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ORIGINAL ARTICLE

A multi-perspective concept mapping study of problems associated with traumatic brain injury

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Abstract

Objective: To develop a model of the problems of persons with traumatic brain injury that includes multiple perspectives as well as the multi-dimensional nature of the phenomena.
Design: Concept mapping, a multi-variate modelling strategy, was employed to produce an exhaustive inventory and concept map of TBI-related problems based on input from patients, family caregivers and professional providers.
Results: The eight-cluster concept map included the following dimensions: social competence, intimacy, behavioural, maturity/independence, neurophysiological, mood, executive functions and non-executive functions.
Conclusions: An underlying two-dimensional conceptual model of TBI problems is proposed with relevance for theory, practice and further research.

Introduction

One of the most challenging aspects of addressing traumatic brain injury (TBI) is that one's definition of 'the problem' is likely to differ as a function of whether the perspective is that of the injured person, the family caregiver or the professional provider. This issue is particularly salient with brain injuries when self-awareness of deficits is one of the presenting problems, as is often the case [1, 2]. For example, a recent study investigated the degree to which patients and therapists concur on the extent of decrements and found that their perspectives do indeed differ in terms of the degree and nature of patients' impairments in functioning [3].

In addition to the issue of multiple perspectives is the multi-dimensionality of brain injury. Across the literature in the past 2 years, published studies on specific problems have included, but are not limited to, cognitive [4–7], vocational [8–10], inter-personal [11–14], affective [11, 15–18], self-concept [15], suicide [19], personality [20], sexual [21–23], substance abuse [24], family [25, 26], existential [27] and quality of life [28, 29]. An exhausting but by no means an exhaustive list. Such specificity is very much necessary in the conduct of focused empirical research but lacks conceptual generality and coherence.

The challenges of multiple perspectives and multi-dimensionality have not impeded investigators from studying the many specific problems related to brain injury. For example, of the 448 articles (excluding letters and book reviews) published in this journal from January 2000 until the present (the tenth issue of 2004), nearly half ($n = 213$; 48%) have been devoted to one or more specific TBI-related problems. Note that this is a conservative estimate in that test development and validation studies were not included in the counting of problem-focused studies. This state of affairs might be very welcoming to the investigator searching on

a particular keyword; but the theoretician looking for connections, the therapist attempting to consistently and validly conceptualize patients, the programme evaluator looking for a model of outcomes or the student just looking for a conceptual framework with which to understand the consequences of brain injuries is likely to conclude his or her search unsuccessfully.

Recently, Wilson [30] confronted a similar situation in cognitive rehabilitation of TBI and produced a comprehensive conceptual model of rehabilitation. At the heart of Wilson's graphic model are 'current problems' (p. 105). The problem construct is inextricably linked to assessment, prognosis, treatment and outcome. Wilson strongly argued that, whatever the form of the model, the primary focus should be on *what* needs to be rehabilitated. The 'what' should include 'real-life, functional problems', 'associated problems such as mood or behavioural problems in addition to cognitive difficulties' and 'should involve the person with the brain injury, relatives and others in the planning and implementation of cognitive rehabilitation' ([30], p. 99). This clearly points to the centrality of *problems* resulting from TBI as a kind of common currency in the field and to the importance of incorporating the observations of the several kinds of 'everyday experts' in the life of the person with a TBI.

Four major dimensions of problems are listed in Wilson's model: cognitive, emotional, psychosocial and behavioural. It may be fair to say that these categories have the advantage of being sufficiently general to be comprehensible to researchers and practitioners across diverse sub-fields related to brain injury but may not be definitive in the absence of supporting data. Other researchers who have evaluated long-term sequelae from the patient's and the family's perspectives (e.g. [31, 32]) have suggested two- and three-factor models of post-injury deficits, focused on general complaints, severity and somatization. The European TBI Consensus Group identified five dimensions: physical, cognitive, behavioural, emotional and social [29]. All of these proposed categories of problems may be said to have face validity, but are lacking in empirically derived construct validity.

