

Self-awareness of deficits in adults with traumatic brain injury: how best to measure?

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Some method of assessing self-awareness of deficits in patients with traumatic brain injury (TBI) is required to increase our understanding of the phenomenon, and to then evaluate strategies for clinical intervention with patients who lack such self-awareness. Options for the assessment of self-awareness of deficits following TBI are reviewed. The most commonly used method is comparison of patients' self-rating on questionnaires of functional abilities with ratings by relatives or staff on the same questionnaires. An additional method of assessment, an interviewer-rated semi-structured interview is proposed (the Self-Awareness of Deficits Interview), and some preliminary inter-rater reliability data are presented. However, quantitative methods of evaluating self-awareness have shortcomings, and qualitative research may be more appropriate in some circumstances. An approach which makes use of multiple measures to evaluate self-awareness of deficits is recommended.

Introduction

Lack of self-awareness of deficits is a potential obstacle to successful rehabilitation and reintegration following traumatic brain injury (TBI). In clinical settings this tendency for patients to deny or minimize dysfunction is often termed a 'lack of insight' [1]. Lack of self-awareness is seen to be a cause of poor motivation and resistance to treatment in patients with TBI. It is felt that unrealistic expectations may initially act as a 'buffer' protecting the patient from grim reality [2]. Furthermore, it appears that increases in awareness of deficits may be accompanied by emotional distress [3,4]. However, it is generally understood that a persisting lack of awareness of deficits will hamper the rehabilitation process [5]. Research to support the above clinical impressions is somewhat limited, although a number of theories explaining the phenomenon have been proposed [6]. A variety of interventions are used with patients who lack self-awareness [7], yet little empirical evidence exists to demonstrate their effectiveness. It seems obvious that some means of assessment of self-awareness is required in order to conduct meaningful research into the process of self-awareness, and to evaluate the outcome of strategies for clinical intervention with patients who lack awareness. The options for the assessment of awareness of deficits are reviewed here, and the development of a new assessment technique described.

Defining self-awareness of deficits

Before any construct can be empirically evaluated we require a clear definition. Prigatano and Schacter [8] have highlighted the fact that there are no simple definitions

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of the term 'awareness'. A common theme in the literature is that self-awareness is a process which involves the integration of information from both external reality and inner experience, as reflected in the definition of self-awareness as 'the capacity to perceive the "self" in relatively "objective" terms whilst maintaining a sense of subjectivity' (p. 13) [8]. Therefore, self-awareness involves the interaction between thoughts (knowledge of a situation in an objective sense) and feelings (or an appreciation or unique interpretation of the situation in a subjective sense) [8].

In the context of head injury, self-awareness can be summarized using a three-level model [9]. The first level is self-awareness of the injury-related deficits themselves; that is the particular physical, cognitive, social and emotional deficits apparent post-injury. This aspect equates with the objective awareness or 'knowledge of' deficits. Self-awareness of some deficits, particularly physical disabilities, is often achieved more readily than self-awareness of social and emotional competence [10]. Secondly, self-awareness extends to awareness of the functional implications of deficits for independent living, work, driving leisure and other everyday activities. This second aspect equates with the subjective appreciation or unique interpretation of deficits. A third aspect of self-awareness, one which is commonly impaired following TBI, is an ability to set realistic goals, the ability to predict one's future state accurately, or prognosis.

Methods of assessment of self-awareness of deficits

A number of strategies have been utilized to form a quantitative evaluation of self-awareness of deficits in patients with TBI. The most common strategy involves the comparison of patients' self-ratings of their function with another measure which is considered to be more objective. Deaton [7] identified three such methods of assessment based on difference scores between two perspectives or measures of function. These were: (1) the difference between patients' self-ratings and those made by their families; (2) the difference between patients' self-ratings and those made by rehabilitation staff; and (3) the difference between the patients' estimates of their abilities and actual performance on neuropsychological tests.

