

## Complexity, not Severity: Reinterpreting the Sliding Scale of Capacity

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### **Abstract:**

In this paper, we focus on the definition and application of the sliding scale of capacity. We show that the current interpretations of the sliding scale confound distinct features of the medical decision, such as its urgency, its severity, or its complexity, that do not always covary. We propose that the threshold for assessing capacity should be adjusted based solely on the cognitive complexity of the decision at hand. We further suggest that the complexity of a decision should be identified based on a patient's particular cognitive deficits. We utilize the current research on the types of deficits that characterize amnesic dementias and examine which types of medical decisions might be most complex for patients with that type of dementia. We conclude that applying the sliding scale based on individualized judgments of cognitive complexity will improve accuracy of assessment of capacity and enable capable patients to participate in medical decision making.

**Key words:** Capacity, dementia, cognitive complexity, sliding scale, medical decisions, cognitive deficits

### **1. Introduction**

Between 2015 and 2055 the population over 65 in the United States is predicted to increase by 80%.<sup>1</sup> Over the last 25 years, increase in the average lifespan has resulted in an overall greater prevalence of dementia. Currently, 50 million people

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<sup>1</sup>Favreault MM, Gleckman H, Johnson RW. Financing long-term services and supports: Options reflect trade-offs for older Americans and federal spending. *Health Affairs* 2015;34(12):2181-91.

live with dementia globally and this number is expected to increase to 152 million by 2050.<sup>2</sup> Independent of severity of disease, dementia has been shown to limit capacity in 54% of patients.<sup>3</sup> As a result, the responsibility of determining whether patients with dementia have capacity to make medical decisions is increasingly laid on the individual physician caring for each patient.

Although there are a variety of characterizations of decisional capacity, in the United States, most require the ability to understand relevant medical information and to appreciate the medical situation and its consequences.<sup>4</sup> When assessing capacity, clinicians may also use their discretion in applying a sliding scale of capacity, which requires a higher threshold of capacity for decisions that are either more consequential, (e.g., irreversible end-of-life choices), or those that are more complex, (e.g., consent for a placebo-controlled trial).

In this paper, we examine the sliding scale of capacity and point out deficiencies in its current formulation. We argue that the sliding scale of capacity should not take into account the severity of the decision because judgments of severity rest on subjective evaluations of acceptable risks and benefits. We propose instead that the threshold for capacity assessments should be adjusted based solely on the complexity of a medical decision. To provide an objective grounding to the notion of complexity, we utilize current research on the types of cognitive deficits that characterize amnesic dementias and identify the types of medical decisions most complex for patients based on their cognitive impairments. We conclude that decisional capacity can be most accurately measured when the sliding scale of capacity is applied based on cognitive complexity based in individual cognitive deficits.

## **2. Obstacles in Assessing Capacity of Patients with Dementia**

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<sup>2</sup> Christina P. World Alzheimer's report 2018. Alzheimer's disease internationals: world alzheimer report 2018;2018:1-48.

<sup>3</sup> Sessums LL, Zembrzuska H, Jackson JL. Does this patient have medical decision-making capacity? *Jama* 2011;306(4):420-7.

<sup>4</sup> Appelbaum PS. Assessment of patients' competence to consent to treatment. *New England Journal of Medicine* 2007;357(18):1834-40.

Autonomy in the clinical setting is characterized as the ability of each patient to accept or reject a proposed medical treatment.<sup>5</sup> There are two distinct but connected concepts used to frame decision making: competence and decisional capacity. In the legal setting, judges make assessments of competence to determine an individual's global ability to make a decision. In the clinical setting, physicians make determinations of decisional capacity, which is the task-specific ability to make a particular medical decision. Although assessments of capacity are frequently made based on informal interactions between patients and physicians,<sup>6</sup> formal assessment tools exist, such as the MacArthur Competence Assessment Tool for Treatment (MacCAT-T), Competency to Consent to Treatment Instrument (CCTI), and the Hopemont Capacity Assessment Interview.<sup>78910</sup> The MacCAT-T is based on the dominant view of capacity as resting on the abilities to: 1) communicate a choice; 2) understand relevant information; 3) appreciate the situation and its consequences; and, 4) reason about choices.

In part because assessments of capacity are not frequently conducted based on formal tools of assessment, physicians remain inconsistent in determining capacity for all patients and especially for those patients with dementia. Daniel Marson et al. showed that physicians' judgement of capacity for mild Alzheimer's Disease patients was only 56% in agreement compared to 98% agreement for controls.<sup>11</sup>

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<sup>5</sup> Beauchamp TL. The right to die as the triumph of autonomy. *Journal of Medicine and Philosophy* 2006;31(6):643-54.

