NÅR LIVET VENDES PÅ HOVEDET:
ET STUDIE AF SELVINDSIGT EFTER HJERNESKADE

KANDIDATAFHANDLING
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WHEN LIFE TURNS UPSIDE DOWN:
A STUDY OF
SELF-AWARENESS OF DEFICITS FOLLOWING ACQUIRED BRAIN INJURY

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Acquiring a brain injury can cause a wide range of behavioural and cognitive impairments, some impairments so severe that they cause a loss of specific functions, such as hemiplegia, aphasia or amnesia. The disabling nature of brain injuries in general makes it even more puzzling that a significant number of patients are completely unaware of their deficits.

During my internship at Hjerneskadecentret - Aarhus I encountered patients with a wide variety of deficits following brain injury; however, the patients who most stood out were those who seemed to be unaware of the severity or even existence of their injuries and their potential future consequences. Their reality and perception of the situation seemed in contrast to other patients’ reactions, who often expressed a feeling of seeing their life and dreams crumble in front of them. Even though the patients who were largely unaware of their complications after acquiring a brain injury were somehow protected from the resulting reflections and emotional reactions, they nonetheless encountered difficulties, because they were unaware of their current lack of previous competencies. These problems either appeared to be of no importance to them, or completely irresolvable, because they had no understanding of what caused them in the first place.

My supervisor, Lene Bayley, explained their perception of reality in a way that improved my understanding and profound interest of the deficits of awareness this group of patients experience. She believed that they experience their life “sideways”, meaning that their unawareness of their deficits meant that they were often out of tune with what was happening around them because they were unable to see a link between cause and effect, since the cause, being their deficits, did not exist to them.

The patients’ lack of insight and understanding of the severity of their deficits often led to considerable frustration for the relatives, as well as the other patients and rehabilitation staff. A further recurring complication for this group of patients was the tendency for patients to have delayed emotional reactions to the frequently traumatising event of acquiring a brain injury, and in understanding the consequences this might have for their future life in terms of employability and social interaction.
When I looked into the research on impaired self-awareness after brain injury, I found that there was a growing level of interest in expanding knowledge about the neurological pathogenesis and the long-term consequences of this phenomenon. However, I also experienced that this area of research was diverse and inconclusive, and that the literature was separated from the clinical practice, regarding which patient groups were assessed. Moreover, the use of resources and questionnaires that did not reflect the ones in rehabilitation.

A clinical observation I encountered at Hjerneskadecentret - Aarhus was that deficits in awareness following brain injury were often connected to patients to a lesion in their right hemisphere. This observation had the subtle effect of the rehabilitation staff being more attentive of these and the possibility of impaired self-awareness in this group of patients. However, this was an observation that was only partly supported in research and often based on patients who were not comparable with what was seen in the rehabilitation.

The inspiration and aim for conducting my thesis (consisting of two articles, a review and a study), was to gain insight into the research conducted in this area relating to the long-term consequences of being unaware of deficits following brain injury and to see if the clinical observations at Hjerneskadecentret - Aarhus were consistent with the patients’ data and other related research. This led to a review examining the relationship between impaired self-awareness and outcome following rehabilitation, along with a study investigation of the hemispheric differences in patients with impaired awareness and its implications for emotional stability following rehabilitation.

My intention was that the analyses conducted by this thesis could contribute to a better understanding of the common, but complex phenomenon of impaired self-awareness. I also wished to ensure that this awareness is advantageous to the patients and clinicians, and not an additional distressing factor for the patient.

I would like to express my gratitude to Hjerneskadecentret - Aarhus for placing the data to my disposal in this thesis, and giving me insight into the puzzling world of living with a brain injury. My sincere and grateful thanks are also extended to the former clients and relatives at Hjerneskadecentret - Aarhus, who took their time and effort to complete the extensive questionnaires. Special thanks should be given to my supervisor, Lars Larsen MSc, PhD, for his professional guidance and valuable support on this thesis.
ABSTRACT

Background: Impaired awareness after brain injury is a deficit commonly experienced during rehabilitation. An increasing amount of research has examined its impact on long-term vocational and emotional outcomes. However, this research has lacked consistency in terms of both measures and in findings. Objective: To review research that examines the relationship between level of awareness and vocational and emotional outcome, and to evaluate these findings, methods and their transferability to a clinical setting. Method: A systematic literature search for articles that examine the implications of impaired awareness on outcomes following rehabilitation. Results: The literature search revealed 17 articles that were eligible for inclusion. A considerable amount of empirical support was found for a positive relationship between improved awareness and employability, although this was less consistent for depressive symptoms and psychosocial and emotional stability. Conclusion: The comparability and transferability of the articles’ findings are limited, which underlines the lack of a criterion standard for both awareness and outcome. Researchers should aim at developing valid and reliable measures and be attentive to the applicability of their findings.
INTRODUCTION

The consequences and deficits related to acquiring a brain injury are most commonly understood in terms of visible or noticeable losses of functions, including paralysis, memory problems and aphasia. Less attention is given to the loss of metacognitive functions, which ensure that patients can monitor, reflect and act upon his or her behaviour. Deficits in these areas of functions are less visible and, to some extent, less permeating than the loss of direct cognitive or physical functions. However, in the last 20 to 30 years there has been an increasing focus and recognition in rehabilitation and neuropsychology that metacognitive deficits can be just as damaging to a patient’s or relatives’ wellbeing and outcome after brain injury.

A metacognitive deficit observed in patients following brain injury is that of impairment of self-awareness. While the incidence of awareness deficits following brain injury varies depending on several factors, including time since injury and the severity, type and location of the brain injury, a study found that 76 to 97% of participants showed some degree of awareness deficits depending on the method of measurement used (Sherer, Bergloff, Boake, High & Levin, 1998).

Prigatano and Schacter (1991) defined self-awareness as the ability to perceive oneself in relatively objective terms. When this ability is impaired as a consequence of brain injury, the patient often lacks the capacity for self-reflection and self-monitoring as well as the recognition of physical, cognitive and psychosocial deficits following brain injury, and thus lacks the awareness of the potential implications for their lives. Consequently, the patient will not be willing to, or capable of, applying compensatory strategies, and might lack the motivation to engage in therapy or rehabilitation (Prigatano & Schacter, 1991). Furthermore, the lack of self-awareness and self-reflection of deficits following brain injury might result in patients pursuing unrealistic goals for the future (Prigatano, 1988; Sherer et al., 1998). Impaired self-awareness has received increased attention in rehabilitation psychology because its consequences have been related to limited responsiveness to rehabilitation and outcome in terms of lowered employability and emotional distress (Fleming, Strong & Ashton, 1998; Sherer, Hart & Nick, 2003).

A key aim of rehabilitation following brain injury is to prepare patients for a return back to their pre-injury lives, including work and family relationships, and therefore rehabilitation practices are engaged in the search for deficits after brain injury that have the highest predictability in terms of
patient outcome. The self-awareness of deficits has been proposed as a possible predictor for outcome and the potential patient benefit from rehabilitation (Sherer et al., 1998; Sherer et al., 2003). If self-awareness can act as a possible predictor for outcome after brain injury, it can be a valuable measure in rehabilitation.

In a review by Ownsworth and McKenna (2004) that examined factors related to employment outcome, they found that there was insufficient research that examined the possible relationship between self-awareness and employment after brain injury. Nevertheless, based on the assumption that this area of rehabilitation psychology is receiving increasing focus in research, this article will continue the examination of the relationship between self-awareness and employment, as well as including other possible outcomes to which self-awareness can be related.

**IMPAIRED SELF-AWARENESS AS A PHENOMENON**

Earlier, a definition of self-awareness was given, and a few examples of the possible consequences that such an impairment might have for a patient after acquiring a brain injury have also been presented. However, as has been argued by other reviews in this field, a clear and distinct definition of impaired self-awareness has been sought for, but not found (Fleming et al., 1996; Smeets, Ponds, Verhey & van Heugten, 2012).

Impairment of self-awareness is not an “all or none” phenomenon, it is instead a deficit that has a broad-spectrum of possible forms, degree and of impairment and type of brain injury from which it emerges (Campodonico & McGlynn, 1995).

This area of neuropsychology originates from Babinski’s early observations of the unawareness of hemiplegia following brain injury, which, in 1914, he termed anosognosia (Prigatano, 2003). In later years, the unawareness of impairments in other domains and less physical deficits, such as impairment in psychosocial adjustment and cognitive functions, has been included in the phenomenon (Prigatano, 2003). In the broadening of this area, other terms have been included in the pursuit to define the unawareness some patients show of neurological or neuropsychological impairments following brain injury that are otherwise noticeable to attentive others, such as relatives or clinicians (Prigatano, 2005). Such impairments include unawareness, awareness deficits and impaired awareness or self-awareness, and they are more commonly used to describe an unawareness of a broader spectrum of deficits than anosognosia. The terms will be used interchangeably in this review.
The lack of a clear definition of impaired self-awareness as a deficit following brain injury might originate from the heterogeneity of the phenomenon (Bisiach, 1999). More than a century after Babinski first coined the term anosognosia, there is still no consensus about the pathogenesis of this phenomenon (Smeets et al., 2012).

Furthermore, as proposed by Crosson et al. (1989), self-awareness of a deficit includes several aspects and levels of awareness. They argued that awareness could be divided into three levels in a hierarchical model with intellectual awareness as the lowest level, emergent awareness as the second level and the anticipatory awareness as the third and highest level (Crosson et al., 1989). The model distinguishes between simply being aware of a loss of function following brain injury as a fundamental level of awareness (intellectual awareness), having the level of awareness to recognise the deficit when arising (emergent awareness) and being aware of the possible consequences of the deficit as well as having sufficient awareness to anticipate when these consequences might arise (Crosson et al., 1989).

The model by Crosson et al. (1989) serves as a good guideline for understanding the complexity of the processes of awareness, and exemplifies that unawareness of a deficit can have different levels of implication on a patient’s life.

In general, impaired self-awareness following brain injury must be treated as a diverse phenomenon, one which describes the patient’s inability to accurately perceive, understand and act upon losses of function following brain injury (Prigatano, 1999).

**OPERATIONALISATION OF AWARENESS - IN RESEARCH AND IN PRACTICE**

The growing interest in self-awareness of deficits following brain injury has resulted in an increased focus on developing objective measures for awareness assessment. This interest is present in both research and in rehabilitation, and both might benefit from an objective assessment method of awareness on several points (Campodonico & McGlynn, 1995). Primarily, rehabilitation practice might benefit from using an objective assessment of awareness at different times over the course of rehabilitation, particularly at the outset of the programme, as a part of the general assessment, so that relevant and effective rehabilitative interventions can be applied. In addition, a measure of awareness level can act as an indicator for patients’ progress throughout, and following, the course of rehabilitation. Furthermore, the assessment of awareness might help the clinicians in creating realistic goals for the patients to pursue and establishing a considerate and informative relation to the patients’ relatives (Campodonico & McGlynn, 1995).
In relation to the research, an objective measure of assessment might provide grounding for new intervention forms that can enhance awareness of deficits following brain injury. Additionally, this area of research has the potential to enhance the understanding of awareness as a metacognitive function (Campodonico & McGlynn, 1995).

Even though an objective assessment method of awareness appears essential for developing relevant and effective interventions in rehabilitation for patients who lack self-awareness, and for research to gain further insight into awareness, self-monitoring and conscious experience, a gold-standard method has not yet been developed. This area of research is instead covered by several assessment techniques that are administered in clinical practice as well as in research, though without a clear definition of a criterion standard for the measure of awareness deficits following brain injury (Smeets et al., 2012).

Fleming, Strong and Ashton (1996) reviewed some of the existing assessment methods of self-awareness of deficits following brain injury. They found that the most commonly used method of assessment is comparing the patients’ own self-rating of their function to a more objective measure. The methods in which the objective measures are obtained differ between assessment strategies, but three common types of objective methods are ratings by significant others, by clinicians or rehabilitation staff, and also neuropsychological test scores. The awareness level is then assessed by looking at the level of discrepancy between the patients’ self-rating of function and the ratings of the patients’ function by significant others or clinicians, or by comparing the patients’ estimates of their personal abilities and their actual scores on neuropsychological tests (Fleming et al., 1996).

The method of using discrepancy between patients’ self-ratings and relatives’ ratings as a measure for the level of awareness is one of the initial, but still most commonly used, ways of operationalising self-awareness of deficits in a quantitative manner (Fleming et al., 1996). The use of a relative’s rating as an objective measure is performed on the assumption that the patient’s perception of their functional level is inaccurate and that relatives can be a valid source of information (Fleming et al., 1996; Jackson et al., 1992).

A widely used and well-documented measure that uses this method is the Patient Competency Rating Scale (PCRS) (Prigatano et al., 1986). This questionnaire has both a self-report form and a relative’s form. It consists of 30 items where the patient and relatives are asked to rate the patient’s
ability to perform different behavioural tasks. These ratings are conducted on a five-point Likert scale ranging from 1, ‘Can’t do’ to 5 ‘Can do with ease’ (Prigatano et al., 1986). The questionnaire covers different areas of function, including emotional status, daily living activities and interpersonal skills (Fleming et al., 1986)

Several of other measures using the same method of measuring level of awareness from the discrepancy between self and relative’s ratings have been used in research. Some of them have been, like the PCRS, developed directly for the purpose of assessing awareness level after brain injury. In contrast, others are questionnaires originally used for assessing other functional deficits with both a self and relatives’ report.

In addition to comparing patients’ self-ratings with relatives’ ratings, another objective measure has also been included in measuring levels of awareness. This measure involves ratings by a clinician who works with the patient in rehabilitation. The clinician’s ratings of the patient’s functional level in different areas are compared to the patient’s own judgement of her or his own functional level (Fleming et al., 1996).

