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ORIGINAL ARTICLE

Brain Injury Sense of Self Scale: psychometric development of a new measure of strength of self-identity after traumatic brain injury

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ABSTRACT

BACKGROUND: There is growing awareness that traumatic brain injury (TBI) can have a significant and troublesome impact of a person's self-identity, yet few measurement tools exist to clinically evaluate this.
AIM: The aim of this paper was to develop a patient-reported measure of strength of self-identity after TBI - the Brain Injury Sense of Self Scale (BISOSS).
DESIGN: Measurement development and validation
SETTING: UK and New Zealand communities.
POPULATION: One hundred and thirty-six people with TBI (68.4% [93/136]) male; mean age 47.9 years, SD 13.0 years; mean time post-TBI 11.2 years, SD 11.1 years; 74.3% (101/136) moderate to severe TBI).
METHODS: Preliminary measurement items were generated from prior qualitative research, a concept analysis, and cognitive interviewing with survivors of TBI. Administration of the draft BISOSS, the Glasgow Outcome Scale, and the Sense of Coherence Scale to participants – with factor analysis, Rasch analysis, and construct validity testing to refine and test the draft BISOSS.
RESULTS: After iterative refinements using the Rasch model to help guide item adjustments, BISOSS was comprised of three subscales (egocentric self, sociocentric self, and relational self), each which fit the Rasch model and demonstrated unidimensionality, adequate precision, absence of differential item functioning and adequate person separation index. BISOSS scores correlated well with employment status, leisure activities and positive family relationships. Participants' responses supported the notion that problems with self-identity were commonplace after TBI, with 40% of respondents self-reporting such problems.
CONCLUSIONS: BISOSS is a valid measure, which conforms to measurement expectations for an interval scale and is in grounded in the language of people with TBI. It is now available as a validated tool for assessing self-identity issues post-TBI. Further work is required to assess whether the scale can change over time or is responsive to interventions targeted at strengthening self-identity.
CLINICAL REHABILITATION IMPACT: Change in self-identity is a commonplace problem following TBI but is seldomly evaluated in clinical practice. BISOSS can be used to explore patient experiences of problems with self-identity after TBI and will help further our understanding of this phenomenon.

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KEY WORDS: Brain injuries; Self concept; Patient reported outcome measures; Psychometrics.

There has been growing awareness of the impact of traumatic brain injury (TBI) on a person's sense of self.[1-11] However, recognition of problems with self-identity as a clinical issue date back to at least 1939 – with Goldstein's paper, *The Organism*, in which he stated that: "It is impossible to consider any illness – but above all, a neurological illness – without reference to the patient's self"[12] (p.11). Goldstein championed a holistic view of psychological wellbeing in neurorehabilitation, recognizing that the effects of TBI cannot be entirely explained by pathophysiology and neuroanatomy; rather that TBI should be seen as an event that has impact on the person as a whole.

The terms self-identity and sense of self refer to "the subjective sense of one's own being", with "sense of self" referring to "the process of producing this subjective sense" and "self-identity" referring to "the product of this process"[13] (p.165). Previously, as the result of a concept analysis derived from previously published literature, we defined "change in sense of self following TBI" as being "a change in one's inner subjective experience as a result of changes in egocentric or sociocentric aspects of self, or in the relationship with one's identity as shared with others [with] these changes [being] of sufficient magnitude that a process of evaluation, acceptance, and adaptation is required to regain a unified sense of self"[14] (p.1043). Theories of self-identity have arisen from philosophy, developmental psychology, social psychology, cognitive psychology, neuroscience, sociology, occupational therapy and linguistics.[14] In literature on TBI, relevant theories have included the egocentric model of self,[15, 16] the sociocentric model of self,[17, 18] social identity theory,[19] Erikson's developmental model of ego identity,[20, 21] Damon and Hart's model of self-understanding,[22, 23] self-identity as memory,[24-26] self-identity as meaningful occupation or role,[11, 27, 28] and self-identity as narrative.[29, 30] Contemporary neuroscience has also suggested the importance of embodied experiences[31, 32] and predictive cognitive processes to the development and maintenance of self-identity.[33]