In summary, the literature makes it abundantly clear that the problems of the person with a TBI are numerous and relevant to theory, treatment and research. In addition, one's perspective on TBI problems varies with one's position as patient, caregiver or provider and all perspectives are valuable. Surprisingly, establishment of an empirically based multi-perspective and multi-dimensional model of the problems of the person with a TBI is not yet evident in the published literature. The present study is an attempt to develop a model of the problems of persons with TBI that includes multiple perspectives as well as the probable dimensional nature of the phenomena.

Capturing the complexities as well as the subtleties of brain injury problems, along with incorporation of the multiple perspectives, poses a significant methodological challenge. It is believed that a relatively recently developed multi-variate research strategy known as Concept Mapping is well suited to the task.

Concept mapping

Trochim [33] described concept mapping as a structured approach to conceptualization of a domain resulting in the graphic depiction of the major constructs. The concept mapping research process typically includes six steps, beginning with identification of experts familiar with the domain of interest and, subsequently, involving the generation, sorting and rating of items that represent specific aspects of the conceptual domain. The concept maps result from a data analytic sequence including multi-dimensional scaling (MDS) of the sorted items and cluster analysis of the resulting MDS map values to identify the major concepts in the domain. To facilitate the process, Trochim has developed an integrated computer program that enables project management, data analysis and reporting. The program, known as *The Concept System*, is available at http://www.conceptsystems.com. The method has been employed in a number of health-related studies (e.g. [34]) and seems to be very well suited to the study of brain injury problems from multiple perspectives.

The specific goals of this study were: (1) to elicit an exhaustive list of problems associated with TBI as characterized by the patient, significant others and pertinent health care providers and (2) to identify a model and item set that may be used in further theoretical, therapeutic and psychometric work to ultimately improve the quality of life of the patient with TBI.

Method

Subjects

Three groups of participants were included in the study: patients, their significant others, and professional care providers.

Patients were identified from the Neuropsychology Clinic database at a Veterans Affairs Medical Center. Eligibility for patient participation included a primary diagnosis of TBI based on neurological examination and being at least 1 year post-injury at the time of study enrolment. Recruitment materials were sent to 45 individuals and 20 of them

completed the study. The age range was from 20 to 76 ($M = 45.6$ years) and all except one were male. This patient sample included 12 European Americans, four African Americans and two Native Americans. The study participants had completed an average of 11.7 years of school ($SD = 1.49$) and most of them were unemployed at the time of the study ($n = 14$, 87%). Years since the occurrence of the brain injury ranged from 2 to 40, with a mean of 15.9 ($SD = 12.0$).

Significant others were solicited from each patient completing the study. These participants either lived with the patient or had contact with him or her several times per week. Usable data were obtained from eight family members, including three parents, four siblings and one girlfriend.

Providers who regularly work with head injured patients were asked to participate in the study. All providers worked in university-affiliated medical settings. Of the 42 solicitations sent, 19 completed the study, including 16 psychologists (10 of whom were neuropsychologists), one neurologist, one psychiatrist and one occupational therapist.

Procedures

Item generation. Upon giving written consent, patients and significant others were interviewed either in person or over the telephone. A licensed neuropsychologist or a doctoral-level psychology research assistant conducted the interviews. Participants were asked to identify all of the problems they had encountered associated with the head injury. Questioning was as open-ended as possible, but prompts were given as needed (e.g. questions about changes in thinking, emotions, behaviour) to elicit as many responses as possible. Interviews typically lasted 20–30 minutes and patients and family members were compensated $10.00 each for their participation.

Provider participants completed the study by mail, listing all of the problems they had observed in working with patients with TBI on the form provided. Providers were not compensated for their participation.

The 47 participants in the brainstorming phase generated 266 items. Two of the investigators (JPD and KD) examined the item lists for redundancy. This level of item analysis resulted in the deletion of 92 duplicate items, leaving a pool of 174 items for the next phases of the analysis.

Item sorting. Eight neuropsychologists (of the 10 who completed the item-generation phase) were selected for their significant experience and expertise in the treatment of patients with TBI. These clinicians completed a free-response sort with the following instructions: 'Please sort the items into as many piles as you see fit and meaningful. Do not leave all items in one pile and do not separate all items into 174 individual piles. Then label each pile with a post-it note and fasten the pile with a rubber band'.

