

Insights into insight

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Knowledge valorization

Mr. S.A. is a 45-year-old elementary school teacher and father of two young children, who suffered a traumatic brain injury due to a biking accident. After a short stay at the hospital he was transferred to a rehabilitation center. Now, after 3 months of rehabilitation, he has recovered from the physical difficulties resulting from the brain injury. He is discharged home and Mr. S.A. immediately wants to return to work. He thinks he can reintegrate, but his wife and neuropsychologist do not think he is ready. His wife has noticed some changes in her husband's behavior. He has become more impulsive and does things before thinking them through. He has also become more aggressive and lashes out to his children for little things. He has trouble planning activities and when he starts a task he seldom finishes it. Especially his impulsivity and aggression can become a problem in the classroom where he is responsible for about 25 children. However, he is not aware of his changed behavior and how this affects his abilities as a teacher. He is frustrated that he is not allowed to return to work and does not understand why. Because he is not aware of the fact that he is not able to perform his job, he does not want to enroll in treatment that can help him control his troubled behavior or to deal with his planning difficulties. He is also not willing to take on a job that suits his new situation better. His neuropsychologist wonders if Mr. S.A.'s unawareness is a consequence of the injury or if he denies his disabilities. It is important to know this because impaired awareness resulting from neurological dysfunction needs a different treatment approach than unawareness resulting from denial of disability. Once she knows the origin of his unawareness she can select possible intervention techniques to improve Mr. S.A.'s awareness of his deficits. 'But which techniques will be most successful?', she wonders.

The above case describes the clinical phenomenon of impaired self-awareness after acquired brain injury. This thesis describes several studies on this topic. In this valorization paragraph the goal is to describe how the knowledge resulting from the research described in this thesis can be made valuable in scientific, clinical and social contexts.

Relevance

The functioning of the brain can be compromised when it gets damaged throughout life. This is called acquired brain injury. Brain injury can be caused by for example a blow to the head, a disruption of blood flow through the brain, or a lack of oxygen caused by for example a cardiac arrest. In the Netherlands about 100.000 to 120.000 new people a year suffer a brain injury.¹ After treatment in the hospital or rehabilitation clinic many of them return home and try to go on with their lives. This is not always easy. About 500.000 people in the Netherlands live with lasting consequences of their brain injury.¹ People experience trouble with physical, cognitive (thinking), emotional, and behavioral abilities. These impairments hinder the daily functioning of these people.

To adequately address these impairments and the consequences they have on daily living, it is important that people with brain injury are aware of their strengths and weaknesses. However, some of them overestimate their competencies and are not aware of the deficits that arose from their injury, such as Mr. S.A. Psychologists and other health care specialists indicate impaired awareness of deficits as the major obstacle in rehabilitation after brain injury.² Nevertheless, clinicians find it hard to deal with awareness impairments. This might be due to the fact that impaired self-awareness is a complex phenomenon and it is difficult to find out what exactly is going on. Like in the case of Mr. S.A., is he unaware *because* of the brain damage or is he unaware because he is *denying* his difficulties? Another obstacle for clinicians is the treatment of unawareness. There is no standard evidence-based treatment protocol available and many clinicians do not know the best approach to treat unawareness in a specific patient, with a specific awareness problem.

The above illustrates the clinical relevance of this topic. With regard to the societal relevance, knowledge on awareness deficits after brain injury can lead to reduction of health care costs. In 2010, in The Netherlands the total costs of stroke and traumatic brain injury were estimated at €2422 million and €1360 million, respectively.³ These costs include direct health care costs (i.e. hospitalizations, treatment, pharmaceuticals, etc.), direct non-medical costs (i.e. special accommodation, informal care), and indirect costs (i.e. loss of productivity in case of work loss and early retirement).³ Since impaired awareness is seen as a major obstacle for rehabilitation, improvement of awareness in the early stages after brain injury could possibly lead to a shorter stay in rehabilitation centers (i.e. reduction of direct health care costs) and better treatment outcomes. If patients like Mr. S.A. know their disabilities they can for example learn to be more independent (i.e. reduction in non-medical costs) and can apply for jobs that suit their abilities better (i.e. reduction of indirect costs).

In this thesis we studied the measurement of impairments in awareness after brain injury and what treatments are available to improve awareness. The results of the studies in this thesis shed more light on the complex phenomenon of impaired self-awareness after brain injury and can help clinicians to address this issue more effectively.

Target groups

Results of this thesis are first of all relevant for people who suffered a brain injury and are unaware of the deficits resulting from the injury and their significant others. They will benefit from the knowledge because of our increased understanding of unawareness and its treatment. Eventually better understanding will improve the care for these patients and their significant others.

The most important target group is the health care professionals, especially neuropsychologists and other members of the rehabilitation team, who work with patients

with acquired brain injury. The results of this thesis can guide them in diagnosing awareness impairments and choosing possible treatment options.

Also, the results of this thesis are relevant for policy makers in health care. They could use the results of this thesis to implement guidelines for measuring and treating awareness impairments after brain injury.

In addition fellow scientists can use the results and recommendations made in this thesis for their own research. For example, our discussion regarding the use of discrepancy scores to measure impaired awareness is very relevant in this respect.

Results from this thesis can be valuable for researchers and clinicians outside the field of brain injury as well. Awareness impairments are, for example, also known in the field of dementia. Awareness phenomena in dementia and brain injury show some similarities.⁴ Presentations of unawareness are in both groups, for example, influenced by psychological and neurocognitive factors. From this perspective our study regarding the differentiation between these factors might be relevant for researchers and clinicians in the field of dementia as well.

