Brown, L., Fish, J., Mograbi, D. C., Bellesi, G., Ashkan, K. and Morris, R. (2019) Awareness of deficit following traumatic brain injury: a systematic review of current methods of assessment. *Neuropsychological Rehabilitation*, (doi: [10.1080/09602011.2019.1680393](https://doi.org/10.1080/09602011.2019.1680393)).

This is the author's final accepted version.

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

<http://eprints.gla.ac.uk/203117/>

Deposited on: 10 December 2019

Enlighten – Research publications by members of the University of Glasgow
<http://eprints.gla.ac.uk>

Awareness of deficit following Traumatic Brain Injury: a systematic review of current methods of assessment

Laura Brown^a, Jessica Fish^a, Daniel C Mograbi^{a,b}, Giulia Bellesi^a, Keyoumars

Ashkan^c & Robin Morris^a

^aKing's College Institute of Psychiatry, Psychology & Neuroscience, London, UK; ^b

Department of Psychology, Pontifical Catholic University of Rio de Janeiro, Brazil, ^c

King's College Hospital, Department of Neurosurgery, London, UK

Contact Dr Laura Brown or Professor Robin Morris. Email: laura.1.brown@kcl.ac.uk

or robin.morris@kcl.ac.uk Address: Department of Psychology, Institute of

Psychiatry, Psychology & Neuroscience, PO78, 4, Denmark Hill, London, SE5 8AF,

UK.

Awareness of deficit following Traumatic Brain Injury: a systematic review of current methods of assessment

Background: Awareness of deficit plays an important role in adjustment following a brain injury and has been noted to impact on engagement with and outcome of rehabilitation. However, there are challenges associated with the assessment of awareness. Aim: To systematically review all instruments used to assess intellectual awareness of deficits following Traumatic Brain Injury (TBI) in adults, and evaluate instrument characteristics (e.g. the format and focus of measures of awareness) and assessment methods adopted. Results: Thirty-four studies, all rated as fair to good quality, were identified and within these twenty-three different assessment tools were adopted. The most common method of assessment was patient-proxy discrepancy, with three frequently used instruments employed in a total of 22 of the 34 studies. Across studies, variability was noted regarding the type of assessment method dependent on various sample demographics (e.g. age of sample) and injury characteristics (e.g. time post injury). Conclusions: There is no consensus on the preferred instrument to assess intellectual awareness of deficits after TBI. Continued instrument development should attempt to incorporate multiple perspectives and assessment should take into account demographic and injury-related factors. An insightful avenue for future research would be to determine which factors are likely to impact awareness measurement.

Keywords: Insight; awareness, traumatic brain injury; psychological assessment; systematic review

Introduction

Traumatic Brain Injury (TBI) is a complex phenomenon having dramatically varied effects. TBI can result in cognitive, physical, emotional and behavioural impairments that lead to permanent or temporary changes in functioning. Reduced awareness of a range of cognitive, emotional, psychosocial and behavioural deficits after TBI is often reported in the clinic (Machamer et al, 2013) and epidemiological data suggest this affects approximately 45% of people with TBI (Flashman & McAllister, 2002). Professionals working in rehabilitation for people with TBI generally agree that

impaired awareness of this type significantly complicates rehabilitation and community reintegration (Robertson & Schmitter-Edgecombe, 2015). In addition to rehabilitation engagement and outcome, awareness deficits have been adversely linked to caregiver distress and patient quality of life (Wise et al, 2005).

The potential impact reduced awareness can have on a patient's recovery and rehabilitation sparked an interest in developing methods of exploring awareness, so that its effects on patient outcome can be studied and efficacy of treatments aimed at improving awareness can be assessed. However, variability exists in the assessment methods chosen, the perspectives sourced and indeed how awareness is defined.

Awareness is difficult to conceptualise as it can be interpreted in different ways. Several researchers consider awareness to be a complex construct with multiple aspects (see Abreu et al. (1997) and Clare (2004) for detailed reviews). Numerous theories and clinical models exist that propose multiple psychological, neuropsychological and biopsychological underpinnings of reduced awareness (see Bach and David, 2006 and FitzGerald et al, 2012, for reviews). These models typically incorporate several 'types' of awareness. Crosson et al (1989) proposed the pyramid model, which was the first multi-dimensional model of awareness. This model conceptualised awareness by proposing three hierarchical levels: intellectual, emergent and anticipatory awareness, and this framework remains prevalent. In the field of TBI, awareness has been described as the ability to recognise deficits, understand their functional implications and establish realistic goals (Fleming et al., 1996). This description relates to intellectual awareness, also termed offline awareness and is often reported as "a basic understanding by patients that an impairment or deficit exists" (Abreu et al, 2001). Toglia and Kirk (2000) further define awareness as "the ability to anticipate the difficulties, recognise errors or monitor performance". This definition relates to both anticipatory and emergent awareness respectively.

Studies suggest strong correlations between emergent and anticipatory awareness, a general construct that has been labelled 'online awareness', but no correlations with intellectual (offline) awareness (O'Keefe et al., 2007). However, across all models, there is a general consensus that awareness can be categorised in this way. For example, unlike the pyramid model, Toglia and Kirk's (2000) more recent Dynamic Comprehensive Model of Awareness (DCMA) does not assume a hierarchical structure. However, it continues to discriminate between offline

1
2
3 awareness (metacognitive or intellectual awareness that exists prior to a task) and
4 online awareness (awareness that exists during or after a task, including error-
5 monitoring and self-regulation).
6
7

8 Toglia and Kirk (2000) further posit a link between metacognitive self-
9 awareness and self-efficacy. However, although distinctions between the two are
10 often difficult to make as both concepts are closely linked, a fine divide does remain.
11 While self-awareness refers to self-knowledge about one's capabilities, self-efficacy
12 refers to the strength of one's belief in the effectiveness of engaging these capabilities
13 to successfully execute tasks and achieve goals (Bandura, 1997). In other words the
14 two relate to discretely different aspects of potential change experienced by an
15 individual. Following TBI an individual may experience a change in their belief or
16 confidence in their ability to do a task (self-efficacy) but this is subtly different to a
17 fundamental acknowledgement that they struggle with a particular skill (intellectual
18 awareness). As a result, self-awareness and self-efficacy should be assessed and
19 reviewed separately.
20
21

22 It has further been suggested that different aspects of such awareness may
23 impact outcome uniquely. For example, reduced online awareness may impact on an
24 individual's safety by limiting a person's ability to recognise when a task action is
25 dangerous (Robertson and Schmitter-Edgecombe, 2015), which may result in them
26 requiring some level of supervision and in turn decreasing their level of
27 independence. Impaired intellectual awareness could impact on a person's appraisal
28 of task difficulty (Robertson et al., 2015), which may limit the effort and engagement
29 given to certain tasks and hinder their understanding of rehabilitation techniques and
30 commitment to treatment programmes.
31
32

33 Robertson et al. (2015) point out that the majority of studies exploring the
34 relationship between self-awareness and rehabilitation outcome have focused on
35 metacognitive or intellectual (offline) awareness (Malec and Moessner, 2000; Fischer,
36 Gauggel and Trexler, 2004). By contrast, few studies have researched the relationship
37 between TBI outcome and measures of online awareness. In addition, Winson et al.
38 (2017) report intellectual awareness to be the most commonly assessed clinically.
39 Therefore, the current paper focuses on intellectual awareness in order to offer a
40 comprehensive review of the most commonly used methods of awareness
41 measurement, with the greatest clinical utility.
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

There are three common approaches to assessing intellectual awareness (Smeets, et al., 2012; Lloyd et al., 2015). One involves comparing patients' self-ratings on questionnaires of functional abilities to informants' ratings. Informant ratings are typically provided by a friend or family member or less frequently, a clinician. A second method involves clinician-lead semi-structured interviews, following which the professional rates the awareness of the patient using their clinical judgement. The third method compares self-ratings against 'objective' task performance, such as performance on neuropsychological tests.

To date, there have been a number of investigations comparing different methods of assessing awareness and their properties. These include a preliminary review concerning acquired brain injury focusing on particular studies (Fleming et al., 1996), a systematic review of awareness following childhood TBI (Lloyd et al., 2015) and a review exploring the effectiveness of interventions targeting awareness (Schmidt et al., 2011). A recent systematic review (Smeets et al., 2012) has explored the instruments used to measure awareness in adults with acquired brain injury (ABI) more generally. Although the effects of non-traumatic ABI and TBI are often noted to have similarities, there is an argument for separating out these categories because of the more specific characteristics of TBI (Chan et al., 2017), including the suggestion that awareness of deficit may be different in TBI from other ABI conditions (Bach and David, 2006). For example, in ABI, the onset time course can be very variable across condition, for example, a slow growing tumour versus encephalitis having differing adaption responses. Additionally, conditions such as stroke are more likely to give rise to specific neuropsychological and neurological deficits, such as hemiparesis and dysphasia. These are less common in TBI and as such, ABI and TBI potentially have differing associated awareness syndromes. Hence, the current review expanded upon Smeets et al's (2012) review findings by focusing specifically on TBI samples and including both instruments for which a measure of intellectual awareness was the intended focus, as well as those which due to design allowed a measure of intellectual awareness to be obtained. The current review, therefore, is warranted to provide a comprehensive overview of the methods commonly used to assess intellectual awareness following TBI specifically.

Objective

The overall aim of this systematic review was to identify the various measures employed to assess intellectual awareness in adult patients following TBI.

Specifically, two research questions were addressed:

- (1) Which measurement instruments/methods have been used in empirical studies investigating intellectual awareness following TBI?
- (2) What are the characteristics, purposes and foci of the measurement instruments employed?

Materials and Methods

The current systematic literature review was carried out according to the PRISMA guidelines (www.prisma-statement.org).

Search sources and strategy

Articles were identified through a systematic computerised search of peer-reviewed papers using the following databases from their inception to the 14th January 2018: Ovid MEDLINE (1946 to 14.01.2018), PsycINFO (1806 to 14.01.2018), Embase (1974 to 14.01.2018) and PsycBITE (2004 to 14.01.2018). This was in line with search engines used in previous relevant reviews by Smeets et al (2012) and Lloyd et al (2015). Databases were accessed and searched by the first author (LB) between 1st December 2017 and 14th January 2018. Examinations of published reviews investigating TBI and awareness deficits were referred to when generating search terms. For Ovid MEDLINE, PsycINFO and Embase key word searching was used for the following terms: TBI, awareness and assessment.

A list of search terms considered within the scope of TBI was generated: traumatic brain injur* or traumatic head injur* or brain injuries or brain damage or intracranial injur* or neurosurgery or neurosurgical lesion* or neurotrauma or acquired brain injur* or TBI or ABI.