Data analysis

Data were analysed using *The Concept System*, Version 1.74. Concept mapping involves a sequence of multi-variate analyses beginning with a two-dimensional non-metric multi-dimensional scaling analysis of the item sort data. The sort data are aggregated into a binary, square symmetry similarity matrix and each item is represented in two-dimensional space in terms of distance from all of the other items. In the present study, a final MDS stress value (a goodness of fit statistic) of 0.278 was obtained after 12 iterations, lower (i.e. better) than the reference value of 0.285 reported by Trochim based on the average of 33 studies (with a range of 0.155–0.352) [35]. Once the MDS solution was obtained, the X–Y values identifying each of the items in two-dimensional space were examined in a hierarchical cluster analysis.

The cluster analysis, based on Ward's algorithm [36], involved an iterative process in which each possible solution from 2 to 20 clusters was examined for interpretability and statistical indicators of adequacy of the solution, as recommended by Trochim [33]. The statistical indicator of interest is the bridging value, an index ranging from 0 to 1 that indicates the degree to which an item was frequently sorted within a particular cluster vs. being placed in other clusters by different participants. High bridging values for a cluster suggest the possibility of a more complex construct that might be better represented in more differentiated clusters, thus encouraging the analyst to continue disaggregating the data into smaller clusters.

In addition to the bridging values, decision-making regarding the optimal clustering is based on the coherence of the cluster in the eyes of the analyst, similar to the process of factor analysis. The concept system allows the analyst to interact with the maps, examining individual statements or clusters of statements as necessary. In the present study, the analysts included a neuropsychologist (KD) and a health psychologist (JPD). Each candidate solution was examined on the basis of both statistical indices and interpretability.

Results

The eight-cluster concept map in Figure 1 was determined to be the optimal concept map on both
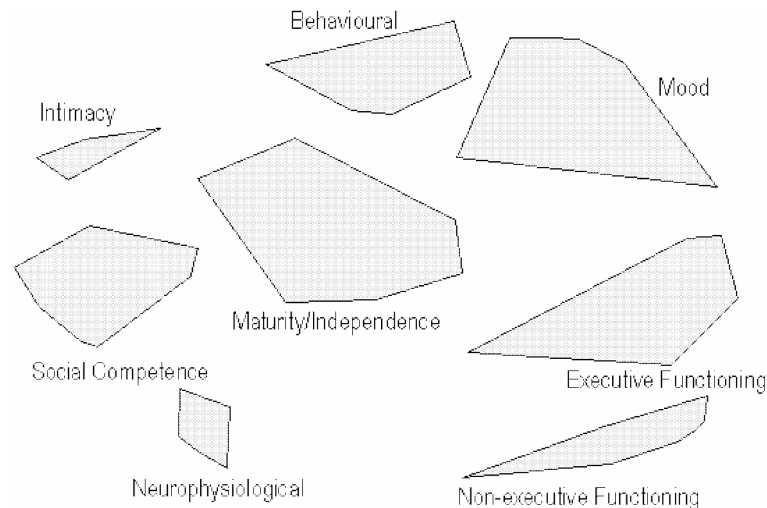
Figure 1. Eight-cluster concept map of TBI problems.

the statistical and interpretive criteria. Statistically, this solution appeared to be optimal because the bridging values for the clusters were relatively low, indicating strong internal consistency of the items. In addition, the items comprising each cluster formed readily identifiable sets of TBI-related problems. The borders of the polygons that make up the map are determined by the placement of the items in the multi-dimensional scaling analysis. Thus, some clusters are relatively large and diverse, while others are smaller and 'tighter', reflecting the degree of common sorting of items within the cluster. The number of items per cluster ranged from 12 in the intimacy cluster to 40 in the mood cluster. A complete listing of all items by cluster with bridging values is presented in Table I. A brief description of each of the eight clusters is provided below.

