

THE UNIVERSITY OF HULL

**An Exploration of the Experiences of Stigma and Community  
Reintegration Following Acquired Brain Injury**

being a Thesis submitted in partial fulfilment of the requirements for the degree  
of Doctor of Clinical Psychology

in the University of Hull

by Emma Louise Minns, BSc (Hons) Psychology, University of Hull

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## Overview of Thesis

This portfolio thesis consists of three parts; a systematic literature review, an empirical study and a set of related appendices. The thesis as a whole considers the experience of stigma and factors that affect community integration following an acquired brain injury (ABI)

The first section is a systematic literature review that explores the factors that affect reintegrating into the community after an ABI. It explores the relationship between numerous different patient, injury, psychological and external factors and community integration. Twenty two papers were reviewed and their findings synthesised using a narrative synthesis approach. Review findings were combined and integrated to generate new perspectives and highlight commonalities and differences within the literature. The findings indicate the complex and multi-dimensional relationship between numerous different factors and levels of community integration following brain injury. The majority of findings were inconsistent and with small effect sizes. However, the review provided interesting points for discussion and highlighted age, severity of injury and ethnicity as predictive factors of community integration. The findings are discussed within the context of wider literature, and recommendations for additional support and targeted interventions post injury are discussed.

The second section of the portfolio is an empirical study that explores the experience of stigma in an acquired brain injury population. A positive psychology framework is adopted and the study also aimed to explore the dialectical nature of experiencing stigma, in line with second wave positive psychology principles. The researcher used semi-structured interviews to obtain

rich information and experiences regarding individuals experience of stigma. Data was analysed using Interpretative Phenomenological Analysis. Six participants between the ages of 37 and 67 were interviewed, 3 of which had sustained a traumatic brain injury, 2 had experienced a stroke and one had contracted encephalitis. Three super-ordinate themes and 10 sub-themes emerged from the data. The findings indicate that participants perceived to experience stigma and discrimination from society but also experience those with a good understanding of their injuries. Post-traumatic growth in terms of developing resilience, empathy and empowerment to create social change was also evident. The interaction between both good and bad experiences may have contributed to the development of PTG and also highlights the dialectical nature of experiencing stigma. The findings are discussed in the context of wider literature and the implications for strategies to increase public understanding of brain injury and facilitate social contact between those with and without injuries.

The third section consists of a set of appendices relating to both the systematic literature review and the empirical paper. A reflective statement and an epistemological statement can also be found within the appendices. The statements consider the researcher's motivation behind the research, the positions and assumptions underlying the research and their experience of conducting the research.

**Total Word Count: 33, 532** (including tables, appendices and references)

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## **Part One: Systematic Literature Review**

**Factors that predict Community Integration following Acquired Brain Injury: A Systematic Review**

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*'Brain Injury'*

Please see Appendix A for the instructions for contributors

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## **Abstract**

**Objective:** Community integration (CI) is a complex, multi-dimensional concept that is often seen as the ultimate goal for brain injury rehabilitation. This is perhaps due to the positive psychological effects associated with community integration, such as increased quality of life and well-being. Unfortunately, those who have experienced a brain injury often struggle to maintain a productive and social life. Clinicians have stressed the importance of specific, and targeted, interventions to increase levels of CI post-injury. This study aimed to systematically review the literature regarding factors that predict community integration after an acquired brain injury.

**Design and Methodology:** Four databases were searched, between November 2017 and March 2018. Twenty-two studies which met the inclusion criteria were included and reference lists were manually searched to identify remaining eligible studies.

**Results:** Findings were synthesised in to a narrative account which highlighted the vast array of factors that affect CI. Specifically, age, ethnicity and level of disability were found to be predictive of CI following ABI.

**Conclusions:** Recommendations for additional support and targeted interventions post injury are discussed.

**Key words:** *Traumatic Brain Injury, Acquired Brain Injury, Community Integration*

## Introduction

Acquired brain injury (ABI) is a major health problem which causes an individual to be admitted to hospital every ninety seconds in the United Kingdom [1]. ABI is an umbrella term that refers to brain damage that is acquired after birth. There are a multitude of possible causes such as traumatic brain injury, encephalitis, hypoxia, brain haemorrhage, tumour and stroke. Stroke is the second largest cause of death worldwide [2] and Traumatic brain injury is a major cause of death and disability in the United States [3]. ABI is an umbrella term that refers to brain damage that is acquired after birth. ABI's are associated with both short, and long-term, alterations in cognitive, behavioural, physical and emotional functioning [4]. Mild brain-injury can result in long-term cognitive problems which can have a detrimental effect on an individual's life. A study by Rimel, Giordani, Barth, Boll and Jane [5] found that out of 424 individuals with a minor head injury 79% suffered from persistent headaches, and 59% described problems with memory attention, concentration and judgement.

### *Community Integration*

Community integration following acute-care or post-acute rehabilitation is often seen as the ultimate goal of brain injury rehabilitation [6, 7, 8, 9]. It has also been used as a benchmark to assess the effectiveness of rehabilitation after injury [10]. Community integration is a complex, and multi-dimensional, construct with no universal definition. However, McColl et al [11] outlined broad themes based on qualitative accounts of what community integration means to individuals with brain injuries. The four themes are: general integration, social

support, occupation, and independent living. General integration relates to the ability of an individual to find their way around, conform with societal norms and be accepted. Social support is defined as having both close and diffuse relationships in the community, including family, friends and members of society. Occupation consists of the ability to engage in enjoyable leisure activities and productive occupations that provide individuals with a sense of purpose and structure. Lastly, the ability to live independently includes being able to make everyday decisions and life choices including having control over living situations.

#### *CI and Quality of Life (QoL)*

Research has found that levels of community integration predict positive psychological outcomes. Chun, Lee, Lundberg, McCormick and Heo [12] found that community integration through an adapted sports program predicted QoL on psychological, social and environmental domains for people with physical disabilities. Moreover, Wilson, Jaques, Johnson and Brotherton [13] found that increased community participation through attendance of a structured support group improved the well-being of adults with an intellectual disability. These results have also been documented in a brain injury population. For example, Burleigh, Farber and Gillard [14] found that increased social interaction, a component of community integration, was associated with greater life satisfaction 8-23 years after TBI. Corrigan, Bogner, Mysiw, Clinchot and Fugate [15] found that greater life satisfaction was associated with leading a social and productive life one to two years post TBI. Similarly, Steadman-Pare, Colantonio, Ratcliff, Chase and Vernich [16] found that participation in work and leisure activities were significantly associated with long term QoL in a TBI population.

### *Community Integration in a Brain Injury Population*

Despite the clear advantages associated with community integration there is a wealth of literature documenting a reduction in integration following brain injury. Research suggests that those who have suffered a TBI struggle to maintain interpersonal relationships, and social and productive lifestyles. Wood and Yurdakul [17] concluded that out of 131 adults with TBI 49% were either separated, or divorced, from their partners 5-8 years after their injuries. They argued that this was due to the stress and burden placed on their partners and the neurobehavioural symptoms associated with brain injury. This is slightly higher than the national average which reports that 42% of marriages end in divorce [18]. Similar results were found by Kersel, Marsh, Havill and Sleigh [19] who found that 38% of their sample of adults with severe TBI experienced relationship breakdowns at 1 year post-injury. Altered sexual ability may also play a role in the breakdown of intimate relationships after TBI [20].

Evidence also suggests that individuals struggle to return to work following their injuries. Shames, Treger, Ring and Giaquinto [21] revealed that between 12-70% of those with a TBI return to work (RTW) and that greater injury severity and lack of insight predict lower RTW rates. The authors suggest that the complex relationship between pre-morbid characteristics, post-injury factors and personal and environmental factors account for the wide variation in RTW rates following TBI. Research has also suggested that only 30% of individuals with severe TBI return to work in the first two years after injury [22, 19].

Furthermore, individuals find it difficult to maintain friendships following their injuries, which often results in social isolation. Finset, Dynnes, Krogstad and

Berstad [23] found that social networks markedly decline after TBI, with individuals receiving more social support from family than friends. Poor emotional adjustment, and low-functional recovery were associated with reduced levels of support. Similarly, in an exploratory study of friendship and social isolation following TBI Salas, Cassassus, Rowlands, Pimm and Flanagan [24] found that individuals become socially isolated through the loss of old friends, and difficulties creating new friendships. Participants believed that it was the long-term cognitive and behavioural problems associated with their injuries that resulted in isolation. Similar findings were highlighted by Mukherjee, Reis & Heller [25], who found that women with TBI experience social isolation which is partly due to the invisible nature of cognitive difficulties. Difficulties with social integration can be a long-term problem associated with brain injuries, with research highlighting that individuals can present with social difficulties 5 years after injury [26].

Given the difficulties associated with maintaining a social and productive lifestyle following brain injury it is unsurprising that individuals show poorer levels of overall community integration. Corrigan, Smith-knapp and Granger [27] found that community integration levels, as measured by the CIQ were lower than the general population five years post-injury. Similarly, Migliorini, Enticott, Callaway, Moore and Willer [28] found that community-dwelling individuals with TBI and high-support needs were 540 times more likely to report poorer levels of community integration compared with the general population.

### **Cognitive, Behavioural and Emotional consequences of ABI**

Individuals with an ABI may struggle to reintegrate in to the community due to the cognitive, behavioural and emotional consequences of ABI. Literature has suggested that individuals with brain injuries experience clinically significant levels of anxiety, depression and post-traumatic stress disorder following their injuries which is higher than the general population [29]. This may be associated with increased withdrawal and social isolation. Individuals with ABI also present with cognitive problems that may affect their ability to reintegrate in to the community. Milders, Fuchs and Crawford [30] found that compared to the general population individuals with severe brain injuries were impaired at recognising expressions of emotions and social faux-pas. Research has also suggested that compared to the general population those with an ABI show a decreased ability to empathise with others following their injuries [31]. Moreover, research has suggested that individuals with an ABI may exhibit high levels of verbal aggression, inappropriate social behaviors and lack of initiation [32]. Tateno, Jorge and Robinson [33] highlighted that those with an ABI display significantly greater levels of aggressive behaviour than those without a brain injury in the first 6 months after injury. This heightened level of aggression was found to be associated with poorer psychosocial functioning.

### *Predicting Community Integration amongst those with Mental Health and Intellectual Difficulties*

Research has shown that community integration is associated with positive psychological outcomes for individuals despite their difficulties. Numerous studies have successfully identified factors that predict community integration in mental health and Intellectual Disability samples. Specifically, research has shown that residing in supported accommodation [34], and experiencing high



levels of perceived stigma [35], are predictive of poor community integration amongst individuals with Mental Health difficulties. Conversely, a stable home environment [36], choice in living accommodation [37], being female, and an increased sense of community [38] is associated with greater levels of community integration in those with mental health difficulties. Moreover, greater income, access to support services and an increase in daytime activities predict greater community integration in those with intellectual disabilities [39].

### *Recognition of Need for Community Integration after ABI*

There is growing government recognition of the importance of long-term rehabilitation after ABI, including the need to reintegrate individuals into the community. National clinical guidelines for the rehabilitation of individuals following brain injury in the UK highlight the need for services to be planned jointly with health and social services. This includes assisting people with employment, housing, and education provisions following injury [40]. A recent review of clinical practice guidelines on rehabilitation after ABI in twenty countries found that community integration recommendations were made in sixteen of those countries. The main focus centred on making recommendations regarding how individuals can lead a productive life through driving and returning to work [41]. Despite clinical guidelines highlighting the importance of community integration after brain injury, clinicians require information that has ecological validity [8]. Following a review of 30 intervention studies interested in promoting community integration after brain injury, McColl [8] concluded that there was a need for highly individualised and tailored support. Similarly, a more recent review by Tate, Wakim and Genders [42] assessed the efficacy of community-based interventions to improve social and

leisure activities following brain injury. They found limited evidence of effectiveness, and again concluded that interventions need to be more specific. It is therefore crucial that clinicians understand the factors that predict community integration in a brain injury population to help inform targeted and individualised interventions.

A previous review by Reistetter and Abreu [43] assessed whether community integration could be predicted following rehabilitation in a Traumatic Brain Injury (TBI) sample. However, this was not the sole focus of the review, as the authors were also interested in how community integration is best measured, whether social and activity participation effects community integration, and whether community integration affects QoL. Seventeen studies documenting variables that could predict community integration were reviewed. The findings were mixed, and inconsistent with the most prominent variables reported to be injury severity, age, gender, education, premorbid employment, living environment, functional performance, disability, emotional status, and cognition. The review did not report significance values, direction of the relationships between variables or effect sizes. Just one significant finding was often cited as evidence of the predictive value of variables. Moreover, a scoping search of the literature revealed that numerous relevant articles have been published since the review by Tate and Abreu [43]. Given the limitations of the only existing review, the current study aimed to provide a comprehensive and systematic synthesis of the up to date literature focussing purely on the predictors of community integration in people with ABI. This ensures that the focus is on studies whose primary aims were to investigate predictors of community integration.

As a result, the current review aimed to address the following question: *What factors predict community integration following ABI?*

## **Methods and Materials**

### Search Strategy

Between November 2017 and February 2018 electronic databases were searched for relevant literature using the EBSCO host service ([www.ebscohost.com](http://www.ebscohost.com)). The databases were psycINFO, psycARTICLES, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and MEDLINE. These were used to ensure that relevant literature published by psychological, nursing, and other medical professionals was identified. To ensure similar reviews had not been completed, a search for existing systematic literature reviews was also conducted. One review was identified that was published in 2005 by Reistetter and Abreu [43]. One of the four aims of this review was to assess whether community integration could be predicted after rehabilitation for TBI specifically. However, a scoping search of the literature highlighted that numerous relevant studies had been published after 2005 and it was decided that the current review was still necessary to include literature regarding ABI, and to integrate literature published after 2005.

The search terms used were “brain injur\*” or “head injur\*” or “head trauma” or ABI or TBI and communit\* integrat\* or participat\*. Relevant articles that featured these key search terms in their titles, subjects, or abstracts, and met the inclusion criteria, were identified. Search limits were also used to ensure that only peer-reviewed papers published in English were presented. The reference lists of relevant articles were thoroughly searched to identify other relevant

papers for the review (see appendix B for a pictorial representation of the search strategy).

### *Study Selection Criteria*

Initially, during the scoping phase selection criteria were kept broad in order to capture all relevant literature. From the initial scoping search it was apparent that studies included a wide range of populations, including papers focusing specifically on paediatric brain injury, veterans and older adults. Moreover, a limited number of papers included participants who had experienced stroke specifically. As these populations were in the minority of relevant papers, it was decided that they would be excluded to prevent an unrepresentative presentation. However, a wide age-range of 18 to 90 years was included in order to consider factors that affect community integration across the ages. Inclusion and exclusion criteria are detailed below:

#### *Inclusion Criteria:*

- Studies with participants aged 18-90 with a diagnosis of ABI
- Studies with quantitative designs
- Studies written in the English language
- Studies published in peer-reviewed journals

#### *Exclusion Criteria:*

- Studies that only describe the pattern of community integration rather than investigating the factors that affect it
- Intervention studies
- Studies with participants who have additional physical, developmental or intellectual difficulties
- Dissertations, individual case-studies literature reviews and other non-empirical papers
- Studies specifically referring to stroke, children, older adults or veterans. Stroke was excluded as the demographic of people that experience strokes are usually older adults compared to other forms of injury such as traumatic brain injury that occur more frequently in younger adults. Those who suffer a stroke may therefore have very different experiences of community integration and this may affect the findings. Moreover, during the scoping search only a handful of studies included participants who had experienced a stroke specifically and so it was decided to exclude these studies. Thus making the literature review quite specific to TBI.

### *Search Outcome*

A total of 2,294 articles were retrieved using the 4 databases. After applying search limiters to exclude those not peer-reviewed or written in English 1,863 papers remained. Following the removal of duplicate literature 1,407 articles were left for further analysis. After reviewing the titles, 49 articles were identified for full text exploration. A thorough search of the reference lists highlighted a

further 3 papers which met the inclusion criteria meaning a total of 52 papers were read and assessed against the inclusion and exclusion criteria. This resulted in 30 papers been excluded. The majority of excluded studies did not meet the inclusion criteria because they were intervention studies concerned with improving community integration levels after brain injury. A total of 22 papers published between 1994 and 2018 were included in the review. Only directly relevant findings are reported in this review due to the large number of outcomes explored in many of the studies. Please see Figure 1 for a diagrammatic representation of the article selection process.

#### *Data Extraction and Quality Assessment*

Relevant information including the design, participant characteristics, community integration measures used, and relevant findings were extracted using a bespoke data extraction form (See appendix C) and reported in Table 1.

