THE UNIVERSITY OF HULL

The Impact of Impaired Self-Awareness on the Assessment of Fatigue and Rehabilitation in Brain Injury

being a Thesis submitted in partial fulfilment

of the requirements for the degree of Doctor of Clinical Psychology

in the University of Hull

by

Rebecca Di Somma

BSc (Hons) Psychology, University of York

August 2022

Acknowledgments

Firstly, I would like to thank all the services, clinicians and participants who took time to support and take part in this study. Thank you for your interest and participation in the research and for being so open and passionate about exploring and improving assessment and treatment within the field. It has been a privilege to work with you all and hear about your experiences which I will take with me in my career.

I would also like to thank my research and field supervisors Dr Peter Fleming and Dr Stephen Evans for developing the initial concept of the research and supporting me with their extensive knowledge and passion within the neuropsychology field. Thank you for your encouragement and understanding throughout this project, it has not been an easy process, but your support, patience and continued enthusiasm has made this research possible. Another thank you to Maureen Twiddy for your support with statistical analysis, your knowledge and expertise has been integral for this project, and I value your compassion and help throughout the data analysis process.

A big thank you to all my friends, family and fellow trainees who have provided me with support every step of the way. Particular thanks to Kate, my fellow trainee within this project, thank you for being by my side whilst we conducted these projects together and for always being empathetic and providing me with help whenever needed.

Finally, thank you to my Mum and Dad, who have always been there to encourage me to achieve my goals. Thank you for your support, love and understanding, and for always believing in me. I cannot express my gratitude towards you both for everything you have done for me.

Overview

This portfolio thesis involves three parts. Part one includes a systematic literature review, part two includes an empirical paper and part three includes the appendices.

Part one- Systematic Literature Review

The Systematic Literature Review explored the impact of impaired self-awareness (ISA) on the process of rehabilitation in acquired brain injury populations. This review identified 16 studies which were analysed using Narrative Synthesis. Four key themes arose from the analysis, including goal setting, treatment adherence, engagement and willingness to change and time spent in hospital. The findings explored the impact that ISA can have on different areas of the rehabilitation process and how this can impact on recovery. The clinical implications and areas for further research are described.

Part two- Empirical Paper

The empirical paper is part of a larger project to validate and explore the Brain Injury Fatigue Scale (BIFS). The BIFS is an unpublished measure of fatigue that is widely used in clinical practice. This study investigated the degree of agreement between the self and proxy (i.e., carer/relative/friend) ratings of the BIFS and explored what variables best predict any differences in scores, including level of awareness and patients' mood. Eleven individuals with acquired brain injuries (ABI) or neurological conditions and their proxies completed the BIFS and Patient Competency Rating Scale (PCRS). Patients also completed the Hospital Anxiety and Depression Scale (HADS) and their demographic data was collected. This study found that that 63.64% of patients rated their fatigue within the same clinical cut off category as their proxies' ratings. It was also found that ISA and mood did not predict BIFS-Discrepancy scores. This study therefore found a moderate level of agreement between patient and proxy BIFS

ratings; however, it also emphasises the importance of using proxy ratings scales within this area, which has not previously been explored. Further research identifying factors that impact self and proxy ratings of fatigue is required.

Part three- Appendices

Part three includes the appendices relating to the systematic literature review and the empirical paper, as well as the epistemological and reflective statements.

Total word count

19,822 (including tables, figures, references and appendices)

Contents

Page Number

.

.

List of Tables and Figure

Part One- Systematic Literature Review

Page Number

Part Two- Empirical Paper

.

Part One- Systematic Literature Review

A Review of the Impact of Impaired Self-Awareness on the Process of Rehabilitation in Acquired Brain Injury

Rebecca Di Somma[1], Dr Peter Fleming[1]*, Dr Stephen Evans[2] & Dr David Quinn[3]

[1] Department of Clinical Psychology, Faculty of Psychological Health, Wellbeing and Social Work, Aire Building, University of Hull, Hull, HU6 7RX

[2] Psychological Medicine Department, The Old Chapel, Bootham Park, York, YO31 8HE

[3] Halliday Quinn Limited, The Stable, Mews Cottage, Carey Herefordshire, HR2 6NF

*Corresponding Author Email: p.fleming@hull.ac.uk

This paper is written in the format ready for submission to the Brain Injury Journal (see Appendix C for submission guidelines)

Word count: 4635 (excluding abstract, references, tables, and figures)

Abstract

Background: Impaired self-awareness (ISA) is common in individuals with an acquired brain injury (ABI) and can lead to reduced awareness of one's difficulties. Previous reviews have found that ISA impacts on functional outcomes in rehabilitation. However, to date there has not been a systematic review which examines how ISA impacts on the process of rehabilitation in ABI populations. This review aims to explore this.

Method: A literature search was conducted on several databases in March 2022, including Academic Search Premier, CINAHL, MEDLINE, APA PsycARTICLES and APA PsycINFO. 16 articles were selected for the review and were analysed using Narrative Synthesis.

Results: Four themes arose from the findings, including goal setting, treatment adherence, engagement, and willingness to change and time spent in hospital. ISA was found to impact on the value ABI participants placed on rehabilitation, which decreased treatment compliance, motivation, and engagement. ISA also impacted on goal setting and behaviour and resulted in a longer length of time spent in hospital.

Conclusion: This review emphasises the impact of ISA on various aspects/processes of rehabilitation in ABI and provides considerations of how clinicians might adapt interventions to manage these difficulties.

Keywords: Impaired self-awareness, insight, anosognosia, brain injury, rehabilitation

Introduction

An acquired brain injury (ABI) refers to injury to the brain that occurs after birth and is not genetic, degenerative, or caused by birth trauma, childhood learning disabilities or developmental delays. ABI's include traumatic brain injury (TBI) and stroke (1). Individuals with an ABI can experience behavioural, physical, emotional, and cognitive impairments. Examples of these difficulties include fatigue (2), executive functioning deficits (3) and self-regulation difficulties (4). Despite these impairments, ABI individuals can present with reduced awareness of their difficulties (5).

Impaired self-awareness (ISA) has been defined as the inability to identify and understand the extent of one's impairments (6). ISA is found to be prevalent in ABI, with it being seen within 73% of stoke patients at admission and 42% at discharge (7). ISA is also found in 20% (8) and 41% (9) of TBI patients and is influenced by factors including injury severity (8) and time post injury (28).

ABI individuals are found to experience ISA of a range of difficulties, including executive functioning (10), emotional recognition (11), fatigue (12) and functional dependence (13). Patients can underestimate their difficulties in these areas which can lead to poorer functional outcomes in rehabilitation (**Error! Bookmark not defined.**), as well as difficulties with community re-integration (14), and employability (15). One study found that 71.2% of clinicians rated self-awareness as important within rehabilitation and 69.3% rated it as important for rehabilitative success (16). Identifying and managing ISA is therefore crucial within rehabilitation.

Previous reviews have focused on the impact of ISA on functional outcome from rehabilitation, including poorer activity levels, lower employability, emotional distress, poorer social cognition, and reduced executive functioning (17, 18). One review conducted by Dromer et al (19) investigated the impact of ISA on functional outcome and the predictors of ISA after TBI, including the cognitive, behavioural, social, and emotional impact of ISA on everyday life. This review referred to the impact of ISA on the rehabilitative process itself, including poorer goal setting and treatment adherence, but this was not the primary aim of the study.

Although previous reviews have investigated the impact of ISA on functional outcomes within rehabilitation (19, 20), a review on how ISA impacts on the rehabilitative process itself has not been conducted. This would be beneficial for clinicians and services working with ABI individuals to identify barriers to rehabilitation due to ISA and what adaptations could be made to improve recovery.

Rehabilitation can occur in a range of settings including both inpatient/hospital settings and community working. It has been defined as specialist support, including interventions to aid individuals to manage their difficulties and learn or preserve skills (21). This definition will be used within this review with rehabilitation characterised as recovery with direct clinician involvement, including frequent appointments of specialist support within inpatient and outpatient rehabilitation programmes.

This review will therefore explore how ISA can impact on the process of rehabilitation in ABI populations, which will provide insight into areas of treatment that are affected by ISA and how clinicians and services can adapt rehabilitation to improve recovery.

Methods

Search Strategy

A systematic literature search was completed in March 2022. The search engine EBSCOhost was used to search the literature on the following databases: Academic Search Premier, CINAHL, MEDLINE, APA PsycARTICLES and APA PsycINFO.

Search Terms

Search terms were selected based upon common terminology used within the titles and abstracts of existing literature. The search terms used were:

Brain injur* OR TBI OR ABI OR head injur* OR head traum* OR stroke*

AND

Lack of insight OR lack of awareness OR reduced insight OR reduced awareness OR anosognosia OR self-aware* OR awareness deficit* OR insight deficit* OR limited awareness OR limited insight

AND

Impact* OR effect* OR influence* OR outcome* OR result* OR consequence* OR experience*

AND

Rehab* OR interven* OR support* OR treat* OR therap*

Three search limiters were applied to return articles that were written in English, peer-reviewed and from academic journals.

Inclusion and Exclusion Criteria

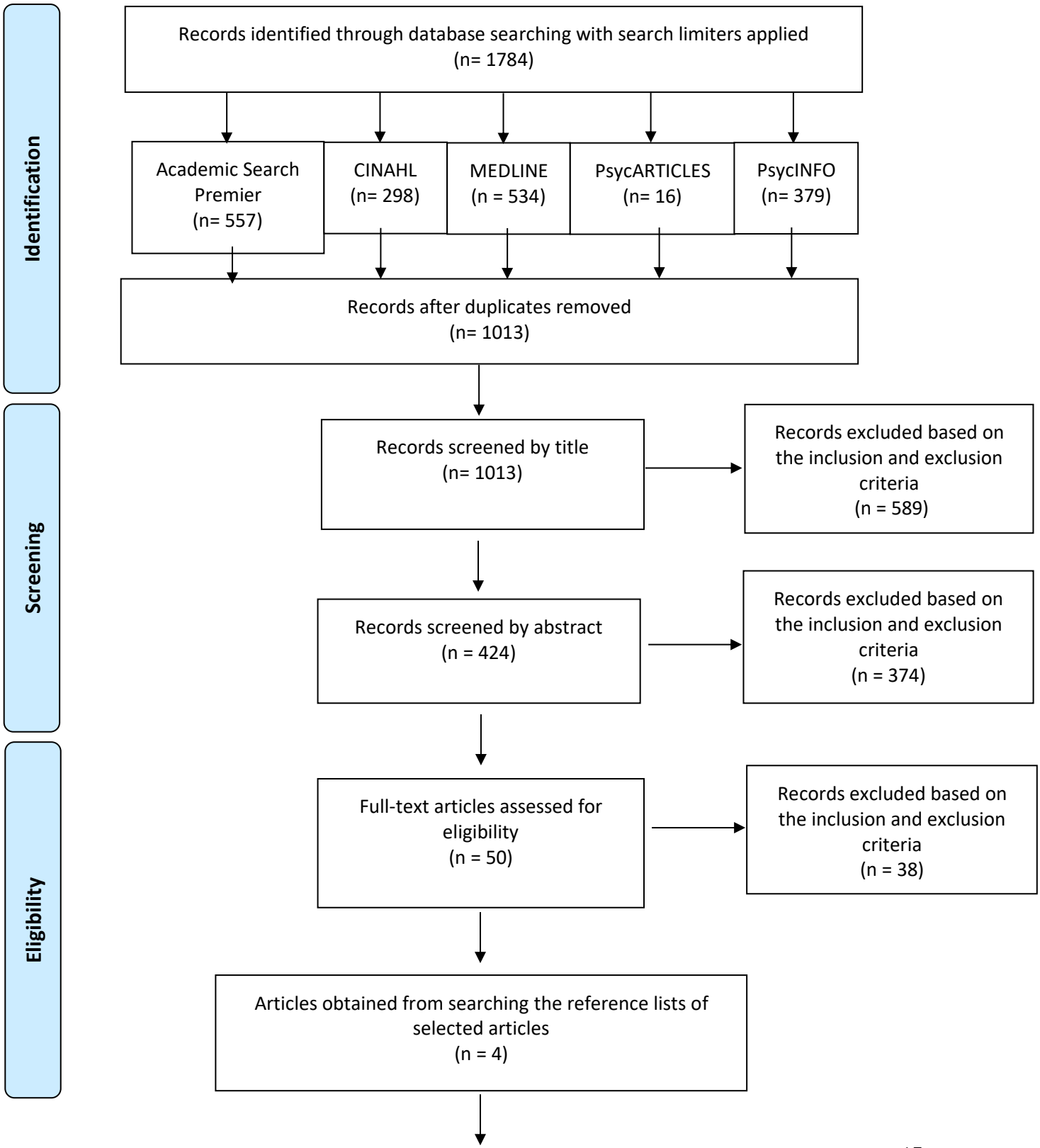
The inclusion criteria for the selected articles included studies that involve participants with ABI's or professionals who work closely with ABI individuals, studies that included a description of how ISA can/cannot have an impact on the rehabilitation process, and peer-reviewed journals. The exclusion criteria included studies not in the English language and any literature reviews, discussion papers, conference abstracts or case studies. The exclusion criteria also included studies that focused on the impact of ISA on functional outcomes or activity at follow up rather than on the process of rehabilitation itself.

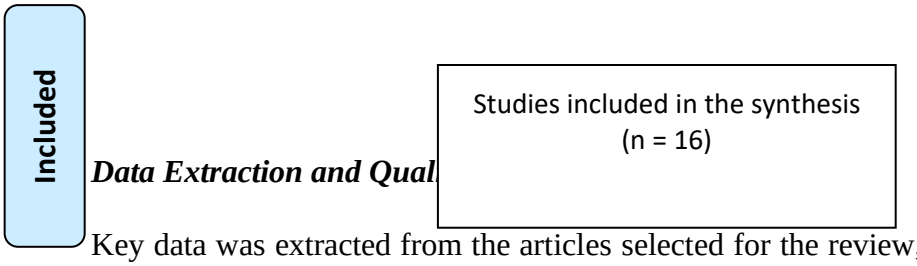
Article Screening and Selection Strategy

The search generated 1784 articles, 771 of them were duplicates, leaving 1013 for screening. The articles within the search were screened by their title to assess for relevancy. Where relevance could not be determined by the article titles, their abstracts or full texts were reviewed. 50 studies met the inclusion criteria. After this initial screening, the full text of the articles was reviewed using the inclusion criteria, 38 papers were excluded, leaving 12 papers remaining. The reference lists of the remaining articles were then examined, and 4 further relevant papers were found. 16 articles were therefore included within this review. Figure 1 shows a PRISMA flow diagram (22) of the screening and selection process.

Figure 1

PRISMA Flow Diagram (22) Outlining the Article Selection Process





Data Extraction and Qual

Key data was extracted from the articles selected for the review, including the research aims, design, participant characteristics, type of rehabilitation, self-awareness measure, key findings, and conclusions. This information can be seen in Table 1. The Mixed Methods Appraisal Tool (MMAT) (23) was then used to assess the quality of the articles (Appendix D). The MMAT was selected as it critically appraises studies with different methodologies, including quantitative, qualitative, and mixed method studies, which was required for this review. The MMAT involves two screening questions to assess if a study is suitable for the analysis. The studies are then rated on five questions, which vary across each methodology, making 5 the highest score. Appendix E shows the results of the quality assessment.

From the quality assessment, no papers were excluded as they all provided valuable information for the review. Table 1 shows the scores from the quality assessment. Interrater reliability was established by selecting 4 studies at random to be rated by an independent peer reviewer (two qualitative and two quantitative). The level of agreement was 90%. Any discrepancies found were discussed until an agreement was met.

Data Analysis

The data extracted from the articles were analysed using Narrative Synthesis. This method was used as the review was exploratory and the articles varied in methodology. Narrative Synthesis uses words to explore relationships and integrate findings from multiple studies to 'tell a story' of the results (24). This method was therefore deemed to be the most appropriate form of analysis for the data extracted for the review. The Narrative Synthesis guidelines outlined by

Popay et al (24) were adhered to throughout the analysis. During the data analysis process, the articles were read through in depth and key data relating to the research question were extracted from each article. The articles were then assessed for similarities in their methods and results and were grouped together based on the similarities of their findings.

Results

Overview of Included Studies

In total, 16 studies were included in the review (25-40). The studies varied in their methodology, however the underlying concept of investigating the impact of ISA on aspects of rehabilitation in ABI was consistent between the studies. Table 1 shows an overview of the included studies.

Study aims

All studies investigated how ISA can affect different aspects of rehabilitation. Within this, four studies explored the impact of ISA on rehabilitation generally (28, 30, 38, 40), four studies investigated the impact of ISA on motivation, engagement, treatment adherence and willingness to change (32, 33, 36, 37), two studies explored the impact of ISA on goal setting (26, 29), one study investigated the impact of ISA on discharge from hospital (39) and one study explored the impact of ISA on the therapeutic alliance (31).

Additionally, four studies (25, 27, 34, 35) did not set out to specifically investigate the impact of ISA on rehabilitation, however they aimed to explore factors that affect ABI rehabilitation and found the impact of ISA as a result. Despite this, the results from these studies were considered valuable for the review and were included in the analysis.

Table 1. Overview of included studies

Reference	Research Aims	Design	Participant Characteristics	Type of Rehabilitation	Self-awareness measure	Key Findings	Conclusions	Quality assess-ment
Doig, Fleming, Cornwell and Kuipers (2009) (25)	To explore the experiences of client-centred goal-directed therapy from clients, therapists, and family members	Qualitative semi-structured interviews	12 individuals with TBI, their significant other and their clinicians Ten men and two women	Outpatient rehabilitation programme	The Self-Awareness Deficit Interview (SADI) scores from clinical records and qualitative interviews	- 10/12 patients were able to identify their goals within rehabilitation. - For 2 patients, difficulties with self-awareness and memory impacted on goal setting and ownership. - Goals can be used to improve self-awareness and participation	- Self-awareness can impact on client-centred goal setting - Goals can provide structure to overcome these difficulties.	5/5
Prescott, Fleming and Doig (2019) (26)	To identify client-centred goal setting and participation in goal setting in ABI patients and how ISA impacts on this.	Quantitative measures and semi-structured interviews	35 adults with an ABI 24 men and 11 women	Outpatient rehabilitation	The Awareness Questionnaire	- Goal setting was found to be highly client-centred regardless of level of self-awareness.	- ISA does not affect engagement in client-centred goal setting.	3/5
Prescott, Fleming, and Doig (2017) (27)	To investigate clinicians' experience of goal setting with ABI clients in the community	Qualitative interviews	22 clinicians that provide rehabilitation to individuals with ABI in the community	Outpatient rehabilitation	Qualitative interviews	- ISA can impact on participation in client-centred goal setting. - Adaptations to tackle this include structured communication and metacognitive skills.	- ISA can impact on goal setting. - Adaptations can be put in place to manage this.	5/5

			22 females					
Richardson, McKay and Ponsford (2014) (28)	To investigate self-awareness in the first year after TBI and the factors that impact on awareness change	Longitudinal study – quantitative analysis	60 TBI individuals 50 men and 10 women	Inpatient rehabilitation	The Self-Awareness Deficit Interview (SADI)	- Awareness improved within the first year after TBI. - Females had better awareness and set more realistic goals at the beginning of rehabilitation.	- Time after injury impacts on awareness. - Females had better awareness and set more realistic goals at the beginning of rehabilitation	4/5
Fischer, Gauggel and Trexler (2004) (29)	To explore the relationship between awareness, goal setting and outcome in rehabilitation.	Quantitative measures	63 patients with different aetiologies of ABI 32 men and 31 women	Outpatient rehabilitation programme	Clinicians' judgement of awareness and scores on the Patient Competency Rating Scale (PCRS)	- ISA resulted in less realistic goal setting and lower outcome in rehabilitation. - Self-awareness predicted 32% of the variance in goal setting ability and 33% of the variance for outcome in rehabilitation. However, it only accounted for 4% of the variance in goal setting in cognitive tasks and 5% of performance in cognitive tasks.	- Self-awareness impacts on goal setting capability and outcome in a long-term rehabilitation, however it has less of an impact in short-term experimental tasks.	4/5
Trudel, Tryon and Purdum (1998)	To investigate the long-term impairment of ISA in closed	Quantitative measures	63 individuals with CHI	Outpatient rehabilitation	Self vs clinician ratings on the Scales of	- ISA was associated with maladaptive behaviour, higher distractibility, lower vocational and	- ISA can affect several aspects of rehabilitation	3/5

(30)	head injuries (CHI)		50 men and 13 women		Independent Behaviour (SIB)		residential status, and higher preservation		
Schonber-ger, Humle, Teasdale (2006) (31)	To investigate the relationship between patient compliance, awareness, and the therapeutic alliance in brain injury rehabilitation	Quantitative measures	86 ABI patients 55 men and 31 women	Outpatient rehabilitation programme	Awareness was measured using a four-item scale developed by Fleming, Strong and Ashton (1996) (41)	-	The therapeutic relationship had an influence on awareness and awareness led to positive changes in the therapeutic relationship. - Awareness was related to treatment compliance.	-	A good therapeutic relationship and awareness is crucial in rehabilitation	4/5
Trahan, Pepin and Hopps (2006) (32)	To investigate the frequency of ISA in TBI and explore the relationship between ISA and treatment adherence	Quantitative measures	24 TBI patients, and their clinicians 20 men and 4 women	Inpatient rehabilitation	Self vs clinician ratings on the short version of the Problem Checklist of the Head Injury Family Interview	-	TBI patients underestimated their behavioural and cognitive difficulties. - ISA was linked to poor treatment adherence.	-	ISA is seen in individuals with a TBI and is linked to poor treatment adherence	4/5
O'Callag-han, McAllister and Wilson (2012) (33)	To investigate the impact of self-awareness on readiness to engage in therapy	Qualitative in-depth interviews	14 adults with TBI and 9 significant others 8 men and 6 women	Experiences explored within inpatient and outpatient services	Qualitative interviews	-	Self-awareness and willingness to be active in rehabilitation were important factors for engagement, as this allowed for uptake of treatment ideas and strategies.	-	Self-awareness and readiness for therapy are important factors within rehabilitation	5/5