- *Maturity/independence.* The most striking feature of the map is the centrality of the maturity/independence cluster, reflecting the primary relationship of maturity and independence to all other clusters. This cluster is significant not only for its central position, but also because the items represent core aspects of personal functioning. This cluster includes such items as 'inability to plan for the future', 'childlike responses' and 'loss of long term goals'. Altogether, there are 20 items in this cluster.
- *Intimacy.* This cluster reflects the difficulties of maintaining close relationships following a brain injury. The items in the intimacy cluster include 'unable to maintain a relationship with a significant other', 'divorce' and 'sexually inappropriate behaviour'. Twelve items are included in the intimacy cluster.
- *Social competence.* Many of the items in this cluster reflect the difficulties in post-injury adjustment

commonly seen in this population. These issues include such items as 'poor self-monitoring', 'difficulty keeping a job' and 'requires much follow-up'. The 15 items seem to reflect the impact of a brain injury on the social behaviour necessary for effective treatment participation and adjustment.

- *Neurophysiological.* This cluster includes 'seizures', 'arousal deficits', 'less physically fit', 'chronic pain' and 18 other items related to the physical impact of a brain injury or deficits in physical function that may result.
- *Behavioural.* This cluster includes some psychotic symptoms such as 'delusional' and 'hears things' as well as other serious symptoms such as 'suspicious of people' and 'dangerous'. A few of the items reflect less severe problems in psychological functioning such as 'restless', 'low self-confidence' and 'ineffective grieving', but most reflect more serious disturbances of behaviour. The cluster was composed of 14 items in all.
- *Mood.* The large cluster called mood included 'nervous', 'scared', 'depression', 'emotional lability' and 36 others. Some of the items primarily reflect depression and anxiety, but many others refer to changes in the variability or expression of emotion. The number of items in this cluster was by far the largest, suggesting that brain injury is associated with a wide range of problems in emotion and mood.
- *Executive functions.* Two neuropsychological clusters emerged discriminating between executive and other cognitive functions. The executive functions included 'inability to organize tasks', 'difficulty with sequencing', 'perseveration' and 13 other problems.
- *Non-executive functions.* Some examples of the non-executive functions are 'poor retrieval' and

Table I. TBI problems by cluster (bridgings in parenthesis).

Cluster and item

Cluster 1: Social competence
(51) unrealistic about abilities (0.37)
(115) impaired awareness of cognitive deficits (0.41)
(114) unaware of actions (0.42)
(49) impaired expectations (0.45)
(16) denial of disability (0.46)
(113) poor self-monitoring (0.53)
(110) inappropriate attributions regarding patient behaviour (0.53)
(53) problems in adjustment to disability (0.54)
(50) difficulty keeping a job (0.56)
(54) job problems (0.56)
(1) institutionalized (0.56)
(25) lack of resources for patient care (0.60)
(27) requires much follow-up (0.63)
(171) decreased insight into own situation (0.64)
(33) sexual difficulties (0.68)
Cluster 2: Intimacy
(30) unable to maintain a relationship with significant other(0.27)
(32) relationship problems (0.27)
(31) divorce (0.29)
(129) poor social skills with the opposite sex (0.29)
(133) regressed social interaction (0.29)
(28) rejection of family (0.30)
(126) impaired awareness of social skill deficits (0.31)
(132) lack of social awareness (0.31)
(131) inappropriate sexual remarks (0.33)
(26) over-controlled by family (0.38)
(72) social withdrawal (0.45)
Cluster 3: Behavioural
(107) delusional (0.33)
(106) compulsions (0.34)
(61) low self-confidence (0.36)
(145) difficulty controlling emotions (0.41)
(147) dangerous (0.49)
(69) emotional dependency (0.49)
(130) suspicious of people (0.52)
(135) violent behaviour (0.56)
(138) hostility (0.56)
(8) hear things (0.58)
(70) decreased libido (0.61)
(36) ineffective grieving (0.68)
(45) restless (0.78)
(109) hypervigilance (0.84)
Cluster 4: Maturity/independence
(118) childlike responses (0.40)
(121) immature behaviour (0.40)
(128) caustic joking (0.40)
(120) childish attempts to manage disappointment with pleasure seeking (0.43)
(29) lack of interest in others (0.44)
(149) outspoken (0.45)
(127) bluntness in speech (0.45)
(55) inability to plan realistically for the future (0.48)
(56) loss of long-term goals (0.48)
(144) lack of self-control (0.50)
(152) impulsive behaviour (0.50)
(153) decreased inhibition (0.50)
(150) egocentric behaviour (0.50)
(119) arrested level of maturity (0.50)
(117) poor medication compliance (0.55)
(116) increased substance abuse (0.55)

