This stage involves determining the relationships between the identified studies

Stage	Purpose
5. Translating the studies into one another	This involves drawing comparisons of analogies, metaphors and interpretations found across the studies, while preserving the central findings present in each study.
6. Synthesising translation	This stage entails determining whether any of the comparisons form an overarching pattern or give rise to conflicting interpretations
7. Expressing the synthesis	This stage pertains to effectively conveying the synthesized information in a suitable manner to the target audience

Consistent with Noblit and Hare's (1997) meta-ethnography approach, the subject matter for this literature review draws from an intellectual interest identified in the area of brain injury. Following narrowing down of the research topic, the author was interested in conducting a qualitative literature review to gain greater insights from the perspectives of adults with brain injury. Conducting a broad literature search and comparison of existing meta-synthesis relevant to this topic highlighted the significance of positive reconstruction of identity after brain injury as reflected in the systematic reviews and participant's accounts. Following subsequent discussions with the research supervisor, a literature review exploring the experiences of positive identity reconstruction from the perspectives of adults with TBI was the subject of focus for the present meta-synthesis.

Systematic Literature Search

Once the aims of the review and the research question were clearly defined, the next stage entailed systematic search of qualitative literature to identify potentially relevant research articles and to exclude those that are not pertinent in addressing the research question – What are the internal processes that contribute to positive adaptive reconstruction of identity in individuals with traumatic brain injury?

Search Strategy

Qualitative literature on positive reconstruction of identity in TBI were searched within four electronic bibliographic databases: PsycINFO, MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Web of Science. These databases were chosen for their extensive coverage of research topics in the fields of psychology, social sciences, nursing, and medicine (Grant, 2019). Past studies have well-documented the challenges in searching and locating qualitative research studies from databases due to their poor indexing techniques (Evans, 2002; Flemming & Briggs, 2007; Shaw et al., 2004). To overcome this issue, the present study used a combination of effective search strategies such as utilising free-text items, using thesaurus terms specific to each database, and incorporating broad free-text-terms as recommended by Shaw and colleagues (2004).

The key terms used in all three electronic search strategies were specifically selected to increase the sensitivity and coverage for qualitative methodologies, particularly related to the positive reconstruction of identity in adults following TBI. Search terms from a prior meta-synthesis published in this area of research focus were also included. In addition, the research supervisor, and another author in this area of research were consulted following which ‘post-traumatic growth’ was included as a key search term due to its theoretical overlap with identity reconstruction. Finally, special issues articles published in the Disability and Rehabilitation journal, Journal of Rehabilitation Medicine, and Neurorehabilitation and Neural Repair (NNR) were also searched for additional records. Table 1.2 lists the key search terms and the combinations used.

Table 1.2 Key search terms and combinations used, including truncations

Search number	Construct	Keyword terms (variations)	Subject terms (database)
1	Identity	Selfhood* (selfhood/s) Self-concept* (self-concept/s) Self-perception* (self-perception/s) Personhood* (personhood/s) Personality change* (personality change/s)* Identit* (identity/ies) Post-traumatic growth PTG Combines with *OR*	Self-Concept, Self-Perception, Subjectivity, Narratives, Personality change, Identity crisis, Identity formation, Life experiences (PsycINFO); Self-concept, Identity Crisis, Personhood (MEDLINE); Self-concept, Identity (CINAHL); Web of Science
2	Traumatic brain injury	Brain injur*(acquired brain injury/ies, traumatic brain injury/ies) Head injur* (head injury/ies) ABI TBI Combines with *OR*	Traumatic Brain Injury, Head Injuries (PsycINFO); Brain Injuries (MEDLINE); Brain Injurues, Head Injuries (CINAHL); Post-traumatic growth (Web of Science)
3	Searches 1 and 3 were combined with *AND*		

Tools in the databases were utilised to restrict the search to peer-reviewed articles published in English. The results from the searches were imported to the reference management software, Zotero, to enable an efficient screening process. Scientific papers published until March 2023 were searched. Although no start date was specified in the database, the earliest paper found was dated back to 1989.

Inclusion and Exclusion Criteria

Following the key term search completion as per Table 1.2, the duplicates were removed from the imported list of papers. Subsequently, each paper was screened by title and abstract based on the inclusion and exclusion criteria listed in Table 1.3. In cases where it was unclear whether a paper met the inclusion criteria based on the title and abstract alone, the full text was accessed, and a decision was arrived based on reading the paper. If any uncertainty still persisted, the supervisor reviewed the full text, and a final consensus was reached.

Table 1.3: The list of inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
1. Research articles published in peer-reviewed journals	
2. Research articles published in English language only	Papers not published or accessible in English
3. Research articles that used qualitative methods for primary data collection and analysis	Articles using secondary data e.g., Review articles
4. Research articles where the participants were adults with TBI	Studies with mixed samples - i.e., TBI alongside other types of brain injury.
5. Research articles that incorporated data from other informants (family members, carers, health care professionals) in addition to data from TBI survivors were included. However, the data from these other informants were not included in the analysis	Papers were excluded if the data from the participants with TBI could not be clearly distinguished from data from the other participants.
6. Research articles with findings pertaining to processes of identity change and positive adaptive reconstruction of self after TBI	
7. Studies containing findings relating to post-traumatic growth after TBI	

The inclusion criteria specifically encompassed studies that utilized qualitative methods for data collection and analysis. Furthermore, studies were eligible for inclusion if they collected data from adult participants with TBI. Studies that included data from other informants (e.g., family members, professionals) were also considered. However, only the data from these other informants were not included as the study focuses only on perspectives of TBI survivors. Finally, studies that reported findings on the processes of identity change and positive adaptive self-reconstruction after TBI were also included in this review.

Systematic Screening Process

In total 1861 papers were identified using key search terms. Following the screening of title and abstract for all papers, full text papers were read for relevancy using the inclusion and exclusion criteria listed in Table 1.3. The systematic screening process was conducted using Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) model (Moher et al., 2009) which resulted in 30 papers. Figure 1.2 illustrates the process of systematic screening of papers using the PRISMA model, highlighting the inclusion and exclusion criteria applied at various stages and the final number of papers included in this review.

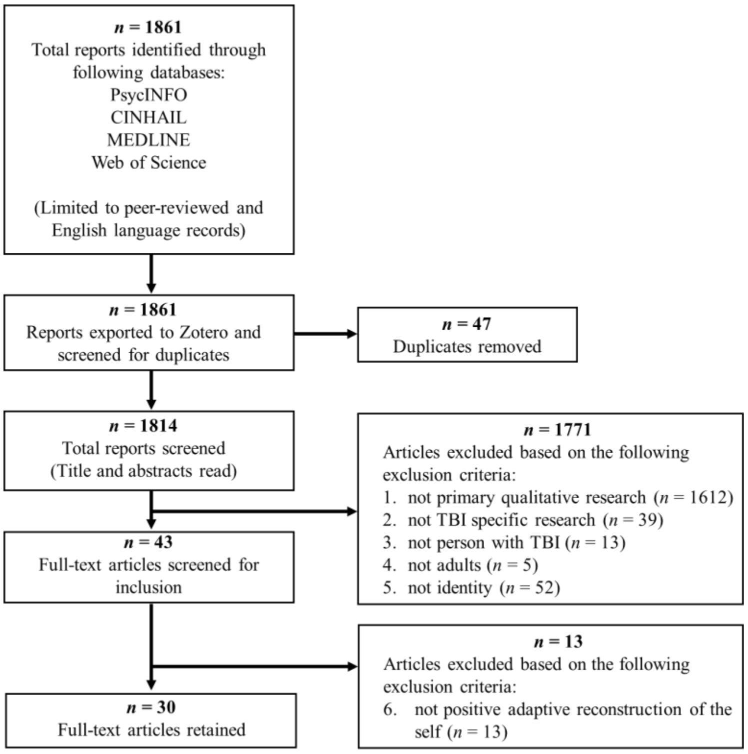

Figure 1.2 PRISMA flowchart illustrating the process of screening the papers

Table 1.4 summarises the characteristics of the final set of research papers included in the synthesis. The sample size of the research studies varied wherein the smallest sample size consisted of one participant (Lawson et al., 2008; Sabat et al., 2006; Walsh et al., 2020), while the largest sample size consisted of 60 participants (Chamberlain, 2006). Overall, the review contained data from 400 participants, from ages 18 years to 64 years who experienced mild to severe TBI. The post-TBI duration in participants ranged from 7 months to 36 years. Participants in the review were recruited from a range of settings such as inpatient settings, outpatient clinics, residential support, charitable organisations and from the community.

While a variety of methods of analysis was adopted, the main methodological approaches included: phenomenology (12 studies), thematic analysis (9 studies) and grounded theory (8 studies).

Table 1.4: The final list of papers analysed in the meta synthesis following the systematic selection process

Title, author, year of publication	Aim (s) of study	Participants	Data collection and analysis	Method of analysis	Main reported themes
Cahill et al., 2014	To explore the experiences and processes individuals having a brain injury go through during college or university to overcome obstacles	N= 8, TBI, currently enrolled in some form of educational program	Semi-structured interviews. The initial interviews ranged from 60 to 90 min in length.	Interpretative qualitative design	Three themes emerged: 1. Balancing act 2. Reality versus injury 3. Square peg in a round hole
Chamberlain, 2006	To explore the experience and meaning of surviving TBI, from the perspective of the survivors	N=60; 40 men, 20 females; age range -18 to 81 years; mild to critical TBI	Unstructured in-depth interviews were conducted. with each participant and their family member); 45-60 minutes per interview	Qualitative content analysis	5 overarching theme areas were reported: 1. Regret and grief within self 2. Insensitivity of health professionals 3. Invisibility of self 4. Stranded self, and 5. Recovery in self
Cloute et al., 2008	To explore identity construction in individuals who sustained a severe traumatic brain injury (TBI)	N=6; age range 22 – 60 years; post-injury duration - 4 to 20 yaers, together with one or two significant others; age range 40 – 69 years).	Interviews were conducted with an individual with a severe TBI together with their significant others	Discourse analysis	The following four themes were identified: 1. Medical model referencing 2. Dependence as intrinsic to TBI 3. TBI as deficit 4. Progression and productivity as key life-defining features

Title, author, year of publication	Aim (s) of study	Participants	Data collection and analysis	Method of analysis	Main reported themes
Crisp, 1993	To explore the meaning and experiences of living with TBI in participants and understand their psychosocial responses	N =10; males= 6, females = 4; mild to moderate TBI; post-TBI duration – 3-20 years	Series of 7-10 in-depth interviews conducted over across 12 months, each interview lasted for 40-75 minutes	Thematic analysis/grounded theory method	Four types of respondents emerged on a continuum from Type 1 (low sense of wellbeing) to Type 4 (high sense of wellbeing)
Douglas, 2013	To explore the self-perceptions of adults with severe TBI several years post-injury	N=20; 16 men, 4 females; age range: 21-54 years; Moderate to very severe TBI as a result of RTA; post-injury duration - 5 to20 years	In-depth interviews. One interview with each participant; 90-180 minutes per interview	Grounded Theory	Three main themes emerged from the data. 1. Who I am 2. How I feel about myself 3. Staying connected
Downing et al., 2021	To examine positive factors for recovery in individuals who sustained severe TBI three years earlier.	N= 25; nine individuals with TBI and 16 close-others of participants with TBI (close-others were spouses or other family members of 16 other TBI participants). mean age at injury was 36.96 years.	Semi-structured interviews were conducted over-the-phone at approximately 3 years post-injury	Reflexive thematic analysis	Positive factors identified were grouped into the three broad themes: 1. Having a support network 2. Being positive and engaged 3. Getting good care

Title, author, year of publication	**Aim (s) of study**	**Participants**	**Data collection and analysis**	**Method of analysis**	**Main reported themes**
Fadyl et al., 2019	To investigate subjective experiences of recovery and adaptation following TBI from the perspective of people with the injury and the family and/or friends most closely involved in their recovery	People experiencing TBI (n = 52) and their significant others (n = 37)	Semi-structured interviews at 6-, 12- and 24-months post-injury.	Thematic analysis	Two overarching themes were captured in the analysis: 1. Making room for recovery, and 2. Cultivating important resources
Freeman et al., 2015	To explore perceived changes in the sense of self and emotional distress and growth in TBI survivors	N= 9 males, age range 22-59 years, post-TBI duration – 17 months to 21 years.	Semi-structured interviews	Thematic analysis	Emerging themes were: 1. “self-criticism”, 2. “need to be as others want me to be” 3. “withdrawal”
Gelech & Desjardins, 2011	To examine the construction of self-following acquired brain injury from an experience-centred perspective	N=4, 3 males and 1 female, age range -7 to 55 years, postinjury duration - 4 to 21 years, moderate to severe TBI	Life history interviews and semi structured interviews were carried out with each participant on separate occasions no more than 10 days apart	Thematic, syntactic, and deep structure analysis	The main theme of this work is – the construction of self, following acquired brain injury The subthemes are: 1. Public aspects of the self 2. Private aspects of the self 3. Reinventing selfhood in the wake of acquired brain injury

Title, author, year of publication	Aim (s) of study	Participants	Data collection and analysis	Method of analysis	Main reported themes
Hoogerdijk et al., 2011	To explore how TBI survivors make sense of their adaptation process and occupational performance	N=4; Males =3; females = 1; age range- 33 to 61 years; post-TBI duration – 20 to 27 months	Semi-structured interviews conducted twice	Narrative approach/ IPA	Main narratives on adaptive process were 1. a necessary struggle to gain a new identity 2. facilitated by engagement in familiar occupations in familiar environments 3. a protracted learning process that continues long after rehabilitation ends 4. individual and situated
Howes et al., 2005	To understand post-TBI experiences in women	N= 6 females, age range – 30-51 years; post-TBI duration – 7 months to 25 years	Semi-structured interviews	IPA	The main themes were: 1. awareness of change 2. the emotional reaction; struggling to make sense 3. adaptation and acceptance
Jones & Curtin, 2011	To explore the interconnection between masculine identity and participation in male TBI survivors	N= 8 males, age range – 24 to 66 years, post-TBI duration – 31 years	Semi-structured interviews	Grounded theory analysis	Main narratives were: 1. non-acceptance of reformulated masculinity 2. accepting reformulated masculinity for the sake of others 3. accepting and personally valuing a reformulated
Jumisko et al., 2005	To explore the meaning of feeling well for people with moderate or severe traumatic brain injury.	N= 8. Participants were two women and six men with	Seven participants were interviewed by in their homes and one participant at the	Phenomenological hermeneutic interpretation	The themes were 'finding strength', 'regaining control over everyday life', 'being close to

Title, author, year of publication	Aim (s) of study	Participants	Data collection and analysis	Method of analysis	Main reported themes
		moderate or severe TBI, aged between 29–53 years (median 41 years) The participants had lived with TBI for between 7–15 years (median 10 years).	interviewers' workplace. Interviews lasted between 45–77 minutes (median 55) and was later transcribed verbatim		someone' and 'being good enough'.
Klinger, 2005	To examine the processes and experiences of occupational adaptation and identity following TBI.	N=7; 6 males, 1 female; age range 29-45 years; TBI; post-injury duration 2-16 years;	In-depth, semi-structured interviews lasting for 90 minutes per interview	Constant comparative method	Data generated five main themes: 1. I am who I am, but I am not who 2. Who I am is intimately and completely intertwined with what I do and how I do it I was before 3. Adapting means accepting the new me 4. I am different, thus I must change my doing 5. I am different, thus I must change the environment in which I do things

Title, author, year of publication	Aim (s) of study	Participants	Data collection and analysis	Method of analysis	Main reported themes
Knox et al., 2017	To explore how decision making contributes to conceptualise self after severe TBI.	N=8; participants with a severe TBI chronic phase (7–29 years) post-injury	In depth unstructured interviews, two or three interviews over a 12-month period. Interviews ranged from approximately 45 to 155 min in length	Constructivist grounded theory	Three main themes were identified: 1. Self through decision-making participation 2. Experiencing support through participation 3. Shaping self-concept through decision making
Lawson et al., 2008	To understand lived experience of rehabilitation in people with TBI and poly-trauma	N=1, female; age and number of years post TBI not stated. Moderate TBI	Autoethnographic reflection on participant's original article, journal notes, and poetry writing, as well as interview data collected 4 years later.	To understand lived experience of rehabilitation in people with TBI and poly-trauma	The themes extracted were: 1. The importance of continuity of self in the face of life-altering injury 2. Importance of client-centred care and the meaningful inclusion of clients in the decision-making aspects of their care
Lefkovits et al., 2021	To qualitatively explore the long-term experience of living with TBI.	N=30; (60% male) age range 35–86 years; post-injury duration 10-31 years	Semi-structured interviews	Thematic analysis	A thematic map connecting three themes associated with living long-term with a TBI was drawn: 1. The domains of life impacted by TBI 2. The rehabilitation process

Title, author, year of publication	Aim (s) of study	Participants	Data collection and analysis	Method of analysis	Main reported themes
					3. The factors that have aided and impeded recovery
Levack et al., 2014	To develop a comprehensive understanding of the concept of identity change in TBI survivors	N= 49; males = 34, females = 15, age range – 21-79 years, post-TBI duration – 6 months to 31 years	Eight regional focus groups	Concept analysis methodology/grounded theory	Identity change could involve changes in: 1. component parts 2. integral processes 3. whole-system disruption.
Libeson et al., 2020	To explore the return-to-work experience in TBI survivors who received comprehensive vocational rehabilitation,	N=15; post-injury duration 4.5 years, moderate to severe TBI	Semi-structured interviews	Thematic analysis	Following 12 themes were reported: 1. Motivation to return to work 2. Family and social support 3. Readiness for return 4. Employer support 5. Work modifications 6. Financial incentives 7. The role of the occupational therapist 8. Work preparation 9. Client involvement 10. RTW programme 11. Cognitive and mood problems 12. Physical injuries

Title, author, year of publication	Aim (s) of study	Participants	Data collection and analysis	Method of analysis	Main reported themes
MacQueen et al., 2020	To investigate the masculine identity experiences following TBI	N=10; males, age range 21–67 years, TBI.	Interview structure not reported	Interpretative phenomenological analysis	Three superordinate themes emerged from the analysis: 1. Doing life and relationships differently 2. Self-perceptions and the perceived view of others 3. Managing the impact of TBI as a man
Muenchberger et al., 2008	To examine processes and experiences of identity change in TBI survivors.	N=6; 4 men, 2 women; age range 22-42 years, TBI	In-depth narrative/life-story interviews with critical incident technique.	Interpretative qualitative research design using a phenomenological approach. Thematic analysis of data.	Major themes were identified from three identity transition points: 1. Contraction of self 2. Tentative balance 3. Expansion of self: Sub- themes include: 1. A purposeful journey 2. Managing self 3. Inter-dependence 4. Working towards goal 5. Future thinking 6. Holism
Nalder et al., 2012	To examine the lived experiences of individuals with TBI during the first 6 months	N=16; age range 18–60 years, TBI.	Semi-structured interviews	Thematic analysis using framework approach	Two main themes were reported: 1. Wanting normality

Title, author, year of publication	Aim (s) of study	Participants	Data collection and analysis	Method of analysis	Main reported themes
	following discharge from hospital.				2. Changed perspective on life
Nochi, 2000	To explore the narratives of coping in TBI survivors	N=10; 8 males, 2 females, age range 24-54 years; TBI; post-injury duration 3-28 years.	Semi-structured interviews.	Grounded theory	Common narratives were classified into five categories: 1. The self, better than others 2. The grown self 3. The recovering self 4. The self, living here and now, and 5. The protesting self
Petrella et al., 2005	To explore different factors that improve productive activities after TBI	N=6, 4 males, 2 females; age range 18 to 64 years; post-injury duration, 14 years average	Semi-structured interviews	Interpretive research paradigm/ Grounded theory methodology	1. opportunity to try 2. support and feedback from others 3.experimenting 4. participants' appraisals of themselves
Roundhill et al., 2007	To understand the experience of occupational adaptation from the perspective of ABI survivors	N=2; 2 males; participants age range 30 and 45 years	Semi structured interview	Phenomenological; Colaizzi's approach	Three main themes were found: 1. Things are different now 2. Acceptance 3. Just another chapter

Title, author, year of publication	**Aim (s) of study**	**Participants**	**Data collection and analysis**	**Method of analysis**	**Main reported themes**
Sabat et al., 2006	To understand identity construction processes pre- and post-TBI	N=1, male.	Multiple in-depth semi-structured interviews were conducted.	A qualitative, life history research methodology	The emerging themes are: 1. Developing a resistance identity as a product of early pre-TBI experience 2. Moving from loss of self to reconstruction of self-post-TBI 3. Constructing a positive self-identity post-TBI
Shotton et al., 2007	To understand the process and appraisal of coping and psychosocial adjustment in individuals with TBI.	(N=9), age range over 18 years, post-injury duration at least 2 years.	Semi-structured interviews	Interpretative phenomenological analysis was used	The emergent themes included: 1. 'waking up' - understanding TBI 2. 'I keep going' - coping with TBI 3. 'I knew I'd get better' - beliefs about TBI 4. 'the benefits have far outweighed the consequences' - searching for positives. These themes highlighted the adaptive and fluid way in which participants coped over time.

Title, author, year of publication	**Aim (s) of study**	**Participants**	**Data collection and analysis**	**Method of analysis**	**Main reported themes**
Soeker, 2011	To understand the experience of return to work and the adaptive strategies used in TBI survivors	N= 10; males = 9, females = 1, age range – 23-57 years, post-TBI duration not reported	Semi-structured interviews	Morse and Field qualitative analysis	Four emerging themes were reported: 1. Sense of loss of former self 2. uncertainty about future 3. Road to self-acceptance and self-belief 4. participation in occupation enables growth
Strandberg, 2009	To explore the changeover process, support, and consequences experienced by adults who acquired traumatic brain injury (TBI)	N=15,10 males and 5 females, age range 28–56 years; post-injury - 5 months to 17 years	In-depth qualitative interviews	latent-content analysis	The themes were: **the meaning of care**, a question of formal and/or informal support; **the meaning of action**, a question of activity versus inactivity; **autonomy,** a question of dependence versus independence; **social interaction**, a question of encounter and/or treatment; **the theme of changes**, a question of process versus stagnation; and **emotions,** an oscillation between hope versus hopelessness.
Walsh et al., 2020	To understand lived experience of an individual from a social cure perspective to a consideration.	N=1; age 40 years	Semi-structured interview	Interpretative phenomenological analysis (IPA)	Three themes were identified: 1. Paradox 2. Shifting perspectives

Title, author, year of publication	Aim (s) of study	Participants	Data collection and analysis	Method of analysis	Main reported themes
					3. Self under stress, linked by uncertainty

Quality Appraisal

There is a substantial debate over the most effective approach to judge the methodological quality of qualitative research, as well as the usefulness of structured checklists and framework for critical appraisal of qualitative studies (Carroll et al., 2012; Dixon-Woods et al., 2007; Hannes, 2011). Some researchers acknowledge that quality frameworks do not generate consistent appraisal of research due to the subjective nature of the process (Boeije et al., 2011; Dixon-Woods, 2004; Dixon-Woods et al., 2007). There is an argument among researchers that predetermined checklists may not be very useful, considering the diverse range of qualitative designs and theoretical viewpoints that exist within qualitative research. (Carroll et al., 2012; Dixon-Woods et al., 2006; Hannes et al., 2010). However, there is also a general consensus that quality assessments allow the researcher to identify significant methodological flaws which can potentially impact the credibility of the research findings (Britten et al., 2017).