Tobler-Ammann, Weise, Knols, Watson, Sieben, de Bie and de Bruin (2018) (34)	To explore the experiences of stroke patients in terms of activity performance, body perceptions and hopes and expectations	Qualitative semi-structured interviews	7 stroke patients with unilateral spatial neglect 5 men and 2 women	Inpatient rehabilitation	Qualitative interviews and performance on the Behavioural Inattention Test	-	Patients moved from initial lack of awareness to emergent awareness during rehabilitation. - Awareness was necessary for the use of coping strategies and engagement in treatment.	-	Awareness is a prerequisite for utilising coping strategies within rehabilitation	5/5
Downing, Bragge and Ponsford (2018) (35)	To identify practices of cognitive rehabilitation in Australia and factors that affect this	Quantitative and qualitative survey	221 professionals who have experience working with TBI and cognitive rehabilitation. Demographics on gender not specified	Experiences explored within inpatient and outpatient services	Online survey	-	ISA impacts on success due to lack of engagement and ability to retain and implement strategies.	-	ISA can impact on recovery	3/5
Fleming, Strong and Ashton (1998) (36)	To explore the relationship between outcome, self-awareness, motivation, and emotional distress in TBI individuals	Quantitative analysis	55 TBI patients 40 men and 15 women	Inpatient rehabilitation	The The Self-Awareness Deficit Interview (SADI) and the Patient Competency Rating Scale (PCRS)	-	The high self-awareness group was associated with more motivation and emotional distress than the low self-awareness group. - However, self-awareness did not impact on outcome	-	Self-awareness is associated with motivation to change and higher levels of emotional distress, however it does not impact on	4/5

							rehabilitative outcome	
Lam, McMahon, Priddy and Gehred-Schultz (1988) (37)	To investigate level of change in head injured individuals and how this affects treatment performance, including the impact of ISA on readiness to change	Quantitative measures	45 individuals with head-injuries and their clinicians 26 men and 19 women	Outpatient rehabilitation	The Treatment Performance Scale	- Participants who had better self- awareness were more willing to change and had better treatment performance.	- Assessing stages of change, including awareness of deficits, is important in rehabilitation	3/5
Hartman-Maeir, Soroker and Katz (2001) (38)	To investigate the prevalence and impact of Anosognosia for Hemiplegia (AHP) in stroke patients on rehabilitation	Quantitative measures	46 stroke patients with severe motor deficit 35 men and 11 women	Inpatient rehabilitation	The Awareness Interview and a task choice method	- AHP resulted in patients being unable to maintain safety measures, which impacted on discharge status.	- AHP has an impact on the safety level and functional outcome of stroke patients within rehabilitation.	4/5
Jehkonen, Ahonen, Dastidar, Koivisto, Laippala Vilkki and Molnar (2001) (39)	To investigate factors impacting on discharge from hospital after stroke, including anosognosia	Quantitative measures	49 patients with right hemisphere stroke 30 men and 19 women	Inpatient rehabilitation	Anosognosia was examined using questions outlined by Bisiach, Vallar, Perani,	- Unawareness of illness was one of the factors that increased time spent in hospital.	Unawareness of illness was one of the predictors of discharge from hospital	3/5

					Papagno and Berti (1986)			
Pedersen, Jorgensen, Nakayama, Raaschou and Olsen (1996) (40)	To identify the frequency and consequences of anosognosia on functional outcome in stroke patients	Quantitative measures	566 stroke patients 274 men and 292 women	Inpatient rehabilitation	Anosognosia was examined using questions outlined by Bisiach, Vallar, Perani, Papagno and Berti (1986)	- 21% of patients displayed anosognosia at admission. - Anosognosia resulted in poorer functional outcomes, longer time spent in hospital and reduced likelihood of independent living after discharge.	- Anosognosia is prevalent in stroke populations and has an impact on rehabilitation	4/5

Sample

All studies included ABI individuals or professionals who work closely with ABI individuals. TBI was the most researched sample, which was included in five studies (25, 28, 32, 33, 36), followed by stroke patients recruited in four studies (34, 38-40). Furthermore, two studies included individuals with head injuries (30, 37) and two studies recruited professionals who work closely with TBI and ABI individuals (27, 35). The remaining three studies recruited patients with a variety of ABI's (26, 29, 31).

Severity of injury varied within the studies, with most studies recruiting individuals with mild to severe ABI (26, 28, 34, 39, 40), six studies contained individuals with severe ABI (25, 30, 32, 36-38) and one study contained individuals with moderate to severe ABI (33). Additionally, two studies did not specify severity of injury (29, 31) and two studies recruited professionals that work with individuals with a variety of ABI severities (27, 35). The majority of the studies focussed on ABI individuals who were within one-year post-injury, except for two studies that contained patients with an average of 7 years (30) and 1.22 years (31) post injury, and one study that did not specify time post-injury (33).

All studies included both male and female participants, except one study that did not identify gender demographics (**Error! Bookmark not defined.**). All studies contained a sample size between 7-86 participants, except two studies that contained 556 (40) and 221 (35) participants. Furthermore, most studies included adults aged 18-65, except for five studies that included participants over the age of 65 (29, 34, 38-40).

Type of rehabilitation

This review contained an even number of studies conducted within inpatient and outpatient rehabilitation services, with seven studies conducted within each (as seen in Table 1). The remaining studies (n=2) explored the experiences of professionals and patients within both inpatient and outpatient services (33, 35).

Study design and self-awareness measures

Studies varied in their measurement of self-awareness, five studies used standardised measures of awareness, including the Self-Awareness Deficit Interview (SADI) (25, 28), the Patient Competency Rating Scale (PCRS) (29), both the SADI and the PCRS (36) and the Awareness Questionnaire (AQ) (26). 11 studies did not use standardised measures of awareness and instead used cognitive tasks and qualitative interview methods to establish level of awareness and the impact of ISA on rehabilitation (27, 30-34, 37-40). One study used an online survey which identified self-awareness as a factor that impacts on rehabilitation (35).

Quality of Included Studies

Overall, all qualitative studies in this review (25, 27, 33, 34) were rated with a maximum score of 5/5 on the MMAT quality rating scale. Of the quantitative studies seven were scored 4/5 (28, 29, 31, 32, 36, 38, 40), these studies were therefore deemed as good quality in their approach, data analysis and interpretation. Of the remaining quantitative studies, three scored 3/5 (30, 37, 39), which was due to a high risk of non-response bias (30, 39), 'gold standard' measures not being used (37, 39) and the sample strategy not being defined (30, 37). All mixed method studies scored 3/5 (26, 35), which was due to the quality criteria of each methodology not being adhered to, a lack of rationale for using a mixed method design (35) and inconsistencies within the results not being addressed (26).

Narrative synthesis of findings

Key findings were extracted from the 16 studies within this review, which formed four themes as to how ISA impacts on the process of rehabilitation. These four themes were: Goal setting, Treatment adherence, Engagement and willingness to change and Time spent in hospital. These themes were then split into subthemes, as seen in Table 2:

Table 2

Key themes formed from the included studies

Main theme	Subthemes
Goal setting	• Client centred goal setting • Realistic goal setting
Treatment Adherence	• Behavioural difficulties • Compliance in treatment
Engagement and willingness to change	• Engagement in tasks • Motivation and willingness to change
Time spent in hospital	• Time spent in hospital and likelihood of discharge

Goal setting

Client-centred goal setting

Three studies investigated the role of ISA on setting client-centred goals in outpatient rehabilitation programmes. The findings of the studies varied, with two studies finding that ABI patients were able to engage in client-centred goal setting (25, 26), whilst one study indicated that ISA impacted on participation in client-centred goal setting (27).

Two studies identified that, through service user, clinician and significant other reports, the majority of mild-severe ABI participants with ISA were able to identify and engage in client-centred goals (25, 26), however they did take longer to set goals than those without ISA (26). Furthermore, 2/12 TBI participants and their significant others expressed that ISA did impact on client-centred goal setting which was due to participants being unable to identify the extent of their difficulties, therefore they did not place importance on goal setting (25). It was suggested that client-centred goal setting can be used as a tool to provide structure within rehabilitation and was a motivating factor for TBI participants. It was concluded that goals can be used to help participants identify progress and improve their self-awareness and participation within treatment (25).

However, Prescott, Fleming and Doig's (26) study scored low on the quality rating scale and within their reduced self-awareness group they only contained a sample of ABI patients whose ISA severity was low, which may explain the lack of significant difference found between the ISA group and the high self-awareness group. Furthermore, methodological limitations were present, including the use of unstructured interviews and professionals not being blinded to the ratings.

One study that contradicted these findings found that, from clinician's ratings, ISA impacted on participation within client-centred goal setting for ABI individuals (27). Techniques such as structured communication to identify treatment needs, providing feedback and implementing metacognitive strategies, were identified as ways in which clinicians can improve self-awareness and participation in goal setting (27).

Realistic goal setting

Two studies, both of high quality, investigated the impact of ISA on realistic goal setting within inpatient (28) and outpatient (29) rehabilitation programmes. Across both studies ISA was found to impact on realistic goal setting within ABI populations. It was also found that, within TBI participants, females had better self-awareness than males at the beginning of treatment and as a result they set more realistic goals at the start of rehabilitation (28). Across these studies it was suggested that increased awareness results in individuals being able to understand their limitations and identify the impact of their difficulties on their future ability, resulting in more realistic goals being set. Fischer et al (29) found that ISA accounted for 33% of the variance in the ability to set goals within long-term rehabilitation, however it only accounted for 4% variance in short-term treatment, therefore the impact of ISA on goal setting within short term treatment requires further research.

Treatment Adherence

Behavioural difficulties

Within two studies it was found that, from patient and clinician reports, ISA resulted in challenging behaviour within ABI rehabilitation. One study found that, within a sample of closed head injured individuals in long-term outpatient rehabilitation, ISA was associated with maladaptive behaviour, as measured by the original Scales of Independent Behaviour index, which assessed areas including functional independence and adaptive functioning. ISA was also related to greater distractibility and perseveration within rehabilitation (30). However, a detailed description on how these factors impacted on rehabilitation was not present and this study contained a low-quality rating score due a lack of description of the sampling strategy and a high risk of non-response bias.

Another study found that, from clinician reports, ISA led to TBI patients being unable to learn and modify their behaviour, as well as retain and implement treatment ideas and strategies. It was therefore reported that self-awareness is crucial for the success of rehabilitation (34).

Compliance in treatment

Two studies, both of high quality, investigated the impact of ISA on compliance in treatment within both inpatient (32) and outpatient (31) rehabilitation settings. Across both studies, ISA was found to impact on treatment adherence and compliance in ABI populations, it was suggested that awareness of difficulties resulted in individuals being more willing to engage and participate in rehabilitation. ISA was also found to impact on the development and quality of the working alliance between the patient and clinician, with a positive therapeutic alliance also increasing patient's awareness (31).

Engagement and willingness to change

Engagement in tasks

Three studies explored the impact of ISA on engagement within both inpatient and outpatient rehabilitation services, two of which were of high quality (33, 34). All three studies used a qualitative methodology. It was found that from patient, significant other and professional reports in TBI (33, 35) and Stroke (34) populations, ISA impacted on the readiness and willingness to engage in rehabilitation. This was found to be due to patients with ISA being unable to learn and adjust their behaviour, as well as take on, maintain, and implement treatment ideas and strategies.

Downing et al (35) found that ISA particularly affected engagement in rehabilitation for executive functioning difficulties, it was suggested that strategies to manage executive

dysfunction should be implemented, including environmental and task adjustments. However, along with a low-quality rating, these results were derived from an online survey therefore more in-depth qualitative assessment or quantitative research is required in this area to collect richer, more robust data.

Motivation and willingness to change

Two studies investigated the impact of ISA on motivation and willingness to change within inpatient (36) and outpatient (37) ABI populations. One study found that head injured participants who had better awareness of their difficulties were more willing to change and had better treatment performance. In contrast, participants with ISA were more likely to be within the pre-contemplation stage during treatment as they were unable to identify the value of rehabilitation and were therefore unwilling to change (37). However, this study contained a low-quality rating due to the sample strategy not being defined and 'gold standard' measures not being used.

Similarly, another study found that ISA in TBI participants resulted in lower motivation to change within rehabilitation, however it did not find a difference in outcome between the high and low self-awareness groups. It was suggested that although ISA is important within treatment, it may not be the sole factor that contributes to outcome within rehabilitation, with other factors including severity of injury, mood, or cognitive difficulties (36). However, these studies were conducted in 1988 (37) and 1998 (36), therefore they may not reflect current rehabilitation approaches or guidance.

Time spent in hospital

Time spent in hospital and likelihood of discharge

Three studies found that, within stroke populations, patients with ISA spent a longer time in hospital and had a decreased likelihood of being discharged than those who were aware of their difficulties (38, 39, 40). It was suggested that this was due to patients with ISA not being able to gain the skills required to be discharged and live independently, including the inability to maintain safety measures (38). This is also found within Tobler-Ammann et al's (34) study where stroke patients were unaware of their abilities which increased their risk of injury. However, these studies included patients with severe ABI, who presented with more widespread and complex support needs which also impact the length of time required in rehabilitation and the likelihood of being discharge to independent living.

It was also found that the frequency of ISA was higher in patients who were admitted to hospital more than 3 days after their stroke onset, suggesting that ISA led to a delay in patients seeking help (40). This study contained a large sample of 566 stroke patients, however it defined ISA as a lack of awareness of hemiplegia or hemianopia, decreasing the generalisability of the results.

Discussion

Overview of results

This review aimed to investigate the impact of ISA on the process of rehabilitation in ABI populations. Four themes arose from this review, including goal setting, treatment adherence, engagement and willingness to change and time spent in hospital.

ISA was found to impact on realistic goal setting in ABI populations within both inpatient and outpatient rehabilitation (28, 29). However, research on the impact of ISA on client-centred goal setting were mixed, with two studies reporting that ABI participants with ISA were able

to engage in client centred goal setting, however they took longer to set goals (25, 26). Alternatively, a subset of participants did express that ISA impacted on client-centred goal setting (25, 27), which was due to participants being unable to identify their difficulties and therefore the importance of goal setting (25). These mixed results could be due to methodological limitations within these studies including small sample sizes and a low ISA severity within one study, which may explain the lack of significant difference found between the awareness groups (26).

Within inpatient and outpatient settings, ISA in ABI populations was found to impact on treatment compliance, engagement, motivation, willingness to change and the working alliance between the clinician and patient (31-35). ISA also was associated with maladaptive behaviour and higher distractibility; however, this was not defined (36). Additionally, ABI participants with ISA were unable to retain and implement ideas and strategies and were unable to learn and adjust their behaviour, particularly in cognitive rehabilitation (35). Furthermore, it was found that ABI participants were more likely to be within the pre-contemplation stage during treatment and were not able to identify the value of rehabilitation and were therefore unwilling to change (37).

Additionally, within stroke populations, ISA resulted in a longer time spent in hospital and a decreased likelihood of discharge (38-40). This was due to patients being unable gain the skills and safety measures required to be discharged (38). ISA may also lead to a delay in patients seeking support (40), however further research is required.

Clinical implications

This review found that goal setting can be used as a tool to help participants identify progress and improve their self-awareness and participation within treatment (25). It was also suggested that professionals should provide extra support and adaptations to allow ABI individuals with ISA to effectively engage in the goal setting process. Techniques that were suggested included structured communication to identify treatment needs, providing feedback, and implementing metacognitive strategies (27).

Goal setting was found to provide structure within rehabilitation and was a motivating factor for ABI participants (25), therefore the lack of participation in goal setting due to ISA could have also contributed to the lack of motivation found within this review (36, 37). It is therefore suggested that clinicians can utilise goal setting to improve self-awareness and enhance motivation. Additionally, ISA was found to impact on the therapeutic relationship and research has found that the therapeutic alliance is an important factor goal setting (25), therefore the impact of ISA on the therapeutic alliance may have an impact on goal setting, linking two themes found within this review. Thus, techniques to develop the therapeutic relationship and in turn enhance self-awareness (31) is essential within rehabilitation. One technique includes motivational interviewing which, within samples of ABI individuals with ISA, has been found to enhance the therapeutic relationship and increase acceptance of impairments, as well as engagement in rehabilitation, including realistic goal setting (42).

ISA resulted in a lack of engagement within rehabilitation, with ABI participants being unable to learn and adjust their behaviour, as well as take on, retain, and implement treatment ideas and strategies (33-35). Individuals with ISA were also more likely to be in the pre-contemplation stage during treatment and were unwilling to change or identify the value of

rehabilitation. Self-awareness is therefore a crucial factor within the success of rehabilitation and clinicians should take these factors into account during treatment and implement techniques and adaptations to enhance self-awareness and educate ABI individuals on their stage of change.

Given all these factors it is suggested that rehabilitation should not occur until ABI individuals have gained awareness of their difficulties so that they are able to fully engage in treatment, this may include delaying intervention with appropriate supervision and monitoring put into place (33). However clinical care guidelines in brain injury rehabilitation promote early intervention (43, 44). These guidelines are therefore disrupted by ISA, which causes difficulties for clinicians and pressure on services that provide brain injury rehabilitation (32). Therefore, adaptations and techniques within rehabilitation and services are required to enhance self-awareness and treatment adherence early on within intervention.

It is recommended that an educational approach is provided to ABI individuals with ISA in the early stages of rehabilitation for patients to learn about their difficulties, experience setbacks and be given time to adjust (30, 45). O'Callaghan et al (33) found that TBI participants need to go through a process of grieving their old self and accepting their impairments to achieve acceptance and readiness to change and engage in rehabilitation. It is suggested that only after ABI patients have gained self-awareness can they engage in treatment (46).

Additionally, research has found that specific models of intervention can be implemented regardless of level of awareness, including strategy training (47). Studies have also identified

adaptations that can be put into place to increase self-awareness, including adjustments to activities and the environment (48), which can be implemented within rehabilitation.

However, another difficulty arises within inpatient services when patients are unable to be discharged due to a risk to safety and a lack of skills required to live independently (38-40), which can cause further pressure on services as well as clinicians. ISA is therefore a crucial aspect to be considered by services, and appropriate provisions for patient safety and to increase self-awareness are required, including indirect working and behavioural management.

Quality of review and future research

The articles selected within this review varied in methodology, however similarities between the aims, design, participant characteristics and findings of the studies can be grouped together and compared. Overall, the articles with this review provide important insight into the impact of ISA on the process of ABI rehabilitation, which is crucial for clinicians as well as services providing brain injury rehabilitation.

Most studies in this review contained a high-quality rating, with 11 studies receiving a score of 4 or 5 on the MMAT quality rating scale, they were therefore deemed as good quality in their approach, data analysis and interpretation. The remaining studies were scored 3/5 mainly due to non-response bias, 'gold standard' measures not being used, and the sample strategies not being defined, as described above.

Studies within this review used a variety of methods to establish ISA, including standardised measures of awareness, qualitative methods, performance on cognitive tasks and self-reported

performance on multiple tests. Previous reviews have found that a variety of techniques can be used to measure awareness, including self-versus-other reports, performance-based measures, interviews, and clinician ratings (18). Therefore, although the ISA measurements differed between studies, all studies were able to identify subsets of participants with ISA and described how this then impacted on rehabilitation.

Furthermore, this review did not include case studies, discussion papers or conference abstracts to ensure high quality studies were included, however this may have excluded data relevant for this review and key information may have been missed. Furthermore, it may also be the case that some ABI individuals with significant ISA were unable to complete self-awareness measures or agree to take part in studies, which therefore could also exclude valuable information which should be considered in future research.

Conclusion

This review found that within both inpatient and outpatient rehabilitation services, ISA impacted on the value that ABI participants placed on rehabilitation, which decreased treatment compliance, motivation, and engagement. ABI participants with ISA were more likely to be in the pre-contemplation stage during treatment and were unable to retain and implement ideas and strategies or learn and adjust their behaviour. ISA also led to an increase in length of time spent in hospital. These results are crucial for clinicians and services providing ABI rehabilitation in terms of adaptations that are required within treatment and appropriate provisions that are needed within services.

References

1. Brain Injury Association of America. What is the difference between acquired brain injury and traumatic brain injury? 2022 (accessed 28th April 2022). https://www.biausa.org/brain-injury/about-brain-injury/nbiic/what-is-the-difference-between-an-acquired-brain-injury-and-a-traumatic-brain-injury.

2. Cooper J, Bateman A, Reynolds F. An evaluation of a fatigue management intervention for people with acquired brain injury: an exploratory study. British Journal of Occupational Therapy. 2009; 72(4): 174-179

3. Mazaux J, Masson F, Levin HS, Alaoui P, Maurette P, Barat M. Long-term neuropsychological outcome and loss of social autonomy after traumatic brain injury. Archives of Physical Medicine and Rehabilitation. 1997;78(12): 1316-1320

4. Ownsworth TL, McFarland K, Young R. Development and Standardization of the Self-Regulation Skills Interview (SRSI): A New Clinical Assessment Tool for Acquired Brain Injury. The Clinical Neuropsychologist. 2000;14(1): 76-92

5. Noe E, Ferri J, Caballero MC, Villodre R, Sanchez A, Chirivella J. Self-awareness after acquired brain injury. Journal of Neurology. 2005;252: 168-175

6. Ownsworth T, Fleming J, Strong J, Radel M, Chan W, Clare L. Awareness typologies, long-term emotional adjustment and psychosocial outcomes following acquired brain injury. Neuropsychological Rehabilitation. 2007;17(2): 129-150

7. Hartman-Maeir A, Soroker N, Oman SD, Katz N. Awareness of disabilities in stroke rehabilitation: a clinical trial. Disabil Rehabil. 2003;25(1): 35–44.

8. Bivona U, Costa A, Contrada M, Silvestro D, Azicnuda E, Aloisi M, Catania G, Ciurli P, Guariglia C, Caltagirone C, et al. Depression, apathy and impaired self-awareness following

severe traumatic brain injury: a preliminary investigation. Brain Injury. 2019;33(9): 1245-1256

9. Fleming J, Strong J, Roderick A. Cluster Analysis of Self-Awareness Levels in Adults with Traumatic Brain Injury and Relationship to Outcome. Head Trauma Rehabilitation. 1998; 13(5): 39-51

10. English M, St Pierre ME, Delahay A, Parente R. Efficacy of self-perception after traumatic brain injury. NeuroRehabilitation. 2016;39(1): 45-52

11. Spikman JM, Milders MV, Visser-Keizer AC, Westerhof-Evers HJ, Herben-Dekker M, van der Naalt J. Deficits in Facial Emotion Recognition Indicate Behavioral Changes and Impaired Self-Awareness after Moderate to Severe Traumatic Brain Injury. PLoS ONE. 2013;8 (6): 1-7.

12. Chiou KS, Chiaravalloti ND, Wylie GR, DeLuca J, Genova HM. Awareness of Subjective Fatigue After Moderate to Severe Traumatic Brain Injury. J Head Trauma Rehabil. 2016;31(3): 60-68

13. Villalobos D, Caperos JM, Bilbao A, Bivona U, Formisano R, Pacios J. Self-Awareness Moderates the Association Between Executive Dysfunction and Functional Independence After Acquired Brain Injury. Achieves of Clinical Neuropsychology. 2020;35: 1059-1068

14. Robertson K, Schmitter-Edgecombe M. Self-awareness and traumatic brain injury outcome. Brain Injury. 2015;29(7): 848-858.