(40) decreased ability to initiate activity independently (0.55)
(174) poor financial judgement (0.58)
(156) more talkative (0.67)
(44) easily startled (1.00)
Cluster 5: Neurophysiological
(2) seizures (0.05)
(3) less physically fit (0.05)
(4) balance problems (0.05)
(5) other pain (0.05)
(6) headaches (0.05)
(10) decreased taste (0.05)
(11) hearing loss (0.05)
(12) decreased sense of smell (0.05)
(13) hemiplegia (0.05)
(14) chronic pain (0.05)
(15) multiple fractures (0.05)
(18) paralysis (0.05)
(19) opthalmoplegia (0.05)
(24) motor weakness (0.05)
(7) light sensitive (0.10)
(9) sensitive to loud sounds (0.10)
(17) sensory extinction (0.11)
(22) visual field cuts (0.11)
(20) ANS hyperarousal (0.11)
(21) ANS hypoarousal (0.11)
(83) stuttering (0.12)
(65) arousal deficits (0.12)
Cluster 6: Mood
(46) nervous (0.06)
(47) scared (0.06)
(48) worried (0.06)
(35) exaggeration of cognitive deficits by anxiety or depression (0.07)
(41) anxiety (0.07)
(42) panic (0.07)
(37) lack of emotion (0.08)
(38) unusual affect (0.08)
(34) mood disorders (0.08)
(146) more emotional (0.08)
(63) cry easily (0.09)
(137) emotional lability (0.08)
(140) under-modulated affect (0.08)
(151) exaggerated affect (0.10)
(139) increased lethality (0.10)
(71) increased emotional upset (0.10)
(141) irritability (0.11)
(142) more easily angered (0.11)
(64) flat affect (0.11)
(108) catastrophic reactions (0.12)
(62) tearfulness (0.12)
(104) paranoid (0.12)
(105) grandiose (0.12)
(57) depression (0.13)
(68) suicidal (0.13)
(143) bad temper (0.17)
(43) stressed out (0.23)
(59) less excited about things (0.28)
(67) apathy (0.28)
(39) frustration with deficits (0.36)
(154) impatient (0.39)
(148) lowered frustration tolerance (0.40)
(155) hyper (0.47)
(66) loss of initiative (0.51)

(Continued)

Table I. TBI problems by cluster (bridgings in parenthesis).

