

Volume One

Research Component

**ACCEPTANCE AND POSITIVE IDENTITY
RECONSTRUCTION FOLLOWING ACQUIRED BRAIN
INJURY**

by

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Overview

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (Clin.Psy.D) at the University of Birmingham. The thesis is comprised of two volumes, which present the research (Volume One) and clinical (Volume Two) components.

Volume One

This volume contains three chapters. The first chapter presents a meta-synthesis of qualitative literature regarding processes which contribute to positive identity experiences following acquired brain injury. The second chapter presents a qualitative study of the journey towards acceptance as experienced by those with an acquired brain injury. The third chapter is a public domain briefing document, which was specifically developed to disseminate the research findings to the research participants involved in this study, and other relevant stakeholders such as professionals within brain injury services.

Volume Two

Volume two consists of five clinical practice reports (CPRs). The first CPR presents the case of 13-year-old girl's experience of anxiety and panic formulated from cognitive behavioural and systemic perspectives. The second CPR presents a single case experimental design treatment study of cognitive behavioural therapy for the obsessive and compulsive symptoms of a nine-year-old boy. The third CPR presents a service evaluation of the utility of family feedback reports within an intellectual disabilities research centre. The fourth CPR presents an account of consultation to a service user experiences project. The final report is the abstract of an orally-presented case study of a compassion focused intervention for a 74-year-old woman experiencing depression.

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CHAPTER ONE

Literature Review

Understanding the processes which contribute to positive experiences of self-identity following acquired brain injury: A meta-synthesis of qualitative literature

Abstract

Background: Loss of identity following acquired brain injury (ABI) has been well described in the literature. There is a lack of understanding regarding how individuals manage challenges to identity following ABI and maintain or construct a positive identity. This meta-synthesis seeks to derive an understanding of processes which may contribute to positive identity experiences following ABI.

Method: A meta-synthesis of qualitative literature concerning processes which contribute to positive identity experiences following ABI was conducted. 30 articles were identified through a systematic literature search. Article quality was appraised using an appraisal framework, and a thematic synthesis was conducted (Thomas & Harden, 2008).

Results: The synthesis highlighted themes regarding continuity of self, acceptance, redefining of self and self-worth. The role of achievements and other people facilitating positive identity construction were also identified.

Discussion: This review highlights the potential individual differences between identity redefinition and experiences of continuity of self. The subjective nature of a qualitative meta-synthesis and the possibility that broader literature not included for review may be relevant to identity reconstruction are acknowledged as limitations. Further research into processes of identity redefinition and continuity are required, and may help identify what interventions would be most helpful in managing identity challenges following ABI.

Introduction

Identity

Identity is a multi-faceted construct, consisting of different interacting components. Self-identity refers to how individuals subjectively construe themselves, including their perceptions regarding their own unique, enduring qualities (self-concepts) that distinguish themselves from others (Ownsworth, 2014; Stets & Burke, 2000). Identity also includes a systemic, relational component. Social-identity comprises how individuals define themselves according to affiliations to social groups and positions within social systems (Gelech & Desjardins, 2011; Ownsworth, 2014; Stets & Burke, 2000). These identities are suggested to result in identity standards which guide identity-consistent behaviour (Stets & Burke, 2000), for example the self-concept “I am helpful” may guide helping behaviour.

Self-esteem is an evaluative component of identity concerned with how individuals judge their own worth or value (Fennel, 2005; Fennel, 2016; Ownsworth, 2014). Self-esteem includes evaluations of competence and worth (Cast & Burke, 2002). These evaluations consist of conscious and unconscious cognitive appraisals about the self, and are associated with affective experiences, for example anxiety or low mood (Curvis, Simpson & Hampson, 2016). Self-identity, social-identity and self-esteem influence each other (Cast & Burke, 2002; Stets & Burke, 2000). For example, experiences associated with social-identity such as roles, feedback from others, or stigma, could reinforce or constrain perceptions of self-identity and impact upon self-esteem (Curvis et al., 2016; Gelech & Desjardins, 2011; Lucksted & Drapalski, 2015; Stets & Burke, 2000).

Acquired Brain Injury and Identity

Acquired brain injury (ABI) encompasses any non-progressive, non-congenital injury to the brain. This can include traumatic brain injuries (TBI), cerebrovascular events, infections, and tumours. ABI can result in a range of consequences including cognitive, emotional, communicative and physical impairments, which, in turn, impact on engagement in valued roles and activities such as employment and relationships with family and friends. (Ponsford, Sloan, & Snow, 2012; Turner-Stokes, 2003). Such consequences can have long-term impact on the individual's identity. Changes to identity following ABI have become increasingly well documented in the literature, particularly regarding the sense of loss of identity (Nochi, 1998; Ownsworth, 2014) and changes to self-concept following injury (Beadle, Ownsworth, Fleming & Shum, 2016).

In their seminal work on self-concept and ABI, Tyerman and Humphrey (1984) identified discrepancies of post-injury self-concept compared to pre-injury self-concept, including negative characterisations of the post-injury self as bitter, dependent, frustrated, irritable and of less worth, and an expectation of recovery to pre-injury self. A contemporary systematic review of self-concept changes identified negative changes to self-concept following TBI (Beadle et al., 2016). Stroke survivors administered the Head Injury Semantic Differential Scale (HISD) (Tyerman & Humphrey, 1984) also reported changes between their past (pre-stroke) and current self-concept (e.g., Ellis-Hill & Horn, 2000). They identified themselves as less capable, independent, in control, satisfied, interested, active, confident and of less value, than prior to their stroke. More negative self-concept ratings have been found in individuals with TBI compared to uninjured control groups (Ponsford, Kelly & Couchman, 2014), in addition to lower self-esteem, and higher levels of anxiety and depression.

These changes to self-concept may be considered a catastrophic threat or loss to an individual's sense of self (Gracey, Evans & Malley 2009; Myles, 2004). For example, following ABI an individual may recognise that they are unable to meet pre-injury roles or demands, or act consistently with how they would have prior to the ABI, which in turn may result in greater negative self-evaluations (Myles, 2004). Themes regarding loss of self have also been identified within qualitative literature regarding recovery following ABI. This is particularly notable regarding the challenges injury posed to social identity (Chamberlain, 2005; Freeman, Adams & Ashworth, 2015; Gelech & Desjardins, 2011; Muenchberger, Kendall & Neal, 2008). Nochi (1998) proposed that following TBI loss of self was experienced through loss of self-knowledge, comparison of post and pre-injury experiences, and the threat societal labels posed to the individual's sense of self.

Given the evidence of negative identity experiences, consideration must be given to the potential impact of negative identity perceptions on self-esteem and general psychological well-being. Self-discrepancy theory suggests that when a discrepancy between the actual self and idealised or ought self occurs, we may be more likely to experience depressive and anxious symptomology (Higgins, 1987; Higgins, Klein & Strauman, 1985). Cantor et al. (2005) suggested that discrepancy between pre-injury and post-injury identity following TBI may contribute to psychological distress. Systematic review by Beadle et al. (2016) concluded that negative self-identity and discrepancy with pre-injury self was associated with greater emotional distress. Negative comparison of the post-injury self to the pre-injury self has been found to be positively associated with lower subjective quality of life (Vickery, Gontovsky & Caroselli, 2005), positively associated with depression and grief, and negatively associated with self-esteem and awareness (Carroll & Coetzer, 2010). In a review of factors associated with self-esteem following ABI (Curvis et al., 2016), it was concluded that individuals with

ABI have lower levels of self-esteem, and greater changes in perceived identity and self-concept were associated with lower self-esteem. This review also identified numerous factors associated with lower self-esteem, including higher levels of perceived loss, negative coping styles and appraisals of coping, and challenges to functional independence. Furthermore, Curvis et al. (2016) identified associations between self-esteem and psychological wellbeing and distress, including depression. The literature suggests negative identity experiences following ABI are associated with a range of negative outcomes including functioning and emotional wellbeing. This highlights the need to develop a greater understanding of processes which may be able to mitigate these effects and promote positive identity experiences.

The experiences of loss in relation to identity and self-concept is clearly evidenced in the quantitative and qualitative literature, however there is also some evidence that not all identity experiences after ABI are negative. Quantitative studies have found participants described positive changes and continuation of positive self-concepts between pre- and post-injury selves (Beadle et al., 2016). Consistency of personality traits such as friendly, calm, caring and hopeful (Ellis-Hill & Horn, 2000); and positive changes such as increased maturity, appreciation and responsibility (Tyerman & Humphrey, 1984) have been reported. Qualitative studies which have sought to understand the subjective experience of self and identity have also found evidence of positive identity experiences following brain injury, including continuity of self-identity (Gelech & Desjardins, 2011), acceptance of the injury and current self (Howes, Benton & Edwards, 2005) and a felt experience of growth or redefinition of self (Fraas & Calvert, 2009; Muenchberger et al., 2008). Gelech and Desjardins (2011) encapsulated this: “Survivors constructed the brain injury experience as one in which the self ultimately underwent a moral growth process rather than one that was dominated by grief, loss, reduction or diminution.” (p.70). The integration of positive and

negative identity experiences within the overarching processes of identity reformation following ABI should therefore be considered.

Within the literature some models of identity processes have been proposed. Thomas, Levack and Taylor (2014) suggested an integrative model of identity following TBI which may also hold relevance to the wider ABI population. This model was derived by concept analysis of literature relevant to identity following TBI. Thomas et al. (2014) proposed that identity becomes disrupted following TBI. Identity consists of egocentric and socially constructed components of identity, and identity shared with others. Self-awareness is suggested to mediate self-identity following TBI, as did opportunities to express and experience identity through meaningful occupation. Whilst this model provides a useful overview of identity following TBI, it does not consider in depth the processes which may underpin successful identity adaption following brain injury. A process based model was proposed by Muenchberger et al. (2008), describing how identity transitions may occur following TBI. This model proposed that experiences of loss and negative self-comparison occur, and thereafter individuals experience identity growth or expansion. Interestingly, this model suggests that these experiences persist, rather than proposing a finite end to identity transition. This proposal is likely to be applicable to individuals with ABI more broadly. Individuals may experience positive changes to identity following processing of negative impact of ABI, however the extent to which ABI negatively affects individuals' self-identity may vary; and some individuals may not successfully process the negative impact. Given this individual variation, it is prudent to seek to understand the processes involved in successfully negotiating the challenges created for self-identity by ABI.

Several valuable reviews relating to identity following brain injury have been conducted, ranging from scoping reviews of literature regarding identity following ABI, which are not systematic in nature, reviews of quantitative studies of changes to self-concept following TBI, and reviews of quantitative studies of identity-based interventions (Beadle et al., 2016; Bryson-Campbell, Shaw, O'Brien, Holmes, & Magalhaes, 2013; Ownsworth & Haslam, 2016; Segal, 2010). These reviews have not, however, included a) detailed synthesis of the qualitative literature, or b) a sustained focus on processes that appear to contribute to positive experiences of self-identity following ABI. This review aims to complement the existing literature by providing an in-depth review of qualitative studies of how ABI survivors may successfully address challenges to their self-identity resulting from ABI. A better understanding of these processes may contribute to the development of interventions to support those with an ABI to negotiate more effectively the challenges that the brain injury poses to their identity.

Research question: What does qualitative literature tell us about processes that appear to contribute to successfully managing the challenges ABI poses to self-identity, and to positive identity experiences following ABI?

Method

A literature search was conducted on 02.04.17 to source papers that explored the impact of ABI on identity. Papers were then searched for findings relating to processes which appear to contribute to successfully managing the challenges ABI poses to identity. Three electronic databases were searched for articles in peer-reviewed journals; PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and MEDLINE. These databases were selected to encompass a wide range of psychological, medical and healthcare

journals. No year limits were applied to the search. Search terms (see Table 1) were selected to maximize the search yield based on language used within existing literature, and suggested subject headings within electronic databases. Search terms were used as keyword searches (within title, abstracts, key concepts, and headings) and database subject headings. Terms were combined with the Boolean Operators and/or.

Table 1. Search terms

Search A (OR)	Search B (OR)	Search C (OR)
brain injur* head injur* brain damage traumatic brain injur* acquired brain injur* stroke cerebrovascular brain tumo?r* brain infection*	identit* self selves self-esteem personhood* self-concept* self-discrepanc* self-perception* self-evaluation* self-congruenc*	Qualitative Theme* Interview* Narrative* Thematic analys* Interpretative phenomenological analys* Narrative analys* Content analys* Discourse analys* Grounded theory Phenomenolog*
Final Search: A, B and C terms combined with "AND"		

Due to the documented difficulties identifying qualitative research within the literature (EPPI-Centre, 2010; Flemming & Briggs, 2007), in addition to the electronic search, identified articles reference lists and lists of articles which cited them were searched for additional relevant material. Due to time constraints hand-searching of relevant journals was not conducted.

Following removal of duplicate articles from the databases, articles were filtered according to inclusion and exclusion criteria detailed in Table 2. Papers which included content from other populations or data from individuals without ABI were excluded as it was deemed unfeasible to separate findings solely based on ABI survivor experience when they were aggregated within analyses. Tools within the databases were used to aid this process

when applying criteria regarding language, population and literature type. Study methodology was manually assessed through abstract screening due to poor database indexing of methodology (EPPI-Centre, 2010). Criteria were further applied through title and abstract screening. Qualitative exploration of processes contributing to positive identity was assessed according to whether authors had explicitly linked data or themes to identity reconstruction, self-worth or self-concepts. When ambiguity regarding an article meeting criteria arose, the full article was screened, particularly regarding study findings relating to processes contributing to positive identity experiences. Studies were included if they contained some findings relating to processes contributing to positive identity experiences even if these findings were not the primary focus of the original study. This approach was undertaken as it has been acknowledged in the literature that relevant findings may be present in qualitative studies in which the focus of primary research studies may differ from the meta-synthesis research question (Ring, Ritchie, Mandava, & Jepson, 2011; Sandelowski & Barroso, 2007).

Table 2. Inclusion and exclusion criteria

Inclusion	Exclusion
English written	Non-English papers
Empirical qualitative papers	Opinion pieces, literature reviews and quantitative research
Adult acquired brain injury population	Other populations such as neurodegenerative conditions, and individuals with mental health difficulties
Qualitative exploration of processes contributing to positive identity experience	Papers relating to child populations
Peer reviewed journals	Papers including data from individuals without ABI e.g. families, professionals

Quality Appraisal

There is ongoing debate regarding the use of quality criteria and checklists for appraisal of qualitative research (Ring et al., 2011). This is due to a combination of factors, including differences in methodology, changing standards of research over time, debate regarding what constitutes quality in qualitative research, and the applicability of terms such as reliability and validity. Whilst some advocate quality appraisal (Walsh & Downe, 2005), others caution that exclusion based on quality criteria may introduce bias and limit the knowledge pool (Sandelowski & Barroso, 2002). Sandelowski and Barroso (2002) rather advocate a more flexible, reflexive use of quality criteria. Articles were therefore assessed for quality to inform critical review of the data, but were all included in the synthesis to maximise the data pool. The National Institute of Health and Clinical Excellence's qualitative literature quality appraisal framework was selected from "Methods for the development of NICE public health guidance" (NICE, 2012) to evaluate the quality of the articles selected for inclusion in this meta-synthesis. See Appendix A for the framework, and refer to NICE (2012) for further guidance on framework implementation. Consideration was made whether qualitative case studies identified for review should be appraised using different criteria, however it was decided that the NICE qualitative criteria maintained the standards that would also be desirable in a qualitative case study, as detailed by Baxter and Jack (2008).

Data Extraction and Synthesis

There are various methods described in the literature for meta-synthesis, including narrative review, thematic synthesis, meta-ethnography, meta-study and grounded theory (please see Barnett-Page & Thomas (2009) and Ring et al., (2011) for discussions of methodologies). This review employed the thematic synthesis approach to analysis as detailed

by Thomas and Harden (2008). This approach was used as it provides a method for synthesising findings from different types of qualitative research, including the development of interpretative themes which can “go beyond” original study findings. There are both similarities and distinctions between this approach and other meta-synthesis approaches; for example, although thematic synthesis and meta-ethnography are both interpretative of primary research, meta-ethnography would seek to develop a model of the phenomena of interest, which was not the aim of this review. In addition, Thomas and Harden provide clear guidelines for synthesis which serves to enhance the transparency of the procedure employed. Following their procedure, the entire results/findings sections of papers were extracted for analysis. Both direct quotations and researcher interpretations detailed in findings were included as data for meta-synthesis, and no weighting of greater importance or value was applied to either type of information (Thomas & Harden, 2008).

Thematic synthesis consisted of three stages: 1) line by line coding of extracted material, 2) identification of descriptive themes from coded material, and 3) development of more analytical, interpretative themes. Throughout this process of analysis, the research focus on positive identity experiences and processes was maintained, particularly during the latter stage of interpretative analysis. Following initial coding, all findings extracts and themes relevant to the research question were compiled in an Excel table to facilitate further analysis and organisation of themes. This is an amendment to Thomas and Harden’s (2008) original recommendation that all study findings should be included. This amendment was justified as the amount of material relevant to the research question was relatively small in several of the primary studies which also included material of no relevance to the research question.

Reflexivity

As a trainee clinical psychologist I am interested in, and have previous experience working in brain injury services, although I do not have personal experience of ABI. During the course of reviewing this literature I was aware of my own interest in the potential for positive identity experiences following ABI. It is acknowledged that this specific focus of the meta-synthesis means that alternative narratives about negative identity experiences have not been included. This does not imply that these processes do not occur, and this meta-synthesis should be considered alongside existing literature about negative identity experiences. The subjectivity of appraising and reviewing qualitative articles is recognised, and I was aware that I erred on the side of inclusivity when screening articles for inclusion.

Search Results

Database searching on Medline, PsycINFO and CINAHL yielded 1160, 646 and 206 articles respectively. Following removal of duplicates and exclusions, 27 articles remained for inclusion. An additional 3 articles were identified through reference and citation searching, yielding a total of 30 articles for meta-synthesis. See Figure 1 for summary of articles screened for final inclusion in review.

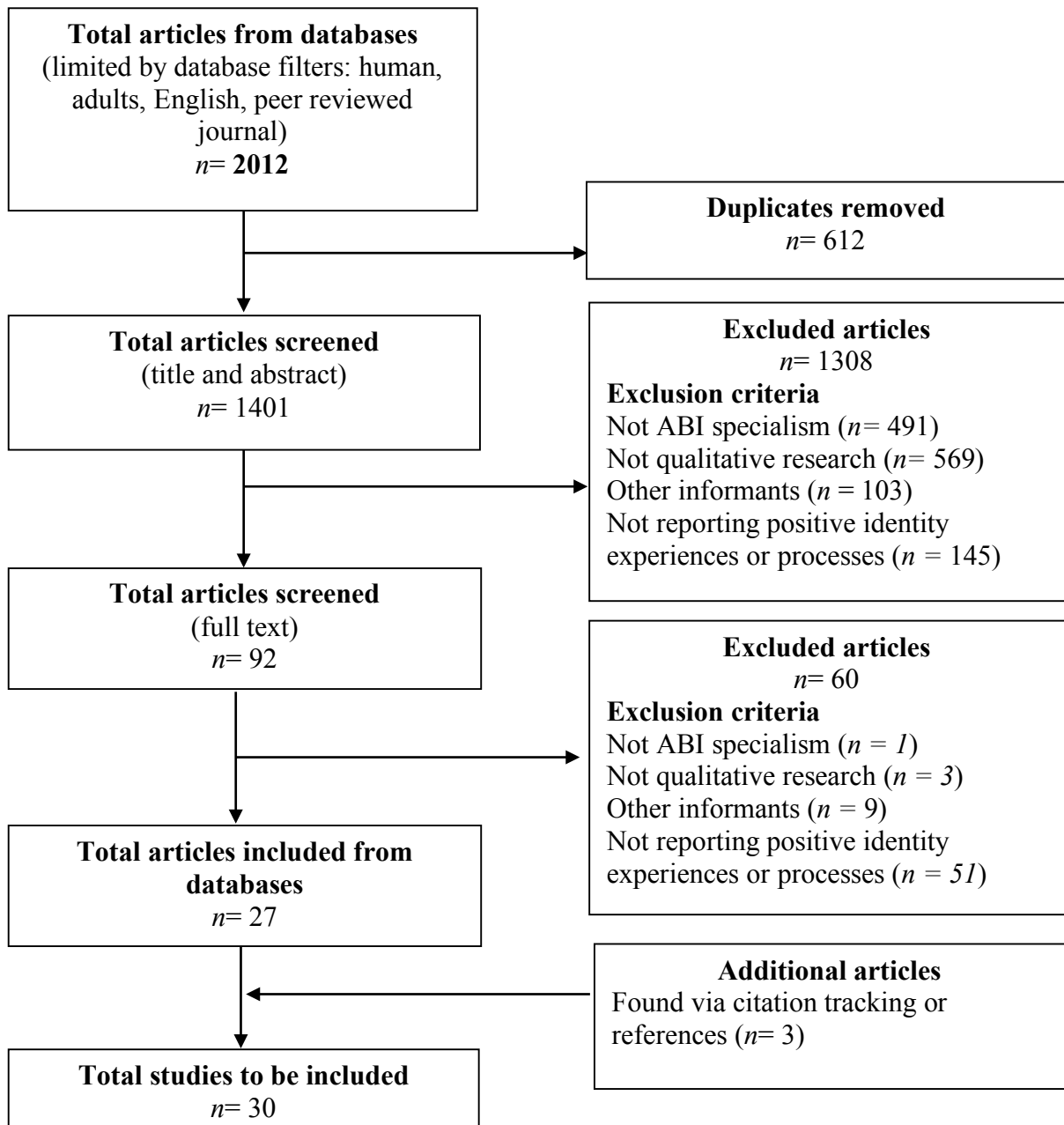


Figure 1. Search results flowchart

Study Characteristics

Characteristics of the 30 studies included for meta-synthesis are detailed in Table 3.

