THE UNIVERSITY OF HULL

The relationship between shame, self-discrepancies and adjustment after an acquired brain injury, and if peer support groups can help.

Being a Thesis submitted in partial fulfilment of the requirements for the degree
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Overview

This portfolio thesis comprises of three parts: a systematic literature review, an empirical paper, and the corresponding appendices.

Part one consists of a systematic literature review tasked with examining the evidence for the use of peer support groups within acquired brain injury. The studies included varied considerably across a range of factors including: type of acquired brain injury, group setting, structure, and duration. As such, whilst the findings were generally in support of the use of peer support groups, it is difficult to make reliable conclusions about how these can most effectively function and be used.

Part two is comprised of an empirical paper which investigated the relationship between shame and self-discrepancies as predictors of adjustment following an acquired brain injury, using quantitative methodology to interpret participants' responses on a range of self-report measures. The results suggested that shame and the pre-injury vs post-injury self-discrepancy predict adjustment following an acquired brain injury. Additionally, the paper provides further evidence for the presence of both shame, and self-discrepancies between the pre-injury self and post-injury self, and post-injury self and ideal self, after an acquired brain injury.

Part three contains the accompanying appendices for the previous two sections.

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Peer support groups after acquired brain injury: A systematic review

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Abstract

Background: Participating in peer support groups can be a useful way to obtain support, problem solve, and widen social networks. However, there has been no systematic literature review examining the evidence for the use of peer support groups after an acquired brain injury (ABI).

Objective: This review sought to systematically evaluate the evidence for the effectiveness of peer support groups after ABI's.

Methods: The literature review was conducted in November 2018, searching a number of databases against the inclusion and exclusion criteria, and additional searches of reference lists were also conducted. A quality assessment tool was used to examine the quality of the research included in the narrative synthesis.

Results: 13 studies were included in this review. Limited evidence was found for the psychosocial effectiveness of peer support groups in ABI, but a range of benefits and helping factors were reported based on the experience of group participation. The benefits and helping factors of taking part in a peer support group can be summarised as: being connected, interacting with others, and providing and receiving support.

Conclusions: The findings of this review suggest that peer support groups could be a promising intervention to support individuals and promote adjustment following an ABI. Variability in the structure and setting of the peer support groups means that future research is needed to understand the optimal conditions for a peer support group following an ABI.

Key words: Brain injury, Stroke, Peer Support Groups.

Introduction

Adjusting to life after an ABI can involve managing: activity restrictions (e.g. driving or employment), increased reliance on family, changes within roles and relationship, and financial hardship [1, 2]. As such, services involved in the rehabilitation of individuals who have experienced ABI, such as neurorehabilitation units, community teams and voluntary organisations should provide support to help individuals with ABI navigate these changes. One possible intervention, which can be facilitated across all of the above levels of rehabilitation, is peer support groups.

Peer support groups can be defined as being composed of individuals who share a similar problem and come together to provide mutual help and support [3]. Peer support groups can be both professionally or peer led, with one review reporting that over 60% of peer support groups were facilitated by a professional [4]. The same review also noted the diversity of locations used to house peer support groups, including hospitals, churches, shopping centres, and empty office buildings. As such there appears to be diversity in the way peer support groups are facilitated, and the crucial element to a peer support group appears to be the coming together of members to cope with the unique challenges their common problem or health condition creates.

In terms of the positive outcome of peer support groups, research has documented that they provide a unique sense of community, offer the opportunity to be accepted, and gain information from others [5], as well as offer the opportunity to socialise and broaden social networks [6]. Peer support groups offer individuals the opportunity to safely share challenges and problem solve, which individuals with an ABI have been shown to desire [7].

Peer support groups may therefore be a useful intervention for addressing some of the unique issues associated with adjusting to life following an ABI.

As such, the aim of this systematic review is to evaluate the evidence for the effectiveness of peer support groups after ABI’s.

Method

Data sources and search strategy

A systematic literature search was conducted across the following four databases: PsycINFO, PsycARTICLES, MEDLINE, and Cumulative Index to Nursing and Allied Health Literature (CINAHL). These databases were selected to cover a wide range of psychological and health literature.

A scoping search was conducted to ensure that a systematic literature review had not already been completed in relation to peer support groups and ABI’s, and no review was found. During a scoping search, the search terms of relevant studies were examined to help identify the search terms most likely to identify articles relevant to this review. The following search terms were used to search article titles and abstracts:-

"brain injur*" OR "head injur*"OR "head trauma*" OR "brain trauma*"

OR TBI OR ABI OR stroke*

AND

Peer* OR “Support Group*” OR “Group Support” OR “Social Group”

The search term “OR” was used to allow for the various ways of saying “acquired brain injury” and “peer support group”. The “*” search terms was used to ensure that words that have multiple endings, for example “brain injury” or “brain injuries” were included.

Search limiters

A number of limiters were applied to the searches. Studies had to be published in a peer-reviewed journal and be published in the English language.

Inclusion and exclusion criteria

Studies were included if they met the following inclusion and exclusion criteria (Table 1).

Table 1: Inclusion and exclusion criteria.

Inclusion Criteria	**Rationale**
Peer reviewed journal articles only	To ensure that articles reviewed were of a reputable quality
Published in the English language	To ensure that articles were not subject to bias or errors in translation
Includes participants whose ABI occurred after the age of 18.	In order to only review studies relevant to adults (18+) who had experienced an ABI.
Employs a peer support group for individuals with ABI.	In order to capture information pertinent to this reviews aims.
The majority of data (over 50%) is obtained from individuals who have experienced an ABI.	To ensure that the data is relevant to the research question, without excluding studies because they include family members or carers.
Measured using quantitative or qualitative methods.	To allow for all data relevant to the question to be considered.
Exclusion Criteria	**Rationale**
Case studies or literature reviews	Case studies were excluded due to inability to generalise findings, and literature reviews were excluded as this review aims to review original findings.

studies aimed specifically at developing a peer support group, with no evaluation.	To ensure that studies included data that was relevant to the research question
Peer support groups aimed specifically and only with family members.	To ensure that this research remains focused on how peer support groups are for individuals with ABI's.
Study that uses a 1-to-1 peer support model, e.g. peer mentorship.	This uses a different modality of peer support than peer support groups.
Studies reporting data about self-management groups, or group therapy (e.g. a CBT group) for ABI's.	These two types of groups have specific aims that differ from the primary aim of peer support groups.

Article selection summary

The systematic literature review search was carried out on 23rd November 2018, and found 3072 studies, which was reduced to 2623 when the limiters were applied. The titles of these studies were then screened, and any that appeared irrelevant to the research questions were removed, leaving 74 studies. The abstracts of the 74 remaining studies were then screened against the inclusion and exclusion criteria. Of these studies, 25 studies appeared to fit the criteria for inclusion, and so the full texts of these studies were read. This resulted in 11 studies being identified as relevant and fitting for this review. The reference lists of these studies were screened, and a further 2 articles were identified as suitable. Key authors were also contacted, but this yielded no further studies.

This process is highlighted by a PRISMA Diagram [8] in Figure 2.

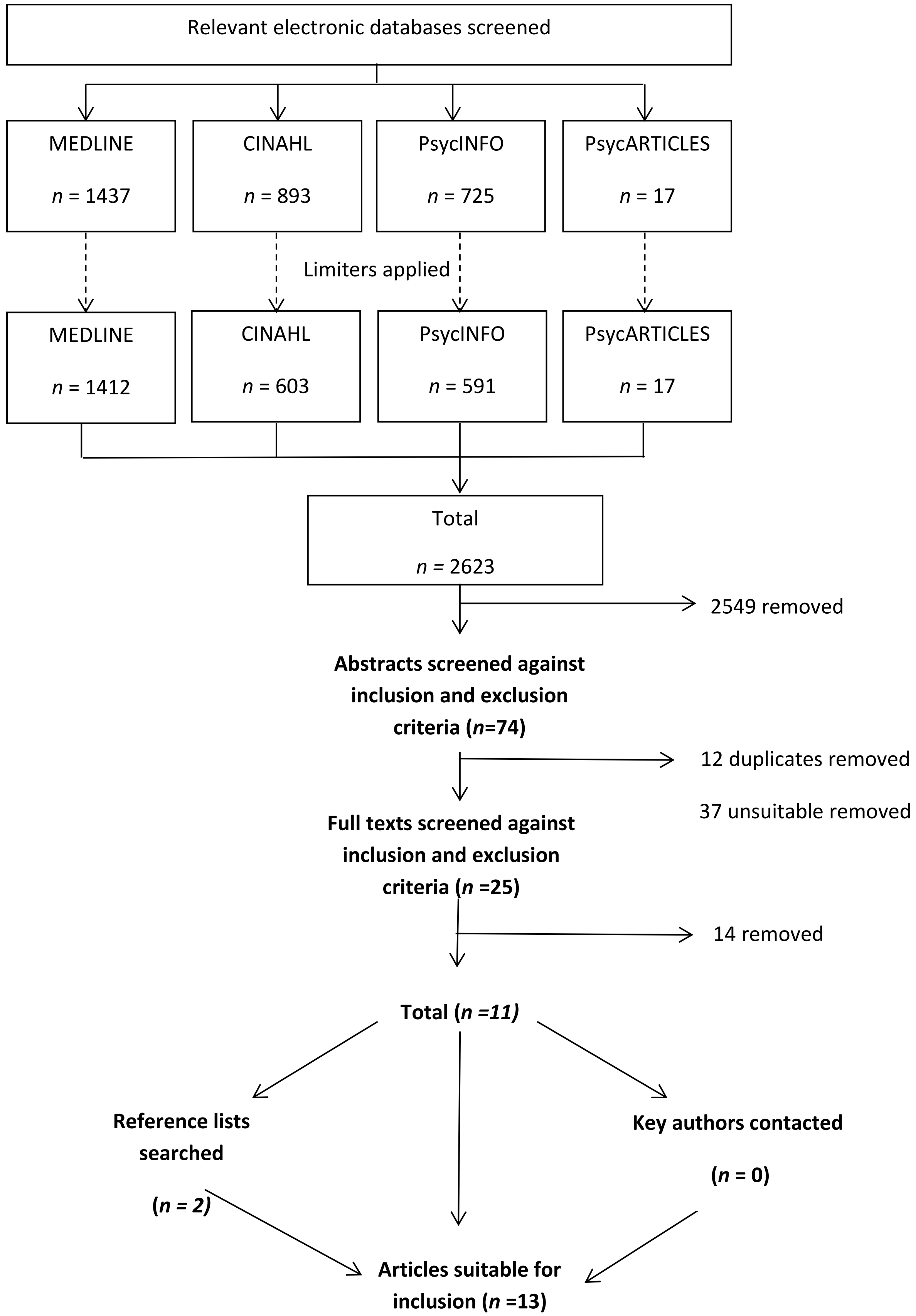
Relevant electronic databases screened
MEDLINE n = 1437
CINAHL n = 893
PsycINFO n = 725
PsycARTICLES n = 17
Limiters applied
MEDLINE n = 1412
CINAHL n = 603
PsycINFO n = 591
PsycARTICLES n = 17
Total n = 2623
2549 removed
Abstracts screened against inclusion and exclusion criteria (n=74)
12 duplicates removed
37 unsuitable removed
Full texts screened against inclusion and exclusion criteria (n =25)
14 removed
Total (n =11)
Reference lists searched (n = 2)
Key authors contacted (n = 0)
Articles suitable for inclusion (n =13)

Figure 1: PRISMA diagram showing article selection. Adapted from: Liberati et al., “The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration.” PLoS medicine. 2009 Jul 21;6(7):e1000100.

Quality review

The methodological quality of each study was checked using the Mixed Methods Appraisal Tool (MMAT) [8]. The MMAT (see Appendix A) was selected as it is can be used across different methodologies, making it suitable for the current review as the 13 studies to be reviewed consisted of quantitative, qualitative, and mixed method studies. The MMAT consists of 2 screening questions which a study must pass in order to be considered suitable for the MMAT. Following this there are five questions which vary across the different types of methodology, making five the highest achievable score. In order to assess the inter-rater reliability of the scoring, a selection of studies (23%, one quantitative, one qualitative, one mixed methods) were marked independently by both the reviewer and a peer, and reviewed for consistency of scoring. The same scores were assigned in each study that were checked for inter-rater reliability.

Data analysis

As the studies varied in methodologies and due to the exploratory nature of the research, the most appropriate way to analyse the results was narrative synthesis. Narrative synthesis adopts a textual approach to synthesise evidence focusing on a wide range of questions, and identify or explain patterns and findings [9], which can be summarised as new themes. However the process of narrative synthesis maintains a systematic approach to searching and quality appraising data, rather than simply verbally describing it.

For this review, the narrative synthesis process was adapted from Popay et al's., guidelines [10]. First a data extraction table was created, and the articles were read through in depth. Each article was then assessed for methodological quality, as a way to indicate the reliability and validity of the research and the findings. The articles were then examined for patterns of similarities and differences within their methods and results, and these findings were discussed under headings pertinent to each research question.

Results

Overview of included studies

In total, 13 studies were included in this review [11-23]. The studies included all broadly evaluated peer support groups; however they all focused on different aspects which can be separated based on their research questions. Five studies looked explicitly at the effectiveness of peer support groups using pre vs post, or post group measures, five studies examined the experience of individuals who attended a peer support group, and three studies identified helping factors for peer support groups.

Quality of included studies

The MMAT quality checklist found differences in the quality of the included studies, and trends seem to be linked to the type of methodology used. Both of the quantitative studies included were of good quality, scoring a 4 and 5, whereas the three mixed methods studies all scored a 3 or less. The reasons for the mixed methods studies scoring lower on the quality checklist were due to the absence of an adequate rationale for using mixed methods, and a lack of integration of quantitative and qualitative results. Additionally, one study used mixed methods to answer two different questions within the research and so the quantitative and qualitative data were not integrated, which is the main strength of using mixed methods [14]. Of the remaining 8 studies which all used qualitative methods, 6 studies scored a 5 on the MMAT suggesting they were of good quality and were appropriate in their selection of approach, extraction and presentation of data, interpretation of results, and this was consistent throughout the research. Of the 2 remaining studies which scored lower on quality, similar areas of weakness were noted in relation to the interpretation of results not being substantiated by data and correspondingly, a lack of coherence between data sources, collection, analysis and interpretation.

Table 2: A descriptive table of included studies.

