

THE UNIVERSITY OF HULL

**An exploration of self-compassion, acceptance and third-wave  
psychological approaches for people with brain injuries and  
neurological conditions**

being a thesis submitted in partial fulfilment of the requirements  
for the degree of  
Doctor of Clinical Psychology  
in the University of Hull

By

Jade Ambridge  
BSc (Hons) Psychology, University of York

June 2018

## **Acknowledgements**

I would like to express my gratitude to the participants, their families and their clinicians for taking the time to complete this survey, without whom this thesis would not have been possible. I also pay gratitude to the services and charities that have supported me in the process of recruitment, and welcomed me at groups and meetings.

I would like to acknowledge my supervisors, Pete and Lauren, for their continuous and unwavering support. Thank you for being bringing such a wealth of knowledge to this project, and for your enthusiasm right from the start. I am also grateful to Tim, whose speedy email replies were always appreciated and kept anxiety at bay.

Finally, I would like to thank all of my family and friends. My mum for her endless support and for always being so excited to read anything I have written. My dad for his humour and ability to always keep me grounded. My grandparents for their belief in me throughout my life. My friends for their encouragement, for sticking by me despite distance, and for reminding me that there is a life outside of psychology. A special thanks goes to Jen for her ability to be both a source of serious support, and of silly jokes. And to my fellow trainees, for the fun, peer support, and the knowledge that we have been in the same boat through all of this.

## Overview

This portfolio thesis has three parts: a systematic literature review, an empirical report and supporting appendices.

**Part One:** A systematic literature review in which empirical papers utilising Acceptance and Commitment Therapy for people with neurological conditions and acquired brain injuries are reviewed for effectiveness for psychological flexibility and wellbeing. A systematic database search identified sixteen studies to be reviewed. Methodological considerations of studies were considered, and their findings were examined using narrative synthesis. Clinical implications and suggestions for future research are discussed.

**Part Two:** An empirical paper combining qualitative and quantitative methodologies to explore the implications of feeling personally responsible for a brain injury. The quantitative component aimed to examine the relationship between perceived responsibility for injury and shame, and whether self-compassion moderated this relationship. The qualitative data was analysed thematically to explore participants' experiences of shame, responsibility and self-compassion. The findings are discussed in relation to theory and implications for clinical practice and future research.

**Part Three:** Appendices supporting the systematic literature review and the empirical paper, and a reflective statement on the research process.

**Overall word count (excluding appendices): 26,109**

## Table of Contents

Section	Page
Acknowledgements	2
Overview	3
Table of contents	4
List of tables and figures	5
<b>Part One: Systematic literature review</b>	
Abstract	8
Introduction	9
Method	14
Results	28
Discussion	44
References	52
<b>Part Two: Empirical paper</b>	
Abstract	60
Introduction	61
Method	69
Results	76
Discussion	89
References	99
<b>Part Three: Appendices</b>	
Appendix A: Reflective statement	104
Appendix B: Author guidelines for submission to ‘Neuropsychological Rehabilitation’	110
Appendix C: Data extraction form	114
Appendix D: Quality checklist	115
Appendix E: Quality assessment results	117
Appendix F: Author guidelines for submission to ‘Brain Injury’	118
Appendix G: Advertisement for recruitment	123
Appendix H: Participant information sheet	124
Appendix I : Staff/family member information sheet	127
Appendix J: Participant consent form	130
Appendix K : Staff/family consent form	131
Appendix L: Participant debriefing page	132
Appendix M: Confirmation of ethical approval	133
Appendix N: Demographic Questionnaire	146
Appendix O: Self-Compassion Scale (Short-form)	148
Appendix P: Responsibility Item	149
Appendix Q: State Shame and Guilt Scale	150
Appendix R: Hospital Anxiety and Depression Scale	151
Appendix S: Awareness Questionnaire	153
Appendix T: Qualitative questions	155
Appendix U: Example of coding process in thematic analysis	156
Appendix V: Epistemological statement	157

## List of Tables and Figures

<b>Part One: Systematic literature review</b>		<b>Page</b>
Figure 1: The ACT Hexaflex		10
Figure 2: Summary of article selection process		16
Table 1: Summary of study characteristics and key findings		20
Table 2. Summary of measures used by reviewed papers		34
<b>Part Two: Empirical paper</b>		
Figure 1. The Y-Shaped Model of Rehabilitation		64
Table 1: Visual representation of hypothesised relationships between variables		68
Table 2: Demographic characteristics of overall sample		77
Table 3: Mean scores and standard deviation of each variable for overall sample		79
Table 4: Inter-correlations between predictor variables		80
Table 5. Multiple linear regression illustration		83
Table 6: Super-ordinate themes and descriptions of corresponding sub-ordinate themes with example quotes, identified using thematic analysis of participants' responses to seven open questions.		84
<b>Part Three: Appendices</b>		
Table 1: Quality assessment results		117
Table 2: Example of thematic analysis coding process		156

**Part One**  
**Systematic Literature Review**

J. M. Ambridge<sup>a\*</sup>, P. Fleming<sup>a</sup>, L. Henshall<sup>b</sup>

*<sup>a</sup>Doctorate In Clinical Psychology Programme, Faculty of Health Sciences,  
Aire Building, University of Hull, Hull, HU6 7RX.*

*<sup>b</sup>York House, Brain Injury Rehabilitation Trust, Heslington Road, York,  
YO10 5BN*

\*Corresponding Author – Email address; [j.ambridge@2015.hull.ac.uk](mailto:j.ambridge@2015.hull.ac.uk),  
Telephone number: 01482 464106

This paper is written in the format ready for submission to  
Neuropsychological Rehabilitation. Please see Appendix B for Author  
Guidelines.

**Word count (excluding abstract, references and tables): 9,475**

*A review of the effectiveness of Acceptance and Commitment Therapy (ACT) for psychological flexibility and wellbeing in individuals with neurological difficulties*

**Abstract**

Acceptance and Commitment Therapy (ACT) is a psychological therapy which aims to develop “psychological flexibility”, a group of skills which help individuals to accept difficult thoughts and experiences that are out of their control, whilst striving to engage in valued behaviour. Its focus on acceptance is an effective approach for people experiencing chronic health problems, in which distress related to one’s condition can be common. There has been growth in the application of ACT for people with neurological conditions, and this paper aimed to systematically review the literature on the effectiveness of ACT interventions for the psychological flexibility and wellbeing of people with neurological conditions. 16 studies were reviewed to assess methodological quality, and intervention effectiveness was synthesised narratively. Psychological wellbeing and psychological flexibility measures were both considered. The results indicated that ACT may be an effective intervention for improving the psychological wellbeing and flexibility of people with neurological conditions; however, further research utilising more rigorous methodologies is needed before ACT can reliably be compared with other well-established therapies to firmly establish its effectiveness for this population. The perceived effectiveness of ACT does not depend on condition type, but effectiveness is enhanced if individual sessions are provided over longer time periods with more therapist contact.

**Keywords**

Systematic review; effectiveness; Acceptance and Commitment Therapy; neurological conditions; psychological wellbeing; psychological flexibility



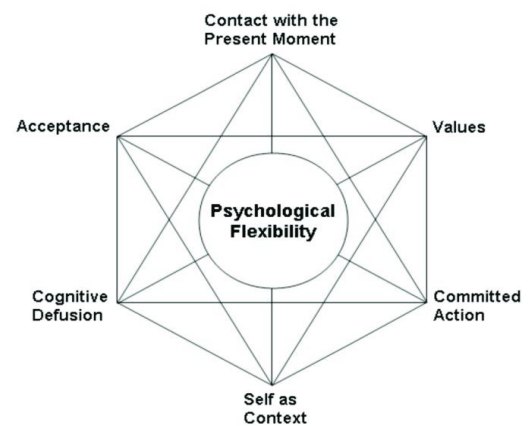
## **Introduction**

Acceptance and Commitment Therapy (ACT) is one of several psychological interventions which have been categorised as “third wave” behavioural psychological therapy. Traditionally, Western forms of behavioural psychological therapy have been broken down into three “waves”, or general systems of rules, assumptions and practices (Öst, 2008). The first wave focused primarily on the reduction of “problematic” behaviours and emotions, and utilised principles of classical behavioural conditioning (Hayes, 2016). However, some argue that this approach is limited as it does not target any internal psychological desires, cognitions or processes associated with problematic behaviours (Holmes et al, 2002). As a result, the second wave propelled the development of therapies such as Cognitive Behavioural Therapy (CBT), which acknowledged a person’s thoughts, feelings and cognitive processes (Beck, 2011), without abandoning the recognisably important behavioural principles of first-wave methodologies. These approaches emphasised the benefit of challenging unhelpful thoughts to help to alter negative core beliefs (Beck, 2011).

Although second wave therapies are effective for reducing mental health difficulties and improving quality of life (Beck, 2011), they are subject to criticism. First and second wave approaches can be seen to quantify human struggle into compartmentalised systems and models, which may not account for all contextual factors (Öst, 2008). Indeed, some argue that challenging thoughts is a process which individuals find difficult and provides no added value to therapy (Longmore & Worrell, 2007). Third wave approaches have begun to recognise the importance of how an individual interprets their context and events, and the consequences of this for wellbeing (Kangas & McDonald, 2011). These newer approaches have drawn from traditional viewpoints of Tibetan Buddhism, mindfulness and compassion, to develop therapies

such as Compassion-Focused Therapy (CFT), Mindfulness-Based Cognitive Therapy (MBCT), and ACT.

ACT recognises first and second wave therapies, but has distinctions which differentiate it from being a part of either of these earlier approaches. ACT draws upon Relational Frame Theory (RFT), which suggests that humans constantly make associations between events and words to form a basis for our understanding of the world (Hayes et al, 2001). Therefore, psychological events and difficulties exist as a result of language and how a person interacts with this context. If combinations of language and cognition lead to inability to change unhelpful behaviours, this can result in “psychological inflexibility” (Bluett et al, 2014). The goal of ACT is to increase psychological flexibility through the targeting of 6 core processes, combined into the ACT “Hexaflex” (Fig. 1); contact with the present moment to experience the world directly and view behaviour as in control of the person; acceptance of events without unnecessary attempts to change them; cognitive defusion to step back from difficult thoughts and reduce their literal quality; seeing oneself as an “observer” of thoughts (self as context), feelings and experiences; recognising what a person values as important in life; and taking committed action to live a life that aligns with recognised values (Hayes, 2016). These six processes overlap, but can be grouped into mindfulness and acceptance processes (acceptance, defusion, contact with the present moment and self as context) and commitment and behaviour change processes (contact with the present moment, self as context, values and committed action) (Ciarrochi, Bilich, & Godsell, 2010). The opposite of psychological



**Figure 1.** *The ACT Hexaflex (Hayes, 2004)*

flexibility is termed psychological inflexibility or “experiential avoidance”, to explain a person’s avoidance of thoughts, feelings, memories, physical sensations and other personal experiences, to the point of unavoidable harm (Hayes, 2004). During ACT, the therapist will work flexibly with the client on both of these processes, through the non-linear use of language (such as metaphors and stories), with the ultimate goal of developing psychological flexibility (Hayes et al, 2006).

ACT has been used widely to effectively reduce psychological distress in many populations. Öst (2014) conducted a meta-analysis of 60 randomised-controlled trials which used ACT with individuals with varying psychological difficulties and psychiatric diagnoses, including depression, psychosis, anxiety, substance misuse, personality disorders and stress. While a small body of research meant that this review could not reliably conclude that ACT is yet a well-established treatment for any specific disorder, it did describe its individual effectiveness for depression, psychosis, Obsessive-Compulsive Disorder (OCD), stress, anxiety and substance misuse. Indeed, Bluett et al (2014) carried out a review of the use of ACT for individuals with anxiety and OCD. This review of 63 studies revealed a significant correlation between ACT processes and the reduction of anxiety and OCD symptoms. A-Tjak et al (2015) meta-analysed 39 randomised controlled trials which applied ACT to psychological health difficulties, and demonstrated that it was consistently more effective than treatment as usual or placebo. Despite evidence for the effectiveness of ACT for mental health difficulties, the majority of reviews and studies consistently conclude that further research which uses stringent methodologies, such as large sample sizes, control groups and double-blind assessment, needs to be carried out. This will further reinforce the reliability of the evidence base for ACT for mental health difficulties, before it can be compared to very well-established therapies such as CBT (Bluett et al, 2014).

ACT is being increasingly applied with individuals with physical and chronic health conditions. Research suggests that ACT is particularly appropriate for these populations as its aim is to increase psychological flexibility, rather than directly reduce distress (Hayes, 2016). Its focus on striving towards valued behaviour while accepting difficult thoughts and feelings, rather than attempting to alter them as in CBT, may be particularly effective for individuals experiencing health conditions in which it is often realistic to have negative beliefs and distress about an illness which is out of a person's control (Graham et al, 2016). For example, Veehof and colleagues' (2011) review included 10 randomised controlled trials of ACT for chronic pain. They demonstrated a "small-to-medium" improvement to psychological wellbeing, which had similar effects to CBT. Graham et al (2016) reviewed 18 studies which used ACT with chronic and long-term conditions, including HIV, cancer and epilepsy. Overall, these reviews concluded that the effects of ACT for these populations were promising, and individually studies report great benefits for improved wellbeing and quality of life for participants. However, the reviews highlighted that a lacking number of randomised controlled trials and high quality studies meant it was again difficult to conclude that ACT is a yet well-established intervention for physical and chronic conditions.

There is a limited but ever-increasing body of evidence which uses ACT when working psychologically with people with neurological difficulties and conditions, such as acquired brain injuries (ABI) including traumatic brain injury (TBI), epilepsy, multiple sclerosis and stroke, amongst others. Despite the fact that many individuals with ABI and neurological conditions have only mild to moderate brain and cognitive impairments (Busch & Alpern, 1998), they frequently experience high levels of anxiety, depression and psychological distress (Seel & Kreutzer, 2003). CBT, which targets thoughts and behaviours, is an effective intervention for anxiety and depression in many clinical populations (Stewart & Chambless, 2009), but ABI and neurological conditions

(Waldron Casserly & O’Sullivan, 2013). For example, Hodgson et al (2005) found CBT was no more effective in reducing social anxiety and self-esteem in people with ABI than no intervention. This may be because interventions such as CBT require extensive cognitive capacity and motivation, which some people with ABI and neurological conditions may not possess as a result of their condition (Bradbury et al, 2008). Additionally, the nature of neurological conditions may mean the individual has to make adjustments to their life to adapt to the long-term and possibly unremitting nature of their conditions, which may be a difficult process to accept (Kangas & McDonald, 2011). Therefore, although CBT can be helpful for people with ABI, it may also be pertinent to consider alternative psychological interventions which could appropriately treat these populations with their different requirements and capacities, as well incorporate the role their brain injury might play in contributing to their distress. ACT may therefore be useful due to its focus on increasing psychological flexibility rather than altering psychological events and thoughts, in a similar way to its perceived applicability in chronic and long-term conditions (Kangas & Macdonald, 2011).

Previous literature reviews have evaluated the use of ACT in some conditions, including epilepsy (Graham et al, 2016). Additionally, Ashworth, Evans & McLeod recently described studies using ACT for ABI in their chapter within *Neuropsychological Rehabilitation: The International Handbook* (Wilson et al, 2017). However, these reviews did not include other neurological conditions and difficulties, may be missing studies published since their searches, and did not describe in detail the impact of each intervention on participants’ measures of psychological wellbeing and flexibility. To the author’s knowledge, no previous systematic review of the literature has exclusively examined the effectiveness of ACT for improving psychological flexibility and wellbeing amongst people with common non-degenerative neurological

conditions, including TBI, ABI, epilepsy, multiple sclerosis, migraine, stroke, brain tumour, and functional neurological disorders.

### **Research question**

What is the effectiveness of Acceptance and Commitment Therapy interventions for the mental wellbeing and psychological flexibility of individuals with neurological difficulties?

### **Methods**

#### ***Search Protocol***

Five online databases were selected and searched up to and including February 2018. These used the EBSCOhost service to access PsycINFO, MEDLINE, PsycARTICLES, CINAHL Complete and Academic Search Premier. Retrieved articles were manually searched for additional references. Search terms were generated by listing alternatives for “neurological conditions” and individual conditions. This paper did not consider the more rapid degenerative diseases or conditions, such as Parkinson’s or dementias. Boolean operators were used to broaden the search. The alternative acronym of “ACT” for “Acceptance and Commitment Therapy” was not used within the final search as this produced an excess of irrelevant results.

The following terms were used for the online database search:

"brain tumo\*" or "multiple sclerosis" or "ms" or "traumatic brain injur\*" or "tbi" or "acquired brain injur\*" or abi or encephalitis or hypoxia or "neurological condition\*" or "neurological difficult\*" or "neurological disorder\*" or "neurological problem\*" or epilep\* or migraine\* or stroke\* or "Parkinson's Disease\*" or "functional neurological condition\*" or "functional neurological disord\*" or "psychogenic neurological

condition\*" or "psychogenic neurological disord\*" or "non epileptic attack disord\*" or "non epileptic seizure\*" or "functional stroke" or "functional limb weakness"

AND

“Acceptance and Commitment Therap\*”

The inclusion and exclusion criteria for the review were;

Inclusion:

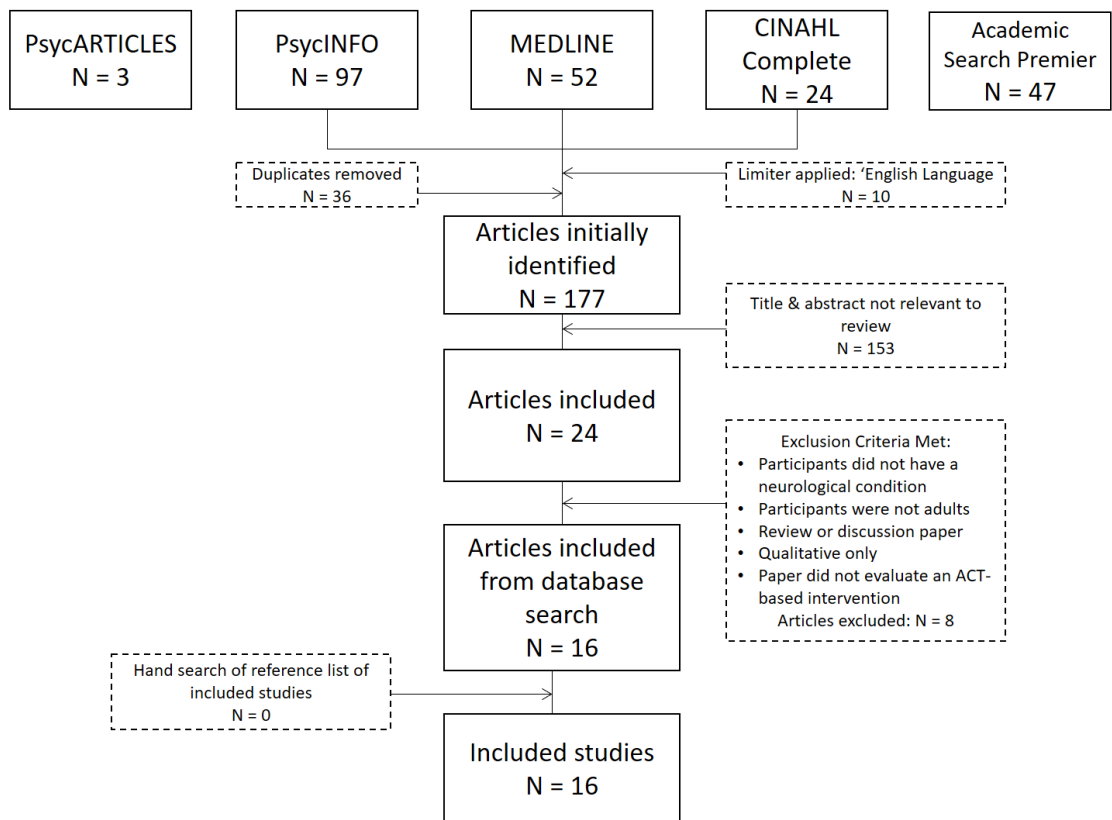
- Paper evaluated the use of an ACT intervention
- Paper evaluated at least one measure of psychological or mental wellbeing
- Participants were adults with a neurological condition (TBI, ABI, epilepsy, multiple sclerosis, migraine, stroke, brain tumour and functional neurological disorders)

Exclusion:

- Participants did not have a neurological condition
- Participants had a diagnosis of dementia, Parkinson’s Disease or other degenerative neurological condition
- Participants were not adults, or their injury/condition was from before the age of 18 years old
- Review or discussion papers
- Papers evaluated qualitative results only
- Paper did not evaluate an ACT-based intervention
- Paper not in English language

- Paper not peer reviewed

All abstracts and titles were initially read. Articles which did not meet the exclusion criteria met were read in full and re-evaluated using the inclusion criteria. Figure 2 illustrates the article selection process. Sixteen papers were included in the review at the end of the selection process.



**Figure 2.** Article selection process flowchart.



### ***Data Extraction***

The data extraction form can be found in Appendix C. Data was extracted on the basis of the following points;

1. Research aims and design (including presence of control or comparison group).
2. Characteristics of participants (including sample size and type of neurological condition).
3. Procedure and nature of intervention (including session number, session delivery and relation to traditional ACT protocol).
4. Findings and results relating to psychological wellbeing and flexibility, and how this was measured.

### ***Quality Assessment***

This review utilised the Downs and Black (1998) checklist to measure study quality. This checklist was chosen because it was found to have good reliability for randomised and non-randomised controlled trials of healthcare interventions. The item “Was an attempt made to blind those measuring the main outcomes of the intervention?” was removed because therapists carrying out psychotherapy interventions cannot be blinded due to the nature of their involvement in the work (Dewhurst, Novakova & Reuber, 2015). The final checklist used to assess the quality of studies reviewed therefore contained 21 items (see Appendix D) with a minimum possible score of 0 and a maximum possible score of 21, where higher scores imply greater quality. 4 of the studies were quality assessed by a second rater to assess inter-rater reliability and to minimise the risk of bias on reporting. There was a 97% agreement between the two raters. The two raters discussed any discrepancies between ratings to reach a consensus score. The final quality ratings for individual items can be found in Appendix E, and total scores are summarised in Table 1. It is important to highlight that quality scores obtained did not determine a study’s inclusion in the review, but findings from the quality assessment are considered during the narrative synthesis.

### ***Data Synthesis***

Due to the nature of the studies reviewed, a narrative synthesis methodology was used. A meta-analysis was not considered to be appropriate because studies varied too widely in design, participant numbers and quality scores. Therefore, findings and data related to the effectiveness of interventions for mental health and wellbeing will be summarised, compared and combined through descriptive text, rather than statistics. As outlined by Popay (2006), narrative synthesis uses words and text to summarise the results of a synthesised review, in order to “tell a story”. To conduct this narrative

synthesis, this review firstly used a database search to retrieve relevant studies. It then organised the findings to describe any patterns in how ACT operates for the different conditions, considered factors that might explain these patterns, and finally examined the strength of the evidence.

**Table 1.** Summary of study characteristics and key findings

Study (Authors; Year; Country)	Aim(s) of study	Characteristics of Participants (Gender; Age; Sample size)	Design	Type of neurological condition /disorder/ difficulty	Description of ACT intervention	Control/ comparison group	Measurement of psychological or mental wellbeing/quality of life	Key findings	Quality Score
<b>Bomyea, Lang &amp; Schnurr (2017; USA)</b>	To describe the response of patients with TBI to an ACT intervention.	Participants were military veterans diagnosed with an anxiety or depressive disorder using Diagnostic and Statistical Manual-Version 5 (DSM-V) criteria. N = 129	RCT	TBI	12 x individual weekly sessions of ACT	12 x individual weekly sessions of Present Centred Therapy (PCT)	SF-12 (PW) BSI-18 (PW) Pre-treatment (T0) Mid-treatment (T1) Post-treatment (T2)	Significant improvement on BSI over time for both interventions (Model 1 p=.001; model 2 p<.01) Significant improvement on SF-12 (mental health subscale) over time for both interventions (Model 1 p<.01 model 2 p<.001) No significant improvement on SF-12 (physical health subscale) for both groups (Model 1 p=.24; model 2 p=.46)	20
<b>Dewhurst, Novakova &amp; Reuber (2015; UK)</b>	To explore the effectiveness of an ACT psychological intervention for patients with epilepsy; to assess whether ACT	Participants selected by researchers, all patients at the same clinic (76.7% female; 48% employed; 19-75 age range). N = 60	Cohort	Epilepsy	6-20 x weekly/ fortnightly sessions of ACT delivered individually or in the presence of a	None	NDDI-E (PW) SF-12 (PW) GAD-7 (PW) Pre-treatment (T0) Post-treatment (T1) Follow-up 6 month (T2)	Significant improvement in NDDI-E scores between T0 (Mean=19, IQR=4.25) and T1 (Mean=15.5, IQR=7) (p<.001). Significant improvement in GAD-7 scores between T0 (Mean=15, IQR=6.25) and T1 (Mean=7, IQR=12.25)	15

treatment is cost-effective.

family member/friend by a Cognitive Behavioural Psycho-therapist with training in ACT.

( $p < .001$ ). Significant improvement in Mental Health Summary of SF-12 scores between T0 (Mean=25.89, IQR=17.49) and T1 (Mean=38.39, IQR=18.11) ( $p < .001$ ).

