

# Cognitive Fluctuations as a Challenge for the Assessment of Decision-Making Capacity in Patients With Dementia

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## Abstract

Decision-making capacity (DMC) is an indispensable prerequisite for medical treatment choices, including consent to treatment, treatment discontinuation, and refusal of treatment. In patients with dementia, DMC is often affected. A particular challenge in assessing DMC are cognitive fluctuations that may lead to a fluctuation in DMC as well. Cognitive fluctuations are a diagnostic core feature of dementia with Lewy bodies and occur in Parkinson's and Alzheimer's diseases. In this article, these challenges are discussed and suggestions for assessing the DMC of patients with dementia with cognitive fluctuations are presented.

## Keywords

decision-making capacity, autonomy, cognitive fluctuations, dementia with Lewy bodies, Alzheimer's disease, Parkinson's disease

## Decision-Making Capacity and the Importance of its Assessment

Decision-making capacity (DMC) is an indispensable prerequisite for medical treatment choices, including consent to treatment, treatment discontinuation, and refusal of treatment, and thus, the basis for patients' right to self-determination. Two moral requirements are entailed in DMC evaluations: respect for the autonomy of those who are able to make their own decisions and provision of protection for those with diminished decisional capacity. In view of these ethical implications, a careful assessment of DMC is essential.<sup>1,2</sup>

The following cognitive criteria for medical DMC have been proposed and are widely used in research and practice<sup>3</sup>: (1) ability to understand relevant information, (2) ability to appreciate the nature of the disorder and the possibility that treatment could be beneficial, (3) ability to reason about the treatment choices, and (4) ability to communicate a choice. Thus, what matters is not the question of what a person has decided (the decision outcome) but how the person came to that specific choice (the decision-making process).<sup>4</sup>

Many mental and physical disorders can affect DMC to a large extent.<sup>5-7</sup> Decision-making incapacity is associated with a broad range of clinical conditions, such as various forms of dementia, delirium, organic amnesic syndromes, brain injury, and disorders of consciousness, such as coma, vegetative and minimally conscious states as well as psychiatric diseases, such as schizophrenia or severe depression, or medically induced or illness-induced impaired consciousness of critically unstable patients too ill to participate in decision making.<sup>8</sup> Decision-

making capacity may vary across different situations or tasks, which is called decisional relativity.<sup>2</sup> For example, a person may have DMC for matters of everyday life (eg, what to eat) but may not be sufficiently capable of making decisions regarding medical treatment.

In the last 2 decades, more and more standardized assessment tools for DMC have been developed.<sup>9</sup> Among well-validated and frequently used assessment tools are, for instance, the Mac Arthur Competence Assessment Tool<sup>3</sup> and the Capacity to Consent to Treatment Instrument.<sup>10</sup> Such tools not only provide a structure for the DMC assessment process but also give the assessing health care professional the possibility to document in detail which mental capacities are affected to which degree and how they were examined. The more serious a certain decision, the more appropriate and detailed documentation and integration in the patient's medical record should be.

## Cognitive Fluctuations in Different Forms of Dementia

"Cognitive fluctuations are spontaneous alterations in cognition, attention, and arousal"<sup>10</sup> and have also been described "as periods of behavioral confusion, inattention, and incoherent

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speech alternating with episodes of lucidity and capable task performance.”<sup>11</sup> Although cognitive fluctuations are a core feature of dementia with Lewy bodies, they also occur in Parkinson’s disease, Alzheimer’s disease, and vascular dementia.<sup>12-15</sup> In 12% of patients with Alzheimer’s disease, cognitive fluctuations occur.<sup>11</sup> Cognitive fluctuations “significantly affect both clinical rating of dementia severity and neuropsychological performance” such as episodic memory, semantic memory, working memory, visuospatial abilities, and logical thinking.<sup>11</sup> Between dementia with Lewy bodies and Alzheimer’s disease, the following differences have been found:

Descriptions of fluctuating cognition in DLB [dementia with Lewy bodies] had a spontaneous, periodic, transient quality, which appeared to reflect an interruption in the ongoing flow of awareness or attention that impacted on functional abilities. Descriptions of fluctuations in AD [Alzheimer’s disease] frequently highlighted episodes of memory failure, or a more enduring state shift in the form of ‘good’ and ‘bad’ days, typically occurring in response to the cognitive demands of the immediate environment.<sup>16(p382)</sup>

