

COMMENTARY

Functionality, the capacity to make decisions and awareness in patients suffering from Alzheimer's disease

Commentary on “Modelling the impact of functionality, cognition, and mood state on awareness in people with Alzheimer's disease” by Fischer *et al.*

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Awareness is difficult to define, particularly in cases of chronic, degenerative diseases. It represents a multifaceted construct, since some people may be aware of part of their deficits but not of others, or they are aware of their deficits but do not comprehend their impact on daily life (Gambina *et al.*, 2015; Mograbi and Morris, 2018; Moro *et al.*, 2021). Anosognosic patients sometimes deny their deficits verbally (i.e. explicit anosognosia), but in fact behave as if they know on some level that they cannot do certain things (i.e. implicit awareness, see Moro *et al.*, 2021) and ask for help or give up on a potentially dangerous action (e.g. standing up without help). There are also patients who, although they are apparently aware of their deficits, are convinced that they are still able to carry out daily activities alone and are not able to anticipate the consequences of their failures (i.e. anticipatory awareness, Moro *et al.*, 2021). In the context of dementia, awareness is considered as “a reasonable or realistic perception or appraisal of a given aspect of one's situation, functioning or performance, or of the resulting implications, which may be expressed explicitly or implicitly” (Clare *et al.*, 2011, pp. 396).

Due to its complex nature, there has been a debate on the contribution of cognitive, emotional, and environmental factors in awareness (e.g. Gambina *et al.*, 2015). The study by Fischer and colleagues (2019) is very up-to-date since it refers to an area of research which is continuously being enriched by new ideas and suggestions. Their research involved testing various models by means of advanced statistical procedures (i.e. Structural Equation Modeling). Specifically, this compares the contribution of three dimensions to awareness, namely cognitive functions, depressive mood, and functionality. They examined a large group of patients and reached the conclusion that

functionality directly influences awareness, while the impact of cognitive functions and depressive mood is only indirect (and mediated by functionality). This result is relevant as it means that the traditional notion that anosognosia is a direct consequence of cognitive deficits potentially needs to be rethought. Furthermore, it accounts for the inconsistencies between previous studies on the topic, in which a correlation between awareness and cognitive functions was not always found (Ecklund-Johnson and Torres, 2005; Sunderaraman and Cosentino, 2017).

However, the relationship between functionality and awareness is still to be fully understood. In fact, following Fischer and colleagues, it is impairments in daily life activities that prevent Alzheimer's patients from engaging in certain actions, which then prevents them from becoming aware of dementia-introduced changes at a functional level (Fischer *et al.*, 2019). Patients with very mild dementia (and still able to carry out most daily activities) might thus be expected to be aware of their deficits. Unfortunately, studies on patients in the initial stages of the illness do not support this hypothesis and indicate that disorders in awareness may arise very early on (Gambina *et al.*, 2014, 2015).

Another aspect that deserves attention is the definition of the term “functionality.” If functionality represents a crucial requirement for awareness, the question then concerns the meaning to be attributed to the very concept of functionality. In line with many other studies on the subject, in order to define functionality, Fischer and colleagues evaluated the patients' degree of independence based on their performance in a number of instrumental activities (e.g. shopping, managing one's own medications, making meals, keeping track of current

events, and managing one's own finances, Pfeffer *et al.*, 1982). However, it is well known that functional deficits due to impairments in sensorimotor or cognitive functions (such as memory, attention, language, or calculation disorders) do not correspond to the ability to express choices with respect to those aspects of daily life for which awareness is necessary. In other words, a reduced degree of functionality does not automatically involve a reduction in the person's capacity to make decisions (Kim, 2011; Kim and Appelbaum, 2006). Patients may be impaired with respect to both cognitive functions and instrumental daily life activities, but maintain their ability to consent to medical treatments, to act as a witness, to make a will or to vote and so on.