Terms considered within the scope of awareness were generated: *awareness or anosognosia or insight or self-awareness or self-perception or self-concept or denial.

Terms focused on methods of assessing awareness included: proxy or overestimate* or underestimate* or agreement or discrepancy or perspective. These search terms were then combined with the term ‘assessment’.

The key search terms and synonyms relating to each were combined using Boolean operators. Limiters and filters were used to apply the inclusion and exclusion criteria (detailed with eligibility criteria section).

In PsycBITE, a specialised database for brain injury research, the target areas of “insight/awareness/knowledge of condition”, age group “adults”, neurological group “TBI/head injury” and language “English” were selected.

Manual searching for additional studies was also carried out by consulting reference lists of previous reviews on the topic of awareness in TBI and screening for titles that included key terms. The full search strategy for each database can be found in Appendix A. The first author (LB) completed the article selection procedure. In case of doubt, the collaborating authors were consulted on the specific article. Any lack of agreement was discussed to reach consensus regarding article inclusion.

Definitions:

In the present review, TBI and awareness measures were conceptualised as follows:

Definition of Traumatic Brain Injury:

Using definitions provided by the briefing paper on head injury from the National Institute for Health and Care Excellence (NICE, 2014)

(<http://www.nice.org.uk/guidance/qs74/documents/head-injury-briefing-paper2>).

Traumatic Brain Injuries were those defined as resulting from external physical trauma often due to accidents, assaults or head injury. We excluded non-traumatic brain injuries derived from either internal or external sources (e.g. stroke, brain tumours, infection, poisoning, hypoxia, ischemia, encephalopathy or substance abuse). Studies including congenital disorders, neurodegenerative disorders and dementias and disorders of consciousness (DOC/PDOC) and samples with mixed cause of injury were also excluded.

Definition of awareness measures

Only methods and measures used to assess intellectual awareness, defined as a “subjective acknowledgement, observation or recognition of one’s own abilities” (Sherer et al, 1998), were included. Hence, for example, when reviewing papers adopting performance-based methods, those that focused on anticipatory awareness (e.g. predicting performance on a specific task) were excluded. Instruments for which assessing intellectual awareness is the primary aim, as well as those adapted by design

to enable a measure of intellectual awareness were included. For example, measures that included both self and proxy ratings, thus allowing a level of intellectual awareness to be identified, were considered awareness measures. Using previous reviews as a guide (Fleming et al, 1996; Smeets et al, 2012), the relevant instruments from the selected articles were divided into three formalised methods, commonly reported to assess intellectual awareness (Smeets et al, 2012; Lloyd et al, 2015). The first was a self-proxy rating discrepancy method. This involved comparing a patient's self-report of their cognitive, emotional, psychosocial and behavioural functioning to another person's rating of the patient's abilities in these areas, typically an informant's (either a significant other or clinician) on the same scale. Clinician rated was the second method. Included measures typically were clinician-led interviews following which the professional rated the awareness of the patient using their clinical judgement. The third was a performance-based discrepancy method in which the level of awareness was derived from the difference between patients' self-report about their functioning and their objective test performance. Only measures focused on intellectual awareness of neuropsychological factors common following TBI (namely cognitive, emotional and behavioural effects, as described in Azouzi et, 2017) were included. Therefore, papers focused on very specific practical tasks (e.g. driving ability) were excluded. This enabled a focus on measures that individually covered as broad a range of abilities or challenges as possible within this population. For all methods it was necessary that the measure yielded data producing quantifiable outcomes. To achieve this, only quantitative measures that produced a score on a scale (i.e. measures able to quantify the degree of intellectual awareness) were included, whilst measures producing a dichotomous presence or absence of awareness were excluded.

Eligibility criteria

To be included in the review, articles had to meet the following criteria: (1) articles described an empirical study assessing intellectual awareness after TBI; (2) TBI and intellectual awareness measures were conceptualised as described above; (3) all participants had sustained a TBI and were adults (>18 years) at time of study participation; (4) studies had been published as original articles in peer-reviewed journals; (5) articles were written in English; (6) the articles had been published from inception of the relevant searched databases to 14th January 2018. Unpublished

dissertations, conference proceedings, abstracts without locatable full texts, case reports, theoretical and review articles were all excluded. To maintain focus, only empirical studies focused specifically on the assessment of intellectual awareness in TBI samples were included. This meant that intervention studies or validation studies focused on tool development were excluded. This enabled the authors to limit the scope of the studies and in turn limit the number of appropriate papers included to within recommended guidelines for systematic reviews (e.g. (<50 papers; Robinson et al, 2015). Furthermore, as will be reported in the discussion, the exclusion of intervention or validation studies did not alter overall findings.

Study selection

The initial search from all four databases identified 2707 articles. Six additional studies were identified via manual searching but there were 690 duplicate records making the number of potentially relevant studies 2023. The resulting studies were evaluated according to the inclusion criteria described above. This process was completed in four phases (see Figure 1 for a pictorial summary of the study selection process). *Phase 1* involved a preliminary screening of titles to exclude studies with no apparent relevance to the current review aims. *Phase 2* involved screening the abstracts of all remaining studies. *Phase 3* involved full text screening of the remaining studies. Studies were excluded with reference to the described eligibility criteria. *Phase 4* involved comparing summarised key information from each of the remaining studies against the eligibility criteria. This process resulted in 34 studies deemed eligible for review.

Quality assessment

The information gathered from the final selection of studies was assessed for methodological quality and risk of bias. It should be recognised that no ‘gold standard’ tool for the quality assessment of studies currently exists (Katrack et al, 2004). The present review solely included quantitative research studies; therefore the ‘Checklist for assessing the quality of quantitative studies (Kmet, Lee & Cook, 2004) was applied. This tool typically offers overall scores ranging from 0-28. Items were scored on the specific criteria (Yes = 2, Partial = 1, No = 0). Items not applicable to a particular study design were marked ‘N/A and were excluded from the calculation of the total quality score. Three criteria were excluded from all studies as these related to

intervention studies, which were not included in the current review, and therefore a maximum total score of 22 could be obtained. Higher scores represented a stronger methodological quality. Good quality was defined as scores greater than 17; fair quality was defined as scores above 9 and poor quality was defined as scores of 8 and below (see Appendix C for quality rating given for each included study). A second rater (GB) independently evaluated seven (20%) of the total number of studies using the quality criteria to check for agreement. The checklist and rating procedure were discussed before ratings were made to ensure consistency in interpretation of the checklist items. Inter-rater reliability for the quality scores of these seven papers was calculated in SPSS (version 24) using intra-class correlation and was found to be .97, which is considered excellent. Remaining disagreements were resolved through discussion to determine a final rating.

Data synthesis

Across the studies included there was variability in participants’ age, severity of injury, time since injury and significant variability in the object of intellectual awareness (i.e. domain of functioning for intellectual awareness was assessed) and assessment methods adopted. As a result, and in line with Lloyd et al (2015), meta-analysis was not used to synthesise the data. Findings are instead summarised in Tables 1 and 2 and described in subsequent sections.

Insert Figure 1 here

For Peer Review Only

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Insert Table 1 here

For Peer Review Only

Insert Table 2 here

For Peer Review Only

Results

This section begins with a brief description of the included studies, detailing factors that are particularly relevant to the assessment of intellectual awareness following TBI. The papers will then be discussed and critiqued to meet the aims of the review.

Rating of study quality

Overall, the methodological quality of the studies included in the review ranged from fair to good, with scores ranging from 14 to 22 (mean 19, SD 2.10) out of 22 on the ‘Checklist for assessing the quality of quantitative studies’ (Kmet, Lee & Cook, 2004, see Appendix C). Five studies were rated fair and 29 good quality. In line with the specific aims of the current review, higher quality studies involved better specification of TBI sample characteristics (e.g. injury severity; specified cause of injury) and provided a clear description of the approach for assessing awareness. Common limitations across studies that impacted on their quality rating included: a lack of clarity regarding time since injury and omitting estimates of variance for main results.

Characteristics of the included studies

Demographic characteristics of study samples

The sample sizes varied widely across studies, from 14 (Chiou et al, 2016) to 168 (Richardson et al, 2015). All included studies reported the average age of patient groups at time of study participation. However, only two studies specified patient age at injury (Anderson et al, 1989; Kelley et al, 2014). Information regarding the number of male versus female participants who had sustained a TBI was reported by all studies, with the percentage of male participants ranging from 52% to 100%. Further summary of study characteristics is presented in Table 1 and highlights the variation in sample and injury characteristics dependent on the type of assessment method adopted.

Injury characteristics across TBI studies

TBI was generally conceptualised as evidence of head trauma and altered consciousness, with length of PTA and brain scanning findings as additional aspects. All studies reported samples as comprised of individuals who experienced/survived TBI and four further described their samples as military personnel or veterans (French et al, 2014; Kelley et al, 2014; Lanham et al, 2000; Vanderploeg et al, 2007). Cause of

injury was explicitly specified in 20 studies, with the most common cause being motor vehicle accidents (MVA). All studies reported the severity of the brain injury experienced by participants by categorising severity using mild, moderate and severe classifications. The majority of studies comprised participant groups with injury severity that spanned the spectrum from mild to severe. Only one study (Donders et al, 2015) focused on mild injury specifically. The same distribution of severity was seen when splitting studies by the method of awareness assessment used, as can be seen in Table 1. With the exception of Murrey et al (2005), all studies made reference to the method used to classify severity. See Appendix B for further details of injury severity and cause.

Time post injury

Twenty-seven studies reported means and standard deviations of the days, months or years since injury. Three studies reported median values (Bivona et al, 2008; Ciurli et al, 2010; Kelley et al, 2014). The mean length of time since injury across studies was 37.4 months (SD 34.6). Sixteen studies reported the range of time since injury, which varied greatly from 0.09 months (3 days) to 576 months (48 years). Four studies made no reference to time since injury (Anderson et al, 1989; Geytenbeek et al, 2017; Niemeier et al, 2014; Pagulayan et al, 2007). However, two of these (Geytenbeek et al, 2017; Pagulayan et al, 2007) were longitudinal studies, so although mean data was not available relating to time post injury for each participant, they did report their follow-up timeframes as one, three and six months and one and twelve months respectively. Table 1 highlights how the mean time post injury for those studies adopting patient-proxy measures appear in with that of the full sample. However, the mean time post injury for samples in studies using the clinician rated (Richardson et al, 2014) and performance-based discrepancy measures (Anderson et al, 1989; French et al, 2014) are shorter (both <12 months) than when using the patient-proxy measure. For the studies adopting multiple measures, mean time since injury for these samples appeared longer (54.1 months, SD=50.6).