A number of scales have been used in past attempts to quantify change in a person's sense of self after TBI, including the Head Injury Semantic Differential Scale (HISDS),[34] Selves Adjective Checklist,[35] Rosenberg's self-esteem levels,[36] Tennessee Self-Concept Scale,[37, 38] and various personality inventories.[6] These existing scales all have limitations. Only the HISDS has been specifically designed for people with TBI.[34] Change in personality, while overlapping with change in self-identity, is conceptually different and often evaluated clinically from a third-party perspective rather than reflecting a person's internal sense of having a changed self.[14] The HISDS and the Tennessee Self-Concept Scale are both based on a retrospective comparison of self-concept prior to injury with current self-concept, to produce a measure of perceived change.[34, 39] Self-concept however is only one part of the construct of self-identity,[9, 13, 14] and retrospective self-report introduces considerable systematic bias to outcome measurement, even in people without brain injury.[40] Thus there is a need to develop better measures of problems with self-identity following TBI.[3, 7]

The aim of this research was to develop a psychometrically robust measure of strength of self-identity after TBI – one that conformed to expectations for interval scale measurement,[41] reflected point-in-time experiences of self-identity (without need for retrospective comparison), and one that is grounded in the language and experiences of people with TBI. Prior to this study, we first completed two projects to operationalize the concept we intended to measure: 1) a grounded theory investigation of the lived experience of change in self-identity after TBI[42] and 2) a concept analysis examining how changes and reconstruction of self-identity after TBI have been conceptualized in past research.[14] The outcome of these projects was to develop a preliminary framework and list of candidate items for a potentially new measure: the Brain Injury Sense of Self Scale (BISOSS).

Materials and methods

The University of Otago Human Ethics Committee (Health) in New Zealand (Project 13/137) and from the National Research Ethics Service Committee London (Protocol number: P140220) approved this study. All participants provided written consent.

Initial item generation

We derived draft measurement scale items for BISOSS from the concepts and language that emerged from our qualitative investigation of lived experiences of change in self-identity after TBI.[42] Based on this research, we organized draft items into three sections: 1) "How I feel about myself"; 2) "How other people treat me"; and 3) "How I feel about my place in the world". We used the Patient-Reported Outcome Measurement Information System Co-operative Group's guidelines to develop and test the draft items,[43] aiming for a reading age of 12 years.[44] We used results from our concept analysis to evaluate and refine items, providing a scientific and philosophical foundation to the draft measure.[14] Thirteen participants took part in cognitive interviews to pilot the draft items, during their development, prior to full scale data collection.[43]

At the end of this process we had a three-part draft questionnaire, with 45 items. Each item was a statement about self-identity with a four-point Likert-style response scale (strongly disagree, disagree, agree, strongly disagree). Q1 was an item about global difficulty with sense of self and was not included in summative analyses ("I feel that I have problems with my self-identity or am unsure about who I am"), but was used to provide an approximate anchor for subsequent validity testing of the summated multi-item scores.

Participant recruitment

We recruited participants from TBI support and rehabilitation services in New Zealand (the Brain Injury Association and ABI Rehabilitation) and the UK (two National Health Service Trusts, and branches of Headway). Participants needed to be over 18 years at injury; at least six months following TBI; have sustained a period of loss of consciousness, confusion or amnesia associated with the injury event; and be able to consent for themselves. We excluded people who reported a history of head injury with no disturbance of consciousness or focal neurological symptoms or who had post-concussion symptoms only.

Data collection

We collected all data by face-to-face interview between 2013 and 2015. All participants provided demographic information (age, gender, ethnicity, employment status, marital status, educational history, time since injury) and completed the prototype BISOSS questionnaire and the Glasgow Outcome Scale – Extended (GOS-E).[45] We classified severity of TBI based on the Mayo TBI severity classification system.[46] Fifty participants also completed the Sense of Coherence scale.[23] An additional question with the same four point scale as other BISOSS items was added to give a broad evaluation of problems with self-identity: "I feel that I have problems with my self-identity or am unsure about who I am." We hypothesized that strong sense of self should show a strong positive correlation with meaningful occupation and family relationships (as assessed with GOS-E) and a moderate positive correlation with Sense of Coherence. We estimated severity of injury from reports of duration of loss of consciousness or post-traumatic amnesia.

Development of BISOSS using Rasch analysis

We used Rasch analysis (RUMM 2030 software)[24] for internal validation and construction of BISOSS as this method has several distinct advantages over classical test theory.[18, 25] Rasch analysis utilizes a 1-parameter (item difficulty) probabilistic model to generate interval level data from ordinal counts and is recommended as the most suitable measurement model for construction and validation of rating scales within social sciences.[26] A detailed description of Rasch analysis has been presented elsewhere.[27] Rasch validated scales produce interval level data, allowing the use of parametric statistics and calculation of means and change scores, which is not always the case with ordinal level scores produced from classical test theory analyses.