Data synthesised from these studies was derived from a total of 357 participants (222 male, 155 female). The age range of participants was 18-85 years, and time since injury ranged from 6 months to 42 years.

Table 3. Study characteristics

Study	Aims	Sample	Setting	Method
Anderson & Whitfield (2013)	To understand how social resources might enhance stroke survivors' participation in personally meaningful activities	9 individuals with stroke 6 males, 3 females Age range 53-64 years Time post stroke approx. 6-10 years	Canada Interviews conducted at participants' homes, or a nearby location of their choice	Semi-structured interviews Grounded theory, situational analysis
Chamberlain (2006)	To understand the experiences of self, and expressed meanings, relating to survival and recovery following TBI	60 individuals with TBI 40 male, 20 female Average age 38 years Time post-TBI 1 year	Australia Majority of interviews took place in participant homes	Narrative interviews Qualitative content analysis, narrative analysis
Chow & Nelson Becker (2010)	To understand the resiliency of the Chinese female stroke survivor	11 females with stroke Age range 45-81 years Time post stroke 5 months - 22 years	China Location of interviews not reported	2 Semi-structured interviews across 3 years Qualitative analysis as described by McCracken (1988)
Crisp (1993)	To understand experiences of living with a TBI and psychosocial responses to TBI	10 individuals with TBI 6 male, 4 female Age range 22-50 years Time post-TBI 3-20 years	Australia Community settings	7-10 interviews per participant across 12 months Thematic analysis/grounded theory

Douglas (2013)	To explore how individuals who have sustained severe TBI conceptualise self	20 individuals with TBI 16 male, 4 female Age range 21-54 years Time post-TBI 5-20 years	Australia Interviews took place in participant homes	Interview Grounded theory analysis
Eriksson & Tham (2010)	To identity experiences of occupational gaps during the first year after stroke	4 individuals with stroke 3 males, 1 female Age range 50-61 years Time post stroke 1 year	Sweden Interviews took place in rehabilitation unit, participant homes, or at the University	4 Semi-structured interviews over 1 year Empirical Phenomenological Psychological method analysis
Fraas & Calvert (2009)	To determine the factors leading to successful recovery	31 individuals with ABI 21 male, 10 female Age range 21-66 years Time post ABI 22-432 months	USA Community based post-rehabilitation programme	Semi-structured life story interviews Thematic analysis
Freeman, Adams & Ashworth (2015)	To understand individuals' sense of self and emotional distress and growth following TBI	9 males with TBI Age range 22-59 years Time post-TBI 17 months - 27 years	UK Neuropsychological rehabilitation centre. 2 interviews occurred in participants homes	Semi-structured interviews Thematic analysis
Gelech & Desjardins (2011)	To examine the construction of self following ABI	4 people 3 male, 1 female Age range 37-55 years Time post-ABI 4-21 years	Canada Interviews conducted at the rehabilitation centre and participant homes	Life history and semi-structured interview Thematic, syntactic, and deep structure analysis
Gelech, Bayly & Desjardins (2017)	To analyse how survivors construct the self in a female ABI survivor self-help group	5 females with ABI Age range 36-64 years Time post injury 6-42 years	Canada 10 self-help group sessions	Recordings of group sessions Sociolinguistic interactional analysis

Glintborg (2015)	To investigate identity reconstructions and changes throughout recovery following ABI	42 individuals with ABI 28 male, 14 female Age range 18-66 years Time since injury 1 year	Denmark First interview conducted in hospital Second interview conducted in participants' homes	2 Semi-structured interviews a year apart Thematic content analysis
Hoogerdijk, Runge & Haugboelle (2011)	To understand how individuals make sense of their adaption process and occupation	4 individuals with TBI 3 male, 1 female Age range 33-61 years Time post-TBI 20-27 months	The Netherlands Interviews conducted in participants' homes.	2 semi-structured interviews Narrative analysis
Howes, Benton & Edwards (2005)	To explore the experience of life post ABI for women	6 women with ABI Age range 30–51 years Time post-injury 7mo - 25years	UK Interviews conducted in referring hospital	Semi-structured interviews IPA
Hutton & Ownsworth (2017)	To explore the experience of sense of self and continuity in younger adults after stroke	10 individuals with stroke 3 males, 7 females Age range 26-70 years Time post stroke 6 months - 31 years	Australia 8 interviews conducted at participants homes, 2 at rehabilitation centre	Semi-structured interviews Phenomenological analysis
Jones & Curtin (2011)	To understand interactions between masculine identity and participation of men living with traumatic brain injury	8 males with TBI Age range 24-66 years Time post-TBI 2-31 years	Australia Majority of interviews took place in participants' homes	Semi-structured interviews Grounded theory analysis
Klinger (2005)	To understand the process of occupational adaptation after traumatic brain injury	7 individuals with TBI 6 male, 1 female Age range 29-45 years Time post-TBI 2-17 years	Canada Community based	Semi-structured interviews Constant comparative method

Kouwenhoven, Kirkevold, Engedal, Biong & Kim (2011)	To describe the lived experience over time in stroke survivors suffering from early depressive symptoms	9 individuals with stroke 3 males, 6 females Age range 30-85 years Time post stroke 6-18 months	Norway Interviews took place at participant homes, work-places and over the telephone	3 Semi-structured interviews at 6, 12 & 18 months post stroke Hermeneutic phenomenological approach
Levack et al. (2014)	To develop a client driven conceptual framework of self identity difficulty post ABI to produce an outcome measure	49 individuals with TBI 34 male, 15 female Age range 21-79 years Time post-TBI 6 months - 36 years.	New Zealand	8 regional focus groups Grounded theory analysis
Lorenz (2010)	To describe the lived experience of an ABI survivor by exploring her search for a new identity	1 female Age 52 years Time since injury 17 years	Photovoice project within a brain injury support group Interview conducted at authors home	Case study Series of reviewing of photographs within a photovoice group and in a photo-elicitation interview Narrative analysis
Martin, Levack & Sinnott (2015)	The lived experience and perceptions of individuals with ABI regarding life goals	5 individuals with ABI 2 male, 3 female Age range 51-62 years Time post-ABI 1 - 36 years	Residential rehabilitation setting	Semi-structured interviews Interpretative phenomenological analysis
Medved & Brockmeier (2008)	To investigate how individuals with autobiographical memory impairments experience their sense of self	7 individuals with ABI 3 male, 4 female Age range 27-76 years Time post-injury 1 year	Interviews conducted at participants' homes	2x semi-structured interviews Ideographic and discursive approach
Muenchberger, Kendall & Neal (2008)	To understand turning points and processes that underpin identity change for individuals with brain injury	6 individuals with TBI 4 male, 2 female Age range 22-42 years Time post-injury 1 - 25+ years	Australia	Life storytelling interview Thematic analysis

Nochi (2000)	To explore the narratives of individuals who seem to cope with changed lives following TBI	10 individuals with TBI 8 male, 2 female Age range 24 - 54 years Time post-TBI 3-28 years	USA Local TBI support group	Interviewing and participant observation Grounded theory analysis
Parsons & Stanley (2008)	To explore the experience of occupational adaptation for individuals post ABI	2 male participants aged 30 and 45 years Time since injury not reported	Australia	Semi-structured interviews 1-2hrs Thematic analysis
Price-Lackey & Cashman (1996)	To explore how one woman, experienced and adapted to a traumatic head injury	1 female with TBI, age not reported, time since injury not reported	Not reported	Case study Two life history interviews, over 1 year Narrative analysis
Sabat, Moodley & Kathard (2006)	To explore the nature and process of self-identity construction pre- and post-TBI	1 male with TBI Age 31 Time post injury 12 years	South Africa Location of interviews not reported	Case study 3 Life story interviews Narrative analysis
Soeker (2011)	To explore experience of return to work and adaptive strategies	10 individuals with brain injury 9 males, 1 female Age range 31-64 years Time since injury not reported	South Africa 2 interviews conducted at participant workplaces, 6 at participant homes and 2 at hospital	Semi-structured interviews Qualitative analysis described by Morse and Field (1996)
Stone (2005)	To understand how young female stroke survivors understand the stroke and its effects within the context of their lives	23 females with stroke Age range 23-57 years Time post stroke 3-33 years	Canada, USA, UK Participant homes, 3 in alternative local settings	Semi-structured interviews Qualitative - analysis method not specified

Swart, & Horton (2015)	To explore the experiences and perspectives of aphasia trainers from one Conversation Partners Scheme	8 individuals with stroke and aphasia 4 males, 4 females Age range 38-66 years Time since stroke not reported	UK Interviews took place in participants' homes or at local university	Semi-structured interviews Thematic analysis
Wolfenden, & Grace (2012)	To explore the experiences of young, survivors of stroke returning to work and identity re-establishment	5 females with stroke Age range 34-44 years Time post stroke 1-9 years	Australia Location of interviews not reported	Semi-structured interviews Critical interpretivist approach Analysis method not reported

Quality Appraisal

Quality appraisal was conducted using the NICE qualitative quality appraisal framework (NICE, 2012). Quality appraisal of individual

papers is summarised in Table 4.

Table 4. *Quality appraisal summary*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
	Crisp (1993)	Frans & Calvert (2009)	Geleach & Desjardins (2011)	Hoogwerf, Künge & Haugboeile (2011)	Hovew, Benton & Edwards (2005)	Jones & Curtin (2011)	Kinger (2005)	Levack et al (2014)	Muenchberger, Kendall & Neal (2008)	Parsons & Stanley (2008)	Soeker (2011)	Camberlain (2006)	Douglas (2013)	Freeman, Adams and Astworth (2015)	Gimhng (2015)	Martin, Levack & Simon (2015)	Melved & Brockmeier (2008)	Nochi (2000)	Anderson & Whitefield (2013)	Chow & Nelson Becker (2010)	Erksson & Tham (2010)	Geleach, Bayly & Desjardins (2017)	Hutton & Owsworth (2017)	Kouwenhoven, Krikewold, Engedal, Brong & Kim (2011)	Stone (2005)	Swart, & Hooton (2015)	Wolenden, & Grace (2012)	Lorenz (2010)	Price-Lackey & Cashman (1996)	Sabat, Moodley & Kahard (2006)
Theoretical approach																														
1. Is a qualitative approach appropriate																														
2. Is the study clear in what it seeks to do?																														
Study de sign																														
3. Is research design/methodology defensible/rigorous?																														
Data collection																														
4. Was the data collection carried out?																														
Trustworthiness																														
5. Is the role of the researcher clearly described?																														
6. Is the context clearly described?																														
7. Were the methods reliable?																														
Analysis																														
8. Is the data analysis sufficiently rigorous?																														
9. Is the data 'rich'?																														
10. Is the analysis reliable?																														
11. Are the findings convincing?																														
12. Are the findings relevant to the aims of the study?																														
13. Are conclusions clear and plausible?																														
Ethics																														
14. Is the reporting of ethics clear and coherent?																														
Overall quality assessment																														
Overall assessment																														

Yes	Green
Key	Orange
Unsure	Yellow
No	Red

Theoretical approach: Background literature and aims were clearly summarised within all papers, except for two studies (7, 9).

Study Design: 12 studies were rated as “not sure” regarding appropriateness of study design (1, 3, 4, 7, 12, 15, 17, 18, 22, 25, 27, 28) as they did not detail a clear rationale for application of the approach utilised. In some cases, a reference was provided, but an explanation or justification for the referenced method was absent.

Data collection: The majority (n=25) provided appropriate, description of data collection procedures, including recording/transcription. Five articles were rated as not sure; three did not provide any information regarding content of interview schedule (10, 15, 20), whilst two did not provide detail of recording/transcription (24, 28).

Trustworthiness: The limited reporting of the role of the researcher and reflexivity is an area of relative weakness within this dataset. Ten articles made some attempt at reflexivity, for example explaining how the study was introduced to participants (2, 10), referencing use of a reflective diary (23), acknowledging dual roles as clinicians and researchers (4) or possible theoretical positions (7, 11). Only four articles were rated as providing clear descriptions of the role of the researcher (13, 24, 25, 28).

According to the quality criteria, reliability of methodology is determined by appropriateness of the method for the research aims, and use of triangulation methods. Whilst all studies appeared to employ appropriate methods, the majority (n = 17) were rated as “not sure” regarding method reliability as they did not include any triangulation (e.g. through a secondary method of data collection). This is considered an area of relative weakness within the meta-synthesis dataset. Consideration should be given to the reason for this weakness within these studies. It is acknowledged that, within this review, studies which included data

from other informants (e.g. carers) but in which the basis of the summaries or interpretations was unclear (i.e. it was unclear whether it derived from the person with the ABI or another source) were excluded. This does introduce a negative bias against finding triangulation within the articles sampled. However, in the case of studies specifically about the subjective experience of a particular population, reliability may not be enhanced by inclusion of other informant groups.

Analysis: The majority of studies (n = 19) provided detailed description of a systematic method of analysis. Although the majority of studies (n = 26) included rich data, this was often not present in support of all interpretations within findings. Analysis procedures were rated as “reliable” for 19 studies. Common methods to enhance reliability were member checking, and analysis checking by second researchers or supervisors. Eight articles were rated as “not sure” (1, 9, 11, 14, 16, 18, 23, 24) as, although they referenced procedures there was no information regarding how any discrepancies were addressed. Five articles were rated as “unreliable” (4, 15, 20, 22, 27) as they did not detail any processes to enhance analysis reliability.

The majority of studies (n = 24) were rated to have “convincing” findings. Four articles were rated as “unconvincing” (1, 17, 20, 28) as the interpretations presented were not clearly grounded in presented data, and higher levels of interpretations were employed without acknowledgment of this. Two articles were rated as “not sure” (22, 26) as, although the findings seemed plausible and coherent, there was limited data to support them. 12 studies were considered to have “inadequate” conclusions (1, 3, 6, 9, 11, 12, 15, 17, 20, 25, 26, 28). For the most part, this was due to a lack of consideration of research limitations or clinical implications. In four of these studies, however, some of the conclusions drawn were considered to be less plausible or grounded in the findings presented (12, 17, 15 20).

Ethics: Ethical approval was reported in the majority of studies ($n = 21$). Seven studies were rated as “inappropriate” (1, 7, 18, 20, 22, 28, 29) as they made no reference to ethical approval or procedures, whilst two were rated as “not sure” (2, 8), as they cited procedures such as informed consent, but did not specify receipt of ethical approval.

Overall Assessment

According to guidance on use of this appraisal tool (NICE, 2012), overall assessment should be based on the number of quality criteria met/unmet, and the likelihood that this would influence overall study conclusions. In summary, 15 studies were classified as good quality (++), 10 as fair quality (+), and five as poor quality (-). Studies of poor quality could be excluded from analysis, however in this instance it was considered appropriate to include them as further evidence of themes. Caution was made in interpreting findings from these papers however, in particular ensuring no themes were derived solely on the basis of these papers.

It is observed that quality appraisal described here is based on the reporting within articles, and does not necessarily reflect the quality of the study undertaken. Greater subjectivity of some criteria was observed during application of the framework, specifically with reference to 9) richness of data, 11) findings convincing and 13) conclusions plausible (See Appendix A for framework). Brevity of journal articles is likely to contribute to issues regarding quality appraisal of qualitative papers.

Findings

A summary of the themes emerging from the meta-synthesis is presented in Table 5.

Table 5. Meta-synthesis themes

Theme	Subtheme	N studies contributing to theme
Continuity of self		18
Acceptance		20
Redefining self	Personal growth	20
	Redefining social roles	17
	Recovery	8
	Resisting a disabled self	11
Self -worth		17
External contributors to positive identity	The role of others	10
	Achievement	9

Continuity of self

Some participants described continuity of self – that they were still the same person as before the injury: "I haven't undergone extreme personality change . . . I feel the same as I've always been" (Crisp, 1993, p.399). For some, core aspects of their identity were considered intact post-injury: "Tracey's identity did not hinge on physicality. She identified with being patient, compassionate and understanding" (Wolfenden & Grace, 2012, p.206); "I'm probably still a bit loud. I like going to see friends, that sort of thing. And going out." (Martin, Levack & Sinnott, 2015, p.11).

Continuation of pre-injury traits, values and interests influenced future life goals and choices (Hoogerdiijk, 2011). Opportunities to engage in activities and roles that are consistent with these traits, values and interests appeared to reinforce the experience of a continuous self:

Being a trainer also gave many participants a link back to their pre-stroke roles and a sense that their skills and knowledge were not irrelevant. This all helped to reconnect and create a sense of continuity between who they had been and who they now were [...] “because it gives me a link back to my past what I used to be able to do. Because, when you have what I had, and you’ve gone through it, you think there’s absolutely nothing that you can contribute, everything, all your experience is just gone, and being a conversation partner, it gives me some link to what I used to do.” (Swart & Horton, 2015, p.204)

Some highlighted the consistency between current roles and activities and their pre-injury identity. This could involve an appraisal of new roles and activities as extensions or developments of previous identities: "The jewellery course I'm doing [is] an extension of my trade as a Fitter and Turner, I'm working with metal still. So it's great." (Jones & Curtin, 2011, p.1573); “I make things out of nothing, So the chef in me is still there, I make things out of nothing, So that’s what my freezer is full of, things like that” (Lorenz, 2010, p.871). One participant explained how he has always had a strong interest and enjoyment in volunteering and helping others. This value continued post-injury and contributed to a positive identification of himself as an empathic person:

Well, I think it is the joy of helping others. Because...If I look back over the years, then it has always been like that. I have always had a passion about speaking to other people. Well, how to say it, be a..., how to say it, an empathic person...right [...] And I have always been there if someone needed it. (Glintborg, 2015, p.14)

Recognising continuity of self appeared to foster a sense of satisfaction and, perhaps, validates their identity and bolsters their self-esteem:

Even when I didn't have ways in terms of accomplishment and achievement that I'd had before, I still had value. There are times of standing outside and looking at myself in my process [of recovery] and appreciating my own determination [and] say "Well, at least I've got that." And I discovered that... who I was as a core person wasn't lost and wasn't damaged (Price-Lackey & Cashman, 1996, p.311)

Some participants were proud of enduring traits they felt had positively contributed to their recovery: "I wouldn't be as far along the recovery process if I hadn't been determined. So I thank myself for being dogged." (Hutton & Ownsworth, 2017, p.8).

Challenges to a continuous identity included difficulties in enacting roles and activities that were consistent with pre-injury identity: "I'm a very different person to who I was. I think it's - myself, you know, inside is still me, but it's the-who I am in society where I fit, that's what I don't know anymore" (Levack et al., 2014, p.6). For some, changes to their own abilities made identity-consistent activity difficult: "No, I'd say the [things that are important to me] are pretty much the same, but it's my ability to be able to achieve them which has changed" (Martin et al., 2015, p.11). Gelech and Desjardins (2011, p.68) describe how the perceptions of others can be a threat to this sense of coherence: "I have changed in other people's eyes for sure, 'cause every time my mom sees me she cries. Yeah. But I still feel like the same person. It makes me sad, uh, makes me angry."

The impact of cognition on identity experiences has not been considered in detail within this sample of literature, with the exception of a study of severe memory impairment and identity (Medved & Brockmeier, 2008). Medved and Brockmeier (2008) suggested that seven participants with anterograde memory impairments had maintained a sense of identity

continuity through processes such as the importing of pre-injury memories and adoption of information told by others as memory:

“I question everything. I'm curious. I want to know how things work, how they are made, where they are from. Why I question everything, and since I've had my aneurysm, and realize my memory at times is really really bad, I question everyone. I tell my employees if you don't understand you **MUST** ask me.” [...] The tenor of her narrative is that she continues to be regarded by others as a figure of authority, as someone who is knowledgeable and competent despite her 'bad' memory. (Medved & Brockmeier, 2008, p.473)

The authors interpret the woman's response as a memory importation, through which she experiences continuity with her pre-injury identity despite no longer working. It is unclear from the article whether participants were fully aware of the extent of the difficulties, for example if the woman quoted above was aware that she was no longer working. Their findings were not evidenced in other studies reviewed, and, within the study itself, were not compared to the experience of individuals without such memory impairments. This study was rated as poor quality, and these findings must therefore be taken with caution. This study does however illustrate an alternative narrative regarding how cognitive impairment may not always result in a disruption of self. Further research regarding identity for individuals with severe cognitive deficits is advised.