15. Sherer M, Hart T, Nick TG, Whyte J, Nakase Thompson R, Yablon SA. Early impaired self-awareness after traumatic brain injury. Arch Phys Med Rehabil. 2003;84(2): 168-176

16. Winkens I, Van Heugten CM, Visser-Meily JMA, Boosman H. Impaired self-awareness after acquired brain injury: clinicians' ratings on its assessment and importance for rehabilitation. J Head Trauma Rehabil. 2014;29(2): 153-156

17. Ownsworth T, Clare L. The association between awareness deficits and rehabilitation outcome following acquired brain injury. Clinical Psychology Review. 2006;26: 783-795.

18. Dromer E, Kheloufi L, Azouvi P. Impaired self-awareness after traumatic brain injury: A systematic review. Part 1. Assessment, clinical aspects and recovery. Annals of Physical and Rehabilitation Medicine. 2021;64: 1-8

19. Dromer E, Kheloufi L, Azouvi P. Impaired self-awareness after traumatic brain injury: A systematic review. Part 2. Consequences and predictors of poor self-awareness. Annals of Physical and Rehabilitation Medicine. 2021;64: 1-9

20. Leung D, Liu K. Review of self-awareness and its clinical application in stroke rehabilitation. International Journal of Rehabilitation Research. 2011;34(3): 187-195

21. Dixon RA, Backman L. Principles of compensation in cognitive neurorehabilitation. In: Stuss DT, Winocur, G, Robertson, IH, editors. Cognitive neurorehabilitation. Cambridge University Press. 1999. p. 59–72.

22. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta- Analyses: The PRISMA Statement. PLoS Med. 2009;6(7): 1-6.

23. Hong QN, Pluye P, Fabregues S, Bartlett G, Boardman F, Cargo M, Dagenais P, Gagnon M, Griffiths F, Nicolau B, O'Cathain A, Rousseau M, Vedel I. Mixed Methods Appraisal Tool (MMAT) Version 2018 User Guide. McGill. 2018.

24. Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, Britten N, Roen K, Duffy S. Guidance on the conduct of narrative synthesis in systematic reviews. A Product from the ESRC Methods Programme Version. 1, 92; 2006.

25. Doig E, Fleming J, Cornwell PL, Kuipers P. Qualitative exploration of a client-centered, goal-directed approach to community-based occupational therapy for adults with traumatic brain injury. American Journal of Occupational Therapy. 2009;63(5): 559-568.

26. Prescott S, Fleming J, Doig E. Effect of self-awareness on goal engagement and outcomes after acquired brain injury. The British Journal of Occupational Therapy. 2019;82(12), 726-731

27. Prescott S, Fleming J, Doig E. Rehabilitation goal setting with community dwelling adults with acquired brain injury: A theoretical framework derived from clinicians' reflections on practice. Disability and Rehabilitation: An International, Multidisciplinary Journal. 2017;40(20), 2388-2399.

28. Richardson C, McKay A, Ponsford JL. The trajectory of awareness across the first year after traumatic brain injury: The role of biopsychosocial factors. Brain Injury. 2014;28(13), 1711-1720.

29. Fischer S, Gauggel S, Trexler LE. Awareness of activity limitations, goal setting and rehabilitation outcome in patients with brain injuries. Brain Injury. 2004;18(6), 547-562.

30. Trudel TM, Tryon WW, Purdum CM. Awareness of disability and long-term outcome after traumatic brain injury. Rehabilitation Psychology. 1998;43(4): 267-281.

31. Schonberger M, Humle F, Teasdale TW. The development of the therapeutic working alliance, patients' awareness and their compliance during the process of brain injury rehabilitation. Brain Injury. 2006;20(4): 445-454.

32. Trahan E, Pepin M, Hopps S. Impaired Awareness of Deficits and Treatment Adherence Among People With Traumatic Brain Injury or Spinal Cord Injury. J Head Trauma Rehabil. 2006;21(3): 226-235

33. O'Callaghan A, McAllister L, Wilson L. Insight vs readiness: Factors affecting engagement in therapy from the perspectives of adults with TBI and their significant others. Brain Injury. 2012;26(13): 1599-1610.

34. Tobler-Ammann B, Weise A, Knols RH, Watson MJ, Sieben JM, de Bie RA. Patients' experiences of unilateral spatial neglect between stroke onset and discharge from inpatient rehabilitation: A thematic analysis of qualitative interviews. Disability & Rehabilitation. 2020;42(11), 1578-1587.

35. Downing M, Bragge P, Ponsford J. Cognitive rehabilitation following traumatic brain injury: A survey of current practice in Australia. Brain Impairment. 2019;20(1), 24-36.

36. Fleming JM, Strong J, Ashton R. Cluster analysis of self-awareness levels in adults with traumatic brain injury and relationship to outcome. The Journal of Head Trauma Rehabilitation. 1998;13(5), 39-51.

37. Lam CS, McMahon BT, Priddy DA, Gehred- Schultz A. Deficit awareness and treatment performance among traumatic head injury adults. Brain Injury. 1988;2(3): 235-242.

38. Hartman-Maeir A, Soroker N, Katz N. Anosognosia for hemiplegia in stroke rehabilitation. Neurorehabilitation and Neural Repair. 2001;15(3), 213-222

39. Jehkonen M, Ahonen J, Dastidar P, Koivisto A, Laippala P, Vilkki J, Molnar G. Predictors of discharge to home during the first year after right hemisphere stroke. Acta Neurologica Scandinavica. 2001;104(3), 136-141.

40. Pedersen PM, Jørgensen HS, Nakayama H, Raaschou HO, Olsen TS. Frequency, determinants, and consequences of anosognosia in acute stroke. Journal of Neurologic Rehabilitation. 1996;10(4), 243-250.

41. Fleming, J., Strong, J., and Ashton, R. (1996). Self-awareness of deficits in adults with traumatic brain injury: how best to measure? *Brain Inj.* 10: 1–15.

42. Medley AR, Powell T. Motivational Interviewing to promote self-awareness and engagement in rehabilitation following acquired brain injury: A conceptual review, Neuropsychological Rehabilitation: An International Journal. 2010;20(4): 481-508

43. Scottish Intercollegiate Guidelines Network. Brain injury rehabilitation in adults, a national clinical guideline. Healthcare Improvement Scotland. 2013.

44. National Institute for Health and Care Excellence. Head injury: assessment and early management, clinical guideline. National Institute for Health and Care Excellence. 2014.

45. Peoples H, Satink T, Steultjens E. Stroke survivors' experiences of rehabilitation: a systematic review of qualitative studies. Scand J Occup Ther. 2011;18: 163–171.

46. Kortte KB, Hillis AE. Recent trends in rehabilitation interventions for visual neglect and anosognosia for hemiplegia following right hemisphere stroke. Future Neurol. 2011;6: 33–43.

47. Skidmore ER, Swafford M, Juengst SB, Terhorst L. Self-Awareness and Recovery of Independence With Strategy Training. The American Journal of Occupational Therapy. 2018;72(1): 1-5

48. Lindstrom AC, Eklund K, Billhult A, Carlsson, G. Occupational therapists' experiences of rehabilitation of patients with limited awareness after stroke. Scandinavian Journal of Occupational Therapy. 2013;20: 264-271

Part Two- Empirical Paper

The Brain Injury Fatigue Scale: Self Versus Other Ratings of Fatigue

Rebecca Di Somma[1], Dr Peter Fleming[1]*, Dr Stephen Evans[2] & Dr David Quinn[3]

[1] Department of Clinical Psychology, Faculty of Psychological Health, Wellbeing and Social Work, Aire Building, University of Hull, Hull, HU6 7RX

[2] Psychological Medicine Department, The Old Chapel, Bootham Park, York, YO31 8HE

[3] Halliday Quinn Limited, The Stable, Mews Cottage, Carey Herefordshire, HR2 6NF

*Corresponding Author Email: p.fleming@hull.ac.uk

This paper is written in the format ready for submission to the Journal of Neuropsychology (see Appendix F for submission guidelines)

Word count: 5429 (Excluding abstract, references, tables, and figures)

Abstract

Background: This study sought to investigate what may influence any differences between self and proxy ratings on the Brain Injury Fatigue Scale (BIFS). The influence of impaired self-awareness (ISA) and mood were examined.

Method: Eleven ABI/neurological condition patients and their proxies completed the BIFS and Patient Competency Rating Scale (PCRS). Patients also completed the Hospital Anxiety and Depression Scale (HADS) and their demographic data was collected.

Results: It was found that 63.64% of patients rated their fatigue within the same clinical cut off category as their proxies' ratings. It was also found that ISA and mood did not predict BIFS-Discrepancy scores.

Conclusion: These findings show a moderate level of agreement between patient and proxy BIFS ratings; however, they also emphasise the importance of using proxy ratings scales within this area, which has not previously been explored. These results were preliminary findings which require replication with a larger sample.

Keywords: fatigue, acquired brain injury, neurological condition, self-awareness, insight

Introduction

Acquired Brain Injury (ABI) and Fatigue

In 2018 it was estimated that 304,800 people were admitted to hospital in England with an ABI (Barber et al, 2019), which is defined as a brain injury that occurs after birth and is not genetic, degenerative, or caused by birth trauma (Brain Injury Association of America, 2022). ABI's include stroke and traumatic brain injury (TBI) (Menon and Bryant, 2019). In 2019 it was estimated that 1 in 6 people live with a neurological condition in England, which is defined as a condition that affects the brain, nerves, and spinal cord, including Multiple Sclerosis (MS) and Parkinson's Disease (Neurological Alliance, 2019).

An ABI/neurological condition can cause several cognitive, physical, behavioural, and affective impairments, including memory difficulties (Levin, 1990), executive functioning deficits and psychomotor processing difficulties (Mazaux et al, 1997), emotional distress (Hoofien, Gilboa, Vakil and Donovick, 2001) and self-regulation difficulties (Ownsworth, McFarland and Young, 2000).

A further difficultly seen in ABI/neurological condition populations is fatigue (Cooper, Reynolds and Bateman, 2009; Minden et al, 2006). Central fatigue, which is seen in several neurological and non-neurological conditions, is characterised by mental and physical fatigue; mental fatigue involves difficulties initiating and maintaining attentional processes, whilst physical fatigue involves difficulties initiating and maintaining physical activity that requires self-motivation (Chaudhuri and Behan, 2000). Activities that require mental or physical effort are found to be predictive of fatigue in ABI/neurological conditions (Ziino and Ponsford, 2005).

Mental and physical fatigue have been reported in 68.5% of TBI patients (Ouellet and Morin, 2006) and 29-70% of stroke patients (Nadarajah and Goh, 2015). Fatigue was found to be a persistent symptom in TBI 2-5 years after discharge from a rehabilitation programme (Olver, Ponsford & Curran, 2009); therefore, it can have a long-term impact on patients' functioning. Additionally, fatigue has been found to be one of the most common symptoms in MS, with it being seen in 83.1% of MS patients (Minden et al, 2006). Fatigue is also shown to be one of the main symptoms causing impaired quality of life in patients with MS (Krupp, 2003), including affecting sleep, mood, and occupational and social life (Schwartz, Coulthard-Morris and Zeng, 1996). However, severity of injury has not been found to influence level of fatigue in ABI/neurological conditions (Chesnel et al, 2018).

Fatigue can be highly debilitating as it can cause several impairments to patients' day-to-day life, including sleep issues, anxiety, and cognitive disturbances (Ouellet and Morin, 2006), as well as attentional process deficits (Ziino and Ponsford, 2006). Fatigue can also affect individuals' everyday functioning, as mental and physical exhaustion can lead to individuals spending more time in bed, decreasing general productivity (Beaulieu-Bonneau and Morin, 2012). Furthermore, mental fatigue is found to be associated with decreased employment status, within both ABI (Palm, Ronnback and Johansson, 2017) and MS (Smith and Arnett, 2005). This in turn impacts on patient's recovery processes and occupational functioning (Belmont, Agar, Hugeron, Gallais and Azouvi, 2006).

Additionally, low mood and stress is found to have an impact on patient's level of fatigue within both ABI (Malley, Wheatcroft and Gracey, 2014; Schnieders, Willemsen and de Boer, 2012) and MS (Flachenecker et al, 2002), which needs to be considered when examining self-reports of fatigue.

Fatigue Scales

Several measures to assess for fatigue within ABI/neurological condition populations exist (Ziino and Ponsford, 2005). These measures are used to assess the extent and impact fatigue has for an individual, which can contribute to interventions and monitoring the recovery process. However, patients have reported that fatigue is not given sufficient recognition when planning interventions (Malley, 2017).

The Brain Injury Fatigue Scale (BIFS; Quinn, Jones, Fokias and Moss, 2004)

The BIFS is an unpublished measure of fatigue, which includes 20 items that are rated using a five-point Likert scale. The BIFS classifies scores from "normal" to "profound" fatigue. This measure was developed by Quinn, Jones, Fokias and Moss (2004) who, in an unpublished study, administered the scale to 65 ABI patients, 32 individuals with a mental health difficulty and 31 healthy controls. It was found that the BIFS showed a high degree of internal validity and reliability, with a significant proportion of the total variance of the scale (55%) being attributed to overall fatigue and the other two factors being pre-morbid ability and subsequent disability. It was also found that there was a significant relationship between ABI and fatigue even after accounting for the impact of mood. There is currently a project underway which is seeking to develop a normative dataset for the BIFS and explore its psychometric properties.

Whilst the BIFS is currently unpublished, it is used in clinical practice to measure fatigue in ABI/neurological condition populations and is used as a measure within fatigue management research (Cooper, Reynolds and Bateman, 2009). The BIFS also contains self and proxy rating scales, which is not seen in other fatigue measures (Michielsen, De Vries and Van Heck, 2003; Krupp, Alvarez, LaRocca & Scheinberg, 1988). The BIFS would therefore be able to identify

discrepancies between self and proxy ratings, which could be indicative of ISA. This would help clinicians guide rehabilitation strategies and approaches to supporting patients. However, the BIFS proxy rating scale was not analysed within the original study, therefore the relationship between the scores on the self and proxy rating scales and factors that influence this has not been explored.

Impaired Self-Awareness (ISA)

Although self-report measures of fatigue exist within these populations, it is found that individuals with an ABI/neurological condition show a pattern of under and over reporting of their cognitive, behavioural, and affective difficulties on self-report questionnaires as compared to relative/caregiver measures or psychometric tests (Rubin, Klonoff and Perumparaichallai, 2020; McKay, Rapport, Bryer and Casey, 2011; Smeets, Vink, Ponds, Winkens and van Heugten, 2017). Reduced awareness of one's difficulties is common in individuals with damage to the frontal lobes of the brain, which occurs in a range of ABIs/neurological conditions. (Spikman and van der Naalt, 2010; Hebscher, Barkan-Abramski, Goldsmith, Aharon-Peretz and Gilboa, 2016). ISA is also found in 58% of MS patients and is found to impact on activities of daily living and functional outcomes (Reich, Arias, Torres, Halac and Carlino, 2015).

ISA is defined as individuals being unable to identify and understand their difficulties or the impact they have on their day-to-day life (Ownsworth et al, 2007). ABI/neurological condition patients are found to experience reduced awareness of their fatigue levels (Chiou, Chiaravalloti, Wylie, DeLuca and Genova, 2016).

The consideration of ISA is important as it is found to impact on patient's compliance within treatment (O'Callaghan, McAllister and Wilson, 2012), occupational functioning (Sherer et al, 2003) and community re-integration (Robertson and Schmitter-Edgecombe, 2015) within ABI/neurological conditions. ISA can also result in a risk to safety when individuals are unaware of the demands of tasks (Rubin, Klonoff and Perumparaichallai, 2020).

Self and Other Scales

Due to the ISA seen in patients with an ABI/neurological condition, self-versus-proxy (i.e., relatives, carers etc.) rating scales can be used to assess patients' difficulties and identify any potential ISA. Self and proxy rating scales are commonly used in ABI/neurological condition populations to assess for quality of life (Aza et al, 2020), cognitive abilities (Teasdale et al, 1997), executive functioning (Emmanouel, Mouza, Kessels and Fasotti, 2014) and personal and social functioning (Powell, Beckers, and Greenwood, 1998).

Proxy rating scales are completed by individuals who know the patient well, including carers, relatives, or clinicians. These reports can be used to avoid bias that can occur when relying solely on self-reports (Olino and Klein, 2015) and can pick up any ISA which would impact on the accuracy of the results. Studies have found that patients with ISA can over or underestimate their difficulties which leads to a higher discrepancy between self and proxy ratings (Fischer, Trexler and Gauggel, 2004; Noe et al, 2005).

Research on other factors that affect self and proxy ratings is mixed however there is evidence that self-reports are affected by mood. One study found that ABI patients who overestimated their difficulties showed fewer depressive symptoms, whereas those who underestimated their difficulties showed higher levels of depressive symptoms (Smeets et al, 2014). Furthermore,

Miller et al (2013) found that self-ratings of impairments are related to emotional difficulties rather than reflecting actual impairment, in that participants over or underestimated their difficulties depending on their mood. This is also seen in multiple sclerosis patients where one study found that symptoms of depression and anxiety were related to the accuracy of self-reports (Goverover, Chiaravalloti and DeLuca, 2005). These studies therefore indicate that mood can affect self-reports which would lead to a higher discrepancy between self and proxy ratings.

Research has found that 'clinician', 'family' and 'significant other' ratings of patient functioning were related, and they differed from patient self-ratings, emphasising the importance of the use of proxy rating scales (Sherer et al, 2003). Proxy report scales are also found to be more sensitive to symptom and functional changes than self-report scales (Lin, Lu, Wong, and Chen, 2014).

Research rationale

This study investigated the degree of agreement between self and proxy ratings of the BIFS and explored what variables best predict any differences in scores. Based on the available evidence, this was done by comparing the BIFS discrepancy scores with level of awareness and patients' mood, including depression and anxiety levels. The results of this study will determine whether ISA or mood impact on self-ratings of fatigue in individuals with an ABI/neurological condition and will therefore determine the importance of proxy rating scales in clinical practice.

Research hypotheses

The research hypotheses for this study are:

1. ISA will be the main predictor of discrepancy between self/proxy ratings on the BIFS.
2. Patients' depression scores will be predictive of greater patient/proxy discrepancies on the BIFS.
3. Patients' anxiety scores will be predictive of greater patient/proxy discrepancies on the BIFS.

Method

Study Design and Recruitment

A between-groups design was employed in which eleven ABI/neurological condition patients and their proxies completed the BIFS and PCRS. Patients also completed the HADS. The independent variables were PCRS level of awareness score (which was calculated using PCRS-Patient and PCRS-Proxy scores and converted into categorical variables i.e. patient ratings higher, proxy ratings higher or congruent ratings), Patient HADS anxiety score and Patient HADS depression score. The dependent variable was the discrepancy score between the BIFS-Patient and BIFS-Proxy ratings.

A total of eleven ABI/neurological condition patients and their proxies were recruited from NHS services within the Yorkshire and Lincolnshire region. Recruitment took place between March 2022 and August 2022. The researcher discussed the study within service team meetings, and clinicians used the inclusion and exclusion criteria to identify patients that would be suitable for the study. Five patients and four proxies completed the scales within clinical appointments with the clinician, two patients and three proxies were sent the measures to complete and send back via email/post, and four patients and four proxies completed the scales via telephone with the researcher.

Patient demographic data and information about their ABI/neurological condition was collected through clinical records by their clinician, including gender, age, type of injury/diagnosis and length of time post injury/diagnosis/onset of symptoms (see Appendix G).

Inclusion and Exclusion Criteria

The inclusion criteria for both the patient and proxy group included being proficient in English, aged over 18 years and having capacity to consent to take part in the study. This included having the ability to read and understand the participant information sheet, being able to appreciate that taking part is voluntary, having the ability to choose to decline to participate and being able to appreciate what the data will be used for. The inclusion criteria for the patient group also included having experienced any type of ABI or neurological condition including TBI, Stroke, MS or Parkinson's Disease. Anyone meeting this criterion also needed to have a suitable proxy, including a family member or friend who knew them well.

The exclusion criteria for both the patient and proxy group included having difficulties comprehending or producing speech to the level necessary to complete the questionnaire. The exclusion criteria for the patient group also included neurodevelopmental issues before the age of 18 and pre-existing health conditions related to fatigue (e.g., chronic fatigue, chronic pain, or endocrine disorders).

Ethical approval for this study was given by the Faculty of Health Sciences Ethics Committee (University of Hull) and the Health Research Authority (see Appendix H).

Measures

The Brain Injury Fatigue Scale (Quinn, Jones, Fokias and Moss, 2004)

The BIFS is an unpublished 20 item assessment of fatigue which contains a self and proxy rating scale (see Appendices I and J). The BIFS assesses physical fatigue, mental fatigue, emotional distress, sleep/rest, and social/activities of daily living functioning. Each item on the BIFS is scored from 0-5 with a score of 5 signifying higher levels of fatigue. The results therefore range from 20-100, with higher scores being representative of greater patient fatigue levels. The fatigue classifications for the BIFS are Normal (scores below 61), Abnormal (scores between 61-69), Severe (scores between 70-79) and Profound (scores above 79).

The Patient Competency Rating Scale (Prigatano et al , 1986)

The PCRS is a 30-item assessment that evaluates level of awareness by measuring patient's ability to conduct practical skills on a five-point Likert scale. The PCRS contains a self and proxy scale (see Appendices K and L) and assesses patient's cognitive skills, psychosocial skills, activities of daily living and emotional liability (Kolakowsky-Hayner, Wright and Bellon, 2012). The PCRS is found to have acceptable test-re-test reliability and strong internal consistency for both the self and proxy scales (Fleming, Strong and Ashton, 1996). Each item on the PCRS is scored from 0-5 with a score of 5 signifying higher levels of awareness. The results therefore range from 30-150, with higher scores being representative of greater levels of patient awareness. Level of awareness can be inferred in three different ways, including calculating the patient and proxy discrepancy score, as well as calculating the number of items the patient scored higher, the proxy scored higher and the patient and proxy score the same. Patients were then classified based on which of the three scores was the highest.

The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

The HADS is a 14 item self-report scale of depression and anxiety in medical populations of patients (see Appendix M). The HADS consists of seven questions composing the depression

subscale and seven questions composing the anxiety subscale. Each item is scored from 0-3 with a score of 3 signifying higher levels of depression/anxiety. Subscale scores therefore range from 0-21 with scores between 8-10 indicating mild depression/anxiety, 11-14 indicating moderate depression/anxiety and 15-21 indicating severe depression/anxiety. Scores below 8 are not indicative of emotional distress (Stern, 2014). The HADS has been found to be a reliable tool for depression and anxiety disorders in ABI patients (McKenzie, Downing and Ponsford, 2018).