<b>Dindo et al (2012; USA)</b>	To assess whether an ACT-based intervention would reduce anxiety and depression levels and improve psychological flexibility for patients with migraine.	Participants recruited via advertisements  N = 45	RCT	Migraine	5 hour 1 x day ACT training with migraine education workshop delivered as a group of 5-8 patients N=31(97% female; mean age 32.5 years)	Treatment as Usual (TAU) N=14 (86% female; mean age 33.5 years)	HRSD (PW) IDAS (PW) SF-36 (PW) Pre-treatment (T0) 2 weeks post-treatment (T1) 6-week follow-up (T2) 12-week follow-up (T3)	Significant difference in HRSD scores at T3 between ACT group (Mean=12.9) and TAU group (Mean=22.2) ( $p < .001$ ); more improvement in ACT group. Significant difference in IDAS scores at T3 between ACT group (Mean=45.7) and TAU group (Mean=60.8) ( $p < .001$ ); more improvement in ACT group. Significant difference in HRSD scores at T3 between ACT group (Mean=60.1) and TAU group (Mean=46.8) ( $p < .001$ ); more improvement in ACT group.	17
<b>Graham et al (2015; UK)</b>	To deliver an ACT intervention for a patient with post-stroke anxiety.	Participant recruited from hospital department (Male; aged in early 40s).	Case study	Stroke	9 x ACT sessions delivered individually by a Trainee Clinical	None	DASS-21 (PW) AAQ-II (PF) Measured every session	Reduction in DASS-21 Stress, Anxiety and Depression subscale scores between Session 1 (Stress=36; Anxiety=24; Depression=18) and Session 9 (Stress=20;	11

N=1

Psychologist

Anxiety=8; Depression=12).  
Improvement in AAQ-II scores between Session 1 (25) and Session 9 (13).

<b>Graham et al (2017; UK)</b>	To outline and evaluate the effectiveness of an ACT intervention for a patient with Functional Movement Disorder.	Participant recruited from neuropsychological department (Female; aged early 20s). N=1	Case study	Functional Movement Disorder	6 x ACT sessions delivered individually	None	CORE-10 (PW) AAQ-II (PF) Pre-treatment (T0) Post-treatment (T1)	Reduction in CORE-10 scores between T0 (21/40) and T1 (2/40) (RCIa=5.91) and on the AAQ-II between T0 (31/49) and T1 (12/49) (RCIa=6.22).	14
<b>Graham, O'Hara &amp; Kemp (2018, UK)</b>	To use an ACT intervention to reduce symptom interference through improving psychological flexibility.	Participants recruited from a neurorehabilitation service (No gender demographics; Age range 18-65 years). N=8	Cohort	Functional neurological disorders	6 -10 x ACT sessions delivered individually weekly or fortnightly.	None	CORE-10 (PW) AAQ-II (PF) Pre-treatment (T0) Post-treatment (T1)	Large improvement in CORE (d=1.70) for participants; four participants showed reliable improvements. Medium improvement in AAQ-II (d = .77) for participants, with reliable improvement in 4 cases.	17
<b>Harrison et al (2017; UK)</b>	To examine the efficacy of a telephone combined CBT and ACT self-management programme	Participants recruited from pool of participants from previous by the same authors (57.1% female; Age range 37-65	Cohort	Multiple Sclerosis	8 x weekly sessions of guided CBT and ACT with 3 hours of telephone support	None	AEQ (PF) CPAQ-8 (PF) Pre-treatment (T0) Post-treatment (T1) 1 month follow-	3 of 7 participants showed significant improvements in pain severity and interference; no summary statistical results provided.	15

	for patients with multiple sclerosis.	years). N = 7					up (T2) 3 month follow-up (T3)		
<b>Huddleston et al (2018, USA)</b>	To assess the feasibility and effectiveness of a 1 day ACT plus migraine education workshop.	Participants were veterans with diagnosis of migraine and depression recruited through advertisements (36% female; age range 18-75 years). N=25	Cohort	Migraine	One-day x ACT plus migraine education workshop delivered to groups of 4-6 participants.	None	HRSD (PW) HRSA (PW) IDAS (PW) CPAQ-8 (PF) AAQ-II (PF) Pre-treatment (T0) 3-month follow-up (T1)	Significant improvement in HRSD scores between T0 (Mean=20.09; SD=3.55) and T1 (Mean=12.14; SD=4.63) and in HRSA scores between T0 (Mean=23.62; SD=3.88) and T1 (Mean=17.05; SD=3.25) (p<.01). Almost significant reduction in IDAS between T0 and T1 (p<.06). Significant improvement in CPAQ scores between T0 (Mean=41.71; SD=16.08) and T1 (Mean=50.19; SD=19.15) (p<.01) and in AAQ-II scores between T0 (Mean=36.86; SD=7.24) and T1 (Mean=31.33; SD=8.27) (p<.05).	18
<b>Kangas et al (2015; Australia)</b>	To investigate whether an ACT intervention for patients with brain tumours can reduce anxiety and	Participants recruited from oncology hospital department (75% female; age range 30-60 years). N = 4	Cohort	Brain tumour	6 x 90-min weekly sessions of ACT delivered individually. 2 x 90-min fortnightly booster	None	BDI-II (PW) STAI (PW) AAQ-II (PF)  Pre-treatment (T0) Post-treatment (T1) 1 month follow	3 participants no longer met criteria for anxiety or depression at T3.  3 participants' AAQ-II scores improved between T1 and T2.	13

	depression and improve quality of life.				sessions of ACT delivered individually.		up (T2) 3 month follow up (T3)		
<b>Lundgren et al (2006; South Africa)</b>	To develop and evaluate an ACT treatment programme for patients with epilepsy.	Participants recruited from inpatients and outpatients at the same epilepsy clinic in South Africa, all participants considered to be below poverty line and 9 required an interpreter (52% female; age range 21-55 years). N=27	RCT	Epilepsy	4 x sessions of ACT;  2 x individual sessions 2 x group sessions N=14	4 x sessions of supportive therapy (ST) over 5 weeks; 2 x 3 hr group sessions 2 x 1.5 hr individual sessions N=13	SWLS (PW) Pre-treatment (T0) Post-treatment (T1) 6 month follow-up (2) 12 month follow-up (T3)	Significant difference in SWLS scores between T0 and T3 for ACT (T0 Mean=3.79, SD=1.73; T3 Mean=.62, SD=.86) and ST groups (T0 Mean=5.84, SD=3.56; T3 Mean=5.80, SD=3.51; T3 Mean=5.80, SD=3.51) (p<.001); more improvement in ACT group.	17
<b>Lundgren et al (2008; India)</b>	To evaluate and compare the effects of ACT and yoga treatments for epilepsy.	Patients from a community outpatient clinic selected by researchers (33% female; 18-55 year age range; all required an interpreter to deliver intervention).	RCT	Epilepsy	2 x sessions of ACT; 1 x delivered individually; 1 x delivered in a group setting of 6-8 participants. N = 8	4 x sessions of yoga treatment.  N = 10	SWLS (PW) Pre-treatment (T0) Post-treatment (T1) 6 month follow up (T2) 12 month follow up (T3)	Strong effect from T0 to T1 for ACT group on SWLS; these changes were not significant over time to T2 and T3 (F(3,27) = 1.75). Significant increase in SWLS for yoga group between T0 and T3 (F(3,21) 4.49).	15



		N = 18							
<b>Mo'Tamedi, Rezaemaram &amp; Tavallaie (2012; Iran)</b>	To examine whether an ACT intervention can reduce pain, disability and emotional distress for patients with chronic headache.	Participants recruited from a headache clinic in Iran (100% female; age range 19-55 years). N = 30	RCT	Chronic headache/ Migraine	MTAU combined with 8 x weekly ACT sessions over 2 month period, delivered in a group. N = 11 (4 participants did not complete treatment)	Medical treatment as usual (MTAU) Group  N = 15	STAI-T (PW) Pre-treatment (T0) Post-treatment (T1)	Significant difference in STAI scores between T0 and T1 for MTAU group (T0 Mean=44.21, SD=5.08; T1 Mean=44.67, SD=4.72) and ACT group (T0 mean=43.5, SD=5.7; T1 Mean=28.73, SD=10.79) (p<.001); more improvement in ACT group.	18
<b>Nordin &amp; Rorsman (2012; Sweden)</b>	To evaluate the effect of an ACT group intervention for patients with multiple sclerosis and related distress.	Participants recruited from neuropsychological department (Age range 36-55; 80% female)  N = 20	RCT	Multiple Sclerosis	5 x ACT sessions delivered in a group over 15 weeks  N = 10	5 x sessions of relaxation training (RT) delivered in a group over 15 weeks  N=10	HADS (PW) BDI (PW) AAQ-II (PF)  Pre-treatment (T0) Post-treatment (T1) 3-month follow-up (T2)	Significant difference in HADS depression scores between T0 and T1 for ACT (T0 Median=5; T1 Median=3) and RT (T0 Median=7; T1 Median=4) groups (p<.05); RT showed larger decline. Significant improvement in AAQ-II scores between T1 (Median=49) and T2 (Median=52) for ACT group (p<.05). Significant reduction in BDI scores for ACT group between T0 (Median=13) and T1 (Median=12) (p<.05).	27

<b>Pakenham et al (2017; Australia)</b>	To pilot and evaluate the feasibility of an ACT-based resilience group intervention for patients with multiple sclerosis.	Participants recruited via advertisements (72.9% female; age range 49.3 years). N = 31	Cohort	Multiple Sclerosis	7 x weekly group sessions of a combined ACT and resilience training programme 1 x booster session 5 weeks later N=17 in each group	None	DASS-21 (PW) MSAQ (PF) DDS (PF) MAAS (PF) Valued Living Questionnaire Pre-treatment (T0) Post-treatment (T1) 3-month follow-up (T2)	Significant improvement in depression on DASS-21 between T0 (Mean=12.10, SD=4.11) and T1 (Mean=10.68, SD=3.23) (p<.05). Significant improvement in stress on DASS-21 between T0 (Mean=14.89, SD=5.05) and T2 (Mean=12.82, SD=3.76) (p<.05). Significant improvement in MSAQ scores between T0 (Mean=69.43, SD=6.04) and T1 (Mean=72.17, SD=4.53) (p<.05).	18
<b>Sheppard et al (2010, USA)</b>	To examine the effectiveness of an ACT workshop for people with MS.	Participants recruited from hospital department (80% female; mean age 53.13 years) N = 15	Cohort	MS	5 hour one day x ACT workshop delivered to a group	None	BDI-II (PW) SF-36 (PW) MAAS (PF) Pre-treatment (T0) Post-treatment (T1)	Significant reduction in BDI scores between T0 (Mean=19.40; SD=10.68) and T1 (Mean=11.09; SD=11.41) No significant improvement in MAAS between T0 and T1 (p>.05). No significant improvements in Mental Component of SF-36.	16
<b>Whiting et al (2017; Australia)</b>	To examine the feasibility of ACT in TBI, investigate its	Participants recruited from an outpatient rehabilitation service (both	Case study	TBI	7 x sessions of ACT delivered in a dyad.	None	DASS-21 (PW) HADS (PW) SF-12 (PW) PANAS (PW) AAQ-ABI (PF)	P1 showed reliable change (RCI) for PANAS between T0 and T1 (p<.05) but no significant changes for other measures.	14

therapeutic effect, and review the suitability of measures, treatment protocol and delivery method.

male; aged 19 and 29).  
N = 2

AAQ-II (PF)  
Pre-treatment (T0)  
Post-treatment (T1)

P2 showed reliable change (RCI) for an improvement in DASS-21, PANAS, HADS, AAQ-ABI scores, and SF-12 between T0 and T1 ( $p < .05$ ).

*Notes for Table 1*

PW – Psychological Wellbeing; NDDI-E – Neurological Disorders Inventory for Epilepsy; SWLS – Satisfaction with Life Scale; SF-36 – Short Form Health Survey; DASS-21 – Depression Anxiety Stress Scales; BDI-II – Beck Depression Inventory; STAI-T – State Trait Anxiety Inventory; BSI-18 – Brief Symptom Inventory; HRSD – Hamilton Rating Scale for Depression; HRSA – Hamilton Rating Scale for Anxiety; IDAS – Inventory of Depression and Anxiety Symptoms; HADS – Hospital Anxiety and Depression Scale; GAD-7 – Generalised Anxiety Disorder Scale

PF – Psychological Flexibility; AAQ-II – Acceptance and Action Questionnaire; AAQ-ABI – Acceptance and Action Questionnaire for Acquired Brain injury – CPAQ-8 – Chronic Pain Acceptance Questionnaire; AEQ – Avoidance-Endurance Questionnaire; MSAQ-8 – Multiple Sclerosis Acceptance Questionnaire; MAAS – Mindful Attention Awareness Scale; DDS – Drexel Defusion Scale

## **Results**

### *Overview of included studies*

#### **Characteristics of participants**

10 of 16 reviewed studies were conducted in either the UK or the USA. Three studies were carried out in Australia, one in India, one in Iran, one in South Africa and one in Sweden. Some participants in both of Lundgren et al's papers (2006; 2008) required an interpreter to deliver the intervention to participants in their own language, and Mo'Tamedi, Rezaemaram and Tavallaie (2012) translated their intervention materials into Farsi for participants. Participants were mostly opportunistically recruited through selection of outpatients and inpatients from a hospital department or service, and their clinicians were sometimes also the researchers that delivered and reported the intervention. Three studies used advertising and screening methods to recruit participants (Dindo et al, 2012; Pakenham et al, 2017; Huddleston et al, 2018). Harrison et al (2017) recruited from the same pool of participants from a previously published study by the same lead author (Harrison et al, 2015). Two of three case studies examined only male participants (Graham et al, 2014; Whiting et al, 2017) and one study involved all female participants (Mo'Tamedi, Rezaemaram & Tavallaie, 2012). The other studies ranged from 33% female (Lundgren et al, 2008) to 86% female (Dindo et al, 2012). Graham, O'Hara and Kemp (2018) described limited demographic data.

#### **Design and procedure**

Six studies used a randomised-controlled trial (RCT) design, wherein participants were randomly assigned to an intervention or control group (Lundgren et al, 2006; 2008; Mo'Tamedi, Rezaemaram & Tavallaie, 2012; Nordin & Rorsman, 2011; Dindo et al, 2012; Boomyea, Lang & Schnurr, 2017). Of these, numbers of participants ranged from

N=18 (Lundgren et al, 2008) to N=129 (Boomyea, Lang & Schnurr, 2017). The control group was sometimes offered an alternative psychologically-informed intervention, such as Person-Centred Therapy (Bomyea, Lang & Schnurr, 2017) and supportive therapy (Lundgren et al, 2006). Other control groups received interventions with no psychological element, such as relaxation training (Nordin & Rorsman) and yoga (Lundgren et al, 2008), while Mo'Tamedi, Rezaemaram and Tavallaie (2012) and Dindo et al (2012) used (medical) treatment as usual to compare the outcomes of their interventions against.

Seven studies used a cohort design (Sheppard et al, 2010; Dewhurst, Novakova & Reuber, 2015; Kangas et al, 2015; Harrison et al, 2016; Pakenham et al, 2017; Graham, O'Hara & Kemp, 2018; Huddleston et al, 2018), and numbers of participants ranged from N=4 (Kangas et al, 2015) to N=60 (Dewhurst, Novakova & Reuber, 2015). For the three studies utilising a case study or dyad design; Graham et al (2014; 2017) examined one participant, whilst Whiting et al (2017) evaluated two participants in a dyad.

All studies collected pre and post-treatment data, and Graham et al (2015) and Bomyea, Lang and Schnurr (2017) also collected data throughout the intervention. Over half (N=9) of studies collected follow-up data, time periods of which ranged from 2 weeks (Dindo et al, 2012) to 12 months following intervention (Lundgren et al, 2006). The median time interval in which participants were followed-up was 9 weeks.

Overall, studies varied widely in their length and intensity of intervention, as well as number of participants and method of therapy delivery. Although this helpfully allowed this review to comment on and explore the effectiveness of ACT across several different contexts, it also makes it difficult to draw reliable conclusions about the global effectiveness of ACT due to the limited number of studies within each of these categories.

## **Intervention nature and delivery methods**

Seven of 16 reviewed studies delivered their intervention to participants as a group. The size of groups ranged from N=2 (Whiting et al, 2017) to 17 participants (Pakenham et al, 2017). Some studies provided one-day workshops (Sheppard et al, 2010; Dindo et al, 2012; Huddleston et al, 2018), whilst others delivered sessions over a period of weeks or months (Mo'Tamedi, Rezaemaram & Tavallaie, 2012; Nordin & Rorsman, 2012; Whiting et al, 2017; Pakenham et al, 2017). Six studies provided face-to-face individual sessions of ACT either weekly or fortnightly; the highest number of individual sessions was by Dewhurst, Novakova and Reuber (2015), who provided a maximum of 20 sessions, whilst the lowest was 6 sessions from both Kangas et al (2015) and Graham and colleagues (2017). Lundgren et al (2006; 2008) used a combination of group and individual ACT sessions. Harrison et al (2017) was the only study to provide part of their intervention over the telephone. Some papers combined ACT with elements of other programmes; Dindo et al (2012) and Huddleston et al (2018) provided a migraine education workshop alongside ACT training, Pakenham et al (2017) combined ACT with a resilience training programme, and Harrison et al (2017) combined ACT with Cognitive Behavioural Therapy (CBT).

## ***Measures***

As mentioned, a core aim of ACT is to increase psychological flexibility and reduce experiential avoidance (Hayes et al, 2012; see Figure 1). This can help individuals to feel better equipped to deal with difficult thoughts, feelings and experiences, and choose actions which reflect what the person values in life. Although ACT can and does have a positive impact on pre-defined psychiatric symptoms, such as those of depression (Ost, 2014), it does not aim to reduce these in the way that other therapies such as CBT might target. Therefore, the use of measures which focus on psychological flexibility skills,

such acceptance and mindfulness, are often more appropriate than using psychiatric symptom-based measures when evaluating the effectiveness of ACT (Bond et al, 2011). Despite this, just over half (N=10) of the reviewed studies included a psychological flexibility measure. The remaining studies included measures of psychological wellbeing, such as depression, anxiety and general mental health measures. Therefore, this review will outline and compare both approaches to outcome measures, and will from this point refer to traditional psychiatric symptom-related measures as “psychological wellbeing”.

### **Psychological flexibility**

Seven of the ten papers which used a psychological flexibility measure utilised the Acceptance and Action Questionnaire-Version 2 (AAQ-II; Bond et al, 2011), making it the most common measure of psychological flexibility in this review. The AAQ-II is a 7-item one-factor measure of psychological flexibility, which uses a 7-point Likert scale in which a higher score equates to poorer flexibility. In addition to the AAQ-II, Whiting et al (2017) used the Acceptance and Action Questionnaire - Acquired Brain Injury (AAQ-ABI; Whiting et al, 2014), a 9-item scale which assesses acceptance and avoidance of thoughts which might occur following a brain injury. It uses a 5-point Likert scale, and again higher scores indicate psychological inflexibility.

Harrison et al (2017) used a modified version of the Avoidance-Endurance Questionnaire (AEQ; Hasenbring, Hallner & Rusu, 2009), which assesses avoidance and endurance behaviours in response to chronic pain, and the Chronic Pain Acceptance Questionnaire (CPAQ-8; McCracken, Vowles & Eccleston, 2004), a 20-item measure of engagement and willingness to accept pain. Both measures use a 6-point Likert scale, and higher scores suggest more psychological flexibility. Pakenham et al (2017) used several psychological flexibility measures, including a multiple sclerosis-specific

measure of acceptance (Multiple Sclerosis Acceptance Questionnaire (MSAQ; Pakenham & Fleming, 2011), which has 7 items and uses a 7-point Likert scale, the Mindful Attention Awareness Scale (MAAS; Brown & Ryan, 2003) to measure mindfulness, the Valued Living Questionnaire (Wilson et al, 2010) to measure values, and the Drexel Defusion Scale (DDS; Forman et al, 2012) to measure ability to cognitively defuse. Sheppard et al (2010) also administered the MAAS. Of these studies, only Harrison et al (2017) did not also measure psychological wellbeing.

There is a perspective that psychological flexibility is a fundamental aspect of health, as it takes into account a range of abilities, such as ability to adapt to different situations and maintain balance (Kashdan & Rottenberg, 2010). However, psychological flexibility can also be considered to be less well understood and more abstract than other measures, which may make its validity harder to determine. Additionally, the papers in this review used many different types of psychological flexibility outcome measure that often focus on different parts of the Hexaflex. Therefore, it is important to acknowledge the variability in this type of measure.

### **Psychological wellbeing**

Ten papers measured symptoms of depression and/or anxiety. Graham et al (2015), Whiting et al (2017) and Pakenham et al (2017) used the Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995), a 21-item 3-point scale measure of depression, anxiety and stress. The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), a 14-item scale which measures anxiety and depression, was used by Whiting et al (2017) and Dindo et al (2012), and the Inventory of Depression and Anxiety Symptoms (IDAS; Watson et al, 2007) was also used by Dindo et al (2012) and Huddleston et al (2018). The Beck Depression Inventory-Version 2 (BDI-II; Beck, Brown & Steer, 1996) was used by two papers (Kangas et al, 2015; Sheppard et al,



2010) to measure depression, and utilises 21 items with a 4-point scale. Dindo et al (2012) and Huddleston et al (2018) gave the Hamilton Rating Scale for Depression (HRSD; Hamilton, 1960), and Huddleston used the Hamilton Rating Scale for Anxiety (HRSA; Hamilton, 1959), to measure depression and anxiety respectively. The State Trait Anxiety Inventory (STAI; Spielberger et al, 1983), a 20-item measure of anxiety which uses a 4-point Likert scale, was used by Kangas et al (2015) and Mo'Tamedi, Rezaiemaram and Tavallaie, 2012. Dewhurst et al (2015) provided the Generalised Anxiety Disorder Assessment (GAD-7; Spitzer et al, 2006), which includes 7 items on a 4-point scale to measure anxiety.

A further nine studies used general measures of mental health. Five (Sheppard et al, 2010; Dindo et al, 2012; Dewhurst, Novakova & Reuber, 2015; Whiting et al, 2017; Bomyea, Lang & Schnurr, 2017) gave the Full or Short-Form Health Survey (SF-36 or SF-12; Ware et al, 2008; Jenkinson et al, 1996) which has 36 or 12 equivalent items to assess mental wellbeing. Graham and colleagues (2017; 2018) gave participants the CORE-10 (Barkham et al, 2012), a 10-item measure of psychological distress. Finally, Lundgren et al (2006; 2008) used the Satisfaction with Life Scale (SWLS; Diener et al, 1995), a 5-item 7-point Likert Scale measure of the positive or negative judgments a person has towards their life. A total of nine studies collected information about both psychological wellbeing and psychological flexibility. Table 2 summarises the measures used by each paper included in this review.

**Table 2.** *Summary of measures used by reviewed papers.*

	<b>Measure</b>	<b>Study/ies</b>
<b>Psychological Flexibility</b>	AAQ-II	Nordin & Rorsman (2012); Graham et al (2015); Whiting et al (2017); Graham et al (2017); Huddleston et al (2018); Graham, O’Hara & Kemp (2018)
	AAQ-ABI	Whiting et al (2017)
	AEQ	Harrison (2017)
	CPAQ-8	Harrison (2017); Huddleston et al (2018)
	MSAQ	Pakenham et al (2017)
	DDS	Pakenham et al (2017)
	VLQ	Pakenham et al (2017)
	MAAS	Sheppard et al (2010); Pakenham et al (2017)
<b>Psychological Wellbeing</b>	NDDI-E	Dewhurst, Novakova & Reuber (2015)
	SF-12	Dewhurst, Novakova & Reuber (2015) Bomyea, Lang & Schnurr (2017); Whiting et al (2017)
	SF-36	Sheppard et al (2010)
	SWLS	Lundgren et al (2006); Lundgren et al (2008)
	DASS-11	Graham et al (2015); Pakenham et al (2017); Whiting et al (2017)
	HADS	Nordin & Rorsman (2012); Whiting et al (2017)
	BDI-II	Sheppard et al (2010); Nordin & Rorsman (2012); Kangas et al (2015)
	STAI-T	Mo’Tamedi, Rezaieemaram & Tavallaie (2012);
	HRSD	Dindo et al (2012); Huddleston et al (2018)
	HRSA	Huddleston et al (2018)
	IDAS	Dindo et al (2012); Huddleston et al (2018)
	CORE-10	Graham et al (2017)
	BSI-18	Bomyea, Lang & Schnurr (2017);
	GAD-7	Dewhurst, Novakova & Reuber (2015); Graham, O’Hara & Kemp (2018)
	PANAS	Watson (1988)

### ***Effectiveness of intervention***

#### **Traumatic Brain Injury**

Traumatic brain injuries (TBI) are usually the result of external force impact, such as following a road traffic incident, a fall, being involved in a physical fight or during dangerous sports (Whiting et al, 2017). Whiting et al (2017) delivered 7 sessions of ACT to two male participants with diagnoses of TBI that occurred between 17-20 months prior to the study. Participants were aged 19 (P1) and 29 (P2), and were recruited through selection of patients from an outpatient neurorehabilitation service. The researchers delivered 7 manualised sessions of ACT to the dyad, focusing on areas

such as values, acceptance, committed action and defusion, and measured both psychological flexibility and depression and anxiety pre- and post-intervention. P2 demonstrated significant improvement to both psychological flexibility and mental wellbeing, whilst P1 only showed clinically significant improvement to low mood. Despite this, qualitatively P1 felt he had made improvements in committed action and did achieve goals set at the start of therapy. The authors believed that receiving the intervention as a dyad allowed each participant to have sufficient time with the therapist whilst also benefitting from group processes. However, its lower quality rating reflects this study's lack of control group and the small number of participants, making it difficult to generalise these findings to the larger TBI population.

Bomyea, Lang and Schnurr (2017) used a control group in their study which compared 12 weekly individual sessions of ACT (N=62) with 12 sessions of Person-Centred Therapy (PCT) (N=67). Participants in both groups either did or did not have a diagnosis of TBI, to compare the potential influence of the presence of a TBI for the effectiveness of ACT for an individual. The ACT intervention followed a manualised approach and considered areas such as awareness, acceptance, committed action and values. Researchers measured psychological symptoms pre-, mid- and post-treatment, and overall found improvements in both groups, and that presence of TBI was not a predictor of treatment effectiveness. The study concluded that people with TBI need not receive different treatment for psychological difficulties, and that ACT is effective for this population. Its higher quality rating is indicative of the methodological strengths of this study with its large sample. However, it did not measure psychological flexibility and instead largely focused on whether the treatment reduced some of the more physical implications of TBI, such as mobility issues and degree of disability. This makes it difficult to conclude whether the intervention helped participants to develop

psychological flexibility, and whether this could have helped them to manage the enduring physical limitations that can be present post-TBI.