Authors, year, and country	**Main aims**	**Design**	**Participants**	**Type of ABI**	**Group format and aims**	**Measures**	**Main findings**	**Quality score**
Cutler, Nelson, Nikoloski, & Kuluski (2016). Canada.	To investigate how participating in a peer support group impacts on psychosocial adjustment.	Qualitative, Interviews	16 participants 7 male 9 female	Varied ABI	• Maximum of 10 patients. • Held over 8 biweekly/16 weekly sessions. • Facilitated by professional. • Set content each week.	N/A	Pre group, participants felt a disrupted sense of self. Participants felt an enhanced psychosocial adjustment from taking part in the group, which helped move towards an adapted sense of self.	5/5
Oehring, & Oakley (1994). USA.	To investigate the preferences, and feelings of young (<65) stroke survivors who attend support groups.	Qualitative, Survey	10 participants (8 stroke survivors, 2 family members of stroke survivors) Gender not reported	Stroke	• Aims not reported. • Recruited from 4 different groups with varying formats.	N/A	Participants reported the support groups as fulfilling, and a place they were able to interact with peers. Participants highlighted that they had different needs to older stroke survivors.	5/5
Schwartzberg (1993). USA.	To identify helping factors in a peer-developed support group for persons with head injury.	Qualitative, Ethnographic	8 core group members and a further 5 who attended regularly over a 16 month period. 11 females 2 males	Varied ABI	• Meets weekly for 2 hours. • Format not reported.	N/A	Participants reported positive attributes such as believing and feeling part of the group because members have common problems and can validate each other through sharing and receiving information.	5/5

Authors, year,and country	**Main aims**	**Design**	**Participants**	**Type of ABI**	**Group format and aims**	**Measures**	**Main findings**	**Quality score**
Schulz (1993). USA	This is a follow up study of Schwartzberg's (1993) study to determine participants perceptions of helping factors in the group.	Qualitative. Semi-structured interviews.	4 participants 3 female, 1 male	Varied ABI	• Meets weekly for 2 hours. • Format not reported.	N/A	Results support Schwartzberg's findings, but under a broader scope and with some exceptions. This suggests some differences between the participant observer perspective and the survivors perspective.	5/5
Tregea, & Brown (2013). Australia	To identify the core components of a successful peer-led aphasia support group.	Qualitative, Ethnography	26 participants (19 with aphasia, 7 family members – including 3 group leaders) recruited from 4 groups 16 males 10 females	The cause of the aphasia in the 19 participants was not reported.	• Format and frequency of support groups recruited from was not reported. • Peer-led.	N/A	Results suggest a number of themes are important including: friendship, informality, a supportive communication environment, providing support, and practical considerations for the timing and location of meetings. Factors enabling the start up of groups was also reported.	5/5
Slark, Makahamadze, Catangui, Stear, & Amorim (2011). UK	To develop and report the findings from a focussed support group for stroke survivors, and their carers/family.	Qualitative, Thematic analysis of session evaluations.	84 participants attended across the 6 support groups run. Gender not reported	Stroke.	• A pilot support group consisting of monthly meetings over 6 months. • Each session had a theme, and was centred around discussions with specialists and peers.	N/A	Key themes were that: participants were not afraid to speak out, and found it useful to share experiences. Participants found Powerpoints and specialist's delivering information as useful. Participants also made recommendations on changes to future groups.	3/5

Authors, year, and country	Main aims	Design	Participants	Type of ABI	Group format and aims	Measures	Main findings	
Morris, & Morris (2011). UK	To examine stroke patients, carers, and volunteer supporters experience of peer support groups during hospital rehabilitation.	Qualitative, Semi-structured interviews	10 participants (7 stroke survivors, and 3 carers) 6 males 4 females	Stroke.	• Approximately bi-weekly sessions that were 1.5 hours in length. • Topics set by recipients at each session, and these topics were discussed in whole group/small group discussions. • Professional led.	Therapeutic Factors Inventory.	Participants reported that participation in the group was useful and they found benefits such as: helpful information, advice, making new connections and increased awareness of stroke.	5/5
Pierce & Salter (1988). USA.	To develop and report the findings of a stroke support group.	Qualitative	Number of participants and gender split not reported	Stroke	• Frequency of group was not reported. • Each session was 1 hour in length. • Professional led.	N/A	Members developed friendships and support, and were able to share experiences and coping strategies.	1/5
Muller, Toth-Cohen, & Mulcahey (2014). USA.	To develop and evaluate a hospital based peer support group for younger individuals with stroke.	Mixed.	13 participants 10 males 3 females	Stroke	• The group ran 9 times over an 18-week period. Each session was 90 minutes long and focused on a specific module. • Professional led.	Stroke Inventory Questionnaire (Duncan, Wallace, Studenki, Lai, & Johnson, 2001), Community Integration Questionnaire (Dijkers, 2000), and a post group survey.	Participants demonstrated improved socialisation, healthy coping, and role attainment following participation in the group.	3/5

Authors, year, and country	Main aims	Design	Participants	Type of ABI	Group format and aims	Measures	Main findings	
Sadler, Sarre, Tinker, Bhalla, & McKevitt (2017). UK.	To develop and test the feasibility of a novel peer support group intervention to promote resilience after stroke.	Mixed.	11 participants 7 males 4 females	Stroke	• The group ran weekly, for 6 sessions. • Each session consisted of 2 x 50 minute long module sessions. • Peer-led (2 stroke survivors). • Mixture of group discussions, reflective activities, with input from specialists.	Brief Resilience Scale (Smith, Dalen, Wiggens,Tooley, Christopher, & Bernard, 2008), Frenchay Activities Index, Medical Outcomes Study – SF 12, Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983).	Participants experienced a marginal change in resilience scores. Secondary measures found no changes in activity levels, and depression scores, and slight increases were reported for physical health quality of life, mental health quality of life, and anxiety.	1/5
Vandiver, & Christofero-Snider (2000). USA.	To describe a pilot of a community based psychosocial support group.	Mixed, Survey	49 at pre-test 15 at post-test 69% males at pre test Post test gender split not reported	TBI	• Meets twice a month in the evenings. • Format is "member directed".	The self efficacy scale (Sherer, Maddux, Mercandante, Prentice-Dunn, Jacobs, & Rogers,1982)	Participants experienced positive changes according to self-efficacy scale scores. Participants consistently identified relations and finances as their perception for a good quality of life.	2/5

Authors, year, and country	**Main aims**	**Design**	**Participants**	**Type of ABI**	**Group format and aims**	**Measures**	**Main findings**	**Quality score**
Backhaus, Ibarra, Parrott, & Malbec (2016). USA.	To compare two group treatments for individuals with brain injury and their caregivers in perceived self-efficacy, and emotional and neurobehavioral functioning.	Quantitative.	19 participants 9 in intervention group (all males) 10 in control Peer support group (4 female 6 male)	Varied ABI.	• The group ran weekly, for 16 weeks, and each session lasted for 2 hours. • Professional led. • Provided with topics to aid discussion, but peer-directed.	Brief Symptom Inventory – 18 (Derogatis, 2001), Brain Injury Coping Skills Group Questionnaire (Backhaus, Ibarra, Klyce, Trexler, & Malec, 2010), Frontal Systems Behavioural Scale (Grace, & Malloy, 2001), Group Climate Questionnaire (Dies, & MacKenzie, 1993).	Participants showed greater perceived self-efficacy after taking part in the peer support group.	4/5
Pasquarello (1990). USA.	To develop and evaluate a stroke recovery group	Quantitative	10 participants 6 male 4 female	Stroke	• The group ran weekly for 3 months. Each session was 45 minutes long. Professional led. • An agenda was set in each session, but participants could bring topics of interest. • Allocated time for sharing feelings and experiences.	An idiosyncratic stroke group questionnaire comprising of 10 statements. Participants rated each statement on a 5 point likert scale where 1 was "did not cover this", and 5 was "outstanding in covering this"	Participants rated the group most favourably as a means of obtaining psychosocial support.	5/5

Participants

Stroke survivors were the most frequently researched sample, and were included in 7 studies [11, 12, 13, 14, 15, 22, 23]. This was followed by 5 studies who recruited participants who had experienced a range of ABI's or did not specify the ABI [15, 17, 19, 20] and including one paper recruiting participants who had aphasia but did not report the cause [21]. Only one paper used participants who had exclusively experienced a traumatic brain injury [14].

Participant's age was reported in all studies apart from two [11, 22]. Using the 18-65 age range to describe 'adults', and >65 age range to describe 'older adults', six studies focused exclusively on adult populations [12, 14, 17, 18, 19, 20] and none focused exclusively on 'older adult' populations. The remaining studies spanned both the adult and older adult age categories. Where the range or standard deviation was not reported, the mean was used to assign the group to either the 'adult', or 'older adult' description.

Gender was reported in 10 studies, all of which recruited both male and female participants. Three studies did not report the gender of participants [11, 18, 22].

Sample size

Sample size varied between studies from 4 individuals in one paper [20] to 84 in another [22]. With the exception of Slark et al., [22] and Vandiver et al., [14] ten studies fit within a 4-26 individuals range, showing small sample sizes were predominantly used. However whilst Slark et al., [22] reported that 84 participants attended over the 6 weeks, they do not report how many of the same participants attended each group, which may make the sample size misleading. Additionally one paper did not report how many people took part [11].

Research origin and age

Of the thirteen studies, the majority were conducted in the USA (8), followed by the UK (3), Canada (1), and Australia (1). The articles varied in age, with seven taking place during the 2010's, one taking place during the 2000's, four taking place in the 1990's, and the oldest paper taking place in 1988.

Research methods

There was a large amount of variability between the studies reviewed. Five studies reported on developing and evaluating a peer support group, seven studies evaluated a newly developed/existing peer support group/groups, and one study used a peer support group as a control group in an evaluation. For methodology, eight studies used qualitative methods, two studies used quantitative methods, and three used mixed methods.

Synthesis of findings

Initial findings

Perhaps the most notable finding from the 13 studies reviewed was the diversity of ways that peer support groups have been facilitated following ABI. There was variety between the studies in terms of: setting (inpatient vs. outpatient vs. community), facilitator (peer led vs. professional led), format (fixed vs. flexible), and aims of the paper (pre and post evaluation vs. experience of the group vs. helping factors).

The most notable relationship between these variables seemed to be between the setting of the support groups and whether they were peer led or professionally led. For example, of the six studies where the groups were based within a community setting, five of the groups labelled themselves as peer led, and one community paper did not report the content of the groups or how they were facilitated. Of the two studies where the groups were based within outpatient settings, both were facilitated by professionals, and of the four studies where the groups were based in inpatient settings, these were all also facilitated by professionals from a range of disciplines. Finally, one paper reported its group was held in a 'rehabilitation centre' although it was unclear if this was for inpatient or outpatients, and this was also facilitated by professional.

When thinking about the format of the groups, the most notable contrast was whether they followed a fixed structure, whereby the topics or sessions were pre-planned by professionals or if they were flexible, whereby topics may be offered to group as starting points but the session content, discussions, or timetable was peer led. Of the studies that reported on the format of the group (n=8), six followed a flexible structure, and 2 followed a pre-determined fixed timetable (these programs were devised through literature searches and/or existing service evaluations). Thinking about format and its relationship to other factors, led to further examples of the diversity between groups, for example, both of the fixed structure groups were professionally led and based in hospitals, yet within the flexible format there were also two groups that were professionally led and based in hospitals.

Due to above variance in the studies, any one of the factors could have been used to separate and report the results of this review. In keeping with the primary research aim of evaluating the evidence for the use of peer support groups after ABI, the results have been reported according to the aim of the paper across the following

2 categories: 1) evaluations of the effectiveness of peer support groups, and 2) evaluations of the experience of peer support groups.

1. Evaluations of peer support groups using pre vs post measures

Within the four studies that offer insight into the effectiveness of peer support groups, the focus of the groups and the measures used to evaluate these varied, although they could all be described under the umbrella term of psychosocial adjustment. The four studies are varied in terms of: type of ABI, peer support group setting, length of peer support group, and structure of peer support group. That being said, three of the four studies report improvements in aspects linked to psychosocial adjustment including self-efficacy, and community integration [12, 14, 15]. The final study examined offered mixed results, with no statistically significant findings reported [13], and amongst all of the studies there were aspects of psychosocial adjustment which remained unchanged.

Two studies looked at individual's perceived self-efficacy after partaking in a peer support group. Vandiver and Christofero-Snider [14] devised a twice monthly, community based psychosocial support group for adults with traumatic brain injury and evaluated the impact the group had had on its members using the Self-Efficacy Scale [24] and an idiosyncratic quality of life (QoL) questionnaire which asked 3 questions about present QoL, future QoL, and recommendations for services . Findings showed that compared to baseline, after 6 months participants showed increased self-efficacy scores ($p<0.5$), suggesting that individuals experienced more perceived mastery after attendance at the group. Aspects of QoL remained unchanged and related to lifestyle/personal factors beyond the focus of the groups, such as a person's financial position. Similarly Backhaus, Ibarra, Parrott, and Malec [15] compared a peer-directed support group, for individuals with acquired brain injury that met for 2 hours weekly over 16 weeks, to a CBT coping skills group. They found that participants in the peer support group showed a significant improvement in perceived self-efficacy, measured using the Brain Injury Coping Skills Questionnaire [25] after the peer support group (p<0.001). This paper also looked at emotional functioning and neurobehavioral functioning (caregiver ratings), and found no significant change across time.

Additionally, Sadler, Sarre, Tinker, Bhalla, and McKevitt [13] reported the findings of a peer support group for stroke survivors aimed primarily at increasing resilience. This paper compared scores on the Brief Resilience Scale [26] from before the group, to the end of the group 6 weeks later, and found a marginal increase in mean resilience scores (pre-group mean = 3.6; post-group mean – 3.8). Secondary measures showed no change in activity levels, depression scores, and slight increases in physical health quality of life, mental health quality of life, and anxiety. The authors offer a possible explanation for the limited change, being that the follow up time was short and there were difficulties with missing data.

Finally, Muller, Toth-Cohen, and Mulcahey [12] evaluated how participation in a fortnightly hospital based group impacted younger individuals who had experienced a stroke (<65). The group objectives aimed to support adjustment through health related quality of life concepts including social, emotional, and role difficulties. As such the Stroke Impact Scale (SIS) [27] and Community Integration Questionnaire (CIQ) [28] were used at baseline and upon completion of the group, alongside a post group survey. Results found significant positive changes across the SIS handicap domain and both the total CIQ score and CIQ home integration score, although significance was not reached across SIS self-perceived recovery score, and the CIQ social, and productivity domains.

2. Evaluation of the experience of peer support groups

In total, nine studies looked at the experience of peer support groups and will be outlined below. Again, the studies included varied across many of the aforementioned logistical and practical aspects, for example the peer group setting. All of the nine studies broadly examined the experience of taking part in a peer support group, but there were subtle differences in research aims and the specific focus of the research within this. Within this section, five studies evaluated or reported the findings of participation in a peer support group, one paper looked at the preferences and feelings of those taking part in a peer support group, and three further studies examined specific helping factors of peer support groups. On the whole, a number of positive experiences were noted across the studies, with only one negative experiences being reported [23].

Positive findings from taking part in peer support groups were found across a number of studies. Pierce and Salter [11] developed a support group at a rehabilitation hospital aimed at providing a safe, accepting environment to express feelings and conflicts, supporting problem solving, and promoting help seeking behaviour. Outcomes were noted as: members developing friendships and a network of support, encouragement of problem sharing and solving within the group, shared expression of feeling, and sharing of coping strategies. Similarly, Slark, Makahamadze, Catangui, Stear, and Amorim [22] developed a monthly support group (6 sessions) aimed at ‘encouraging stroke survivors, their careers, and family members to confidently enjoy life after stroke through provision of information, education, advice, and support’. Group evaluations were completed at the end of each session and themes were identified. Participants found it beneficial to share their experiences, and get away from the ward routine. Participants praised the group sizes, as smaller groups meant they were not afraid of speaking out, the presentation of information on the slides, and receiving information from a doctor’s session.

Further positive findings come from Cutler, Melson, Nikoloski, and Kuluski [17], and Morris and Morris [23] who report about the participation in a peer support group for adults recovering from brain injury. Cutler et al., [17] evaluated a peer support group that took place in an outpatient rehabilitation service. They used semi-structured interviews, conducted 1-6 months after completion of the group and identified 3 core themes: 1) disrupted sense of self (pre group), 2) enhanced psychosocial adjustment through shared experience (during the group), 3) adapted sense of self (post group). Morris and Morris [23] examined how patients experienced a hospital based bi-weekly group. They reported that on the whole, participation in the group was beneficial to participants, and included participants learning helpful information, making connections, and having an increased awareness of stroke. However, group processes such as upward and downward comparison were also noted, which could be unhelpful and upsetting to some individuals.

Pasquarello [16] also noted the positive experience of taking part in a weekly peer support group for individuals who were recovering from a stroke in a hospital. After 3 months, an evaluation was completed to measure the group against its objectives to 1) provide information, 2) offer psychosocial support, 3) offer assistance information, and 4) promote lifestyle change. The evaluation asked participants to read statements such as ‘learn about the causes of stroke’ and rate on a 1 to 5 likert scale as to how well the group covered that area. The group was rated most favourably as a way to obtain psychosocial support, for example by sharing feelings and meeting other stroke patients.

Further insight, but with an additional focus on the preferences of participation in a peer support group, comes from Oehring and Oakley [18] who report the findings from a survey of community based stroke support groups for younger stroke survivors (<65). Participants identified a number of unique problems to having had a stroke younger (e.g. an interrupted career), and the majority stated that they identified a discussion format where issues could be talked over, as all participants reported feeling as though they came to help each other. When asked about their preferred format, a number of participants reported finding it difficult to understand speakers, and stated they would like to have discussions around relationships after stroke, returning to work, and how to 'survive by yourself', amongst others. Although focusing on the preferences, this study reports similar findings to previous studies, such as sharing and discussing issues, and helping each other.