Study design

Out of the final selection of 34 studies, 29 had a cross-sectional design and five a longitudinal design. Eight cross-sectional studies included a control group (see Appendix B for further details of the control groups).

The studies were conducted across eight different countries with the most contributions from the USA (15 studies) followed by the UK and Canada (5 studies each). The publication dates of the studies ranged from 1989-2017. The previous review investigating awareness measures in adults with brain injury was conducted in 2012 (Smeets et al, 2012). From our search, we found 12 studies published since 2012. The majority (n=10) used patient-proxy measures (Bivona et al, 2014: Awareness Questionnaire: AQ; Chiou et al, 2016: AQ, Modified Fatigue Impact Scale: MFIS; Dockree et al, 2015: Cognitive Failures Questionnaire: CFQ, Frontal Systems Behaviour Questionnaire: FrSBe, Patient Competency Rating Scale: PCRS; Donders et al, 2015: Behaviour Rating Inventory of Executive Function-Adult: BRIEF-A; Geytenbeek et al, 2017: Mayo-Portland Adaptability Inventory - MPAI-4; Goverover et al, 2014: AQ; Kelley et al, 2014: TBI Follow-Up Interview: TBIFI; Niemeier et al, 2014: FrSBe, PCRS; Richardson et al, 2015: AQ; Zimmerman et al, 2017: PCRS); one used a clinician rated measure (Richardson et al, 2014: Self-Awareness of Deficits Interview - SADI) and one used the performance-based discrepancy method (French et al, 2014: Neurobehavioural Symptom Inventory - NSI vs. neurocognitive performance).

Research question 1: Methods used in empirical studies investigating awareness deficits following TBI

Three different intellectual awareness assessment methods (patient-proxy discrepancy ratings, clinician rated scales and performance-based discrepancies) were used across the studies identified, with patient-proxy discrepancies being the most common. Across these three methods, 23 different assessment tools were identified (see Table 2).

Table 2 highlights the AQ and PCRS as the most commonly used measures to assess intellectual awareness in TBI samples, with each appearing in nine studies. Two of the studies that adopted the PCRS measure specified that they used translated versions for their study populations (Prigatano et al, 1998: Spanish; Zimmerman et al, 2017: Brazilian). The FrSBe was used by four studies and the CFQ (Cognitive Failures Questionnaire) and CIQ (Community Integration Questionnaire) used in two studies each. All of these are patient-proxy discrepancy measures. The SADI, a clinician rated measure, was also used in three studies. All remaining measures appeared once only.

Variability existed in the number of measures that studies used to assess intellectual awareness. Twenty-four studies used a single measure of intellectual awareness and 10 studies used multiple measures (see Table 2: studies using multiple measures are in italics). Of the studies using one measure to assess intellectual awareness, 21 studies used a patient-proxy discrepancy measure of which only five adopted patient-clinician discrepancy ratings. Three of these five (Carroll et al, 2011; Niemeier et al, 2014; Sherer et al, 1998) used both the patient-significant-other and patient-clinician versions of the same measure. The remainder used the patient-significant other rating only. Of the remaining three studies employing a single method, one administered a measure from the clinician-rated method (Richardson et al, 2014 (SADI) and two studies used a performance-based discrepancy measure (Anderson et al, 1989; French et al, 2014). Of the six studies using two measures, four of these used two measures from the same method, namely two patient-proxy discrepancy measures (Chiou et al, 2016 (AQ, MFIS); Hart et al, 2009 (AQ, PCRS); Kelley et al, 2014 (CIQ, TBIFI); Niemeier et al, 2014 (PCRS, FrSBe). The remaining two studies combined a patient-proxy discrepancy measure and a clinician rating scale (Bogod et al, 2003 (Dysexecutive Questionnaire: DEX, SADI); Lanham et al, 200 (Katz Adjustment Scale: KAS; Neurobehavioural Rating Scale: NBRS insight item). Two of the three studies that administered three measures used different patient-proxy discrepancy measures (Dahlberg et al, 2006 used the CIQ; the Craig Handicap Assessment and Reporting Techniques-Short Form: CHART-SF and the Social Communication Skills Questionnaire-Adapted: SCSQ-A) and Dockree et al, 2015 used the CFQ, FrSBe, PCRS) and one study (Morton et al, 2010) combined the use of two patient-proxy discrepancy measures (DEX, SADI) with a clinician rated measure (AQ). The one study to use four measures, (O’Keeffe, et al, 2007) administered three patient-proxy rating scales (CFQ, FrSBe, PCRS) and one clinician rated measure (Awareness Interview-Adapted: AI-A).

Research question 2: Characteristics of measurement instruments employed

Format (i.e. method and design of assessment tool)

Only five measures (AQ, PCRS, SADI, NBRS insight item, AI-A) are specifically designed to assess intellectual awareness. All others, through design, allowed a measure of intellectual awareness to be derived. Table 2 provides basic information on the key features and focus of the measures of intellectual awareness adopted in the

included papers. The AQ, PCRS, DEX and EBIQ all had separate versions to allow not only patient and significant other ratings, but also patient-clinician discrepancy ratings to be obtained. Of the studies that adopt patient-proxy measures a preference appears for the patient-SO version over the patient-clinician version. Three studies (Carroll et al, 2011; Sherer et al, 1998 (AQ); Niemeier et al, 2014 (PCRS) combine and use both patient-SO and patient-clinician versions, and two studies (Bogod et al, 2003 (DEX); Medley et al, 2010 (EBIQ) solely use the patient-clinician version. Three measures allow a comparison of present and pre-morbid ratings on patient functioning, allowing changes in functioning to be highlighted. These are the AQ, FrSBe and KBCI and all are patient-proxy measures. All other assessment measures refer solely to the present self, adopting a focus on post-injury functioning.

Focus (i.e. domain of functioning assessed)

Of the 19 patient-proxy discrepancy measures employed across studies, 18 were delivered in questionnaire format. Thirteen of these questionnaires measures were administered in full (AQ, BRIEF-A, CFQ, CIQ, DEX, EBIQ, FrSBe, KBCI, MFIS, MPAI, NFI, PCRS, SCSQ). The majority of these covered multiple domains which could be explored independently, the common areas being cognitive, emotional/affective and social, whereas two of these measures were designed to assess only one domain: the BRIEF-A assessed executive functions and the SCSQ focused on social communication skills. For the remaining five patient-proxy measures (CAPM, CHART-SF, KAS, MPAI-4, SIP), only specific subscales of the questionnaire were employed, typically those most relevant to the focus of the study. The one exception to the questionnaire method used was the TBIFI, which is a clinician lead interview in which the self-reported responses of individuals with TBI and their family members are rated on a Likert scale and then compared. Questions on this interview measure are pre-defined, but cover a range of domains.

The performance-based method tended to focus on intellectual awareness in relation to the cognitive domain specifically. French et al (2014) adopted a self-rating tool, the NSI, to compare participants' scores on this to objective performance on cognitive testing. The authors only included selected items related to targeted areas of cognition from this inventory. Anderson et al (1989) and O'Keeffe et al (2014) used the AI, which primarily includes questions targeting patients' views of their abilities across a number of cognitive skills. By comparison, for the clinician-rated method,

both the SADI and the NBRS do not specify domains of functioning, thus allowing the clinician choice as to the various areas of deficit they may wish to explore. This differentiates these measures from both the other interview-based techniques above and the questionnaire-based measures.

All measures allowed participants to appraise the abilities of the individual with TBI in terms of strengths and difficulties. However, only three studies explored the implications of these deficits in everyday life. Again, each of these adopted patient-proxy discrepancy measures. Dahlberg et al (2006) used the occupation and social integration subscales of the CHART-SF to measure social participation and community integration, as well as the CIQ to assess engagement in home, social and work activities. The CIQ was also used by Kelley et al (2014). Dawson et al (2005) used the community integration subscales of the KAS.

All measures across all methods allow a certain degree of intellectual awareness to be ascertained. In the case of the clinician rated and performance-based methods the level of awareness was derived by collating the information gained from the measure adopted (e.g. interview or inventory) to create an index score. Although the range of these indices was relatively limited (e.g. 0-3) they still provide information on the degree of intellectual awareness as opposed to simplifying this to a dichotomous outcome (e.g. the presence or absence of awareness).

Discussion

The purpose of the paper was to provide a systematic review of measurement instruments and their properties used to assess intellectual awareness following TBI. To the best of the authors' knowledge, our review is the first to have systematically considered the assessment of intellectual awareness in an adult TBI sample specifically, with previous reviews having used samples of mixed aetiology (Smeets et al, 2012).

Our systematic search identified thirty-four studies and our review highlights the diversity of instruments in the TBI field. Within these thirty-four papers, twenty-three different measurement instruments were identified, split by the three assessment methods adopted. The most commonly adopted method of assessment for TBI samples was the patient-proxy method with 19 of the measures following this approach. A further two clinician-rated measures and two performance-based discrepancy tasks were also identified.

Within the patient-proxy measures, family members or significant others were most frequently used as proxies, with only four studies exploring patient-clinician discrepancies. This is of note given that the existing literature often questions the accuracy of relatives' judgements about patients' functioning, speculating that clinician report may be less emotionally loaded than relatives (Lanham et al, 2000; Howland et al, 2017). Alternatively, however, the relatives may have greater exposure to the behaviour of the person with TBI and so be seen as having greater potential knowledge. A further challenge highlighted by Toglia and Kirk (2000) relates to the varying specificity of items within patient-proxy measures, which they assert, may impact the knowledge an individual is using to evaluate and respond. It has been reported that agreement levels between patients and family members may be higher when item content is specific (Gasquoine, 1992). However, in reviewing the specific items of the commonly reported measures from the current review, it appears that items are often worded in more general terms. For example, the AQ asks respondents to rate how good they are at "planning things now compared to before injury?" and the FrSBe asks respondents to rate the frequency in which they "Do or say embarrassing things". These items are not only open to individual interpretation (as, for example, no examples of planning are offered), but also are reliant on the respondent appraising the behaviour as odd or inappropriate. Some items are slightly more specific, for example the PCRS asks respondents to rate how much of a problem they have "starting a conversation in a group?" However, here, ambiguity may remain as to whether this is a group they know well or not, and how this is interpreted could alter the response given.

Studies have also reported different rates of agreement between respondents (patients and proxies) dependent on the specific areas of functioning being assessed. The greatest agreement is noted for sensory and motor difficulties experienced and the poorest agreement is for items pertaining to emotional and behavioural changes (Seel, Jeffrey et al, 1997). This may be linked to clear differences in the observable nature of each of these. However, whatever the reason, it highlights that if a measure has a stronger focus on either of these areas (i.e. an increased number of items relating to sensory and motor difficulties), this may result in a shift in the level of disagreement and in turn impact the outcome level of awareness reported. Given that varying agreement levels have been noted to relate to

item specificity and content, this appears a crucial factor to consider in choice of instrument and also in future tool development.