Patient-relative comparison

Comparisons between the perspective of the patient and the perspective of a relative have been used as a starting point to quantify awareness of deficits [11]. Underlying this form of evaluation is the assumption that patients' perceptions are likely to be distorted or unreliable [12–14]. For this reason the validation of patient self-reports against the reports of informants is recommended in clinical practice. A number of researchers have utilized the patient-relative comparison method with questionnaires of general behavioural changes after TBI [15–19], and in other neurological conditions such as Huntington's disease [20]. Sunderland and his colleagues have used the comparison of patient and relative reports to evaluate everyday memory function [21,22].

Perhaps the most widely documented means of evaluating self-awareness in TBI research is the Patient Competency Rating Scale (PCRS) [11,23], in which both the patient and a significant other rate the ease with which the patient is able to perform functional activities. A five-point Likert scale is used to rate how difficult or easy it is to perform 30 different behavioural tasks. The scores range from 1, which indicates 'can't do', to 5, which indicates 'can do with ease'. Both the patient and relative make judgements according to how they consider the patient would perform the task. No actual task performance is involved. The PCRS is quite

interpreted, and covers the areas of functional ability (for example, how much of a problem do I have in preparing my own meals?), interpersonal skills (for example, how much of a problem do I have in recognizing when something I say or do has upset someone else?), and emotional status (for example, how much of a problem do I have in keeping from being depressed?).

Since its development the PCRS has been used in several valuable studies of awareness of deficits after brain injury [10,23–25]. Scoring on the PCRS has been approached in three different ways. The simplest method [23,24] is to calculate the average perceived competency score across all 30 items for both patient and relative. the assessor is then able to gain an overall impression of the discrepancy between the patient's and the relatives perspective. However, this method is not sensitive to differences in patient and relative ratings on individual items.

An alternative method is to compute the following three scores: (1) the number of items in which the patient rating is greater than the relative rating (that is, the patient perceives greater competence than the relative); (2) the number of items in which the patient rating equals the relative rating; and (3) the number of items in which the patient rating is less than the relative rating (that is, the patient perceives less competence than the relative). Patients are then classified into three groups on the basis of which score is highest. Using this method with a sample of 64 TBI patients, Prigatano and Altman [25] found most subjects (53%) fell into the second group, as the patient and relative ratings were equal on the majority of items.

A third method of scoring reported by Prigatano *et al.* [10] is to consider the actual magnitude difference between the patient and relative ratings on specific items. For example, if subtraction of the relative rating from the patient rating gives a positive value, the patient can be considered to overestimate his or her ability on that behavioural item. This method of scoring not only takes magnitude difference into account, but allows for the fact that patient and relative ratings may be disparate, depending on the different items of the scale. For instance, Prigatano *et al.* [10] used this method to demonstrate that patients tended to overestimate their abilities compared to relatives on items relating to emotional and social behaviour, but tended to agree on items relating to activities of daily living.

Reliability data on the PCRS have revealed acceptable test–retest reliability for 17 patients ($r = 0.97$) and their relatives ($r = 0.92$). Test–retest correlations using Pearson's r of individual items were significant for 27 out of 30 items for patients (i.e. $p < 0.05$) and 28 out of 30 items for relatives [10]. Although a small study, these results are encouraging, indicating that the PCRS is a potentially useful instrument for self-awareness research.

Another instrument for assessing self-awareness, the Head Injury Behaviour Scale (HIBS) was developed by Godfrey *et al.* [17]. In a similar fashion to the PCRS it describes 20 behavioural items which are rated on a four-point Likert scale by both patient and relative. Raters are asked to indicate if the behaviour is a problem to them and, if so, to indicate how much distress it causes them. Two scores can be obtained from the data: the number of problems and a distress score. Comparison of scores between patient and relative gives an indication of the accuracy of the patient's self-awareness, and the appropriateness of emotional reaction to recognized deficits. Encouraging preliminary results in reliability and validity studies have been reported. Internal consistency was high for both patient and relative ratings (Cronbach's alpha = 0.93 and 0.87, respectively) and moderate test–retest reliability over 1 year (intra-class correlation coefficient $r = 0.68$) has been reported.

