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Impaired Self-Awareness After Acquired Brain Injury: Clinicians' Ratings on Its Assessment and Importance for Rehabilitation

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Background: Impaired self-awareness is a potential obstacle to successful rehabilitation. **Objective:** To obtain clinicians' ratings of the importance of self-awareness for brain injury rehabilitation and use of instruments to assess self-awareness. **Participants:** One hundred sixty-three members of 3 major Dutch organizations for neuropsychology or rehabilitation. **Main Measure:** Online survey addressing: (1) factors participants consider important for the course and success of rehabilitation, (2) whether they assess patients' levels of self-awareness, and (3) the instruments they use to do so. **Results:** Of the 163 respondents, 116 (71.2%) considered self-awareness to be important for the course of rehabilitation; 113 (69.3%) considered it to be important for the success of rehabilitation. One hundred fifty-six clinicians (95.7%) reported assessing patients' levels of self-awareness, but only 12 (7.4%) reported using standardized instruments specifically designed for this purpose. The instruments most frequently reported to be used were the Awareness Questionnaire and Patient Competency Rating Scale. **Conclusions:** It is difficult to capture different aspects of self-awareness in a standardized manner. There is a need for instruments that are valid and reliable and that have good clinical utility. **Key words:** assessment, brain injury, rehabilitation, self-awareness

“IMPAIRED SELF-AWARENESS” generally denotes a reduced ability to appraise one's strengths and weaknesses and their implications for daily life activities.¹ Reported prevalence rates of impaired self-awareness in patients with acquired brain injury have ranged from 30% to 97%.^{2,3} Impairments of self-awareness are associated with long-term emotional dysfunction due to unrealistic expectations of recovery and with less favorable treatment outcomes on factors such

as employment status, discharge Barthel Index, and independent living.^{4–9}

Diminished self-awareness is a potential obstacle to rehabilitation success and societal reintegration following acquired brain injury. It is therefore important to consider self-awareness as a matter of the highest priority in rehabilitation programs and to assess it regularly throughout rehabilitation.

We wanted to find out whether rehabilitation professionals agree that self-awareness is an important influence on the course and success of rehabilitation and, if so, whether they assess self-awareness and what instruments they use in routine clinical practice.

In a survey of expert opinions, we investigated the following:

1. Clinician ratings of importance of self-awareness for the course and success of brain injury rehabilitation.
2. Instruments used in Dutch rehabilitation practice to determine the degree of impairment of self-awareness.

METHODS

In December 2010, a Web link to an online survey was sent by e-mail to the members of 3 major Dutch

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The authors declare no conflicts of interest.

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professional organizations for neuropsychology or rehabilitation: (1) the Rehabilitation Psychology and Neuropsychology sections of the Dutch Association of Psychologists (682 members); (2) the Dutch Working Group of Rehabilitation Physicians for Stroke (40 members); and (3) the National Platform for Cognitive Rehabilitation (112 members).

Respondents were asked to select from a list of 16 factors a maximum of 5 that they considered to be most important for the course and success of rehabilitation. These 16 factors were age, gender, education, injury location, physical problems, cognitive impairments, premorbid functioning, psychosocial functioning, personality, impaired self-awareness, motivation, learning ability, cooperation, coping style, learning style, and the therapist's level of experience. We chose these factors—based on our own clinical experience and extensive literature research—as those we thought most likely to influence the course and success of rehabilitation. Respondents were allowed to add factors to the list. In addition, they were asked to indicate whether they typically assess patients' levels of self-awareness during rehabilitation and what instruments they use to do so.

Statistical analysis

Respondents' characteristics and the survey results are presented using descriptive statistics (frequency count, mean, SD). One author (H.B.) categorized the reported assessment instruments as follows: questionnaires specifically designed to assess self-awareness; tests or questionnaires not specifically designed to assess self-awareness; observation of behavior; or undefined (for cases in which respondents did not elaborate on what they did). The results were checked by a second author (I.W.). There was no disagreement between the 2 authors. Data were analyzed using SPSS version 18.0.