A scale that has included this level of measure, as well as the comparison between patients’ self-ratings and relatives’ ratings, is the Awareness Questionnaire (AQ) by Sherer, Bergloff, Boake, High & Levin (1998). The AQ has a patients and relatives form, where both the patient and relative rate the patient’s functioning in relation to physical, cognitive and behavioural areas, as well as functioning in community areas. The patients and relatives are asked to rate the patient’s functional level before and after acquiring a brain injury on a five-point Likert scale, from 1 indicating ‘Much worse’ to 5 ‘Much better’ level of functioning compared to pre-injury. On the third form, the clinician rates the patient’s functional level post injury as well as the patient’s level of awareness perceived by the clinician (Sherer et al., 1998).

The last common type of comparison is between patients’ estimates of their functional level, often in relation to cognitive abilities, and their actual performance on neuropsychological tests (Fleming et al., 1996). This can also be performed with the AQ, where it is possible to compare the patient’s ratings on the cognitive ability items with the actual performance on neuropsychological tests (Sherer et al., 1998).
In their review, Fleming, Strong and Ashton (1996) present another strategy for assessment of awareness after brain injury. They devised a structured interview form, the Self-Awareness of Deficits Interview (SADI), where the interviewer scores the patient’s awareness and abilities in three areas. These three areas include the patient’s self-awareness of deficits, their self-awareness of functional implications of deficits and the patient’s ability to set realistic goals. The SADI presents a measure that provides both qualitative and quantitative data, since the patient’s response is rated on a four-point scale, whereby a score of 0 indicates no lack of self-awareness and 3 indicates severe lack of self-awareness (Fleming et al., 1995).

As pointed out by Smeets et al. (2012) and Fleming et al. (1996), little attention has been given to the psychometric qualities of the existing instruments that have been developed to measure awareness of deficits. In a systematic literature review by Smeets et al. (2012), they revealed that, in addition to being the most commonly assessed, the PCRS, AQ and SADI were also the instruments with the most psychometric information and the best psychometric properties.

As shown above, the phenomenon of impaired self-awareness is not only difficult to describe and define, it is also difficult to measure (Prigatano, 1999).

**OUTCOME AS A MEASURE - WHAT IS SUCCESSFUL REHABILITATION?**

The acquirement of a brain injury does not only burden the patient, but the family and relations of the patient are also affected. Furthermore, the often long lasting consequences in terms of cognitive and psychosocial deficits might result in the patient not returning back to the premorbid level of function, both in terms of employment, and also in terms of social and communal activities (Smith & Godfrey, 1995). This a great cost for the patient, their relatives as well as for society, which makes it one of the key incentives for finding a measure that assesses outcome of rehabilitation in a way that is both functionally relevant, and gives some predictability of the patient’s vocational and social outcome.

This has been a complex and difficult task, as evidenced in the fact that rehabilitation psychology has not been able to settle on a specific outcome measure, one that is valid, functionally relevant and sensitive to change (Smith & Godfrey, 1995)

Measures of functional abilities have often been used to assess the level of progress in rehabilitation, but even patients with substantial cognitive and social deficits are able to perform
daily living activities, yet still have worsened long-term outcomes in terms of employment. Similarly, neuropsychological tests are still a common measure of progress in rehabilitation practice even though they have been criticised for not being sensitive to changes and not being related to functional outcome (Prigatano et al., 1986; Smith & Godfrey, 1995). Even though measures of functional abilities and neuropsychological tests are being used as assessment methods of outcome after rehabilitation, they still lack the ability to predict and assess the patient’s long-term employability or emotional stability, which is required by a good and functional relevant outcome measure.

Instead of relying on questionnaires about functional abilities or neuropsychological test scores, some research has assessed patients’ vocational outcome or employability after ended rehabilitation (Ownsworth, Desbois, Grant, Fleming & String, 2006; Ownsworth et al., 2007). These assessment methods are often ratings of patients’ levels of employment in the short-term after acquiring a brain injury and ended rehabilitation.

Another method of assessing outcome after rehabilitation is using measures of emotional status and psychosocial outcome. These include, for example, ratings of depression, emotional wellbeing and psychosocial adjustment (Fleming et al., 1998). This type of outcome assessment offers a quality-of-life perspective on outcome achievement, where the patients’ subjective sense of wellbeing is in focus, rather than focusing on progress in specific functional areas (Scherer, 1995)

As shown above, outcomes after brain injury and ended rehabilitation can be assessed in various ways, ranging from specific, primarily objective, functional and cognitive measures of outcomes to more longsighted and subjective outcomes in terms of measures of employability and wellbeing. As shown above, this results in a broad spectrum of strategies for outcome assessment. However, the main incentive of rehabilitation after acquired brain injury is to establish patients’ awareness of their disabilities post-injury and teach them to act upon strengths and weaknesses in order to accommodate to their pre-injury surroundings. Therefore, one could argue that outcome assessment should be able to incorporate a measure of a patient’s ability to do so (Scherer, 1995). Accordingly, this review will primarily focus on outcome assessments that measure employability, as this is a more objective perspective of functioning and assessment related to at the patient’s subjective rating of quality-of-life.
The preceding introduction to the complex, but still common, phenomenon of impaired awareness of deficits following brain injury indicates that awareness deficits can have a large range of possible implications for the patient’s engagement in, and the effectiveness, of rehabilitation, as well as return to pre-injury level of function, including work and quality of life. This necessitates the need for an outcome measure, one that is both valid and can serve as an indicator for the patients’ recovery after brain injury.

Therefore, the aim of this systematic review was to generate an overview of the findings of this area of research in rehabilitation psychology, and attempt to answer the following research questions: (1) Is self-awareness of deficits following brain injury related to potential outcomes in terms of employability, and emotional and psychosocial adjustment after ended rehabilitation? (2) How is awareness and outcome operationalised in relation to studying the relationship between the two? (3) Are these findings and assessment methods transferable to clinical practice?

**METHOD**

**SELECTION OF ARTICLES, MEASURES AND DOMAINS OF OUTCOME**

Articles were selected through a systematic computerised literature search using PubMed and PsycInfo the 16th. of December 2015. Both searches consisted of two specific components, awareness and brain injury. Details of search terms are shown in table 1.

<table>
<thead>
<tr>
<th>DATABASE</th>
<th>SEARCH</th>
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<tbody>
<tr>
<td>PsycInfo</td>
<td>((unawareness OR &quot;impaired self-awareness&quot; OR &quot;awareness deficit&quot;) AND</td>
</tr>
<tr>
<td></td>
<td>&quot;brain injur*&quot;) AND (stype.exact(&quot;Scholarly Journals&quot;) AND PEER(yes))</td>
</tr>
<tr>
<td>PubMed</td>
<td>(&quot;unawareness&quot;[All Fields] OR &quot;impaired self-awareness&quot;[All Fields] OR</td>
</tr>
<tr>
<td></td>
<td>&quot;awareness deficit&quot;[All Fields]) AND &quot;Brain Injuries&quot;[Mesh]</td>
</tr>
</tbody>
</table>

Duplicates were removed and articles were selected if they described an empirical study and had been written in English. Review articles, theoretical papers and case reports were excluded.
Articles were not selected if they focused on anosognosia for hemiplegia, unawareness in terms of unconsciousness or if the article was not initially designed to assess the relationship between awareness and an outcome measure. Furthermore, articles were only included if the participants assessed had acquired a brain injury, thus articles assessing awareness in neurodegenerative diseases, such as Alzheimer’s and Huntington’s disease, were not included in this review. These exclusion criteria were set in order to secure a homogenous area of research in relation to measures and awareness deficits assessed.

Additionally, a few articles were found through some key articles in this field of neuropsychology, and included on the same terms as the other articles in this review.

**MEASURES FOR AWARENESS AND OUTCOME ASSESSED**

Unlike Smeets et al. (2012), this review included articles using other, less specific, measures for assessing awareness, than the three more common measures; SADI, AQ and PCRS.

Vocational outcome and employability were assessed in several ways, and both reports of employment outcome and ratings of functioning in terms of employability were included as measures. Ratings of depression, psychosocial functioning, life satisfaction and emotional distress were accepted as outcome measures for personal wellbeing.

**OTHER FACTORS ASSESSED**

Other factors regarding the articles were also considered. These included demographics of the population of brain-injured patients assessed, such as gender and mean age (if mean age was not attainable, median age was included in this review). Furthermore, the size of study population and injury type (e.g. traumatic brain injury, acquired brain injury or closed head injury) were also included in this review.
RESULTS

The literature search identified 201 articles relevant for evaluation based on the search criteria set – see table 1. An evaluation based on the inclusion criteria proposed above revealed 77 potentially relevant articles for review; however, after full text evaluation 17 articles met the specified inclusion criteria and were included in the review (Figure 1).

Figure 1. Flowchart of the selection of articles
Among these published studies, 12 measurement instruments for assessing level of awareness following brain injury were found. Some of the instruments were administered in different forms (for example self-ratings vs. relatives’ or clinicians’ ratings).

Additionally, no consistency was found in specific instruments used for assessing outcome after rehabilitation. Instead, two overall types of outcomes were assessed; these were, as predicted, ratings of employability or vocational activity and wellbeing, including measures of psychosocial adjustment and emotional stability. Furthermore, it was found that ratings of depression or depressive symptoms were, in particular, frequently used as a measure for outcome in terms of wellbeing following brain injury and it was found that more than half of the measures of wellbeing were measures assessing levels of depression. Based on these findings, the outcome measures assessing level of depression were treated as a separate group of outcome measures.

Overall twenty-three comparisons of level of self-awareness and outcome were found, where nine of these were employment outcomes (including community integration), eight were measures of depression and six were different measures of wellbeing, including emotional stability or distress and psychosocial functioning. This was found because several of the included studies aimed at studying the relationship between self-awareness and different types of outcomes in terms of both employment, depression and emotional wellbeing (e.g. Fordyce & Roueche, 1986; Hoofien, Gilboa, Vakil & Barak, 2004; Ownsworth & Fleming, 2005; Ownsworth et al., 2007).

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year of publication</th>
<th>(n)</th>
<th>% of men</th>
<th>Mean age</th>
<th>Type of injury</th>
<th>Measure of self-awareness</th>
<th>Outcome measure (sig. level)</th>
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<tr>
<td>Evans, Sherer, Nick, Nakase-Richardson &amp; Yablon</td>
<td>2005</td>
<td>96</td>
<td>73 %</td>
<td>32</td>
<td>TBI</td>
<td>AQ (clinician - patient rating)</td>
<td>Depressive symptoms (ns) + life satisfaction ($p &lt; .02$)</td>
</tr>
<tr>
<td>Fleming, Strong &amp; Ashton</td>
<td>1998</td>
<td>55</td>
<td>72,7 %</td>
<td>25</td>
<td>TBI</td>
<td>SADI PCRS (HIBS as control)</td>
<td>Depressive symptoms ($p &lt; .001$)</td>
</tr>
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</table>

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<table>
<thead>
<tr>
<th>Authors</th>
<th>Year of publication</th>
<th>(n)</th>
<th>% of men</th>
<th>Mean age</th>
<th>Type of injury</th>
<th>Measure of self-awareness</th>
<th>Outcome measure (sig. level)</th>
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<tr>
<td>Fordyce &amp; Roueche</td>
<td>1986</td>
<td>28</td>
<td>nm</td>
<td>24.5</td>
<td>Brain Injured (mostly TBI)</td>
<td>PCRS</td>
<td>Employability (ns) + emotional functioning (ns)</td>
</tr>
<tr>
<td>Godfrey, Partridge, Knight &amp; Bishara</td>
<td>1993</td>
<td>66</td>
<td>83 %</td>
<td>24.3-27.13</td>
<td>closed head injury (CHI)</td>
<td>HIBS (self-other) The Neuropsychological Impairment Scale (NIS) (self-other),</td>
<td>Emotional distress (p &lt; .001)</td>
</tr>
<tr>
<td>Hoofien, Gilboa, Vakil &amp; Barak</td>
<td>2004</td>
<td>61</td>
<td>84 %</td>
<td>39</td>
<td>TBI</td>
<td>Self-evaluation of cognitive disabilities vs. neuropsychological test scores.</td>
<td>Employability (p &lt; .05) + psychiatric functioning (ns)</td>
</tr>
<tr>
<td>Kelley, Sullivan, Loughlin, Hutson, Dahdah, Long, Schwab &amp; Poole</td>
<td>2014</td>
<td>62</td>
<td>90 %</td>
<td>35 (median)</td>
<td>TBI</td>
<td>TBI Follow-Up Interview (TBIFI) (patient - relative rating)</td>
<td>Employability (ns)</td>
</tr>
<tr>
<td>Kortte, Chwalisz &amp; Wegener</td>
<td>2003</td>
<td>30</td>
<td>65 %</td>
<td>33.15</td>
<td>BI</td>
<td>PCRS</td>
<td>Depressive symptoms (ns)</td>
</tr>
<tr>
<td>Malec &amp; Moessner</td>
<td>2000</td>
<td>62</td>
<td>77.4 %</td>
<td>34.8</td>
<td>ABI</td>
<td>Mayo-Portland Adaptability Inventory: (MPAI) (clinician - patient rating)</td>
<td>Employability (p &lt; .02)</td>
</tr>
<tr>
<td>Malec, Testa, Rush, Brown &amp; Moessner</td>
<td>2007</td>
<td>135</td>
<td>62 %</td>
<td>35.7-42.5</td>
<td>TBI</td>
<td>Neurobehavioral Functioning Inventory (NFI) (patient - relative rating)</td>
<td>Depressive symptoms (p &lt;0.0001)</td>
</tr>
<tr>
<td>Noé, Ferri, Vaballero, Villodre, Sanchez &amp; Chirivella</td>
<td>2005</td>
<td>62</td>
<td>71 %</td>
<td>35,4</td>
<td>Mostly TBI</td>
<td>PCRS</td>
<td>Depressive symptoms (ns)</td>
</tr>
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### Table 2. Included articles