Other research findings indicate that patients with TBI are less accurate or less consistent in self-rating than controls, particularly in the case of severe TBI patients [26] and non-oriented TBI patients [27]. In contrast, other workers have commented that patients' self-reports may be more accurate than previously thought [5,28–30]. For example, Tyerman and Humphrey [5] found that TBI patients could provide valuable first-hand information and insight into personal change, although they clung to unrealistic hopes for the future. Additionally, results of a study of emotional disorder in acute severe TBI patients indicated that patients were able to complete self-reports scales reliably, both in terms of high test–retest reliability, and good agreement with reports of close others [31].

Although head-injury patients generally *do* tend to under-report difficulties compared with their relatives (for example Brooks *et al.* [15]), relatives themselves may demonstrate varying levels of denial and decreased awareness. Factors influencing the accuracy of relatives' reports include increased stress levels and fatigue, the personality type of the relative [32], and the length of time post-injury [33]. Similarly, Cavello *et al.* [34] found that families do not all respond in the same way, and cautioned against the convention of relying on family reports for reliable information about the performance of the person with TBI.

In the early stages post-injury both the family and the patient are normally in a state of denial, and the family may believe their injured relative will make a full recovery [35,36]. It is sometimes only when formal rehabilitation is finally discontinued that the family realizes that some deficits are permanent, and the mourning process starts. It is doubtful, therefore, whether relatives would be able to provide accurate reports on patients' status before this time. Exploration by Krefling [37] into the relationship between patients, families and service providers revealed that patients and families may experience a double-bind in their communications with health professionals. For example, family members can face a dilemma in determining how much information it is safe to reveal to staff, especially if there are potential implications for rehabilitation involvement. In any assessment of relatives' perceptions, relatives may be placed in vulnerable situations which may bias their reports regarding the patient's behaviour. However, the experience of a significant other, living and dealing with the person with TBI on a daily basis, remains a vast source of information to researchers.

Patient-health professional comparison

Another approach is to compare the patient self-ratings with ratings by a health professional who works with the patient. For example, Fordyce and Roueche [23] added the additional perspective of a treating staff member as a comparison to the relative and patient perspectives on the PCRS. Inter-staff ratings for 28 subjects showed high reliability (average $r = 0.92$) [23]. Similarly, the Brain Injury Rehabilitation Scale (BIRS) has been used by Farmer and Frank [16] to rate progress from the perspective of patient, family and treating staff. Additionally, comparison of patient and staff ratings of the patient's physical, cognitive and sociobehavioural skills on visual analogue scales was the chosen technique for investigating insight in a heterogeneous group of patients undergoing rehabilitation [38], and in a sample of 18 TBI patients [39].

The judgement of health professionals may also be coloured by interpersonal factors, and may be limited by the fact that health professionals usually have no first-hand knowledge of patients' premorbid personalities. Other factors which may influence staff ratings include mood, attitude towards the patient, experience

performance, and interpretation of poorly defined items on scales [40]. Until further research is conducted in this area, the practice of obtaining information about patient performance from multiple sources, including patient, relative and staff members, must be continued [16].

Comparison with test performance

A third approach to quantifying self-awareness of deficits is to compare patients' reports of their abilities on selected tasks with actual task performance. Allen and Ruff [26] used a questionnaire to evaluate the self-awareness of TBI patients and controls in the areas of sensorimotor function, attention, mathematics, language and intelligence, learning and memory, and reasoning. Self-ratings were compared with performance on neuropsychological testing in the same areas to determine the relative accuracy of self-ratings of TBI patients [26].