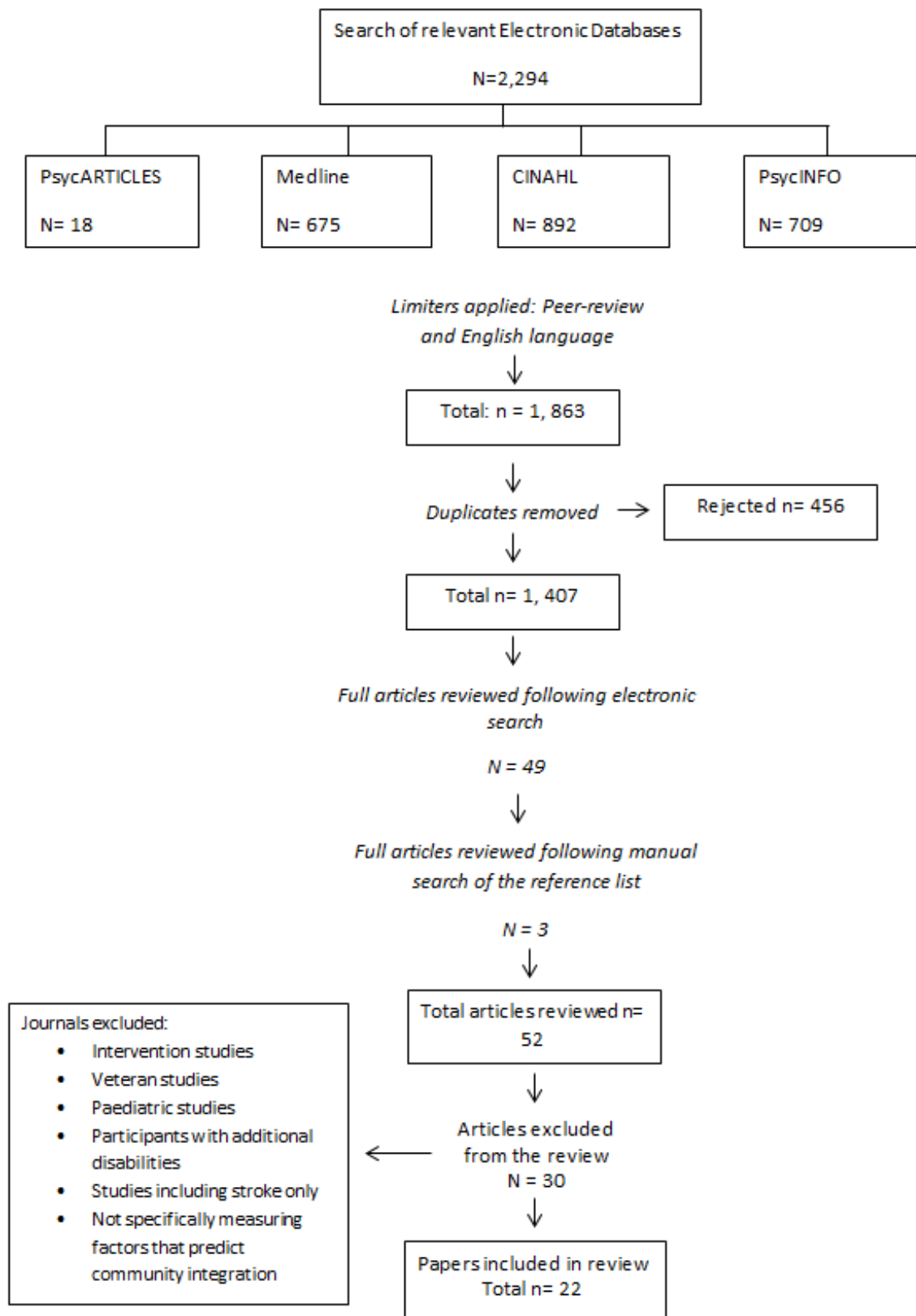
A quality assessment was undertaken on all included articles. Poor quality ratings did not result in the exclusion of papers from the review. However, it provided a measure of the reliability and validity of their findings. There was no standard quality checklist deemed appropriate for the assessment of studies in this review. Therefore, a tailor made checklist was created by the first author, incorporating elements of both the Downs and Black checklist, and the National Institute for Clinical Excellence (NICE) checklist for correlational studies. The employed checklist (See Appendix D) consisted of 28 items with particular consideration given to items deemed appropriate to assess cohort studies, and longitudinal research designs. Studies were given a score of one on each item if they adequately met the criterion. Items could be left blank if they were deemed

inappropriate for the study. These items were also excluded from the percentage calculations in order to enable direct comparisons of the studies.

### *Data Synthesis*

A narrative synthesis was used to summarise the findings from the studies, and to report themes within the literature. Due to a lack of relevant information and diversity of variables reported statistical methods of data synthesis was inappropriate. Instead, a narrative account is presented to provide a comprehensive summary of the literature. This involved combining and integrating findings in order to generate new perspectives and highlight commonalities and differences within the literature [44].

Figure 1. A diagrammatic representation of the article selection process





## Results

### *Methodological Quality*

The methodological quality of the included studies was assessed by the first author. Studies ranged widely in quality from 35% [45] to 89% [46]. Millis et al [35] had the lowest quality rating due to lacking relevant information such as clearly defined aims, sample method, participant demographics and data analysis strategy. Furthermore, the study had a small sample size, and did not report on length of time post-injury. Contrastingly, Hart et al [46] obtained the highest quality rating, adopting an extensive longitudinal design with a clear rationale that used suitable measures, and considered numerous explanatory variables. A sub-set of papers were checked by a peer-researcher to ensure inter-rater reliability, and any differences in scores were discussed until a consensus was reached.

Overall, studies differed in terms of sample size, explanatory variables been considered, and community integration measures used. Generally, studies included a clear rationale for their research with relevant aims and a good overview of the literature. The majority of papers also included a range of participant demographic characteristics, a clearly outlined procedure, including data collection and statistical analysis with clear and relevant findings. Table 1 shows the overall methodological quality rating for including studies.

## ***Overview of Included Studies***

### *Sample Characteristics*

Table 1 provides an overview of the reviewed studies. Twenty of the studies included participants who had experienced a mild, moderate, or severe TBI only. Perry Woollard, Little and Shroyer [47] was the only study to include those with other types of acquired brain injury as well as traumatic brain injury. Six papers did not specify the severity of the injury. Time post-injury of the participants ranged from an average of 1 month to 8 years. Sample sizes of the studies ranged considerably from 23 to 504 participants. The vast majority of papers included both male and female participants with brain injuries although one study did not report the gender of participants [48]. The vast majority of studies included more male than female participants. This is in keeping with the prevalence rates of traumatic brain injury that suggest that more men experience TBI than women [49, 50]. Study samples consisted of working age participants with average ages ranging from 31 to 49. One study did not report the participant's age [51]. Studies were mostly conducted in the USA and Australia.

### *Study Design*

All of the 22 studies were quantitative with observational study designs. Of these 22, 6 were prospective cohort designs, 5 used a retrospective cohort design, 7 were cross-sectional and 3 were longitudinal.

### *Community Integration Measures*

As there is no widely agreed definition of community integration, a wide range of measures were used in the studies. However, the majority of studies (n=13) used the Community Integration Questionnaire [52]. Two studies used the Participation Assessment with Recombined Tools-Objective [PART-O; 53] One study used the Sydney Psychosocial Reintegration Scale [SPRS; 54] One study used the Reintegration to Normal Living index [RNLI; 55]. Four studies used more than one measure of community integration. Rapport et al [48] and Rapport, Bryer and Hanks [56] both used the Community Integration Measure [CIM; 57] and Craig Handicap Assessment and Reporting Technique [CHART; 58]. Sander et al [59] and Winkler, Unsworth and Sloan [60] both used three measures of community integration in their studies (CIQ, CIM, CHART & CIQ, CIM, SPRS).

### *Main Themes*

An 'inside-out' approach will be used to discuss the main themes of this review. Firstly 'inside' factors will be explored including: participant characteristics, psychological factors and injury characteristics. The wider 'outside' context of environmental factors will also then be explored.

Table 1. Summary of included papers and their findings

Study (Year) Location	Design	Sample size	Type and severity of BI	Time post-injury CI assessed	CI measure	Predictor variables (measures)	Key findings (effects size) (cc= correlation coefficient)	Quality ratings
<b>Andelic et al.(2016)</b> Norway	Longitudinal study	105	Moderate/severe TBI	1, 2, 5 years	CIQ	<b>Demographic factors:</b> Gender age, education level, marital status, employment status <b>Injury characteristics:</b> GCS, LOS, injury severity, cause of injury, CT scan, time since injury <b>Pre-injury characteristics:</b> Pre-injury employment status	Being single at time of injury p<0.001, higher level of education p<0.01, being employed at time of injury p<0.001, shorter length of PTA p<0.001, longer time post-injury P<0.001.	88%
<b>Doig et al. (2001)</b> Australia.	Retrospective cohort	208	TBI (severity NS)	3.5 years (mean)	CIQ	<b>Demographic factors:</b> Age, Education level, <b>Injury characteristics:</b> LOS, GCS. Disability level <b>Post-injury factors:</b> RTW	Lower CIQ scores were predicted by older age p<0.01 n <sup>2</sup> = 0.049, lower DRS scores on discharge p<0.001 n <sup>2</sup> =0.116 and longer length of acute stay in hospital p<0.01 n <sup>2</sup> =0.053.	81%
<b>Fleming et al. (2014)</b> Australia	Longitudinal Study	135	Mild/moderate-extremely severe TBI	1, 3, 6 months	SPRS	<b>Injury characteristics:</b> LOS, Disability level (MPAI-4) <b>External Factors:</b> Environmental barriers (CHIEF)	Longer acute hospital stay (LOS p<.001 -24), greater impairments (MPAI-4 p<.001, CC = -60) and increased environmental barriers (CHIEF p<.001, CC = -23) were associated with poorer CI	84%

<b>Fleming et al. (1999)</b> Australia	Retrospective cohort	208	Mild/moderate-extremely severe TBI	3.5 years (mean)	CIQ	<p><b>Demographic factors:</b> Gender age, education level, employment status</p> <p><b>Injury characteristics:</b> PTA, LOS, GCS. Injury severity, Disability level (DRS)</p> <p><b>Cognition (BRISC, LGPT)</b></p> <p><b>Post-injury factors:</b> ADL (MBI), Return to work</p> <p><b>Pre-injury factors:</b> Pre-injury employment status</p>	Higher levels of community integration were predicted by younger age (p=0.001), shorter duration of PTA (p=0.05) and length of stay in acute care (acute LOS p=0.05), lower disability rating (DRS total p<0.01), higher ADL ability (MBI p=0.05) and higher cognitive ability (BRISC p=0.05).	77%
<b>Gerber et al. (2016)</b> Canada	Prospective cohort	63	Mild, moderate and severe TBI	4 years (mean)	CIQ	<p><b>Demographic factors:</b> age</p> <p><b>Cognition:</b> RAI-HC</p> <p><b>Post-injury factors:</b> ADL (RAI-HC)</p> <p><b>Psychological factors:</b> QoL (QOLIBRI), QoL and functioning (RAI-HC)</p> <p><b>Injury Characteristics:</b> Disability level (DRS)</p>	Higher levels of CI were predicted by higher cognitive ability (p=0.000 rho=0.513), lower level of disability at follow-up (DRS total: p<0.000 rho=0.683) and better ability to perform ADL (ADL: p<0.001 rho=-0.505)	88%
<b>Hart et al. (2005)</b> USA	Longitudinal study	94	Moderate to Severe TBI	>6 months & 1 year	CIQ	<p><b>Demographic factors:</b> Ethnicity</p> <p><b>Psychological factors:</b> Life Satisfaction (SWLS), Affective state</p>	White participants had significantly higher scores than African Americans participants on the CIQ social integration scale only (p<0.01).	89%

<b>Juengst et al. (2014).</b> USA	Retrospective cohort	64	Complicated mild Moderate severe TBI	>6 months	PART-O	<p><b>Psychological factors:</b> Satisfaction with participation (PART-S), Positive and negative affect (PANAS), self-awareness</p> <p><b>Injury Characteristics:</b> Injury severity, time since injury</p>	Higher satisfaction with participation (PART-S: $p < .001$ .438), Positive emotions (PANAS: $p < .001$ , $CC = .372$ ), better awareness (SRSI: $p < .01$ , $CC = -.277$ ) and higher cognitive ability (cognition composite score: $p < .01$ ) predicted better community integration.	77%
<b>Kim et al. (2013)</b> Canada	Retrospective cohort	243 (TBI from physical assault: 24)	TBI (severity NS)	3-6 months	RNLI	<p><b>Demographic factors:</b> Gender, age, employment status, living status, comorbidities</p> <p><b>Injury Characteristics:</b> LOS, use of rehab services, cause of injury, Hospital discharge destinations</p> <p><b>External factors:</b> Urban/rural living</p> <p><b>Cognition:</b> Motor independence (FIM), cognitive independence (FIM)</p> <p><b>Pre-injury factors:</b> Substance misuse</p>	Higher levels of community integration was associated with younger age ( $p < 0.05$ ) fewer comorbidities ( $p < 0.01$ ), not been admitted to rehabilitation services ( $p < 0.01$ ), Being employed prior to injury ( $p < 0.01$ ), no history of drug or alcohol abuse ( $p < 0.01$ ), being discharged home after acute-care ( $p < 0.01$ ) and unintentional versus intentional cause of injury ( $p < 0.05$ ).	67%

<b>Linden et al. (2005)</b> Northern Ireland	Cross-sectional	30	TBI (severity NS)	6 years	CIQ	<b>Demographic factors:</b> Gender	Female controls were more integrated into their communities than males with brain injuries ( $p < 0.05$ ).	67%
<b>Mahalik et al. (2007)</b> Columbia	Cross-sectional	26	TBI (severity NS)	41 months	CIQ	<b>Demographic factors:</b> Spirituality (INSPIRIT) <b>Psychological factors:</b> psychological coping (WAYYS)	No significant relationship between spirituality or coping and community integration.	77%
<b>Millis et al. (1994)</b> USA	Prospective cohort	23	Moderate to severe TBI	1 year	CIQ	<b>Cognition:</b> Neuropsychological measures (BVFD; WCST; WMS-R; LGPT; RAVLT; Trails A&B)	Higher CIQ score was predicted by higher scores on the Rey Auditory Verbal Learning Test ( $p < .05$ , $CC = .51$ ) and Trails B test ( $p < .05$ , $CC = -.52$ ).	35%
<b>Perry et al. (2014)</b> USA	Cross-sectional	34	ABI (severity NS)	52 months	CIQ	<b>Demographic factors:</b> age <b>Injury factors:</b> Time post injury <b>Cognition:</b> Balance and Gait (DGI; CBMS & TMWT)	No significant correlations were found between measures of balance and gait and CIQ total score. However, higher CIQ productivity scale scores were predicted by better gait (DGI; $p < .05$ 0.38), gait speed ( $p < .05$ 0.52), balance and mobility (CBMS; $p < .05$ 0.47). Older age also predicted lower CIQ productivity scale scores ( $p < .05$ - 0.53).	73%

<b>Poritz et al. (2018)</b> USA	Cross-sectional	504	Intubated – severe TBI	6.2 years	PART-O	<b>Psychological factors:</b> perceived stigma	Higher levels of perceived stigma predicted lower community integration (p<0.05).	73%
<b>Rappport et al. (2008)</b> USA	Retrospective cohort	261	Mild, moderate & severe TBI	5.2 years	CIM CHART	<b>Demographic factors:</b> age <b>External factors:</b> Social support <b>Injury factors:</b> GCS <b>Post-injury factors:</b> Driving status (DS; BDQ) <b>Psychological factors:</b> affective state	Drivers were significantly more integrated than non-drivers as shown on the CHART subscales: Social Integration (p=.009 n2=.04), Occupation (p<.001 n2=.14), Social Mobility (p<.001 n2=.10).	85%
<b>Rappport et al. (2006)</b> USA	Cross-sectional	51	Mild, moderate & severe TBI	8.8 years	CHART CIM	<b>Demographic factors:</b> GCS, age <b>Psychological factors:</b> Perceived social support (SPS), Negative affect (PANAS) <b>Post-injury factors:</b> Driving status, Use of alternative transport, Barriers to driving (BDQ)	Drivers were better integrated than non-drivers on the CHART Social mobility (p=.002 n2= 0.18) and Occupation (p<.001 n2=30). Fewer perceived barriers to driving (BDQ) also showed a significant and moderate correlation with higher CIM total scores (p<0.001 0.14), CHART Mobility (p<0.05 0.09) and CHART Occupation subscales (p<0.05 0.10).	85%
<b>Rath et al. (2003)</b> USA	Cross-sectional	60	Mild, moderate & severe TBI	3.6 years	CIQ	<b>Demographic factors:</b> Age, education level <b>Cognition:</b> Problem solving ability (WCST), Social problem solving performance (PPSS)	Worse self-appraisal of Social Problem Solving ability was significantly associated with lower CIQ scores (PSI; p<0.05). The Problem Solving Confidence subscale had the strongest	82%



						<b>Psychological factors:</b> Social problem solving self-appraisal (PSI)	correlation with CIQ total scores (p<0.01 -.53).	
<b>Rosenthal et al. (1996)</b> USA	Prospective cohort study	302	TBI (severity NS)		CIQ	<b>Demographic factors:</b> Race/ethnicity, age, Income <b>Injury-related factors:</b> PTA, Disability level <b>Post-injury factors:</b> Substance misuse <b>External factors:</b> Family income	Minority status (p<.001), older age at time of injury (p<0.001), Family income (p<0.05), premorbid alcohol use (p<0.05), premorbid drug abuse (p<0.01) and disability level (DRS: p<0.001) predicted lower CIQ total score.	78%
<b>Sander et al. (2009)</b> USA	Prospective cohort study	151	Mild, moderate & severe TBI	6 months	CIQ CIM CHART	<b>Demographic factors:</b> Age, gender, education level, Race/ethnicity, Income <b>Injury-related factors:</b> GCS	After controlling for age, education, injury severity and income there was a SS difference among racial/ethnic groups on CIQ total (p<0.05) White participants had greater CIQ scores compared to black participants (p<0.01 r=0.22). People with less than high school education (p<0.01 0.19) and more severe injuries (p<0.05 r=0.18) also had lower scores.	78%