<sup>6</sup> Hermann H, Trachsel M, Biller-Andorno N. Physicians' personal values in determining medical decision-making capacity: a survey study. *Journal of medical ethics* 2015;41(9):739-44.

<sup>7</sup> Appelbaum PS, Grisso T. The MacArthur treatment competence study. I. *Law and human behavior* 1995;19(2):105-26.

<sup>8</sup> Dunn LB, Nowrangi MA, Palmer BW, Jeste DV, Saks ER. Assessing decisional capacity for clinical research or treatment: a review of instruments. *American Journal of Psychiatry* 2006;163(8):1323-34.

<sup>9</sup> Edelstein B. Hopemont Capacity Assessment Interview manual and scoring guide. Morgantown, WV: West Virginia University 1999.

<sup>10</sup> Marson DC, Ingram KK, Cody HA, Harrell LE. Assessing the competency of patients with Alzheimer's disease under different legal standards: A prototype instrument. *Archives of neurology* 1995;52(10):949-54.

<sup>11</sup> Marson DC, McInturff B, Hawkins L, Bartolucci A, Harrell LE. Consistency of physician judgments of capacity to consent in mild Alzheimer's disease. *Journal of the American Geriatrics Society* 1997;45(4):453-7.

Although dementia can limit recall of diagnostic and treatment information, individuals with mild dementia have been shown to be able to participate in clinical decision making.<sup>12</sup>

The variations in progression and cognitive fluctuations for each dementia subtype compound the difficulties in determining capacity. Dementia is accompanied by impairments in memory, orientation, executive function, and behavioral changes over time.<sup>13</sup> As dementia worsens so does a patient's decisional capacity. Compared to normal adults, those with mild Alzheimer's Disease were substantially more likely to experience declines in CCTI defined capacity standards at the end of a two year period.<sup>14</sup>

Previous research<sup>151617</sup> has centered specifically on the progression of incapacity in Alzheimer's Disease and failed to address how clinical decision-making capacity further varies based on the subtype of dementia, which account for a significant portion of dementia patients. Among, Medicare fee-for service beneficiaries the most common subtype of dementia was Alzheimer's disease (43.5%) followed by Vascular (14.5%), Lewy Body (5.4%), Frontotemporal Lobe (1.0%), and alcohol induced (0.7%).<sup>18</sup>

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<sup>12</sup> Moyer J, Karel MJ, Azar AR, Gurrera RJ. Capacity to consent to treatment: empirical comparison of three instruments in older adults with and without dementia. *The Gerontologist* 2004;44(2):166-75.

<sup>13</sup> Trachsel M, Hermann H, Biller-Andorno N. Cognitive fluctuations as a challenge for the assessment of decision-making capacity in patients with dementia. *American Journal of Alzheimer's Disease & Other Dementias* 2015;30(4):360-3.

<sup>14</sup> Huthwaite J, Martin R, Griffith H, Anderson B, Harrell L, Marson D. Declining medical decision-making capacity in mild Alzheimer's disease: A two-year longitudinal study. *Behavioral Sciences and the Law* 2006;24(4):453-63

<sup>15</sup> See note 14, Huthwaite, Martin, Griffith, Anderson, Harrell, Marson 2006:453-63.

<sup>16</sup> Fellows LK. Competency and consent in dementia. *Journal of the American Geriatrics Society* 1998;46(7):922-6.

<sup>17</sup> Marson DC, Hawkins L, McInturff B, Harrell LE. Cognitive models that predict physician judgments of capacity to consent in mild Alzheimer's disease. *Journal of the American Geriatrics Society* 1997;45(4):458-64.

<sup>18</sup> Goodman RA, Lochner KA, Thambisetty M, Wingo TS, Posner SF, Ling SM. Prevalence of dementia subtypes in United States Medicare fee-for-service beneficiaries, 2011-2013. *Alzheimer's & Dementia* 2017;13(1):28-37.

Vascular dementia is the second most prevalent dementia subtype and has a significantly different time course for each patient. It can occur with a wide range of signs, symptoms, and onsets depending on the cerebral location and acuity of disease.<sup>19</sup> Determining capacity for these patients, therefore, requires significant follow-up at multiple different timepoints. By contrast, patients with Lewy Body dementia frequently develop frontal-executive as well as attentional impairments earlier in the disease. These patients can also lack the deficit in memory function initially seen in Alzheimer's Disease and other forms of dementia.<sup>20</sup> Finally, patients with frontotemporal lobe dementia typically have changes in personality accompanied by disinhibition and impulsivity prior to cognitive deficits. Prior research has even shown that decision-making can be impaired in these patients even if they have preserved cognitive function.<sup>21</sup> These variations in which cognitive deficits develop and when they arise among dementia subtypes ultimately complicates the establishment of a universal standard for the determination of capacity.