In using this method of assessment the problems associated with relying on relatives or staff to provide an objective and accurate measure of the patient's function are eliminated. Unfortunately, the administration of a battery of neuropsychological tests with each patient is likely to be a costly and time-consuming means of assessment, compared to the use of questionnaires. Additionally, some debate has highlighted the fact that there may be discrepancies between performance on neuropsychological tests and functional efficiency in everyday life [40]. However, it would be interesting to compare not just the patients' report, but also the relatives' and staff reports, against the actual scores on test performance.

Other questionnaires

Researchers have used a wide variety of questionnaires to gather quantitative data on other measures of function from the perspective of the person with TBI. Examples include the Sickness Impact Profile [18], the Change Assessment Questionnaire [41], the Acceptance of Disability Scale [42], the Disability Effects Questionnaire [43], a Semantic Differential Scale [5], the Minnesota Multiphasic Personality Inventory [19,27], the Brief Symptom Inventory [44], and the General Health Questionnaire and scales of depression and anxiety [31]. Additionally the Katz Adjustment Scale (relatives form) has commonly been used to rate emotional and personality adjustment on the patient form the perspective of a family member [13,27,44–46].

While each of these questionnaires evaluates the head-injury experience as reported by the patient or family, the Change Assessment Questionnaire (CAQ) [41] will be reviewed here in more detail because of its direct relevance to the concept of self-awareness of deficits. The CAQ was adapted for use in head injury research by Lam *et al.* [41] from a scale used with individuals with addictive behaviour. Based on Prochaska and DiClemente's [47] Stages of Change model, the CAQ identifies three stages of change (pre-contemplation, contemplation and action) related to self-awareness of the problem and readiness to change behaviours resulting from the head injury. The three stages are conceptualized as follows:

- (1) Pre-contemplation: the person is entering into a treatment situation but does not think s/he has a problem, or does not want to change. He or she may feel pressured or coerced by others to participate in treatment.

- (2) Contemplation: the person is beginning to be aware that a problem exists. He or she is struggling to understand the problem (i.e. cause, solution) and is seeking more information, but has not made a commitment to change.
- (3) Action: the person had actively started to change the behaviour (p. 236) [41].

Eight items from each stage of change are rated by the patient using a five-point Likert format, with 1 indicating strong disagreement and 5 indicating strong agreement. A total score for each stage is calculated, allowing patients to be clustered according to stage of change. The items focus on cognitive head-injury problems (e.g. attention and learning, memory and concentration, decision-making, and problem-solving problems), rather than physical deficits. As well as self-awareness of cognitive deficits the CAQ measures engagement or readiness to engage in behavioural change. Sample items from the three stages include:

- (1) Pre-contemplation: being here is pretty much a waste of time for me because the head injury problems do not have anything to do with me.
- (2) Contemplation: I have head injury problems (like attention and learning, memory and concentration, decision-making and problem-solving problems) and I really think I should work on them.
- (3) Action: at times my head injury problems are difficult, but I'm working on them (p. 237) [41].

A sample of 45 TBI patients was clustered into three groups on the basis of CAQ profiles by Lam *et al.* [41]. The clusters were a Pre-contemplation group, who denied deficits, an Ambivalent group, who had mixed feelings about their deficits but showed some readiness to change, and a Participation group who were aware of their deficits and were actively trying to change. There were significant differences in treatment performance scores as rated by therapists among the three groups $F(2,44) = 23.95$ $p < 0.0001$, indicating a relationship between CAQ scores and performance in treatment. The Pre-contemplation group showed the worst performance in treatment, followed by the Ambivalent group, and then the Participation group. Internal consistency was demonstrated with Cronbach's alphas of 0.85 for the Pre-contemplation scale, 0.91 for the Contemplation scale, and 0.92 for the Action scale [41]. Further studies are required to establish the reliability and validity of the instrument for the TBI population.

