



Assessing decision-making capacity at end of life[☆]



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ABSTRACT

Objective: Patients with terminal illness often face important medical decisions that may carry ethical and legal implications, yet they may be at increased risk for impaired decisional capacity. This study examined the prevalence of impairment on the four domains of decisional capacity relevant to existing legal standards.

Method: Twenty-four adults diagnosed with a terminal illness completed the MacArthur Competence Assessment Tool for Treatment, a semi-structured measure of decision-making capacity and measures of cognitive functioning and psychological distress.

Results: Approximately one third of the sample demonstrated serious impairment on at least one domain of decisional capacity. The greatest proportion of impairment was found on subscales that rely heavily on verbal abilities. Decisional capacity was significantly associated with cognitive functioning and education, but not with symptoms of anxiety or depression.

Conclusions: This study is the first to examine decisional capacity in patients with terminal illness relative to legal standards of competence. Although not universal, decisional impairment was common. Clinicians working with terminally ill patients should frequently assess capacity as these individuals are called on to make important medical decisions. Comprehensive assessment will aid clinicians in their responsibility to balance respect for patient autonomy with their responsibility to protect patients from harm resulting from impaired decisional capacity.

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Patients with terminal illness are responsible for making important healthcare decisions. Even after their disease has progressed beyond cure, patients may need to establish advanced directives, decide whether to enter clinical trials or accept palliative care interventions, and decide whether to forego potentially curative treatment and enter hospice care [1–3]. Some of the decisions faced by terminally ill individuals can be controversial, such as those regarding physician-assisted suicide (where legal), to reject life-sustaining interventions, and to accept interventions that may directly or indirectly hasten death. Further, many medical interventions provided to patients at end of life can be costly and invasive [4,5]. Even very ill patients are expected to actively participate in their own healthcare decision making [6]. However, as their disease progresses, the decision-making capacity for many patients may deteriorate, whether the result of age, hospitalization, treatment side effects or the disease itself [7–9]. In these situations, an assessment of the patient's decision-making capacity is required to determine whether the

patient retains the capacity to make “competent” treatment decisions. Capacity assessments provide a mechanism for safeguarding patient autonomy and self-determination while protecting them from the harm that might arise from ill-informed decisions [10,11].

Clinicians are largely responsible for determining when patients are incapable of making competent treatment decisions [12]. In decades past, determinations of decision making capacity were based largely on the diagnosis of a mental disorder alone, or on a global assessment of the patient's mental status [12]. Many physicians still rely on global assessments of cognitive functioning to assess decision-making capacity [13,14], but the accuracy of these simplistic approaches is questionable. For example, one study found that a frequently used measure of cognitive functioning, the Mini Mental State Examination [15], was a modest predictor of decisional capacity but no cutoff score yielded adequate sensitivity and specificity [16]. Thus, critics have argued that cognitive measures such as the Mini-Mental State Examination (MMSE) are not adequate to evaluate the patient's specific capacities to understand, appreciate and reason about information related to a particular treatment [17].

In the last two decades, empirical studies of decisional capacity in patients with advanced illness has led to the development of several instruments intended to measure the key functional abilities that correspond to the different legal standards for decision making competence [12]. Although there is no universal legal standard for competence, researchers have identified four components that are

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central to judicial determinations of competence and provide the basis for the model of consent capacity: ability to express a choice (Choice), ability to understand and recall disclosed information (Understanding), ability to appreciate the significance of the decision (Appreciate), and ability to rationally manipulate information into a decision that is consistent with one's values and preferences (Reasoning) [18,19]. The instruments designed to assess these legal standards provide greater standardization than assessments based solely on a clinical interview and are increasingly considered the “gold standard” of capacity assessment [20].

Research using standardized measures of decision-making capacity has provided insight into patterns of decisional impairment within specific patient populations. Impairment in decision-making capacity has been demonstrated in elderly adults relative to younger adults [21–27], and in those with schizophrenia relative to adults without a psychiatric illness [28–33]. Research on the impact of depression, however, has been more equivocal, as the impact of depression on decision-making is less severe than for many other mental illnesses (i.e., schizophrenia, schizoaffective disorder, bipolar disorder). Although some studies have found impairment in depressed adults relative to healthy adults, these effects may be due to changes in cognitive functioning, such as memory and executive function impairments [28–30,34–37]. Not surprisingly, progressive, disabling neurological disorders that cause cognitive impairment, such as Alzheimer's disease and Parkinson's disease, have also been linked to impaired decision-making capacity [16,20,38–45].