Acceptance

Acceptance of different losses and experiences following ABI was postulated to be important to identity reconstruction for some participants. This included acceptance of changes to social identity/roles, accepting impairments and limitations, and accepting

perceived changes to self. Acceptance of these changes was suggested by some to include a grieving process (Fraas & Calvert, 2009; Freeman, Adams & Ashworth, 2015; Price-Lackey & Cashman, 1996; Sabat, Moodley & Kathard, 2006).

For some, it involved a perceived ending of the old self and embracing the new 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); "I will never go back to the old [me]. That [person] died when they did the operation" (Fraas & Calvert, 2009).

Accepting changes to how they defined themselves also enabled some participants to be open to exploring new identities, as articulated by a participant who presented the loss of their identity as analogous to the loss of a relationship:

I started thinking about my creative process as being like a husband who died and if I was ever going to move on with my life I had to be open to new relationships. I could grieve and let go and accept a new relationship. And that allowed me to begin to write in a new way with a new process. The most positive thing to learn from the accident is ... that things will never be the same again. (Price-Lackey & Cashman, 1996, p.312)

Soeker (2011) suggested that existential reflection may also influence acceptance of self: "The participants felt that reflection on their circumstances facilitated self-acceptance regarding their brain injury. One participant explained that he reflected on why he was injured and about almost dying. This aided him in accepting his current circumstances" (Soeker, 2011, p.86). Whilst many other studies made reference to existential sense-making and gratitude regarding life, this was not explicitly related to acceptance or identity.

Reconstruction of identity included acceptance of changes in their wider life, particularly relating to their social identity, such as occupation: "She [his manager] judged the situation better than I realised at the time. Actually, I couldn't perform my job properly anymore. I pretended I could, but I couldn't" (Hoogerdijk, 2011, p.125). Acceptance of changes to social identity could include acceptance of new domestic roles (Jones & Curtin, 2011), or changes to relationships and engagement with social activities and groups:

They accepted some changes - such as moving from being a fiancé to a single man, or being forced to give up sporting activities - as losses in social identity. Most of these losses were considered permanent, irreparable, and non-negotiable. (Gelech & Desjardins, 2011, p.66)

For some, acceptance of social changes was interpreted as a process contributing to identity reconstruction:

The women did have to accept some losses as they reconstructed their new identities. "The friends that understand are good, but ones that sort of say "oh I'm not sure about that" well I've learnt that they're not really good friends... I don't think they could handle it... I've said well that's their loss." (Howes et al., 2005, p.136)

Some studies identified that acceptance could be a challenging process which takes time (Fraas & Calvert, 2009; Muenchberger et al., 2008). This was articulated in Klinger (2005): "So that doesn't happen overnight that's for sure, that takes some time... And you're struggling to get a new identity or at least retain what's left of the old one. And kind of adapt it" (Klinger, 2005, p.10). This distinction between finding a new identity and retaining pre-injury identity may contribute to the challenge of identity reconstruction following injury. As individuals are struggling to make sense of the impact of the injury on themselves, they may

explore different ways to integrate the injury experience into their self-narrative. Some were able to accept changes to self, whilst striving to re-establish their identity: “They were willing to accept that their capabilities had changed, but determined to reclaim activities that were important to their sense of identity” (Wolfenden & Grace, 2012, P.207).

The value and importance of acceptance seemed to vary, for some ambivalence regarding acceptance could be ongoing. Levack et al (2014) found participants had conflicting views regarding acceptance of a new self, with some rejecting the notion of acceptance. Others viewed acceptance as a positive, hope-imbued process:

Acceptance is not giving up of possibilities. It's the opposite. For me, acceptance was more of a positive thing. It was accepting, well, this is where I am now, But I don't have to stay here. But this is reality now, and I know what to work with. (Lorenz, 2010, p.867)

Even when acceptance appeared to be helpful and valued, the process was challenging (Crisp, 1993; Hoogerdijk, 2011; Muenchberger et al., 2008).

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)

Others identified that acceptance was a necessity: "I just have to accept that I have got that brain damage. It's not going to go away - it's there. I have to live with it" (Parsons & Stanley, 2008, p.234).

Redefining self

Some participants underwent a process of redefining their identity. This included recognising personal growth, redefining social roles, recovery and resisting a disabled self.

Personal Growth

Experiences of personal growth following ABI included appreciation of improvements as a person, as a result of their experience and recognition of moral growth. These included positive redefinitions of self: “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. I used to be a very negative guy” (Sabat et al., 2006, p.22). Some highlighted positive traits such as being friendly or more empathetic towards others (Levack et al., 2014), and greater compassion, experience, patience, and respect for life (Gelech & Desjardins, 2011).

Some experienced a moral growth: "I think it [the TBI experience] has really expanded my appreciation of other people and their problems" (Nochi, 2000, p.1798). This contributed to positive appraisals of self:

I think in a lot of ways, 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)

For some, post-injury life experiences had contributed to a change in values, which participants interpreted as contributing to an improved self: “I’m not the pubbing and clubbing type of girl anymore, I did that that when I worked and had the hangovers and that was enough” (Howes et al., 2005, p.136).

I'm a better person because I realise that my family are the most important people. Not my old friends, not people who I thought were cool. It was my family that cared about me, that did things for me. I am different, and I try to be as nice to my family as I can. (Fraas & Calvert, 2009 p.322)

For some, the ABI was experienced as an opportunity for self-improvement (Nochi, 2000):

The motorbike accident fitted in well with me trying to put my life back together because there was a big wake up [...] I could have died like that [clicks fingers] , I went 'I really should do something a bit more positive with my days on the planet.' (Jones & Curtin, 2011, p.1573)

It may be that when pre-injury life was constructed as negative, for example due to drug and alcohol use (Jones & Curtin, 2011; Martin et al., 2015; Nochi, 2000), the ABI may be more likely to be perceived as a positive opportunity for self-improvement. Redefining self in the context of perceptions of personal growth may be more challenging when pre-injury life is perceived as meaningful and successful.

Redefining social roles

Social engagement and contribution to society were often important in positive identity construction: “Within this theme there was a strong subtheme of being able to contribute to relationships, through the enacting of roles, rather than just being in receipt of care and support” (Martin et al., 2015, p.8). Social identities were re-established or re-defined for many participants. Engagement in social roles was important to participants’ sense of self, and often corresponded with a perceived continuity of their pre-injury values and goals. This could include returning to previously valued social identities:

Well, the best aspect is it gave you an identity back. That a person's back in the workforce. Then you can feel proud; say, "Yeah, I work at London Drugs." People think, "Good, he's a part of—a productive member again," you know? It's good." (Gelech & Desjardins, 2011, p.67)

Redefining social roles could include taking on new roles that were consistent with the pre-injury self, or extending their involvement in previous roles:

I want to continue with this. The next job will be within this [ABI]. I want to create a local association of "The Brain Cause" [a user association] [...] Because... I have done this for many years; I have worked in an association for children [...] Well, it's natural for me also to do it within brain injury. (Glintborg, 2015, p.14)

Meaningful social roles could include family roles: "Helping his partner and children to 'do whatever they want' provides structure and meaning for Markus, compensating for the loss of his former identity as a worker" (Jones & Curtin, 2011, p.1576). Others found alternative, unexpected, meaningful social identities, which may be related to new values or interests following ABI:

"I say I gotta do something, I mean I didn't expect that... I mean, I says what can we do? Look at the people, the people that come that just had a stroke and aphasia. I want to start a foundation, so when we came to home we said let's do it." (Fraas & Calvert, 2009, p.322)

Recovery

Within some studies, recovery was identified as an important process in identity construction following injury. Some individuals strove to recover pre-injury traits or abilities,

and felt a reconnection with their pre-injury self or identity when recovery was achieved (Swart & Horton, 2015):

I'm feeling more like I used to and I'm more what I was like before . . . Yeah. So I think, yes I have identity pre-stroke; I've had an identity a bit different post-stroke. I've been going on the speed hump to get back to my pre-stroke self and now I'm nearly there. (Wolfenden & Grace, 2012, p.209)

This may also relate to notions of continuity of self. When participants are able to reconnect with previous abilities, traits, interests and roles because of recovery, it may be easier to recognise continuity. For example, in Hutton and Ownsworth (2017), participants who perceived stroke to have less impact on their life also tended to describe greater continuity of self: "I've come through fairly positively. It's something that's happened but it hasn't limited me...It doesn't have to define who you are...You can be someone who had had a stroke and still be who you were before that" (Hutton & Ownsworth, 2017, p.10).

Resisting a disabled self

Some studies highlighted that participants promoted their individuality or normality, by implicitly and explicitly resisting discourses about disability or ABI as part of their identity. Some participants did not identify ABI as a core part of their identity:

'Brain injury' in any of its descriptive forms was absent in the personal attributes category; none of these people defined themselves by the brain injury [...] It simply meant that, at this point in their lives, it was not conceptualized as an essential attribute of the self. (Douglas, 2013, p.66)

"I don't feel brain injured as far as how my brain works or how I experience reality. I was in a coma for so long and I couldn't walk or talk for a year. They say that's more

evidence that I have a brain injury. But I don't feel brain injured, so it's like, just a story to me. I don't feel anything wrong with my brain, [but] they insist that I'm brain injured. Well wouldn't they know?" (Gelech & Desjardins, 2011, p.67)

This quote also illustrates the active resistance towards labels of brain injury applied by other people. There was a sense that some participants wanted to maintain their sense of individuality, and not be defined as disabled: 'I like people to know who I am; We are all different' (Douglas, 2013, p.68). This could also involve a sense of self-continuity: "I am priceless. I am unique. Everything about me marks who I am. My thumbprints. My voice. I am an individual. And no one can take that away from me" (Sabat, et al., 2006, p.22).

Phoebe did not identify with being disabled, and she was determined to restore her identity as functional despite impairment: "The thought process inside my head was, 'Disability is other people and disability isn't me. I'm not disabled and I'm not going to be disabled'" (Wolfenden & Grace, 2012, p.206)

Some reconceptualised the meaning of "normality," defining their sense of self within this: "Ok, I've had a head injury. Ok, I don't have a leg... That's normal for me. Normal is what you believe. I believe I'm normal" (Nochi, 2000, p.1799). One study identified group processes which appeared to contribute to this:

They collaborated to normalise and destigmatise common injury related impairments (that is, to counter their shameful or discrediting connotations), positively shifting the significance of these challenges through the recognition of shared experiences. (Gelech, Bayly & Desjardins, 2017, p.9)

It could be that defining self as able and "normal" is a protective mechanism against the perceived threat of ABI on identity, and the social threat of disability stigma. In other

instances, less identification with ABI and associated disability may enable participants to feel that they have left the injury behind and have moved onto a different phase in their life. This may be more achievable when the ABI has less disabling effects on the individual, as discussed in the recovery subtheme.

Self-worth

Enhanced self-worth in relation to identification of positive self-concepts was identified by some studies: “As survivors declared themselves “artistic”, “creative”, “friendly”, or “observant” they affirmed their value and worked to symbolically elevate their identities” (Gelech et al., 2017, p.7). Greater experiences of self-worth may be experienced as a positive identity is reconstructed: “I’m content with myself. I rarely have bad days—just positive” (Douglas, 2013, p.66). Some participants clearly articulated that they valued their post-injury self:

I am 180% another person. I'm much more calm; I don't have anger anymore; I don't have fits. For a while I just wanted to get back to my old self [and] my little life, and just be normal again. Well, I will never be normal, I don't want to be normal, I like the person I am. (Fraas & Calvert, 2009, p.322)

Positive changes to self-concept following injury related to greater contentedness with self: “I was a bit of a Plain Jane but now I’m a Super Woman...I do like being unique. I suppose if I was a Plain Jane fading in the background I wouldn’t receive the same sort of experiences” (Hutton & Ownsworth, 2017 p.10).

I used to get very stressed out about everything before ... I know that I am definitely MORE laid back, I don't, um - I would say, the way I, I would say it is, I'm more

comfortable in my own skin. Yes, I am... I'm happier being me than I was before I had the haemorrhage. (Stone, 2005, p.22)

Processes such as acceptance, continuity and redefinition of self may engender a sense of self-worth post-ABI. In addition, pride in relation to achievements, enactment of meaningful social roles, and recovery post-ABI may function to enhance self-worth:

In giving to others, Paul's feelings of self-worth were reaffirmed. He used his communication skills positively and to his benefit, despite the dysarthria. Paul was able to view the events of his life as meaningful and purposeful, thus empowering him with hope and the ability to perceive and maintain an important role in society. (Sabat et al., 2006, p.23)

External contributors to positive identity

Achievement

For some, achievements resulted in pride and an increased sense of self-worth. This is suggested to bolster self-esteem following ABI, and to contribute to positive identity reconstruction (Levack et al., 2014). Achievement could be experienced as a result of engagement in social roles, as discussed in the 'redefining of social roles' subtheme. Achievement could also occur in the context of recovery:

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)

One participant enthusiastically expressed “the great news” that he had managed to achieve a desired occupation. After great effort and methodical training, he could read again. This ability also contributed to preserving his sense of self and social identity. (Erikson & Tham, 2010, p.188)

For others, achievements could be in interests or hobbies:

John experienced a sense of accomplishment and pride in his weekly woodworking activity and referred to the enjoyment he received from creating leather products for sale. His interview illustrated how his sense of self after ABI had emerged from the activities he was engaged in. (Martin et al., 2015, p.15-16)

Others experienced achievement in the context of work:

I think it was about the fact that I found something that I liked, I got excited about and someone else acknowledged it and that ... confirmed that what I was doing was on the right track and that made me more excited and it and to take it on to the next level and that's what I feel now. I'm deciding for 'me' now ... it wasn't about the job itself it was about getting it. It was about the acknowledgement that I could do something ... someone said I could do it. (Muenchberger et al., 2008, p.987)

The role of others

This theme focuses on the roles others can have in promoting a positive identity reconstruction following ABI. Validation, recognition of abilities and encouragement from others could contribute to promoting self-worth: “Respect, validation and acceptance provided by good friends contributed significantly to the participants' sense of being valued people.” (Levack et al., 2014, p.5). This could come from a range of sources, such as friends, employers and others with a brain injury: “... it wasn't about the job itself it was about getting

it. It was about the acknowledgement that I could do something ... someone said I could do it" (Muenchberger et al., 2008, p.987).

For example, a survivor who took great pride in her creative abilities became known as the “artist” of the group. Throughout the programme, other group members worked to reinforce this positive identity, legitimising her competency in the course of social interaction. The support and endorsement provided by fellow group members helped to legitimise these positive signs of the self and promote a more flattering perception of personal identity. (Gelech et al., 2017, p.9)

One aspect of the contribution of others is reinforcing a sense of normalcy:

Ah, but you know it's my friends. They don't look at me like there's something different. When I complained about, you know, not being able to hit the [golf] ball, she says, 'Boy, you're just like the rest of us'. You know so they, they're very encouraging, but they don't make me feel like there's something wrong with me. (Anderson & Whitfield, 2013, p. 825-826)

Other ABI survivors may play a particularly important role in providing a sense of normalcy, as well as more general validation of self:

Connection with others with ABI could facilitate perception of positive self-concepts, "when I'm at [ABI programme] I'm a nicer person. But I'm just a normal person with them, we all have our problems, from an accident or stroke. But when we are all together everyone completely understands." (Fraas & Calvert, 2009, p.322)

In other instances, downward comparisons with others with an ABI could facilitate positive appraisals of self: "A lot of people are a lot worse off than I am, and - knock it off.

"You're getting better; they never will." (Nochi, 2000, p.1798). However, as noted by Gelech, et al. (2017), comparison with other ABI survivors may also have a detrimental effect on sense of self if individuals perceive themselves to be worse off.

Discussion

This review synthesizes the available evidence regarding processes that appear to contribute to successfully managing the challenges ABI poses to identity. All themes were derived from multiple papers, and no themes were based predominantly on data from papers rated as poor quality. Themes included continuity of self, acceptance, redefining of self (personal growth, redefining social roles, recovery, resisting a disabled self), self-worth, and external contributors to positive identity (achievements, the role of others). This review highlights the potential individual differences between identity continuity and redefinition. For some, identity was experienced as continuous, and may undergo a process of adaptation, as changes are assimilated into the individual's retained identity. In contrast, some described a redefinition of self, which appears to involve an acceptance and radical reworking of a new, pre-injury self. Further research into these processes is required. This may help identify how these differences may impact on other aspects of the person, such as self-esteem, social roles, relationships with others, and what interventions could be most helpful.

Continuity of self: Experiences of continuity of self were described, whereby some participants felt that they were the same person as they were prior to injury, or that core aspects of themselves and their values remained unchanged despite the ABI. Quantitative research has also found evidence of identity continuity in stroke (Secrest & Zeller, 2003). Establishing continuity of self may protect against self-esteem difficulties, as greater

perceived changes in identity and self-concept have been associated with lower self-esteem following ABI (Curvis et al., 2016).

Acceptance: Acceptance processes are suggested to occur as some individuals come to terms with changes or perceived losses to themselves, or their wider life. Loss following ABI is well documented (Nochi, 1998; Roundhill, Williams & Hughes, 2007; Ownsworth, 2014). If individuals perceive distinct changes to their sense of self, or loss of aspects of their identity, acknowledgement and acceptance of these changes will be essential in moving forward and letting go of the past self. This may be a necessary process for individuals to focus on the future and establish a new positive identity post-ABI.

Personal Growth: Experiences of growth of self, and identification of positive self-concepts were described. This is consistent with literature which has found participants have identified positive self-concepts following ABI, in addition to negative changes to self (Beadle et al., 2016; Ellis-Hill & Horn, 2000; Tyerman & Humphrey, 1984). There is a growing evidence base regarding the occurrence of post-traumatic growth (PTG) following ABI (Grace, Kinsella, Muldoon & Fortune, 2015), and an increasing recognition that facilitating growth is a helpful rehabilitative aim (Gracey, Evans & Malley, 2009).

Redefining social roles: Many participants re-engaged with or redefined social identities following ABI. Opportunities to maintain existing social identity, or foster new social identity, can afford opportunities for self-esteem development and a more robust positive self-identity. Social identity may also contribute to a perceived sense of greater identity continuity, when engagement in a role is perceived to relate to pre-injury values or interests. This highlights the importance of opportunities for social roles and occupations as a rehabilitation goal.

Recovery: For some participants, recovery of self was important for positive identity reconstruction. Understandably, recovery may result in greater experiences of self-continuity and ability to re-engage with pre-injury identities. Given the chronicity of ABI symptomatology, complete recovery may not occur (Ponsford, Sloan, & Snow, 2012; Turner-Stokes, 2003). It is important to consider how to promote positive identity with individuals striving for recovery, if recovery is likely to be limited.

Resisting a disabled self: This synthesis highlighted how some participants resisted perceived negative identities, and promoted self-concepts that focused on being normal, individual and able. The impact of stigma and negative labelling from others is already recognised (Nochi, 1998). Developing able narratives, whilst concurrently promoting acceptance of possible disability, is an important rehabilitation goal. However, whilst defining self in opposition to a disability narrative may be a positive process, resistance towards ABI could also be indicative of denial-based coping, which may need to be considered in clinical settings (Klonoff, 2010).

Self-worth and achievement: Processes such as acceptance, continuity of self and positive appraisals of self may foster self-worth. Pride in relation to achievements, enactment of meaningful social roles, and recovery post-ABI may also enhance self-worth. According to self-esteem theory (Caste & Burke, 2002), verification of identity at group and individual levels produces feelings of competency and self-worth, which increases self-esteem. Self-verification of identity involves the process of being able to enact identity roles consistently with the internal identity standards the individual holds (Caste & Burke, 2002). If, for example, an individual holds an identity self-concept “I am helpful,” and is then unable to help others as desired, they may feel a loss of self-esteem. Opportunities to re-engage in

behaviour consistent with the desired identity (for example in social roles) could therefore promote self-esteem development and a more robust positive self-identity.

The role of others: This review highlighted the potential role of other people in facilitating a positive post-ABI identity. As an individual strives to maintain their identity, or develops a new, positive identity, validation and support from others can promote their identity (Gelech, et al., 2017; Nochi, 2000). However, if others undermine or devalue the identity the ABI survivor is trying to establish, the survivor may not be able to maintain said positive identity (Nochi, 2000). Caste and Burke (2002) suggest identity is also influenced by other's behaviour towards us, if other people's behaviour is inconsistent with our identity. Following ABI, if a survivor's desired identity is discrepant with how others behave towards them, this could cause distress, and challenge self-esteem and identity maintenance.

Limitations

The subjective nature of a qualitative meta-synthesis is a limitation of this review. Producing second order interpretations of qualitative studies is inherently subjective, and affected by the subjectivity of included studies. Regarding quality appraisal, studies were not rated by a second reviewer, and therefore inter-rater reliability cannot be determined.