<b>Sandhaug et al. (2015)</b> Norway	Prospective cohort study	57	Moderate and severe TBI	2 years	CIQ	<b>Demographic factors:</b> Marital status <b>Injury-related factors:</b> PTA, LOS, use of rehab services, GCS, injury severity	Living with a spouse (p<0.01), use of rehabilitation services (p<0.001), lower GCS score (p<0.05), shorter PTA (p<0.001), and longer length of acute hospital stay (p<0.01) predicted better community integration.	77%
<b>Willemse-van Son et al. (2009)</b> The Netherlands	Longitudinal	119	Moderate to severe TBI	3, 2, 12, 18, 24, 36 months	CIQ	<b>Demographic characteristics:</b> Gender, age, education level, ethnicity <b>Injury-related factors:</b> GCS, LOS, cause of injury, pre-injury hospital discharge destination, Hypoxia/hypertension/hypothermia, CT scan <b>Pre-injury factors:</b> Pre-injury community integration, pre-injury living status, pre-injury employment status <b>Post-injury factors:</b> ADL (BI) <b>Cognition:</b> Functional independence (Motor: FIM, Cognition: FAM)	Older age (p<0.01), low premorbid community integration (p<0.01), being discharged to inpatient rehabilitation services or a nursing home (p<0.05) and less ability to perform ADL (p<0.01) all predicted lower community integration scores.	96%
<b>Wagner et al (2000)</b> USA	Prospective cohort	120	Mild, moderate & severe TBI	1 year (mean)		<b>Demographic factors:</b> Gender, age, ethnicity, education level <b>Premorbid factors:</b> employment, drug and	Minority status (p<0.05), violent mechanism of injury (p<0.01), premorbid disability (p<0.05) and psychiatric diagnosis (p<0.05), premorbid drug and alcohol use (p<0.05), education level less	

<b>Winkler et al. (2006)</b> Australia	Cross-sectional	40	Very severe to extremely severe TBI	8.8 years	CIQ CIM SPRS	alcohol use, disability, psychiatric disease <b>Injury factors:</b> Mechanism of injury, GCS,  <b>Demographic factors:</b> Age, education level <b>Injury-related factors:</b> PTA, LOS, income <b>Pre-injury characteristics:</b> pre-injury community integration, pre-injury productivity, pre-morbid intelligence (NART) <b>External factors:</b> social support (MOS-SSS) <b>Post-injury factors:</b> Behaviour (CBS), Level of disability (LDSQ)	than high school (p<0.001), and premorbid unemployment (p<0.05) were predictors of lowers community integration at 1-year post-injury. Older age (p<0.05), longer PTA (p<0.01), higher disability levels (p<0.001) and loss of emotional control (p<0.05) all predicted lower levels of community integration.	81%
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CIQ: Community Integration Questionnaire [52], GCS: Glasgow Coma Scale, LOS: Length of Stay, CT: Computerised Tomography, RTW: Return to Work, MPAI-4: Mayo Portland Adaptability Inventory 4 [61], SPRS: Sydney Psychosocial Reintegration Scale [54], CHIEF: Craig Hospital Inventory of Environmental Factors [62], PTA: Post-Traumatic Amnesia, DRS: Disability Rating Scale [63], BRISC: Barry Rehabilitation Inpatient Screening of Cognition [64], LGPT: Lafayette Grooved Pegboard Test [65], ADL: Activities of Daily Living, MBI: Modified Barthel Index [66], RAI-HC: Resident Assessment Instrument, Home Care [67], QoL: Quality of Life, QOLIBRI: Quality of Life in Brain Injury [68], SWLS: The Satisfaction With Life Scale [69], PART-O; Participation Assessment of Recombined Tools, Objective [53], PART-S: Participation Assessment of Recombined Tools, Subjective [70], PANAS: Positive and Negative Affect Schedule [71], RNLI: Reintegration to Normal Living Index [55], FIM: Functional Independence Measure [72], INSPIRIT: Index of Core Spiritual

Experiences [73], WAYYS: Ways of Coping Scale [74], BVFDT: Benton Visual Form Discrimination Test [75], WCST: Wisconsin Card Sorting Task [76], WMS: Weschler Memory Scale [77], RAVLT: Rey Auditory Verbal Learning Test [78], Trails A & B [79], DGI: Dynamic Gait Index [80], CBMS: The Community Balance and Mobility Scale [81], TMWT: Ten Metre Walk Test [82], CIM: Community Integration Questionnaire [57], CHART: The Craig handicap assessment and reporting technique [58], DS: Driving Status, BDQ: Barriers to Driving Questionnaire [83], SPS: Social Provision Scale [84], PPSS: The Personal Problem-Solving System [85], PSI: The Problem-Solving Inventory [86], BI: Barthel Index [87], FAM: Functional Assessment Measure [88], NART: National Adult Reading Test [89], MOS-SSS: Medical Outcome Study- Social Support Survey [90], CBS: Current Behaviour Scale [91], LDSQ: The Lambeth Disability Screening Questionnaire [92].

## Findings

### ***Patient Characteristics***

*Age at injury:* Out of five studies assessing age at injury four consistently found that older age at the time of injury predicted lower levels of community integration on the CIQ. Doig, Fleming and Tooth [93] found that older age predicted lower levels of community integration. Using cluster analysis, the data was divided into subsets based on levels of CI; working group (n=78), balanced group (n=46), and poorly integrated group (n=84). The poorly integrated group was, on average, 6.5 years older than the working group. However, this relationship was weak ( $n^2=0.049$ ). Similarly, Winkler et al [60] divided their sample into two groups, 'High CI group' (n=22) and 'Low CI group' (n=18), and found that worse community integration was associated with older age. Rosenthal et al [51] also found older age to be a major determinant of predicting lower levels of community integration on CIQ total scores, and each of the CIQ subscales. Moreover, Willemse-van Son, Ribbers, Hop and Stam [94] found that older age predicted lower levels of community integration on the CIQ at 36 months post injury. Although there seems to be reliable evidence of the effect of age at injury, Doig et al [93] was the only study to report the size of effect and as a result, it is not clear whether the relationship was consistently weak across studies.

*Age at Follow-up:* Out of six studies assessing the effect of age at follow-up, four found significant but inconsistent effects. Fleming et al [95] found that of the demographic variables age, years of education, gender, and occupational status, age was the only variable to uniquely contribute to the prediction of CIQ

total score as well as scores on the social integration and productivity subscales. Older participants were more likely to have lower levels of overall community integration, social integration and productivity than younger persons. This finding was replicated by Kim et al [96], who found that older age at the time of follow-up was significantly related to lower RNLI scores. However, the correlation between age and total RNLI score was weak. Perry et al [47] found that older age at follow-up was a significant predictor of lower community integration on the productivity subscale of the CIQ, but not the CIQ Total, Home or Social subscales. The authors suggested that this may be due to younger participants receiving more support than older people to be productive members of the community, and re-enter education/past vocations. Contrastingly, Sander et al [59] found that older age at follow-up was associated with higher levels of community integration on the CHART-SF Occupation Scale. Thus, suggesting that older participants had greater levels of participation in work, school, household repairs and hobbies. This difference in findings highlights the complexity of the relationship between age and levels of community integration. It may also highlight the lack of consensus between defining older age in the literature.

*Education:* Out of eight studies that assessed the relationship between level of education and community integration, four found a significant relationship. Andelic et al [97] found that having a higher level of education (more than 12 years in education) was associated with better community integration over the three time points (1, 2 and 5 years) than those with a lower level (less than 12 years in education). Likewise, Sander et al [59], Rath, Hennessy and Diller [98] and Wagner, Hammond, Sasser, Wiercisiewski and Norton [99] found that less than a high school education was predictive of lower levels of community

integration. The correlation between education and CI levels varied from small to moderate.

*Ethnicity:* Four studies found a significant relationship between ethnicity and community integration, with non-minority consistently being found to show better community integration than those with minority status. Hart et al [46] found white participants to have better social integration than African Americans at 1-year follow up. Rosenthal et al [51] also found that minority status predicted lower levels of community integration on the CIQ total score, Productivity and Social Integration subscales. Similarly, Sander et al [59] found that white participants had greater levels of community integration compared to black and Hispanic participants. Black participants also had lower scores than Hispanics on the Productivity subscale. Moreover, Wagner et al [99] found that minority status was predictive of lower community integration levels when compared to non-minority status on the CIQ total score. The correlations between ethnicity status and community integration were weak.

*Employment and Income:* Three out of five studies found a significant but weak correlation between being employed prior to injury, and higher levels of community integration as measured by the CIQ [97, 99], and RNLI total and Daily Functioning subscales [96]. Additionally, three studies explored the relationship between income and levels of community integration. One study found a non-significant relationship between pre-injury income and community integration [60]. Two studies found a significant relationship between income at follow-up and levels of community integration. Rosenthal et al [51] found that annual family income at 1-year post injury was a significant determinant of community integration. Higher family income was associated with better

integration on the CIQ total score, Productivity and Social Integration subscales. Sander et al [59] examined the relationship between personal annual income and community integration using the CIQ, CHART-SF and CIM in an ethnically diverse sample. They found that higher personal income was associated with increased community integration on the CIQ Social Integration Scale, CHART-SF Social Integration subscale, CHART-SF Mobility subscale, total CIM score as well as the CIM Belonging and CIM Independent Participation Scale.

*Gender:* Out of six studies only two found an effect of gender of community integration levels. Willemse-van Son et al [94] found that males had significantly lower community integration levels than females in a TBI population, as measured by the CIQ. Linden, Crothers, O'Neill and Mccann [100] found a statistically significant difference between female controls and a TBI population on levels of community integration as measured by the CIM. Female controls were more integrated into the community than brain injured individuals.

*Comorbidities:* Kim et al [96] found a significant relationship between number of comorbidities at 6 month follow-up and levels of community integration. Fewer comorbidities were associated with higher scores on the RNLI total and Daily Functioning subscale. Moreover Wagner et al [99] found that premorbid disability and psychiatric illness was predictive of lower levels of community integration at 1 year post-injury.

*Civil Partnership Status/Living Status:* Three studies assessed the relationship between civil partnership status/living status, and levels of community integration. All three studies found significant, but inconsistent, results in moderate to severe TBI populations using the same measure of CI (CIQ).



Andelic et al [97] assessed the levels of community integration across three time points: one, two and five years after TBI. A hierarchical linear model found that participants who had a partner at the time of the injury had lower community integration scores over time than those who had been single. Moreover, Willemse-van Son et al [94] found that those living with a partner or parent prior to the injury had lower levels of community integration at 36 month post-injury. Contrastingly, Sandhaug, Andelic, Langhammer and Mygland [101] found that living with a spouse 2 years post-injury was associated with higher levels of community integration.

*Substance Misuse:* Two studies found that both premorbid drug and alcohol use were predictive of lower levels of community integration on the RNLI [96, 99]. Post-injury alcohol and drug misuse was also found to be associated with lower scores on the CIQ total, and all three subscales [51].

*Pre-injury Community Integration:* Willemse-van Son et al [94] found that lower levels of pre-injury community integration predicted lower levels of community integration at 36 months post-injury. However, Winkler et al [60] found no relationship between pre-injury and post-injury community integration.

## **Psychological factors**

*Quality of Life:* Gerber, Gargaro and McMackin [102] found a moderate correlation between quality of life and autonomy on the QOLIBRI, and greater community integration.

*Satisfaction and Affect:* Juengst, Arenth, Raina, McCue and Skidmore [103] found that satisfaction with participation, as measured by the PART-S, was

moderately correlated to greater community integration. Moreover, they found a weak correlation between positive affect (interest, energy and pride) and greater community integration.

*Perceived Stigma:* Poritz et al [104] found that increased perceived stigma predicts worse community integration.

*Problem Solving Self-appraisal:* Rath et al [98] found that worse self-appraisal of social problem solving ability was significantly related to worse community integration. Confidence in problem-solving ability was the strongest correlate of community integration with a moderate relationship.

### **Injury Characteristics**

*Post-Traumatic Amnesia (PTA):* Five studies assessed the relationship between length of PTA and integration levels. They consistently found that shorter length of PTA was associated with better community integration. Andelic et al [97] found that having a shorter length of PTA was associated with better community integration over three time points (1, 2 and 5 years) than those with longer PTA. Doig et al [93] found that the poorly integrated group had a significantly longer duration of PTA (>30 days) than both the balanced and working groups. However, the size of effect was small. Similarly, Sandhaug et al [101], Winkler et al [60] and Fleming et al [95] also found that a shorter length of PTA predicted higher community integration.

### *Level of Disability*

*At Inpatient Rehabilitation Discharge:* Three studies consistently found that higher levels of disability (as measured by the Disability Rating Scale) following discharge from rehabilitation services predicted lower levels of community integration. Doig et al [103] found that the poorly integrated group had significantly higher DRS scores than the balanced and working groups. Rosenthal et al [51] found that the DRS predicted lower scores on the CIQ total, and each of the three CIQ subscales (productivity, social integration and home integration). Whereas, Fleming et al [95] found that level of disability was a significant predictor on the CIQ total score, Home Integration and Social Integration subscales.

*At Follow-up:* Three studies found moderate to strong correlations between level of disability at follow-up and community integration. Gerber et al [102] found that DRS was strongly correlated with CIQ total score and moderately correlated with each of the CIQ sub-scales at 4 year follow-up. Winkler et al [60] found that individuals in the low integration group had higher ratings of disability on the LDSQ. Similarly, Fleming, Nalder, Alves-Stein and Cornwell [105] found a moderate correlation between higher disability rating on the MPAI-4, and lower community integration at 6-month follow-up.

### *Length of Stay*

Out of seven studies, six found significant relationships between LOS in hospital/rehabilitation services, and community integration [103, 105, 95, 101, 94, 96]

*Length of Acute Hospital Stay:* Three studies found a consistent, yet weak, relationship between longer length of acute hospital stay, and worse community

integration. Doig et al [103] found that participants in the poorly integrated group had significantly longer hospital LOS than the balanced and working groups. Moreover, Fleming et al [105] found that longer LOS predicted lower community integration on the SPRS total. Fleming et al [95] found inconsistent results that longer hospital stay predicted lower levels of community integration on the CIQ total and Home integration subscales only.

*Discharge Destination/Length of Rehabilitation Stay:* Three studies found inconsistent results regarding the relationship between discharge destination/LOS in inpatient rehabilitation and community integration. Sandhaug et al [101] found that accessing rehabilitation services, and a longer stay in rehabilitation, predicted better community integration. Willemse-van Son et al [94] found that being discharged from hospital to inpatient rehabilitation, or a nursing home, predicted lower levels of community integration than being discharged home at 36 months post-injury. This could be due to the fact that those with more severe injuries are discharged to rehabilitation services instead of home, and the severity of their injuries negatively effects community integration. Kim et al [96] found that shorter duration of rehabilitation was associated with better community integration but this finding became not significant when entered in to the final regression model.

*Glasgow Coma Scale:* Out of seven studies that evaluated the relationship between GCS score and community integration, three found significant results. Sandhaug et al [101] and Wagner et al [99] found that lower Glasgow coma scale scores in the acute phase predicted worse levels of community integration at one and two years post-injury on the CIQ. Sander et al [59] also found that those with lower GCS scores in the acute phase had significantly worse levels

of community integration than those with lower scores on the CIQ total, CIQ productivity subscale, and CHART-SF Occupation subscale.

**Revised Trauma Score (RTS) and Trauma and Injury Severity Score (TRISS):** Wagner et al [99] found a significant relationship between the RTS and TRISS score in the acute-phase and CIQ score 1 year post-injury but the relationships between the variables were weak.

**Activities of Daily Living:** Gerber et al [102] found a moderate to strong relationship between ability to perform Activities of Daily living and increased CIQ total score. Moreover, Willemse-van Son et al [94] found that increased dependence on others for ADL at hospital discharge predicted lower community integration levels at 36 months post-injury.

**Balance and Gait:** Perry et al [47] found a significant, yet weak, relationship between balance/gait and the CIQ productivity subscale, suggesting that difficulties with walking/balancing has a negative effect on levels of productivity in the community, but not on home or social integration.

**Cause of Injury:** Out of four studies that considered the relationship between cause of injury and community integration, two found significant results. Kim et al [96] assessed the relationship between unintentional and intentional (caused by physical assault) TBI. They found that those in the intentional TBI group had significantly lower levels of community integration on the RNLI total and Daily Functioning subscales. Rosenthal et al [51] found less consistent results that those who sustained their TBI through violent injury had significantly lower community integration on the CIQ productivity subscale than did those who sustained their injury through a vehicle related incident, a fall, or other injury.

*Time Post-injury:* Andelic et al [97] found that greater time post-injury was moderately correlated with greater levels of community integration. Community integration improved over one, two and five years post-injury.

*Cognitive Factors:* Four studies assessed the relationship between cognitive ability at follow-up, and community integration. Gerber et al [102] used the RAI-HC to obtain interviewer ratings of memory and cognitive skills. They found a weak to moderate correlation between better cognitive ability, and higher community integration on the CIQ total score and each of the CIQ subscales. Juengst et al [103] found a weak correlation between better cognition at follow-up and higher levels of community integration. Millis et al [45] found a positive moderate relationship between two tests of speed, flexibility, memory, and attention, and CIQ total score at one year post injury. Fleming et al [95] evaluated the relationship between cognitive ability at rehabilitation discharge and community integration. They found that higher cognitive abilities predicted better community integration on the CIQ total, social integration and productivity subscales at 3.5 years post-injury.