<table>
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<th>Authors</th>
<th>Year of publication</th>
<th>(n)</th>
<th>% of men</th>
<th>Mean age</th>
<th>Type of injury</th>
<th>Measure of self-awareness</th>
<th>Outcome measure (sig. level)</th>
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</thead>
<tbody>
<tr>
<td>Ownsworth &amp; Fleming</td>
<td>2005</td>
<td>67</td>
<td>76% for TBI, 47.6% for ABI sample, 67.2% overall</td>
<td>TBI: 34 ABI: 44</td>
<td>46 TBI 21 ABI</td>
<td>SADI</td>
<td>Depressive symptoms (ns) + hopelessness (p &lt; .05)</td>
</tr>
<tr>
<td>Ownsworth, Desbis, Grant, Fleming &amp; Strong</td>
<td>2006</td>
<td>50</td>
<td>68 %</td>
<td>38.4</td>
<td>ABI</td>
<td>SADI</td>
<td>Employability (p = .004)</td>
</tr>
<tr>
<td>Ownsworth, Fleming, Strong, Radel, Chan &amp; Clare</td>
<td>2007</td>
<td>86</td>
<td>67 %</td>
<td>38.4</td>
<td>ABI</td>
<td>SADI (AQ as control)</td>
<td>Employability (p &lt; .05) + Psychosocial outcome (p &lt; .01)</td>
</tr>
<tr>
<td>Richardson, McKay &amp; Ponsford</td>
<td>2015</td>
<td>168</td>
<td>66.7 %</td>
<td>43.78</td>
<td>TBI</td>
<td>AQ</td>
<td>Depressive symptoms (p &lt; .01)</td>
</tr>
<tr>
<td>Robertson &amp; Schmitten-Edgecombe</td>
<td>2015</td>
<td>90</td>
<td>69 %</td>
<td>37.189</td>
<td>TBI</td>
<td>Metacognitive awareness: The Problems in Everyday Living Questionnaire (PEDL) Anticipatory awareness and self-regulation The Rey Auditory Verbal learning Test (RAVLT) - prediction of recall. Error-monitoring: The letter fluency task and five-point task.</td>
<td>Employability (ns)</td>
</tr>
<tr>
<td>Sherer, Bergloff, Levin, High, Oden &amp; Nick</td>
<td>1998</td>
<td>66</td>
<td>76 %</td>
<td>31.7</td>
<td>TBI</td>
<td>AQ</td>
<td>Employability (p = .01)</td>
</tr>
<tr>
<td>Sherer, Hart, Nick, Whyte, Thompson &amp; Yablon</td>
<td>2003</td>
<td>129</td>
<td>84 %</td>
<td>33 (median)</td>
<td>TBI</td>
<td>AQ (clinician - patient rating)</td>
<td>Employability (p = .03)</td>
</tr>
</tbody>
</table>
MEASURES OF SELF-AWARENESS

In table 3, an overview of the specific measures for assessing self-awareness in relation to outcome is given. The table shows that, in the articles included in this review, more than half of them used one of the primary measurement instruments for assessing levels of self-awareness following brain injury. Furthermore, they were used in two-thirds of the comparisons between self-awareness and outcome. As the table shows, out of these comparisons, most were performed based on using SADI as a measure for levels of awareness.

<table>
<thead>
<tr>
<th>Measures used to assess awareness</th>
<th>Level of employment/employability</th>
<th>Depressive symptoms</th>
<th>Other emotional or psychosocial outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCRS</td>
<td>significant</td>
<td>I</td>
<td>I</td>
</tr>
<tr>
<td>AQ</td>
<td>II</td>
<td>I</td>
<td>I</td>
</tr>
<tr>
<td>SADI</td>
<td>II</td>
<td>I</td>
<td>II</td>
</tr>
</tbody>
</table>

Other measures:

| self-ratings vs. relative's ratings (TBIF, MPAI, HIBS, NFI) | I | I | I | |
| selv-rating of ability vs. actual test scores | I | I |   | I |
| Clinicans ratings (CRS) |   |   | I | |

The remaining approaches to assessing level of awareness differed in their methods of measurement. However, common for almost all of the measures was that they were originally developed for purposes other than assessing awareness after brain injury. Four of them were common questionnaires used for assessing other behavioural or emotional deficits after brain injury, and included both a self report and relatives’ version (e.g., HIBS, TBIFI, MPAI) (Godfrey, Partridge, Knight & Bishara, 1993; Kelley et al., 2014; Malec & Moessner, 2000; Malec et al., 2007).
Additionally, two assessment methods were measures that compared patients’ prediction of ability versus their actual performance on neuropsychological tests (Hoofien et al., 2004; Robertson & Schmitter-Edgecombe, 2015). One of the measures was through a measure originally intended for the assessment of awareness following brain injury, but differing from the PCRS, AQ and SADI in that it is only administered as a clinician’s version. The Clinical Rating Scale (CRS) is a clinician rating regarding the level of awareness in patients after brain injury, and was used in Kortte, Wegener & Chwalisz (2003).

**MEASURES OF OUTCOME**

Table 3 also shows which types of outcomes after rehabilitation that are assessed in the included articles. As mentioned earlier, no overall coherence was found regarding which instruments were administered in the assessment of outcome after rehabilitation. However, table 3 shows that emotional wellbeing, when including both measures of depression as well as measures of psychiatric, psychosocial and emotional stability as the assessment methods of wellbeing, were the most common assessment methods of outcome.

When looking at the three groupings of outcomes, based on the three common types of outcome measures found, table 3 shows that ratings of employment and depressive symptoms are most commonly assessed as an outcome in relation to self-awareness. Furthermore, table 2 reveals that the last group of measures used to assess outcome are diverse, ranging from emotional, psychiatric functioning to psychosocial outcome and life satisfaction.

**SELF-AWARENESS AND OUTCOME - ARE THEY RELATED?**

Table 3 also shows the studies’ findings in terms of revealing a significant relationship between awareness and outcome. However, table 3 does not reveal the ways in which self-awareness is related to the outcome assessed. Two different directions for relationships between self-awareness and outcomes were found. First of all, there was a tendency for higher levels of awareness (or increase in awareness of deficits) being related to greater employment outcomes or vocational activity. Consequently there were, for six out of nine studied relationships between awareness and employment outcome, a positive relationship between level of awareness and employment (Kelley et al, 2014; Ownsworth et al., 2006; Ownsworth et al., 2007; Robertson & Schmitter-Edgecombe, 2015; Sherer et al., 1998; Sherer et al., 2003). Secondly, it was found that improved awareness of deficits was generally related to an increase in depressive symptoms reported by the patients, when the relationship was found at all. Only three of the eight relationships between awareness and...
depression assessed were found to be significant (Fleming et al., 1998; Malec et al., 2007; Richardson, McKay & Ponsford, 2015).

For the last group of outcomes assessed, which were a diverse group of measures, different relationships between self-awareness and outcome were found. First of all, a relationship between level of awareness and outcome in terms of this type of measure in four out of the six relations studied in the articles was found. More precisely, a significant relationship between level of self-awareness and outcomes in terms of hopelessness, emotional distress, life satisfaction and psychosocial outcome was revealed (Evans, Sherer, Nick, Nakase-Richardson & Yablon, 2005; Godfrey et al., 1993; Ownsworth & Fleming, 2005; Ownsworth et al., 2007). However, unlike the way in which self-awareness was related to outcome in terms of employment and depression, this group of outcome measures showed a difference in how the level of self-awareness was related to outcome. Impaired self-awareness was related to lower levels of psychosocial outcome and increased hopelessness (Ownsworth & Fleming, 2005; Ownsworth et al., 2007). In contrast, improvement in awareness of deficits was related to higher levels of emotional distress and patients reporting lower levels of life satisfaction than in patients with impaired awareness (Evans et al., 2005; Godfrey et al., 1993).

OTHER FACTORS ASSESSED

As table 2 shows, other factors were also examined in the included studies. These factors were the demographics of the patients included in the studies, which were essential for their transferability to the general population of patients with brain injury. In particular, these were mean age, distribution of men and women and type of injury the patients had acquired. Furthermore, the sizes of the studies were also included (see table 2).

Demographically, it was found that the mean age of the participants included in the studies ranged from 24.5 to 44, and that the participants in the studies were most commonly in their mid-thirties. It was also found that the percentage of men included in the studies ranged from 62-90%. Additionally, table 2 shows a general trend in the type of brain injuries included in the studies assessed in this review. The most common type of brain injury the patients included in the studies had acquired was a traumatic brain injury (TBI).

The demographics of the studies reported in table 2 show that the most common participant in the studies included, are most likely to be male, in his thirties and have suffered a traumatic brain injury. It was also found that the studies ranged in size from 28 to 168 participants.
DISCUSSION

Findings of this review

The purpose of this review was to provide an overview of the research performed to examine rehabilitation outcomes related to awareness deficits following brain injury in the area of rehabilitation psychology. This is in addition to examining the different measures used to assess self-awareness and outcome, and reviewing the findings of relationships between awareness and possible outcomes in terms of employability, and emotional and psychosocial adjustment.

A literature search identified 17 relevant studies to be included in this review, and an evaluation of the studies’ findings revealed that the three instruments; SADI, AQ and PCRS were the most commonly administered measures for assessing awareness deficits. Additionally, it was found that wellbeing in terms of psychiatric and emotional functioning was the most common measure used to assess outcome related to awareness, although there were no consistency regarding which specific instrument was used to assess this. Three groups of different types of measures used to assess outcome after rehabilitation emerged, these were outcomes in terms of employability, depression or depressive symptoms, and other emotional or psychosocial outcomes.

The studies’ findings differed in both significance and type of relation to awareness. A reasonably stable and positive relation was found in several studies between heightened awareness and better employability, while a less consistent relationship was found between increased awareness of deficits and a higher level of depressive symptoms. Furthermore, a mixed relationship was found between levels of awareness and other emotional or psychosocial outcomes.

The results from examining the research in this area of rehabilitation psychology reveal that some studies, particularly those examining a relation between awareness and employability, were able to find that a patient’s awareness of deficits following brain injury can be related to how well this person is able to return his or her pre-injury surroundings.

As predicted and emphasised earlier in this review, it was found that these findings were, though largely coherent, established through the use of widely different instruments in diffusely defined areas, as both awareness and outcome can be considered to be.
COHERENT RESULTS BASED ON DIVERS MEASURES

This review demonstrates that, even though the most commonly used instruments for assessing level of awareness were the AQ, SADI and PCRS, twelve different instruments for assessing level of awareness were nonetheless found. This underlines the lack of consistency in assessment of awareness in this area of research, as well as indicating that the current measures are not sufficiently comprehensive, since there is a continuing development of new measures to assess awareness of deficits following brain injury.

In Smeets et al.’s (2012) review of the instruments used to measure awareness, they found 39 different instruments used to assess impaired self-awareness. Moreover, they proposed that potential issues in research of awareness are that researchers often develop their own means or instruments, with the result that few instruments or assessment methods are used frequently or by others than themselves (Smeets et al., 2012).

A similar picture was found in the articles included in this review, since the researchers who used either the AQ or SADI in their studies had often been associated with the development of the measure in the first place. The AQ was originally developed by Sherer, Bergloff, Boake, High & Levin (1997), and Sherer was co-author on three out the four studies included in this review that used AQ to assess awareness. The SADI was originally developed by Fleming, Strong and Ashton (1996), and to some extent, they were co-authors on all of the studies that used SADI as an awareness measure in this review.

This indicates that it is not uncommon that the researchers that are most engaged in this area of research, have developed their own means for assessment of awareness, which supports Smeets et al.’s (2012) findings.

This tendency can have profound implications for the comparability of the findings in this area of research. Given that some of the most productive researchers prefer to use their own measures, it can have the potential consequence of forming a gap between the research conducted and the use of the specific measures.

The diversity in the measures themselves can also widen the gap between the comparability of the findings. As presented in the introduction, the three common instruments for assessing the level of awareness that have developed by leading researchers in this area of rehabilitation psychology differ conceptually and in assessment methods used. The SADI stands out by being the only interview-based instrument, and the AQ and PCRS differ in their approaches to ascertaining levels.
of awareness in the questionnaires, where the AQ, unlike the PCRS, includes pre-injury status as well as a possible separate rating of awareness level by a clinician.

The lack of a golden measure for assessing awareness following brain injury not only has potential implications for the comparability of the findings in research, it can also have clinical implications in terms of the transferability of the instruments to clinical settings.

First of all, the lack of extensive psychometric properties of the instruments available for awareness assessment can negatively impact upon the transparency of the quality of the specific instruments, which might make it difficult for the clinicians to choose which instrument to administer in their clinical practice (Smeets et al., 2012).

The three common instruments, AQ, SADI and PCRS, also differ regarding administration. As noted earlier, both the AQ and PCRS are, in the most cases, questionnaires with a self-report and relatives report form. They are easy to administer and take around 10 minutes to complete. In contrast, the SADI is an interview, with an interviewer who must know the form comprehensively, and it takes 20-30 minutes to administer and it is recommended that the interviewer should be able to include information and interviews with relatives and rehabilitation staff in their assessment (Fleming et al., 1996; Smeets et al., 2012).