Thinking specifically about helping factors, Schwartzberg [19] used ethnographic methodology to investigate of a fortnightly peer support group for individuals who had experienced a head injury, by embedding herself within the group as a participant observer. She summarised group experiences and processes into the following ten helping factors or themes: 1) telling other about one's own pain and suffering, 2) actively listening to familiar pain and suffering in others, 3) accepting that there is a problem with group recognition of the problem, 4) grieving and laughing about daily situations, 5) receiving validation from others similar experiences, 6) being accepted by others and not having to hide one's disability, 7) supporting the survivors survival, 8) giving and receiving practical suggestions, 9) receiving and giving information from personal experiences, 10) distinguishing head injury problems from normal problems. Schwartzberg [19] concluded that the theme of legitimization and acceptance is important in understanding the findings, and that the findings support Lieberman's [29] four necessary conditions for a group to be perceived as helpful: cohesiveness, saliency, cognitive restructuring, and diversity of experiences. Similarly, and supporting these results, Schulz [20] conducted follow up research of Schwartzberg's [19] research using semi-structured interviews to determine participant's perceptions of helping factors, and if these differed from the ones identified by Schwartzberg [19]. Schulz [20] identified 11 helping factors which can be summarised as participants benefiting from connection, support, and learning as a result of interacting with others who share the same problems. Schulz's [20] findings support Lieberman's [29] core conditions, and Schwartzberg's [19] results, with the exceptions of some helping factors such as 1) socialising, 2) finding out about other perspectives, 3) learning about others limitations and strengths, and 4) hope, not being present in Schwartzberg's [19] paper. Additionally, Tregea, and Brown [21] used focused ethnography to understand and interpret helping factors in a peer support group for individuals with aphasia using observations, interviews, and focus groups. The results highlighted 5 key themes required for an established aphasia peer support group, including 1) friendships, 2) informality, 3) a supportive communication environment, 4) providing support, and 5) the right time and place.

As evidenced above, there are a range of positive outcomes that have been reported from taking part in a peer support group, with only one paper reporting a negative experience to taking part in a peer support group, being the comparison to others [23]. Across the studies, certain themes were noted and these can be grouped under the following 4 themes: obtaining friendship and support [11, 16, 20, 21, 23], expression of feelings [11, 16, 19, 22], sharing of coping strategies [11, 18, 19], and gaining information [20, 22, 23]. Whilst other positive outcomes were noted, the main four themes found across studies all seem to support the use of peer support groups for ABI's. Interestingly, whilst the aims of the research included in this section differ, in that some studies aimed to uncover the experience and others aimed to uncover specific helping factors, there was overlap in that the same themes were found across studies.

Discussion

Overview of research findings

The aim of this systematic literature review was to evaluate the evidence for the effectiveness of peer support groups after ABI's. From examining the research, it is clear that there is heterogeneity within the research studies used which need to be considered when addressing the aims of this review. As highlighted in the results section, the quality of the studies used were generally good with over half of the studies (7/13) scoring 5/5 on the MMAT, although it was noted that some research was of a lower quality showing variation exists. Other differences were noted across approach (quantitative vs. qualitative vs. mixed methods), methodology (interviews vs. surveys vs. measures), age range of participants (adult: 18-65 years vs. older adult: 65+ vs. mixed age: 18+), type of acquired brain injury (TBI vs. mixed ABI vs. stroke), focus of peer support groups (psychosocial adjustment vs. general support and information vs. specific factors like resilience). This variation could be due to peer support groups for ABI's being a relatively new research area, with over half of the studies included in this review being published in the last 9 years. Additionally the heterogeneity in ABI service delivery and provision could also account for variation within this review.

1. Evaluations of peer support groups using pre vs post measures

Within the research that evaluated peer support groups using pre vs. post measures, the evidence is mixed although on the whole supports the use of peer support groups. Three studies reported significant positive changes from participation in peer support groups, which spanned increased self-efficacy [14, 15] and socialisation, healthy coping, and role attainment [12]. A different paper failed to show any significant changes from taking part in a peer support group aimed at increasing resilience, although both marginal positive and negative effects were noted [13].

On the whole, the results suggest participation in a peer support group can lead to positive changes post ABI. Explanations for the absence of any significant results from Sadler et al., [13] could be due to 1) missing data, and 2) the group only being run for 6 weeks. The research documenting significant positive changes are all noted to involve groups which have taken place over longer periods of time (16 weekly sessions, bi-weekly for six months, 9 times over 18 weeks), and it could be that the length of group intervention is influencing the effectiveness of the group.

Interestingly, Muller et al., [12] measured perceived self-efficacy as a secondary measure using the SIS and did not find positive changes in perceived efficacy score, as previously found [14,15]. One explanation for this could be due to the way the groups were facilitated. Significant improvements to self-efficacy were found in groups that used less structure, and emphasised that group structure e.g. topics of conversation were peer led, whereas Muller et al.'s [12] peer support group was documented to be more structured and prescriptive (although this was based on a previous survey with stroke patients). The process of being encouraged to shape the group and its content may be an empowering experience for participants, which could explain the differences in perceived self-efficacy documented within this research.

2. Evaluation of the experience of peer support groups

Whilst there is variation in the outcomes experienced by participants in peer support groups, the experiences seem largely positive. As highlighted in the results section, the common themes across studies can be summarised under 4 broad themes: obtaining friendship and support, expression of feelings, sharing of coping strategies, and gaining information. Although the studies varied in their research aims, for example uncovering helping factors compared to exploring the experience, the findings from both groups of paper were similar in the four aforementioned themes. This suggests that the positive outcomes of peer support groups and the helping factors of peer support groups are not mutually exclusive areas. It is most likely that the ingredients needed for a successful peer support group such as it being a supportive environment, in turn end up being something that participants value and report as a positive outcome, for example ‘receiving support’. Finally, one paper did note that downward and upward comparison did occur in the groups [23], which could be a negative experience for participants, although this was not noted across other studies.

These findings seem consistent with existing literature on the positive outcomes of peer support groups, which include: sharing problems and gaining mutual support and help [3], and gaining information and broadening social networks [4]. These factors being identified as helpful and positive is fitting with the difficulties reported by individuals post ABI. As previously mentioned, changes after an ABI can include: difficulties with relationships, changes in activity participation, and loss of role [1]. Taking part in a peer support group could provide opportunities to relieve some of these difficulties, as individuals have the opportunity to connect and socialise with others, to share, contribute, and help others in the group, and by also giving individuals the opportunity to get out and partake in the group and associated activities.

Interestingly there were a number of differences between the settings and structure of the peer support groups, but at face value, this does not seem to have impacted on the positive outcomes reported by participants. It seems that simply being surrounded by those with similar difficulties in a safe, contained environment could be the catalyst to promote positive experiences for individuals after an ABI. Although the studies are limited by small sample sizes, the promising results suggest future investigation is warranted.

Methodological limitations and future research

Perhaps the most notable limitation of this review relates to the studies used, and the variety in: the format, setting, aim, length of peer support group, and population used. Although the findings on the whole are positive in relation to the use of peer support groups following ABI, it is difficult to make comparisons across studies, to decipher what the most effective or useful peer support group format may be. At the moment there are a number of unanswered questions around factors such as the length of a peer support group and how changing these factors influences participants' experiences or the effectiveness of the group. Additionally there are no studies comparing participation in a peer support group to a control group, to help establish if the positive effects noted in this review are from partaking in a peer support group. Future research should focus on establishing a framework for peer support groups that hold the most success following an ABI. This could include using control groups to establish if there is a need for peer support groups following ABI and where this need lies, for example during recovery in hospital or following discharge in the community. This will strengthen the evidence base, which is currently comprised of relatively incomparable studies that all differ across the aforementioned factors such as: type of ABI, setting, frequency etc.

Social and clinical implications

In the national context of an over stretched health care system [30], peer support groups could be a low cost way of addressing a sought after need by ABI survivors, and help facilitate with adjustment needs. National guidance suggests that everyone who has experienced an ABI should be offered psychological support [31], however research has noted that there is an increased demand on services and lack of available resources [32]. This can result in inadequate or no service provision, and/or access to services being dependent on where you live [33].

As such, peer support groups could be a way to increase access to support after an ABI or manage waiting lists, especially in places where services are not as readily available. The variety between the peer support groups reported in this paper evidence that these groups can be adapted based on the needs of specific populations and services, for example a peer support group could be established by staff to begin with and then later progress to being member or volunteer run. In many of the studies cited in this review, the ‘professional’ running the group varied between trainee/assistant psychologists, nurses, social workers, and occupational therapists. With little cost to services, aside from providing staff if necessary and a space to hold a group, peer support groups could be a way to provide group support to those struggling to adjust to life after an ABI.

Conclusions

On the whole it appears that peer support groups are associated with a range of positive outcomes. This research considered the evidence for peer support group across two broad categories: 1) the effectiveness, and 2) the experience. On the whole, the effectiveness of peer support groups is mixed, and this could be linked to variations in the structure and length of the peer support groups. These variations, along with a lack of controlled studies, mean that the conclusions from the research are limited. That being said, positive effects on psychosocial adjustment have been reported with specific focus on self-efficacy, socialisation, health coping, and role attainment. Similarly, key outcomes from studies looking at the experience of these groups has also highlighted socialising and coping strategies, along with further themes of expression of feelings and gaining information. Therefore across all studies, the most evidence for peer support groups after ABI seems to be in relation to socialising and coping or coping strategies, although a range of positive outcomes pertinent to psychosocial adjustment are noted. Peer support groups could fulfil crucial needs for individuals with an ABI, such as the opportunity to work through and problem solve issues, as well as feel empowered, offer a new role, and connect and build relationships with others in a similar situation.

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Part Two: Empirical Paper

Shame, Self-discrepancies and Adjustment after Acquired Brain Injury

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Shame, self-discrepancies and adjustment after acquired brain injury

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Abstract

Background: Individuals with acquired brain injuries (ABI) can experience poor adjustment, and both shame and self-discrepancies have been found to influence this.

Objectives: To explore the relationship between shame and self-discrepancies, and the extent that these factors predict adjustment post-ABI.

Methods: 62 participants with an ABI were recruited by opportunity sampling. Participants completed the following self-report questionnaires: the Hospital Anxiety and Depression Scale, the Quality of Life after Brain Injury Scale, the Internalised Shame Scale, and the Head Injury Semantic Differential Scale – III.

Results: Participants showed significant discrepancies between how they viewed their current self, compared to their ideal or pre-injury self, with the present self being rated more negatively. Both sets of self-discrepancies (present self vs pre-injury self; present self vs ideal self) were positively correlated to shame. Finally, shame and the pre-injury vs present self-discrepancy were found to predict adjustment (emotional distress and quality of life).

Conclusions: Shame and self-discrepancies both appear to play a crucial role in adjustment following an ABI. However the relationship between shame and self-discrepancies needs more consideration to understand how these variables may interact to predict adjustment.

Key words: Brain injury, shame, self-discrepancy, adjustment.

Introduction

Acquired brain injury (ABI) refers to a brain injury, which occurs after birth and is not part of a genetic or congenital disorder, for example Traumatic Brain Injury (TBI), stroke, or hypoxia [1]. An ABI can drastically change an individual’s life as a result of altered cognition and thought processes, and changes in behavioural, emotional, physical and social domains [1].

Following an ABI, it is noted that there is an increased prevalence of psychiatric disorders, particularly of depression and anxiety [2], with some studies reporting prevalence rates of up to 30% [3, 4]. As such, psychosocial adjustment, which is termed as the process of becoming aware of, making sense of, and adapting to changes, is an important element to recovery [1]. Tate and Broe [5] suggest that important variables impacting psychosocial adjustment following a TBI include: severity of injury and impairments, behavior regulation, along with specific factors of psychosocial functioning such as occupational activities, interpersonal relationships and independent living skills. Additionally, some research has used markers such as levels of anxiety and depression [6, 7] and quality of life score [8, 9] to indicate how ‘adjusted’ a person is thought to be. In order to reduce emotional distress and support individuals to achieve psychosocial adjustment, a clear understanding of the complex emotional changes which can occur post ABI, and why they occur, is needed.

In one review, Gracey and Onsworth [10] reference: self-discrepancies, which are differences between internal representations of the self, goal setting; social and personal identity change; wellbeing; and self-awareness, as all having a role to play in emotional adjustment post ABI. Amongst these different aspects, it was noted that discrepancies were common and this was synthesised into a framework for understanding adjustment called the Y-shaped model [11]. This model suggests that following an ABI, individuals experience a prominent sense of threat to self (present self vs ideal/past self), which causes them to adopt conscious and non-conscious coping strategies. These strategies work in the short term but fail to resolve the self-discrepancies, which leads to poor psychosocial outcomes and emotional distress in the long term [11].

As highlighted in Figure 2, individuals post ABI should aim to reduce the perceived discrepancies between their ‘current self’ (or post ABI self), and their ‘aspired self’ (pre ABI self or ‘ideal’ self).

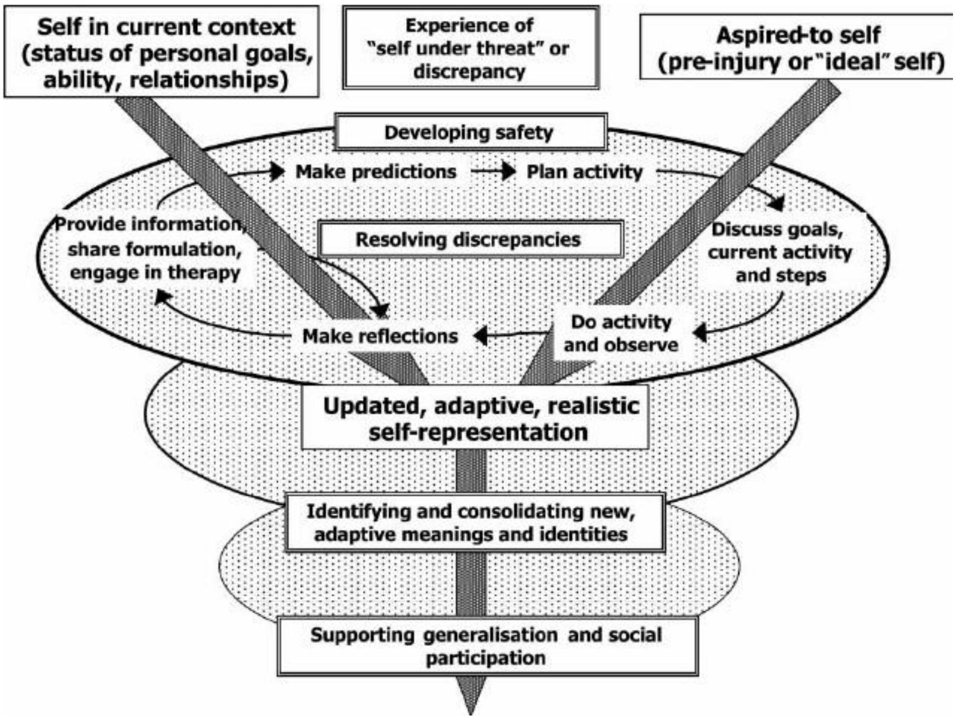

Figure 2: The ‘Y-shaped’ model [11].

Research within ABI populations has supported the idea that self-discrepancies between internalised representations of the self, called ‘self-guides’, play a key role in producing emotional distress, an idea first proposed by Higgins [12]. As outlined by the Y-shaped model, self-discrepancies often occur when comparing perceptions of the pre injury self and the post injury or ideal selves [11]. Research has documented negative changes in self-concept following an ABI [13, 14], and this pre-injury vs. present self-discrepancy is positively associated with emotional distress [15, 16, 17]. Additionally, Cantor et al., [18] measured affective distress (anxiety and depression) and self-discrepancies in 21 individuals with mild to severe TBIs. They found strong correlations between affective distress and pre injury vs present self-discrepancy, and present self vs ideal self-discrepancy.

