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Shame, self-discrepancies and adjustment after acquired brain injury

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Abstract

Objectives: To explore the relationship between shame and self-discrepancies and the extent that these factors predict adjustment after an acquired brain injury (ABI).

Method: 62 participants with an ABI completed the following self-report qualitative 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. Data was analysed using correlations, repeated ANOVAS and multiple regression models.

Results: A significant self-discrepancy was found between the present self and the pre-injury self, with the present self being rated more negatively. This self-discrepancy was found to be positively correlated to shame, and these two variables 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.

Keywords: Brain Injury, Shame, Self-discrepancies, Adjustment.

Introduction

Psychosocial adjustment after an Acquired Brain Injury (ABI) is the process of becoming aware of, making sense of, and adapting to changes, and is an important element to recovery [1]. A range of variables have been suggested to impact psychosocial adjustment following an ABI, including: severity of injury and impairments, behavior regulation, along with specific factors of psychosocial functioning such as occupational activities, interpersonal relationships and independent living skills [2].

One way of conceptualising the process of psychosocial adjustment following ABI was proposed by Gracey , Evans, and Malley [3] in the 'Y shaped Model' – figure 1. In this model, discrepancies between the present or post brain injury self and the pre-injury or 'aspired to self', are suggested to create and maintain a sense of threat to self, known as self-discrepancies. This threat causes individuals to adopt conscious and non-conscious coping strategies which work in the short term but fail to resolve the self-discrepancies in the long term leading to poor psychosocial outcomes [3], an idea also proposed by Higgins' self-discrepancy theory [4]. Correspondingly, research within ABI populations has documented that negative changes in self-concept can occur following an ABI [5, 6], and that this pre-injury vs. present self-discrepancy is positively associated with emotional distress [7, 8, 9, 10].

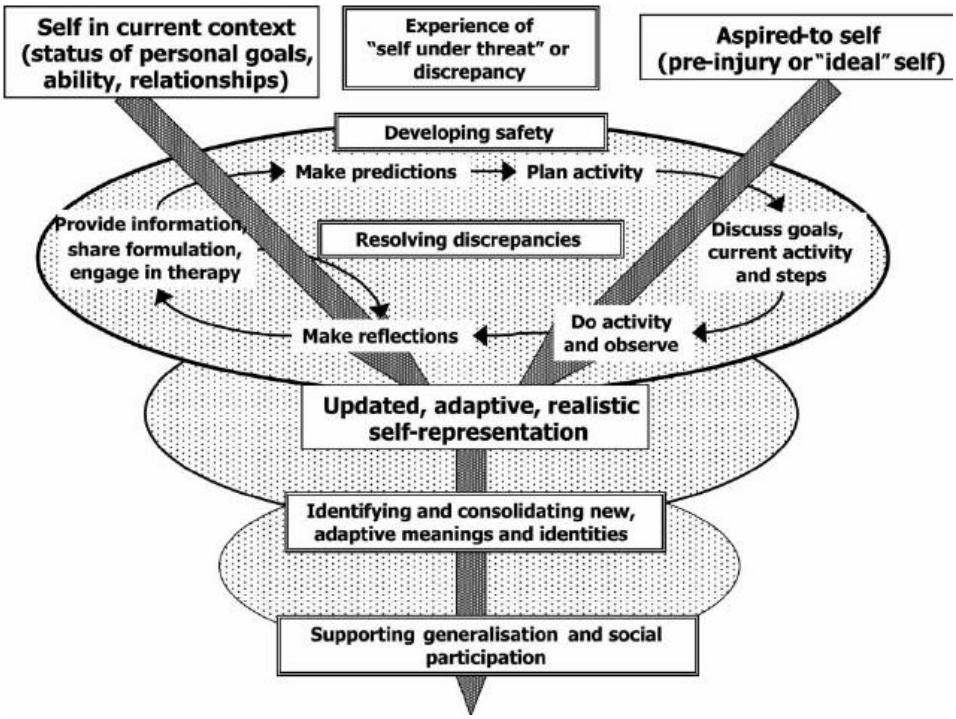

Figure 1: The 'Y-shaped' model [11].

Another key element that has been implicated in emotional distress post ABI is shame [11-15], which is associated with negative evaluations about the whole self, whereby the shamed individual feels unworthy, small, or defective [16]. In its simplest form, shame can be seen as developing in response to a perceived discrepancy of the self, or how others view us [17], and as such could be linked to self-discrepancies.

Support for a link between shame and self-discrepancies has been documented outside of ABI populations in two studies, one using students and one using new mothers [18, 19]. In both cases shame and self-discrepancies were found to be related, which is something that has not been examined in an ABI population despite both factors being implicated in other research.