*Challenging Behaviour:* Winkler et al [60] found that increased loss of emotional control as measured on the Challenging Behaviour Scale predicted lower levels of community integration on the CIM, CIQ and SPRS combined.

## **Environmental Factors**

*Environmental Barriers:* Fleming et al [105] found that environmental barriers measured by the CHIEF had a weak negative correlation with levels of community integration on the SPRS. Specifically, the physical barriers subscale of the CHIEF was a significant, yet weak, predictor of SPRS total score, and the

four SPRS subscales: Work, Leisure, Relationships and Independent Living Skills. Thus, suggesting that environmental barriers, mainly physical barriers have a detrimental effect on productivity, relationships, and independent living.

*Driving:* Rapport et al [48] found that drivers were significantly more integrated than non-drivers on the CHART-SF Mobility and Occupation subscales. Perceived barriers to driving were also moderately correlated to total CIM score, CHART-SF Mobility and Occupation subscales. Similarly, Rapport et al [56] found that non-drivers had lower levels of community integration on each of the CHART subscales after controlling for injury severity, social support, negative affectivity, and use of alternative transport. They found a large correlation between driving status and occupation. Thus, indicating that both driving status, and perceived barriers to driving, has a detrimental effect on integration, productivity, and mobility.

## **Summary**

Studies in this review varied significantly in terms of study quality, sample sizes, time post-injury, and injury severity. A wide range of factors affecting community integration were considered. Results were inconsistent, and numerous studies did not report effect sizes so the strength of the relationships between predictor and outcome variables were unclear. Several variables showed a strong relationship with an individual's level of community integration, including the age of an individual, their ethnicity and the severity of their injury.

## **Discussion**

The aim of this review was to conduct a thorough systematic literature review of studies that investigated the relationship between individuals with an ABI, and levels of community integration, and to explore factors associated with community integration.

The review highlighted a wide range of factors that affect community integration, although, for the majority of factors the results were inconsistent, with weak correlations. The reviewed studies varied considerably in terms of their sample sizes, severity of brain injury, and time-post injury. Findings from the review must therefore be considered with caution, especially when attempting to generalise findings to the wider population. The majority of studies assessed the relationship between patient and injury characteristics when predicting levels of community integration. A small number of studies considered psychological and external factors. The vast amount of factors considered within this review highlights the sheer complexity of the relationship between numerous variables and community integration. Unfortunately, due to many of the studies adopting cross-sectional designs, cause and effect between the variables could not be established. The majority of findings were inconclusive across the four domains, replicating the findings of Reistetter and Abreu [43]. However, the review provided a rich information source and interesting points for discussion. Specifically, the review highlighted age, ethnicity and level of disability as factors to consider when predicting community integration.

### *Age*



Several studies found a relationship between older age and lower levels of community integration. This finding supports previous literature which has demonstrated an increased risk of negative outcomes following brain injury for older adults compared to younger adults. Goleburn, Golden and Goleburn [106] reviewed eighteen studies that assessed outcomes after TBI. They found that older adults had higher mortality rates, a decreased likelihood of returning home, and declines in cognitive and affective functioning post-injury. Negative outcomes, including reduced community integration, following TBI in older adults could be due to multiple factors. Firstly, it may be harder for older adults to engage in productive occupations following injury. Senathi-Raja, Ponsford and Schonberger [107] studied 112 participants with mild to severe TBI. They found that older participants exhibited higher rates of unemployment following injury than younger participants. Moreover, research has suggested that older individuals are at higher risk of functional [108] and cognitive decline [109] after injury. Increased functional decline could be due to older adults experiencing worse health problems post TBI. Breed, Flanagan and Watson [110] found that individuals over the age of 55 experienced worse health symptoms including headaches and joint pain than both younger participants with TBI and age-matched controls.

However, previous literature has also demonstrated negative psychosocial outcomes in older adults without brain injury. Pinto and Neri [111] found that out of thirty-one studies assessing patterns of social participation in old age, twenty-one found a reduction in social engagement. Similarly, a study by Dawson and Chipman [112] showed a link between older age and poorer leisure participation. It is therefore difficult to establish whether experiencing a brain injury results in negative outcomes for older adults, or whether negative

outcomes are associated with older age itself. The existing literature suggests that some older age adults are at an increased risk of experiencing lower levels of community integration and other psychosocial outcomes following injury.

### *Ethnicity*

Participant's ethnicity was found to be a strong predictor of community integration post-injury with Black and Hispanic participants having lower levels of community integration than white participants. However, the effect sizes between ethnicity and community integration levels were small. This supports the findings from previous literature that individuals from an ethnic minority have poorer outcomes following brain injury than white individuals. This includes poorer functional outcomes and functional independence [113, 114], and lower return to work rates [114]. Research has also suggested that African-Americans have poorer self-reported life satisfaction than Caucasians one year post-injury after controlling for injury severity and functional status [115]. One possible explanation for minority group members experiencing poorer outcomes post-TBI is due to racial disparities in health care. Reviews of the literature base have shown that there are significant differences in access to medical care based on race/ethnicity that cannot be explained by severity of disease or the availability of health services [116]. These disparities are most well-documented in stroke and cardiac problems, with minority individuals having less access to diagnostic interventions. There have also been a number of health care disparities found following brain injury. Bowman, Martin, Sharar and Zimmerman [117] found that African-Americans and Hispanics were less likely to be discharged to rehabilitation services than white individuals following TBI after controlling for injury severity. Similarly, Burnett et al [118] highlighted that individuals with

minority group status receive less intense, and fewer, occupational health sessions than non-minorities.

### *Injury Severity*

The review highlighted that injury severity as measured by PTA, length of stay and disability level predicts poorer community integration following injury. These findings support literature regarding the predictive ability of injury severity. For example, Tate and Broe [119] found that initial injury severity was a major determinant of psychosocial functioning in adults with very severe TBI 6 years after injury. Similarly, Brown et al [120] found that length of PTA predicted disability levels, rates of independent living, and levels of engagement in productive activity. Walker et al [121] found that PTA was associated with disability level 2 years post injury. They suggested that if PTA ended before 4 weeks good recovery was most likely at 2 years post-injury, but if PTA lasted more than 8 weeks severe disability was the most likely outcomes at 2 years post-injury. Lastly, Weber et al [122] found that length of stay in hospital was an independent predictor of quality of life after TBI. These results highlight the importance of assessing initial injury severity for accurate outcome predictions [120] which will allow for the implementation of targeted interventions.

### *Shared Characteristics*

As well as assessing the relationship between older age, ethnicity and injury severity and community integration in isolation it may also be useful to consider the commonalities amongst these variables in order to address any underlying themes. One possible underlying theme amongst these variables is a lack of access to health and social care services. Previous literature has suggested

that older adults, individuals from ethnic minorities and those with disabilities all have worse access to healthcare. Guo, Du, Hu and Zheng [123] highlighted that healthcare services were used less by older adults and concluded that more effort is needed to enhance healthcare service use in the ageing population. Similarly, in an Annual Review of Public Health Fiscella and Sanders [124] found widespread and persistent racial disparities in healthcare. In a review of the existing literature Scheppers, Van Dongen, Dekker, Geertzen and Dekker [125] found that they were three levels of potential barriers to accessing services; patient, provider and system. The patient level refers to demographic variables of the individual whereas the provider level is the skills and attitudes of the care providers, and the system level is the organisation of the wider healthcare system. Moreover, a recent study by Sakellariou and Rotarou [126] investigated the differences in healthcare between those with and without disabilities in the UK. They found that people with severe disabilities were more likely to have unmet needs, especially in terms of receiving mental health support and accessing prescribed medication. The authors suggested that cost, transportation difficulties and long waiting lists were the main barriers to accessing appropriate services. The possible shared characteristic of a lack of access to healthcare services amongst older adults, minority groups and those with more severe injuries highlights the need to provide high quality and accessible care to vulnerable members of society. This may help individuals to access holistic health care and in-turn increase their levels of community integration.

## **Limitations of the Studies**

There are numerous limitations associated with the methodological and theoretical underpinnings of the studies in this review. Only one study assessed levels of community integration following other types of ABI rather than solely assessing traumatic brain injury. This is an important consideration for future research, as differences in functional improvements following injury has been found between TBI and other types of brain injury [127] which could affect levels of community integration. Moreover, potentially confounding variables were not controlled for in many of the studies when assessing factors that affect community integration. Ethnicity and age were found to be significantly correlated with community integration, but these factors were not considered, or controlled for in all of the studies. Studies that failed to control for these variables are in danger of reporting unreliable findings regarding the association between predictor variables and levels of community integration. Future research should therefore consider and control for these factors to reduce the likelihood of biased results.

Moreover, the majority of the study participants were community-dwelling individuals who lived in urban areas, and had good access to social support and leisure activities. The studies failed to consider the effect that living in a rural location could have on levels of integration despite this been shown to influence CI in different clinical populations [128]. Future research should therefore assess the factors that predict levels of community integration after brain injury in those residing in rural areas, to assess whether these individuals have specific needs.

Additionally, the reviewed studies adopted numerous different measures to assess levels of CI. The RNLI, SPRS, and the CIM are all subjective measures of community integration. Whereas, the CIQ, PART-O and CHART all measure objective levels of community integration. Hall, Bushnik, Lakisic-Kazazic, Wright and Cantagallo [129] found that the CHART provides additional information on social, cognitive, and occupational functioning but takes longer to administer than the CIQ. Despite the apparent differences amongst community integration measures Salter, Foley, Jutai, Bayley and Teasell [9] found that all of the measures assessed the same underlying principles of community integration. Specifically, all measures assessed levels of productivity, social integration, and relationships. They also found that the CIQ and RNLI were the most reliable, and valid, assessment measures. However, Kuiper, Kendall, Fleming and Tate [130] found that the SPRS had greater internal consistency than the CIQ, highlighting a lack of clarity in the literature.

Juengst et al [103] was the only study in this review to assess participants' subjective satisfaction in community integration levels. Future research would benefit from assessing subjective satisfaction associated with community integration rather than focusing solely on levels of integration. Studies should continue to explore the relationship between the numerous variables reported in this review and their effect on levels of community integration, especially psychological, and external factors. This would provide researchers with more robust evidence regarding their effects, which could help to inform future research and interventions.

## **Conclusion and Clinical Implications**

The current literature review provides a summary of the research regarding factors that predict community integration following brain injury. The reviewed evidence suggests that there are numerous factors which affect reintegration into the community. The majority of findings were inconsistent, which supports the findings from Reistetter and Abreu [43]. However, several factors showed a strong relationship with levels of community integration, including the age of an individual, their ethnicity and the severity of their injury. Individuals who are older at the time of injury, from an ethnic minority group, or are more severely injured should be recognised as individuals who may require extra support to reintegrate back into society. They should therefore be offered specifically targeted post-acute interventions to support them to reintegrate in to the community. Lastly, clinicians should ensure that individuals from an ethnic minority are able to access adequate health and social care following injury.

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## **Part Two: Empirical Paper**

# **An Exploration of the Experience of Perceived Stigma Following Acquired Brain Injury**

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## **Abstract**

**Objective:** The majority of the stigma literature to date focuses on the detrimental effects of stigmatisation, such as reduced self-efficacy and self-esteem. However, there is a growing body of literature which suggests that not all responses to stigma are negative, and that some individuals can become righteously angry at the stigma they receive and even empowered to create social change. This study aimed to explore the experience of stigma for individuals following Acquired Brain Injury (ABI).

**Design and Methodology:** Semi-structured interviews were utilised to obtain qualitative data from 6 participants with an ABI. Interpretative phenomenological analysis was used to analyse and interpret data.

**Results:** Three super-ordinate themes and nine sub-themes emerged from the data. Super-ordinate themes to emerge were 'Normalisation through good understanding', 'Discrimination through poor understanding' and 'Post-traumatic Growth'.

### **Conclusions:**

Individuals with ABI experience others as being misunderstanding of their injuries and their residual difficulties following brain injury. This leads to those with ABI perceiving high levels of stigma and discrimination from society as a result of this. However, individuals also experience those with a good understanding of their injuries, mainly through brain injury supports groups. Individuals, therefore, identify with those who understand their injuries and this high-group identification leads to the development of PTG and empowerment to create social change.

**Keywords:** Brain injury, Stigma, Positive Growth.

## Introduction

Stigma has been defined by Goffman as the application of a negative label to an individual who deviates from societal norms [1]. The negative label becomes the focus of people's attention and diminishes any other positive attributes the individual may hold. This leads to viewing the person as not entirely human and creating a 'stigma theory'; an interpretation which explains their perceived inferiority and danger they present [1]. According to Link and Phelan [2], stigmatised individuals experience status loss due to being rejected, socially excluded and devalued. This leads to them experiencing poorer housing, income, education, psychological well-being and health [3]. Researchers have proposed several different components of stigma, including public stigma, perceived stigma and self-stigma. The social-cognitive model of public stigma attempts to understand the general public's reactions to stigmatised individuals and consists of three components: stereotypes, negative attitudes and discriminatory behaviours [4]. The model proposes that a lack of understanding can result in stereotypes which in-turn lead to the formation of negative attitudes and discriminatory behaviours.

Corrigan, Watson and Barr [5] have differentiated between public stigma and the internal experiences of stigmatised individuals. Perceived stigma relates to an individual's awareness of the negative stereotypes, prejudices and behaviours associated with their condition. Whereas self-stigma is defined as the internalisation of, and agreement with, these negative stereotypes. Self-stigma can be explained using the Modified Labelling Theory Approach [6], which argues that during socialisation we internalise the negative stereotypes associated with stigmatising conditions and what it would mean to acquire such

status. Thus, if an individual then goes on to develop a stigmatising condition, the negative stereotype becomes associated with the self and this creates self-stigma [4]. Due to the variations in stigma definitions in the literature, Link and Phelan [2] emphasise the importance of researchers stating which type of stigma they are reporting on. The current research was interested in perceived stigma.

To protect themselves from stigma, individuals either choose to conceal their condition [1], withdraw from society, or educate those around them [4]. When assessing stigma in relation to disability, Watson and Larson [7] argue that it is important to account for the different aspects of stigma and the specific nature of the disability. Jones et al [8] specify six dimensions of stigma, which can vary depending on the stigmatising condition. These are concealability, origin, course, aesthetic qualities, disruptiveness and peril. Concealability refers to the visibility of the condition, and can be linked to Goffman's [1] terms; the discredited and the discreditable. According to Goffman [1], the discredited are those who have a disability that is easily observed physically, whereas, the discreditable are those who do not have physical signs of disability.

The majority of the current stigma literature focuses on the detrimental effects of stigmatization, such as how individuals are devalued, stereotyped and exposed to prejudice [9]. This results in a wholly negative image of stigmatized individuals and suggests that those who face stigma are damned to a life of judgement, rejection, and failure [10]. Fine and Asch [11] argue that, by portraying members of stigmatized groups in this way, we are creating helpless victims and simply adding to the list of undesirable characteristics which further help to strengthen the stereotype. However, more recent literature has

suggested that there is not a uniform response to stigma. Not all individuals are negatively affected by stigma; some are indifferent to the stigma they receive, whilst others feel righteously angry towards an unjust society, which can result in empowerment and energy to create change [4, 7]. Both Corrigan and Watson [4], and Watson and Larson [7], outline mediators which may predict an individual becoming indifferent to or empowered by the stigma they experience. Both papers cite group identification and perceived legitimacy as a mediating factor in how individuals respond to public stigma.

Individuals with a brain injury have received attention in the literature as researchers attempt to understand the general public's awareness of brain injuries and their treatment in society. Research has indicated that the public hold several common misconceptions regarding head injury and recovery. A systematic review by Ralph and Derbyshire [12] highlighted that the general public lack awareness of the symptoms post-injury and held misconceptions regarding memory difficulties and recovery. The review also showed that the public hold more negative attitudes towards survivors of ABI, compared to those with more visible injuries such as believing individuals to be aggressive, dependent and unhappy. Research has suggested that a lack of understanding, regarding an individual's injuries, can result in stigma [13, 12, 4]. It is, therefore, unsurprising that those with head injuries often receive negative reactions from others. In a qualitative study of individuals experiences post injury, Morris et al [14] highlighted how individuals are often treated as less capable, ignored or over-looked. Individuals also believed they had experienced discrimination, in terms of struggling to find employment, and being excluded from peer groups. These negative reactions were often due to a lack of understanding of brain injury, in part due to a lack of visible markers of injury. These findings are

consistent with the social cognitive model of public-stigma, which suggests that negative attitudes can result in discriminatory behaviours [4].

However, despite the difficulties encountered by those with brain injuries, there is growing recognition of positive psychological outcomes following injury. The current research adopted a Positive Psychology perspective, which aims to study positive individual traits, subjective experiences and institutions [15]. Through this approach it has been found that individuals with an ABI experience high levels of post-traumatic growth after injury [16], including a redefined sense of self [17] and an increased appreciation of their life and relationships [18]. Moreover, positive psychological interventions have been shown to help individuals adjust to their injuries in a positive and meaningful way [19]. However, what is yet to be considered in the literature is the experience of perceived stigma and the reactions to such experiences in a brain injury population.