Overall, these studies show that ACT can be an effective intervention for people with TBI, and people with TBI need not receive differential treatment. These studies both delivered individual sessions of ACT over a similar time period, making it more reliable to compare and conclude from both of their results. However, this can only be concluded for ACT delivered via individual sessions, and it is unclear how long effectiveness lasted for. Moreover, Bomyea, Lang and Schnurr (2017) examined a significantly higher number of participants than Whiting et al (2017), and both studies used different measures, making it difficult to reliably compare all aspects of these studies and reliably conclude that ACT is effective for all cases of TBI.

## **Epilepsy**

Epilepsy is a condition characterised by recurring seizures which can cause damage to the brain (Dewhurst, Novakova & Reuber, 2015). Lundgren and colleagues (2006; 2008) carried out two RCTs for people with epilepsy, using the same measures of psychological wellbeing and following the Hayes and Stroschal (2005) treatment protocol. The first (2006) compared a combination of 4 individual and group sessions of ACT to 14 participants, with 4 sessions of supportive therapy to 13 participants. Participants were patients from the same epilepsy service in South Africa, and considered to be from a lower socio-economic background. Measures were recorded pre, post-treatment and at 6- and 12-month follow-up, and findings indicated that the ACT group showed more significant improvements to wellbeing scores for every time-point compared to controls. Lundgren et al (2008) then compared the effects of two sessions of ACT (N=8) with four sessions of yoga (N=10). This study recognised a strong improvement to psychological wellbeing from pre- to –post-treatment for the

ACT group, but this change was not significant. Indeed, a significant improvement was shown for the yoga group for the same measure. Lundgren et al's studies received similar satisfactory quality ratings as they contained similar sample sizes and account for their use of RCT methodology and applicability of findings.

Dewhurst, Novakoa and Reuber (2015) carried out a cohort study with 60 (76.7% female) participants aged 19-75 years. A CBT therapist with ACT training delivered between 6-20 individual sessions, which contained epilepsy education and exercises related to values, committed action, compassion and mindfulness. Anxiety and depression were measured at baseline, post-treatment and at 6-month follow-up, and there was a significant improvement in both between baseline and post-treatment. The researchers also demonstrated an almost significant reduction in frequency of epileptic seizures. However, the study commented on the limitations of lack of control group and thus exploratory nature of the study which is reflected by the moderate quality rating, and that the presence of only one therapist can make it difficult to separate therapist and treatment effects.

Collectively ACT has been shown here to be effective for epilepsy, especially when delivered individually over a longer period of time. ACT was less effective than a course of yoga when considering only psychological wellbeing (Lundgren et al, 2008), but this study delivered fewer sessions to fewer participants, which might have impacted the effectiveness and longevity its ACT intervention. The participants in Dewhurst, Novakova and Reuber's (2015) study received a high number of individual sessions, which could explain the more positive outcomes for participants' psychological wellbeing, in comparison to Lundgren et al's (2006; 2008) findings.

### **Brain Tumour**

Brain tumours are a collection of abnormal cells in the brain, and can be cancerous or

non-cancerous (Vescovi, Galli & Reynolds, 2006). Kangas et al (2015) carried out the only study of ACT for participants with a brain tumour in this review. They adapted a manualised ACT protocol for people with brain tumours, and provided 8 weekly and fortnightly individual sessions to four majority female (75%) participants. Participants had been diagnosed with cancer between 6.1 years and 6 months prior to the study, although this paper did not report information about the grade or severity of tumours. Participants also met the criteria for a diagnosis of either a depressive or anxiety disorder. Anxiety, depression and psychological flexibility were measured pre-, post-treatment and at 1- and 3-month follow-up; following treatment, 75% of participants no longer met criteria for a diagnosis of anxiety or depression and had increased psychological flexibility. The study considered whether the medical treatment for brain tumours, which can cause fatigue and cognitive difficulties, could have made it difficult for participants to commit to consistent ACT practice, especially between sessions at home. Additionally, this study had only a small number of participants, and its clinical nature may make it difficult to apply the findings to clinicians working with patients with brain tumours in other settings, such as time-limited work. Therefore, the quality of this study was rated lower than others.

Overall, ACT was effective for the majority of participants with brain tumours in this study. It would be helpful to explore whether the severity and grade of tumour impacted each participants' ability to engage and sustain the intervention, as this information was not included in this study. Additionally, there was a lack of available studies which utilised ACT for people with brain tumours, which limits the reliability of Kangas et al (2015) and its ability to apply its findings and conclusions to all patients with this condition.

## **Stroke**

Strokes occur when the blood supply to parts of the brain is cut off (Go et al, 2014). Graham and colleagues (2015) assessed the effectiveness of ACT for a male in his early 40s who experienced a stroke several months prior to the study. The participant was provided with 9 sessions of ACT by a Trainee Clinical Psychologist, which followed techniques and interventions from Harris (2009) and Hayes and Smith (2005) and focused on areas such as acceptance and defusion, and spent time developing an extensive psychological formulation. Depression, anxiety and psychological flexibility were measured after every session. The results indicated a reduction in all measures between sessions 1 and 9, and the participant had also returned to work which had been a value-orientated goal. This study was limited as it only considered one participant, and wondered whether the intervention might have been impacted by the fact that it was delivered by a novice clinician. This study received the lowest quality rating of all papers included in this review, which is reflective of its case study methodology and lack of clear follow-up data. As there are no other studies available which used ACT for stroke, it is important to be cautious when generalising the findings of this case study to the entire population, due to the likelihood that individual factors affecting the participant could have affected findings.

## **Multiple Sclerosis**

Multiple Sclerosis (MS) is a disease of the nervous system which can lead to lesions, inflammation and damage to the brain (Lassmann, 2018). Sheppard et al (2010) examined the effectiveness of a one-day group ACT workshop for 15 (80% female) participants with MS. The intervention included psychoeducation about MS and essential ACT components such as acceptance, values-clarification, mindfulness and cognitive defusion. Depression was measured pre- and post-treatment, and reduced

significantly following intervention. However, no significant improvements were found for psychological flexibility, specifically for the development of mindfulness skills, meaning that ACT was not effective for psychological flexibility in this study. This study received a higher quality rating as it clearly illustrated participant characteristics and provided detailed statistical analysis reports. However, Sheppard et al (2010) did not collect any follow-up data, making it difficult to ascertain whether the effects of the workshop would be long-lasting. Psychological flexibility can be considered to be a longer-term skill, which needs to be practiced in order for improvements and developments to be evident. Therefore, it may be unlikely for improvements to yet be noticeable by participants immediately after this workshop and before being able to practice the skills on an everyday basis.

Nordin and Rorsman (2012) carried out an RCT comparing five group ACT sessions (N=11) with five group sessions of relaxation training (RT) (N=10) for people with MS. The ACT group followed a similar protocol to Sheppard et al (2010), but this study measured both psychological wellbeing and flexibility pre-treatment, post-treatment and at 3-month follow-up. The ACT group demonstrated significant improvements in depression from pre- to post-treatment, and psychological inflexibility levels from pre-treatment to follow-up. The RT group overall showed more decline in combined depression and anxiety symptoms than the ACT group, although this was not maintained at follow-up. Therefore, the study concluded that ACT appears to be more effective in the long-term for people with MS, and its quality rating supports its reliability. Nevertheless, this study would have benefited from a wait-list control group to examine validity of findings, as the two treatments differed in homework and daily practice which may make it hard to directly compare their effects.

Harrison et al (2017) supported seven participants through a home-based eight session self-administered ACT intervention, with three total hours of telephone support.



The treatment plan included MS education, acceptance, and values and defusion work, and was approved by several individuals with MS diagnoses, demonstrating utilisation of service user involvement in intervention development. The study measured psychological flexibility pre- and post-treatment and at 1-month and 3-month follow-up, and reported that three participants showed improvements in psychological flexibility and acceptance. The remaining participants either reported no changes or worsened levels of psychological flexibility. The quality rating of this study was similar to the average quality of the other reviewed papers. This study commented that the ACT sessions were relatively complex to be conducted at home, and wondered whether eight sessions was too short to be effective for patients with MS and if increased therapist interaction could have helped with this. The study also did not compare outcomes or report detailed information and statistical analyses, making it difficult to draw valid conclusions or directly compare its outcomes with the other MS studies.

In sum, ACT can be effective for reducing depression and anxiety and improving psychological flexibility for some people with MS; however, it appears that ACT tends to be less effective for MS if it is delivered with minimal therapist contact. The described studies also did not all collect follow-up data, use control groups or examine a great number of participants.

## **Migraine**

Migraines are a neurological disorder characterised by episodes of severe headaches, nausea and hypersensitivity (Ferrari et al, 2015). Mo'Tamedi, Rezaieamaram and Tavallaie (2012) carried out an RCT in Iran to compare 8 weekly group sessions of ACT (N=11) with Treatment as Usual (TAU) (N=15) for females with diagnoses of migraine. The ACT intervention focused on the core processes within the ACT hexaflex, and anxiety was measured pre- and post-treatment. The ACT group

demonstrated significantly lower anxiety levels following the intervention than TAU, and the study concluded that ACT was effective for reducing distress, rather than for reducing pain intensity. This paper was rated high quality due to factors such as its use of RCT and detailed statistical analysis reports. However, the study was limited as it was one of the first to adapt an ACT protocol for migraine, which may have meant the intervention was not yet adjusted accordingly. It would have also benefited from a larger sample size to increase the reliability of the findings, and a follow-up measure to assess longevity.

Dindo et al (2012) carried out another RCT comparing TAU (N=14) with a one-day ACT combined ACT and migraine-education workshop (N=31). The workshop briefly focused on the areas of the hexaflex, and depression was measured pre-treatment, 2 weeks post-treatment, and at 6-week and 12-week follow-up. Those in the ACT condition showed more improvement than TAU for depression levels by the final follow-up, and the quality rating of this paper further demonstrates the illustrated effectiveness of ACT over time. However, as there were more participants in the experimental group, it may be difficult to conclude that the difference in final outcomes was solely due to the intervention due to likelihood of confounding participant variables.

More recently, Huddleston et al (2018) delivered another one-day ACT workshop combined with migraine education to 25 participants with migraine. They measured depression, anxiety and psychological flexibility pre-treatment and at 3-month follow-up, and found a significant improvement for all measures following the intervention. This paper also received a high quality rating as a result of its detailed aims and analysis reports. Despite this, the lack of control group in this study may make it harder to combine the findings with the other migraine studies. Huddleston et al (2018) also did not measure immediate post-treatment outcome measure scores; it

would have been helpful to have this data available to further examine whether the effects of their intervention had improved or reduced since the immediate end of the study.

Collectively, ACT appears to effectively improve the psychological flexibility and wellbeing of people with migraines. However, the majority of these studies utilised a one-day workshop and delivered the intervention to a group. There is a likelihood that participants would have been impacted by life changes between the intervention and follow-up, which may impact psychological wellbeing and flexibility. It might have been helpful to extend the follow-up and include a control group to ascertain whether changes were due to the intervention, before concluding that ACT should always be delivered to people with migraine.

### **Functional Neurological Disorders**

People with functional neurological disorders (FND) usually experience neurological symptoms without a clear disease or diagnosis as an explanation (Baek et al, 2017). Graham and colleagues (2017; 2018) conducted two studies using ACT with people with different types of FND. The first (2017) examined the outcome of 6 sessions of ACT for a female with functional movement disorder, characterised by unexplained motor symptoms of tremors and jerks. The intervention focused on improving psychological flexibility through attending to values, mindfulness and meaningful activity. Psychological flexibility and wellbeing were measured pre- and post-intervention, and there was an improvement in all measures by the end of the intervention. However, this study experiences the same limitations and lower quality ratings as the other case studies as the nature of studying one individual means participant effects are high, making it difficult to generalise findings to the rest of the FND population.

Graham, O'Hara and Kemp (2018) then carried out a larger study of 8 participants with varying symptoms of FNDs. They provided between 8-10 individual sessions of ACT which centred on engagement, openness and awareness. The study used the same measures and time-points as the 2017 paper, and demonstrated a large improvement in psychological wellbeing ( $d=1.70$ ), and a “medium effect size” ( $d=.77$ ) for psychological flexibility. These findings reinforce the findings of the 2017 paper and its high quality improves the validity of the overall findings about ACT for FND but the small sample size does make it important to be tentative when applying these results more generally.

Together, these papers indicate the increasing usefulness of ACT for improving the psychological wellbeing and flexibility of people with FND. However, samples were small and it would be useful for this burgeoning research area to continue to examine its effectiveness across more types of FND. It is also important to highlight that these studies were both led by the same author, which could have had implications for the way they chose to design the study and collect data.

## **Discussion**

This review aimed to bring together the research assessing the effectiveness of ACT interventions for the psychological wellbeing and flexibility of people with different types of neurological conditions. The quality of each paper was examined, as well as the design, nature of the intervention delivery and methods of measuring outcomes. All studies utilised self-report methods; one paper measured only psychological flexibility, six measured only psychological wellbeing and nine measured both. Interventions all tended to draw from processes within the ACT hexaflex (Figure 1; Hayes, 2004). Due to heterogeneity of studies, such as number of participants, intervention procedure and design, this review assessed effectiveness using a qualitative narrative synthesis

approach.

This review included 16 papers spanning numerous neurological conditions, including TBI, epilepsy, brain tumour, stroke, MS, migraine and FNDs. The brain tumour and stroke categories contained only one paper as the growing yet currently limited body of research meant a scarcity of available studies, within which there are not consistent rigorous methodologies. Although this may make it difficult to draw firm conclusions about ACT for stroke and brain tumour populations, the findings of Graham et al (2015) and Kangas et al (2015) can still be compared to studies with similar methodologies mentioned in this review. The majority of papers reviewed demonstrated that ACT helped to improve psychological flexibility and psychological wellbeing across neurological conditions. The six RCT studies benefitted from the utilisation of control groups, which varied between the provision of alternative treatments to no treatment in particular. It is important to note the differences between studies which compared ACT with well-established therapeutic approaches, such as Person-Centred Therapy (Bomyea, Lang & Schnurr, 2017) or relaxation techniques (Nordin & Rorsman, 2012), rather than no intervention at all. RCTs which used the former approach are more helpful as they demonstrate that not only is ACT better than doing nothing at all, it appears to be more effective than some established therapies for people with neurological conditions. This review also highlighted that some of the control interventions, such as yoga, were just as effective as ACT interventions (Lundgren et al, 2008). This makes it important to consider all alternatives when offering treatment for psychological wellbeing and flexibility. However, there were no other studies with similar findings to reinforce the validity of yoga over ACT, and ACT has still been shown to be effective compared to some other control interventions.

The cohort design studies concluded similar findings, but lack of control groups and usually smaller sample sizes of this methodology affects reliability of results. The

three case studies reported more detailed results as they often collected data after every session, allowing for analysis of a richer bodies of data. However data was based on a few individuals, making it subject to confounding factors which could have impacted how well participants were able to engage in the intervention, such as whether the person had experienced psychological difficulties prior to their injury, or their coping style. Watson et al (1999) highlighted the different ways people coped with diagnoses of cancer; a “fighting spirit” type would play an active role in challenging their condition and have a positive attitude towards its outcome, while a “helpless” type would assume their cancer could not be controlled and feel threatened by this. Therefore, individual participants in studies such as Graham et al (2015; 2017) are likely to have different coping styles which could impact how much of an active role they play in their rehabilitation, including engaging in an ACT intervention. It is therefore important to be hesitant when applying these results to larger populations of people with neurological conditions. Additionally, not all studies collected follow-up data (Mo’Tamedi, Rezaiemaram & Tavallaie, 2012; Sheppard et al, 2010; Graham et al, 2015; Whiting et al, 2017; Graham et al, 2017; Bomyea, Lang & Schnurr, 2017; Graham, O’Hara & Kemp, 2018). This makes it difficult to conclude whether the ACT intervention was effective in the long-term for conditions such as TBI, stroke, migraine, MS and functional disorders.

The case studies and seven of the cohort and RCT studies provided individual rather than group sessions of therapy. This mode of delivery could have strengthened participant-therapist relationships and resulted in a more person-centred therapy, factors which usually have positive outcomes for therapy (Lambert & Barley, 2001). It is important to consider this when working with people with neurological conditions, who are likely to be affected by additional factors due to the nature of their injury. These might include their condition, its psychological impact, their coping style, adjustment

processes and how much support they have around them (Hoofien et al, 2001). Therefore, studies which provided individual sessions, such as Dewhurst, Novakova and Reuber (2015) and Bomyea, Lang and Schnurr (2017), would be able to tailor sessions to each participant's individual factors, explaining their effective results. This may also explain the less effective outcomes in Harrison and colleagues' (2017) paper, which was the only study to use a self-management intervention with limited telephone support. As components of ACT can be considered complex (Hayes et al, 2001), the participants with MS in this study might have benefitted from more therapist contact to combat any condition-related difficulties with engaging in the intervention independently, such as affected cognition.

By the same note, studies that delivered their intervention to large groups may have struggled to ensure that sessions could be tailored to every group member. For example, both Mo'Tamedi, Rezaiemaram and Tavallaie (2012) and Nordin and Rorsman (2012) delivered multiple sessions of ACT to groups of at least 11 people, which were effective for psychological flexibility and wellbeing for people with migraine and MS, respectively. However, there are several processes within ACT, such as identification of values and goal-setting to take action towards these, which may have been difficult to introduce to a group. Indeed, group studies which only consisted of a one-day ACT workshop (Sheppard et al, 2010; Dindo et al, 2012; Huddleston et al, 2018) and had little or no follow-up data have similar limitations. It would probably have been difficult to identify and work on every participants' values and goals and teach defusion and acceptance techniques, whilst also acknowledging the role of each individual's neurological condition, in one day. These studies also provided no data about achievement of goals, and the longer-term impact of developing psychological flexibility for coping with a neurological condition. However, the group studies did generally demonstrate at least short-term improvements for their participants'

psychological wellbeing and flexibility, which has implications for the utilisation of group-based therapy for people with neurological conditions. Moreover, groups can simultaneously treat more than one patient with fewer clinicians, which also makes them financially valuable to services.

Another consideration of this review was whether each study chose to measure psychological wellbeing, or more traditional psychiatric symptoms such as anxiety or depression levels, collectively described here as “psychological wellbeing”. One of the core aims of ACT is to increase an individual's ability to manage difficult experiences, emotions and thoughts through the cumulative skill of psychological flexibility, rather than directly reduce symptoms (Hayes, 2014). This would suggest the appropriateness of studies delivering ACT to measure psychological flexibility, but this was not the case for 6 of the 16 reviewed papers. Although ACT has a positive impact on difficulties such as anxiety and depression (Öst, 2014), these symptoms need not necessarily have reduced for an ACT intervention to be considered effective. Rather, the person's relationship and response to their difficulties is more important (Hayes, 2014). Perhaps if more studies had chosen to measure psychological flexibility, their findings may have been more valid for describing the participants' experiences of the intervention and better related to the ethos of ACT (Hayes, 2001). Consistent use of similar measures would help in drawing comparisons between studies, as this review relied on comparing different outcomes due to the limited body of literature.

It is also interesting to highlight that only Harrison et al (2017) chose to measure just psychological flexibility. As noted, the underpinnings of ACT would suggest that measuring psychological flexibility is the most effective evaluation of its effectiveness, but the majority of studies in this review who measured psychological flexibility still also measured the more traditional symptoms of psychiatric diagnoses. As ACT is a newer psychological therapy, demonstrating its effectiveness for more familiar



psychological symptoms may make it easier to explain and translate its applicability to those who are less familiar with its underpinnings. This would also allow for the direct comparison of ACT with more well-established therapies, such as CBT, which would be more likely to evidence their effectiveness by the direct reduction of psychiatric symptoms. This principle may help to explain why the majority of studies in this review utilised both ACT-related measures as well as more familiar and widely-used psychological wellbeing measures.

The neurological conditions included in this review varied in their descriptions and functional impact. For example, conditions such as stroke, TBI and epilepsy will affect people differently, depending on which area of the brain has been damaged, severity of damage and range of resulting difficulties. Other conditions such as migraine and MS may demonstrate similar symptoms due to the more predictable trajectory of the conditions, although this will still depend on factors such as condition severity and pre-morbid functioning (Werner & Engelhard, 2007). Nevertheless, all neurological conditions impact cognition, executive functioning, and psychological wellbeing (Seel & Kreutzer, 2003). This review indicates that ACT may be effective and useful for improving the psychological flexibility and wellbeing of people with neurological conditions, and this effectiveness does not appear to be dependent on type of condition. The nature of ACT might make it applicable for people with neurological conditions whose cognitive functioning is affected and thus might struggle to engage in more intricate cognitive techniques that other therapies, such as CBT, often make use of. ACT allows the therapist to adjust its content and focus depending on personal factors, and its emphasis on accepting what is not within the individual's control is especially relevant for all neurological diagnoses. Nevertheless, the studies described in this review experience some limitations which are important to consider when examining how effective ACT can be for this population.

### *Limitations*

Firstly, the use of ACT amongst people with neurological conditions is still a new and growing area. The majority of reviewed studies were published within the past decade and increasingly within the last few years, which hopefully indicates that more high-quality trials will continue to be published in the future. This is to be expected as although ACT has been in development for around 25 years (Hayes et al, 2001), its attention and application did not begin to gain traction until the start of the 21st century (Öst, 2014). As ACT is a newer area of focus, the quality of studies reviewed was varied. The majority (N=10) of reviewed studies did not compare their intervention with a control group, and 7 did not collect follow-up data. This makes it difficult to accurately conclude that the ACT was the sole contributor for participants' improvements, and how long these improvements were maintained for. Varying designs made it challenging to directly compare and contrast each study, as different methodologies will inevitably impact results. The studies tended to recruit participants through opportunity sampling. This means that participants were likely selected by researchers, who were also often their clinicians, based on a considered prediction that they would be able to engage in the intervention. Therefore, participants may be less representative of each neurological condition population, especially for individuals who might be less psychologically minded and thus motivated to engage in psychological therapy.

The number of studies within each condition was low, with stroke and brain tumour containing one reviewed study each (Graham et al, 2015; Kangas et al, 2015). This makes it hard to compare these papers, and the availability of more trials for each condition would have helped with drawing reliable conclusions. All studies used self-report to collect outcome data; although this approach is helpful because it allows participants to directly provide information regarding their experiences, it is limited

because it relies on the provision of valid data. Participants may have wanted researchers to believe that they had made more improvements than they had, perhaps due to social desirability bias, producing exaggerated results. This is especially likely to be the case if the researchers were participants' clinicians whom they had formed good therapeutic relationships with. Additionally, as neurological conditions can affect an individual's cognitive abilities and insight into their condition and capabilities (Bogod et al, 2003), self-report data may not be reflective of other people's experiences of a person with such a condition. This review is also susceptible to publication bias as usually only research meeting certain level of quality will be published and disseminated for public viewing.

Another limitation of this review was that it did not focus on one measurement. A decision was made to comment on both psychological flexibility and wellbeing, as the limited body of research meant there were not enough studies that used the same measure. Commenting on two outcomes allowed this review to evaluate the available ACT interventions for adults with neurological difficulties; however, these measures targeted very different areas of functioning, making it hard to directly compare those studies which did not measure both. This reason, along with the varying quality of studies, led to the decision to take a narrative synthesis approach rather than conduct a meta-analysis. Meta-analysis would have allowed for more statistical analysis of effectiveness, perhaps increasing the ability to draw robust conclusions about the effectiveness of ACT for neurological populations. Based on this, it may have also been useful to explore any qualitative research regarding ACT for people with neurological difficulties, which allows for richer data about participants' experiences and benefits gained from such interventions.

### ***Conclusions and implications and directions for future research***

This review indicates that ACT has the potential to improve the psychological wellbeing and psychological flexibility of people with neurological conditions despite type and functional impact of condition. This review described the application of ACT for several conditions, and concluded these findings for interventions delivered individually and in groups, and across interventions ranging from one-day to longer-term. The interventions tended to have similar content and followed components of the Hexaflex (Hayes, 2001). It is also probable that ACT will be most effective for people with neurological conditions if it is delivered with sufficient therapist contact, and over more than a period of a one-day workshop (Harrison et al, 2016). This information is helpful as research demonstrates that neurological conditions impact quality of life and wellbeing (Seel & Kreutzer, 2003), and ACT will be an appropriate intervention to attend to this (Hayes, 2001). This will hopefully have implications for the future development of manualised ACT interventions that are tailored to the needs of people with neurological conditions, which would be useful for clinicians to refer to when working with these populations. Before this, more studies are needed to further illuminate whether there are parts of ACT which are more effective, and whether these components relate to any specific neurological conditions. Further research would also benefit from the use of randomised-controlled trials with higher numbers of participants, and the consistent collection of follow-up data.

### **References**

- A-tjak, J. G., Davis, M. L., Morina, N., Powers, M. B., Smits, J. A., & Emmelkamp, P. M. (2015). A meta-analysis of the efficacy of acceptance and commitment therapy for clinically relevant mental and physical health problems. *Psychotherapy and Psychosomatics*, 84(1), 30-36.
- Barkham, M., Bewick, B., Mullin, T., Gilbody, S., Connell, J., Cahill, J., & Evans, C. (2013). The CORE-10: A short measure of psychological distress for routine use in the psychological therapies. *Counselling and Psychotherapy Research*, 13(1), 3-13.