It is possible that other studies not identified for review may have included relevant content to positive identity construction following ABI. Other relevant processes may be present in literature regarding ABI recovery, but were missed because they were not explicitly linked by the authors to identity. In addition, focusing on positive identity constructions, and not including literature focusing on the negative impact on identity could be considered a limitation. However, against this, it could be suggested that, rather than attempting to synthesize such a large body of research, it would be more appropriate to consider the results

of this synthesis alongside these other bodies of evidence, such as loss or PTG literature (Grace et al., 2015). The decision to not include data from other informants also limits the data set for review. Although this synthesis was interested in understanding the subjective experience of identity reconstruction from the perspective of ABI survivors, considering data provided by family members and professionals may have yielded additional insights regarding this process. The synthesis included participants with any type of ABI, such as TBIs and stroke, a range of injury severities, and participants at different stages of recovery. This could be considered a limitation because amalgamating the findings across these sources of variation may have masked some differences relating to these variables.

Clinical Implications

This study makes suggestions regarding processes which, if promoted during rehabilitation, may enhance positive self-identity following ABI. Opportunities for meaningful social roles and achievement may facilitate self-worth and a positive sense of self. Consideration should also be made to how survivors' personal support networks may be able to support and validate the development or maintenance of a positive identity post-ABI. The importance of addressing identity issues within ABI rehabilitation has been increasingly recognized in literature (Biderman, Daniels-Zide, Reyes & Marks, 2006; Coetzer, 2008; Ownsworth & Haslam, 2016; Yeates, Gracey & McGrath, 2008; Ylvisaker & Feeney, 2000). The "Y shaped model" of change processes recommends that rehabilitation should be structured with identity as a central component (Gracey et al., 2009). This model recommends that complex integrated interventions should first address core identity-related discrepancies, including social discrepancies, self-discrepancies and interpersonal discrepancies. Following this, the model proposes interventions aimed at promoting further psychological growth and development of post-injury identity, which is consistent with findings in this review.

The potential benefits of rehabilitation interventions (such as psychotherapy, family interventions, cognitive rehabilitation and activity-based interventions) on self-concept have been reviewed (Ownsworth & Haslam, 2016). However, the findings did not provide strong evidence for such benefits, partly due to the scarcity of research which included self-concept or identity-related outcomes. The authors advocated the need for further identity-based intervention studies. Gelech et al. (2017) explored positive identity processes within a female self-help group, providing preliminary evidence for how a strengths-based, peer group intervention may facilitate positive identity construction. Additional interventions suggested in the literature include Acceptance and Commitment Therapy (ACT; Myles, 2004), Compassion Focused Therapy (CFT; Ashworth, Evans & McLeod, 2017) and Cognitive Behavioural Therapy (CBT; Dewar & Gracey, 2007). ACT (Hayes, 2004; Hayes, Strosahl & Wilson, 1999) may be helpful in facilitating identity continuity and facilitate acceptance, personal growth, and facilitation of achievements. Person-as-context and cognitive defusion could be used to help individuals take a meta-cognitive perspective and experience their sense of self as greater than the experiences they have. Through this, survivors can learn to observe and experience difficult thoughts and feelings about ABI, rather than experiencing them as a core part of themselves. Focusing on values in therapy could help individuals recognise continuity or change in values, and provide opportunity to take action according to these, for example in redefining social roles. CFT (Gilbert, 2010) is suggested to be an effective intervention for those experiencing shame and self-criticism. Individuals who are struggling with positive identity reconstruction following injury may experience these thoughts and feelings, and may benefit from a CFT approach to foster self-acceptance and bolster self-worth. Further research on the application and utility of these approaches for individuals following ABI is required to establish a robust evidence base.

Research Implications

There is still a limited range of research regarding positive identity reconstruction, and often literature focuses on the earlier experiences of identity loss following ABI. Further investigation of processes contributing to positive identity reconstruction may yield more data to further inform rehabilitation practice. Further research into the role others may have in facilitating identity change is also advised. The implications of injury severity and cognitive profiles on identity reconstruction should be considered. Severity of injury may moderate identity reconstruction, as perceptions of continuity may be more challenging where the impact of the injury has been more severe. Furthermore, it may be more challenging for individuals with severe injuries to re-engage with person-centred values and purposeful activity. Whilst Medved and Brockmeier (2008) suggested individuals with severe memory impairments may not perceive themselves as substantially different, this has not been established in other research. Indeed, others have suggested memory impairments could result in a disruption to identity as a result of being unable to construct a coherent self-narrative (Levack et al., 2014; Nochi, 1998). As highlighted above, further research is also required to establish how interventions may address the challenges ABI poses to identity.

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CHAPTER TWO

Empirical Research Paper

The Journey towards Acceptance following Acquired Brain Injury: An Interpretative Phenomenological Study

Abstract

Background: Acceptance has increasingly been recognised as a clinically relevant construct in a range of settings, and has become central to many third wave cognitive behavioural therapies including acceptance and commitment therapy, compassion focused therapy and dialectical behavioural therapy. Literature suggests acceptance within an acquired brain injury (ABI) population may mediate adaptation, including engagement in rehabilitation, vocational activities and emotional well-being. There is no current qualitative research explicitly exploring what acceptance may mean for individuals with an ABI.

Aims: To seek an understanding of acceptance from the lived experiences of those who have sustained an ABI, including factors which might help or hinder the process of acceptance.

Method: Nine semi-structured interviews were conducted with individuals who had sustained an ABI at least one year prior to interview. Interviews explored acceptance within the recovery journey using a timeline. Data was then analysed using Interpretative Phenomenological Analysis.

Results: Five superordinate themes regarding the process of acceptance during the recovery journey were identified; facing up to change, acceptance, ambivalence about acceptance, moderators of acceptance, and the ongoing struggle.

Conclusions: Acceptance is suggested to be a clinically relevant, ongoing experience following ABI, which requires awareness and understanding regarding ABI. Participant experiences provide useful insights regarding how acceptance may be facilitated. Consideration should be made to how acceptance-based interventions may be suited for this population. Future research could explore in more detail some of the issues that might contribute to individual differences in acceptance, such as severity of injury or dispositional traits such as optimism.

Introduction

Theoretical and Clinical Conceptualisations of Acceptance

Acceptance is widely assumed to be an important part of dealing effectively with major life events and circumstances. Acceptance has received increasing interest in a range of clinical settings, including mental health (Mizock, Russinova & Millner, 2014), chronic pain (McCracken & Eccleston, 2005; Vowles, McCracken, & Eccleston, 2007) and multiple sclerosis (Pakenham & Flemming, 2011). For example, in chronic pain, an acceptance-based interdisciplinary programme resulted in greater acceptance scores, reductions in reported pain and improvements in functioning (McCracken & Eccleston, 2005). Associations have been found between greater levels of acceptance and reduced functional disability, depression and pain-related anxiety (McCracken & Eccleston, 2005; Vowles, McCracken, & Eccleston, 2007). Alongside these developments, there has been increasing interest over the past few decades in the development of third-wave cognitive and behavioural therapies in which acceptance plays a key role. Such approaches include Acceptance and Commitment Therapy (ACT; Hayes, 2004; Hayes, Strosahl & Wilson, 1999), Dialectical Behaviour Therapy (DBT; Linehan, 1993; Linehan, 2014), Mindfulness-based Cognitive Therapy (MBCT; Segal, Williams & Teasdale, 2012) and Compassion Focused Therapy (CFT; Gilbert, 2009; 2010).

Establishing a clear conceptualisation of what acceptance means is an important part of developing these approaches and applying them in various clinical contexts. According to ACT, acceptance is an active, non-judgemental process of accepting experiences as they are in the moment without feeling the need to change them (Hayes, 2004). Acceptance is viewed as an antidote to the experiential avoidance contributing to human suffering (Hayes, Luoma, Bond, Masuda & Lillis, 2006). Alongside the other components of the ACT model,

acceptance allows a person to develop greater psychological flexibility to be able to move towards valued life experiences. Within the other third wave approaches referenced, acceptance is also described as an active, non-judgemental approach towards feelings and experiences, which is essential to validation of experiences by both therapist and client (Gilbert, 2010; Linehan, 1993).

These conceptualisations of acceptance associated with the third-wave therapies are very general. It could be argued that there are more specific components involved in acceptance, and that these may vary in different contexts. A better understanding of context-specific processes may facilitate more effective application of acceptance-based therapies. The need for context-specific conceptualizations of acceptance is evident in the research literature in the form of an expanding raft of specialism-specific measures of acceptance, often derived from the Acceptance and Action Questionnaire (Hayes et al., 2003), such as the Chronic Pain Acceptance Questionnaire (McCracken, Vowles, & Eccleston, 2004), and the Multiple Sclerosis Acceptance Questionnaire (Pakenham & Fleming, 2011). The Acceptance of Disability Scale has also been developed for wider disability populations (Groomes & Linkowski, 2007; Linkowski, 1971).

Some research has attempted to elaborate more specific components of acceptance. In early works, Dembo, Levington and Wright (1975) and Wright (1983) developed a theoretical model of acceptance of loss following physical disability (see also Keany & Glueckauf, 1993). The model suggests that four key value changes facilitate acceptance of loss following physical disability (Dembo et al., 1975; Keany & Glueckauf, 1993; Wright, 1983), as described in Table 1.

Table 1. Value changes described in acceptance of loss theory (Keany & Glueckauf, 1993)

1	<i>Enlargement of scope of values:</i> A reorganisation of values, whereby individuals' focus on values beyond those intrinsically linked to the disability, including finding meaning or purpose in life.
2	<i>Subordination of physique:</i> Lesser focus on values relating to physical capacities, self-worth is characterised by other traits, such as personality.
3	<i>Containment of the effects of disability:</i> Viewing the disability as a possession, rather than a core trait of the individual, thereby preventing spread of the disability to other aspects of the person.
4	<i>Transition from comparative values to asset values:</i> Less focus on comparisons with pre-injury self or other people, and a greater focus on one's strengths and abilities.

More recently, a qualitative study of acceptance relating to mental health concluded that acceptance comprised a process of developing one's identity, alongside acceptance-orientated thoughts and positive emotions, and behaviour that was consistent with acceptance of one's mental health (Mizock et al., 2014). A qualitative study of acceptance relating to chronic pain associated with rheumatoid arthritis suggested acceptance involves the following processes; naming the illness, realizing the illness, resisting the illness, 'hitting the bottom' and integrating the illness (Kostova, Caiata-Zufferey, & Schulz, 2014). In chronic pain, processes of realising the need for help, diagnosis, absence of cure, realising it could be worse, redefining normal and acceptance were described (LaChapelle et al., 2008). Acceptance has also been suggested to hold negative meaning for some, such as connotations of resignation (LaChapelle, Lavoie, & Boudreau, 2008; Mizock et al., 2014).

Acquired Brain Injury and Acceptance

ABI can result in a range of long-term consequences including cognitive, emotional, and physical impairments. Such impairments can have long term implications for social, vocational and well-being outcomes (Hoofien, Gilboa, Vakil, & Donovanick, 2001; Ponsford, Olver & Curran, 1995; Ponsford, Sloan, & Snow, 2012; Teasdale & Engberg, 2005; Wood &

Rutterford, 2006). It has been suggested that acceptance is associated with a range of important rehabilitation outcomes such as employment (Ezrachi, Ben-Yishay, Kay, Diuer & Rattok, 1991; Melamed, Groswasser & Stern, 1992), depression and emotional difficulties (Hoofien et al., 2001; Townend, Tinson, Kwan & Sharpe, 2010) and engagement in rehabilitation and adaptive functioning (Klonoff, 2005; Medley & Powell, 2010). It should be noted that research into this area is in its infancy, with some literature based on clinical experience rather than empirical data (Klonoff, 2005; Medley & Powell, 2010). Other studies (Ezrachi et al., 1991; Hoofien et al., 2001; Melamed et al., 1992) did conduct quantitative studies, but acceptance was not the primary focus of the research. These studies also employed the Acceptance of Disability Scale (Linkowski, 1972), a measure of global acceptance of functional limitation. This scale has not been empirically validated in an ABI population therefore should be interpreted with caution.

Some qualitative literature regarding recovery following ABI has also discussed acceptance, although acceptance has never been the primary aim of an ABI study. Some identified the importance of acceptance of the new post-ABI self (Fraas & Calvert, 2009; Klinger, 2005; Levack et al., 2014; Parsons & Stanley, 2008). Levack et al. (2014) and Fraas and Calvert (2009) concluded that learning to accept the new post-injury self was an important part of positive identity reconstruction. Acceptance of changes to self has been suggested to facilitate moving forward with life post injury, and making adaptations to aid this, for example being able to engage in new interests (Klinger, 2005; Parsons & Stanley, 2008). Acceptance has been linked to insight and readiness to engage in therapy following TBI (O'Callaghan, McAllister & Wilson, 2012). This research suggests that although acceptance has not been a primary research focus, it may have relevance in the recovery journey

following ABI. Through qualitative research, ABI survivors may have an important contribution to make in developing a better understanding of acceptance.

Despite the suggestion that acceptance following ABI is a clinically relevant construct there are currently no well-developed conceptualisations or theories of acceptance specific to this population. The acceptance of loss model (Keany & Glueckauf, 1993) has not been validated with an ABI population, and may not fully account for the complexity of consequences post-ABI. In Klonoff's book *Psychotherapy after Brain Injury* (2010) a model of acceptance is described. Acceptance is described as "patient's ability and willingness to cope with their new reality and identity" (Klonoff, 2010), and is proposed to develop following improvements in self-awareness. Acceptance is suggested to facilitate psychological adjustment following ABI, leading to improved engagement in rehabilitation and better quality of life. According to Klonoff, psychological processes such as denial and resistance may indicate low levels of acceptance. Although this model provides a context relating to the importance of acceptance, it does not adequately explain what acceptance entails and how it may be facilitated or hindered following ABI. The model also appears to be based on clinical experience rather than systematic research.

There are increasing calls within ABI literature for the application of ACT and other third wave therapies such as CFT to be further investigated (Ashworth, Evans, & McLeod, 2017; Kangas & McDonald, 2011; Whiting, Deane, Simpson, McLeod & Ciarrochi, 2017; Whiting, Simpson, McLeod, Deane & Ciarrochi, 2012). Whilst recommendations have been made regarding the application of ACT to an ABI population, further research is required to establish a robust evidence base to inform practice. Whiting et al. (2012) provide a protocol for a randomised control trial of ACT for ABI, and an ABI-specific measure of psychological

flexibility, the AAQ-ABI has been developed (Whiting, Deane, Ciarrochi, McLeod & Simpson, 2015).

In summary, acceptance is considered an important variable in ABI rehabilitation and acceptance-based interventions are increasingly being used in this context. However, there is a need to develop an improved understanding of the specific components of acceptance following ABI, and processes which may hinder or promote acceptance in this context. Such understanding could facilitate the application of acceptance-based interventions such as ACT in ABI, and may be of more general use in helping those with an ABI to adjust and adapt to the consequences of their injury. The primary aim of the present study is to seek an understanding of acceptance from the lived experiences of those who have sustained an ABI.

Method

Design

Interpretative phenomenological analysis (IPA) is increasingly used in qualitative research in a range of clinical and health contexts, including with individuals with acquired brain injury (Howes, Benton & Edwards, 2005; O'Callaghan, Powell & Oyebode, 2006; Shotton, Simpson & Smith, 2007). IPA is underpinned by principles of phenomenology, idiography and hermeneutics (Smith, Flowers & Larkin, 2009). Accordingly, IPA research aims to understand events from the perspective of the individuals experiencing them, respecting the similarities and differences of such experiences. The phenomenological focus of IPA was considered appropriate to the aim of this research, in exploring the phenomenological experience of acceptance. Furthermore, it was expected that participants' experience of acceptance would not be uniform, and the idiographic nature of IPA would allow exploration of individual variation of experience. Finally, the double hermeneutic

nature of IPA allows the researcher to further interpret both what the participant is communicating directly, and processes which the individual may be less aware of (Pietkiewicz & Smith, 2012). The explicit interpretative role of researcher in IPA was considered appropriate, given the challenges cognitive difficulties may pose on participants' abilities to reflect and articulate on more abstract aspects of their experience (Paterson & Scott-Findlay, 2002).

Ethics

Local ethical approval was secured for the study through NHS Health Research Authority (see Appendix B). All participants were provided with an information sheet, and were encouraged to discuss any questions or queries with the author prior to providing written informed consent (see Appendices C and D). All participants were made aware that their participation was voluntary and would not affect their care, and that they could withdraw their data up to one week after their participation. In addition, participants were informed how their anonymised data would be used, including the use of quotations in written reports, possible publications and presentations.

Recruitment and Participants

Recruitment was conducted through NHS community head injury rehabilitation services. Clinicians provided recruitment leaflets (see Appendix E) to service users who met the inclusion/exclusion criteria. In addition, the recruitment letter was circulated within the services to allow for service user self-referral. Inclusion and exclusion criteria for participation are detailed in Table 2.

Table 2. Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
1) Individuals who have experienced an acquired brain injury and are at least 1 year post- injury in receipt of post-acute care only.	1) Non-English speaking
2) Individuals must be able to engage in interview process.	2) Co-morbidity of other mental or physical health conditions including neurodegenerative conditions
3) Individuals should have made some progress in acceptance of head injury.	
4) Adults only.	

Within qualitative research with a focus on exploring detailed experiences of participants, large samples are impractical in terms of analysis and reporting, and smaller samples are recommended, for example 6-10 participants (Morse, 2000; Smith, Flowers, & Larkin, 2009). This study aimed to recruit 8-10 participants, as it was recognised that some participants may be less able to give rich, detailed accounts due to consequences of their ABI. Three women and six men participated in the study (see Table 3). All participants had experienced some form of ABI, and were at least one-year post injury. All participants were either identified by themselves or by clinicians known to them to have made some progress in accepting their experience of head injury, and were judged able to engage in an interview process by clinicians and following a screening telephone call with the author.

Table 3. Summary of participants at time of interview

Name	Summary
Anita¹	Anita is a 50-year-old woman who sustained a subarachnoid haemorrhage approximately 3 years prior to interview. Anita received input from specialist brain injury services at the time of her injury. At time of interview she was living at home with her 2 children and was not working.
Denise	Denise is a 49-year-old woman. She sustained a traumatic brain injury following a fall 32 years ago, and another traumatic brain injury 3 years prior to interview as a result of a road traffic accident. Denise received input from specialist brain injury services at the time of both injuries. At time of interview she was living at home with her child, and engaging in part time work.
John	John is a 43-year-old man who sustained a traumatic brain injury following a road traffic accident approximately 10 years ago. John received input from specialist brain injury services at the time of his injury, although felt this input focused on physical impairments. At time of interview John was living at home

	with his wife and children, and was volunteering with local head injury services.
Kevin	Kevin is a 49-year-old man who sustained a traumatic brain injury following a road traffic accident approximately 32 years prior to interview. Kevin's access to specialist brain injury services was significantly delayed following his injury. At time of interview Kevin was living alone at home, and was volunteering with local head injury services.
Lucy	Lucy is 63-year-old woman who sustained a traumatic brain injury following a road traffic accident 15 years prior to interview. Lucy's diagnosis and access to specialist brain injury services was significantly delayed following her injury. At time of interview Lucy was living alone at home, and was not working. Lucy was tearful during the interview, and acknowledged that she did not feel she has been able to completely accept her injury and the impact it has had on her yet.
Matthew	Matthew is a 52-year-old man who sustained a traumatic brain injury following a road traffic accident approximately 4 years prior to interview. Matthew received input from specialist brain injury services at the time of his injury. At time of interview Matthew was living at home with his wife and child, and was volunteering with local head injury services.
Rob	Rob is a 59-year-old man who sustained a traumatic brain injury following a road traffic accident approximately 4 years ago. Rob received input from specialist brain injury services at the time of his injury. At time of interview Rob was living at home with his wife, and continuing to work part time.
Stuart	Stuart is a 39-year-old man who sustained a traumatic brain injury following a road traffic accident approximately 10 years prior to interview. Stuart's diagnosis and access to specialist brain injury services was significantly delayed following his injury. At time of interview Stuart was living alone at home, and was not working.
Tom	Tom is a 36-year-old man who sustained a traumatic brain injury following a road traffic accident approximately 17 years prior to interview. His experience of recovery was complicated by substance and alcohol use. At time of interview he lives with his wife and children, and engages in public speaking/advocacy work.

¹ *Participants will be presented with anonymised pseudonyms for the purpose of confidentiality.*

Procedure

Data was collected through one semi-structured interview with each participant, ranging in duration from 1 hour and 3 minutes to 1 hour and 40 minutes. Interviews were conducted in the participant's home, or in NHS or University facilities. The interview schedule (Appendix F) was in two parts; a timeline was used to allow participants to describe their experiences since their injury until time of interview, followed by additional questions

regarding their experience of acceptance relating to ABI. This included what acceptance meant to them, and what processes may have helped or hindered their experience. This schedule was used flexibly; additional prompts were used to generate further understanding of topics which arose. All interviews were audio-recorded and transcribed for analysis.