Freeman et al [20] argues that research regarding the impact of perceived stigma on survivors of ABI is crucial. Similarly, Link and Phelan [2] argue that research regarding stigma is important in order to gain a greater understanding of those who successfully challenge the stigmatizing process. There is also a need to focus on disease-specific experiences of perceived stigma, in order to develop targeted and meaningful interventions [21]. To date, there has been no direct study on the experience of perceived stigma in a brain injury population and the outcomes of such experiences. Given the wealth of information regarding positive psychological outcomes after brain injury, a Positive Psychology perspective would offer a framework in which we can explore the phenomenology of experiencing perceived stigma.



More recent developments, in the field of positive psychology, have resulted in what has been termed 'Second Wave Positive Psychology'. This offers a new way of conceptualising positive experiences and is based on the premise that positive and negative experiences are of a dialectical nature. Thus, suggesting that although experiences are polar opposites, they are intrinsically linked, in that one experience cannot exist without the other and cannot be separated [22]. The proposed study is, therefore, also concerned with the dialectical nature of experiencing stigma and whether the negative experience of being stigmatised can result in positive growth.

This study aimed to use the theoretical framework provided by Positive Psychology in an exploratory manner, to develop an understanding of the experiences of stigma for individuals with an ABI. So far, stigma has been understood as a wholly negative experience; however, the literature has failed to consider whether stigma may result in positive psychological growth in individuals with brain injuries. In accordance with these aims, the research had the following research questions:

1. Do individuals with a brain injury experience perceived stigma?
2. What are the positive and negative experiences associated with experiencing perceived stigma?
3. Is the experience of stigma dialectical in nature i.e. are the positive and negative experiences intrinsically linked?

## **Method and Materials**

### **Design**

This research adopted a qualitative design, utilising semi-structured interviews to explore the experience of stigma amongst individuals with an ABI. Interview data was transcribed and analysed using Interpretative Phenomenological Analysis [IPA: 23].

### **Recruitment**

Participants were recruited using a purposive sampling strategy to ensure a sufficiently homogenous participant group for analysis. Individuals were included if they had an occurrence of an acquired brain injury (ABI), were proficient in the use of English Language, and were aged 18 years or older at the time of injury. Participants also had to be at least 18 months' post injury, as the literature suggests that the vast majority of recovery, from mild to severe ABI, occurs within this time frame [24]. Additionally, individuals were also excluded if they were undergoing active medical treatment (aside from regular medications), such as surgery or regular inpatient or community rehabilitation. Individuals who had sustained their injuries very recently, and who were still in active rehabilitation or uncertain as to what their future may entail might have found the study too emotive. They may also not have had adequate time to adjust to their injuries, and to experience the positive and negative outcomes associated with being stigmatised. This study, therefore, focused on those with more stable circumstances post injury.

Participants were also required to be able to give informed consent to participation and have adequate hearing and speech to participate in the

interviews. Individuals were excluded if they had an overtly physical disability, such as individuals who use wheelchairs, as this may have prevented the research exploring stigma associated with the head injury alone. Individuals with specific neurological conditions or neurodegenerative conditions were excluded, as they may experience stigma and adjustment issues unique to their diagnosis or stage of illness progression. Lastly, individuals who sustained their brain injury before the age of 18 years of age, and/or have a history of learning disability prior to the age of 18 were excluded as this study is interested in adults with ABI only.

## **Sample**

The sample consisted of six participants who self-reported a diagnosis of ABI. This is in-keeping with the recommendations of a sample size of between 4-10 participants for IPA doctoral research [23]. Participants were recruited through brain injury charity support groups in the North of England. Potential participants were provided with information, through either the relevant charities or face to face. Further information was provided to participants through telephone contact and those who met the inclusion criteria and wished to participate were scheduled for interview. Demographic information and written consent was obtained at interview.

The sample consisted of 4 males and 2 females, between the ages of 37 and 67 years ( $M=50$ ). 3 participants had experienced a traumatic brain injury, 2 had experienced a stroke and 1 had contracted encephalitis. Self-reported time post-injury ranged from 3 to 31 years ( $M=18$ ). All participants identified

themselves as White British, 3 participants lived independently and 3 lived with their partner/spouse.

### **Data Collection**

The study was reviewed and approved by the School of Health and Social Work Research Ethics Committee at the University of Hull (See Appendix F). A copy of the information sheet given to participants is located in Appendix H.

All participants took part in a semi-structured interview conducted by the first author. Open-ended interview questions were utilised to provide points for exploration (See Appendix K). A curious and open stance was adopted in order to explore the participant's experiences of interactions with others after their injury. The term stigma was not used in the interview questions, to prevent leading the participant's. In particular, participants were prompted to consider good and bad experiences of how they had been treated by their family, friends and members of the wider community following their injuries.

Two interviews were conducted at the homes of the participants, a further three interviews were conducted on the University of Hull campus and one interview was conducted over the telephone. Interviews lasted between 32 and 58 minutes.

### **Data Analysis**

Data was analysed using Interpretative Phenomenological Analysis (IPA), which focuses on the lived experiences of individuals, in order to explore and construct meaning of complex phenomena. Individual perspectives are

considered, before then embedding this information into the wider context of the data set as a whole [23].

This process initially involved transcribing the data and re-reading transcripts several times, to aid familiarity. Three levels of exploratory analytic coding (descriptive, linguistic, and conceptual) were considered for each transcript, with anything of interest being noted in the right hand column of the documents. Emergent patterns and themes were then identified and noted in the left hand column. The relationship within and between themes was then explored through a process of mapping out themes and assessing their commonalities and differences. Themes were tabulated, and cross-referenced with participant quotes, to establish consistency and reliability.

IPA actively involves both the participant and researcher when attributing meaning to individual's experiences. There is a focus on the awareness of the researchers own beliefs affecting the interpretation and understanding of phenomena [25]. The lead researcher utilised a reflective journal to reflect on their own personal perceptions of the findings. The researcher had attended a workshop interested in individual's personal accounts of their injuries and their treatment in society. They also had voluntary experience with individuals with intellectual disabilities, which focused on organising recreational activities. These experiences highlighted both the difficulties of living with a disability and the positive aspects of living well with a disability such as the ability to develop resilience against difficulties they may face. The researcher, therefore, believed that disability can encompass many difficulties but that it is possible to live well with a disability, including enjoying life and developing strength and resilience.

## **Ensuring Quality**

Yardley [26] describes numerous broad ways in which the quality of IPA research can be ensured. They argue the importance of been sensitive to the context of the research. The researcher demonstrated this by having an awareness of the existing literature regarding stigma and brain injury and appreciating the difficult topic the research was interested in. The researcher ensured that participants were put at ease during the interviews and showed empathy and understanding to their experiences. Yardley [26] also suggests the use of supervision to guarantee IPA research is done rigorously. The researcher therefore attended frequent supervision meetings in order to discuss potential themes. The researcher also selected a sample that was appropriate to the research question and thought carefully about the inclusion and exclusion criteria for the study. Lastly, Yardley [26] argues that IPA research should be transparent and the researcher therefore attempted to be as transparent as possible in terms of why they choose the research questions and their underlying beliefs and assumptions on the topic. The researcher also included the interview schedule in the write-up as suggested by Yardley [26].

## **Results**

Three super-ordinate themes and nine sub-themes emerged from individuals accounts and are displayed in table 1. The results indicate three overarching themes relating to individuals understanding of brain injuries and the experience of positive psychological change following injury.

Table 1. Themes Relating to *Participants' Experiences Post-injury*

<b>Super-ordinate theme</b>	<b>Sub-theme</b>	<b>Participant</b>
Misunderstanding	1. <i>Experiences of misunderstanding</i>	P1, P2, P4, P5,
	2. <i>"Nobody can see you've had a brain injury"</i>	P1, P2, P3, P4,
	3. <i>"People treat you like a rapist"</i>	P1, P2, P5, P6,
Good understanding	1. <i>"Brilliant Family"</i>	P1, P2, P3, P4, P6,
	2. <i>"In the same boat"</i>	P1, P3, P4, P6,
	3. <i>"Symbiotic Relationship"</i>	P3, P4, P6,
Positive outcomes	1. <i>"Look on the bright side"</i>	P1, P2, P3, P4, P6,
	2. <i>"it's okay not be okay"</i>	P1, P3, P4, P5,
	3. <i>"I want to help other people"</i>	P1, P2, P3, P5,

## **Misunderstanding**

This theme relates to participants perceiving high levels of stigma from society, due to the poor understanding of the public and professionals regarding brain injuries.

### **1.1. 1. Experiences of misunderstanding**

Participants discussed individuals in the community, as well as family and friends, misunderstanding the symptoms of brain injuries and the long-term effects of their injuries. This misunderstanding from others was present both for participants who had their injuries decades ago and those who had their injuries more recently, suggesting that unfortunately, this is not something that has improved over time. It was apparent that these experiences, and the negative

emotions associated with them, were still raw for participants, highlighting the impact these experiences had had.

*“I’m sure people didn’t have a good understanding of brain injury at the time”  
(P2)*

*“Sometimes I get a bit frustrated about that [lack of understanding] and I think for a while my husband was in that category as well” (P4)*

*“Some people don’t quite understand the tiredness side of it they just kind of say ‘why don’t you just try not sleeping in the day’ almost like I’m been a bit ermmm, I can’t quite describe it, like soft” (P4)*

This lack of understanding resulted in public and professional misconceptions regarding brain injury. For example, individuals believing that participants were intoxicated or had been using illicit substances. This resulted in the participants being viewed in a negative light. Participant four told of a distressing experience when a door-man wrongly perceived his symptoms as him being intoxicated. His brother had to defend the fact that he is disabled, highlighting the importance of a supportive family.

*“Before that we went to [bar name] and we was walking towards it and we went to go in and they stopped me at the door and said ‘nah’ because of my slurred voice etc. They thought I was pissed and my brother said he’s not pissed he’s disabled” (P4)*

Participants one and five appeared to be both shocked and angry that healthcare and non-health care professionals believed that they were



intoxicated or had taken an overdose. Two of these experiences occurred in hospital settings immediately following the participants brain injuries, when they may have been relying on healthcare professionals to be the only ones to understand what had happened. This could have made the experience even more difficult and intolerable.

*“My mum had a look at my eyes and they were pin point pupils so I was rushed to [hospital name]. They [members of staff at hospital] thought he’d slipped me drugs and I’d had a drugs overdose” (P1)*

*“I went to the cyber café and there was this bloke in a suit started asking who I was and what I was doing there and I showed him my headway card that says I’ve got a brain injury and he said ‘have you been drinking?’, he was the vice principal!” (P1)*

*“A doctor put his nose towards mine and I remember the colour of his bow tie and every feature of him and he said ‘What drugs have you taken? Have you taken any alcohol with your drugs? Have you overdosed on purpose?’” (P5)*

These experiences are recalled in great detail, including being able to remember what the professionals were wearing at the time. This seemed to emphasise the negative experience they had had as it was retold almost like a traumatic flashback, which the participants were reliving when describing it. This may be due to a level of injustice regarding participants feeling that professionals, especially doctors, should understand brain injuries and disabilities. This sense of injustice and incongruence could be why participants one and five remember the incidents in such great detail, decades after they had occurred. Participant one’s experience also highlights a poor understanding

of brain injury, despite the recent initiative by Headway UK to improve understanding through issuing Brain Injury Identity Cards. This also highlights the widespread issue concerning members of the public misidentifying those with brain injury as intoxicated, as it has received national attention.

Participant one further highlights how members of the public lack understanding of the diversity of impairments after injury, resulting in a stereotyped view of those with ABI. It appears as though individuals have a negative view of brain injuries and there is a sense from participant one that individuals may get written off and be abandoned after an injury due to this lack of understanding.

*“They think I sit in a corner dribbling because people don’t realise that every head injury is different and they imagine someone who’s had a brain haemorrhage sat in a corner dribbling, either that or they’ll be in a wheel chair”*  
(P1)

It is, therefore, apparent that members of the public hold negative attitudes towards individuals with brain injuries, and create stereotypes regarding how individuals with a brain injury behave.

### **1.2. 2. “Nobody can see you’ve had a brain injury”**

Participants believed that the general public’s lack of understanding regarding their brain injuries was, in part, due to having an “invisible disability” (P5). Participants appeared to be angry with the general public about this, feeling a sense of injustice that their injuries were misunderstood and that individuals did not consider that they may have had a brain injury.

There was a sense of frustration from two participants that members of the public did not consider that they have had a brain injury but instead assumed their presentation was down to other factors.

*“Because you can’t see a disability you don’t think about it, you don’t think maybe he’s had a brain injury or something, you don’t think about that you just think are there drugs or drink or whatever” (P1)*

*“That’s the impossible thing about brain injury because nobody can see you’ve had a brain injury” (P2)*

The difficulties associated with having a ‘hidden disability’ also caused difficulties in the workplace for participant five. His employers knew about his brain injury but did not understand the residual difficulties associated with his injury, partly because of the lack of visible markers of injury. There appears to be a sense of anger that an individual from the welfare department, whose job it is to look after staff members’ wellbeing, could not tell that he was not okay. This left participant five in a predicament of not knowing how to explain his difficulties to his employers.

*“One of our managers came in and somebody from welfare came in and said ‘oh you look well, you look fine’ and I thought ‘I’m not’, he said ‘What’s the matter with you then?’ and I thought what do I say?” (P5)*

There also appeared to be a sense of frustration, felt by participants, that individuals did not understand the complexities of their hidden injuries. Participant five described having to leave the room to scream or cry to relieve the feelings of frustration at individuals who assumed he was fine.

*“Well, I got my movement back up to a point where it wasn’t a problem with me and then people were coming round and bringing me books and stuff like that and saying ‘well you look well’ and I was thinking ‘I don’t feel well’ so I said excuse me I need to go to the bathroom so I went to the bathroom and screamed or cried or whatever” (P5)*

In both of participant five's accounts there seemed to be a sense of not knowing how to tell people about his injuries. He disclosed thinking that he was not okay, but was unsure of how to communicate this. This may have also caused feelings of resentment towards individuals who assumed he was okay, as this presented him with a dilemma of not knowing how to explain how he really felt. However, this also highlights the impossible position that others are in, when trying to understand brain injuries, as even individuals with the injuries struggle to explain their difficulties.

This sense of anger, injustice and frustration led to participant five considering the hypothetical benefits of having visible impairments, compared to a hidden disability, as a way of increasing understanding.

*“In some respects if I’d have ended up with spasticity as they called it or a physical disability or in a wheel chair things would have been a whole lot different, because I have an invisible disability they’re not aware of it” (P5)*

It almost appears as though participant five is battling with the idea of wanting physical impairments, or to be in a wheelchair, as he believes this would increase public understanding. This highlights the powerful impact having a ‘hidden disability’ has had on participant five, as it led him to consider the

benefits of visible impairments, which in his pre-injury life, he probably would never have contemplated or wished upon himself.

However, there was incongruence on this matter between the participants as one participant felt strongly that they wanted to hide their disability away and *“act normal” (P6)*.

*“One thing I did want to say is that I don’t want anybody outside knowing that I’m disabled” (P6)*

*“I’m a very proud person when it comes to this sort of thing, I don’t want anybody to know” (P6)*

Participant five outlined the benefits of people knowing about their injury and saw visible impairments as a mechanism to achieving increased understanding. Whereas, participant six alluded to the fact that having a hidden disability was advantageous as she is more able to hide it from the public. This could be due to the negative attitudes members of the public hold regarding brain injury.

### **1.3. 3. *“People treat you like a rapist”***

Four participants explained how the formation of negative attitudes regarding brain injury, led to them perceiving negative reactions and discriminatory behaviours from others.

Two participants were damning in their accounts of how people were less willing to engage with them after their brain injuries. There seemed to be a sense of confusion regarding why this was, with participant two explaining that people

could choose to have the time for him and yet they were still unwilling to engage with him.

*“I still find that I’m getting people as soon as they know what’s happened to me they don’t speak to me and I think why?” (P1)*

*“Well people are less willing to engage with you...I think people...it’s not that people can’t find the time for you... I know people have the time for you.” (P2)*

Moreover, participant two expressed that he wanted others to treat him like a ‘normal’ person.

*“I’d just like people on the streets to treat people with brain injuries like they were normal people and not people with a problem, sometimes it feels like people treat you like a rapist” (P2)*

This suggests that he has had experiences of being treated differently and as if he was not normal. Suggesting that he has been treated like a rapist highlights the strength of the negative reactions and poor treatments he has perceived, as this gives rise to such a strong and emotive comparison.

Participant four perceived negative judgement from others when she used to meet up with a friend. Her perception of being judged by members of the public was severe enough to elicit a feeling of anxiety. Moreover, the use of the term “used to” suggests that the feeling of anxiety resulted in her no longer participating in this social activity. This may have led to a decrease in self-esteem and confidence in social situations.

*“because I used to go out and meet my friend last year for coffee and every single time I went I used to feel anxious and as if people were judging you” (P4)*

One participant felt that the negative reactions he experienced had a detrimental effect on his family.

*“I was more upset for my family because I was holding them back because of the reactions I was getting so I was really upset” (P3)*

In stating that he had held his family back he appears to be assigning blame to himself. He was extremely upset by this, and there was a sense of guilt and him feeling responsible despite the fact members of the public were the ones treating him negatively. This highlights how experiencing negative reactions from others can be multi-faceted, in that negative treatment can upset the individual and also make them feel guilty for the effect they are having on their families.