In addition to difficulties in assessing capacity due to permanent cognitive changes due to disease progression, cognitive fluctuations within progression stage can frustrate determinations of capacity as well. Cognitive fluctuations are identified as spontaneous alterations in cognition, attention, and arousal and are characterized by the presence of drowsiness, disorganized thoughts, starting spells, and daytime sleepiness.<sup>22,23</sup> Their impact on cognitive function can range from significant daily disparities in Mini-Mental State Exam (MMSE) scores—a test used to measure cognitive function in dementia—to episodes of stupor with complete loss of ability

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<sup>19</sup> Román GC. Clinical forms of vascular dementia. In: *Vascular Dementia*: Springer; 2005:7-21.

<sup>20</sup> 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.

<sup>21</sup> Manes F, Torralva T, Ibáñez A, Roca M, Bekinschtein T, Gleichgerrcht E. Decision-making in frontotemporal dementia: clinical, theoretical and legal implications. *Dementia and geriatric cognitive disorders* 2011;32(1):11-7.

<sup>22</sup> See note 13, Trachsel, Hermann, Biller-Andorno. 2015:360-3.

<sup>23</sup> Escandon A, Al-Hammadi N, Galvin JE. Effect of cognitive fluctuation on neuropsychological performance in aging and dementia. *Neurology* 2010;74(3):210-7.

to communicate. Cognitive fluctuations can be present in as many as 80-90% of patients with Lewy Body Dementia.<sup>22</sup> Patients with vascular dementia have also been shown to have a higher prevalence of cognitive fluctuations compared to those with Alzheimer's Disease.<sup>24</sup> These episodes have been shown to confound tests used to assess capacity at specific points in time.<sup>25,26</sup> David Lee et al. found that problems with consciousness, daytime sleepiness, and daytime function can be used to predict cognitive fluctuation and to discriminate between patients with Lewy body dementia and non-Lewy body dementia.<sup>27</sup> While their novel test helps determine how cognitive predictors vary among dementia subtypes, the authors do not explore just how these cognitive fluctuations might affect capacity. As demonstrated by Lee et al., individuals with Lewy Body Dementia specifically have different features of altered cognition which also might be associated with limitations in capacity. Cognitive fluctuations make it difficult to distinguish between irreversible cognitive changes that permanently impair capacity and modulation of capacity that are due to reversible causes, which in turn could result in erroneously limiting the autonomy of patients still capable of making their own medical decisions.

### **3. Correlating Cognitive Deficits with Impairments in Decisional Capacity**

As described by Marson and Lindy Harrell, certain aspects of cognitive decline within each dementia stage can correspond with a patient's decisional capacity.<sup>28</sup> Patients with mild dementia have deficits in short-term and delayed memory, but remain able to engage in most aspects of their treatment decisions. As dementia progresses and approaches the moderate stage, these patients demonstrate

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<sup>24</sup> See note 23, Escandon, Al-Hammadi, Galvin 2010;74(3):210-7.

<sup>25</sup> See note 13, Trachsel, Hermann, Biller-Andorno 2015;30(4):360-3.

<sup>26</sup> Walker M, Ayre G, Cummings J, Wesnes K, McKeith I, O'brien J, et al. Quantifying fluctuation in dementia with Lewy bodies, Alzheimer's disease, and vascular dementia. *Neurology* 2000;54(8):1616-25.

<sup>27</sup> Lee DR, McKeith I, Mosimann U, Ghosh-Nodjal A, Grayson L, Wilson B, et al. The dementia cognitive fluctuation scale, a new psychometric test for clinicians to identify cognitive fluctuations in people with dementia. *The American journal of geriatric psychiatry* 2014;22(9):926-35.

<sup>28</sup> Marson D, Harrell L. Neurocognitive changes associated with loss of capacity to consent to medical treatment in patients with Alzheimer's disease. *Processing of medical information in aging patients: Cognitive and human factors perspectives* 1999:109-26.

increasing anterograde and retrograde amnesia as well as global impairment of core abilities required for decisional capacity. By the time dementia is clinically labeled as severe, patients lack almost all cognitive function resulting in absence of capacity.<sup>29</sup> However, what these stages fail to capture is exactly when a patient reaches that point of incapacity. Every progression is different and not every patient loses their capacity at the same time point in disease.<sup>30</sup> A systematic review of 32 studies focused on predicting capacity in dementia patients found predictions to be heterogenous in how they measured decisional capacity and when in the course of disease the patients actually lost capacity.<sup>31</sup> This warrants a more targeted approach to assessing capacity that is not overly reliant on dementia stages, but takes into account an individual's specific cognitive deficits as they emerge through the progression of the disease.