Rasch analysis involves iterative response data examination and item modification to fit the observed data to the Rasch model while preserving the meaningfulness of the item pool according to one's understanding of the concept being measured. For questionnaires with polytomous answer categories, either the unrestricted Partial Credit model (different response thresholds across items) or the Rating Scale model (the same response thresholds across items) can be applied, and a likelihood ratio test was used to determine the most appropriate model. A series of technical procedures were performed according to published recommendations[28, 29] that included: 1) Examination of overall model fit; 2) examination of thresholds, and rescoring if thresholds are disordered; 3) examination of individual person and item fit, and sequential deletion of items or persons showing significant misfit (standardized residuals $>|\pm 2.5|$); 4) assessing for differential item functioning (DIF) by age at injury, gender, time since injury and severity of injury; 5) test for unidimensionality using a principle component analysis (PCA) of standardized residuals implemented in RUMM2030 ("the t-tests procedure");[31, 32] 6) assessing for local dependency; and 7) examination of person-item threshold distributions. Five person factors – age at injury, time since injury, severity of injury, gender, and ethnicity – were identified as relevant variables to consider when analyzing for DIF. Missing data is handled within RUMM2030 as part of the Rasch analysis.

Sample size

For 99% confidence that stable item calibrations to within±0.5 logit are obtained, 108-243 people are needed (if targeting is good to poor); 64-144 people are needed for 95% confidence. We aimed for a sample size of approximately 100 to 150 participants.

Table I.—*Participant characteristics.*[46]

Total number recruited (UK/NZ)		136 (102/34)
Male (%)		93 (68.4)
Marital status (%)	Married/in a committed relationship	53 (39.0)
	Not specified	1 (0.7)
Ethnic group (%)	White British/ NZ European	122 (89.7)
	Other	14 (10.3)
Age at interview (years), N.=135	Mean (SD)	47.9 (13.0)
	Median	50
	Range	18-79
Age at TBI (years), N.=135	Mean (SD)	36.8 (15.1)
	Median	33
	Range	17-75
Time since TBI (months), N.=135	Mean (SD)	134 (133)
	Median	84
	Range	6-576
Severity of TBI* (%)	Mild	31 (23.5)
	Moderate/severe	101 (74.3)
	Not classified	4 (2.9)
Glasgow Outcome Scale (GOSe) (%)	3/4	52 (38.2)
	5/6	71 (52.2)
	7/8	13 (9.6)
Employment status (%), N.=136	Paid employment (full time)	23(11) (16.9)
	Voluntary/ unpaid employment	23 (16.9)
	Unable to work	62 (45.6)
	Unemployed but seeking work	10 (7.4)
	Other	18 (13.2)

*Severity of TBI was categorized based on the Mayo TBI severity classification System.[46]

Results

We recruited 136 participants (34 New Zealand; 102 UK). On average, participants were 47.9 (standard deviation (SD) 13.0) years old and 11.2 years (SD 11.1) post-TBI. The majority (74.3%; 101/136) were estimated to have sustained moderate to severe TBI (Table I).[46]

Initial analysis

The research log of participant feedback indicated that participants had substantial problems rating their agreement with one question (Q31 "I have been rejected by people who were important in my life") because the question involved two components: rejection and the importance of the person doing the rejecting. This item was therefore removed from further analysis.

A Likelihood-Ratio Test was performed on the remaining 44 item data set in RUMM, χ^2 probability=0.0001, confirming that the unrestricted Partial Credit model should be employed. The initial analysis had ordered item-category thresholds but showed low category frequencies (fewer than 10 responses) for 25 of the items, which required rescoring by merging response categories.[30] Person fit was assessed and one participant showed significant misfit to the model's expectations with a fit residual of 5.249 and an aberrant response pattern and was therefore removed from the remainder of the analysis.