Structured interviews

An alternative means of quantitative assessment is the use of structured interview questions, the responses to which are subsequently scored by the interviewer according to a rating scale. This method of classifying patients has been used in two studies of lack of self-awareness, or anosognosia, for hemiplegia and hemianopia. Bisiach *et al.* [48] followed a standard procedure to classify patients according to a four-point scale as follows:

- 0= The disorder is spontaneously reported or mentioned by the patient in reply to a general question about his or her complaints.
- 1= The disorder is reported only following a specific question about the affected function.
- 2= The disorder is acknowledged only after is demonstration through routine techniques of neurological examination.
- 3= No acknowledgement of the disorder can be obtained

Cutting [49] investigated anosognosic phenomena in a sample of 100 acute hemiplegic patients using a structured questionnaire. Patients were considered anosognosic if they expressed denial when asked general questions such as 'Why are you here?', 'What is the matter with you?', 'Is there anything wrong with your arm or leg?'. Further questioning aimed at identifying other anosognosic phenomena such as anosodiaphora (unconcern or indifference regarding an acknowledged deficit); 'Is it a nuisance? How much trouble does it cause you?', or misoplegia (hatred of the affected limb); 'Do you dislike the arm? Do you hate it'.

Markova and Berrios [50] designed a semistructured interview to accompany an insight scale for use in psychiatry. The interview included questions such as 'What do you see as being the problem?', 'Do you feel any different to your normal self?', 'How?' and 'How do you think other people view you?—strangers/relatives/friends?'. The qualitative information obtained from the interviews was used to verify patient responses on the insight scale. Although not used in Markova and Berrios' study, patient responses in an interview such as this could be quantified according to a predetermined rating scale like the four-point scale used by Bisiach and colleagues [48].

The use of structured interviews by Bisiach *et al.* [48], Cutting [49], and Markova and Berrios [50] to investigate other populations with disorders of self-awareness suggests that this may be a possible means of evaluating self-awareness following TBI. Yet the above studies did not provide reliability estimates for scoring the interview responses. Such reliability examination would be a useful step towards validating structured interviews as a means of assessment.

Levine *et al.* [51] used a structured interview with 40 TBI patients and 26 controls to determine their level of self-understanding and interpersonal negotiation strategies. They evaluated the interview responses according to developmental levels of social cognition. Only the self-understanding component of the interview will be discussed here, because of its relevance to self-awareness. The construct self-understanding was divided into four self-schemes (physical, active, social and psychological). The interviewer asked subjects a series of questions encouraging them to describe themselves in these four terms. Sample interview questions are:

How have you changed since before your injury?
 How have you changed socially since before your injury?
 How did you get to be the way you are?
 What did you hope for in life?
 Do you think you'll be the same or different five years from now? (p. 167) [51].

The interview responses are then divided into scorable 'chunks' or segments mentioning one characteristic of self. These are rated according to developmental levels of social cognition to give a numerical value for each self-scheme [51].

Other researchers have relied on structured interviews to gather information about problems experienced by patients and relatives following TBI [15,52]. The researchers scored the interview responses on scales to give quantitative data for analysis. These studies, and the Levine *et al.* study [51], provide a precedent for an interviewer-scored structured interview for the evaluation of self-awareness following TBI. An interview, the Self-Awareness of Deficits Interview, has been devised by the authors, and a preliminary inter-rater reliability study is reported here.

Self-awareness of deficits interview

The Self-Awareness of Deficits Interview (SADI) is an interviewer-scored structured interview devised by the authors for the purposes of obtaining both qualitative and quantitative data on the status of self-awareness following TBI (see Appendix). The interview is based on the model of self-awareness described earlier [9], and therefore has three areas of questioning: (1) self-awareness of deficits; (2) self-awareness of functional implications of deficits; and (3) ability to set realistic goals.

In each area a number of questions are asked by the interviewer in an attempt to establish the patient's level of self-awareness. The questions were based in part on previous structured interviews [50,51]. Questions can be adapted or reworded by the interviewer within the context of the interview, and prompts can be included to elicit more information, provided the essence of the questions remains unchanged. The patient's responses are transcribed verbatim as much as possible by the interviewer during the interview, or can be recorded on audiotape.