Procedure

To reduce pressure on services, the data collection procedure was kept flexible and was adapted to fit with each service. Overall, within all services clinicians gave patients who met the inclusion and exclusion criteria the study information sheet (see Appendix N), consent form (see Appendix O) and researcher contact details during their initial/routine clinical appointment. They were then given up until their next clinical appointment to decide if they would like to take part in the study. Alternatively, patients gave their clinician verbal consent to take part in the study and their contact details were securely emailed to the researcher who contacted the patient via telephone to answer any questions and send the consent form via email.

Once patients consented to take part in the study, they either completed the scales (i.e., the BIFS-Patient, PCRS-Patient and HADS) with their clinician as part of their clinical appointment (n= 5) or they were sent the scales and consent forms to complete and send back to their clinician via email/post (n= 2). Alternatively, if patients consented to be contacted by the researcher, their contact details were passed onto the researcher who then contacted the

patient via telephone to complete the scales (n= 4). Patient demographic data, consent forms and questionnaires were securely sent via email to the researcher.

If the patient's proxy attended the clinical appointment with the patient, they were given the relevant information sheet (see Appendix P) and consent form (see Appendix Q) and were given up until the patient's next clinical appointment to decide if they would like to take part in the study. Once consent was gained, the clinician either gave the proxy the scales (i.e., BIFS-Carer and PCRS-Relative) to complete whilst they waited for the patient (n= 4), or the proxies were sent the scales to complete and send back to the clinician via email/post (n= 3). The consent forms and questionnaires were securely emailed to the researcher. If the proxy did not attend the appointment with the patient, the patient took the relevant information sheet, consent form and researcher contact details to their proxy, who then contacted the researcher if they wanted to take part in the study (n= 4). Any questions that the proxy had were answered over the telephone with the researcher and they were given up to a week to decide if they would like to take part in the study, their consent form was sent via email to the researcher and the scales were completed over the telephone with the researcher.

Data analysis

GPower Version 3.1.9.6 software (Faul, Erdfelder, Lang & Buchner, 2008) was used to determine that the independent variables in the regression model use a total of 3 degrees of freedom. To detect a large effect size of 0.35 for this with 80% power and using a 5% significance level for statistical testing, a total of 36 independent observations on all variables were required for both the patient and proxy ratings, so in total 72 participants were required.

Due to this study exploring BIFS discrepancy scores against PCRS discrepancy scores and mood, PCRS scores were converted into categorical variables during the regression analysis to ensure that the data could be reliably interpreted. Level of awareness was therefore inferred by using the patient and proxy discrepancy score, as well as calculating the number of items the patient scored higher, the proxy scored higher and the patient and proxy score the same. Patients were then classified based on which of the three scores was the highest. BIFS discrepancy scores were calculated by subtracting the PCRS-Patient with the PCRS-Proxy ratings, for analysis these scores were inputted into the regression model as a continuous variable ignoring the direction of the discrepancy.

Descriptive statistics were calculated for the BIFS, PCRS and HADS scores. Histograms of the data identified that the data was not normally distributed, therefore medians were reported within the descriptive statistics. Correlation coefficients were used to analyse the associations between the BIFS, PCRS and HADS scores, as well as the demographic data. A linear regression analysis was then used to analyse the predictive strengths of the PCRS categorical variables, HADS anxiety scores and HADS depression scores on the BIFS discrepancy scores. All statistical analyses were performed on SPSS Version 27 (IBM, 2020).

Results

Demographic Information

Eleven ABI/neurological condition patients and their proxies were recruited. Patient demographic information is shown in Table 1. Information on proxy respondents can be seen in Table 2. From Table 1 it can be seen that the age of patients ranged from 18-63 years (Median=52), furthermore time since injury/diagnosis/onset of symptoms ranged from 6-288 months (Median=33.50). In terms of type of injury five (44.45%) patients were living with a

TBI, three (27.27%) patients were living with a Stroke and three (27.27%) patients were living with MS. Regarding the proxy data (Table 2), one (9.09%) proxy rated that they knew the patient 'pretty well' and 10 (90.91%) rated that they knew the patient 'very well'.

Table 1. Patient demographic information

Demographic information	Number of patients
Gender	
Male	4
Female	7
Age	
18-29	2
30-39	0
40-49	2
50-59	5
60-63	2
Injury/diagnosis	
Traumatic Brain Injury	5
Stroke	3
Multiple Sclerosis	3
Length of time post injury/diagnosis (years)	
0-1	3
1-2	2
2-3	1
3-4	1
4-5	0
5-10	0
11+	4

Table 2. Information on proxy respondents

Proxy information	Number of proxies
Proxy's relationship to the patient	
Mother	1
Spouse	6
Child	1
Sibling	2

Friend	1

Descriptive Statistics

Descriptive statistics for each measure are shown in Table 3. It can be seen that on average proxies rated patients fatigue levels on the BIFS (Median=79) similar to patients' self-ratings (Median=88). Furthermore, on average proxies rated patients higher and therefore more competent on the PCRS (Median=102) than patients' self-ratings (Median=99.36). The results also show a low BIFS discrepancy (Median=1) and PCRS discrepancy (Median=-7)

Table 3. Descriptive statistics for each measure

Measure	Median	Variance	Range
BIFS-Patient	88	363.42	30-91
BIFS- Proxy	79	201.87	51-98
BIFS Discrepancy	1	176.76	-23-21
PCRS-Patient	99.36	260.86	71-125
PCRS-Proxy	102	416.86	61-127
PCRS Discrepancy	-7	221.40	-23-23
HADS-Depression	9	9.62	4-16
HADS-Anxiety	13	30.09	1-20

Regarding clinically significant cut offs for the HADS-Depression scores, three patients were classified as 'normal' (range 0-7), four were classified 'mild depression' (range 8-10), three

were classified ‘moderate depression’ (range 11-14) and one was classified ‘severe depression’ (range 15-21). Using the same cut off scores for the HADS-Anxiety ratings, three patients were classified as ‘normal’, two were classified ‘mild anxiety’, three were classified ‘moderate anxiety’ and three were classified ‘severe anxiety’.

Regarding clinically significant cut offs for the BIFS scores, one patient and one proxy scored patients fatigue within the ‘normal’ category (range 20-60), three patients and two proxies scored patients fatigue within the ‘abnormal’ category (range 61-69), zero patients and three proxies scored patients fatigue within the ‘severe’ category (range 70-79) and seven patients and five proxies scored patients fatigue within the ‘profound’ category (range 79-100). Overall, 27.27% of patients rated their fatigue at a higher clinical cut off category than their proxies, 9.03% of proxies rated patients’ fatigue at a higher clinical cut off category than patients and 63.64% of patients and proxies rated patients’ fatigue within the same clinical cut off category. However, within this all differences were marginal and within one clinical cut off category.

Statistical Analysis

Correlational analyses were conducted for the patient and proxy ratings on the BIFS, PCRS and HADS, as well demographic data (i.e., gender, age, length of time post injury/diagnosis/onset of symptoms and type of injury), which can be seen in Table 4. This analysis found that BIFS-Patient ratings were significantly positively correlated with BIFS-Proxy ratings ($r=0.717$, $p<0.05$), indicating that as patient ratings on the BIFS increased, proxy ratings of the BIFS also increased. BIFS-Patient ratings were also significantly positively correlated with BIFS-Discrepancy scores ($r=0.667$, $p<0.05$), indicating that as patient ratings on the BIFS increased, BIFS discrepancy scores also increased. Furthermore, this analysis found that BIFS-Proxy ratings were significantly positively associated with age ($r=0.731$,

$p<0.05$), indicating that as age increased, proxies' ratings on the BIFS increased. BIFS-Proxy ratings were also significantly negatively correlated with PCRS-Proxy ratings ($r= -0.618$, $p<0.05$), which was plotted into a scatter graph seen in Figure 1. From Figure 1 it can be seen that as PCRS-Proxy ratings increased, BIFS-Proxy ratings decreased.

This analysis also found that PCRS-Proxy ratings were significantly negatively correlated with type of injury ($r= -.643$, $p<0.05$). A scatter graph was used to plot this, which can be seen in Figure 2. From Figure 2 it can be seen that proxies rated patients with MS (assigned as category one) and Stroke (assigned as category two) at a higher competency than patients with TBI (assigned as category three). Furthermore, HADS depression scores were found to be significantly positively correlated with type of injury ($r= .607$, $p<0.05$). A scatter graph was used to plot this, which can be seen in Figure 3. From Figure 3 it can be seen that patients with a TBI (assigned as category three) rated their depressive symptoms at a higher level than patients with MS (assigned as category one) and Stroke (assigned as category two).

Additionally, PCRS-Patient ratings were found to be significantly positively correlated with PCRS-Proxy ratings ($r=0.692$, $p<0.05$), indicating that as patient ratings on the PCRS increased, proxy ratings on the PCRS also increased. PCRS-Patient ratings were also significantly negatively correlated with depression scores ($r= -0.771$, $p<0.01$), indicating that as patient scores on the PCRS increased, depression scores decreased. Furthermore PCRS-Proxy scores were significantly negatively correlated with PCRS-Discrepancy scores ($r=-0.621$, $p<0.05$).

Correlations did not show a relationship between the BIFS discrepancy scores and the PCRS discrepancy scores. A scatter graph was used to plot this, which can be seen in Figure 4. As

can be seen in Figure 4 there was no association between BIFS discrepancy scores and the PCRS discrepancy scores.

Table 4. Correlation coefficients

Variable	BIFS-Patient	BIFS-Proxy	BIFS-Discrepancy	PCRS-Patient	PCRS-Proxy	PCRS-Discrepancy	HADS-Depression	HADS-Anxiety	Type of injury	Age	Gender	Length of time post injury /diagnosis /onset of symptoms
BIFS-Patient	1	.717*	.667*	-.486	-.369	-.021	.166	.401	.441	.540	-.157	.364
BIFS- Proxy	.717*	1	-.040	-.386	-.618*	.429	.090	.402	.331	.731*	.170	.099
BIFS-Discrepancy	.667*	-.040	1	-.285	.131	-.489	.142	.146	.279	-.008	-.407	.417
PCRS-Patient	-.486	-.386	-.285	1	.692*	.136	-.771**	.049	-.600	-.212	-.165	-.248
PCRS-Proxy	-.369	-.618*	.131	.692*	1	-.621*	-.498	.097	-.643*	-.203	-.101	.157
PCRS Discrepancy	-.021	.429	-.489	.136	-.621*	1	-.154	-.080	.231	.048	-.040	-.484
HADS-Depression	.166	.090	.142	-.771**	-.498	-.154	1	-.113	.607*	-.134	.314	-.081
HADS-Anxiety	.401	.402	.146	.049	.097	-.080	-.113	1	.080	.136	.312	.565
Type of injury	.441	.331	.279	-.600	-.643*	.231	.607*	.080	1	-.063	.289	-.117
Age	.540	.731*	-.008	-.212	-.203	.048	-.134	.136	-.063	1	.132	.014
Gender	-.157	.170	-.407	-.165	-.101	-.040	.314	.312	.289	.132	1	-.147
Length of time post injury/diagnosis/onset of symptoms	.364	.099	.417	-.248	.157	-.484	-.081	.565	-.117	.014	-.147	1

** $p<0.01$ (2-tailed); * $p<0.05$ (2-tailed)

Figure 1. Scatter graph of the relationship between BIFS-Proxy and PCRS-Proxy ratings

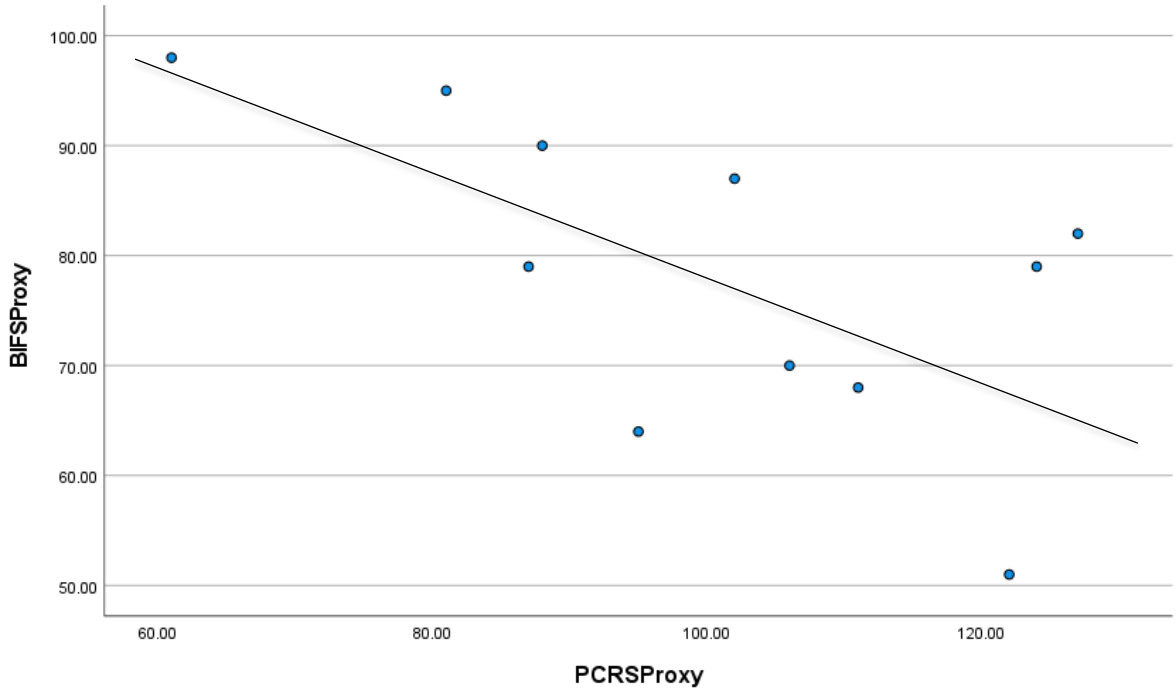


Figure 2. Scatter graph of the relationship between PCRS-Proxy and Type of Injury

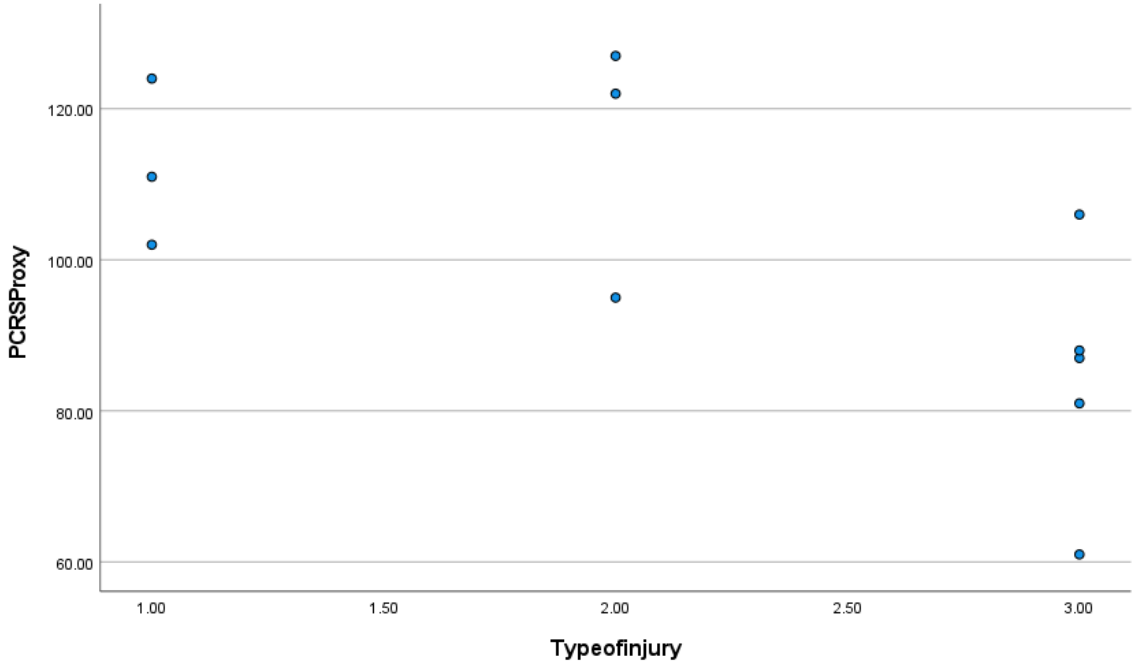


Figure 3. Scatter graph of the relationship between HADS-Depression and Type of Injury

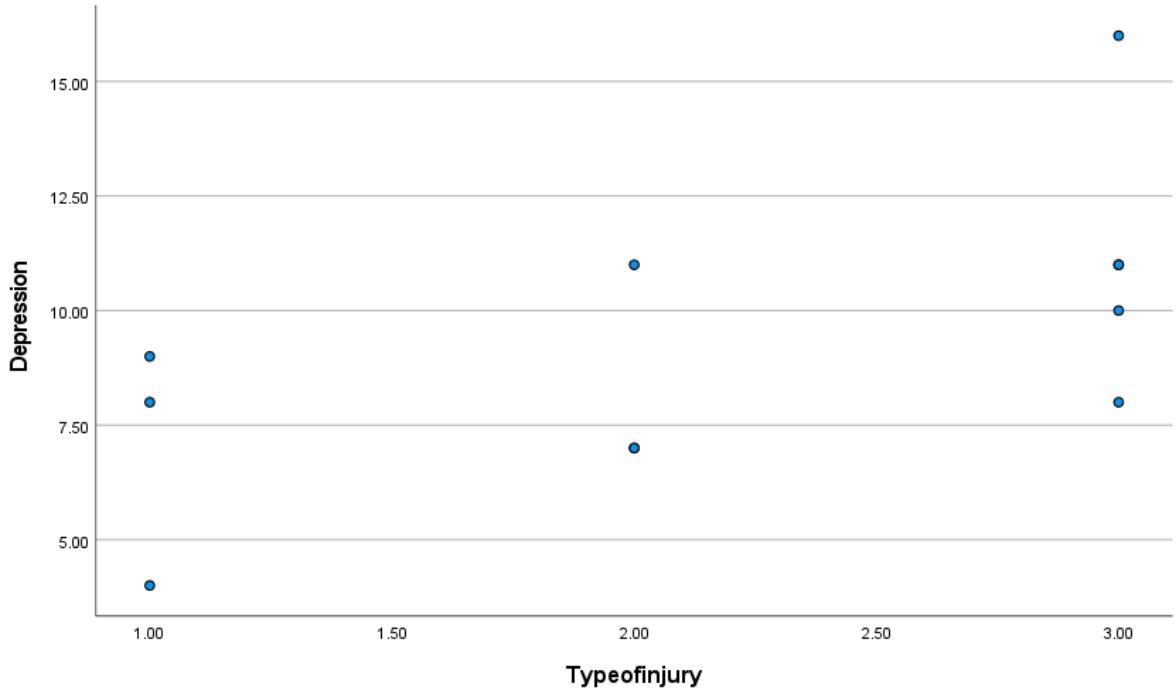
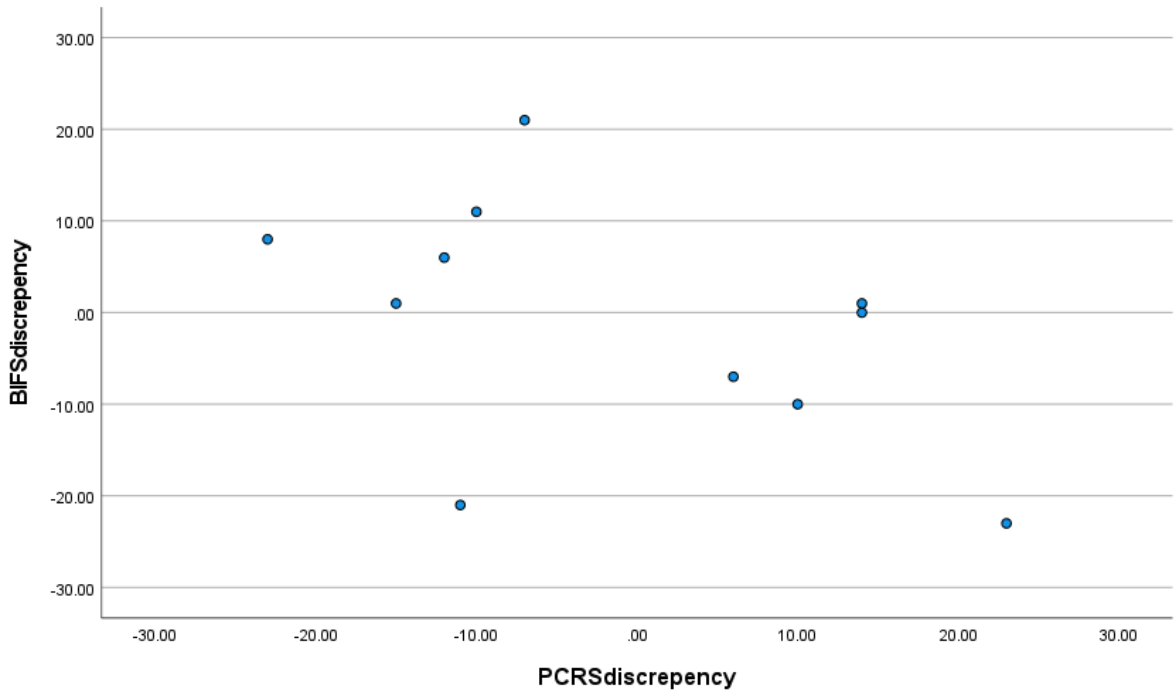


Figure 4. Scatter graph of the relationship between BIFS-Discrepancy and PCRS-Discrepancy ratings



Hypothesis 1. ISA will be the main predictor of discrepancy between self/proxy ratings on the BIFS

Exploratory analysis was undertaken using a linear regression model to establish the predictive strength of PCRS categorical variables (i.e. patient ratings higher (n=3), proxy ratings higher (n=4) or congruent ratings (n=4) on the BIFS-Discrepancy ratings (which was inputted ignoring the direction of the discrepancy). Results of this regression analysis are shown in Table 5. It can be seen that PCRS ratings did not significantly predict BIFS-Discrepancy scores (r^2= -.088, df=1, p=.671).

Table 5. Regression analysis for hypothesis 1

Model Summary

Model	R	R Square	Adjusted R Square	Std Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.145	.021	-.088	8.74434	.021	.193	1	9	.671

ANOVA

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	14.738	1	14.738	.193	.671
	Residual	688.171	9	76.463		
	Total	702.909	10			

Hypothesis 2. Patients' depression scores will be predictive of greater patient/proxy discrepancies on the BIFS.