A number of studies that attempt to map changes in cognitive function to impairments in capacity use the four elements of capacity specified by the MacCAT-T. Most of these studies focus on amnesic dementias, specifically Alzheimer's dementia. Consider the study by Ronald Gurrera et al., who recruited subjects with mild to moderate dementia and tested their performance on a battery of neuropsychological tests to determine auditory and visual attention, logical memory, language, and executive function.<sup>32</sup> They compared their performance on neuropsychological tests with their performance on capacity assessments using a variety of assessment tools, including the MacCAT-T. Performance on neurocognitive tests was significantly predictive of the patient's performance on the assessments of capacity; in particular, it was most strongly predictive of the patients' performance on the understanding element of capacity. In an additional study, Jennifer Moye et al., conducted a longitudinal study where they assessed capacity in patients with mild to moderate dementia.<sup>33</sup> This study showed that patients with dementia experience significant loss of decisional capacity over a 9-

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<sup>29</sup> See note 28, Marson, Harrell 1999:109-26.

<sup>30</sup> Moye J, Karel MJ, Gurrera RJ, Azar AR. Neuropsychological predictors of decision-making capacity over 9 months in mild-to-moderate dementia. *Journal of general internal medicine* 2006;21(1):78-83.

<sup>31</sup> Kim SY, Karlawish JH, Caine ED. Current state of research on decision-making competence of cognitively impaired elderly persons. *The American journal of geriatric psychiatry* 2002;10(2):151-65.

<sup>32</sup> Gurrera R, Moye J, Karel M, Azar A, Armesto J. Cognitive performance predicts treatment decisional abilities in mild to moderate dementia. *Neurology* 2006;66(9):1367-72.

<sup>33</sup> See note 30, Moye, Karel, Gurrera, Azar 2006;21(1):78-83.

month period. When first tested, patients showed deficits primarily in understanding, but when retested in nine months, they showed deficits in understanding, ability to reason logically, and in appreciation.

A study by Ozioma Okonkwo et al. comparing patients with amnesic mild cognitive impairment (MCI), a potential precursor to Alzheimer's Disease, to healthy controls also observed that patients with MCI were able to express a consistent treatment choice but were significantly impaired in their ability to understand, appreciate, and reason about treatment.<sup>34</sup> Justin Huthwaite et al. concluded that patients with mild Alzheimer's dementia had retained the ability to express a choice and making a reasonable choice, but performed below controls on understanding, reasoning, and appreciation.<sup>35</sup> In this 2-year longitudinal study, patients' retained decisional capacity over the first year despite noted deficits. However, at the two-year mark many of the participants were judged to be unable to make medical decisions. As Paul Appelbaum notes, many patients with mild cognitive impairment retain their ability to make medical decisions, but in order to accurately determine their abilities to make treatment choices it is best to use a structured tool for capacity assessments.<sup>36</sup>

#### **4. Sliding the Scale to Account for Cognitive Complexity**

A sliding scale of capacity was characterized in the 1982 Presidential Commission's report as the requirement for increased scrutiny of decisions with "substantial consequences."<sup>31</sup> James Drane proposes a model for applying the sliding scale of capacity based on the risks associated with medical situations.<sup>32, 33</sup> For low-risk life sustaining treatments, Drane suggests that patients need only be aware of the situation, while for decisions that are potentially harmful and against standard practice, a patient must appreciate and understand the implications of his or her decision. The tendency to take risk into account may explain why

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<sup>34</sup> Okonkwo O, Griffith H, Belue K, Lanza S, Zamrini E, Harrell L, et al. Medical decision-making capacity in patients with mild cognitive impairment. *Neurology* 2007;69(15):1528-35.

<sup>35</sup> See note 14, Huthwaite, Martin, Griffith, Anderson, Harrell LE, Marson 2006:453-63.

<sup>36</sup> Appelbaum PS. Consent in impaired populations. *Current neurology and neuroscience reports* 2010;10(5):367-73.



patients are judged as able to appoint surrogates, a decision often considered low in risk, even as they lose the ability to make other medical decisions.