The responses are rated on a four-point scale similar in format to the scale used by Bisiach *et al.* [48] as described above, but the rating scale was adapted to cover the multitude of deficits following TBI. A score of 0 indicates no disorder of self-awareness and a score of 3 indicates a severe disorder of self-awareness. In designing the rating scale a number of points were taken into consideration. Firstly, patients with TBI may display 'borderline' awareness in which they acknowledge certain deficits (notably physical limitations), and ignore others (such as cognitive and personality changes), or they can describe problems that others have noticed, but patients themselves are not convinced that these deficits exist [10,53]. Secondly, understanding the functional implications of deficits may be limited by a lack of opportunity to try various tasks in the acute post-injury phase. Thirdly, adjustment of pre-injury goals [53] is important in the evaluation of self-awareness (H. Godfrey, personal communication, 1993). Finally, in scoring an individual's responses on the rating scale, the interviewer needs some background knowledge on the patient's current level of function (e.g. mobility, functional memory and cognitive status, living situation, prognosis). Therefore, discussion with relatives and staff who have a close association with the patient is recommended.

Inter-rater reliability

Subjects. Preliminary inter-rater reliability data for the SADI were gathered using a sample of 25 TBI patients from a head-injury rehabilitation unit of a large metropolitan hospital. All patients were between 3 and 9 months post-severe TBI, aged 15–65 years, had experienced post-traumatic amnesia of greater than 24 hours, and could communicate in English.

Procedure. The first author interviewed the subjects using the SADI and recorded patients' responses to interview questions verbatim during the interview. Four additional occupational therapists were selected for inclusion in the reliability study, which, including the first author, gave a total of five raters. All raters had some experience in brain injury rehabilitation. Raters were given an explanation of the SADI by the first author and a brief practice using the rating scale. Written information on each patient, detailing the nature of the injury, persisting deficits and current functional status (which was compiled from review of the medical records and discussion with treating therapists) was provided to each rater. The five raters independently scored level of self-awareness for the three

Table 1. ANOVA and intra-class correlation coefficients (ICCs) for inter-rater reliability data for the Self-Awareness of Deficits Interview with 25 subjects and five raters

Source	Sum of squares (SS)				d.f.	Mean squares (MS)			
	Section			Total score		Section			Total score
	1	2	3			1	2	3	
Between subjects	74.27	75.09	105.25	709.25	24	3.9	3.13	4.39	29.55
Within subjects									
Between judges	1.23	11.89	2.49	24.29	4	0.38	2.97	0.61	6.07
Residual (error)	15.57	30.31	20.75	100.11	96	0.32	0.22	0.22	1.04
ICC (2,1)						0.78	0.57	0.78	0.82

for each patient using the four-point rating scales, and using the transcribed interview as their data.

Results. Intra-class correlation coefficients (ICC) were calculated for the scores in each of the three sections (ranging from 0 to 4), and for the total of the scores (ranging from 0 to 12). ICC were chosen over classical reliability indexes such as Pearson's *r* to avoid obtaining misleading results, as can occur in reliability studies [54–56]. Following the guidelines of Shrout and Fleiss [57], ICC(2,1) was selected as the appropriate statistic to allow generalization to other raters within the same population, and to describe the reliability in terms of any one rater who may later use the test. The data were recorded in a two-way raters versus subjects ANOVA matrices, and ICC values obtained from Bartko's formula [56] (see Table 1). The results indicated fair agreement between the raters on the three sections of the SADI with ICC values of 0.78, 0.57 and 0.78, respectively. The scores on the three subsections combined has an acceptable ICC of 0.82. In this preliminary study raters did not have the opportunity to observe interviews directly, but were restricted to forming judgements on the basis of transcribed interview responses. However, the findings suggest that it may be worthwhile to investigate other aspects of reliability of the SADI, such as inter-rater agreement during direct interview observation.