Our review reveals that a number of factors may influence the choice of instrument (e.g. time post injury, domain of interest assessed). With reference to chronicity, it appears that particular methods are preferred dependent on the time post-injury. For patient samples assessed closer to injury, clinician rated and performance-based discrepancy methods were adopted. These may rely more on examiner judgement, and focus more on objective performance, which are typically explored earlier post-injury when the patient may be experiencing more acute difficulties with concentration and adjustment. This pattern of objective assessment methods or clinician rating methods being used earlier on in recovery could relate to the fact that patients are still engaged with services (i.e. in hospital or in active outpatient rehabilitation) thus those methods are more implementable (i.e. can be observed) and appropriate (i.e. patients have not long returned home so relatives do not understand or have experience of the changes in their relative as yet). The longer time since injury for patient-proxy measurement conversely may reflect the shift in care emphasis to the relative. Patient-proxy measures are typically questionnaire based, often requiring a level of independence in completion, therefore the longer duration since injury, the more likely this might occur. Additionally, assessing later post-injury provides the patient with some experience of community living and increased opportunities to notice changes and challenges. With regards to the specificity of the targeted domains of intellectual awareness assessed, the patient-proxy measures showed greatest variation in the range of domains and breadth of functions assessed, marking these apart from the clinician-rated and performance-based discrepancy methods. However, it should be noted that exceptions exists, with the SADI, a clinician-rated method, also showing variation in the domains assessed. This great variation amongst how instruments are used makes comparing across study outcomes difficult, but positively marks a flexible use of the instrument in order to gain a wealth of information, which likely has positive clinical utility.

Additional variation across instruments was noted regarding the timings of assessment. The majority of instruments focused on current post-injury functioning. However, for two of the commonly used patient-proxy measures in this review, (the AQ and the FrSBe) respondents were asked to rate how well they are currently functioning compared to before the injury (i.e. better, the same or worse; AQ or in the

case of the FrSBE, rate both pre- and post-injury functioning). Both allow an index of change to be assessed and suggest that this change index is valued following TBI. There is debate regarding whether the measures of awareness that involve pre-post-ratings may be more complex than those focused solely on current functioning (Niemeier et al, 2014), which if true may again make cross study comparison challenging and as such may warrant further attention.

An important feature of awareness is the heterogeneous presentation, which has resulted in greater reliance on measurement instruments that are able to quantify the degree of awareness impairment and are suited to both clinical and research use. This seems important, as having research based around practical and useable tools will be of most benefits when applying these clinically. The current review only included measures that obtained a quantitative output. However, qualitative methods do exist (e.g. nominal group techniques (Willer et al, 1991); in-depth discussion and descriptive case studies (Karpman et al, 1985). Systematically exploring the frequency of use of more qualitative assessment of awareness could form an interesting comparative future review.

Our review confirms that there appears a range of instruments assessing intellectual awareness, particularly patient proxy measures. However, awareness assessment was not the intended focus for the majority, with many instruments adapted by researcher design to assess patient's awareness (e.g. BRIEF-A, CFQ, CAPM, CHART-SF, CIQ, DEX, EBIQ, FrSBe, KAS, KBCI, MFIS, MPAL,MPAI-4, NFI, SIP, SCSQ-A, TBIFI, NSI). Adaptations typically included creating an informant version of a measure to provide a discrepancy rating. Typical reasons for this were that the measure in question was already included as part of the test battery and adapting it to allow a measure of awareness did not extend testing time or increase the demands placed on patients. However, these adaptations are not validated and although appear to have good face validity, caution is needed before judging their psychometric properties and further research would be of benefit.

Overall the patient-proxy method appeared to show a number of strengths as a tool to assess awareness in TBI compared to clinician rated and performance-based methods, potentially highlighting the reason for its preference. To briefly summarise, it allows multiple perspectives to be gained (although this is also true for the SADI, a clinician rated measure), it appears to offer the greatest flexibility in the domain assessed, versions exist and adaptations are simple to include pre- and post-injury

variants providing a reference on which to mark post-injury change, and the rating scale scoring system adopted provides a quantifiable degree of awareness. However, it should be noted that currently no criterion ‘gold standard’ exists and given the flexible use of the instruments employed, it appears unlikely that a single ideal means of evaluating awareness of deficits following TBI will appear in the immediate future. Given the promise of patient-proxy reports, in this absence, a sensible approach seems to be to focus efforts on the development of patient-proxy methods. Further research is required to continue to establish the reliability and validity of recognised assessment instruments and to provide reliability estimates for newer, more experimental assessment tools.

As Toglia and Kirk (2000) point out, in order to succeed in developing effective assessment tools, a comprehensive model of awareness is needed. Existing models of awareness do aim to reflect the complex and multi-dimensional nature of awareness, with some recognising it as consisting of hierarchical interdependent levels (Crosson et al, 1989) and others proposing a more dynamic relationship that also considers an individual’s knowledge and beliefs (Toglia and Kirk, 2000). However, regardless of the model, each discriminates between online and offline awareness in some capacity supporting the notion that different ‘types’ of awareness exists. Furthermore, empirical studies investigating the impact of rehabilitation outcomes on different types of awareness highlight the benefits of looking at awareness types separately, with interventions reported to be more beneficial if targeted to a specific type of awareness (Robertson and Schmitter-Edgecombe, 2015). Given the bidirectional relationship in which a model or conceptualisation can direct how we define, measure and interpret awareness both clinically and in research, and how empirical results can highlight how consistent data is with existing theories, as well as provide information on how awareness may be further conceptualised, continued review is encouraged.

The quality of the studies included in the current review was relatively high. However, a number of factors thought to be crucial determinants of awareness (e.g. severity of injury, chronicity) (Morton et al, 2010) were often omitted, impacting on our ability to make definite claims about the findings. Firstly, a number of studies did not specify the nature of the TBI and secondly, although all studies reported the age of samples at time of assessment, with the exception of two studies, the age of the sample *at time of injury* was not specified. This created ambiguity as to whether all

individuals in the sample experienced TBI in adulthood. Moreover, the majority of studies did not include controls groups, which raises questions regarding our confidence in the effectiveness of the assessment tool, particularly in terms of the extent to which differences between self and proxy ratings may be detected and appear in non-TBI samples versus TBI samples.

This review was designed to capture all measurement instruments published in empirical studies using relatively inclusive search criteria. This meant that it expanded on the number of measures identified by Smeets et al (2012). However, the review may be limited by the nature of the search strategies and corresponding target words used across databases. Although every attempt was made to ensure that articles relating to the construct of intellectual awareness were included, it is possible that some articles were missed as a result of the breadth of database searches and the vast amount of literature the search yielded.

Despite our broad inclusion of instruments, we applied stricter exclusion criteria regarding the types of articles included. It could be argued that our relatively strict exclusion criteria, excluding validation and intervention studies, may have impacted the number of measures identified. However, a brief review of the methods in the excluded studies identified only one additional measure, namely the IoWA personality Index, suggesting that our criteria worked appropriately to contain the number of papers identified, but not overly limit identification of the measures employed.

There is a risk of bias in this review covering several areas. There is a language bias as only articles found in English databases were assessed and articles written in English were considered. Given that the initial search was carried out by a single author (the primary author) researcher bias may exist influencing paper inclusion. However, all named authors were consulted on the inclusion of papers, minimising this concern. Only studies published in journals were included in this review. Grey literature was excluded, as it was difficult to access further information beyond abstracts from poster presentations at conferences or brief conference proceedings. The fact that studies reporting significant results are more likely to be published than ones reporting non-significant results is well known. It is possible therefore that this review may suffer from some element of bias relating to published studies.

As we have previously asserted, the current review was designed to solely capture assessment instruments used with people following TBI. This may be a reason for a number of commonly used scales appearing less frequently than may be expected (e.g. DEX and DEX-R). Conducting a similar review focused on ABI or possibly comparing the two groups may therefore be informative. This may provide a clearer picture as to the more sensitive measures dependent on the type of injury. Our current review did not look at the effectiveness of the instruments included (e.g. whether they successfully differentiated patients by level of awareness, which would be a logical next step.

Recommendations and future directions:

The impact of awareness on engagement with, and outcome of, successful rehabilitation is repeatedly noted (Winson et al, 2017). Improving our understanding of awareness, starting with how best to assess it, therefore, is an area deserving of further attention. Following our review, recommendations for future research include the following:

- (1) A more detailed examination and inclusion of participants' TBI history: In particular studies might report age at injury and specify the cause of injury from valid and reliable sources.
- (2) Using a control sample: This was lacking in most previous studies and attention to this in future research may expand and strengthen available evidence. Alternatively, studies might use scales for which standardised data is already available related to awareness measurement.
- (3) Ensuring established psychometric properties for all measures used: As previously mentioned, it was beyond the scope of the current review to look at the psychometric properties of the measures (particularly experimental adaptations) and the effectiveness of the assessment instrument employed. This would include reviewing the sensitivity, validity and reliability of commonly employed measures. However, both of these would be areas to systematically follow up. We would recommend doing so focused on a particular sample group (e.g. TBI or ABI) in order to constrain conclusions made to the particular patient group of interest.
- (4) Using conjoint awareness methods to provide a balance approach: Patient-proxy methods currently appear the preferred method of assessment, although

the variation between specific instruments is large. Focusing efforts of instrument development around tools that provide multiple perspectives might be of benefit.

- (5) Attention to be given to the specificity of the wording of questions or statements for respondents to rate should be considered in future tool development in order to aid item interpretation and consistency of responses.
- (6) Determining the factors that impact on awareness measurement: This has been studied extensively in other conditions such as dementia (Clare et al, 2012). Of interest would be more systematic study of the factors affecting measurement, for example the quality of the patient-proxy relationship, personality traits and disposition of the patient and significant proxy and patient self-efficacy ratings.

Conclusions

In conclusion, given the variety of different approaches and instruments used in the included studies, this review reveals that there still lacks a consensus about the preferred instrument to assess intellectual awareness deficits after TBI specifically. There still appear to be major gaps in our understanding of how best to measure awareness and to date no single ideal method exists. Currently there appears a preference for employing patient-proxy measures, but our findings suggest increased attention should be given to factors thought to influence proxy ratings, as well as those impacting patient ratings. Development of a standard for the measurement of awareness would facilitate comparability across studies, which would produce improved estimates of TBI impairment and recovery patterns. Given the far-reaching impact reduced awareness can have not only on rehabilitation, but also on both family and community integration, sound assessment is vital. As such continued input into this area is recommended.