Visual timelines were used within interviews to facilitate engagement in interview by providing a context within which to discuss acceptance. This is consistent with literature which suggests visual methods can assist interview processes and reflection (Sheridan, Chamberlain, & Dupuis, 2011). This is likely to be particularly helpful for individuals with ABI, who may find taking part in a relatively lengthy interview, maintaining focus on a topic, recollection of past experiences, and reflection on abstract concepts challenging due to cognitive impairments (Douglas, 2013; Paterson & Scott-Findlay, 2002). The timeline provided a visual aid to address such issues. Scaffolding strategies such as cueing, and re-orientating participants during the interview were also used, and breaks were encouraged if participants appeared fatigued (Douglas, 2013; Paterson & Scott-Findlay, 2002).

Analysis

Interpretative phenomenological analysis was conducted using the methodology detailed by Smith, Flowers and Larkin (2009). This consisted of a detailed process of annotation and initial coding, followed by identification of themes for each transcript (see Appendix G for an excerpt of annotated transcript). After each transcript was analysed in detail, themes from all transcripts were compared and contrasted to develop a series of higher order themes, which aimed to encapsulate commonalities across the interviews, whilst retaining the individual meaning and experiences described.

Credibility of the themes was established through several processes. Final themes and transcripts were reviewed by an IPA supervisor, and discrepancies within the themes were discussed and refined within supervision to ensure themes were grounded in the interview data. A reflective diary was used as a way of addressing potential bias, and to begin early analysis through identification of potential themes (see Appendix G for a summary). Excerpts from the interviews are also used extensively to illustrate how the themes are grounded in the interview data.

A written account of the final themes was provided to study participants for member checking (see public dissemination document). Two participants chose to give feedback regarding the summary. Findings were also verbally presented to a group of nine multi-disciplinary professionals to further enhance credibility. The group held 1-33 years of experience working in inpatient and community ABI rehabilitation. The themes presented were reported to be consistent with the experiences of both the participants who gave feedback, and the professionals group.

Analysis

The themes which emerged in this study are summarised in Table 4, and presented in further detail below with illustrative excerpts¹. Table 4 details which participants contributed to each theme, but there is no intention to suggest that themes with greater participant contributions are more significant. Rather, contributions from more participants may reflect

¹ To assist with illustration of excerpts, unrequired text has been replaced with [...], and [text] either replaces identifiable information or provides extra information to clarify the context of a quote. Utterances such as ‘erm’ have been removed to enhance readability.

greater commonality of the theme, whilst those with fewer contributors could reflect a more abstract theme which fewer participants could articulate. For example, *honesty and embracing ABI* is derived from three participants, however others may have experienced similar processes but have been less able to articulate them due to the more abstract nature of this theme.

Table 4. Themes and participants' contributions to sub-ordinate themes

Super-ordinate theme	Sub-ordinate themes	Anita	Denise	John	Kevin	Lucy	Matthew	Rob	Stuart	Tom
Facing up to change	Awareness and Understanding	√	√	√	√	√	√	√	√	√
	Avoidance, denial and striving for normality	√	√	√	√	√	√	√	√	√
	Emotional experience of facing change	√	√	√	√	√	√	√	√	√
	The doubting, different self	√	√	√		√	√	√	√	
Acceptance	Occurrence and Permanence	√	√	√			√	√	√	√
	Moving on from loss and changes	√	√		√	√	√	√	√	√
	Honesty and embracing ABI	√	√							√
	Shifting emotions and positive reappraisals	√	√		√		√	√	√	√
	Self-acceptance	√			√	√	√		√	√
Ambivalence about acceptance		√	√	√	√	√	√	√	√	
Moderators of acceptance	The role of others	√	√	√	√	√	√	√	√	√
	Increasing recognition of positive experiences	√	√	√				√	√	√
	A hopeful future	√	√	√	√	√	√	√	√	√
The ongoing struggle		√	√	√	√	√	√	√	√	

Facing up to change

This theme describes the processes experienced prior to development of acceptance. Precursors to acceptance included developing *awareness*, followed by an emerging *understanding* of the brain injury. They are important to the development of acceptance, as

acceptance would not be possible if an individual is unaware or unable to understand the changes that have occurred. *Denial*, *avoidance* and *striving for normality* also worked against the development of acceptance. The *emotional experiences of facing change*, and the experience of *the doubting different self* are also discussed.

Awareness and Understanding

In the immediate stages of recovery most participants described a lack of awareness of difficulties associated with their ABI beyond physical difficulties. Reasons for this varied; some participants spoke of preoccupation with physical injuries, whilst others experienced initial stages of recovery as overwhelming and were not thinking too much about the ABI, as described by Matthew: “the head injury actually I didn’t give a second thought to, I thought just because I was there and alive, I was alright.”

Awareness developed gradually over time. This was often driven by attempts to regain normal life activities, and through feedback from others. Anita exemplified this in her observations of her return home from hospital:

I remember my daughter saying “mom I put it on the left-hand side”, and I’m sitting up in my bed and trying to think, left hand side what does that mean? And that’s when I knew something was not right.

Rob identified how through engagement in activities he was previously skilled at, he began to recognise difficulties post injury:

I had figured, something wasn’t quite right because I’d been doing some logic puzzles and failing miserably, wasn’t until there that, realised something wrong partly because I got headaches, and dizziness and stuff like that.

Rob recalled instances where he was aware that he experienced difficulties, but was not fully aware of the extent of these difficulties:

The other problem is I didn't realise, and you don't realise, that I was as bad as I was. I realised that my memory wasn't as good but I didn't really realise that I was as bad as I was, which is this bit about how can you accept something if you can't remember what it was like to be in that state, be in a different state.

Over time many participants described attempts to understand experiences relating to their ABI. Matthew identified how, despite an awareness of changes to himself, he was initially unable to understand these experiences: "I didn't understand how my emotions were changing, my personality was changing, my moods was changing..." This was an experience shared by most participants. Anita identified various attempts to make sense of the difficulties she was experiencing:

I just thought "oh it's all these drugs, maybe I just need to rest and my eyes were still quite swollen," and I thought maybe it's all of that. So I kind of put it all down to that. "I thought, is it because I haven't done this stuff for a while?" I couldn't understand it.

Participants described understanding developing over time, facilitated by information acquisition including professional input, assessment and diagnoses. John emphasised the importance of understanding through education: "you can understand, you can understand. I think the education in it, there should be more education in it." The majority of participants experienced the benefits of developing understanding through interactions with services, as described by Lucy:

I didn't understand until the head injury people, [professional] told me what was going on. And they said I'd got sensory processing disorder, so I get really overwhelmed with stuff and my eyes don't work properly, well I didn't know any of this then.

Some participants articulated their distress when they were not able to understand the symptoms they were experiencing. This was particularly salient for Stuart, Kevin and Lucy, who did not access ABI services for several years post injury because their injuries went undiagnosed. Stuart highlighted how this lack of knowledge hindered his experience of acceptance: "That I'd been so long without the knowledge probably. Made me angry, that I'd been trying to tell people for years and no one listened to me." Anita also experienced this as a barrier to acceptance:

I think not helped would be, not helped, would be. Not getting the proper help, like, professionally [...] Yes from all of that. That hasn't helped because, it didn't anchor anything, didn't give me any clarity about what my condition was, I had no idea.

Emotional experiences associated with facing change

This theme describes the emotional experiences of participants as they became increasingly aware of the consequences of the injury. Many participants described negative affective experiences earlier in their recovery, which often related to a lack of understanding of the consequences of the injury, and striving for normality. Anita identified how growing awareness of her difficulties was distressing: "The girls would get me a magazine or "mum here's your book," and I, I couldn't even take the first sentence or line. That was disturbing for me." Lucy also described ongoing anxiety during her recovery when she did not understand her experiences: "it was just an overwhelming fear. I'm imagining it's how agoraphobics feel, this was weeks down the line you know, and I'd not been out, and I was

just, I just felt like a crushing sort of crippling anxiety.” Some described suicidal ideation and self-harm, as described by John: “I was still having the complications, trying to cope with them, didn’t understand, had suicidal thoughts, which were quite intense, came on more regular than usual.”

Emotional experiences may be a consequence of increasing awareness of difficulties, in the absence of complete understanding. This was described by Matthew: “I didn’t understand how my emotions were changing, my personality was changing, my moods was changing [...] I were a lot more tearful, really, really strong feelings of guilt.” These feelings may underpin the use of avoidance, denial and striving for normality as coping strategies. John and Rob both suggested that denial may occur spontaneously as the brain’s way of coping with the ABI. John reflected on his earlier recovery:

Which I think at the time you don’t think things are as severe as they are, or, I think the brain has a cut-off point as if to say, “look don’t think of it as being as severe” but it was.

It should be noted that in some instances these experiences may also have been heightened by emotional lability resulting from the brain injury, as articulated by Stuart and Denise. For Tom, addressing his emotions resulted in a return to pre-injury coping: “I started drinking again and doing what I did to deal with the feelings I had. You know, I didn’t know any other way.”

Lucy identified how her emotions shifted when her difficulties were recognised by professionals as ABI after a long period of not knowing: “Because somebody believed me. I think so, I think initially relief. And now I know it’s true I feel cross.” Lucy identified why acceptance remained such a challenging process for her: “Because it makes me less than

doesn't it? [I: Accepting it makes you less than?] Yeah, because if you don't accept it you can pretend everything is alright can't you, for a bit." This statement reflects that Lucy may not emotionally be able to accept the changes and threat that the injury poses to her sense of self, and finds denial a helpful strategy. Lucy still experiences anger regarding her injury, which she manages with avoidance and humour: "If I don't think about it I can cope, if I think about it I get really cross"

It's like, I make a joke out of it, and if I make a joke out of it it's ok. [...] if I think about it in terms of less than jokey, it makes me really cross. I cope, I think, I manage my anger by having a sense of humour.

The doubting, different self

Many participants identified their sense of self as different following ABI, drawing on comparisons with their pre-injury sense of self, or identity. In earlier stages of recovery, where there may be less acceptance, some participants described self-critical thoughts and doubts regarding their own experiences. Anita described the changes in herself following injury by comparing to her pre-injury self:

Because I don't recognise on parts who I've become now and who I was before.

Because who I was before is still quite attractive, I was a highflyer, you know, I was a power dresser, I looked the business, I had money, and all the status and all of that.

Stuart spoke of pre-injury life, and described a loss of his sense of self, which he found highly distressing: "That I wasn't the same, that I'd lost a piece of myself, the good part, the good part, the bit that enabled me to be the person I was." He identified that he used to spend a great deal of time comparing his current self with his pre-injury self, and that this had a

negative effect on his wellbeing: “I spent a lot of time comparing what I’m like now, to what I was like, it was possibly the worst thing that I could’ve done.” Lucy described feeling less than her pre-injury self, which was a significant threat to her identity: “It makes me less than [...] Less than. Less than I was before. [...] I’ve always been competent, always been capable, I have to hold my daughter’s arm when I’m going round the shops, *please*.”

Some participants described experiencing self-criticism and doubt following ABI. This was particularly notable for the individuals who did not have an understanding regarding their ABI, including Stuart and Lucy. Stuart described blaming himself for the difficulties he was having:

Not knowing and basically pretty much blaming yourself for not getting better, is really, really hard and that’s pretty much what I did because I thought “basically there’s nothing wrong with you, you just need to [claps his hand] sort your psychology out, get back on the horse mate, come on.”

For some, there was a sense of doubt regarding experiences associated with the brain injury, and the impact on the individual. Lucy identified an ongoing sense of doubt regarding her symptoms: “Well somewhere in me, I still think I’m faking it.”

Although Denise did have some understanding regarding her injury, she also described self-doubt:

I ended up feeling, and, but having talked to lots of other head injured people, how you’re supposed to be aware of something, that you know, that everyone, it’s almost like you end up feeling like you’re making it up. So how can you accept something that nobody, almost the whole, everything’s kind of like “oh well it doesn’t matter, if

you can't think about picking a cup of tea up what does it matter?" So you end up thinking you're imagining it.

These processes of doubt and self-criticism may contribute to invalidation of the individual's experiences following brain injury, resulting in greater emotional distress and dislike of self. This was described explicitly by Matthew:

I definitely went through a stage where I didn't like myself, I didn't like what I'd become, I felt useless, worthless, I probably still do to a certain extent. I can't give what I used to give with regards time, energy, and that's, that's a bloke's pride getting in the way there.

Denial, avoidance and striving for normality

Many participants identified that during earlier stages of recovery they experienced some form of resistance towards the ABI, and a striving to return to pre-injury life. For some this included denial, and avoidance-based coping strategies. Some of this denial and striving for normality may have also related to a lack of understanding regarding the severity or consequences of ABI, as well as emotional processes relating to acceptance.

Anita described her own experience of denial:

So all these things a year on I picked up, but I was in total denial, I kept thinking oh they'll come back, as soon as I start to cut down on the meds, I thought oh this'll. So there was continuous denial.

Many hoped, and strove, for a return to normality, as described by Rob:

Well you're hoping you're going to get better I think, and you tend to, initially put it down to, some of it you put down to the fact that you're ill, and you're getting better and it's all going to come right on the night.

Denise also described attempts to return to her previous lifestyle, and a gradual realisation that this may not be achievable: "I was on that oh try and get back into doing everything that I was doing, but realised that wasn't happening quickly." Stuart also identified trying to return to his life and previous ways of managing difficult experiences: "I always basically just tried to get back on the horse as they say, I was taught that by my family and, it's a good way of doing things."

Tom described resisting thinking about his brain injury: "I didn't, I don't think I wanted to, I was just resistant, resisting it I guess." Tom described how part of his resistance of his brain injury was due to the label of brain injury: "so having a traumatic brain injury, you know, maybe I didn't want to have that label on me, you know." He perceived this was influenced by his childhood experience of having a disabled family member and the attitudes of others to this person. This experience was similar for Anita:

I thought I don't have a brain injury what's she talking about? And I remember chucking it onto one side. [...] I just thought brain injury's like when someone can't even talk or they're in a coma, or whatever, I think that's where I sort of processed it at.

Denise also recognised a resistance towards her first brain injury, and engaging in attempts to overcome it:

That it was something to get over or push past or you know get healed. I just went on this major healing, tried to understand stuff to try and reconnect with my body and try and get it under control.

Denise went on to describe an externalisation of her head injury from her sense of self:

I still had that thing where I'd accepted that it had happened, but it was like, like there was a head injury, like, like this head injury tiredness and ordinary tiredness, and like that was separate, and almost like a separate being.

This process was also experienced by Tom: "I just acted as if it wasn't there it wasn't part of me. Because I could walk, I thought I had healed from it you know?" Anita also experienced a degree of separation in the earlier phases of her recovery, whereby she found it hard to recognise herself immediately following her injury, partly due to physical changes:

When I saw that I was horrified, I didn't recognise myself, I thought "who is this *person*?" And then I thought I think I was just shocked and just, I think I was, yeah, I was just really shocked, and I thought, I actually thought it wasn't me at a point as well.

This separation of self may represent a protective defensive mechanism earlier in recovery.

This process may allow participants to protect and retain their sense of self through separating the injury from their central identity.

Both Denise and Tom identified that use of substances helped them cope with their experiences following their injuries, but that this way of coping may have resulted in them not facing up to the consequences of their ABI. Tom described alcohol use: "Alcohol, you know that just, trying to bury, what I was trying to bring up." In addition, Tom recognised that

substance misuse helped him to mask his symptoms and avoid the need to disclose his injury to others:

I could say it helped me run, escape from my new reality, you know it's, it definitely was you know, because if you're high, you know people aren't going to judge you by the way you sound or "wait did you hear what he just said?" [Tom laughs] you know it's like "yeah he's high." So maybe I was using it as a smokescreen or a cover.

For Denise, there was a clear difference between her experiences following her second injury compared to the first. Denise described greater acceptance and less resistance following her second injury: "so rather than fighting it, I suppose, so on some level accepting "right ok I'm going to, what's this teaching me? What didn't I get?" Not consuming alcohol following her second injury may have aided Denise's experience of acceptance: "probably not drinking this time, has made it a lot easier to accept because you're not, I suppose alcohol you know it's like a way of switching off from it." Denise identified a host of coping strategies she had developed as alternatives to consuming alcohol.

The experience of denial or avoidance was suggested to be a barrier to management of the ABI, as described by Stuart: "if you deny a problem, deny you have a problem, you're never going to fix that problem." John also identified this when reflecting on his experiences of supporting other ABI survivors: "I've seen people with head injuries bury their heads in the sand because they're not coping. And it's sad to see because there is a way out, there are coping strategies to help people."

Acceptance

This theme describes the experiences of acceptance, including what participants felt they had to accept following ABI, and the processes which occurred. Acceptance of the occurrence of the event itself was followed by acceptance of permanence, as individuals came to terms with the likelihood that the injury may have long term consequences. Experiences of loss and changes associated with injury consequences were gradually accepted. Coping strategies such as denial, avoidance and striving for pre-injury normality reduced, and some participants experienced a greater honesty with themselves. As individuals became less preoccupied with losses and differences of self, some experienced more frequent positive thoughts and emotions, and a gradual acceptance of self.

Occurrence and Permanence

Many participants describing accepting that the head injury had occurred; for example, Anita stated: “so there’s the stable things I do accept, like this has definitely happened, and I accept that.” Denise also identified this level of acceptance earlier in her recovery, explaining that, despite accepting the injury had occurred, she was still experiencing some difficulty accepting the impact of the injury in terms of symptoms:

I got to a place where I accepted it, well it was almost like that, part of me, but I still had that thing where I’d accepted that it had happened, but it was like, like there was a head injury, like, like this head injury tiredness and ordinary tiredness, and like that was separate, and almost like a separate being.

Gradually over time participants identified an acceptance that the effects of the injury may be long lasting, and may not recover to the extent they had previously hoped. John

described accepting that he will not be able to repair the injury, and the importance of learning to cope with or manage the consequences of the injury: “there’s nothing I can do about it, in the sense that there is no fix, [...] it will never, never go away.” Matthew echoed this statement, describing a change in his acceptance of the chronicity of brain injury:

The acceptance that life’s not going to be the same, no matter how much you want it to be. It’s not like recovering from a broken leg or such like, this is something that’s broken that can’t really be fixed, to tell you the truth, that’s how I was feeling.

Moving on from loss and changes

Many participants explicitly spoke about acceptance of losses, and the experience of moving on from them. For Anita, part of acceptance was accepting her present experience within the moment, rather than being preoccupied with the past, or the future:

Maybe acceptance is to be present now, and not to compare it with how it was before, or how you want it to be in the future, maybe acceptance is just to accept it for now, right now, just to be present right now, this minute, this day, and that’s it.

The loss of valued interests, hobbies and occupations were spoken about by some participants. Matthew described his experience of grieving for these losses:

Your life is totally different, and when you start losing the things that you love so much, like the cycling, like the work, and you go through a grieving process because you’ve lost these things, it’s a shock, it’s a real shock...

Tom described his experience of understanding and accepting the changes to both his abilities and his social identity:

Accepting the brain injury and what did I have to process. I had to be, I had to be willing to understand that I might get off track, you know I might be able to identify with people that are 40 years older than me or that are going through life's changes, you know and might be forgetful of certain things at times.

Rob reflected on his pre-injury intellect and how others responded to him at work pre-injury, and recognised that he has had to accept changes to his cognitive abilities:

I'd come out with all of this stuff, not even realising they're all going like this [demonstrates mouth open] so all of a sudden you can't do that. It's, that, it's a big acceptance in the fact that, that sort of like, in my case the fact that my intellectual superiority is not where it was, is somewhat irritating.

Kevin described an acceptance of changes to his abilities as a result of the injury, such as his communication abilities:

Yeah I've accepted that I can't get my point of view across, at one time I'd have got frustrated, why can't I say what I mean. I can't find, use the word, have to find another word, partial, oh that's it, partial. I accept I've got to slow down and do what I want to do a lot, lot less.

Kevin and Lucy both acknowledged difficulty with acceptance of losses, and anger associated with these. Lucy stated: "I lost everything, because of people's - because of being invisible, or people's incompetence. Through no fault of my own, I lost my home, my pension, everything. Completely everything." It is hypothesised that Lucy and Kevin may still be going through a grieving process associated with their experiences.

Honesty with self and embracing ABI

Some participants articulated their experience of becoming more honest with themselves and embracing the injury as part of themselves. Anita explicitly connected self-honesty to acceptance: “I think acceptance is maybe to stop the denial. Maybe acceptance means to stop the denial, to be that honesty with self.” Tom identified that through being honest with himself about his ABI and alcoholism he was more able to be honest with others, which he found beneficial: “Reaching out, being true to myself, you know, honest, open and willing, Being, you know being able to share with other individuals.” For Denise, the reduction in resistance against her ABI meant integrating the injury into her sense of self:

That’s the bit I think has changed. It’s, it’s almost, I don’t, I mean I still for a while was doing that “look my head’s bad,” almost like a separate entity but now it’s just like, if things are coming up or I’m feeling tired it feels like it’s melded into one being more than not so, so that’s the thing, the other acceptance, that I’m not separating it so much. It’s possibly as well, maybe not so extreme, but it’s I think I do just see myself more as one being.