The Cochrane collaboration advises that evaluation of methodological quality of research should essentially involve a review of the fundamental criteria such as rigour, trustworthiness, risk of bias and coherence in reporting (Noyes et al., 2011). The current review assessed the quality of the included studies and credibility of their conclusions using the Critical Appraisal Skills Programme (CASP) among other frameworks as it is freely available, can be applied to a number of qualitative designs and has been extensively used (Long et al., 2020). Studies were only excluded if they failed to meet the criteria 1 and 2 which evaluate whether the aims of study were clearly stated and the appropriateness of using a qualitative methodology respectively. All 30 papers were read and marked a “(✓)” if they met the criteria, “(×)” if the criteria were clearly not met and “(?)” if they were partially met. In making these decisions, the guidance provided with the CASP framework was followed (see Appendix A). Overall methodological quality of each study was summarised in a separate column. Table 1.5 provides a summary of the quality appraisal for the review papers included in this study.

Table 1.5: Overview of quality appraisal for the review conducted in this study

Study	Clear statement of aims?	Qualitative approach appropriate	Research design appropriate to address aims?	Recruitment strategy appropriate to address aims?	Data collected in way that addressed research issue?	Researcher-participant relationship considered?	Ethical issues considered?	Data analysis rigorous?	Clear statement of findings?	Valuable research?	Overall methodological quality
Cahill et al., 2014	✓	✓	✓	?	✓	?	?	✓	✓	✓	Appropriate qualitative approach was used. Research design and the choice of data analysis methods were appropriate. Sample size sufficiency not reported. Data saturation was reported. Ethical approval was reported. Ethical considerations were not clearly expressed. There was some indication of the role of the researchers. However, the impact of their positionality on the research process was not explored. Data analysis was rigorous. Member checking was completed. Analysis was peer-reviewed. Negative case analysis was conducted.
Chamberlain, 2006	✓	✓	?	?	✓	?	✓	✓	✓	✓	The study did not provide information on the qualitative approach used and the underpinning theoretical framework. Justification for the choice of using Qualitative Content analysis was not provided. Rationale for participant selection and recruitment procedures were not clearly stated. Methodological triangulation approach utilised for data collection. Data saturation was reached. Lack of reflexivity. The role of the researchers and potential bias was not explored, considering this study was part of a major research project. Ethical considerations were clearly expressed. Data analysis was rigorous.
Cloute et al., 2008	✓	✓	✓	?	✓	✓	x	✓	✓	✓	Appropriate qualitative approach was used. Research design and the choice of data analysis methods were appropriate for a discursive approach. Appropriate data collection methods were utilised. Justification for participant selection and sample size were not clearly expressed. Ethical approval was not reported. No reference to ethical procedures were made. The role of the researchers was clearly described, including the positionality of individual researchers and use of reflective notes during the research process. Data analysis was rigorous and trustworthy. Member checking and peer review reported.
Crisp, 1993	✓	✓	?	?	✓	x	x	✓	✓	✓	The study did not provide information on the qualitative approach used and the underpinning theoretical framework. Justification for the choice of using thematic analysis was not provided. Insufficient information provided on the participant recruitment procedure. Participant selection criteria was not described. The dual role of the researcher-clinician was acknowledged. However, lack of reflexivity on how this impacted the research process. Ethical approval not

	🟩	🟩	🟨	🟨	🟩	🟥	🟥	🟩	🟩	🟩	reported. Data analysis conducted by a single researcher undermines rigour. Some indication of member checking was provided.
Douglas, 2013	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	No limitations
Downing et al., 2021	✓	✓	✓	✓	?	?	✓	✓	✓	✓	Appropriate qualitative approach was used. Research design and the choice of data analysis methods were justified. Appropriate data collection methods were utilised. Data saturation and sample sufficiency was not reported. Information on the interview schedule was not provided. Lack of reflexivity on the researcher's role. Data analysis was rigorous and trustworthy. Interpretations were supported by the presented data.
Fadyl et al., 2019	✓	✓	✓	✓	✓	?	x	✓	✓	✓	Appropriate qualitative approach was used. Research design and the choice of data analysis methods were justified. Appropriate data collection methods were utilised. Ethical considerations were not clearly stated. Lack of reflexivity Data analysis was rigorous and trustworthy.
Freeman et al., 2015	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	Constructionist approach was appropriate to address the aims of the study. Research design and the choice of data analysis methods were justified. Appropriate data collection methods were utilised. Data saturation was reached. Ethical considerations were clearly expressed. The researcher-participant relationship was clearly expressed. Data analysis was rigorous, conducted by two independent researchers and peer-reviewed. Reflective notes were considered during analysis. However, member-checking was not reported.
Gelech & Desjardins, 2011	✓	✓	?	✓	✓	x	?	?	✓	✓	An appropriate qualitative approach was adopted. The research design and the choice of data analysis were appropriate. Justification for the methodological choices was unclear. Appropriate data collection methods were utilised. Ethical considerations were not clearly expressed. The role of the researcher was not clearly described. Data were analysed by two researchers. No reference was provided regarding methods used to enhance reliability of analysis.
Hoogerdijk et al., 2011	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	An appropriate qualitative approach was adopted. The research design and the choice of data analysis techniques were consistent with the narrative approach. Information on participant selection criteria including non-respondents were clearly reported. Data collection methods and ethical considerations were clearly expressed. Good reflections on the dual role of the researcher-therapist and the potential impact on the research process. Reliability of analysis unclear. Research analysis was conducted solely by the primary author. Credibility of the study was undermined by not using member checking.
Howes et al., 2005	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	An appropriate qualitative approach was adopted. The research design and the choice of using IPA were justified. Appropriate data collection methods were utilised. Sufficiently rich data were presented to support the findings. Data analysis was rigorous. Lack of reflexivity and the

	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟩	🟩	impact of the role of the researcher was not considered.
Jones & Curtin, 2011	✓	✓	✓	✓	✓	?	?	✓	✓	✓	Appropriate qualitative approach, research design and data analysis methods were used. However, justification for participation selection and sample size were not stated. Ethical considerations were not clearly stated. Some indication of reflexivity, such as writing field notes. However, the role of researcher and potential bias were not explored. Employed appropriate methods such as triangulation and member checking to strengthen credibility of research findings.
Jumisko et al., 2005	✓	✓	✓	✓	✓	?	✓	✓	?	?	Appropriate qualitative approach, research design and data analysis methods were used. Sampling approach and data collection methods were appropriate. Ethical considerations were clearly stated. Some indication of reflexivity, such as acknowledgement of researcher's preconceived notions. Although how this influenced the research process could have been explained. Higher level interpretations were not supported by the data presented. Conclusions and contribution of research to clinical practice is unclear.
Klinger, 2005	✓	✓	?	?	?	✓	x	✓	✓	✓	Appropriate qualitative approach was used. However, justification for the choice of qualitative methods was not provided. Justification for participant selection and sample size were not clearly expressed. Information on the content of interview schedule was not provided. Ethical approval and ethical considerations were not reported. Peer review, journaling and member checking methods were used to improve trustworthiness. The researcher-participant relationship was not clearly expressed.
Knox et al., 2017	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	Appropriate qualitative approach, research design and data analysis methods were used. Sampling approach and data collection methods were appropriate. Ethical considerations were reported. There was some indication of reflexivity, such as acknowledging the dual role of clinician-researcher. Although how this influenced the research process could have been explained better. Data analysis was rigorous and analysed independently by two researchers. Information regarding methods used to enhance reliability and resolve discrepancies were clearly stated.
Lawson et al., 2008	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	No limitations
Lefkovits et al., 2021	✓	✓	✓	✓	✓	x	?	✓	✓	✓	Appropriate qualitative approach was used. Research design and the choice of data analysis methods were justified. Sampling procedure and selection criteria were clearly described. Appropriate data collection methods were used. Some indication of ethical consideration. However, ethical approval was not reported. Lack of reflexivity on the role of the researcher. Data analysis was reliable and trustworthy. Analysis was conducted by multiple authors and member checking was conducted. Clear statement of findings and research limitations.
Levack et al., 2014	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	Grounded theory was relevant to address the aims of this study. Research design and data analysis were consistent

	🟩	🟩	🟩	🟩	🟩	🟥	🟩	🟩	🟩	🟩	with the qualitative approach. Appropriate sampling procedures and data collection methods were utilised. Data saturation was reported. There is some indication of the role of the researchers. Data was analysed independently by two authors and findings were peer reviewed to strengthen the reliability and trustworthiness of the study. Negative case analysis was reported. There was some consideration of the researcher-participant relationship. Potential bias in research could have been explored.
Libeson et al., 2020	✓	✓	✓	?	✓	?	x	✓	✓	✓	Appropriate qualitative approach was used. Research design and the choice of data analysis methods were justified. Sample size justification and data saturation were reported. However, there was insufficient information on the recruitment process. Ethical approval and ethical considerations of the study were not reported. Lack of reflexivity and the role of the researcher was unclear. Data analysis was rigorous. Multiple authors reviewed the data and themes enhancing credibility and trustworthiness. Lack of consideration of research limitations.

Study	**Clear statement of aims?**	**Qualitative approach appropriate**	**Research design appropriate to address aims?**	**Recruitment strategy appropriate to address aims?**	**Data collected in way that addressed research issue?**	**Researcher-participant relationship considered?**	**Ethical issues considered?**	**Data analysis rigorous?**	**Clear statement of findings?**	**Valuable research?**	**Overall methodological quality**
MacQueen et al., 2020	✓	✓	✓	?	✓	✓	?	✓	✓	✓	Appropriate qualitative approach was used. Research design and the choice of data analysis methods employed were justified. Some justification provided for participant selection. Sample size sufficiency not reported. Appropriate data collection methods were utilised. Some indication of ethical consideration, but not clearly reported. The impact of the role of researcher on data and conclusions drawn were considered and bias explored. Analysis was rigorous and interpretations were clearly drawn from the presented data. Use of a reflective journal, second researcher for review of analysis and recording the decision-making process enhanced the trustworthiness.
Muenchberger et al., 2008	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	Appropriate qualitative approach was adopted. Interpretative qualitative research design and thematic analysis techniques aligned with the phenomenological approach used. Data collection methods were clearly described including sample interview questions and schedule. Ethical considerations were clearly expressed. Data analysis was rigorous and conclusions were clearly stated. Several steps taken to enhance the reliability and validity including analysis by two independent researchers and member checking. Lack of reflexivity on the impact of the role of researchers on research.
Nalder et al., 2012	✓	✓	✓	✓	?	x	?	✓	✓	✓	An appropriate qualitative research approach was adopted. The research design and the choice of thematic analysis was justified. Appropriate data collection methods were utilised. Data analysis was rigorous. However, there was insufficient information on how the phase one study was used to guide participant selection. Data saturation and justification for the sample size were also not reported. Ethical considerations were not clearly reported. Lack of reflexivity and the role of researcher was not adequately considered, especially given this was part of a two-phased research.
Nochi, 2000	✓	✓	✓	✓	✓	?	x	✓	✓	✓	Appropriate qualitative approach, research design and data collection methods were employed. However, information on data saturation or sample size justification were not provided. There was some indication of reflexivity, such as acknowledging the dual role of clinician-researcher. However, the impact of this on the research process could have been explained better. Ethical approval and recognition of ethical procedures were not reported. Rigorous analysis of data, review from a second researcher and member checking enhanced the trustworthiness of the study.
Petrella et al., 2005	✓	✓	✓	✓	✓	x	x	?	✓	✓	Appropriate qualitative approach, research design and data collection methods were employed. There is lack of reflexivity on the researcher's role and how the possible theoretical position might have impacted the research

	🟩	🟩	🟩	🟩	🟩	🟥	🟥	🟨	🟩	🟩	process. The study did not report whether an ethical approval was obtained. No reference to ethical procedures such as informed consent was made. Ethical considerations were not stated clearly. Various methods were referenced to address the credibility and validity of the study. Some of the interpretations developed were not clearly supported by the data, undermining the rigor of the analysis.
Roundhill et al., 2007	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	No limitations
Sabat et al., 2006	✓	✓	✓	✓	✓	?	✓	?	✓	✓	The research design and the choice of using narrative analysis were appropriate for a life history approach. Appropriate data collection methods were utilised. Validity of the research was ensured by using triangulation or multiple methods of data collection such as medical records, journals and photo albums and member checking. However, the themes were not sufficiently supported by the presented data. Although the importance of the researcher's reflexive position was acknowledged, the role of researcher in shaping the research process and the potential bias were not addressed adequately.
Shotton et al., 2007	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	An appropriate qualitative approach was adopted. The research design and the choice of using IPA were justified. Appropriate data collection methods were utilised. Sufficiently rich data were presented to support the findings. Data analysis was rigorous. Necessary steps were taken to enhance reliability and credibility of findings including peer review through multiple analyst consensus, member checking and use of computer software. However, there is a lack of acknowledgement of how the researcher's role impacted the research findings.
Soeker, 2011	✓	✓	?	✓	✓	?	✓	?	✓	✓	An appropriate qualitative approach was adopted. The research design and the choice of data analysis techniques were justified. Appropriate data collection methods were utilised. Common procedures to enhance reliability, credibility, dependability and transferability of the study including member checking, peer examination of the findings and recognition of bias were referenced. However, there was no explanation of how the discrepancies were resolved. Lack of reflexivity and the role of researcher was not adequately considered.
Strandberg, 2009	✓	✓	✓	?	✓	?	✓	✓	?	?	An appropriate qualitative approach was adopted. The research design and the choice of data analysis techniques were justified. Appropriate data collection methods were utilised. However, there was insufficient information on the recruitment process and the criteria for participant selection were not stated. The validity of the study is questionable due to a lack of reflexivity and consideration of the role of the researcher and potential bias. It appeared that the themes were drawn based on the questions asked rather than inducted from the data, which might possibly impact the results and conclusions. Lack of consideration of research limitations.

(Walsh et al., 2020)	✓	✓	✓	?	✓	✓	x	✓	?	?	An appropriate qualitative approach was adopted. The research design and the choice of data analysis techniques were justified. Appropriate data collection methods were utilised. However, there was insufficient information on the recruitment process and the rationale for participant selection was not stated. Ethical approval not stated. Necessary steps taken to enhance reliability of the study. Consensus reached among researchers during analysis of data. Good reflexivity. Combining results and methods sections made it challenging to comprehend the interpretations.

Of the thirty papers, fifteen indicated some methodological flaws, but overall, the methodological quality was considered to be reasonably good. Eight papers indicated very few methodological issues and were assessed to be of high quality. Overall, the review papers included in the study had fairly good methodological quality adding credibility to the participant accounts synthesised and re-interpreted in this review. According to Sandelowski and Barroso (2002), regardless of weakness in the studies, exclusion of papers may result in the omission of important information. As a result, to ensure that relevant information was not overlooked, no paper was excluded based on the CASP quality assessment.

Quality appraisal of the review papers identified two main areas of methodological weakness. Firstly, the researcher-participant relationship was not clearly expressed which could potentially influence the overall validity of the included papers. Secondly, a number of papers provided insufficient information on the participant selection criteria and sampling procedures increasing the risk of sample bias. Finally, a number of studies did not report ethical approval or ethical considerations. It is important to note that these issues may relate to poor reporting practices rather than poor research practice. They suggest uncertainty rather than providing definite evidence of error. Taken together with the generally good ratings of quality, this suggests one can be reasonably confident that the findings represent the experience of the participants.

The key findings of the quality assessment of the review papers are summarised below.

1. Research design

Twenty-five of the 30 papers stated a clear rationale for the qualitative approach utilised in the research. The remaining five studies lacked adequate justification regarding the research design employed. Thus, they ‘partially met’ this criterion. In specific, two studies (2, 4) did not provide details regarding the wider theoretical framework underpinning the research. Whilst three studies (9, 14, 28) reported the data analysis methods used (such as constant comparative method, thematic analysis), they did not provide a rationale for their decision.

2. Sampling procedure

A majority of the studies (n = 21) provided sufficient information on the sampling procedure including participant selection criteria. Out of the nine studies that ‘partially met’ this criteria, four studies (4, 19, 29, 30) did not clearly report the participant recruitment procedure. Five studies did not report justification for sample size (1, 2, 3, 14, 20).

3. Data collection

Data collection methods were described clearly in a majority of the studies except three papers. Two papers did not report the content and structure of the interview (6, 14), whereas one paper (22) did not report the method of data collection such as audio recording or written notes.

4. Reflexivity

Lack of reflexivity and inadequate reporting of the role of the researcher was a main weakness in the dataset. Thirteen papers reported some level of reflexivity. Only three papers referenced the use of reflective journals or field notes (3, 12, 20); seven papers acknowledged the roles as clinician-researchers (4, 15, 18, 23, 26, 27, 30); three papers made an attempt to minimise bias (13, 20, 28), but they did not elaborate on how this was accomplished.

5. Ethical considerations

Two main weaknesses were identified in the reporting of the ethical consideration in a number of studies reviewed. Firstly, ethical approval was not cited in eight studies (3, 4, 14, 17, 19, 23, 24, 30). Secondly, six papers provided limited or no indication of the ethical procedures (such as informed consent, confidentiality) and ethical considerations (1, 7, 9, 12, 20, 22).

6. Data analysis

A majority of the papers reported a fairly detailed account of the analysis techniques adopted. Nineteen papers (2, 3, 6, 7, 9, 10, 11, 12 ,14 ,15, 16, 17, 19, 21, 23, 25, 26, 27, 30) described different strategies utilised to enhance credibility of the research such as triangulation methods, member checking of data and analysis, keeping field logs and multiple researchers involved in the analytic process. Three papers reported the use of field notes and memos (20, 24, 28). However, they did not elaborate on how this helped them with the decision-making process. Only two studies (1, 18) reported negative case analysis.

7. Findings

A majority of the review papers provided a clear statement of findings except three papers (13, 29, 30). Of these, one study (13) reported higher level interpretations which were not supported by the data presented. In one study (29), themes were not inducted directly from the data, but were constructed based on the questions presented. Combining results and methods sections made it challenging to comprehend the interpretations in one study (30).

8. Value of research

A majority of the review papers discussed their valuable contribution in terms of practical significance and future research. Conclusions and contribution of research to clinical practice were unclear in two studies (13, 30). Research limitations were not considered leading to inadequate conclusions in another study (29).

Data Analysis and Synthesis

The current meta-synthesis followed the steps for synthesis recommended by Noblit and Hare (1997). However, more emphasis in the synthesis process was placed on first-order constructs (participants' accounts of their experience expressed in their own words) than on second-order constructs (i.e. the original authors' interpretations of participant accounts), although the second-order constructs were taken into account in making sense of the first-order constructs. Specifically, the decision was made to include themes only if they were clearly supported by direct quotations from participants. This differs from other meta-ethnographic approaches that synthesise themes wholly from second-order constructs (Toye et al; 2014). The approach was justified given that the themes of identity were not well-developed in most of the papers and therefore the second-order themes related to identity were limited in number and richness. Moreover, papers sometimes included material relevant to a theme about identity that the authors did not themselves develop into a theme. Although more emphasis was placed on direct quotes, the themes of the original authors were still considered because, at times, they did provide an insightful synthesis of a range of direct quotations.

In line with phase three of Noblit and Hare’s (1997) approach, which involves reading the articles, all 30 publications were studied in their entirety with an emphasis on their results section, which contains significant findings of the analysis. In qualitative studies, researchers typically present their analyses as themes and sub-themes, accompanied by relevant quotes from the participants. Moving forward, phase four (establishing connections between the studies) and phase five (translating concepts across studies) of Noblit and Hare's (1997) approach were implemented.

During this stage, the researcher undertook the task of "translating" concepts across the studies by examining the similarities and differences between themes and concepts to identify a higher order theme. Firstly, recurring themes, concepts and codes were identified across the themes and sub-themes of papers that explored the experiences of people with TBI. A qualitative analysis software NVivo was used to create an extraction grid. Once the relevant papers were imported onto the software, and read multiple times, the initial ideas were categorised in the form of 49 key words, metaphors and phrases (See Appendix B). Following this process, direct quotes from participants and original author’s interpretations were extracted and organised in the extraction grid for further analysis. The next step involved extracting only those parts of themes or sub-themes that were relevant to the research question.

Moving forward, 25 initial reciprocal translations were generated from data containing similar themes (See Appendix C). The participant quotes and author's interpretations for each reciprocal translation were re-read from the studies. Translations with similar concepts were merged further. For example, similar concepts such as 'Redefined roles', 'Positive and engaged' and 'Sense of achievement' were merged to later form a higher order theme 'Redefined roles and activities'. Broader concepts such as 'Self-belief' were deconstructed and relevant data was incorporated into other translations such as 'Spirituality' to form meta-theme 'Chosen one'. Finally, translations such as 'acute hospital setting' were not identified as a theme emerging from positive identity experiences of TBI survivors as they only contained suggestions for improving acute services. This approach was consistent with the phase six of the Noblit and Hare's (1988) approach to meta- ethnography for synthesising translations. Finally, four main themes and 3 sub-themes emerged from these translations and synthesis. Data containing full reciprocal translations including the reference and the authors and the proportion contributed towards each theme is shown in Appendix D. The themes and sub-themes were then expressed in the results section constituting the seventh and final step of Noblit and Hare's (1988) meta- ethnography approach.

Reflexivity

Brain injury has been an area of interest even before pursuing my doctoral training in Clinical Psychology. My previous work experience in acute Neurotrauma and neurorehabilitation services further strengthened my interests in understanding the emotional impact of brain injury. During the course of developing my research questions, I became more aware of my own philosophical perspectives aligning with the principles of positive psychology, which supports the notion that people have inherent skills and competencies to overcome adversities in life. Therefore, I was interested in exploring how individuals adapt to major life transitions such as brain injury and the potential for positive reconstruction of identity in TBI survivors.

During the research process, a reflective document was created to keep track of my decision-making process and how my internal beliefs and assumptions impacted the research. This was particularly useful in highlighting how my non-western background with a focus on humanistic existential perspectives perhaps led to the development of themes such as ‘The Chosen one’. On the other hand, it is also important to acknowledge that I initially struggled to recognise how the theme of ‘sense of pride’ as TBI survivors may have contributed to positive identity construction in some individuals. Upon reflection in supervision, I realised how the conceptualisation of pride varied in different cultures and the cultural emphasis of humility over pride could have perhaps impacted my analysis process initially.

Overall, it is important to note that although the current meta-synthesis highlighted the experiences of positive identity reconstruction following TBI, it is also essential to recognise the prevalence of negative internal experiences among TBI survivors. Therefore, it is recommended to consider the findings of this review in tandem with the processes contributing to negative changes in one’s identity.

1.5. Results

In this section, the synthesis of the results from the conducted meta-ethnography study is presented in detail as four themes. Table 1.6 presents a brief summary of the identified themes and subthemes from the conducted review.

Table 1.6: Identified themes and sub-themes

Theme	Subthemes
Acceptance	
Valuing oneself as a better person	Re-evaluating values and beliefs
	Redefined roles and activities
	Being more empathetic towards other
Sense of pride	
Chosen One	

Theme One: Acceptance

Several participants reported that the acceptance of the fact that they have changed after TBI was essential for a positive reconstruction of their identity (Mamman et al., 2022). This theme represents the participant's realisation and acceptance of the changes to the self, following TBI. In particular, it outlines participant's perspectives on what acceptance involves and the various consequences of TBI they had to accept. At first, the participants had to come to terms with the occurrence of the TBI event. When participants realised that their injury might have long-term implications, they subsequently accepted the permanence of the event.

