

## Anosognosia and rehabilitation: Definitions, practice implications, and directions for future research

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**Abstract:** Anosognosia, the unawareness of impairment, affects a broad range of clinical populations. Patients presenting with anosognosia deny their deficits and are unlikely to appreciate the merits of participating in rehabilitation. This review paper, written by two Master of Occupational Therapy students, explores pertinent research on the concept of anosognosia and its potential relationship to rehabilitation outcomes. As well, we discuss some of the clinical implications in treating individuals with anosognosia. The information in this article will be relevant to any discipline working with people with decreased insight, as it has implications not just for rehabilitation potential, but also how practitioners approach and interact with individuals about their condition.

**Keywords:** Cognitive Disorders, Neurological Rehabilitation, and Occupational Therapy

### 1. Introduction

Consciousness is the psychological function by which we understand and integrate cognitive experiences about ourselves and the external world (Orfei et al., 2007). This function can be impaired by physiological harm or physical trauma, leading to changes in an individual's awareness (Orfei et al., 2007). Anosognosia has been defined as “a disorder in which a patient affected by a brain dysfunction does not recognize the severity of deficits in sensory, perceptual, motor, affective, or cognitive functioning”

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(Orfei et al., 2007, p. 130). Patients with anosognosia may deny that they have deficits related to injury or disease and create excuses for their resulting functional difficulties (Thomas, 2015). This lack of awareness is generally considered a barrier to effective rehabilitation (Katz, Fleming, Keren, Lightbody, & Hartman-Maeir, 2002). Consider the following scenarios, based on actual fieldwork experiences:

*Eddie is a young man who sustained a traumatic brain injury after a car accident. After several weeks in hospital the question arises as to whether Eddie is ready for rehab. Eddie is physically independent, but has no knowledge of where he is, why he is in hospital, and is unaware of his deficits. Daily cognitive intervention has little effect. What is the best course of action for Eddie? Will*

*rehabilitation be successful for him?*

*Vera is an older woman with significant cognitive impairment who has had a below knee amputation. She received a prosthetic leg and is re-learning functional activities. During therapy she frequently disputes staff observations and insists she can do everything independently. Are there ways to “reach” this patient more successfully? How long do you persist with rehabilitation? Is Vera’s behaviour the result of lack of insight into her limitations?*

Inspired by these experiences, the authors undertook a review of pertinent research into the area of insight and how it affects rehabilitation outcomes. This article presents our findings and discusses some of the clinical implications in treating individuals with anosognosia.

## **2. Anosognosia and Denial**

A distinction between anosognosia and other unawareness syndromes has not always been clear in the literature. The terms denial, lack of insight, imperceptions of disease, anosognosia, and unawareness deficits have all been used interchangeably to describe both neurologically and psychologically based unawareness phenomena (Kortte & Wegener, 2004). Both denial and anosognosia are characterized by difficulty recognizing and accepting the nature and impact of injury, disease, and illness. However, research is now beginning to differentiate the two concepts. It has been suggested that denial arises from a psychologically protective (i.e. coping) mechanism, while anosognosia stems from

neurological dysfunction (Kortte & Wegener, 2004; Orfei et al., 2007; Prigatano, 2009). Individuals experiencing denial have illness information consciously available to them, but are able to dismiss it or reinterpret it in an attempt to cope. Those with anosognosia may not even have this information available for contemplation (Kortte & Wegener, 2004). Denial of illness and anosognosia also appear to have different behavioural presentations (Kortte & Wegener, 2004). The literature suggests that avoidance behaviours are associated with denial of illness but not with anosognosia. In addition, patients with denial might react with anger or resistance when provided with feedback about their performance or deficits, while under similar circumstances patients with anosognosia are more likely to display surprise or indifference (Katz et al., 2002; Orfei et al., 2007). Anosognosia has been recognized in a wide variety of conditions such as brain injury (including stroke and traumatic brain injury), and dementia and mild cognitive impairment, as well as schizophrenia, Huntington’s, Anton syndrome, and many more (Katz et al., 2002; Prigatano, 2009). We now examine several of these in further detail.

