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Top Ten Tips Palliative Care Clinicians Should Know About Medical Decision-Making Capacity Assessment

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Abstract

Palliative care (PC) clinicians treat seriously ill patients who are at increased risk for compromised decision-making capacity (DMC). These patients face profound and complex questions about which treatments to accept and which to decline. PC clinicians, therefore, have the especially difficult task of performing thorough, fair, and accurate DMC assessments in the face of the complex effects of terminal illness, which may be complicated by fluctuating acute medical conditions, mental illness, or cognitive dysfunction. This study, written by a team of clinicians with expertise in PC, ethics, psychiatry, pediatrics, and geriatrics, aims to provide expert guidance to PC clinicians on best practice for complex DMC assessment.

Keywords: medical decision making, life-sustaining treatment, decision-making capacity, capacity assessment, serious illness, surrogate decision maker

Introduction

Palliative care (PC) clinicians specialize in both symptom management and in guiding patients through complex medical decision making, including whether to forgo life-sustaining treatment or accept burdensome or risky interventions. Yet even as clinicians strive to identify and craft treatment plans based on a patient's values, they must recognize that serious illness may compromise a patient's decision-making capacity (DMC). Forty percent of hospice patients, for instance, manifest impaired DMC, with the percentage rising to 70% in the final days of life.[1,2]

The stakes could not be higher: overriding the decision of a patient with sufficient capacity violates the right of autonomy, whereas honoring the decision of a patient with impaired capacity may fail to honor their heartfelt goals, potentially adding insult to injury. PC clinicians must, therefore, be adept at assessing DMC.

At first glance, the widely accepted DMC criteria by Appelbaum and Grisso—namely to understand, appreciate, rationalize, and communicate a decision—might make DMC assessment appear straightforward.[3,4] However, the process of assessing DMC may be profoundly complicated due to patient factors such as cognitive disability, developmental stage, mental illness, and sometimes rapidly fluctuating clinical status, leading to varying assessment of capacity.[5] To aid clinicians in this complex task, we put forward this expert guide to help clarify best practices for capacity assessments that commonly arise during PC practice.

Tip 1: Decision-Making Capacity Implies That a Person Can Make an Autonomous Choice; Clinicians Should Use Specific Criteria to Determine If a Patient Has Capacity for a Medical Decision

DMC refers to the ability of a person to make an autonomous choice, which is a requirement for providing informed consent. There are four criteria patients must meet to demonstrate medical DMC:

1. Understand the ongoing clinical situation and how this relates to the current potential treatment options

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2. Demonstrate prognostic awareness in applying personal values to decision making
3. Use sound reasoning that is consistent with their expressed goals in making a decision
4. Possess the ability to convey a decision by some form of communication.[4,6]

The first step in evaluating DMC is to minimize or eliminate communication barriers that would limit the patient from understanding the clinician. Once addressed, the clinician should proceed with a structured interview to determine DMC or use a validated DMC tool.[7] To navigate the aforementioned criteria, the tasks the clinician must complete during the directed clinical interview are as follows:

1. Assess medical knowledge: Encourage the patient to discuss the information they have received regarding their medical condition and treatment options.
2. Determine prognostic awareness: Engage the patient in conversation regarding potential consequences and benefits of each choice, including effects on function, longevity, and quality of life.
3. Ask the patient to explain their choice and rationale: Ensure that the patient is able to explain how they came to a decision and the personal impact of that decision. Explore any discrepancies between stated values and the choice decided upon.
4. Make a capacity determination, if possible.[7]

Table 1 shows how the tasks of DMC assessment align with accepted capacity criteria. Notably, DMC may still be uncertain after a structured interview for a number of reasons, including lack of patient engagement in the interview or uncertain influence of a psychiatric or cognitive condition. If an assessment is uncertain, a formalized tool such as the MacArthur Competence Assessment Tool (MacCAT-T)[4] or the Aid to Capacity Evaluation,[7] or a formal consultation to psychiatry or ethics, may be helpful.

Tip 2: Capacity Assessments Performed by Clinicians Have *De Facto* Legal Standing, Can Subsequently Be Reversed by Clinicians If Patient Capacity Changes, and Should Be Documented Appropriately

In the United States, physician assessment of medical DMC has legal standing and should be documented in the medical record along with the rationale underlying the assessment. Notably, some states also allow other licensed practitioners such as nurse practitioners and psychologists to make capacity assessments. When a clinician determines that a patient lacks DMC, the legal term ''incompetent *de facto*'' for medical decisions may then be applied to the patient.[4,8] This term means that the clinician's assessment of DMC is legally valid in lieu of evaluation by the court. Importantly, a clinician should repeat DMC assessment as clinical circumstances change and should reverse a previous assessment if a patient regains DMC or loses DMC they once had.