In the initial analysis, there was clear evidence of a misfit to the model (item-trait Chi-squared interaction P=0.002) and multidimensional structure, with 22.0% (30/136) of the *t*-tests between person estimates derived from items that positively loaded on the first factor of a PCA of the standardized residuals compared to person estimates derived from items that negatively loaded being significant. For acceptable unidimensionality this should be <5%.[31, 32] There was no evidence of DIF. The three sections of the questionnaire were examined separately as individual subscales and as subtests. However the problems with poor fit and multidimensionality persisted, so the structure of the data was examined with factor analysis before any further Rasch analyses (Supplementary Digital Material 1, Supplementary Text File 1 for details regarding the factor analysis). Factor analysis supported the existence of a three-factor structure, once one item was removed (Q46 "I feel left out," which correlated poorly with the rest of the scale) and some items were regrouped. The three sec-

TABLE II.—*Questionnaire items grouped into three subscales before and after Factor Analysis.*

Subscale 1: Egocentric Self (17 items)	Subscale 2: Sociocentric Self (18 items)	Subscale 3: Relational self (8 items)
3. I have a clear idea of who I am 4. I feel in control of my actions 5. I feel like I know where my life is going 6. I feel like a whole complete person 7. There are bits of my life that don't hang together 8. I feel clear about what I am capable of 9. I am able to achieve goals I set for myself 10. I feel like I try to be someone I'm not 11. I live more in the past than the present 12. I feel the story of my life makes sense 13. I accept myself for who I am 14. I sometimes behave in a way that doesn't seem like me 15. I feel confused about who I am 16. I sometimes feel like I am living someone else's life 17. I am not who I want to be	32. I feel that other people value my point of view 33. I feel like there is a place in the world for me 34. I know where I fit in the world 35. I am generally satisfied with my relationships with other people 36. I feel like a useful member of my community 37. I am able to do things for other people 38. I have a sense of belonging to a community 39. I feel there is purpose and meaning in my life 40. The things I do give meaning to my life 42. I feel I am labelled by others 43. I am able to express myself in the things I do 44. Other people treat me as an equal 45. I wish there were more people in my life	18. I feel valued by people who are important to me 19. I feel understood by people who are important to me 20. I feel accepted by people who are important to me 21. I have a close relationship with someone who makes me feel valued as a person 22. My family have a good understanding of who I am 23. My family accepts me for who I am 24. I feel like a valued member of my family 25. I feel respected by my family
Items moved following Factor Analysis *		
	2. I know what is important to me	
	26. I have friends who accept me for who I am	
	27. I feel valued by my friends	
	28. I feel respected by my friends	
29. I feel that people expect me to be someone I'm not		
	30. I feel that other people think I'm useless	
41. Other people see me in the same way I see myself		

*Numbering refers to the initial order of questions in the draft BISOSS scale. Q1 was not scored and Q31 was removed at an earlier stage following negative feedback. Items were initially grouped as follows: Q2-17 into section 1 "How I feel about myself", Q18-31 into section 2 "How other people treat me" and Q32-45 into section 3 "How I feel about my place in the world". The factor analysis broadly concurred with this structure but a few items mapped better into a different section from the one they were initially allocated and the arrows indicate where an item has been reassigned to a different subscale. The subscales have been renamed - section 1 has become "Egocentric subscale"; section 2 "Relational subscale" and section 3 "Sociocentric subscale."

tions of the questionnaire were named 1) egocentric; 2) sociocentric; and 3) relational subscales (Table II). These item groups were then further analyzed as separate scales with Rasch.

Egocentric subscale (BISOSS-E)

Initial fit statistics (Analysis BISOSS-E; Table III) were consistent with fit to the Rasch model with a mean item fit residual of 0.151 (SD 1.039) and mean person fit residual of -0.279 (SD 1.463). Item-trait Chi-square interaction P value was 0.668, also consistent with fit to the model. Person separation index (PSI), an indicator of internal consistency similar to Cronbach's alpha, was 0.92. Thresholds were ordered but Q7 needed category merging because of low number of responses in one category. There was no evidence of local dependency or DIF. Tests for unidimensionality were acceptable. The person-item threshold distribution plot showed a good range of item difficulty covering a range from -2.0 logits to +2.0 logits (Figure 1). Overall, the egocentric subscale performed well, showing good fit to the model, meeting the model's expectations of invariance and unidimensionality. It was well targeted and had good discriminatory ability. No consequential local item dependence was found.

Sociocentric subscale (BISOSS-S)

Initial summary statistics (Analysis BISOSS-S; Table III) showed reasonable fit to the model with mean item fit -0.112 (SD 1.386) and mean person fit -0.452 (SD 1.734). However, the summary statistics demonstrated a lack of invariance with a significant Chi-squared interaction of <0.001. This subscale showed clear evidence of multidimensionality with 19/132 (14.39%) *t*-tests positive at the 5% significance level. There was evidence of significant (>0.3 above the average correlation) local dependency between the three items asking about relationships with friends (Q26, Q27, Q28). There was no evidence of DIF.

