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## Special Article

## Protocol for the Assessment of Patient Capacity to Make End-of-Life Treatment Decisions

Richard B. Stuart DSW, ABPP\*, Stephen Thielke MD, MS, MA

Department of Psychiatry, University of Washington, Seattle, WA

## A B S T R A C T

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Patients' right to decide what happens to their bodies, especially around the end of life, is enshrined in legislation across the world, but questions often arise about whether a patient is capable of meaningfully participating in such decisions. Because of uncertainties about capacity, care providers and administrative agencies often must decide whether to honor, or even to elicit, patients' wishes. General decision-making capacity has been well studied, but few clear protocols exist for ascertaining capacity at the end of life. Without clear guidelines about how to assess capacity, medical staff may ignore assessment and operate from invalid assumptions. In the interests of protecting patients' agency, we propose a straightforward protocol for assessing capacity to make decisions about end-of-life interventions.

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## Meaning of Incapacity

Although the terms *incompetence* and *incapacity* are often used interchangeably, they are significantly different. Incompetence refers to an enduring *general* inability to act prudently. When applied, it entails a loss of various personal liberties. It is established through judicial proceedings.<sup>1</sup> In contrast, capacity means "an individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a healthcare decision."<sup>2</sup> Although clinicians often view capacity as a continuum, from a legal perspective patients either do or do not possess it.<sup>1</sup> Capacity is a *state* that can be lost and regained. It is issue- and time-specific. It is an action, not a manifestation of personality. For instance, patients with mental illnesses who may face adjustment difficulties in many areas can nevertheless be capable of making informed decisions about the treatment they receive.<sup>3</sup> Decision-making capacity is a complex process that requires high-level executive functioning,<sup>4</sup> with 3 particular skills: (1) fluid intelligence, or the ability to reason, think abstractly, and solve problems, (2) metacognition, or the ability to reflect on one's own thinking and reasoning process<sup>5</sup>; and (3) numeracy,<sup>6</sup> the ability to reason using probabilities.

Failing to consider capacity can result in moral and practical harms. Assuming that patients do not have capacity around certain decisions, when in fact they do, violates fundamental principles of self-determination. Assuming that patients have capacity, when in fact they do not, potentially jeopardizes their well-being by allowing them to make ill-considered decisions. This is particularly important given the finding that 45% of the patients in 58 treatment settings lacked decision-making capacity.<sup>7</sup>

## When to Evaluate Capacity

Patients are presumed to have capacity unless there is strong reason to believe otherwise. Either staff or a patient's loved ones can identify the need for capacity evaluation when (1) the patient refuses beneficial treatments that meet the community standard of care, or (2) the patient requests treatments that are regarded as potentially harmful or futile. In these instances, the *process* that patients use to explain their requests is the critical concern, not the requests per se. For instance, a patient who refused a life-prolonging intervention might be assumed to have capacity if the rationale was prevention of unnecessary suffering, but not if the rationale was that its use would cause the death of a loved one.

The rigor of the assessment should be proportionate to the gravity and urgency of the decision. For example, a moderately depressed patient's refusal to take an antidepressant may seem ill advised but would not require the same level of evaluation as the decision by a middle-aged man with a subarachnoid hemorrhage who refused to have a neurosurgery that could save his life.

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\* Address correspondence to Richard B. Stuart, DSW, ABPP, PO Box 236 Edmonds 98020, WA.

E-mail address: [rbstuart88@gmail.com](mailto:rbstuart88@gmail.com) (R.B. Stuart).

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## What to Do When Evaluation Is Impossible

Patients must be capable of participating in evaluation of their capacity. Such incapacity can be the result of multiple factors, including dementia, adverse reactions to medications, alcohol, or street-drugs, or prolonged sleep deprivation.<sup>8</sup> For instance, critical decisions must sometimes be made during surgical procedures, and a patient cannot be expected to make decisions during or immediately after anesthesia.

Providers have 5 options if a patient is unable to participate meaningfully in a capacity evaluation, and a critical decision cannot be safely delayed.

1. Consult and honor the patient's advance directive, POLST, MOLST, MOELI<sup>9</sup> or other orders.
2. Find a surrogate who has the authority to act for, and who can appropriately represent, the patient.
3. If the patient has not designated a surrogate, most states authorize a series of "default" options, for example, spouse, adult children, parents, adult siblings, or any adult who has exhibited special concern for the patient and who is familiar with the patients' values.<sup>10</sup>
4. Search the patient's medical record to establish a precedent for the pending action.
5. If doubts remain, and/or if patients are "unbefriended," that is, have no interested parties,<sup>11</sup> call upon the institution's ethics committee. Ethics committee consultation is also strongly indicated when options 3 or 4 are employed.