High levels of perceived discrimination also occurred in the workplace and within social groups, with participant two believing that his brain injury prevented him from engaging in recreational activities or gaining employment.

*“The companies are meant to be positive about people with disabilities. It’s not the companies’ fault it’s the people, the interviewers. Like I know they pretend that’s not how they treat people but that’s just the way the world is, they’ll always think the person without the disability is a better candidate than the person with a disability.” (P2)*

There is a sense of indignation in participant two's account, with him stating it is just the way the world is. This is, perhaps, because he felt that his injury prevented him from gaining employment for twenty years, despite having two degrees.

*"The problem is even though you have two degrees people think brain injury? He's not as good as the person without the brain injury so..." (P2)*

Individuals, therefore, appeared to perceive high levels of negative attitudes and discriminatory behaviours from the general public. It was clear that participants perceived people as being less willing to engage with them, as judging them and discriminating against them because of their injuries. The negative treatment and discriminatory behaviours individuals perceived seem to result from the public having a poor understanding of brain injuries, in part due to the sometimes invisible nature of ABI.

### **Good understanding**

This theme is in contrast to the poor understanding theme and can be understood in terms of opposite but connecting parts of the stigma experience. Participants experience individuals with a poor understanding of their injury, which results in high levels of perceived stigma. However, they also experience individuals with a good understanding of their injuries and this served to normalise their difficulties.

#### **2.1. "Brilliant Family"**



Participants conveyed the importance of feeling supported by their family members and how this support stemmed from a good understanding of their injuries. It was apparent that a good understanding was necessary in order for family members to provide both emotional and practical support. This type of support appeared to fulfil the function of normalising their experiences: the antithesis of stigmatisation. This sense of normalisation in everyday activities counteracted perceived stigmatisation that might otherwise occur, as explained by Participant three:

*“I think they tried to normalise it as much as possible. My brother in law used to take me to appointments every day” (P3)*

The use of the word ‘normalise’ indicates a sense of awareness that in the participant’s world things had changed but perhaps a new normal was being established. There was an acknowledgement regarding the extent to which this could be achieved. This suggests that an understanding of the limits of the new normal was required by the participant and their family.

Participants one and four both drew on the experiences of understanding with their mothers and indicate a level of absolute trust in their support.

*“Well my mother, she was more my best friend because she used to do nursing and things like that, she understood” (P1)*

*“Like my mum, my mums always been like that, she’s always been understanding and helpful, like she’ll take my boys because my husband works away quite a bit so if I’m really tired she’ll say ‘I’ll have them for a few hours’ you know just so I can go to sleep” (P4)*

Trust in support received also emerged in Participant six, who was made to do things she did not want to do, suggesting that understanding also involved aspects that were recognised as positive by families, but not necessarily by people with brain injuries. This had the effect of anti-stigmatisation in that it suggests activities were undertaken that were normalising.

*“I have a very good support network. They made me do things that I didn’t want to do and that was the right thing to do because I was trying to give up” (P6)*

Participant three felt lucky for having such a supportive family, with his sister supporting him for 20 years. This highlights the need for long-term support following brain injury and how family are able to offer this.

*“I’m lucky really because I had a brilliant family who have been there, well my sister, my sisters been brilliant and she’s been there for the first 20 years” (P3)*

## **2.2. ‘In the same boat’**

Participants highlighted the importance of attending brain injury support groups, and forging new friendships with other individuals. These individuals had similar experiences, and therefore understood their injuries so they were “in the same boat” (P1, P6). This helped participants to create a new identity after their injuries, and helped develop a sense of belonging and normalisation for them that they may not have felt in society.

*“It was good to liaise with people that had similar stories” (P3)*

*“It’s amazing all the things you can do and everybody’s in the same boat so that’s good for me” (P6)*

*“You can go and meet people who have been in the same boat and you can swap notes if you like” (P1)*

These new friendships provided individuals with practical support concerning their injuries and ensuing symptoms. One particular contact that participant four had helped to normalise her difficulties. Additionally, she alluded to the fact that others, without a good understanding of her injury, assumed that she is different and is a ‘weirdo’. This highlights the importance of others understanding the symptoms of a brain injury in order to normalise and accept affected individuals.

*“I’ve got a contact there where I can say ‘oh I’ve got this, you know, is it linked to the encephalitis or is it something related? And she’s really helpful and really nice” (P4)*

*“It’s really useful and I think it’s just having somebody that understands that you’re not been a weirdo” (P4)*

### **2.3. Symbiotic Relationships**

Participants described the “symbiotic” (P3) nature of the new relationships they had developed. As well as experiencing others as understanding and helpful, there was a sense of the participants “giving something back” (P4) to those who have helped them. This act of caring for, and helping others, appeared to increase participant’s self-esteem and self-worth which may have otherwise reduced following the injury, due to experiencing high levels of perceived stigma in society.

*“It just feels nice to think you’re giving something back because they’ve given so much to us” (P4)*

This symbiotic relationship included offering support to other group members and fundraising/campaigning for individuals, or the wider group as a whole.

*“It’s nice to draw on other people’s experiences, see if we can help them and see if they can help us” (P6)*

*“We had an event last year just for people with strokes to raise some money for a lad called [person’s name] who had a stroke at [young age]” (P6)*

*“I’m doing a run next year for the [Charity name]” (P4)*

### **Positive outcomes**

This theme relates to the development of post-traumatic growth after injury. Participants experience high levels of perceived stigma from society but also experience the opposite end of the spectrum of those who have a good understanding of their injuries. Participants, therefore, identify themselves with those who have a good understanding of their injuries. This enables the development of good social support, which ultimately results in the development of PTG and empowerment to create social change. This highlights the dialectical nature of experiencing stigma as it is associated with both negative and positive outcomes.

#### **3.1. “Look on the bright side”**

Participants made positive social comparisons, between themselves and other individuals in less fortunate circumstances. This was facilitated by meeting others in less fortunate circumstances at brain injury support groups. The comparisons related to the participants situations, including the severity of their injuries and level of social support.

By manipulating their social comparisons and comparing themselves to others in less fortunate circumstances, participants were able to adopt a positive outlook and develop a sense of resilience towards surviving their injuries.

*“It’s hard because they don’t understand, they’re 5 and 8 so it’s hard for them isn’t it but you know it could be a lot worse” (P4)*

*“Yeah it is and also you see that you’re actually not that bad when you see some of them and you think my god, you know” (P1)*

*“It’s not easy to struggle on your own. I know there are some people that don’t have anybody” (P6)*

Positive social comparisons also enabled participants to feel grateful that their injuries and situations were not as dire as others. This sense of gratitude may also help to buffer against stigma and help participants to cope with the negative reactions they experience by allowing them to focus on the positive elements of their situations rather than dwelling on the negatives.

*“You have to think of the positives, I’m very lucky, I’m very lucky” (P6)*

*“I think I have to look on the bright side of what I’ve got rather than thinking about what I’ve lost I guess” (P4)*

*“I know it could be a lot worse and I have to keep thinking that so I’m grateful to still be here to be honest” (P4)*

Participant three felt grateful for what they had and was able to focus on the positive elements in his life due to the realisation that life was precious. This suggests that their injury led to them developing a new perspective on life, perhaps due to encountering the possibility of death.

*“Well it’s [life] the only one you’ve got isn’t it so be grateful for what you’ve got. Don’t focuses on what you’ve lost think about what you’ve got” (P3)*

This newly developed sense of gratitude and positive outlook on life also allowed participants to engage in new enjoyable experiences.

*“Well normally, if nothing had happened to me I wouldn’t have done them but now I can do them so it’s something you’ll sort of never do again” (P1)*

*“Because of my brain injury I’ve done some things that’s I’d probably never have done. Like I probably would have never been involved in the world scout jamboree” (P2)*

### **3.2. “It’s okay not be okay”**

As a result of their injuries and the stigma they experienced, participants developed a sense of resilience, acceptance, and became more empathetic towards others. This again highlights the dialectical nature of experiencing discrimination and stigma as this negative experience led to the individuals redefining their sense of self and developing positive personality traits.

For some participants their injuries made them feel a sense of pride in who they are and a confidence to defy societal norms and be themselves. There was also an element of participants redefining themselves and creating their own norms.

*“I’ve got the confidence to be myself and I’m not going to change for anybody”  
(P1)*

*“Like I feel like it’s okay not be okay. I think I kinda told myself I had to be normal and had to be like everyone else but now I’m just like I can’t be so there’s no point in trying I have to just be who I am” (P4)*

One participant discussed how their injuries had changed their outlook on life and led to the development of empathy for others

*“I think it [stigma] made me more empathic and understanding and more sort of willing to accept people’s limitations” (P3)*

Being able to empathise with others led to two participants volunteering at local hospitals in order to support those in a similar situation.

*“I think that helps in hospital talking to patients. Due to my empathic nature I know where they’re coming from because I’ve been through it.” (P3)*

*“They used to say I’ve got a referral for you so I used to go see people in the hospital, guys that were struggling or ladies, I used to go talk to them. I used to go see them in the rehab unit and I used to go see them at home” (P5)*

### **3.3. “I want to help other people”**

Participants wanted to improve people's understanding due to their own experiences that good understanding leads to normalisation of their injuries, whereas poor understanding results in discrimination and stigma. Participant's ability to empathise with others led to them wanting to improve understanding and increase normalisation to prevent others experiencing similar negative experiences. It appeared as though participants felt a sense of pride and heightened self-esteem through improving public understanding, in the same way individuals felt positive emotions by helping others in their support groups. This again highlights the dialectical nature of experiencing stigma as it can result in discrimination but also empowerment to help others.

*"Well, it's strange really, because of the problems I've had I want to help other people. I know how hard it is when you've had a brain injury because people don't accept you" (P2)*

This was achieved by forming support groups and educating others about brain injuries.

*"I went to the [place name] and they were some other people there with, in the same position of myself and they were as angry as I was and we decided to do something about it so what we did is we formed a group called [stroke group name]." (P5)*

*"People are still ignorant and they need teaching, they need educating and I'm trying to teach them, 'cus I don't want other people to go through what I've been through" (P1)*



Participant three felt strongly about the benefits of educating those around them about their injuries as it helps integrate brain injured people into society. It appears as though education helps non-brain injured people to accept those with brain injuries and to prevent them being viewed in a negative light. This then prevents them from being ostracised by society and from experiencing stigmatisation and discrimination due to their injuries, by helping to reduce the formation of negative attitudes and stereotypes.

*“It [education] helps disabled people and non-disabled people embrace them in society rather than sort of almost be on the outside of society” (P3)*

## **Discussion**

### *Summary of Findings*

Participants in this study experienced high levels of perceived stigma from society. This is partly due to members of the public, and some professionals, having a poor understanding of the impairments and presentations associated with brain injuries. This lack of understanding resulted in the formation of negative attitudes and stereotypes towards those with brain injuries. Participants then perceived to experience negative treatment and discriminatory behaviours from members of the public. However, individuals also experienced those with a good understanding of their injuries, mainly through their family members and the attendance of brain injury support groups. This led to participants aligning themselves with those who understand and normalise their injuries, resulting in the development of good networks of social support. Good social support contributed to the development of PTG and empowerment to create social change. These findings highlight the dialectical nature of stigma as

the experience comprised of both negative and positive aspects that were intrinsically linked.

### *Perceived Stigma*

The results of this study indicate that individuals with ABI's perceive members of the public and some professionals to misunderstand their injuries. It appears that those with brain injuries perceive some members of the public, professionals, friends and family members to have a poor understanding of the residual difficulties and recovery process associated with their injuries. Swift and Wilson [27], highlighted that non-health care professionals have a poor understanding of the cognitive and behavioural difficulties associated with brain injury. The participants in the study also perceived some health-care professionals to misunderstand their injuries. This perceived misunderstanding of their injuries led to participants believing to experience negative reactions and discrimination from others. This included a lack of engagement from others, struggling to gain employment and experiencing difficulties participating in recreational activities with non-brain injured peers following injury. Participants also disclosed feeling as if they were not treated like 'normal' people and felt anxious and judged by members of the public. This had a detrimental effect on the participants and led to them withdrawing from social activities and feeling a sense of guilt regarding the negative effects this poor treatment was having on their family. This supports research which suggests that those with brain injuries may experience negative reactions from others [14], and that misinformation regarding an individual's injuries can result in stigma, in this case, perceived stigma [13, 12, 4].

## *Visibility of Illness*

The misunderstanding individuals with brain injuries perceived, by some members of the public and professionals, could be partly due to the sometimes invisible nature of brain injuries. Participants repeatedly commented on the frustrations of having a 'hidden disability' and how this contributed to the poor understanding that individuals had of their injuries. In his early work on stigma, Goffman [1] distinguished between individuals whose stigmatized characteristics are immediately apparent to others (the discredited) and those whose stigmatized characteristics are invisible (the discreditable), suggesting that individuals may be treated differently depending on the visibility of their disability. Romano [28] also hypothesised that people feel more threatened by invisible disabilities compared to physical handicaps, due to not being able to understand why the individual is acting differently. Previous research has suggested that the general public fail to recognise brain injury as a hidden disability and expect an outward manifestation of injury [29]. Failure to recognise individual's brain injuries leads to negative outcomes for those with the injury. McClure [30] found that members of the public are more likely to attribute negative behaviours to the individual rather than the injury if there are no visible markers of brain injury, compared to when there are visible markers. This suggests that visible impairments shape the public's perceptions of the behaviours of people with brain injuries. Similarly, Swift and Wilson [27] found that the expectations placed on individuals with brain injuries by others, are based on visibility. Those with hidden disabilities have higher expectations placed on them due to overestimation of their abilities.

### *Social Support*

Participants experienced high levels of perceived stigma from society. This led to participants seeking out individuals with a good understanding of brain injuries which resulted in high levels of social support (Theme 1.1.). This provided the participants with an experience of normalisation, which counteracted their negative experiences of perceived stigma. There is a wealth of literature highlighting the positive outcomes associated with adequate social support after trauma. Receiving good social support can 'buffer' against the stress associated with the physical, cognitive and psychosocial impairments of disability [31]. Research has suggested that high-group identification can act as a protective factor against stigma, as it enables people to create a positive identity due to their interactions with the group [4, 7]. This is mirrored by the findings of this study, that attendance at support groups enabled participants to redefine societal norms and increase their self-esteem, partly through their ability to gain purpose in "giving something back" (Theme 1.2.).

### *PTG*

Participants appeared to experience PTG following their injuries, such as developing a sense of resilience and empathy, having a more positive outlook on life and feeling empowered to create social change. This supports the literature which informs us that individuals with brain injuries can experience positive psychological outcomes following injury [16, 17]. It would appear that as a result of participants experiencing perceived stigma and discrimination, from those who did not understand their injuries, they chose to identify themselves with those who did understand their injuries. One way this was

achieved was through attending brain injury support groups and aligning themselves with others who shared similar experiences. This gave participants a normalising and non-judgemental environment in which PTG such as resilience, empathy and empowerment developed. This also highlighted to participants the need to improve understanding to reduce perceived stigma and discrimination for themselves and others. The relationship between good social support and PTG has been previously highlighted [32].

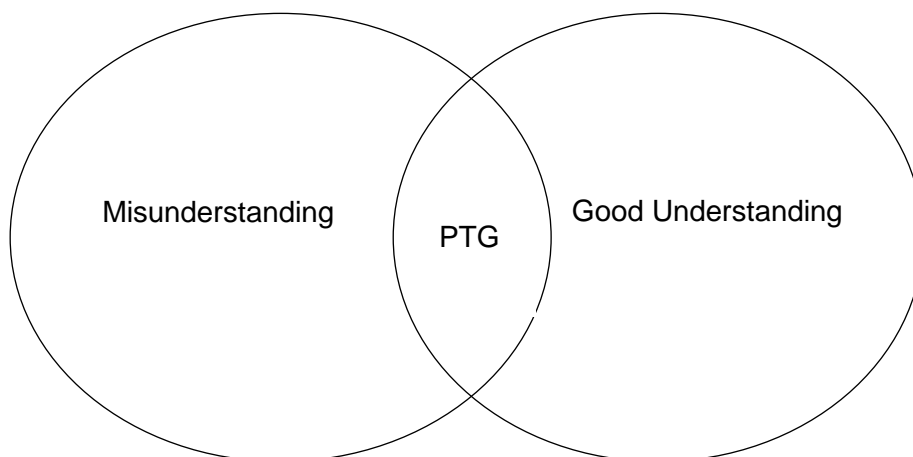
Social support has been conceptualised as a way of positively influencing an individual's appraisal of the traumatic event [33]. The findings from this study suggest that attending support groups allowed participants to appraise the injury event differently, through making downward social comparisons between themselves and others in the group. Participants compared themselves to those brain-injured peers, who were in a worse situation in terms of injury severity and support systems (Theme 3.1). These findings are in agreement with the literature which suggests that making downward social comparisons is a mechanism through which PTG can occur [34, 10, 35, 36, 37]. These selective social comparisons create a sense of self-efficacy and eliminate feelings of inequality [10].

Making downward social comparisons also led to a sense of gratitude regarding injury severity and what participants had in life. This supports the finding by Hawley and Joseph [18], that brain injury can result in an increased appreciation for life. It has been found that a sense of gratitude, after experiencing a trauma, can help individuals find meaning in life and interpret life as a gift [38]. This can be achieved through making comparisons between an actual and an imagined outcome [39]. Gratitude has also been found to promote

PTG after trauma [40]. Ruini and Vescovelli [41] found that gratitude was strongly associated with PTG in a sample of women with breast cancer.