Another key element suggested to underpin emotional distress post ABI is shame, which is associated with negative evaluations about the whole self, whereby the shamed individual feels unworthy, small, or defective [19]. Gilbert and Andrew [20] note that shame can take two forms, internal shame which occurs in response to negative self-evaluations, or external shame which occurs in response to concerns about evaluations from others. Therefore in its simplest form, shame can be seen as developing in response to a perceived discrepancy of the self, or how others view us [20].

Research in support of this idea comes from Freeman, Adams, and Ashworth [21] who investigated the experience of the self following TBI. They concluded that internal shame, external shame, and self-criticism formed part of the emotional experience of individuals post TBI and was related to distress. Shame has also been suggested to underpin ‘emotional turmoil’ [22], and has emerged as a theme in research considering the experience of living with an ABI [23, 24, 25]. To date, the research into shame post ABI has been qualitative in nature and the relationship between shame and emotional distress or adjustment has not been tested.

Rationale for Study

The prior mentioned research areas support the idea that shame and self-discrepancies may play a role in emotional distress and adjustment post ABI. However, to the author’s knowledge no research has considered that these two factors could be linked and interacting in an ABI population. For example, it could be that experiencing a self-discrepancy leads to shame, or that experiencing shame leads to a motivation to strive for unrealistic goals post ABI, which produces or maintains a self-discrepancy. Support for the possibility of a link between these two variables has been found outside of ABI populations. Tangney, Niedenthal, Covert, and Barlow [26] investigated the relationship between self-discrepancies and shame proneness in 229 undergraduate students, and found that the two variables were related. Additionally, Liss, Schiffrin, and Rizzo [27] examined the relationships between self-discrepancies, shame, guilt, and fear of negative evaluation in 181 mothers of children aged 5 and under. They found that both guilt and shame were related to maternal self-discrepancies, reported by bivariate correlations.

The current research sought to investigate if self-discrepancies (pre injury self vs present self; present self vs ideal self) and shame were present in an ABI sample, and if these variables were correlated. Additionally, this research examined if self-discrepancies (pre-injury self vs present self) predict adjustment, which for the purpose of this paper is defined through quality of life score and anxiety and depression score. This can be broken down into the following aims and hypotheses.

Current Study: research aims and hypotheses

1.) To explore the following self-discrepancies:

    a) The discrepancy between the pre injury self and present self. It is hypothesised that there will be a significant difference between the ABI participant's ratings of their pre injury vs. present self. Individuals are expected to rate their present selves more negatively than their pre injury self.

    b) The discrepancy between the present self and the ideal self. It is hypothesised that there will be a significant difference between the ABI participant's ratings of their present vs. ideal self. Individuals are expected to rate their present self more negatively than their ideal self.

2.) To explore if self-discrepancies (pre injury vs. present self; present vs. ideal self) correlate to shame. It is hypothesised that shame and self-discrepancies (pre injury vs. present; present vs. ideal) will be significantly correlated, whereby the larger the self-discrepancy score, the larger the shame score.

3.) To explore whether levels of shame and self-discrepancy (pre injury vs. present self) predict adjustment (emotional distress and quality of life) in participants. It is hypothesised that shame and self-discrepancy (pre injury vs. present self) both predict adjustment (emotional distress and quality of life), where the higher the levels of shame and self-discrepancy, the poorer the adjustment (higher emotional distress and lower quality of life).

Methods

Participants

A total of 63 participants who had experienced an acquired brain injury were included. Recruitment took place through local charity-run ABI support groups and via word of mouth (see Figure 3).

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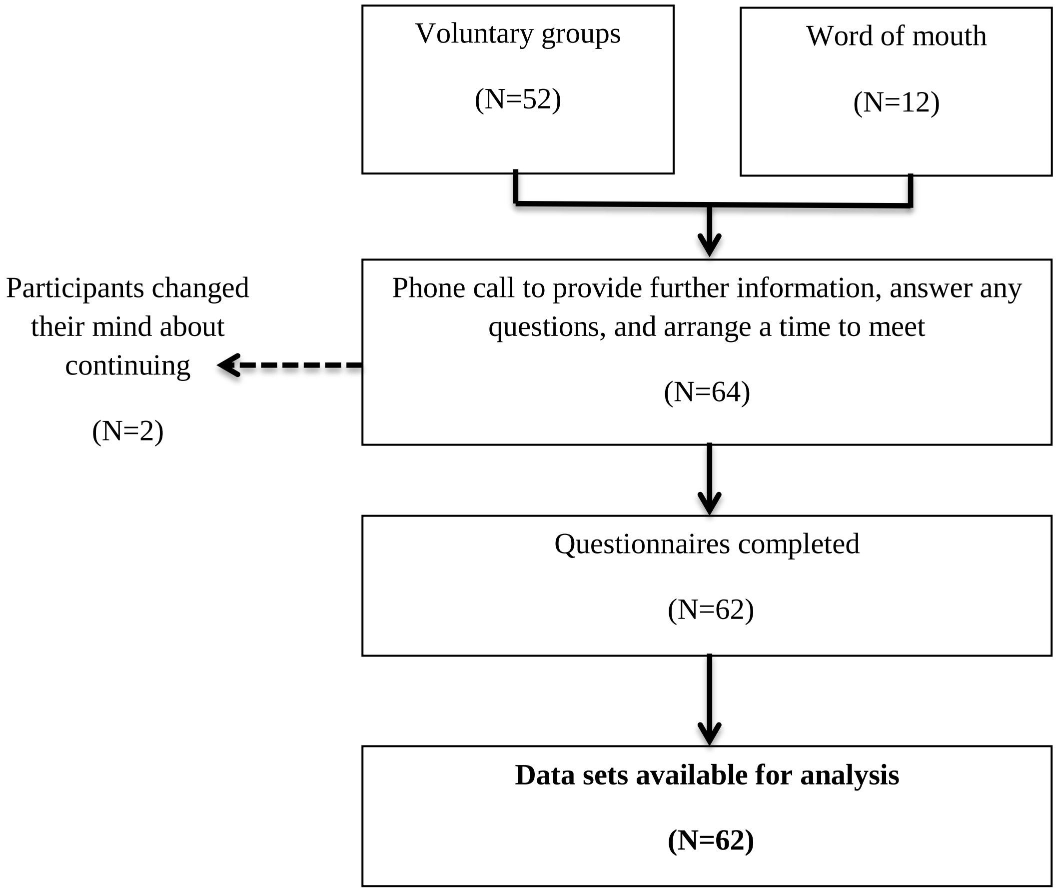

Figure 3: A flowchart highlighting the recruitment process.

The researcher attended 12 local ABI groups during August and September 2018 and gave a five minute verbal presentation which covered the content provided in the information sheet (Appendix E). Each potential participant was then checked against the inclusion and exclusion criteria and offered the chance to ask questions. If an individual was identified as suitable, and they wanted to take part, their contact details were obtained via a ‘permission to contact’ form (Appendix F). The researcher waited a minimum of 24 hours before contacting participants to allow time to consider participation. Participants were given a further opportunity on the phone to ask questions or opt out, and a meeting time and place was agreed to complete the measures.

Inclusion and exclusion criteria

Participants were included if they were 18 years or over when the ABI occurred and were at least 12 months post ABI. Additionally, their first language had to be English, and they had to have sufficient cognitive and communicative abilities to weigh up the information on the information sheet, to appreciate their right to withdraw, understand how their information will be used, and have sufficient mental capacity to give informed consent. Participants were excluded if they had a previous severe physical disability, neurodegenerative disease, neurodevelopmental difficulties, or learning disability. These groups were excluded as it was considered that such patients may experience self-discrepancies related to their diagnosis or condition which was not considered a primary aim of this study.

Study design

A repeated measures design was used, where all participants completed the same outcome measures. The independent variables (IV’s) were shame and self-discrepancies (pre-injury self vs present self; pre-injury self vs ideal self), and the dependent variables (DV’s) were quality of life, anxiety, and depression.

The researcher met with each participant on one occasion, which lasted from 30-60 minutes. All data collection took place in a quiet, private room, which was predominantly in participants’ homes. After reading the information sheet (Appendix

E) and providing informed consent (Appendix G), the researcher enquired about visual/motor difficulties which would require assistance with completion of the questionnaires. If the participant required assistance the researcher and participant would work through the questionnaires together, and those who were able to complete the questionnaires independently did so. The researcher provided the same standardised instructions, and did not provide any additional information to those who required help completing the questionnaires. All participants were asked to provide demographic information (Appendix H) which included: age, gender, ethnic origin, marital status, employment status, job title, the year that their ABI occurred, and the type of ABI sustained. Following this they were asked to work through the six questionnaires, in a predetermined, computer generated randomised order, which took approximately 45 minutes. Participants were offered the chance to have a break after completing three questionnaires. Upon completion of the questionnaires, participants received a debrief sheet, which contained sources of support (Appendix I). A summary email detailing the findings of the study was offered to participants, and their details were taken if they expressed interest in this.

The study was conducted in line with the protocol that was approved by the North East National Research Ethics Committee (Appendix J).

Outcome measures

The Head Injury Semantic Differential Scale – III [28](Appendix K)

The Head Injury Semantic Differential Scale – III (HISDS-III) uses 18 bipolar adjective pairs (e.g., calm–irritable) rated on a seven point scale (one = negative pole and seven= positive pole) to measure discrepancies between an individual's self-concepts (pre injury self, present self, and ideal self). Scores on each of the 18 pairs are summed to give a total value of self-concept, where higher scores indicate a more positive view of self (range 18-126). Individuals are asked to complete the measure three times, in relation to the aforementioned self-concepts. The HISDS-III is the only measure of self-discrepancy which is specific to brain injury, and has been found to have high internal consistency (0.92-0.93) [29]. Although no factor analysis has been conducted, it is a brief, theory guided measure which has been used in stroke and mixed brain injury populations [30, 31] and was therefore used in this study.

Internalised shame scale [32](Appendix L)

The Internalised Shame Scale (ISS) is a self-report, 30 item measure which takes approximately ten minutes to administer. It has 24 negatively worded items to measure intense affect and self-cognition shame scores, and six positively worded self-esteem items. It asks participants to rate how often they experience particular thoughts or feelings; such as ‘I feel intensely inadequate and full of self-doubt’ across a five point likert scale. The ISS has been shown to have high internal consistency alpha coefficients (0.88 to 0.96), and high temporal stability [33]. Although the scale has not been used in an ABI population, this was not perceived as a limitation given that no study has quantitatively measured shame in this group. Therefore, the measure was selected due to its closed questioning style and ease of understanding, which is less cognitively demanding than shame measures that use scenario based questions.

Hospital anxiety and depression scale [34](Appendix M)

The Hospital Anxiety and Depression Scale (HADS) is a 14 item self-report measure which takes approximately five minutes to complete. Participants are asked to indicate their level of familiarity to statements on a four point likert scale, where a higher total score indicates higher emotional distress (range 0-42). The measure was chosen over other mood measures, as it has been widely used in ABI populations [35, 36, 37] has demonstrated a two factor solution in good correspondence with the HADS subscales for anxiety and depression, as well as high correlations with other mood measures [38].

The quality of life after brain injury [39] (Appendix N)

The Quality of Life after Brain Injury (QOLIBRI) is a 37 item self-report measure which spans six subscales. Answers for the first four subscales (cognition, self, daily life and autonomy, and social relationships) are coded on a five point scale, where one is not at all satisfied and five is satisfied, whereas the final two subscales (emotions and physical symptoms) are reverse scored. The measure was selected as it is the only quality of life measure designed specifically for the ABI population [40] and has been shown to have good internal consistency (Cronbach's alpha ranges from 0.75-0.89) and good reliability (correlations from 0.78-0.85). There have been a number of publications in relation to the measure's development and validation [41], and therefore.it was deemed to be more suitable and specific than more general measures such as the Satisfaction with Life Scale [42].

Statistics

Repeated measures ANOVA were used to compare differences across participant's pre-injury, present, and ideal selves (HISDS-III scores) to examine if self-discrepancies exist. A self-discrepancy would exist if there was a significant difference between a participants pre-injury self HISDS-III score vs. present self HISDS-III score, and present self HISDS-III score and ideal self HISDS-III score. A significant difference that is negative in nature would suggest a worsening of self-concept as the person has lost points on the HISDS-III score, and the converse would be suggested if a positive difference was reported. Correlational analyses were conducted to explore the relationship between shame (ISS score) and self-discrepancies (HISDS-III scores). Finally, multiple regression models were used to determine if shame and pre injury vs. present self-discrepancy score predict each aspect of adjustment (QOLIBRI score, HADS-A score, and HADS-D score). Post hoc multiple regression tests were also conducted to examine the individual effects of each IV (shame and self-discrepancy) on each DV (QOLIBRI, HADS-A, HADS-D). Although post-hoc tests were not originally planned, due to the findings that the pre-injury vs. post injury self and shame were significant in predicting all aspects of adjustment when combined, post hoc tests were conducted to investigate if they would independently predict each aspect of adjustment.

Test assumptions were checked depending on the requirements of the statistical method. Tests of normality were carried out using the Kolmogorov-Smirnov test, scatter plots were inspected for linearity, and collinearity and residual checks were completed for the regression models. All statistical analysis was performed using SPSS version 25.0 [43].

Power analysis

GPower Version 3.1.9.2 software [44] was used to determine the sample size for multiple regressions. The sample size required to detect a change in R-squared statistic corresponding to an effect size of 0.2, where an effect size of 0.15 is conventionally labelled ‘medium’ [45], was found to be 52 participants using $\alpha = 0.05$ and power = 0.8.

Results

Missing data

Across the data set, there were a total of 12 missed items which occurred exclusively on the ISS measure. This occurred across seven participants with a maximum of three missed items from one participant. As this was considered a low rate of missing data across the ISS (12 missing/1488 responses), means for the scale were worked out and assigned to the missing data for each participant.

Descriptive statistics

Demographics of participants

The age of participants ranged from 25 to 92 years of age, with the mean being 63.39 years (*SD*=14.61). The mean time since ABI was 7.08 years (*SD*=7.96), with a range of 1 to 45 years, and in terms of type of ABI, 55 (88.7%) participants reported a stroke, 4 participants reported a tumour (6.5%), and 3 reported a TBI (4.8%). With regards to gender, 34 participants (54.8%) were male and 28 (45.2%) were female. All participants (100%) reported being ‘white British’.

Marital status was reported as follows: 38 (61.3%) participants were married, 5 (8.1%) were divorced, 6 (9.7%) were single (never married), 9 (14.5%) were widowed, 3 (4.8%) were living with partner, and 1 (1.6%) was separated. For employment, 14 (22.6%) of participants reported being employed, and 48 (77.4%) reported that they were not employed.

Descriptives

The mean scores across each measure are shown in Table 3. On average, participants rated themselves highest, and therefore the more positively on the

HISDS-III ideal (*M*=119.31, *SD*=8.37), followed by the HISDS-III past (*M*=104.32, *SD*=15.38), and then the HISDS-III present (*M*=83.16, *SD*=19.97).

In terms of clinically significant cut offs, for HADS-A 29 participants were classified ‘normal’ (range 0-7), 12 were classified ‘mild’ (range 8-10), 15 were ‘moderate’ (range 11-14), and 6 were ‘severe’ (range 15-21). For HADS-D the same ranges apply and 41 participants were classified as ‘normal”, 13 were ‘mild’, 6 were ‘moderate’, and 2 were ‘severe’. For ISS, 46 participants had ‘low shame’ (range 0-49), 5 had ‘frequent experiences of shame’ (range 50-59), and 11 had ‘high shame’ (range 60-96).

Table 3: Descriptive statistics of the measures used.

Measure	**Mean**	**SD**	**Variance**	**Range**
HISDS-III Past	104.32	15.38	236.45	58-126
HISDS-III Present	83.16	19.97	398.89	41-123
HISDS-III Ideal	119.31	8.37	70.05	74-126
QOLIBRI	58.26	17.62	310.62	24-93
ISS	36.48	22.67	513.70	0-90
HADS A	8.10	4.44	19.73	1-18
HADS D	6.73	3.81	14.50	0-19

Statistical analysis

Research question one: Are there self-discrepancies between the pre injury vs. present self; present vs. ideal self).