The current study sought to investigate if pre-injury vs present self-discrepancies and shame were present in an ABI sample, and if these variables were correlated. Additionally, this study examined if pre-injury vs present self-discrepancies predict adjustment, which for the

purpose of this paper is defined through quality of life score and anxiety and depression score. Specifically, it was hypothesised:

a) Individuals would rate their present selves more negatively than their pre injury self, and this would cause a significant self-discrepancy.

b) Shame and the pre-injury vs. present self-discrepancy would be significantly correlated, whereby the larger the self-discrepancy score, the larger the shame score.

c) Shame and the pre-injury vs. present self-discrepancy would 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 62 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. Inclusion criteria were as follows: 18 years or over when the ABI occurred, at least 12 months post ABI, and spoke English as first language. Exclusion criteria were as follows: previous severe physical disability, neurodegenerative disease, neurodevelopmental difficulties, learning disability, or language or cognitive impairment which restricted their capacity to consent to the study.

Procedure

The research was advertised at local ABI groups, which included groups from Headway and the Stroke Association, via a verbal presentation. Participants volunteered their contact details if they were interested in taking part, and after a minimum of 24 hours, the researcher

contacted participants to assess suitability and arrange a time and place to complete the measures. 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. Those that required assistance with completion of questionnaires were helped by the researcher.

Demographic information was obtained first, and then participants were asked to work through the six questionnaires, in a predetermined, computer generated randomised order. Participants were offered the chance to have a break half way through.

Primary measures

The Head Injury Semantic Differential Scale – III [20]

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, and present 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 for each type of self-concept. 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) [21]. 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 [22, 23] and was therefore used in this study.

Internalised shame scale [24]

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, where higher scores indicate more feelings of shame. The ISS has been shown to have high internal consistency alpha coefficients (0.88 to 0.96), and high temporal stability [25]. 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 [26]

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). This is made up of an anxiety subscale and a depression subscale which combine to make an overall score. This measure was chosen over other mood measures, as it has been widely used in ABI populations [27, 28, 29] 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 [30].

The quality of life after brain injury [31]

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. Higher scores indicate a higher quality of life, with 0 representing the worst possible quality of life, and 100 representing the best possible quality

of life. The measure was selected as it is the only quality of life measure designed specifically for the ABI population 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) [32].

Data Analysis

All statistical analysis was performed using SPSS version 25.0 [33]. Repeated measures ANOVA were used to compare differences across participant's pre-injury self and present self (HISDS-III scores) to examine if self-discrepancies exist. A self-discrepancy would exist if there was a significant difference between a participant's pre-injury self HISDS-III score vs. present 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 pre-injury vs present 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).

Results

Participant characteristics

Of the 62 participants (34 males and 28 females), 55 reported a stroke, 4 reported a tumour, and 3 reported a TBI. Further participant demographics including age, time since injury, type of injury, marital status, employment status, and ethnicity can be found in Table 1.

Table 1. Sample demographics and clinical characterises

Variable	*N*=62 Mean (SD)
Age	63.39 (14.61)
Years post injury	7.08 (7.96)
Gender	***N* = 62**
Male	34 (54.8%)
Female	28 (45,2%)
Type of injury	***N* = 62**
Stroke	55 (88.7%)
Tumour	4 (6.5%)
TBI	3 (4.8%)
Ethnicity	***N* = 62**
White British	62 (100%)
Marital status	***N* = 62**
Married	38 (61.3%)
Divorced	5 (8.1%)
Single (never married)	6 (9.7%)
Widowed	9 (14.5%)
Living with partner	3 (4.8%)
Separated	1 (1.6%)
Employment status	***N* = 62**
Employed	14 (22.6%)
Not employed	48 (77.4%)

Measures

Results of the measures are shown in Table 2. In terms of descriptive cut offs, the mean HADS-A score fell within the 'mild' category, the mean HADS-D score fell within the 'normal' range, and the mean ISS score fell within the 'low shame' range. Participants rated themselves more positively pre injury (*M*=104.32, *SD*=15.38), compared to their present self

(*M*=83.16, *SD*=19.97), and this difference was found to be significant, (F (1,61) = 54.93, $p<0.001$). With regards to quality of life, the mean QOLIBRI score was 58.26 (*SD*=17.62). Qualitative descriptors are not available for the HISDS-III or QOLIBRI.

Table 2. Scores on HISDS Past and Present, QOLIBRI, ISS, HADS-A, and HADS-D.

Measure	**Mean (SD)**
HISDS-III Past	104.32 (15.38)
HISDS-III Present	83.16 (19.97)
QOLIBRI	58.26 (17.62)
ISS	36.48 (22.67)
HADS-A	8.10 (4.44)
HADS-D	6.73 (3.81)

Correlations

Pre-injury 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, or points on the HISDS-III the individual had lost from their pre-injury to their present self, the larger the ISS score (indicating more shame).

Multiple regression models

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.

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.

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.

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.

Post-hoc Analysis

As an attempt to further understand the relationship between shame and pre-injury vs. present self-discrepancy and its ability to predict QOLIBRI, HADS-A, and HADS-D, post hoc tests were conducted to examine the individual predictability of shame and pre-injury vs. present self-discrepancies on the aforementioned outcomes.