Shifting emotions and positive reappraisals

Some participants experienced a reduction in anger resulting from acceptance. Stuart described how earlier in his recovery he was angry about his difficulties, but that acceptance has resulted in a reduction in these emotions:

And I’m still tired, quite how it works I’m not entirely sure but I just manage it as it happens now, but it used to stress me out and anger me that it was happening to me.

Now, because I've accepted that it does happen, I'm like, "well you can be angry about it if you want but, what're you fucking worrying about?"

Denise identified tolerating negative emotions following her injury, rather than actively trying to fix her injury through application of different coping strategies:

I suppose because I'd got that going on it was almost like, like I had to sort this out for me, and just, kind of just sit with it and deal with the emotion rather than just trying to find lots of ways. You know, go on some healing mission, it's like right just be with it, and just be really sad, and be really annoyed, now you've got a second head injury.

And yeah, resent, resent that I might have sorted it out with my partner if I hadn't have had the second head injury, you know.

Rob also recognised a change in his emotional response to the injury, which he related to acceptance and being able to let go of experiences which he would previously have remained preoccupied and frustrated with: "I think now I just put up with it much more. Ok I know I can't do some of the things I want to do so it can be annoying, but let's just move on after 30 seconds." Stuart too described a greater ability to let go of unhelpful preoccupations or ruminations regarding his brain injury:

Because it happened to you, and that's natural, and that's the way the brain works as well, but you don't concentrate on it, it's not something you, you talk about, or put out there, it's not something you adhere to in your mind, it's not something you are controlled by in your mind.

Tom described a shift in his perspective of life and his focus on the future through accepting his injury:

That's just my, my awakening, to grab life by the horns, and not, not live in fear, not be afraid of acknowledging what is my new reality, because you know life is, there's so much more to this life than being a, a survivor you know?

Not only does Tom not feel frightened, he views himself as someone who is not just surviving, but thriving. Anita also experienced a change in her perspective post injury, identifying how her values had been clarified through acceptance:

There's such an awareness of who you are and what's actually important in your life. And I actually thought the most silliest things were really important to me and after brain injury it's like, if I don't go for a walk once a day in nature, you know that is so important to me.

Some participants expressed a gratitude regarding their life. This appears to be a shift away from the preoccupation with losses which occurred earlier in recovery. Stuart described himself as "lucky," Anita stated: "there's this sense of gratitude, there's this real sense of I'm alive, and it's a gift, so that's where it's at." Matthew echoed this sentiment: "I just thank my lucky stars every day that I'm still here." As participants became more able to accept losses, changes and permanence of injury, it is hypothesised that negative emotional reactions reduce.

Self-acceptance

For some, the process of acceptance also involved greater acceptance of the current self. Anita reflected on comparisons between her pre-injury and current identity, but described an acceptance of these changes and a re-evaluation of self-worth:

I don't recognise on parts who I've become now and who I was before. Because who I was before is still quite attractive, I was a highflyer, you know, I was a power dresser, I looked the business, I had money, and all the status and all of that. I let, the, my job, define who I was then. But now, trying to accept me for who I am now, I'm still that person, but I've actually - I think I've improved a million-fold.

Stuart described a shift in the self-comparisons he was making earlier in his recovery. He described how understanding and accepting that he had a head injury helped him to stop negatively comparing his current self with his pre-injury self: "Because they're [his pre-injury and post-injury selves] not comparable, actually knowing and accepting that you've had something, that you've got some form of issue..." Matthew also described how accepting the person he is following his injury has resulted in less dislike of himself:

I don't feel as down on myself anymore. Not like I used to do. Yeah it's accepting that you're a different person now and the sooner you get your head round that, that you have changed a little bit, the better.

Some participants described a reduction in self-criticism. Stuart described a reduction in the blame he experienced regarding a relationship breakdown that occurred following his ABI: "beforehand as I say I just used to blame myself for everything, but that probably didn't help me in accepting the individual parts that I was responsible for and not actually blaming myself for a load of other things as well." Tom identified that acceptance resulted in him being less critical of himself and experiences relating to brain injury: "I'm less critical of myself, less apologetic for my shortcomings, you know that I do have or experience because of my injury." Kevin echoed this: "Maybe I don't beat myself up quite as bad for not getting on."

Lucy still appeared to struggle with acceptance however and experienced self-doubt and criticism, although to a lesser degree. She attributed this to the duration of invalidation of her experiences by others: “There’s still an underlying thing “you’re faking, you’re making it up, you’re faking, you’re making it up.” And I think that’s on the back of all this stuff.” This may also be reflective of the stage of acceptance Lucy is at within her recovery, as she acknowledged she did not feel she had accepted her injury and related experiences.

Ambivalence about the value of acceptance

Participants varied in the extent to which they viewed acceptance as an important or valuable part of their recovery, and in the extent to which the concept of ‘acceptance’ was a useful one. Most participants expressed some degree of ambivalence regarding acceptance following ABI, with many preferring different terms. It was highlighted that the term has negative connotations of resignation, and that it implies finality and closure in a way that does not capture the ongoing struggle to come to terms with what has happened. Some participants reflected on the personal and cultural values and expectations that confer a negative valence on acceptance.

Although most participants acknowledged the value of acceptance as a process, they still preferred different terms. Despite believing that acceptance was an important process, Rob preferred the word ‘tolerance’: “you could use the word tolerance I suppose, of the situation, which would allow frustration to fit in there better then, because you’d say I’m tolerating it but I can get frustrated. Whereas before I really didn’t tolerate it.” Matthew consistently used the phrase “you’ve got to get your head round it” within his narrative in preference to ‘acceptance’. Similarly, Tom and John both thought acceptance was important,

but both spontaneously used the word ‘acknowledge’ to describe the experience. John explained why this distinction was important to him:

There is a word I’m after and, acceptance, if I say acknowledge, I think that’d be a better, acceptance means to come to terms with, I don’t think you can ever come to terms with it, you can never, what’s happened has happened, but still, I mean I get my off days, I’m not completely 100% still, I suppose you can accept to a certain extent, but you can understand.

John preferred ‘acknowledgement’ because it was more effective than ‘acceptance’ in allowing that he experienced an ongoing struggle to come to terms with what had happened to him. For him, ‘acceptance’ appeared to have connotations of completion and finality that were inconsistent with this. These connotations were also undesirable to Kevin:

To come to terms with and, I can come to terms with the fact I’ve got a head injury, but I can’t come to terms with living with it 100%. I obviously live with it better than I did, in that period of time, but, do I? [pauses] Sorry I’ve got a head injury that’s it? No, it ain’t in my nature.

A minority of participants felt that acceptance implied undesirable resignation and were more definite in their rejection of it. Lucy did not identify with acceptance of her brain injury, but felt understanding was highly important:

I don’t think it’s the right word. I think understanding would be better. For me it would be better. Acceptance feels like, lie back and you’ve had it, you know, it feels like. But understanding, understanding seems more active, acceptance seems more passive, and I don’t like the acceptance thing. Understanding is better for me,

acceptance I don't care for, understanding yes, I like that, there's more energy in understanding, acceptance just seems like you've rolled over and given up.

Kevin also reflected on the negative connotations, regarding acceptance as a defeat and placing greater value on understanding: "You're admitting defeat, you've given up, you're defeated, you've not been what you thought you should've done [...] Comprehend, understanding, I think maybe understanding would be a better way of, for me, for other people possibly not."

This individuality may in part represent differing stages of acceptance that participants had reached, but may also be moderated by personal and cultural values and expectations. Lucy identified that her resistance against her injury and the undesirability of acceptance related to the importance of maintaining her sense of self and role within her family:

There's a bit of me kicking against it. And that's from being young and small, and not, I'm the eldest of 5 daughters, you know my mum was hospitalised my sister was killed and I had to bring a family up. So if I'm not fully 100% what's going to happen to everything else?

There was a suggestion that acceptance may be less desirable in an individualistic culture, and that societal drives to improve and repair may impact upon acceptance. Rob described this:

Over here, we're not taught to accept are we, we're taught to argue, taught to discuss our position, particularly in the Western education system, particularly in the British education system, it's all built around argument. So the, the idea of dumb acceptance if you like.

Denise described how despite acceptance of injury, she experiences an ongoing need to improve, underpinned by societal expectations:

It's an acceptance that it's happened, but at the same time, always pushing. But we live in that society don't we, it's like "oh you're feeling sad, quick take this," or I don't know "your legs not working better, you can try all." Do you know what I mean? Where there's always a push isn't there?

Moderators of Acceptance

This theme described moderators of acceptance; which included the role of others, reframing and valuing positive experiences, and a hopeful future. Responses from other people could both facilitate and hinder acceptance. Acceptance also appeared to be facilitated when participants were more able to consciously recognise positive experiences, and experienced optimism regarding having a meaningful future post-ABI.

The role of others

Acknowledgement and understanding from others appeared to facilitate participant understanding of their ABI. In addition, understanding from others appeared to validate many participants' experiences. This seemed to assist in the process of accepting losses and change, and overcoming self-doubt and blame. In contrast, doubt, denial and lack of understanding from others (e.g. associated with assessments in the context of a compensation claim for their injury) hindered the process of acceptance because it made it difficult to understand the experiences, and move on from them.

Acknowledgement and understanding from others

This theme describes how personal support networks, other ABI survivors, and professionals facilitated acceptance by acknowledging and understanding the experience of ABI. The experience of acknowledgment and understanding from others facilitated participants' own understanding of their injury, and appears to provide a source of validation regarding experiences associated with ABI. It is suggested that this validation legitimises the experience of ABI, and allowed participants to feel less alone, and perhaps less defensive regarding their own experiences, thus aiding the process of acceptance of losses and change. For some, this may have helped in the process of overcoming self-doubt and blame.

For many participants, others helped them to understand their ABI, and the impact it was having on them. Stuart described how accessing services, and having his difficulties explained to him by professionals was helpful: "I didn't understand it before I got diagnosed by [psychologist] and he actually explained stuff about having a brain injury."

In addition to helping foster understanding, many participants identified that acknowledgement and validation from others helped them to accept, although they did not explicitly identify how this was helpful. When discussing factors which may have helped her acceptance of injury, Denise identified the value of understanding and acknowledgment from others:

I suppose that's the thing isn't it, the times when you're talking with people who, like get head injury, or even just give it some acknowledgement, I suppose it's, it's normal human things isn't it, being seen, being heard.

It is hypothesised that professionals provide a sense of authenticity to participant experiences. Lucy identified the value of the acceptance she experienced from head injury rehabilitation professionals. She explained how genuine acceptance and care from such professionals had helped her to rebuild her own trust in herself, rather than doubting her experiences:

And she'll say something, and I'll think "aaw, she really does know and care, she really does know I'm struggling, I really aren't faking it am I." So every time they say something nice to me, or do something for me, it like reinforces that I am worth, that I have been hurt, that I'm not fibbing.

For Stuart, other people acknowledging his injury aided his acceptance: "it makes it a lot easier knowing that other people think that, other people have seen it." Stuart perceived acceptance of himself from his family as a very powerful facilitator:

My family [...] That they don't care what I'm like [cries] [...] no one, no one wants to admit that you've changed because it, it, means it has happened, means you've got a problem, but – and although I have changed, they stuck with me through the bit when I was really not me, you know what I mean?

The importance of family acceptance was also described by Matthew and Tom. Matthew echoed the importance of his family accepting who he is now, his changed self:

The sooner that your family accept that you're not what you were [the better], and it's a big thing for them as well, for [my wife] especially, it was hard for her to accept that I was different, she couldn't understand what was happening to me and I mean, obviously this is my close family, my other family as well, my sister, my

nieces and [wife]'s parents, they know what I am now, and they've accepted that I'm not like the old Matthew I used to be.

For Tom, acceptance and understanding from his family also afforded him the sense of not being alone with his brain injury:

You know the family is, huge in accepting and, caregivers, if they're not able to accept it why should I? What's going to, you know why am I going to stand on a lone pillar and be like "oh look, you're my family and I love you but, you know this happened, this is what's going on, this is how it feels."

It is hypothesised that when family members understand ABI, and continue to be present and demonstrate their belief in the individual with ABI, this may help the individual with ABI to overcome feelings of self-criticism and dislike and facilitate the process of coming to accept and value themselves again.

Shared experience with other brain injury survivors aided acceptance for some, through understanding and validation of experiences. Kevin described how meeting others with ABI helped him develop his understanding and acceptance of his own difficulties, alongside the professional input he received:

Oh, how they explained it, oh like that, oh I do do that, I am like that. Having other people, "Oh I do that." Because everybody's experience will be slightly different or, totally different, or, and you, it's, it's perfectly natural for me to be at the moment how I am. [...] But when you see somebody that is, starts talking and being rude, I do that! It's, it's belt and braces isn't it, somebody's reinforcing it by doing it, and somebody's telling you about it.

John described how this shared experience benefited his acceptance:

I opened up [...] And you would relate to them, and understand, and one of my, how could I put it, classic lines, was because we'd have to say how we felt about stuff, and what was going on and stuff and obviously then you start making that connection to what other people are saying. Like, do you know what, I feel like that as well. I understand where you're coming from on that one.

Rob also experienced a compensation claim as a public acknowledgement of the legitimacy of his ABI: "I suppose in some ways you're more accepting because you've got something for it, someone else has agreed that you've got a head injury because obviously some people say you haven't." The experience of compensation processes on acceptance will also be discussed within the next theme *doubt, denial and lack of understanding from others*.

Doubt, denial and lack of understanding from others

This theme describes how other people's doubt, denial and lack of understanding could be a barrier to acceptance. Many participants recalled instances when their experiences had been doubted by others. This doubt from others seemed to hinder acceptance as participants were prevented from gaining a clear understanding of the changes that is the precursor of acceptance. John recalled times he sought advice from professionals and was told his difficulties were not related to his brain injury:

I went to the Doctors, and the doctors in [omitted], and "Oh John it's nothing." It just got brushed off, I said "look I've had these sorts of feelings, I've had a brain injury before," "oh have you?" I says "yeah," I said "look, you know" "oh no, no, no, you'll be over the worst on that sort of thing you know off you go."

Rob, Matthew and Lucy experienced doubt and denial from others as part of the process of making a compensation claim in relation to their brain injury. This seemed to be a hindrance to acceptance because participants were unable to move on from a focus on the losses associated with their injury, and because the validity of their attempts to understand their experiences in terms of the brain injury was called into question. Lucy summarised this when she described her experience of seeking compensation:

Because the powerful people in my life, by omission sometimes, told me, or by not omission sometimes, the court publicly shamed, you know the Judge said “you’re no more traumatised than you would be if you went into hospital, had an anaesthetic, had an operation and came out.” But that leaves a big heavy imprint in your soul. And that’s in front of all your friends and all your family.

Matthew recalled the impact disbelief from others had on him:

That had a big effect on me, people, you know people not believing me and not realising what I was going through, and I think that’s - you’re going to have to excuse me I’m filling up a bit here.

Rob identified the frustration denial from others caused him, and his need to defend himself and his experiences: “that annoyed me, I knew, I know there’s something wrong, I know I’m not as good as I was, and it annoys me when people say there’s nothing wrong with me.”

The experience of not being understood by the wider community was a barrier to acceptance for many participants. Denise described how invisibility of her injury coupled with others’ lack of understanding regarding ABI made it more difficult for her to accept ABI:

I know what it is, one of the things is that because you look normal, nobody else thinks about head injury but it, because it affects so much, [...] so you're trying to accept something but most people aren't even aware or bothered, or don't see why you would be bothered, but they forget that your brain does everything.

This lack of understanding and negative experiences of support from others resulted in experiences of isolation and loneliness for many participants, as stated by John: "it's a lonely world out there when you've got a head injury." Tom recalled the impact of feeling alone following his brain injury: "I felt so alone in my brain injury because 17 years ago there weren't many people going around standing on the mountain top saying "I have a brain injury!" These experiences perhaps reflect the importance of shared experiences with other brain injury survivors, as a means of validating and normalising the impact of brain injury. Sharing the ABI with family, peers and professionals, and experiencing normalisation and validation, may help promote acceptance of ABI and associated challenges as the experiences related to ABI can be understood, authenticated, and the individual feels less isolated.

Reframing and valuing positive experiences

Some participants described processes of consciously reframing their experiences, and placing greater value on positive life experiences. This may foster acceptance by allowing individuals to move on from the negative experiences and losses associated with facing change. John described a conscious process of trying to focus on positives during his recovery: "I mean you know, I always look at life as 1 step forward is 1 less step back erm, and I try and look at that in a positive way."

Denise described that learning to focus her attention on positive experiences aided her experience of acceptance:

Even simple practices like gratitude practise, so which is basically just when you're feeling shit then just say thank you for 21 things. But do it as a practise, so on the days where you feel like everything is just over, then you, it's a lot easier to pull that tool out in a way, and "oh yes actually I am alive, ok you know my head injury still is getting better, I've got a lot of support, and you know oh yeah I've got a roof over my head" and it's like come on, just because I wanted to go there but I can't, but actually I'm safe, I'm fed, I'm clothed, do you know?

Stuart explained how recognition of his own recovery and improvements also facilitated his experience of acceptance: "one of the things that probably helped me accept most is I've actually got better, and am of sound enough mind to run my life properly again." Anita accepted that what she had prior to the injury may be lost, but that what she has now is as valuable to her: "I'm never going to get that back of who I was and where I was but you know what it's ok because what I've got now, is equally if not better than what I had before..." Despite the loss of some of his abilities, Rob identified that he has been able to find other ways to maintain valued activities and recognise his strengths: "I have found alternative ways to do things, so it's just an acceptance that I'm not as bright as I was, but I'm still brighter than most people so."

A hopeful future

Establishing a meaningful future and feeling optimistic regarding life after brain injury also appeared to facilitate acceptance, although it might also hinder it. Some participants expressed hope regarding their future, which was distinct from the previous striving for pre-injury normality. This was described by Matthew: "there is light at the end of

the tunnel, your life's not over it's just different." Rob articulated how hope for a different future is part of his acceptance of ABI:

Acceptance is coming to terms with something really, it's coming to terms with the fact that things aren't the way they were, they are the way they are, but that doesn't necessarily mean they can't be different in the future.

Some participants expressed an interest in neuroplasticity, and the notions that they may continue to experience some degree of further recovery with time, as described by Denise: "but that things can still change and be healed almost, or like with the brain, I'm really interested in the whole brain neuroplasticity thing, yes. Yeah." For some of the participants, feeling hopeful regarding the future may help facilitate acceptance of the changes they have experienced following ABI because it is easier to accept a challenging reality which has some prospect of improvement than one in which there is no prospect of improvement and which therefore one might be motivated to continue to avoid. Conversely, hope may also represent an ongoing struggle to accept.

Finding meaningful purpose in life following ABI may also facilitate acceptance through fostering an expectation that things will improve. Anita reflected on how her plan for the future provided motivation and purpose, facilitating her acceptance of ABI:

You have to have a plan, and you have to keep pushing, you have to keep extending the boundaries, when it feels comfortable for you. And then that becomes purpose and I think without purpose especially within brain injury there's no acceptance of it.

Purpose, for many, was identified through advocacy and working with others with ABI. The delivery of a valuable service to others also served to enhance their sense of self-worth. Tom described how his role in his family and his advocacy role have fostered his self-acceptance:

To be here fully, for my family, you know, and yes of course, to be an advocate, I never thought I'd be an advocate for people with addiction difficulties, people with mental health issues [...] I've done so many cool things, I never thought I'd be a source for individuals to find comfort with themselves.

This experience was shared by John, helping others fostered his sense of self-worth, alongside the experience of being valued and respected by others:

I succeeded in such a way of turning someone's life around, to the point of which he thought he'd never be at. And working. And [professional] saw that. All the team saw that, and they thought it was amazing, I'm no miracle worker, I am who I am, I get on with people who have a head injury and I can relate to them.

All participants expressed the importance of establishing purpose within their lives following ABI. This included speaking of establishing meaningful roles, such as roles within their families, and occupational and volunteering opportunities. Whilst some participants had found, or were seeking out purposeful roles, Kevin spoke of his perceived lack of purpose as a challenge to acceptance, in his analogy of seeking success in life as climbing a mountain:

If we go to the analogy with the old hill, the mountain. A man, sees a mountain, you're on top of the mountain, old man with a mountain in the back, in the distance. And I still think I should be climbing it [my mountain], and getting better in myself, so

how can I not, how can I accept it if I can't climb my mountain? You've wasted your life unless you try.