Drane's account of the sliding scale and subsequent accounts join together the gravity of the decision, its importance, and its complexity making the precise trigger for heightening the threshold ambiguous. For example, some of the research focused on capacity across different decisions,<sup>34</sup> includes the complexity of the decision into the characterization of the sliding scale. It is important, here, to make clear that the severity and the complexity of a decision do not necessarily covary. It might be easy to understand the risks and benefits of an appendectomy precisely because the severity of the consequences of the decision, i.e., life or death, contribute to its simplicity. Similarly, it is very complex to wade through a number of different treatments with uncertain risks and benefits, e.g., two different chemotherapies with comparable side-effects and limited benefits, where a refusal would not have severe consequences. Finally, there is no reason to think that important decisions are the most complicated. Although identifying a surrogate is often considered easier than consenting for a complicated surgical procedure, choosing an appropriate surrogate is an important decision that might have permanent consequences on the patient's health, longevity, and well-being.

The tendency of physicians to follow a risk-based application of the sliding scale was identified in the study by Scott Kim et al., where the variability in judgments about decisional capacity was mediated by the assessor's perception of the riskiness of the decision.<sup>34</sup> Drane similarly describes emergency situations where a patient's assent to treatment without a thorough informed consent, is enough because refusing treatment would lead to death or disability and the treatment would avert these serious harms.<sup>32</sup> The amount of time available to assess capacity or the urgency of a decision do not have much to do with the patient's ability to make a decision. If the assumption is that a person has the capacity to consent, then even in situations where it might seem rational or beneficial to accept treatment, treating without consent is not appropriate. Given the evidence provided by Guerra et al., that individuals who were not able to understand, appreciate or reason about treatment, were still able to express a choice, which is all that would be required in assent, indicates that accepting it as sufficient for consent means that many people without capacity would have been treated without proper informed consent for them or their surrogates.<sup>27</sup>

In this case, the application of the sliding scale occurs because everyone agrees that the treatment is overwhelmingly beneficial and the decision to accept an individual's consent is based not on their ability to make a medical decision but on

considerations regarding the benefits of treatments. Similarly, if the sliding scale of capacity is used to move up the threshold required to make a risky treatment choice, e.g., a psychiatrist decides that the same score on the MacCAT-T would be sufficient to accept the consent of an individual opting for life-saving treatment but not for a risky trial involving a sham surgery, the decision to deem an individual as having capacity would be partially based on assessments of the risks of treatment by the psychiatrist. In both cases, the ability of the individual to make a particular decision is not the sole basis for the judgment of capacity.

As Elyn Saks argues, the sliding scale sets up an evaluator as the judge of determining the specifics of what constitutes a good or bad decision.<sup>35</sup> Furthermore, the actual ability to make a decision seems to remain unknown because the decision to let the patient refuse or accept was not made based only on their ability to make a decision. Therefore, impressions about the severity of the decision might limit the decisions available to patients with cognitive deficits based on considerations distinct from their ability to make decisions.

Consider, for example, the study by Kim et al. compared that ability of patients diagnosed with AD to consent for either a randomized clinical trial, a randomized clinical trial that included a sham surgical procedure as a placebo arm, or to appoint a healthcare proxy.<sup>36</sup> The study utilized two distinct tools to assess capacity. For the capacity to participate in research, the participants were assessed using the MacArthur Competence Assessment Tool for clinical research (MacCAT-CR). To assess the ability to appoint a proxy, the study developed an assessment tool called, Capacity to Appoint a Proxy Assessment (CAPA). This tool followed the four categories of decisional capacity but utilized a differently structured questionnaire. Kim et al. found that only a minority of participants were found to have the capacity to consent for the trial with a surgical component, only 3.8% were assessed as competent.<sup>36</sup> However, 37.7% of participants were deemed capable of participating in a randomized clinical trial and 54.8% were judged to be able to appoint the proxy using CAPA. These results could be interpreted as supporting the task-specific or situational nature of decisional capacity or they might be interpreted as reflecting the use of the sliding scale by those who assessed the participants capacity. It could be the case that capacity individuals with AD retained their ability to appoint surrogates or it could be that the evaluator lowered the threshold for their assessment because they made judgments about the nature of the decision.

We maintain that utilizing the sliding scale of capacity based on the complexity of the decision aligns better with the goal of assessing capacity in order to respect

patient autonomy. Judgments of severity or importance can only be made by imposing subjective evaluations about what constitutes a severe harm or a great benefit. Although medical decision making requires such evaluations, the goal of assessments of capacity is to allow the patient to make decisions based on their own assessment of what constitutes a benefit or a harm.