- Beck, A. T., Steer, R. A., & Brown, G. K. (1996). Beck depression inventory-II. *San Antonio, 78*(2), 490-8.
- Beck, J. S. (2011). Cognitive-behavioral therapy. *Clinical Textbook of Addictive Disorders*, 474-501.
- Bluett, E. J., Homan, K. J., Morrison, K. L., Levin, M. E., & Twohig, M. P. (2014). Acceptance and commitment therapy for anxiety and OCD spectrum disorders: An empirical review. *Journal of Anxiety Disorders*, 28(6), 612-624.
- Bogod, N. M., Mateer, C. A., & Macdonald, S. W. (2003). Self-awareness after traumatic brain injury: A comparison of measures and their relationship to executive functions. *Journal of the International Neuropsychological Society*, 9(3), 450-458.
- Bomyea, J., Lang, A. J., & Schnurr, P. P. (2017). TBI and treatment response in a randomized trial of acceptance and commitment therapy. *The Journal of Head Trauma Rehabilitation*, 32(5), E35-E43.
- Bradbury, C. L., Christensen, B. K., Lau, M. A., Ruttan, L. A., Arundine, A. L., & Green, R. E. (2008). The efficacy of cognitive behavior therapy in the treatment of emotional distress after acquired brain injury. *Archives of Physical Medicine and Rehabilitation*, 89(12), S61-S68.
- Brown, K. W., & Ryan, R. M. (2003). The benefits of being present: mindfulness and its role in psychological well-being. *Journal of Personality and Social Psychology*, 84(4), 822.
- Busch, C. R., & Alpern, H. P. (1998). Depression after mild traumatic brain injury: a review of current research. *Neuropsychology Review*, 8(2), 95-108.
- Ciarrochi, J., Bilich, L., & Godsell, C. (2010). Psychological flexibility as a mechanism of change in acceptance and commitment therapy. *Assessing mindfulness and acceptance processes in clients: Illuminating the theory and practice of change*, 51-75.
- Dewhurst, E., Novakova, B., & Reuber, M. (2015). A prospective service evaluation of acceptance and commitment therapy for patients with refractory epilepsy. *Epilepsy & Behavior*, 46, 234-241.
- Diener, E. D., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment*, 49(1), 71-75.
- Dindo, L., Recober, A., Marchman, J. N., Turvey, C., & O'Hara, M. W. (2012). One-day behavioral treatment for patients with comorbid depression and migraine: a pilot study. *Behaviour Research and Therapy*, 50(9), 537-543.
- Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology & Community Health*, 52(6), 377-384.
- Ferrari, M. D., Klever, R. R., Terwindt, G. M., Ayata, C., & van den Maagdenberg, A. M. (2015). Migraine pathophysiology: lessons from mouse models and human genetics. *The Lancet Neurology*, 14(1), 65-80.

- Go, A. S., Mozaffarian, D., Roger, V. L., Benjamin, E. J., Berry, J. D., Blaha, M. J., & Fullerton, H. J. (2014). Heart disease and stroke statistics—2014 update: a report from the American Heart Association. *Circulation*, *129*(3), e28-e292.
- Graham, C. D., Gillanders, D., Stuart, S., & Gouick, J. (2015). An acceptance and commitment therapy (ACT)–based intervention for an adult experiencing post-stroke anxiety and medically unexplained symptoms. *Clinical Case Studies*, *14*(2), 83-97.
- Graham, C. D., Gouick, J., Krahe, C., & Gillanders, D. (2016). A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions. *Clinical Psychology Review*, *46*, 46-58.
- Graham, C. D., Stuart, S. R., O’Hara, D. J., & Kemp, S. (2017). Using acceptance and commitment therapy to improve outcomes in functional movement disorders: a case study. *Clinical Case Studies*, *16*(5), 401-416.
- Graham, C. D., O’Hara, D. J., & Kemp, S. (2018). A case series of Acceptance and Commitment Therapy (ACT) for reducing symptom interference in functional neurological disorders. *Clinical Psychology & Psychotherapy*.
- Hamilton, M. A. X. (1959). The assessment of anxiety states by rating. *Psychology and Psychotherapy: Theory, Research and Practice*, *32*(1), 50-55.
- Hamilton, M. A. X. (1967). Development of a rating scale for primary depressive illness. *British Journal of Clinical Psychology*, *6*(4), 278-296.
- Harris, R. (2009). *ACT made simple: An easy-to-read primer on acceptance and commitment therapy*. New Harbinger Publications.
- Harrison, A. M., McCracken, L. M., Jones, K., Norton, S., & Moss-Morris, R. (2017). Using mixed methods case-series evaluation in the development of a guided self-management hybrid CBT and ACT intervention for multiple sclerosis pain. *Disability and Rehabilitation*, *39*(18), 1785-1798.
- Hasenbring, M. I., Hallner, D., & Rusu, A. C. (2009). Fear-avoidance-and endurance-related responses to pain: Development and validation of the Avoidance-Endurance Questionnaire (AEQ). *European Journal of Pain*, *13*(6), 620-628.
- Hayes, S. C., Barnes-Holmes, D., & Roche, B. (Eds.). (2001). *Relational frame theory: A post-Skinnerian account of human language and cognition*. Springer Science & Business Media.
- Hayes, S. C., Strosahl, K., Wilson, K. G., Bissett, R. T., Pistorello, J., Toarmino, D., & Stewart, S. H. (2004). Measuring experiential avoidance: A preliminary test of a working model. *The Psychological Record*, *54*(4), 553-578.
- Hayes, S. C., & Smith, S. (2005). *Get out of your mind and into your life: The new acceptance and commitment therapy*. Oakland, CA: New Harbinger.

- Hayes, S. C., & Stroschal, K. (2005). *A practitioner's guide to acceptance and commitment therapy*. New York, NY: Springer.
- Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and commitment therapy: Model, processes and outcomes. *Behaviour Research and Therapy*, *44*(1), 1-25.
- Hayes, S. C. (2016). Acceptance and Commitment Therapy, Relational Frame Theory, and the Third Wave of Behavioral and Cognitive Therapies—Republished Article. *Behaviour Therapy*, *47*(6), 869-885.
- Hodgson, J., McDonald, S., Tate, R., & Gertler, P. (2005). A randomised controlled trial of a cognitive-behavioural therapy program for managing social anxiety after acquired brain injury. *Brain Impairment*, *6*(3), 169-180.
- Holmes, J., Neighbour, R., TARRIER, N., Hinshelwood, R. D., & Bolsover, N. (2002). All you need is cognitive behaviour therapy? The “evidence” is weaker than claimed. *BMJ*, *324*(7332), 288-294.
- Hoofien, D., Gilboa, A., Vakil, E., & Donovan, P. J. (2001). Traumatic brain injury (TBI) 10? 20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain Injury*, *15*(3), 189-209.
- Huddleston, C., Martin, L., Woods, K., & Dindo, L. (2018). One-Day Behavioral Intervention for Distressed Veterans with Migraine: Results of a Multimethod Pilot Study. *Military Medicine*.
- Jenkinson, C., Layte, R., Jenkinson, D., Lawrence, K., Petersen, S., Paice, C., & Stradling, J. (1997). A shorter form health survey: can the SF-12 replicate results from the SF-36 in longitudinal studies? *Journal of Public Health*, *19*(2), 179-186.
- Kangas, M., & McDonald, S. (2011). Is it time to act? The potential of acceptance and commitment therapy for psychological problems following acquired brain injury. *Neuropsychological Rehabilitation*, *21*(2), 250-276.
- Kangas, M., McDonald, S., Williams, J. R., & Smee, R. I. (2015). Acceptance and commitment therapy program for distressed adults with a primary brain tumour: a case series study. *Supportive Care in Cancer*, *23*(10), 2855-2859.
- Lambert, M. J., & Barley, D. E. (2001). Research summary on the therapeutic relationship and psychotherapy outcome. *Psychotherapy: Theory, Research, Practice, Training*, *38*(4), 357.
- Lassmann, H. (2018). Multiple sclerosis pathology. Cold Spring Harbor Perspectives in Medicine, a028936. Oakland, CA: New Harbinger
- Longmore, R. J., & Worrell, M. (2007). Do we need to challenge thoughts in cognitive behavior therapy? *Clinical Psychology Review*, *27*(2), 173-187.

- Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy*, *33*(3), 335-343.
- Lundgren, T., Dahl, J., Melin, L., & Kies, B. (2006). Evaluation of acceptance and commitment therapy for drug refractory epilepsy: a randomized controlled trial in South Africa—a pilot study. *Epilepsia*, *47*(12), 2173-2179.
- Lundgren, T., Dahl, J., Yardi, N., & Melin, L. (2008). Acceptance and commitment therapy and yoga for drug-refractory epilepsy: a randomized controlled trial. *Epilepsy & Behavior*, *13*(1), 102-108.
- McCracken, L. M., Vowles, K. E., & Eccleston, C. (2004). Acceptance of chronic pain: component analysis and a revised assessment method. *Pain*, *107*(1-2), 159-166.
- Mo'tamedi, H., Rezaemaram, P., & Tavallaie, A. (2012). The effectiveness of a group-based acceptance and commitment additive therapy on rehabilitation of female outpatients with chronic headache: preliminary findings reducing 3 dimensions of headache impact. *Headache: The Journal of Head and Face Pain*, *52*(7), 1106-1119.
- Nordin, L., & Rorsman, I. (2012). Cognitive behavioural therapy in multiple sclerosis: a randomized controlled pilot study of acceptance and commitment therapy. *Journal of Rehabilitation Medicine*, *44*(1), 87-90.
- Öst, L. G. (2008). Efficacy of the third wave of behavioral therapies: A systematic review and meta-analysis. *Behaviour Research and Therapy*, *46*(3), 296-321.
- Öst, L. G. (2014). The efficacy of Acceptance and Commitment Therapy: an updated systematic review and meta-analysis. *Behaviour Research and Therapy*, *61*, 105-121.
- Pakenham, K. I., & Fleming, M. (2011). Relations between acceptance of multiple sclerosis and positive and negative adjustments. *Psychology & Health*, *26*(10), 1292-1309.
- Pakenham, K. I., Mawdsley, M., Brown, F. L., & Burton, N. W. (2018). Pilot evaluation of a resilience training program for people with multiple sclerosis. *Rehabilitation Psychology*, *63*(1), 29.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M. & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme Version, 1*, b92.
- Seel, R. T., Kreutzer, J. S., Rosenthal, M., Hammond, F. M., Corrigan, J. D., & Black, K. (2003). Depression after traumatic brain injury: a National Institute on Disability and Rehabilitation Research Model Systems multicenter investigation. *Archives of Physical Medicine and Rehabilitation*, *84*(2), 177-184.
- Sheppard, S. C., Forsyth, J. P., Hickling, E. J., & Bianchi, J. (2010). A novel application of acceptance and commitment therapy for psychosocial problems associated with multiple sclerosis: Results from a half-day workshop intervention. *International Journal of MS Care*, *12*(4), 200-206.



- Spielberger, C. D., & Gorsuch, R. L. (1983). *State-trait anxiety inventory for adults: Manual and sample: Manual, instrument and scoring guide*. Consulting Psychologists Press.
- Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine*, *166*(10), 1092-1097.
- Stewart, R. E., & Chambless, D. L. (2009). Cognitive-behavioral therapy for adult anxiety disorders in clinical practice: A meta-analysis of effectiveness studies. *Journal of Consulting and Clinical Psychology*, *77*(4), 595.
- Veehof, M. M., Oskam, M. J., Schreurs, K. M., & Bohlmeijer, E. T. (2011). Acceptance-based interventions for the treatment of chronic pain: a systematic review and meta-analysis. *Pain*, *152*(3), 533-542.
- Waldron, B., Casserly, L. M., & O'Sullivan, C. (2013). Cognitive behavioural therapy for depression and anxiety in adults with acquired brain injury. What works for whom? *Neuropsychological Rehabilitation*, *23*(1), 64-101.
- Ware, J. E., Kosinski, M., Bjorner, J. B., Turner-Bowker, D. M., Gandek, B., & Maruish, M. E. (2008). *User's manual for the SF-36v2 health survey*. Quality Metric.
- Watson, D., Clark, L. A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: the PANAS scales. *Journal of Personality and Social Psychology*, *54*(6), 1063.
- Watson, M., Haviland, J. S., Greer, S., Davidson, J., & Bliss, J. M. (1999). Influence of psychological response on survival in breast cancer: a population-based cohort study. *The Lancet*, *354*(9187), 1331-1336.
- Watson, D., O'hara, M. W., Simms, L. J., Kotov, R., Chmielewski, M., McDade-Montez, E. A. & Stuart, S. (2007). Development and validation of the Inventory of Depression and Anxiety Symptoms (IDAS). *Psychological Assessment*, *19*(3), 253.
- Werner, C., & Engelhard, K. (2007). Pathophysiology of traumatic brain injury. *British Journal of Anaesthesia*, *99*(1), 4-9.
- Whiting, D. L., Deane, F. P., Ciarrochi, J., McLeod, H. J., & Simpson, G. K. (2015). Validating measures of psychological flexibility in a population with acquired brain injury. *Psychological Assessment*, *27*(2), 415.
- Whiting, D. L., Deane, F. P., Simpson, G. K., Ciarrochi, J., & McLeod, H. J. (2017). Acceptance and Commitment Therapy delivered in a dyad after a severe traumatic brain injury: A feasibility study. *Clinical Psychologist*.
- Wilson, B. A., Winegardner, J., van Heugten, C. M., & Ownsworth, T. (2017). *Neuropsychological Rehabilitation: The International Handbook*. Routledge Handbooks.
- Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, *67*(6), 361-370.

**Part Two**  
**Empirical Paper**

# **The influence of self-compassion on perceived responsibility and shame following acquired brain injury**

Jade Ambridge<sup>1\*</sup>, Peter Fleming<sup>1</sup> and Lauren Henshall<sup>2</sup>

<sup>1</sup>Clinical Psychology Doctorate Programme, Faculty of Health Sciences, Aire Building, University of Hull, Cottingham Road, Hull, HU6 7RX

<sup>2</sup>York House, Brain Injury Rehabilitation Trust, Heslington Road, York, YO10 5BN

\*Corresponding Author - Email address: [j.ambridge@2015.hull.ac.uk](mailto:j.ambridge@2015.hull.ac.uk)  
Telephone number: 01482 464106

This paper is written in the format ready for submission to Brain Injury.  
Please see Appendix F for Author Guidelines

**Word count (excluding abstract, references and tables): 8,835**

## **Abstract**

There is a limited but growing evidence base regarding the higher levels of shame for people with brain injuries, and its negative implications for recovery. Self-blame for injury can be associated with shame and self-criticism, while self-compassion can effectively target shame to improve psychological wellbeing. This study used mixed-methods to investigate the influence of perceived personal responsibility for injury on shame, and whether self-compassion moderates this relationship. Data was collected from 66 participants with acquired brain injuries via the administration of standardised measures, including several open-style questions. Data was analysed using descriptive statistics, correlations, multiple regression and thematic analysis. Significant relationships were found between self-compassion, shame and anxiety and depression, but responsibility for injury was not correlated with any examined variables. The thematic analysis revealed the ways participants' injuries affected their perceived level of functioning, its consequences for sense of self, shame and self-compassion. Therefore, people with brain injuries might experience shame in a different way to people without these conditions due to the injury's impact on functioning, providing rationale for using third-wave approaches to encourage skills of self-compassion and acceptance, such as Acceptance and Commitment Therapy, Compassion-Focused Therapy and mindfulness. Study limitations and considerations for future research are discussed.

## **Keywords**

Acquired brain injury – third-wave – self-compassion – responsibility – shame

## **Introduction**

The term ‘compassion’ describes understanding and empathising with others’ distress, a process which can help people to care for themselves during distress (1; 2). Gilbert explains that compassion involves being sensitive to the suffering of the self and others, with a conscious commitment to the alleviation of suffering (2). Self-compassion is based on the finding that when people experience negative events and become distressed, they tend to treat themselves more unkindly than they would another in the same situation (3). Neff (2) suggests self-compassion is based on three facets; self-kindness, which involves treating oneself with kindness and being non-critical during difficult circumstances; common humanity, which is being able to recognise that difficulties are a normal part of life; and mindfulness, which is having a balanced approach to one’s cognitions and emotions. Research outlines that people who experience shame due to fear that they are different from others, and are self-critical about this, can struggle to be self-compassionate. This can result in increased sensitivity to threats of criticism from the self and others, possibly negatively implicating psychological wellbeing and quality of life (4).

“Third-wave” behavioural psychological approaches are grouped as such because they built on earlier “first” and “second” wave behavioural psychological therapies by introducing an emphasis on how an individual interprets their context and events, and the implications of these interpretations for psychological wellbeing (5). Traditional viewpoints of Tibetan Buddhism, mindfulness and compassion were drawn upon to develop therapies such as Compassion-Focused Therapy (CFT) (2), Acceptance and Commitment Therapy (ACT) (6) and Mindfulness-Based Therapies (MBCT) (7). CFT describes three evolved emotion regulation systems which underpin how we relate to ourselves and others (2). These are: the threat system, which deals with noticing

threat and providing anxiety responses; the drive system, which guides us to seek out evolutionarily essentials such as food; and the soothe system, which helps us to feel comforted (2). Over-activity of the threat and/or drive systems is common for individuals with high shame, causing underactivity of the soothe system. CFT aims to increase activation of the soothe system and the ability to practice (self-)compassion through improving skills related to wellbeing, empathy and non-judgment (2). ACT aims to develop “psychological flexibility”, a group of skills which help individuals to accept difficult experiences, thoughts and discourses which are out of their control, whilst striving to engage in fulfilling behaviours to live a valued life (5). Mindfulness-based therapies encourage mindfulness techniques such as meditation and breathing exercises to help individuals focus on the present moment and treat difficult thoughts and experiences in a way as to avoid over-attachment with them (8). Both ACT and MBCT have similar approaches to CFT by emphasising the importance of compassion and understanding as a helpful approach to take when a person is going through a period of adjustment or feeling their difficulties are out of their control. The similar concepts and goals of these approaches can make it appropriate to use an amalgamation of third-wave therapies with individuals (9).

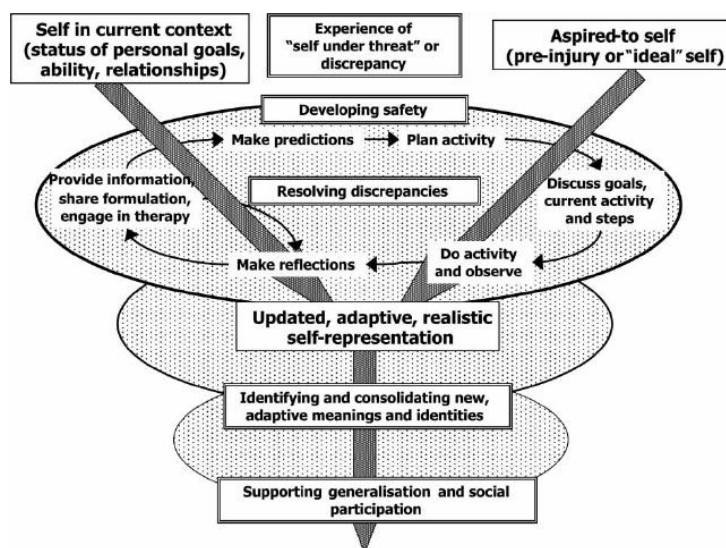
Lack of self-compassion and presence of high shame and self-criticism have been linked to poorer psychological wellbeing in various health populations. Przedziecki and colleagues (10) studied 279 women following breast cancer treatment. They found that individuals with disturbed body image were more distressed and had lower levels of self-compassion. Further to this, for cancer and chronic illnesses, a relationship was found between lower self-compassion and self-criticism, and increased depressive and stress symptoms, as well as decreased quality of life (11). These studies indicate the negative implications of low compassion for psychological wellbeing.

Similar research has investigated the impact of blaming oneself for illnesses and health conditions. Bennett et al (12) studied levels of self-blame in 115 women with newly diagnosed breast cancer. They distinguished between blame due to behavioural choices (behavioural self-blame) and/or as a result of their personality (characterological self-blame). They found that behavioural self-blame negatively impacted participants' adjustment processes following their diagnosis, and led to poorer psychological wellbeing. Another study compared 96 patients with lung cancer, 30 patients with breast cancer and 46 patients with prostate cancer; within the lung cancer group, 91.7% were former smokers (13). Patients with lung cancer had higher cancer-related stigma, and the smokers specifically experienced more shame and guilt. This paper concluded that the belief that one caused their own cancer was correlated with higher levels of guilt, shame, anxiety and depression. Moreover, for 1109 men with colorectal cancer, 31% reported stigma, and self-blame was strongly associated with depressive symptoms (14). Self-blame often accompanies self-criticism, anxiety, shame and guilt following negative events (15), and as compassion theory suggests, people experiencing these difficulties would benefit from learning to be self-compassionate (2). These studies illustrate that higher shame and higher responsibility for illness or condition shame may also equate to lower self-compassion, which subsequently has detrimental effects for psychological wellbeing.

Moreover, studies have illustrated that individuals with brain injuries experience low self-compassion and higher levels of self-criticism (16; 17), and respond well to CFT (18; 19; 20). However, there is limited research which examines why self-compassion levels are lower, and whether this is linked to self-blame as seen in health populations. Acquired brain injuries (ABI) and diseases can be "organic", whereby they are caused by physical or physiological changes to the brain, or present from birth and

occur without involvement of the individual, such as haemorrhages, infection, hypoxia and encephalopathy (21). Brain injuries can also be acquired through self-initiated behaviours and lifestyle choices. For example, an individual who receives a traumatic brain injury from participating in dangerous sports, through dangerous driving leading to road traffic incidents, and being involved in physical fights, or a stroke due to lifestyle choices (22) Thus, in a similar way in which this has been shown in health samples, there may be consequences for how much an individual feels personally responsible or blames themselves for the circumstances that led to their brain injury.

The findings of neurorehabilitation studies form a basis for these conceptions. Literature emphasises the importance of a positive self-concept for adjustment and psychological wellbeing during recovery from brain injury (23; 24). The “Y-Shaped” model of rehabilitation (Figure 1; 25) outlines the processes involved in efficacious neurorehabilitation. The model suggests that if a person has inconsistencies between their current self and their pre-injury/ideal self, they can experience threat which hampers recovery. For example, if a person is focused on performing the exact same duties at work as their pre-injury self, their perceived lack of current ability to do so might lead to feelings that they are a failure or not good enough. Indeed, people with brain injuries typically have a more negative sense of current



**Figure 1.** *The Y-Shaped Model of Rehabilitation (Gracey, Evans & Malley, 2009)*



self that contributes to poorer psychological wellbeing (26). Discrepancies between pre-injury and post-injury selves can lead to weaker self-concept and more shame in individuals with TBI, and thus poorer adjustment outcomes (17). Lewington (27) and Jones and Morris (28) both highlighted that following brain injury, individuals found it difficult to adjust to receiving care from their parents, part of which involved shame and self-criticism about being a disappointment. To manage these difficulties, the Y-Shaped model would encourage the individual to be supported to resolve discrepancies by making goals and using realistic adaptations to form an identity which is more representative of the current self. Therefore, it appears important to encourage the formation of self-compassion and acceptance to manage expectations and possible shame whilst also acknowledging strengths.

Literature has emphasised that managing self-concept, self-criticism, blame and shame is an important component of psychological interventions for ABI. Jones and Morris (28) found in their study that an individual who directed blame towards their mother for their brain injury experienced increased levels of psychological distress, suggesting the implications for perceived responsibility for injury. A study indicated that individuals responded to hypothetical vignettes about organic injuries with a more positive attitude, and concluded that if the person is perceived to have contributed towards their injury, they are viewed more negatively and with less sympathy (22). An important link can be drawn here with a study that investigated whether being liked and accepted by others affects the way a person perceives themselves (29). The study found that being liked by others led to more positive evaluations of the self, indicating the powerful impact of others' judgements for sense of self. Hart et al (21) distinguished between "intentional" brain injuries, which the study defined as those in which the individual had a clear role such as following involvement in dangerous sport, and

“unintentional” brain injuries, which the study defined as an injury in which the individual did not play a clear role such as encephalitis meningitis. They found that individuals with “intentional” injuries were more likely to blame others for their injury. Additionally, increased self-blame was linked to reduced levels of depression in this study, possibly due to the increased control and ability to take responsibility from a positive perspective. This may illustrate that taking responsibility could be a coping mechanism, and doing so in a non-critical and judgmental way may suggest use of self-compassion techniques. Indeed, other compassion-based coping mechanisms have been highlighted by Gelech and Desjardins (30), who noted that if an individual considers the brain injury process to be positive and something they could mentally and emotionally recover and grow from, they were more likely to experience self-compassion and retain their sense of self. This may indicate that attributes such as taking responsibility in a self-compassionate way may be protective against poor psychological wellbeing.

### *The Present Study*

Literature suggests that self-compassion is a protective factor against poor psychological wellbeing, poor adjustment, high shame and high self-criticism for people with brain injuries. It has also been suggested that the level of responsibility a person feels they have for their injury may impact shame and psychological wellbeing (21). Therefore, this study aimed to investigate whether self-compassion could moderate the effect of perceived responsibility on shame in this population. Thus, self-compassion could be a protective mechanism against the shame which has resulted from high self-blame for injury. This could help to explain why therapies which target self-compassion are effective in these samples, and help to tailor other psychological therapies that are used for individuals going through adjustment to be more appropriate

for people with brain injuries and neurological conditions. This might include CFT, as well as Acceptance and Commitment Therapy (ACT) and Mindfulness-Based Cognitive Therapy (MBSR), which have similar goals in relation to the development of skills related to self-compassion and acceptance.

Studies have also shown that people with acquired brain injuries can sometimes minimise or deny their level of dysfunction, and this lack of insight might be a potential obstacle to successful rehabilitation (31; 32). However, lack of insight might also be protective, by acting as a “buffer” to protect the patient from a potentially difficult reality (33). Therefore, lack of self-awareness might act in a similarly protective way to self-compassion, and result in reduced levels of shame. Therefore, it appeared important to control for this variable when looking at the relationship between perceived responsibility, shame and self-compassion.