Test assumptions were checked and found that Mauchly’s Test of Sphericity indicated a significant result (X^2=17.414, *df*=2, *p*<0.001) showing that sphericity cannot be assumed. As such, Greenhouse-Geisser was used to adjust for statistical significance and compare for within subjects effects, which were found to be significant (F=114.098, df=1.598, 97.451, p<0.001). Additionally checks for normality found non-significant results across the two self-discrepancies suggesting normality can be assumed, and the following p-values and confidence intervals can be accepted.

Participants reported a mean loss of -21.16 (SD=22.48) points from the HISDS-III past to the HISDS-III present, and this difference was found to be significant (F=54.93, df=(1,61), p<0.001, 95% *CI* (-28.19,-14.13)). Participants reported their mean HISDS-III ideal self to be 36.15 (SD=19.52) points higher than their reported mean HISDS-III present score, and the difference between these scores was also found to be significant (F=216.22, df=(1,61), p<0.001, 95% *CI*=(30.09,42.20)). This suggests the hypotheses that individuals will rate their present selves more negatively than their pre injury self, and their present self more negatively than their ideal self can be accepted.

Research question two: What is the relationship between self-discrepancies (past vs. present self, and present vs. ideal self) and shame?

Checks for normality showed that the data was normally distributed, and visual inspections of the plots for linearity showed the scatter plots showed a linear relationship.

Past vs. present self-discrepancies were found to be significantly negatively correlated (r=-0.4, p<0.01) to ISS score. Therefore the larger the discrepancy (the more points on the HISDS-III the individual had lost from their past to their present self), the larger the ISS score. Present vs. ideal self-discrepancies were found to be significantly positively correlated (r=0.46, p<0.01) to ISS scores. Therefore as the discrepancy increases (the larger the amount of points a person would have to gain from their present self to reach their ideal self), so does ISS Score. This suggests the original hypotheses that shame and self-discrepancies (pre injury vs. present; present vs. ideal) will be significantly correlated, whereby the larger the self-discrepancy score, the larger the shame score can be accepted. Scatterplot diagrams displaying these correlations can be found in appendix O.

Research question three: Do the past vs. present self-discrepancy and shame, predict each aspect of adjustment (QOLIBRI, HADS-A, HADS D)

Scatterplots were visually inspected and observed to show weak relationships between these variables, and so multiple regressions were carried out for all three dependent variables. Checks for normality suggested all residuals were normally distributed, except for HADS-D which showed a significant result on the Kolmogorov-Smirnov test (p<0.01, df=2), and as a result bootstrapping was used to adjust the data. Variation inflation factors were assessed and all found to be >10 suggesting there were no multicollinearity problems across the regression models for HADS-A, HADS-D, and QOLIBRI.

1) Quality of life after brain injury (QOLIBRI)

The change in R-squared was statistically significant when past vs. present self-discrepancy and the ISS were added to the model (R-square change=0.435; F=22.024, df=2,57, ; p<0.001), using the unstandardised beta parameter estimate. Table 4 highlights the regression parameter estimates, where model 1 refers to age and gender, and model 2 refers to ISS and self-discrepancy scores when age and gender are controlled for. This suggests that the hypothesis that shame and self-discrepancy predict poor quality of life can be accepted.

Table 4: Regression parameter estimates for QOLIBRI

Model	Variable	Parameter Estimate	Standard Error	T Value	P value	95% Confidence Intervals
1	Constant	60.967	11.079	5.479	0.000	38.528-82.866
	Gender	-1.090	4.716	-0.231	0.818	-10.526-8.346
	Age (years)	-0.014	0.162	-0.084	0.934	-0.337-0.310
2	Constant	90.195	9.670	9.328	0.000	70.831-109.558
	Gender	-0.160	3.617	-0.044	0.965	-7.402-7.082
	Age (years)	-0.192	0.129	-1.483	0.144	-0.451-0.067
	ISS	-0.467	0.088	-5.299	0.000	-0.643 - -0.291
	Past vs. Present Discrepancy	0.118	0.086	-1.373	0.175	-0.054-0.291

2) HADS-Anxiety (HADS-A)

The change in R-squared was statistically significant when past vs. present self-discrepancy and the ISS were added to the model (*R*-square change=0.364; *F*=20.765, *df*=2,57, *p*<0.001) using the unstandardised beta parameter estimate. Table 5 highlights the regression parameter estimates, where model 1 refers to age and gender, and model 2 refers to ISS and self-discrepancy scores when age and gender are controlled for. This suggests that the hypothesis that shame and self-discrepancy (pre injury vs. present self) both predict high emotional distress, can be accepted in relation to anxiety score.

Table 5: Regression parameter estimates for HADS-A

Model	Variable	Parameter Estimate	Standard Error	T Value	P value	95% Confidence Intervals
1	Constant	13.373	2.596	5.152	0.000	8.179-18.567
	Gender	1.361	1.105	1.231	0.223	-0.850-3.571
	Age (years)	-0.114	0.038	-3.016	0.004	-0.190 - -0.038
2	Constant	6.512	2.294	2.838	0.006	1.918-11.106
	Gender	1.133	0.858	1.321	0.192	-0.585-2.852
	Age (years)	-0.072	0.031	-2.348	0.022	-0.134- -0.011
	ISS	0.110	0.021	5.263	0.000	0.068-0.152
	Past vs. Present Discrepancy	-0.023	0.020	-1.138	0.260	-0.064-0.018

3) HADS-Depression (HADS-D)

The change in R-squared was statistically significant when past vs. present self-discrepancy and the ISS were added to the model (*R*-square change=0.159; *F*=5.378, *df*= 2,57, *p*<0.05) using the unstandardised beta parameter estimate. Table 6 highlights the regression parameter estimates, where model 1 refers to age and gender, and model 2 refers to ISS and self-discrepancy scores when age and gender are controlled for. This suggests that the hypothesis that shame and self-discrepancy (pre injury vs. present self) both predict high emotional distress, can be accepted in relation to depression score.

Table 6: Regression parameter estimates for HADS-D (with bootstrapping)

Model	Variable	Parameter Estimate	Standard Error	T Value	P value	95% Confidence Intervals
1	Constant	6.719	2.066	2.806	0.005	2.828-11.159
	Gender	0.052	1.019	0.051	0.956	-2.069-2.421
	Age (years)	-0.001	0.035	-0.031	0.978	-0.080-0.060
2	Constant	3.154	2.553	1.235	0.172	-1.413-7.941
	Gender	-0.025	0.955	-0.026	0.983	-2.124-2.193
	Age (years)	0.018	0.034	0.519	0.660	-0.061-0.080
	ISS	0.052	0.023	2.227	0.053	-0.002-0.100
	Past vs. Present Discrepancy	-0.028	0.023	-1.237	0.250	-0.075-0.015

Post-hoc Analysis

Shame and QOLIBRI, HADS-A, HADS-D score

Shame was found to significantly predict QOLIBRI score (*R*-square change=0.417; *F*=41.526, *df*=1,58, *p*<0.001), HADS-D score (*R*-square change=0.136; *F*=9.143, *df*=1,58, *p*<0.005), and HADS-A score (*R*-square change=0.352; *F*=40.03, *df*=1,58, *p*<0.001).

The past vs. present self-discrepancy was found to significantly predict QOLIBRI score (*R*-square change=0.158; *F*=10.887, *df*=1,58, *p*<0.005), HADS-D score (*R*-square change=0.086; *F*=5.427, *df*=1,58, *p*<0.05), and HADS-A score (*R*-square change=0.121; *F*=9.474, *df*=1,58, *p*<0.005).

Discussion

Overview of findings

Self-discrepancies

This study aimed to explore if self-discrepancies existed between the pre-injury self vs. present self, and the present self vs. the ideal self. It was hypothesised that participants would rate their present self more negatively than both their pre-injury self and their ideal self, and the results found support for both of these hypotheses.

These findings fit with previous research that has documented that negative changes to self-concept occur following an ABI, when comparing present self to pre-injury self [13, 14, 16, 17, 18], and when comparing present self to the ideal self [11, 18]. Perhaps the simplest way to understand the presence of these self-discrepancies is to acknowledge the life-changing impact of an ABI, which span behavioural, emotional, physical and social domains [1]. Changes to social interaction, activity participation, cognitive abilities, and functional impairments have all been found to influence self-concept following ABI [1]. These changes could explain how self-discrepancies are created between how an individual sees themselves currently, as compared to before their injury, and how they would like to be.

Self-discrepancies and shame

The hypotheses that both sets of self-discrepancies would be correlated to shame were also supported. In both instances, as the self-discrepancy increased so did shame, suggesting a relationship exists between these variables. This supports previous research outside of an ABI population that has observed a link between these two variables [26, 27].

Gilbert and Andrews’ [20] explanation of shame as occurring in response to negative self-evaluations can offer an explanation for this finding. As both self-discrepancies were associated with negative self-evaluations from the present self, for example ‘why can’t I be more patient’ (ideal self), or ‘I was more patient before my ABI’ (past self), the presence of shame would logically follow as a result of these comparisons. Additionally, Higgins’ [12] self-discrepancy theory predicts that an actual vs ideal discrepancy, which Cantor [18] suggested could also be used to understand the preinjury vs. present discrepancy, leads to shame. Both of these theories could therefore explain how shame and self-discrepancies are linked, proposing that shame could occur as a result of self-discrepancies.

Alternatively, shame could be thought of as contributing or causing self-discrepancies. Lewis [46, 47] summarises both external and internal shame as the ‘exposed self’. When an individual experiences this, consequences include feeling as though the outside world is against them, and experiencing their internal world becoming critical and hostile [48]. Therefore, if an individual with an ABI experiences shame, this may cause or exacerbate a negative present self-concept, which could create self-discrepancies between how they are, and how they were (pre-injury self) or would like to be (ideal self). Additionally, shame has also been suggested to have a motivating effect [49], causing individuals to strive for change. In the context of ABIs this could cause an individual to aim for their pre-injury self or ideal self causing a self-discrepancy to occur.

Self-discrepancies, shame and adjustment

Finally, the results supported the remaining hypothesis which was that shame and self-discrepancy (pre injury vs. present self) would together predict poorer adjustment (higher emotional distress and lower quality of life).

As no research has considered the combined impact of shame and self-discrepancies on adjustment in an ABI population, previous supporting research on shame and adjustment, and self-discrepancies and adjustment will first be considered in relation to the findings. With regards to the pre-injury vs present self-discrepancy and adjustment, studies have highlighted a link between this self-discrepancy and higher emotional distress [11, 15, 16, 17, 18] and lower quality of life [50] in ABI populations. This fits with both Graceys' [14] Y shaped model, and Higgins' [12] self-discrepancy theory which both suggest self-discrepancies can lead to emotional distress, and poorer adjustment. Additionally, shame has emerged as forming part of the emotional experience post ABI [21, 22], and has been linked to higher emotional distress [51, 52, 53]. Whilst the relationship between shame and quality of life has not been examined in an ABI population, a link between high shame and low health related quality of life has been found in other health populations [54]. This can be explained through the theoretical underpinnings of compassionate mind theory [55] which sees shame as forming a key component of emotional distress. The findings therefore fit with previous research and theories, although no one theory could explain how both shame and self-discrepancies predict adjustment.

One possibility is that, as a relationship was found to exist between shame and self-discrepancies and that these predict adjustment following an ABI, these two variables may co-exist in a complex interacting relationship (see Figure 4 – theory 3). Theoretical models could have failed to consider the role of shame or self-discrepancies co-existing due to the lack of research evidencing this relationship. For example in Gracey's [14] Y-shaped model, the experience of the 'self under threat' could also contain shame as a pertinent emotion which coincides with self-discrepancies and leads to poor adjustment.

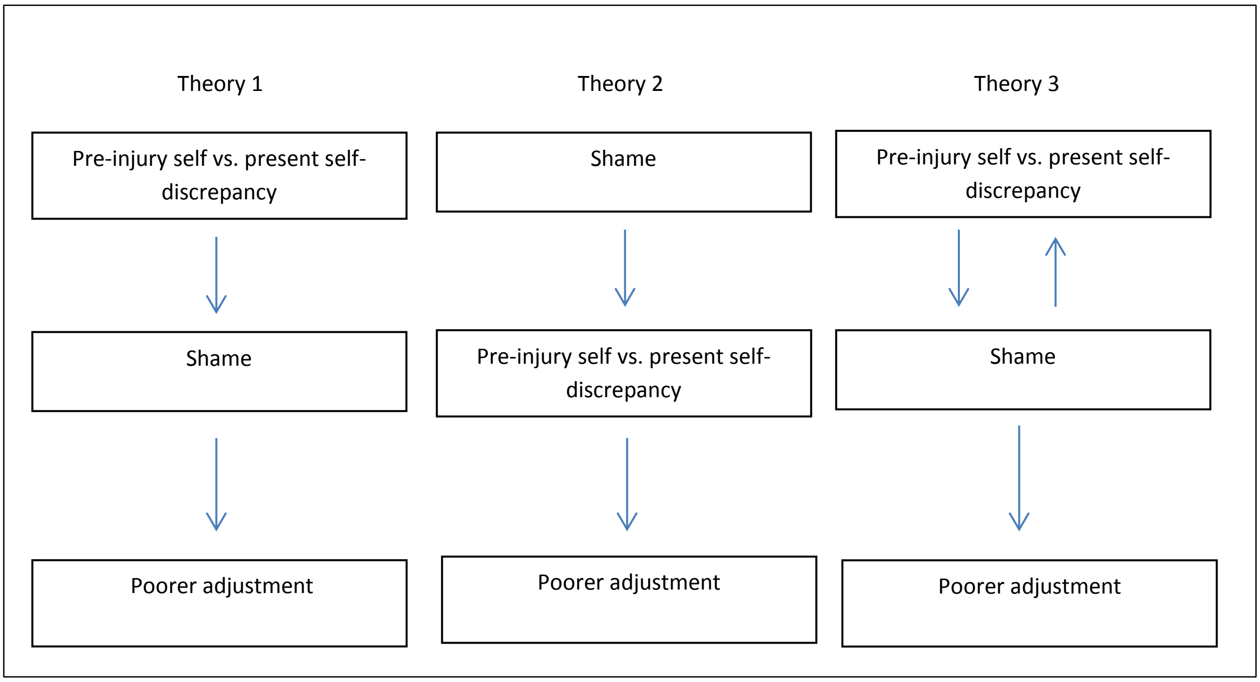

Figure 4: Possible relationships between shame, self-discrepencies, and adjustment.

Post hoc tests were conducted to attempt to uncover if both variables were required to significantly predict adjustment, by testing the individual effect of shame and self-discrepancies on each aspect of adjustment. The finding that both shame and preinjury vs present self-discrepancy independently predicted each aspect of adjustment, suggests that both variables may not need to be present to predict adjustment, although the evidenced relationship between them should not be ignored. An alternative possibility is that high shame or high self-discrepancies may predict each other, which then leads to poorer adjustment (see Figure 4 - theories 1 and 2).

Clinical implications

This research has highlighted that shame and self-discrepancies play an integral role to adjustment after an ABI, and should be acknowledged in psycho-social rehabilitation. An assessment of both shame and self-discrepancies could be beneficial, and completion of measures such as the ones used in this study could compliment a clinical interview and be repeated to mark changes over time. These factors should also be considered with regards to psychological therapy that is offered, as therapeutic approaches that target these areas may be more effective. For example Compassion Focused Therapy [55] addresses issues of shame, and Acceptance and Commitment Therapy [56] promotes acceptance rather than denial of negative feelings. Both CFT and ACT could be used to support people who have high levels of shame and self-discrepancies, and evidence for the use of these therapies in neurological conditions has begun to emerge [51, 52, 53, 57].

Limitations and future research

This study had a number of limitations which future research should consider. Firstly, the primary research questions were centred on adjustment, although in the literature there is no one definition on how adjustment should be measured. As previously stated, there are a number of variables thought to underpin adjustment, and no one suitable measure to capture these variables holistically. Although one measure, Ryff's scales of psychological well-being [58], appeared to cover the widest range of areas pertinent to adjustment, the validity of the measure and it having six distinct dimensions has been questioned and criticised [59, 60]. As such, this study considered adjustment in relation to key areas such as emotional distress and quality of life as these were felt to be the most important areas to capture and have been focused on within previous literature [6, 7, 8, 9]. Further consideration should be given to how adjustment is defined post ABI, to allow for the development of more encompassing ways to measure this.