Exploratory analysis was undertaken using a linear regression model to establish the predictive strength of Depression scores on the BIFS-Discrepancy variable (which was inputted ignoring the direction of the discrepancy). Results of this regression analysis are shown in Table 6. It can be seen that depression scores did not significantly predict BIFS-Discrepancy scores (r^2= -.111, df=1, p=.953).

Table 6. Regression analysis for hypothesis 2

Model Summary

Model	R	R Square	Adjusted R Square	Std Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.020	.000	-.111	8.83566	.000	.004	1	9	.953

ANOVA

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	.289	1	.289	.004	.953
	Residual	702.620	9	78.069		
	Total	702.909	10			

Hypothesis 3. Patients' anxiety scores will be predictive of greater patient/proxy discrepancies on the BIFS.

Exploratory analysis was undertaken using a linear regression model to establish the predictive strength of Anxiety scores on the BIFS-Discrepancy variable (which was inputted ignoring the direction of the discrepancy). Results of this regression analysis are shown in Table 7. It can be seen that anxiety scores did not significantly predict BIFS-Discrepancy scores (r^2= -.053, df=1, p=.500).

Table 7. Regression analysis for hypothesis 3

Model Summary

Model	R	R Square	Adjusted R Square	Std Error of the Estimate	R Square Change	F Change	df1	df2	Sig. F Change
1	.228	.052	-.053	8.60448	.052	.494	1	9	.500

ANOVA

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	36.576	1	36.576	.494	.500
	Residual	666.334	9	74.037		
	Total	702.909	10			

Discussion

Overview of findings

BIFS discrepancy ratings

This study aimed to investigate the agreement between the self and proxy ratings of the BIFS and explore what variables best predict any differences in scores. Based on the available evidence, this was done by comparing the BIFS discrepancy scores with level of awareness and patients' mood, including depression and anxiety levels. Despite aiming for a sample size of 36 pairs of patients and proxies, it was unfortunately only possible to recruit 11 pairs of patients and proxies, consequently the results reported in this study are only considered preliminary findings.

Overall, within this sample 90.91% of patients and 90.91% of proxies rated patients' fatigue at categories of "abnormal" fatigue and above, demonstrating the high level of fatigue experienced by patients with an ABI/neurological condition, which fits with previous research (Ouellet and Morin, 2006; Minden et al, 2006). The results of this study also found that 63.64% of patients rated their fatigue within the same clinical cut off category as their proxies' ratings, indicating a high level of agreement between patients and proxies BIFS ratings within this sample.

Additionally, correlational analysis found that patient and proxy ratings on the BIFS were significantly positively correlated, indicating a high level of agreement in self and proxy ratings.

Fatigue and ISA

Within this study it was found that 27.27% of patients rated their abilities at a higher level than their proxies, 36.36% of patients rated their abilities at a lower level than their proxies and 36.36% of patients rated their abilities at a similar level to their proxies. Correlational analyses found that PCRS-Patient and PCRS-Proxy ratings were significantly positively correlated, suggesting that within this sample as patients self-report of their competence increased so did their proxy's ratings. These results therefore indicate that within this sample there were no notable impaired self-awareness difficulties. PCRS-Proxy ratings were also negatively correlated with BIFS-Proxy ratings, indicating that as proxies' ratings of patient competence increased, their ratings of patient fatigue decreased. Additionally, PCRS-Proxy ratings were negatively correlated with type of injury, with proxies rating patients with MS and Stroke at a higher competency than patients with TBI.

The results of this study found that PCRS ratings did not significantly predict BIFS discrepancy scores. These results therefore do not support hypothesis one which stated that ISA will be the main predictor of discrepancy between self and proxy ratings on the BIFS.

Overall, within this sample patients experienced a high level of fatigue whilst having strong agreements between self and proxy ratings on the PCRS, indicating that there was a low level of ISA experienced within this sample. This may be due to individuals with higher ISA being more likely to have greater levels of cognitive difficulty and were therefore less able to participate or consent to take part in the study.

Fatigue and mood

Within this study, 36.36% of patients reported experiencing moderate-severe levels of depression, and 54.55% of patients reported experiencing moderate-severe levels of anxiety.

Correlational analysis found a significant negative relationship between PCRS-Patient and depression scores, indicating that as patient ratings of their competence increased, their depression levels decreased. Furthermore, it was found that depression scores were positively correlated with type of injury, in that patients' with a TBI rated their depressive symptoms at a higher level than patients with MS and Stroke. No relationship was found between depression/anxiety scores and fatigue ratings or PCRS-Discrepancy scores (i.e., level of awareness).

The results of this study found that neither depression or anxiety ratings significantly predicted BIFS discrepancy scores. These results therefore do not support hypothesis two or three which stated that patients with higher anxiety/depression scores will show a greater discrepancy on the BIFS compared to their proxy's rating.

Overall, mood was found not to impact on self-ratings of fatigue. This could be due to 63.64% and 45.45% of patients in this sample experiencing normal-mild levels of depression and anxiety respectively, which would explain why mood did not have a significant impact on fatigue ratings. This again could be due to individuals with higher levels of depression and anxiety being unwilling to participate or consent to take part in the study.

Clinical implications

This study found that within this sample 63.64% of patients rated their fatigue within the same clinical cut off category as their proxies' ratings. It was also found that ISA and mood did not predict BIFS-Discrepancy scores.

This study adds to research on the use of proxy ratings scales within clinical practice, which has previously focused on the use of these scales to assess for cognitive abilities (Emmanouel, Mouza, Kessels and Fasotti, 2014) and personal and social functioning (Powell, Beckers, and Greenwood, 1998). The use of proxy ratings scales to measure fatigue has not been previously explored. Overall, this study showed a moderate level of agreement between patient and proxy ratings of fatigue on the BIFS, however it also showed that a proportion of patients (36.37%) scored their fatigue levels within a different clinical category to their proxies, which emphasises the importance of proxy rating scales within this area to avoid bias that can occur when replying solely on self-reports, which aligns with previous research (Olino and Klein, 2015).

These results therefore demonstrate the importance of the self and proxy rating scales of the BIFS, which is not seen in any other fatigue measure. The lack of use of proxy rating scales within this area may therefore be impacting on the assessment and treatment of fatigue within rehabilitation of ABI/neurological condition patients and requires further research.

Despite previous research on the impact of ISA and mood on self-reports of fatigue, the results of this study found that level of awareness and mood did not predict BIFS-Discrepancy scores. One explanation could be that due to the variety of injuries/diagnoses in this sample, including those with neurological conditions, this could have led to a sample of individuals who were cognitively intact and did not experience ISA of their injury/diagnosis. Another explanation may come from illness representation research, which has found that that over time individuals become more aware of their difficulties as their representation of their illness increases (Diefenbach and Leventhal, 1996). This results in a decrease in discrepancy between actual and perceived difficulties over time. Within the sample in this study, patients' length of time

post injury/diagnosis/onset of symptoms ranged from 6-288 months, therefore it can be assumed that the majority of patients had beliefs about their illness that have converged over time.

Limitations and further research

One limitation of this study was the low sample size, which resulted in a loss of power within the results found. Due to this only an exploratory analysis was undertaken. Plans to continue data collection have been discussed with both supervisors with the hope of increasing the sample size and increasing the probability of finding more substantial results in support of the original hypothesis.

Another limitation within this study was the variation in the sample, including type of injury/diagnosis and length of time post injury/diagnosis/onset of symptoms. This included having both ABI and neurological condition patients within the study sample, who experienced their condition from 6-288 months. This was initially done to ensure that patients with a wide variety of conditions that may experience ISA were included within the sample. However, this variation may have led to a sample of individuals who were cognitively intact and therefore did not experience ISA of their difficulties. Furthermore, research has found that awareness of physical difficulties can precede awareness of behavioural and cognitive difficulties (Seel, Kreutzeer and Sander, 1997), which could be due to physical difficulties being the main focus early in recovery to improve functioning and independence. This may therefore explain the low level of ISA seen within this sample.

A further limitation within this study is the variation that existed within the methodology by using a flexible procedure. This was initially done to reduce service pressures and fit with the

preferences and ways of working within each service. However, despite this, the variety within the methodology, including recruitment and data collection may have led to bias within the findings, including some patients completing questionnaires with the proxy present, which would have influenced the data collected. However, this may only have occurred when patients were asked to complete the questionnaire and send them back to their clinician, which occurred in 18.18% of cases.

Conclusion

In conclusion, this study is the first to explore the self and proxy ratings of the BIFS, including investigating its discrepancies and factors that impact on this, including ISA and mood. Through exploratory analysis, this study found a high level of fatigue experienced by ABI/neurological condition patients. It was also found that 63.64% of patients rated their fatigue within the same clinical cut off category as their proxies' ratings. ISA and mood were not found to predict BIFS-Discrepancy scores. The findings from this study show a moderate level of agreement between patient and proxy ratings on the BIFS, however it also emphasises the importance of using proxy ratings scales within this area, which has not previously been explored. Further research identifying factors that impact self and proxy ratings of fatigue is required.

References

Aza, A., Verdugo, M. A., Orgaz, M. B., Andelic, N., Fernandez, M., & Forslund, M. V. (2020). The predictors of proxy- and self- reported quality of life among individuals with acquired brain injury. *Disability and Rehabilitation.* 1-12

Barber, S., Woodhouse, J., Powell, T., Long, R., Beard, J., Kennedy, S., Harker, R., & Sutherland, N. (2019). Acquired Brain Injury. *House of Commons Library.*

Beaulieu-Bonneau, S., & Morin, C. M. (2012). Sleepiness and fatigue following traumatic brain injury. *Sleep Medicine.* 13(6): 598-605

Belmont, A., Agar, N., Hugeron, C., Gallais, B., & Azouvi, P. (2006). Fatigue and traumatic brain injury. *Annales de readaptation et de medicine physique.* 49: 370-374

Brain Injury Association of America. (2022). *What is the difference between acquired brain injury and traumatic brain injury?* Available at: https://www.biausa.org/brain-injury/about-brain-injury/nbiic/what-is-the-difference-between-an-acquired-brain-injury-and-a-traumatic-brain-injury (accessed 28th April 2022).

Chaudhuri, A., & Behan, P. O. (2000). Fatigue and basal ganglia. *Journal of the Neurological Sciences.* 179: 34-42

Chesnel, C., Jourdan, C., Bayen, E., Ghout, I., Darnoux, E., Azerad, S., Charanton, J., Aegerter, P., Pradat-Diehl, P., Ruet, A., Azouvi, P., & Vallat-Azouvi, C. (2018). Self-awareness four years after severe traumatic brain injury: discordance between the patient's and relative's complaints. Results from the PariS-TBI study. *Clinical Rehabilitation*. 32(5): 692-704

Chiou, K. S., Chiaravalloti, N. D., Wylie, G. R., DeLuca, J., & Genova, H. M. (2016). Awareness of Subjective Fatigue After Moderate to Severe Traumatic Brain Injury. *J Head Trauma Rehabil.* 31(3): 60-68

Cooper, J., Reynolds, F., & Bateman, A. (2009). An evaluation of a fatigue management intervention for people with acquired brain injury: an exploratory study. *British Journal of Occupational Therapy.* 72(4): 174-179

Diefenbach, M. A., & Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *Journal of Social Distress & the Homeless. 5*(1): 11–38.

Emmanouel, A., Mouza,E. M., Kessels, R. P. C., & Fasotti, L. (2014). Validity of the Dysexecutive Questionnaire (DEX). Ratings by patients with brain injury and their therapists. *Brain Injury.* 28(12): 1581-1589

Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G* Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior research methods*, *39*(2), 175-191.

Fischer, S., Trexler, L. E., Gauggel, S. (2004). Awareness of activity limitations and prediction of performance in patients with brain injuries and orthopedic disorders. *J Int Neuropsychol Soc JINS*. 10: 190–199.

Flachenecker, P., Kumpfel, T., Kallmann, B., Gottschalk, M., Grauer, O., Rieckmann, P., Trenkwalder, C., Toyka, K. V. (2002). Fatigue in multiple sclerosis: a comparison of different rating scales and correlation to clinical parameters. *Multiple Sclerosis.* 8(6): 523-526

Fleming, J., Strong, J., and Ashton, R. (1996). Self-awareness of deficits in adults with traumatic brain injury: how best to measure? *Brain Inj.* 10: 1–15.

Goverover, Y., Chiaravalloti, N., & DeLuca, J. (2005). The relationship between self-awareness of neurobehavioral symptoms, cognitive functioning, and emotional symptoms in multiple sclerosis. *Muli Scler.* 11(2): 203-212

Hebscher, M., Barkan-Abramski, M., Goldsmith, M., Aharon-Peretz J., & Gilboa, A. (2016). Memory, Decision-Making, and the Ventromedial Prefrontal Cortex (vmPFC): The Roles of Subcallosal and Posterior Orbitofrontal Cortices in Monitoring and Control Processes. *Cerebral Cortex.* 26(12): 4590-4601

Hoofien, D., Gilboa, A., Vakil, E., & Donovick, P. J. (2001). Traumatic brain injury (TBI) 10-20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain Inj. 15(3):* 189-209

IBM Corp. Released 2020. *IBM SPSS Statistics for Windows, Version 27.0.* Armonl, NY: IBM Corp

Kolakowsky-Hayner, S. A., Wright, J., & Bellon, K. (2012). A brief overview of the Patient Competency Rating Scale: updates and additions to the COMBI. *J Head Rehabil.* 27(1): 83-85

Krupp, L. B. (2003). Fatigue in Multiple Sclerosis, Definition, Pathophysiology and Treatment. *CNS Drugs.* 17: 225-234

Krupp, L. B., Alvarez, L. A., LaRocca, N. G., & Scheinberg, L. C. (1988). Fatigue in Multiple Sclerosis. *JAMA.* 45(4): 435-437

Levin, H. S. (1990). Memory deficit after closed head injury. *Journal of Clinical and Experimental Neuropsychology.* 12(1): 129-153

Lin, C., Lu, M., Wong, J., & Chen, C. (2014). Comparison of physician-rating and self-rating scales for patients with major depressive disorder. *Journal of Clinical Psychopharmacology.* 34(6): 716-721

Malley, D. (2017). Managing fatigue in adults after acquired brain injury. *Neuropsychological rehabilitation: The International Handbook. Routledge Taylor & Francis Group. Cambridge* 391-402

Malley, D., Wheatcroft, J., & Gracey, F. (2014). Fatigue after Acquired Brain Injury a model to guide clinical management. *ACNR.* 14(2): 17-19

Mazaux, J., Masson, F., Levin, H. S., Alaoui, P., Maurette, P., & Barat, M. (1997). Long-term neuropsychological outcome and loss of social autonomy after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation.* 78(12): 1316-1320

McKay, C., Rapport, L. J., Bryer, R. C., and Casey, J. (2011). Self-Evaluation of Driving Simulator Performance After Stroke. *Top Stroke Rehabil. 18(5): 549-561*

McKenzie, D. P., Downing, M. G., & Ponsford, J. L. (2018). Key Hospital Anxiety and Depression Scale (HADS) items associated with DSM-IV depressive and anxiety disorder 12-months post traumatic brain injury. *Journal of Affective Disorders.* 236: 164-171

Menon, D. K., & Bryant, C. (2019). Time for change in acquired brain injury. *Lancet Neurol.* 18(1): 28

Michielsen, H. J., De Vries, J., & Van Heck, G. L. (2003). Psychometric qualities of a brief self-rated fatigue measure: The Fatigue Assessment Scale. *J Psychosom Res.* 54(4): 345-352

Miller, R. M., Haws, N. A., Murphy-Tafiti, J. L., Hubner, C. D., Curtis, T. D., Rupp, Z. W., Smart, T. A., & Thompson, L. M. (2013). Are Self-Ratings of Functional Difficulties Objective or Subjective? *Applied Neuropsychology: Adult.* 20(3): 179-186

Minden, S. L., Frankel, D., Hadden, L., Perloff, J., Srinath, K. P., & Hoaglin, D. C. (2006). The Sonya Slifka Longitudinal Multiple Sclerosis Study: methods and sample characteristics. *Multiple Sclerosis.* 12: 24-38

Nadarajah, M., & Goh, H. (2015). Post-stroke fatigue: a review on prevalence, correlates, measurement, and management. *Topics in Stroke Rehabilitation.* 22(3): 208-220

Neurological Alliance. (2019). Neuro Numbers 2019. *The Neurological Alliance.* 1-15

Noe, E., Ferri, J., Caballero, M. C., Villodre, R., Sanchez, A., Chirivella, J. (2005). Self-awareness after acquired brain injury–predictors and rehabilitation. *J Neurol.* 252: 168–175.

Oh, I., Wang, G., & Mount, M. K. (2011) Validity of observer ratings of the five-factor model of personality traits: a meta-analysis. *J Appl Psychol.* 96(4): 762-773

Olino, T. M., & Klein, D. N. (2015). Psychometric comparison of self- and informant-reports of personality. *Assessment.* 22(6): 655-664

Olver, J. H., Ponsford, J. L., & Curran, C. A. (2009). Outcome following traumatic brain injury: a comparison between 2 and 5 years after injury. *Brain injury.* 10(11): 841-848

O'Callaghan, A., McAllister, L., & Wilson, L. (2012). Insight vs readiness: factors affecting engagement in therapy from the perspectives of adults with TBI and their significant others. *Brain Injury.* 26: 1599-1610

Ouellet, M., & Morin, C. M. (2006). Fatigue following traumatic brain injury: Frequency, characteristics, and associated factors. *Rehabilitation Psychology*. 51(2), 140–149

Ownsworth, T., Fleming, J., Strong, J., Radel, M., Chan W., & Clare, L. (2007). Awareness typologies, long-term emotional adjustment and psychosocial outcomes following acquired brain injury. *Neuropsychological Rehabilitation.* 17(2): 129-150

Ownsworth, T. L., McFarland, K., & Young, R. (2000). Development and Standardization of the Self-Regulation Skills Interview (SRSI): A New Clinical Assessment Tool for Acquired Brain Injury. *The Clinical Neuropsychologist.* 14(1): 76-92

Palm, S., Ronnback, L., & Johansson, B. (2017). Long-term mental fatigue after traumatic brain injury and impact on employment status. *J Rehabil Med.* 49(3): 228-233

Powell, J.H., Beckers, K., & Greenwood, R, J. (1998). Measuring progress and outcome in community rehabilitation after brain injury with a new assessment instrument- The BICRO - 39 scales. *Arch Phys Med Rehabil*, 79: 1213-1225.

Prigatano, G. P., & Fordyce, D. J., Zeiner, H. K., Roueche, J. R., Pepping, M., & Wood, B. C. (1986). Cognitive dysfunction and psychosocial adjustment after brain injury. *In Neuropsychological Rehabilitation after brain injury (Baltimore: John Hopkins University Press)*

Quinn, D., Jones, C., Fokias, D., & Moss, A. (2004). An investigation of the relationship between mood, fatigue and function in people that have sustained an acquired brain injury. *(Unpublished PhD thesis) Birmingham: University of Birmingham*

Reich, E., Arias, E., Torres, C., Halac, E., & Carlino, M. (2015). Anosognosia and self awareness in multiple sclerosis. *Journal of the Neurological Sciences.* 357: 1-2

Robertson, K., & Schmitter-Edgecombe, M. (2015). Self-awareness and traumatic brain injury outcome. *Brain Injury*. 29 (7/8): 848-858.

Rubin, E., Klonoff, P., & Perumparaichallai, R. K. (2020). Does self-awareness influence caregiver burden? *NeuroRehabilitation.* 46(4): 511-518

Schnieders, J., Willemsen, D., & de Boer, H. (2012). Factors contributing to chronic fatigue after traumatic brain injury. *J Head Trauma Rehabil.* 27(6): 404-412

Schwartz, C. E., Coulthard-Morris, L., & Zeng, Q. (1996). Psychosocial correlates of fatigue in multiple sclerosis. *Rehabilitation.* 77(2): 165-170

Seel, R., Kreutzer, J., & Sander, A. (1997). Concordance of patients' and family members' ratings of neurobehavioral functioning after traumatic brain injury. *Arch Phys Med Rehabil*. 78:1254-1259.

Sherer, M., Hart, T., Nick, T. G., Whyte, J., Nakase Thompson, R., & Yablon, S. A. (2003). Early impaired self-awareness after traumatic brain injury. *Arch Phys Med Rehabil.* 84(2): 168-176

Smeets, S. M. J., Ponds, R. W. H. M., Wolters Gregório, G., Pouwels, C. G. J. G., Visscher, A. J., Winkens, I., & van Heugten, C. M. (2014). Impaired awareness of deficits in

individuals with neuropsychiatric symptoms after acquired brain injury: Associations with treatment motivation and depressive symptoms. *Neuropsychology.* 28(5): 717–725.

Smeets, S. M. J., Vink, M., Ponds, R. W. H. M., Winkens, I., & van Heugten, C. M. (2017). Changes in impaired self-awareness after acquired brain injury in patients following intensive neuropsychological rehabilitation. *Neuropsychol Rehabil.* 27(1): 116-132.

Smith, M. M., & Arnett, P. A. (2005). Factors related to employment status changes in individuals with multiple sclerosis. *Multiple Sclerosis.* 11: 1-8

Spikman, J. M., & van der Naalt, J. (2010). Indices of impaired self-awareness in traumatic brain injury patients with focal frontal lesions and executive deficits: implications for outcome measurement. *Journal of Neurotrauma.* 27(7): 1195-1202.

Stern, A. F. (2014). The Hospital Anxiety and Depression Scale. *Occupational Medicine.* 64(5): 393-394.

Teasdale, T. W., Christensen, A., Willmes, K., Deloche, G., Braga, L., Stachowiak, F., Vendrell, J. M., Castro-Caldas, A., Laaksonen, R. K., & Leclercq, M. (1997). Subjective experience in brain injured patients and their close relatives: A European Brain Injury Questionnaire Study. *Brain Injury.* 11(8): 543-564

Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale (HADS). *Acta Psychiatr Scand.* 67(6): 361-370

Ziino, C., & Ponsford, J. (2005). Measurement and prediction of subjective fatigue following traumatic brain injury. *J Int Neuropsychol Soc.* 11 (4): 416-425

Ziino, C., & Ponsford, J. (2006). Selective attention deficits and subjective fatigue following traumatic brain injury. *Neuropsychology, 20*(3), 383

Part Three: Appendices

Appendix A. Epistemological Statement

Within research there are several different positions that researchers can take based on their assumptions and experiences. Ontological and epistemological stances underpin these positions and can influence the approach, methodology and data analysis a researcher can take (Richie, 2013). It is therefore important that researchers are aware of their position and how this can affect their research. This statement will explore the ontological and epistemological positions that underpin this thesis and how they have shaped each aspect of the work.