### **2.1 Brain Injury**

It is estimated that the majority of individuals with acquired brain injury (ABI) (including traumatic brain injury and stroke) have an unawareness syndrome (Kortte & Wegener, 2004). According to Katz et al. (2002), Canadian occupational therapists working with survivors of traumatic brain injury (TBI) report lack of insight and/or unawareness to be one of the most frequent cognitive impairments observed in adult clients. Studies of patients with ABI support the

view that unawareness can negatively impact the effectiveness of rehabilitation (Kortte & Wegener, 2004). Individuals who are unaware of their impairments are more likely to refuse to participate in therapy, are perceived as more difficult to work with, and tend to take on more than they can handle without asking for help (Kortte & Wegener, 2004). In the case of TBI, research has shown that impaired self-awareness negatively correlates with functional outcomes following inpatient neurorehabilitation, as well as with long term employability (Prigatano, 2009). Impaired self-awareness is also associated with poor adherence to rehab activities and greater difficulties establishing a working relationship with therapists (Katz et al., 2002).

The evidence on effective treatment approaches for individuals with ABI and anosognosia is limited. One study found that elements of self-awareness could be addressed through group cognitive rehabilitation, cognitive behavioural therapy, and social skills training (Katz et al., 2002). Some evidence has suggested that a feedback and review technique can be helpful, while other evidence suggests direct confrontational feedback can increase agitation (Katz et al., 2002). A few very small-scale studies have looked at the use of a game format to improve awareness in a less threatening way (Katz et al., 2002). The research that currently exists does not provide strong evidence to support one approach over another.

With respect to stroke patients, anosognosia is often reported in conjunction with left hemiplegia and left

neglect<sup>1</sup>, and is therefore associated with damage to the right cerebral hemisphere (Gialanella, Monguzzi, Santoro, & Rocchi, 2005; Orfei et al., 2007). These patients will typically deny their hemiplegia, or behave as if nothing has changed since their stroke (Orfei et al., 2007). The presence of anosognosia with hemiplegia has been repeatedly linked with poor functional outcomes, and may negatively influence the rehabilitation process (Prigatano, 2009; Starkstein, Jorge, & Robinson, 2010). In one study, Gialanella et al. (2015) compared the functional recovery of patients with anosognosia, left neglect, and hemiplegia. Their results indicated that patients with anosognosia typically improved less after a rehabilitation program, causing the authors to conclude that the presence of anosognosia with left neglect and hemiplegia negatively impacts rehabilitation outcomes (Gialanella et al., 2005).

## 2.2 Neurodegenerative Disorders

In Alzheimer's disease (AD) and Mild Cognitive Impairment (MCI) anosognosia generally manifests as a lack of insight or awareness into impairments affecting one's activities of daily living or cognitive functioning, particularly memory (Koltai, Welsh-Bohmer, & Schmechel, 2001; Mak, Chin, Ng, Yeo, & Hameed, 2015). Anosognosia is very common in AD, with the prevalence estimated between 30 and 80 percent (Mak et al., 2015). A recent study (Mak et al., 2015) comparing AD

<sup>1</sup> Hemiplegia is paralysis on one side of the body, while neglect refers to difficulty in an individual's ability to notice and respond to stimuli on one side of the body (Radomski & Trombly Latham, 2014).

and MCI found that 56 percent of participants with AD and 49 percent of participants with MCI had mild anosognosia. In the MCI group, higher scores on measures of anosognosia were associated with greater caregiver burden. The authors speculate this increased burden is potentially the result of patients refusing advice from caregivers and professionals. In the study's AD group, higher anosognosia scores were associated with greater apathy. Based on their research, Mak et al. (2015) suggest that anosognosia, when it appears, occurs early on in disease progression. Given previous evidence that anosognosia in AD is associated with poor outcomes, the presence of anosognosia in MCI could therefore be an important predictor of subsequent progression to AD and its associated functional deterioration.