Limitations of quantitative research methods

The use of questionnaires and structured interviews to quantify self-awareness of deficits relies solely on the patients' ability to understand verbal (or written) questions, and to verbalize their understanding of deficits. A number of patients are therefore unable to be assessed using such methods, due to speech and language disorders. Additionally, *intellectual awareness* of deficits is only the first step towards full self-awareness. As hypothesized by Crosson and colleagues [58], patients first gain the ability to acknowledge intellectually that certain deficits exist, and to recognize the implications of deficits. Further along in the development of self-awareness, patients are able to recognize problems related to deficits when they are actually occurring (*emergent awareness*), and finally to anticipate when a problem is likely to occur because of deficits (*anticipatory awareness*). Questionnaires and interviews evaluate intellectual awareness only. Evaluation of emergent and anticipatory awareness requires of

task performance in a variety of situations, accompanied by timely questions by a trained professional [53].

Deaton [7] has pointed out that the emphasis on verbal aspects may result in neglect of behavioural manifestations. For example a patient may verbally deny the existence of any problems, yet still participate appropriately in treatment, or he or she may verbally identify specific cognitive deficits, but fail to modify behaviour accordingly for safety, such as continuing to drive against recommendation. In behavioural terms the patients with impaired self-awareness may display unconcern, poor self-monitoring and self-regulation of behaviour, and failure to interact with the environment in a socially appropriate manner [59]. These behavioural aspects of disorders of self-awareness may be more readily identified and explored through qualitative enquiry.

Workers such as Krefting [60] and Crisp [28] have advocated qualitative research as an alternative and more effective means of gaining an in-depth understanding of the area of self-awareness of deficits. Researchers using qualitative methods have identified key elements of self-awareness of deficits through investigations of the many facets of life following TBI. Methods include nominal group technique [61,62], in-depth discussion and descriptive case studies [63], and ethnographic study [60]. Qualitative research investigates phenomena from an insider's perspective, as opposed to an outsider's, or rehabilitation professional's perspective [28]. Indeed, as Tyerman and Humphrey [5] commented, 'it is the subjective impairment which represents distressing reality for these patients' (p. 14). However, while qualitative research allows the generation of new theories through naturalistic enquiry and inductive analysis [64], it may be unable to answer certain research questions often dwelt upon in head-injury research, such as those involving prognosis, and efficacy of treatment.

One further problem in the assessment of self-awareness of deficits in the TBI population is aetiology of the disorder. A distinction is made in the literature between organic disorders of self-awareness, which are attributed directly to brain damage, and psychological disorders of self-awareness, in which there is denial of deficits but no organic brain syndromes, such as occurs in defensive denial [65]. Although it is doubtful whether defensive denial is the primary cause of disorders of self-awareness following TBI, current debate acknowledges that it probably to some extent contributes to the problem in some patients [66–68]. However, the nature and extent of that contribution is not yet understood [67]; nor has an objective means for separating and measuring them in the individual been developed [69]. In the patient with impaired self-awareness it is not possible, using known assessment methods, to ascertain to what extent the problem is organic in origin, or to what extent is psychological.

Conclusion

In summary, then, the issue of awareness following head injury is, as noted by Schacter [70], 'one of the enduring mysteries of the human mind' (p. 174). Given this, there is not likely to be a single ideal means of evaluating self-awareness of deficits in the individual with TBI in the immediate future. In the absence of one omnibus test an approach which makes use of multiple measures—including questionnaires, interviews and, where possible, observation—is recommended. Information should be obtained from multiple sources, including patient, relative and staff, particularly in early stages post-injury when relatives may be in denial. We propose an interviewer-scored structured questionnaire (the Self-Awareness of Deficits Interview) which may be used as an adjunct to the current available means of quantifying self-awareness.