An ontological stance is based on the assumptions that an individual has about reality, including its meaning and nature (Slevitch, 2011). There are two main ontological positions, realist and relativist. Realism refers to a position that truth exists and is objective, measurable and static, whereas relativism refers to a position that there are multiple meanings to reality and that it is subjective, contextual, and dynamic (Willig, 2019).

Epistemology refers to how knowledge is acquired and developed, which can therefore influence approach and methodology within research (Slevitch, 2011). Quantitative and qualitative research methodologies are based on different epistemological stances. Quantitative methods are underpinned by a positivist perspective which states that reality is objective and can be observed and tested (Yilmaz, 2013). On the other hand, qualitative methods are underpinned by a constructivism perspective which states that there are multiple truths and that meaning is constructed through individuals' perspectives and experiences (Richie, 2013).

Whilst reflecting on my own ontological and epistemological position, I found that I saw value in both approaches and therefore did not fit solely into one stance. Hence, I found that I fit

more into an alternative stance of critical realism, which combines elements from both the positivist and constructionist positions. The critical realist stance states that events and reality can be observed however they need to be interpreted further to identify factors underlying them (Willig, 2012). The critical realist position also promotes utilising methodologies that are appropriate for the aims of the research (McEvoy and Richards, 2006). This stance therefore values both quantitative and qualitative methodologies which were utilised within this thesis.

Within the systematic literature review a qualitative methodology of Narrative Synthesis was used as this piece of research was centred around exploring key themes as to how impaired self-awareness (ISA) can impact on the process of rehabilitation in acquired brain injury populations. Therefore, within this piece of work a more exploratory approach was beneficial to extract information from articles with qualitative, quantitative, and mixed methodologies. This is also combined with an objective measure of article quality. This allowed for objective observation to be utilised alongside qualitative methods to explore key themes within the articles.

Within the empirical paper, as it was exploring the discrepancies between the self and proxy ratings of the Brain Injury Fatigue Scale (BIFS) and what factors influence this, including ISA and mood, a quantitative approach was deemed most appropriate. This was due to objective measurements being required to collect the information necessary to explore and validate the BIFS. Objective measurements were also taken for ISA and mood as this allowed for a statistical analysis to be conducted without researcher bias to investigate the impact that these factors may have on the BIFS results. Therefore, it was assumed that objective measurements taken from the BIFS will provide results that are probable facts, and that the validation of this measure will provide it with a quality criterion based on validity, reliability, and objectivity.

In conclusion, whilst reflecting that a critical realist stance fit best with my views, I was able to see the value of using both qualitative and quantitative methods within research. This thesis therefore utilised each of these methodologies based on what was most appropriate for the research aims and to answer the research questions.

References

McEvoy, P., & Richards, D. (2006). A critical realist rationale for using a combination of quantitative and qualitative methods. *Journal of Research in Nursing, 11*(1), 66-78.

Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (Eds.). (2013). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Sage Publications.

Slevitch L. (2011). Qualitative and quantitative methodologies compared: Ontological and epistemological perspectives. *Journal of Quality Assurance in Hospitality & Tourism*. 12(1): 73-81.

Willig, C. (2012). Perspectives on the epistemological bases for qualitative research. In H. Cooper, P. Camic, D. Long, A. Panter, D. Rindskof, & K. Sher (Eds.), *APA handbook of research methods in psychology (Volume 1: Foundations, planning, measures, and psychometrics* (pp. 5–21). Washington, DC: American Psychological Association.

Willig, C. (2019). Ontological and epistemological reflexivity: A core skill for therapists. *Counselling and Psychotherapy Research.* 19(3): 186-194.

Yilmaz, K. (2013). Comparison of quantitative and qualitative research traditions: Epistemological, theoretical, and methodological differences. *European Journal of Education.* 48(2): 311-325.

Appendix B. Reflective Statement

The Empirical Paper

Choosing a research topic

Whilst starting the doctorate I was open to a lot of different areas, models, and ways of working. Whilst I saw this as a strength as I was a "blank canvas" to be able to develop as well as adapt to a variety of different areas, this also came with a lot of uncertainty, especially when picking a research concept. However, although I saw myself as a "blank canvas" at the start, from the research methods lectures I realised that I did have a preference within certain research models, in that I was more drawn to quantitative work. As I reflected on this, I believe this came from being brought up with vets within my family who always valued science and maths within their profession. I believe this also came from doing advanced research methods within my undergraduate degree, therefore I was experienced in conducting quantitative analysis within software's such as SPSS, which further increase my preference towards quantitative research.

As I began to explore several ideas for research, I was aware that this piece of work would be with me for the next 3 years, therefore, I decided to use the research fair to help me narrow down my area of interest. Within the research fair, there was one project that caught my interest instantly, which was Pete and Stephen's research project to validate and publish the Brain Injury Fatigue Scale (BIFS). Before starting the doctorate, Neuropsychology was an area that I had been drawn to, however I did not have many opportunities to volunteer or conduct research within this area. I was also attracted to the idea of contributing to the validation of a scale that would be used within practice and would therefore shape the assessment and intervention of brain injury patients. This was something that I valued from my family, who have also completed published pieces of work.

Seeing the value this piece of research would add to the neuropsychology field and within practice, as well as the enthusiasm both Pete and Stephen showed for the project, helped me make my decision and once I left the research fair I knew that this was the area I wanted to be involved in.

Designing the research

Due to the interest within this project, another trainee also completed a study within the overarching project of validating the BIFS. This came with a lot of benefits, including being able to share ideas and develop a plan as a team. Due to the initial aims of the project, it was also hoped that NHS ethics could be conducted early, which provided hope and excitement as I had been warned about the length of time NHS ethics would take. Due to there being two trainees within this project, it was decided that the other trainee would investigate the psychometric properties of the scale itself and I would identify the value of the self and other rating scales by exploring any discrepancies between the scales and investigating whether impaired self-awareness or mood impacted on this.

However, a downside to this way of working was that each study was required for the project, therefore when delays came within each study, this led to the project being put on hold until clarity was reached, which was the start of the first delays in this project.

When discussing what scales would be used within the study, the mood, self-awareness, and fatigue measures were decided quickly and efficiently. However, the factors that were more difficult to navigate were brain injury severity, length of time post-injury and type of injury. This was due to mixed research in this area as well as difficulty in being able to reliably assess

and compare these factors within the sample. Therefore, although the factors included in this study were the main variables that would affect self-ratings of fatigue, there was a sense that a larger piece of work would be required in future research, which was thought about throughout the entire process. Through reflection this came from a need for perfectionism within my work, which throughout this process has been something I was able to reflect on and I came to realise that aiming for this perfection was not achievable and that this study did not need to include all these factors just for the idea of perfectionism.

Ethics

Due to the nature of this project, NHS ethical approval was required. Completing the paperwork for the ethics process was completed relatively early on, however due to delays within the entire project itself, it was not submitted until a few weeks after the paperwork was complete. Furthermore, due to staff shortages and leave within both university and NHS ethics, there were delays in gaining ethical approval, with approval not being gained until December 2021. This left limited time for data collection. Therefore, the excitement of the prospect of the study getting started as early as possible then led to worry due to the delays faced.

Data collection

Recruiting services for this project was initially a smooth process, at the start around four services had expressed their interest in being involved in the study. However, as time went on this became more difficult, with one service not getting back in touch after ethical approval and another study wanting more input into the project which we were unable to accommodate, therefore they no longer expressed their interest. This left two services willing to be involved, which were approved within ethics. However due to the delays in ethics, staff leave, difficulties with communication and staff workload due to covid-19, the process of contacting services and

attending team meetings did not start until January-February 2022. Recruitment therefore did not start until March 2022 which then led on to the summer holidays, this meant clinicians were on leave, which led to further delays in data collection.

It became a great concern that not enough data was going to be gathered from just these two services. This then led to a mad scramble to identify more services to be part of the study, another service agreed to take part however recruitment did not start until end of May 2022 as ethics adjustments were required, which again was delayed due to a staff shortage. Furthermore, despite this third study agreeing to take part in the project, clinicians were unable to identify anyone suitable for the study therefore no data was collected from this service.

The data collection process overall was extremely tight and stressful and not enough data was collected as originally hoped. It was agreed that to ensure the study is sufficiently powered to be published, data collection would continue until October 2022 and the data would be added to the analysis for publication.

Additionally, due to all contact being conducted via email or Microsoft Teams, I had to learn to tolerate the lack of control that I had over these delays, and I found myself torn between sending another email to follow up and speed the process along and ensuring I don't overwhelm staff members. This lack of control was especially difficult as the thesis deadline had already been postponed and pressure was mounting. I had to learn to focus on what I could control and ensure that all other aspects of the work were up to date as data collection would be ongoing until the very last moment.

However, despite these delays, the number of services that offered to be involved within the study, as well as the clinicians who offered their time to help with the study, showed the importance and value they placed on the research. Furthermore, the patients and proxies recruited to the study were keen to be involved and take part in the project. The participants also expressed the value they saw within this research and the hope that this would help improve assessment and treatment within the field, which was refreshing and encouraged me to carry on.

Data analysis

Due to the delays described above, data collection was completed at the end of July, which left a short amount of time for data analysis, which was challenging. Help from a statistician was sought early on as getting my head around the statistics was something that I was able to do whilst data collection was still ongoing. However, although help with statistics was sought early on, the way in which the analysis could be conducted and interpreted was more difficult than originally thought, which was due to discrepancy scores on two of the scales used producing results that could be positive or negative depending on the direction. This therefore made data analysis and interpretation difficult, and a decision had to be made to make the predictor variables categorical and the outcome variable continuous whilst ignoring the direction of the discrepancy, which was the best way to be able to interpret the results.

Systematic Literature Review

Choosing a topic for the systematic literature review (SLR) was an extremely difficult task, mainly due to reviews within the original ideas of the SLR already being conducted, or there would not be a sufficient amount of research in that area. This left little scope for reviews in areas related to the empirical paper. Picking the topic for the review therefore took the longest

amount of time and hours were spent conducting literature searches on questions only to find that similar reviews had been completed or only a small number of studies were conducted in that area. It therefore took a few questions and searches to find the right area, which was a lethargic task that decreased my enthusiasm for the work, I remember feeling as though I would never complete the project. This became a frustrating task, especially due to the delays and pressures of the empirical paper at the same time. I felt stuck in one place for the review for what felt like months. However, once a topic was found and the final papers were chosen, I felt a sense of relief which reinvigorated my love for research and encouraged me to keep going.

Summary

In summary the whole research process has not been as straightforward as first thought and delays at each step of the process has led to data collection being conducted up until the last moment and not enough data being collected for sufficient power, which was extremely stressful and tiring. Furthermore, difficulties with data analysis led to adaptations having to be made to the analysis in order to interpret the results as reliably as possible. However, data collection and analysis are still ongoing to ensure that the research is sufficiently powered to be published. Although it has been a long and stressful journey, I have a great appreciation and value for research, and I have found achievements within each step of this project. Furthermore, as someone who likes to be in control and prides herself in being organised and prepared, this process really allowed me to develop as a person and tolerate uncertainty and hiccups along the way and face them head on. I have learnt first-hand the difficulties, as well as the rewards of completing research and what I can do to improve in the future.

Appendix C. Author Guidelines for the Brain Injury Journal

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements.

AUTHOR SERVICES
Supporting Taylor & Francis authors

For general guidance on every stage of the publication process, please visit our Author Services website.

EDITING SERVICES
Supporting Taylor & Francis authors

For editing support, including translation and language polishing, explore our Editing Services website

SCHOLARONE MANUSCRIPTS™

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

Contents

- Health and Safety
- Submitting Your Paper
- Data Sharing Policy
- Publication Charges
- Copyright Options
- Complying with Funding Agencies
- My Authored Works

About the Journal

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

Please note that this journal only publishes manuscripts in English.

Brain Injury accepts the following types of article: Original Paper, Review, Case Study, Book Review, Letter to the Editor, Commentary.

Brain Injury is committed to improving and maintaining the consistency and quality of manuscripts submitted and published. Authors are strongly encouraged to review and comply with the reporting guidelines relevant to their submission. Reviewers have been instructed to evaluate submissions on the basis of their conformity to the guidelines. More information on guidelines for different study types: case reports (www.care-statement.org), diagnostic accuracy (www.stard-statement.org), observational studies (http://strobe-statement.org), randomized controlled trial (www.consort-statement.org), systmatic reviews, meta-analyses (www.prisma-statement.org).

Open Access

You have the option to publish open access in this journal via our Open Select publishing program. Publishing open access means that your article will be free to access online immediately on publication, increasing the visibility, readership and impact of your research. Articles published Open Select with Taylor & Francis typically receive 95% more citations* and over 7 times as many downloads** compared to those that are not published Open Select.

Your research funder or your institution may require you to publish your article open access. Visit our Author Services website to find out more about open access policies and how you can comply with these.

You will be asked to pay an article publishing charge (APC) to make your article open access and this cost can often be covered by your institution or funder. Use our APC finder to view the APC for this journal.

Please visit our Author Services website if you would like more information about our Open Select Program.

*Citations received up to 9th June 2021 for articles published in 2016-2020 in journals listed in Web of Science®. Data obtained on 9th June 2021, from Digital Science's Dimensions platform, available at https://app.dimensions.ai
**Usage in 2018-2020 for articles published in 2016-2020.

Peer Review and Ethics

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer reviewed by independent, anonymous expert referees. If you have shared an earlier version of your Author's Original Manuscript on a preprint server, please be aware that anonymity cannot be guaranteed. Further information on our preprints policy and citation requirements can be found on our Preprints Author Services page. Find out more about what to expect during peer review and read our guidance on publishing ethics.

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.

A typical paper for this journal should be no more than 5000 words

Style Guidelines

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

Please use American spelling style consistently throughout your manuscript.

Please use single quotation marks, except where 'a quotation is "within" a quotation'.

Please note that long quotations should be indented without quotation marks.

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

Letters to the Editor can be signed by a maximum of three authors, should be between 750 and 1,250 words, may contain one table/figure and may cite a maximum of five references. All Letters should be submitted via ScholarOne Manuscripts and should contain a Declaration of Interest statement.
Some journals set a maximum length for submissions. Though *Brain Injury* does not have a specific limit, we prefer that manuscripts not exceed 5,000 words excluding abstract, references, tables, and figure legends. If articles are greater than 5,000 words, authors may be asked to shorten their manuscript.

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 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 us here.

References

Please use this reference guide when preparing your paper.

Taylor & Francis Editing Services

To help you improve your manuscript and prepare it for submission, Taylor & Francis provides a range of editing services. Choose from options such as English Language Editing, which will ensure that your article is free of spelling and grammar errors, Translation, and Artwork Preparation. For more information, including pricing, visit this website.

Checklist: What to Include

1. **Author details.** Please ensure everyone meeting the International Committee of Medical Journal Editors (ICMJE) requirements for authorship is included as an author of your paper. Please ensure all listed authors meet the Taylor & Francis authorship criteria. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. 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. Read more on authorship.

2. Should contain a structured abstract of 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. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. Between 3 and 5 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
5. **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].
6. **Disclosure statement.** This is to acknowledge any financial or non-financial interest that has arisen from the direct applications of your research. If there are no relevant competing interests to declare please state this within the article, for example: *The authors report there are no competing interests to declare*. Further guidance on what is a conflict of interest and how to disclose it.
7. **Biographical note.** Please supply a short biographical note for each author. This could be adapted from your departmental website or academic networking profile and should be relatively brief (e.g. no more than 200 words).

8. **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.
9. **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.
10. **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.
11. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for color, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For information relating to other file types, please consult our Submission of electronic artwork document.
12. **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.
13. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
14. **Units.** Please use SI units (non-italicized).

Using Third-Party Material

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. More information on requesting permission to reproduce work(s) under copyright.

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/Welcome-funded papers, the grant number(s) must be included in the declaration of interest statement. Read more on declaring conflicts of interest.

Clinical Trials Registry

In order to be published in a Taylor & Francis journal, all clinical trials must have been registered in a public repository, ideally at the beginning of the research process (prior to

participant recruitment). Trial registration numbers should be included in the abstract, with full details in the methods section. Clinical trials should be registered prospectively – i.e. before participant recruitment. However, for clinical trials that have not been registered prospectively, Taylor & Francis journals requires retrospective registration to ensure the transparent and complete dissemination of all clinical trial results which ultimately impact human health. Authors of retrospectively registered trials must be prepared to provide further information to the journal editorial office if requested. The clinical trial 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 original research papers involving humans, animals, plants, biological material, protected or non-public datasets, collections or sites, must include a written statement in the Methods section, confirming ethical approval has been obtained from the appropriate local ethics committee or Institutional Review Board and that where relevant, informed consent has been obtained. For animal studies, approval must have been obtained from the local or institutional animal use and care committee. All research studies on humans (individuals, samples, or data) must have been performed in accordance with the principles stated in the Declaration of Helsinki. In settings where ethics approval for non-interventional studies (e.g. surveys) is not required, authors must include a statement to explain this. In settings where there are no ethics committees in place to provide ethical approval, authors are advised to contact the Editor to discuss further. Detailed guidance on ethics considerations and mandatory declarations can be found in our Editorial Policies section on Research Ethics.

Consent

All authors are required to follow the ICMJE requirements and Taylor & Francis Editorial Policies on privacy and informed consent from patients and study participants. Authors must include a statement to confirm that any patient, service user, or participant (or that person's parent or legal guardian) in any type of qualitative or quantitative research, has given informed consent to participate in the research. For submissions where patients or participants can be potentially identified (e.g. a clinical case report detailing their medical history, identifiable images or media content, etc), authors must include a statement to confirm that they have obtained written informed consent to publish the details from the affected individual (or their parents/guardians if the participant in not an adult or unable to give informed consent; or next of kin if the participant is deceased). The process of obtaining consent to publish should include sharing the article with the individual (or whoever is consenting on their behalf), so that they are fully aware of the content of the article before it is

published. Authors should familiarize themselves with our policy on participant/patient privacy and informed consent. They may also use the Consent to Publish Form, which can be downloaded from the same Author Services page.

Health and Safety

Please confirm that all mandatory laboratory health and safety procedures have been complied within 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 Behavioural 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.

Submitting Your Paper

This journal uses ScholarOne Manuscripts to manage the peer-review process. If you haven't submitted a paper to this journal before, you will need to create an account in ScholarOne. Please read the guidelines above and then submit your paper in the relevant Author Centre, where you will find user guides and a helpdesk.

If you are submitting in LaTeX, please convert the files to PDF beforehand (you will also need to upload your LaTeX source files with the PDF).

Please note that *Brain Injury* uses Crossref™ to screen papers for unoriginal material. By submitting your paper to *Brain Injury* you are agreeing to originality checks during the peer-review and production processes.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about sharing your work.

Data Sharing Policy

This journal applies the Taylor & Francis Basic Data Sharing Policy. Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes a long-

term preservation plan. If you are uncertain about where to deposit your data, please see this information regarding repositories.

Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer-reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

Publication Charges

There are no submission fees, publication fees or page charges for this journal.

Color figures will be reproduced in color in your online article free of charge. If it is necessary for the figures to be reproduced in color in the print version, a charge will apply.

Charges for color figures in print are £300 per figure ($400 US Dollars; $500 Australian Dollars; €350). For more than 4 color figures, figures 5 and above will be charged at £50 per figure ($75 US Dollars; $100 Australian Dollars; €65). Depending on your location, these charges may be subject to local taxes.

Copyright Options

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. Read more on publishing agreements.

Complying with Funding Agencies

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for you. Check funders' open access policy mandates here. Find out more about sharing your work.

My Authored Works

On publication, you will be able to view, download and check your article's metrics (downloads,

citations and Altmetric data) via My Authored Works on Taylor & Francis Online. This is where you can access every article you have published with us, as well as your free eprints link, so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to promote your research.

Queries

If you have any queries, please visit our Author Services website or contact us here.

Updated 22nd November 2021

Appendix D. Mixed Methods Appraisal Tool (MMAT)

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

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

Appendix E. Quality Assessment Results for the Reviewed Articles (based on the MMAT)

Article	Category of Study Designs					Overall Score
	Qualitative					
	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis, and interpretation?	
Doig, Fleming, Cornwrll and Kuipers (2009)	Yes	Yes	Yes	Yes	Yes	5/5
O'Callaghan, McAllister and Wilson (2012)	Yes	Yes	Yes	Yes	Yes	5/5
Prescott, Fleming, and Doig (2017)	Yes	Yes	Yes	Yes	Yes	5/5
Tobler-Ammann, Weise, Knols, Watson, Sieben, de Bie and de Bruin (2018)	Yes	Yes	Yes	Yes	Yes	5/5
	Quantitative Descriptive					

	4.1. Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?	
Fischer, Gauggel and Trexler (2004)	Yes	Yes	Yes	No	Yes	4/5
Fleming, Strong and Ashton (1998)	Yes	Yes	Yes	No	Yes	4/5
Hartman-Maeir, Soroker and Katz (2001)	Yes	Yes	Yes	No	Yes	4/5
Jehkonen, Ahonen, Dastidar, Koivisto, LaippalaVilkki and Molnar (2001)	Yes	Yes	No	No	Yes	3/5
Lam, McMahon, Priddy and Gehred-Schultz (1988)	No	Yes	No	Yes	Yes	3/5
Pedersen, Jorgensen, Nakayama, Raaschou and Olsen (1996)	Yes	Yes	No	Yes	Yes	4/5

Richardson, McKay and Ponsford (2014)	Yes	Yes	Yes	No	Yes	4/5
Schonberger, Humle, Teasdale (2006)	Yes	Yes	Yes	No	Yes	4/5
Trahan, Pepin and Hopps (2006)	Yes	Yes	No	Yes	Yes	4/5
Trudel, Tryon and Purdum (1998)	No	Yes	Yes	No	Yes	3/5
	Mixed Methods					
	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	5.2. Are the different components of the study effectively integrated to answer the research question?	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	
Downing, Bragge and Ponsford (2018)	No	Yes	Yes	Yes	No	3/5
Prescott, Fleming and Doig (2019)	Yes	Yes	Yes	No	No	3/5

Appendix F. Author Guidelines for the Journal of Neuropsychology

JNP AUTHOR GUIDELINES

Sections

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at http://www.editorialmanager.com/jnp

Click here for more details on how to use Editorial Manager.

All papers published in the *Journal of Neuropsychology* are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

Data protection:

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at https://authorservices.wiley.com/statements/data-protection-policy.html.