Participants also emphasised that acceptance of the fact that they have changed was essential in moving forward from their experiences and consequences of brain injury. "*I have two choices: I can either be happy and accept what is happening and look forward to the future or be sad and regret what is done*" (Sabat et al., 2006, p. 22)

One participant acknowledged that accepting their new limitations and coming to terms that they cannot perform tasks as they once could helped them adjust. Moreover, the participant’s compassion towards their post-injury self could have fostered acceptance. *“Just take everything as it comes. Take it slowly. Let yourself get used to it. Don’t try and be like your old person. No, you just know you’re never going back. Just accept it, it’ll be okay”*. (Mamman et al., 2022, p. 2112)

Moreover, the participants seemed to comprehend the relationship between their brain injury and the functional limitations in their daily lives, acknowledge the permanence of the situation, and consequently re-evaluate their previous standards of performance. Acceptance of the changes in their self-identity enabled participants to embrace the idea that identity changes after TBI may not necessarily be negative.

> *I was beginning to understand that there is this limitation thing that may be more pronounced than I thought it was, or maybe the limits are bigger than I thought they were (laughs). That’s when I started having to accept that there are some things that have changed, and there is nothing I can do about it… Not that that may be a bad thing. You know, it’s that—well, is the glass half empty or half full thing. But admitting that it’s not full any longer, I think is a big step.* (Petrella et al., 2005, p. 650)

For some participants, acceptance involved acknowledging the losses resulting from TBI, particularly loss of an envisioned future-self and missed chances for positive life experiences. Thus, the concept of acceptance was generally complex as it might represent various aspects, both negative and positive aspects in different people. For instance, for some participants acceptance involved letting go of their aspirations either short-term or long-term. However, accepting the challenges associated with their TBI helped people to move forwards and prioritise their recovery as they gained better insight into their strengths and limitations.

> *Up until that point, I had actually contemplated the idea that I could eventually some day return to work. That was a realization process, I guess for me to sort of say, well maybe*

> *this is not going to happen. And I guess there is an acceptance—a period of time when you start accepting the way things are and although you've learned whatever coping strategies and or ways of dealing with things, it's time to say, well this is the way it is, it's not going to change.* (Petrella et al., 2005, p. 650)

Some participants also acknowledged and gradually accepted the perceived loss of their pre-injury self and embraced their post-injury self.

> *It's probably only in the last year that I've actually accepted that other person [myself prior to the accident] was somebody else, and I'm a new me now. But that's a new thing for me"* (Levack et al., 2014, p.4); *"There is a big step of acknowledgment that has to happen… you have to acknowledge that you need to find new things. […] But it's hard to lay all those things to rest because that is what you've been doing your whole life. But you have to lay those things to rest, before you get started on the new things.* (Klinger, 2005, p. 12).

Theme Two: Valuing Oneself as a Better Person

The theme is about individuals with a TBI perceiving themselves as a better person. This was observed as three sub-themes: (1) Participants experienced a shift in values and priorities, distancing themselves from materialism and selfishness; (2) Participants found a sense of self-improvement by engaging in roles and activities aligned with their newly adopted social and altruistic values. They recognised changes in their approach to fulfilling responsibilities; (3) Participants developed a stronger self-identity by developing empathy towards others and aligning with their new values. Empathy became integral to their lives, shaping their aspirations, improving self-perception, and fostering positive identities.

Re-evaluating Values and Beliefs

Participants viewed themselves as a better person because of change in values and priorities away from a more materialistic and selfish position that characterises both the pre-injury self and the values of society in general, to a more social and altruistic position. This sub-theme illustrates how participants valued the process of preserving their own values rather than conforming to social norms of having a stable employment, relationship, and financial situation that marked a successful life. Participants in the studies expressed a strong desire to challenge societal norms that value and prioritise materialism in life. Participants discussed about re-examining their values and beliefs and deciding their priorities in life despite the possibility of judgement and criticism from society.

> *…and when you go through something like that you realize that the emphasis people put on certain things aren't really that important. It's not that important to show people that you are good, …. there are a lot more important things in life than what other people think* (Muenchberger et al., 2008, p. 987).

Other participants contrasted their new values and priorities with their own former values, rather than those of society generally. They commented on how they felt a better person compared to their pre-injury self.

> *This head injury stopped me going down the road I was. . .it made me reflect on my life before, saying 'Don't go down that road again'. I was a complete nutter. I thought to myself 'You weren't actually going anywhere. And the friends you did were a load of nut-cases, with no life and no prospects* (Roundhill et al., 2007, p. 249).
>
> *I'm completely different, because in my younger days I was a bit of a tearaway. I've quietened down. It's definitely positive, because I would have probably ended up in prison, for a long time, or dead* (Roundhill et al., 2007, p. 249).
>
> *I used to be very naive and 'carefree. But the accident has transformed my life, the way I see things. I feel more grounded. I 'm able to see the lighter side of things."* (Sabat et al., 2006, p. 22).

This shows how the TBI event transformed some participants' perspectives about their self and their worldview. Participants were able to evaluate their post-injury selves as stable and better than their former selves by internalising positive values, personal attributes, and beliefs. This allowed them to construct a positive post-injury self-identity.

Redefined Roles and Activities

Participants also viewed oneself as a better person because of their involvement in roles and activities that reflect the social and altruistic values that one has adopted. Some participants additionally acknowledged how their post-injury experiences led to changes in the way they accomplished their roles and responsibilities as men. For instance, both John and George highlighted valuing their role in community development.

Prior to his brain injury, George placed emphasis on the value of his work and his role in meeting the materialistic needs of his family and John regarded himself as *"a man about town."* Nonetheless both of them believed that injury seemed to have influenced a behavioural change and redefined their concept of male identity as illustrated in the below excerpt.

I've got no idea what I'm gonna do but at least I'll spend some more time with my kids. You know so at least, after having this happen, I think family's a very big thing for you. You know. It's all very nice to have money, which I have a bit of money, done all right for myself, but it puts a different perspective to what's important, and in my eyes, family is ... (MacQueen et al., 2020, p. 308).

I've joined the PA (Parents Association) at my [child's] school, because I've got the time to do it and I want to contribute... (MacQueen et al., 2020, p. 308).

David described that after being hospitalised due to excessive alcohol consumption, he questioned his existence in the world. This enabled David to reflect that he was worthy as a person, and this inspired him to change his circumstances accordingly.

I'm like, what am I worth, what am I here for, on this planet? What do I do? I ended up in the hospital from drinking too much. And that's when I realized that I have to find something"….So, I got involved. And right away, I just didn't drink. It all changed. Because I felt like I was worth something... (Mamman et al., 2022, p. 2112).

One participant, Robert, explained how he redirected his priorities and found his life's renewed meaning in parenting his children after realising he wouldn't be able to continue his occupational role.

I had to keep telling myself that it's okay that you're not working, you still are, you're raising children here. That's a big job in itself. So that was the biggest push. If I couldn't have that, then I was going to raise my kids the best that I can. Without this strong motivation, I *wouldn't be sitting here talking to you and we wouldn't be having all this right now...* (Mamman et al., 2022, p. 2112).

Having the opportunity to spend time with his children post-TBI was valued by yet another participant.

> *The time I've spent with (my daughter) is a real bonus, there's no way I would have spent that time with her before the injury .... If you have a brain injury, get yourself a child because they're wonderful therapy. Me and (daughter), we, we learnt to walk together, although she's probably better than me now .... she can run, I can't (laughs).... They are a great therapy* (Shotton et al., 2007, p. 864).

Hence, involvement in roles and activities that reflect the social and altruistic values that individuals adopt enable them to adapt positively to their encountered post-TBI changes.

Being More Empathetic Towards Others

Participants also developed a more positive self-identity through embodying their new values in the empathy they felt towards others. Joshua articulated his intention to provide help to others in a similar manner to the support he received:

> *I think that I was in a bad place, but I was able to, I had people around me, I had people to help me. For me knowing that those people were there, changed my life, and changed the trajectory of my life…So, I think I'm in a position where I want to be able to help and I can say I was in your shoes, I was where you were a couple years ago, three years ago, I'm doing much better because of the people who were there* (Mamman et al., 2022, p. 2113).

In addition, participants also acknowledged improvement in personal attributes such as being more compassionate and caring in their daily life.

> *I'm actually more compassionate and caring than before. I've become a very good husband".* "*It's one good thing with the head injury that I do actually care about other people now. And know they exist!. . .I'm more patient as well. More patient with people who've got disabilities* (Roundhill et al., 2007, p. 250).

Some participants commented on how they could understand and empathise with the problems of other people as a result of their own difficult TBI experience: *"I think it [the TBI* *experience] has really expanded my appreciation of other people and their problems"* (Nochi, 2000, p. 1798).

While others described developing a connection with other TBI survivors as they could identify with the challenges and negative consequences of TBI in others through their own experience: *"I feel like I can relate to people who've gone through stuff because I know what I've been through. And I know how I felt when people reacted in different ways to me"* (Mamman et al., 2022, p. 2113).

Constructing a positive identity by increasing one's capacity for empathy, tolerance, and understanding others was also frequently associated with altruistically driven goals and behaviours in some participants. "*I'm glad I had my accident because it's made me into a better person. It's made me help people. If I see a lady across the road with shopping I will run over and help her*". (Douglas, 2013, p. 68).

Some participants reflected on how they desired to uplift others through their own experiences, while few other were found to cultivate compassion for people with disabilities. Appreciating differences in other people and fostering tolerance helped them to see themselves as a better person following their TBI. *I want to help others; I could put together a programme to be used for teenagers about making the right choice about drinking."* (Douglas, 2013, p. 68).

In addition, taking a productive role based on the prosocial and altruistic values helped participants to see oneself as a better person and motivated them to move forward in life.

> *I'm a better person now than I was before the accident… Now when I see someone walking down the street, I don't necessarily think they're retarded, I have a lot more tolerance and a lot more appreciation for somebody that might look a little different; what they might have been through* (Klinger, 2005, p. 12).

Thus, developing empathy for others became essential to their life, led their future aspirations, helped them to feel better about themselves, and promoted construction of positive identity in each participant.

Theme Three: Sense of Pride

Participants in this theme reported a sense of pride despite the adversities they faced. Some participants expressed feeling pride in simply surviving their injury and appreciated just being alive. Meanwhile, others found a sense of pride in their recovery as triumph over a near-death experience. Additionally, some participants found pride in the progress they have made, surpassing the odds and defying expectations.

Regardless of their ability to function optimally after the TBI, some individuals took pride in having survived the injury and were grateful to be just alive. *"Yeah, I do have a sense of pride about it. Yeah... even though I didn't achieve nothing, that's all... I just feel good that I'm still here..."* (Freeman et al., 2015, p. 206).

Some participants reported that having a sense of pride in what they have achieved and coming back from the dead gave them an optimistic attitude towards their life and meaningful relationships which enhanced their self-worth. "*I feel proud to be as good as what I am. For what I was, I was on my death bed, I'm proud to be what I am. I'm just lucky that people treat me for what I am"* (Crisp, 1993, p. 399).

Some participants highlighted taking pride in how much progress they made, particularly against the expectations and predictions of others.

> *The doctors, the nurses, the therapist, they were saying, this isn't gonna happen, this is going to be this way. And I know the stubbornness or whatever, I just smiled and said, 'sure thank you I appreciate that', and then just not going to let that happen to me. Having that mindset is a big part of how I am today, the recovery I've been through* (Mamman et al., 2022, p. 2113).

Others emphasised the significance of being proud of one's accomplishments and reminding oneself of their strength, resilience, and determination to become a better person in spite of adversities.

> *I don't want to forget how bad I was because - I feel that I've worked so hard and trying to be better that - why should I forget it? I deserve a pat on the back for it. I like the idea of being - a guy that has been through something this bad. And I'm strong enough, mentally and physically to conquer it. I like that feeling* (Nochi, 2000, p. 4).

In the face of challenging experiences associated with TBI, certain participants displayed remarkable resilience and a profound sense of pride as survivors. Their pride stemmed from recognizing the value of their own existence and acknowledging the unwavering determination they demonstrated throughout the recovery journey. Despite discouraging viewpoints from both family members and healthcare professionals, these individuals maintained a steadfast belief in their ability to triumph over the adverse effects of TBI. Their determination, resolve, and overall contentment with life served as powerful motivators, driving them forward.

Theme Four: Chosen One

This theme focuses on the personal accounts of participants who viewed themselves as a special and a chosen person after involving in a near-death experience during the TBI event. Experiencing a near-death event enabled participants to value their existence and be appreciate of their second chance at life. For some participants this enabled deeper reflections into the meaning of life and understanding the valuable aspects of their life. In others, this meant realigning their goals and finding strength in religion and relationships.

Participants noted that experiencing a near-death moment from the TBI event instilled in them a sense that they had been saved for a reason.

> *I think after having the accident you know, it's like if I died right now, I've got to know that everything I do is good. Because you never know. I never knew that the accident was going to happen so I see that I'm still alive and I must be here for a reason, so, got to keep going* (Muenchberger et al., 2008, p. 986).

Some participants were found to experience religious or spiritual awakening and perceived their TBI-event as a divine intervention to improve their present-self. This enabled them to take a positive outlook towards future and work towards becoming a better version than their pre-injury selves.

> *I believe that God is supreme. He is in charge of absolutely everything. And if He wanted this to happen, there had to be a way. It had to be His Will. If God is willing, who am I to question that? He has helped to improve my life. Things can only get better.* (Sabat et al., 2006, p. 23).

Some participants viewed their TBI experience as a second chance in life that made them unique people and helped them to rebuild their identity.

> *In regards to the expansion of identity, survival following TBI represented a 'second chance' at life, as one participant explained, 'I question everything because I feel that the ''born again'' day made me a different person.* (Muenchberger et al., 2008, p. 986)

Some participants reflected on their existence and believed that there was a higher purpose and meaning to their life. This existential reflection helped them to find strength in spirituality and meaningful relationships to overcome the challenges in life. This enabled them to recognise and appreciate aspects of their life that was valuable to them and focus on their self.

> *Having the accident ruined my life . . . but I sort of feel that's life on earth . . . this has been sent to make me for some reason which I don't understand . . . So I believe this part of my life is a bit horrible but maybe there's a reason . . . my religion is good support . . . I feel very secure with the affection of my family and friends and other people* (Crisp, 1993, p. 399).

Several participants in this theme reflected on their near-death experience and believed they were special and chosen to be alive for a higher purpose. The perception of being chosen and special emerged from their own existential reflections following near-death experience and from valuing positive attributes in their lives such as having a supportive family, religion and support from the community.

1.6. Discussion

This review identified several processes that may contribute to a positive adaptive reconstruction of identity following TBI from existing body of qualitative literature and synthesised the findings into a number of overarching themes. The identified themes include – acceptance, valuing oneself as a better person (re-evaluating values and beliefs, redefined roles, and activities, being more empathetic towards others), sense of pride, and chosen one.

Acceptance

Acknowledging and embracing the changes associated with a TBI have been identified as a key component for developing a more positive sense of self (Biderman et al., 2006; Simpson et al., 2012). Prior research studies emphasise that acceptance not only enables embracing the multiple facets of self, including the positive and negative effects of TBI, but also enables setting realistic expectations and hopes for recovery (Simpson et al., 2012). In the presented review, acceptance of changes in oneself was found to be a crucial and necessary initial step towards developing a positive self-perception. It highlights that striving to revert to one's former self implies discontent and dissatisfaction with one's present identity.

Valuing Oneself as a Better Person

This theme encompasses three sub themes – Re-evaluated values and beliefs, Redefined roles and activities, and being more empathetic towards others. Participants within this theme constructed a more positive self-identity, driven by a shift in their values and priorities in life. They also reconstructed a positive identity by adjusting or changing their social roles and life priorities according to their values to reflect more of their altruistic self. These experiences of personal growth and recognition of positive self- concepts such as compassion, empathy and other altruistic traits has been well documented in post-traumatic growth (PTG) literature (Grace et al., 2015; Kinsella et al., 2020).

Sense of Pride

Participants derived a sense of pride when reflecting on their personal journey after TBI, acknowledging the progress they have made and their achievements in various personal and social roles. Some individuals felt immense pride in just surviving a life-threatening experience. This idea of survivor pride is connected to Herman's (1992, p. 202) claim that underlying beliefs such as "at least I have myself " is strongly associated with positive recovery.

Chosen One

This final theme underscores how individuals experiencing adverse life events such as TBI are able to perceive the value of their life, recognise their inner strengths, and reformulate their goals accordingly. This stems primarily from their belief that they have been saved for a higher and special purpose in life. Underlying this sense of being the chosen one with special purpose was perhaps an appreciation for the opportunity of a second chance in life. Participants' accounts highlighted that surviving a life-threatening event served as a catalyst for positive self-perceptions, reinforcing the importance of their life and existence, and inspiring their determination towards recovery and leading a purposeful life.

Limitations

Limitations of the reviewed papers

The quality appraisal suggested that one can have a reasonable level of confidence that the findings of the papers were a good representation of the experiences of the participants. The general level of quality, according to the CASP criteria, was reasonably good. Some papers received lower ratings for not clarifying ethical issues or the researcher-participant relationship, but this might reflect poor reporting practice rather than any methodological faults. Of more concern was the fact that some papers failed to provide clear information about participant recruitment processes, although, again, this may be due to poor reporting than a methodological flaw.

Limitations of the review

While the present review employed a thorough search strategy to identify articles containing relevant data, it is possible that some potentially valuable and relevant articles may still have been overlooked due to the use of different terminology. For example, publications that covered related concepts like self-esteem, self-sufficiency, or more general constructs such as psychological well-being or quality of life. Moreover, the inclusion of research articles whose main focus was not positive identity reconstruction but still contained useful data posed an additional challenge. There are questions on how successfully the topic of identity reconstruction was addressed in those studies. In fact, a number of included studies lacked in-depth exploration of identity-related concepts. This factor may have had an impact on the degree of interpretation and the conclusions that might be drawn from them – a known limitation in synthesising qualitative research (Zimmer, 2006). Furthermore, as the studies synthesised in this review used a cross-sectional research design, it was not possible to ascertain how these processes may evolve over time.

Another limitation of this work pertains to the quality review. Since the quality of included papers were not verified independently by a second researcher, inter-rater reliability could not be ascertained during the quality appraisal. The personal bias of the author of this review may have influenced the process of interpreting the study findings and the creation of higher order themes. The author was conscious of their philosophical interest in the topics of existentialism, In order to minimise this bias, the author also discussed the emerging themes with a research supervisor experienced in qualitative research and made a conscious attempt to ensure that the viewpoints of participants from various philosophical perspectives were taken into consideration.

Although the focus of this meta-ethnography was on the processes aiding TBI survivors in positive identity reconstruction, excluding data from other informants such as family members, carers, and professional experts, may have limited the exploration of these factors. Finally, limiting the inclusion to English-language articles; the lack of research from cross-cultural perspectives; and significant variations in participant characteristics (e.g., severity and time since TBI), could affect the generalisability of the presented results.

1.7. Clinical and Research Implications

The current review has identified various internal processes, including intrapersonal and relational processes, that enable TBI survivors to rebuild their sense of self in a positive and meaningful way. In doing so, this review offers recommendations for clinical practices that, if implemented during rehabilitation, may promote positive and adaptive reconstruction of self-identity in TBI survivors. Based on the findings of this review, it can be suggested that rehabilitation and psychotherapy goals aimed to help individuals re-evaluate and develop acceptance of their post-injury selves may be a vital first step in positive identity construction following TBI.

In addition, the review suggested the importance of assisting individuals with TBI in reflecting on and redefining their values and priorities in life. This has an effect in aiding them to align their life choices with these reshaped values and priorities. Embracing and acting upon values that one can live by, as opposed to values that are no longer attainable, may provide a crucial foundation for a positive self-identity. Acceptance and Commitment Therapy (ACT) recognises that not living life in accordance with one’s values is a major source of psychological distress and poor wellbeing. ACT has been used with success in ABI to reduce psychological distress and improve wellbeing (Sander et al., 2021). This review offers a possible explanation for the particular effectiveness of this approach in brain injury and suggests ways in which the therapy may be usefully focused. For example, in the context of brain injury, assisting individuals to change and reshape values, while also ensuring that they can realistically live a life aligned with those redefined values. Although this aspect is not part of the standard approach of ACT, it may hold significance for individuals with brain injuries.

In summary, clinical studies and research indicate that intervention strategies should generally aim to assist people in understanding the changes and losses brought on by the injury. It is crucial to support them in developing acceptance towards their post-injury changes; to help them manage negative emotions during this process; and to facilitate the growth of a stable, coherent, and positive sense of self that can acknowledge and embrace these post-injury changes (Levack et al., 2014). Supporting people to understand and adjust to these changes has largely been the primary focus of intervention in this area. However, there is a scarcity of research on how to effectively support individuals to maintain and develop a stable, coherent, and positive sense of self. A systematic review of intervention studies that targeted self-identity or self-esteem as an outcome variable (Ownsworth & Haslam (2011) identified only one study that particularly focussed on improving post-injury self-identity. Similarly, the evidence base for promoting a positive self-identity in intervention studies targeting couples is also very limited. Therefore, the presented meta-ethnography has made an attempt to address some of these research gaps.

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CHAPTER 2: Empirical Paper: The Impact of Continuity of Identity in Individuals with Acquired Brain Injury

2.1 Abstract

Background: Acquired Brain Injury (ABI) is a life-changing neurological event that can have a detrimental effect on an individual's neurocognitive, physical, behavioural, and emotional functioning. Coping with these changes often poses a significant challenge to an individual's self-identity and can substantially impact their psychological wellbeing. According to Continuity Theory, when faced with adverse life circumstances, individuals with a stronger sense of inner continuity tend to have better psychological well-being outcomes. However, in the context of ABI, there is a lack of research on the potential benefits of maintaining inner continuity. Therefore, this study attempts to shed light on whether a sense of internal continuity is associated with improved psychological outcomes as predicted by Continuity Theory.

Method: A cross-sectional research design was used to investigate the impact of internal continuity in 30 individuals with ABI recruited locally and nationally from Headway, a charity organisation supporting brain injury survivors and their families. Participants completed a set of eight questionnaires measuring continuity in identity, self-esteem, depression, anxiety, stress, grief, meaning in life, pre- and post-injury self-discrepancy and level of insight.

Findings: The psychometric properties of the Continuity of Self-Identity Questionnaire showed satisfactory internal consistency and good construct validity. Bivariate correlational analyses and multiple regression analyses showed that a strong sense of inner continuity had a significant positive association with self-esteem and adjustment after brain injury and negative association with depression and stress.

Conclusion: This research provides insightful information on the continuity of identity in the

context of brain injury. Consistent with the Continuity theory and the multifaceted nature of self-identity, promoting both external continuity of behaviours and sustaining internal continuity in interventional studies represent important suggestions for future research.

2.2 Introduction

Concept of Self-identity

Self-identity broadly refers to an individual’s perception of who they are, based on their characteristics such as personal attributes, core values, social roles, goals, and life experiences (Ownsworth, 2014; Turner, 1975). The term "self-identity" is frequently used interchangeably with the terms "sense of self" and "self-concept," and it is closely associated with the concept of psychological continuity (Oyserman et al., 2012). It is widely regarded as a complex, multidimensional construct encompassing a person’s past-, present-, and future-self (Sharma, 2014). Self-identity drives decision-making and goal pursuits (Light, 2017), and is closely related to one’s sense of achievement, life satisfaction (Reich et al., 2013) and overall psychological well-being (Ritchie et al., 2011). Several intrinsic (psychological) and extrinsic (sociocultural influence, significant life events) factors influence the development of one’s self-identity (Jetten et al., 2012; Legrand & Ruby, 2009). Despite being generally regarded as a stable factor, self-identity, is in principle, fluid and evolving during the lifetime and is influenced by life experiences pertinent to one's psychological and physical characteristics, group membership, social roles, and participation in meaningful activities (Zahavi, 2008). Stressful life events, transitions in life, unfavourable feedback from the external world, and major illness have all been reported to contribute to changes in self-identity over the course of an individual's life (Caddell & Clare, 2010; Feinberg, 2011).