TBI. Clearly further research is required to continue to establish the reliability and validity of recognized assessments, to provide reliability estimates for newer assessments, and to identify relationships between assessments.

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Appendix: Self-Awareness of Deficits Interview

1. *Self-awareness of deficits*

Are you any different now compared to what you were like before your accident? In what way? Do you feel that anything about you, or your abilities has changed?

Do people who know you well notice that anything is different about you since the accident? What might they notice?

What do you see as your problems, if any, resulting from your injury? What is the main thing you need to work on/would like to get better?

Prompts

Physical abilities (e.g. movement of arms and legs, balance, vision, endurance)?

Memory/confusion?

Concentration?

Problem-solving, decision-making, organizing and planning things?

Controlling behaviour?

Communication?

Getting along with other people?

Has your personality changed?

Are there any other problems that I haven't mentioned?

2. *Self-awareness of functional implications of deficits*

Does your head injury have any affect on your everyday life? In what way?

Prompts

Ability to live independently?

Managing finances?

Look after family/manage home?

Driving?

Work/study?

Leisure/social life

Are there any other areas of life which you feel have changed/may change?

3. *Ability to set realistic goals*

What do you hope to achieve in the next 6 months? Do you have any goals? What are they?

In 6 months time, what do you think you will be doing? Where do you think you will be?

Do you think your head injury will still be having an affect on your life in 6 months time?

If yes: how?

If no: are you sure?

Scoring

1. Self-awareness of deficits

- 0 Cognitive/psychological problems (where relevant) reported by the patient/client in response to general questioning, or readily acknowledged in response to specific questioning.
- 1 Some cognitive/psychological problems reported, but others denied or minimized. Patient/client may have a tendency to focus on relatively minor physical changes (e.g. scars) and acknowledge cognitive/psychological problems only on specific questioning about deficits.
- 2 Physical deficits only acknowledged; denies, minimizes or is unsure of cognitive/psychological changes. Patient/client may recognize problems that occurred at an earlier stage but denies existence of persisting deficits, or may state that other people think there are deficits, but he/she does not think so.
- 3 No acknowledgement of deficits (other than obvious physical deficits) can be obtained, or patient/client will only acknowledge problems that have been imposed on him/her, e.g. not allowed to drive, not allowed to drink alcohol.

2. Self-awareness of functional implications of deficits

- 0 Patient/client accurately describes current functional status (in independent living, work/study, leisure, home management, driving), and specifies how his/her head injury problems limit function where relevant, and/or any compensatory measures adopted to overcome problems.
- 1 Some functional implications reported following questions or examples of problems in independent living, work, driving, leisure, etc. Patient/client may not be sure of other likely functional problems, e.g. is unable to say because he/she has not tried an activity yet.
- 2 Patient/client may acknowledge some functional implications of deficits but minimizes the importance of identified problems. Other likely functional implications may be actively denied by the patient/client.
- 3 Little acknowledgement of functional consequences can be obtained; the patient/client will not acknowledge problems: except that he/she is not allowed to perform certain tasks. He/she may actively ignore medical advice and may not engage in risk-taking behaviours, e.g. drinking, driving.

3. Ability to set realistic goals

- 0 Patient/client sets reasonably realistic goals, and (where relevant) identifies that the head injury will probably continue to have an impact on some areas of functioning, i.e. goals for the future have been modified in some way since the injury.
- 1 Patient/client sets goals which are somewhat unrealistic, or is unable to specify a goal, but recognizes that he/she may still have problems in some areas of function in the future, i.e. sees that goals for the future may need some modification, even if he/she has not yet done so.
- 2 Patient/client sets unrealistic goals, or is unable to specify a goal, and does not know how he/she will be functioning in 6 months time, but hopes he/she will return to pre-trauma, i.e. no modification of goals has occurred.
- 3 Patient/client expects without uncertainty that in 6 months time he/she will be functioning at pre-trauma level (or at a higher level).