Despite the importance of decision making in terminally ill patients, only two published studies have specifically examined decisional capacity in this population. Sorger and colleagues [46] found that hospitalized cancer patients receiving end-of-life care were significantly more impaired on several measures intended to tap ability to provide informed consent when compared to relatively healthy elderly comparison subjects. Physical functioning and age were the strongest predictors of decision-making capacity in this sample. However, there was no association between decisional capacity and other demographic or psychiatric (i.e., depression) variables. Similarly, Burton et al. [47] examined the relationship between cognitive functioning and ability to provide informed consent in a sample of patients receiving hospice care. Study findings supported the relationship between impaired decisional capacity and global cognitive functioning. Overall, the results of these studies indicate that advanced illness is associated with impairments in decision-making capacity, but the precise mechanism underlying these impairments is not known. Moreover, the measures used to assess decisional capacity have been broad-based measures of cognitive functioning; no research to date has specifically targeted the elements of decision making that are relied upon by courts and clinicians.

The present pilot study sought to extend this nascent literature by utilizing a standardized method to assess decision-making capacity in patients with terminal illness. Specifically, the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) [48,49] was used to examine decision-making capacity in the four domains directly relevant to existing legal standards: *choice*, *understanding*, *appreciation* and *reasoning*. This study examined the prevalence of impairment on these four standards of decision-making, as well as associations with measures of cognitive functioning (MMSE) and psychological distress (i.e., depression and anxiety).

1. Method

1.1. Participants

Terminally ill patients were recruited from a 200-bed palliative care hospital in the Metropolitan New York City area. All participants had a diagnosis of an incurable, life-limiting illness (primarily stage IV

cancer) and a life expectancy of less than 6 months. This study utilized a convenience sample of patients. Prospective patients who were capable of participating in the study were referred to the investigators by their treating physicians. Hospital records were then reviewed to determine whether patients were English-speaking, alert and responsive enough to be able to comprehend information disclosed during the informed consent process (i.e., able to communicate, not overtly delirious). Because the goal of this study was to assess decision-making capacity across a range of abilities, patients with some cognitive impairment were included provided they were able to comprehend the informed consent material and provide seemingly relevant answers to questions. This low threshold for study participation (an “assent” standard) is consistent with both case law and the research literature on informed consent [19,50], as an acceptable threshold for participation in research when the risks are negligible. Interviews were conducted in a private room, at the patient's bedside. The institutional review boards of all participating institutions approved the study.

Twenty-eight patients were approached for participation and 25 patients agreed to participate in the study; one participant elected to discontinue the study before providing sufficient data to permit analysis, resulting in a final sample of 24. The average participant age was 69.2 years (S.D.=13.1; range: 35–88). The majority of the sample was female (66.7%, $n=16$) and Caucasian (83.3%, $n=20$). Two-thirds of participants completed at least some college ($n=16$), and 25% ($n=6$) were married. The majority of participants identified as Catholic (58.3%, $n=14$). The participants had a range of diagnoses. The most common diagnosis was breast cancer ($n=5$, 20.8%). All remaining diagnoses were held by two or fewer participants. Thirteen participants completed the first [artificial nutrition and hydration (ANH)] version of the MacCAT-T (54.17%) and 11 completed the second [end-stage renal disease (ERD)] version (45.83%). These two groups did not differ in age, years of education, gender, race, ethnicity, marital status, religion or MMSE score. There were no significant differences on MacCAT-T subscale scores by MacCAT-T version.

1.2. Procedures

All patients who agreed to participate were interviewed briefly to elicit relevant demographic information including age, sex, race, ethnicity and education. Decision-making capacity was assessed using the MacCAT-T, a semi-structured, interview-based instrument that consists of a vignette presenting the participant with a medical disorder, the recommended treatments and associated risks and benefits, and potential alternative treatments [19]. Although the MacCAT-T was initially developed to help guide the assessment of actual proposed treatments, researchers have typically utilized hypothetical treatment decisions in order to permit a standardized administration and inquiry [16,41]. In this study, two versions of the MacCAT-T were administered, one addressing the decision to accept or reject ANH for cachexia (severe malnutrition or “wasting syndrome”) and one pertaining to hemodialysis in the context of ERD. In each version, the participant was asked to imagine that he or she had been diagnosed with a terminal disease and that the proposed treatment was necessary to extend life. Participants received inadequate, partial or adequate ratings for each MacCAT-T item (scores of 0, 1 and 2 respectively), and these scores were summed to generate subscale scores for Understanding (0–6), Appreciation (0–4), Reasoning (0–8); and Choice (0–2). Prior research using the MacCAT-T in a sample of adults with psychiatric illness has demonstrated a high degree of inter-rater reliability and test-retest reliability over a 1-month period [49,51], although reliability was not assessed in the present study. Past research has also demonstrated a moderate correspondence between MacCAT-T scores and physician's judgments of decisional capacity [52,53].

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