ABI and Self-identity

Acquired Brain Injury (ABI) is a life altering neurological event that can have a devastating effect on an individual’s course and quality of life (Ownsworth, 2014; Wilkie et al., 2021). Although significant changes in the neurocognitive, physical, behavioural and emotional functioning have been well documented in people experiencing mild to severe ABI, the impact of ABI can be complex and unique to each individual (Belanger et al., 2005; Cappa et al., 2011). Coping with these changes often poses a major challenge to an individual's self-identity, and the difficulties in dealing with these challenges can also be detrimental to one's psychological wellbeing (Carroll & Coetzer, 2011; Villa et al., 2021).

Research suggests that individuals often have an idiosyncratic response to these challenges (Nochi, 2000; Ownsworth, 2014). While several ABI survivors have described a "loss of self" and a "shattered identity", others succeed in preserving a sense of continuity in their identity and fundamentally perceive themselves as unchanged from their pre-injury self (Gelech & Desjardins, 2011; Haslam et al., 2008; Medved & Brockmeier, 2008; Nochi, 1998).

Continuity Theory

Continuity Theory was originally developed by Atchley (1989) as a framework to explore and understand the processes that enable older adults to adapt to the changes associated with the process of normal ageing. A fundamental assumption underlying this theory is the existence of a central, coherent structure that maintains continuity in both internal structures such as cognitive patterns, dispositions, behaviours, as well as external structures such as valued life roles, relationships and meaningful activities throughout one's lifetime (Atchley, 1989).

Atchley (1989, 2001) postulates that continuity is a dynamic process that enables an individual to embrace changes in life without causing major disruptions to their sense of self. Over the time, Continuity Theory has been used as a framework to understand processes that enable adaptability in the face of other critical life events, including major illness (Cuskelly & O'Brien, 2013; Llewellyn et al., 2014; Östman, 2016). This theory considers both internal psychological continuity and continuity of external circumstance to be crucial elements to successful adaption. Continuity Theory suggests that despite substantial changes in external circumstances, individuals can still maintain internal psychological continuity. However, maintaining continuity in the external circumstances of an individual can sustain internal continuity, indicating an interdependence between these two aspects.

According to Atchley (1989), individuals develop self-appraisals encompassing personality traits, cognitive abilities, values, goals, and feedback from others over the course of their lives. These self-appraisals solidify into global generalizations that form the basis of continuity of identity. The continuity of identity remains intact despite changes in aspects of internal and external resources and serves as the basis for psychological safety (Atchley, 2006). Atchley (2006) hypothesised that internal continuity is crucial for individuals to maintain their overall psychological wellbeing and attain maximum life satisfaction. There are several reported benefits of internal continuity. Foremost, internal continuity serves as a frame of reference that allows comprehending and making sense of one's own actions, cognitions, and response to the external world. Thus, providing a sense of predictability, integrity and coherence about oneself and the external world (Breheny & Griffiths, 2017; Somers, 1994).

A lack of internal continuity makes one's sense of self as well as their external world unpredictable and difficult to comprehend (Atchley, 1989). Secondly, as internal continuity drives behaviour and interaction with the external world, it is crucial for planning, judgement, and decision-making (Berger & Luckmann, 1966). The lack of internal continuity can impact recognition of personal goals, values, moral systems, and preferences, resulting in a loss of sense of meaning and direction in life (Atchley, 2006). Furthermore, absence of direction in life can contribute to increased stress in planning and decision-making. In addition, being unpredictable and impassive towards life can also contribute to a sense of lack of control in life. Consequently, discontinuity can lead to a sense of powerlessness. Finally, internal continuity is vital for self-evaluation and maintaining one's self-esteem (Atchley, 1989). With internal continuity, self-esteem can be maintained or increased over time, assuming the individual has a considerable level of self-esteem prior to the life transition. Conversely, discontinuity causes disruption in the feelings of positive self-esteem.

Continuity and Discontinuity of Identity in ABI

External Continuity in ABI

In terms of external discontinuity in ABI, qualitative studies have shed light on various disruptions experienced in the post-injury sense of self compared to their pre-injury self. For example, Campbell et al. (2013), in a qualitative scoping review on occupational identity in ABI survivors, identified themes such as *"feelings of disruption "*, and *"missing something that was once valued "*. However, the context of Continuity Theory was not explicitly included in these investigations. In another thematic synthesis of 33 qualitative studies conducted by Satink et al. (2013) the major themes that emerged from 17 qualitative papers on stroke survivors included the *"struggle with discontinuity in social roles "*, *"discontinuity in fulfilling gender roles "*, which caused distress in spousal relationships (Thompson & Ryan, 2009). However, from the perspective of Continuity Theory, the loss or discontinuity of one or more external circumstances does not necessarily affect the stability of one's internal identity. Therefore, it remains unclear from these qualitative accounts whether the reported discontinuities in social roles, relationships, and employment are confined to those specific domains or result in global disruption of one's internal continuity.

Several quantitative studies have demonstrated that promoting social group membership and maintaining outward continuity can improve psychological outcomes and have a positive impact on psychological well-being in the context of ABI and other life transitions (Haslam et al., 2008; Iyer et al., 2009). Similarly, Walsh et al. (2017) found in their neurorehabilitation study that increased social support was associated with positive emotional states, such as low levels of anxiety and depression measured by the HADS (Hospital Anxiety and Depression Scale) in ABI survivors. However, these studies do not offer conclusive evidence on whether social membership improves psychological well-being by enhancing internal continuity. It is possible that positive feedback from peers, a sense of belonging in social groups, and a sense of purpose in life arising from participation in social activities may contribute to the positive psychological wellbeing observed in these studies. In conclusion, the existing body of literature does not provide convincing evidence on the question of whether maintaining external continuity enhances psychological well-being through the process of sustaining internal continuity.

Internal Continuity in ABI

In terms of internal continuity, qualitative studies have extensively described the changes in overall internal self-representations that indicate a disruption in the sense of self. In one study, participants reported experiencing thoughts such as, *"I feel like a stranger"*, and *"I am not the person I was"* (Lorenz, 2010, p. 875). Additionally, some reported a sense of being lost (Jumisko et al., 2005) or experiencing emptiness and disconnectedness (Soeker, 2011). Jumisko et al. (2005) highlighted in their qualitative study that a majority of participants reported to have lost a valuable aspect of themselves, despite finding it difficult to articulate the nature of this loss. This breakdown of self as a unitary identity was described by Muenchberger et al. (2008, p. 985) as *"fragmentation of oneself "*.

Although the experience of discontinuity is widely reported in qualitative studies, it is worth noting that some participants also report a sense of continuity. Pallesen (2014), in a phenomenological qualitative study involving 15 stroke survivors, reported that despite experiencing substantial and immediate disruption to their objective sense of self, participants reported a coherence between their pre- and post-injury sense of subjective self. Similarly, in a separate phenomenological qualitative study with 10 young stroke survivors (Ownsworth et al., 2019), some participants described how personality characteristics such as optimism, stubbornness, and determination helped them adapt to changes after ABI and preserve a continuity of self. In another qualitative study, Clarke and Black (Clarke & Black, 2005) reported that despite physical disability, some participants were able to maintain a sense of continuity by engaging in valued activities that were an important aspect of their pre-injury self.

Quantitative research that has examined discrepancies between pre-injury and post-injury evaluation of self in ABI survivors has suggested that larger discrepancies are associated with lower psychological wellbeing in individuals (Beadle et al., 2016). The Head Injury Semantic Differential Scale (HISD) is a widely utilised tool for measuring self-discrepancies between pre- and post-injury sense of self in individuals with ABI (Tyerman & Humphrey, 1984). Studies assessing psychological wellbeing have found that greater self-discrepancy between pre- and post-injury sense of self in individuals with ABI was associated with high levels of depression (Cantor et al., 2005; Carroll & Coetzer, 2011). In addition, Caroll and Coetzer (2011) found that greater self-discrepancies were associated with poor self-esteem, sense of loss, poor adjustment and grief in individuals with brain injury (as measured on Brain Injury Grief Inventory). Overall, research studies have highlighted a strong association between negative self-discrepancies and psychological distress in ABI survivors (Cantor et al., 2005; Wright & Telford, 1996).

2.3 Study Rationale and Aims

According to Continuity Theory, when faced with adverse life events and major life transitions, individuals with a stronger sense of inner continuity experience low levels of stress and anxiety, a clearer sense of purpose in life, and a higher level of self-esteem (assuming they had satisfactory functioning in these areas prior to the event). There is some clinical and research evidence supporting this in the area of ABI. Prior research has demonstrated that individuals reporting higher self-discrepancy between their pre- and post-injury concept of self tend to experience higher levels of stress, depression, and anxiety, increased grief, lower self-esteem, and poor adjustment or acceptance of brain injury (Cantor et al., 2005; Carroll & Coetzer, 2011). However, it is important to note that self-reported discrepancies between the pre- and post-injury selves (as measured on the HISDS), albeit closely related to the construct of inner continuity, is a distinct concept. While even a relatively few significant changes might be adequate to disrupt the sense of internal continuity, some individuals may maintain a global sense of inner continuity despite being aware of the significant changes that have occurred following the event. To provide a more direct test of the predictions of Continuity Theory, it would be useful to measure internal continuity more directly.

Within the ABI literature, there is currently no published measure specifically designed to assess internal continuity. A measure had been developed in the current study for this purpose, but there was very limited evidence about its psychometric properties. Therefore, a secondary aim of the research was to collect some data about this measure. The psychometric properties of the measure were ascertained by examining its internal reliability, while its construct validity was assessed by investigating its correlation with the HISDS measure. Drawing from Continuity Theory and previous research using pre and post injury self-discrepancy measures like the HISDS, the primary objective of this study was to investigate the predictions regarding the association between inner continuity and a range of psychological variables.

It is important to consider the potential confounding factor of participants' level of awareness when examining the relationship between the self-identity continuity questionnaire, the HISDS, and these psychological outcome variables (Carroll & Coetzer, 2011; Smeets et al., 2014). For instance, it is unclear whether an individual with high levels of internal continuity exhibit high levels of self-esteem because they perceive a sense of continuity with their pre-injury self despite the changes or because they lack awareness of the changes that have occurred. To account for this, a measure of self-awareness was obtained by comparing the discrepancy between the participant's ratings of the effects of the ABI with ratings provided by a significant other. This measure of self-awareness was included in the statistical analysis to control for the effects of varying levels of awareness, thus addressing this potential confounding factor. This potential confound has not been investigated in previous studies of pre-post discrepancies in self-identity.

Aims and Hypotheses

The aims and hypotheses of this study are provided below.

Primary aim

Aim 1: To test the predictions of Continuity Theory that those who experience continuity of self-identity will have better psychological outcomes, controlling for variance in insight.

Hypothesis: Scores on the SIBIQ will be associated with less stress, depression, and anxiety; higher self-esteem; a greater sense of meaning and purpose in life; a reduced sense of loss and greater acceptance; and these associations will remain even after controlling for variations in the level of insight.

Aim 2:

Secondary aims

Aim 2: To evaluate some of the psychometric properties of a new measure of internal continuity - the Self-identity after brain injury questionnaire (SIBIQ)

Hypothesis 2: That the internal reliability of the SIBIQ would be above 0.7 and its correlation with the HISDS (convergent validity) would be moderate-to-large (0.3 to 0.5).

Aim 3: To replicate the findings of Carroll and Coetzer (2011) about the correlations of the HISDS with a range of psychological outcomes, and to investigate whether those associations remain when controlling for variance in insight.

Hypothesis: Negative changes to self-concept (measured by greater differences between pre-injury and post injury self-concept ratings on the HISDS) will be associated with higher levels of depression and grief, and lower levels of self-esteem, and these associations will remain even after controlling for variations in the level of insight.

Aim 4: To investigate whether SIBIQ is a better predictor of psychological outcomes compared to HISDS.

Hypothesis: In a hierarchical regression, SIBIQ scores will explain a significant degree of the variance in outcome scores over and above that explained by the HISDS difference scores.

2.4 Research methodology

The following section provides a detailed account of the data sources, research methods, data analysis techniques used in this study.

Ethical Considerations in Data Collection

The research was approved by the University of Birmingham Science, Technology, Engineering and Mathematics (STEM) ethical review team (See Appendix E) and conducted in accordance with the University of Birmingham's code of practice for research. The Principal Investigator on the project was Dr Gerard Riley from the University of Birmingham. In terms of the risk to participants, there was a possibility of experiencing some distressing thoughts regarding the brain injury during the research. Therefore, participants were advised to complete the questionnaires at Headway in the presence of the researcher to minimise this risk. In addition, participant information leaflet (patient and family member) which included the contact information for the relevant sources of support was given to all participants. Participants who appeared visibly distressed during participation were given the option of withdrawing from the study or rescheduling the appointment at a later time. The electronic data generated from data collection was held on a secure server at the University of Birmingham IT system. The data is accessible only to the research team.

Participants

Adults with acquired brain injuries were recruited nationwide, predominantly from Headway, UK, as well as from other charitable organisations in the UK engaged in supporting people with brain injury and their families. A family member of each participant was recruited, where possible, to complete a family member questionnaire (relating to awareness of the impact of the injury). For cases where a family member was unavailable to participate in the research, a clinician from Headway was asked to complete the questionnaire. The inclusion criteria for participants were as follows: a) a history of acquired brain injury b) above 18 years of age, c) capacity to consent, and d) deemed by Headway staff to be capable of meaningfully completing questionnaires about themselves. Participants were excluded if: a) their brain injury occurred either less than 6 months or more than 10 years at the time of answering the questionnaires, b) if there were any associated risks with their participation (this was assessed by a Headway staff), or c) if their command of English is insufficient to allow them to complete the questionnaires meaningfully.

Participant Recruitment Procedure

Power Analysis

Prior to the data collection, a power analysis was conducted to estimate the minimum sample size required to detect a significant effect size for the research study. Power analysis performed on G*Power (Faul et al., 2007), a statistical power analysis program, revealed that a minimum sample size of 26 was required to detect a large effect ($r = 0.5$) for a significance level (α) of 0.05 and statistical power ($1 - \beta$) of 0.80 for a correlational study and a multiple regression where the interest is in the significance of a contribution made by a single variable ($f = 0.35$, $1 - \beta = 0.80$). In other words, a sample size of 26 or higher increases the probability of obtaining true positive results ($1 - \beta$).

Small or moderate size effects suggest limited practical significance as the smaller magnitude of change in outcomes may not justify pursuing it as a key target for intervention (Sullivan & Feinn, 2012). The interest was therefore in detecting large effect sizes.

In terms of the sample size for demonstrating reliability and validity, previous research studies have estimated that a minimum sample size of 40 participants is required to demonstrate a meaningful psychometric evaluation of a measure (Hobart et al., 2012; Rea & Parker, 2014).

Although the consensus varies depending on the field of research, Hobart et al. (2012) highlighted that in a sample size of 40 participants, reliability and validity estimates were robust approximately 75 % of the time.

Therefore, a sample of at least 40 participants was targeted for the psychometric analysis and at least 26 for the other aims of the study.

Recruitment

Research recruitment flyers were distributed at four Headway centres in Birmingham and Solihull. The research flyers including the consent-to-contact forms (See Appendix F) were also emailed to 30 Headway centres and other charitable organisations nationally. See Appendix G for the list of organisations contacted for participant recruitment. Out of the 30 centres contacted, six Headway centres expressed their interest in supporting participant recruitment. Those who were interested in learning more about the research were given a participant information leaflet (see Appendix H). In addition, an envelope containing an explanatory letter plus a consent-to-participate form (see Appendix I), and a participant information leaflet for their family member (see Appendix J) was sent. They were asked to complete the consent-to-contact form and return this to a member of staff at Headway.

Subsequently, those participants who agreed to take part in this study were contacted by the researcher over the telephone or email and were given an opportunity to ask any questions. The researcher checked whether they met the inclusion criteria for the research, as well as checked their capacity to consent and willingness to participate in the study and obtained their consent-to-participate (Appendix K). As difficulties recruiting a family member was foreseen, participants were not excluded from the study if a family member was not available to take part. In addition, arrangements were also made about how the family member questionnaire would be completed and returned. The family members were given the choice of sending the forms via pre-paid mail, dropping them off at Headway, or sending the researcher an electronic mail with a scanned copy of the completed questionnaire.

An appointment was scheduled at a convenient time and location for individuals who wished to participate. Meetings with participants were held at Headway centres during the normal office hours. In addition to in-person completion of the questionnaires, participants were given the option of completing the questionnaires over the telephone.

The research was also advertised on the Headway national website and their official twitter media platform and included a link to the online questionnaires for the participant and a separate link for the family member. The questionnaires were completing using the Qualtrics survey platform.

Although enough participants were recruited to meet the power requirements described above for investigating the main aim and the other aims (N=30), it proved difficult to recruit the 40 participants required for the psychometric evaluation in the time available. To facilitate recruitment by reducing the demands of participation, the study was readvertised on the Headway website and their Twitter account as requiring participants to complete only the demographic questionnaire and the SIBIQ. The brevity of the questionnaire was highlighted in the research advertisement to improve participant response rates. There was also no requirement for another person to complete the Awareness Questionnaire. An additional 10 participants were recruited in this way.

Research Methods - Measures

Most of the questionnaires are not furnished in the appendix due to copy-right infringement. Appendix L contains the demographic questionnaire and Appendix M contains the SIBIQ.

Demographic Questionnaire

This questionnaire (See Appendix K) contains demographic questions for the participant and some questions about the brain injury.

The Head Injury Semantic Differential Scale (HISDS)

The HISDS was developed to evaluate perceived changes in identity in TBI survivors (Tyerman & Humphrey, 1984). This measure was devised using a semantic differential rating scale (Carroll & Coetzer, 2011) and has been extensively used in ABI population (Beadle et al., 2016; Doering et al., 2011; Ellis-Hill & Horn, 2000; Vickery et al., 2005). Moreover, HISDS scale is sensitive to the perceived changes in the self-concept specific to brain injuries and in the context of rehabilitation and group therapies (Tyreman, 2012). In this study, the HISDS was used to examine whether earlier research findings on the impact of self-discrepancy in ABI were replicated. In addition, this measure was used to validate the newly developed direct measure of continuity of identity.

The HISDS comprises of 18 bipolar pairs of personality attributes, such as bored-interested, unhopeful-hopeful, dependent-independent, active-inactive, etc. Participants were required to rate their pre-injury as well as post-injury concept-of-self on a 7-point scale, (where '1' denotes the positive end of spectrum and '7' denotes the negative end of the spectrum). The overall scores vary from 20 to 140, with higher values corresponding to a more positive perceptions of the self. Self-discrepancy scores are measured by calculating the difference between pre-injury and post-injury self-ratings. A negative score denotes a less favourable perception of the current self in comparison to one's pre-injury self. Multidimensional aspects of change including the emotional, physical and social aspects are captured in this scale (Doering et al., 2011).

The HISDS has demonstrated a high internal reliability, with a Cronbach's alpha coefficient (α) of 0.93 (Ellis-Hill and Horn, 2000). Research has also shown excellent internal consistency (0.92-0.93) and convergent validity of HISDS with other established scales such as

Rosenberg Self Esteem Scale, Brain Injury Grief Inventory and measures of depression and anxiety (Carroll, & Coetzer, 2011).

Brain Injury Grief Inventory (BIGI)

Coetzer et al. (2011) developed the BIGI, a tool specifically devised for use in brain injury survivors. The BIGI comprises of 20 self-reported items that assess loss and adjustment, the two key components of grief after brain injury. Eleven items evaluate the feelings of “loss” after brain injury. An example question includes *“I have found myself longing for the time before my brain injury”*., Nine items evaluate "adjustment" following brain injury. An example question includes, *“I have accepted the fact that I have a brain injury”*. The participants were required to rate these statements on a scale of ‘0’ to ‘3’; where ‘0’ denotes “never”, ‘1’ denotes “sometimes” and ‘2’ denotes “mostly”. The scores obtained from the *loss* and *adjustment* subscales were analysed independently in this study.

Despite the small sample size (N=25) in the original study, acceptable values of test-retest reliability and concurrent validity of BIGI were demonstrated (Ruddle et al., 2005). The *loss* subscale demonstrated higher internal consistency than the *adjustment* subscale, and test-retest reliability yielded a higher correlation coefficient of 0.89 ($p < 0.01$) for the loss scale in comparison to the 0.58 ($p < 0.05$) for the adjustment scale (Ruddle et al., 2005). The BIGI measure was utilised in the current study to measure participant’s experiences of grief from their perceived loss following brain injury. In a previous study, Carroll and Coetzer (2011) demonstrated a positive correlation between perceived identity change as measured by the HISDS-III and the subscales of loss ($r = 0.53$) and adjustment ($r = 0.35$) on the BIGI. The current study aims to investigate whether similar associations between grief and perceived identity change are replicated in this study.

Rosenberg Self Esteem Scale (RSES)

The RSES is a brief, unidimensional construct that measures self-esteem (Rosenberg, 1965). It is a self-report questionnaire that comprises 10 statements related to global self-esteem. Participants are required to rate their general feelings about themselves on a four-point Likert scale. The RSES scale includes positively worded statements such as - *"On the whole, I am satisfied with myself"*, and negatively worded statements such as *"I feel I do not have much to be proud of"*. Response options range from 0-4, where 0 denotes strongly disagree, 1 denotes disagree, 2 denotes agree and 3 denotes strongly agree. Statements 2, 5, 6, 8 and 9 are reverse scored.

The scores on the responses are summed to provide a measurement of self-esteem. The total scores range from 0-30, with scores above 25 indicating high self-esteem, scores between 15-25 indicating a normal range of self-esteem, and scores below 15 indicating low self-esteem. The RSES was used in the current study as it has been extensively researched and regarded as a gold standard tool for measuring self-esteem (Hatcher & Hall, 2009). In addition, the RSES has been widely used in brain injury populations in several research studies (Anson & Ponsford, 2006; Cooper-Evans et al., 2008; Keppel & Crowe, 2000; Vickery et al., 2005). The RSES was found to demonstrate good test-rest reliability (Cooper-Evans et al., 2008) and high internal consistency with a Cronbach's alpha coefficient value of 0.89 within the brain injury population (Carroll & Coetzer, 2011). Moreover, past studies demonstrate that the RSES has acceptable convergent validity (Cooper-Evans et al., 2008) and correlates positively with well-established scales of depression ($r = 0.65$), anxiety ($r = 0.71$) and correlates negatively with measures of self-discrepancy measured by HISDS-III (Carroll & Coetzer, 2011).

Depression, Anxiety and Stress Scale 21(DASS21)

The DASS- 21 is a 21-item self-reported instrument devised by Lovibond (1995) based on the tripartite model of depression and anxiety (Clark & Watson, 1991). The DASS-21 is a brief version of the original DASS measure comprising 42 items. The DASS tool was developed initially to evaluate distinct components of stress, anxiety and depression subscales within a single measure (Lovibond & Lovibond, 1995).

The DASS-21 was used in this study to primarily examine the emotional and behavioural effects of depression, anxiety, and stress. It does not evaluate cognitive and physical symptoms such as sleep difficulties, sexual dysfunction and loss of appetite which can correlate with TBI sequelae and potentially confound the results (Ownsworth et al., 2008). Several studies have demonstrated the clinical utility of the DASS instrument in evaluating a range of emotional states following brain injury (Ownsworth et al., 2011; Var & Rajeswaran, 2012) and as a screening tool in neurorehabilitation (Dahm et al., 2013; Randall et al., 2017).