For the sake of clarity, clinicians should use the term ''capacity'' rather than ''incompetence *de facto*'' in the medical record to avoid confusion with legal incompetence. Legal incompetence can only be determined by the court and may pertain to decision-making domains beyond those in medicine, depending on the circumstances. When a person is declared legally incompetent by the court in one or more domains, guardianship may then be assigned.[8,9] The court's assessment stands until the court reevaluates the case—only the court and not a clinician may reverse the finding of legal incompetence. Importantly, a person who has been declared legally incompetent may still

Table 1. A Quick Guide to Capacity Assessment

Task	*Capacity criteria*
Step 1: Optimize communication Provide (if needed): - Sensory aids - Writing instrument - Interpreter	[] Communicate Patient can consistently and reliably express complex thought (may be nonverbal)
Step 2: Assess medical knowledge Suggested approach: - Open-ended questions - Provide any missing information - Establish receipt of new information	[] Understand Patient can explain relevant treatment options (including option for no intervention)
Step 3: Assess prognostic awareness Suggested approach: - Use ask-tell-ask technique - Provide any information - Be prepared to address emotion	[] Appreciate Patient can explain how treatments would affect their health/situation
Step 4: Ask for choice and rationale Assess for: - Internal logic/values - Signs of mood disorder - Signs of cognitive dysfunction	[] Reason Patient can discuss rationale for a choice by applying personal logic
Step 5: Make a capacity assessment (if able)	[] All boxes checked = capacity

Table content adapted from Grisso and Appelbaum[4] and Barstow et al.[7]

retain the capacity to make certain medical decisions. Medical ethics or legal counsel may be helpful for clarification in those situations.

Tip 3: Capacity Is Decision Dependent and Can Change as a Patient's Condition Changes; a Patient May Have Capacity for One Decision But Not Another in the Exact Same Moment

Rather than strictly present or absent, DMC should be thought of as a spectrum of decision-making abilities. Capacity is dependent on the question being asked in the context of a patient's cognitive function. At the extremes of the spectrum, DMC can be completely absent (as in the case of a comatose patient) or fully present (which includes the ability for abstract and future thought).[4]

The middle of the spectrum represents a gray area often described as simple or partial DMC. It reflects a range of factors unique to each patient, including cognitive processing abilities, health care literacy, language fluency, and education. This baseline may be further affected by more acute factors such as pain, delirium, and emotions.[7] Because some of these variables are dynamic, DMC can change depending on the patient's condition.

Independent of patient-specific factors, individual medical choices also range both from simple to complex and low risk to high risk. The more complex and higher risk the question is, the more the patient will need to demonstrate complex cognitive thought to be determined to have DMC. For example, although a patient may not have capacity to consent to a surgery, they might have the simpler capacity to designate a proxy.[10] Each component—patient cognitive abilities, choice complexity, and choice risk—requires careful assessment by the clinician, and, especially when capacity is not present, documentation should reflect the clinician's specific rationale for why a patient lacks sufficient DMC for a particular decision.

Tip 4: When a Patient Lacks Capacity, the Appropriate Surrogate Should Be Identified; Decisions Made by the Surrogate Should Reflect the Values of the Patient, and Not Necessarily the Values of the Surrogate

When timely medical decisions are necessary, a surrogate decision maker can assist the patient who lacks DMC by practicing substituted judgement, which means that the surrogate must attempt to make choices in the same way that the patient would have done.[11] Importantly, a patient may also choose to defer decisions to another person, even if DMC is retained. It is the surrogate's responsibility to prioritize the patient's values and preferences above their own and thus mirror the decisions the patient would make under the same circumstances. Surrogate decision makers can be identified by previously completed legal documentation (e.g., health care power of attorney). In the absence of documentation, clinicians should follow their state's statutes regarding surrogate hierarchy (if one exists), which may vary in formal designation order and documentation.[12,13]

Surrogate decision making is more complex in certain populations. Incarcerated patients, for example, can voice personal values and preferences, but the prison warden typically serves as the legal medical decision maker. This dual loyalty is complex and at times conflicting, and requires balancing obligations to the corrections system and the responsibility to promote the patient's health and advocate for their preferences.[14]

Pediatric decision making differs still and must take into account the patient's evolving potential for complex understanding. Legal guardians or parents should apply the best interest standard in decision making for their child, which means they must strive to place the child's best interests above their own.[15] As they grow older, children should be offered increasing roles in medical decision making, alongside their caregivers. Adolescents under the age of majority are often capable of and desire involvement in complex decision making. Such involvement promotes autonomy and ensures alignment of the care plan with desired goals.

Tip 5: Decision-Making Capacity Develops Over Time as the Brain Matures: Some Pediatric Patients May Be Ready to Make Complex Decisions Well Before They Turn 18, and Some Adults May Not Be Ready

Although the age of majority, or the age at which a child is legally treated as an adult, is 18 years in nearly every state, some states grant ''consent authority'' to younger patients depending on circumstances, such as high school graduation, legal emancipation, or assessment of DMC.[16] Even when consent authority is not present, minors should be offered opportunities to provide their assent for decisions that impact their health and life,[17] and even practice making decisions relevant to their health care starting when developmentally able.[18]

The capacity for decisional autonomy develops at different rates among patients based on personal factors that include family and community roles, personal maturity, emotional and cognitive development, medical exposure, life experiences, and communication opportunities.[19,20] Although reasoning and logical thought are cognitive hallmarks of adolescence, maturation relevant to social perspective, emotional judgment, impulse control, and risk-reward processing continues to develop through early adulthood. Importantly, this emotional development may stagnate depending on complex factors such as chronic childhood illness, substance use disorder, or history of trauma.[21] Thus, even for adults who have reached legal age of decision making, PC providers should consider facilitating communication that respects developmental stage.[22]

Tip 6: Patients with Capacity Have the Right to Make Decisions That Are Not Consistent with Clinician Recommendations; as Such, Clinicians Should Be Extraordinarily Attentive to Personal and Professional Biases During Assessments

The role of the clinician is to provide information free of personal bias, offer only those therapies that are medically appropriate, and ensure that the patient has adequate understanding of treatment options.[7] In many cases, clinicians can make a strong recommendation for treatments that are of clear benefit to the patient. Even when medical evidence in support of certain treatments is overwhelming, the principle of autonomy allows the patient with DMC to refuse those treatments.[23]

Should a patient refuse a recommended treatment, the patient's rationale should be thoroughly explored. Often,

choices that do not align with medical recommendations are based on a patient's own internal logic and personal values, and these values may be very different from those of the clinician or, indeed, the patient's own family members.

Clinicians should recognize how their own values may introduce bias into a conversation, especially when the patient is facing life-limiting illness where treatments are not curative. In these cases, clinician advice and recommendations become less prescriptive and more descriptive. For example, a clinician may have strong personal feelings about gastrostomy tube after a stroke based on previous experiences. By separating personal experience from the patient's experience, the clinician will be able to avoid imposing their values on the patient during the conversation and can then more objectively focus on the preferences of the patient.[24]

As long as the patient demonstrates clear understanding of the treatment options, alternatives, and associated risks, and is able to explain their choice using internal rationale, then the patient retains capacity and has the right to make that choice.[4]

Tip 7: When Patient Actions Are Incongruent with Their Stated Values, Further Exploration Is Warranted and Should Include Assessment for Mental Health Disorders

In chronic medical conditions such as diabetes or coronary artery disease, patients often value preserving longevity and preventing complications. Despite these stated values, however, nonadherence to dietary recommendations or medical therapy occurs. The risks of nonadherence in chronic conditions often lie in the indeterminate future, and as such, these situations do not usually prompt evaluation of DMC.

In acute or life-threatening conditions, however, nonadherence to recommended therapies may result in substantial imminent risk to the patient and prompt urgent evaluation of DMC. For example, if a patient with a goal of survival presents to the hospital seeking treatment to cure infectious endocarditis secondary to intravenous drug use and then requests to leave the next day against medical advice, the risk of death or serious morbidity from infection is extremely high.

Regardless of the situation, all cases of nonadherence to a previously determined treatment plan warrant further exploration by the clinician as to the rationale behind incongruent patient actions (such as leaving against medical advice) and values (such as desiring longevity or cure). A clinician's inquisitive and nonjudgmental approach in such situations will help build rapport with the patient, explore the source of conflict, and may result in opportunities for motivational interviewing in certain scenarios.[25] As the clinician explores rationale with the patient, careful attention should be paid to the patient's medical knowledge and prognostic understanding, as well as their emotional processing of that information.[26]

The clinician should also evaluate for cognitive dysfunction and screen for any mental health disorders that may impair patient insight into health decisions and affect DMC. Substance use disorders, for example, may result in conflicting first-order desires (wanting to use a drug) and second-order desires (wanting to not want to use a drug) that explain discordant actions and values.[23] In some cases, formal consultation by psychiatry or ethics may be appropriate. Ensuring that the patient has access to appropriate decision-making support from family or someone close, even if the patient retains DMC, can also be extremely helpful.[26]

Tip 8: Patients with Chronic Mental Health Conditions Often Retain Complex Decision-Making Capacity

Mental illness encompasses many different diagnoses of varying types, severity, and chronicity that impact the way an individual thinks, emotes, behaves, and interacts with their environment.[27] Serious and persistent mental illness (SPMI) can last for many years and may cycle in and out of remission.[28] Disorders of thought, such as schizophrenia, psychotic disorders, and delusional disorders, as well as mood and anxiety disorders, may have a direct impact on cognitive processing and short-term values that result in patients making choices they would have not otherwise made due to their current state of mental health.

The presence of mental illness including SPMI and substance use disorder (SUD), however, does not automatically equate to decisional incapacity. Patients with or without SPMI may make decisions that are internally rational (i.e., aligned with their own value system, beliefs, and preferences).[29] Fluctuating decisional capacity may occur when high stress levels, changes in environment, or disruption in routines trigger SPMI or SUD relapse.[27,28] Assessment and acknowledgement of risk of suicide and the treatment of reversible cognitive impairments are necessary.[29,30]

Primary and PC clinicians are often able to determine capacity through ongoing discussions about patients' value systems and with the aid of cognitive evaluation instruments such as the MacCAT-T.[29–31] Assessing duration of SPMI, intensity, patterns over time, and history of treatment is crucial. Clinicians can promote decision making with transparency, communication aids, and collaborating with family and friends as collateral support.[30] The specialized skill set of PC clinical social workers can be especially helpful in assessing and responding to complex mental health issues when DMC is in question.[32] Formal referrals to psychiatrists and counselors may be needed in some cases.

Tip 9: Acutely Altered Emotional States Due to Trauma or Suicidal Ideation May Temporarily Affect Capacity

The presence of altered emotional states due to trauma, suicidal ideation, or recent suicidal behavior complicates DMC. Virtually all theories of autonomy agree that independence from controlling influences is an essential condition of autonomous decisions.[33] Reasoning is a legal standard of capacity that requires the ability to compare treatment alternatives in a rational or a logical manner and is typically the most challenging standard to evaluate.[34] Patients with acute trauma (e.g., new-onset paraplegia) often suffer from post-traumatic stress symptoms, including exaggerated negative beliefs about themselves, distorted self-blame for the events surrounding the trauma, or persistent shame that may warp reality and alter their ability to make rational decisions, particularly if they fail to see the benefits of treatment. Similarly, patients with suicidal behavior or ideation may have similar beliefs or worse, including delusions that they deserve to be punished or to be dead.

DMC requires normative judgment, which informs how a person ought to be or may permissibly be treated. Patients

who have recently undergone a traumatic experience (either self-inflicted or otherwise) may not advocate for themselves, particularly when the potential consequences are grave. Furthermore, given the frequently novel situations of acute traumatic experiences, assessment of DMC in these situations may be more difficult due to the relative lack of previously established beliefs and goals that may be seen with chronic illness.

Tip 10: Patients Who Lack Capacity May Still Have the Right to Refuse Treatment

Patients with capacity have the right to refuse any treatment, even one that is life-sustaining. However, a patient who lacks capacity is also able to refuse certain treatments. Although not a violation of autonomy (which such a patient is unable to exercise), administering a treatment over objection nevertheless compromises the patient's bodily integrity. The fact that the patient is unable to appreciate the nature of their condition or the risks, benefits, and alternatives of possible treatments does not render the intervention benign. On the contrary, such an intervention might be even more traumatizing for the lack of appreciation of its medical indication, which is why many states require a court order to proceed with nonemergent involuntary treatment.[35,36]

Several factors need to be taken into consideration when determining whether to proceed with treatment over objection. The first considers the gravity of the patient's condition and the time sensitivity of the proposed treatment. A patient who lacks capacity and who may die without immediate intervention, which they likely would have accepted if they retained DMC, should be treated over their objection. Absent time pressure, the expected duration of the patient's lack of capacity becomes relevant. There may be benefit in temporarily deferring the treatment if a patient could regain DMC, such as in the case of an electrolyte abnormality, but not for a patient with profound dementia who will likely continue to refuse it. Finally, one must consider the duration and burden of the proposed treatment. Imposing a one-time treatment with clear benefit may well be justified but not ongoing treatment that repeatedly compromises the patient's bodily integrity.

Conclusion

Capacity assessment requires clinicians to balance the ethical principles of protecting patient autonomy, advocating for care that is in the best interest of the patient (beneficence), and upholding the pillar of justice by ensuring fair and bias-free assessments of DMC. This is especially true for vulnerable populations who are more likely to lack DMC, such as those who are hospitalized, are experiencing serious illness, are mentally ill, have cognitive impairment, or who are approaching the end of life. PC clinicians, with expertise in communication and compassionate patient-centered care, are especially well suited to perform this role when these ethical principles pull at each other. For the most complex situations, multidisciplinary supports such as ethics committees, legal teams, social workers, and psychiatry consultants are essential to support the patient and clinician together and to ensure the accurate determination of DMC and appropriate delivery of care.

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