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COMMENTARY

What is at stake in decision-making capacity tools?

A meta-analysis is published in this issue of *International Psychogeriatrics* titled "Decisional capacity to consent to treatment and research in patients affected by Mild Cognitive Impairment–A systematic review and meta-analysis" (Parmigiani *et al.*, 2020). Its objective is to compare the ability to decide to take treatment or participate in clinical research of Mild Cognitive Impairment (MCI) patients versus Alzheimer's patients and patients without neurocognitive disorders. Patients affected by MCI are at higher risk of impaired capacity to consent to treatment and research compared to healthy patients, despite being at lower risk compared to patients affected by Alzheimer disease. So clinicians and researchers need to carefully evaluate decisional capacity in MCI patients providing informed consent. A small number of studies was included in the analyze so it was not possible to determine many factors associated with decisional capacity in patients with MCI. It was not possible to conclude completely.

Indeed, this study suffers of the current heterogeneity of existing tests of decisional capacity. It exists at several levels: on the type of capacity tested, the type of test, the methodology of the studies and the populations studied (Gilbert *et al.*, 2017) (Pennington *et al.*, 2018). There is no Gold standard for assessing decision-making capacity but there are a few validated tests such as the MacCAT-T (Grisso *et al.*, 1997) or the UBACC (Jeste *et al.*, 2007). They all include four dimensions of decision-making capacity, which are understanding, reasoning, appreciation and choice (Appelbaum, 2007). Despite their multiplicity, these tests are essential for assessing decision-making ability because clinicians' judgement is not sufficient. Indeed, it is known that there is inter-observer variability (Janofsky *et al.*, 1992) (Fazel *et al.*, 1999) which can lead to two different assessments for the same patient.

Moreover, there is an over-confidence bias in any clinical evaluation (Miller *et al.*, 2015) which causes the clinician to be too certain of his judgment. This is the case for clinicians who overestimate MCI patients (Oshima *et al.*, 2020). This bias can be controlled by the use of decision-ability tests that decrease inter-rater variability through the use of standardized tools. These tests require that examiners be trained to optimize the effectiveness of the assessment and leave as few items as possible to the assessor's discretion (Pennington *et al.*, 2018). Specialized training on concepts of capacity and legal definitions improves reliability and reproducibility among assessors.

One may wonder whether the method chosen, to assess the ability to decide by going through the four steps mentioned above, is the most appropriate method? Indeed as quoted in the article there is the possibility for patients who cannot pass the tests for evaluating the capacity to decide, to assess whether the choice they have made is an authentic choice that corresponds to their usual values. When the patient is no longer able to make his will explicit, we can accept the choice when it corresponds to what the patient would have done if he did not have neurocognitive disorders according to the values that we know of him (Kim, 2011). An inconsistency between the patient's values and beliefs and the decision he makes may lead the clinician to doubt such an ability. Some difficulties with this approach are worth noting. First of all, this full and complete knowledge of the person being cared for is an ideal that is difficult to achieve within certain practices (e.g. emergency unit) and because of the context specific to the hospital environment. Moreover, the qualification of a capacity for self-determination is dependent on the clinical competence of the clinician to evaluate it and facilitate its expression. The care receiver's decisions may also be confronted with the clinician's opinion. Consequently, it is not uncommon for a patient's decision to go against the proposed medical orientation to raise questions about the patient's capacity for self-determination. A distinction must therefore be made between "unreasonable" decision and inability to decide. Like consent, refusal must be free and informed: decisions made by a person who is capable of making his or her own decisions must be respected, even though they may be contrary to the clinician's opinion.

We highlight here one of the major problems in assessing the capacity to decide by these tests, which is the lack of consideration of the emotions and values of the individual (Grisso and Appelbaum, 2006). We know that they are involved in the decision-making process and that they are fundamental when decisions are complex (Charland, 2006). Tests evaluating decision-making capacity only take into account the cognitive and rational

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process of the decision and not the irrational part related to our emotions. Yet the field of research on the impact of emotions and values on decision-making capacity is expanding and tends to demonstrate that they fundamentally and predictably influence decision-making (Lerner *et al.*, 2015).

Similarly, intuition, which is defined as direct and immediate knowledge that does not require the use of reasoning, sometimes intervenes in decision-making, particularly in complex decisions (Remmers and Michalak, 2016).

In this meta-analysis, it was only possible to carry out analyses of seven studies. This is certainly due to all the obstacles just mentioned in the evaluation of decision-making capacity. To make things even more complex, in addition to taking into account values and emotions, some suggest the interest of evaluating suffering, and introducing psychosocial evaluation into the evaluation of decision-making capacity, but no standardized evaluation tool exists.

This study (Parmigiani *et al.*, 2020) seems to show that the decision-making capacity of MCI patients could be overestimated due to an impairment of comprehension capacities.

In addition, we know that this lack of comprehension worsens in MCI patients who progress to Alzheimer's disease (Okonkwo *et al.*, 2007). This ability is influenced by the level of education and intelligence and the way information is presented.

However, it is possible to improve their understanding and thus improve their ability to make decisions (Buckles *et al.*, 2003). Indeed, this study shows that even in mildly demented patients, repetition of information leads to improved understanding and consent to participate in clinical research.

Perhaps one way to avoid erroneous assessment of decision-making capacity would be to make shared decisions between the patient and the health care team. Indeed, shared decisions help to maintain the patient's capacity for autonomy (Groen-Van de Ven *et al.*, 2018; Gulbrandsen *et al.*, 2016).

When we share the decision with the patient, he is supported during the decision-making process, for example by improving his understanding, which enables him to express himself on things he has not understood. But it also helps him to make decisions in line with his values and objectives (Mejia *et al.*, 2019). Clinicians need to identify patients' preferences and cognitive weaknesses and adapt communication strategies and the amount and presentation of information. Accompanying the patient in decision-making increases patient knowledge and the accuracy of risk perceptions, reduces decision-making conflicts, and decreases the passivity of some patients who tend to let the doctor or family make the decision for them. In addition, it increases congruence between values and choices and improves patient–physician communication (Stacey *et al.*, 2017).

Shared decision-making improves patient autonomy by forcing the evaluator to adapt the information content to the patient's cognitive level. This can restore confidence in MCI patients who do not yet have a loss of autonomy despite their cognitive complaint, but who may already be struggling to make certain decisions.

Mouna Romdhani
Neuro-Psycho-Gériatrie, Hôpital Bretonneau (APHP)
Email: mouna.romdhani@aphp.fr

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