The DASS-21 consists of 7 items each in the subscales of depression, anxiety and stress. Participants are required to indicate the degree to which they experienced the symptoms over the last week. Responses are recorded on a 4 point- scale ranging from '0' to '3', where '0' denotes 'Did not apply to me at all', '1' denotes 'applied to me to some degree', or some of the time, '2' denotes 'applied to me to a considerable degree, or a good part of time', and '3' denotes 'applied to me very much, or most of the time'. The scores on the subscales are summed and multiplied by two. The total scores obtained from the sum of 3 subscales (range = 0-42). Scores above '10' on the depression subscale, '8' or higher on the anxiety subscale and '15' or higher on the stress subscale represent the clinical range of depression, anxiety and stress; respectively. The DASS-21 demonstrated good internal consistency of the subscales of depression, anxiety and stress with a Cronbach's alpha (α) of 0.84, 0.76. and 0.89 respectively in the clinical population of depression and anxiety disorders (Borg et al., 2022). It has shown acceptable test-retest reliability (r = 5.78) and validity in TBI population (Ownsworth et al., 2018). Previous research studies have also demonstrated strong concurrent validity of DASS-21 scales with other well-established and valid instruments of depression, anxiety and stress including the

Becks' Depression Inventory (r = 0.79), Beck's Anxiety Inventory (r = 0.85), State-Trait Anxiety Inventory trait (r = 0.86) (Antony et al., 1998).

Awareness Questionnaire (AQ)

The AQ is a brief, self-report instrument that measures impaired self-awareness following ABI (Sherer et al., 1998). The AQ tool has been widely used in the ABI population.) The AQ is a widely used brief, self-report instrument for measuring impaired self-awareness following ABI (Hellebrekers et al., 2017; McBrinn et al., 2008; Perry & Coetzer, 2020; Sherer et al., 2002). The AQ tool consists of three versions, namely, the patient, family or significant other and clinician questionnaire. The patient and family (or significant other) version comprises 17 items, while the clinician version comprises 18 items. Participants are required to rate the patient's current functioning in comparison to their pre-injury levels. Responses are recorded on a 5-point Likert scale with responses ranging from '1' (much worse) to '5' (much better). A rating of '3' denotes 'about the same' as pre-injury. Example question on the patient questionnaire include- *"How good is your ability to live independently now as compared to before your injury?"*. Example question on the family member or clinician questionnaire includes *"How good is the patient's ability to live independently now as compared to before his/her injury?"* Scores on the individual items are summed to provide a total score for participant and family member/clinician ratings (range 17-85).

A score of 51 indicates that the person is most likely functioning at their pre-injury levels. Discrepancy in self-awareness was calculated by subtracting family member or clinician ratings from the patient's ratings (range – 68 to + 68).

A discrepancy score of 20 or higher implies a clinically significant impairment of awareness (Evans et al., 2005). Although rarely reported, negative values indicate an overestimation of their problems (Giacino & Cicerone, 1998; Prigatano & Altman, 1990). The

AQ tool demonstrated a strong internal consistency with a Cronbach's coefficient (α) of 0.88 for the patient and a significant other version (Sherer et al., 1998). Recent studies have demonstrated a Cronbach's coefficient (α) of 0.91 for the clinician version and acceptable values for all the four subscales (Carroll & Coetzer, 2011). Although test-retest reliability has been reported in only one study (Hellebrekers et al., 2017), previous studies have shown a correlation between impaired awareness and severity of TBI (Sherer et al., 1998; Sherer et al., 2003). Moreover, Sherer et al. (2002) indicated the predictive value of impaired self-awareness in employment outcomes following TBI.

Meaning in Life Questionnaire (MLQ)

This questionnaire was used in this study to assess the extent to which people with brain injury believed their life has a meaning. The MLQ is a brief, 10-item self-report measure that examines the degree to which an individual perceives a sense of meaning in life and desires to seek a purpose in life (Steger et al., 2006). The construct of meaning in life has demonstrated a strong correlation with overall wellbeing and is a critical component of eudemonic models of wellbeing (Ryff & Keyes, 1995). The MLQ consists of 2 subscales that measure distinct constructs on the sense of the meaning in life.

Of the 10 items, items 1, 4, 5, 6 and 9 constitute the *presence of meaning* subscale. Item 9 is reverse-coded. This includes questions such as, *"I have a good sense of what makes my life meaningful"*. The remaining items constitute the *meaning in life subscale*. This includes questions such as *"I am always looking to find my life's purposed*. Participants were required to rate their responses on a 7-point Likert scale ranging from '1' to '7', where '1' denotes 'Absolutely Untrue', '2' denotes 'Mostly Untrue', '3' denotes 'Somewhat Untrue', '4' denotes 'Can't Say True or False', '5' denotes 'Somewhat True', '6' denotes 'Mostly True' and '7' denotes 'Absolutely True'. Individual items were summed to yield a total score of meaning in life (range = 5 to 35). and. higher scores in this measure indicate a greater sense of meaning and pursuit for meaning in life (Steger & Shin, 2010).

Several studies have demonstrated good internal consistency of the MLQ tool, with Cronbach's α ranging from 0.80 to 0.90 for the *search for meaning* and *presence of meaning* subscales (Duffy & Raque-Bogdan, 2010; Keefer et al., 2019; Schulenberg et al., 2011). In addition, Keefer et al. (2019) also demonstrated acceptable reliability values in the same study (Presence: α = 0.86, Search: α = 0.93). Concurrent validity of the MLQ is supported by its correlation with similar measures including the Purpose in Life questionnaire and Life Regard Index questionnaire (Steger et al., 2006). In the context of brain injury, previous studies have demonstrated the clinical utility of the meaning in life variable in enhancing the psychological and existential well-being and its role in positive adaptation after spinal injuries and tumours of brain (deRoon-Cassini, Terri, A. et al., 2013; Ownsworth & Nash, 2015). However, none of these studies used the MLQ to measure meaning in life in brain injury survivors.

The MLQ was therefore used in the current research due to several strengths such as brevity, stable factor structure, strong internal consistency, and reliable discriminant validity for the *search for meaning* construct in comparison to (other) existing measures (Steger et al., 2006).

Self-identity After Brain Injury Questionnaire (SIBIQ)

The *Self-identity after Brain Injury questionnaire* comprises six self-report items that measure perceptions of continuity of identity in people after brain injury. This questionnaire (See Appendix L) was devised for the purpose of this study and intends to address the research gap in existing literature by providing a direct measure of perceptions of continuity. The items in this questionnaire were adapted from the Birmingham Relationship Continuity Measure (BRCM-ABI) developed by Yasmin et al. (2020). The BRCM (ABI) is a 23-item questionnaire that evaluates partners' perceptions of relationship continuity following a brain injury. Of the

23-items, 6 items (items 7, 10, 13, 17, 20 and 22) measure partner's perceptions of the continuity of identity in the person with brain injury.

The *SIBIQ* was loosely adapted from these 6 items. Participants are required to rate their responses on a Likert scale of '1' to '5', where '1' denotes 'strongly agree, '2' denotes 'agree', '3' denotes 'not sure', '4' denotes 'disagree' and '5' denotes 'strongly disagree'. Items 2, 4 and 6 were reverse scored as they were negatively worded. Example questions include: *"Since the brain injury, I sometimes feel like I don't really know myself anymore"*. Individual items were summed to provide a total score of perceived continuity of identity, that ranges from '6' to '30'. Higher scores indicate a greater perceived continuity of self-identity after brain injury. The reliability and validity of the measure are reported in the results section.

Research Design

This study employed a cross-sectional research design with the Continuity in Self-Identity scores and the HISDS difference scores as the Independent variables (IVs). The Dependent Variables (DV's) included - depression, anxiety, stress, self-esteem, loss after brain injury, adjustment after brain injury, meaning in life. Additionally, the reliability and validity of the new questionnaire used in this study, i.e., SIBIQ were also investigated.

The discrepancy in awareness score was used as the control variable.

2.5 Data Analysis and Research Findings

An overview of this section is outlined below-

- Firstly, the characteristics of the sample are presented.
- The next section explains how the data were examined for their suitability for parametric analysis.
- Descriptive statistics for all the variables are reported.
- Next, a correlation matrix demonstrating the associations between each variable is provided.
- Finally, the analyses to address the four aims of the research are then described.

Participant Characteristics

Thirty participants consented to participate in the research study and completed all the research questionnaires required for the investigation of primary aim and secondary aims. Out of 30 participants, the family members, or carers of 10 participants were able to complete the family member questionnaire. For 20 participants where a family member was unavailable to take part, a clinician at Headway completed the clinician-based questionnaire. The participant sample was diverse, especially in terms of age and the length of time since the injury. The participants were predominantly male (80.65 %): 77.42 % of participants identified their ethnic origin as white British, 12.90 % identified themselves as British Asian, and 6.45 % as Black ethnic group. The mean age of the participants in this study was 52.64 years (*SD* = 11.09, range 24-71). The median duration of time since the brain injury was 6.68 years (*SD* = 3.85, range 1-18.60). In terms of the type of brain injury sustained, the majority of participants had stroke (35.4 %), followed by TBI (25.8 %), haemorrhage (16.2 %), infections including meningitis and encephalitis (12.9 %) and hypoxia (3.2 %).

An additional 10 participants were recruited who completed only the demographic questionnaire and the SIBIQ required for the psychometric evaluation. The demographic characteristics of the sample recruited for psychometric evaluation (N= 30+10) were predominantly male (65.8%). The mean age of the participants was 51.36 years (*SD* = 13.07, range 19-71). The mean duration of time since the brain injury was 5.92 years (*SD* = 3.12, range 1-18.60). In terms of the type of brain injury sustained, the majority of participants had stroke (34.2%), followed by TBI (29%), haemorrhage (15.8%), infections including meningitis and encephalitis (18.4 %) and hypoxia (2.6 %).

Missing data

A small number of participants did not complete all of the questionnaires as they inadvertently did not receive some questionnaires at Headway. Listwise deletion was applied to address this missing data. This method was adopted as there were only limited instances of missing data and there was no apparent correlation between the variables being measured and the missing data. Hence, it could be assumed that the data were missing completely at random. Moreover, listwise deletion provides unbiased estimates of the parameters in these situations. Therefore, the primary drawback of losing a significant amount of data from listwise deletion during an analysis did not apply in the current circumstance (Van Buren, 2018).

Preliminary Analyses

Preliminary analysis was conducted to test the key assumptions of the linear regression model. The data was thoroughly screened for outliers (Osborne & Overbay, 2004). The standardised residual values (Std. Residual Min = –1.60, Std. Residual Max = 1.04) and box plots were analysed to detect outliers, and data entry errors; which showed no outliers in the sample. For each analysis, Mahalanobis distance statistical measure was calculated to detect multivariate outliers, and no cases were identified to have extreme values compared to the normal distribution. Following this collinearity was examined, by inspecting the tolerance and variation inflation factor.

The principal assumptions of linear regression are that any relationship between the variables is linear; the error terms are normally distributed and independent; and the variance of the error terms show homoscedasticity (Ernst & Albers, 2017). Q-Q plots were examined to check the assumption of normality, and residual plots for the assumptions of linearity and homoscedasticity (See Appendices N, O, and P). The autocorrelation function of the residuals was examined for independence of the error terms. Although the error terms for the AQ-difference variable showed non-normality, previous research (Ernst & Albers, 2017) suggests that linear regression is relatively robust in terms of non-normal distributions provided the other assumptions are met. Therefore, the data were deemed suitable for linear regression analysis. Table 2.1 shows the descriptive statistics (mean, standard deviation, and range) for each variable in this study.

Table 2.1: Descriptive statistics

Variables	N	Range	Possible Min/Max	Obtained Min/Max	Mean	Median	Standard Deviation	Skewness (Std. Error)	Kurtosis (Std. Error)
SIBI	30	22	6/30	6/28	17.67	18	5.73	-.095 (.427)	-.467 (.833)
AQDiff	30	48	-68/68	-13/35	4.97	2.5	9.40	1.297 (.427)	2.753 (.833)
HISDSDiff	28	127	-120/120	-47/80	27.87	27.5	24.85	-.438 (.427)	2.036 (.833)
BIGILoss	30	17	0/22	1/18	11.37	12.5	4.83	-.547 (.427)	-.425 (.833)
BIGIAdjustment	30	12	0/18	4/16	10.87	11	3.13	-.354 (.427)	-.358 (.833)
RSES	30	23	0/30	3/26	16.37	17	4.88	-.238 (.427)	-.914 (.833)
Depression	29	40	0/42	0/40	14.47	12	11.79	.427 (.427)	-.831 (.833)
Anxiety	29	34	0/42	0/34	9.27	8	8.70	1.392 (.427)	2.030 (.833)
Stress	29	38	0/42	0/38	16.10	14	11.23	.545 (.427)	-.699 (.833)
Presence of meaning	30	26	5/35	9/35	21.60	20	7.82	.202 (.427)	-1.034 (.833)
Search for meaning	30	25	5/35	8/33	22.17	22.5	7.01	-.411 (.427)	-.776 (.833)

SIBI: Self-Identity after Brain Injury; AQDiff: Difference in awareness; HISDSDiff: Difference between pre- and post-injury self-concept; BIGILoss: Loss after brain injury; BIGIAdjustment: Adjustment after brain injury; RSES: Self-esteem; Depression; Anxiety; Stress; Meaning in Life

Correlational Analyses

Bivariate correlational analyses were conducted in preparation for the analyses addressing the research hypotheses. A series of correlational analyses were performed to establish the relationship between the two IVs and the set of seven DVs and one control variable. Multiple correlational analyses were anticipated to increase the probability of family-wise error rate (Tabachnick & Fidell, 2014). A correction was used to reduce the family-wise error rate by adjusting the p-value of alpha to a more conservative level of 0.01 (Tabachnick & Fidell, 2014). Table 2.2 shows the results of correlational analysis.

Consistent with hypothesis 1, Continuity of self-identity after brain injury was associated with low levels of depression, anxiety, and stress, as well as higher self-esteem (strongest correlation with SIBI) and better adjustment following brain injury. The three variables that did not correlate with the SIBI were the difference in awareness variable, loss following brain injury variable and search for meaning variable. However, the lack of correlation with the measure of awareness was not hypothesised in this study.

Table 2.2: Results of correlational analysis

Correlation

		SIBI	AQDiff	HISDSDif	BIGILoss	BIGIAdjustment	RSES	Depression	Ar
1. SIBI	Pearson Correlation	--							
	N	30							
2. AQDiff	Pearson Correlation	.327	--						
	Sig. (2-tailed)	.078							
	N	30	30						
3. HISDSDiff	Pearson Correlation	-.455*	-.322	--					
	Sig. (2-tailed)	.015	.094						
	N	28	28	28					
4. BIGILoss	Pearson Correlation	-.179	.006	.397*	--				
	Sig. (2-tailed)	.345	.973	.037					
	N	30	30	28	30				
5. BIGIAdjustment	Pearson Correlation	.506**	.094	-.312	-.510**	--			
	Sig. (2-tailed)	.004	.623	.106	.004				
	N	30	30	28	30	30			
6. RSES	Pearson Correlation	.687**	.256	-.589**	-.374*	.575**	--		
	Sig. (2-tailed)	<.001	.171	<.001	.042	<.001			
	N	30	30	28	30	30	30		
7. Depression	Pearson Correlation	-.513**	-.292	.489**	.539**	-.514**	-.657**	--	
	Sig. (2-tailed)	.004	.125	.010	.003	.004	<.001		
	N	29	29	27	29	29	29	29	
8. Anxiety	Pearson Correlation	-.472**	-.448*	.241	.204	-.451*	-.409*	.623**	
	Sig. (2-tailed)	.010	.015	.225	.289	.014	.027	<.001	
	N	29	29	27	29	29	29	29	
9. Stress	Pearson Correlation	-.514**	-.244	.557**	.691**	-.585**	-.661**	.825**	
	Sig. (2-tailed)	.004	.202	.003	<.001	<.001	<.001	<.001	
	N	29	29	27	29	29	29	29	
10. Presence of meaning	Pearson Correlation	.365*	.118	-.213	-.365*	.459*	.723**	-.538**	

	Sig. (2-tailed)	.047	.533	.277	.048	.011	<.001	.003
	N	30	30	28	30	30	30	29
11. Search for meaning	Pearson Correlation	-.091	.129	-.060	.220	-.208	-.128	.234
	Sig. (2-tailed)	.632	.496	.762	.243	.270	.501	.222
	N	30	30	28	30	30	30	29

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

SIBI: Self-Identity after Brain Injury; AQDiff: Difference in awareness; HISDSDiff:Difference between pre- and post-injury self-concept; BIGILoss: Loss after brain injury; BIGIAdjustment: Adjustment after brain injury; RSES: Self-esteem; Depression; Anxiety; Stress; Meaning in Life

Analyses

Aim 1

The primary aim was to test the predictions of Continuity Theory that individuals who experience continuity of self-identity will have better psychological outcomes, after controlling for variance in insight.

Hypothesis 1: Scores on the SIBIQ will be associated with less stress, depression, and anxiety (as measured by the DASS); higher self-esteem (RSES); a greater sense of meaning and search for meaning in life (MLQ); and a reduced sense of loss and greater acceptance (BIGI); and these associations will remain even after controlling for variations in the level of insight (AQ difference score).

Multiple regression analyses were conducted to test this hypothesis, in which the predictor variables were the SIBIQ scores and the AQ difference score, and the outcome variable was each of the independent variables in turn. As discussed in the methods section, impaired self-awareness after brain injury in this study was calculated by subtracting family member or clinician ratings from the patient's ratings on AQ measure. The higher the discrepancy between family member/clinician rating and patient self-rating, the greater the impairment of awareness after brain injury. However, it is important to note that this method assumes the carer (family members/clinician) ratings to be a more accurate appreciation of observed deficits compared to patient self-ratings. Although previous studies have utilised the carer/patient discrepancy scores, this may not be an accurate method of measuring impaired awareness (Perry & Coetzer, 2020).

Since a series of regression analyses were performed, there is a high probability of inflated family-wise error rate from multiple testing (Tabachnick & Fidell, 2014). The family-wise Type I error rates were controlled by using a more stringent alpha level (α) of 0.01 for analysing the regression results (Araujo, 2020; Tabachnick & Fidell, 2014).

Table 2.3. summarises the results of multiple regression analyses performed with SIBIQ as the predictor variable and AQ difference as the control variable.

Table 2.3. Results of multiple regression analyses performed with SIBIQ and AQ difference as the predictor variables.

Outcome variable	**Predictor variable**	**Standardised Beta coefficient**	**Part correlation**	**p value**
Depression**	AQ Difference	-.225	-.174	.300
	SIBIQ	-1.023	-.457	.010
Anxiety*	AQ Difference	-.355	-.345	.039
	SIBIQ	-.388	-.377	.026
Stress**	AQ Difference	-.129	-.125	.459
	SIBIQ	-.483	-.496	.009
RSES**	AQ Difference	.036	.034	.811
	SIBIQ	.675	.638	<.001
Presence of meaning MIQ	AQ Difference	-.001	-.001	.996
	SIBIQ	.365	.345	.065
Search for meaning MIQ	AQ Difference	.178	.168	.381
	SIBIQ	-.149	-.141	.461
BIGI loss	AQ Difference	.073	.069	.720
	SIBIQ	-.202	-.191	.320
BIGI adjustment **	AQ Difference	-.080	-.076	.650
	SIBIQ	.532	.503	.005

*p<.05; **p<.01

The results were partly consistent with the predictions of Continuity theory, where in continuity of self-identity was positively associated with self-esteem, adjustment to brain injury and negatively associated with depression and stress. However, inconsistent with hypothesis 1, the study showed no significant association between continuity in self-identity and; anxiety, loss and meaning in life variables.

Aim 2

The aim was to evaluate some of the psychometric properties of a new measure of internal continuity - the Self-identity after brain injury questionnaire (SIBIQ).

Hypothesis 2: The internal reliability of the SIBIQ would be above 0.7 and its correlation with the HISDS difference score (convergent validity) would be moderate-to-large (0.3 to 0.5).

Reliability Analysis and Validity of the SIBIQ Measure

Reliability analysis of the SIBIQ measure was conducted to assess whether the questionnaire reflected consistency in measuring the intended construct. The Cronbach's coefficient (α) for the SIBIQ measure was found to be 0.819, indicating acceptable levels of internal reliability of the questionnaire (Ponterotto & Ruckdeschel, 2007). Table 2.4 provides a summary of the total-item statistics for the SIBIQ measure.

Table 2.4: Reliability statistics

Questions	Scale Mean (if Item Deleted)	Scale Variance (if Item Deleted)	Corrected Item-Total Correlation	Cronbach's Alpha (if Item Deleted)
Question 1	14.5610	21.102	.714	.764
Question 2	14.4146	21.699	.533	.801
Question 3	14.7317	21.151	.602	.786
Question 4	13.7561	20.839	.651	.775
Question 5	13.9512	19.748	.629	.780
Question 6	13.4634	24.455	.388	.826

A comparison of the α values of the six individual items on the questionnaire, revealed that item six, which reads *"The brain injury hasn't taken away the most important bits of who I am"*, had an alpha value (α=0.826) slightly higher than the overall Cronbach alpha value (0.819). However, the corrected item-total correlation of all other individual items was above 0.5 except for item six, which had a correlation of 0.388, indicating a comparatively low correlation of item six with the overall score from the scale. This item performed relatively poorly compared to other items and may need to be omitted or changed.

Convergent Validity

A bivariate correlational analysis showed a moderate association between the SIBIQ and HISDS difference score ($r = -0.455$; $p = 0.015$), thus indicating good convergent validity.

Aim 3

The aim was to replicate the findings of Carroll and Coetzer (2011) about the correlations of the HISDS with a range of psychological outcomes, and to investigate whether those associations remain when controlling for variance in insight.

Hypothesis 3*:* Negative changes to self-concept (measured by greater differences between pre-injury and post injury self-concept ratings on the HISDS) will be associated with higher levels of depression (DASS), and grief (BIGI loss and adjustment), and lower levels of self-esteem (RSES), and these associations will remain even after controlling for variations in the level of insight (AQ difference score). Table 2.5 compares the correlation results of the current study and the findings of Carroll and Coetzer's (2011) study.

Table 2.5: Comparison of correlation results of the current study with the findings of Carroll and Coetzer's (2011) study.

Outcome variables correlated with HISDS difference score	**Carroll & Coetzer**	**Present study**
Depression (Depression subscale from HADs in C&C; depression subscale from DASS in present study)	r= .580** p< .01	r= .489** p= .010
BIGI loss	r= .529** p< .01	r= .397* p= .037
BIGI adjustment	r= -.354* p< .05	r= -.312 p= .106
RSES	r= -.365* p< .05	r= -.589** p< .001

*p<.05; **p<.01

Consistent with Carroll and Coetzer's (2011) research, the correlation analysis showed that the HISDS difference score significantly correlated with depression, and self-esteem (strongest correlation), but the correlations with loss and adjustment were smaller in the present study and, in the case of adjustment, the p-value was not below .05.

It is important to note that Carroll and Coetzer's (2011) research primarily looked at the associations between HISDS and depression, loss, adjustment and self-esteem. The research did not investigate the other variables that were part of the current study. In addition, Carroll and Coetzer's study (2011) did not control for variation in levels of insight. To address this research gap, the current study conducted multiple regression analyses with AQ difference as the control variable and the HISDS difference score as predictor.

The results were partly consistent with hypothesis 3, where HISDS difference score was negatively associated with self-esteem and these associations remain even after controlling for variations in the level of insight (AQ difference score). However, the present study showed no significant association between HISDS and depression, loss, and adjustment after brain injury after controlling for variations in the level of insight (AQ difference score). Table 2.6 Summarises the results of multiple regression analyses performed with HISDS and AQ differences as the predictor variables.

Table 2.6. Results of multiple regression analyses performed with HISDS and AQ difference as the predictor variables.