There are already some applications of the sliding scale that include considerations of cognitive complexity when applying the sliding scale of capacity. One study characterizes decisions about whole genome sequencing as complex because patients might be too overwhelmed by information to consent.<sup>37</sup> Similarly, in the article by Kim et al., the psychiatrists assessing patient's capacity to accept participation in a research study took into account both the riskiness and the complexity of the decision and as a result required a higher threshold in order to say that the patient has the ability to make a decision.<sup>36</sup> Implicitly it seems that complexity is tied to retention of novel or medically intricate material or in situation where decisions are fraught with uncertainty.<sup>26, 37</sup>

These attempts to identify complex decisions fail to take into account that difficulties in decision making depend on the cognitive abilities of individual decision makers and not just on the features of the decision. What might be a simple decision for an individual with uncompromised short-term memory might be difficult for an individual who has mild cognitive impairment. In addition, complexity that is defined primarily based on the requirements of learning new medical information, might fail to capture an individual's ability to appreciate information. It also underestimates the difficulties related to employing and prioritizing individual preferences.

It is important to address a potential criticism of the focus on complexity. Buchanan and Brock argue that physicians must weigh respect for autonomy against consideration of a patient's wellbeing when determining decisional capacity.<sup>38</sup> Although we agree that a physician ought to consider more than autonomy when assessing whether to respect the patient's decisions, these considerations should not be included into assessments of capacity. This is because the weight of other considerations, such as concerns for the wellbeing of the patient, are calibrated in relation to an individual's ability to make decisions. For example, there are almost no considerations related to beneficence that could be used to override a capacitated refusal of treatment. But if a patient lacks capacity, then considerations of which treatments are more likely to be beneficial become most important. Imbedding considerations of wellbeing into an assessment of

capacity prevents a moral deliberation that fully takes into account the patient's ability to make decisions for themselves.

## **5. Decisional Capacity as Task Specific**

In order to propose an individualized notion of cognitive complexity based on each individual's cognitive deficits we rely on the task specific conception of decisional capacity. Although the task specific view of capacity is accepted in clinical practice, it is not without critics. For example, Charles Culver and Bernard Gert, have argued that capacity is a global ability for two reasons: First, they argue that capacity cannot be task specific because it is a property of a person and not a feature of a particular decision. Second, they argue that the conception of capacity as task specific would lead to an asymmetry in the ability to accept and refuse the same treatment.<sup>39</sup>

Let us consider their argument that capacity has to be characterized as a global ability first. Emerging research supports the task specific approach to capacity assessment as individuals with dementia will continue to be able to make some decisions even as their ability to participate in medical decision-making decreases.<sup>36</sup> In addition, Culver's and Gert's conceptual criticism do not provide convincing reasons to redefine capacity as a global ability.<sup>39</sup> In order for an ability to be attributed to an individual, it does not need to be an invariable and permanent feature of that individual. It might be best to conceive of decisional capacity as a dispositional and context specific capacity to make medical decisions. For example, an individual who has very good working memory for numbers might at the same time be very poor at remembering names. In addition, the same person might vary in their ability to perform the same task depending on their level of fatigue or alertness. The ability is intrinsic because it is the individual who has the disposition to remember a string of numbers or names, but it is nonetheless context or task specific because the individual might not be able to express the ability to the same degree in every context. Similarly, the temporary character of cognitive fluctuations supports the dispositional character of capacity given that an individual might experience even significant fluctuations in cognitive function but return to baseline once the fatigue or drowsiness diminishes. The dispositional and context dependent feature of capacity supports a task specific approach to capacity, but it also highlights the role of contextual features, e.g., communication, mode of information presentation, etc., in decision making. This in turn could provide clues for how to mitigate the effects of cognitive decline and restore decisional capacity by adjusting the situational features that might affect it.

The second criticism is that the characterization of capacity would generate asymmetries in judgments of capacity between accepting or refusing the same treatment. This asymmetry, however, supports the view that decisional capacity is best characterized as task specific. Culver and Gert argue that if capacity is task specific, then a patient could be deemed to have the capacity to accept life-saving treatment, e.g., dialysis, but lack the capacity to refuse that same treatment.<sup>39</sup> Although such an asymmetry might seem counterintuitive, it becomes less so if refusing and accepting a treatment are construed as different decisions with each requiring different abilities. Although it might be true that the facts about diagnosis, prognosis, and treatment alternatives are shared across both decisions, there are facts related to the consequences of refusing treatment that would be distinct from the details required to accept treatment. To refuse treatment, an individual would have to be able to understand that refusal would lead to death as well as understand details about how the dying process would unfold. Similarly, an individual accepting treatment would have to understand what is required for dialysis and the quality of life that would be maintained during treatment. Thus, refusing or accepting dialysis are distinct decisions that require the ability understand distinct future scenarios.