Also, due to the method of recruitment, there were a number of factors within the population that need to be considered. Firstly the therapeutic benefits of being in a support group need to be considered as attendance could have contributed to the lower rates of anxiety, depression, and shame (47% scored 'normal' for anxiety, 66% scored 'normal' for depression, and 74% scored in the low shame range). Interestingly, the average age being 63 suggests that the peer support groups that were used to recruit from appear to be favoured by older adults. Research has documented that younger survivors of ABI's value specialised support groups aimed at younger adults (under 65 years of age) due to there being unique aspects to their situations, for example having never achieved independence from parents, which older ABI survivors could not relate to [61]. Therefore, younger participants may not be as accessible through typical ABI support groups.

Correspondingly, it has been documented that younger ABI survivors have specific needs which differ to older survivors, most likely in relation to differences in life stages. In the aforementioned paper, younger ABI survivors reported the impact on: their interrupted career, their children or childrearing, their sexuality, and the need to continue to be a breadwinner. These are issues that are not as likely to be as pertinent to older adults, and therefore future research would benefit from being cross-sectional in order to understand how age influences self-discrepancies, shame, and adjustment. Future research could also look at the time since injury in relation to these factors. In this study, the average time post injury was seven years, and was made up exclusively by participants who had been discharged back to the community. Assessing these factors at different stages of recovery, for example six months after discharge compared to two years after discharge, may offer insight into if self-discrepancies are evident immediately from discharge, or if they develop over time as a person attempts to reintegrate back into their previous life. This in turn could help identify when the most useful time to offer a psychological intervention is. For example, self-discrepancies being present at six months post ABI could be expected as a normal stage of recovery as a person attempts to adjust to life after their injury. However, if self-discrepancies remained years later, this research would suggest that a person would have poorer psychosocial adjustment, and therefore there may be a clinical rationale to try and reduce these.

Conclusions

This study further evidenced the presence of self-discrepancies following an ABI, and is the first to quantitatively measure shame in this population, and show that a relationship exists between these two variables in individuals with ABI. High levels of shame and self-discrepancies were found to predict poorer adjustment, although the exact nature of this relationship should be investigated further. These findings support previous research in these areas, and fit with theories of emotional distress and adjustment post ABI. Future research should unpick the relationship between shame and self-discrepancies further, to better understand how the variables interact to predict adjustment.

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Part Three: Appendices

Appendix A – Epistemological Statement

Within the realm of research, where varied approaches, methods, and forms of analyses exist, it is imperative to spend some time exploring the ontological and epistemological that a researcher takes. It is only by doing this that the researcher can begin to understand how their own biases, consciously and unconsciously, shape the research they facilitate.

The ontological position a researcher takes is concerned with questions around reality, or 'what is there', and as such varies enormously between individuals [1]. Each researcher will use their meta-programs [2], or internal representation of reality, to favour which evidence to pursue and which evidence to ignore. In contrast, a researchers epistemological position focuses on the nature of knowledge or and how it is acquired, for example 'how do you know it' [1]. A researcher's epistemological stance therefore influences their choice in methodology, and in turn the methods used.

Quantitative and qualitative research are both underpinned by contrasting epistemological stances, with quantitative methodology being firmly rooted in a positivist perspective. The positivist approach suggests that knowledge is acquired from verified observations or measurements, which the researcher is separate from [3]. Within the positivist stance, there is no room for the subjective opinions or biases of the researcher, as a clear view of reality is needed. In contrast, the interpretivist position see's that knowledge is based on interpretation, and as such the researcher cannot be disentangled from their research with their focus being on perceived realities as opposed to facts [4].

Both the systematic literature review and the empirical research presented in this paper are underpinned by a positivist stance. This means that the researcher believed that shame, self-discrepancies, and adjustment are concepts that can be measured. As such, it was important to use measures that were perceived to be both reliable and valid, in order to provide evidence towards the questions raised at the start of this research. Additionally, by using quantitative methods, statistical analysis that was free from researcher bias, was used to allow for probability testing. By adopting a positivist stance and the accompanying methods, patterns and relationships that are pertinent to this area of research and population of participants can be established.

By having an awareness of the position a researcher takes, they are able to consider the assumptions they have made when attempting to answer a research question. Within the field of psychology, one of the pertinent criticisms for using the positivist approach is that it limits the understanding of human experiences by using rigid, predefined rules or measures. That being said, by identifying patterns that can be replicated with larger numbers of participants, it is easier to build a plethora of evidence to support change, for example the need for a specific intervention within a population.

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Appendix B – Reflective Statement

The empirical paper

Designing the research

Completing this research was one of the aspects of the Doctorate course that I was most looking forward to. Being brought up in a house that valued maths and science, I've always found myself drawn to these areas and consider myself to have a passion for research. I knew before I even considered the different research areas that I wanted to do a quantitative study, having always been good with statistics and navigating SPSS, and with it fitting with own ontological stance. Trainee's in previous years made reference to there being something 'drawing' each trainee to their research area, and although I would have denied there being one at the start, I later realised that I was subconsciously drawn to brain injury for a number of reasons. Most notably is my interest in areas such as biology, medicine, and neuroanatomy, which lend themselves closest (in my opinion) to neuropsychology, compared to clinical psychology in general. Additionally, I was drawn to this research area because of how definite and irrefutable brain injuries are, in comparison to other typical 'diagnosis' I came across on the course, like depression or anxiety. There is no probable or contextual basis to a brain injury, in the same way there is for depression, you either have one, or you don't. Comparably, whilst there are many factors that contribute to somebodies likelihood of being diagnosed with depression, these matter much less in brain injury. Brain injuries are relentless, unforgiving, and can happen to anybody, regardless of socio-economic status, race, gender, or background.

I’ve always had a personal interest in shame as an emotion, considering is effects and experience to be grossly overlooked, and I focused on this area to begin with. During initial conversations with Pete and Lauren, we struggled to substantiate our experiences or ideas of shame within brain injury populations as a result of a lack of research in this area, and so we opted to maintain shame as a focus but research this alongside adjustment more generally. Gracey’s Y shaped model gave our project a theoretical framework , and the notion of ‘old me’ vs ‘new me’ after a brain injury has turned out to be the most crucial ideas in understanding the findings from this research.

Having focused on the areas I wanted to investigate (1. shame, 2. self-discrepancies, and 3. adjustment), the next logical step was deciding how I was going to measure them. For both shame and self-discrepancies there were obvious measures to choose that had been widely used and validated, and so these made for easy choices. However, finding a measure of adjustment, that was suitable for this population, was nothing short of a nightmare! There was no pre-packaged, validated, normed measure that advertised itself as an ‘adjustment’ measure, and I soon realised from scouring the literature that previous studies selected an array of measures to attempt to capture adjustment. This led to countless conversations about how adjustment is even defined, and what would be the most meaningful way to capture this, without overloading participants with measures. I eventually opted to the two areas that I, and previous research, felt most appropriate to focus on, presence of anxiety and depression, and quality of life. Whilst this was in no means a perfect, or the most holistic way to capture adjustment, I realised very early on in this research that aiming for perfection is often not an achievable aim within research. Instead I opted to focus on creating something well considered, grounded in research, and most importantly, feasible.

Data collection

I had made connections with two local psychologists who kindly agreed to help with recruitment, meaning I had to undertake the process of NHS ethics. It was drilled into us all as trainees that this process is long and arduous, and should be started as soon as possible. I could not help but think of this mammoth task as something that would hugely deter individuals from completing research within the NHS, although having completed the process, I hope it would be quicker next time.

Feeling impatient with the wait to get participants via my recruitment contacts, I attended numerous voluntary support groups to advertise my research, which I believe was fundamental for me meeting my targets with relative ease. The groups I attended were incredibly open and receptive to research, and it was a lovely way to meet participants and give them the opportunity to chat face to face without committing to the research. I like to think that my own passion for this project also aided with recruitment, and I truly believe that enthusiasm goes long a way.

Whilst getting participants details was easy, the actual collection of data was time consuming, with an hour being allocated to each participant, plus travel time. I had months where evenings and weekends were spent travelling around Hull and East Yorkshire, with participants back to back, and I think towards the end when I reached nearly 100 hours, I began to question if I should have used alternative methods such as online surveys. That being said, I was welcomed into participants houses, introduced to family members, made countless cups of coffee, and trusted with participants stories. I think it was only really when I started meeting participants that I began to question my choice of methods, as I discovered people had a lot more to say than my measures allowed for. The richness of the data that I would have got if I had used mixed methods, or been able to capture their comments, humour, and advice in some way, would have far extended the numbers I ended up with. However, thinking back to my initial aims for the research, I know my methodology was the right choice, although meeting so many incredible brain injury survivors has given me lots of direction for future studies.

Data analysis

After collecting all of my data, I was keen to analyse my data to uncover whether I had found significant results. I spent many an hour under the guidance of the department's statistician Eric, working through tests, and learning about test assumptions. I now know that a significant result cannot be taken at face value, and instead must stand up to a number of post-hoc tests. Luckily my results stood strong after this lengthy investigation, and I was pleased to discover that my hypothesis had all been supported. This aspect of the research was completed relatively quickly, and it felt somewhat impersonal that each participant's time came down to a series of numbers and p values. Again I wondered if I would have felt differently if I had been able to substantiate my findings with some words or narratives. I feel that is something I will continue to consider when planning future research, although I wonder if this is a case of the 'grass being greener on the other side' rather than a change in my beliefs about research.

Report writing

Writing the report to accompany my empirical study was one of the most enjoyable aspects of the research. Having been responsible for every aspect of the research and spending hours attending groups, meeting participants, and deliberating with supervisors, I approached the report as my opportunity to evidence the hard work that I had been putting in for months. I broke the task down into sections, working through a paragraph each day, and soon the report had taken shape without me feeling stressed or resentful towards the write up. It was hard at times to be concise because I wanted to show every avenue that I had considered or explored, and I had to remind myself that those reading it may not have the same level of passion for this area that I do. This section of the report confirmed what I already knew, which was that I consider my written skills to be one of my stronger suites, and that I enjoy writing about subjects I care about.

The Systematic Literature Review (SLR)

Deciding where to start when reflecting on my experience of the SLR probably holds a lot of parallels to actually starting it. Whilst the empirical has a meticulous order of tasks to work through, meaning there was a clear goal at all times, the SLR felt like a mass of unknowns that I was not sure how to approach. As a self-proclaimed research lover, at the start of this SLR I was surprised with how little enthusiasm I had to completing this part of the portfolio. I feel as though it is harder to have a sense of 'ownership' over this work, as although I am the one completing it, part of me feels as though I've just summarised others work rather than adding anything new or worthwhile. However I found once I actually got through the ordeal of finding a question, then finding out it had already been done, then changing it to another question, to find out there was only 3 papers, to actually finalising the question, I actually enjoyed it more than I initially anticipated. Once I had the papers and began working through analysing the data and writing the report up, I found that I was able to make connections or observations about the papers that made me view

SLR’s as a worthwhile process. Although I swore at one point I would never complete another SLR, I can actually see the value in both what they contribute, and the fact that I believe them to be an easier piece of research to conduct that the empirical (simply thinking about things like the number of hours of data collection or applying for ethics took). Having always stated that I wanted to continue to do research when I have qualified, I wonder if SLR’s may be a more feasible place to start, rather than planning another empirical study alongside working full time. In fact, I already have a number of ideas that I would like to pursue.

Summary

All in all, this research process has been thoroughly enjoyable, with only a few minor hiccups along the way. Although the portfolio thesis is a mammoth task, and the amount of time and effort it takes to produce should not be understated, I’m a true believer in starting early, being organised and proactive, and breaking it down into smaller tasks. I attribute my relative absence of stress in relation to my thesis to these factors, rather than luck or ‘every project being different’. Whilst the latter is true, I also feel that it is also important to remember that each trainee is different, in both their skills and the way they approach their research. For example, whilst I was revelling in all things research, there were other aspects of the course that I found more challenging. As such, I am unashamedly proud of myself, and not afraid to admit it, for the way I have tackled this project and of the work I have produced. I hope to continue to nurture my passion for research, and remain involved with the University of Hull throughout my career, and am already eagerly awaiting the next research opportunity.

Appendix C – Brain Injury Guidelines for Authors

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our Author Services website.

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SCHOLARONE MANUSCRIPTS™

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the guide for ScholarOne authors before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

About the journal

Brain Injury is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal’s Aims & Scope for information about its focus and peer-review policy.

Peer review

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer-reviewed by expert referees. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Preparing your paper

Brain Injury is committed to improving and maintaining the consistency and quality of manuscripts submitted and published. Authors are strongly encouraged to review and comply with the reporting guidelines relevant to their submission. Reviewers have been instructed to evaluate submissions on the basis of their conformity to the guidelines. The table below provides information about guidelines for different study types.

Study Type	**Name**	**Source**
Case reports	CARE	www.care-statement.org/

Diagnostic accuracy	STARD	www.stard-statement.org/
Observational studies	STROBE	http://strobe-statement.org/
Randomized controlled trial	CONSORT	www.consort-statement.org
Systematic reviews, meta-analyses	PRISMA	www.prisma-statement.org/

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

Submission types

Brain Injury accepts the following types of submissions: original research and Letters to the Editor. Letters to the Editor will be considered for publication subject to editor approval and provided that they either relate to content previously published in the Journal or address any item that is felt to be of interest to the readership. Letters relating to articles previously published in the Journal should be received no more than three months after publication of the original work. Pending editor approval, letters may be submitted to the author of the original paper in order that a reply be published simultaneously.

Letters to the Editor can be signed by a maximum of three authors, should be between 750 and 1,250 words, may contain one table/figure and may cite a maximum of five references. All Letters should be submitted via ScholarOne Manuscripts and should contain a Declaration of Interest statement.

Some journals set a maximum length for submissions. Though *Brain Injury* does not have a specific limit, we prefer that manuscripts not exceed 5,000 words excluding abstract, references, tables, and figure legends. If articles are greater than 5,000 words, authors may be asked to shorten their manuscript.

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Formatting and templates

Papers may be submitted in any standard file format, including Word and LaTeX. Figures should be saved separately from the text. The main document should be double-spaced, with one-inch margins on all sides, and all pages should be numbered consecutively. Text should appear in 12-point Times New Roman or other common 12-point font. For all manuscripts, gender-, race-, and creed-inclusive language is mandatory. Use person-first language throughout the manuscript (i.e., persons with brain injury rather than brain injured persons).

Notes on style. All authors are asked to take account of the diverse audience of ***Brain Injury*** . Clearly explain or avoid the use of terms that might be meaningful only to a local or national audience.

Some specific points of style for the text of original papers, reviews, and case studies follow:

- *Brain Injury* prefers US to 'American', USA to 'United States', and UK to 'United Kingdom'.
- *Brain Injury* uses conservative British, not US, spelling, i.e. colour not color; behaviour (behavioural) not behavior; [school] programme not program; [he] practises not practices; centre not center; organization not organisation; analyse not analyze, etc.
- Single 'quotes' are used for quotations rather than double "quotes", unless the 'quote is "within" another quote'.

- Punctuation should follow the British style, e.g. 'quotes precede punctuation'.
- Punctuation of common abbreviations should follow the following conventions: e.g. i.e. cf. Note that such abbreviations are not followed by a comma or a (double) point/period.