Disclosure of interest:

The authors report no conflict of interest

References:

- Abreu, B. C., Seale, G., Scheibel, R. S., Huddleston, N., Zhang, L. & Ottenbacher, K. J. (2001). Levels of self-awareness after acute brain injury: How patients' and rehabilitation specialists' perceptions compare. *Archives of Physical Medicine and Rehabilitation*. Vol. 82(1) pp. 49-56.
- Anderson, S. W. & Tranel, D. (1989). Awareness of disease states following cerebral infarction, dementia, and head trauma: Standardized assessment. *The Clinical Neuropsychologist*. Vol. 3(4), pp. 327-339.
- Azouvi, P., Arnould, A., Dromer, E. and Vallat-Azouvi, C. (2017). Neuropsychology of traumatic brain injury: An expert overview. *Revue Neurologique*. Vol. 173(7-8), pp. 461-472.
- Bach, L. J. & David, A. S. (2006). Self-awareness after acquired and traumatic brain injury. *Journal of Neuropsychological Rehabilitation*. Vol. 16(4), pp. 397-414.
- Bandura, A. (1997). *Self-efficacy. The exercise of control*. New York: WH Freeman and Company.
- Bivona, U., Ciurli, P., Barba, C., Onder, G., Azicnuda, E., Silvestro, D. et al (2008). Executive function and metacognitive self-awareness after severe traumatic brain injury. *Journal of the International Neuropsychological Society*. Vol. 14(5), pp. 862-868.
- Bivona, U., Riccio, A., Ciurli, P., Carlesimo, G.A., Delle Donne, V., Pizzonia, E. et al (2014). Low self-awareness of individuals with severe traumatic brain injury can lead to reduced ability to take another person's perspective. *Journal of Head Trauma Rehabilitation*. Vol. 29(2), pp.157-171.
- Bogod, N. M., Mateer, C. A. & Macdonald, S. W. (2003). Self-awareness after traumatic brain injury: A comparison of measures and their relationship to executive functions. *Journal of the International Neuropsychological Society*. Vol. 9(3), pp. 450-458.
- Carroll, E. & Coetzer, R. (2011). Identity, grief and self-awareness after traumatic brain injury. *Neuropsychological Rehabilitation*. Vol. 21(3), pp. 289-305.
- Chan, V., Mollaveva, T., Ottenbacher, K. J. & Colantonio, A. (2017). Clinical profile and comorbidity of traumatic brain injury among younger and older men and women: a brief research notes. *BMC Research Notes*. Vol. 10(1), Article No: 371.

- Chiou, K. S., Chiaravalloti, N. D., Wylie, G. R., DeLuca, J. & Genova, H. (2016). Awareness of subjective fatigue after moderate to severe traumatic brain injury. *Journal of Head Trauma Rehabilitation*. Vol. 31(3), pp. 60-68.
- Ciurli, P., Bivona, U., Barba, C. & Onder, G. (2010). Metacognitive unawareness correlates with executive function impairment after severe traumatic brain injury. *Journal of the International Neuropsychological Society*. Vol. 16(2), pp. 360-368.
- Clare, L. (2004). The construction of awareness in early-stage Alzheimer's disease: A review of concepts and models. *British Journal of Clinical Psychology*. Vol. 43(2) pp. 155-175.
- Clare, L., Melis, S. M., Martyr, A., Roberts, J., Whitaker, C. J., Markova, I. S., Roth, I. et al (2012). The influence of psychological, social and contextual factors on the expression and measurement of awareness in early-stage dementia: testing a biopsychosocial model. *International Journal of Geriatric Psychiatry*. Vol. 27(2), p. 167-177.
- Crosson, B., Barco, P. O., Velozo, C. A. et al (1989). Awareness and compensation in post-acute head injury rehabilitation. *Journal of Head Trauma Rehabilitation*. Vol. 4(3), pp. 46-54.
- Dahlberg, C., Hawley, L., Morey, C., Newman, J., Cusick, C.P., & Harrison-Felix, C. (2006). Social communication skills in persons with post-acute traumatic brain injury: Three perspectives. *Brain Injury*. Vol. 20(4), pp. 425-435.
- Dawson, D., Markowitz, M. & Stuss, D. T. (2005). Community integration status 4 years after traumatic brain injury. Participant-Proxy Agreement. *Journal of Head Trauma Rehabilitation*. Vol. 20(5), pp. 426-435.
- Dockree, P. M., Tarleton, Y., Carlton, S. & FitzGerald, M. C. C. (2015). Connecting self-awareness and error-awareness in patients with traumatic brain injury. *Journal of the International Neuropsychological Society*. Vol. 21, pp. 473-482.
- Donders, J., Oh, Y.I. & Gable, J. (2015). Self- and informant ratings of executive functioning after mild traumatic brain injury. *Journal of Head Trauma Rehabilitation*. Vol. 30(6), pp. 30-39.
- Fischer, S., Gauggel, S. & Trexler, L. E. (2004). Awareness of activity limitations, goal setting and rehabilitation outcome in patients with brain injuries. *Brain Injury*. Vol. 18, pp. 547-562.

- FitzGerald, M.C.C., Carton, S., O'Keefe, F., Coen, R. F. & Dockree, P. M. (2012). Impaired self-awareness following acquired brain injury: current theory, models and anatomical understanding. *The Irish Journal of Psychology*. Vol. 33 (2-3), pp. 78-85.
- French, L. M., Lange, R. T. & Brickell, T. A. (2014). Subjective cognitive complaints and neuropsychological test performance following military-related traumatic brain injury. *Journal of Rehabilitation Research & Development*. Vol. 51(6), pp. 933-950.
- Flashman, L.A., & McAllister, T.W. (2002). Lack of awareness and its impact in traumatic brain injury. *NeuroRehabilitation*, Vol. 17(4), pp. 285-296.
- Fleming, J., Strong, J. & Ashton, R. (1996). Self-awareness of deficits in adults with traumatic brain injury: how best to measure? *Brain Injury*. Vol. 10(1), pp. 1-15.
- Gasquoine, P. G. (1992). Affective state and awareness of sensor and cognitive effects after closed head injury. *Neuropsychology*. Vol. 4, pp. 187-196.
- Geytenbeek, M., Fleming, J., Doig, E. & Ownsworth, T. (2017). The occurrence of early impaired self-awareness after traumatic brain injury and its relationship with emotional distress and psychosocial functioning. *Brain Injury*. Vol. 31(13-14), pp. 1791-1798.
- Goverover, Y. & Chiaravalloti, N. (2014). The impact of self-awareness and depression on subjective reports of memory, quality-of-life and satisfaction with life following TBI. *Brain Injury*. Vol. 28(2), pp. 174-180.
- Hart, T., Seignourel, P. J. & Sherer, M. (2009). A longitudinal study of awareness of deficit after moderate to severe traumatic brain injury. *Neuropsychological Rehabilitation*. Vol. 19(2), pp. 161-176.
- Howland, M., Allan, K.C., Carlton, C. E., Tatsuoka, C., Smyth, K. A. & Sajatovic, M. (2017). Patient-rated versus proxy-rated cognitive and functional measures in older adults. *Patient-related Outcome measures*. Vol. 15(8), pp. 33-42.
- Karpman, T., Wolfe, S. & Vargo, J. W. (1985). The psychological adjustment of adult clients and their partners following closed-head injury. *Journal of Applied Rehabilitation Counselling*. Vol. 17, pp. 28-33.
- Katrak, P., Bialocerkowski, A. E., Massy-Westropp, N., Saravana Kumar, V.S. and Kelley, E., Sullivan, C., Loughlin, J. K., Hutson, L., Dahdah, H.N., Long, M. et al (2014). Self-awareness and neurobehavioural outcomes, 5 years or more after moderate to severe brain injury. *Journal of Head Trauma Rehabilitation*. Vol. 29(2), pp. 147-152.

Kmet, L. M., Lee, R. C. & Cook, L. S. (2004). Standard Quality Assessment Criteria for evaluating primary research papers from a variety of fields. HTA Initiative.

Available: <http://www.ahfmr.ab.ca/frames3.html>

Lanham, R. A., Weissenburger, J. E., Schwab, J. E., Schwab, K. A. & Rosner, M. M. (2000). A longitudinal investigation of the concordance between individuals with traumatic brain injury and family or friend ratings on the Katz Adjustment Scale. *Journal of Head Trauma Rehabilitation*. Vol. 15(5), pp. 1123-1138.

Larson, M. J. & Perlstein, W. M. (2009). Awareness of deficits and error processing after traumatic brain injury. *Clinical Neuroscience and neuropathology*. Vol. 20(16), pp. 1486-1490.

Lloyd, O., Ownsworth, T., Fleming, J. & Zimmer-Gembeck, M. J. (2015). Awareness deficits in children and adolescents after traumatic brain injury: A systematic review. *The Journal of Head Trauma Rehabilitation*. Vol. 30(5), pp. 311-323.

Machamer, J., Temkin, N. & Dikmen, S. (2013). Health-Related Quality of Life in Traumatic Brain Injury: Is a Proxy Report Necessary. *Journal of Neurotrauma*. Vol. 30(22), pp. 1845-1851.

Malec, J. F. & Moessner, A. M. (2000). Self-awareness, distress and postacute rehabilitation outcome. *Rehabilitation Psychology*. Vol. 45, pp. 227-241.

Malec, J. F., Testa, J., Rush, B. K., Brown, A. W. & Moessner, A. M. (2007). Self-assessment of impairment, impaired self-awareness, and depression after traumatic brain injury. *Journal of Head Trauma Rehabilitation*. Vol. 22(3), pp.156-166.

Medley, A. R., Powell, T., Worthington, A., Chohan, G. & Jones, C. (2010). Brain injury beliefs, self-awareness, and coping: A preliminary cluster analytic study based within the self-regulatory model. *Neuropsychological Rehabilitation*. Vol. 20(6), pp. 899-921.

Morton, N. & Barker, L. (2010). The contribution of injury severity, executive and implicit functions to awareness of deficits after traumatic brain injury (TBI). *Journal of the International Neuropsychological Society*. Vol. 16(6), pp. 1089-1098.

Murrey, G. J., Hale, F. M. & Williams, J. D. (2005). Assessment of anosognosia in persons with frontal lobe damage: Clinical utility of the Mayo-Portland adaptability inventory (MPAI). *Brain Injury*. Vol. 19(8), pp. 599-603.

National Institute for Health and Care Excellence (NICE): Health and social care directorate, Quality standards and indicators, Briefing paper (2014).