This study also assessed the impact of these concepts on psychological wellbeing, including the facets of anxiety and depression, based on the findings of previous research (17; 21; 26). Research has suggested that the definitions of abstract concepts such as self-compassion and shame can differ between individuals (34), making it difficult for standardised measures to consistently and accurately measure these ideas. Therefore, this study included a qualitative component which allowed participants to freely explore these concepts for themselves and aimed to measure these concepts in further detail.

### *Research Questions*

The study investigated the following research questions;

1. Are there relationships between self-compassion, self-awareness, shame, perceived responsibility (PR) and anxiety and depression for people with brain

injuries?

Hypothesis 1.1

Significant positive correlations will exist between strength of PR and levels of shame, anxiety and depression

Hypothesis 1.2

Significant positive correlations will exist between shame, self-awareness and anxiety and depression

Hypothesis 1.3

Significant negative correlations will exist between self-compassion and shame, and anxiety and depression

**Table 1.** *Visual representation of hypothesised relationships between variables*

	<b>Shame</b>	<b>Perceived Responsibility (PR)</b>	<b>Self-Compassion</b>	<b>Self-Awareness</b>	<b>Anxiety &amp; depression</b>
<b>Shame</b>		Positive	Negative	Positive	Positive
<b>Perceived Responsibility</b>	Positive		No prediction	No prediction	Positive
<b>Self-Compassion</b>	Negative	No prediction		No prediction	Negative
<b>Self-Awareness</b>	Positive	No prediction	No prediction		Positive
<b>Anxiety &amp; Depression</b>	Positive	Positive	Negative	Positive	

2. Does self-compassion moderate the impact of PR on levels of shame in brain injury?

Hypothesis 2:

As self-compassion increases, the impact of PR on shame will reduce, resulting in a significant interaction between self-compassion and PR.

3. What are people with brain injuries' experiences of self-compassion, shame and perceived responsibility following a brain injury?

## **Method**

### *Design*

This study employed a cross-sectional design, collecting both quantitative and qualitative data through self-report questionnaires. The dependent variable was shame, and the predictor variables were perceived responsibility for injury, self-compassion, gender, time since injury and level of awareness into injury.

### *Measures*

Measures are displayed in Appendices N-T.

### Demographics

Participants were asked to disclose their age, gender, relationship status, level of education, how much time had passed since their injury, which service setting best applied to them and how long they had been in contact with their service.

### Self-compassion

Self-compassion was measured using the Short Self-Compassion Scale (35), a shortened version of The Self-Compassion Scale developed by Neff et al (1). Designed for use with individuals aged 14 and over, it consists of 26 items related to self-kindness, mindfulness and common humanity. This scale has been administered to 24 participants with brain injuries to measure the effectiveness of a CFT intervention, demonstrating its previous use with individuals with brain injuries (36). To develop this measure and test its reliability and validity, Neff et al (1) provided a pool of potential self-compassion items to a group of participants, and selected the final scale items based on their reliability and factor loadings onto subscale themes. Content validity was found to be high because it was found that participants with high self-compassion levels reported that they were equally kind to self and others, whereas low self-compassion levels led to participants reporting that they were kinder to others than to themselves. Neff & Pommier (2013; 37) found the reliability of this scale to be high ( $\alpha = .93$ ).

### Self-Awareness

The Awareness Questionnaire (AQ) (38) was used to measure self-awareness and insight. This is a 17-item form which asks the subject to use a 5-point Likert scale to rate their degree of difficulty in a number of tasks and functions. Responses are compared to those of a staff or friend/family member who knew the participant well and rated identical items. The discrepancy between the two scores indicated participants' level of self-awareness; the larger the discrepancy, the less awareness the individual was considered to have into their functioning. The AQ has adequate construct validity ( $p=.34-.39$ ), excellent internal consistency ( $\alpha=.88$ ) and excellent to adequate test-retest reliability for the participant ( $ICC=.80$ ) and other person forms ( $ICC=.66$ ), respectively

(39). The AQ has been used with participants with brain injuries (40; 41) and is appropriate to use with this client group.

#### Perceived responsibility

Perceived responsibility (PR) was measured by asking participants to rate how much they perceive themselves to be responsible for their injury, on a percentage scale between 0 - 100. This design is similar to other studies, including an investigation into the role of PR in the development of post-traumatic stress disorder (PTSD) for people with brain injuries following a road traffic accident (42). This method has also been used for studies which gathered information related to responsibility when investigating distress and (PTSD) in people with ABI (43; 44).

#### Shame

Shame was measured using the State Shame and Guilt Scale (SSGS) (45), a self-report measure consisting of 15 items to measure guilt, shame and pride. This measure has been used in a study which investigated shame in individuals with cancer (13). In young adult samples this measure had high levels of internal consistency, test-retest reliability, and predictive and convergent validity with an  $\alpha$  ranging from .82 to .89 for each subscale (46).

#### Psychological well being

Psychological wellbeing was measured using the Hospital Anxiety and Depression Scale (HADS) (47), a self-report measure consisting of 14 items to measure anxiety and depression. This measure was used for people with brain injuries (18; 20). A literature review looked at the reliability and validity of the HADS from 747 papers; factor analyses revealed that the HADS subscales aligned well with the two factors of

depression and anxiety, and correlations between the two subscales varied from .40 to .74, showing that the scale has strong validity (48).

### Qualitative questions

The following questions were used to explore participants' experiences of perceived responsibility, shame and self-compassion.

- 1) How positively or negatively do you view yourself following your brain injury?
- 2) How different is this to how you would have viewed yourself prior to your brain injury?
- 3) How kindly do you treat yourself?
- 4) How did your brain injury happen?
- 5) How responsible were other people for any part of your brain injury happening?
- 6) How responsible were you for any part of your brain injury happening?
- 7) What have been your biggest achievements or areas of growth/development since your brain injury?

### *Procedure*

Individuals with acquired brain injuries were invited to take part in an anonymous online (Online Surveys; 49) or paper-based survey between September 2017 and February 2018. They were recruited from six National Health Services (NHS) and the Brain Injury Rehabilitation Trust (BIRT) inpatient and outpatient neurorehabilitation services, and six local and national voluntary and charitable brain injury organisations from across Yorkshire and Northern Lincolnshire, including Headway, The Stroke Association, The Encephalitis Society, Paul for Brain Recovery, The Brain Tumour Charity and the Epilepsy Society. The researcher contacted the Clinical Psychologist at



each NHS and BIRT service, who introduced the study to their service users who met the criteria to take part. The researcher then visited these services to meet potential participants, assess inclusion and exclusion criteria, collect informed consent, and assist with filling out of the questionnaires and the staff/family/friend section of the self-awareness scale.

The researcher attended events run by the charitable and voluntary organisations to introduce the study, assess inclusion and exclusion criteria and provide potential participants of the survey with Freepost envelopes to be returned to the researcher. Alternatively, the researcher provided these potential participants with a link for an online version of the survey, hosted by Online Surveys (49). Upon following the link, potential participants were presented with an information sheet (Appendix H), a description of the inclusion criteria, and a consent form. Following completion of the survey, participants were presented with a debriefing page (Appendix L) or debriefed by the researcher in person.

Some participants did not complete the AQ due to the need for another person to fill out the second form, particularly those recruited from voluntary or charitable organisations. It was emphasised during the procedure that participants should complete the rest of the questionnaires independently and leave the AQ items blank if they were unable to ask another person to complete their part of the survey.

Approval for the study was granted by the London-Surrey NHS Research Ethics Committee.

### *Participants*

The inclusion criteria specified that participants: must have experienced an acquired brain injury which occurred after the age of 18; must have English as a first language; must be 18 years or older; and must currently be in contact with an active rehabilitation setting for their injury, or in contact with a community or voluntary service related to acquired brain injury. Exclusion criteria included: diagnosis of a degenerative condition, learning disability or neurodevelopmental condition; lack of capacity to consent to take part in the study; lack of ability to comprehend or produce speech to the levels necessary for the tasks; and diagnosis of Post-Traumatic Stress Disorder in relation to the brain injury, derived from review of patient records, self-disclosure or confirmation from a primary clinician involved with the participant. Participants' injuries included but were not limited to TBI, stroke, epilepsy, encephalitis, brain tumour and meningitis, with the majority of participants recruited from inpatient settings.

### *Power Analysis*

A calculation based on whether self-compassion moderates the effect of PR on shame was carried out to inform how many participants were required. This hypothesis was tested by adding an interaction term, self-compassion x PR, to a regression model with five predictors: self-compassion, PR, self-awareness, time since injury and gender. In the absence of sufficient information about the likely regression R-squared statistics before and after adding the interaction term, an effect size of 0.12 was assumed for the moderation. This is a slightly smaller effect size than 0.15 which is conventionally labelled "moderate". To detect an effect size of this magnitude with 80% power using a 5% significance level, 68 participants were required.

### *Data Analysis Procedures*

Data was analysed using IBM SPSS Statistics version 24.0 for Windows. Descriptive statistics were used to analyse the demographic data, psychological wellbeing and the variance in level of responsibility for injury. A significance level of 5% was used for all statistical tests.

Pearson's correlation coefficient was used to examine the correlational relationships between the predictor variables and to test Hypothesis 1.1-1.3.

Linear multiple regression analyses were completed to explore the degree to which the demographic and predictor variables could explain participants' varying scores of shame, and to carry out a moderation analysis to test the validity of Hypothesis 2. The moderating effect of self-compassion was analysed by examining the change in  $R^2$  when an interaction between PR and self-compassion was added to a multiple regression model containing PR, self-compassion, gender, time since injury and self-awareness. 46 of 66 participants (69.7%) completed the measure of self-awareness, and thus two regression analyses were fitted; one which included the self-awareness measure with  $N=46$  participants, and a second which did not include the self-awareness measure and the full range of data available.

Time since injury was recorded as categorical; however, an interval level measure was created by replacing the time interval categories by their midpoints in months, with "5+ years" being replaced by 66 months. The two regression analyses were repeated with this new interval level measure for time since injury replacing the categorical measure, in case it gave increased power despite the loss of accuracy in the information. However, the primary analysis is considered to be the regression analysis

with the self-awareness data included and with time since injury treated as a categorical predictor variable

Qualitative data was collected through 7 open questions related to participants' views of themselves, how kind they were towards themselves, their responsibility for their injury and what they felt their biggest achievements since their injury had been. The data was analysed using thematic analysis, utilising the six-step approach by Braun and Clarke (50). Firstly, the data was read repeatedly by the first author and semantic patterns were extracted. Secondly, the data was organised into codes according to the category of the question. These initial codes were reviewed by the first and second authors to generate, omit, combine and divide codes, and the fourth step involved allocating these codes into themes. Superordinate and subordinate themes were then created from these, which were labelled and defined before presentation in a tabular format alongside exemplar quotes for this report.

## **Results**

### *Descriptive Statistics*

#### Demographic Characteristics

Demographic data is presented in Table 2. Of a total of 66 participants, 65 (98.5%) completed all of the questionnaires within the study, with the remaining participant providing only demographic information. Of all participants, 32 (48.5%) were male. Their ages ranged from 18-65+ years, with the majority of participants aged between 45-54 years (N=14; 21.2%). The majority identified as single (N=29; 43.9%) or married/in a domestic partnership (N=25; 37.9%). Four participants explained that they had studied at postgraduate level (6.1%), whilst the majority had a GCSE-level education (N=37; 56.1%). The time passed since brain injury for each participant ranged

from less than 6 months (7.6%) to over 5 years (N=21; 31.8%). The majority of

**Table 2.** *Demographic characteristics of the overall sample*

<b>Demographic</b>	<b>Overall sample (N=66)</b>
<b>Age groups</b>	
18-24 years	5 (7.6%)
25-34 years	10 (15.2%)
35-44 years	13 (19.7%)
45-54 years	14 (21.2%)
55-64 years	12 (18.2%)
65+ years	11 (16.7%)
<b>Gender</b>	
Male	34 (51.5%)
Female	32 (48.5%)
<b>Relationship status</b>	
Single	29 (43.9%)
Married/domestic partnership	25 (37.9%)
Widowed	3 (4.5%)
Divorced	7 (10.6%)
Separated	2 (3%)
<b>Highest level of education</b>	
GCSE	37 (56.1%)
A-Level	14 (21.2%)
Degree	10 (15.2%)
Post-Graduate	4 (6.1%)
<b>Time since injury</b>	
Less than 6 months	5 (7.6%)
6 months-1 year	12 (19.7%)
1-2 years	15 (22.7%)
2-3 years	4 (6.1%)
3-4 years	4 (6.1%)
4-5 years	4 (6.1%)
5+ years	21 (31.8%)
<b>Participant setting</b>	
Inpatient	12 (18.2%)
Outpatient	11 (16.7%)
Community/Voluntary	38 (57.6%)
Inpatient & Community/Voluntary	1 (1.6%)
Outpatient & Community/Voluntary	4 (6.1%)

participants were recruited from community or voluntary settings (57.6%), with a similar number recruited from inpatient settings (N=12; 18.2%) and outpatient settings (N=11; 16.2%). A smaller number of participants identified as belonging to both inpatient and community (N=1) and outpatient and community settings (N=4). Pearson's Chi Squared tests were carried out for the categorical variables (age, gender, relationship status, level of education and time since injury) to test for differences between participant settings. The Chi Squared tests revealed a significant difference between a participant's setting and their level of education ( $p=.027$ ), with the majority of participants reporting they were from a Community setting and had achieved a GCSE level education (N=22). There were no other relationships between setting and the remaining demographic characteristics ( $p>0.05$ ). A One Way ANOVA revealed that time since injury was not significantly different between settings ( $F(4, 61)=1.267$ ,  $p>0.05$ ).

#### *Predictor Variables*

A Shapiro-Wilk test of normality revealed that the data collected for participants' levels of anxiety ( $p=.350$ ) and depression ( $p=.118$ ) were normally distributed, while self-compassion, responsibility and insight were not normally distributed ( $p<.001$ ). Scaled score means and their corresponding standard deviations for each variable were calculated for all measures and can be found in Table 3. The level of shame (mean=11.51; SD=4.82) was higher for this sample than a control sample of students without brain injuries from a previous study, in which their mean was 6.71 (SD=2.60) (46), suggesting that the participants in this study had higher levels of shame than people without brain injuries.

An independent samples T-test revealed a significant difference between the setting from which participants were recruited and whether they completed the AQ (mean=2.52, SD=1.13) or did not complete the AQ (mean=2.8, SD=.62;  $t(64)=-1.03$ ,  $p=0.003$ ). This indicated that participants recruited from inpatient and community settings were more likely to complete the AQ.

54.5% of participants rated themselves as 0% responsible for their injury, indicating a floor effect for this variable.

<b>Variable</b>	<b>Mean (SD) score of overall sample</b>
Shame (Shame subscale of SSGS)	11.51 (4.82)
Self-Compassion (SCS-SF overall)	5.69 (1.15)
Self-Awareness (AQ)	5.93 (6.01)
Responsibility	23.48 (32.89)
Anxiety (Anxiety subscale of HADS)	9.29 (5.24)
Depression (Depression subscale of HADS)	7.67 (4.09)

**Table 3.** Mean scores and standard deviation of each variable for overall sample

#### Are the predictor variables related?

Relationships between the predictor variables was examined through Pearson's Product Moment correlation coefficient and are presented in Table 4. Due to the non-normal distribution of some of the predictor variables, bootstrapped P values are included. Shame, as measured by the shame-subscale of the SSGS, was significantly positively correlated with depression and anxiety as measured by the HADS subscales. This suggests that as levels of shame increase, so do levels of depression and anxiety, a finding which supports Hypothesis 1.2. Shame was significantly negatively correlated

with self-compassion, as measured by the SCS, suggesting that as self-compassion increases, shame decreases. Shame was also negatively correlated with self-awareness at the .1 level. Self-awareness was measured using the AQ, which was based on the rule that the more discrepancy between the “participant” and “other person” scores, the less self-awareness the participant has. Therefore, shame was shown to decrease as the discrepancy increased (less insight). This suggested that the more insight a person had into their abilities, the greater the possibility of them experiencing shame.

A significant negative correlation was evident between self-awareness and anxiety, suggesting that as self-awareness increases, anxiety decreases. Additionally, a further negative relationship at the .1 level was demonstrated between anxiety and self-

	Shame	Perceived Responsibility	Self-Compassion	Self-Awareness	Anxiety	Depression
<b>Shame (SSGS subscale score)</b>	X	$r = -.054$ ( $p=.725$ )	$r = -.483^{**}$ ( $p=.001$ )	$r = -.290^+$ ( $p=.054$ )	$r = .681^{**}$ ( $p<.001$ )	$r = .525^{**}$ ( $p<.001$ )
<b>Perceived Responsibility</b>	$r = -.054$ ( $p=.725$ )	X	$r = -.113$ ( $p=.459$ )	$r = -.156$ ( $p=.308$ )	$r = -.180$ ( $p=.237$ )	$r = -.320^*$ ( $p=.032$ )
<b>Self-Compassion (SCS score)</b>	$r = -.483^{**}$ ( $p=.001$ )	$r = -.113$ ( $p=.459$ )	X	$r = .235$ ( $p=.121$ )	$r = -.288^+$ ( $p=.055$ )	$r = .080$ ( $p=.603$ )
<b>Self-Awareness (SAS discrepancy score)</b>	$r = -.290^+$ ( $p=.054$ )	$r = -.113$ ( $p=.459$ )	$r = .235$ ( $p=.121$ )	X	$r = -.385^{**}$ ( $p=.009$ )	$r = -.155$ ( $p=.309$ )
<b>Anxiety (HADS subscale score)</b>	$r = 0.681^{**}$ ( $p<.001$ )	$r = -.180$ ( $p=.237$ )	$r = -.288^+$ ( $p=.055$ )	$r = -.385^*$ ( $p=.009$ )	X	$r = .548^{**}$ ( $p<.001$ )
<b>Depression (HADS subscale score)</b>	$r = .525^{**}$ ( $p<.001$ )	$r = -.320^*$ ( $p=.032$ )	$r = .080$ ( $p=.603$ )	$r = -.155$ ( $p=.309$ )	$r = .548^{**}$ ( $p<.001$ )	X

**Table 4.** Pearson’s  $r$  inter-correlations and bootstrapped  $P$  values between the predictor variables.

**\*\*.** Correlation is significant at the .01 level (2-tailed).

**\*** Correlation is significant at the .05 level (2-tailed).

**†.** Correlation is significant at the .1 level (2-tailed)



compassion, implying that someone who feels anxious is less likely to have high self-compassion levels, providing evidence for Hypothesis 1.3.

A significant negative relationship was also found between perceived responsibility and depression, indicating that depression decreased as feelings of responsibility increased. However, no other significant relationships were found between perceived responsibility and the main predictor variables. Finally, depression and anxiety were significantly positively correlated, suggesting that an individual who is experiencing high levels of low mood is also very likely to meet the criteria for higher levels of anxiety.

However, it is important to highlight that while correlational and regression analyses can demonstrate relationships between variables, causal effects cannot be detected. For example, good self-compassion skills could be the reason someone feels less shameful, or low levels of shame may have contributed to an individual's ability to be self-compassionate.

Is Shame related to an individual's Perceived Level of Responsibility for their injury, and is this relationship moderated by Self-compassion?

Of a total of 66 participants, 46 (69.7%) completed both the participant and other person sections of the self-awareness questionnaire. An independent samples T-test was carried out to examine the potential differences between participants who did and did not complete the self-awareness questionnaires. This analysis revealed no significant differences between these groups for all demographic, predictor and dependent variables ( $p > .05$ ). Therefore, as this study initially aimed to investigate the influence of self-awareness on the relationships between the predictor and dependent variables and

there were no significant differences between participants who did not complete the self-awareness questionnaire, the main model of regression included only the 46 participants who provided information about their level of self-awareness.

A multiple regression model was used to investigate whether there was an association between shame, PR and self-compassion. The two predictor variables (self-compassion and PR) were centred, and then entered into a multiple regression model with shame, gender, time since injury and self-awareness, to predict shame based on PR and self-compassion. The results indicated that gender was significantly associated with shame ( $\beta=-4.425$ ,  $SE=-1.041$ ,  $t=-4.260$ ,  $p<.001$ ), with females demonstrating higher levels of Shame (mean female SSGS score=13.67,  $SD=4.56$ ; mean male SSGS score=9.55,  $SD=4.21$ ). No significant association was found for time since injury (95% Confidence Intervals=-6.33, -1.91;  $p>.05$ ).

A significant regression coefficient was found for self-awareness and shame ( $\beta=-.190$ ,  $SE=-.090$ ,  $t=-2.102$ ,  $p=.043$ ). This suggests that as self-awareness decreased, i.e. the discrepancy of the AQ increased, so did shame. The results also illustrated a significant regression coefficient for self-compassion ( $\beta=-1.615$ ,  $SE=.515$ ,  $t=-3.138$ ,  $p=.003$ ). This demonstrates that as self-compassion levels increased, participants' levels of shame decreased. The regression coefficient for PR was not statistically significant ( $\beta=-.003$ ,  $SE=.017$ ,  $t=-.158$ ,  $p=.875$ ). The results from the other three regression models mentioned in the data analysis procedure illustrated similar results. As PR was not significantly associated with any other variables or demographic information in the models or correlations, further analysis to test for the moderating effect of self-compassion on the relationship between PR and shame was not carried out. A representation of the regression analysis is illustrated in Table 5.

	<b>B</b>	<b>Standard Error</b>	<b>t</b>	<b>P Value</b>	<b>95% Confidence Interval</b>
<b>Gender</b>	-4.115	1.096	-3.756	.001	(-6.340; -1.891)
<b>Time since injury</b> (Less than 6 months)	1.851	2.206	.839	.407	(-2.627; 6.329)
<b>Time since injury</b> (6 months – 1 year)	1.271	1.485	.856	.398	(-1.743; 4.286)
<b>Time since injury</b> (1 year – 2 years)	.128	1.423	.090	.929	(-2.761; 3.016)
<b>Time since injury</b> (2 years – 3 years)	6.680	3.481	1.971	.057	(-.207; 13.926)
<b>Time since injury</b> (3 years – 4 years)	1.885	1.872	1.007	.321	(-1.916; 5.686)
<b>Time since injury</b> (4 years – 5 years)	.011	2.522	.004	.997	(-5.109; 5.131)
<b>Insight</b>	-.190	.090	-2.102	.043	(-3.73; -.006)
<b>Responsibility</b>	-.003	.017	-.158	.875	(-.037; .032)
<b>Self-compassion</b>	-1.615	.515	-3.138	.003	(-2.660; -.570)

**Table 5.** Multiple linear regression of the relationships between shame and the predictor and control variables.

### **Qualitative Analysis**

Concepts such as shame, self-compassion and psychological wellbeing can be difficult to quantify, as definitions and experiences of each concept tend to vary between individuals (34). Therefore, in addition to the quantitative analysis, this study also included open questions for participants to explore their experiences of shame, self-compassion and responsibility. Thematic analysis (50) was utilised to examine the responses of 42 (63.6% response rate) participants to the open questions. The Braun & Clarke (50) thematic analysis guidelines were followed to ensure that the data was of a good quality prior to the development of themes. This involved both the researcher and co-researchers examining and rating the raw data to consider whether it was relevant to the qualitative research questions. These ratings were then compared to confirm good inter-rater reliability. Any responses which were very limited or unrelated to the

questions were then excluded from theme development in the final analysis. Of the participants who responded to the qualitative questions, 22 were female (52.4%), and an average of 41 participants responded to each question. Following coding (Appendix T), four super-ordinate themes were identified, which can be found in Table 5 along with their corresponding sub-ordinate themes and quotes. Three of the super-ordinate themes related to participants' experiences of themselves due to and following their injury, while the last super-ordinate theme described their areas of growth since their injury.

**Table 6.** Super-ordinate themes and descriptions of corresponding sub-ordinate themes with example quotes, identified using thematic analysis of participants' responses (N = 42; 63.6% of total participants) to seven open questions."

