

CAPACITY ASSESSMENT IN PSYCHOLOGICALLY AND COGNITIVELY COMPLEX PATIENTS REQUESTING MEDICAL AID IN DYING: A CASE DISCUSSION

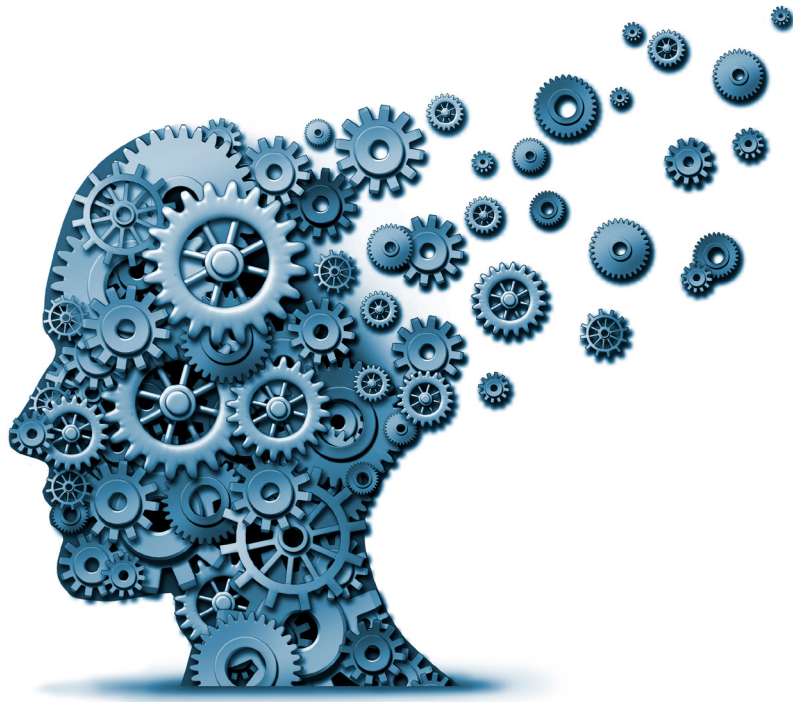
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ABSTRACT: In all states where medical aid in dying is legal, an individual must be able to demonstrate the ability to make and communicate an informed decision to health care providers. The various statutes in states where aid in dying is legal provide limited and imprecise guidance to practitioners regarding standards for capacity evaluations. There is an even greater paucity of guidance when it comes to clinical assessment of patients whose capacity is in question. This paper aims to provide insight into two patients' requests for aid in dying and outlines recommendations for assessing decisional capacity. The authors describe a best practice approach in capacity assessment in psychologically complex patients requesting clinician assisted death. We discuss the applicability and generalizability of employing these recommendations for patients whose capacity is unclear at initial presentation.

KEYWORDS: Capacity assessment, medical aid in dying, heart failure, MAID.

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1. INTRODUCTION

In 2016, Colorado voters passed the Colorado End of Life Options Act.¹ This legislation stipulates that a patient may only pursue aid in dying if “the individual’s attending physician has determined the individual has mental capacity.” As outlined by the Act, “mental capacity” means that, in the opinion of an individual’s attending physician, consulting physician, psychiatrist, or psychologist, the individual has the ability to make and communicate an informed decision to health care providers.¹ The statute does not go into greater detail to guide clinicians when mental capacity is unclear, nor does it describe standards for evaluations to achieve reasonable certainty around questions of patient capacity. The evaluation and assessment of capacity to meet legal and clinical standards is left to the care team.

All other states where aid in dying is legal have similar provisions for capacity determinations. Yet due to the lack of established best practices, it is likely that considerable heterogeneity exists in the clinical application of these assessments for aid in dying. Our paper’s aim is to help provide a scaffolding from which best practices for aid-in-dying capacity assessments could be constructed.

There is a paucity of research regarding capacity assessment in the setting of aid in dying, though its importance is noted nationally and abroad.^{2,3,4} Foundational work and current research on informed decision-making emphasizes the importance of a patient’s capacity. This suggests that a considerable proportion of terminally ill patients may lack decision-making capacity by standardized assessment and that physicians may fail to detect decisional impairments otherwise

identified by these assessments.^{5,6,7} Our paper aims to provide insight into two patients' requests for aid in dying and outlines recommendations for assessing decisional capacity, including a semi-structured interview (Appendix 1).