Moreover, experiencing normalisation and gratitude, through good social support led to the development of empathy for others in a similar situation. Research has suggested that individuals with brain injuries show a reduction in their ability to empathise with others after injury [42-45]. However, it is clear from this study that participants developed empathy for others and actively wanted to prevent others experiencing perceived stigma from society like they had. This led to individuals feeling empowered to create social change through educating others around them and by forming support groups. This supports previous research which argues that there is not just one negative response to stigma, but that stigma can result in empowerment to create social change and that this can result from high group identification [4, 7].

### *The Dialectical Nature of Stigma*



*Figure 1. A Diagrammatic Representation of Study Themes.*

Figure 1 presents a diagrammatic representation of the interaction between good and bad experiences and how this may lead to PTG. Individuals perceived stigma and discrimination from society, which resulted in participants aligning themselves with those with a good understanding of their injuries through brain injury support groups. By surrounding themselves with others who shared similar experiences, participants developed good social support networks and were able to utilise techniques such as downward social comparisons. This led to participant's developing PTG as they developed resilience, empathy and a greater appreciation of life. Moreover, the interaction between positive and negative experiences highlighted to participant's the distinct differences in how they were treated by others, based on other people's level of knowledge and understanding of ABI. Due to this, participants appeared to develop a sense of empowerment to create social change, by educating those around them in order to increase understanding and, therefore, reduce perceived stigma for themselves and others. This supports Second Wave Positive Psychology Principles [22, 45] as it highlights the dialectical nature of experiencing stigma, in that positive experiences such as experiencing PTG and feeling empowered to create social change, arose out of the negative experience of perceiving stigma and discrimination. This also highlights how positive and negative experiences can co-exist, rather than a good experience resulting from a bad experience, they continue to be intrinsically linked with PTG evolving whilst simultaneously encountering difficult experiences [46].

### *Limitations and Future Research*

There are a number of limitations associated with this research study. Firstly, the study adopted a small sample size, meaning that a limited number of

people's experiences were heard and explored. However, efforts were made to keep the sample as homogenous as possible. The majority of the sample was male, in keeping with the gender bias observed in brain injury statistics [47, 48]. Limits were also placed on time since injury, age at injury and type of brain injury as seen in the inclusion criteria. It is difficult to obtain a truly homogenous sample due to the complex nature and different severities of brain injury, all of which can significantly affect an individual's experiences. Participants in this research were all community-dwelling individuals with access to good social support through brain injury charity support groups. Previous research has suggested that social support can positively influence how individuals appraise trauma and their sense of gratitude towards life. It is therefore possible that access to good social support may have affected the participant's experiences of perceived stigma and growth. Future research should therefore explore the experience of perceived stigma in non-community dwelling individuals with an ABI, who may not have access to adequate social support and may therefore have very different experiences of perceived stigma.

Moreover, this study adopted a cross-sectional design but future research would be required to utilise longitudinal measures to assess the impact of time post-injury on individual's experiences of stigma and growth. This is important, as previous research has suggested that higher levels of PTG are associated with longer time post-injury [16].

### *Clinical Implications*

Social interventions, to reduce stigma in a brain injury population, should focus on not only increasing the public understanding of brain injuries but also



facilitating social contact between those with and without brain injuries. Research has suggested that social contact and knowledge can reduce negative attitudes and discrimination in other stigmatised populations, including those with mental health difficulties [49, 50]. The Time to Change campaign, launched in 2009, emphasised the importance of social contact between those with and without mental health problems as a way of reducing stigma and discrimination. In a review of the campaigns effectiveness, Evans-Locko et al [51] found that awareness of the campaign was associated with greater knowledge about mental health and more favourable attitudes and behaviours towards those with mental health conditions. Social contact at events helped to positively change people's attitudes, with greater change occurring if the social contact was meaningful and of a high quality. Additionally, research has found that indirect social contact, through the use of media videos, can also improve public attitudes and social inclusion, and reduce stigma in a learning disability sample [52].

Moreover, Redpath et al [53], highlighted how participants who had personal experience of individuals with brain injury, expressed less prejudicial attitudes and were more likely to engage with brain injured individuals than were those who did not have personal experience. It is, therefore, apparent that strategies and campaigns to reduce stigma and discrimination are necessary in an ABI population. The focus of these should be on increasing public knowledge and the facilitation of high quality social contact between those with and without brain injuries. Social contact can be achieved through face-to-face means and also through indirect videos documenting the personal stories of those with ABI.

Moreover, given the high levels of perceived stigma experienced in this study it would appear that interventions should also focus on reducing perceived stigma following brain injury. Research has suggested that increased social inclusion through a social enterprise scheme can successfully reduce perceived stigma and discrimination in a mental health population [54]. Individuals should also be supported to process their injuries and accept the residual difficulties associated with brain injury. This may help individuals feel more able to disclose their injuries and reduce the levels of stigma they perceive. Third Wave Psychological Therapies, such as Acceptance and Commitment Therapy (ACT) has been shown to successfully reduce perceived stigma in a substance abuse population [55] and may be utilised to reduce perceived stigma in a brain injury population. Research has also suggested that ACT can reduce levels of anxiety and depression after brain injury [56].

### *Conclusions*

Overall, the findings of this study indicate that poor understanding of brain injury can result in stigma and discrimination. This is partly due to the hidden nature of brain injuries, resulting in public misconceptions. However, participants also experienced normalising and positive experiences at brain injury support groups. This led to high-group identification which facilitated the development of resilience and empathy. Experiencing distinct differences between those with a good and poor understanding of their injuries led to participants feeling empowered to create social change, in order to prevent others experiencing stigma and discrimination. It is possible, that without the interaction between good and bad experiences, the participants may not have experienced the same levels of PTG, developed resilience or have been empowered to create

social change. These findings support Second Wave Positive Psychology principles as they highlight the dialectical nature of stigma, as it encompasses both positive and negative experiences. The findings also highlight that there is not just one response to stigma but that individuals can respond by identifying with others in a similar situation which can lead to positive outcomes. This provides researchers with a different perspective of the stigma process and of those who successfully challenge the stigma they experience.

It is important that the experience of stigma and responses to stigma continue to be explored in a brain injury population. Strategies and campaigns to improve public knowledge about ABI, and facilitate meaningful social contact between those with and without brain injuries, are vital to reduce stigma in this population. Moreover, individuals should be supported to reduce the amount of perceived stigma they experience through social inclusion strategies and being provided with psychological therapies such as ACT.

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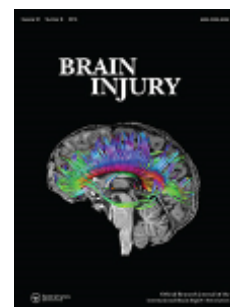
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## **Part Three: Appendices**

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Study Type	Name	Source
Case reports	CARE	<a href="http://www.care-statement.org/">www.care-statement.org/</a>

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

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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).

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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'.

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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 a shift from heurism to constructivism in the design of [British] science courses'.

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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).

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### **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
<i>11 or more authors</i>	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, Lavalley 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>.

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

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*For multiple agency grants*

This work was supported by the <Funding Agency #1> under Grant <number xxxx>; <Funding Agency #2> under Grant <number xxxx>; and <Funding Agency #3> under Grant <number xxxx>.

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## Appendix B: Pictorial representation of search strategy

### Search History/Alerts

[Print Search History](#)
[Retrieve Searches](#)
[Retrieve Alerts](#)
[Save Searches / Alerts](#)

<input type="checkbox"/> Select / deselect all <a href="#">Search with AND</a> <a href="#">Search with OR</a> <a href="#">Delete Searches</a> <span style="float: right;"><a href="#">Refresh Search Results</a></span>			
Search ID#	Search Terms	Search Options	Actions
<input type="checkbox"/> S6	 S1 AND S5	Search modes - Boolean/Phrase	<a href="#">View Results (2,294)</a> <a href="#">View Details</a> <a href="#">Edit</a>
<input type="checkbox"/> S5	 S2 OR S3 OR S4	Search modes - Boolean/Phrase	<a href="#">View Results (393,923)</a> <a href="#">View Details</a> <a href="#">Edit</a>
<input type="checkbox"/> S4	 AB communit* N3 (integrat* or participat*)	Search modes - Boolean/Phrase	<a href="#">View Results (29,259)</a> <a href="#">View Details</a> <a href="#">Edit</a>
<input type="checkbox"/> S3	 T1 communit* N3 (integrat* or participat*)	Search modes - Boolean/Phrase	<a href="#">View Results (6,976)</a> <a href="#">View Details</a> <a href="#">Edit</a>
<input type="checkbox"/> S2	 SU communit*	Search modes - Boolean/Phrase	<a href="#">View Results (376,992)</a> <a href="#">View Details</a> <a href="#">Edit</a>
<input type="checkbox"/> S1	 "brain injur*" or "head injur*" or "head trauma" or ABI or TBI	Search modes - Boolean/Phrase	<a href="#">View Results (186,338)</a> <a href="#">View Details</a> <a href="#">Edit</a>

Appendix C: Data Extraction Form

Review Journal (include full citation details)	
<p><b>Study Characteristics</b></p> <p><i>Research questions/aims:</i></p> <p><i>Replication of previous study?</i></p> <p><i>Study location:</i></p> <p><i>Study design:</i></p> <p><i>Sub-groups compared?</i></p>	
<p><b>Participant Characteristics</b></p> <p><i>Sample size:</i></p> <p><i>Participant demographics</i></p> <p><i>Age</i></p> <p><i>Gender</i></p> <p><i>Ethnicity</i></p> <p><i>Education</i></p> <p><i>Time post-injury</i></p> <p><i>Brain injury severity</i></p>	
<p><b>Participant Recruitment</b></p> <p><i>Recruitment method and location (e.g. neurorehab unit)</i></p>	

<p><i>Inclusion/exclusion criteria</i></p>	
<p><b>Measures</b></p> <p><i>Measures used to assess levels of community integration</i></p> <p><i>Other measures used for correlations</i></p>	
<p><b>Results</b></p> <p><i>Statistical tests used</i></p> <p><i>Main findings (Differences between groups found?)</i></p> <p><i>Findings comparable to previous studies?</i></p>	
<p><b>Conclusions</b></p> <p><i>Clinical Implications</i></p> <p><i>Limitations:</i></p>	
<p><b>Further comments</b></p>	

Appendix D: Quality Checklist Form

Quality criteria for quantitative studies	Quality rating: Yes (1) OR No (0) OR Not applicable (-)	Comments
	Journal reviewed  Author(s)  Title	
<p><b>Section 1 Reporting</b></p> <p><b>Abstract adequately discusses:</b></p> <p><i>1 Objectives/Aims/Hypotheses</i></p> <p><i>2 Design</i></p> <p><i>3 Method</i></p> <p><i>4 Results</i></p> <p><i>5 Conclusions</i></p>		
<p><b>6. Appropriate and clearly focussed research question(s)/aim(s)</b></p> <p><i>7 Main outcomes to be measured clearly described in introduction or method? (if the main outcomes are first mentioned in the Results section, the question should be answered no.)</i></p>		
<p><b>8 Design appropriate to study research question(s)?</b></p>		
<p><b>Section 2 Population</b></p> <p><i>9 Sample representative of the group from which it is drawn (i.e. public or students)</i></p> <p><i>10 Participant demographics adequately reported? (i.e. gender; age; education level)</i></p> <p><i>11 Response rate reported?</i></p>		



<p><b>Subgroups of participants (only relevant to those studies with comparison groups)</b></p> <p><i>12 If relevant, have differences between subgroups, which may influence results been acknowledged? (e.g. age; gender; employment status) (If differences (age; gender etc) have been explored then answer yes)</i></p>		
<p><b>13 If relevant, were participants randomly allocated to groups?</b></p> <p><i>(If subgroups were distinguished on the basis of participant demographics (i.e. males and females) and hence could not be randomly allocated, mark as n/a)</i></p>		
<p><b>Section 3 - Method</b></p> <p><b>14.</b> Confounding factors identified and controlled. (e.g. gender, age, education)</p> <p><b>15</b> Sampling method reported and appropriate</p> <p><b>16</b> Data collection method reported and appropriate</p>		
<p><b>Section 4 - Measures</b></p> <p><i>17. Are the main outcome measures used accurate and reliable?</i></p> <p><i>18. Was the follow-up time meaningful? (E.g. was it long enough to assess long-term effects/was it too long that participants were lost to follow up?)</i></p>		
<p><b>Section 5 - Data analysis</b></p> <p><i>19. Data analysis strategy reported</i></p> <p><i>20. Data strategy analysis appropriate to research question(s)</i></p> <p><i>21. Multiple explanatory variables considered in the analysis.</i></p>		

<p><b>22.</b> <i>If relevant, have actual probability values been reported (e.g. 0.035 rather than &lt;0.05) for the main outcomes except where the probability value is less than 0.001?</i></p> <p><b>23.</b> <i>Does the study report all the values of all correlations computed?</i></p>		
<p><b>Section 6 - Findings</b></p> <p><b>24.</b> <i>Main findings clearly described</i></p> <p><b>25.</b> <i>Findings and conclusions are relevant to initial research question(s)</i></p> <p><b>26.</b> <i>Findings are generalizable to the source population</i></p> <p><b>27.</b> <i>Clinical Implications reported</i></p> <p><b>28.</b> <i>Limitations reported</i></p>		
<p style="text-align: right;"><b>Total Score</b></p> <p style="text-align: center;"><b>% of relevant criteria met</b></p>		

### Consent Form

**Title of Project:** An exploration of the experience of stigma amongst people who have an acquired brain injury

**Name of Researcher:** Emma Minns

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 08/04/2016 (Version 3) for the above study. I have had the chance to think about the information, ask questions and have had these answered so that I understand what is expected of me.

2. I understand that taking part is voluntary and that I am free to withdraw up to the point of the data being analysed, without giving any reason and this will not affect my medical care or legal rights.

3. I agree to take part in the interview and understand that it will be recorded.

4. I confirm that direct quotes from the interview may be used in future publications and understand that they will not be linked to me.

5. I understand that some of the data collected during the research may be looked at by individuals from the University of Hull, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.

Name of Participant:

Date:

Signature:

---

*Appendix F: Ethical Approval*

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*Appendix G: Ethical Approval Following Amendment*

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## **Participant information sheet**

**Title of the study:** An exploration of the experience of stigma amongst people who have an acquired brain injury

We would like to invite you to take part in a research study. This sheet will explain why the research is being done and what would happen if you took part. **Someone will go through the information sheet with you and answer any questions you have before you decide if you want to take part.** This should take around 30 minutes.

### **What is the research about?**

This research is interested at looking at how individuals with a brain injury feel that they have been treated since their injury by their family, friends and the wider community, and how this made these individuals feel. It also interested in looking at whether people believe these experiences to be positive or negative and whether they believe anything has changed for them personally as a result of how they have been treated by people. I would like to invite you to consider taking part in this study.

### **Why is the research being done?**

This research is part of the Clinical Psychology training programme at the University of Hull. It is hoped this research will help to further understand how people with a brain injury feel that they are treated by their family, friends and community after their injury and whether these experiences are believed to be positive or negative. This research may be able to help inform strategies that will help people with a brain injury reintegrate into society and will aid the understanding of how people are treated after their injuries and how this makes those with a brain injury feel.

### **Why have you been asked to take part?**

You have been asked to take part as you have experienced a brain injury and will have valuable knowledge and experience about what this is like and how people have treated you since your injury. A maximum of 8 individuals will be asked to take part as this is the recommended number of people to recruit for exploratory studies undertaken whilst on the university course.

### **Do I have to take part?**

No. It is up to you whether you want to take part. The researcher (Emma Minns) will tell you about the research and go through this information sheet. If you agree to take part, you will then be asked to sign a consent form. You will be given a copy of the information sheet and the signed consent form.

### **What will happen if I take part?**

If you would like to take part, you will be invited to an interview with the researcher which will last an hour or two. The interviews will take place either at your own home or somewhere else which is convenient for you. The interview will be at a date and time that are suitable for you. Interviews can also be conducted over the telephone or via Skype.

During the interview, you will be asked questions about how you feel that you have been treated since your head injury, how this made you feel and whether you think you have changed because of been treated this way. You can answer all the questions or choose not to answer some if you don't want to.

The interviews will be recorded so that they can be listened to and typed up later. All of the recordings and typed up interviews will be kept locked away and have no personal details on them.

### **What are the possible disadvantages/risks involved in taking part in this study?**

As this research requires you to speak about how you have been treated since your brain injury, you may find this upsetting or distressing. If this happens, you will be provided with information about where you could go for support. You will be given this after the interview. However, you can also stop the interview at any time if you no longer want to continue. If the researcher becomes concerned about your well-being/safety they may share this information with your GP, but this will be discussed with you first.

### **What are the possible benefits of taking part in this study?**

Although there will be no direct benefit or payment as a result of your involvement in this study, some people find it useful to talk about their experiences. By taking part in this research you are also helping to add to the understanding of how individuals are treated by their family, friends and society and how this makes them feel. This may be able to help inform strategies that will help people with a brain injury reintegrate into society following their injuries.

### **What will happen if I no longer want to take part in the research?**

If you agree to take part in the research but then change your mind, that will not be a problem and you do not need to give a reason for this. You will just need to let the researcher know before they start analysing the data.