Cluster and item
(111) tangentiality (0.53)
(136) emotional volatility
(57) tired (0.59)
(103) obsessions (0.70)
(23) insomnia (0.82)
Cluster 7: Executive functioning
(157) inability to organize tasks (0.27)
(161) decreased ability to categorize (0.27)
(162) get mixed up easily (0.27)
(172) difficulty sequencing (0.27)
(160) can't keep track of time (0.29)
(158) decreased abstract reasoning (0.39)
(170) perseveration (0.42)
(111) increased frontal lobe symptoms (0.43)
(164) poor ability to plan (0.47)
(166) black/white thinking (0.53)
(52) needs very routine tasks (0.59)
(168) difficulty in prioritizing daily tasks (0.59)
(74) poverty of speech (0.63)
(169) lack of structure in thought process (0.71)
(86) communication problems (0.76)
(73) poverty of thought (0.81)
Cluster 8: Non-executive functioning
(76) poor retrieval (0.00)
(77) must be reminded to do things (0.00)
(78) loses things (0.00)
(79) loss of procedural memory (0.00)
(80) forgetfulness (0.00)
(81) decreased memory consolidation (0.00)
(82) anterograde memory impairment (0.00)
(75) poor learning (0.03)
(94) can't keep track of conversations (0.03)
(101) impaired orientation (0.03)
(95) inattention to detail (0.06)
(96) attentional variability (0.07)
(99) decreased selective attention (0.07)
(100) distractibility (0.07)
(102) decreased concentration (0.07)
(173) trouble adding numbers in head (0.09)
(84) trouble using words that he/she used to know (0.10)
(85) trouble reading (0.10)
(159) poor problem solving ability (0.11)
(165) decreased IQ performance (0.11)
(123) needs more time to process instructions (0.16)
(124) decreased information processing speed (0.16)
(125) slow thinking (0.16)
(87) decreased ability to visually process information (0.18)
(167) unable to visualize problem solving (0.20)
(88) spatial deficit (0.21)
(89) constructional dyspraxia (0.21)
(90) geographical dyspraxia (0.21)
(91) decreased left–right awareness (0.21)
(97) unilateral inattention (0.21)
(98) decreased visual scanning (0.21)
(122) behavioural slowing (0.21)
(93) apraxia (0.26)
(92) sensorimotor neglect (0.50)

'attentional variability', in addition to 23 others. The problems in this cluster included issues related to memory, concentration, language and spatial deficits.

Are there more basic dimensions underlying the eight-cluster model?

As noted previously, Wilson suggested a four-dimensional classification of problems, including cognitive, emotional, psychosocial and behavioural and other authors have suggested two, three and five factor models. The next level of analysis was to examine whether the eight-cluster model might be compatible with a more basic representation of brain injury problems. It appears that the eight-cluster model may in fact be a function of two bipolar dimensions. In Figure 2, two intersecting dimensions are represented. One dimension (the 'North–South') includes emotion and cognition. The other dimension (the 'East–West') reflects intra-personal vs. inter-personal problems. Crossing the two dimensions creates four domains that represent the possible combinations of the problem dimensions. The eight clusters in the model could be overlaid on the two-dimensional figure and interpreted as reflecting varying combinations of the dimensions. For example, an item such as 'Gets mixed up easily' would reflect cognitive and intra-personal aspects. The central dimension has been labeled 'Independence' because of the salience of the concept to other concepts in the map and because it may best represent what is lost as a result of a TBI and what is found as a result of successful treatment.

Discussion

Previous descriptions of the complex problems following TBI have most often been limited to a small number of general factors. The nuances of social relationships, including those with family, significant others and treatment providers, suggest the need to take those perspectives into account as well when producing a comprehensive description of the post-TBI experience. This study produced an exhaustive list of problem areas from these three groups of stakeholders. Their problem identification resulted in 174 discrete items. From these items, an eight-cluster model was developed via multi-variate analysis of item similarities. The clusters of maturity/independence, intimacy, social competence, neurophysiological, executive functioning, non-executive functioning, mood and behavioural problems emerged as both statistically and conceptually sound in their representation of this syndrome. The primacy of maturity and independence, relative to other kinds of problems, the distinctions between intimate and other types of social relationships and the differentiation of mood and behavioural disturbances as outlined in the map enrich understanding of these problems. These eight clusters show
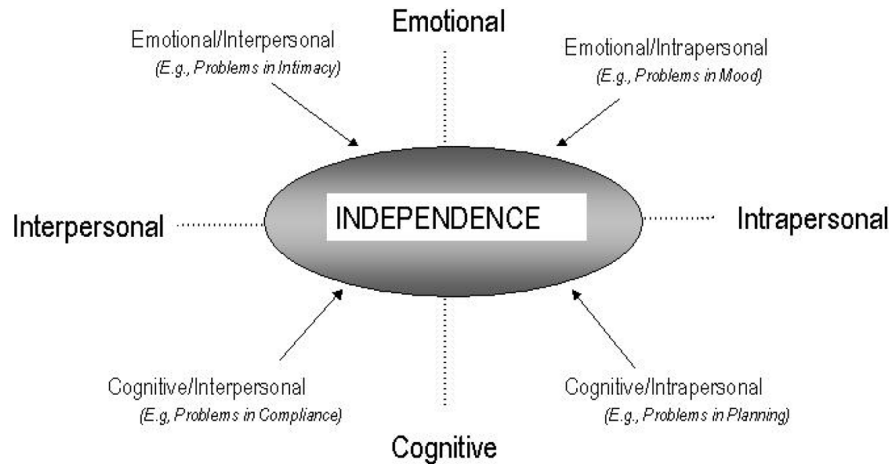
Figure 2. Two-dimensional model of TBI problems.

potential to better individualize the profiles of patients with TBI.