Products and innovation

There are no standard protocols for measuring and treating awareness. Therefore, the results of this thesis were put together to provide guidelines for measuring awareness. This is described in the General Discussion of the thesis. Clinicians working with patients with awareness impairments can use these guidelines to find appropriate measurement instruments to get a better picture of the awareness problem at hand. Also, a systematic review was conducted into the treatments available to improve impaired self-awareness. Some preliminary guidelines were proposed, which clinicians can use to decide which treatment course to take.

Furthermore, in Dutch clinical practice clinicians are searching for guidelines on how to make a distinction between awareness impairments due to neurocognitive factors and awareness impairments due to psychological factors. One specific product that serves this purpose is the Clinician's Rating Scale for evaluating Impaired Self-Awareness and Denial of Disability after brain injury (CRS-ISA-DD). This scale can be employed to investigate if the awareness impairment is primarily due to neurocognitive factors or due to the psychological factor denial. The instrument has two scales. One scale lists ten behaviors indicative of impaired self-awareness due to neurocognitive factors and the other scale lists ten behaviors indicative of impaired self-awareness due to denial. For example, when faced with a behavioral failure, patients with neurocognitive based impaired self-awareness might be stunned or confused, while patients with denial are likely to be easily upset, frequently have explanations as to why they do poorly on certain tests and discount the role of their brain injury.

We investigated the psychometric properties, as well as the feasibility of the CRS-ISA-DD in Dutch clinical practice. It was found that this tool had excellent inter-rater reliability, good internal consistency, and was feasible. Results regarding the convergent validity were mixed and future research is necessary to confirm the validity of this scale.

Implementation

The knowledge acquired from the studies in this thesis will be used to make a contribution to the 'Guideline neuropsychological rehabilitation acquired brain injury' from the Dutch consortium Cognitive Rehabilitation. In 2007 these guidelines were published and an update will be presented in 2016. A new chapter about impaired self-awareness of deficits will be added and will be written by the author of this thesis. The knowledge resulting from the thesis will be used to write recommendations for clinical practice. Persons who will use the 'Guideline' will be all persons involved with the care of people with acquired brain injury, such as (neuro)psychologists, cognitive trainers, physical therapists, occupational therapist and rehabilitation physicians.

To implement the CRS-ISA-DD in Dutch practice first the validity of the scale must be confirmed. In our study the sample of patients was biased and we had too few patients with impaired self-awareness. In new research this selection bias should be prevented. It would take 1,5 tot 2 years to complete such a study (preparation, data collection and analysis).

In case the validity of the CRS-ISA-DD is confirmed a Dutch translation of the scale and instruction manual need to be developed. A Dutch translation was already made for the purpose of the study described in Chapter 3 of this thesis. However, in the meantime the English version of the scale is revised, therefore the Dutch version needs to be revised as well. Also, a scale manual is not available, neither in English nor Dutch. The development of a Dutch version of the scale and a manual would approximately take three months. The two researchers who completed the scale for the study described in Chapter 3 should do this. They are familiar with the scale and have the best knowledge to make such a manual.

Once the Dutch version and manual are finished the scale should be made freely available to clinicians and researchers. The English version of the scale is freely available as well. The Dutch scale could be made available by publishing the scale on www.meetinstrumentenzorg.nl, a Dutch website that consists of a database of Dutch versions of assessment tools that can be used in clinical practice and research. To inform clinicians the scale is available, a manuscript about the scale and the validation study could be submitted to the Dutch Journal of Neuropsychology (Tijdschrift voor Neuropsychologie) or an announcement could be included in newsletters to members of professional organizations such as the Dutch Association for Neuropsychology (Nederlandse Vereniging voor Neuropsychologie).

What to do with Mr. S.A.?

To get an understanding of Mr. S.A.'s awareness impairment, his neuropsychologist should apply multiple tests. She especially wonders if Mr. S.A.'s awareness impairment is caused by neurocognitive factors or by psychological factors. To find this out she could use the CRS-ISA-DD.

Once she has a picture of the awareness impairment of Mr. S.A. she can determine a course of action. One option is to try to improve Mr. S.A.'s awareness. There is no standard treatment protocol for improving awareness of deficits, but in our systematic review on treatment of unawareness she can find some tentative guidelines that can help her decide on a treatment plan for Mr. S.A.

If the treatment is effective, Mr. S.A. becomes more aware of his disabilities. He will be able and motivated to learn strategies on how to control his behavior and how to plan his lessons for his job as a teacher. Or he may start to accept that he cannot do this kind of work anymore and has to look for alternatives. He can also learn how to control his behavior at home so he will not lash out to his kids. This makes the situation at home more tolerable and Mr. S.A.'s constant struggle to pursue goals that are not realistic will end. He will never be the same person as he was before the injury, but due to his gained self-knowledge he can better adapt to the situation than if he was not aware.

References

1. Stokman M, Verhoeff H, Heineke D. *Navigeren naar herstel: bouwstenen voor clientgerichte en samenhangende zorg ten behoeve van mensen met een hersenletsel*. Hersenstichting Nederland; 2011.
2. Winkens I, Van Heugten CM, Visser-Meily JM, Boosman H. Impaired self-awareness after acquired brain injury: clinicians' ratings on its assessment and importance for rehabilitation. *The Journal of head trauma rehabilitation*. 2014;29(2):153-156.
3. Gustavsson A, Svensson M, Jacobi F, et al. Cost of disorders of the brain in Europe 2010. *European Neuropsychopharmacology*.21(10):718-779.
4. Ownsworth T, Clare L, Morris R. An integrated biopsychosocial approach to understanding awareness deficits in Alzheimer's disease and brain injury. *Neuropsychological Rehabilitation*. 2006;16(4):415-483.