But even if the facts required for refusal of treatment are not distinct for those that are required for the acceptance of treatment, there are still ways of distinguishing between the two kinds of decisions by pointing out that they entail the endorsement of different values. Thus, the step of capacity that requires reasoning about treatment, would require taking into account distinct values in order to come to the conclusion to accept or to refuse treatment. For example, it could be the case that an individual has a long-standing preference for life-prolonging treatment and acceptance of treatment would require merely the application of that previously endorsed value. Refusal, however, might require either an amendment to previously held values or a conceptual revision that would enable the patient to change their values and forego life-sustaining treatment. One could argue that this revision of previously held values would require additional cognitive resources that might be more difficult for individuals who are experiencing cognitive deficits due to dementia. This could then explain how the same individual could have the ability to accept life-sustaining treatment but lack the ability to refuse it. Individuals can differ in their ability to make decisions in situations where the decisions are different, either because they require the understanding and appreciation of distinct medical facts or because they entail the application of different values.

Ultimately, even if it were the case that refusal and acceptance of a particular decision require the understanding and appreciation of all the same information and the application of all the same values, this would not be sufficient to argue that decisional capacity is not task specific. It would just mean that the decision, i.e., to accept or refuse, would be exactly the same and impose the same cognitive demands. Thus, an individual who has the capacity to accept dialysis would have the ability to refuse dialysis because even though the expressed choice would be different, the process required to reach both decisions is exactly the same; this would not speak against the task specificity of capacity.

## **6. Identifying A Complex Decision**

Now that we have provided a justification for the task-specific assessment of capacity, we can further substantiate our claim that cognitive complexity should also be characterized in a decisions-specific and individualized way. In this section, we aim to provide a notion of cognitive complexity related to decision making grounded in evidence about cognitive deficits incurred by individuals with amnesic dementias. By tying the notion of complexity to individual deficits, we make the identification of complex decisions evidence-based and not solely reliant on the evaluator's impressions of complexity. In what follows, we focus on patients with amnesic dementias, in particular those with AD, mainly due to the prevalence of related empirical studies. Given the distinct deficits across dementia types, it might be the case that cognitive complexity would have to be characterized differently for patients with distinct dementias, but that will remain a topic for future research.

In earlier sections, we emphasized that attempts to identify cognitive deficits that cause incapacity were only partially successful and we recognize that our characterization of cognitive complexity will trail the successes and the limitations of research on that topic. Nonetheless, there is currently enough evidence to identify that the cognitive abilities supporting understanding and logical reasoning are the most likely to be affected for individuals suffering from AD. Thus, decisions that rely on those capabilities are the most complex for individuals with AD. In this context, dementia offers the opportunity to explore how understanding a decision's complexity can affect determination of capacity.

Before we explore the cognitive deficits caused by AD, let us identify some of the decisions that an individual with an early diagnosis of dementia might face. The types of decisions that an individual might need to make after a diagnosis of dementia would include, appointing a surrogate decision maker, choosing

independent living or assisted living, treatment options for dementia, treatment for co-morbidities, end-of life decision making (e.g., preferences regarding resuscitation, intubation and administration of antibiotics) and decisions about participation in research. In what remains, we will explore how deficits in elements of decisional capacity can modulate the complexity of medical decisions faced by patients with dementia.

Moye et al. found that the understanding element of capacity can be predicted through performance on certain cognitive tests.<sup>40</sup> For example, confrontation naming (e.g., the ability to accurately name pictured objects) and conceptualization were predictive on the performance of the understanding portion across a variety of different measures. One of the consistent findings is that with the progression of AD, patients become less able to exhibit the understanding component of decisional capacity.<sup>25, 27, 40</sup> Understanding required to make a medical decision usually entails the ability to learn new information related to a particular diagnosis prognosis and treatment alternative. The earliest and most conspicuous deficit in Alzheimer's disease is impairment of episodic memory, though visuospatial skills and semantic memory are also affected to a lesser degree. Initially, there is difficulty encoding new memories, while there is preservation of immediate recall (e.g., rehearsing a phone number), procedural memory (e.g., knowing how to do long division), and recollection of remote facts (e.g., childhood events).

A demonstration of understanding requires the patient to paraphrase the medical information disclosed by a clinician. Thus, understanding might not simply rely on rote memorization, which seems to be preserved in patients with AD, and might require the cognitive resources of learning. Decisions that put a burden on short-term memory are particularly complex for individuals with AD. For example, patients with dementia are likely to have more co-morbidities than individuals of similar age without the diagnosis of dementia. These co-morbidities can include diabetes, chronic obstructive pulmonary disorder, and musculoskeletal disorders.<sup>41</sup> Thus, treatments related to a newly identified co-morbidity might be complex for an individual with deficits in short-term memory. In addition, decisions that require more thorough understanding related to efficacy might also be more complex. This idea is particularly important to consider given the recent approval by the Food and Drug Administration (FDA) approval of aducanumab for the treatment of AD. Patients would have to understand that prevention of the development of amyloid plaques might not prevent the progress of AD. In this case, the sliding scale of capacity would be applied not based on judgments, risk, or importance but on the likelihood that this patient has the capacity to learn this information.