In addition, further examination of the model suggested that two bipolar dimensions might underlie the broad set of problems related to brain injury. These dimensions are partially consistent with prior reports. For example, the dimensions of cognition and affect appear in other models [29, 30]. Wilson [30] suggested behavioural and psychosocial categories. The present model varies slightly from this, with a bipolar inter-personal and intra-personal dimension. In addition, the authors wish to state strong agreement with Wilson [30] that the focus of any rehabilitation model should be *what* needs to be rehabilitated. Such an emphasis may help to create a common conceptual and linguistic basis for patients, family members and providers in addition to concretizing the focus of assessment and treatment.

It may be worth noting that the study illustrates the potential usefulness of concept mapping when confronting the issue of multiple perspectives in subjective health studies. The procedures involve a user-friendly combination of qualitative (in the initial brainstorming) and quantitative (in the multi-dimensional scaling and cluster analysis) techniques that help to bridge the differences in perspective of patients, caregivers and providers.

With regard to assessment and treatment implications, there are some promising future directions. As Zasler and Martelli [37] recently noted, there is a need for a system for rating the sequelae of mild TBI that accounts for the vast majority of cases. Clinically, there are indications of progress in evidence-based treatment in other challenging areas. For example, problem-solving therapies have been receiving increasing attention in both medical and non-medical populations [38–40]. A solid empirically based model of problems of patients with

TBI would seem to be an important component of developing problem-solving therapies for persons so affected and their loved ones.

There are several important methodological limitations in the present study that must be appreciated in considering the implications of the results. First, only one of the participant groups, the neuropsychologists, completed the sorting. An important issue is whether the results would be replicated with additional or different participants. The neuropsychologist experts were thought to have a comprehensive knowledge base, having seen thousands of cases and being familiar with the technical terminology that describes many of the issues associated with brain injuries. However, there are numerous other professional specialties with expertise in this area, including physiatrists, neurologists, physical and occupational therapists, rehabilitation counsellors and others.

In addition, the large number of items generated may be comprehensive, but is too large to be immediately practical in assessment or treatment planning. The problems identified were presumably all post-trauma (as in the instructions to participants), but the patients and caregivers might have produced some items that preceded the injury (e.g. low self-confidence) or were made more intense by the injury and may, therefore, not be a direct result of the trauma. It is also possible that some issues were under-represented (e.g. tiredness was included, but fatigue was not). The external and content validity of the concept map is dependent on the degree to which it represents a comprehensive inventory of problems and this issue can only be evaluated via replication. In addition, the sample was relatively small, primarily male and drawn from the population of military veterans treated at one medical centre. The sample should not be seen as representative of the general population of persons with TBI or even

veterans with TBI. The proposed two-dimensional model may well represent the data in the present study, but it may include interpretations that other analysts could reasonably question. For example, it could be argued that rotating the North–South axis 45° could result in a somatic rather than a cognitive pole. These kinds of issues have been the subject of extensive debate and study in personality, vocational psychology and quality of life research (e.g. [41–45]). At this stage, such debate based on additional data collections and analyses would be very desirable in the study of the structure of TBI problems. The present model might have greatest value as a heuristic for further study, with construct and content validation as ultimate goals.

The next set of tasks will be to replicate the study with different patients, caregivers and providers and to then focus on constructing an instrument based on this model. Longer-term implications include plans for rehabilitative interventions and their evaluation, ultimately contributing to the evolution of an evidence-based approach to improving the quality of life of person's coping with problems associated with TBIs.

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