Experiencing a hopeful, meaningful future post-ABI may facilitate acceptance by allowing participants to move on from the negative experiences and losses experienced, to focus on their future with optimism that the rest of their life may still hold value. It is hypothesised that in conjunction with reframing and valuing positive experiences, these processes may contribute to a sense of achievement. This may promote the individual's sense of their own self-worth, thus bolstering self-acceptance following ABI.

The ongoing struggle of acceptance

For some participants, there was an ongoing struggle within the processes of facing up to change, and acceptance. As previously noted, ambivalence was present in most narratives. Acceptance was not a finite goal, but rather was experienced as an ongoing process. Frustration continued to occur, and life events could present new, ongoing challenges to acceptance.

Stuart described his ongoing struggle with acceptance: "Because as much as I don't want to, I've accepted it [cries]. Basically. Still don't want to." Anita identified that for her, acceptance is an ongoing, daily process:

I think on a day-to-day basis every day is different so the acceptance is something we work on, on a daily basis. Not to say that I don't accept I think, I just accept where I'm at every day, so maybe, nothing is ever 100% so there's a contradiction to it, so I think it's an ongoing process.

Matthew described experiencing difficult days, which are a challenge to acceptance of his injury:

I don't know if you ever get totally your head round it [...] I still have days when I think "yeah, I can do anything today," and I still have little lapses like that, still thinking that I know best.

Many participants described ongoing frustrations associated with accepting their injury. Denise described how, despite accepting, she continues to experience frustration regarding the impact of the injury on her life:

It's things like I knew it would be stupid to get into riding motorbikes, but it's like somebody told you that it wouldn't be a good idea and so it's like there's an, a kind of acceptance of that but an annoyance with it, it's like, like a lot of my friends still rode motorbikes and things and, it's like I can't do that.

Rob also recognised the ongoing frustration he experiences:

I think you can accept the fact that you're not going to get back to what you were, but there's no reason you can't get frustrated because you can't do it. I don't think the two are, the two are, the two can exist together, they're not, you know, you can accept the fact you're not what you were, but you can still get frustrated by it. I can't see anything wrong by that.

Whilst Kevin described the need to accept where he is and what he's got, he still experienced a great struggle with this process, and was unhappy regarding his position in society: "You've got to keep trying, you don't give up, you have to accept where you are, you have to accept it but you don't, really, you can never really be happy with it can you." Within his interview,

Kevin described many frustrations regarding his experiences of society as unfair, and a wasted life. Kevin did not appear to have been able to accept some of the negative long-term consequences of his injury.

New life challenges also presented new challenges to acceptance of head injury. Denise identified the challenge to her acceptance when she experienced resignation following a relationship breakdown, which coincided with her second head injury:

So I was really, on one level I was like “I’ve just got to get this head injury thing kind of, yeah accept it this time and look for the gift and all that kind of thing,” and at the same time, almost just “I’m done, I can’t, I’ve just had enough now.”

When asked if anything else may aid acceptance in the future Matthew highlighted how new events may present new challenges to acceptance: “the next biggest hurdle for me would be getting back to work in some shape or form. Because that’ll be another massive test for me I think, that to do something on a regular basis...” This suggests that Matthew recognises that new, potentially difficult, situations may challenge his current acceptance of his brain injury.

Discussion

This study is, to our knowledge, the first qualitative study with a focused exploration of acceptance following ABI. The emerging themes (see Figure 1 for overview) provide new insights into the experience of acceptance following ABI.

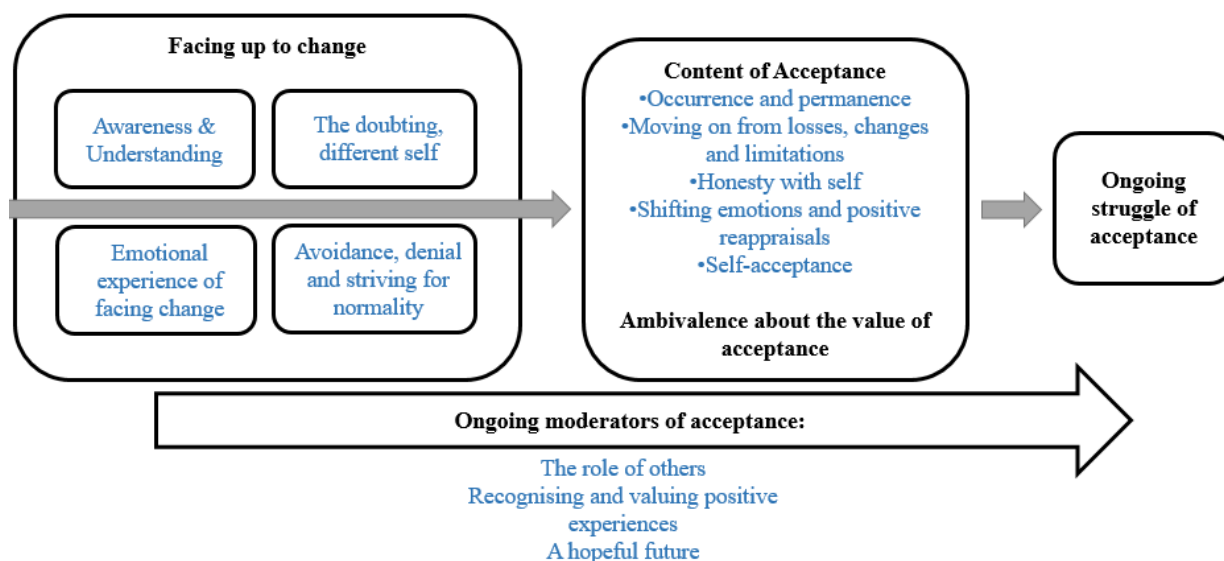


Figure 1. Schematic summary of themes

Participants described processes of becoming aware and trying to understand changes resulting from the ABI. This was associated with negative emotions, such as anxiety and anger. Some made comparisons with their pre-injury self, and expressed self-dislike and doubt. Denial, and striving to return to pre-injury life was common. Acceptance meant acknowledging that the changes were real, were due to the ABI and were likely to be permanent. Through acceptance, participants described processes of moving on from perceived losses and associated negative emotions and responses. There was ambivalence about the value of acceptance, and acceptance was identified as an ongoing process. Acceptance could be facilitated by other people, recognising and valuing positive experiences, and establishing a hopeful future.

Facing change: During the earlier phase of recovery, individuals with ABI experienced the process of facing change, and developed awareness and understanding of these changes. This is consistent with qualitative studies regarding awareness post-TBI (O'Callaghan et al., 2006), and recovery following ABI (e.g. Freeman, Adams & Ashworth,

2015; Howes et al., 2005). Concurrent with these experiences, this study found evidence of some of the emotional challenges associated with facing change, and individuals' experience of denial and striving for pre-injury life, which was also identified by O'Callaghan et al. (2006). Prigatano (2012) identified challenges distinguishing between awareness difficulties and defences such as denial. Further research distinguishing between awareness deficits and denial may be beneficial, however in clinical instances it is likely to remain a challenge to disentangle these processes. The study highlights the importance of diagnosis and timely provision of information about ABI to develop awareness and understanding, which is consistent with guidance regarding neurological rehabilitation (Turner-Stokes, 2003).

Acceptance: Through recovery participants described a shift from non-acceptance, to a gradual acceptance of change and permanence of ABI. Acceptance of change has emerged in other qualitative studies (e.g. Gelech & Desjardins, 2011; Klinger, 2005; O'Callaghan et al., 2006; Parsons & Stanley, 2008). In this study, some described becoming more honest with themselves about the brain injury, embracing the injury as part of themselves, and a reduction in negative thoughts, and emotions such as anger. For some, acceptance included greater self-acceptance and less negative comparisons of themselves. Whilst negative self-comparisons are identified in the literature, there is also evidence positive self-conceptualisation post-TBI (Beadle et al., 2016), and qualitative descriptions of redefinition of self (Muenchberger et al., 2008). Overlap to acceptance in other conditions is noted, for example acceptance of rheumatoid arthritis included processes such as reappraising values, positive thinking processes and accommodating arthritis as part of self (Kostova et al., 2014), and acceptance of mental health included integrating mental health as part of the self, and positive emotional experiences and thoughts (Mizock et al., 2014).

Identified aspects of acceptance align with some of the overarching value changes proposed in acceptance of loss theory (Dembo et al., 1975; Keany & Glueckauf, 1993; Wright, 1983). According to acceptance of loss theory, acceptance of disability involves processes which prevent disability from devaluing the individual. Adjustment to the individual's value system is proposed, ensuring actual or perceived losses do not negatively affect the value of existing abilities. Four key value changes are described, as presented in Table 5.

Table 5. Value changes described in acceptance of loss theory (Keany & Glueckauf, 1993)

1	<i>Enlargement of scope of values:</i> A reorganisation of values, whereby individuals' focus on values beyond those intrinsically linked to the disability, including finding meaning or purpose in life.
2	<i>Subordination of physique:</i> Lesser focus on values relating to physical capacities, self-worth is characterised by other traits, such as personality.
3	<i>Containment of the effects of disability:</i> Viewing the disability as a possession, rather than a core trait of the individual, thereby preventing spread of the disability to other aspects of the person.
4	<i>Transition from comparative values to asset values:</i> Less focus on comparisons with pre-injury self or other people, and a greater focus on one's strengths and abilities.

Some participants did describe processes which may represent enlargement of scope of values, for example reframing and valuing positive experiences and exploring a hopeful future and purposeful roles. Transitions from comparative to asset values appeared to occur for some, as self-acceptance involved shifting away from unhelpful self-comparisons. In this study, containment of the effects of disability was not overtly discussed, participants did not appear to describe their brain injury as a negative defining aspect of themselves, however two did described embracing the injury as part of themselves. This is consistent with Mizock et al. (2014) and Kostova et al. (2014) who postulated acceptance of health conditions included an assimilation of conditions into their identity, without negative connotations. Further research regarding how injury is integrated with the self may be helpful. In contrast to acceptance of

loss theory, subordination of physique was not present in this study. This difference is important as ABI does not always result in overt physical changes. For some, a shift away from physical status may be less relevant. The impact of invisibility of injury on acceptance would benefit from further research.

Ambivalence about acceptance: Some of the research participants in this study expressed ambivalence regarding the term ‘acceptance.’ Qualitative research with individuals with chronic pain has also found ambivalence regarding acceptance (Biguet, Nilsson Wikmar, Bullington, Flink & Löfgren, 2016; Kostova et al., 2014; LaChapelle et al., 2008). In a review of literature regarding acceptance and denial in physical health, the use of labels such as denial and acceptance were considered potentially unhelpful (Telford, Kralik & Koch, 2006). The authors suggested such labels could be internalised by patients, and use of labels amongst clinicians could cloud their ability to actively listen to and validate the patient’s personal experience. Rejection of the label ‘acceptance’ should be borne in mind in clinical contexts, as it’s use could be experienced as invalidating and result in rifts in therapeutic relationships.

The ongoing struggle: This study highlights the ongoing struggle of acceptance. Other research has suggested that recovery following ABI may be an ongoing non-linear process, for example in relation to general adjustment to ABI (Roundhill et al., 2007) and identity reconstruction (Muenchberger et al., 2008). This may be explained by the known long-term consequences of ABI (Ponsford et al., 1995; Wood & Rutterford, 2006). This emphasises the importance of access to neurological rehabilitation services throughout life post-ABI, which is consistent with clinical guidelines regarding rehabilitation following ABI (Turner-Stokes, 2003).

The role of others as moderators: The role of understanding, normalisation and validation through others has been highlighted in this study. This is consistent with other research which has demonstrated the importance of social support and validation (Chamberlain, 2006; Levack et al., 2014), including peer support following stroke (Leahy, Desmond, Coughlan, O'Neill & Collins, 2016). This is important as invalidation is posited to contribute to mistrust and invalidation of own experiences, contributing to negative emotions including fear, anger and shame (Linehan, 1993). Several theorists have proposed that our understanding and evaluation of ourselves is primarily derived from, and sustained by, interactions with others (Ownsworth, 2014). From this perspective, social interactions are vital to developing self-understanding and self-acceptance following ABI (Douglas, 2012; Gracey & Ownsworth, 2012). Acceptance by others (in the form of understanding and validation) may be critical in facilitating self-acceptance. Relating with other ABI survivors as a facilitator of positive self-identity has been suggested (Gelech, Bayly & Desjardins, 2017; Nochi, 2000). Identification with other ABI survivors may foster self-acceptance, as identification with social groupings is suggested to be a primary determinant of one's sense of self and self-worth (Hogg & Abrams, 1990; St Claire & Clucas, 2012).

Optimism: Reframing and valuing positive experiences, and belief in a hopeful, positive future appeared facilitative of acceptance. These processes may be explained by optimism. Scheier and Carver (1985, 1987) suggest dispositional optimism is a generalised expectancy for favourable outcomes. Greater positive outcome expectancy is suggested to encourage effort towards an outcome, whilst lower optimism may result in less effort towards an outcome. In health contexts, optimists were suggested to use more adaptive coping and positive reappraisals (Carver, Scheier & Segerstrom, 2010; Nes & Segerstrom, 2006). Optimism was correlated with acceptance of stressful events, when events were perceived as

uncontrollable (Carver, Scheier, & Weintraub, 1989; Scheier, Weintraub, & Carver, 1986).

Optimism may facilitate acceptance of changes, through facilitating beliefs that hardships can be dealt with and motivating survivors to address challenges resulting from ABI. In contrast, individual's lacking optimism may be more avoidant and find it more challenging to accept and adapt to such challenges as they feel more hopeless regarding them.

Clinical Implications

Feedback from the multi-disciplinary professionals group suggested that difficulties with acceptance were experienced as a major barrier for ABI survivors engaged in rehabilitation. This is consistent with suggestions by Klonoff (2005) and Medley and Powell (2010). As discussed in the introduction, there has been increasing interest in the development of third wave therapies. Research into the application of these therapies after ABI is still in its infancy, with the current evidence base consisting of a small number of small-scale studies (see Ashworth et al., 2017). Establishing a clear conceptualisation of what acceptance means, and what processes may help or hinder acceptance post-ABI, is an important part of developing these approaches for ABI. The findings of the current study provide some guidance for clinicians on these issues.

Conceptually, ACT appears particularly applicable to the needs of individuals following ABI, given the central role of acceptance and negotiating negative experiences without necessarily changing them. Given the finding in this study of the potential importance of fostering a hopeful, purposeful future, ACT focus on value-driven action appears relevant. Compassion focused therapy may also be an appropriate intervention to address difficulties some individuals with ABI may experience regarding their sense of self, fostering self-acceptance and self-compassion (Ashworth et al., 2017). The present study also highlighted

the ambivalence that some participants felt about the language and concept of acceptance. This suggests that it may be important to address this issue in therapeutic contexts by exploring the person's feelings towards acceptance.

Given the importance of acknowledgement and validation from others highlighted in this study, fostering the ability of clinicians and significant others to provide validation appears important. Furthermore, the potential benefits of peer-support programmes should be considered. A systematic review of peer-mentoring interventions following TBI (Morris, Fletcher-Smith & Radford, 2017) found some evidence of improvements in behavioural control, mood, coping and quality of life following peer-mentoring. Although the reviewed evidence came from small-scale studies of varied quality, it suggests that peer-mentoring would benefit from further research. The benefits of peer-support have also been investigated in stroke literature (Kessler, Egan & Kubina, 2014) and for family members of individuals with ABI (Bellon, Sando, Crocker, Farnden & Duras, 2017). Benefits cited by Bellon et al. (2017) included access to information, connection with others, and opportunities to give back to others with ABI. In wider health research, benefits to the individuals providing peer-support have been suggested, including self-acceptance (Schwartz & Sendor, 1999). Potential benefits of peer-support are consistent with the previous suggestion regarding the important role others with an ABI may play in a person's self-acceptance (Hogg & Abrams, 1990; St Claire & Clucas, 2012). This role merits further investigation.

Research Limitations

As with any qualitative study, the subjectivity of semi-structured interviewing and interpretative analysis is a limitation. To enhance the credibility of these findings several processes were employed, as described elsewhere. Not every participant contributed to every

sub-theme, and some participants' contributions were subject to greater interpretation by the author. This is reflective of the challenges of interviewing individuals with ABI about an abstract concept (Paterson & Scott-Findlay, 2002). Another limitation of the study is that seven of the participants were recruited from the same service, and may have been known to each other. As such, it is a possibility that some of the language used and opinions may have been co-produced. As an IPA study with a small sample size, care should be taken in generalizing the findings; however, the themes identified here may have relevance for other ABI survivors. The variation within the sample was considered representative of ABI populations, and allowed exploration of the idiosyncrasies of experiences.

Efforts were made to ensure interviews were not overly protracted, however completion of the timeline and acceptance questions in one interview may have been overwhelming for some participants. It could have been beneficial to complete interviews across two sessions, which may have allowed for deeper exploration of acceptance. Future qualitative research with individuals with ABI may benefit from providing interview questions before participation to allow time for reflection prior to interview.

Research Implications

Future research could explore in more detail some of the issues that might contribute to individual differences in acceptance, such as service access, nature of injury including severity, the degree of trauma or disability associated with the ABI, differences in social relationships, and dispositional characteristics such as optimism. More detailed investigation of aspects of acceptance such as changes in values and priorities may also be warranted, particularly given the importance of value-based action according to ACT, and value change in the acceptance of loss model (Dembo et al., 1975; Keany & Glueckauf, 1993; Wright,

1983). Additionally, quantitative methods could be used to triangulate the evidence about acceptance provided in this and other qualitative studies. Further pursuit of this could be facilitated by the development of an ABI-specific acceptance measure. Finally, further work is needed to address how these findings about the specific nature of acceptance in the context of ABI can be translated and applied to the delivery of acceptance-based therapies such as ACT in ABI.

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CHAPTER THREE

Public Dissemination Document

Acceptance after Acquired Brain Injury

Study Feedback

Introduction

Brain injury can cause lots of difficulties and changes in the lives of brain injury survivors. Acceptance is considered an important outcome which could help in recovery. Acceptance after brain injury has not been researched in detail. There is little understanding of what acceptance means or how it develops.

This study aimed to find out more about the experience of acceptance for brain injury survivors. We were interested in what acceptance means to them, and what may help or hinder acceptance.

Method

Nine people who had a brain injury at least one year ago were interviewed about their life since their injury happened. They talked about acceptance following the injury, and what acceptance meant to them. Interviews were analysed by the researcher, and themes about acceptance were developed.

Results

Facing change

Early in recovery, all people interviewed described becoming more aware of their injury and symptoms. As they became more aware of their injury most described developing understanding about the brain injury. Clinical staff could help this process by providing

explanations and space to talk about the injury. Some interviewees were unable to understand their injury because they did not have access to services.

Difficult feelings were experienced after the brain injury. Becoming more aware of difficulties made some people feel very unhappy and anxious. This was especially difficult when people were unable to understand the experiences they were having. Some people described ways that they distanced themselves from their injury earlier in recovery. This may have been a way of protecting themselves from the changes that were happening. Some thought they were in denial. Others tried to avoid the injury and think about it as not a part of themselves. Many hoped to return to how they were before their injury, and tried hard to achieve this.

Feeling like a different person after their injury was experienced by some. This meant some survivors were more negative and critical of themselves, and did not always like themselves. Some were uncertain about the experiences they were having, and did not always trust their own thoughts or feelings.

Acceptance

Early in recovery, some did not accept the brain injury, other than accepting that the injury had happened. Over time, participants began to accept the long-term nature of brain injury. They slowly came to terms with the losses and changes they had experienced. This included changes in their own abilities, or lost job roles or hobbies. Some described becoming more honest with themselves about the brain injury. They accepted the injury as part of themselves. For some, acceptance meant that they felt less angry about the brain injury. They were more able to let go of frustrations, and noticed positive things in their life more easily. Some

participants also became more accepting of themselves, accepting that they may be different but were still worthy.

Uncertainty about acceptance

Most people thought acceptance after injury was a helpful, but difficult process. Some thought acceptance was not the right word. They did not like that it might imply that they had reached a point where they no longer felt frustrated about their injury, or they felt that acceptance suggested resignation or defeat. Many preferred other words, such as acknowledgment or tolerance to reflect this.

Some people did not think they could accept the brain injury. Going a long time without understanding the injury, being disbelieved by others, and feeling that they had been unable to engage in a meaningful life seemed to contribute to this.

Ongoing process of acceptance

Several people thought that acceptance was an ongoing process, rather than an end point they would reach. Different daily experiences could be a challenge to acceptance, for example starting a new job.

Things that helped or hindered acceptance

The role of others

Clinical staff, family, friends and others with brain injury may all influence acceptance. They could help survivors to understand their brain injury. Understanding from other people also helped some survivors accept losses and change, and overcome self-doubt and blame. This may be because other people understanding the person with brain injury helped them to feel

that their experiences were real and valid. Acceptance was more difficult when other people did not believe the person with brain injury, or did not understand the injury. Compensation could also be a challenge. Ongoing claims made it difficult for survivors to move forward from the injury.