<b>Super-ordinate theme</b>	<b>Sub-ordinate theme</b>	<b>Description</b>	<b>Example quotes</b>
<b>Achievement &amp; Growth</b>	Physical achievements	Perceived achievements in physical and bodily abilities since injury	<i>'Learning to walk (with a frame or stick).'</i>
	Mental/ cognitive achievements	Perceived achievements in cognitive and mental abilities since injury	<i>'My memory is improving a little.'</i>
	Employment/ volunteering	Involvement in employment or voluntary roles since injury	<i>'Getting back to work and changing my job for a better one, and now playing and umpiring netball at the same level before I came.'</i>
	Acceptance & gratitude	Valuing ideas about acceptance and gratitude regarding injury	<i>'Huge acknowledgement and gratitude that I have been very lucky.'</i>
	Education	Educational achievements since injury	<i>'Doing Open University courses and learning sign language despite being told that I would never be able to</i>

			<i>learn anything.'</i>
	Independence	Improved sense of independence since injury	<i>'Living independently, relearning how to drive a car.'</i>
	Relationships & social	Improved relationships and involvement in communities since injury	<i>'Making lots of new friends.'</i> <i>'Going to the Headway meeting as I find it very stressful to meet people I don't know.'</i> <i>'Meeting others through my disability.'</i>
	No perceived achievements	Unclear what has improved or been an area for growth since injury	<i>'I don't feel I have achieved anything.'</i>
<b>Sense of self</b>	Change to self-worth & confidence	Loss or changes to self-worth and confidence as a result of injury	<i>'I feel worthless and like I'm causing more unnecessary stress and worry to my family.'</i>
	Sadness & shame	Sadness & shame about the implications the injury has had on life	<i>'I view myself badly now. Don't like the thought of having a stroke.'</i>
	Positive sense of self	Positive sense of self despite challenges caused by injury	<i>'I am slower but wiser after brain injury. I wouldn't want to go through it again but I am a better person for it. I accept my deficit and am positive.'</i>
	Motivation to improve	Feeling motivated to improve/make adaptations to help sense of self	<i>'I say "come on do this", try to push myself in physio to walk further and get more strength.'</i>
	Self-criticism	Presence of self-critical thoughts and beliefs about the injury	<i>'I beat myself up a lot, I used to be able but now I'm not.'</i>

and their role

<b>Self-Compassion</b>	Struggling with self-compassion	Finding it hard to be compassionate towards the self	<i>'I'm hard on myself. It's a chore and feels like too much effort sometimes to even try and do something nice for myself.'</i>
	Strong self-compassion skills	Development of strong ability to be self-compassionate	<i>'I still value myself as a meaningful individual who has something to offer society.'</i>
	Striving for self-compassion	Making efforts to be more self-compassionate	<i>'Beginning to try to value myself for myself, rather than just external achievements.'</i>
	Compassion for others vs self-compassion	Finding it easier to be compassionate to others than the self	<i>'In my best moments I can be kind and compassionate, but I am generally more understanding towards others.'</i>
<b>Functional impact of Injury</b>	Cognitive abilities	Commenting on how the brain injury impacted cognitive abilities	<i>'It is like my thinking and memory aren't as fast as they used to be.'</i>
	Employment	Commenting on how the brain injury impacted employment	<i>'Before my car crash I was an active professional woman with a busy career in front of me so I was quite upbeat about myself.'</i>
	Confidence	Commenting on how the brain injury impacted the person's confidence	<i>'I was more confident and self-assured and took more risks.'</i>
	Independence	Commenting on how the brain injury impacted the person's level of independence	<i>'[I] have to rely on others to do things I can't do now.'</i>
	Mental Health	Commenting on how the brain	<i>'Unable to do things I could do before as I suffer with</i>

		injury impacted mental health difficulties	<i>tiredness and anxiety when I go out or in large crowds.'</i>
	Physical abilities	Commenting on how the brain injury impacted physical abilities	<i>'I was a keen cyclist and used to push myself to do that. Did lots of walking and always took the longest route.'</i>
	Relationships /Social	Commenting on how the brain injury impacted relationships and social life	<i>'I am more insular, lacking confidence and more reluctant to socialize with other than with very close family and friends.'</i>
<b>Responsibility</b>	Feeling responsible in some way	Perceived view that the individual or another is personally responsible for their injury in some way	<i>'No one else involved at all.'</i>
	Shame & guilt	Shame and guilt about the role they or others may have played in their injury	<i>'It was one of those things. I also had a cancer but it is not how I planned my retirement and it is hard to cope with my devastation and the impact on my spouse.'</i>

### Summary of Results

The results of the quantitative analysis revealed that self-compassion was negatively correlated with shame, indicating that shame decreased as self-compassion increased. Shame was negatively correlated with an increasing discrepancy of the AQ, which indicates lack of insight into functioning. This suggests that poorer self-awareness was associated with a decrease in shame; although it is important to highlight that this relationship was significant at the .1 level. Shame also increased alongside a participant's level of anxiety and depression. Females also had significantly higher levels of shame than males in the sample, although there were no other differences in

variable outcomes in terms of the remaining demographic characteristics. There were also no significant differences in the mean predictor and dependent variables between the settings from which participants were recruited. Perceived responsibility was significantly negatively correlated with depression, but no other significant relationships were evidence between PR, shame, self-compassion and the demographic variables. Therefore, self-compassion could not be considered to be a moderating variable for the relationship between PR and shame.

The analysis from the responses to the qualitative questions provided more data about participants' experiences. A major theme centred on the direct "Functional Impact of a Brain Injury" on facets of functioning, such as for cognitive and physical abilities. The "Sense of Self" theme described how participants felt about themselves in relation to their brain injury; for example, some participants commented on having sustained a positive sense of who they were despite their injury, while many others described feeling sadness and shame about the implications of their injury on their lives. This links to the quantitative finding that shame was higher in this sample compared to people without brain injuries (51). Another identified theme was "Self-Compassion", and while some participants described themselves as having a good ability to be kind to themselves, others reported difficulties with this. A subordinate theme within "Self-Compassion" was "Self-criticism", in which participants explained that they often spoke to themselves critically in relation to how their brain injury had changed their abilities. A link can be drawn between this theme and the quantitative findings about self-compassion and its associations with shame and psychological wellbeing; while self-compassion was protective against shame, participants in this sample did have lower levels of self-compassion than people without brain injuries in other studies (48). A smaller number of participants described feeling responsible for their injury, and feeling some shame and guilt about their role. However, the quantitative data illustrated that



responsibility was not associated with any of the variables, which may explain why participants did not comment in-depth on the link between responsibility and shame, and whether this was influenced by self-compassion.

The final theme was “Achievement and Growth”, which categorised responses related to participants’ achievements since their injury. Participants described achievements in different areas of functioning, such as for physical and cognitive abilities, as well as for their social relationships and independence. A link could be drawn between participants who provided qualitative data and their level of self-awareness. 33 of 49 participants (71.74%) who completed the Awareness Questionnaire also provided qualitative data, and an independent samples t-test revealed that no significant differences between the self-awareness scores of participants who did and did not provide qualitative data ( $p=.169$ ). This indicates that participants who provided qualitative information had the same level of insight into their condition as the rest of the sample.

## **Discussion**

This study aimed to examine the relationships between perceived responsibility for injury, shame and self-compassion for individuals with acquired brain injuries. It also examined the secondary relationships between these primary variables and self-awareness, anxiety and depression, and explored participant’s experiences of these concepts through thematic analysis. Hypothesis 1.1 predicted that as PR increased, so would shame, anxiety and depression. The findings of this study largely did not support this hypothesis as PR was only significantly associated with depression, and not the main predictor and dependent variables. There was a trend for shame, self-compassion

and anxiety decreasing as PR increased, although these trends were not to a significant level.

A potential explanation for this finding is that responsibility is a difficult concept to accurately capture through the use of a single item, as this study utilised by replicating similar study methodologies (42). This single item may not have been enough to fully explore participants' thoughts about their role in their injury, as responsibility could have different implications depending on the type of ABI. For example, an individual who has had a stroke may feel responsible due to lack of exercise, poor diet, or being a smoker, whilst someone with a TBI may blame themselves for driving too fast, or for getting into a physical fight. Indeed, Hart et al (21) illustrated that participants who could objectively be considered to be responsible for their brain injury were more likely to attribute the blame towards others. Therefore, some participants may have thus responded to present themselves in a way they perceived to be positive; indeed, a floor effect was found wherein 54% of participants rated themselves as "0%", making the results less reliable statistically as there were not enough participants who rated themselves towards the higher percentages. The use of the word "responsibility" might have associations with "blame", and participants may have responded to this question in a way as to avoid appearing that they were to blame for their injury.

Moreover, there is a possibility that some participants viewed taking responsibility to be a positive experience and not necessarily a blameful one, which actually resulted in a reduction in shame, anxiety and depression, similar to the findings of a Hart et al (21). Taking responsibility could be seen to be acknowledgment of a person's own role in their injury, but without feelings of guilt. An association could be drawn here with the concept of locus of control; if someone believes they have control

over their own life and has an “internal” locus of control (52), they are more likely to have lower levels of depression, than someone with an “external” locus of control who contributes their lives to be in control of others or concepts such as fate (53). Studies which examined locus of control for people with brain injuries found that those with high external locus of control had decreased quality of life and mood disturbance (54; 55). The participants who blamed others for their injury in Hart et al’s study (21) could perhaps be considered to have an external locus of control, which would also explain the higher levels of depression for this group. From this, taking responsibility could mean the person is acknowledging the control they have over their lives and ability to recover, perhaps bringing them closer to acceptance and the ability to move forward and resulting in less shame. This is an alternative to an inability or a refusal to blame the self and instead projecting this onto others. This would explain the significant negative correlation shown between perceived responsibility and depression; perhaps taking responsibility resulted in improved mood because participants were able to acknowledge their role in the cause of their injury, and use this as an experience from which to recover.

However, it is important to highlight that the trends between PR and the other predictor and dependent variables were not significant so reliable conclusions cannot yet be drawn about this. As PR was not significantly correlated with self-compassion or shame, a decision was made not to carry out the planned moderation analysis, and thus Hypothesis 2 was not supported by the findings of this study. The qualitative responses did indicate that some participants did blame themselves for their injury, and felt sadness and shame about this. However, it may have been helpful to ask participants directly about the more positive aspects of taking responsibility, such as feeling more in control, in order to examine these concepts further.

The finding that shame was significantly positively correlated with anxiety and depression supported Hypothesis 1.2, and links to previous literature that people with high levels of shame tend to have poorer psychological wellbeing. This provides evidence that people with brain injuries show similar patterns to individuals without brain injuries regarding these associations, and suggests that it would be appropriate to use established psychological therapies to manage these difficulties, including CFT and ACT. The finding that anxiety, and to a lesser extent shame (P value significant at the .1 level), increased along with increased self-awareness a participant had into their condition supported Hypothesis 1.2. This could indicate the protective nature of poor self-awareness for difficult psychological experiences such as shame, anxiety and depression in people with brain injuries; less insight into a condition may make it less likely for a person to perceive its potentially negative impact on their lives and sense of self. The development of awareness has been illustrated to be associated with increased distress for individuals with ABI (56). Toglia and Kirk (57) highlighted that although insight and the psychologically motivated symptom of “denial”, which functions to protect a person from stressors, are distinct processes it can be difficult to identify which process is at play for individuals with a brain injury. This provides rationale for assessing self-awareness when providing psychological support for individuals with brain injuries. However, as the AQ relies on another person to rate the participant its reliability may be affected as it is difficult to know if this person was familiar with every aspect of the participant’s functioning. Participants who responded to the qualitative items were likely to have more insight into their conditions to be able to provide in-depth descriptions about their experiences, making it difficult to incorporate the qualitative data into explanations for the significant associations between anxiety and self-awareness.

Hypothesis 1.3 was partially supported by the finding that self-compassion was significantly negatively correlated with shame, and with anxiety at the .1 level. This indicated that people with high self-compassion had less shame and anxiety, possibly providing evidence for the protective nature of self-compassion (1). This reinforces the appropriateness of CFT and other therapies which target self-compassion to improve the anxiety levels of people with brain injuries. However, while anxiety and depression were significantly positively correlated, depression was not correlated with self-compassion, demonstrating less of a relationship between depression and self-compassion for this sample. It is important to again highlight that correlations do not indicate causality and the relationship between self-compassion and anxiety was not significant at the .05 level, and further research needs to be conducted before self-compassion can be reliably concluded to be protective for all aspects of psychological wellbeing.

The thematic analysis emphasised that participants found it difficult to be compassionate to themselves, and that often it felt easier to show compassion towards others. A link could be drawn between this and the theme of functioning, in which participants explained the ways in which their brain injury had affected their perceived level of functioning. Difficulties with self-compassion would likely contribute towards the described feelings of self-criticism regarding participants' altered abilities, and explain the correlations between self-compassion, shame and anxiety. As mentioned, the "Y-Shaped" model suggests that if a person has discrepancies between the functioning and abilities of their current self and "ideal self", this is likely to hamper adjustment and recovery (25). The thematic analysis might indicate that participants were experiencing distress regarding their changed abilities, possibly contributing to feelings of shame.

Another theme centred on self-worth, as participants commented that their sense of worth and usefulness had changed as a result of their injury, possibly leading to discrepancies between current and ideal selves and subsequent sadness and shame because of this. Difficulties with self-compassion would likely contribute towards feelings that participants were “not good enough” since their injury, and explain the higher than average levels of shame from the quantitative analysis. This finding is similar to that of Ownsworth and Oei (16), who found that people with brain injuries can struggle with self-compassion and subsequently experience shame. Additionally, Gracey et al (24) highlighted the importance of having a positive sense of self for the promotion of adjustment and recovery in brain injury. This study therefore strengthens the validity of the available literature for the importance of targeting shame and sense of self during psychological therapy with people with brain injuries, in order to improve wellbeing and adjustment processes.

When encouraged, participants were readily able to describe their biggest areas of growth or achievement since their injury to form the theme of “growth and achievement”, with only a small number who did not or were unable to answer this item (N=10). This suggests that although the participants in this study frequently acknowledged their difficulties and subsequent feelings of shame and self-criticism, they remained able to reflect on the more progressive and positive aspects of their recovery. This provides optimistic implications for the ability of people with brain injuries to be able to consider their strengths, an important skill for approaches such as CFT and ACT which can help individuals to focus on what is within their control in order to improve their sense of self-worth, identity and psychological wellbeing.

## Limitations

One of the limitations of this study was its reliance on self-report to collect information about the variables. Although self-report does allow for direct collection of data about participants' experiences, it is more susceptible to bias and the potential for participants to provide less valid information, perhaps in order to please the researcher or present a more positively perceived image about themselves. It is also important to acknowledge that there were few available measures for variables such as self-compassion and shame, of which few had been used extensively within neurological populations and thus their reliability could be questioned. For example, the SCS may describe the more "feminine" conceptualisation of compassion, rather than the more "masculine" traits such as protection or courage (58), perhaps leading to some participants reporting falsely low levels of self-compassion as their definition of compassion differed from the items. The challenge of self-report standardised questions being limited in their exploratory nature was partly overcome through the collection of qualitative data.

It is important to highlight some challenges regarding the qualitative questions. These questions were designed to help participants explore specific concepts related to self-compassion, shame and perceived responsibility for injury. However, participants did not comment in depth to some of the questions, especially those related to responsibility. Therefore, perhaps the questions could have been designed to be more explicit about the topics they were aiming to explore. Alternatively, further research could make use of semi-structured interviews as a method of collecting qualitative data, as this would allow the researcher to be more flexible and adaptable if participants did not appear to be providing responses relating to the research aims.

This study was also limited by the relatively small sample. Although the target sample size was achieved, the recruitment of more participants could have allowed for a more reliable analysis and in-depth information about the variables and their potential associations. However, it is important to acknowledge that it was challenging to access and collect data with the target population, and achieving a bigger sample would have likely been difficult within the time-frame of this study. The study was also limited in that the number of participants who completed the AQ was smaller than the total number of participants, meaning that the full set of data could not be included for the regression analyses.

Although the adoption of mixed-methods may have meant that each component could not be analysed and reported to the same level as a study employing only one of these methodologies, this methodology was deemed the most effective way of gathering in-depth information about shame, self-compassion and responsibility for people with brain injuries. Furthermore, this study centred on responsibility for brain injury, which is a new area with a sparse literature. Although this made the weight of the initial hypotheses limited, this study did outline that it would be exploring an understudied yet important area, and thus would have been difficult to accurately predict all of the expected results. Additionally, information about participants' type of brain injury was not collected in this study. Collecting this information may have allowed for further exploration of the relationships between how responsible a person felt for their injury, and the type of injury they have.

It is also pertinent to acknowledge that this study aimed to measure responsibility, but some participants may have interpreted this question to be asking whether they intentionally "blamed" themselves for their injury. While the concept of responsibility might capture the objective role a person played in their injury, self-blame



otherwise describes the more subjective process of an individual believing that they have a level of personal control over their injury occurring, and might feel guilty as a result (Mantler, Schellenberg & Page, 2003). Responsibility does not always necessarily lead to self-blame; thus, a person might be responsible for their injury but not blame themselves, or vice versa. This study attempted to manage this by asking participants about their perceived level of responsibility to examine their own subjective beliefs about their injury; however, some participants may have interpreted this as self-blame and thus responded accordingly, possibly reducing the validity of this measure. This may also have been impacted by how much insight participants had into their condition, as less insight is likely to mean the person feels less responsible and experiences less self-blame.

Several suggestions can be made for potential exploration in future research. The current study represents participants' responses to the measures at only a single point in time, and therefore lacks information about whether participants' levels of shame, self-compassion and responsibility changes over the course of their injury. Therefore, further studies could employ a longitudinal design measuring how the variables might change over time, and whether responsibility is affected by factors such as time since injury; for example, to examine whether an individual feels more or less responsible one month after their injury compared to 5 years after. This could help to investigate whether responsibility for injury plays a role in adjustment to injury, in a similar way to how Bennett et al (12) found that blaming oneself for a cancer diagnosis had a negative impact on adjustment processes. The measure of responsibility could be adapted to improve its statistical flexibility, such as asking participants to choose between options instead of rating on a percentage scale, in order to avoid replicating a similar floor effect. Additionally, responsibility could have been explored in more depth by asking different open questions about how responsibility had affected participants and

considering the role of self-blame, rather than directly asking participants if they were responsible. If the study were to be replicated it would also be important to ensure all participants were able to complete the measure of self-awareness, perhaps by recruiting from more inpatient settings in which there would be a higher chance of another appropriate person being available to complete the second part of the measure, such as a nurse who knew the participant well.

### Conclusions and implications for practice and future research

This study appears to be the first of its kind which explores the relationships between the consequences of perceived individual responsibility for brain injury and the ability to practice self-compassion. It has given strength to the literature base that people with brain injuries can experience levels of shame, anxiety and depression, and also struggle to be kind towards themselves. The thematic analysis revealed that participants had changes to their sense of self, and worth, due to their injury changing their level of functioning, and feelings of sadness and shame.

Although this study could not reliably conclude that higher level of responsibility directly contributed towards shame and poorer psychological wellbeing, it does lead to many further thoughts for additional research. Firstly, the role of responsibility should be considered from different perspectives, rather than relying only a singular rating on percentage scale, before we can reliably conclude whether it is a relevant factor for adjustment to brain injury. As discussed, responsibility may have different definitions for individuals, and thus be both a positive or negative experience with different implications, respectively. More research could explore potential links between responsibility and participants' locus of control, of which Wielenga-Boiten et al (54) illustrated to be an important factor for better psychological recovery following a brain injury. Research focusing on a clinical sample that is objectively known to have

had a degree of responsibility for their injury may be useful, such as a male only TBI group whose injuries occurred through dangerous driving or sports. This could help to determine how much, or little, an ABI group known for a biased demographic considers the causality of their injury and whether this has any bearing on their sense of self, and thus whether it is a relevant factor to consider in ABI research and neurorehabilitation.

Previous research had explored others' perceptions of the causes of hypothetical brain injuries, and found more negative assumptions were made about cases which they believed the person to be responsible for their injury (22). Therefore, future research could ask participants directly about their perceptions of whether other people view them to be responsible for their injury, and if they think they are treated differently as a result. This could help to highlight the implications for sense of self and wellbeing resulting from the perception of others' judgements of people with brain injuries (29). It may also be helpful to consider what ABI populations attribute their shame to, such as their functional abilities or sense of self. This could be broadened further by studying the shame and compassion levels of the family members of individuals with brain injuries, and whether this could have implications for the role of family therapy as part of rehabilitation.

Overall, a suggestion can be made that people with brain injuries experience shame and self-compassion in a different way to people without brain injuries due to the role their injury has played in their functioning; therefore, a rationale is provided for the use of third-wave approaches which encourage skills of self-compassion and acceptance, such as ACT, CFT and mindfulness. This study also provides evidence for the need to tailor these psychological therapies to incorporate the known factors associated with difficulties adjusting to a brain injury, such as its impact on sense of self and functioning, in order to make them more appropriate for people with brain injuries and neurological conditions.

## References

1. Neff KD. The development and validation of a scale to measure self-compassion. *Self and Identity*. 2003 Jul 1;2(3):223-50.
2. Gilbert P. Introducing compassion-focused therapy. *Advances in Psychiatric Treatment*. 2009 May 1;15(3):199-208.
3. Terry, M. L., & Leary, M. R. (2011). Self-compassion, self-regulation, and health. *Self and Identity*, 10(3), 352-362.
4. Kaufmann G. *The Psychology of Shame*. New York. 1989.
5. Kangas M, McDonald S. Is it time to act? The potential of acceptance and commitment therapy for psychological problems following acquired brain injury. *Neuropsychological Rehabilitation*. 2011 Apr 1;21(2):250-76.
6. Hayes SC. *Acceptance and Commitment Therapy and the New Behaviour Therapies: Mindfulness, Acceptance, and Relationship*. 2004.
7. Kabat-Zinn J. Mindfulness-based interventions in context: past, present, and future. *Clinical psychology: Science and Practice*. 2003 Jun 1;10(2):144-56.
8. Morgan D. Mindfulness-based cognitive therapy for depression: A new approach to preventing relapse. 2003: 123-125.
9. Öst LG. Efficacy of the third wave of behavioural therapies: A systematic review and meta-analysis. *Behaviour Research and Therapy*. 2008 Mar 1;46(3):296-321.
10. Przewdziecki A, Sherman KA, Baillie A, Taylor A, Foley E, Stalgis-Bilinski K. My changed body: breast cancer, body image, distress and self-compassion. *Psycho-Oncology*. 2013 Aug 1;22(8):1872-9.
11. Pinto-Gouveia J, Duarte C, Matos M, Fráguas S. The protective role of self-compassion in relation to psychopathology symptoms and quality of life in chronic and in cancer patients. *Clinical Psychology & Psychotherapy*. 2014 Jul 1;21(4):311-23.
12. Bennett KK, Compas BE, Beckjord E, Glinder JG. Self-blame and distress among women with newly diagnosed breast cancer. *Journal of Behavioural Medicine*. 2005 Aug 1;28(4):313-23.
13. LoConte NK, Else-Quest NM, Eickhoff J, Hyde J, Schiller JH. Assessment of guilt and shame in patients with non-small-cell lung cancer compared with patients with breast and prostate cancer. *Clinical Lung Cancer*. 2008 May 1;9(3):171-8.
14. Phelan SM, Griffin JM, Jackson GL, Zafar SY, Hellerstedt W, Stahre M, Nelson D, Zullig LL, Burgess DJ, Ryn M. Stigma, perceived blame, self-blame, and depressive symptoms in men with colorectal cancer. *Psycho-oncology*. 2013 Jan 1;22(1):65-73.
15. Lutwak N, Panish J, Ferrari J. Shame and guilt: Characterological vs. behavioral self-blame and their relationship to fear of intimacy. *Personality and Individual Differences*. 2003 Sep 1;35(4):909-16.
16. Ownsworth TL, Oei TP. Depression after traumatic brain injury: conceptualization and treatment considerations. *Brain Injury*. 1998 Jan 1;12(9):735-51.

17. Shields C, Ownsworth T. An integration of third wave cognitive behavioural interventions following stroke: a case study. *Neuro-Disability and Psychotherapy*. 2013 Apr 1;1(1):39-69.
18. Ashworth F. Soothing the injured brain with a compassionate mind: Building the case for compassion focused therapy following acquired brain injury. *Neuro-Disability and Psychotherapy*. 2014 Jan 1;2(1-2):41-79.
19. Ashworth F, Clarke A, Jones L, Jennings C, Longworth C. An exploration of compassion focused therapy following acquired brain injury. *Psychology and Psychotherapy: Theory, Research and Practice*. 2015 Jun 1;88(2):143-62.
20. Ashworth F, Gracey F, Gilbert P. Compassion focused therapy after traumatic brain injury: Theoretical foundations and a case illustration. *Brain Impairment*. 2011 Sep;12(2):128-39.
21. Hart T, Hanks R, Bogner JA, Millis S, Esselman P. Blame attribution in intentional and unintentional traumatic brain injury: Longitudinal changes and impact on subjective well-being. *Rehabilitation Psychology*. 2007 May;52(2):152.
22. Redpath SJ, Linden MA. Attitudes towards behavioural versus organic acquisition of brain injury. *Brain Injury*. 2004 Sep 1;18(9):861-9.
23. Cantor JB, Ashman TA, Schwartz ME, Gordon WA, Hibbard MR, Brown M, Spielman L, Charatz HJ, Cheng Z. The role of self-discrepancy theory in understanding post-traumatic brain injury affective disorders: A pilot study. *The Journal of Head Trauma Rehabilitation*. 2005 Nov 1;20(6):527-43.
24. Gracey F, Palmer S, Rous B, Psaila K, Shaw K, O'Dell J, Cope J, Mohamed S. "Feeling part of things": Personal construction of self after brain injury. *Neuropsychological Rehabilitation*. 2008 Nov 1;18(5-6):627-50.
25. Gracey F, Evans JJ, Malley D. Capturing process and outcome in complex rehabilitation interventions: A "Y-shaped" model. *Neuropsychological Rehabilitation*. 2009 Dec 1;19(6):867-90.
26. Tangney JP. Perfectionism and the self-conscious emotions: Shame, guilt, embarrassment, and pride. 2002.
27. Lewington PJ. Counselling survivors of traumatic brain injury. *Canadian Journal of Counselling and Psychotherapy/Revue Canadienne de Counseling et de Psychothérapie*. 1993 Oct 1;27(4).
28. Jones L, Morris R. Experiences of adult stroke survivors and their parent carers: a qualitative study. *Clinical Rehabilitation*. 2013 Mar;27(3):272-80.
29. Srivastava S, Beer JS. How self-evaluations relate to being liked by others: Integrating sociometer and attachment perspectives. *Journal of Personality and Social Psychology*. 2005 Dec;89(6):966.
30. Gelech JM, Desjardins M. I am many: The reconstruction of self following acquired brain injury. *Qualitative Health Research*. 2011 Jan;21(1):62-74.
31. Bogod NM, Mateer CA, Macdonald SW. Self-awareness after traumatic brain injury: A comparison of measures and their relationship to executive functions. *Journal of the International Neuropsychological Society*. 2003 Mar;9(3):450-8.