Outcome variable	Predictor variable	Standardised Beta coefficient	Part correlation	p value
Depression*	AQ Difference	-.102	-.095	.596
	HISDS Difference	.453	.425	.025
RSES**	AQ Difference	.041	.039	.812
	HISDS Difference	-.576	-.545	.002
BIGI loss*	AQ Difference	.211	.199	.276
	HISDS Difference	.464	.440	.021
BIGI adjustment	AQ Difference	-.045	-.043	.824
	HISDS Difference	-.326	-.309	.116

*p<.05; **p<.01

Aim 4

Aim was to investigate whether SIBIQ is a better predictor of psychological outcomes compared to HISDS.

Hypothesis 4: In a hierarchical regression, SIBIQ scores will explain a significant degree of the variance in outcome scores over and above that explained by the HISDS difference scores.

A series of hierarchical regressions were conducted where each of the outcome variables were entered as the dependent variable; the HISDS difference score was entered as a predictor in step 1, and then the SIBIQ score was entered in step 2 of hierarchical regression model in SPSS. The study examined whether there was a significant change in the R-squared value, and the relative size of the two part-correlations (i.e. which part-correlation was larger). Variables that showed no relationship with the IV such as the *meaning in life* variables and the *loss after brain injury* subscale were excluded from the hierarchical regression analysis (Tabachnick & Fidell, 2014).Table 2.7 shows standardized beta coefficient, part correlation and p-value for each variable in the second model of the hierarchical regression, as well as the change in R-squared from Step 1 to Step 2 and the associated p-value.

Table 2.7 Results of the hierarchical regression analysis

Outcome variable	**Predictor variables in Step 2**	**Standardised Beta coefficient**	**Part correlation**	**P value**	**R^2 change**	**P value**
Depression	HISDS Difference	.318	.277	.111	.090	.086
	SIBIQ	-.345	-.300	.086		
Anxiety	HISDS Difference	.078	.067	.724	.083	.140
	SIBIQ	-.332	-.288	.140		
Stress	HISDS Difference	.414	.360	.036	.063	.132
	SIBIQ	-.290	-.252	.132		
RSES**	HISDS Difference	-.377	-.336	.023	.173	.006
	SIBIQ	.467	.415	.006		
BIGI Adjustment	HISDS Difference	-.155	-.138	.450	.094	.100
	SIBIQ	.345	.323	.100		

*For change in R-squared, $p<.01$

The results were partly consistent with hypothesis 4. The SIBIQ explained a significant amount of the variance in self-esteem scores over and above that explained by the HISDS difference score. However, although it explained some additional variance in the other variables, these amounts were not statistically significant.

2.6 Discussion

From the perspective of Continuity Theory, maintaining a sense of self-continuity during an adversity could be beneficial as it provides a sense of purpose, predictability, and security in dealing with the challenges of change, thereby reducing the negative emotional impact of the changes. Nevertheless, investigating the possible impact of perceived continuity on psychological functioning has thus far received sparse consideration in the ABI research.

This study successfully addressed this research gap in the literature by investigating the impact of perceived continuity on post-injury psychological outcomes including depression, anxiety, stress, self-esteem, loss, and adjustment to brain injury and meaning in life. The aims of this research study were to investigate whether some survivors maintain a sense of continuity in identity despite acknowledging the changes after ABI and whether continuity has benefits on psychological functioning. In addition, this study also aimed to investigate the psychometric properties of a new self-identity measure designed specifically for the purpose of this research.

The objective of this study was to examine the extent to which perceived continuity of identity impacts various psychological outcomes regardless of the extent of awareness of difficulties. This study is unique in that it contributes to the existing literature in ABI research from the perspective of Continuity Theory. The primary objective of this study was to explore whether perceived continuity of identity predicts depression, anxiety, stress, grief, self-esteem and meaning in life among the brain injury population.

Hypothesis 1

The first hypothesis predicts that in accordance with the Continuity theory, higher levels of continuity of self-identity on the SIBIQ will be associated with lower levels of depression, anxiety, and stress; higher self- esteem; a greater sense of meaning and purpose in life; a reduced sense of loss, and greater acceptance; and that these associations would remain even after controlling for variation in the level of insight.

The findings of regression analysis showed significant associations between internal continuity and; depression, stress, self- esteem and adjustment when the level of insight was controlled. However, there was no significant association between internal continuity and the remaining three variables, namely, anxiety, loss and meaning in life. These results were partly supportive of the hypothesis.

Hypothesis 2

The second aim of this study was to evaluate some of the psychometric properties of the SIBIQ. The internal reliability of the SIBIQ and its correlation with the HISDS were examined, with the expectation that it would show a satisfactory level of internal reliability (at least 0.7) and a moderate-to-large correlation ($r = 0.3$ to 0.5).

The internal reliability and validity of the SIBIQ was evaluated in a sample of 40 participants with varying aetiologies and severity of ABI. The Cronbach’s alpha reliability coefficient value for the SIBIQ was high (alpha= 0.819) indicating a good internal consistency of the items in the questionnaire (George & Mallery, 2003). The convergent validity of the scale was evaluated using the HISDS, a widely used scale to measure the changes between pre and post-injury concept of self in ABI population (Reddy et al., 2017). Consistent with the initial hypothesis, the SIBIQ and the HISDS showed moderate correlation (Pearson’s correlation coefficient ($r = –0.455$) as they both measure closely related constructs of self-identity.

Hypothesis 3

The third aim was to replicate the findings of Carroll and Coetzer (2011) about the correlations between HISDS and a range of psychological outcomes, and to further examine whether those associations remain even after controlling for variance in insight. Difference between pre and post injury self-concept ratings on the HISDS were examined, with the expectation that greater discrepancies will be associated with higher levels of depression, grief, and lower levels of self-esteem.

The HISDS difference score significantly correlated with depression and self-esteem at the alpha = .01 level, and with loss (BIGI) at the alpha = .05 level, but it was not significantly associated with adjustment (BIGI). The results only partly replicated the findings of Carroll and Coetzer (2011), who reported significant associations between the HISDS difference score and four outcome variables using an alpha level of .05. When variance in the degree of awareness was taken into account in the regression, the part correlations were lower than the zero order correlations, but remained significant at the alpha=.05 level (except for adjustment). This suggests that the degree of awareness had little impact on the association between the HISDS difference score and these outcome variables.

Hypothesis 4

The fourth aim was to investigate whether SIBIQ was a strong predictor of psychological outcomes compared to HISDS. Hypothesis 4 predicts that SIBIQ will contribute to a significant degree of the variance in outcome scores over and above that explained by the HISDS difference scores.

The findings showed that SIBIQ accounted for a significant proportion of variance on the self-esteem scores over and above that explained by the HISDS difference score.

In summary, the following significant findings were consistent with the predictions of Continuity Theory:

1. Internal continuity was associated with high self-esteem, better adjustment to brain injury, lower levels of depression and stress.

2. Discontinuity was associated with low self-esteem, poor adjustment to brain injury, higher levels of depression and stress.

Contrary to the predictions of Continuity Theory, there was no correlation between internal continuity and the two subscales of the Meaning in Life questionnaire (MLQ). Speculating on this matter, the part correlation with the ‘Presence of Meaning’ subscale was moderate (r=.345; p=.065) and the lack of a significant effect may have been due to the relatively low statistical power of the test. However, this is unlikely to be the explanation for the poor correlation with the ‘Search for Meaning’ subscale, as the part correlation was negligible (r=-.141). Another relevant consideration is that the questionnaire used in the study has not been validated for use specifically in brain injury population. As discussed in earlier sections, previous research studies that investigated psychological and existential wellbeing in individuals with brain injury did not use the MLQ to assess the meaning in life variable. It is possible that the measure lacks validity.

Besides the MLQ, the results were found to show that the association between the measure of internal continuity and the wellbeing variables (such as anxiety, andloss after brain injury), were no longer significant when the level of insight was controlled. However, the strength of the relationships, as indicated by the beta coefficients (part correlations) between the variables were relatively high (see table 2.3) apart from the loss (BIGI) variable. Controlling for the level of insight did not affect the strength of association between the internal continuity and the wellbeing variables. This suggests that the lack of significant association between some of the variables in the regression analyses might be attributed to the small sample size in this study, and the limited statistical power to detect more moderate correlations.

In summary, this study is the first to use a direct measure (SIBIQ) of internal continuity to explore the links between self-identity and well-being outcomes. As discussed in the introduction, previous studies have approached these issues from a different perspective and employed the HISDS (Carroll & Coetzer, 2011; Ruddle et al., 2005) to examine whether differences between pre- and post- injury concepts of the self, had potential association with psychological well-being (Cantor et al., 2005; Carroll & Coetzer, 2011). These studies demonstrated that individuals experiencing greater discrepancy in their self-concept before and after injury demonstrated poor adjustment after brain injury. Studies have also stated the influence of demographic factors such as age on the adjustment after brain injury scores, with younger people reporting better adjustment to TBI in comparison to older people. Factors such as "finding the meaning" in life and experiencing "identity crisis" is a more familiar experience in younger age in comparison to old age and potentially facilitates adjustment to loss after ABI (Davis & Nolen-Hoeksema, 2001; Persinger, 1993).

As noted earlier, the concept of a lack of difference between the pre-and post- injury self, overlaps with, yet is distinct from the concept of internal continuity. It is possible for an individual to acknowledge differences between their pre- and post- injury self while still maintaining a sense of internal continuity. Interestingly, the correlations between measures of well-being and internal continuity were generally stronger compared to those between well-being and the HISDS. Furthermore, in the hierarchical regression analysis reported for hypothesis 4, there was a significant change in the R-squared value when the SIBIQ score was added to the model (with the HISDS difference score entered in the first step) and, apart from the Loss (BIGI) variable, the change was not negligible and in the expected direction for the other outcome variables (Table 2.7). This suggests that a global sense of internal continuity, as opposed to perceptions of specific changes between the pre- and post-injury self, may be more influential in understanding why some individuals have better well-being outcomes after a brain injury than others.

Limitations

A major limitation of this study was the use of a non-probability (non-random) and opportunistic sampling technique. As a result, it is uncertain to what extent the sample in this study is representative of the wider ABI population. Therefore, the generalisability of the psychometric estimates of the scale, and of the findings about what variables are associated with internal continuity, are unclear.

In terms of the development of the SIBIQ, this was based on a questionnaire to address the perceptions of a spouse or partner about the continuity of the identity of a person with brain injury. In future, conducting expert panel reviews would provide important feedback on aspects such as clarity, conciseness, and relevance of the items in the questionnaire (DeVellis & Thorpe, 2021; Morrison & Embretson, 2018). This can enhance the content validity of the questionnaire. Moreover, the relatively low corrected item total correlation score for item 6 (0.383), in comparison to the other items indicates potential ambiguity in the wording of item 6. An alternative solution to this would be to change the negatively worded item 6 to a positively worded item as negative wording has often shown to create ambiguity in responses (DeVellis & Thorpe, 2021). Evaluating the psychometric properties of the questionnaire with a larger sample would also be useful.

Another limitation of this study includes the utilisation of self-report measures to investigate the relationship between several psychological factors. Cooper-Evans et al. (2008) demonstrated the reliability of self-report measures such as the RSES in the severe TBI population. However, other studies have questioned the reliability and validity of these measures due to the potential impact of several patient factors such as fatigue, cognitive impairment and overlap of psychological and somatic symptoms in the ABI population (Curvis et al., 2018). Moreover, due to the cross-sectional design of this study, the causal inferences between perceived continuity of identity and the psychological variables cannot be drawn.

Finally, the relatively small sample size reduced the statistical power of the study to detect significant results (Faber & Fonseca, 2014). This could be a possible explanation for the lack of significant associations between HISDS and grief that were reported in previous studies (Carroll & Coetzer, 2011; Cooper-Evans et al., 2008). Indeed, the strength of correlation between the HISDS, and adjustment after brain injury, depression and self-esteem were comparable to previous studies (Carroll & Coetzer, 2011). However, the present study used a more conservative alpha value of 0.01 in the statistical analysis in comparison to the previous studies which could be another reason for the lack of consistency with previous research findings. Post-hoc power analysis with the alpha set at 0.01 value revealed that a minimum sample size of 39 would be required to detect a moderate size effect. Future research with larger sample size would also enable performing sophisticated analysis in determining whether internal continuity is more strongly associated with some wellbeing variables than others.

2.7 Clinical and Research Implications

A new tool to measure self-identity in the brain injury population was designed and its psychometric properties were examined in brain injury survivors. The internal consistency and validity of the SIBIQ were in the acceptable range. Future research is required to evaluate this questionnaire further. Administering the questionnaire to a larger sample could establish more reliable estimates of its psychometric properties. Evaluation by a panel of people with lived experience could establish its validity and potentially result in improvements or adjustments.

The questionnaire for the most part showed the correlations with psychological wellbeing predicted by Continuity Theory. Research with larger samples could establish these associations with more confidence. A stricter alpha level (p=.01) was adopted as multiple tests were conducted in the analysis, thereby reducing the power of the analyses. Some of the findings were associated with a p-value below 0.5 or approximated significance. A larger sample would enable the hypotheses to be tested with an appropriate level of power. A larger sample would also allow for more sophisticated statistical analysis, such as determining whether internal continuity is more strongly associated with some wellbeing variables than others.

Future research could also benefit from exploring more appropriate questionnaires. The Meaning in Life questionnaire, for instance has not been validated for use in acquired brain injury. A questionnaire with specific focus on the experience of those living with brain injury would have provided a more robust test of this prediction of Continuity Theory.

Longitudinal studies exploring the experience of continuity of self-identity over time would also be valuable. Investigating how the experience changes over time in relation to outcome variables would provide a more effective test of the prediction that a sense of continuity contributes to improved wellbeing outcomes. Additionally, examining the factors influencing these changes over time could also offer some valuable insights into preventing negative identity change and fostering positive change.

Depending on the outcome of this future research, another direction for future research is the development of intervention to enhance the sense of inner continuity of people living with brain injury. As suggested by some researchers (Ownsworth & Haslam, 2016) supporting individuals in resuming pre-injury activities and meaningful social roles can reduce the discrepancy between pre- and post-injury sense of self, that causes emotional distress. This can in turn promote external continuity. While encouraging the continuation of external behaviours like pursuing pre-injury goals and hobbies may promote internal continuity (Atchley, 1989), it might not be adequate by itself. Interventions that directly improve internal continuity may be needed. Psychotherapy interventions that support individuals to appreciate their core values and aspects of self-identity despite transitions and changes in life may be beneficial as it is possible to maintain a continuity with one’s pre-injury self by appreciating qualities that have not changed. Vickery et al.'s (2005) group intervention focused on the concept of self-complexity, which argues that identity has several facets and that some facets of self can be preserved even in the face of challenging circumstances (Linville, 1985, 1987). Future research could also further investigate the relevance of narrative approaches such as the ‘Life Thread Model’ (Ellis-Hill et al., 2008) in promoting internal continuity. Ellis-Hill and colleagues (2008) argue that developing a coherent narrative of one’s life story in an orderly manner facilitates meaning-making of the changes and transition. Moreover, the sense of coherence and predictability resulting from this process enables an individual to face the challenges and look forward to the future with more confidence, direction and purpose.

In conclusion, despite the methodological limitations, this study addressed key issues relating to the investigation of identity changes in ABI survivors. In particular, the present study examined the relatively little-known interaction between psychological continuity and emotional well-being from the perspective of Atchley's Continuity theory in ABI population. In addition, the study also demonstrated that consistent with the theoretical predictions, a sense of continuity of identity has benefits associated with positive psychological outcomes, while discontinuity is associated with negative psychological outcomes. In doing so, this research provides insightful information on the continuity of identity in the context of brain injury as well valuable clinical implications. Therefore, in order to develop psychological interventions addressing identity challenges in ABI survivors, it might be quite useful to understand how some people maintain a sense of continuity in their identity. This is where this study has made an attempt using Continuity Theory to comprehend the impact of continuity on brain injury.

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CHAPTER 3: Press Release for the Systematic Literature Review

University of Birmingham Press Release

Background

Traumatic Brain injury (TBI) is defined as any damage to the brain caused by an external force. TBI interrupts regular brain function and can have a major effect on an individual's cognitive abilities, emotions, behaviours, and physical well-being. These changes can profoundly impact not only the person’s life but also their immediate families and community. Individuals with TBI often struggle to carry out their everyday tasks, maintain their relationships and engage in social and recreational activities. These challenges can negatively affect their self-identity, which encompasses beliefs about their- abilities, general qualities, and unique characteristics as a person.

While a majority of TBI-survivors tend to have a negative self-evaluation, some individuals successfully manage to build a positive identity following TBI. Understanding the processes that support the growth of a positive identity in these TBI survivors is valuable as this knowledge can enable health care professionals to provide appropriate support. However, there is a lack of literature reviews that particularly examines the internal processes that contribute to the development of a positive self-identity.

What did the review do?

A meta-ethnography approach was employed to synthesise findings from several research studies that examined the subjective experiences of positive identity development from the perspectives of TBI survivors. Firstly, a thorough and systematic literature search technique was used to locate pertinent research studies, following which the quality of each research paper was evaluated using a well-known checklist for quality review. Finally, the data from these research publications were retrieved and analysed to identify patterns or distinctions across them.

What did the review find?

The research studies revealed several internal psychological processes that facilitated positive identity development in individuals following TBI. Acceptance of the changes in one's life after TBI was viewed as an important step in the development of a positive self-identity. It was found that people who shifted their values and priorities in life from materialistic pursuits towards altruistic behaviours, such as helping others in similar situations and contributing to their communities, experienced personal growth and positive identity. In addition, reflecting on their personal journey after TBI and appreciating the progress and achievements made in their personal and social life also contributed to positive identity development. Finally, having gone through a near-death experience enabled some individuals to believe they were spared for a special purpose. This belief motivated them in taking positive action and improving their lifestyle, which subsequently impacted their self-identity in a positive manner.

What do the review findings mean?

Based on the findings of this review, it can be suggested that rehabilitation and therapy goals aimed to help individuals re-evaluate and come to terms with the fact that they have changed may be a crucial first step in building positive identity following TBI. In addition, the review highlights the significance of helping people with TBI to reflect on and reshape their values and priorities in life, enabling them to make life choices that better align with these revised perspectives. Having values and priorities that are congruent with one's abilities and circumstances, rather than values and priorities that one can no longer successfully live by, may provide an important foundation for a renewed positive self-identity.

CHAPTER 4: Press Release for the Empirical Paper

University of Birmingham Press Release

Background

Acquired Brain Injury (ABI) is a life changing event that can drastically change a person's course of life. Coping with these challenges often poses a serious problem to an individual’s sense of who they are as a person. While a majority of ABI survivors describe changes in their identity or disruption in their sense of who they were as a person, some individuals still perceive themselves as fundamentally unchanged after the event.

According to Continuity Theory in psychology, when confronted with challenging circumstances and transitions in their lives, individuals who maintain a strong inner continuity – in other words, those who feel they are essentially the same person as they were before the event – tend to experience lower levels of stress, anxiety, have a clearer sense of their purpose in life, and exhibit greater self-confidence.

Understanding how some individuals maintain this sense of continuity can provide valuable insights when providing care and support to those who are struggling. However, in the context of ABI, there is a lack of research investigating the potential benefits of maintaining inner continuity.

What did the study do?

This study recruited a total of thirty participants who had a history of ABI to investigate the potential benefits of maintaining inner continuity. A newly developed questionnaire specifically designed for the purpose of this study was used to directly measure participants' internal continuity. In addition, participants filled seven questionnaires that measured their levels of stress, anxiety, depression, self-esteem, meaning in life, and grief following brain injury. Data was then analysed using regression analysis to explore the influence of inner continuity on individuals with brain injury.

What did the study find?

In general, individuals who perceived a stronger sense of inner continuity had higher levels of high self-esteem, lower levels of depression and stress, and displayed better adaptation to brain injury. These positive benefits of inner continuity persisted even when the affected individuals had a good understanding of the changes and challenges resulting from ABI. Conversely, those who perceived a lack of continuity in their identity exhibited lower self-esteem, higher levels of depression and stress, and showed poor adjustment to their brain injury. Furthermore, statistical analyses indicated that the newly developed measure (questionnaire) can be considered as a reliable tool for assessing internal continuity in individuals with brain injury.

What do the review findings mean?

The study represents a pioneering effort by being the first to use a direct measure of internal continuity to explore the links between self-identity and well-being outcomes. The findings indicate that, when compared to existing measures, the concept of a global sense of internal continuity may hold greater significance in understanding why some individuals have better wellbeing outcomes following a brain injury than others.