RESULTS

Respondents

We received 174 completed questionnaires. Duplicates ($n = 1$) and those from respondents who did not indicate their profession ($n = 10$) were excluded, leaving a total of 163 completed questionnaires. Among the respondents were 36 physiatrists (22.1%), 1 psychiatrist (0.6%), 83 psychologists (50.9%), 24 occupational therapists (14.7%), 15 cognitive trainers/therapists (19.2%), 3 physical therapists (1.8%), and 1 psychology assistant (0.6%). Mean number of years of clinical experience was 9.0 (SD = 6.9; range, 0–29); mean age was 39.4 years (SD = 9.9; range, 22–65). Not all respondents answered all questions.

Factors viewed as influencing the course and success of brain injury rehabilitation

The factors “cognitive impairments,” “self-awareness,” and “learning ability” were most frequently mentioned as being important for the course and success of rehabilitation. One hundred twenty-seven clinicians (77.9%) considered cognitive impairments to be a factor influencing the course of rehabilitation, whereas 107 clinicians (65.6%) considered them to influence the success of rehabilitation. One hundred sixteen clinicians (71.2%) endorsed self-awareness as an important factor for the course of rehabilitation, whereas 113 (69.3%) considered it important for the success of rehabilitation. Ninety-three clinicians (57%) selected learning ability as an important factor for the course of rehabilitation, whereas 90 (55.2%) viewed it as an influence on the success of rehabilitation.

Assessment instruments used

Of the 163 participating clinicians, 156 (95.7%) reported that they assessed patients' self-awareness during rehabilitation but only 37 respondents (22.7%) reported using 1 or more instruments.

Twelve respondents (7.4%) reported using standardized instruments specifically designed to assess self-awareness. The questionnaires most frequently used were the Awareness Questionnaire (AQ) and the Patient Competency Rating Scale (PCRS).^{3,10} Seventeen clinicians (10.4%) reported using (neuropsychological or occupational) tests or questionnaires that are not specifically designed to assess self-awareness (eg, the Dysexecutive questionnaire of the Behavioral Assessment of the Dysexecutive Syndrome and the Assessment of Motor and Process Skills).^{11,12} No further information was collected about the way in which the clinicians used these tests and questionnaires to draw inferences about self-awareness. Eight clinicians (5.5%) reported observing their patients' behavior during the performance of neuropsychological or occupational tests, using unstructured observations. Finally, one clinician reported using “Ben-Yishay's method” whereas another clinician used “Crosson's model,” without explaining in detail what they did. The other 126 clinicians (77.3%) reported that they did not use an instrument to assess self-awareness.

DISCUSSION AND CONCLUSIONS

The great majority of participants regarded self-awareness as important for the course and success of rehabilitation after brain injury. Although almost all indicated that they assessed their patients' levels of self-awareness during rehabilitation, only some reported using structured and standardized instruments specifically designed to assess this factor.

In a systematic review, Smeets et al¹³ recently found the PCRS¹⁰ and the AQ³ to be 2 of the 3 instruments to assess impaired self-awareness that have good psychometric properties. The third instrument that stood out in terms of quality according to Smeets et al was the Self-Awareness of Deficits Interview (SADI).¹ However, very few of our respondents reported using the PCRS or AQ and none used the SADI.

One reason why our respondents used few formal assessment instruments may be that there are no empirically supported Dutch versions available. There is no Dutch version of the SADI. Both the PCRS and the AQ have been translated into Dutch, but these translated versions have not been validated.

Second, both the PCRS and the AQ assess only 1 level or aspect of self-awareness, namely, patients' knowledge about their disabilities.¹³ There is no simple definition of the term "awareness," but several models describe self-awareness as a construct consisting of different aspects or levels. Although there is no empirical evidence supporting these models, they can be useful guidelines for clinicians. Crosson et al¹⁴ described self-awareness as a hierarchically ordered construct consisting of 3 levels: intellectual awareness (a person's ability to describe deficits); emergent awareness (ability to recognize difficulties as they are happening); and anticipatory awareness (ability to predict when difficulties will arise). More recent interactional models have criticized the hierarchical structure of this model and differentiate between metacognitive knowledge or declarative knowledge about one's abilities, which would incorporate elements of intellectual awareness, and online monitoring of performance during tasks, which relates to emergent and anticipatory awareness.¹⁵ Rehabilitation

therapists not only need to know whether patients understand their deficits (intellectual awareness or online monitoring) but also need to observe whether patients are able to monitor and adjust their behavior (emergent and anticipatory awareness or online monitoring). Only then can therapists decide which treatment best fits the patients' abilities. However, there are no valid and reliable instruments that cover all these aspects.¹³

Several limitations of this study should be noted. First, no response rate could be calculated since some respondents may be members of more than 1 of the 3 organizations and hence have received the questionnaire more than once. Also, members of the Dutch Association of Psychologists do not necessarily work in rehabilitation settings, which may have caused them to disregard our questionnaire. Still, the response rate appears to have been low, which might reduce the representativeness of our findings. Second, respondents had to choose from a list of predefined factors; they might have formulated different answers if they had been presented with open-ended questions. On the contrary, respondents were allowed to add factors that were not listed. Finally, all respondents were Dutch, which may limit the generalizability of our findings to other countries. However, the systematic review by Smeets et al did include international articles on measures of self-awareness. We think it is safe to assume that there are no other instruments available other than those mentioned in the survey and the review articles and that both in the Netherlands and in other countries, it remains difficult to assess all aspects or levels of self-awareness in a standardized manner.

In conclusion, we believe that there is a need for instruments that are valid and reliable and that have good clinical utility.

REFERENCES

1. Fleming J, Strong J, Ashton R. Self-awareness of deficits in adults with traumatic brain injury: how best to measure? *Brain Inj.* 1996;10:1–16.
2. Sherer M, Bergloff P, Levin E, High WM Jr, Oden KE, Nick TG. Impaired awareness and employment outcome after traumatic brain injury. *J Head Trauma Rehabil.* 1998;13(5):52–61.
3. Freeland J. Awareness of deficits: a complex interplay of neurological, personality, social and rehabilitation factors. *Magazine.* 1996;4:32–34.
4. Ownsworth T, Fleming J. The relative importance of metacognitive skills, emotional status and executive functioning in psychosocial adjustment following acquired brain injury. *J Head Trauma Rehabil.* 2005;20(4):315–332.
5. Prigatano GP, Fordyce DJ, Zeiner HK, Roueche JR, Pepping M, Wood B. Neuropsychological rehabilitation after closed head injury in young adults. *J Neurol Neurosurg Psychiatry.* 1984;47:505–513.
6. Trahan E, Pepin M, Hopps S. Impaired awareness of deficits and treatment adherence among people with traumatic brain injury or spinal cord injury. *J Head Trauma Rehabil.* 2006;3:226–235.
7. Trudel TM, Tryon WW, Purdum CM. Awareness of disability and long-term outcome after traumatic brain injury. *Rehabil Psychol.* 1998;43:267–281.
8. Sherer M, Hart T, Nick TG, Whyte J, Thompson RN, Yablon SA. Early impaired self-awareness after traumatic brain injury. *Arch Phys Med Rehabil.* 2003;84:168–176.
9. Pedersen PM, Jorgensen HS, Nakayama H, Raaschou HO, Olsen TS. Frequency, determinants, and consequences of anosognosia in acute stroke. *J Neurol Rehabil.* 1996;10:243–250.
10. Prigatano GP, Altman IM, O'Brien KP. Behavioral limitations that traumatic-brain-injured patients tend to under estimate. *Clin Neuropsychol.* 1990;4:163–176.
11. Wilson BA, Burgess PW, Emslie H, Evans JJ. *Behavioral Assessment of the Dysexecutive Syndrome: Test Manual.* Bury St Edmunds, England: Thames Valley Test Company; 1996.
12. Fisher AG. *Assessment of Motor and Process Skills.* 3rd ed. Fort Collins, CO: Three Star Press; 1999.

13. Smeets SMJ, Ponds RWHM, Verhey FR, Van Heugten CM. Psychometric properties and feasibility of instruments used to assess awareness of deficits after acquired brain injury: a systematic review. *J Head Trauma Rehabil.* 2012;27(6):433–442.
14. Crosson B, Barco PP, Velozo C, et al. Awareness and compensation in postacute head injury rehabilitation. *J Head Trauma Rehabil.* 1989;4:46–54.
15. Toglia J, Kirk U. Understanding awareness deficits following brain injury. *NeuroRehabilitation.* 2000;15:57–70.