The higher degree of attentional impairment and fluctuation in dementia with Lewy bodies relative to patients with Alzheimer’s disease might be caused by more severe deficits in higher cortical functions in dementia with Lewy bodies compared to Alzheimer’s disease.<sup>17</sup> Additionally, cognitive fluctuations are particularly strong in patients with delirium. In delirium, mental abilities get suddenly and seriously disturbed, which leads to confusion and problems of thinking (eg, changes in perception, attention, or mood). In the context of the present article, this is important because dementia is a major risk factor for delirium.<sup>18</sup> Unfortunately, delirium is sometimes interpreted as a natural progression of dementia. However, in dementia, memory and intellectual capacities typically decrease slowly over months or years. In contrast, the onset of delirium is faster and develops within hours or days. Compared to most forms of dementia, symptoms of delirium have higher fluctuation.

## A Challenge for the Assessment of DMC

Dementia goes along with impairments in memory, orientation, executive functions, and behavior, among others.<sup>19-22</sup> Regarding DMC, researchers have found that “relative to controls and patients with Parkinson’s disease, patients with Alzheimer’s disease were impaired on the consent ability of understanding the medical treatment situation and choices”.<sup>23(p483)</sup> Furthermore, in terms of the appreciation criterion, various studies have shown that illness awareness (or insight)<sup>24</sup> decreases as Alzheimer’s disease advances.<sup>25,26</sup> Patients with Parkinson’s disease were impaired in consent ability to show a treatment choice.<sup>23</sup> Moreover, executive dysfunction was a major neurocognitive factor for incapacity in such patients.<sup>27</sup>

A pooled analysis following a systematic review showed that independent of the severity of the disease approximately 54% of patients with Alzheimer’s disease and 42% of patients

with Parkinson’s disease show incapacity.<sup>22</sup> For other forms of dementia, such as with Lewy bodies, there are currently no such estimates.

It has been shown that DMC largely depends on neuropsychological functions such as attention, concentration, memory, understanding, and reasoning.<sup>31-34</sup> Deficits in one of these neuropsychological areas can compromise DMC and in the worst case lead to complete incapacity for certain tasks or decisions.<sup>28,30</sup>

These findings provide the basis to assume that cognitive fluctuations are associated with fluctuations in DMC. However, this association has never been empirically tested. Decision-making capacity not only changes during different situations and tasks (decisional relativity), additionally and because of cognitive fluctuations, it may also change over time. It follows that the assessment of DMC must be case specific, task specific, and time specific.<sup>3</sup>

These requirements constitute a difficult challenge for the assessing clinician. On the one hand, the case, task, and time specificity must be taken seriously, which means that DMC can change from one moment to another in the worst case. On the other hand, the law demands that DMC or incapacity is clearly ascribed to persons for important decisions such as medical treatment choices.

## Suggestions for DMC Assessment of Patients Having Cognitive Fluctuation

The attribution of incapacity applies only to 1 specific task or decision and only to 1 specific point in time. The assessing physician who claims incapacity has to prove her or his assumption for the relevant task or decision. For little children or for persons with severe mental disabilities, this claim is relatively easy to establish whether complex decisions are involved. In case of doubt, an individual is considered to have DMC until the opposite is proven.

For patients having cognitive fluctuations, it is important that the physician choose a day or a point in time in which the patient is in good shape compared to other days or moments. Information about different treatment options, risks, as well as informed consent should be best discussed at this point in time.

## How to Identify Whether the Patient is Currently in Good Shape

Often patients realize whether they are currently in good shape. Therefore, physicians should first rely on the opinion of the patients themselves. In addition, close collaboration with relatives or with the responsible care team can be essential for finding an appropriate moment for the assessment. Usually, relatives know from their everyday experience with the person whether he or she currently is in good shape compared to other days or moments or whether he or she is currently stressed, depressed, agitated, tired, or in another reduced state. Furthermore, the help of relatives in the DMC assessment process is

important for other reasons. The significance of social embeddedness, intimate relationships, and deep attachments for an agent's deliberation<sup>35</sup> was equally highlighted by feminist<sup>36</sup> and communitarian philosophers.<sup>37</sup> Thus, personal relationships and the social environment in which a person lives affect her or his autonomy. Because relatives generally know best which statements or decisions of their next of kin are autonomous and genuine, it is important to include relatives in the DMC assessment process.