Further analyses were run, with the scale being sequentially modified by removal of four items to eliminate local dependency and misfit (Q27, Q28, Q42, Q45). Fit of the modified scale to the model was improved and satisfactory. The person-item threshold distribution plot for the

TABLE III.—*Summary of iterative analyses fitted to the partial credit Rasch model.*

Analysis name	Item Location mean (SD)	Person Location mean (SD)	Item Fit Residual mean (SD)	Person fit residual mean (SD)	Chi-squared interaction P value	PSI	Uni-dimensionality Number of significant *t*-tests (%)	Lower bound 95% CI
Initial	0 (0.63)	0.65 (1.23)	0.08 (1.64)	-0.48 (2.31)	0.002	0.96	30/136 (22.06)	
BISOSS-E	0 (0.43)	0.03 (1.39)	0.15 (1.04)	-0.28 (1.43)	0.65	0.92	10/134 (7.46)	0.038
BISOSS-Er*	0 (0.39)	0.09 (1.39)	0.17 (1.05)	-0.27 (1.46)	0.67	0.91	11/134 (8.21)	0.045
BISOSS-S	0 (0.44)	0.20 (1.36)	-0.11 (1.39)	-0.45 (1.73)	<0.001	0.91	19/132 (14.39)	0.107
BISOSS-Sr*	0 (0.43)	0.27 (1.39)	-0.12 (1.28)	-0.43 (1.71)	0.006	0.90	20/132 (15.15)	0.114
BISOSS-Sa	0 (0.45)	0.26 (1.37)	-0.10 (1.32)	-0.41 (1.62)	0.002	0.89	14/132 (10.61)	0.069
BISOSS-Sb	0 (0.46)	0.23 (1.44)	-0.10 (1.25)	-0.46 (1.62)	0.02	0.89	12/132 (9.09)	0.054
BISOSS-Sc	0 (0.44)	0.18 (1.45)	-0.10 (1.19)	-0.52 (1.69)	0.28	0.89	9/135 (6.87)	0.030
BISOSS-R	0 (0.68)	0.38 (1.89)	-0.34 (1.29)	-0.54 (1.46)	0.09	0.88	2/118 (1.69)	-
BISOSS-Rr*	0 (0.52)	0.16 (1.89)	-0.34 (1.24)	-0.53 (1.45)	0.03	0.84	2/117 (1.71)	-
BISOSS-Ra	0 (0.53)	0.18 (1.96)	-0.36 (1.17)	-0.64 (1.50)	0.91	0.83	0/115	-
BISOSS-Rb	0 (0.37)	0.27 (1.95)	-0.22 (1.12)	-0.54 (1.32)	0.69	0.83	1/115 (0.87)	-
BISOSS-Rc	0 (0.34)	0.29 (1.85)	-0.50 (1.13)	-0.81 (1.72)	0.68	0.78	3/130 (2.31)	-
BISOSS-Rd	0 (0.57)	0.13 (1.92)	-0.23 (0.76)	-0.55 (1.30)	0.36	0.79	0	-

PSI: Person Separation Index.
r* indicates a rescore analysis.