It can be argued that the administrative aspect of the instruments’ transferability is important, because the administration of tests, questionnaires and interviews forms a significant part of the rehabilitation practice. Most rehabilitation practices have a set of neuropsychological tests and assessment questionnaires that are administered during enrolment in the programme, and at the end in order to chart the progress of the patients (Cushman & Scherer, 1995). This is performed to identify the patients’ deficits following brain injury, as well as the competencies and resources of the patient, in order to construct a suitable rehabilitation programme (Cushman & Scherer, 1995). Given that the administration of tests and questionnaires is comprehensive in both terms of resources and time, it might be desirable for the clinical practice to use a measure that is feasible, easy to administer and does not require a great deal of time or resources to administrate. Both the AQ and the PCRS are suitable in this respect, whereas the SADI is more consuming in terms of time and resources.

The aspect of feasibility and convenience is not only present in the clinical practice. As seen in this review, a significant number of the instruments used in the included articles were instruments originally developed and intended for other uses than assessment of awareness level after brain injury.
injury. A possible reason for this is that the research is often conducted in cooperation with rehabilitation clinics or rehabilitative programmes, where feasibility and the economisation of resources is a priority in the administration of assessment measures. As seen in Malec & Moessner (2000), the use of MPAI serves a double purpose, by contributing with a discrepancy measure from the patient’s and relatives’ report, as well as providing the information about the patients’ adaptability and functioning after brain injury, including ratings of pain, anxiety and depression, as it was originally intended.

However, the tendency to use other measures not originally developed for assessment of awareness of deficits, also emphasises the absence of a useful criterion measure for awareness. As long as there is no clear criterion for how and what to measure when assessing level of awareness following brain injury, it is difficult to argue that the instruments originally developed for assessing awareness, such as the AQ, SADI and PCRS serve as better measures.

The diversity of measures seen in the articles included in this review indicates that the absence of a clear definition and a golden measure as operationalisation of awareness of deficits following brain injury has several implications, both for research and for the transferability of findings and instruments to the clinical practice. Moreover, findings of the studies in this review to some extent indicate a coherence in a relationship between the level of awareness of deficits and outcome, particularly concerning employability. Despite this, the inconsistency in measures used to assess awareness as well as outcome complicates the validity of the overall findings in this area of research. As shown above, the comparability and strength of the findings are weakened because of the lack of certainty in that the instruments actually measure awareness as they are intended to do.

In their review of factors related to employment outcome following traumatic brain injury, Ownsworth and McKenna (2004) found, an insufficient amount of research of self-awareness in relation to employment outcome to actually examine the findings in this area. However, they emphasised that this area of rehabilitation psychology needs to focus on research with well-designed methodology as well as standardised measures of self-awareness (Ownsworth and McKenna, 2004).

The discussion above underlines Ownsworth and McKenna’s (2004) point. The research regarding the relationship between self-awareness and outcome following brain injury is firstly sparse, and secondly inconsistent in its use of measures to assess self-awareness, as well as outcome. This has significant implications for what can be derived upon the findings of this research.
SUCCESSFUL REHABILITATION - A SUBJECTIVE OR OBJECTIVE MATTER?

The diversity in domains measured and used as possible indicators for outcome in the studies included in this review demonstrate how extensively a brain injury affects the life and functional abilities of the patient. It also clearly shows that rehabilitation psychology is unable to settle on an outcome measure that is valid, functionally relevant and sensitive to change, as proposed by Smith and Godfrey (1995).

Moreover, it is also evident from the studies included in this review, that a measure of outcome is not only intended to serve as an indicator for how successful patients are in returning back to their pre-injury surroundings, but frequently also serves a measure of successful rehabilitation and to verify the effectiveness of the rehabilitation programmes.

As presented earlier in the results of this review, the findings of a relationship between self-awareness and outcome varied depending on which type of outcome measure was assessed. While improvement in self-awareness was related to better vocational outcomes, it was also found to be related to worsened emotional outcome in terms of depressive symptoms, emotional distress and lower levels of life satisfaction (Evans et al., 2005; Fleming et al., 1998; Godfrey et al., 1993; Kelley et al., 2014; Malec et al., 2007; Ownsworth et al., 2006; Richardson et al., 2015; Sherer et al., 1998; Sherer et al., 2003).

Moreover, lower levels of self-awareness of deficits were found to be related to lower levels of psychosocial functioning and increased feelings of hopelessness (Ownsworth & Fleming, 2005; Ownsworth et al., 2007).

As shown above, self-awareness of deficits is not exclusively related to positive and improved outcome after rehabilitation. Instead, the research appears to indicate that becoming aware of one’s deficits and their implications on one’s life following a brain injury can lead to emotional consequences and be related to an increase in depressive symptoms, emotional distress and lower levels of life satisfaction (Evans et al., 2005; Fleming et al., 1998; Godfrey et al., 1993; Malec et al., 2007; Richardson et al., 2015). However, the research also indicates that lack of insight into one’s deficits following a brain injury can have negative consequences in terms of higher levels of hopelessness and lower levels of psychosocial functioning, even though patients with an impaired self-awareness tend to report fewer depressive symptoms (Ownsworth & Fleming, 2005; Ownsworth et al., 2007).
One must also be hesitant in drawing a straight line from self-awareness being related to outcome to treating self-awareness as a predictor for the patient’s outcome following brain injury. First of all, just because a relationship exists, it does not necessarily indicate a causal relationship between the two factors assessed, especially because the methodological layouts for the assessment of the relationship between self-awareness and outcome vary across studies.

Some of the studies included in this review assessed the relationship between the two factors as the improvement in self-awareness, while some assessed the relationship between self-awareness at the start of the rehabilitation programme and level of employment at the end of the programme. This diversity in the assessment of the relationship between self-awareness and outcome has the consequence of rendering it impossible to comment on the predictability of self-awareness for outcome, based on the general findings in this area of research. Nonetheless Sherer et al. (2003) actually sought to examine the direct predictive value of impaired self-awareness for employability and, upon assessing the relationship between early assessed awareness level of deficits shortly after acquiring a brain injury and level of employability at discharge from rehabilitation, found that self-awareness was a strong predictor for employability.

Another differentiation to be made in relation to the types of outcome assessments found is that they vary in subjectivity of measure. The employment outcomes serve as a measure for the functional aspect of returning back to pre-injury living following a brain injury, and are often rated objectively in terms of months or level of employment. In contrast, outcome in terms of wellbeing, including both ratings of depressive symptom, hopelessness and emotional stability, serves as a personal indicator for how challenging it is to return to pre-injury living, and is often rated by the patient him or herself.

It can be argued, based on the use of discrepancy measures for awareness assessment, that using self-reported levels of wellbeing as outcome measures with patients showing impaired awareness of deficits, can serve as a possible bias. This is because this group of patients might not have the sufficient insight into their own deficits and their complications for return to their pre-injury surroundings, to experience the emotional distress often related to these traumatic circumstances.

In rehabilitation literature in general, there is a consensus that patients acquiring a brain injury are more exposed to experiencing depressive symptoms, although the prevalence varies depending on assessment method used and because of a lack of psychiatric interviews with a clear diagnostic criterion (Ownsworth & Oei, 1998).
The general tendency for patients with an acquired brain injury to respond to the repercussions of their deficits with emotional distress corresponds with the findings of Fleming et al. (1998), Malec et al. (2007) and Richardson et al. (2015), who found that increased awareness was related to an increased level of depressive symptoms. Furthermore, the overall inconsistency in the findings of the articles included in this review might also indicate that the quality of the measures used to assess depressive symptoms varies.

This wide spread in both quality and thoroughness of the measures used to assess outcome in the different areas weakens the generalisability of the overall findings of the studies included in this review and underpins the need for an outcome measure that is valid, functionally relevant and sensitive to change. The achievement of this would allow the setting of a criterion standard for measuring outcome after brain injury.

Nonetheless, the findings still imply that self-awareness of deficits after acquiring brain injury are related to outcome to some extent, both in terms of positive and negative effects on the patient’s life following rehabilitation. However, this review also underlines the necessity of being cautious when interpreting the overall findings of this area of research cautions against ascribing all outcome findings to the patients’ levels of self-awareness.

**GENERALIZABILITY, TRANSFERABILITY AND QUALITY OF FINDINGS**

The demographics of the participants in the included studies showed a tendency for an uneven distribution of male participants, more precisely, patients who had suffered a traumatic brain injury who were in their mid-thirties.

More than half of the studies reviewed only had participants with TBI included in their studies. This selection of patients with a specific type of brain injury has some advantages for the reliability of the results, but it also comes with certain consequences in terms of the transferability and generalisability of findings.

The general population of patients with an acquired brain injury ranges in severity and type of injury acquired, and includes patients who have suffered a traumatic brain injury, patients with cerebrovascular accidents, anoxia and tumours, etc. The general population of patients with brain injury experience a wide range of symptoms and deficits, but often have the same course of hospitalisation and the rehabilitation opportunities. This means that most rehabilitation facilities have a broad range of patient types with different types of brain injuries.
It can therefore be argued that the selection of a group of patients with a specific type of brain injury in research does not correspond with the actual population of patients with brain injury seen in rehabilitation. This weakens the transferability of the findings to clinical use and interpretation, and as pointed out by Sherer et al. (1997), patients with TBI are more likely to be male in their twenties to thirties, and have suffered a brain injury from motor vehicle crashes. This further narrows the comparability of TBI patients with the general population of patients with brain injury even more.

Additionally, a similar tendency was found for the studies included in this review, as presented in the results, the common participant in these studies was most likely to be a male in his mid-thirties. It can therefore be argued that a large proportion of the studies in this area of research base their studies on a patient group that is not comparable to the general population of patients with brain injuries, which might weaken the transferability of their findings to the clinical practice.

The use of a specific group of patients with certain similarities in type of injury, age and gender can serve to strengthen the reliability the findings. This is because the sample is more homogenous and it is therefore more likely, that the effect measured is a systematic effect, and not caused by other interfering factors (Capitani & Laiacona, 1999). Additionally, this also heightens the replicability of the results in future research.

The preceding discussion indicates that the findings of the studies in this area of research are, although being reliable and to some extent possibly replicable, still difficult to transfer and apply to the general population of patients with brain injuries that constitute the normal population of the rehabilitation programmes. This tendency to use TBI patients serves a purpose in research as its ensures a more homogenous group of patients, and heightens the comparability of the findings with already existing research. However, this interferes with its applicability to the clinical settings, which can have the consequence of creating a gap between research and clinical practice.

**Findings are more than a p-value**

Table 2 revealed another characteristic of the studies included in this review. The studies varied immensely in sample size, which can also have implications for the interpretation and comparison of the findings.

As presented earlier, the main findings of the articles included in this review were examined based on the significance of their findings. Comparing findings based on these values across studies
differing largely in sample size, might result in giving more meaning to significant findings of studies with a larger sample size than studies with a smaller sample size that are unable to report a significant finding (Field, 2009). This is also known as a Type II Error, meaning that the null hypothesis is falsely accepted, i.e., the relationship is present, but not powerful enough to be significant (Field, 2009). Because of this risk, the effect sizes of the studies were analysed in the following table.

Table 4. Effect size of studies included

<table>
<thead>
<tr>
<th>Study</th>
<th>Size</th>
<th>p value</th>
<th>Effect size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evans et al., 2005</td>
<td>96</td>
<td>p &lt; .02</td>
<td>***</td>
</tr>
<tr>
<td>Fleming et al., 1998</td>
<td>55</td>
<td>p &lt; .001</td>
<td>***</td>
</tr>
<tr>
<td>Fordyce &amp; Roueche, 1986</td>
<td>28</td>
<td>NS</td>
<td>Not obtainable</td>
</tr>
<tr>
<td>Godfrey et al., 1993</td>
<td>66</td>
<td>p &lt; .001</td>
<td>**</td>
</tr>
<tr>
<td>Hoofien et al., 2004</td>
<td>61</td>
<td>p = 0.06</td>
<td>***</td>
</tr>
<tr>
<td>Kelley et al, 2014</td>
<td>62</td>
<td>p &lt; .02</td>
<td>**</td>
</tr>
<tr>
<td>Kortte et al., 2003</td>
<td>30</td>
<td>NS</td>
<td>No effect size</td>
</tr>
<tr>
<td>Malec &amp; Moesner, 2000</td>
<td>62</td>
<td>NS</td>
<td>Not obtainable</td>
</tr>
<tr>
<td>Malec et al., 2007</td>
<td>135</td>
<td>p &lt; .0001</td>
<td>**</td>
</tr>
<tr>
<td>Noé et al., 2005</td>
<td>62</td>
<td>NS</td>
<td>Not obtainable</td>
</tr>
<tr>
<td>Ownsworth &amp; Fleming, 2005</td>
<td>67</td>
<td>NS</td>
<td>No effect size</td>
</tr>
<tr>
<td>Ownsworth et al., 2006</td>
<td>50</td>
<td>p &lt; .004</td>
<td>Not obtainable</td>
</tr>
<tr>
<td>Ownsworth et al., 2007</td>
<td>86</td>
<td>p &lt; .05</td>
<td>Not obtainable</td>
</tr>
<tr>
<td>Rishardson et al., 2015</td>
<td>168</td>
<td>p &lt; .01</td>
<td>Not obtainable</td>
</tr>
<tr>
<td>Robertson et al., 2015</td>
<td>90</td>
<td>NS</td>
<td>Not obtainable</td>
</tr>
<tr>
<td>Sherer et al., 1998</td>
<td>66</td>
<td>p &lt; .01</td>
<td>Not obtainable</td>
</tr>
<tr>
<td>Sherer et al., 2003</td>
<td>129</td>
<td>p = .03</td>
<td>**</td>
</tr>
</tbody>
</table>

* = small effect size at Cohen’s d more than 0.1. ** = medium effect size at 0.3, *** = large effect size at 0.5
For the studies, where it was obtainable, the level of effect size was calculated and presented in the table above. Unfortunately, some of the studies did not however report adequate information from their statistical findings in order to analyse the effect size.