32. Fleming JM, Strong J, Ashton R. Self-awareness of deficits in adults with traumatic brain injury: How best to measure?. *Brain injury*. 1996 Jan 1;10(1):1-6.
33. Sherer M, Hart T, Nick TG, Whyte J, Thompson RN, Yablon SA. Early impaired self-awareness after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*. 2003 Feb 1;84(2):168-76.
34. Pauley G, McPherson S. The experience and meaning of compassion and self-compassion for individuals with depression or anxiety. *Psychology and Psychotherapy: Theory, Research and Practice*. 2010 Jun 1;83(2):129-43.
35. Raes F, Pommier E, Neff KD, Van Gucht D. Construction and factorial validation of a short form of the self-compassion scale. *Clinical Psychology & Psychotherapy*. 2011 May 1;18(3):250-5.
36. O'Neill M, McMillan TM. Can deficits in empathy after head injury be improved by compassionate imagery? *Neuropsychological Rehabilitation*. 2012 Dec 1;22(6):836-51.
37. Neff KD, Pommier E. The relationship between self-compassion and other-focused concern among college undergraduates, community adults, and practicing meditators. *Self and Identity*. 2013 Mar 1;12(2):160-76.
38. Sherer M, Hart T, Nick TG. Measurement of impaired self-awareness after traumatic brain injury: a comparison of the patient competency rating scale and the awareness questionnaire. *Brain Injury*. 2003 Jan 1;17(1):25-37.
39. Engel, E., Peipert, A., & Ehrlich-Jones, L. (2018). Measurement Characteristics and Clinical Utility of the Awareness Questionnaire in Individuals with Traumatic Brain Injury. *Archives of Physical Medicine and Rehabilitation*, 99(4), 813-814.
40. Hellebrekers D, Winkens I, Kruiper S, Van Heugten C. Psychometric properties of the awareness questionnaire, patient competency rating scale and Dysexecutive Questionnaire in patients with acquired brain injury. *Brain Injury*. 2017 Sep 19;31(11):1469-78.
41. Rigon J, Burro R, Guariglia C, Maini M, Marin D, Ciurli P, Bivona U, Formisano R. Self-awareness rehabilitation after Traumatic Brain Injury: A pilot study to compare two group therapies. *Restorative Neurology and Neuroscience*. 2017 Jan 1;35(1):115-27.
42. Schnyder U, Wittmann L, Friedrich-Perez J, Hepp U, Moergeli H. Posttraumatic stress disorder following accidental injury: rule or exception in Switzerland?. *Psychotherapy and Psychosomatics*. 2008;77(2):111-8.
43. Delahanty DL, Herberman HB, Craig KJ, Hayward MC, Fullerton CS, Ursano RJ, Baum A. Acute and chronic distress and posttraumatic stress disorder as a function of responsibility for serious motor vehicle accidents. *Journal of Consulting and Clinical Psychology*. 1997 Aug;65(4):560.
44. Fitzharris M, Fildes B, Charlton J, Tingvall C. The relationship between perceived crash responsibility and post-crash depression. *Annual Proceedings/Association for the Advancement of Automotive Medicine 2005*: 49.

45. Marschall D, Sanftner J, Tangney JP. The state shame and guilt scale. Fairfax, VA: George Mason University. 1994.
46. Tangney JP, Dearing RL. Our “intrapersonal” relationship. The self in shame and guilt. *Shame and Guilt*. 2002;52.
47. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*. 1983 Jun 1;67(6):361-70.
48. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale: an updated literature review. *Journal of Psychosomatic Research*. 2002 Feb 1;52(2):69-77.
49. Onlinesurveys.ac.uk. (2018). Online surveys. [online] Available at: <https://www.onlinesurveys.ac.uk/> [Accessed 7 Aug. 2018].
50. Terry G, Hayfield N, Clarke V, Braun V. Thematic analysis. *The SAGE handbook of qualitative research in psychology*. 2017 May 18:17-37.
51. Marschall DE. Effects of induced shame on subsequent empathy and altruistic behavior (Doctoral dissertation, George Mason University). 1997.
52. Rotter JB. Development of locus of control. *Pareek Training Instruments in HRD and OD*. 1954.
53. Yu X, Fan G. Direct and indirect relationship between locus of control and depression. *Journal of Health Psychology*. 2016 Jul;21(7):1293-8.
54. Moore AD, Stambrook M. Coping strategies and locus of control following traumatic brain injury: relationship to long-term outcome. *Brain Injury*. 1992 Jan 1;6(1):89-94.
55. Wielenga-Boiten JE, Heijenbrok-Kal MH, Ribbers GM. The relationship of health locus of control and health-related quality of life in the chronic phase after traumatic brain injury. *The Journal of Head Trauma Rehabilitation*. 2015 Nov 1;30(6):424-31.
56. Port A, Willmott C, Charlton J. Self-awareness following traumatic brain injury and implications for rehabilitation. *Brain Injury*. 2002 Jan 1;16(4):277-89.
57. Toglia J, Kirk U. Understanding awareness deficits following brain injury. *Neurorehabilitation*. 2000 Jan 1;15(1):57-70.
58. Seppala EM. Feeling It: Are Women Really More Compassionate. *Psychology Today*. 2013.

## **Appendix A: Reflective Statement**

I am in a state of somewhat disbelief that this thesis' journey is now approaching its end, as I prepare to write my reflections on its process. I hope that this statement will be able to give the reader some insight and context into the process of producing this thesis, and what the journey has been like for me.

### Topic choice

At the beginning of my Doctorate course the prospect of choosing a thesis topic which would remain with me for the next three years felt daunting. I had recently completed my undergraduate dissertation, and although I had found its subject interesting, I do admit I had not been as engaged and excited about the topic as I wish I could have been. I knew that I wanted my thesis project to express more of my own interests and identity as a psychologist, and put some pressure on myself at the beginning of the course to achieve this. However, I can reflect now that when I began to develop my thesis topic I was at such an early stage of my clinical training, I was not even sure what my interests and identity as a psychologist were yet. I was introduced to different types of psychological therapies during the first few weeks of teaching, some of which I was entirely unfamiliar with. One such area were "third-wave" therapies, which included mindfulness-based therapies, Compassion-Focused Therapy (CFT) and Acceptance and Commitment Therapy (ACT). I liked the approach that these therapies took in accepting what is out of a person's immediate control, and taking a more compassionate approach to difficult thoughts, experiences and discourses. I enrolled in the 10-week Mindfulness-Based Stress Reduction



(MBSR) course in the hope that it would give me both skills which I could transfer to my clinical work, and inspiration in developing my thesis topic.

Around the same time I attended the fourth year research fair and met with Pete, who had offered ideas about how third-wave approaches and ideas could be used for people with brain injuries. I had not had any prior experience with working with this clinical population, but after talking through with Pete it was clear that we would be able to find a project that might interest us both. I was also introduced to Lauren, a previous Hull trainee whose own thesis topic was related to compassion and third-wave approaches, and who was now working in a neuropsychological setting. I feel incredibly lucky to have had Pete and Lauren on my team throughout this process, both of whom have been continual sources of support and information. I felt pleased that we were all on the same page and were enthusiastic about how these psychological approaches might apply to and eventually benefit people with brain injuries, and I was excited about the prospect of developing a project with them.

### Empirical paper

After initially crafting and then disregarding several topic ideas due to their unfeasibility within this thesis' timeframe, including the development of a measurement of self-compassion for people with brain injuries, we agreed to explore the role that an individual might play in influencing the cause of their injury, and how self-compassion could help with this. A decision then had to be made about whether to use a qualitative or quantitative methodology. I had initially planned to use only a quantitative approach, as this is what I was

familiar with and had always seen myself doing. Lauren explained that she had had a similar dilemma when crafting her study's methodology, but had found it really valuable to include a qualitative component to allow for a deeper exploration of participants' experiences. I agreed that as the concepts I was planning to examine were rather abstract and subjective, it would be worthwhile to include some open questions to allow participants space to explore them in further detail. My prediction that a lot participants would leave these questions blank was largely incorrect; the majority of participants responded to these items in great detail and had clearly valued having the chance to express themselves. I knew at that point that I had made the right decision in using a mixed-methods approach, and am grateful for the encouragement from my supervisors to do so.

I had some difficult experiences when it came to data collection, as my measures did explore some potentially distressing topics. I visited a number of NHS and BIRT service bases to assist service users with completing the survey, and thus met personally with the majority of my participants. I was grateful to be able to do this rather than only using the online survey in which I would have had no context to the people who were providing my study with data. However, I did find it hard to sit with people and ask what I felt were quite personal and sensitive questions, often for up to an hour at a time. I had procedures in place for the potential for participants to become distressed, although thankfully I had no experiences of any significant distress. Despite this, some participants did tell me that they had found some of the questions upsetting as they asked about things the person probably would not think about on a daily basis. At times I felt torn between my role as a researcher who was

there just to collect data, and my role as a clinician who instinctively wanted to support this person who was telling me about their difficulties. It felt helpful to find a middle ground to this dilemma by using the debrief to explore any issues once the participant had finished the questionnaire.

I was fortunate enough to be supported by lots of fantastic services and clinicians during data collection for this study. I had felt worried about the time I would be taking out of people's already busy schedules, but was delighted with how excited so many services were to be able to help out. Lots of clinicians, services and service users were enthusiastic about the project and wanted to be kept in the loop about its findings, and at times it felt like a lot of work to keep up contact with all of these people. However, this high level of engagement proved to me that this study had real meaning, and helped me to feel motivated to do this project and its participants as much justice as I could.

### Systematic Literature Review

Shaping a topic for my systematic literature review (SLR) was a more straightforward process than the honing of ideas it took for my empirical paper. My original idea was to review the available studies utilising third-wave psychological approaches for people with acquired brain injuries. The first hurdle to this was the discovery that a recently published book (Wilson et al, 2017) included a chapter that described studies which had used ACT and CFT for acquired brain injury. I was disappointed that my initial idea seemed to have been carried out, but unsurprised as this was very much a rapidly-growing area of interest. I spent a few months trying to search for alternative ideas, but found

myself returning to my original idea and how I could make it work. After further examination it became apparent that neither the book chapter nor any other paper had recently systematically reviewed the literature on third-wave therapies for people with brain injuries and neurological conditions, or focus on any specific measures of its effectiveness.

I had initially wanted to review all third-wave therapies, and although there was a limited evidence base, it was still too large to be able to use this topic for my SLR within this thesis' timeframe. With support from my supervisors we decided to focus only on ACT, and expand the clinical population to include neurological conditions. After deciding on the topic I was really able to throw myself into the SLR and found the writing-up process rather enjoyable. I could easily imagine reading this paper as a clinician, and finding it a helpful way of summarising whether ACT would be a helpful route to take when working with people with brain injuries and neurological conditions. Visualising the real clinical implications that my SLR could have certainly helped me to feel excited about it.

### The end

I found myself thinking a lot about endings during the write-up stage. At times it has felt difficult to see beyond the hand-in date as it has often felt like such an enormous hurdle. With the hand-in date fast approaching and my thesis and training both coming to an end after three years of work, I am starting to be able to think about life post-thesis. I am excited and nervous about the next stage of my life, and preparing for this ending has led me to reflect on how this research has helped to shape me as a clinician. I have learned about the importance of

being kind to oneself through distress, which for me has meant being able giving myself a break from working without feeling guilty. I had wanted my thesis to represent more of me and my own interests, and I am pleased to have been able to achieve this. Although my thesis and training is coming to an official end, I know my own learning will continue as I move into a role as a qualified Clinical Psychologist, and I am excited to take what I have learned from this process into the next stage of my journey.

## **Appendix B: Author guidelines for submission to Neuropsychological Rehabilitation**

### **About the Journal**

*Neuropsychological Rehabilitation* is an international, peer-reviewed journal publishing high-quality, original research. Please note that this journal only publishes manuscripts in English.

*Neuropsychological Rehabilitation* accepts the following types of article: original articles, scholarly reviews, book reviews.

Neuropsychological Rehabilitation is an international, peer-reviewed journal, publishing high-quality, and original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy. Please note that this journal only publishes manuscripts in English. This journal accepts the following article types: original (regular) articles, scholarly reviews, and book reviews.

### **Peer Review**

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be single blind peer reviewed by independent, anonymous expert referees.

### **Preparing Your Paper**

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

### **Structure**

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

### **Word Limits**

Please include a word count for your paper. There are no word limits for papers in this journal.

### **Style Guidelines**

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Please use British (-ize) spelling style consistently throughout your manuscript.

Please use double quotation marks, except where "a quotation is 'within' a quotation". Please note that long quotations should be indented without quotation marks.

### **Formatting and Templates**

Papers may be submitted in Word or LaTeX formats. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s). Word templates are available for this journal. Please save the template to your hard drive, ready for use. If you are not able to use the template via the links (or if you have any other template queries) please contact [authortemplate@tandf.co.uk](mailto:authortemplate@tandf.co.uk).

## References

Please use this [reference guide](#) when preparing your paper.

An [EndNote output style](#) is also available to assist you.

## Checklist: What to Include

1. Author details. Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) [requirements for authorship](#) is included as an author of your paper. Please include all authors' full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted.
2. Should contain an unstructured abstract of 200 words.
3. Between 5 and 5 keywords.
4. Funding details. Please supply all details required by your funding and grant-awarding bodies as follows:  
*For single agency grants*  
This work was supported by the [Funding Agency] under Grant [number xxxx].  
*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].
5. Disclosure statement. This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research.
6. Data availability statement. If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). [Templates](#) are also available to support authors.
7. Data deposition. If you choose to share or make the data underlying the study open, please deposit your data in a [recognized data repository](#) prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
8. Geolocation information. Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can

index your paper's study area accurately in JournalMap's geographic literature database and make your article more discoverable to others. [More information](#).

9. Supplemental online material. Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about [supplemental material and how to submit it with your article](#).
10. Figures. Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, GIF, or Microsoft Word (DOC or DOCX). For information relating to other file types, please consult our [Submission of electronic artwork](#) document.
11. Tables. Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
12. Equations. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about [mathematical symbols and equations](#).
13. Units. Please use [SI units](#) (non-italicized).

### **Using Third-Party Material in your Paper**

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission.

### **Disclosure Statement**

Please include a disclosure statement, using the subheading "Disclosure of interest." If you have no interests to declare, please state this (suggested wording: *The authors report no conflict of interest*). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the declaration of interest statement.

### **Clinical Trials Registry**

In order to be published in a Taylor & Francis journal, all clinical trials must have been registered in a public repository at the beginning of the research process (prior to patient enrolment). Trial registration numbers should be included in the abstract, with full details in the methods section. The registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the [WHO International Clinical Trials Registry Platform \(ICTRP\)](#). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the [ICMJE guidelines](#).

### **Complying With Ethics of Experimentation**



Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All papers which report in vivo experiments or clinical trials on humans or animals must include a written statement in the Methods section. This should explain that all work was conducted with the formal approval of the local human subject or animal care committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the Declaration of Helsinki.

### **Consent**

All authors are required to follow the ICMJE requirements on privacy and informed consent from patients and study participants. Please confirm that any patient, service user, or participant (or that person's parent or legal guardian) in any research, experiment, or clinical trial described in your paper has given written consent to the inclusion of material pertaining to themselves, that they acknowledge that they cannot be identified via the paper; and that you have fully anonymized them. Where someone is deceased, please ensure you have written consent from the family or estate. Authors may use this Patient Consent Form, which should be completed, saved, and sent to the journal if requested.

### **Health and Safety**

Please confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae.

Please include all relevant safety precautions; and cite any accepted standard or code of practice. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

## Appendix C: Data Extraction Form

<b>General</b>	
Author(s)	
Year of publication	
Title of study	
Research aims	
Research design	
Peer reviewed?	
<b>Participants</b>	
Gender	
Age	
Type of neurological condition/disorder/difficulty	
Country	
Use of interpreter?	
Sample size	
<b>Intervention</b>	
Description of ACT intervention content	
Duration	
Mode of delivery	
Control or comparison group?	
Randomised?	
<b>Outcomes</b>	
Measurement of psychological flexibility and/or psychological flexibility	
When measured	
Statistical analysis	
Main findings	
<b>Conclusions</b>	
Study conclusions	
Quality score	

## Appendix D: Quality Checklist

<b>Reporting</b>			
1. Is the hypothesis/aim/objective of the study clearly described?	Yes 1	No 0	
2. Is the main outcome of psychological wellbeing and/or flexibility clearly described in the introduction or methods section?	Yes 1	No 0	
3. Are the characteristics of the patients included in the study clearly described?	Yes 1	No 0	
4. Are the interventions of interest clearly described?	Yes 1	No 0	
5. Are the distributions of principal confounders in each group of subjects to be compared clearly described?	Yes 1	No 0	
6. Are the main findings of the study relating to psychological flexibility and/or psychological wellbeing clearly described?	Yes 1	No 0	
7. Does the study provide estimates of the random variability in the data for the main outcomes?	Yes 1	No 0	
8. Have actual probability values been reported? (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?)	Yes 1	No 0	
<b>External validity</b>			
9. Were the subjects asked to take part in the study representative of the entire population from which they were recruited?	Yes 1	No 0	Unable to determine 0
10. Were those subjects who were prepared to participate representative of the entire population from where they were recruited?	Yes 1	No 0	Unable to determine 0
<b>Internal validity - bias</b>			
11. Was an attempt made to blind the study subjects to the intervention they received?	Yes 1	No 0	Unable to determine 0
12. If any of the results of the study were based on "data dredging" was this made clear?	Yes 1	No 0	Unable to determine 0

13. In trials and cohort studies, do the analyses adjust for different lengths of follow-up of participants, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?	Yes 1	No 0	Unable to determine 0
14. Were the statistical tests used to assess the outcomes of psychological flexibility and wellbeing appropriate?	Yes 1	No 0	Unable to determine 0
15. Was compliance with the intervention(s) reliable?	Yes 1	No 0	Unable to determine 0
16. Were the main outcome measures used accurate (valid and reliable)?	Yes 1	No 0	Unable to determine 0
<b>Internal validity – confounding</b>			
17. Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?	Yes 1	No 0	Unable to determine 0
18. Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?	Yes 1	No 0	Unable to determine 0
19. Were study subjects randomized to intervention groups?	Yes 1	No 0	Unable to determine 0
20. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	Yes 1	No 0	Unable to determine 0
21. Were losses of patients to follow-up taken into account?	Yes 1	No 0	Unable to determine 0

### Appendix E: Quality assessment results

Study	Checklist item																					Total /21
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	
Lundgren et al (2008)	1	1	1	1	0	1	0	0	0	1	1	1	1	1	1	1	1	0	1	0	1	15
Mo'Tamedi, Rezaemaram & Tavallaie (2012)	0	1	1	1	0	1	1	1	0	0	1	1	1	1	1	1	1	1	1	1	1	18
Bomyea, Lang & Schnurr (2017)	1	1	0	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	20
Lundgren et al (2006)	1	1	1	1	0	1	1	0	0	1	1	1	1	1	1	1	1	1	1	0	1	17
Nordin & Rorsman (2012)	1	1	1	1	0	1	0	0	0	1	1	1	1	1	1	1	1	1	1	1	1	17
Dindo et al (2012)	1	1	1	1	0	1	0	1	0	1	1	1	1	1	1	1	1	1	0	1	1	17
Dewhurst, Novakova & Reuber (2015)	1	1	1	1	0	1	1	0	0	0	1	1	1	1	1	1	1	0	0	1	1	15
Harrison et al (2017)	1	1	1	1	0	1	0	1	0	0	1	1	1	1	1	1	1	0	0	1	1	15
Kangas et al (2015)	0	1	1	1	1	1	0	0	0	0	1	1	1	1	1	1	1	0	0	0	1	13
Pakenham et al (2017)	1	1	1	1	0	1	1	1	0	1	1	1	1	1	1	1	1	1	0	1	1	18
Sheppard et al (2010)	1	1	0	1	0	1	1	0	0	1	1	1	1	1	1	1	1	1	0	1	1	16
Huddleston et al (2018)	1	1	1	1	1	1	1	1	0	0	1	1	1	1	1	1	1	1	0	1	1	18
Graham, O'Hara & Kemp (2018)	1	1	0	1	1	1	1	0	0	1	1	1	1	1	1	1	1	1	0	1	1	17
Whiting et al (2017)	1	1	1	1	0	1	0	0	0	0	1	1	1	1	1	1	1	1	0	0	1	14
Graham et al (2017)	1	1	1	1	1	1	0	0	0	0	1	1	1	0	1	1	1	1	0	0	1	14
Graham et al (2015)	0	1	1	1	0	1	0	0	0	0	1	1	1	0	1	1	1	1	0	0	1	12

## **Appendix F: Author guidelines for submission to Brain Injury**

### **Submission types**

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

### **Structure**

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

### **Formatting and templates**

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

### **Notes on style**

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

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

- Brain Injury prefers US to 'American', USA to 'United States', and UK to 'United Kingdom'
- Brain Injury uses conservative British, not US, spelling, i.e. colour not color; behaviour (behavioural) not behavior; [school] programme not program; [he] practises not practices; centre not center; organization not organisation; analyse not analyze, etc.
- Single 'quotes' are used for quotations rather than double "quotes", unless the 'quote is "within" another quote
- Punctuation should follow the British style, e.g. 'quotes precede punctuation'.
- Punctuation of common abbreviations should follow the following conventions: e.g. i.e. cf. Note that such abbreviations are not followed by a comma or a (double) point/period.
- Dashes (M-dash) should be clearly indicated in manuscripts by way of either a clear dash (-) or a double hyphen (- -).
- Brain Injury is sparing in its use of the upper case in headings and references, e.g. only the first word in paper titles and all subheads is in

upper case; titles of papers from journals in the references and other places are not in upper case.

- Apostrophes should be used sparingly. Thus, decades should be referred to as follows: 'The 1980s [not the 1980's] saw ...'. Possessives associated with acronyms (e.g. APU), should be written as follows: 'The APU's findings that ...', but, NB, the plural is APUs.
- All acronyms for national agencies, examinations, etc., should be spelled out the first time they are introduced in text or references. Thereafter the acronym can be used if appropriate, e.g. 'The work of the Assessment of Performance Unit (APU) in the early 1980s ...'. Subsequently, 'The APU studies of achievement ...', in a reference ... (Department of Education and Science [DES] 1989a).
- Brief biographical details of significant national figures should be outlined in the text unless it is quite clear that the person concerned would be known internationally. Some suggested editorial emendations to a typical text are indicated in the following with square brackets: 'From the time of H. E. Armstrong [in the 19th century] to the curriculum development work associated with the Nuffield Foundation [in the 1960s], there has been a shift from *heurism* to constructivism in the design of [British] science courses'.
- The preferred local (national) usage for ethnic and other minorities should be used in all papers. For the USA, African-American, Hispanic, and Native American are used, e.g. 'The African American presidential candidate, Jesse Jackson...' For the UK, African-Caribbean (not 'West Indian'), etc.
- Material to be emphasized (italicized in the printed version) should be underlined in the typescript rather than italicized. Please use such emphasis sparingly. n (not N), % (not per cent) should be used in typescripts.
- Numbers in text should take the following forms: 300, 3000, 30 000. Spell out numbers under 10 unless used with a unit of measure, e.g. nine pupils but 9 mm (do not introduce periods with measure). For decimals, use the form 0.05 (not .05).

### **Style guidelines**

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

### **References**

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

and nonterminal punctuation (e.g., semicolons, colons). Reference numbers should not be placed in parentheses.

### **Checklist: what to include**

1. Author details. Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) [requirements for authorship](#) is included as an author of your paper. Please include all authors' full names, affiliations, postal addresses, and email addresses on the cover page. Where appropriate, please also include [ORCiDs](#) and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the published article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that authorship may not be changed after acceptance. Also, no changes to affiliation can be made after your paper is accepted. Read more on authorship [here](#).
2. Structured abstract. This summary of your article is normally no longer than 200 words. For papers reporting original research, state the primary objective and any hypothesis tested; describe the research design and your reasons for adopting that methodology; state the methods and procedures employed, including where appropriate tools, hardware, software, the selection and number of study areas/subjects, and the central experimental interventions; state the main outcomes and results, including relevant data; and state the conclusions that might be drawn from these data and results, including their implications for further research or application/practice. For review essays, state the primary objective of the review; the reasoning behind your literature selection; and the way you critically analyse the literature; state the main outcomes and results of your review; and state the conclusions that might be drawn, including their implications for further research or application/practice. Read tips on [writing your abstract](#).
3. Keywords. Keywords are the terms that are most important to the article and should be terms readers may use to search. Authors should provide 3 to 5 keywords. Please read our page about [making your article more discoverable](#) for recommendations on title choice and search engine optimization.
4. Funding details. Please supply all details required by your funding and grant-awarding bodies as follows:  
For single agency grants  
This work was supported by the <Funding Agency> under Grant <number xxxx>.  
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>.
5. Disclosure statement. With a disclosure statement you acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance, please see our page on [what is a conflict of interest and how to disclose it](#).



6. Supplemental online material. Supplemental material can be a video, dataset, fileset, sound file, or anything else which supports (and is pertinent to) your paper. Supplemental material must be submitted for review upon paper submission. Additional text sections are normally not considered supplemental material. We publish supplemental material online via Figshare.
7. Figures. Figures should be high quality (600 dpi for black & white art and 300 dpi for color). Figures should be saved as TIFF, PostScript or EPS files. Figures embedded in your text may not be able to be used in final production.
8. Tables. Please supply editable table files. We recommend including simple tables at the end of your manuscript, or submitting a separate file with tables.
9. Equations. If you are submitting your manuscript as a Word document, please ensure that equations are editable. Please see our page on [mathematical symbols and equations](#) for more information.

### **Author agreement / Use of third-party material**

Authors are responsible for obtaining permission to reproduce copyrighted material from other sources and are required to sign an agreement for the transfer of copyright to the publisher. As an author you are required to secure permission if you want to reproduce any figure, table or extract text from any other source. This applies to direct reproduction as well as "derivative reproduction" (for which you have created a new figure or table which derives substantially from a copyrighted source). Please see our page on [requesting permission to reproduce work\(s\) under copyright](#) for more guidance. Authors are required to sign an agreement for the transfer of copyright to the publisher. All accepted manuscripts, artwork, and photographs become property of the publisher.

Guidelines for medicine and health publications

### **Disclosure of interest**

Please include your disclosure statement under the subheading "Disclosure of interest." If you have no interests to declare, please state this (suggested wording: The authors report no conflict of interest). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the declaration of interest statement. [Read more on declaring conflicts of interest here.](#)

### **Clinical Trials Registry**

In order to be published in a Taylor & Francis journal, all clinical trials must have been registered in a public repository at the beginning of the research process (prior to patient enrollment). Trial registration numbers should be included in the abstract, with full details in the methods section. The registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the [WHO International Clinical Trials Registry Platform \(ICTRP\)](#). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the [ICMJE guidelines](#).