Appendices

Appendix A: CASP checklist (2018)

	Screening questions	
1	Was there a clear statement of the aims of the research? *Consider:* *a. What was the goal of the research?* *b. Why it was considered important.* *c. The relevance of research*	Yes Can’t tell No
2	Is a qualitative methodology appropriate? *Consider:* *a. If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants* *b. Whether qualitative research is the right methodology for addressing the research goal*	Yes Can’t tell No
	Further questions	
	Appropriate research design	
3	Was the research design appropriate to address the aims of the research? *Consider:* *a. If the researcher has justified the research design (e.g., whether they have discussed how they decided which method to use?)*	Write comments here
	Sampling	
4	Was the recruitment strategy appropriate to the aims of the research? *Consider:* *a. If the researcher has explained how the participants were selected* *b. If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study*	Write comments here

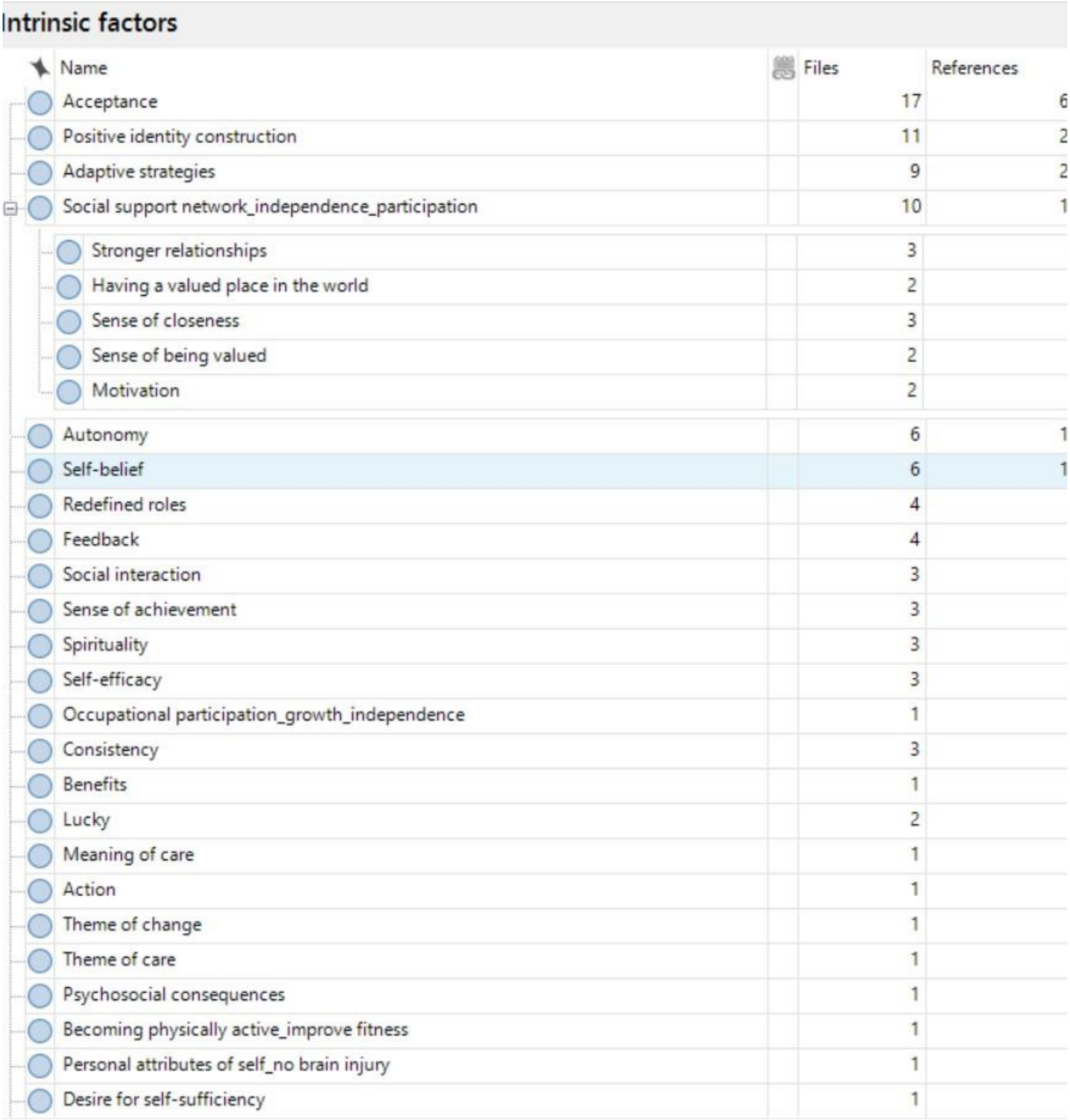
	c. If there are any discussions around recruitment (e.g., why some people chose not to take part)	
	Data collection	
5	Was the data collected in a way that addressed the research issue? *Consider:* *a. If the setting for data collection was justified* *b. If it is clear how data were collected (e.g., focus group, semi-structured interview, etc)* *c. If the researcher has justified the methods chosen* *d. If the researcher has made the methods explicit (e.g., for the interview method, is there an indication of how interviews were conducted, did they use a topic guide)* *e. If methods were modified during the study. If so, has the researcher explained how and why?* *f. If the form of data is clear (e.g., tape recordings, video material, notes, etc)* *g. If the researcher has discussed saturation of data*	Write comments here
	Reflexivity	
6	Has the relationship between the researcher and participants been adequately considered? *Consider whether it is clear:* *a. If the researcher critically examined their own role, potential bias, and influence during: the formulation of research questions, data collection, including sample recruitment and choice of location* *b. How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*	Write comments here

	Ethical Issues	
7	Have ethical issues been taken into consideration? *Consider:* *a. If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained* *b. If the researcher has discussed issues raised by the study (e. g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)* *c. If approval has been sought from the ethics committee*	Write comments here
	Data Analysis	
8	Was the data analysis sufficiently rigorous? *Consider:* *a. If there is an in-depth description of the analysis process* *b. If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?* *c. Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process* *d. If sufficient data are presented to support the findings* *e. To what extent contradictory data are considered* *f. Whether the researcher critically examined their own role, potential bias, and influence during the analysis and selection of data for presentation*	Write comments here
	Findings	
9	Is there a clear statement of findings? *Consider:* *a. If the findings are explicit*	Write comments here

	b. If there is an adequate discussion of the evidence both for and against the researcher's arguments *c. If the researcher has discussed the credibility of their findings (e.g., triangulation, respondent validation, more than one analyst.)* *d. If the findings are discussed in relation to the original research questions*	
	Value of the research	
10	How valuable is the research? *Consider:* *a. If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature?)* *b. If they identify new areas where research is necessary* *c. If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*	Write comments here

Appraisal, C. Skills Programme. (2018). *CASP Qualitative Checklist*.

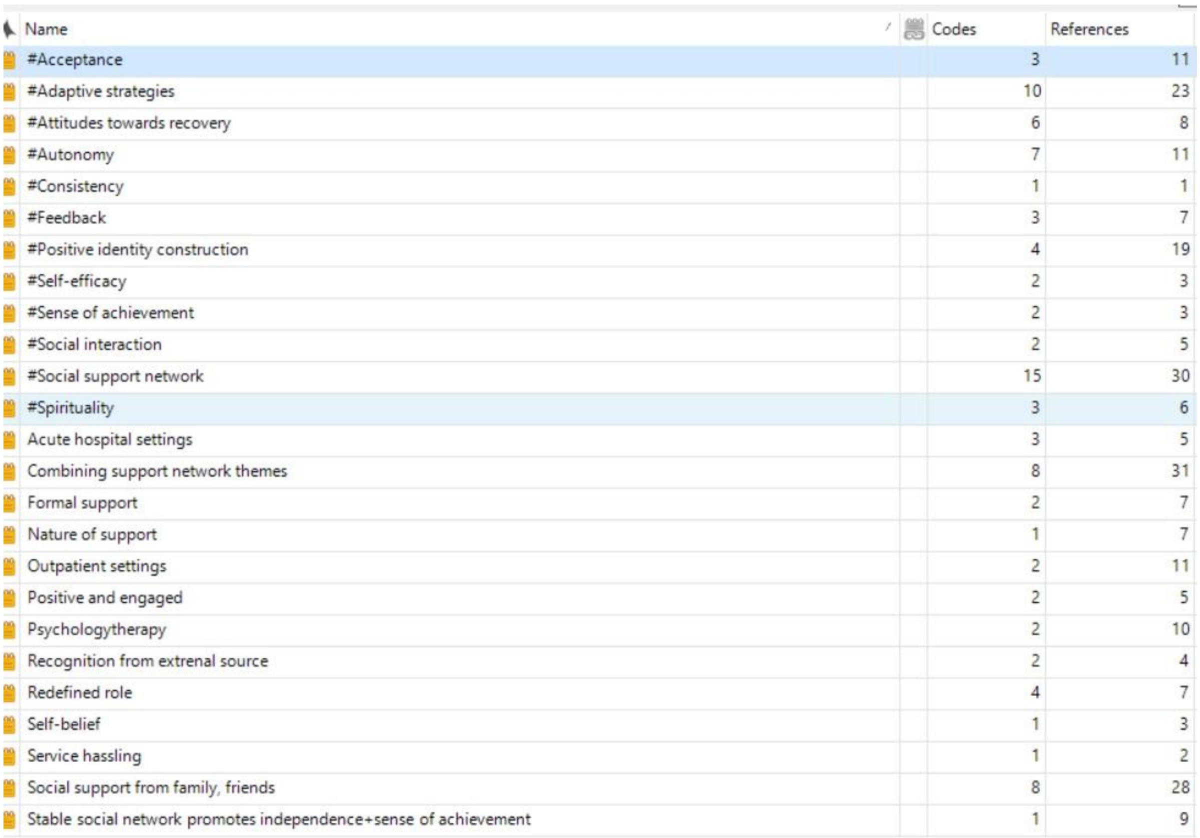
Appendix B: Initial Codes Generated in NVivo



Intrinsic factors

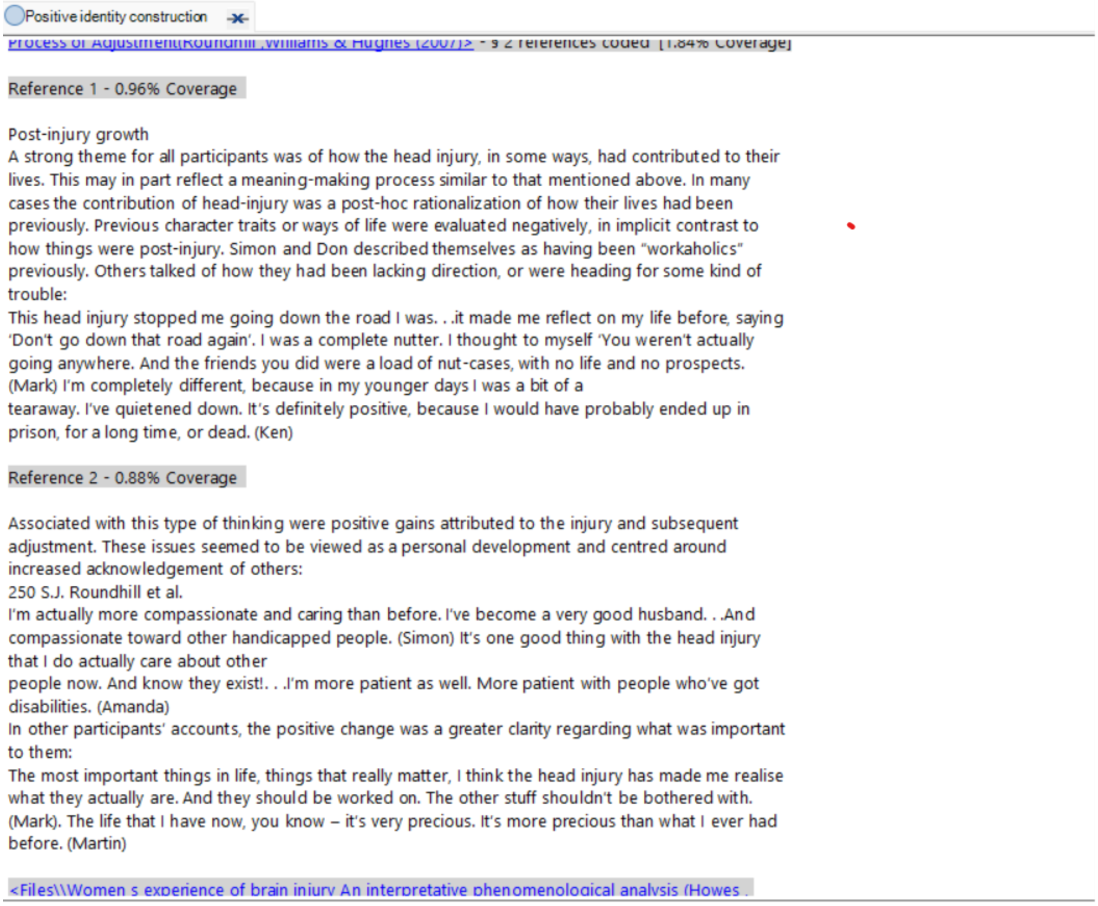
Name	Files	References
Acceptance	17	6
Positive identity construction	11	2
Adaptive strategies	9	2
Social support network_independence_participation	10	1
Stronger relationships	3	
Having a valued place in the world	2	
Sense of closeness	3	
Sense of being valued	2	
Motivation	2	
Autonomy	6	1
Self-belief	6	1
Redefined roles	4	
Feedback	4	
Social interaction	3	
Sense of achievement	3	
Spirituality	3	
Self-efficacy	3	
Occupational participation_growth_independence	1	
Consistency	3	
Benefits	1	
Lucky	2	
Meaning of care	1	
Action	1	
Theme of change	1	
Theme of care	1	
Psychosocial consequences	1	
Becoming physically active_improve fitness	1	
Personal attributes of self_no brain injury	1	
Desire for self-sufficiency	1	

Appendix C: Initial Reciprocal Translations Generated



Name	Codes	References
#Acceptance	3	11
#Adaptive strategies	10	23
#Attitudes towards recovery	6	8
#Autonomy	7	11
#Consistency	1	1
#Feedback	3	7
#Positive identity construction	4	19
#Self-efficacy	2	3
#Sense of achievement	2	3
#Social interaction	2	5
#Social support network	15	30
#Spirituality	3	6
Acute hospital settings	3	5
Combining support network themes	8	31
Formal support	2	7
Nature of support	1	7
Outpatient settings	2	11
Positive and engaged	2	5
Psychologytherapy	2	10
Recognition from extrenal source	2	4
Redefined role	4	7
Self-belief	1	3
Service hassling	1	2
Social support from family, friends	8	28
Stable social network promotes independence+sense of achievement	1	9

Appendix D: Reciprocal Translations including References



Process of Adjustment(Roundhill ,Williams & Hughes (2007)> - § 2 references coded [1.84% Coverage]

Reference 1 - 0.96% Coverage

Post-injury growth
A strong theme for all participants was of how the head injury, in some ways, had contributed to their lives. This may in part reflect a meaning-making process similar to that mentioned above. In many cases the contribution of head-injury was a post-hoc rationalization of how their lives had been previously. Previous character traits or ways of life were evaluated negatively, in implicit contrast to how things were post-injury. Simon and Don described themselves as having been "workaholics" previously. Others talked of how they had been lacking direction, or were heading for some kind of trouble:
This head injury stopped me going down the road I was. . .it made me reflect on my life before, saying 'Don't go down that road again'. I was a complete nutter. I thought to myself 'You weren't actually going anywhere. And the friends you did were a load of nut-cases, with no life and no prospects. (Mark) I'm completely different, because in my younger days I was a bit of a
tearaway. I've quietened down. It's definitely positive, because I would have probably ended up in prison, for a long time, or dead. (Ken)

Reference 2 - 0.88% Coverage

Associated with this type of thinking were positive gains attributed to the injury and subsequent adjustment. These issues seemed to be viewed as a personal development and centred around increased acknowledgement of others:
250 S.J. Roundhill et al.
I'm actually more compassionate and caring than before. I've become a very good husband. . .And compassionate toward other handicapped people. (Simon) It's one good thing with the head injury that I do actually care about other
people now. And know they exist!. . .I'm more patient as well. More patient with people who've got disabilities. (Amanda)
In other participants' accounts, the positive change was a greater clarity regarding what was important to them:
The most important things in life, things that really matter, I think the head injury has made me realise what they actually are. And they should be worked on. The other stuff shouldn't be bothered with. (Mark). The life that I have now, you know – it's very precious. It's more precious than what I ever had before. (Martin)

<Files\\Women s experience of brain injury An interpretative phenomenological analysis (Howes .

Appendix E: Ethical Approval Letter

From: Gerard Riley (Psychology)
Sent: 29 November 2021 10:14
To: Nandini Rajendran (ClinPsyD Clinical Psy FT (NBF))
Subject: Fw: Application for Ethical Review ERN_19-1301

Hi Nandini

Please find below the email confirming the committee's full approval of the project. You only get an email confirmation - nothing more official. Sam Waldron is still part of the committee - so perhaps, when you forward the email to Headway, you should just say that she can be contacted if they have any questions about the approval.

Gerry

Dr Gerard Riley

Associate Professor

Clinical Psychology

Doctorate Centre for Applied

Psycholo[redacted]

UNIVERSITY OF BIRMINGHAM | CENTRE FOR APPLIED PSYCHOLOGY

From: Samantha Waldron (Research Support Group)
Sent: 02 December 2019 11:32
To: Gerard Riley (Psychology)
Subject: Application for Ethical Review ERN_19-1301

Dear Dr Riley,

Re: "The impact of continuity of self-identity following brain injury"

Application for Ethical Review ERN_19-1301

Thank you for your application for ethical review for the above project, which was reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly brought to the Committee’s attention by the Principal Investigator and may necessitate further ethical review.

Please also ensure that the relevant requirements within the University’s Code of Practice for Research and the information and guidance provided on the University’s ethics webpages (available at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research- Ethics/Links-and-Resources.aspx) are adhered to and referred to in any future applications for ethical review. It is now a requirement on the revised application form (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University’s guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University’s H&S Unit at healthandsafety@contacts.bham.ac.uk.

Kind regards,

Ms Sam Waldron
Research Ethics
Officer Research
Support Group

C Block Dome (room 132)

Aston Webb Building

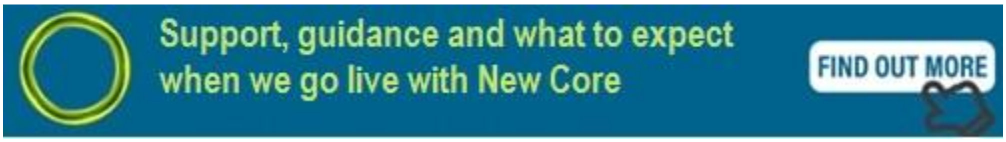
University of Birmingham

Edgbaston B15 2TT

Tel: [redacted]
Email: [redacted]

Please remember to submit a new Self-Assessment Form for each new project. Click Ethical Review Process for further details regarding the University’s Ethical Review process.

Click Research Governance for further details regarding the University’s Research Governance and Clinical Trials Insurance processes, or email researchgovernance@contacts.bham.ac.uk with any queries



Appendix F: Flyer plus consent to contact form

Are you interested in taking part in research?

Study title: *The impact of continuity of self-identity following brain injury*

This study is led by Dr. Gerry Riley from the University of Birmingham.

What is the purpose of the study?

This research is about whether people feel changed as a person after a brain injury, and what effect this has on how they cope with the injury.

What would I have to do?

- You will be asked to complete some questionnaires about yourself. These questionnaires should 15-30 minutes to complete. Help will be available if you need it.
- A member of your family will also be asked to complete one questionnaire. This should take less than 5 minutes.

Am I eligible to take part?

You can take part if:

- You have had a traumatic brain injury or stroke or some other kind of brain injury
- You live with a member of your family

You can't take part if:

- You are under 18
- Your brain injury happened less than 6 months ago
- Your brain injury happened more than 10 years ago

What should I do if I am interested in finding out more?

If you are interested in finding out more about participating in the study please complete the details on the other side of the page and give it to a member of Headway staff. They will explain to you what happens next.

CONSENT TO CONTACT

I agree to a member of the research team contacting me. The researcher will give me more information about the study. I will also have a chance to ask questions about the research.

I prefer to be contacted by:

○ THE RESEARCHER SPEAKING TO ME AT HEADWAY

○ PHONE CALL

○ TEXT

○ EMAIL

Please tick the one that suits you best.

If you want contact by phone or email, please provide details below:

Phone number: …………………………………………………

Email address: ……………………………………………………

…………………………………… ………………………………..

Name (Please print) Signature

Researcher use only: Participant ID number:

Appendix G: List of organizations contacted for participant recruitment

1. Headway Birmingham and Solihull
2. Headway Kent
3. Brain and Spine organisation, UK
4. UKABIF organisation
5. Headway Thames Valley
6. Headway Sussex
7. Headway Leicester
8. Headway Herefordshire
9. Headway Somerset
10. Headway Cardiff
11. Headway-Southampton
12. Headway East London
13. Headway Northampton
14. Headway Luton
15. Headway Oxford
16. Headway Blackpool
17. Headway South Staffordshire
18. Headway Essex
19. Edinburgh Headway
20. Headway Lincolnshire
21. Headway Shropshire
22. Headway Central Lancashire
23. Headway Devon
24. Headway Gloucestershire
25. Headway-Cambridgeshire
26. Headway Suffolk
27. Headway North London
28. Headway East London
29. Headway Milton Keynes
30. Headway Lancaster

Appendix H: Participant information leaflet

UNIVERSITY OF
BIRMINGHAM

Participant Information Leaflet

Study title: The impact of continuity of self-identity following brain injury

We would like to invite you to take part in our research study. Before you decide, we would like you to understand what the research involves.

A member of the research team will go through this leaflet with you and answer any questions you have. Ask us if there is anything that is unclear.

Please feel free talk to others about the study before deciding whether to take part.

This study is being conducted at the University of Birmingham. The research is led by Dr. Gerard Riley [redacted]

What is the purpose of the study?

After a brain injury, some people compare themselves as they are now to how they were before the injury. We are interested in the emotional impact of these comparisons – whether they are linked to what the person feels about the brain injury and about life generally.

Why have I been invited to take part?

You have been invited to take part because you have had a brain injury. This may have been a head injury, a stroke, a brain tumour or some other problem.

Am I eligible to take part?

To take part, you must answer YES to the following questions:

- Are you aged 18 or over?
- Did your brain injury happen after 2009?
- Did your brain injury happen at least 6 months ago?
- Do you live with a family member who would be willing to fill in a questionnaire about you?

If you answered NO to any of these questions, please discuss this with a member of the research team.

Do I have to take part in the study?

Absolutely not. Do not take part if you are not sure you want to, or have any doubts about taking part. Deciding not to take part will not have any consequences for you, and will not affect your attendance at Headway.

What happens next?

A member of the research team will contact you. They will check that you are eligible to take part, and give you the chance to ask any questions you might have.

If you do not want to take part, tell them you are not interested. You do not have to give a reason.

If you do want to take part, they will arrange a date to meet up with you.

What will happen if I agree to take part?

Before the arranged meeting, a member of the research team will contact you to make sure that you still want to meet. If you have decided not to take part, tell this to the researcher. You do not have to give a reason.

If you want to go ahead, you will meet up with a member of the research team at the time you have arranged. The researcher will go through this leaflet with you, and give you another chance to ask any questions you have about the study. The researcher will also check that a family member has agreed to fill in a questionnaire about you. Unfortunately, you cannot take part unless a family member agrees to do this.

If you wish, you can decide at this meeting not to take part. You do not have to give a reason why you do not want to take part.

If you decide to take part, the researcher will ask you to sign a consent form. You will then fill in 7 questionnaires:

- 1 short one about yourself and the brain injury
- 2 about how you compare yourself as you are now to how you were before the brain injury
- 4 about what you feel about the brain injury and about life generally

These questionnaires should take 15-30 minutes to complete. The researcher will be available to give you any help you may need, or answer any questions. If you wish, the researcher can read out the questions and fill in the questionnaires for you.

If you get tired, you can take a break or even arrange a second meeting with the researcher to finish off the questionnaires.

One of the questionnaires asks about how the brain injury has affected you. Your family member will also complete a version of this questionnaire.

Where will the study take place?

Your meeting with the researcher will take place at Headway on a day that you normally attend.

How long will my participation in the study take?

When you meet the researcher, it will take about 15 minutes to go through this leaflet, to give you the chance to ask any questions, and for you to sign the consent form.

Filling in the questionnaires will then take another 15-30 minutes at the most.

What will happen if I do not want to carry on with the study?

Even if you agree to take part and sign the consent form, you can decide during the meeting with the researcher that you no longer want to take part. This is not a problem at all. You do not need to explain why you want to stop. It will not have any consequences for you, and will not affect your attendance at Headway.

If you decide to stop during the meeting, any questionnaires that you have completed will be destroyed immediately, along with your consent forms. No record of your involvement will be kept.
If you decide after the meeting that you no longer wish to be part of the study, you should let the research team know - either by emailing [redacted] or phoning [redacted] and leaving a message. All the information you have given us will be destroyed, and no record of your involvement will be kept. If you want to withdraw in this way, <u>you must let us know within 7 days of the meeting.</u> After that, it will not be possible to withdraw from the study.

What will happen to the results of the research study?

The results of the study will be written up by the student as part of their University degree. The results may also be published in academic journals and presented at academic conferences.

A summary of the results will be sent to Headway at the end of the study. Headway staff will give you a copy of this if you want it. The research team will also offer to do a presentation of the results to Headway staff and clients.

Expenses and reimbursement

The research will take place at Headway on a day that you normally attend, and so you will not have any extra expenses. Unfortunately, we are unable to provide any money to reimburse you for participating.

Will the information I provide be treated confidentially?

The consent forms and the questionnaires you complete will be kept confidential. The information will be accessible only to the research team and those authorised by the University of Birmingham to conduct an audit of research data. Your name will not be included in any write-up or presentation of the findings.

To protect your identity, you will be given a participant number. This will be written on the questionnaires and on the consent forms. The questionnaires will not contain your name or any other identifying information.

If you say or do anything that raises concern about your safety or the safety of others, the researcher is obliged to inform a member of Headway staff about their concern even if you do not consent to this.

Where will the data be stored?

The consent forms will be kept in a locked filing cabinet in a locked office at the University. The questionnaires will be kept in a separate locked filing cabinet in the same office.

The scores from the questionnaires will be entered into an electronic file and stored on the password-protected University computer system. This file will not contain your name or any other information that would allow you to be identified.

What will happen to the data after the study has ended?

In accordance with the requirements of the University of Birmingham, the consent forms and questionnaires will be kept for 10 years. After this they will be securely destroyed.

What are the possible disadvantages and risks of taking part?