<https://www.nice.org.uk/guidance/qs74/documents/head-injury-briefing-paper2>

[Accessed 14.01.2018]

Niemeier, J. P., Perrin, P., B. Holcomb, M. G., Rolston, C. D., Artman, L. K., Juan, L. & Nersessova, K. S. (2014). Gender differences in awareness and outcomes during acute traumatic brain injury recovery. *Journal of Women's Health*. Vol. 23(7), pp. 573-580.

O'Keeffe, F., Dockree, P., Moloney, P., Carton, S. & Robertson, I. H. (2007). Awareness of deficits in traumatic brain injury: a multidimensional approach to assessing metacognitive knowledge and online-awareness. *Journal of the International Neuropsychological Society*. Vol. 13(1), pp. 38-49.

Pagulayan, K. F., Temkin, N. R., Machamer, J. E. & Dikmen, S. S. (2007). The measurement and magnitude of awareness difficulties after traumatic brain injury: A longitudinal study. *Journal of the International Neuropsychological Society*. Vol. 13(4), pp. 561-570.

Prigatano, G. P. (1996). Behavioural limitations TBI patients tend to underestimate: A replication and extension to patients with lateralized cerebral dysfunction. *The Clinical Neuropsychologist*. Vol. 10(2), pp. 191-201.

Prigatano, G. P., Bruna, O., Mataro, M., Munoz, J. M., Fernandez, S. & Junque, C. (1998). Initial disturbances of consciousness and resultant impaired awareness in Spanish patients with traumatic brain injury. *Journal of Head Trauma Rehabilitation*. Vol. 13(5), pp. 29-38.

Richardson, C., McKay, A. & Ponsford, J. L. (2014). The trajectory of awareness across the first year after traumatic brain injury: The role of biopsychosocial factors. *Brain Injury*. Vol. 28(13-14), pp. 1711-1720.

Richardson, C., McKay, A. & Ponsford, J. L. (2015). Factors influencing self-awareness following traumatic brain injury. *Journal of Head Trauma Rehabilitation*. Vol. 30(2), pp. 43-54.

Robertson, K. & Schmitter-Edgecombe, M. (2015). Self-awareness and traumatic brain injury outcome. *Brain Injury*. Vol. 29(0), pp. 848-858.

Robinson, P. & Lowe, J. (2015). Literature reviews vs systematic reviews. *Australian and New Zealand Journal of Public Health*. Vol. 39(2), pp. 103.

Roche, N. L., Fleming, J. M. & Shum, D. H. (2002). Self-awareness of prospective memory failure in adults with traumatic brain injury. Vol. 16(11), pp. 931-945.

- Sawchyn, J. M., Mateer, C. A. & Suffield, J. B. (2005). Awareness, emotional adjustment, and injury severity in postacute brain injury. *Journal of Head Trauma Rehabilitation*. Vol. 20(4), pp. 301-314.
- Schmidt, J., Lannin, N., Fleming, J. & Ownsworth, T. (2011). Feedback interventions for impaired self-awareness following brain injury: A systematic review. *Journal of Rehabilitation Medicine*, Vol. 43(8), pp. 673-680.
- Seel, R. T., Jeffrey, M. S., Kreutzer, S. & Sander, M. (1997). Concordance of Patients' and Family Members' Ratings of Neurobehavioural Functioning After Traumatic Brain Injury. *Archives of Physical Medicine Rehabilitation*. Vol. 78, pp. 1254-1259.
- Sherer, M., Boake, C., Levin, E., Silver, B.V., Ringholz, G. & High W.M Jr. (1998). Characteristics of impaired awareness after traumatic brain injury. *Journal of the International Neuropsychological Society*. Vol. 4(4), pp. 380-387.
- Smeets, S. M. J., Ponds, R. W., Verhey, R.F. & van Heugten, C. M. (2012). Psychometric properties and feasibility of instruments used to assess awareness of deficits after acquired brain injury: A systematic review. *Journal of Head Trauma Rehabilitation*. Vol. 27(6), pp. 433-422.
- Toglia, J. & Kirk, U. (2000). Understanding awareness of deficits following brain injury. *Neurorehabilitation*. Vol. 15, pp. 57-70.
- Willers, B. S., Allen, K. M., Liss, M. et al. (1991). Problems and coping strategies of individuals with traumatic brain injury and their spouses. *Archives of Physical Medicine and Rehabilitation*, Vol. 72, pp. 460-467.
- Winson, R., Wilson, B. A. & Bateman, A. (2017). *The Brian Injury Rehabilitation Workbook*. The Guildford Press.
- Wise, K., Ownsworth, T. & Fleming, J. (2005). Convergent validity of self-awareness measures and their association with employment outcome in adults following acquired brain injury. *Brain Injury*. Vol. 19(10), pp. 765-775.
- Vanderploeg, R. D., Belanger, H. G., Duchnick, J. D & Curtiss, G. (2007). Awareness problems following moderate to severe traumatic brain injury: Prevalence, assessment methods, and injury correlates. *Journal of Rehabilitation Research & Development*. Vol. 44(7), pp. 937-950.
- Zimmerman, N., Mograbi, D. C., Hermes-Pereira, A., Fonseca, R. P. & Prigatano, G. P. (2017). Memory and executive functions correlates of self-awareness in traumatic brain injury. *Cognitive Neuropsychiatry*. Vol. 22(4), pp. 346-360.

Table 1: Summary of study characteristics split by unawareness assessment method
(full demographic information can be found in Appendix B).

	All studies	Patient-proxy	Clinician rated	Method Performance-based discrepancy	Miscellaneous (studies using multiple measures) Studies (n) Max=10
	Studies (n) Max=34	Studies (n) Max=21	Studies (n) Max=1	Studies (n) Max=2	
Age of TBI sample (yrs)					
Mean (SD)	35.3 (12.4) (n=33)	35.2 (12.2) (n=21)	42.9 (16.6) (n=1)	28.1* (n=2)	36.2 (11.8) (n=9)
Median	35 (n=1)				35 (n=1)
Range	18-72 (n=13)	18-72 (n=7)	N.S	18-56 (n=2)	18-70 (n=4)
Time since injury (months)					
Mean (SD)	37.4 (34.6) (n=27)	36.6 (34.8) (n=17)	7.7 (4.1) (n=1)	6.2 (5.3) (n=1)	54.1 (50.6) (n=8)
Median	8.2, 9, 10.8 (n=3)	8.2, 10.8 (n=2)			9 (n=1)
Range	0.09-576 (n=16)	2-479 (n=9)	N.S	1-24 (n=1)	0.09-576 (n=6)
<12 months (<1 year)	10	6	1	1	2
12-36 months (1-3 years)	9	8	0	0	1
37-60 months (3-5 years)	5	3	0	0	2
61+ months (>5 years)	6	2	0	0	4
Not specified	4**	2	0	1	1
Specified age at injury	2	0	0	1	1
Included control group	8	5	0	1	2
Stated cause of injury	20	11	1	1	7
Severity classification					
Mild	1	1	0	0	0
Moderate - Severe	7	2	0	1	4
Severe	7	6	0	0	1
Full range***	19	12	1	1	5
Setting					
Inpatient	3	1	0	0	2
Outpatient	19	15	1	0	3
Mixed	3	2	0	0	1
Not specified	9	3	0	2	4

*SD only reported for one of the studies **Two of these studies were longitudinal and as such reported the time points at which data was collected *** Participants in the study were mixed (i.e. spanned the mild, moderate and severe categories of injury).

Table 2: Methods (n=3) and instruments (n=23) used to assess intellectual awareness.

Method	Instrument	Focus/Key features	Index of awareness	Times used	Study
Patient-Proxy discrepancy ratings (n=19)	AQ	Pre- and post-injury metacognitive functioning: cognitive, behavioural/affective, motor/sensory	Self vs. SO	7	Bivona et al (2008; 2014); Chiou et al (2016); Goverover et al (2014); Hart et al (2009); Morton et al (2010); Richardson et al (2015)
			Self vs. SO and self vs. clinician	2	Carroll et al (2011); Sherer et al (1998)
	PCRS	Post-injury functioning; behavioural, cognitive, emotional factors; ADLs, cognitive, interpersonal functioning, emotional regulation	Self vs. SO	8	Ciuri et al (2010); Dockree et al (2015); Hart et al (2009); O'Keefe et al (2007); Prigatano et al (1996; 1998*); Sawchyn et al (2005); Zimmerman et al (2017*)
			Self vs. SO & self vs. clinician	1	Niemer et al (2014)
			Self vs. SO	4	Dockree et al (2015); Larson et al (2009); Niemer et al (2014); O'Keefe et al (2007)
	CFQ	Post-injury focus; measures propensity for everyday failures in memory, perceptions and action slips	Self vs. SO	2	Dockree et al (2015); O'Keefe et al (2007)
	CIQ	Post-injury focus; engagement in home, social and work activities	Self vs SO	2	Dahlberg et al (2006); Kelley et al (2014)
	DEX	Three factor (cognitive, emotional, and motivational) questionnaire measuring post-TBI deficits	Self vs. clinician	1	Bogod et al (2003)
			Self vs. SO	1	Morton et al (2010)
	KAS	Post-injury; community integration subscales Focused on belligerence, social irresponsibility, orientation, speech/cognitive dysfunction subscales	Self vs. SO	1	Dawson et al (2005)
			Self vs. SO (concordance ratings)	1	Lanham et al (2000)
	BRIEF-A	Focus on current functioning; rating of executive behaviours	Self vs. SO	1	Donders et al (2015)
	CHART-SF	Focus on current functioning: Measures societal participation and community integration; two subscales used: occupation and social integration.	Self vs SO	1	Dahlberg et al (2006)
			Self vs SO	1	Roche et al (2002)
	CAPM	Focus on current functioning: Prospective memory failure in everyday activities; Two components rated: BADL & IADL	Self vs SO	1	Medley et al (2010)
	EBIQ	Focus on current functioning: Cognitive, emotional and social difficulties following BI	Self vs. clinician	1	Vanderploeg et al (2007)
	KBCI	Pre- and post-injury functioning; assesses executive, interpersonal and emotional behaviours	Self vs SO	1	Chiou et al (2016)
	MFIS	Post-injury functioning; assess physical, cognitive & psychosocial domains	Self vs. SO	1	