As shown in table 4, only the findings by Hoofien et al. (2004) were found to show a large effect size despite not being able to report a significant relationship between level of self-awareness and vocational functioning. Overall, it was found that the studies reporting significant findings were also able to show a medium to large effect size when analysed.

This indicates that the possibility of Type II Errors is present, but the analysis conducted by this review is not sufficient enough to denote it as a general problem. Nevertheless, the preceding findings also indicate that the significant results obtained are unlikely to be made upon a Type I Error, where the null hypothesis is rejected on false terms, since most of the studies had an effect size ranging from medium to large.

**SUMMARY**

The preceding discussion revealed that the findings of this articles review of the existing literature’s findings of the relationship between self-awareness and outcome is complex and one must be cautious in interpreting the findings, especially in comparing the findings to each other.

Three overall groups of outcome types emerged: employability, depression or depressive symptoms and other emotional or psychosocial outcomes. Although research was more consistent in finding a relationship between improvement in self-awareness of deficits and employability compared to depressive symptoms and other emotional outcomes, these findings remain, as found by Ownsworth and McKenna (2004), still sparse and inconsistent in types of measures used.

As noted earlier, the inconsistency in measures used for assessing self-awareness might be related to two tendencies in this area of research. First, as observed by Smeets et al. (2012), researchers in this area tend to develop their own means for assessing self-awareness, and this preference was also found in the studies included in this review. Secondly, a tendency to use the same questionnaire for evaluating level of psychosocial or emotional adjustment and level of self-awareness by comparing the self and the relatives’ reports was found. Both of these tendencies point to one critical aspect of this area of rehabilitation psychology, which is the lack of a criterion standard measure for assessing self-awareness of deficits following brain injury. This has consequences for both the validity and generalisability of the findings in research and for the transferability of findings and measures to clinical practice.
The measures used to assess outcome in terms of how successful patients were in returning back to their pre-injury surroundings were also found to vary, with a wide spread in both quality and thoroughness of assessment. Furthermore, the discussion revealed that using primarily objective measures for outcome, as seen with employability, might lead to a misinterpretation of how well the patients cope with life following a brain injury, since higher levels of depressive symptoms also can be related to improved self-awareness.

Equally, it was found that the comparability of the studies’ findings was weakened by the variety in sample sizes of the studies included. The effect size of the studies’ findings was therefore compared in order to account for Type II Errors, as well as Type I Errors. It was found that the articles reporting significant findings also had a tendency to have a medium to large effect size, indicating low possibilities of Type I Errors. Unfortunately, the effect size was not obtainable for a large part of the studies reporting non-significant findings.

Nevertheless, the samples of participants in the studies reviewed were found to be relatively homogenous. This characteristic of the research samples heightens the generalisability as well as replicability of the studies, but weakens the transferability of findings to the clinical practice, since the samples do not represent the general population of patients with an acquired brain injury.

**CLINICAL IMPLICATIONS AND FUTURE RESEARCH**

The preceding discussion not only revealed several aspects of which one should be hesitant in interpreting the findings of the research in this area of rehabilitation psychology, but also revealed that self-awareness of deficits following a brain injury is a far-reaching phenomenon, when it comes to affecting the patient’s life.

In respect to the clinical applicability of the studies’ research, the preceding discussion emphasises the need for a criterion standard for assessing self-awareness, in order to secure the validity and generalisability of findings, but also to secure an applicability of the findings, as well as the measures to a clinical setting.

A barrier for achieving a gold standard measure for self-awareness might be the lack of a suitable and clear definition of the phenomenon of impaired self-awareness, as shown in the introduction.
Nevertheless, in spite of the diffuse findings of the studies reviewed, the rehabilitation practice should be attentive to self-awareness deficits and of how to accommodate these in rehabilitation in order to accommodate the possibility of patients lacking motivation for engaging in rehabilitation. Improved knowledge about impaired self-awareness might lead to better use of resources, and lessen the frustration for patients, relatives and staff, as well as for perceiving improvements in awareness of deficits following brain injury as a functional gain for the patient. As suggested by some of the studies included in this review, improved self-awareness of deficits might lead to an increase in depressive symptoms, which is a common repercussion of living with a brain injury. Because of the prevalence and severity of this, the rehabilitation practices should be supportive and attentive of the patients' emotional wellbeing.

Future research should aim at being representative of the general population of patients with an acquired brain injury, so that the rehabilitation practices can benefit from their findings. The research should also be attentive of the validity of its measures, especially when assessing diverse and complex phenomena such as self-awareness and outcome following brain injury.

Overall, the preceding discussion underlines the need for research in the area of rehabilitation psychology to go hand in hand with the clinical practice of rehabilitation in order to accommodate the difficulties experienced by the patients and the rehabilitation staff.

**LIMITATIONS**

This review was designed to include all research examining the relationship between self-awareness and outcome, although studies including ratings of functional outcomes were excluded because of their lack of insight into how the patients function in pre-injury surroundings. Even though the aim of the review was to broaden the search as much as possible, some articles still may have been overlooked.

A possible consequence of the strict exclusion criteria concerning qualitative studies and not including studies concerning anosognosia might be that potentially good articles have been excluded from this review. However, this was done to ensure a higher level of comparability of the studies and their findings, and to ensure replicability of the reviews findings.
CONCLUSION

This present review investigated the level of empirical support for a relationship between self-awareness and outcome following brain injury, the measures used to study the relationship between the two, as well as the transferability of the measures and the findings to clinical practice. The results of this review revealed that the level of empirical support was greatest for a positive relationship between heightened self-awareness and better employability, while less consistent support was found for increased awareness to be related to an increase in reported depressive symptoms. The results also revealed that the measures used to assess both self-awareness and outcome varied both in type and quality.

This review highlighted the need for a criterion standard for measuring self-awareness of deficits following brain injury, in order to secure a higher level of validity, generalisability and transferability of the study’s findings. Moreover, it underlined the importance of a subjective as well as an objective measure of outcome to ensure a valid assessment of how the patients are adapting to their pre-injury surroundings.

To conclude, this review emphasises the need for a further understanding of impaired self-awareness of deficits following brain injury and its consequences for the patients’ subsequent life. This understanding must be gained through a collective and collaborative effort from both the clinical practice and the researchers in this field, so that patients and rehabilitation psychology in general can gain from their findings.
REFERENCES


A STUDY OF HEMISPHERIC DIFFERENCES IN PATIENTS WITH IMPAIRED SELF-AWARENESS FOLLOWING ACQUIRED BRAIN INJURY AND ITS IMPLICATIONS FOR EMOTIONAL STABILITY FOLLOWING REHABILITATION

ABSTRACT
This retrospective study investigates the relationship between unawareness, hemispheric location of injury and emotional distress. Data from 159 people with cerebrovascular accidents and relatives’ reports on the Katz Adjustment Scale (KAS) before and after rehabilitation were used. The study was conducted in two parts. The first examined the relationship between awareness level and hemispheric location of injury, finding support for the study’s hypothesis that participants with a right hemispheric lesion were found to show significantly higher levels of impaired self-awareness. In the second part, the participants were grouped by their awareness level and, in contrast to expectations, it was found that there was no significant difference in emotional distress following rehabilitation between patients with impaired self-awareness and patients with a sufficient level of self-awareness of deficits. These findings suggested that the period following injury and hemispheric location is related to the return of insight. The limitations and implications of these findings for the assessment of awareness in patients with acquired brain injury in rehabilitation are discussed.
INTRODUCTION

Over the past 20-30 years, there has been an increasing recognition of the fact that common deficits after brain injury reach beyond memory problems, aphasia and hemiplegia. Increasing attention, both in research and in clinical settings, is directed to its implications on higher cognitive functions, personality, awareness and the consequences it has on the wellbeing of patients and their relatives. This heightened focus on the magnitude and complexity of implications after acquired brain injury puts the rehabilitation enterprise in a challenging position. Given that rehabilitation has the aim of facilitating recovery, understanding, coping and wellbeing after acquiring brain injury, it requires a thorough understanding of the individual’s problems and ways to accommodate them.

The insight the rehabilitation professionals gain regarding the patient’s psychosocial problems and complications after brain injury is often acquired through interviews, self-reports, relatives reports and ratings of function on different types of questionnaires. However, sometimes this information is incoherent or distorted by a discrepancy in the patient’s and relative’s ratings and reports of problems and the functional level. This discrepancy hinders the development of an accurate and tailored rehabilitation programme, as well as good contact with, and involvement of, the patient as well as the relatives (Prigatano, 1991).

Nevertheless, a discrepancy in ratings and reports of problems after brain injury from patients and relatives is more than just problematic for structuring of rehabilitation programmes. This can also indicate that the patient might lack insight into the functional and emotional complications following the acquisition of a brain injury. This lack of insight is connected to how the patients perceive themselves in their interaction with the external world. It might be a consequence of a skewness in the patients’ perception and reflection of their personal reality, which hampers the self-monitoring and self-reflection critical for a person’s self-awareness (Goldberg & Barr, 1991; Galin 1992).

Therefore, lack of awareness of deficits and reduced self-awareness is an obstacle to successful rehabilitation as well as social and emotional functioning after brain injury (Prigatano, 1991).

A DIVERSE PHENOMENON

Babinski provided the name for anosognosia more than a century ago in 1914 to describe a phenomenon present in some patients, who were unaware of their deficits in motor control
following a stroke (Bisiach & Geminiani, 1991). The phenomenon was, in the following years, observed in patients suffering from other handicaps following brain injury. The term is most often associated with unawareness of hemiglia, or unawareness of other physical or sensory deficits. The phenomenon may include a patient being unaware of a paralysed limb following a stroke, thus giving some early indications that anosognosia could not purely be described in psychological terms such as denial, but may be associated with neurological deficits, such as disruption of specific neural circuits in the brain as a consequence of brain injury (Jorge, 2010).

This neurological approach to understanding the unawareness seen in the phenomenon anosognosia has, in more recent years, been applied to other areas of awareness deficits after brain injury (or other types of neurodegenerative disorders, such as Alzheimer’s disease and dementia) (Fleming, Strong & Ashton, 1998; Prigatano & Schacter, 1991; Prigatano, 1999). These deficits, of which some patients with brain injuries appear unaware, are often deficits in higher cognitive functions such as executive functions, memory, decision making and complex processes in regulating behaviour and social interaction (Jorge, 2010).

As Galin (1992) states, patients with common deficits following brain injury still function as an integrated person, who can act upon the challenges that the deficits might offer in everyday life. However, if the patient lacks the awareness of such deficits, and therefore his or her capacity for self-reflection is disabled, the patient suddenly comes across as being somewhat separated from reality, and their actions might appear peculiar. Furthermore, without the knowledge and awareness of the deficits, the patients might not be able or motivated to realise or act upon their implications. Galin (1992) even argues that lack of insight, awareness problems and disorders of self-monitoring can negatively affect what makes the person an entity and that this has profound implications for the patient:

“Many neurological injuries interfere with orientation in the “objective” world, but it is more damaging to a person’s integration to be out of touch with the dimensions of “personal” reality through loss of self-monitoring than to be out of touch with the externals through sensory loss or paralysis.” (Galin, 1992, p. 152)

The persistence, prevalence and diversity of awareness problems after brain injury suggests that the phenomenon is complex, not only to define, but also in its effects on rehabilitation and in its
operationalisation. The term anosognosia does not refer to a distinct symptom, but instead to the diverse aspects of patients’ behaviour in relation to their illness (Bisiach & Geminiani, 1991).

The term anosognosia has been used in relation to several types of awareness problems following an acquired brain injury, but this article will principally use awareness deficits, unawareness, impaired self-awareness and so forth interchangeably to define the problems of self-monitoring, self-reflection and knowledge processing of deficits after acquired brain injury. The key reason for this being that the term anosognosia is still closely related to unawareness of specific handicaps such as hemiplegia (Vuilleumier, 2004). The use of the wording unawareness, instead of anosognosia, is to ensure that deficits of other, more diffuse domains, such as psychosocial behaviour, regulation of emotions and so forth, are included.

**CHARACTERISTICS OF IMPAIRED SELF-AWARENESS**

As proposed above, a characteristic of impaired awareness after brain injury is the diversity of brain injuries it emerges from, as well as the difference in types of awareness disorders (Prigatano, 1999). Research has not been able to characterise impaired self-awareness by the severity of brain injury or to the overall neuropsychological function of a patient (Prigatano & Altman, 1990, Lanham, Weissenburger, Schwab & Rosner, 2000). Based on the heterogeneity of this phenomenon, it might consequently appear difficult to specify the characteristics of how impaired self-awareness displays itself in patients after acquired brain injury, but the literature and research in this area of neuropsychology provides a great amount of detail, from both clinical examples and studies, of the behavioural patterns and consequences of deficits in awareness.

A characteristic often seen in patients with impaired self-awareness in rehabilitation is that they lack the motivation for participating in rehabilitation, as well as being less likely to be compliant in therapy and training (Prigatano, 1999). This is supported by Fleming et al. (1998) who found that patients with higher self-awareness demonstrate higher levels of motivation to change.

However, Fleming et al. (1998), also found that the patients with a higher level of self-awareness reported a higher level of emotional distress than in patients with an impaired level of self-awareness. These findings are consistent with the characteristic that higher levels of awareness of deficits after brain injury are associated with higher levels of depression (Smith & Godfrey, 1995). Both findings underline the importance of support and monitoring of patients in rehabilitation, and
that patients with awareness problems are more disposed to experiencing more insight and awareness in the period following the end of rehabilitation, when the support may not be available (Godfrey, Knight & Partridge, 1996). Furthermore, the period until the patients experience further insight into their deficits, might be a time where they have little understanding of their reduced capabilities and thus, a time of frustration and repeated failure (Godfrey et al., 1996).