The ethical challenges generated by these situations encourages giving patients the opportunity to define values and preferences for care before the time that they become incapacitated, for instance prior to a surgery.

## How to Undertake Capacity Evaluation: Context and Assumptions

Capacity evaluation is an interactive process that requires thoughtful attention to several key factors.

### Setting and Context

Capacity assessment should be undertaken in a setting in which there is privacy and freedom from distraction, neither of which is readily available in most emergency rooms or intensive care facilities.

#### A. Establishing rapport and showing respect

Providers should establish rapport and gain patients' trust to achieve their voluntary participation, including explanation of their reasoning. It is important to attend to details like speaking with patients at eye level, and addressing them respectfully, for example, "Ms A" rather than by first name. It also helps to ask a question or two that allow patients to feel that their identity is respected, for example, "How were you getting along before you were admitted to the hospital?" or "Are we doing enough to make you comfortable?"

#### B. Attending to cultural issues

Because patients' decisions are profoundly influenced by their cultural perspective,<sup>12</sup> when possible, providers should learn enough about their beliefs in order to build understanding and minimize the risk of inadvertently making inappropriate statements. Because each person has a unique interpretation of cultural influences, it is best to ask about patients' individual beliefs rather than to treat them as stereotypes.<sup>13</sup>

#### C. Explaining medical terminology

An often-overlooked aspect of cultural interaction is the need to translate medical terminology into words that are familiar to patients. Patients are prone to accept more aggressive intervention if they do not understand what is being proposed,<sup>14</sup> often because they do not appreciate that palliative care is compassionate and often life-prolonging. Various instruments can assess patients' knowledge about general and specific health concerns.<sup>15</sup>

#### D. Communication barriers

It is necessary to assess other potential barriers to participation including patients' vision and hearing, and fluency in the language being used, including any age- or ethnically related variations. Steps should be taken to overcome these deficits, for example, by providing sign- and/or foreign-language interpreters.

#### E. Health literacy and numeracy

Patients must possess sufficient capacity to understand basic health information,<sup>16</sup> and to reason using mathematical concepts such as probability and risk.<sup>17</sup> Patients who do not understand the meaning of words like "resuscitation" and "artificial nutrition," or phrases like "a 10% chance of improvement," will be limited in information exchange, deliberating, and deciding,<sup>18</sup> which are at the core of meaningful decision making.

Although there are no widely accepted and validated measures of health literacy and numeracy,<sup>19</sup> providers can evaluate patients' understanding by asking them to use their own words to describe the terms and procedures. This process enhances patients' ability to deal appropriately with information about their status, and the options for managing it. If patients understand the terms and concepts, their requests will more likely influence their care,<sup>20</sup> and be less likely to being challenged and annulled.<sup>21</sup> Taking the time to assess and develop these abilities and to adjust the discussion accordingly is therefore time well spent.

### Structured Instruments

It would be convenient if capacity could be accurately assessed using a standardized instrument. Unfortunately, psychological tools cannot in themselves predict individual responses with enough fidelity to account for values and preferences around end-of-life care.<sup>22</sup> Therefore, direct observation of the patient's behavior while making a specific decision at a specific time is essential. When necessary, the process can be strengthened by using one or more of the many instruments that have been developed to assess general cognitive functioning<sup>23,24</sup> as well as cognitive impairments.<sup>25–27</sup>

Many instruments have been developed to evaluate decision-making capacity formally. Most use orally administered case vignettes that the patient is asked to discuss in structured terms that are then scored [eg, the MacArthur Competence Assessment Tool (MacCAT-T),<sup>28</sup> the Structured Interview for Competency Incompetency Assessment and Ranking Inventory,<sup>29</sup> and the Assessment of Capacity to Consent to Treatment (ACCT).<sup>30</sup>] The ACCT assesses 4 domains:

- Understanding—the ability to comprehend diagnostic and treatment-related information, including the ability to comprehend, attend, encode, store, and retrieve words and phrases;
- Appreciation—the ability to determine the personal significance of treatment information including insight, benefits, and foresight about its potential benefits;
- Reasoning—the ability to compare alternatives in light of their consequences, including the ability to articulate reasons applicable to the patient's life situation;

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