Preprint policy:

This journal will consider for review articles previously available as preprints. Authors may also post the submitted version of a manuscript to a preprint server at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

2. AIMS AND SCOPE

The Journal of Neuropsychology publishes original contributions to scientific knowledge in neuropsychology including:

- clinical and research studies with neurological, psychiatric and psychological patient populations in all age groups
- behavioural or pharmacological treatment regimes
- cognitive experimentation and neuroimaging
- multidisciplinary approach embracing areas such as developmental psychology, neurology, psychiatry, physiology, endocrinology, pharmacology and imaging science

The following types of paper are invited:

- papers reporting original empirical investigations
- theoretical papers; provided that these are sufficiently related to empirical data

- review articles, which need not be exhaustive, but which should give an interpretation of the state of research in a given field and, where appropriate, identify its clinical implications
- brief reports and comments
- case reports
- fast-track papers (included in the issue following acceptation) reaction and rebuttals (short reactions to publications in JNP followed by an invited rebuttal of the original authors)
- special issues.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

- Research papers should be no more than 6000 words (excluding the abstract, reference list, tables and figures). Multiple citations for a single point are usually duplicative and authors are urged to cite the best reference. In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.
- Brief communications are short reports of original research or case reports. They are limited to a maximum of 1500 words (excluding the abstract, reference list, tables and figures) and have a total of up to three tables or figures, and no more than 10 references.
- Theoretical or review articles are full-length reviews of, or opinion statements regarding, the literature in a specific scientific area. They should be no more than 4000 words (excluding the abstract, reference list, tables and figures) and have no more than 45 references. Multiple citations for a single point are usually duplicative and authors are urged to cite the best reference. In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.
- Please refer to the separate guidelines for Registered Reports.
- All systematic reviews must be pre-registered.

4. PREPARING THE SUBMISSION

Free Format Submission

Journal of Neuropsychology now offers free format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this can be a single file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.
- The title page of the manuscript, including a data availability statement and your co-author details with affiliations. *(Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)* You may like to use this template for your title page.

Important: the journal operates a double-blind peer review policy. Please anonymise your manuscript and prepare a separate title page containing author details. *(Why is this important? We need to uphold rigorous ethical standards for the research we consider for publication.)*

- An ORCID ID, freely available at https://orcid.org. *(Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)*

To submit, login at https://www.editorialmanager.com/jnp/default.aspx and create a new submission. Follow the submission steps as required and submit the manuscript.

If you are invited to revise your manuscript after peer review, the journal will also request the revised manuscript to be formatted according to journal requirements as described below.

Revised Manuscript Submission

Contributions must be typed in double spacing. All sheets must be numbered.

Cover letters are not mandatory; however, they may be supplied at the author's discretion. They should be pasted into the 'Comments' box in Editorial Manager.

Parts of the Manuscript

The manuscript should be submitted in separate files: title page; main text file; figures/tables; supporting information.

Title Page

You may like to use this template for your title page. The title page should contain:

- A short informative title containing the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);
- A short running title of less than 40 characters;
- The full names of the authors;
- The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
- Abstract;
- Keywords;
- Data availability statement (see Data Sharing and Data Accessibility Policy);
- Acknowledgments.

Authorship

Please refer to the journal's Authorship policy in the Editorial Policies and Ethical Considerations section for details on author listing eligibility. When entering the author names into Editorial Manager, the corresponding author will be asked to provide a CRediT contributor role to classify the role that each author played in creating the manuscript. Please see the Project CRediT website for a list of roles.

Abstract

Please provide an abstract which gives a concise statement of the intention, results or conclusions of the article. The abstract should not include any sub-headings.

- Abstracts for Research Papers should not exceed 250 words.
- Abstracts for theoretical or review articles should not exceed 250 words.
- Abstracts for brief communications should not exceed 80 words.

Keywords

Please provide appropriate keywords.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Main Text File

As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors.

The main text file should be presented in the following order:

- Title
- Main text
- References
- Tables and figures (each complete with title and footnotes)
- Appendices (if relevant)

Supporting information should be supplied as separate files. Tables and figures can be included at the end of the main document or attached as separate files but they must be mentioned in the text.

- As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors. Please do not mention the authors' names or affiliations and always refer to any previous work in the third person.
- The journal uses British/US spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

References

This journal uses APA reference style; as the journal offers Free Format submission, however, this is for information only and you do not need to format the references in your article. This will instead be taken care of by the typesetter.

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

Click here for Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association. The following points provide general advice on formatting and style.

- **Language:** Authors must avoid the use of sexist or any other discriminatory language.
- **Abbreviations:** In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.
- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website for more information about SI units.
- **Effect size:** In normal circumstances, effect size should be incorporated.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

Wiley Author Resources

Manuscript Preparation Tips: Wiley has a range of resources for authors preparing manuscripts for submission available here. In particular, we encourage authors to consult Wiley's best practice tips on Writing for Search Engine Optimization.

Article Preparation Support: Wiley Editing Services offers expert help with English Language Editing, as well as translation, manuscript formatting, figure illustration, figure formatting, and graphical abstract design – so you can submit your manuscript with confidence.

Also, check out our resources for **Preparing Your Article** for general guidance and the **BPS Publish with Impact infographic** for advice on optimizing your article for search engines.

5. EDITORIAL POLICIES AND ETHICAL CONSIDERATIONS

Peer Review and Acceptance

Except where otherwise stated, the journal operates a policy of anonymous (double blind) peer review. Please ensure that any information which may reveal author identity is blinded in your submission, such as institutional affiliations, geographical location or references to unpublished research. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review. Before submitting, please read the terms and conditions of submission and the declaration of competing interests.

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:
- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with patient populations is appropriately defined
- the word count is within the stated limit for the Journal (i.e. 6000 words)

The *Journal of Neuropsychology* is committed to a fast and efficient turnaround of papers, aiming to complete the review process in under two months.

Further information about the process of peer review and production can be found in 'What happens to my paper?' Appeals are handled according to the procedure recommended by COPE. Wiley's policy on the confidentiality of the review process is available here.

Research Reporting Guidelines

Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it. Authors are encouraged to adhere to recognised research reporting standards. The EQUATOR Network collects more than 370 reporting guidelines for many study types, including for:

- Randomised trials: CONSORT
- Systematic reviews: PRISMA
- Interventions: TIDieR
- Clinical case reports: CARE

We encourage authors to adhere to the APA Style Journal Article Reporting Standards for:

- Manuscripts that report primary qualitative research
- Manuscripts that report the collection and integration of qualitative and quantitative data
- Manuscripts that report new data collections regardless of research design

We also encourage authors to refer to and follow guidelines from the FAIRsharing website.

Conflict of Interest

The journal requires that all authors disclose any potential sources of conflict of interest. Any interest or relationship, financial or otherwise that might be perceived as influencing an author's objectivity is considered a potential source of conflict of interest. These must be disclosed when directly relevant or directly related to the work that the authors describe in their manuscript. Potential sources of conflict of interest include, but are not limited to: patent or stock ownership, membership of a company board of directors, membership of an advisory board or committee for a company, and consultancy for or receipt of speaker's fees from a company. The existence of a conflict of interest does not preclude publication. If the authors have no conflict of interest to declare, they must also state this at submission. It is the responsibility of the corresponding author to review this policy with all authors and collectively to disclose with the submission ALL pertinent commercial and other relationships.

Funding

Authors should list all funding sources in the Acknowledgments section. Authors are responsible for the accuracy of their funder designation. If in doubt, please check the Open Funder Registry for the correct nomenclature: https://www.crossref.org/services/funder-registry/

Authorship

All listed authors should have contributed to the manuscript substantially and have agreed to the final submitted version. Authorship is defined by the criteria set out in the APA Publication Manual:

"Individuals should only take authorship credit for work they have actually performed or to which they have substantially contributed (APA Ethics Code Standard 8.12a, Publication Credit). Authorship encompasses, therefore, not only those who do the actual writing but also those who have made substantial scientific contributions to a study. Substantial professional contributions may include formulating the problem or hypothesis, structuring the experimental design, organizing and conducting the statistical analysis, interpreting the results, or writing a major portion of the paper. Those who so contribute are listed in the byline." (p.18)

Data Sharing and Data Accessibility Policy

The *Journal of Neuropsychology* recognizes the many benefits of archiving data for scientific progress. Archived data provides an indispensable resource for the scientific community, making possible future replications and secondary analyses, in addition to the importance of verifying the dependability of published research findings.

The journal expects that where possible all data supporting the results in papers published are archived in an appropriate public archive offering open access and guaranteed preservation. The archived data must allow each result in the published paper to be recreated and the analyses reported in the paper to be replicated in full to support the conclusions made. Authors are welcome to archive more than this, but not less.

All papers need to be supported by a data archiving statement and the data set must be cited in the Methods section. The paper must include a link to the repository in order that the statement can be published.

It is not necessary to make data publicly available at the point of submission, but an active link must be included in the final accepted manuscript. For authors who have pre-registered studies, please use the Registered Report link in the Author Guidelines.

In some cases, despite the authors' best efforts, some or all data or materials cannot be shared for legal or ethical reasons, including issues of author consent, third party rights, institutional or national regulations or laws, or the nature of data gathered. In such cases, authors must inform the editors at the time of submission. It is understood that in some cases access will be provided under restrictions to protect confidential or proprietary information. Editors may grant exceptions to data access

requirements provided authors explain the restrictions on the data set and how they preclude public access, and, if possible, describe the steps others should follow to gain access to the data.

If the authors cannot or do not intend to make the data publicly available, a statement to this effect, along with the reasons that the data is not shared, must be included in the manuscript.

Finally, if submitting authors have any questions about the data sharing policy, please access the FAQs for additional detail.

Open Research Initiatives.

Recognizing the importance of research transparency and data sharing to cumulative research, *Journal of Neuropsychology* encourages the following Open Research practices.

Sharing of data, materials, research instruments and their accessibility. Journal of Neuropsychology encourages authors to share the data, materials, research instruments, and other artifacts supporting the results in their study by archiving them in an appropriate public repository. Qualifying public, open-access repositories are committed to preserving data, materials, and/or registered analysis plans and keeping them publicly accessible via the web into perpetuity. Examples include the Open Science Framework (OSF) and the various Dataverse networks. Hundreds of other qualifying data/materials repositories are listed at the Registry of Research Data Repositories (http://www.re3data.org). Personal websites and most departmental websites do not qualify as repositories.

Open Research Badges. In partnership with the non-profit Center for Open Science (COS), *Journal of Neuropsychology* offers all submitting authors access to the following three Open Research Badges—Open Materials, Open Data, and Preregistered Research Designs. We also award all qualifying authors Open Research Badges recognizing their contributions to the Open Research movement. The Open Research practices and associated award badges, as implemented by the Center for Open Science and supported by *Journal of Neuropsychology*, are the following:

The Open Materials Badge recognizes researchers who share their research instruments and materials in a publicly-accessible format, providing sufficient information for researchers to reproduce procedures and analyses of published research studies. A list of certified data repositories can be accessed at re3data.org or fairsharing.org. Guidelines about the use of data repositories can found at websites such as The Wellcome Trust (https://wellcomeopenresearch.org/for-authors/data-guidelines) and the Center for Open Science (https://cos.io/).

The Open Data Badge recognizes researchers who make their data publicly available, providing sufficient description of the data to allow researchers to reproduce research findings of published research studies. An example of a qualifying public, open-access database for data sharing is the Open Science Framework repository. Numerous other data-sharing repositories are available through various Dataverse networks (e.g., http://dataverse.org) and hundreds of other databases available through the Registry of Research Data Repositories (http://www.re3data.org). There are, of course, circumstances in which it is not possible or advisable to share data publicly. For example, there are cases in which sharing participant data could violate confidentiality. In these cases, the authors may provide an explanation of such circumstances in the Alternative Note section of the disclosure form. The information the authors provide will be included in the article's Open Research note.

The Preregistered Badge recognizes researchers who preregister their research plans (research design and data analysis plan) prior to engaging in research and who closely follow the preregistered design and data analysis plan in reporting their research findings. The criteria for earning this badge thus include a date-stamped registration of a study plan in such venues as the Open Science Framework (https://osf.io) or Clinical Trials (https://clinicaltrials.gov) and a close correspondence between the preregistered and the implemented data collection and analysis plans.

Authors will have an opportunity at the time of manuscript submission to inform themselves of this initiative and to determine whether they wish to participate. Applying and qualifying for Open Research Badges is not a requirement for publishing with *Journal of Neuropsychology*, but these badges are further incentive for authors to participate in the Open Research movement and thus to increase the visibility and transparency of their research. If you are interested in applying, please note that you will be asked to complete the Disclosure Form when submitting a revised manuscript.

More information about the Open Research Badges is available from the Open Science Framework wiki.

Publication Ethics

Authors are reminded that the *Journal of Neuropsychology* adheres to the ethics of scientific publication as detailed in the *Ethical principles of psychologists and code of conduct* (American Psychological Association, 2010). The Journal generally conforms to the Uniform Requirements for Manuscripts of the International Committee of Medical Journal Editors (ICJME) and is also a member and subscribes to the principles of the Committee on Publication Ethics (COPE). Authors must ensure that all research meets these ethical guidelines and affirm that the research has received permission from a stated Research Ethics Committee (REC) or Institutional Review Board (IRB), including adherence to the legal requirements of the study county.

Note this journal uses iThenticate's CrossCheck software to detect instances of overlapping and similar text in submitted manuscripts. Read Wiley's Top 10 Publishing Ethics Tips for Authors here. Wiley's Publication Ethics Guidelines can be found here.

ORCID

As part of the journal's commitment to supporting authors at every step of the publishing process, the journal requires the submitting author (only) to provide an ORCID iD when submitting a manuscript. This takes around 2 minutes to complete. Find more information here.

6. AUTHOR LICENSING

WALS + standard CTA/ELA and/or Open Access for hybrid titles

You may choose to publish under the terms of the journal's standard copyright agreement, or Open Access under the terms of a Creative Commons License.
Standard re-use and licensing rights vary by journal. Note that certain funders mandate a particular type of CC license be used. This journal uses the CC-BY/CC-BY-NC/CC-BY-NC-ND Creative Commons License.

Self-Archiving Definitions and Policies: Note that the journal's standard copyright agreement allows for self-archiving of different versions of the article under specific conditions.

BPS members and open access: if the corresponding author of an accepted article is a Graduate or Chartered member of the BPS, the Society will cover will cover 100% of the APC allowing the article to be published as open access and freely available.

7. PUBLICATION PROCESS AFTER ACCEPTANCE

Accepted Article Received in Production

When an accepted article is received by Wiley's production team, the corresponding author will receive an email asking them to login or register with Wiley Author Services. The author will be asked to sign a publication license at this point.

Proofs

Once the paper is typeset, the author will receive an email notification with full instructions on how to provide proof corrections.

Please note that the author is responsible for all statements made in their work, including changes made during the editorial process – authors should check proofs carefully. Note that proofs should be returned within 48 hours from receipt of first proof.

Early View

The journal offers rapid publication via Wiley's Early View service. Early View (Online Version of Record) articles are published on Wiley Online Library before inclusion in an issue. Before we can publish an

article, we require a signed license (authors should login or register with Wiley Author Services). Once the article is published on Early View, no further changes to the article are possible. The Early View article is fully citable and carries an online publication date and DOI for citations.

8. POST PUBLICATION

Access and Sharing

When the article is published online:

- The author receives an email alert (if requested).
- The link to the published article can be shared through social media.
- The author will have free access to the paper (after accepting the Terms & Conditions of use, they can view the article).
- For non-open access articles, the corresponding author and co-authors can nominate up to ten colleagues to receivea publication alert and free online access to the article.

Promoting the Article

To find out how to best promote an article, click here.

Wiley Editing Services offers professional video, design, and writing services to create shareable video abstracts, infographics, conference posters, lay summaries, and research news stories for your research – so you can help your research get the attention it deserves.

Measuring the Impact of an Article

Wiley also helps authors measure the impact of their research through specialist partnerships with Kudos and Altmetric.

9. EDITORIAL OFFICE CONTACT DETAILS

For help with submissions, please contact: Hannah Wakley, Associate Managing Editor (jnp@wiley.com) or phone +44 (0) 116 252 9504.

Author Guidelines updated 14th October 2019

Appendix G. Demographic Information Sheet

Demographic Information Sheet

Age:

_____

Gender:

- ☐ Male
- ☐ Female
- ☐ Non-binary
- ☐ Prefer not to say

Injury/diagnosis:

_____

Length of time post injury/diagnosis/onset of symptoms (in months):

_____

Appendix H. Ethical Approval Confirmation

UNIVERSITY OF HULL

University of Hull
Hull, HU6 7RX
United Kingdom
T: +44 (0)1482 463336 | E: e.walker@hull.ac.uk
w: www.hull.ac.uk

PRIVATE AND CONFIDENTIAL
Rebecca Di Somma
Faculty of Health Sciences
University of Hull
Via email

5th July 2021

Dear Rebecca

REF FHS351 - The Brain Injury Fatigue Scale: Self versus other/relative ratings of fatigue

Thank you for submitting your ethics application to the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee

UNIVERSITY OF HULL

Liz Walker | Professor of Health and Social Work Research | Faculty of Health Sciences
University of Hull
Hull, HU6 7RX, UK
www.hull.ac.uk
e.walker@hull.ac.uk | 01482 463336
@UniOfHull /UniversityOfHull universityofhull

UNIVERSITY OF HULL

Dr David Richards, FEI
Pro-Vice-Chancellor (Research & Enterprise)
University of Hull
Hull, HU6 7RX
United Kingdom
T: +44 (0)1482 466732 | E: David.Richards@hull.ac.uk
W: www.hull.ac.uk

15 October 2021

Rebecca Di Somma
University of Hull

Dear Rebecca,

Project Title: "The Brain Injury Fatigue Scale: Self versus other/relative ratings of fatigue"
RS155

I am writing to confirm that the University of Hull has agreed to act as sponsor, subject to approval being granted in accordance with the Department of Health Research Governance Framework for the project: "The Brain Injury Fatigue Scale: Self versus other/relative ratings of fatigue" .

Yours sincerely,

Dr David Richards, FEI
Pro-Vice-Chancellor (Research & Enterprise)
(Chair of University Research Committee)

cc Dean
Research Governance

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Miss Rebecca Di Somma
Doctorate in Clinical Psychology
Aire building, University of Hull
Cottingham Road, Hull
HU6 7RX

Email: approvals@hra.nhs.uk

10 December 2021

Dear Miss Di Somma

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The Brain Injury Fatigue Scale: Self versus other/relative ratings of fatigue**
IRAS project ID:	**302834**
REC reference:	**21/SW/0171**
Sponsor	**University of Hull**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **302834**. Please quote this on all correspondence.

Yours sincerely,
Gemma Oakes

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Miss Katie Skilton*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only) [University Public Liability Insurance Form]	1.0	23 September 2021
IRAS Application Form [IRAS_Form_26102021]		26 October 2021
Letter from sponsor [Sponsor Insurance Certificate]		15 October 2021
Letter from sponsor [Sponsor letter]		15 October 2021
Organisation Information Document [OID]	1.3	28 October 2021
Other [Ethical Review Amendments Form]	1.0	23 November 2021
Participant consent form [Patient Consent Form]	1.4	14 November 2021
Participant consent form [Relative Consent Form]	1.4	14 November 2021
Participant information sheet (PIS) [Patient Information Sheet]	1.6	14 November 2021
Participant information sheet (PIS) [Relative Information Sheet]	1.6	14 November 2021
Research protocol or project proposal [Research protocol]	1.4	15 November 2021
Schedule of Events or SoECAT [SOE]	1.3	28 October 2021
Summary CV for Chief Investigator (CI) [CI CV]		23 July 2021
Summary CV for supervisor (student research) [supervisor CV]		19 May 2020
Summary CV for supervisor (student research) [Secondary supervisor CV]		27 October 2021
Validated questionnaire [BIFS-P]		
Validated questionnaire [BIFS-R]		
Validated questionnaire [HADS]		
Validated questionnaire [PCRS-P]		
Validated questionnaire [PCRS-R]		

IRAS project ID	302834

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
This is a non-commercial sponsored study being undertaken in multiple NHS organisations. NHS organisations are to undertake the same research activities	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	As per the Organisation Information Document, there is no funding provided to participating NHS organisations	A Principal Investigator is expected to be in place at the participating NHS site	Where research activities at sites will be undertaken by local staff, it is unlikely that additional arrangements (letters of access or honorary research contracts) will be applicable, except where individuals employed by another Trust or University (e.g. local network staff) are involved, and arrangements are not already in place. For research team members administering questionnaires or surveys only, a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
• The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio. • Please note that the remit of HRA Approval is limited to the NHS involvement in the study. Research activity undertaken at non-NHS sites is therefore not covered and the research team should make appropriate alternative arrangements with relevant management at these organisations to conduct the research there. • The applicant has confirmed sponsor insurance arrangements are in place to cover the design of the study (A76-1 of IRAS is incorrect, but has not been updated to reflect the correct position).

Appendix I. The Brain Injury Fatigue Scale Patient's Questionnaire

BRAIN INJURY FATIGUE SCALE

D A Quinn

PATIENT'S QUESTIONNAIRE

Name: .....
Date: .....

This questionnaire looks at some problems with tiredness and energy after an Acquired Brain Injury. Please read the statements below and indicate your response by ticking the nearest you have experienced over the last month.

1 I have problems with tiredness not associated with being sleepy

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

2 After physical activity I suffer from a loss of energy

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

3 After mental activity, I get tired

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

4 After being out socially, I feel exhausted

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

5 I am unnaturally fatigued the day after activity

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

6 I have much less "get up and go" than I did before my accident/illness

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

7 I now find I tire much more quickly after routine activities (eg: housework, washing hair, shopping etc)

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

8 I find I drop off to sleep during the day, much more than I ever did before

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

9 Over a longer period (ie a month) I sometimes have days when I'm so exhausted I can hardly get out of bed

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

10 When I'm tired, I get much more irritable

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

---

11 When I'm tired, I make more mistakes

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

---

12 I get particularly tired when I have to do anything new

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

---

13 I feel tired even when I don't feel upset or depressed

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

---

14 I find I tire quickly even when doing the things I enjoy the most

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

---

15 When I'm in a group of people, or things are busy, I tire very quickly

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

---

16 I feel much better after a rest

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

---

17 I feel like I never really fully recharge my batteries

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

---

18 Even when I have regular meals and a good night's sleep, I still have problems with fatigue

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

---

19 My tiredness directly affects my ability to do a/my job

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

---

20 My tiredness directly reduces my ability to live my life as I did prior to my illness/accident

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

Appendix J. The Brain Injury Fatigue Scale Carer's Questionnaire

BRAIN INJURY FATIGUE SCALE

D A Quinn

CARER'S QUESTIONNAIRE

Patient's name……
Date:……
Completed by: ……

This questionnaire looks at some problems with tiredness and energy after an Acquired Brain Injury. Please read the statements below and indicate the reply that most accurately reflects the patient over the last month.