- Dashes (M-dash) should be clearly indicated in manuscripts by way of either a clear dash (-) or a double hyphen (- -).
- *Brain Injury* is sparing in its use of the upper case in headings and references, e.g. only the first word in paper titles and all subheads is in upper case; titles of papers from journals in the references and other places are not in upper case.
- Apostrophes should be used sparingly. Thus, decades should be referred to as follows: 'The 1980s [not the 1980's] saw ...'. Possessives associated with acronyms (e.g. APU), should be written as follows: 'The APU's findings that ...', but, NB, the plural is APUs.
- All acronyms for national agencies, examinations, etc., should be spelled out the first time they are introduced in text or references. Thereafter the acronym can be used if appropriate, e.g. 'The work of the Assessment of Performance Unit (APU) in the early 1980s ...'. Subsequently, 'The APU studies of achievement ...', in a reference ... (Department of Education and Science [DES] 1989a).
- Brief biographical details of significant national figures should be outlined in the text unless it is quite clear that the person concerned would be known internationally. Some suggested editorial emendations to a typical text are indicated in the following with square brackets: 'From the time of H. E. Armstrong [in the 19th century] to the curriculum development work associated with the Nuffield Foundation [in the 1960s], there has been The preferred local (national) usage for ethnic and other minorities should be used in all papers. For the USA, African-American, Hispanic, and Native American are used, e.g. 'The African American presidential candidate, Jesse Jackson...' For the UK, African-Caribbean (not 'West Indian'), etc.

- Material to be emphasized (italicized in the printed version) should be underlined in the typescript rather than italicized. Please use such emphasis sparingly.
- n (not N), % (not per cent) should be used in typescripts.
- Numbers in text should take the following forms: 300, 3000, 30 000. Spell out numbers under 10 unless used with a unit of measure, e.g. nine pupils but 9 mm (do not introduce periods with measure). For decimals, use the form 0.05 (not .05).

Style guidelines

Submissions to *Brain Injury* should follow the style guidelines described in *Scientific Style and Format: The CSE Manual for Authors, Editors, and Publishers* (8th ed.). *Merriam-Webster's Collegiate Dictionary* (11th ed.) should be consulted for spelling.

References

References should be presented in a separate section at the end of the document, in accordance with Vancouver system guidelines (see *Citing Medicine*, 2nd ed.). The references should be listed and numbered based on the order of their first citation. Every reference should be assigned its own unique number. References should not be repeated in the list, with each mention given a different reference number, nor should multiple references be combined under a single reference number. Digits in parentheses (e.g., (1, 2)) should be used for in-text citations. Citations should precede terminal (e.g., periods, commas, closed quotation marks, question marks, exclamation point) and nonterminal punctuation (e.g., semicolons, colons). Reference numbers should not be placed in parentheses.

Author listings in references should be formatted as indicated below.

1 author	Smith A
2 to 10 authors	Smith A, Jones B, Smythe C, Jonesy D, Smitty E, Jonesi F, Smithe G, Janes H, Smithee I, Junes J
11 or more authors	Smith A, Jones B, Smythe C, Jonesy D, Smitty E, Jonesi F, Smithe G, Janes H, Smithee I, Junes J, et al.

Models from US National Library of Medicine (NLM) resources (e.g., *MEDLINE, Index Medicus*), should be employed for abbreviating journal titles in the reference section. Examples of common reference types appear below.

Journal article	12. Taylor J, Ogilvie BC. A conceptual model of adaptation to retirement among athletes: a meta-analysis. J Appl Sport Psychol. 1994;6(1):1–20. doi:10.1080/10413209408406462. Cited in PubMed;

	PMID:25888877.
Book	2. Duke JA. Handbook of phytochemical constituents of GRAS herbs and other economic plants. Boca Raton (FL): CRC Press; 2001. 676 p.
Book with titled volume and edition	18. Bowlby J. Attachment and loss. Vol. 3, Loss: sadness and depression . 3rd ed. New York (NY): Basic Books; 1982.
Edited book chapter	34. Gordon S, Lavallee D. Career transitions in competitive sport. In: Morris T, Summers J, editors. Sport psychology: theory, applications and issues. 2nd ed. Brisbane (Australia): Wiley; 2004. p. 584–610.
Edited book chapter with volume and edition	26. Remael A. Audiovisual translation. In: Gambier Y, van Dooslaer L, editors. Handbook of translation studies. Vol. 1. 2nd ed. Amsterdam (Netherlands): John Benjamins; 2012. p. 12–7.
Online/Website	8. United States Census Bureau: Census.gov [Internet]. Washington (DC): United States D; c. 2014. American housing survey: 2013 detailed tables; 2014 Oct 16 [cited 2014 Oct 21]; [1 screen and data files]. Available from: http://www.census.gov/newsroom/press-releases/2014/cb14-tps78.html.
Dissertation/Thesis	26. Allison N. Bacterial degradation of halogenated aliphatic acids [dissertation]. [Nottingham (UK)]: Trent Polytechnic; 1981. 120 p.
Conference presentation	4. Alfermann D, Gross A. Coping with career termination: it all depends on freedom of choice. Paper presented at: 9th Annual World Congress on Sport Psychology; 1997 Jan 23; Netanya, Israel.
Paper/Report	55. Grigg W, Moran R, Kuang M. National Indian education study. Washington (DC): National Center for Education Statistics; 2010 Jun 23. Report No.: NCES 2010-462.
Newspaper	22. Protzman, F. Clamor in the East: East Berliners explore land long forbidden. New York Times (Late ed.).

	1989 Nov 10;Sect. A:1 (col. 2).
Patent	67. Pfeifer A, Muhs A, Pihlgren M, Adolfsson O, Van Leuven F, inventors; AC Immune S.A, Katholieke Universiteit Leuven, assignees. Humanized tau antibody. United States patent US 9,657,091. 2017 May 23.
Computer software with developer	10. Noguera J, Cumby C. SigmaXL. Version 8.0. [software]. Kitchener (Canada): SigmaXL, Inc; 2017 Feb 27.
Computer software without developer	76. SPSS Amos. Version 22.0 [software]. Armonk (NY): IBM; 2013 Aug 13.
Dataset	3. Wang G-Y, Zhu Z-M, Cui S, Wang J-H. Data from: glucocorticoid induces incoordination between glutamatergic and GABAergic neurons in the amygdala [dataset] . 2017 Aug 11 [cited 2017 Dec 22]. In: Dryad Digital Repository [Internet]. Available from: https://doi.org/10.5061/dryad.k9q7h.

Checklist: what to include

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3. **Keywords.** Keywords are the terms that are most important to the article and should be terms readers may use to search. Authors should provide 3 to 5 keywords. Please read our page about making your article more discoverable for recommendations on title choice and search engine optimization.

4. **Funding details**. Please supply all details required by your funding and grant-awarding bodies as follows:

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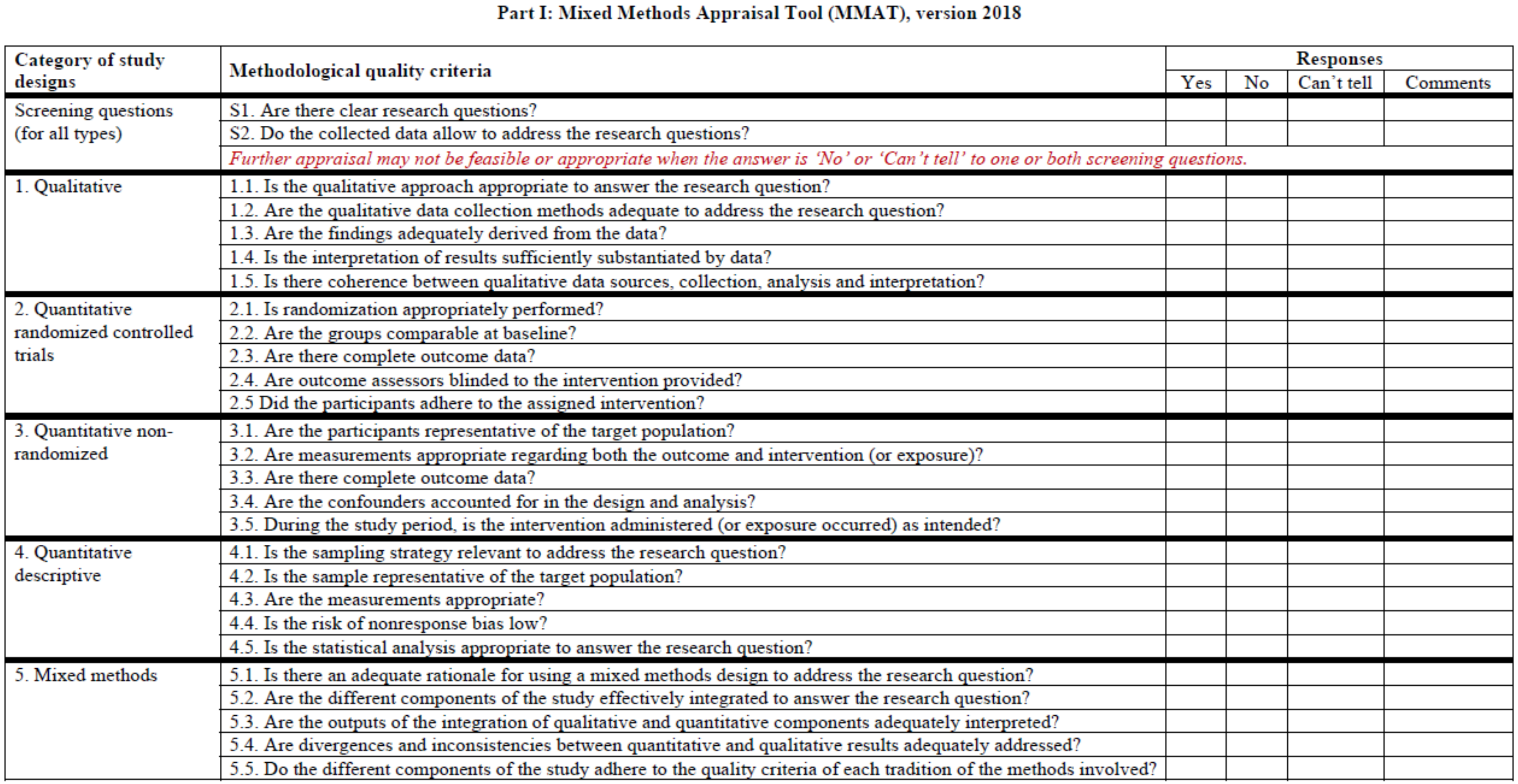
LAST UPDATED 19-07-2018

Appendix D – Mixed Methods Appraisal Tool



Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

Appendix E – Information Sheet

Date:
21/06/2018
Version: 1.1
IRAS ID: 241595

Participant Information Sheet - Shame, Self-Discrepancies, and Adjustment Post Acquired Brain Injury.

Invitation

I would like to invite you take part in a research study that is looking at how factors such as our emotions and view of ourselves influence adjustment in individuals who have had a brain injury. Before deciding if you want to take part I would like you to understand why the research is being done and what it would involve for you. I would therefore ask that you read the following information carefully before making your decision.

Purpose of the study

We know very little about how emotions and the way we view ourselves influence adjustment after an acquired brain injury. This research aims to explore this and discover if these factors are linked.

Why have you been invited to participate?

You have been invited to take part in this research because you are over 18 years of age and have experienced an acquired brain injury. Staff members may give this information sheet to people who meet the criteria to take part in the study, as they may be interested in participating.

Do I have to take part?

No. Participation is completely voluntary and it is up to you to decide to join this study. You will be free to withdraw from this study up to the point of the questionnaires being completed and handed back to the researcher and you do not have to give a reason for this. Your decision will not affect your medical care or your legal rights, and you should not feel any pressure to take part.

What will participating involve?

First you will be asked to provide some general information about yourself. You will also be asked to complete some questionnaires to:

1) Assess your mood and emotions.
2) To think about yourself at 3 different time points (before the acquired brain injury, after the acquired brain injury, and how you view your ideal self).
3) Think generally about your life.

This process will take around 45-60 minutes. The questionnaires are completed in person.

Where will the research take part?

It is up to you where you wish to take part in this study. You can choose to come to the University of Hull for your participation or I can come to your home and you can do the questionnaires there. Additionally you can complete the research at the service/group you have been identified from, as long as there is a suitable space available.

Expenses and payment

Your participation in this study is voluntary. No travel expenses will be reimbursed.

What are the benefits and risks of taking part?

This study involves little risk. However, the questionnaires will ask you to consider how your life has changed since your brain injury and this can be a little upsetting for some people Should this be the case, you are free to discontinue your participation at any point. The researcher will also offer support contacts and help you to gain access to further help from your clinical care team or your GP, if needed. Although there are no known benefits for taking part in this study, your participation may help improve knowledge about factors which influence adjustment post acquired brain injury and therefore help professionals working with people that have experienced an acquired brain injury.

Anonymity and confidentiality

Information obtained in the study will be used only for this study. All information is stored securely for 10 years and will then be destroyed. All information will be anonymised and participants will not be identified by name at any point. We will follow ethical and legal practice and all information about you will be handled in confidence.

What will happen with the results from the study?

The results of this study will be presented in a doctoral thesis, submitted for publication in an academic journal, and may be presented at conferences. No individual participant details will be identified in the presentation of data. If you would like to hear about the findings from the study, you will be asked to provide your name and email address which will be destroyed once the feedback has been emailed out.

Who is organising the study?

This research is carried out as part of a doctorate level training program in clinical psychology with approval from Humber NHS foundation trust.

What if there is a problem?

If you have concerns about any aspects of this study you can contact Dr Pete Fleming at the University of Hull (p.fleming@hull.ac.uk/ 01482 464117). You can also contact the local NHS Patient and Advice and Liaison Service (PALS) on telephone number 01482 303966 or via email: pals@humber.nhs.uk.

What should I do next?

If you wish to take part please inform the member of staff, they will then be able to advise you about what to do next.

For further information

Miss Rachel Hughes and Dr Pete Fleming will be happy to answer any questions about this study at any time:

Email: r.h.hughes@2013.hull.ac.uk/ p.fleming@hull.ac.uk

Address: Miss Rachel Hughes/ Dr Pete Fleming, Clinical Psychology, Aire Building,
University of Hull, Cottingham road, Hull, HU6 7RX

Thank you for taking the time to read this letter!

Yours Sincerely	**Supervised by**	
Rachel Hughes	**Dr Pete Fleming**	**Dr Lauren Henshall**
Trainee Clinical Psychologist	**Clinical Neuropsychologist**	**Clinical Psychologist**

Appendix F – Permission to Contact Form

Date: 29/03/2018
Version: 1.0
IRAS ID: 241595

Permission to be contacted slip - Shame, Self-discrepancies, and Adjustment post Acquired Brain Injury

Please tick all that apply: -

☐ I am interested in taking part in the research.

☐ I would like more information before I decide whether or not to take part.

The following information is to allow contact; it will not be used in the study.

Name: ____

Email Address (if available): ____

Telephone number: ____

Can a message be left at this telephone number (please tick)?

☐ Yes

☐ No

Please return this form to the member of staff who has given it to you, to be returned to Rachel Hughes, Trainee Clinical Psychologist.

Thank you.

Appendix G – Consent Form

Date: 29/03/2018
Version: 1.0
IRAS ID: 241595

City Health Care Partnership CIC
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UNIVERSITY OF HULL

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Humber
NHS Foundation Trust

Hull and East Yorkshire Hospitals
NHS Trust

Consent Form

Title of Project: Shame, Self-Discrepancies, and Adjustment Post Acquired Brain Injury.
Name of Researcher: Miss Rachel Hughes

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 29/03/2018 (Version 1.0) for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, up until all questionnaires have been completed and returned to the researcher, without my medical care or legal rights being affected. ☐

3. I confirm that data obtained from the questionnaires may be used in future publications and understand that this will be anonymised. ☐

4. I understand that data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

5. I agree to take part in the study. ☐

Name of participant Date Signature

Name of researcher/clinician Date Signature

Appendix H – Demographic Information Sheet

Date:
29/03/2018
Version: 1.0
IRAS ID:
241595

ID number (to be completed by the researcher):

This information will be used anonymously in the study. Please answer as many of the following questions, but you do not have to answer anything that you do not want to.