**	MPAI	Post-injury functioning; focus on total and 4 selected subscale scores: communication, emotions, Independent living skills, relationships	Self vs. SO	1	Murray et al (2005)
	MPAI-4	Post-injury functioning; Ability subscale only	Self vs. SO	1	Geytenbeek et al (2017)
	NFI	Post-injury; NFI-Dif = constructed index of SA, combined communication, somatic, memory/attention, motor to assess impairment independent of emotional factors	Self vs SO	1	Malec et al (2007)
	SIP	Post-injury functioning; covers 12 functional domains; study used psychosocial factor, physical factor and total scores	Self vs. SO	1	Pagulayan et al (2007)
Clinician Rated (n=2)	SCSQ-A	Post-injury functioning; social communication skills	Self vs. SO	1	Dahlberg et al (2006)
	TBIFI	Post-injury; cognitive, emotional, neurological symptoms Clinician lead interview, patient/SO respond using Likert scale	Self vs, SO	1	Kelley et al (2014)
	SADI	Post injury focus; gathers qualitative and quantitative information on SA of deficits following TBI; includes patient's knowledge of change since injury (cognitive, behavioural, physical, emotional), functional consequences of impairment and realistic goal setting.	Semi-structured interview	3	Bogod et al (2003); Morton et al (2010); Richardson et al (2014)
	NBRS insight item	Post-injury; item rating level of inaccurate insight and self-appraisal in relation to level of ability and personality change	Single item completed by clinician	1	Lanham et al (2000)
Performance-based discrepancy (n=2)	AI-A	Post-injury functioning; Awareness of current cognitive and motor impairments	Discrepancy between patient self-report on structured interview and test performance	1	Anderson et al (1989); O'Keefe et al (2007)
	NSI vs. neurocognitive test performance	Post-injury ability; 3 items included which measured self-reported cognitive complaints of attention/concentration, memory and processing speed/organisation	Compared self-rated cognitive complaints to test performance	1	French et al (2014)

AQ: Awareness Questionnaire; PCRS: Patient Competency Rating Scale; FrSBc: Frontal Systems Behaviour Scale; CFQ: Cognitive Failures Questionnaire; CIQ: Community Integration

Questionnaire; DEX: Dysexecutive Questionnaire; KATS: Kats Adjustment Scale; BRIEF-A: Behaviour Rating Inventory of Executive Function-Adult; CHART-SF: The Craig Handicap

Assessment and Reporting Technique-Short Form; CAPM: Comprehensive Assessment of Prospective Memory; EBIQ: European Brain Injury Questionnaire; KBCI: Key Behaviours Change

Inventory; MFIS: Modified Fatigue Impact Scale; MPAl/MPAl-4: Mayo-Portland Adaptability Inventory; NFI: Neurobehavioural Functioning Inventory;; SIP: Sickness Impact Profile; SCSQ-

A: The Social Communication Skills Questionnaire-Adapted; TBIFI: TBI Follow-Up Interview; NBRS: Neurobehavioural Rating Scale; AI-A: Awareness Interview-Adapted; NSI:

Neurobehavioural Symptom Inventory; *Prigatano et al (1998) used PCRS but translated to Spanish version; Zimmerman et al (2017) used Brazilian version of PCRS; **Counted MPAl and

MPAl-4 as separate as have slightly different scoring systems; Studies using multiple measures of intellectual awareness appear in italics

Appendix A

Search 4, conducted on 14.01.18

Embase (1974 to current), Ovid MEDLINE (1946 to current) PsycINFO (1806 to current). Added limits: Human, Peer Reviewed Journal, English Language, Human Age Groups Adult <18 to 64 years> Aged <65+ years>

1. traumatic brain injur*.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, uui, tc, id, tm]
2. traumatic head injur*.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]
3. exp brain injuries/
4. exp brain damage/
5. exp traumatic brain injuries/
6. intracranial injur*.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, uui, tc, id, tm]
7. neurosurgery.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, uui, tc, id, tm]
8. neurosurgical lesion*.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, uui, tc, id, tm]
9. neurotrauma.mp. [mp=ti, b, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]
10. acquired brain injur*.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, uui, tc, id, tm]
11. TBI.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]
12. ABI.mp. mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]
13. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14. *awareness/
15. exp anosognosia/
16. exp insight/
17. exp self-awareness/
18. exp self-perception/
19. exp self-concept/
20. exp denial/
21. 14 or 15 or 16 or 17 or 18 or 19 or 20
22. proxy.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]
23. overestimat*. mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]
24. underestimat*.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]
25. agreement.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]
26. discrepancy.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]
27. perspectives.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]
28. 22 or 23 or 24 or 25 or 26 or 27

29. assessment.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kw, fx, nm, kf, px rx, an, ui, sy, tc, id, tm]
30. 28 and 29
31. 21 or 30
32. 13 and 31
 - Ovid MEDLINE 1315
 - PsycINFO 951
 - Embase 3083
33. limit 32 to adulthood <18+ years> [Limit not available in Embase, Ovid MEDLINE; records were retained] (4926)
34. limit 33 to English language (4709)
35. limit 34 to (adult <18 to 64 years> or aged <65+ years>) [Limit not valid in Ovid MEDLINE, PsycINFO; records were retained] (2703)
36. limit 35 to humans [Limit not valid in PsycINFO; records were retained] (2657)
37. limit 36 to peer reviewed journal [Limit not valid in Embase, Ovid MEDLINE; records were retained] (2652)
38. remove duplicates from 37 (**1995**)
 - Ovid MEDLINE 935
 - PsycINFO 112
 - Embase 948

Appendix B: Full study demographic information.

Study/Design	TBI sample		Control sample		TBI age at injury	TBI Time since injury	TBI Classification		Setting
	TBI	Informant	Control	Informant			Cause	Severity	
Anderson (1989) USA Cross-sectional	N=19 (16 males 84%); Age: M=26.8, SD=N.S., 18-44 years	NT	N=32 CVA (21 males) M=57.8, SD=N.S., 28-83 years; N=49 DEM (20 males) M=71.5, SD=N.S., 44-91 years	NT	Brain damage acquired in adulthood	N.S	N.S	GCS score M=6.9, SD=3.0, 3-13 Moderate to severe	N.Spec
Pivona (2008) Italy Cross-sectional	N=37 (29 males 78%); Age: M=32.3, SD=11.6 years	First degree relatives only	NT	NT	N.S	Median interval=0.69 years (IQR: 0.45/8.52)	N.S	GCS > 8 (severe)	OP
Pivona (2014) Italy Cross-sectional	N=28 (21 males 75%); Age: M=37.2, SD=13.3, 18-63 years (split into ISA & ASA)	N=28 first degree relatives; 15 parents, 10 partners, 1 child, 2 sisters	N=28 healthy controls; Age: M=34.5, SD=9.9 years. Age, gender, years in education matched	NT	N.S	ISA: M=83.1, SD=772 days ASA: M=782, SD=627 days	25 (89%) sustained severe closed head injury in RTA	GCS > 8 (severe)	OP
Bogod Canada Cross-sectional	N=40 (32 males 80%) M=37.4, SD=8.37, range 22-66 years	Therapist	NT	NT	N.S	M = 132.73, SD = 103.46, 20-576 months	N.S	19 mild-mod, 21 severe (GCS or PTA/LOC score)	IP & OP
Carroll (2011) UK Cross-sectional	N=29 (21 males 72%) M=46.3, SD=12.9, 22-64 years	N=24; 12 spouses/partners, 6 parents, 3 siblings, 3 children. N=29; Clinician providing rehabilitation f- up	NT	NT	N.S	M=11.17, SD=11.4, 2.24-40 years	N.S	9 mild, 2 moderate, 18 severe (GCS or LOC)	OP
Chiu (2016) USA Cross-sectional	N=14 (10 male 71%) M=45.7, SD=12.5 years	14 significant other, relative or close friend	7 healthy control (1 male) M=41.1, SD=11.6 years, age matched	7 significant other, relative or close friend	N.S	M=73.3, SD=44.9 months	N.S	All moderate to severe (GCS <13)	OP
Giurli (2010) Italy Cross-sectional	N=52 (44 males 85%) M=30.6, SD=11.1 years	First degree relatives only; 40 parents, 10 partners, 2 children	NT	NT	N.S	Median interval =0.9 years (IQR: 0.6/5.5)	N.S	Severe (GCS score 8); median TFC 20 days (IQR: 13/37); median PTA 60 days (IQR: 30/100)	OP
Bahlberg (2006) USA Cross-sectional	N=60 (83% male); M=39, SD=11, 20-63 years	SO; 32% parents, 27% spouses, 20% friends, 12% other (siblings/grandparents/chil dren/carer), 10% no SO	NT	NT	N.S	M=7, SD=6, 1-21 years	Defined as injury to brain caused by external mechanical force (excludes non-traumatic e.g. stroke, hypoxic)	65% severe (GCS 3-8), 13% moderate (GCS 9- 12), 8% mild (GCS 13- 15), 13% unknown	OP
Dawson (2005) Canada Cross-sectional	N=31 (61% male) M=27.97, SD=9.35 years	SO: 48.39% spouse/partner; 32.36% spouse/partner; 32.36%	NT	NT	N.S	Followed prospectively M=4.3,	N.S	14 mild 9GCS 13-15) 17 moderate-severe	OP