Patients in the early stages of dementia might nonetheless remain able to engage in advanced care planning, such as appointing a surrogate decision maker, because those decisions do not require retention of new information and rely on previously established healthcare values. Similarly, patients with dementia remain able to participate in advanced healthcare planning more broadly, which includes end-of-life decision making, such as preferences about resuscitation, mechanical ventilation, and treatment with antibiotics.<sup>42</sup> These types of decisions usually do not entail learning new information but rely on the patient's established values related to quality of life versus length of life.

Another finding is that patients may retain the ability for appreciation, another element of capacity, longer than understanding. Appreciation defined as reasons to doubt the diagnosis or treatment benefits was retained in patients with AD despite deficits in understanding.<sup>25, 43</sup> However, it is important to note that different measures of capacity have low agreement on this particular element of capacity.<sup>12</sup> This might be in part to the particular operationalization of appreciation, which per Appelbaum and Thomas Grisso, requires the application of relevant medical facts to the patient.<sup>44</sup> For example, it requires that a patient be able to apply their knowledge of a particular disease, e.g., diabetes, to themselves. It requires that the patient understands that they have diabetes and what that might mean for their life and health. Defined in this manner appreciation looks more like a type of understanding.

Nonetheless, it could be the case that appreciation is preserved in the early stages of AD because it exploits previously established knowledge. Decisions that require the patient to utilize previously established knowledge are not as complex because the cognitive faculties required for appreciation remain intact for longer in patients with AD. Thus, a patient who has had diabetes prior to dementia might still be able to participate in medical decision-making regarding treatment even if they might lack the ability to retain information about newly diagnosed conditions. Also, while appreciation remains intact decisions about living situation, whether to remain home or move to an assisted-living facility, or end-of-life care might not increase in complexity because they require application of established values.

Yet another element of capacity is the ability to reason rationally about a choice. This ability requires that a patient take into account their current medical condition and treatment alternatives and relate them to already established values to generate a treatment decision. According to Moye et al., this ability includes (among other skills) problem solving, comparative thinking, consequential thinking, and probabilistic thinking.<sup>43</sup> Lessened ability to think rationally about treatment were



predicted by deficits in working memory.<sup>25</sup> Based on this, decisions that require holding in mind several different options, comparing them, and weighing relative probabilities of risks and benefits might be particularly complex for patient with AD. In addition, the study by Kim et al. demonstrated that individuals with dementia were less able to retain their ability to consent to participate in clinical trials as this type of consent also requires knowing that one is participating in research and not merely deciding about treatment. It seems reasonable then to heighten the threshold for assessments for research participation, especially in situations where patients might misunderstand research participation with treatment.<sup>45</sup>

One of the consistent findings, based on Moye et al., Okonkwo al., and Huthwaite et al., is that patients retain the ability to express a choice despite having deficits in all other elements of capacity.<sup>28, 29, 43</sup> The ability to express a choice is often used as the mark of decisional capacity in the clinical setting. The ability to express a choice should not be used as an indication of capacity nor should the fact that the patient is still expressing preferences be the reason to lower the sliding scale. If a patient is expressing a preference despite significant deficits in understanding, appreciation, and reasoning rationally, they are not making a choice. A choice to accept or refuse a particular medical intervention needs to rely on the other three elements of decisional capacity. It makes little sense to argue that a patient who does not understand their current diagnosis and prognosis is nonetheless making a choice to accept treatment for it. Thus, the expression of a preference for a certain type of treatment should prompt an assessment of capacity rather than being interpreted as consent. This could perhaps curtail the underdiagnosis of decisional capacity prevalent for patients who are hospitalized.<sup>11</sup>

## 7. Conclusion

Traditional use of the sliding scale fails to separate severity of a decision from its complexity and leads to the introduction of physician bias. We argued that the sliding scale ought to be applied based on complexity, while still allowing physicians to consider the impact of disease on their assessment of capacity. As shown through the different manifestations of the amnesic dementias, the same decision can become more or less complex based on the capacities of the patient. Physicians should consider how underlying neuropsychiatric states might be affecting complexity and therefore capacity when evaluating their patients. Moreover, this approach avoids the pitfalls of classifying capacity by severity which can lead physicians to allow patients without capacity to make benign decisions and deny more significant decision-making to patients with capacity. As such, this reimagining of the sliding scale allows for a better understanding of the

role of cognitive complexity in capacity, which in turn might lead to a more targeted approach to restoring capacity for some patients.

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