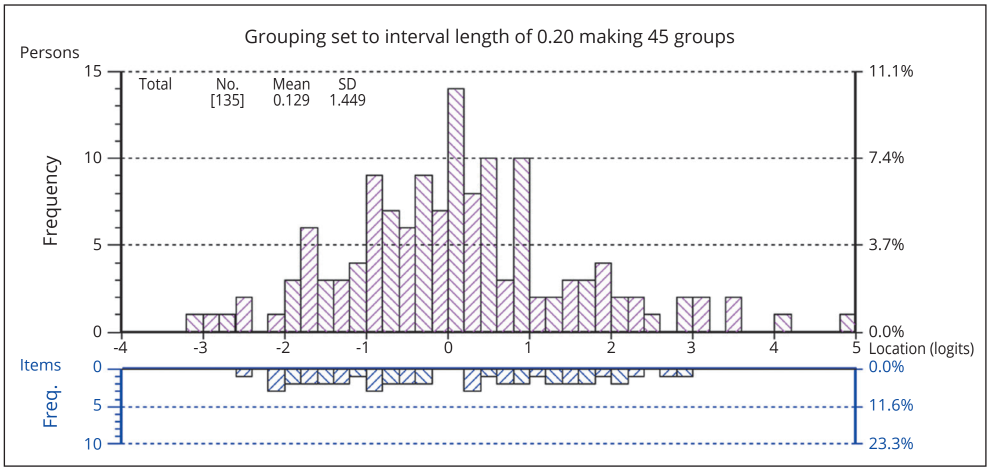

Figure 1.—Person-item threshold distribution for Egocentric subscale (Factor 1).
The items in this subscale are well spread over a range of -2.5 logits to +3.0 logits. There is a lack of items with a threshold at the zero logits mark, but overall the scale shows a good ability to measure people accurately across a range of abilities.

revised items demonstrated good spread of items over a suitable ability range (Figure 2). PSI for the final scale (14 items) was 0.89. No consequential local item dependence was found.

Relational subscale (BISOSS-R)

Initial fit statistics (Analysis BISOSS-R; Table III) were acceptable with a mean item fit -0.362 (SD 1.173) and a mean person fit 0.527 (SD 1.446) and all the items were working across all class intervals (Chi-square probability 0.092). However, there was a significant ceiling effect with 18 participants scoring maximally, reducing the sample size for further analysis to 118 participants. Rescoring for low category response frequency was required for Q22 and Q24.

This subscale met the requirements for unidimensionality with 2/118 (1.69%) *t*-tests significant at the 5% level. However, there was significant local dependency between two items (Q22 and Q23) violating the model's requirements. Subtests can provide one way of handling local dependency in this situation, but this was at the expense of unidimensionality, therefore sequential deleting of items (Q21, Q22) was used to try and improve fit to the model.

The fit was satisfactory and the local dependency solved. The person-item threshold distribution of the final relational subscale showed good targeting and ability to measure across a wide range, *i.e.* -3.0 logits to +3.0 logits. Floor and ceiling effects were apparent with several participants falling outside of this range. This six-item scale showed poor precision however, with no items able to discriminate between people falling in the -1.0 logits to +1.0 logits range (Figure 3). PSI for the final scale (6 items) was 0.79. No consequential local item dependence was found.

Completion and dissemination of BISOSS and an implementation guideline

At the end of Rasch analysis, 36 of the original 45 items had been placed into one of three subscales - BISOSS-E ("How I feel about myself,") BISSOS-S ("How I feel about my place in the world"), and BISOSS-R ("How other people treat me"). Each item is rated on a 4-point Likert-type rating scale from "Strongly agree" to "Strongly disagree." The final BISOSS questionnaire was created with these 36 items along with a guideline for its use. This is freely available for download and use under the terms of the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license from: https://hdl.handle.net/10523/41553.[47] The guideline contains instructions for the administration and scoring of BISOSS, a blank copy of the BISOSS form, and an Excel spreadsheet to facilitate conversion of raw BISOSS scores into interval scores for clinical and research purposes. We recommend that BISOSS is best implemented by an interviewer, however the full BISOSS form has a Flesch-Kincaid Grade Level score of 8.7, which means that it is suitable for people with a reading age of a 13-14 year old, while the BISOSS items alone have a Flesch-Kincaid Grade Level score of 4.8, meaning that people with a reading age typical of 9-11 year olds should be able to make sense of them.