1	2	Cross-sectional		parent; 6.45% child; 6.45% sibling; 6.45% friend)	NT	NT		N.S		SD=0.89 years post-injury			(GCS 3-12)	
3	3	Dockree (2015)	N=62 (49 male 79%); M=34.37, SD=11.85 years	SO: 23 parent; 18 spouse/partner; 10 siblings; 2 friends; 1 offspring; 1 cousin	NT	NT		N.S		Range 2-326 months M=37.53 months	Excluded if injury resulted from non-traumatic reason (e.g. stroke)	5 mild (13-15) 5 moderate (9-12) 37 severe (<8) 14 unknown (GCS)	N.Spec	
4	4	Ireland												
5	5	Cross-sectional												
6	6													
7	7	Donders (2015)	N=100 (52 male 52%); M=39, SD=16	SO: 48 spouse, 34 parent, 18 other	NT	NT		N.S		M=162.25, SD=93.95 days	46 MVC; 27 recreational activities; 18 falls; 9 other	Mild (GCS >12; TFC <30 mins; PTA <24 hours)	OP	
8	8	USA												
9	9	Cross-sectional												
10	10	French (2014)	N=109 (all male); M=29.3, SD=8.7, 19-56 years	NT	NT	NT		N.S		M=6.2, SD=5.3, 1-24 months	Closed TBI sustained primarily in combat; majority blast related incident	45.9% Mild (PTA<24h, LOC<15mins); 25.7% Moderate (PTA 24h-7 days, LOC<24h); 28.4% severe (PTA >7days)	N.Spec	
11	11	Canada												
12	12	Cross-sectional												
13	13													
14	14													
15	15	Eytenbeek	N=81 (67 male 83%); M=37.3, SD=13.5 years	SO: 50 spouse/partner, 26 parents, 5 other	NT	NT		N.S		F-Up 1, 3, 6 months post-injury	N.S	16 mild to moderate; 65 severe (PTA, GCS)	OP	
16	16	2017) Australia												
17	17	Longitudinal												
18	18	Overover (2014)	N=30 (20 male 66%); M=40.3, SD=11.1, 20-54 years	Family/SO – not further specified	NT	NT		N.S		M=9.05, SD=7.33, 1-27.3 years	23 MVA, 1 all, 3 violence, 3 sport	5 Mild, 1 moderate, 20 severe, 4 undetermined (GCS)	OP	
19	19	SA												
20	20	Cross-sectional												
21	21	Hart (2009)	N=123 (99 male 80%); M=33.2, SD=14.6 years	SO: 56% parent, 24% spouse or cohabiting partner, 11% other family member	NT	NT		N.S		Injury to baseline: M=45.3, SD=29.4 days	59% MVC, 18% gunshot or assault with blunt weapon, 11% fall	Severe TBI with mean TFC greater than 1 week and mean PTA of 1 month, GCS	IP	
22	22	SA												
23	23	Longitudinal												
24	24													
25	25	Kelley (2014)	N=62 (56 male 90%; 48 veterans.; 23-70 years (median 35)	N=62 SO: 32 parents, 12 spouses, 8 siblings, 8 close friends	NT	NT		18-62 years (median 25)		5-16 years post-injury (median 9)	Non-penetrating TBI (exclusion criteria included stroke)	Moderate to severe (PTA)	OP	
26	26	SA												
27	27	Cross-sectional												
28	28	Anham (2000)	N=55 (45 male 82%); M=30.0, SD=10.3 years, veterans and active duty military personnel	SO: 20 spouse/mate, 24 parent, 8 friend, 3 other relative	NT	NT		N.S		Baseline: Ave 2 months post-injury (median 39 days, range 3-141 days)	N.S	Spanned range, but more towards moderate to severe (LOC, PTA, neuroimaging)	N.Spec	
29	29	SA												
30	30	Longitudinal												
31	31													
32	32	Arson (2009)	N=16 (12 male 75%); M=30.88, SD=12.98, 18-52 years	SO – primary caregivers: 8 spouses/fiancée, 6 parents, 1 grandparent, 1 aunt	NT	NT		N.S		M=10.69, SD=7.60, 2-29 months	N.S	Severe: M=4.44, SD=1.75, 3-8 (GCS)	N.Spec	
33	33	SA												
34	34	Cross-sectional												
35	35	Malec (2007)	N=93; 42 mild TBI (48% male) M=35.8, SD=20.1 years, 51 mod/severe TBI (61% male) M=35.7, SD=17.3	SO	N=42 orthopaedic controls (62% male)	SO		N.S		M=47.1, SD=44.5 days	N.S	42 mild, 51 moderate/severe (GCS; neuroimaging)	OP	
36	36	SA												
37	37	Cross-sectional												
38	38													
39	39													

1	2	Richardson (2014)	N=60 (50 males 83%); M=42.94, SD=16.66	Close others to corroborate func status and injury related changes	NT	NT	N.S	M=7.73, SD=4.11 months	39 MVA, 8 Pedestrian, 7 Cyclist, 5 Fall, 1 work related	67% severe, 22% moderate, 10.6% mild (PTA, GCS)	OP
3	4	Australia Longitudinal									
5	6	Richardson (2015)	N=168 (112 male 66%); M=43.78, SD=17.15 years	N=105 SO: 37 parents, 45 spouse, 6 siblings, 12 child, 9 friend	NT	NT	N.S	M=53.56, SD=64.63 months	66.7% MVA and motorbikes, 16.1% pedestrian vs. motor vehicles, 8.3% falls, 6.5% cyclists vs. motor vehicle, 2.4% work-related	72% severe, 16.7% moderate, 11.3% mild (PTA, GCS)	OP
7	8	Australia Cross-sectional									
9	10	Roche (2005)	N=33 (79% males); M=29, SD=10.8 years	Close friend or relative; 14 mothers, 7 wives, 5 fathers, 4 husbands, 1 sister, 2 other	NT	N=29 (79% males) non-brain injured controls, age, gender, education matched	N.S	M=52, SD=36 weeks	52% MVA, 15% hit by motor vehicle, 12% fall from moving vehicle/animal, 9% in motor bike accidents, 3% falls, 3% alleged assault, 3% penetrating injury, 3% light plane accident	Severe (GCS < 8, PTA > 24 hours)	OP
11	12	Canada Cross-sectional									
13	14										
15	16	awchyn (2005)	N=166 (88% males); M=39, SD=11.21 years	SO; 55% spouses, 10% parents, 10% siblings, 7% friends	NT	NT	N.S	Mild: M=687, SD=814 days; Mod M=665, SD=506 days. Severe M=745, SD=930 days	43% fall, 21% impact trauma, 23%MVA, remainder sustained crush- type injury, assault, or other trauma	83 mild, 25 moderate, 58 severe (LOC, PTA, GCS)	OP
17	18	Canada Cross-sectional									
19	20	herer (1998)	1: N=64 (52 males 81%) M=28.8, SD=9.8 years 2: N=47 (36 males 76%) M=30.9, SD=12.7 years	1: SO; 14 spouses, 39 parents, 7 siblings, 2 SOs, 2 friends 1: 20 spouses, 19 parents, 4 siblings, 2 grandparents, 2 SO; Clinician	NT	NT	N.S	1: M=13.0, SD=20.8, 0.9-91.6 months 2: M=7.4, SD=12.5	1: non-penetrating TBI, motor vehicle crashes	1: 48 severe, 10 moderate, 6 mild (GCS) 2: 22 severe, 7 moderate, 7 mild (GCS)	N.Spec
21	22	UK Cross-sectional									
23	24	anderploeg (2007) USA Cross-sectional	N=36 (94% male) M=38.9, SD=2.0 years	65% parents or siblings, 27% spouses or SO, 9% friends or other family members	NT	NT	N.S	M=25.5, SD=20.3, 2.4-70 months	Active military personnel. Most were injured in MVA (79%) or falls (12%)	Moderate to severe (PTA and positive neuroimaging)	OP
25	26	immerman (2017) Brazil Cross-sectional	N=65 (48 male 73%); M=36.2, SD=14.1, 18-72 years	Relatives	NT	NT	N.S	M=22.9, SD=22.7, 2- 127 months	Closed TBI	26 mild, 39 moderate- severe (GCS and/or LOC or PTA)	OP

NT = Not tested; N.S = Not Stated; N.Spec = Not Specified; SO = Significant Other; RTC = Road Traffic Collision; MVA = Motor Vehicle Accident; IP = Inpatient; OP = Outpatient; CVA = Cerebrovascular accident; GCS = Glasgow Coma Scale; LOC = Loss of Consciousness; PTA = Post-Traumatic Amnesia; TFC = Time to Follow Commands; Note: If studies included more than one time point, the baseline time point was taken as time since injury indicator.

Appendix C: Quality ratings outcome

Paper	Items of the 'Checklist for assessing the quality of quantitative studies' (Kmet, Lee & Cook, 2004)														Rating	
	Q1	Q2	Q3	Q4	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Total				
Anderson (1989) USA	1	1	2	1	1	1	1	2	2	2	2	16			Fair	
Bivona (2008) Italy	2	1	2		2	1	2	2	1	2	2	19			Good	
Bivona (2014) Italy	2	2	2	1	2	1	2	2	2	2	2	20			Good	
Bogod (2003) Canada	2	2	2	2	1	2	2	1	1	2	2	19			Good	
Carroll (2011) UK	1	2	2	2	2	1	1	2	1	2	2	18			Good	
Chiou (2016) USA	2	2	2	2	2	1	2	2	2	2	2	21			Good	
Ciurli (2010) Italy	2	2	2	2	2	2	2	1	2	2	2	21			Good	
Dahlberg (2006) USA	1	2	2	2	2	2	2	1	0	2	2	18			Good	
Dawson (2005) Canada	2	2	2	1	2	1	2	2	2	2	2	20			Good	
Dockree (2015) Ireland	2	2	2	2	2	2	2	2	2	2	2	22			Good	
Donders (2015) USA	2	2	2	2	2	2	2	2	2	2	2	22			Good	
French (2014) Canada	2	2	2	2	2	2	1	2	1	2	2	20			Good	
Geytenbeek (2017) Australia	1	2	2	1	2	2	2	0	2	2	2	18			Good	
Goverover (2014) USA	2	2	2	2	2	1	2	2	2	2	2	21			Good	
Hart (2009) USA	2	2	1	2	2	2	2	1	2	2	2	20			Good	
Kelley (2014) USA	2	2	2	2	1	2	2	2	1	2	2	20			Good	
Lanham (2000) USA	1	2	2	1	2	2	1	0	2	1	2	16			Fair	
Larson (2009) USA	2	2	2	1	2	1	2	2	2	2	2	20			Good	
Malec (2007) USA	1	1	1	1	1	2	2	0	1	2	2	14			Fair	
Medley (2010) UK	2	2	2	2	1	2	2	0	0	2	2	17			Good	
Morton (2010) UK	2	2	2	2	2	1	1	1	2	2	2	19			Good	
Murray (2005) USA	2	2	2	2	2	2	2	0	0	2	2	18			Good	
Niemeier (2014) USA	2	2	2	2	2	2	2	2	2	2	2	22			Good	
O'Keefe (2007) UK	2	2	2	2	2	1	1	0	2	2	2	18			Good	
Pagulayan (2007) USA	2	2	2	1	2	2	2	2	1	2	2	20			Good	
Prigatano (1996) USA	2	2	2	1	1	1	2	0	0	2	2	15			Fair	
Prigatano (1998) Spain	2	2	2	2	2	1	2	2	2	2	2	21			Good	
Richardson (2014) Australia	2	1	2	2	2	1	2	2	2	2	2	20			Good	
Richardson (2015) Australia	2	2	2	2	2	2	2	2	2	2	2	22			Good	
Roche (2005) Canada	2	2	2	2	2	2	2	1	0	2	2	19			Good	
Sawchyn (2005) Canada	2	2	2	2	2	2	1	0	2	2	2	19			Good	
Sherer (1998) UK	1	2	2	2	1	2	2	1	1	2	2	16			Fair	
Vanderploeg (2007) USA	2	2	2	2	2	2	2	0	2	2	2	20			Good	
Zimmerman (2017) Brazil	2	2	2	2	2	2	2	2	2	2	2	22			Good	

Note: scores 1 – 8 = poor quality; scores 9 – 16 = fair quality; scores 17 – 22 = good quality. Questions 5, 6 and 7 were excluded as these relate to intervention studies and were therefore deemed inappropriate for the current review

PRISMA 2009 Flow Diagram

Figure 1: Flow diagram of study selection process