### **Complying with ethics of experimentation**

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All papers which report in vivo experiments or clinical trials on humans or animals must include a written statement in the Methods section. This should explain that all work was conducted with the formal approval of the local human subject or animal care committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the [Declaration of Helsinki](#).

### **Consent**

All authors are required to follow the [ICMJE requirements](#) on privacy and informed consent from patients and study participants. Please confirm that any patient, service user, or participant (or that person's parent or legal guardian) in any research, experiment, or clinical trial described in your paper has given written consent to the inclusion of material pertaining to themselves, that they acknowledge that they cannot be identified via the paper; and that you have fully anonymized them. Where someone is deceased, please ensure you have written consent from the family or estate. Authors may use this [Patient Consent Form](#), which should be completed, saved, and sent to the journal if requested.

### **Health and safety**

Please confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae.

Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the [International Association of Veterinary Editors' Consensus Author Guidelines on Animal Ethics and Welfare](#) and [Guidelines for the Treatment of Animals in Behavioral Research and Teaching](#). When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

## Appendix G: Advertisement for recruitment

### Research Opportunity



We are recruiting for a study that looks into peoples' **experiences of having a brain injury.**

It will involve filling in questionnaires that will ask questions about your injury, and the way you feel about yourself following your injury. Completing the questionnaires will take around **30 minutes.**

Your participation may help to improve knowledge about brain injuries, and therefore help professionals working with people with brain injuries to improve their wellbeing and care.

**For further information, please email Jade Ambridge at [j.ambridge@2015.hull.ac.uk](mailto:j.ambridge@2015.hull.ac.uk)**

**Or telephone on 01482 464101**

## Appendix H: Participant information sheet

### **The role of self-compassion in perceived responsibility and shame in acquired brain injury**

#### **Participant Information Sheet**

We would like to invite you to take part in a study exploring the way you feel about yourself and your brain injury. Before deciding if you want to take part, we would like you to understand why we are doing the study, and what taking part would involve. Please read this sheet carefully before deciding.

#### **Purpose of study**

We know very little about people's feelings about how they got their brain injury. We also do not know much about whether this links to how kindly you treat yourself, and how sad or happy you feel. This study would like to investigate this, and to do this we need participation from people with different types of brain injuries.

#### **Why have you been invited to participate?**

This study needs people with brain injuries to participate. You have been invited to take part because you are over 18 years of age, have a brain injury and are currently in an active rehabilitation unit or are in contact with a neurorehabilitation service/charity. We give this information sheet to explain the study to people who could take part, as they may be interested in participating.

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

No. Taking part is voluntary and it is up to you to decide whether you want to take part. You can stop taking part at any time while completing the questionnaires in this study. However, once you have finished the questionnaires and handed them back to the researcher, you will not be able to get your answers back. This is because we will make sure none of your forms have your name on them, so we will not know which questionnaire is yours.

#### **What will participating involve?**

This study will involve filling in some questionnaires. This will either be on paper, or online on a device such as an iPad. You will be provided with the questionnaires either by the researcher, who will visit your unit, or by a staff member at your unit. If you are in a rehabilitation unit, you can do the questionnaires on your own in a quiet room, or with help from a staff or family member if necessary. If you are not in a rehabilitation unit, the questionnaires can be emailed or posted to you, or completed at your service base.

First, you will be asked to provide some information about yourself, including your gender, age and level of education. You will then answer questions about how responsible you feel for your brain injury, and how you feel about yourself and your injury. Some questions will have set answers which you can choose from, and some

will ask you to write your answer freely. Once you have completed the questions, you will be asked to give your answers back to the researcher or staff member.

### **Where will the research take part?**

You can complete the questionnaires wherever is most comfortable or convenient for you. This might be at your unit, a community centre, at home, or another location.

### **Expenses and reimbursements**

Taking part in this study will be unpaid.

### **What are the possible risks and disadvantages of taking part?**

You may feel worried or anxious when answering some of the questions, as they might feel quite personal. If you become too upset, you can stop doing the questionnaires at any time. If a staff member notices you becoming upset, they might suggest that you stop completing the questionnaires. However, it is up to you to decide whether you want to continue.

If you are in a rehabilitation unit, you also give your permission for the researcher to tell a member of staff if they notice you becoming upset, to make sure they offer to support you afterwards. The researcher can also give you contact details of services to contact when the study is finished if you are feeling upset.

You might need help from a staff or family member with the questionnaires; for example, to write your answers. You may feel uncomfortable sharing your responses with someone else, and you can stop taking part at any time if you feel this way.

### **What are the possible benefits of taking part?**

Although there are no known benefits for taking part in this study, taking part may help to improve what we know about brain injuries, and help staff working with people with brain injuries to take care of them.

### **Anonymity and Confidentiality**

Information collected in the study will only be used for this study. All information will be stored securely for 10 years and will then be destroyed. Information will be collected by the researcher or staff member at your unit, and will only be used by the researchers. All information will be anonymised, which means that none of your questionnaires will have your name on in order to keep them private. We will follow ethical and legal practice and all information about you will be handled in confidence.

### **What will happen with the results of this study?**

The results of this study will be presented in a doctoral thesis, submitted for publication in an academic journal and may be presented at conferences. No individual participant details will be identified in the presentation of data.

### **Who is organising this study?**

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

**What if there is a problem?**

If you have concerns about any aspects of this study you can contact Dr Pete Fleming at the University of Hull (p.fleming@Hull.ac.uk/ 01482 464008). You can also contact the local NHS Patient and Advice and Liaison Service (PALS) on telephone number 01482 303 966 or via email: pals@humber.nhs.uk.

**What should I do next?**

If you wish to take part please inform the member of staff who gave you this sheet, or contact the researcher directly, and they will then be able to advise you about what to do next.

**For further information**

The researchers, Miss Jade Ambridge, Dr Pete Fleming and Dr Lauren Henshall, will be happy to answer any questions about this study at any time:

<b>Researcher name</b>	<b>Role</b>	<b>Email</b>	<b>Address</b>
Jade Ambridge (Trainee Clinical Psychologist)	Principle Investigator	j.ambridge@2015.hull.ac.uk	Department of Psychological Health and Wellbeing, University of Hull, Cottingham road, Hull, HU6 7RX
Dr Pete Fleming (Clinical Neuropsychologist)	Academic Supervisor	p.fleming@hull.ac.uk	Department of Psychological Health and Wellbeing, University of Hull, Cottingham road, Hull, HU6 7RX
Dr Lauren Henshall (Clinical Psychologist)	Field Supervisor	lauren.henshall@thedtgroup.org	Lauren Henshall, York House, Heslington Road, York, YO10 5BN

This study has been reviewed by the South East Coast Surrey NHS Research Ethics Committee.

**Thank you for taking the time to read this information sheet.**

## **Appendix I: Staff/family member information sheet**

### **The role of self-compassion in perceived responsibility and shame in acquired brain injury**

#### **Carer/Family/Staff Member Information Sheet**

We would like to invite a patient in your care to take part in a research study exploring the way they feel about themselves and their brain injury. Before deciding if they would like to take part, and for you to assist them with this, we would like you to understand why the research is being done, and what it would involve for you. We would therefore ask that you read the following information carefully before making your decision.

#### **Purpose of study**

We know very little about the impact of feeling as if someone has a lot, or little, responsibility for their brain injury. We also know very little about whether this links to how kindly they treat themselves, and their overall wellbeing. This study aims to explore the impact of this, and in order to do so requires participation from individuals with different types of brain injuries.

#### **Why have you been invited to participate?**

This study requires the participation of individuals with brain injuries. Your patient or family member has been invited to take part in this research because they are over 18 years of age, have experienced a brain injury and are currently in contact with a neurorehabilitation service. This study will measure participants' levels of self-awareness, and part of this measurement asks that a staff or family member who knows the participant well fills out a questionnaire about the participant. The patient may also find it difficult to participate independently, and may require assistance from a staff or family member to complete the questionnaire. Therefore, you have been given this information sheet to provide information about filling out your questionnaire, and what your role in assisting the participant might be.

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

No. Participation is completely voluntary and it is up to the patient to decide whether to join this study. It is also up to you to decide whether you agree to complete the questionnaire, or assist the patient to take part in the study. Both you and the participant are free to withdraw from this study at any time whilst completing the questionnaires, but once you have completed and returned the questionnaires to the researcher, you will not be able to withdraw yours or their data. Both yours and the participants' decisions will not affect your medical care or legal rights.

#### **What will participating involve?**

Participants will be asked to fill in questionnaires. These will either be paper based, or online on a device such as an iPad, depending on the resources of the unit. Questionnaires will be completed in a quiet room, and most participants will do this alone. You will be asked to sign a consent form, and then will be free to complete your questionnaire at the same time as the patient, or at a different time, depending on

which is most convenient for you. Once you have completed the questionnaire, you will be asked to return it to the researcher, and will be provided with a summary of findings when the study is finished.

Some participants may require assistance with completing the questionnaires, such as having someone to write down their responses for them. Your role as a staff or family member might be to assist the participant to complete the questionnaires, in any way that they require. The participant will be aware that you will be exposed to their responses, and if they feel uncomfortable with this they can withdraw at any point. Once you have assisted the participant, you will collect the questionnaires and return them to the researcher.

### **Where will the research take part?**

You and the participants can complete the questionnaires wherever is most comfortable or convenient for you both. This might be at the unit, a community centre, at home, or another location.

### **Expenses and reimbursements**

Your role in this study will be voluntary.

### **What are the possible risks and disadvantages of taking part?**

The participant may experience some emotional distress when answering some of the questions, as they explore quite personal parts about themselves, which they may not often think about. Should this become too distressing, they are free to discontinue their participation at any point while completing the questionnaire. If you notice the participant becoming distressed, you may suggest that they stop completing the questionnaires. It may also be appropriate for you to notify the participant's lead clinician to provide follow-up review and support regarding this distress, to ensure that the participant is fully supported. However, it remains the participant's decision to decide whether they want to carry on taking part in the study.

### **What are the possible benefits of taking part?**

Although there are no known benefits for taking part in this study, your support in taking part may help to improve knowledge about brain injuries, and therefore help professionals working with people with brain injuries to improve their wellbeing and care.

### **Anonymity and Confidentiality**

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



**What will happen with the results of this study?**

The results of this study will be presented in a doctoral thesis, submitted for publication in an academic journal and may be presented at conferences. No individual participant details will be identified in the presentation of data.

**Who is organising this study?**

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

**What if there is a problem?**

If you have concerns about any aspects of this study you can contact Dr Pete Fleming at the University of Hull (p.fleming@Hull.ac.uk/ 01482 464008). You can also contact the local NHS Patient and Advice and Liaison Service (PALS) on telephone number 01482 303 966 or via email: pals@humber.nhs.uk.

**What should I do next?**

If you wish to assist with the completion of the staff questionnaire, and/or support a participant to take part in this study, please sign the staff/family member consent form when assisting participants, and return this to the researcher with the participants' consent form and questionnaires.

**For further information**

The researchers, Miss Jade Ambridge, Dr Pete Fleming and Dr Lauren Henshall, will be happy to answer any questions about this study at any time:

<b>Researcher name</b>	<b>Role</b>	<b>Email</b>	<b>Address</b>
Jade Ambridge (Trainee Clinical Psychologist)	Principle Investigator	j.ambridge@2015.hull.ac.uk	Department of Psychological Health and Wellbeing, University of Hull, Cottingham road, Hull, HU6 7RX
Dr Pete Fleming (Clinical Neuropsychologist)	Academic Supervisor	p.fleming@hull.ac.uk	Department of Psychological Health and Wellbeing, University of Hull, Cottingham road, Hull, HU6 7RX
Dr Lauren Henshall (Clinical Psychologist)	Field Supervisor	lauren.henshall@thedtgroup.org	Lauren Henshall, York House, Heslington Road, York, YO10 5BN

This study has been reviewed by the South East Coast Surrey NHS Research Ethics Committee.

**Thank you for taking the time to read this information sheet.**

## Appendix J: Participant consent form

Centre Number:

Study Number:

Patient Identification Number for this trial:

---

### CONSENT FORM - Participant

---

**Title of Project:** The role of self-compassion in perceived responsibility and shame in acquired brain injury

**Name of Researcher:** Jade Ambridge

*Please initial all boxes*

1. I confirm that I have read and understand the information sheet dated 18/07/17 (Version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time whilst completing the study without giving any reason, without my medical care or legal rights being affected. I understand that once I have returned my questionnaires to the researcher, I cannot withdraw my anonymised data.
  
3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from BIRT, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
  
4. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Name of Person                      Date                      Signature of person taking consent.

# Appendix K: Clinician/family member/friend consent form

Centre Number:

Study Number:

Patient Identification Number for this trial:

---

## CONSENT FORM – Staff/Family/Other

---

**Title of Project:** The role of self-compassion in perceived responsibility and shame in acquired brain injury

**Name of Researcher:** Jade Ambridge

*Please initial all boxes*

5. I confirm that I have read and understand the carer/staff member information sheet dated 24/08/17 (Version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

6. I understand that my participation is voluntary, and that I am free to withdraw at any time whilst completing the study without giving any reason, without my medical care or legal rights being affected. I understand that once I have returned my questionnaires to the researcher, I cannot withdraw my anonymised data.

7. For those assisting participants to fill out questionnaires - I understand that by assisting a participant to take part in this study, I will be exposed to their questionnaire responses. I agree that I will keep this information confidential, and will only pass on relevant information if I believe that the participant or someone else could be at risk of harm. (Tick if applicable)

8. I agree to take part in the above study

\_\_\_\_\_

Name of carer/staff member

\_\_\_\_\_

Date

\_\_\_\_\_

Signature

\_\_\_\_\_

Name of Person

\_\_\_\_\_

Date

\_\_\_\_\_

Signature of person taking consent.

## **Appendix L: Combined participant & staff/family member debriefing page**

Thank you for taking part in this study, your participation means a great deal to us.

If you are feeling in anyway upset or distressed as a result of completing this questionnaire, we would encourage you to speak to someone close to you about this, such as a friend, family member or staff member at your Neurorehabilitation service.

You can also seek support from the following places;

The **Headway Brain Injury Association** offers information and advice regarding life after brain injury on its website:

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

**Confidential helpline: 0808 800 2244**

**Samaritans** provide emotional support to anyone in emotional distress, over the telephone, by email or by text message.

<https://www.samaritans.org/>

**Helpline: 116 123**

**Email: [jo@samaritans.org](mailto:jo@samaritans.org)**

**Mind** is a mental health charity which can offer support and advice for anyone experiencing mental health difficulties.

<https://www.mind.org.uk/>

**Helpline: 0300 123 3393**

**Email: [info@mind.org.uk](mailto:info@mind.org.uk)**

If you still have concerns you can contact the Researcher on:

01482 464101

[j.ambridge@2015.hull.ac.uk](mailto:j.ambridge@2015.hull.ac.uk)

You can also seek advice from your GP, or in an emergency telephone 999

## Appendix M: Confirmation of ethical approval

**Removed for  
digital archiving**

**Removed for  
digital archiving**

**Removed for  
digital archiving**

**Removed for  
digital archiving**



**Removed for  
digital archiving**

**Removed for  
digital archiving**

**Removed for  
digital archiving**

**Removed for  
digital archiving**

**Removed for  
digital archiving**

**Removed for  
digital archiving**

**Removed for  
digital archiving**

**Removed for  
digital archiving**



**Removed for  
digital archiving**

## Appendix N: Demographic Questionnaire

1. What is your age? *(Please circle your answer)*

18-24  
25-34  
35-44  
45-54  
55-64  
65+

2. To which gender do you most identify? *(Please circle your answer)*

Male  
Female  
Transgender  
Not listed (Please indicate if you wish)  
Prefer not to say

3. What is your relationship status? *(Please circle your answer)*

Single  
Married or domestic partnership  
Widowed  
Divorced  
Separated

4. What is your highest level of education? *(Please circle your answer)*

GCSE  
A Level  
Degree Level  
Post-Graduate Level

5. How much time has passed since your injury? *(Please circle your answer)*

Less than 6 months  
6 months – 1 year  
1 year – 2 years  
2 years – 3 years  
3 years – 4 years  
4 years – 5 years  
5+ years

6. How long have you been in contact with a rehabilitation/support service?  
(Please circle your answer)

Less than 6 months  
6 months – 1 year  
1 year – 2 years  
2 years – 3 years  
3 years – 4 years  
4 years – 5 years  
5+ years  
No longer in rehabilitation services

7. Which setting best applies to you? (Please circle your answer)

NHS or BIRT Neurorehabilitation service inpatient  
NHS or BIRT Neurorehabilitation service outpatient  
In contact with community/voluntary Neurorehabilitation service

## Appendix O: Self-Compassion Scale (Short-form)

**Removed for  
digital archiving**

## Appendix P: Responsibility item

Please rate how much you think you are responsible for your brain injury on a percentage scale between 0-100, where 0 is not responsible at all, and 100 is fully responsible.

 %

## Appendix Q: State Shame and Guilt Scale

**Removed for  
digital archiving**

## **Appendix R: Hospital Anxiety and Depression Scale**

Please indicate the reply that is closest to how you have feeling **in the past week**.

**Removed for  
digital archiving**

**Removed for  
digital archiving**



## Appendix S: Awareness Questionnaire

**Removed for  
digital archiving**

**Removed for  
digital archiving**

## **Appendix T : Qualitative Questions**

1. How positively or negatively do you view yourself following your brain injury?
2. How different is this to how you would have viewed yourself prior to your brain injury?
3. How kindly do you treat yourself?
4. How did your brain injury happen?
5. How responsible do you think other people were for any part of your brain injury happening?
6. How responsible do you think you were for any part of your brain injury happening?
7. What have been your biggest achievements or areas of growth/development since your brain injury?

## Appendix U: Example of coding process in thematic analysis

Question	Quotes	Open coding	Focused coding	Initial themes
<b>How positively or negatively do you view yourself post-injury?</b>	<i>'I view myself positively, but have to work within the limitations of my acquired brain injury.'</i> <i>'Try to think positively.'</i> <i>'Try to be positive but I can feel when I am not quite right.'</i> <i>'I am a lot more positive now.'</i> <i>'I'm a positive person.'</i> <i>'Like I'm useless and no-one understands.'</i> <i>'Casual throwaway remarks by others like "your memory can't be as bad as mine" are so upsetting.'</i> <i>'More negatively I definitely view myself negatively.'</i> <i>'Reasonably negatively.'</i>	Working with limitations  Trying to be positive  Have always been positive  Feeling useless  Feeling different to other people  Impact of other people's opinions	Positive view of self    Negative view of self  Sadness  Shame	Sense of self
<b>How different is this to how you would have viewed yourself prior to your brain injury?</b>	<i>'Sometimes I want run away and die.'</i> <i>'I feel worthless.'</i> <i>'Like I'm useless.'</i> <i>'Before I came here I used to have loads of motivation whereas now I have none whatsoever, I get judged by everyone, and when that happens it makes me feel worthless about myself.'</i> <i>'I feel awkward in social situations.'</i> <i>'Embarrassed if people talk to me, I don't remember what we were talking about.'</i> <i>'I am more insular, lacking confidence and more reluctant to socialize with other than with very close family and friends.'</i>	Feeling worthless because of injury  Feeling like life is not worth living  Feeling that life is different to before  Feeling less confident socially after the injury  The injury has affected social skills and relationships	Sense of worth/living   Confidence Relationships  Social	Sense of self   Functional impact

## **Appendix V: Epistemological statement**

This statement will describe the epistemological underpinnings of this piece of research, and how this led to the decisions about the research methods that were chosen. Ontology is a term to describe the existence of potential knowledge and beliefs about the world, and epistemology refers to the study of this knowledge, and the methods and ways through which this knowledge can be obtained (Guba, 1990). This leads to the development of theories and hypotheses, and corresponding methodologies to test out theories based on data and information (Patel et al, 2015).

A major distinction that can be made between research approaches is the adoption of quantitative or qualitative methodologies, and the different ontologic and epistemological assumptions of these approaches. Quantitative research aims to measure data in a quantifiable way, such as through the collection of responses through questionnaires that utilise closed questions and rating scales (Coolican, 2017). This usually produces numerical data which can be viewed as “objective”, as it is less susceptible to the ambiguities of interpretation (Barker & Pistrang, 2015). Quantitative data was used widely in the field of experimental psychology during the first half of the 21st century, but researchers became dissatisfied with its perceived inappropriateness for measuring varying human behaviours and experiences (Percy, Kostere & Kostere, 2015). Contrastingly, qualitative research aims to understand the experiences of populations. This is achieved through the collection of richer but less quantifiably measurable data, such as interviews and observations (Percy, Kostere & Kostere, 2015). Although qualitative data has the advantage that it can capture more information and insights that might be missed by quantitative approaches, it is

also very reliant on the interpretation of the researcher and thus susceptible to their biases.

Different schools of sociological thought favour different approaches; “positivists” stress the importance of conducting large-scale quantitative research to examine society as a whole, and uncover social trends. They are of the belief that psychology should utilise the same methodology to study human behaviours as the natural sciences use to study the natural world (Weber, 2004). On the other hand, an interpretivist would favour qualitative research as they stress the importance of the subjective complexity of individuals. Their view is that people understand the world through their own version of reality, making it important to conduct qualitative research to achieve a level of empathetic understanding with others (Weber, 2004).

The contrasting nature and aims of quantitative and qualitative approaches might lead one to the conclusion that they are without similarities. However, Onwuegbuzi and Leech (2005) are of the view that the division of qualitative and quantitative research is counter-productive, and may actually limit the advancement of social and behavioural science. Indeed, Newman & Benz (1998) suggested that both research paradigms exist on the same continuum as both have research aims and use analytical techniques to find meaning.

These historical contexts influenced my own epistemological stance during the selection of my research topic and methodology. While I did not fully concede to either the positivist or interpretivist school of thought, my comfort lay in the collection and interpretation of quantitative research. I have had the most

experience using this methodology, and considered this to be a strong argument for choosing this approach. However, I had been developing in my role as a Clinical Psychologist while considering which methodological approach to take, which had an impact on the way I considered the advantages and disadvantages of qualitative vs quantitative data collection. I was beginning to have real experience of people sharing their complex and very individual experiences with me, and I wondered how well numbers could really quantify human behaviour and thought. Despite this, I was still considerate of my own perceived strengths and weaknesses as a researcher and the time constraints of this project. When selecting a research question and methodology, I wanted to be able to step outside of my comfort zone to expand my research strengths, while also be able to complete a study with which I felt comfortable and could engage with for three years.

My empirical paper aimed to explore the impact of perceived responsibility and self-compassion on the experiences of shame for people with brain injuries. Although was based in previous theory and literature, the body of evidence was limited, especially when applied to the population I was studying. Resultantly, this study was somewhat exploratory in nature. The initial plan was to collect only quantitative data and then statistically analyse the relationships between individual variables, as this is where my experience lay and the main methods utilised by other studies. However, it became apparent through the examination of literature that concepts such as self-compassion and shame can be difficult to quantifiably measure in the same objective way one might measure height or weight, for example. Individual definitions of such concepts differ between individuals and populations (Pauley & McPherson, 2010), and thus I was

concerned that relying on the collection of a single questionnaire to measure each concept could result in a less valid study that missed individual experiences. To tackle this potential problem, the strengths and weaknesses for the inclusion of a qualitative element to the study was examined. Although this would add further time pressures and take me out of my research comfort zone, I also hoped that the inclusion of such methodologies would enhance the richness of the quantitative data, and provide further information about the *experiences* of self-compassion, shame and responsibility for people with brain injuries. Therefore, this study employed a mixed-methods approach to analyse both quantitative and qualitative approaches to the research question.

Thematic analysis was chosen as the method of analysing the qualitative data, and followed the approach of Braun & Clarke (2006). As this study aimed to understand participants' experiences and views of shame, self-compassion and responsibility, a semantic level of analysis was chosen to look at what participants wrote and then categorising them into themes. Braun & Clarke (2006) also differentiated between inductive and deductive approaches when categorising themes. An inductive approach is led only by the data, while a deductive approach might also utilise pre-defined theories and frameworks to guide the initial coding stage. The thematic analysis in this study used a deductive approach as the topics of the open questions related to the predictor variables from the quantitative questions in the survey, and these topics were used to initially code the data.

In sum, this thesis is underpinned by the viewpoint that qualitative and quantitative data both have value for the investigation of its research questions,



and it is the consolidation of both types of data that will provide a richer and fuller picture of findings and their meanings.

## References

- Barker, C., & Pistrang, N. (2015). *Research methods in clinical psychology: An introduction for students and practitioners*. John Wiley & Sons.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.
- Coolican, H. (2017). *Research methods and statistics in psychology*. Psychology Press.
- Newman, I. & Benz, C. R. (1998). *Qualitative–quantitative research Methodology: Exploring the Interactive Continuum*. Carbondale, Illinois: Southern Illinois University Press.
- Patel, S. (2015). The research paradigm–methodology, epistemology and ontology–explained in simple language. *Healthcare, Technology, Participation, Research and a PhD*.
- Pauley, G., & McPherson, S. (2010). The experience and meaning of compassion and self-compassion for individuals with depression or anxiety. *Psychology and Psychotherapy: Theory, Research and Practice, 83*(2), 129-143.
- Percy, W. H., Kostere, K., & Kostere, S. (2015). Generic qualitative research in psychology. *The Qualitative Report, 20*(2), 76.
- Onwuegbuzie, A. J., & Leech, N. L. (2005). Taking the “Q” out of research: Teaching research methodology courses without the divide between quantitative and qualitative paradigms. *Quality and Quantity, 39*(3), 267-295.
- Smith, J. A. (Ed.). (2015). *Qualitative psychology: A practical guide to research methods*. Sage.
- Weber, R. (2004). The Rhetoric of Positivism versus Interpretivism: A Personal View 1. *MIS quarterly, 28*(1), III.