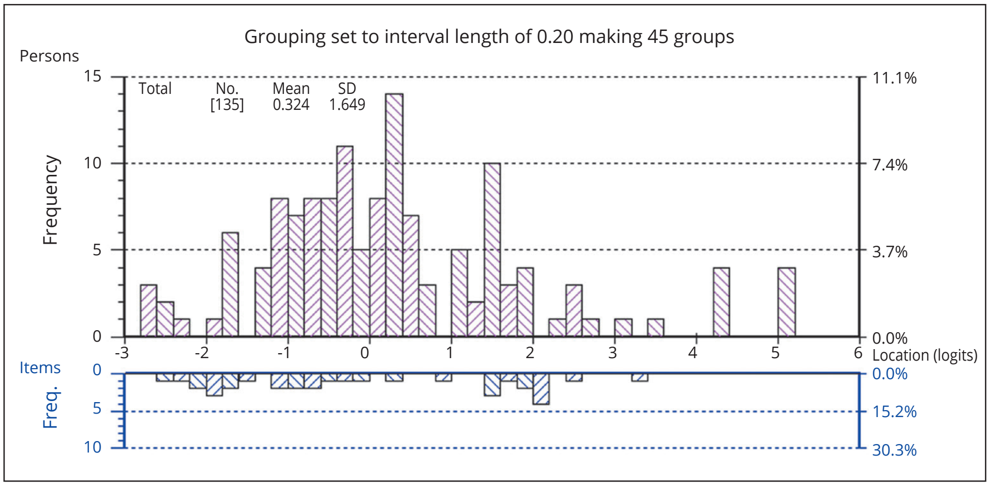

Figure 2.—Person-item threshold distribution for Sociocentric subscale (Factor 2).
The items in this subscale are well spread, covering a range from close to -3.0 logits to just over 3.0 logits. However, there is a skew towards the negative end of the scale with more item thresholds in the 0 to -3.0 range compared with the positive end of the scale. There is a lack of coverage in the zero to +1.0 logits range in particular, showing an inability of the subscale to differentiate between people in this ability range.

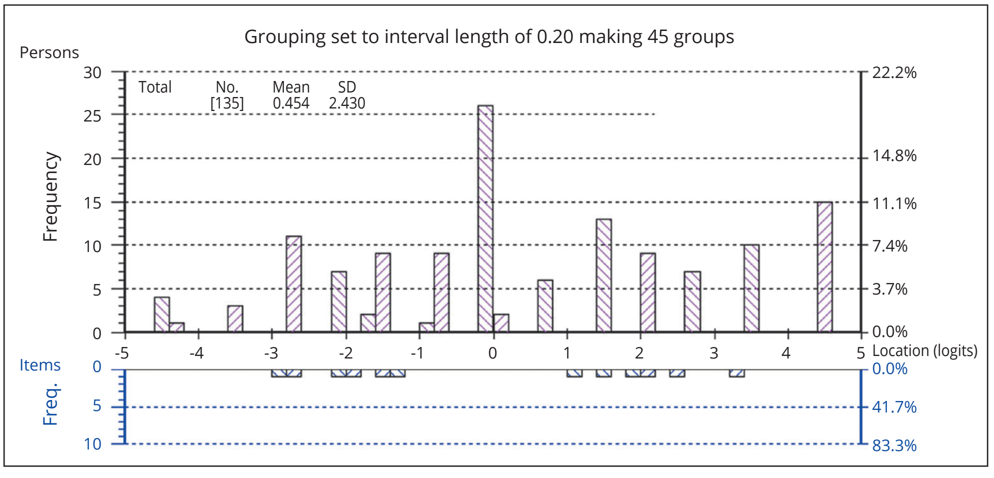

Figure 3.—Person-Item threshold distribution for Relational subscale (Factor 3).
The items cover a range from -3.0 to +3.0 logits but they are significantly clumped in the range -3 to -1 and +1 to +3 with no items available to discriminate in the -1 to +1 logits range of the scale.

Construct validity testing

The calculated person estimates (*i.e.* Rasch transformed BISOSS scores) were used for construct validity testing. The Sense of Coherence scale was challenging for the participants to complete due to the complex question structure and seven-point answer scale. Contrary to the predictions there was no significant correlation between BISOSS scores and SOC scores (Spearman's Rho -0.085 BISOSS-E, -0.076 BISOSS-S and -0.195 BISOSS-R).

The predicted correlations between employment status, resumption of leisure activities (GOS-E question 6) and family relationships (GOS-E question 7) were mostly seen. Independent sample *t*-tests were used to compare BISOSS scores between groups of participants based on their employment status or response to GOS-E questions, with $P<0.05$ being used to indicate significant differences between groups. There was a significant difference in all three subscales between those resuming work and those who had not ($P=0.026$ BISOSS-E, $P<0.001$ BISOSS-S and $P=0.011$ BISOSS-R) and in those reporting family or friendship disruption compared to those who did not ($P<0.001$ for all scales). There was a significant difference in BISOSS scores for egocentric and sociocentric subscales between the groups of participants reporting resuming leisure activities and those who had not ($P<0.001$ BISOSS-E, $P=0.007$ BISOSS-S and $P=0.167$ BISOSS-R).

The predicted correlation between BISOSS scores and responses to Q1, "I feel I have problems with my self-identity or I am unsure about who I am" was also observed (Spearman's Rho 0.64 BISOSS-E, 0.53 BISOSS-S and 0.39 BISOSS-R; $P<0.001$ for each correlation).