### How to Improve the Condition of Patients if They are in Bad Shape

Sometimes it can be necessary to first treat the underlying medical problem responsible for the cognitive fluctuations (eg, delirium) before assessing DMC. That might be a change in drug doses, for instance, a decrease in benzodiazepines that have a sedating effect and compromise cognitive abilities.

Emotional disturbances should be diminished as much as possible by making the person feel at ease. When the stressful nature of the assessment situation negatively affects the patient's cognitive state, the presence or support of relatives might be helpful and provide an atmosphere of familiarity and relaxation.

In addition, relevant information should be provided by using key messages in simple and easy comprehensible language without more details than absolutely required. The communication of such key messages can be further simplified by using aids such as pictures or illustrations. Other DMC improvement techniques might be helpful as well<sup>3,38-40</sup>; interventions such as changing the environment, for example, relocating the meeting from a clinic to the patient's home, may foster capacity.

Patients may have strong cognitive fluctuations during assessment meeting. In this case, only information obtained during the best cognitive moments of the meeting should be used. Beyond these broad suggestions, further empirical investigations into the factors that influence cognitive fluctuations are needed.

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### References

- Berghmans R. Capacity and consent. *Curr Opin Psychiatr*. 2001; 14(5):491-499.
- Buchanan AE, Brock DW. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge, England: Cambridge University Press; 1989.
- Grisso T, Appelbaum PS. *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals*. Oxford, England: Oxford University Press; 1998.
- Berghmans R, Dickenson D, Rudd TM. Mental capacity: in search of alternative perspectives. *Health Care Anal*. 2004;12(4):251-263.
- Appelbaum PS, Grisso T, Frank E, O'Donnell S, Kupfer DJ. Competence of depressed patients for consent to research. *Am J Psychiatr*. 1999;156(9):1380-1384.
- Lapid MI. Decisional capacity of severely depressed patients requiring electroconvulsive therapy. *J ECT*. 2003;19(2):67-72.
- Palmer BW, Dunn LB, Appelbaum PS, et al. Assessment of capacity to consent to research among older persons with schizophrenia, Alzheimer disease, or diabetes mellitus. *Arch Gen Psychiatr*. 2005;62(7):726-733.
- Trachsel M, Mitchell C, Biller-Andorno N. Decision-making incapacity at the end of life: conceptual and ethical challenges. *Bioethics Forum*. 2013;6(1):26-30.
- Lamont S, Jeon Y, Chiarella M. Assessing patient capacity to consent to treatment: an integrative review of instruments and tools. *J Clin Nurs*. 2013;22(17-18):2387-2403.
- McKeith IG, Dickson DW, Lowe J. Diagnosis and management of dementia with Lewy bodies: third report of the DLB Consortium. *Neurology*. 2005;65(12):1863-1872.
- Escandon A, Al-Hammadi N, Galvin JE. Effect of cognitive fluctuation on neuropsychological performance in aging and dementia. *Neurology*. 2010;74(3):210-217.
- Ballard C, Aarsland D, McKeith I, et al. Fluctuations in attention: PD dementia vs DLB with parkinsonism. *Neurology*. 2002; 59(11):1714-1720.
- Ballard C, O'Brien J, Gray A, et al. Attention and fluctuating attention in patients with dementia with Lewy bodies and Alzheimer disease. *Arch Neurol*. 2001;58(6):977-982.
- Walker MP, Ayre GA, Cummings JL. Quantifying fluctuation in dementia with Lewy bodies, Alzheimer's disease, and vascular dementia. *Neurology*. 2000;54(8):1616-1625.
- Metzler-Baddeley C. A review of cognitive impairments in dementia with Lewy bodies relative to Alzheimer's disease and Parkinson's disease with dementia. *Cortex*. 2007;43(5): 583-600.
- Bradshaw J, Saling M, Hopwood M, Anderson V, Brodtmann A. Fluctuating cognition in dementia with Lewy bodies and Alzheimer's disease is qualitatively distinct. *J Neurol Neurosurg Psychiatr*. 2004;75(3):382-387.
- Bradshaw J, Saling M, Anderson V, Hopwood M, Brodtmann A. Higher cortical deficits influence attentional processing in dementia with Lewy bodies, relative to patients with dementia of the Alzheimer's type and controls. *J Neurol Neurosurg Psychiatry*. 2006;77(10):1129-1135.
- Robertsson B, Blennow K, Gottfries CG, Wallin A. Delirium in dementia. *Int J Geriatr Psych*. 1998;13(1):49-56.
- Marson DC, Ingram K, Cody H, Harrell LE. Assessing the competency of patients with Alzheimer's disease under different legal standards. *Arch Neurol*. 1995;52(10):949-954.