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 pre-injury 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

This study had a number of hypotheses. Firstly, it was expected that a significant pre-injury vs present self-discrepancy would exist whereby participants viewed themselves more negatively in the present (following an ABI). Additionally, it was hypothesised that this self-discrepancy would correlate to shame, whereby the higher the self-discrepancy the higher the level of shame. Finally, this research hypothesised that the pre-injury vs present self-discrepancy and shame would significantly predict three aspects of adjustment (quality of life, anxiety, and depression). Support was found for all of the aforementioned hypotheses.

With regards to the finding that negative changes in self-concept occur after ABI, this sits in line with previous research has documented this change when comparing present self to pre-injury self [5, 6, 8, 9, 10]. 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.

The finding that the pre-injury vs present self-discrepancy is correlated to shame score can be interpreted in a number of ways. Gilbert and Andrews' [17] explanation of shame as occurring in response to negative self-evaluations, for example 'I was more patient before my

ABI' (past self) would acknowledge a relationship between these variables. Additionally, Higgins' [4] self-discrepancy theory predicts that an actual vs ideal discrepancy, which Cantor [10] suggested could also be used to understand the pre-injury 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 [34, 35] 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 [36]. 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).

Finally, whilst no research has considered the combined impact of shame and self-discrepancies on adjustment in an ABI population, previous supporting research on each factor can be used to interpret 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 [6-10] and lower quality of life [37] in ABI populations. This fits with both Graceys' [6] Y shaped model, and Higgins' [4] 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 [11, 12], and has been linked to higher emotional distress [38-40]. 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 [41]. This can be explained through the theoretical underpinnings of compassionate mind theory [42] 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 as 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 [6] 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.

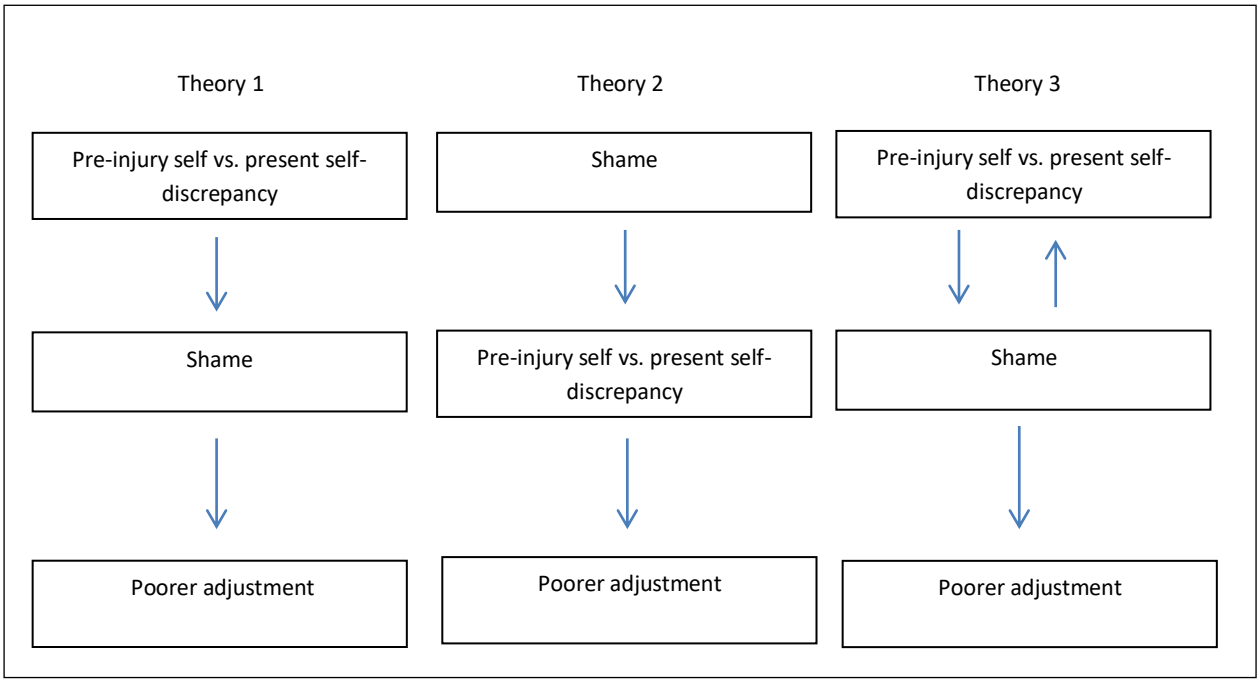

Figure 2: Possible relationships between shame, self-discrepencies, and adjustment.

Post hoc tests were conducted to attempt to help clarify 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).

Limitations and future directions

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 [43], 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 [44, 45]. 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 [46-49]. 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 mean rates of anxiety, depression, and shame found. Additionally the average age of participants was 63, which means the findings may be more representative of individuals in the later stages of their lives. 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 which impact: their interrupted career, their children or childrearing, their sexuality, and the need to continue to be a breadwinner [50]. This could mean that younger participants may not be as accessible through 'typical' ABI support groups, and that they are likely to face issues that are not as pertinent to older adults. Therefore future cross sectioned research would be beneficial 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 whether 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 and shame following an ABI, and showed 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 needs further exploration. 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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