Discussion

Building on our earlier conceptual work,[14, 42] this study provides evidence that BISOSS is a valid interval scale, comprised of three internally consistent unidimensional subscales, which measures strength of self-identity after TBI. Like other complex constructs (*e.g.* quality of life), self-identity cannot be easily summed up in a single score. Nonetheless, the three scales of BISOSS combine together to provide an overall assessment of strength of sense of self.

BISOSS provides a number of advantages of over similar scales. Firstly, BISOSS is a point-in-time measure that is not dependent on a person's ability to remember their life prior to injury. Secondly, BISOSS avoids statements about emotional responses to issues with self-identity, so can be used to evaluate problems with self-identity separately from problems with mood. Thirdly, BISOSS is grounded in language used by people with TBI,[42] so is easy for patients to comprehend, minimizing item misinterpretation.

Fourthly, BISOSS scores fit the Rasch model,[41] which ensures interval data that are valid to use with mathematical functions (*e.g.* means and standard deviations). Fifthly, BISOSS focuses explicitly on a person's sense of self, rather than other constructs such as self-esteem, self-concept or personality.

This study provides further evidence that problems with self-identity are commonplace among people with TBI. While our sample population is likely to not be entirely representative of all people with TBI, it is notable that 40% (54/136) of our study participants agreed with a statement they had problems with their self-identity.

BISOSS is composed of three separate scales. BISOSS-E is an individualistically-orientated factor that incorporated most of the items from the first section of the original questionnaire, "how I feel about myself," along with items relating to self-discrepancy from other sections. BISSOS-S incorporates many of the original items related to the question of "how I feel about my place in the world". This subscale taps into a sense of purpose and meaningful activity, roles and relationships in society and the sense of belonging that this gives. BISOSS-R reports on "how other people treat me" and addresses issues of sense of self arising from close interpersonal relationships.

Applications of BISOSS

In clinical settings, BISOSS can already serve as a tool to initiate conversations about identity issues after TBI, or to help unpick identity problems, without further testing. The items in BISOSS provide a framework to explore what an individual may mean when they describe feelings of change in self-identity and demonstrates the breadth of changes that this sentiment incorporates.

BISOSS can be used to measure strength of self-identity at a single point in time, which can then be evaluated longitudinally by repeated measurement. This data could reveal information about the course of self-identity changes following TBI and the impact of different rehabilitation approaches on identity reconstruction. However, it is unlikely BISOSS could be used to retrospectively score an individual person's strength of self-identity (*e.g.* prior to injury) and, at present, no normative (non-TBI) BISOSS data exists. Currently there is a lack of high quality evidence to support interventions for self-concept change following TBI[4, 9] – a problem BISOSS is now available to help address.

Limitations of the study

Recruitment was challenging in this study. Despite recruiting in two countries, there was a lack of ethnic diversity in the study population. This study was also based on data from the single administration of the questionnaire so no comments can be made on the test-retest reliability or the responsiveness (longitudinal validity) of the scale. Further research is required to address these issues and to expand items in BISOSS-R to provide more precise measurement. In particular, more items that might indicate moderate problems with relational sense of self are needed to cover the mid-range of the BISOSS-R. Further qualitative study involving people with TBI talking about their experiences of relational self-identity should be used to generate additional candidate items, followed by another round of Rasch analysis to test these items and to integrate them into the measure. Additional research is also needed to gather normative BISOSS data from populations of people without brain injury and to explore possible correlations between BISOSS scores and other aspect of clinical presentation after TBI. Finally, BISSOS has yet to be tested in non-English-speaking countries. Cultural differences in understandings of self-identity may impact on the broader applicability of this measure and is another area for future research.

Conclusions

BISOSS is a three-part interval scale measure that can be used to evaluate subjective experiences of problem with self-identity after TBI. BISOSS can be used to explore relationships between problems with self-identity, type of brain injury, severity of injury, and other psychological problems following injury. BISOSS can also be used in clinical trials to examine interventions that are aimed at helping people regain a sense of purpose, meaning, or identity in life after injury.

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Conflicts of interest
The authors certify that there is no conflict of interest with any financial organization regarding the material discussed in the manuscript.

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Authors' contributions
Emily Thomas conducted all data collection, preliminary data analysis, and wrote the first draft of this manuscript. Will Taylor and Richard Siegert advised on the psychometric and Rasch analysis. All authors provided substantial contributions to the conception and implementation of this study and to the write up of this manuscript. All authors read and approved the final version of the manuscript.

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