So, what is the relationship between these capacities and awareness? Capacity has been variously defined as an individual's ability to (i) learn, process, and make decisions based on available information (Gossman *et al.*, 2017); (ii) make decisions relating to activities such as work, driving, looking after relatives, medical issues, and entering into legal contracts (Moberg and Kniele, 2006); and (iii) make context-specific decisions adequately (Moye *et al.*, 2013). Thus, the ability to act indicates an individual's capacity to perform tasks of varying degrees of complexity (for a revision of the literature, see Gasparini *et al.*, 2021), and, although this relies on cognitive functions such as decision-making abilities, it also depends on other factors, in particular the congruency between each individual's ability and the contingencies involved (i.e. the specific situation in which a decision is being taken).

The assessment of capacity is particularly challenging for clinicians (Appelbaum, 2007) who must always seek a balance between the principle of autonomy (i.e. self-determination and the freedom of choice) and patient safety. Indeed, a judgment of incapacity may lead to a significant reduction in a person's rights, but on the other hand, a too benevolent judgment may expose a patient with dementia to various risks (e.g. domestic accidents, failure to plan both simple, and complex actions or a reduction in the assistance they receive). Specific instruments to assess capacity are required (Freedman *et al.*, 1991; Moberg and Kniele, 2006; Gasparini *et al.*, 2021) as standard neuropsychological tests (e.g. for executive functions) have been found to be inadequate (Gambina *et al.*, 2014).

In this capacity assessment, the relationship between awareness and decision-making is crucial. In fact, an inability to recognize one own's difficulties, and in particular being incapable of anticipating potential problems resulting from one own's choices (i.e. anticipatory awareness, Moro *et al.*, 2021), may lead to inappropriate decisions. The clearest example of how

this may cause problems can be seen in the case of Clinical Competence which is necessary whenever patients are requested to sign an informed consent form to express their free and voluntary choice to participate in a course of treatment or a research project (Gasparini *et al.*, 2021). Four components have been identified in clinical competence (Appelbaum, 2007): (i) the ability to comprehend relevant information (Understanding); (ii) the ability to apply that information to one's own situation (Appreciation); (iii) the ability to evaluate the potential consequences of one's own decisions (Reasoning); and (iv) the ability to communicate one's own choices (the Expression of choice). Clearly, appreciation of one's own situation involves self-awareness, as only people who recognize their deficits (and abilities) will be able to make adequate decisions. A similar situation arises in other contexts, such as making financial choices or deciding whether to renew a driving license.

Based on Fisher and colleagues' results and the considerations expressed above, we suggest a further line of research that addresses the gaps in standard neuropsychological examinations of cognitive functions in Alzheimer's patients and specifically investigates the relationship between awareness and decision-making.

It is noteworthy that these two functions seem to share at least partially common neural correlates. Recent studies suggest that anosognosia (as well as decision-making) is associated with lesions in the medial cortical and subcortical structures which involve the default mode network and the networks subserving autobiographical memory and emotional states (Antoine *et al.*, 2019; Pacella *et al.*, 2019).

One may take the view that in the case of chronic, degenerative pathologies, awareness is not really necessary for any potential recovery, as is the case, for example, of treatment for patients suffering from hemiplegia as a consequence of a stroke (Moro *et al.*, 2021) which requires the engagement of the patient in the rehabilitation process. Furthermore, if awareness is reduced in parallel with a reduction in the patients' daily life activities (and the risks associated with these), this deficit will not represent a problem which needs to be dealt with. In contrast, when considering that awareness is crucial in order to maintain an individual's capacity to make decisions, a diagnosis of anosognosia becomes an integral part of the clinical assessment of patients suffering from dementia.

In conclusion, we suggest that an investigation of the relationship between awareness and capacity represents the next phase in the research undertaken by Fisher and colleagues. This will allow clinicians and caregivers to implement any strategies and instruments which will help patients overcome functional deficits and maintain their decision-making abilities

(e.g. to facilitate comprehension of information relevant to the decision process, Moro *et al.*, 2020).

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