A hopeful future and positive experiences

Hope for a positive future after brain injury helped with acceptance. Discovering purpose in life after brain injury was helpful. This included finding meaningful roles, such as roles in their families, and work and volunteering opportunities. Some people tried to focus on positive experiences. This may help acceptance by helping them to move on from negative changes or losses.

Conclusions

Acceptance following brain injury is an ongoing journey that takes time, rather than a destination. Clinical staff should bear in mind that some individuals may be uncertain about acceptance, and it may help to talk about what acceptance means and how survivors feel about it. Understanding about brain injury is essential for acceptance. Clinical staff can help with this. Other people can help survivors accept losses and change, and overcome self-doubt, by providing understanding and validation. Brain injury survivors meeting together, and support for families could be helpful. Acceptance-based therapies, such as Acceptance and Commitment Therapy (ACT), are being used more following brain injury. We hope that this study will help therapists to think about what survivors are struggling with and what might be helpful or unhelpful in acceptance. More research into how acceptance could be developed in therapy would be helpful.

APPENDICES FOR VOLUME ONE

Appendix A: NICE Quality Framework for Qualitative Research

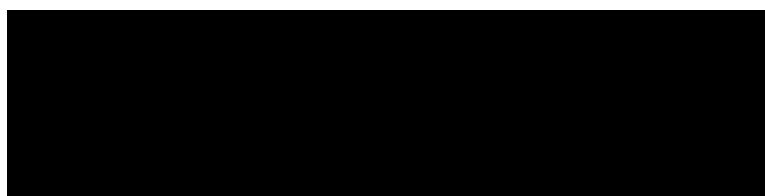
Theoretical approach	
1. Is a qualitative approach appropriate? For example: Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? Could a quantitative approach better have addressed the research question?	Appropriate Inappropriate Not sure
2. Is the study clear in what it seeks to do? For example: Is the purpose of the study discussed – aims/objectives/ research question/s? Is there adequate/appropriate reference to the literature? Are underpinning values/assumptions/theory discussed?	Clear Unclear Mixed
Study design	
3. How defensible/rigorous is the research design/ methodology? For example: Is the design appropriate to the research question? Is a rationale given for using a qualitative approach? Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? Is the selection of cases/sampling strategy theoretically justified?	Defensible Indefensible Not sure
Data collection	
4. How well was the data collection carried out? For example: Are the data collection methods clearly described? Were the appropriate data collected to address the research question? Was the data collection and record keeping systematic?	Appropriately Inappropriately Not sure/ inadequately reported
Trustworthiness	
5. Is the role of the researcher clearly described? For example: Has the relationship between the researcher and the participants been adequately considered? Does the paper describe how the research was explained and presented to the participants?	Clearly described Unclear Not described
6. Is the context clearly described? For example: Are the characteristics of the participants and settings clearly defined? Were observations made in a sufficient variety of circumstances Was context bias considered	Clear Unclear Not sure
7. Were the methods reliable? For example: Was data collected by more than 1 method? Is there justification for triangulation, or for not triangulating? Do the methods investigate what they claim to?	Reliable Unreliable Not sure
Analysis	
8. Is the data analysis sufficiently rigorous? For example: Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results?	Rigorous Not rigorous Not sure/not reported

How systematic is the analysis, is the procedure reliable/dependable? Is it clear how the themes and concepts were derived from the data?	
9. Is the data 'rich'? For example: How well are the contexts of the data described? Has the diversity of perspective and content been explored? How well has the detail and depth been demonstrated? Are responses compared and contrasted across groups/ sites?	Rich Poor Not sure/not reported
10. Is the analysis reliable? For example: Did more than 1 researcher theme and code transcripts/ data? If so, how were differences resolved? Did participants feed back on the transcripts/data if possible and relevant? Were negative/discrepant results addressed or ignored?	Reliable Unreliable Not sure/not reported
11. Are the findings convincing? For example: Are the findings clearly presented? Are the findings internally coherent? Are extracts from the original data included? Are the data appropriately referenced? Is the reporting clear and coherent?	Convincing Not convincing Not sure
12. Are the findings relevant to the aims of the study?	Relevant Irrelevant Partially relevant
13. Conclusions For example: How clear are the links between data, interpretation and conclusions? Are the conclusions plausible and coherent? Have alternative explanations been explored and discounted? Does this enhance understanding of the research topic? Are the implications of the research clearly defined? Is there adequate discussion of any limitations encountered?	Adequate Inadequate Not sure
Ethics	
14. How clear and coherent is the reporting of ethics? For example: Have ethical issues been taken into consideration? Are they adequately discussed e.g. do they address consent and anonymity? Have the consequences of the research been considered i.e. raising expectations, changing behaviour? Was the study approved by an ethics committee?	Appropriate Inappropriate Not sure/not reported
Overall assessment	
As far as can be ascertained from the paper, how well was the study conducted?	++ + —

Appendix B – Ethical Approval

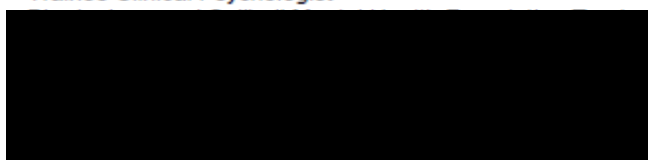


Health Research Authority



17 February 2016

Miss Nicola Burchill
Trainee Clinical Psychologist




Dear Miss Burchill

Study title:	Acceptance following Acquired Brain Injury: A Qualitative Study
REC reference:	16/WM/0015
Protocol number:	ERN_15-1115
IRAS project ID:	190014

Thank you for your letter of 16 February 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, 

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rctforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact [REDACTED] the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Poster]	2	13 November 2015
Copies of advertisement materials for research participants [Interview advertisement letter]	1	02 September 2015
Copies of advertisement materials for research participants [Relatives advertisement letter]	1	02 September 2015
Copies of advertisement materials for research participants [Staff advertisement letter]	1	02 September 2015
Evidence of Sponsor Insurance or Indemnity (non NHS Sponsors only) [Insurance confirmation]		10 December 2015
Interview schedules or topic guides for participants [Interview topic guide]	1	20 October 2015
IRAS Checklist XML [Checklist_12022016]		12 February 2016
Letter from sponsor [Sponsor letter]		10 December 2015
Other [Annotated bibliography]	2	16 November 2015
Participant consent form [Focus group consent form]	2	12 February 2016
Participant consent form [Interview consent form]	2	12 February 2016
Participant Information sheet (PIS) [Participant Information sheet focus group]	4	16 February 2016
Participant Information sheet (PIS) [Participant Information sheet Interviews]	4	16 February 2016
REC Application Form [REC_Form_16122015]		16 December 2015
Research protocol or project proposal [Protocol]	2	12 February 2016
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	10 November 2015
Summary CV for supervisor (student research) [Supervisor cv]		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document 'After ethical review – guidance for researchers' gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

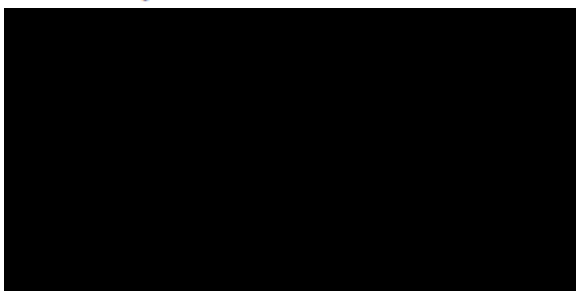
We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

16/WM0015	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



(redacted for confidentiality purposes)

Appendix C – Participant Information Sheet

Participant Information Sheet (Individual Interviews)

Date: 16.02.16 (Version 4)

**UNIVERSITY OF
BIRMINGHAM****PARTICIPANT INFORMATION SHEET****Title of Project: Acceptance following Acquired Brain Injury**

You are being invited to take part in a research study. Before you decide to take part, it is important for you to understand what the research will involve, and why it is being done. Please take time to read this information sheet, and discuss it with others if you wish. Feel free to ask us any questions you may have about the research. We will telephone you within a week to see if you would like to take part.

What is the purpose of this research?

People who have experienced an acquired brain injury (ABI) can experience a range of problems including cognitive, emotional, and physical impairments. Some people who have a brain injury also experience significant changes in their lives afterwards. Acceptance of having a brain injury and the related difficulties is considered an important outcome which could improve rehabilitation, but there is little understanding of what it means or how it develops. We are conducting a study aiming to find out more about how individuals who have experienced a brain injury come to terms with, or begin to accept, the experience of having a brain injury. We are interested in what acceptance means to people who have had a brain injury, and what may help or hinder acceptance.

Why have I been invited to take part?

We are seeking volunteers who are able to meet with us to talk about their experiences since their brain injury happened. You have been invited to take part in the study as we are seeking individuals who have experienced a brain injury at least 12 months ago. It is entirely your choice if you would like to take part in the study, and any care you are currently receiving will not be influenced by your participation.

What will happen to me if I agree to take part?

If you decide that you would like to take part in the study you will be invited to meet with a researcher. This meeting will last in total approximately 1 hour and 30 minutes. The meeting can take part at the University of Birmingham or your home, depending on what would suit you best. If you need to travel to meet us we can offer you £5-£10 reimbursement towards your travel costs.

The researcher will first explain the study and answer any additional questions you may have. If you decide you would like to continue with the study you will be asked to sign a consent form agreeing to take part in the study.

Following this you will have the opportunity to talk to the researcher about your experiences since your brain injury, and how you have understood and managed them. The researcher will use a timeline to help you both talk about your experiences over time; and may ask you some questions around the information you share. This discussion will be recorded using an audio recorder. At the end of the interview the researcher will make sure you are happy with the content you have shared being used in the research, and will write down if there are any pieces of information you would not want to be quoted. You will have an additional week after the interview to decide if you would like any of the material to be omitted from the research.

What if I find talking about my experiences upsetting?

If through the process of discussing your experiences since your brain injury you become upset, you will be able to take a break and will be offered some support by the interviewer, who has experience working with individuals with acquired brain injuries. If you feel you may need further support or advice after the interview the clinicians you are working with can be contacted. The following organisations could also be contacted if you feel you need further support or advice:

[REDACTED]

[REDACTED]

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

If at any time before or during the interview you decide you do not want to participate in the study you have the right to withdraw, without your care being affected. You may leave the interview itself at any time if you wish, and will be able to request for your comments to be removed from the study up to a week after the interview.

What will happen to the information collected about me during the study?

Your contact details will be kept in a secure password-protected computer file. The consent form you will be asked to sign will be kept in a locked filing cabinet at the University of Birmingham. The record of your contact details will be deleted as soon as your participation in the study has been completed. In accordance with University of Birmingham regulations, your consent form will be kept for 1 year following completion of the study.

The recording of your interview and the written transcript will be kept in password-protected computer files. Any personal information that you provide during the

interview that might allow you to be identified will be omitted from the transcript. The audio recording file will be destroyed within 3 years from participation and the written transcript will be kept for 10 years following completion of the study.

The data collected from your interview will be looked at by the research team and may be viewed by people authorised by the University of Birmingham to conduct a research audit. It will not be shared with additional third parties.

If any information disclosed by you suggests you or another person may be at risk, the research team have a duty of care to ensure your safety and the safety of others, and may need to share this information with other professionals.

What will happen to the results of the research study?

After the study is completed we will analyse the information that has been provided to develop an understanding of what acceptance following a brain injury means. This will be written up as a doctoral thesis, and submitted for publication in a scientific journal. We will write a summary of the final results, which will be sent out to all participants in the study. We also intend to present the results to a group of professionals from a brain injury team. Any identifying information about you will not be included in written reports or presentations.

What if I have any questions or concerns?

If you have any questions or concerns about any aspect of this study, you should ask to speak with the chief investigator Nicola Burchill who will do her best to answer your questions. If your questions remain unresolved or you would like to make a complaint you can also contact your local Patient Advice and Liaison Service (PALS), who can be contacted on the following numbers:

[REDACTED]

[REDACTED]

Who is organising this research?

This research is being completed as part of a clinical psychology doctoral thesis at the University of Birmingham, and is not funded by any other organisations or individuals.

The chief investigator leading this piece of work is **Nicola Burchill** (Trainee Clinical Psychologist at the University of Birmingham, employed by Birmingham and Solihull Mental Health Foundation Trust).

Dr Gerard Riley (Clinical Psychologist and tutor at the University of Birmingham) is also involved in the project.

Who has reviewed the study?

Scientific review of the study has been undertaken by the School of Psychology at the University of Birmingham. The study has been approved by an NHS Ethics Committee.

Contact us:

If you would like to discuss any aspect of this research please contact the chief investigator Nicola Burchill on:

Tel: [REDACTED]

Email: [REDACTED]

Post: [REDACTED]

Please keep this information sheet.

Thank you for taking the time to read this sheet and considering this proposal.

(redacted for confidentiality purposes)

Appendix D – Consent Form

Consent form (Individual Interviews)

Date: 12/02/16 (Version 2)

**UNIVERSITY OF
BIRMINGHAM****CONSENT FORM****Title of Project:** Acceptance following Acquired Brain Injury**Chief Investigator:** Nicola Burchill**Participant Identification Number:**.....

Please initial box

1. I confirm that I have understood the information sheet dated 16.02.16 (version 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview. Should I wish to withdraw I understand that I can do so without giving any reason, without my own medical or social care or legal rights being affected. ☐
3. I understand that the research interview will be audio-recorded. ☐
4. I understand that following the research interview I will have a one-week period for reflection. The researcher will then contact me at which point I may omit some parts of my interview, or withdraw entirely from the study without giving any reason, without my own care or legal rights being affected. ☐
5. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. ☐
6. I understand that if I disclose anything that suggests I or another person are at risk of harm from somebody else, the researcher has a duty of care to share information with the NHS team responsible for my care and other relevant organisations to ensure the safety of myself and others. ☐
7. I understand that direct quotes from my interview may be published in any write-up of the data, and used for training purposes, but that my name will not be attributed to any such quotes and that I will not be identifiable by my comments. ☐
8. I agree to take part in the above study. ☐

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

Appendix E – Recruitment Materials

UNIVERSITY OF
BIRMINGHAM

Acceptance after Brain Injury

We are looking for adults who have experienced an acquired brain injury to participate in a research project based at the University of Birmingham.

What is the aim of the research?

The research aims to find out more about how individuals who have experienced a brain injury come to terms with, or begin to accept, the experience of having a brain injury. A brain injury can be a life changing event, and acceptance of having a brain injury and the related difficulties is considered an important outcome which could improve rehabilitation. We are interested in finding out what acceptance means to people who have had a brain injury, and how acceptance might develop over time.

Who can participate?

Anyone who:

- 1) Is aged 18 years or over
- 2) Has experienced an acquired brain injury at least 12 months ago, and is not currently receiving inpatient care
- 3) Is able and willing to meet with an interviewer to discuss the idea of acceptance and how acceptance may develop following an acquired brain injury

What will the research involve?

If you decide that you would like to take part you will be invited to meet with the researcher for approximately 1 hour and 30 minutes. The meeting can take part at your home, or the University of Birmingham, depending on what would suit you best.

The research involves you and the researcher having a conversation about whether you feel you have accepted your brain injury, and what helped, or didn't help, you to accept your brain injury.

How do I get more information or get involved?

To discuss the study and request an information sheet please contact Nicola Burchill on:

- Tel: [REDACTED]
- Email: [REDACTED]
- Post: [REDACTED]

(redacted for confidentiality purposes)

Appendix F – Interview Schedule

Preamble

Introductions

Summary of research and informed consent, including permission to record interview.

Part 1: Establishing background context and rapport

Discussion of the individual's life since the brain injury until present day, including how the injury occurred and significant events and experiences since then, for example leaving hospital, moving home, returning to work, compensation experiences, family events etc.

Part 2: Acceptance focused questions

- 1) People talk a lot about the importance of people accepting their brain injury. What do you think acceptance of a brain injury means?
- 2) Do you feel you've accepted your own brain injury? In what way?
- 3) What helped and what didn't help you towards acceptance?

More detailed sub-questions will be provided for individuals should they require them for example:

- Did any particular events help or hinder your acceptance of the injury?
- Did any particular people help or hinder your acceptance of the injury?
- Has the way you think or talk about the injury changed?
- Future goals/social roles/ value / self-comparisons

Conclusion




Thank you for time and sharing story.

Summarise the interviewees answer to question one and ask if there is anything else they would like to say about acceptance following discussing their own experience in more detail. Ask if there is any additional information they would like to share.

Reminder that they are able to omit any information from the study if they wish to do so in the next week, and will be contacted by the researcher within the week to discuss this again.

Appendix G – Annotated Transcript Sample

- 3 right] I got very frustrated, agitated, aggressive, [i: ok] when I couldn't get it, when I couldn't express
 4 it. But now I've calmed myself down, am working on that and it is, it's a work in progress, erm, I'm
 5 never going to get that back of who I was and where I was [i: yes] but you know what it's ok because
 6 what I've got now, is equally if not better than what I had before, that's where I'm at and that's
 7 where my acceptance is. But acceptance is on a daily basis.
- 8 I: Ok, what do you mean by that?
- 9 Anita: Like some days I can wake up, and everything hurts, and I can't accept where I'm at. [i: ok] So
 10 there's almost this contradiction going on you know, and that's where you have to find the balance
 11 of it. And sometimes I can get up and the joy I feel of just being alive is, it's mind blowing. [i: ok] And
 12 I feel like there's nothing I can't do. I still feel like that, I'd like to say most days, but there's balance,
 13 [i: yeah] you know because one of the things with brain injury is still the fatigue, [i: yes] still the
 14 tiredness, still you know, having to be careful with this that and whatever, erm, but I think you know,
 15 maybe right early on there should be someone you can talk to about it, your emotional state, of
 16 where you're at, because only when you sort of do your emotional state is when you can address all
 17 the other physical and outer stuff but you have to go within to come out, and I know it sounds all
 18 new agey and all of that (both laugh) but believe you me I can't believe where I've been I knew some
 19 of this stuff before the injury but I didn't pay mind to it, but I definitely pay mind to it now and I
 20 know it now, erm, and I think you know acceptance and identity walk together, erm so, the
 21 acceptance of yourself is in the whole entirety of who you are now [i: ok] and accepting what you've
 22 lost, accepting what you've gained, and you have to balance that, it is ultimately about that because
 23 you can drive yourself bonkers.
- 24 I: So when you talk about acceptance, you've given such a lot of interesting information there, your
 25 understanding of what it means to experience acceptance after the brain injury, how would you
 26 define that? What the word means to you, acceptance?
- 27 Anita: I think to start off with it didn't exist for me, because I thought I'm never going to accept this.
 28 I: When did you think that? (gesture at timeline)

	<p>Nicola Accepting that will not be as before Valuing what is there now</p> <p>Themes Accepting loss Valuing the present</p>
	<p>Nicola Acceptance is an ongoing process Good and bad days. Living can be joyful, positive experience, sometimes overwhelmingly so? Gratitude of life? Managing symptoms e.g. fatigue.</p> <p>Themes Acceptance as a daily process Learning to manage experiences Appreciation of life</p>
	<p>Nicola Importance of understanding and talking about emotional experiences, what there should be</p> <p>Themes Service provision Approach and explore emotions</p>
	<p>Nicola Acceptance of identity, self as a whole. Balancing what you have and what you have lost. Negative consequences of not accepting "bonkers"</p> <p>Themes Self-Acceptance Accepting what is lost and gained Risk to wellbeing in not-accepting</p>
	<p>Nicola Initially acceptance seems unfathomable, it will never happen.</p> <p>Themes Absence of acceptance</p>

Appendix H – Reflective Diary Summary

I am a 27-year old White British female trainee clinical psychologist. I have previous experience working in brain injury services and hope to work in this field following qualification. I am very interested in the lived experiences of recovery following ABI and processes of adjustment and acceptance. I am younger than the participants interviewed and they all knew this study was being completed as part of a training programme, which may have influenced their perceptions of myself and engagement in the interviews. Although I have worked in ABI services I do not have personal experience of ABI, which I hope affords me a relatively unbiased stance. I was aware of my own interests in systemic, social and service related issues, which were highlighted in some participants' stories. I remained mindful of ensuring I did not ask leading questions regarding this, and discussed these themes with my supervisor to ensure they were reflective of participant account and not a biased interpretation.

Although the focus of this study was acceptance, I became increasingly aware during the interviewing process of the semantic connotations of acceptance, and whether acceptance was appropriate terminology or may hold negative connotations for some participants. Considering this, interviews developed to include questions regarding terminology and negative beliefs regarding acceptance, rather than assuming it was a positive construct. Throughout the interviews I was conscious of the need to provide scaffolding, without being authoritative or leading in questioning. During the process of analysis, I experienced a personal tension between ensuring that the interpretative elements of the analysis did not involve unjustified over-interpretation, and the analysis maintained representation of participants' experiences. This tension was addressed by comparing themes with transcripts and discussions with an experienced IPA supervisor.