20. Starkstein S, Sabe L, Petracca G, et al. Neuropsychological and psychiatric differences between Alzheimer's disease and Parkinson's disease with dementia. *J Neurol Neurosurg Psychiatr*. 1996; 61(4):381-387.
21. Martin RC, Okonkwo OC, Hill J, et al. Medical decision-making capacity in cognitively impaired Parkinson's disease patients without dementia. *Movement Disord*. 2008;23(13):1867-1874.
22. Sessums LL, Zembrzuska H, Jackson JL. Does this patient have medical decision-making capacity? *JAMA*. 2011;306(4): 420-427.
23. Warner J, McCauley R, Griffin M, Hill K, Fisher P. Participation in dementia research: rates and correlates of capacity to give informed consent. *J Med Ethics*. 2011;34(3):167-170.
24. Dawns M. Awareness in dementia: in the eye of the beholder. *Aging Ment Health*. 2005;9(5):381-383.
25. Zanetti O, Vallotti B, Frisoni GB, et al. Insight in dementia: when does it occur? Evidence for a nonlinear relationship between insight and cognitive status. *J Gerontol Psychol Sci*. 1999; 54(2):100-106.
26. Defanti CA, Tiezzi A, Gasparini M, et al. Ethical questions in the treatment of subjects with dementia. Part I. Respecting autonomy: awareness, competence and behavioural disorders. *Neurol Sci*. 2007;28(4):216-231.
27. Dymek MP, Atchison P, Harrell L, Marson DC. Competency to consent to medical treatment in cognitively impaired patients with Parkinson's disease. *Neurology*. 2001;56(1):17-24.
28. Griffith HR, Dymek MP, Atchison P, Harrell L, Marson DC. Medical decision-making in neurodegenerative disease: Mild AD and PD with cognitive impairment. *Neurology*. 2005;65(3): 483-485.
29. Marson DC, Chatterjee A, Ingram KK, Harrell LE. Toward a neurologic model of competency: cognitive predictors of capacity to consent in Alzheimer's disease using three different legal standards. *Neurology*. 1996;46(3):666-672.
30. Marson DC, Harrell L. Executive dysfunction and loss of capacity to consent to medical treatment in patients with Alzheimer's disease. *Semin Clin Neuropsychiatry*. 1999;4(1):41-49.
31. Moye J, Karel MJ, Gurrera RJ, Azar AR. Neuropsychological predictors of decision-making capacity over 9 months in mild-to-moderate dementia. *J Gen Intern Med*. 2006;21(1):78-83.
32. Palmer BW, Savla GN. The association of specific neuropsychological deficits with capacity to consent to research or treatment. *J Int Neuropsychol Soc*. 2007;13(6):1047-1059.
33. Dreer LE, Devivo MJ, Novack TA, Krzywanski S, Marson DC. Cognitive predictors of medical decision-making capacity in traumatic brain injury. *Rehabil Psychol*. 2008;53(4):486-497.
34. Baumann H. Reconsidering relational autonomy. Personal autonomy for socially embedded and temporally extended selves. *Analyse Kritik*. 2008;30(2):445-468.
35. MacKenzie C, Stoljar N. *Relational Autonomy. Feminist Perspectives on Autonomy, Agency, and the Social Self*. Oxford, England: Oxford University Press; 2000.
36. Christman J. Relational autonomy, liberal individualism, and the social constitution of selves. *Phil Stud*. 2004;117(1/2):143-164.
37. Wirshing DA, Wirshing WC, Marder SR, Liberman RP, Mint J. Informed consent: assessment of comprehension. *Am J Psychiatry*. 1998;155(11):1508-1511.
38. Carpenter WT, Gold JM, Lahti AD, et al. Decisional capacity for informed consent in schizophrenia research. *Arch Gen Psychiatry*. 2000;57(6):533-538.
39. Dunn LB, Jeste DV. Enhancing informed consent for research and treatment. *Neuropsychopharmacology*. 2001;24(6):595-607.
40. Kim SYH. *Evaluation of Capacity to Consent to Treatment and Research*. Oxford, England: Oxford University Press; 2010.