Sex (tick one) ☐ Male ☐ Female

Year of Birth____

Ethnic Origin (e.g. White - British, White – Irish, Asian - British, Black - British, Mixed)

:____

Marital Status (tick one)

☐ Married ☐ Single – Never Married ☐ Living with partner

☐ Divorced ☐ Widowed ☐ Other (please give details)

____

Are you currently employed? (Please tick) ☐ Yes ☐ No

If yes: -

Current occupation: ____

Date of brain injury: __/__/__

How did your brain injury occur? (e.g. stroke, car crash, tumour):________________

Appendix I – Debrief and Sources of Support Sheet

Date:
29/03/2018
Version: 1.0
IRAS ID: 241595

Shame, Self-Discrepancies, and Adjustment Post Acquired Brain Injury

Debrief Sheet

Dear Participant,

Thank you for taking the time to complete this research, your input is appreciated.

The research you have taken part in is interested in the relationship between differences between participant's sense of self before and after a brain injury, and how these may link to shame and adjustment. The questionnaires you have completed looked at these different areas, and this data will be combined with information from other participants and analysed using statistics. This could help to inform psychosocial interventions post brain injury. The information you have provided is being stored securely, and anonymously, and will be kept for 10 years before being destroyed.

Please see the attached document which contains information about local and national sources of support for individuals who have experienced an acquired brain injury. Additionally you are reminded that you can speak to your General Practitioner, or the member of staff who has helped facilitate your involvement in this research, if you require further support.

If you have any further comments or concerns, please contact Dr Pete Fleming.

Many thanks,

Rachel Hughes
Trainee Clinical Psychologist

Sources of support and information regarding Acquired Brain Injury

Headway offers advice, information, and local support groups regarding Acquired Brain Injury on its website:

www.headway.org.uk/

Email: helpline@headway.org.uk

Confidential helplines: 0808 800 2244

PAUL for Brain Recovery (Hull) offers advice, information, and support regarding Brain Injury:

www.paulforbrainrecovery.co.uk/

Email: info@paulforbrainrecovery.co.uk

Telephone: 01482 620229

The **Stroke Association** offers advice, information and local support groups regarding Stroke as a specific type of Acquired Brain Injury:

www.stroke.org.uk/

Email: info@stroke.org.uk

Advice line: 0303 3033 100

Should you have any specific issues regarding taking part in this study then you can contact the **Researcher** on:

Email: R.h.hughes@2013.hull.ac.uk

Telephone: 07516914010

You can also seek advice from your GP

Appendix J – Ethics Approval

REMOVED FOR HARD BINDING

Appendix K – The Head Injury Semantic Differential Scale – III

REMOVED FOR HARD BINDING

Appendix L – Internalised Shame Scale

REMOVED FOR HARD BINDING

Appendix M – Hospital Anxiety and Depression Scale

REMOVED FOR HARD BINDING

Appendix N – The Quality of Life after Brain Injury Scale

REMOVED FOR HARD BINDING

Appendix O – SPSS Output

Descriptive statistics

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean		Std. Deviation
	Statistic	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic
Age (years)	62	67	25	92	63.39	1.856	14.613
Years_Since_ABI	62	44	1	45	7.08	1.011	7.964
HISDS_Past	62	68	58	126	104.32	1.953	15.377
HISDS_Present	62	82	41	123	83.16	2.536	19.972
HISDS_Ideal	62	52	74	126	119.31	1.063	8.370
QOLIBRI	62	69	24	93	58.26	2.238	17.624
ISS_Shame	62	90	0	90	36.48	2.878	22.665
HADS_A	62	17	1	18	8.10	.564	4.442
HADS_D	62	19	0	19	6.73	.484	3.808
Pre_vs_Post_Disrepency	62	115	-73	42	-21.16	2.855	22.483
Post_vs_Ideal_Discrepancy	62	82	-8	74	36.15	2.479	19.516
Valid N (listwise)	62						

Research Question 1: Statistical Tests for Self-Discrepancies (pre injury versus present self; present vs ideal self).

Tests of Within-Subjects Effects

Measure: HISDS

Source		Type III Sum of Squares	df	Mean Square	F	Sig.
HISDS	Sphericity Assumed	40894.978	2	20447.489	114.098	.000
	Greenhouse-Geisser	40894.978	1.598	25598.360	114.098	.000
	Huynh-Feldt	40894.978	1.634	25031.321	114.098	.000
	Lower-bound	40894.978	1.000	40894.978	114.098	.000
Error(HISDS)	Sphericity Assumed	21863.688	122	179.211		
	Greenhouse-Geisser	21863.688	97.451	224.355		
	Huynh-Feldt	21863.688	99.659	219.385		
	Lower-bound	21863.688	61.000	358.421		

Tests of Within-Subjects Contrasts

Measure: HISDS

Source	HISDS	Type III Sum of Squares	df	Mean Square	F	Sig.
HISDS	Level 1 vs. Level 3	27763.613	1	27763.613	54.925	.000
	Level 2 vs. Level 3	81001.306	1	81001.306	216.224	.000
Error(HISDS)	Level 1 vs. Level 3	30834.387	61	505.482		
	Level 2 vs. Level 3	22851.694	61	374.618		

Pairwise Comparisons

Measure: HISDS

1. HISDS Past

2. HISDS Ideal

3. HISDS Present

(I) HISDS	(J) HISDS	Mean Difference (I-J)	Std. Error	Sig.[b]	95% Confidence Interval for Difference[b]	
					Lower Bound	Upper Bound
1	2	-14.984*	1.774	.000	-19.352	-10.616
	3	21.161*	2.855	.000	14.132	28.191
2	1	14.984*	1.774	.000	10.616	19.352
	3	36.145*	2.458	.000	30.094	42.196
3	1	-21.161*	2.855	.000	-28.191	-14.132
	2	-36.145*	2.458	.000	-42.196	-30.094

Research question 2: Self-discrepancies (Past vs. Present Self and Present vs. Ideal Self) and shame.

Correlations

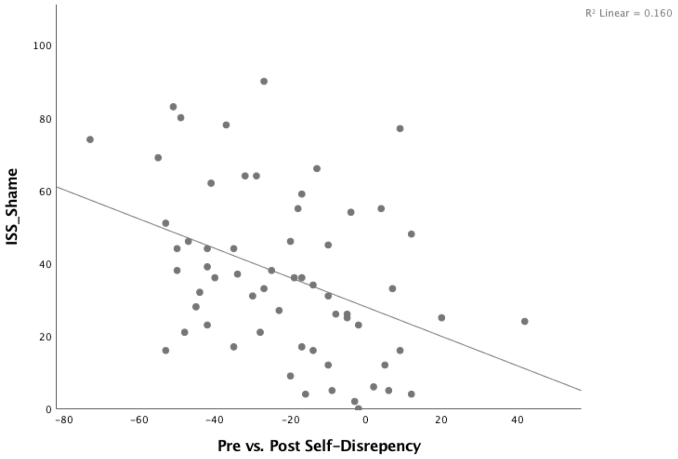
		Pre_vs_Post_Disrepency	ISS_Shame
Pre_vs_Post_Disrepency	Pearson Correlation	1	-.400**
	Sig. (2-tailed)		.001
	N	62	62
ISS_Shame	Pearson Correlation	-.400**	1
	Sig. (2-tailed)	.001	
	N	62	62

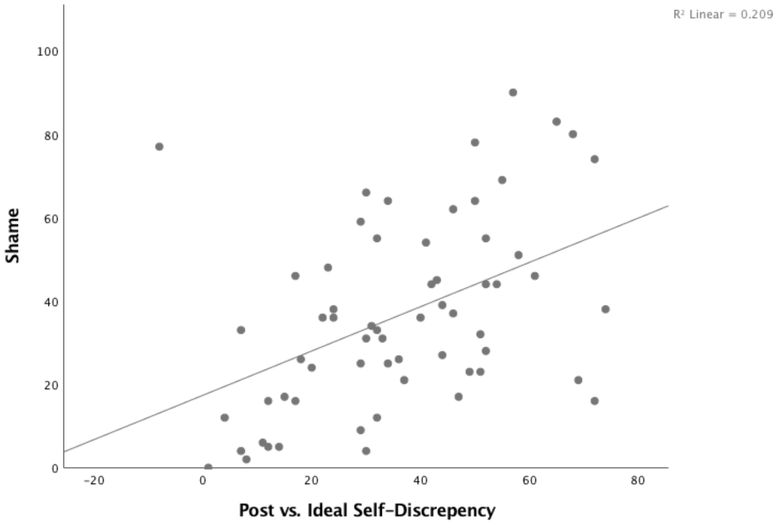
**. Correlation is significant at the 0.01 level (2-tailed).

Correlations

		Post_vs_Ideal_Discrepency	ISS_Shame
Post_vs_Ideal_Discrepency	Pearson Correlation	1	.457**
	Sig. (2-tailed)		.000
	N	62	62
ISS_Shame	Pearson Correlation	.457**	1
	Sig. (2-tailed)	.000	
	N	62	62

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





Hypothesis 3: Self-discrepancy (Past vs. Present Self), shame, and each aspect of adjustment (QOLIBRI, HADS-A, HADS D)

Model Summary[c]

					Change Statistics				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.035[a]	.001	-.033	17.909	.001	.037	2	59	.963
2	.661[b]	.437	.397	13.685	.435	22.024	2	57	.000

a. Predictors: (Constant), Age (years), Gender

b. Predictors: (Constant), Age (years), Gender, Pre_vs_Post_Disrepency, ISS_Shame

c. Dependent Variable: QOLIBRI

Coefficients[a]

		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B
Model		B	Std. Error	Beta	t	Sig.	Lower Bound
1	(Constant)	60.697	11.079		5.479	.000	38.528
	Gender	-1.090	4.716	-.031	-.231	.818	-10.526
	Age (years)	-.014	.162	-.011	-.084	.934	-.337
2	(Constant)	90.195	9.670		9.328	.000	70.831
	Gender	-.160	3.617	-.005	-.044	.965	-7.402
	Age (years)	-.192	.129	-.159	-1.483	.144	-.451
	ISS_Shame	-.467	.088	-.601	-5.299	.000	-.643

Pre_vs_Post_Disrepency	.118	.086	.151	1.373	.175	-.054

Coefficients^{a}

		95.0% Confidence Interval for B	Collinearity Statistics	
Model		Upper Bound	Tolerance	VIF
1	(Constant)	82.866		
	Gender	8.346	.939	1.065
	Age (years)	.310	.939	1.065
2	(Constant)	109.558		
	Gender	7.082	.932	1.072
	Age (years)	.067	.859	1.164
	ISS_Shame	-.291	.769	1.300
	Pre_vs_Post_Disrepency	.291	.818	1.222

a. Dependent Variable: QOLIBRI

Model Summary^{c}

					Change Statistics				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.370^{a}	.137	.108	4.196	.137	4.675	2	59	.013
2	.708^{b}	.501	.466	3.247	.364	20.765	2	57	.000

a. Predictors: (Constant), Age (years), Gender

b. Predictors: (Constant), Age (years), Gender, Pre_vs_Post_Disrepency, ISS_Shame

c. Dependent Variable: HADS_A

Coefficients^{a}

Model		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B
		B	Std. Error	Beta	t	Sig.	Lower Bound
1	(Constant)	13.373	2.596		5.152	.000	8.179
	Gender	1.361	1.105	.154	1.231	.223	-.850
	Age (years)	-.114	.038	-.376	-3.016	.004	-.190
2	(Constant)	6.512	2.294		2.838	.006	1.918
	Gender	1.133	.858	.128	1.321	.192	-.585
	Age (years)	-.072	.031	-.237	-2.348	.022	-.134
	ISS_Shame	.110	.021	.562	5.263	.000	.068
	Pre_vs_Post_Disrepency	-.023	.020	-.118	-1.138	.260	-.064

a. Predictors: (Constant), Age (years), Gender

b. Predictors: (Constant), Age (years), Gender, Pre_vs_Post_Disrepency, ISS_Shame

c. Dependent Variable: HADS_A

Coefficients[a]

Model		95.0% Confidence Interval for B	Collinearity Statistics	
		Upper Bound	Tolerance	VIF
1	(Constant)	18.567		
	Gender	3.571	.939	1.065
	Age (years)	-.038	.939	1.065
2	(Constant)	11.106		

	Gender	2.852	.932	1.072
	Age (years)	-.011	.859	1.164
	ISS_Shame	.152	.769	1.300
	Pre_vs_Post_Disrepency	.018	.818	1.222

a. Dependent Variable: HADS_A

Model Summary[c]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				Sig. F change
					R Square Change	F Change	df1	df2	
1	.007[a]	.000	-.034	3.871	.000	.001	2	59	.999
2	.398[b]	.159	.100	3.613	.159	5.378	2	57	.007

a. Predictors: (Constant), Age (years), Gender

b. Predictors: (Constant), Age (years), Gender, Pre_vs_Post_Disrepency, ISS_Shame

c. Dependent Variable: HADS_D

Coefficients with Bootstrapping[a]

Model		Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B
		B	Std. Error	Beta	t	Sig.	Lower Bound
1	(Constant)	6.719	2.395		2.806	.005	2.828
	Gender	.052	1.019	.007	.051	.956	-2.069
	Age (years)	-.001	.035	-.004	-.031	.978	-.080
2	(Constant)	3.154	2.553		1.235	.172	-1.413
	Gender	-.025	.955	-.003	-.026	.983	-2.124
	Age (years)	.018	.034	.068	.519	.660	-.061
	ISS_Shame	.052	.023	.308	2.227	.053	.002
	Pre_vs_Post_Disrepency	-.028	.023	-.166	-1.237	.250	-.075

Coefficients[a]

Model		95.0% Confidence Interval for B	Collinearity Statistics	
		Upper Bound	Tolerance	VIF
1	(Constant)	11.512		
	Gender	2.092	.939	1.065
	Age (years)	.069	.939	1.065
2	(Constant)	8.265		
	Gender	1.887	.932	1.072

	Age (years)	.086	.859	1.164
	ISS_Shame	.098	.769	1.300
	Pre_vs_Post_Disrepency	.017	.818	1.222

a. Dependent Variable: HADS_D

Post Hoc tests

1. Shame on QOLIBRI score

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				Sig. F change
					R Square Change	F Change	df1	df2	
1	.035[a]	.001	-.033	17.909	.001	.037	2	59	.963
2	.647[b]	.418	.388	13.789	.417	41.526	1	58	.000

a. Predictors: (Constant), Age (years), Gender

b. Predictors: (Constant), Age (years), Gender, ISS_Shame

2. Shame on HADS-D score

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				Sig. F change
					R Square Change	F Change	df1	df2	
1	.007[a]	.000	-.034	3.871	.000	.001	2	59	.999
2	.369[b]	.136	.092	3.629	.136	9.143	1	58	.004

a. Predictors: (Constant), Age (years), Gender

b. Predictors: (Constant), Age (years), Gender, ISS_Shame

3. Shame on HADS-A-score

Model Summary

					Change Statistics				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.370[a]	.137	.108	4.196	.137	4.675	2	59	.013
2	.699[b]	.489	.463	3.255	.352	40.030	1	58	.000

a. Predictors: (Constant), Age (years), Gender

b. Predictors: (Constant), Age (years), Gender, ISS_Shame

4. Past vs. present self-discrepancy on QOLIBRI score

Model Summary

					Change Statistics				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.035[a]	.001	-.033	17.909	.001	.037	2	59	.963
2	.399[b]	.159	.116	16.574	.158	10.887	1	58	.002

a. Predictors: (Constant), Age (years), Gender

b. Predictors: (Constant), Age (years), Gender, Pre_vs_Post_Disrepency

5. Past vs. present self-discrepancy on HADS-D score

Model Summary

					Change Statistics				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.007[a]	.000	-.034	3.871	.000	.001	2	59	.999

2	.293[b]	.086	.038	3.734	.086	5.427	1	58	.023

a. Predictors: (Constant), Age (years), Gender

b. Predictors: (Constant), Age (years), Gender, Pre_vs_Post_Disrepency

6. Past vs. present self-discrepancy on HADS-A score

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				
					R Square Change	F Change	df1	df2	Sig. F Change
1	.370[a]	.137	.108	4.196	.137	4.675	2	59	.013
2	.508[b]	.258	.220	3.924	.121	9.474	1	58	.003

a. Predictors: (Constant), Age (years), Gender

b. Predictors: (Constant), Age (years), Gender, Pre_vs_Post_Disrepency