### **What if there is a problem?**

If you are worried about any part of this study, you can speak to the researcher (Emma Minns: 07926566489) who will try to answer your questions. If you are still unhappy and want to speak to someone else, you can contact either of the researcher's supervisors (details listed below) or the Associate Dean for Research, Faculty of Health and Social Care, University of Hull, Cottingham Road, Hull, HU6 7RX. 01482 463 342.

### **Will my details be kept confidential?**

- All of the information will be kept strictly confidential and anonymised so it will not be possible for anyone to know who you are.
- All of your information will be stored securely in a locked cabinet at the University of Hull and eventually destroyed.
- As this research is being used for a university course, this means that the research will be sent for assessment to the University of Hull. The research will also be sent to a journal, which means that anybody else who is interested in the research will be able to read it but this information will be anonymised beforehand.
- The only time confidentiality may need to be broken is if the researched becomes concerned about your safety or somebody else's. The researcher will talk to you about this first, and think about who may need informing.

### **What will happen to the results of the study?**



After the study is completed the results will be written-up as part of the researcher's thesis and may be submitted for publication in an academic journal or presented at conferences. Some direct quotes from your interview may be used in the write-up but none of your personal details or any identifiable data will be included.

### **Who is organizing and funding the study?**

The researcher is a doctoral student in Clinical Psychology at the University of Hull who is also employed by the Humber NHS Foundation Trust. This study is part of the university course. Research expenses are being provided by the University of Hull.

### **Who is reviewing this research?**

All research at the University of Hull is checked by a group of people, called a Research Ethics Committee. This study has been looked at and agreed by the Faculty of Health and Social Care Research Ethics Committee.

### **I am interested in participating and would like further information**

If you are interested in participating please:

- Contact the researcher via the details on the following page.
- The researcher will then contact you to arrange an initial telephone conversation where they will check your eligibility for the study, go through the information sheet and provide an opportunity for questions. Following this, you will have up to 2 weeks to decide whether you want to participate or not. If the researcher has not heard back from you after two weeks they will contact you via your preferred means to see if you wish to take part and arrange a meeting.

### **Further information and contact details**

If you would like any further information about this research, please contact me (the researcher):

**Emma Minns**

The Department of Health and Psychological Wellbeing

Aire Building, University of Hull

Cottingham Road

Hull

HU6 7RX

Telephone: 07926566489 **(please leave a message if the call is not answered and the researcher will get back to you)**

E-mail: [e.l.minns@2015.ac.uk](mailto:e.l.minns@2015.ac.uk)

**This research project is being supervised by:**

Dr Tim Alexander and Dr Pete Fleming

The Department of Health and Psychological Wellbeing

Aire Building, University of Hull

Cottingham Road

Hull, HU6 7RX

Telephone: Tim Alexander: 01482 464030; Pete Fleming: 01482 464117

E-mail: [T.Alexander@hull.ac.uk](mailto:T.Alexander@hull.ac.uk); [P.Fleming@hull.ac.uk](mailto:P.Fleming@hull.ac.uk)

Thank you for your time, I hope to hear from you soon!

*Appendix I: Demographic Information Sheet*

Participant Number:



**Information about you**

Please tick

**1. What is your age in years?**

.....

**2. Are you male or female?**

Male  Female  Prefer not to say

**3. Which ethnic group describes you best?**

- |   |  |
|---|--|
| <input type="checkbox"/> White British          | <input type="checkbox"/> Other Asian background    |
| <input type="checkbox"/> Other White background | <input type="checkbox"/> Black Caribbean and White |
| <input type="checkbox"/> Black British          | <input type="checkbox"/> Black African and White   |
| <input type="checkbox"/> Black African          | <input type="checkbox"/> Asian and White           |
| <input type="checkbox"/> Black Caribbean        | <input type="checkbox"/> Other Dual Heritage       |
| <input type="checkbox"/> Other Black background | <input type="checkbox"/> Chinese                   |
| <input type="checkbox"/> Indian                 | <input type="checkbox"/> Traveller                 |
| <input type="checkbox"/> Pakistani              | <input type="checkbox"/> Bangladeshi               |
| <input type="checkbox"/> Other Ethnic Group     | <input type="checkbox"/> Prefer not to say         |

**4. Which relationship status describes you best?**

- Single                       In a relationship

**5. Where do you live?**

- I live with my partner/spouse  
 I live independently  
 I live with my family in the house I grew up in  
 I live in supported housing  
 I live with a friend/friends  
 I live somewhere else. Please tell us more about this:

.....

**6. What is your highest level of education?**

.....

**7. What is your employment status?**

- Employed                       Unemployed

**If you are in employment, what is the nature of your work?**

.....

**8. Around how long have you been a member of a Brain Injury Organisation?**

- Less than 6 months
- 6 months-1 year
- 1-3 years
- 4-6 years
- 7-9 years
- More than 9 years

**9. What type of brain injury do you have?**

.....

**10. How did the brain injury happen?**

.....

**11. When did the brain injury happen?**

.....

**Thank you for completing this questionnaire.**



## Research participants needed!

Hi, my name is Emma!

I am doing some research as part of the Doctorate in Clinical Psychology course at the University of Hull.

I'm looking at how individuals with a brain injury are treated by their family, friends and wider community after their injury, and whether this is good or bad.

I am also interested in how people with a brain injury feel about being treated this way and how they have reacted towards this treatment.

### What would this involve?

Taking part in this research would involve speaking to me over the phone to check that you understand the study and can take part and then meeting for a 1:1 interview for around an hour to have a chat about your experiences of how you have been treated.

By taking part in this research you will be helping to contribute to our knowledge of people's social experiences after brain injury.

If you are interested in taking part and would like to know more, please contact the researcher: **Emma Minns**

**07926566489 (If unanswered please leave a message and the researcher will get back to you)**

[e.l.minns@2015.hull.ac.uk](mailto:e.l.minns@2015.hull.ac.uk)



**Thank you for your interest!**

*Appendix K: Semi-structured Interview Schedule*

**General**

- How did your brain injury happen?
- How old were you when your brain injury happened?

**Family members**

1. How do you feel that your family members and friends have treated you since your head injury?

**P:** Can you tell me about a time when you think you have been treated positively by your family and friends?

**P:** Can you tell me about a time when you think you have been treated negatively by your family and friends?

2. Did being treated in this way make you act or think differently about having a head injury?

**P:** How did being treated in this way make you feel?

**P:** Did you do anything differently as a result of being treated this way?

**Community**

3. How do you feel that members of the public have treated you since your head injury?

**P:** Can you tell me about a time when you think you have been treated positively by members of the public since your head injury?

**P:** Can you tell me about a time when you think you have been treated negatively by members of the public since your head injury?

4. Did being treated in this way make you act or think differently about having a head injury?

**P:** How did being treated in this way make you feel?

**P:** Did you do anything differently as a result of being treated this way?

### **Feelings**

5. How has the way people have treated you made you feel?
6. How do you feel about the individuals that have made you feel this way?
7. Would you like to do anything to change the way people treat other individuals with a brain injury in the future?

### **Change over time**

8. Over time, do you feel like your feelings towards how people have treated you has changed?
9. Over time, do you feel like your feelings towards having a brain injury has changed?

### **Sense of self**

10. How do you view yourself in light of how people have treated you since your head injury?

### **In-group dynamics**

11. How has being part of Headway changed the way you view yourself in relation to your head injury?

**P:** How have you found listening to other people's experiences of having a brain injury?

**P:** How has it been meeting other individuals that have had a brain injury?

### **Closing questions**

12. Is there anything you would like you say about your experiences of how people have treated you since your head injury that you have not had chance to say?

**P= Prompts**



**Thank you for talking to me today.**

**If you feel like you might need further support after speaking to me then please see below for sources of support that may be of use to you.**

If you have any questions or problems regarding taking part in the research, then you can contact me: 07926566489

If you are concerned about your health and well being you may want to discuss this with your family or friends or speak your General Practitioner.

Below are a list of organisations that help people who have had brain injuries that you may also find useful:

**Headway Hull and East Rising Organisation**

Offers advice, support and guidance

[www.headwayhero.org.uk](http://www.headwayhero.org.uk)

Free Helpline: 0808 800 2244

**PAUL for Brain Recovery**

Offers, advice, support and guidance

[www.paulforbrainrecovery.co.uk](http://www.paulforbrainrecovery.co.uk)

To speak to the team: 01482 620229

### *Appendix M: Epistemological Statement*

The role of the researchers own experiences, including their assumptions and views can shape how they come to study the world and the type of research they adopt. This can influence our ontological and epistemological positions and lead to different types of research been utilised to produce different types of knowledge. It is therefore important to understand our own positions and views as this allows us to critically evaluate our research and the reasons for choosing certain methodologies.

It is likely that the experiences of individuals with an ABI will be very different from person to person even though they share this umbrella term. Moreover, it also likely that individuals will experience stigma differently and that this will be influenced by life experiences, views, values, beliefs, social relationships and perceptions. This may therefore lead to different interpretations and meanings being attributed to similar experiences. Therefore, the view of the researcher is that individuals are experts in their own experiences and knowledge of how they view the world. Thus, research is a mechanism which allows us to explore experiences in order to learn and understand phenomena. This is something which is missed when we begin quantifying and reducing these experiences in quantitative research and the researcher therefore takes a post-positivist approach to research.

Given the researchers position it was decided that a qualitative exploratory method would be adopted, namely, Interpretative Phenomenological Approach (IPA) Moreover, given the lack of research in this area it is believed that this

exploratory approach will add to our knowledge on the experiences of stigma amongst individuals with an ABI. However, the researcher recognises that IPA relies on double hermeneutics whereby the participants' experiences are understood through the lens of the researcher. Thus, meaning that the researchers own experiences, views and assumptions are an integral part of the research process. It is therefore important to be aware of these assumptions and for these to be managed reflexively. The researcher recognises that they were drawn to researching empowerment in an ABI population as they have an interest in social injustice and in advocating for vulnerable members of society and hold an assumption that individuals with an ABI may experience positive aspects of stigma. However, this will be managed through the use of supervision where themes and interpretations will be discussed.

## *Appendix N: Reflective Statement*

### *Designing the Research*

It was a workshop in my first year of clinical training, in which individuals with a brain injury shared their experiences, where my interest for this research project was first ignited. I was intrigued by the individual stories, and by the sometimes distressing accounts of how they acquired their injuries. The speakers discussed their experience of negative reactions from others, and how they had struggled to return to a 'normal' life following their injuries. It appeared as though these negative experiences often caused more distress than the brain injury itself. I remember feeling saddened that we live in a society that can treat people so cruelly following such harrowing experiences. However, I was most struck by the bravery and courage shown by the individuals to speak out about their experiences, and the sheer strength and resilience that allowed them to maintain a positive life despite the difficulties they had encountered. From this workshop I knew that I wanted my research to allow individuals with a brain injury to share their stories, and experiences, of how they had been treated following their injuries.

I began by researching stigma in relation to a brain injury population, but soon found myself reading around literature relating to mental health stigma. There was very little research interested in stigma in a brain injury population. This made me even more motivated, and determined, to study this area and add to the limited literature base. I found one particular study very interesting, in which it was suggested that individuals with mental health difficulties can react to

experiencing stigma in different ways, and can become angry and empowered. This immediately reminded me of the individuals who so bravely shared their experiences in the workshop, and how they questioned the discrimination and negative reactions that followed their injuries. It also further reminded me of my undergraduate psychology education. I ran a student-led voluntary service which organised day trips and recreational events for adults with Learning Disabilities (LD). During this time, I encountered the numerous difficulties faced by those living with a LD, but also the incredible inner strength which allowed them to live a positive and meaningful life. I realised that I had a real passion in advocating for vulnerable members of society, and for helping individuals to rewrite their narratives from a perspective that encompassed their strength and resilience. As a result, I began developing research ideas which would allow me to explore the experience of stigma in a brain injury population, and how individuals responded to stigma. Ultimately, it was through supervision that my enthusiastic, yet sometimes a little confused, thoughts and ideas were developed into plausible and realistic research questions.

I did, however, encounter numerous dilemmas whilst designing this research. The most pertinent of these was challenging my own assumptions concerning the importance of focussing solely on positive experiences. It became clear that by focussing solely on the positive outcomes associated with experiencing a brain injury I was in danger of minimising the struggles faced on a daily basis by those living with an ABI. This led me to the idea of researching the dialectical nature of experiencing stigma, and how positive and negative experiences may interact.

## *Research Methodology*

I was passionate about exploring individual's experiences in a curious and open manner, and to adopt methodology which would allow participants to become the experts of their own experiences. It was clear that this research lent itself to a qualitative approach. I found this an exciting yet daunting prospect, as it seemed far removed from the search for scientific truth associated with undergraduate psychology. I was also mindful of the fact that qualitative research would only allow for a small number of voices to be heard, but felt like the potential to acquire rich and meaningful data on a neglected research area outweighed this limitation. Despite my initial trepidations, I threw myself into this new challenge and soon began attending brain injury support groups. Not only did this allow me to forge initial relationships, which would later prove instrumental to recruiting potential participants, but I was also able to gauge whether my research would be of interest to those with brain injuries. I found that having this initial direct contact with survivors, and hearing their positive feedback, and desire to take part in research of this nature, was a great motivating factor, which helped me to begin the process of obtaining ethical approval.

### *Obtaining Ethical Approval and Data Collection*

I felt relieved that my research only required university ethical approval, after hearing the lengthy and time consuming process associated with obtaining NHS ethics. I was excited to hear that my project proposal had received ethical approval from the university ethnics committee following only minor

amendments. I wasted no time, and enthusiastically began recruiting participants for my study. I was conscious about beginning recruitment in a timely manner in order to continue the momentum that had been fostered by attending numerous support groups. I gave out posters, and through developing a close relationship with the secretary of the group I managed to get my recruitment poster printed in the monthly newsletter. It was encouraging to see my poster published in the newsletter which was sent to hundreds of people across the area. It appeared as though my initial enthusiasm was well-founded, as I soon began receiving interest from potential participants, and was amongst the first researcher in my cohort to conduct an interview. However, it soon became apparent that the majority of the individuals coming forward for my research unfortunately did not meet the inclusion criteria. At this point in the research I began to panic that I would not recruit enough participants, and considered loosening my strict criteria. However, through supervision I was able to re-evaluate the importance of the criteria, and instead looked at different avenues from which I could recruit. This meant submitting an amendment to my ethical approval, and starting to forge networks with other organisations further afield.

During the interview process I found it difficult to leave my clinical 'hat' at the door, and to be simply present in the moment. I found myself listening to the most difficult, and rewarding, moments of a person's life with no expectations to create formulations or set collaborative goals. Through this process I learnt the power of listening, and allowing a person to explore their own experiences, something which I believe will positively influence my future clinical career.

### *Systematic Literature Review (SLR)*

Initially, I struggled to find an area of research for my SLR that linked to my empirical paper, and that had not already been done. However, during the interviews for my empirical research a number of participants discussed the difficulties associated with reintegrating into the community following their injuries. Conversely, participants also highlighted the need, and importance, of good social support following their injuries, and how this can result in positive outcomes. I became interested in peoples experiences of reintegrating into their communities following brain injury. Following an initial scoping search of the literature I was overwhelmed by the number of studies relating to numerous different variables that had been found to affect community integration. It became apparent that a systematic literature review that integrated these findings would be useful to highlight factors that are predictive of community integration. It would also help to identify those who are more vulnerable to achieving poor levels of community integration and isolation following their injuries. Hearing personal accounts of such difficulties during the interviews for my empirical research definitely helped to bring the journals in my SLR to life. This acted as a motivational tool during the long process of integrating and synthesising such a large amount of data.

### *Report Writing*

Although I had previous experience of writing academic assignments, I found myself daunted by the prospect of writing my thesis portfolio. In part, this was due to feeling a sense of responsibility to accurately portray the experiences of



the participants in my study, and to get things 'right'. However, I was able to reflect on this process in supervision, and in my research journal. I came to realise that I was approaching my qualitative study in the same way as I have approached quantitative research in the past, by searching for a 'right' and 'true' answer. Through recognising this, I was able to put my concerns, and the need to find the 'truth', to one side and let the data speak for itself. This allowed me to fully immerse myself in the data analysis and report writing process, and it became a much more enjoyable experience.

### *Concluding Reflections*

As this research journey draws to an end, I find myself reflecting on the overall experience of designing and conducting my own research. I continue to be passionate about this research area, and providing a platform for individuals with brain injuries to share their stories. Through this process I have learnt about the complexities and interactions associated with human experiences. I will continue to be open to the spectrum of individual's experiences in their entirety, encompassing both positive and negative experiences, in order to gain a more comprehensive understanding of such experiences.

I am indebted to the participants who took part in this research. I am humbled and grateful for the experience of being welcomed into somebody's home and sharing with them the most difficult, and positive experiences of their lives, and to connect with them and share moments of humour and sorrow. I have relearned the importance of listening without judgement or motive, and of providing people with a space to explore their own experiences and feelings. At times this

process of connecting with participants led to the realisation that these experiences could occur in anyone's life, which resulted in a sense of feeling vulnerable. This may result from rejecting the dehumanising view of people with brain injuries, and recognising them as people with human experiences.

I have become more aware of my own assumptions and values, which has made me realise the importance of conducting both research, and clinical work, that are in-line with these values in order to maintain interest and motivation.