In terms of intervention, research suggests that insight is likely a mediator of treatment gain. One study by Koltai et al. (2001) investigated the effectiveness of a Memory and Coping Program among mild to moderate dementia patients and found statistically significant differences among treatment group participants with and without anosognosia. Participants with insight made significantly greater gains in actual memory functioning. The authors speculate that the benefits of intervention may be limited for patients with anosognosia due to decreased motivation and lack of perceived need to work on deficits. However, study participants with anosognosia perceived greater improvement than their peers with insight. This suggests that there may be unexpected benefits to intervention with this population, although further research is needed in this area.

## 2.3 Practical Considerations

In order to treat and adapt their approach for individuals with anosognosia, clinicians first need to be able to reliably identify this phenomenon. Current instruments used to detect anosognosia are large in number, very broad, and difficult to analyze; there is no "gold standard" (Orfei et al., 2007). For example, the Anosognosia Questionnaire for Dementia examines the severity of anosognosia along a continuum, whereas other approaches (see for example Koltai et al., 2001) rate anosognosia as merely absent/present. A more standardized measure would create greater consistency and comparability across populations and studies, and would enable a more reliable assessment of patients with anosognosia (Orfei et al., 2007). With respect to treatment, there is a lack of evidence and guidance regarding effective and appropriate interventions for individuals with anosognosia. One of the primary considerations for rehabilitation practice is choosing between remediation and compensatory approaches. Remediation focuses on building or restoring the individual's awareness of their current capabilities and limitations. Katz et al. (2002) suggest that this approach is most appropriate for clients with a combination of anosognosia and denial. For individuals whose unawareness is primarily denial, increasing their awareness could create emotional harm as this approach would involve breaking down the client's own protective mechanism (Katz et al., 2002).

In contrast, compensatory approaches focus on strategies to support improved or continued functioning without addressing the underlying anosognosia. Katz et al. (2002) suggest that using procedural

training (overlearning an activity until it becomes automatic) and/or a behavioural approach have the potential to improve function for individuals with anosognosia. However, clients with extreme levels of unawareness and denial may resist treatment, and/or be non-compliant with recommendations. In these instances, Katz et al. (2002) recommend using external compensation strategies like modifying the individual's environment and/or their activities, or adding supervision, to promote safety. Treating individuals with anosognosia also raises ethical questions of access, capacity, and client-centeredness. Rehabilitation outcomes for individuals with anosognosia tend to be poorer than their peers with intact insight (Jehkonen, Laihosalo, & Kettunen, 2006). This could have significant effects on the selection of potential candidates for treatment (Koltai et al., 2001). Do we treat only those who have the greatest potential to show objective improvements? Or is self-perceived efficacy also important? In addition, individuals with anosognosia have poor judgement regarding themselves, their capabilities and their needs (Prigatano, 2009). Clinicians may need to decide at what point a client's decision-making capacity should be assessed (Prigatano, 2009). Finally, a client's lack of insight may make it difficult to maintain client-centered principles in goal-setting and treatment. If a client wishes to pursue activities that compromise their safety or that of others, to what extent does a clinician discourage this (Prigatano, 2009)? What if safety is not an issue, but the client is likely to fail at the activity potentially causing emotional harm?

## 2.4 Conclusion

While interest in understanding anosognosia and improving rehabilitation for this population is growing, advances in related research continue to be limited (Prigatano, 2009). Our review of the research highlighted a number of areas that could benefit from further study. First, assessment tools could be improved and standardized to assist with better identification of anosognosia. These tools should help clinicians distinguish between anosognosia and other unawareness syndromes (e.g. denial) because of their differing relationships to functional outcomes (Jehkonen et al., 2006). Further research should also be conducted to better understand the mechanism of how anosognosia influences treatment outcomes (Mak et al., 2014) in order to assist clinicians in developing appropriate and effective interventions. Finally, more evidence is needed on the effectiveness of treatment for individuals with anosognosia. This should include comparing remediation versus compensatory approaches, and examining the impact of specific treatment techniques on outcomes. Recognizing and considering the impact of anosognosia on patients could be invaluable. Understanding this phenomenon will support practitioners to better tailor their goals and interventions, and could lead to improved functional outcomes and quality of life for this diverse population.

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