1 He/she has problems with tiredness not associated with being sleepy

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

2 After physical activity he/she suffers from a loss of energy

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

3 After mental activity, he/she gets tired

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

4 After being out socially, he/she feels exhausted

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

5 He/she is unnaturally fatigued the day after activity

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

6 He/she has much less "get up and go" than before the accident/illness

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

7 He/she now tires much more quickly after routine activities (eg: housework, washing hair, shopping etc)

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

8 He/she drops off to sleep during the day, much more than before

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

---

9 Over a longer period (ie a month) he/she sometimes has days when he/she is so exhausted that he/she can hardly get out of bed

O	O	O	O	O
Never	Infrequently	Occasionally	Quite often	Very frequently
1	2	3	4	5

10 When tired, he/she gets much more irritable

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

11 When tired, he/she makes more mistakes

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

12 He/she gets particularly tired when he/she has to do anything new

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

13 He/she feels tired even when not feeling upset or depressed

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

14 He/she tires quickly even when doing the things he/she enjoys the most

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

15 When in a group of people, or things are busy, he/she tires very quickly

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

16 He/she feels much better after a rest

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

17 He/she never really seems to recharge his/her batteries

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

18 Even when he/she has regular meals and a good night's sleep, he/she still has problems with fatigue

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

19 His/her tiredness directly affects his/her ability to do his/her job

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

20 His/her tiredness directly reduces his/her ability to live life as he/she did prior to the illness/accident

Never	Infrequently	Occasionally	Quite often	Very frequently
O	O	O	O	O
1	2	3	4	5

Appendix K. The Patient Competency Rating Scale Patient's Form

Patient Competency Rating
(Patient's Form)

Source: Prigatano, G. P. and Others (1986). Neuropsychological Rehabilitation After Brain Injury. Baltimore: Johns Hopkins University Press.

Identifying Information

Patient's Name: _____

Date: _____

Instructions

The following is a questionnaire that asks you to judge your ability to do a variety of very practical skills. Some of the questions may not apply directly to things you often do, but you are asked to complete each question as if it were something you "had to do." On each question, you should judge how easy or difficult a particular activity is for you and mark the appropriate space.

Competency Rating

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

_____ 1. How much of a problem do I have in preparing my own meals?

_____ 2. How much of a problem do I have in dressing myself?

_____ 3. How much of a problem do I have in taking care of my personal hygiene?

_____ 4. How much of a problem do I have in washing the dishes?

_____ 5. How much of a problem do I have in doing the laundry?

_____ 6. How much of a problem do I have in taking care of my finances?

_____ 7. How much of a problem do I have in keeping appointments on time?

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

_____ 8. How much of a problem do I have in starting conversation in a group?

_____ 9. How much of a problem do I have in staying involved in work activities even when bored or tired?

_____ 10. How much of a problem do I have in remembering what I had for dinner last night?

_____ 11. How much of a problem do I have in remembering names of people I see often?

_____ 12. How much of a problem do I have in remembering my daily schedule?

_____ 13. How much of a problem do I have in remembering important things I must do?

_____ 14. How much of a problem would I have driving a car if I had to?

_____ 15. How much of a problem do I have in getting help when I'm confused?

_____ 16. How much of a problem do I have in adjusting to unexpected changes?

_____ 17. How much of a problem do I have in handling arguments with people I know well?

_____ 18. How much of a problem do I have in accepting criticism from other people?

_____ 19. How much of a problem do I have in controlling crying?

_____ 20. How much of a problem do I have in acting appropriately when I'm around friends?

_____ 21. How much of a problem do I have in showing affection to people?

_____ 22. How much of a problem do I have in participating in group activities?

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

_____ 23. How much of a problem do I have in recognizing when something I say or do has upset someone else?

_____ 24. How much of a problem do I have in scheduling daily activities?

_____ 25. How much of a problem do I have in understanding new instructions?

_____ 26. How much of a problem do I have in consistently meeting my daily responsibilities?

_____ 27. How much of a problem do I have in controlling my temper when something upsets me?

_____ 28. How much of a problem do I have in keeping from being depressed?

_____ 29. How much of a problem do I have in keeping my emotions from affecting my ability to go about the day's activities?

_____ 30. How much of a problem do I have in controlling my laughter?

Appendix L. The Patient Competency Rating Scale Relative's Form

Patient Competency Rating (Relative's Form)

Source: Prigatano, G. P. and Others (1986). Neuropsychological Rehabilitation After Brain Injury. Baltimore: Johns Hopkins University Press.

Identifying Information

Patient's Name: _____

Date: _____

Informant's relationship to patient (circle one):

1. Mother
2. Father
3. Spouse
4. Child
5. Sibling
6. Grandparent
7. Aunt or uncle
8. Niece or nephew
9. Cousin
10. Friend
11. In-law
12. Ward attendant
13. Other _____

Sex of informant:

Male _____
Female _____

How well is informant acquainted with patient's behavior?

1. Hardly at all
2. Not so well
3. Fairly well
4. Pretty well
5. Very well

Instructions

The following is a questionnaire that asks you to judge this person's ability to do a variety of very practical skills. Some of the questions may not apply directly to things they often do, but you are asked to complete each question as if it were something they "had to do." On each question, you should judge how easy or difficult a particular activity is for them and mark the appropriate space.

Competency Rating

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

_____ 1. How much of a problem do they have in preparing their own meals?

_____ 2. How much of a problem do they have in dressing themselves?

_____ 3. How much of a problem do they have in taking care of their personal hygiene?

_____ 4. How much of a problem do they have in washing the dishes?

_____ 5. How much of a problem do they have in doing the laundry?

_____ 6. How much of a problem do they have in taking care of their finances?

_____ 7. How much of a problem do they have in keeping appointments on time?

_____ 8. How much of a problem do they have in starting conversation in a group?

_____ 9. How much of a problem do they have in staying involved in work activities even when bored or tired?

_____ 10. How much of a problem do they have in remembering what they had for dinner last night?

_____ 11. How much of a problem do they have in remembering names of people they see often?

_____ 12. How much of a problem do they have in remembering their daily schedule?

_____ 13. How much of a problem do they have in remembering important things they must do?

_____ 14. How much of a problem would they have driving a car if they had to?

_____ 15. How much of a problem do they have in getting help when they are confused?

_____ 16. How much of a problem do they have in adjusting to unexpected changes?

1	2	3	4	5
Can't do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

_____ 17. How much of a problem do they have in handling arguments with people they know well?

_____ 18. How much of a problem do they have in accepting criticism from other people?

_____ 19. How much of a problem do they have in controlling crying?

_____ 20. How much of a problem do they have in acting appropriately when they are around friends?

_____ 21. How much of a problem do they have in showing affection to people?

_____ 22. How much of a problem do they have in participating in group activities?

_____ 23. How much of a problem do they have in recognizing when something they say or do has upset someone else?

_____ 24. How much of a problem do they have in scheduling daily activities?

_____ 25. How much of a problem do they have in understanding new instructions?

_____ 26. How much of a problem do they have in consistently meeting their daily responsibilities?

_____ 27. How much of a problem do they have in controlling their temper when something upsets them?

_____ 28. How much of a problem do they have in keeping from being depressed?

_____ 29. How much of a problem do they have in keeping their emotions from affecting their ability to go about the day's activities?

_____ 30. How much of a problem do they have in controlling their laughter?

Appendix M. Hospital Anxiety and Depression Scale

Hospital Anxiety and Depression Score (HADS)

This questionnaire helps your physician to know how you are feeling. Read every sentence. Place an "X" next to the answer that best describes how you have been feeling during the LAST WEEK. You do not have to think too much to answer. In this questionnaire, spontaneous answers are more important

A	**I feel tense or 'wound up':**	
	Most of the time	3
	A lot of the time	2
	From time to time (occ.)	1
	Not at all	0
D	**I still enjoy the things I used to enjoy:**	
	Definitely as much	0
	Not quite as much	1
	Only a little	2
	Hardly at all	3
A	**I get a sort of frightened feeling as if something awful is about to happen:**	
	Very definitely and quite badly	3
	Yes, but not too badly	2
	A little, but it doesn't worry me	1
	Not at all	0
D	**I can laugh and see the funny side of things:**	
	As much as I always could	0
	Not quite so much now	1
	Definitely not so much now	2
	Not at all	3
A	**Worrying thoughts go through my mind:**	
	A great deal of the time	3
	A lot of the time	2
	From time to time, but not often	1
	Only occasionally	0
D	**I feel cheerful:**	
	Not at all	3
	Not often	2
	Sometimes	1
	Most of the time	0
A	**I can sit at ease and feel relaxed:**	
	Definitely	0
	Usually	1
	Not often	2
	Not at all	3

D	**I feel as if I am slowed down:**	
	Nearly all the time	3
	Very often	2
	Sometimes	1
	Not at all	0
A	**I get a sort of frightened feeling like "butterflies" in the stomach:**	
	Not at all	0
	Occasionally	1
	Quite often	2
	Very often	3
D	**I have lost interest in my appearance:**	
	Definitely	3
	I don't take as much care as I should	2
	I may not take quite as much care	1
	I take just as much care	0
A	**I feel restless as I have to be on the move:**	
	Very much indeed	3
	Quite a lot	2
	Not very much	1
	Not at all	0
D	**I look forward with enjoyment to things:**	
	As much as I ever did	0
	Rather less than I used to	1
	Definitely less than I used to	2
	Hardly at all	3
A	**I get sudden feelings of panic:**	
	Very often indeed	3
	Quite often	2
	Not very often	1
	Not at all	0
D	**I can enjoy a good book or radio/TV program:**	
	Often	0
	Sometimes	1
	Not often	2
	Very seldom	3

Appendix N. Patient Information Sheet

UNIVERSITY OF HULL

V 1.6 14/11/21

IRAS ID: 302834

INFORMATION SHEET FOR PARTICIPANTS

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study: The Brain Injury Fatigue Scale: Self versus other/relative ratings of fatigue

I would like to invite you to participate in a research project which forms part of my thesis for the Doctorate in Clinical Psychology course at the University of Hull. The sponsor for this research is the University of Hull. The (York Psychological Medicine Service/Lincolnshire Neuropsychology Service/ Leeds St James University Hospital Neuropsychology Service) will be collaborating with the University of Hull to deliver this study.

We would like to invite you to participate in this research. We are looking for two groups of people for this study:

1. People who have a brain injury or neurological condition
2. Family members or carers of people who have an acquired brain injury or neurological condition

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information by sending an email to r.di-somma-2019@hull.ac.uk.

What is the purpose of the study?

After an acquired brain injury (ABI) or neurological condition, people can experience high levels of fatigue which can interfere with their day-to-day activities. The Brain Injury Fatigue Scale (BIFS) is used by clinicians to assess fatigue in individuals with an ABI and neurological condition. However, there can sometimes be differences in how a patient and their relatives perceive symptoms or difficulties experienced, which can be due to several factors, therefore comparisons of self and other/relative (I, e, family members and carers) reports are useful. The aim of this study is to gather self and other/relative BIFS ratings alongside other measures (such as the Patient Competency Rating Scale and the Hospital Anxiety and Depression Scale) to help us better understand what variables best explain any differences in ratings of fatigue. This will help clinicians plan interventions and improve the quality of life of people with an ABI and neurological condition.

Why have I been invited to take part?

You are being invited to participate in this study because your clinician has identified that you have experienced an ABI or neurological condition and you may or may not be experiencing fatigue.

What will happen if I take part?

If you choose to take part in the study, you will be asked to complete the following questionnaires.

- The Brain Injury Fatigue Scale
- The Patient Competency Rating Scale
- The Hospital Anxiety and Depression Scale

This could be conducted either with your clinician or over the phone or via an online platform (such as Zoom or Microsoft Teams) with the researcher and should take between 15-30 minutes to complete.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part, we will ask you to sign a consent form and you will be given a copy of this consent form to keep. Alternatively, you can contact the researcher to ask any questions that will help you make a decision about taking part and if you decide to take part the researcher will send you a consent form to sign and send back and you will be given a copy of this consent form to keep.

What are the possible risks of taking part?

Participating in the study will require you to comment on your level of fatigue, level of insight and current mood using the questionnaires. There are no identified risks with taking part, however when completing the measures people can sometimes feel a little anxious or upset, if this occurs we will provide contact details for organisations that may be able to help.

What are the possible benefits of taking part?

Taking part in the study will not have a direct benefit to your healthcare, however the information from the questionnaires will be available to your clinician who can choose to use this information as part of your assessment and any treatment they consider appropriate. The information you give us will help us to understand more about the Brain Injury Fatigue Scale and what variables relate to any difference between the self and other/relative ratings of this scale. Ultimately, the data collected from the study will help us to develop the fatigue rating scale so that it can be more widely used to inform patient care in the future.

How will we use information about you?

In this research study we will use information from yourself, your medical records, and your clinician. This information will include your name, contact details, demographic information, information about your brain injury and your questionnaire data. People will use this information to do the research or to check your records to make sure that the research is

being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. This information will also be shared with your clinician to contribute to your clinical records.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. Your data will be processed in accordance with the UK-GDPR and the Data Protection Act 2018. The anonymised data may also be used to support future research and may be shared anonymously with other researchers. This data will be kept for 10 years on secure network drives at the University of Hull.

What are your choices about how your information is used?

You are free to withdraw from the study at any time without having to give a reason. Withdrawing from the study will not affect you in any way. After you have completed the questionnaires, you are able to withdraw your data from the study up to 72 hours after the completion of testing by contacting the researcher, after which withdrawal of your data will no longer be possible as the data will have been anonymised and committed to the final report. If you choose to withdraw from the study we will not retain the information you have given thus far and it will be destroyed.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- At www.hra.nhs.uk/information-about-patients/ and https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/
- By asking one of the research team using the contact details below
- By contacting the University of Hull Data Protection Officer by emailing dataprotection@hull.ac.uk or by calling 01482 466594 or by writing to the Data Protection Officer at University of Hull, Cottingham Road, Hull, HU6 7RX
- By reviewing the University of Hull Research Participant privacy notice: https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/docs/quality/research-participant-privacy-notice.pdf

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest'.

If you are not happy with the sponsor's response or believe the sponsor processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

What will happen to the results of the study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's online repository https://hydra.hull.ac.uk. The research may also be published in academic journals or presented at conferences. If you want to hear about the results of the study then do contact the researcher, Rebecca Di Somma, who will be happy to provide you with a written summary of the research.

Who has reviewed this study?

Research studies are reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and been given a favourable opinion by the Central Bristol Research Ethics Committee.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact the researcher using the following contact details. Due to Covid-19 restrictions access to the university campus or postal system is very limited, consequently if you send anything via the post there will be a delay in responding to you, please use email for all correspondence.

Rebecca Di Somma
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 07976 071078
E-mail: r.di-somma-2019@hull.ac.uk

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the research supervisor's details below for further advice and information, due to COVID-19 restriction contact via email is preferred:

Dr Pete Fleming
Clinical Psychology
Aire Building

The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: +44 (0) 1482 463254
Email address: p.fleming@hull.ac.uk

Alternatively, please contact coo@hull.ac.uk

You may also wish to contact the Patient Advice and Liaison Service using the following contact details:

(For the York Psychological Medicine Service):
Patient Advice and Liaison Service
Tel: 01904 726262
Email: pals@york.nhs.uk

(For the Lincolnshire Neuropsychology Service):
Patient Advice and Liaison Service
Lincolnshire Partnership NHS Foundation Trust
Unit 9, The Point
Lions Way
Sleaford
Lincs
NG34 8GG
Tel: 01529 222265
Email: **lpft.PALS@nhs.net**

(*For the Leeds St James University Hospital Neuropsychology Service)*
Patient Advice and Liaison Service
Tel: 0113 2066261
Email: patientexperience.leedsth@nhs.net

Thank you for reading this information sheet and for considering taking part in this research.

Appendix O. Patient Consent Form

V 1.4 14/11/21

IRAS ID: 302834

UNIVERSITY OF HULL

PATIENT CONSENT FORM

Title of study: The Brain Injury Fatigue Scale: Self versus other/relative ratings of fatigue

Name of Researcher: Rebecca Di Somma

A signed copy of the consent form will be provided to the participant and the researcher

Please initial box

1. I confirm that I have read the information sheet dated 14th November 2021 (version 1.6) 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 without giving any reason, without my medical care being affected. I understand that once I have returned my questionnaires; I can withdraw my data from the study up to 72 hours after the completion of testing by contacting the researcher, after which withdrawal of your data will no longer be possible ☐
3. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐
4. I understand that the information held and maintained by York Psychological Medicine Service/Lincolnshire Neuropsychology Service/ Leeds St James University Hospital Neuropsychology Service ☐
5. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by the regulatory authorities or from the NHS Trust/service, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
6. I give permission for the collection and use of my data to answer the research question in this study. ☐
7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix P. Proxy Information Sheet

UNIVERSITY OF HULL

V 1.6 14/11/21

IRAS ID: 302834

INFORMATION SHEET FOR RELATIVES/OTHERS

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study: The Brain Injury Fatigue Scale: Self versus other/relative ratings of fatigue

I would like to invite you to participate in a research project which forms part of my thesis for the Doctorate in Clinical Psychology course at the University of Hull. The sponsor for this research is the University of Hull. The (York Psychological Medicine Service/Lincolnshire Neuropsychology Service/ Leeds St James University Hospital Neuropsychology Service) will be collaborating with the University of Hull to deliver this study.

We would like to invite you to participate in this research. We are looking for two groups of people for this study:

1. People who have a brain injury or neurological condition
2. Family members or carers of people who have an acquired brain injury or neurological condition

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information by sending an email to r.di-somma-2019@hull.ac.uk.

What is the purpose of the study?

After an acquired brain injury (ABI) or neurological condition, people can experience high levels of fatigue which can interfere with their day-to-day activities. The Brain Injury Fatigue Scale (BIFS) is used by clinicians to assess fatigue in individuals with an ABI and neurological condition. However, there can sometimes be differences in how a patient and their relatives perceive symptoms or difficulties experienced, which can be due to several factors, therefore comparisons of self and other/relative (I, e, family members and carers) reports are useful. The aim of this study is to gather self and other/relative BIFS ratings alongside other measures (such as the Patient Competency Rating Scale and the Hospital Anxiety and Depression Scale) to help us better understand what variables best explain any differences in ratings of fatigue. This will help clinicians plan interventions and improve the quality of life of people with an ABI and neurological condition.

Why have I been invited to take part?

You are being invited to participate in this study because you have been identified as the main relative/carer of an individual who has experienced an ABI or neurological condition who may or may not be experiencing fatigue.

What will happen if I take part?

If you choose to take part in the study, you will be asked to complete the following questionnaires.

- The Brain Injury Fatigue Scale
- The Patient Competency Rating Scale

This could be conducted either with the clinician or over the phone, via email or on an online platform (such as Zoom or Microsoft Teams) with the researcher and should take between 10-20 minutes to complete.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you or the individual whom you are a proxy to in any way. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part, we will ask you to sign a consent form and you will be given a copy of this consent form to keep. Alternatively, you can contact the researcher to ask any questions that will help you make a decision about taking part and if you decide to take part the researcher will send you a consent form to sign and send back and you will be given a copy of this consent form to keep.

What are the possible risks of taking part?

Participating in the study will require you to comment on the individual whom you are a proxy to level of fatigue, level of insight and current mood using the questionnaires. There are no identified risks with taking part, however when completing the measures people can sometimes feel a little anxious or upset, if this occurs we will provide contact details for organisations that may be able to help.

What are the possible benefits of taking part?

Taking part in the study will not have a direct benefit to yourself, however the information you give us will help us to understand more about the Brain Injury Fatigue Scale and what variables relate to any difference between the self and other/relative ratings of this scale. Ultimately, the data collected from the study will help us to develop the fatigue rating scale so that it can be more widely used to inform patient care in the future.

How will we use information about you?

In this research study we will use information from yourself and the questionnaires you complete. This information will include your name, contact details and your questionnaire data. People will use this information to do the research. People who do not need to know

who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. Your data will be processed in accordance with the UK-GDPR and the Data Protection Act 2018. The anonymised data may also be used to support future research and may be shared anonymously with other researchers. This data will be kept for 10 years on secure network drives at the University of Hull.

What are your choices about how your information is used?

You are free to withdraw from the study at any time without having to give a reason. Withdrawing from the study will not affect you in any way. After you have completed the questionnaires, you are able to withdraw your data from the study up to 72 hours after the completion of testing by contacting the researcher, after which withdrawal of your data will no longer be possible as the data will have been anonymised and committed to the final report. If you choose to withdraw from the study we will not retain the information you have given thus far and it will be destroyed.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- At www.hra.nhs.uk/information-about-patients/ and https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/
- By asking one of the research team using the contact details below
- By contacting the University of Hull Data Protection Officer by emailing dataprotection@hull.ac.uk or by calling 01482 466594 or by writing to the Data Protection Officer at University of Hull, Cottingham Road, Hull, HU6 7RX
- By reviewing the University of Hull Research Participant privacy notice: https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/docs/quality/research-participant-privacy-notice.pdf

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest'.

If you are not happy with the sponsor's response or believe the sponsor processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

What will happen to the results of the study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository https://hydra.hull.ac.uk. The research may also be published in academic journals or presented at conferences. If you want to hear about the results of the study then do contact the researcher, Rebecca Di Somma, who will be happy to provide you with a written summary of the research.

Who has reviewed this study?

Research studies are reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and been given a favourable opinion by the Central Bristol Research Ethics Committee.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact the researcher using the following contact details. Due to Covid-19 restrictions access to the university campus or postal system is very limited, consequently if you send anything via the post there will be a delay in responding to you, please use email for all correspondence.

Rebecca Di Somma
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 07976 071078
E-mail: r.di-somma-2019@hull.ac.uk

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the research supervisor's details below for further advice and information, due to COVID-19 restriction contact via email is preferred:

Dr Pete Fleming
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: +44 (0) 1482 463254
Email address: p.fleming@hull.ac.uk

Alternatively, please contact coo@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Appendix Q. Proxy Consent Form

V 1.4 14/11/21

IRAS ID: 302834

UNIVERSITY OF HULL

RELATIVE/OTHER CONSENT FORM

Title of study: The Brain Injury Fatigue Scale: Self versus other/relative ratings of fatigue

Name of Researcher: Rebecca Di Somma

A signed copy of the consent form will be provided to the participant and the researcher

Please initial box

1. I confirm that I have read the information sheet dated 14th November 2021 (version 1.6) 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 without giving any reason. Withdrawing from the study will not affect you in any way. I understand that once I have returned my questionnaires; I can withdraw my data from the study up to 72 hours after the completion of testing by contacting the researcher, after which withdrawal of your data will no longer be possible ☐
3. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐
4. I give permission for the collection and use of my data to answer the research question in this study. ☐
5. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature