

Assessments measuring the perception of deficits in individuals with acquired brain injuries: a review of the literature

Fernanda de Sousa Forattore¹, Rafaela Larsen Ribeiro²

ABSTRACT

Objective: Through a review of the literature, to select assessments measuring the perception of deficits of individuals with acquired brain injuries who have undergone a self-awareness intervention. **Method:** A review in the BIREME and PubMed databases was performed going over the past 10 years. **Results:** In this paper, eleven articles were selected that contained assessments of self-awareness before and after a therapeutic intervention and that had sampled individuals with diagnoses of traumatic brain injury (TBI), stroke, or cerebral tumor. **Conclusion:** A significant number of publications were found from Australia, European countries, and the United States. The instruments mostly used in the studies were the Self-awareness of Deficits Interview (SADI) and the Awareness Questionnaire (AQ). No validated and standardized studies or evaluations were found from Brazil. Thus, development, translation, and adaptation of assessments measuring the perception of awareness in the Brazilian population are required in order to provide an evidence-based practice by the use of intervention models.

Keywords: Brain Injuries, Stroke, Conscience, Questionnaires, Rehabilitation

¹ Occupational Therapist, Instituto de Medicina Física e Reabilitação do Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo.

² Researcher at the Departamento de Psicobiologia/ UNIFESP, Coordinator of the Centro de Diagnóstico Neuropsicológico.

Mailing address:

Centro de Diagnóstico Neuropsicológico
Rafaela Larsen Ribeiro
Rua Loefgren, 1900, Anfiteatro Brasil Tufik
CEP 04040-030
São Paulo - SP
E-mail: rafa@psicobio.epm.br

Received on March 23, 2015.

Accepted on July 16, 2015.

DOI: 10.5935/0104-7795.20150029

INTRODUCTION

Impairment of the self-awareness of deficits has been observed in various neurological disorders and it may be an obstacle to the success of rehabilitation.¹⁻³

Brain disorders such as traumatic brain injury (TBI), stroke (CVA), hypotensive hypoxic injury, encephalitis, and other infectious disorders and brain tumors compromise normal brain function. Each one of these types of neurological disorders is associated with specific patterns of damage in the central nervous system (CNS), and each one is associated with different physical, cognitive, behavioral, and emotional dysfunction syndromes.⁴

Many individuals with acquired brain injury seem to have limited *insight* of how their abilities and behaviors have changed. This is often a gradual deficiency, so much so that the awareness of physical limitations is better than the awareness of cognitive, social, and behavioral limitations. In this way, it can have a negative effect on rehabilitation, because patients who do not perceive their deficits may show little motivation, or refuse or resist treatment.^{2,5}

Prigatano, mentioned by Sohlberg,⁵ argues that self-awareness is an emergent brain function dependent on cognitive and affective states. That work suggests that patients who show awareness deficits have disorders in the affective and cognitive areas.⁵

Crosson et al.⁶ described a hierarchical model of awareness that distinguishes three important aspects of awareness to be considered in the evaluation and treatment. At the basis is one's intellectual awareness, which is the knowledge that a specific function is compromised, it is the capacity to describe functional limitations verbally. Then, there is the emergent awareness, which is the capacity to recognize a problem only when it happens. And last, the anticipatory awareness, which is the capacity to predict that the problem will probably occur as a result of an impairment before a specific activity is performed.⁶

Awareness is not a unit concept and its aspects may be distinguished and linked to different areas of daily function, as shown in the study by Bivona,⁷ which found a significant correlation between the reduction of self-awareness with the increase of problems in some components of the executive functions.⁷ Hoerold et al.⁸ suggested a strong role of the prefrontal cortex in the awareness of deficits. Their study analyzed the correlation of awareness in the left cortex and right prefrontal cortex in comparison with left and right posterior

injuries, including two types of awareness, metacognitive and "online error monitoring." The result of the study was that, while intellectual awareness depends on both the frontal regions, the emergent awareness depends more on the right prefrontal cortex than on the left.⁸

To evaluate the nature or gravity of the awareness deficit requires the identification of psychological and behavioral correlations. The measuring is made through questionnaires and interviews designed to collect quantitative or qualitative information on the capacity for self-awareness.^{2,5}

The three most common methods for measuring awareness are analyzing the verbal descriptions of patients about their functioning, comparing the clinical reports with the reports of other people, and comparing the patients' performance predictions with their current performances.^{3,5}

Comparing the patients' answers to the questionnaires that explore functional levels with the answers from other people is a very common strategy for measuring awareness. The idea is that a member of the family or a health professional will provide a more objective perception of the functioning against the self-appreciation of the patient.^{3,5}

Among the questionnaires that analyze the discrepancy between the individual evaluations and those from informants, two stand out: the PCRS and the AQ.

According to Sohlberg et al.⁵ the PCRS was introduced by Fordyce and Roueche (1986), and it is an instrument that compares the classifications of abilities of patients with those from the team and family members. The patient is classified by the difficulty he would have in performing each task.⁵

In its turn, the AQ, developed by Sherer et al.⁹ differs from the PCRS in that it compares the current functional abilities of the patient with those prior to the injury.¹⁰

A study by Sherer et al.¹⁰ compared the PCRS and the AQ in the measurement of self-awareness deficit in individuals with brain injury trauma and found moderate correlations.¹⁰

Another questionnaire approach is the Self-Awareness of Deficits Interview (SADI) that refers to a structured interview designed to obtain qualitative and quantitative data on the *status* of self-awareness deficits. The patient is questioned in three areas: self-awareness of deficits, self-awareness of the functional implications of deficits, and the ability to establish realistic objectives.³

There are evaluations, however, that do not approach only intellectual awareness, like the Self-regulation Skills Interview (SRSI), which was designed to measure a series of meta-cognitive abilities essential to the planning of rehabilitation, to monitor the progress of an individual, and to evaluate the result of treatment interventions.¹¹

Wise et al.¹² examined the convergent validity between the self-awareness measurements of SADI, SRSI, and AQ in individuals with acquired brain injury and the results showed significant correlations between the measurements.

Owensworth et al.¹³ developed the Self-Perceptions in Rehabilitation Questionnaire (SPIRQ), which is a tool for brief measuring with the purpose of periodically monitoring the self-awareness, motivation, and the emotional reactions of the patient over the course of the rehabilitation.¹³

Therefore, which are the instruments that are most used for evaluation and that measure the perception of deficits of individuals with acquired brain injury during the self-awareness intervention process?

OBJECTIVE

This study is a literature review that selected evaluations published from 2005 to 2015 that measured the perception of deficits of individuals with acquired brain injury submitted to self-awareness intervention.

METHOD

A bibliographic survey was made in the following databases: Bireme, MedLine, and PubMed.

In the Pubmed and Medline databases the following terms were used: "*acquired brain injury*," "*self-awareness*," "*Questionnaire*," and "*rehabilitation*." In the Bireme the following descriptors were used: "*lesão cerebral adquirida*," "*autoconsciência*," "*questionário*," and "*reabilitação*."

The keywords used in this study were described in Portuguese and in English, so as to find the greatest number possible of articles. In total, 70 articles were identified.

A selection of articles was made for this study after reading the texts found. The inclusion criteria was the following:

- studies that included self-awareness evaluations before and after therapeutic intervention;

- studies that, for the application of these evaluations, had individuals diagnosed with traumatic brain injury (TBI), stroke, or brain tumor as their key population;

- articles published in the last 10 years (since 2005);

The exclusion criteria was the following:

- publications with insufficient content to be analyzed;

- articles with subject other than the subject of the present work.

After analyzing the data, 11 studies were selected for the study.

RESULTS

For this study, 11 articles were chosen from among the 70 studies found initially.

The 11 articles were organized in Chart 1, where they are shown concisely with the surname of the first author, country of origin, year of publication, what evaluation instruments were used to measure the awareness, and their purpose. Four (36%) articles were published in Oceania, four (36%) in Europe, two (18%) in North America, and one (10%) in Asia.

The most used evaluation instrument was the Self-awareness of Deficits Interview (SADI), followed by Awareness Questionnaire (AQ). A complete list of instruments that measure awareness used in the studies can be seen in Chart 2.

DISCUSSION

The purpose of this review was to search for the evaluations used in rehabilitation that measured the perception of self-awareness in individuals with acquired brain injuries. The selected articles dealt with interventions to improve the self-awareness of deficits, which are not detailed in the present study.

A significant number of publications were found from Australia, European countries, and the United States. This number may be related with the development and validation of evaluation instruments that measure self-awareness in those countries, such as the Self-awareness of Deficits Interview (SADI), introduced by Fleming et al.³ in 1996 in Australia and the Awareness Questionnaire (AQ), developed by Sherer et al.⁹ in the United States in 1998.

Chart 1. Scheme of the evaluation instruments in increasing order of study publication

AUTHOR/COUNTRY/YEAR	EVALUATION INSTRUMENTS THAT MEASURE AWARENESS	PURPOSE
Anson/Australia/2005 ¹⁴	- Patient Competency Rating Scale (PCRS) - Self-awareness of Deficits Interview (SADI)	To evaluate the ease with which the individual is capable of performing functional tasks, comparing the classifications of the abilities pointed out by the individual and by persons close to him, and to evaluate the capacity of the individual to define realistic goals.
Noé/Spain/2005 ¹⁵	- Patient Competency Rating Scale (PCRS)	To compare the patients' own classifications of his abilities with those from the team and family members.
Owensworth/Australia/2006 ¹⁶	- Self-Awareness of Deficits Interview (SADI) - Awareness Questionnaire (AQ)	To obtain qualitative and quantitative data of the status of self-awareness of deficits and compare current functional abilities of the patient with those prior to the injury.
Fleming/Australia/2006 ¹⁷	- Self-Awareness of Deficits Interview (SADI) - Patient Competency Rating Scale (PCRS)	To evaluate the state of self-awareness in three areas: self-awareness of deficits, self-awareness of functional implications of deficits, and the capacity to define realistic goals.
Roberts/United Kingdom/2006 ¹⁸	- Self-Awareness of Deficits Interview (SADI) - Awareness Questionnaire (AQ)	To evaluate the capacity to define realistic goals and compare the current functional abilities of the patient with those prior to the injury; also to compare the classifications of abilities pointed out by the patient and by persons close to him.
Cheng/China/2006 ¹⁹	- Self-Awareness of Deficits Interview (SADI)	To evaluate the state of self-awareness in three areas: self-awareness of deficits, self-awareness of functional implications of deficits, and the capacity to define realistic goals.
Goverover/United States/2007 ²⁰	- Awareness Questionnaire (AQ) - Assessment of Awareness of disability (AAD) - Self-Regulation Skills Interview (SRSI)	To compare the current functional abilities of the patient with those prior to the injury. To compare the performance of two specific tasks from the Assessment of Motor and Process Skills (AMPS) pointed out by the individual and by the evaluator after performing the activities. To evaluate six meta cognitive abilities: emergent awareness; anticipatory awareness; openness to change; the generation, the degree of use, and the efficacy of strategy.
Lundqvist/Sweden/2010 ²¹	- Self Regulation Skills Interview (SRSI)	To evaluate six metacognitive abilities: emergent awareness; anticipatory awareness; openness to change; the generation, the degree of use, and the efficacy of strategy.
Toglia/United States/2010 ²²	- Awareness Questionnaire (AQ) - Self-Regulation Skills Interview (SRSI)	To compare the current functional abilities of the patient with those prior to the injury; also to evaluate six metacognitive abilities: emergent awareness; anticipatory awareness; openness to change; the generation, the degree of use, and the efficacy of the strategy.
Lloréns/Spain/2012 ²³	- Self-Awareness Deficits Interview (SADI)	To evaluate self-awareness of deficits, functional limitations, and impacts on future plans.
Schmidt/Australia/2013 ²⁴	- Awareness Questionnaire (AQ) = - Self Perception in Rehabilitation questionnaire (SPIRQ)	To evaluate intellectual awareness through the sensory, physical, cognitive, and behavioral domains, comparing the discrepancy of the scores between the participant and the therapist; also to measure the self-perception of rehabilitation in 4 domains: changes in personal plans and in life, emotional reactions, self-perception in rehabilitation, and perceptions during recovery and when returning to normal.

Chart 2. Evaluation instruments that measure awareness used in the 11 articles selected.

EVALUATION INSTRUMENTS IN THE STUDIES	USES
Self-awareness of Deficits Interview (SADI)	6
Awareness Questionnaire (AQ)	5
Patient Competency Rating Scale (PCRS)	3
Self-Regulation Skills Interview (SRSI)	3
Assessment of Awareness of Disability (AAD)	1
Self-Perception in Rehabilitation Questionnaire (SPIRQ)	1

These two evaluation instruments were the most frequently mentioned in the articles selected. Another result observed in a systematic review carried out by Smeets et al.²⁵ referred to three instruments that stood out for their quality: the Awareness Questionnaire (AQ), Self-Awareness of Deficits Interview (SADI), and the Patient Competency Rating Scale (PCRS).²⁵ Although this study pointed out that those quantitative instruments are useful tools in the research, they have limited clinical use because they only measure intellectual awareness.

The Self-Regulation Skills Interview (SRSI), used in three studies from the selected articles and which is semi-structured, is different from the previous instruments, for it is composed of six items that evaluate the metacognition and self-regulating abilities.¹¹ Those six items can be grouped into three factors or indices: awareness, openness to change, and behavioral strategy.¹²

According to Wise et al.¹² when the evaluations are used in combination, they reflect what was proposed by Crosson et al.⁶ a hierarchical model of awareness, in which a variety of evaluations can be used to measure different aspects of self-awareness in individuals with acquired brain injury. They emphasize the need to use standardized evaluations of self-awareness in the context of rehabilitation.¹²

In rehabilitation, the evaluations are important in orienting and selecting the methods of intervention. The information obtained in the evaluations can be used in the planning of patient discharge as well as to measure the effectiveness of the treatment. And the in-depth evaluation of the degree of awareness of deficits can lead to an appropriate treatment with the objective of improving the patient's occupational performance.²⁶

The Assessment of Awareness of Disability (AAD) was used in one of the articles selected. This evaluation was conceived to measure the awareness of a disabled person or as a self-evaluation of the disability in relation to the real performance in activities of

daily living. They compared the performance of two specific tasks of the Assessment of Motor and Process Skills (AMPS) pointed out by the individual and by the evaluator after the execution of the activities. The AMPS is used to measure occupational performance in two instrumental activities of daily living.²⁷

The Self Perception in Rehabilitation Questionnaire (SPIRQ), used in the study by Schmidt et al.²⁴ was developed to be applied periodically, during hospitalized rehabilitation. It is a quick measuring tool, which identifies changes in the self-perception of functioning, in motivation, and in emotional reactions. By the periodicity of application, occupational therapists can monitor the perception of the individual in relation to the objectives of therapeutic intervention and detect signs of emotional suffering that may require a deeper evaluation by a psychologist.¹¹

During this review, no articles published in Brazil or standardized and validated instruments in the country referring to the present theme were found. In Brazil, according to DATASUS²⁸ there were 172,526 cases of stroke in 2012. Gaudêncio et al.²⁹ through the analysis of studies on epidemiology of traumatic brain injury in Brazil, studied 63,360 cases, with the main causes being: falls, transportation, and physical assaults, among other things. Therefore, directing our attention to the rehabilitation of persons with disability is extremely important to guiding the work of the health team in all the stages of care and of the rehabilitation process.

CONCLUSION

Above all, it was concluded that, in Brazil, it is necessary to have studies for the validation of instruments that evaluate the degree of understanding of a person in relation to his or her own physical or perceptual and cognitive impairments, which can have an impact on their occupational performance. The reason is that through standardized and validated instruments, reliable and trustworthy results and

information can be obtained, thus favoring the development of appropriate treatments with defined goals.

REFERENCES

1. Simmond M, Fleming J. Reliability of the self-awareness of deficits interview for adults with traumatic brain injury. *Brain Inj.* 2003;17(4):325-37. DOI: <http://dx.doi.org/10.1080/0269905021000013219>
2. Hart T, Sherer M, Whyte J, Polansky M, Novack TA. Awareness of behavioral, cognitive, and physical deficits in acute traumatic brain injury. *Arch Phys Med Rehabil.* 2004;85(9):1450-6. DOI: <http://dx.doi.org/10.1016/j.apmr.2004.01.030>
3. Fleming JM, Strong J, Ashton R. Self-awareness of deficits in adults with traumatic brain injury: how best to measure? *Brain Inj.* 1996;10(1):1-15.
4. Sohlberg MM, Mateer CA. Distúrbios neurológicos associados às limitações cognitivas. In: Sohlberg MM, Mateer CA. *Reabilitação cognitiva.* São Paulo: Santos; 2009. p.25-58.
5. Sohlberg MM, Mateer CA. Avaliação e controle da inconsciência. In: Sohlberg MM, Mateer CA. *Reabilitação cognitiva.* São Paulo: Santos; 2009. p. 269-97.
6. Crosson B, Barco P, Vellozo CA, Bolesta MM, Cooper P V, Werts D, et al. Awareness and compensation in postacute head injury rehabilitation. *J Head Trauma Rehabil.* 1989;4(3):46-54. DOI: <http://dx.doi.org/10.1097/00001199-198909000-00008>
7. Bivona U, Ciurlri P, Barba C, Onder G, Azicnuda E, Silvestro D, et al. Executive function and metacognitive self-awareness after severe traumatic brain injury. *J Int Neuropsychol Soc.* 2008;14(5):862-8. DOI: <http://dx.doi.org/10.1017/S1355617708081125>
8. Hoerold D, Pender NP, Robertson IH. Metacognitive and online error awareness deficits after prefrontal cortex lesions. *Neuropsychologia.* 2013;51(3):385-91. DOI: <http://dx.doi.org/10.1016/j.neuropsychologia.2012.11.019>
9. Sherer M, Bergloff P, Boake C, High W Jr, Levin E. The Awareness Questionnaire: factor structure and internal consistency. *Brain Inj.* 1998;12(1):63-8. DOI: <http://dx.doi.org/10.1080/026990598122863>
10. Sherer M, Hart T, Nick TG. Measurement of impaired self-awareness after traumatic brain injury: a comparison of the patient competency rating scale and the awareness questionnaire. *Brain Inj.* 2003;17(1):25-37. DOI: <http://dx.doi.org/10.1080/0269905021000010113>
11. Ownsworth TL, McFarland KM, Young RM. Development and standardization of the Self-regulation Skills Interview (SRSI): a new clinical assessment tool for acquired brain injury. *Clin Neuropsychol.* 2000;14(1):76-92. DOI: [http://dx.doi.org/10.1076/1385-4046\(200002\)14:1;1-8;FT076](http://dx.doi.org/10.1076/1385-4046(200002)14:1;1-8;FT076)
12. Wise K, Ownsworth T, Fleming J. Convergent validity of self-awareness measures and their association with employment outcome in adults following acquired brain injury. *Brain Inj.* 2005;19(10):765-75. DOI: <http://dx.doi.org/10.1080/0269905050019977>
13. Ownsworth T, Stewart E, Fleming J, Griffin J, Collier AM, Schimidt J. Development and preliminary psychometric evaluation of the Self-Perceptions in Rehabilitation Questionnaire (SPIRQ) for brain injury rehabilitation. *Am J Occup Ther.* 2013;67(3):336-44. DOI: <http://dx.doi.org/10.5014/ajot.2013.007625>

14. Anson K, Ponsford J. Whobenefits? Outcome following a coping skills group intervention for traumatically brain injured individuals. *Brain Inj.* 2006;20(1):1-13. DOI: <http://dx.doi.org/10.1080/02699050500309791>
15. Noé E, Ferri J, Caballero MC, Villodre R, Sanchez A, Chirivella J. Self-awareness after acquired brain injury-predictors and rehabilitation. *J Neurol.* 2005;252(2):168-75. DOI: <http://dx.doi.org/10.1007/s00415-005-0625-2>
16. Ownsworth T, Fleming J, Desbois J, Strong J, Kuipers P. A metacognitive contextual intervention to enhance error awareness and functional outcome following traumatic brain injury: a single-case experimental design. *J Int Neuropsychol Soc.* 2006;12(1):54-63.
17. Fleming JM, Lucas SE, Lightbody S. Using occupation to facilitate self-awareness in people who have acquired brain injury: a pilot study. *Can J Occup Ther.* 2006;73(1):44-55.
18. Roberts CB, Rafal R, Coetzer BR. Feedback of brain-imaging findings: effect on impaired awareness and mood in acquired brain injury. *Brain Inj.* 2006;20(5):485-97. DOI: <http://dx.doi.org/10.1080/02699050600664665>
19. Cheng SK, Man DW. Management of impaired self-awareness in persons with traumatic brain injury. *Brain Inj.* 2006;20(6):621-8. DOI: <http://dx.doi.org/10.1080/02699050600677196>
20. Goverover Y, Johnston MV, Togliá J, Deluca J. Treatment to improve self-awareness in persons with acquired brain injury. *Brain Inj.* 2007;21(9):913-23. DOI: <http://dx.doi.org/10.1080/02699050701553205>
21. Lundqvist A, Linnros H, Orlenius H, Samuelsson K. Improved self-awareness and coping strategies for patients with acquired brain injury-a group therapy programme. *Brain Inj.* 2010;24(6):823-32. DOI: <http://dx.doi.org/10.3109/02699051003724986>
22. Togliá J, Johnston MV, Goverover Y, Dain B. A multicontext approach to promoting transfer of strategy use and self regulation after brain injury: An exploratory study. *Brain Inj.* 2010;24(4):664-77. DOI: <http://dx.doi.org/10.3109/02699051003610474>
23. Lloréns R, Navarro MD, Alcañiz M, Noé E. Therapeutic effectiveness of a virtual reality game in self-awareness after acquired brain injury. *Stud Health Technol Inform.* 2012;181:297-301.
24. Schmidt J, Fleming J, Ownsworth T, Lannin NA. Video feedback on functional task performance improves self-awareness after traumatic brain injury: a randomized controlled trial. *Neurorehabil Repair.* 2013;27(4):316-24. DOI: <http://dx.doi.org/10.1177/1545968312469838>
25. Smeets SM, Ponds RW, 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):433-42. DOI: <http://dx.doi.org/10.1097/HTR.0b013e3182242f98>
26. Togliá JP, Golisz KM, Goverover Y. Avaliação e tratamento para comprometimentos cognitivo-perceptuais. In: Crepau EB, Cohn ES, Schell BA. Willard & Spackman terapia ocupacional. 13 ed. Rio de Janeiro: Guanabara Koogan; 2011. p.750-88.
27. Tham K, Bernspang B, Fisher AG. Development of the assessment of awareness of disability. *Scand J Occup Ther.* 1999;6:184-90.
28. DATASUS: Departamento de Informática do SUS [base de dados na Internet]. Brasília: Ministério da Saúde, c2014 [citado 2015 Mar 20]. Disponível em: <http://tabnet.datasus.gov.br>
29. Gaudêncio TG, Leão GM. A Epidemiologia do traumatismo crânio-encefálico: um levantamento bibliográfico no Brasil. *Rev Neurocienc.* 2013; 21(3):427-34.