It is possible that you may find some of the questionnaires upsetting to fill in. If this happens, the researcher will give you the option of withdrawing from the study, re-scheduling the meeting to another date, or taking a short break. The researcher will also advise you to speak to a member of Headway staff. Details of other sources of support are given at the end of this leaflet.

What are the possible benefits of taking part?

We do not expect that you will experience any direct benefits from taking part in the study. However, we do hope that the findings may help us to develop therapies in the future that will help people deal more effectively with brain injury.

What if I need to make a complaint?

If you are unhappy about the way in which this research is being carried out, please make a complaint to the research lead (Dr Gerard Riley – [redacted]) or to Dr Jessica Woodhams [redacted], the Head of the Centre for Applied Psychology at the University of Birmingham.

Who has reviewed the study?

This study has been approved by the University of Birmingham's Ethics Committee.

Sources of support

If you feel you need more support in dealing with your brain injury, you should speak to a member of staff at Headway. Alternatively, you should speak to your GP.

The following websites and helplines also provide advice:

- Headway: helpline – 0808 800 2244; website- www.headway.org.uk
- Stroke Association: helpline – 0303 303 3100; website – www.stroke.org.uk
- Brain Injury Group: helpline – 0800 612 9660; website – www.braininjury group.co.uk

Appendix I: Explanatory letter and consent to contact form for family member

Information Leaflet for Family Member

Study title: *The impact of continuity of self-identity following brain injury*

We would like to invite you to take part in our research study. Before you decide, we would like you to understand what the research involves. Please feel free talk to others about the study before deciding whether to take part.

This study is being conducted at the University of Birmingham. The research is led by Dr. Gerard Riley [redacted]

Why have I been invited to take part?

You have been invited to take part because your family member at Headway has expressed an interest in taking part in the study. The study requires the person with a brain injury to fill in some questionnaires, and a family member to complete a questionnaire about the impact of the brain injury.

What is the purpose of the study?

After a brain injury, some people compare themselves as they are now to how they were before the injury. We are interested in the emotional impact of these comparisons – whether they are linked to what the person feels about the brain injury and about life generally.

Am I eligible to take part?

The only requirements are that you live with the person with the brain injury and belong to the same family (including being their partner/husband/wife).

Do I have to take part in the study?

Absolutely not. Do not take part if you are not sure you want to, or have any doubts about taking part. Deciding not to take part will not have any consequences for you, and will not affect your family member’s attendance at Headway.
If you don’t want to take part, please tell your family member this.

What should I do if I want to take part?

Please fill in the ‘consent-to-contact (family member)’ form. Please hand this in to a staff member at Headway in the envelope provided.

What happens next?

A member of the research team will contact you, using the contact details you have provided on the consent-to-contact form. They will check that you are eligible to take part, and give you the chance to ask any questions you might have.

If you have decided you do not want to take part, tell them you are not interested. You do not have to give a reason.

If you do want to take part, the member of the research team will make arrangements to provide you with a ‘consent-to-participate (family member)’ and a questionnaire for you to complete. You can ask for the forms to be posted, e-mailed or handed to you in person at Headway.

The questionnaire is about the effects that the brain injury has had on your relative. You will not be asked any questions about yourself.

The researcher will also make arrangements with you for returning the completed questionnaire and consent-to-participate form. Again, you can choose to post, email or hand them to a member of Headway staff.

How long will my participation in the study take?

Filling in the questionnaire will take about 5 minutes.

What will happen if I do not want to carry on with the study?

You may decide that you no longer want to take part. This is not a problem at all. You do not need to explain why you want to stop. It will not have any consequences for you, and will not affect your relative’s attendance at Headway. Please contact let us know that you no longer want to take part, either by telling a member of staff at Headway or letting us know [redacted] phoning [redacted] and leaving a message).

If you decide after sending back the completed questionnaire that you no longer wish to be part of the study, you should let the research team know - either by emailing [redacted] phoning [redacted] and leaving a message. All the information you have given us will be destroyed, and no record of your involvement will be kept. If you want to withdraw in this way, you must let us know within 7 days of the meeting. After that, it will not be possible to withdraw from the study.

What will happen to the results of the research study?

The results of the study will be written up by the student as part of their University degree. The results may also be published in academic journals and presented at academic conferences.

A summary of the results will be sent to Headway at the end of the study. Headway staff will give you a copy of this if you want it. The research team will also offer to do a presentation of the results to Headway staff and users of the service (including yourself).

Expenses and reimbursement

The research will not involve you making a journey you would not normally make, and so you will not have any extra expenses. Unfortunately, we are unable to provide any money to reimburse you for participating.

Will the information I provide be treated confidentially?

All the information you provide (the consent forms and the questionnaire) will be kept confidential. The information will be accessible only to the research team and those authorised by the University of Birmingham to conduct an audit of research data. Your name will not be included in any write-up or presentation of the findings.

To protect your identity, your family member will be given a participant number. This will be written on the questionnaires and on the consent forms, including the ones that you fill in. The questionnaires will not contain your family member's name, your name or any other identifying information.

Where will the data be stored?

The consent forms will be kept in a locked filing cabinet in a locked office at the University. The questionnaires will be kept in a separate locked filing cabinet in the same office.

The scores from the questionnaires will be entered into an electronic file and stored on the password-protected University computer system. This file will not contain your name or any other information that would allow you to be identified.

What will happen to the data after the study has ended?

In accordance with the requirements of the University of Birmingham, the consent forms and questionnaires will be kept for 10 years. After this they will be securely destroyed.

What are the possible disadvantages and risks of taking part?

It is possible that you may find the questionnaire upsetting to fill in. If this happens, you should speak to a member of Headway staff. Details of other sources of support are given at the end of this leaflet.

What are the possible benefits of taking part?

We do not expect that you will experience any direct benefits from taking part in the study. However, we do hope that the findings may help us to develop therapies in the future that will help people deal more effectively with brain injury.

What if I need to make a complaint?

If you are unhappy about the way in which this research is being carried out, please make a complaint to the research lead (Dr Gerard Riley – [redacted] [redacted]) or to Dr Jessica Woodhams ([redacted]he Head of the Centre for Applied Psychology at the University of Birmingham.

Who has reviewed the study?

This study has been approved by the University of Birmingham's Ethics Committee.

Sources of support

If you feel you need more support in dealing with the effects of the brain injury, you should speak to a member of staff at Headway. Alternatively, you should speak to your GP.

The following websites and helplines also provide advice:

- Headway: helpline – 0808 800 2244; website- www.headway.org.uk
- Stroke Association: helpline – 0303 303 3100; website – www.stroke.org.uk
- Brain Injury Group: helpline – 0800 612 9660; website – www.braininjury group.co.uk

Appendix J: Participant information leaflet for family member

UNIVERSITY OF
BIRMINGHAM

Information Leaflet for Family Member

Study title: *The impact of continuity of self-identity following brain injury*

We would like to invite you to take part in our research study. Before you decide, we would like you to understand what the research involves. Please feel free talk to others about the study before deciding whether to take part.

This study is being conducted at the University of Birmingham. The research is led by Dr. Gerard Riley [redacted].

Why have I been invited to take part?

You have been invited to take part because your family member at Headway has expressed an interest in taking part in the study. The study requires the person with a brain injury to fill in some questionnaires, and a family member to complete a questionnaire about the impact of the brain injury.

What is the purpose of the study?

After a brain injury, some people compare themselves as they are now to how they were before the injury. We are interested in the emotional impact of these comparisons – whether they are linked to what the person feels about the brain injury and about life generally.

Am I eligible to take part?

The only requirements are that you live with the person with the brain injury and belong to the same family (including being their partner/husband/wife).

Do I have to take part in the study?

Absolutely not. Do not take part if you are not sure you want to, or have any doubts about taking part. Deciding not to take part will not have any consequences for you, and will not affect your family member’s attendance at Headway.

If you don’t want to take part, please tell your family member this.

What should I do if I want to take part?

Please fill in the ‘consent-to-contact (family member)’ form. Please hand this in to a staff member at Headway in the envelope provided.

What happens next?

A member of the research team will contact you, using the contact details you have provided on the consent-to-contact form. They will check that you are eligible to take part, and give you the chance to ask any questions you might have.

If you have decided you do not want to take part, tell them you are not interested. You do not have to give a reason.

If you do want to take part, the member of the research team will make arrangements to provide you with a ‘consent-to-participate (family member)’ and a questionnaire for you to complete. You can ask for the forms to be posted, e-mailed or handed to you in person at Headway.

The questionnaire is about the effects that the brain injury has had on your relative. You will not be asked any questions about yourself.

The researcher will also make arrangements with you for returning the completed questionnaire and consent-to-participate form. Again, you can choose to post, email or hand them to a member of Headway staff.

How long will my participation in the study take?

Filling in the questionnaire will take about 5 minutes.

What will happen if I do not want to carry on with the study?

You may decide that you no longer want to take part. This is not a problem at all. You do not need to explain why you want to stop. It will not have any consequences for you, and will not affect your relative’s attendance at Headway. Please contact let us know that you no longer want to take part, either by telling a member of staff at Headway or letting us know [redacted] phoning [redacted] and leaving a message).

If you decide after sending back the completed questionnaire that you no longer wish to be part of the study, you should let the research team know - either by emailing [redacted] phoning [redacted] and leaving a message. All the information you have given us will be destroyed, and no record of your involvement will be kept. If you want to withdraw in this way, you must let us know within 7 days of the meeting. After that, it will not be possible to withdraw from the study.

What will happen to the results of the research study?

The results of the study will be written up by the student as part of their University degree. The results may also be published in academic journals and presented at academic conferences.

A summary of the results will be sent to Headway at the end of the study. Headway staff will give you a copy of this if you want it. The research team will also offer to do a presentation of the results to Headway staff and users of the service (including yourself).

Expenses and reimbursement

The research will not involve you making a journey you would not normally make, and so you will not have any extra expenses. Unfortunately, we are unable to provide any money to reimburse you for participating.

Will the information I provide be treated confidentially?

All the information you provide (the consent forms and the questionnaire) will be kept confidential. The information will be accessible only to the research team and those authorised by the University of Birmingham to conduct an audit of research data. Your name will not be included in any write-up or presentation of the findings.

To protect your identity, your family member will be given a participant number. This will be written on the questionnaires and on the consent forms, including the ones that you fill in. The questionnaires will not contain your family member's name, your name or any other identifying information.

Where will the data be stored?

The consent forms will be kept in a locked filing cabinet in a locked office at the University. The questionnaires will be kept in a separate locked filing cabinet in the same office.

The scores from the questionnaires will be entered into an electronic file and stored on the password-protected University computer system. This file will not contain your name or any other information that would allow you to be identified.

What will happen to the data after the study has ended?

In accordance with the requirements of the University of Birmingham, the consent forms and questionnaires will be kept for 10 years. After this they will be securely destroyed.

What are the possible disadvantages and risks of taking part?

It is possible that you may find the questionnaire upsetting to fill in. If this happens, you should speak to a member of Headway staff. Details of other sources of support are given at the end of this leaflet.

What are the possible benefits of taking part?

We do not expect that you will experience any direct benefits from taking part in the study. However, we do hope that the findings may help us to develop therapies in the future that will help people deal more effectively with brain injury.

What if I need to make a complaint?

If you are unhappy about the way in which this research is being carried out, please make a complaint to the research lead (Dr Gerard Riley – [redacted] [redacted]) or to Dr Jessica Woodhams ([redacted] the Head of the Centre for Applied Psychology at the University of Birmingham.

Who has reviewed the study?

This study has been approved by the University of Birmingham's Ethics Committee.

Sources of support

If you feel you need more support in dealing with the effects of the brain injury, you should speak to a member of staff at Headway. Alternatively, you should speak to your GP.

The following websites and helplines also provide advice:

- Headway: helpline – 0808 800 2244; website- www.headway.org.uk
- Stroke Association: helpline – 0303 303 3100; website – www.stroke.org.uk
- Brain Injury Group: helpline – 0800 612 9660; website – www.braininjury group.co.uk

Appendix K: Demographic questionnaire

Consent to Participate Form

UNIVERSITY OF
BIRMINGHAM

Study title: The impact of continuity of self-identity following brain injury

Lead researcher: Dr Gerard Riley

Please initial each box if you agree:

1. I confirm that I have read and understood the information sheet for this study. I have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to stop taking part at any time, without giving a reason. ☐
3. I understand that if I want to withdraw the questionnaires I have completed from the study, I must contact the research team within 7 days. I understand that it will not be possible to withdraw from the study after this. ☐
4. I understand what I will be expected to do if I take part. ☐
5. I understand what will happen to the information I provide, and the arrangements to ensure its confidentiality and security. ☐
6. I understand that, if I disclose any information that raises concerns about my safety or the safety of others, the researcher will immediately inform a member of Headway staff about this even if I do not want this to happen. ☐
7. I understand what risks may be involved in taking part. ☐
8. I agree to take part in the above study. ☐

....	....	....
Name of participant	Date	Signature
....	....	....

Name of person taking consent Date Signature

Researcher use only: Participant Identification Number:

Appendix L: Demographic questionnaire

Study title: ***The impact of continuity of self-identity following brain injury*.**
Study lead: Dr Gerry Riley

About You

These are some questions about yourself:

Gender:

Age:

What kind of brain injury did you have?

○ Traumatic brain injury
○ Stroke
○ Another kind: Please say what kind

In what month and year did your brain injury happen?

Who else is filling in a questionnaire from your family?

○ Wife / husband / partner
○ Father / mother
○ Brother / sister
○ Son / daughter
○ Other

For researcher use only - ID No.:

Appendix M: Self-identity after Brain Injury Questionnaire

Self-identity after Brain Injury Questionnaire (SIBIQ)

This questionnaire is about how you think about yourself since the brain injury happened. Below are things that people sometimes say about themselves after a brain injury. For each one, decide whether you agree or disagree with it and circle your answer.

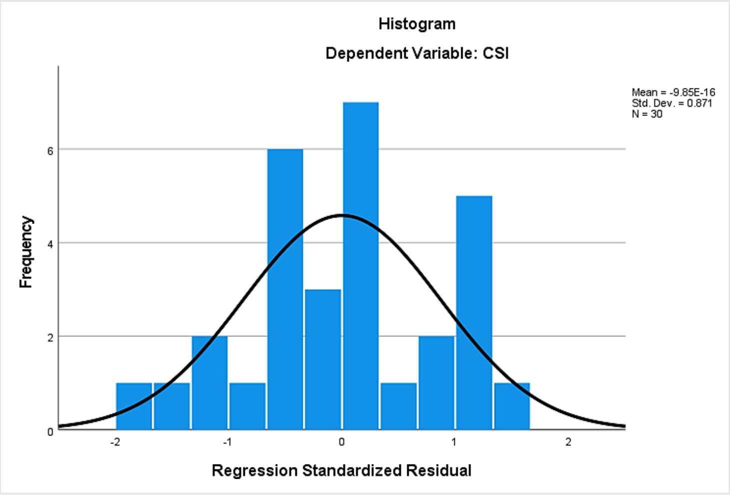
In deciding on your answers, please think about how things were before the brain injury and how things are now.

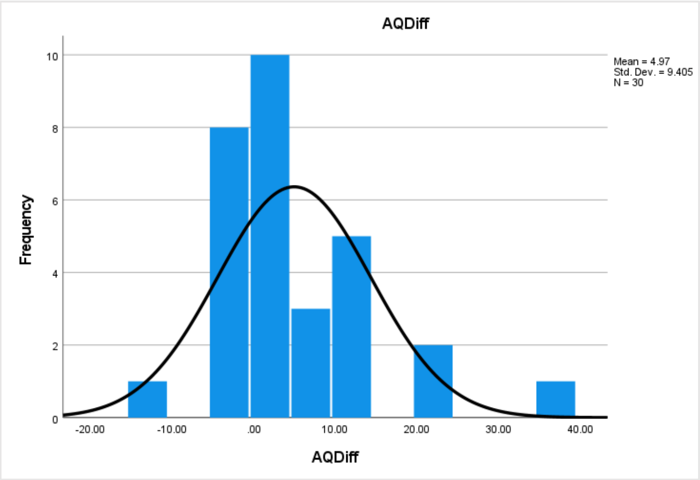
1	Since the brain injury, I sometimes feel like I don't really know myself anymore.	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
2	Despite the changes that have happened because of the brain injury, I still feel like my old self as I was before the injury.	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
3	Compared to how I was before the brain injury, I just feel a very different person now.	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
4	The old me from before is still here – the brain injury hasn't taken that away.	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
5	Sometimes I feel like a stranger to myself.	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
6	The brain injury hasn't taken away the most important bits of who I am.	Strongly agree	Agree	Not sure	Disagree	Strongly disagree

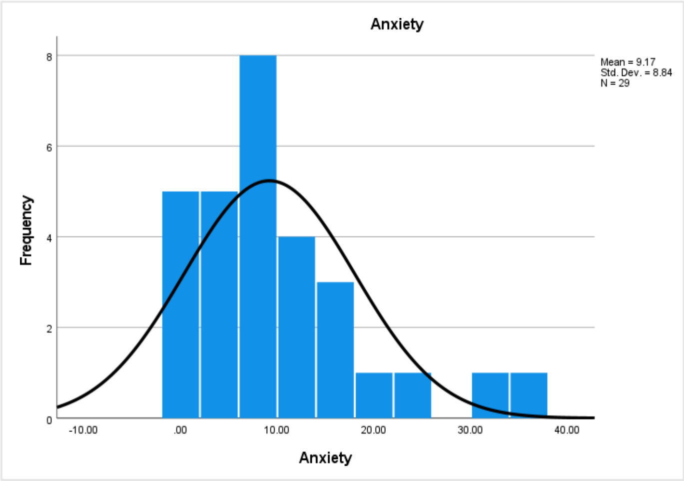
THANK YOU FOR COMPLETING THIS QUESTIONNAIRE

Appendix N: Histogram of standardised residuals

A visual examination of the histogram of standardised residuals and variables showed violation of the assumption of normality of errors (positive skewness).

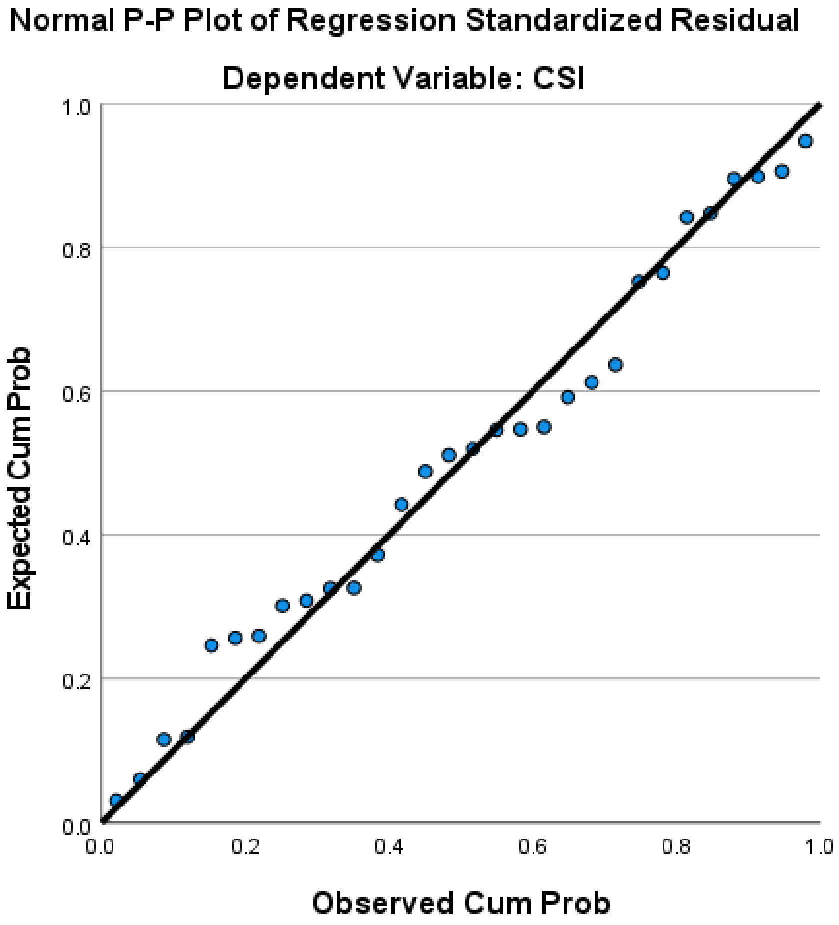


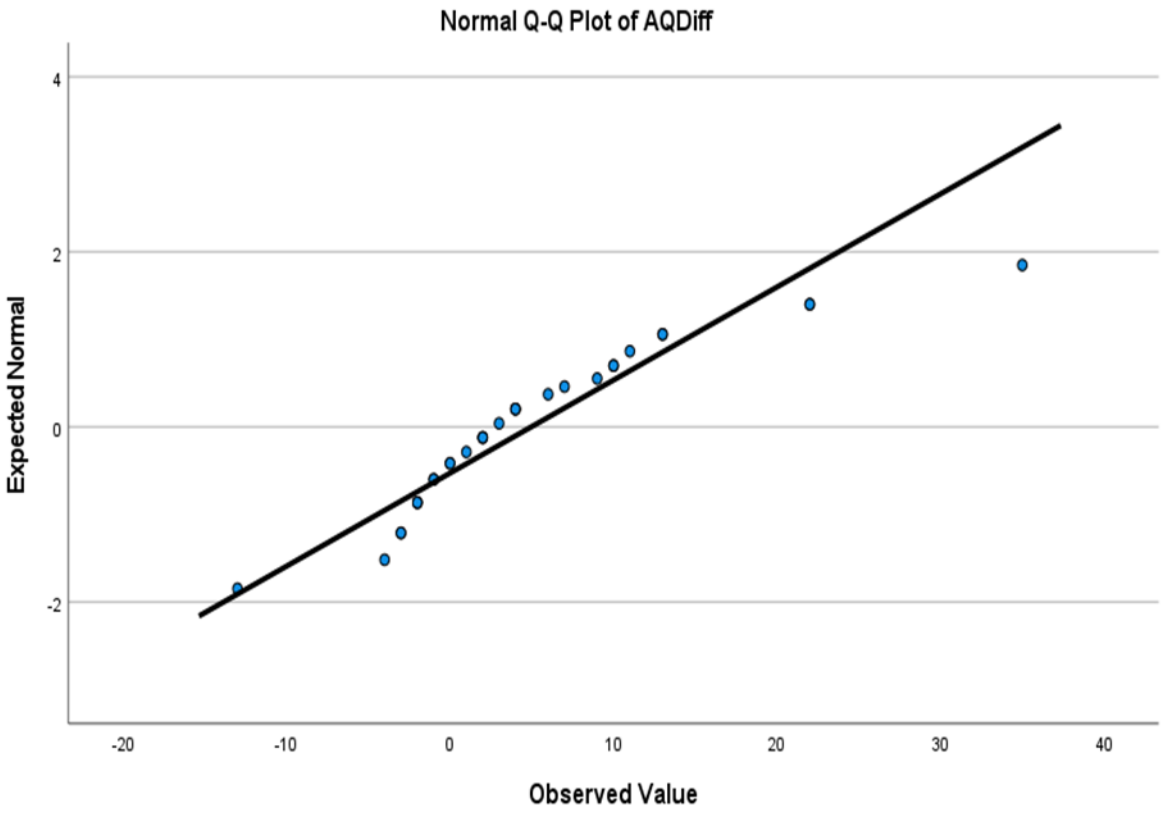




Appendix O: Normal P-P plot of standardised residuals

The normal P-P plot of standardised residuals showed that the data was distributed slightly away from the plot line.





Appendix P: Scatter plot of standardised residuals