Even though impaired self-awareness can act as a temporary buffer for emotional distress, the relatives of these patients do not appear to experience the same. Prigatano, Borgaro, Baker & Wethe (2005) found significant indications of a relationship between a higher level of distress in relatives with patients who showed impaired awareness of difficulties. They argue that, from a clinical point of view, impaired self-awareness of difficulties in psychosocial adjustment and problems with emotional regulation after brain injury in particular, contribute to higher levels of distress in relatives to patients having these awareness problems.

Another characteristic of impaired self-awareness is that lack of awareness of non-physical deficits, like cognitive or psychological deficits, is more common than lack of awareness of physical deficits (Sherer, Boake, Levin, Silver, Ringholz & High, 1998). Additionally, it was found that, when patients with hemiplegia were asked about functioning in daily activities, they showed less awareness than when asked about specific deficits of movement (Marcel, Tegner & Nimmo-Smith, 2004). It therefore appears that the complexity of the patient’s deficits following brain injury is related to the possibility of impaired self-awareness and self-reflection of functioning.

Research has also shown other aspects in which impaired self-awareness has long-term consequences on the patient’s life and wellbeing. Awareness level has often been linked to employability after acquiring a brain injury and researchers have found more favourable long-term employment outcome in patients with higher levels of self-awareness (Ben-Yishay, Piasetsky and Rattok, 1987; Sherer et al., 1998).

Another characteristic of impaired self-awareness after brain injury is that there is no agreement on a specific injury location connected to unawareness deficits (McGlynn & Schacter, 1989). There has been more agreement on a more complex modular approach to deficits on awareness following brain injury (Prigatano & Schacter, 1991).
However, an early observation by Babinski has influenced the research in the field. Babinski not only set the stage for a whole new branch of neurology and neuropsychology by providing a name for the phenomenon, but in his second paper about anosognosia in 1918, he also proposed that unawareness of left hemiplegia is frequently characterised by lesions of the right hemisphere (Prigatano, 2009). This possible lateralisation of impaired self-awareness after brain injury has subsequently been of significant influence to the field. Several studies, using different means for both measures of impaired awareness and lesions indications, have tried to replicate Babinski’s original observations. Ranseen, Smith & Bohaska (1990) found that anosognosia was more pronounced in patients with right-sided lesions, but when Sherer, Hart, Whyte, Nick & Yablons (2005) tried to replicate their findings, they were not able to find associations between right hemispheric lesions and impaired self-awareness.

Despite this, Sherer et al. (2005) did find associations between the number of cerebral lesions and the impairment of self-awareness. This supported Prigatano and Altman’s (1990) findings, where patients who overestimated their behavioural competencies compared to their relative rating had generally suffered from a higher amount of lesions.

As proposed by Goldberg and Barr (1991) the neurophysiological processes of awareness are still unknown, so the understanding of the underlying mechanisms for functioning awareness (and also of non-functioning awareness) is, at best, tentative.

Although there is no agreement on the association between lesion placement and unawareness, or unawareness type, there still appears to be a relationship between the number of lesions, but not necessarily severity of injury, and, by some, lesions of the right hemisphere (Marcel et al., 2004; McGlynn & Schacter, 1989; Prigatano & Altman, 1990; Prigatano, 1991; Ranseen et al., 1990; Sherer et al., 2005).

**OPERATIONALISATION OF (UN)AWARENESS OF DEFICITS**

Unawareness of deficits is not only a heterogeneous phenomenon, it is also operationalised in various ways, both in research and in clinical settings. It appears logical that, as a heterogeneous phenomenon, impaired self-awareness is difficult to settle on as a gold standard of operationalisation.

Despite the lack of an ultimate measure for self-awareness following brain injury, Fleming, Strong and Ashton (1996) highlight in their review of methods of how to measure self-awareness after
brain injury, that the most common way to operationalise unawareness of deficits is by looking at the level of discrepancy. This is measured by the level of incongruence between the patient’s own self report and a more objective measure such as a relative’s or rehabilitation staff’s report or a measure of the patient’s actual abilities. This manner of operationalisation allows a quantitative measure with some level of comparability (Fleming et al., 1996).

A common discrepancy measure is the Patient Competency Rating Scale (PCRS) developed by Prigatano, Altman & O’Brien (1990). The PCRS consists of 30 items, which assess the patient’s daily activities competencies, involving both behavioural, emotional and psychosocial competencies. Both the patient and the relative rate the patient’s competencies on a 5-point Likert scale, the discrepancy score is calculated by subtracting relative’s score (or clinician’s score) from the patient’s score. Patients with a higher rating of competencies than informants (relatives or clinicians) are considered to have an impaired self-awareness of competency level (Prigatano et al., 1990).

Sherer et al., (1998) developed the Awareness Questionnaire (AQ) as an alternative measure, that again uses discrepancy as a measuring of the level of impaired awareness after brain injury, but also includes a rating of the patient’s abilities pre-injury.

As shown with both the PCRS and AQ, the measure of impaired awareness primarily consists of discrepancies between a report of function level of the patient, from both the patient and an informer (relative or clinician). Fleming et al. (1996) observe that several of other self reports have been compared with relatives and/or clinicians reports in the search for a measure of self-awareness using discrepancy. Fleming et al. (1996) furthermore proposes an additional method using an interviewer-rated semi-structured interview, the Self-Awareness of Deficits Interview (SADI).

The discrepancy method is still the most commonly used assessment method, principally because it can generally be easily administered, as well as providing useful information of the competencies of the patient.

Lanham, Weissenburger, Schwab & Rosner (2000) also apply the use of discrepancy between self reports and relatives’ reports, using the Katz Adjustment Scale for a measure of awareness level. The Katz Adjustment Scale (KAS) is a frequently administered 127-item questionnaire, with both a self report and relatives’ report version, rating emotional and psychosocial adjustment (Fleming et al., 1996; Jackson et al., 1992; Katz & Warren, 1998; Lanham et al, 2000). This was originally
intended for evaluating long-term community adjustment following treatment with psychotropic drugs, but is now well implemented in ratings adjustment following brain injury (Fleming et al., 1996; Lanham et al., 2000, McGlynn & Schacter, 1998).

The KAS has not been used in evaluating awareness following brain injury (Lanham et al., 2000). One of the major reasons for this might be that the KAS is often only administered in the relatives’ report form. However, restored norm-material for the self report version of KAS provides psychometric support for the use of KAS as discrepancy measure between self report and relatives report of psychosocial adjustment (Katz & Warren, 1998, Lanham et al, 2000).

Using the KAS in self report and relatives report form, Lanham et al. (2000), divided their participants into three groups, inspired by Prigatano’s (Prigatano, 1991) three awareness types. This is based on a division of the distribution of concordance scores between the participants and their relatives on the KAS. The three groups were termed Unaware, Aware and Hyperaware. The Unaware group represented participants who underreported their problems in comparison to their relatives’ report. The Aware group represented participants who reported their deficits in concordance relatives’ reports. The last group were participants who over-reported their level of deficits compared to the relatives’ report, and were therefore termed Hyperaware.

Lanham et al. (2000) found that the concordance score for both of the groups with a discrepancy between self and relatives’ reports, Unaware and Hyperaware, significantly increased over the course of six months. The participants with an already accurate self report of adjustment remained relatively the same in terms of concordance with relatives’ reports. This indicates that the KAS can serve as a possible measure of a patient’s self-awareness.

**SELF-AWARENESS AND EMOTIONAL RESPONSE TO REHABILITATION**

The aim of any rehabilitation programme is to create awareness of deficits in order to implement resources and tools for the patient to, if not recover, then at least be able to cope with challenges that might occur. If this awareness of deficits is hindered by a lack of self-awareness as a complication after brain injury, it poses several problems for successful rehabilitation. These complications drain the resources of the rehabilitation programme, as well as those of the relatives, since the patients are frequently incapable of self-monitoring and self-reflections of behaviour and mistakes. Therefore, impaired awareness is a burden to both the rehabilitation enterprise as well as the relatives, since it hinders the patients from their employment of the available resources.
In spite of acting as a temporary buffer for emotional distress, impaired self-awareness is still an inconvenience and an emotionally distressing factor for relatives. Furthermore, since improved awareness is related to increased emotional distress, the risk is that these patients might not experience the difficulties and distress while under rehabilitation and therefore not receive the needed support. This suggests that successful rehabilitation might not exclusively be about the amount of rehabilitation but, for this group of patients, be about the right help at the right time.

The motivation for carrying out this retrospective study was to examine the implications of unawareness of deficits after brain injury has on emotional wellbeing as well as emotional response to rehabilitation. Moreover, it was to reveal if there was a hemispheric difference in the emotional wellbeing and awareness of deficits in patients with cerebrovascular accidents, as well as the emotional response to rehabilitation.

As shown with the characteristics of impaired awareness, and as seen in Ranseen et al. (1990) and in Sherer et al. (2005), there is still an interest in looking at the relationship between hemispheric location of lesions and level of impaired self-awareness. Finding a relationship between hemispheric location of lesion and awareness deficits might add to the neurological understanding of self-awareness, as well as improving the rehabilitation staff’s understanding of this group’s deficits and therefore being able to customise the rehabilitation care. The purpose of this study was to investigate the relationship between unawareness, hemispheric location of injury and emotional response to rehabilitation.

It was hypothesised for the first part of the study, that there would be a larger discrepancy between the right-sided brain injured participants reports and their relatives’ reports, than between the left-sided brain injured participants and their relatives’ reports. Moreover, that the right-sided injured patients would show less improvement in emotional distress following the rehabilitation programme compared to left-sided injured patients. For the second part of the study, when comparing participants based on their level of discrepancy, it was hypothesised that participants with the highest discrepancy between self and other ratings would show less improvement in emotional distress than participants with a higher concordance between self and relatives’ ratings.

It was expected, based on Ranseen et al.’s (1990) findings, that right-sided lesioned participants would show a higher level of discrepancy between self report and relatives reports on the KAS.
In addition, it was expected that a possibly higher level of discrepancy in right-sided lesioned participants would show a relationship with less improvement in ratings of emotional distress after ended rehabilitation, compared to participants with a left-sided brain injury.

In relation to Lanham et al.’s (2000) findings, and to Prigatano’s (1991) three type of awareness, it was expected in the study’s second part that participants who underrated their deficits compared to their relatives’ rating will show less emotional response to rehabilitation, by their reduced improvement in emotional distress than participants with a higher concordance between self and relatives’ ratings.

**METHOD**

**SUBJECTS**

The subjects were 159 moderate to seriously brain-injured clients who were consecutive participants in a neuropsychological rehabilitation day programme from 1993 to 2013, each course lasting six months.

The participants were 80 men and 79 women, of 18 to 66 of years of age ($mdn = 47.03$) at the start of their enrolment in the rehabilitation programme at Hjerneskadecentret. Their brain injury was acquired 3 to 157 months previously ($mdn = 14.84$).

These participants formed the subset of a larger sample of brain-injured clients, who were enrolled in the rehabilitation programmes at Hjerneskadecentret. The participants selected for this study were clients from Hjerneskadecentret’s intensive rehabilitation programme. The reason for this selection was that the time between the clients enrolling in the intensive rehabilitation programme acquired their brain injury was generally shorter than for the clients enrolled in the other programmes at Hjerneskadecentret. The larger sample contained a large range of different types and severity of brain injuries, but the sample selected for this study only included clients who suffered from a cerebrovascular accident. These inclusion criteria were set because the study’s aim is to focus upon differences of awareness in relation to the hemispheric location of brain injury. Therefore, the damage locations are often more localised in patients with cerebrovascular accidents than in patients with other kinds of brain injuries including traumatic brain injuries, brain tumours, meningitis, encephalopathy, which are often more diffuse in location of injury.
Table 1. Demographic and severity characteristics of the sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>80</td>
<td>50.3 %</td>
</tr>
<tr>
<td>Female</td>
<td>79</td>
<td>49.7 %</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>78</td>
<td>49.1 %</td>
</tr>
<tr>
<td>Married</td>
<td>59</td>
<td>37.1 %</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>16</td>
<td>10.1 %</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>3.7 %</td>
</tr>
<tr>
<td><strong>Days hospitalized</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;24 hours</td>
<td>2</td>
<td>1.3 %</td>
</tr>
<tr>
<td>&gt;24 hours - 7 days</td>
<td>13</td>
<td>8.2 %</td>
</tr>
<tr>
<td>&gt;7 - 30 days</td>
<td>52</td>
<td>32.7 %</td>
</tr>
<tr>
<td>&gt;30 days</td>
<td>94</td>
<td>59.1 %</td>
</tr>
<tr>
<td><strong>Relationship of KAS informant</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to participant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>18</td>
<td>11.3 %</td>
</tr>
<tr>
<td>Spouse/mate</td>
<td>90</td>
<td>56.6 %</td>
</tr>
<tr>
<td>Child</td>
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<td>3.1 %</td>
</tr>
<tr>
<td>Sibling</td>
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<td>3.8 %</td>
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<tr>
<td>Other relative</td>
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<td>0.6 %</td>
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<tr>
<td>Friend</td>
<td>6</td>
<td>3.8 %</td>
</tr>
<tr>
<td>Other relation</td>
<td>5</td>
<td>3.1 %</td>
</tr>
<tr>
<td>Not mentioned</td>
<td>28</td>
<td>17.6 %</td>
</tr>
</tbody>
</table>
DATA SOURCES

The data was pulled from Hjerneskadecentret's database consisting of journal data created as a part of the rehabilitation programme in the years 1993 to 2013. The database includes information from medical reports, along with details gathered from clients and their relatives through interviews, neuropsychological assessments and the self report’s questionnaires. The journal data includes information about damage location, course of illness, test results from the neuropsychological and physical assessments, demography and their psychosocial adjustment using the KAS.

The clients selected for study through Hjerneskadecentret cannot be considered as representative for the population of brain-injured patients in general, since Hjerneskadecentret’s criteria for referral is selecting a certain group of patients. The criteria for referral to the rehabilitation programmes at Hjerneskadecentret are principally that the clients must be of working age (18-65) and still be able to work. The clients must also have an educational background and a Danish language proficiency sufficient to benefit from rehabilitation. Finally, the clients must be self-sufficient in such a manner that they are capable of daily chores and transport to and from the rehabilitation centre, and have no psychiatric diagnoses requiring treatment or have a substance abuse problem. Therefore, this group of clients might be somewhat more well functioning than the general population of brain injured patients, in relation to age, recovery, motivation and resources.

Neuropsychological Rehabilitation Programme

Hjerneskadecentret is a specialised unit for rehabilitation under the Municipality of Aarhus. The rehabilitation programmes offered by Hjerneskadecentret are programmes that brain injured patients can be referred to after ended hospitalisation.

The clients at Hjerneskadecentret were enrolled in an intensive day programme in small groups of 7-11 participants, for six months. The programme is an interdisciplinary outpatient programme that places primary emphasis on cognitive, psychosocial and physical rehabilitation of deficits after brain injury and intervention and compensation strategies, with the intention of getting the clients back into employment.

Following the 6-month intensive day programme, the clients are monitored by Hjerneskadecentret for a further 12 months. This follow-up period has the aim of supporting the clients’ return to employment.
MEASURES

*Katz Adjustment Scale*

The KAS is administered at the start and end of each rehabilitation programme. This serves several purposes. Since it is administered at the beginning at each programme, it can work as a baseline for the clients’ progress, as well as for the planning of each therapeutic course. The administration at the end of each programme makes it possible to register changes in behaviour and psychosocial adjustment. It is also administered to the client’s relatives, in order to give a relevant (and somewhat objective) insight into the patients’ psychosocial behaviour and to detect any discrepancies in ratings that might indicate unawareness problems.

The KAS was originally developed in the 1960s for evaluating long-term community adjustment following treatment with psychotropic drugs, and updated with larger norm data and a detailed manual in 1998 (Katz & Warren, 1998). Originally, the KAS consisted of several scales, measuring both psychopathology as well as Activities of Daily Living (ADL). It is, however, only part I which is administered at Hjerneskadcentret, since it’s the most commonly-administered scale of the KAS and it gives a descriptive picture of psychosocial problems as well as specific symptoms of psychopathology.

The Katz Adjustment Scale - Part I is administered at Hjerneskadcentret in its original form, with both a Self Report Form and a Relative Report Form. It is the Relative Report form (The KAS-R1) which is the general choice of administration, since there have been many self report instruments developed for obtaining information of patients’ self-ratings of their level of personal and social adjustment, while there are fewer relatives report forms that are able to produce reliable ratings from relatives (Katz & Warren, 1998).

The reason behind the administration of the KAS - Part I in its original form at Hjerneskadcentret, is that it permits a detailed description of psychosocial adjustment, symptoms of psychopathology and an insight into discrepancies in the patients’ and the relatives’ scores, as well as being easily administered and containing everyday language. Another advantage of the KAS is that it only enquires about information concerning the behavioural aspects of psychosocial adjustment, so that the relatives do not have to respond to their beliefs about the levels of the patient’s psychosocial adjustment, but instead focus on the observable behaviour of the clients (Jackson et al., 1992).
The Danish translation was performed by Hjerneskadecentret in 1992 and minor adjustments have been added throughout the years. The questionnaire consists of 127 items, where 100 of the items are included in 15 clusters. Of these, 13 of these clusters make up 6 indexes of psychopathology (Katz & Warren, 1998). The 127 items are rated by the clients and relatives using a four-point Likert format, with 1 indicating ‘almost never’, 2 ‘sometimes’, 3 ‘often’ and 4 ‘almost always’.

The American norms were used in this study, though, in 2001, Hjerneskadecentret collected norm data from 120 acquaintances of the staff at Hjerneskadecentret. While not representative of the general population, it was somewhat representative of the clientele of Hjerneskadecentret. Even though the average score for the Danish norm data was close to that of the American norm data, the Danish norms had a smaller standard deviation than the one of the American norm data, which can act as a source of error.

Based on the norm’s mean scores on the KAS, the T-scores for the clients are calculated for the clusters and indexes. A T-score of 50 represents a score similar to the mean of the norm, whereas a score of 40 or 60 represents a score that deviates one standard deviation for the mean of the norm. A T-score above 60 is a cut-off-score that indicates a heightened amount of symptoms reported, referred to as caseness. A patient with a T-score of 60 on or above is referred to as a case (Katz & Warren, 1998).

Missing items were accounted for by calculating the mean for the rest of the sub-scale if 80% of the items in the sub-scale were present. If the number of missing items was more than 20% of the sub-scale, the score of the sub-scale was not calculated. This is, however, not the manual’s preferred method (Katz & Warren, 1998) for accounting for missing items, instead the manual advises using the median of the sub-scale from the norm data. The missing items were not accounted for in this manner in this study, because of the risk of the median norm score pulling the scale-score closer to the norm, thus using the mean of the rest of the sub-scale is more true to the raw data. Furthermore, Hjerneskadecentret used the same procedure to account for missing items in their follow-up study (Johansen, Pedersen & Laursen, 2004).

The KAS is useful in this research design since it is both a measure for the patient’s psychosocial adjustment and emotional distress, as well as a useful measure of discrepancy between self and relative ratings, as an indicator of impaired self-awareness.
PROCEDURE

As mentioned earlier, the sample forms a subset of a larger sample of brain-injured patients, who were enrolled in the rehabilitation programmes at Hjerneskadecentret. These were selected on the following criteria: enrolled in the intensive day programme, had suffered cerebrovascular accidents and they, as well as one of their relatives, and had filled in the KAS at the beginning and at the end of the rehabilitation programme.

**Hemispheric Defined Subgroups**

In a retrospective analysis for part I, two comparison groups were formulated by dividing the participants by the hemispheric location of their brain injury. As table 2 indicates, four groups were formed, of which 91 of the participants had information about their hemispheric location of their brain injury, and 65 of the participants had no information in their journal about the location of their brain injury. Furthermore, the 91 participants were grouped into three groups; left hemisphere, right hemisphere and bilateral. Of these, 45 of the participants had brain injuries in the right hemisphere, 40 of the participants had brain injuries in the left hemisphere, while only 6 patients had bilateral brain injuries.

<table>
<thead>
<tr>
<th>Hemispheric location of injury</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not reported</td>
<td>68</td>
<td>42.8 %</td>
</tr>
<tr>
<td>Right</td>
<td>45</td>
<td>28 %</td>
</tr>
<tr>
<td>Left</td>
<td>40</td>
<td>25 %</td>
</tr>
<tr>
<td>Bilateral</td>
<td>6</td>
<td>4 %</td>
</tr>
<tr>
<td>Total</td>
<td>159</td>
<td>100 %</td>
</tr>
</tbody>
</table>

The first set of analysis was only drawn regarding the two sub-groups of right- \(n=45\) and left sided \(n=40\) hemispheric brain injured participants.

The discrepancy score for the two groups was calculated by subtracting the standardised total KAS-score \(z\)-score transformation) of the relatives from the participants’ scores from the beginning of the rehabilitation programme.
Their level of emotional distress was found by comparing the means of clients and relatives T-scores on the Depression Index at the beginning and the end of the rehabilitation programme. The number of participants fulfilling the caseness criteria on the Depression Index, indicating a severe level of depressive symptoms, by having a T-score of min. 60 (1 std. from the norm) among the participants in the groups was also compared.

**KAS-Discrepancy Defined Subgroups**

For the second part of the study, three comparison groups were formulated through a retrospective analysis, by dividing the 159 participants into three equal groups based on their discrepancy-score. The discrepancy score was calculated by the difference between the standardised total KAS-score (z-score transformation) of the participants and their relatives at the beginning of the rehabilitation programme. The formulation of three equal groups was performed by a frequency count, with a cut off for the 33.3 and 66.6 percentile, which made three groups of 53 participants in each. The overall discrepancy between clients' and relatives' ratings on the total KAS-score before the rehabilitation programme ranged from -2.67 to 3.74. The first cut off at 33.3% of the participants was at -0.28, which formed group 1 with a discrepancy range from -2.67 to -0.28. This lowest third of the distribution represents those participants who underreported problems compared to the relatives’ ratings, and were therefore termed as being relatively unaware of their problems compared to the other participants. Second cut off (at 66.6%) was at 0.17, which formed group 2 with a discrepancy range from -.28 to 0.17, this middle third of the distribution represents participants who reported their problems in concordance with their relatives’ ratings, thus group 2 were termed as being relatively aware of their deficits compared to the other participants. The highest third of the distribution, Group 3, with a discrepancy ranging from 0.17 to 3.74 contained participants who had reported more problems than their relatives, and were therefore termed as being “hyperaware” of their problems.

Instead of performing a structural analysis for the present data, or using, as Lanham et al. (2000), the empirically derived and revised sub-scales produced by Goran & Fabiano (1993) the original sub-scales of KAS was used for several reasons: The first and foremost reason is that the original sub-scales, with 15 clusters and 6 indexes, represents how the scale is administered and scored in the clinical use at Hjerneskadecentret. The KAS serves the purpose of showing the psychosocial adjustment of the patients, as well as being an indicator for emotional distress and/or discrepancy in self report of problems vs. the relatives’ reports, which the sub-scales, indexes and T-scores allow.
Furthermore, Hjerneskadecentret used the original sub-scales of KAS in their follow-up study; therefore, it allows higher comparability of this study’s results (Johansen et al., 2004).

RESULTS

PART I
Planned contrast revealed that participants with a right-sided lesion had a significant higher discrepancy z-score compared to participants with a left-sided lesion, $t(154) = -2.077, p = 0.039$ (two-tailed). However, participants with a right-sided lesions did not differ significantly in discrepancy z-score compared to participants with no information about the hemispheric location of their brain injury, or bilateral injured participants $t(154) = 0.32, p = 0.749$ (two-tailed).

<table>
<thead>
<tr>
<th>Patient Group</th>
<th>Right</th>
<th>Left</th>
<th>No info</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right</td>
<td>-</td>
<td>-2.077*</td>
<td>0.32</td>
</tr>
<tr>
<td>Left</td>
<td></td>
<td>-</td>
<td>1.889</td>
</tr>
<tr>
<td>No info</td>
<td></td>
<td></td>
<td>-</td>
</tr>
</tbody>
</table>

*Means significantly different at $p <.05$.

Further analysis on the relationship between hemispheric location of injury and emotional response to rehabilitation, using a planned contrast ANOVA (one-way) revealed that despite having a significantly higher discrepancy score, the participants with right sided lesions did not respond significantly less emotionally to rehabilitation compared to left-sided lesioned participants $t(153) = -0.289, p = 0.733$, when comparing the participants scores on the depression index after ended rehabilitation.

PART II
For the second part of the study, all 159 participants were divided into the three KAS discrepancy defined subgroups of Unaware, Aware and Hyperaware. The participants' scores on the depression index after ended rehabilitation were compared for the three groups.
A planned contrast revealed, contrary to what was expected, that the participants in the Unaware group did not show significantly less emotional response after ended rehabilitation compared to the participants in the Aware group, when comparing the participants self-reported scores on the depression index \( t(155) = -0.512, p = 0.609 \).

However, a planned contrast revealed a significant difference in the participants' self-reported scores on the depression index between the Unaware and Hyperaware groups, \( t(155) = -1.98, p = 0.049 \). When comparing the means of the two groups, it shows that the Hyperaware group reported more emotional problems (mean = 59.73) than the Unaware group after end of rehabilitation (mean = 54.87).

This might be expected, since the Unaware group of patients already had a tendency to underrate their deficits/problems compared to the Hyperaware group of patients, who, in contrast, had a tendency to overrate their problems compared to relatives’ ratings.

Furthermore, a planned contrast also revealed a significant difference in the relatives' reports of the participants' emotional distress level in the Unaware and Hyperaware groups \( t(154) = 2.167, p = 0.032 \). Despite this, looking at the means of the depression index score reveals that the relatives of the Unaware group rated those participants to have a higher level of distress after ended rehabilitation (mean = 58.83), than the relatives of the Hyperaware group (mean = 54.15). However, the relatives of the participants in the Unaware group still did not report a higher level of emotional distress than the relatives of the participants in the Aware group, \( t(154) = 1.22, p = 0.224 \) (two-tailed).

<table>
<thead>
<tr>
<th>Tabel 4. Mean score on depression index</th>
</tr>
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<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Mean score on depression index Patient's rating</td>
</tr>
<tr>
<td>Mean score on depression index Relative's rating</td>
</tr>
</tbody>
</table>
As an extended analysis, the hemispheric locations of the participants’ lesions were compared in the three groups. The following table shows the distribution.

<table>
<thead>
<tr>
<th></th>
<th>Right</th>
<th>Left</th>
<th>Other (not reported + bilateral)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unaware</td>
<td>19 (35.8%)</td>
<td>5 (9.4%)</td>
<td>29 (54.7%)</td>
</tr>
<tr>
<td>Aware</td>
<td>10 (18.9%)</td>
<td>19 (35.8%)</td>
<td>24 (45.3%)</td>
</tr>
<tr>
<td>Hyperaware</td>
<td>16 (30.2%)</td>
<td>16 (30.2%)</td>
<td>21 (39.6%)</td>
</tr>
</tbody>
</table>

**DISCUSSION**

**PART I - HEMISPHERIC DIFFERENCES**

The first part of this retrospective study showed support for the first hypothesis, expecting a higher level of discrepancy between self reports and relatives’ reports in participants with lesions in their right hemisphere, when compared to participants with lesions in their left hemisphere. Based on this significant relationship, the study found support for Ranseen et al.’s (1990) findings, that right sided lesioned patients show higher levels of impaired awareness compared to patients with lesions in the left hemisphere following brain injury.

Although showing a relationship between hemispheric location of injury and awareness level following brain injury, this sample did not show a significant difference in emotional response to rehabilitation when compared to the hemispheric location of brain injury. Therefore, even though the right hemisphere lesioned participants showed higher levels of awareness problems, they did not show less emotional response to rehabilitation when compared to participants with a lesion in the left hemisphere. Neither did the participants with lesions in their left hemisphere report higher levels of emotional distress even though they had higher levels of awareness, as could be expected from some of the findings in the awareness literature (Fleming et al., 1998, Smith & Godfrey, 1995). Instead, the emotional distress level did not appear to be related to the hemispheric location of the participants’ brain injury.
One possible explanation for this only partially supported hypothesis is that the awareness level in the right hemisphere lesioned participants did not increase sufficiently throughout the course of the rehabilitation programme to have a substantial effect on the level of emotional distress.

The obtained results must be interpreted cautiously since, although the relationship between having a right hemispheric lesion and displaying higher levels of awareness problems is significant, it is still not possible to establish a theory of a cautionary relationship. Furthermore, one should be resistant in drawing any conclusions about the lateralisation of functions of awareness from these results. As mentioned earlier, the interest in finding a location of function which makes it possible to determine awareness problems based on injury type and location is still strong, but the findings in the literature of awareness are limited, diverse, and to some extent contradictory.

**PART II - SELF-AWARENESS AND RESPONSE TO REHABILITATION**

The second part of this study found that participants in the Unaware group did not respond less successfully in terms of improvement of emotional distress in a 6-month rehabilitation course after acquiring brain injury, when compared to participants in the Aware group. This was found in both the self reports and relatives’ reports of emotional distress on the depression index. These findings suggest that, in the six months of rehabilitation, the most unaware participants did not gain enough self-awareness of their deficits in order to see a relation to their emotional distress level as was expected.

**CHRONICITY**

From looking at the literature, there appears to be several possible explanations for these findings. One being, as suggested earlier, that the participants showing the highest levels of unawareness at the beginning of the rehabilitation programme did not gain substantial awareness of their deficits throughout the rehabilitation programme, which might have ensured that their level of impaired self-awareness still acted as a buffer from the emotional distress. Godfrey, Partridge, Knight and Bishara (1993) found that the relationship between increasing awareness of deficits and emotional dysfunction did not appear before one to three years after acquiring the brain injury. When comparing this to the findings of the current study, it is somewhat consistent with the fact that the discrepancy level between the self reports and the relatives reports in the Unawareness group did not improve significantly over the course of six months in the
rehabilitation programme (t(52)= -1.658, p = 0.103). This, however, somewhat contradicts Lanham et al.’s (2000) findings, where both the Unaware group and Hyperaware group improved significantly in level of discrepancy after six months. In contrast, it was only the Hyperaware group (t(52) = 3.054, p = 0.004) and Aware group (t(52) = - 0.798, p = 0.428) of the current study that showed the same tendency as Lanham et al.’s (2000) findings.

This might indicate that the time since acquiring the brain injury can serve as a mediating factor in how well some patients gain insight and awareness regarding their deficits and how these influence their life and wellbeing.

**EMOTIONAL RESPONSE TO REHABILITATION**

On the other hand, it can also be hypothesised that the rehabilitation course has managed to be emotionally supportive of the difficulties the participants with limited self-awareness might have experienced. However, the findings must still be interpreted cautiously, since a lack of a significant difference in self report of emotional distress on the depression index between the more unaware and aware participants does not necessarily mean that the participants with impaired self-awareness do not have high levels of emotional distress. As seen in Hjerneskadecentret’s follow-up study, the percentage of caseness, indicating an increased amount of depressive symptoms, on the depression index among the participants was still significant after ended rehabilitation (Johansen et al., 2004).

In order to gain further insight into the degree of emotional distress of the participants, the percentages of caseness between the groups was compared. The overall percentage of cases on the depression index after rehabilitation, when looking at the participants’ own reports, was 32.7%, which was in concordance with the relatives’ reports (33.3%).

Nevertheless, when it comes to comparing the Unaware and Hyperaware group to the Aware group, we have to make certain reservations. As mentioned earlier, the participants in the respective groups already showed certain tendencies for either under or over-reporting their deficits when compared to the relatives’ reports. Therefore, when looking at the percentages of cases on the depression index reported by the participants it shows, as expected, that there are lower percentages of participants with an impaired level of self-awareness who rate themselves as having major depressive tendencies (20.8%), than compared to the more aware participants (32.1%). This is particularly
evident when compared to the participants who, at the beginning of the rehabilitation programme, had a tendency to report high levels of deficits (52.8%).

This relationship between awareness level and reports of severe depressive symptoms is inverted, when instead considering the relatives reports. Here, 52.8% of the relatives of participants with an impaired level of self-awareness reported a large amount of depressive symptoms of the participant. In contrast, the relatives of those participants who were overly aware of their deficits reported a similar level of patients with severe depressive symptoms to the one of the relatives to patients that appear to be aware of their deficits (26.4% and 28.3%).

However, as both of the scenarios show, the percentage of clients who after ended rehabilitation show high indications of severe depressive symptoms is still immense, and it can be assumed that some groups of clients are more exposed to either personally experiencing them, or exhibiting them without necessarily being aware.

The interpretations of the data are therefore highly related to which of the informers upon which one bases the findings. However, a strength of the two levels of information, both the subjective and rather objective, is that they can be used to clarify different perceptions of the psychosocial adjustment levels of the participant, as well as conveying some of the difficulties of using either self or relatives reports in assessing post-injury deficits in brain-injured patients.

One might argue that the relatives’ reports of the participants’ symptoms of emotional distress is the most valid, as the KAS is the most commonly administered in the Relative Report form, since, as Katz and Warren (1998) highlight, it is accepted as one of the few relative report forms that are able to show reliable ratings from relatives. On the other hand, the self reports allow a subjective measure of how the individual experiences their psychosocial adjustment following a brain injury and, as a response to the fact that the relatives report form of the KAS is the general choice of administration, the self report is still a valid measure (Heineman, 1995).

**Katz Adjustment Scale as a Multiple Measure**

Considering that the KAS is commonly used as a measure for psychosocial adjustment, including aspects of emotional regulation, psychopathology and wellbeing, it might only be able to identify discrepancies in perceptions of deficits in these aspects of behaviour following brain injury.
Accordingly, a possible explanation for failing to support this study’s hypothesis is that the KAS might be particularly sensitive when being used as a discrepancy measure in reporting awareness problems in relation to psychosocial deficits following brain injury. Therefore, when also used as a measure for level of emotional distress following rehabilitation, the participants of the Unaware group still showed the same, general trend of underreporting emotional deficits. Equally, the Hyperaware group tended to over-report their depressive symptoms compared to their relatives’ ratings.

The preceding discussion exemplifies a limitation of using the same scale as a measure for different aspects of the study’s hypotheses. This weakness is often seen in the literature for awareness deficits, since it limits the validity of measuring self-awareness through discrepancy by subtracting an informer’s report from the self report of the patient’s competencies. Since discrepancy is not a direct measure of awareness level, it is difficult to determine if a difference in ratings of functioning is the same as an unawareness of deficits in that function. This operationalisation of impaired self-awareness lacks the certainty and validity that it measures what it is intended to measure. The difference in reports of the patients’ level of functioning might be due to other causes, such as biases in the relatives' reports. Relatives might overrate or underrate the patient’s deficits because of concerns about the potential implications for the patient’s rehabilitation (Fleming et al., 1996). However, the reports of the relatives, especially on the KAS, are a source of information about the patient that can be difficult to obtain in other ways.

While using the KAS as a double-measure has its implications, it also reveals that one should be hesitant in only administering the KAS in the Relative Report form, as is most common. This study’s findings reveal that scale does not appear to be sensitive to the possibility that some patients do not experience the same levels of deficits as reported by the relative, which might indicate an impaired level of self-awareness. Prigatano (2005) also points out that impairment of a patient’s awareness level does not take place in a vacuum. When a patient acquires a brain injury, they can display a wide range of changes in personality and cognition, and levels of emotional distress rated on the KAS might therefore not be directly related to the patient’s level of awareness. Moreover, it is difficult to determine if the changes in the patients’ level of emotional distress are due to greater awareness of the problems, or an actual increase in the symptoms of emotional distress (Jackson et al., 1992).
METHODOLOGICAL ISSUES

There are limitations to this study since, by using a retrospective design, it was not possible to gather information about the severity of their brain injury or the numbers of lesions, which diminished the comparability of this study’s findings with other research. This limited information also obstructed the study from obtaining information on the hemispheric location for a large group of the participants, as shown in part I of the study.

Another limitation of the study is the use of the original sub-scale division of the KAS. As mentioned earlier, this scale was originally developed for evaluating long-term community adjustment following treatment with psychotropic drugs, and was not originally intended for use in reporting adjustment following brain injury. Therefore, it might not be sensitive to some of the common deficits following brain injury. Other revised sub-scales for KAS have been derived upon analysis of TBI-populations (Jackson et al., 1992; Goran & Fabiano, 1993). The use of the original sub-scales rather than the TBI-adjusted sub-scales might limit the validity of the measure of emotional distress used in this study, and the comparability of the study’s findings with other research using revised sub-scale of the KAS; however, the original sub-scale still has clinical utility (Heineman, 1995).

Furthermore, the only participants selected for this study were patients who had suffered cerebrovascular accidents, yet in this area of research, the most common type of brain injury is traumatic brain injury. The selection criteria were set to ensure a homogeneity in the sample, but nonetheless limit the generalisability and comparability of the study’s findings with other research. However, on the other hand, these selection criteria did ensure an even distribution of men and women in the sample (80 vs. 79), which is uncommon for a sample of TBI patients, which is often characterised by an overload of younger men.

The participants included in this study have all met the selection criteria for enrolment in a rehabilitation programme at Hjerneskadecentret. As mentioned earlier, these criteria might favour a certain, more well functioning, group of patients. This might have implications on the generalisability and transferability of this study’s findings, since the participants are not representative of the general population of brain-injured patients.
DIRECTIONS FOR FURTHER RESEARCH

Based on the current study’s limitations, the relationship between impaired self-awareness of psychosocial adjustment and hemispheric location of injury in patients with cerebrovascular accidents found in this study needs to be examined in a more homogeneous and representative sample of brain injured patients.

Furthermore, the percentage of patients reporting high amounts of depressive symptoms in this study indicate that emotional distress following brain injury is a common consequence of experiencing different functional, cognitive and social deficits. Being able to determine and assess the mediating factors of these depressive symptoms would serve a great purpose in research as well as in clinical practice. It is therefore recommended to examine its relationship to awareness using a separate and more validated measure for depression.

It is noticeable that this area of research is in need of a criterion standard for assessing awareness after brain injury. This would ensure a higher level of validity as well as the reliability and generalisability of the findings in this area of research. The criterion standard should also be feasible and applicable to clinical practice, since research indicates that self-awareness is directly related to outcome in some domains after rehabilitation (Fleming, Strong & Ashton, 1998; Godfrey et al., 1993; Sherer et al., 1998).

CLINICAL IMPLICATIONS

From a clinical point of view, unawareness of psychosocial deficits might have significant consequences for the course and outcome of rehabilitation. Patients with different levels of self-awareness might benefit from different treatment approaches in rehabilitation, such as the timing of rehabilitation and help with self-monitoring to foster the development of self-awareness, and to implement strategies so that improved awareness can act as a functional gain for the patient. The high levels of depressive symptoms indicate that acquiring a brain injury place a strain on the wellbeing of a person, and patients’ wellbeing should be monitored and accommodated within rehabilitation to ensure the best outcome possible. The rehabilitation practice should also be conversant with the possible emotional reactions to awareness of deficits as well as emotional support for relatives of patients with impaired awareness.
CONCLUSION

In summary, this retrospective study found that patients with lesions in the right hemisphere showed a higher level of impaired self-awareness after cerebrovascular accidents. However, no significant differences were found in emotional distress between the two hemispheric groups. For the second part of the study, the participants were classified into three groups, based on their level of self-awareness. However, in contrast to what was expected, no significant difference in emotional distress was found following rehabilitation between patients with an impaired self-awareness and patients with a sufficient level of self-awareness of deficits. However, significant differences were found between the group underreporting and the group over-reporting their deficits, leading to the conclusion that patients with an impaired self-awareness did not gain sufficient awareness throughout the course of rehabilitation to experience emotional distress. This is consistent with the findings that this group of patients were the only group that did not improve significantly in awareness throughout the course of six months of rehabilitation.

Additionally, it was suggested that the use of a single measure for assessing both level of discrepancy and emotional distress served as a possible bias, because the participants that tended to underrate themselves on the whole scale, also appeared to underrate themselves on the depression index compared to the ratings by their relatives. Nevertheless, it also revealed that the KAS in the relative’s report form, when serving as an objective measure of psychosocial adjustment, does not take into account that some patients are not aware of the deficits reported by their relatives.

This research highlights the need for a criterion standard for assessing awareness of deficits following brain injury that is both valid and applicable to clinical practice, so rehabilitation can accommodate the needs for implementing awareness strategies and support in order for awareness to become a functional gain and not a distressing emotional factor.
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