2. METHOD

We describe two cases referred to the Palliative Care Clinic at the University of Colorado Anschutz Medical Campus for the evaluation of eligibility for aid in dying. The need for formal assessment of decisional capacity was determined during the initial palliative care consult, and clinical psychology was consulted for the capacity evaluation. In Colorado, capacity assessments in aid in dying must be undertaken by a licensed clinical psychologist or psychiatrist. For these two patients, we obtained consultations with our clinical psychologists. In other jurisdictions with different legal structures or different access to services and expertise, alternative referral structures may be appropriate. Consulting physicians and representatives of the hospital ethics service provided additional consultation when necessary.

Capacity assessments were guided by an adapted version of the MacArthur Competency Assessment Tool for Treatment (MacCAT-T), combined with a clinical interview that assessed relevant biopsychosocial factors.⁸ The MacArthur Tool consists of a semi-structured interview tailored

to the patient's condition, available interventions, and associated risks and benefits. It evaluates the four most clinically relevant elements of competence: the patient's ability to express a choice (C); to understand information relevant to treatment decisions (U); to appreciate the significance of his or her situation and the treatment decision (A); and to rationally manipulate information in order to make comparisons and weigh treatment options (R).⁹ When appropriate, a cognitive screening was conducted using the Montreal Cognitive Assessment (MoCA) to detect cognitive impairment.¹⁰ A formal capacity assessment report was entered in the patient's medical chart.

3. CASES

Case 1: FW is a man in his forties with congenital absence of his right pulmonary artery. He was referred to the palliative care clinic following successive hospitalizations for heart failure and hypoxic respiratory failure. Each hospitalization had been preceded by episodes of heavy alcohol consumption followed by withdrawal. FW also frequently took more opiate medication than prescribed, especially when feeling despair and hopelessness.

FW considered himself to be "fiercely independent." His goals revolved around the maintenance of that independence, including the ability to work and live alone. He acknowledged depression and

ongoing alcohol use but felt these were separate issues to his aid-in-dying inquiry. He acknowledged that while he did not want to die, he felt strongly that a death on his own terms would be far preferable to a death from the natural progression of his illness.

Reasons for physician referral for capacity assessment:

FW's social isolation, history of maladaptive coping, substance use, and current symptoms of depression all raised concerns about his capacity to qualify for aid in dying. Specifically, we wanted to better understand the role of depression and suicidality as a symptom of depression in his medical decision-making.

Psychologist preparation:

The focus of this interview was on the influence of depression, impulsive behavior, and substance use on the patient's decisional capacity to pursue aid in dying.

Outcome of assessment: FW's mental health history was characterized by life-long anxiety and depression. Depressive episodes characterized by negative self-talk and irritability tended to follow periods of interpersonal conflict. FW stated that this had largely resolved since his hospice team prescribed lorazepam, quetiapine, vilazodone, and zolpidem. Given these medication changes and the improvement of his symptoms of depression, he stopped all alcohol use.

FW explained details of his med-

ical history and prognosis, reporting sadness and frustration related to physical limitations and decline in functional status. He was able to detail the process of requesting and participating in aid in dying. When asked about not engaging in aid in dying, FW stated it would mean dying in a way that was inconsistent with his desired independence. FW openly acknowledged his history of depression, anxiety, and substance use during the interview. FW stated his interest in living well, sharing, "I love living, I'm fighting really hard to live." When asked about suicidality, FW reported a history of fleeting thoughts that life was not worth living, though denied ever having an active plan or intent for suicide.

We determined that FW appeared to have the capacity to pursue aid in dying. He benefited from his psychotherapeutic medications, which highlights the dynamic nature of decisional capacity and the ways it may vary with treatment and/or the severity of psychological symptoms. FW acknowledged concerns about impulsively using medications to hasten his death.

FW's case addresses the impact of both psychiatric and substance use disorders on the decisional capacity to pursue aid in dying. Current recommendations regarding the intersection of capacity and substance use note that in the absence of acute withdrawal or intoxication, those with underlying substance-use disorders largely

possess decisional capacity.¹¹ Likewise, we found that depression did not impact decisional capacity. FW's decision to pursue aid in dying reflected his primary value of self-sovereignty. His value of life-affirmation was demonstrated by his engagement with palliative and hospice services and treatment for his depression. In this way, his decisions around end-of-life care were in line with his stated and practiced values.

Case 2: RS is an 80-year-old male with a history of transthyretin amyloid cardiomyopathy. He expressed interest in aid in dying during his initial palliative care consult. He had recently discontinued participation in a clinical trial due to heavy symptom burden. Subsequently, he experienced four falls, with the last resulting in a two-week hospitalization for an intracranial bleed. RS denied having a significant mental health history, suicidality, or substance use issues.

Reasons for physician referral for capacity assessment: The goal of this assessment was to understand RS's decisional capacity considering neurologic injury.

Psychologist preparation:

The psychologist carefully reviewed the medical notes before and after RS's falls. The capacity assessment consisted of a clinical interview, an adapted MacArthur tool, screening assessments for anxiety (GAD-7) and depression (PHQ-9),^{12,13} and the Montreal Assessment.

Outcome of assessment:

During the interview, RS reported memory changes; he asked for directions to be repeated several times. This was consistent with his performance on the Montreal Cognitive Assessment. He scored 18/30, suggestive of moderate cognitive impairment for the patient's demographic and educational background. RS reported mild symptoms of depression (PHQ-9 = 8/27).

RS consistently expressed his choice to pursue aid in dying. He connected it to discussions with his wife and family about autonomy and dignity at the end of life. This was corroborated by collateral information from the patient's family and medical record review (i.e., his initial palliative care consultation pre-falls). He accurately remembered and described past events, including his medical diagnosis. He also discussed the features of his diagnosis, the impact it was having on his life, and the likely prognosis. RS was able to discuss both aid in dying and the alternatives to achieve a peaceful death. Furthermore, he demonstrated an appreciation of the severity of his medical illness and the impact that both aid in dying and the alternatives would have on his life.

After review of the data obtained during the interview and cognitive screening, the psychologist concluded that RS had the capacity to consent to pursuing aid in dying. He expressed a consistent preference or choice for the option. He

was able to understand the process of the procedure and associated risks and benefits. RS was able to cogently connect aid in dying to his goals of maintaining autonomy and independence and protecting his family from witnessing physical decline and possible suffering.

RS's case addresses capacity in the presence of neurocognitive deficits. Cognitive impairment can feature preserved skills of choice and reasoning, just as it can alter them.^{14,15} A cognitively impaired patient may still retain capacity,

the practice of aid in dying to meet the highest ethical standards. Accordingly, a rigorous, standardized assessment should be adopted and applied by the community of aid-in-dying practitioners. Some possible components of such a standard are proposed in this paper. It is essential to note that we are not proposing the above system of evaluation for all patients considering aid in dying; rather, it is a framework for those whose capacity to make their own medical decisions calls for additional exploration.

“...HIS DECISIONS AROUND END-OF-LIFE CARE WERE IN LINE WITH HIS STATED AND PRACTICED VALUES.”

though such cases require thorough evaluation. Our patient consistently expressed his choice to pursue aid in dying, and was able to explain his understanding and reasoning in a manner that reflected value-concordant decision making.

4. DISCUSSION

It is an obligation of the medical community to establish best practices for capacity evaluations in aid in dying—to reduce variability in the quality of assessments, protect the medically and psychiatrically vulnerable in their requests to access aid in dying, and to develop

While efforts have been made to systematically evaluate decisional capacity among terminally ill patients,^{16,17} specific recommendations related to capacity evaluations in the context of aid in dying have been largely absent. Much of the current discussion on the topic details the importance of potentially aggravating factors—including substance use disorders,^{16,18} underlying mental illness,^{17,19,20} and cognitive changes²¹⁻²⁴—but does not offer substantive assessment guidance.²⁵ The cases presented in this review seek to add clarity to the topic of complex capacity evaluations, offering recommendations

and defining an assessment process to guide cases (Appendix 1). We propose a method that allows for the evaluation of the core components of capacity, and highlights values that guide medical decision-making. Essential to this type of assessment is the flexibility of the practitioner to adapt the investigation style and content to the clinical context, to involve consultative services (i.e., ethics, psychology/psychiatry) when necessary, and to corroborate asserted values with family members and loved ones when possible.

Our case series diagrams one method for delineating patient capacity to choose aid in dying when health professionals have cause for concern. This approach, based on a foundation of the MacArthur Competency Assessment Tool, evaluates the widely accepted four elements of competence: choice, understanding, appreciation, and reasoning. In doing so, it allows the clinician to ascertain the degree to which a patient's choice reflects their lived values rather than an underlying pathology that has led to loss of decisional capacity. This evaluative system can help a patient explore the relationship between psychological symptoms and a request for aid in dying. Additionally, consistency of decision-making processes through the clinical interview, medical record review, and collateral information informed each assessment.

Other standardized assessments certainly exist including the Aid to Capacity Evaluation and the

Hopkins Competency Assessment Test, and other practitioners may have more comfort and facility in applying those tools to capacity evaluations. Moreover, in the context of limited structured data collection on practice patterns, it is hard to ascertain which tools practitioners are using clinically and the degree to which those evaluations meet care standards.

While this paper lays out a clinical framework using the MacArthur Competency Assessment Tool for Treatment, the more pertinent need is for the aid in dying community to coalesce around a standard practice for capacity evaluations that achieves high rigor, is practically applicable, and is flexible enough to reach a capacity determination in a wide variety of clinical contexts. Doing so may diminish practitioner and public concern over the application of aid-in-dying practices in cognitively and psychiatrically complex individuals.¹⁶

5. CONCLUSION

To further the community conversation around standardized practices in aid-in-dying capacity evaluations, we have presented a method for capacity assessments in psychologically complex patients considering aid in dying. These are constructed from existing tools in clinical use and rigorously applied. We consider these methods to be applicable and generalizable, and recommend their use for patients whose capacity is initially unclear.

Table 1. Semi-structured Capacity Assessment Guided by MacCAT-T

1. Clinician uses medical record review to inform assessment of understanding.
2. Clinician may repeat information as needed throughout the assessment.
3. Clinician is transparent that the purpose of the interview is to assess patient’s ability to make medical decisions surrounding medical aid in dying (AID IN DYING).
4. Clinician informs the patient that the results of the assessment will be shared with the referring physician.

Capacity Standard	Prompt/Question	Response
Understanding	Please tell me about your current medical condition/What is your diagnosis?	Patient can name or describe the diagnosis.
	Tell me about your diagnosis? What are the symptoms and features?	Patient can name features and symptoms of the disorder.
	What is your understanding of the course of your disorder?	Patient acknowledges the terminal course of the disorder with a reasonably appropriate time frame.
Appreciation	Your medical team thinks that this medical condition is serious. What do you think?	Patient recognizes that he or she has a serious illness that impacts quality and length of life; if patient disagrees or is ambivalent, can they offer a reasonable explanation of his or her reasoning?
Understanding	Tell me about your treatment options.	Patient is able to say AID IN DYING (or similar) is a treatment option.
	What does AID IN DYING entail?	Patient is able to describe at least two features of AID IN DYING.
	What are your other treatment options?	Patient is able to detail alternative treatment options including enrollment in hospice care, future clinical trials, doing nothing, etc.
	What would this choice entail?	Patient is able to discuss features of the alternative treatment option—for example, hospice care involves receiving care in the home that manages your symptoms.
Understanding	What are the benefits of engaging in AID IN DYING?	Patient is able to describe what he or she perceives as the benefits of AID IN DYING.
	What are the risks associated with AID IN DYING?	Patient is able to acknowledge risks associated with the decision.
Appreciation	Do you think it is possible that AID IN DYING might be of some benefit to you?	Patient is able to describe a potential benefit from this treatment decision that is based in reality.
Choice	Let’s review your treatment choices: You can choose to engage in AID IN DYING or you can (list patient’s other identified treatment option). Which of these seems best for you?	Patient is able to pick a choice. If patient is ambivalent, he or she is able to acknowledge this ambivalence or indecision.
Reasoning	You think (stated choice) would be best; what is it that makes that seem better than the others? If unsure, what would help you to make the decision?	Patient can state either a benefit or the chosen option or risk of the not-chosen option. If unsure, patient is able to describe needed information or decision-making process.
	Earlier we discussed the possible risks and benefits of AID IN DYING; how might access to AID IN DYING influence your daily activities?	Patient can state a benefit of how AID IN DYING would make life easier (i.e., my family would not have to watch me suffer).
	How might not receiving AID IN DYING influence your daily activities?	Patient can describe how not receiving AID IN DYING would impact functioning (i.e., increased symptom burden/physical suffering).

Choice	Now that we have discussed how these treatment options would influence your daily functioning, which treatment option would you want to do?	Patient is able to state a choice or describe ambivalence surrounding decision-making.
Reasoning		Is there logical consistency between patient responses to the first and second "Choice" questions? Patient's final choice is logical given responses to reasoning questions and identifies risks and benefits.

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