

# **End-of-Life Care and Mental Illness: A Model for Community Psychiatry and Beyond**

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**ABSTRACT:** End-of-life care is often influenced by the stereotyping of patients by age, diagnosis, or cultural identity. Two common stereotypes arise from the presumed incompetence of many patients to contribute to end-of-life decisions, and the fear that the discussions themselves will be de-stabilizing. We present a model for end-of-life discussions that combines competence assessment with healthcare preferences in a psychiatric population that faces identical stereotypes. The model, which draws on clinical research in competence and suicide risk assessment, has important implications for all patients in the community who are marginalized or stereotyped during discussions of end-of-life treatment.

**KEY WORDS:** end-of-life care; chronic mental illness; decision-making capacity; healthcare preferences.

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## INTRODUCTION

Multiple influences at the end of life are known to diminish the quality of care. The most insidious of these influences arise from common clinical stereotypes of age, diagnosis, or cultural group. The end-of-life literature is rife with observations that information disclosure is influenced by clinician expectations, assumptions about certain social groups, and the presumed incompetence of certain patients (Morrison et al. 1998, Ersek et al. 1998; Malloy et al. 1992; Layson et al. 1994; Markson 1994). Fearing that end-of-life discussions may cause emotional instability or misunderstanding, many clinicians behave as if family members are better equipped for difficult discussions than patients who remain competent (Fischer et al. 1998; Lo et al. 1986; Brock 1994). It would appear that position statements by professional healthcare organizations (e.g., the AMA, ACP, ACS) and patient surveys endorsing greater attention to end-of-life discussions have not yet penetrated the widespread avoidance of difficult discussions or the presumptions of incompetence (Cassel and Foley 1999).

Poor information disclosure and stereotyped competence assessments are especially problematic because of the status of competence as the workhorse of informed consent doctrine. Without competence (more precisely, decision-making capacity) the information disclosure and voluntary choice about treatment that comprise informed consent cannot occur. Care-givers and families cannot have confidence in decisions of questionable competence, and the clinical focus changes as a result. Without competence, a focus on prior rather than present wishes takes precedence and the patient's active participation in decision-making is undermined. So important is this element of informed consent that without expression of competent wishes, alternative standards of decision-making, namely substituted judgment and best interests, are invoked.

The concern that competence is undermined at the end of life pervades medicine. Distinguishing competent decisions from those that are rendered incompetent by illness is a constant challenge among patients with conditions such as cancer, dementia, neurologic and psychiatric illness (Ritchie et al. 1998; Fellows 1998; Emanuel et al. 1994; Chochinov et al. 1999). These patients demonstrate state-dependent changes in mentation that frequently influence their treatment decisions. The fluctuating nature of such illnesses underscores the importance of competence at the end of life.

Competence to make end-of-life decisions, however, is crucial to any

individual who may become incapacitated. The hope in the end-of-life literature has always been that patients participate in advance care planning before they are encumbered by the acute challenges of their illness (Emanuel 1995). Because this hope remains unfulfilled, an awkward emphasis remains on patients' present competence and the challenges that attend it.

Those who treat mentally ill persons are particularly sensitive to conditions that undermine competence to make treatment decisions. The state-dependent nature of mental illness and the dual presumptions of incompetence and emotional instability resonate in this population because of the stigmatization and discrimination that have accompanied mental illness for centuries. Treatment discussions frequently bypass mentally ill patients because of these vulnerabilities, and are often held with family members or other social supports, or not held at all (Read and Law 1999; Lawrie et al. 1996). This state of affairs is closely allied to conditions that persist in end-of-life care.

We will demonstrate that the misperceptions and treatment barriers facing mentally ill persons parallel those encountered by most patients at the end of life. Our efforts to overcome these barriers among persons with severe mental illness—a previously unstudied population—may consequently give rise to new strategies for improved care among all patients.

### *MENTAL ILLNESS AS A MODEL OF END-OF-LIFE CARE*

The hypothesis that persons with mental illness serve as a microcosm of end-of-life care has been supported by numerous recent surveys conducted within the Massachusetts Department of Mental Health. Just as geriatric and cardiology patients wish that their physicians would initiate discussions regarding future treatment, persons with mental illness describe a lack of communication with their healthcare providers (Massachusetts Department of Mental Health 1998, 1999). Rare discussions about end-of-life care, rarer completion of advance directives, and lack of formal instruments to assess competence of end-of-life choices are common experiences—regardless of diagnosis.

Further validation for this model of end-of-life care derives from psychiatric research already conducted in two important areas: the competence to make treatment choices and the need to conduct difficult treatment discussions. We will address each of these in turn.

*RESEARCH ON COMPETENCE ASSESSMENT:  
THE ABILITY OF PERSONS WITH MENTAL ILLNESS  
TO MAKE COMPETENT DECISIONS*

It is only recently that empirical research on competence to make treatment decisions has been conducted in a systematic manner. Early results from medically ill and mentally ill populations had suffered serious methodologic limitations: a lack of standardized assessments, failure to address more than one standard of competence, and contradictory findings among different patient groups (Appelbaum and Grisso 1995). These shortcomings are now being addressed.

The MacArthur Treatment Competence Studies (sponsored by the well-known philanthropic foundation) continue to generate data from a multi-center, multi-year effort drawing sophisticated comparisons between medical and psychiatric patients (Appelbaum and Grisso 1995, 1995a; Grisso et al. 1995). Standardized interviews have been constructed that offer assessment of comprehension as well as information tailored to a proposed treatment. Tested against each of the established ethical-legal standards of competence (i.e., communicating a choice, understanding relevant information, manipulating information rationally, appreciating the situation and its consequences) these semi-structured interviews offer reproducible and valid assessments of decision-making capacity (Appelbaum and Grisso 1988; Grisso et al. 1997).

The MacArthur results indicate that although patients with mental illness perform less competently than their matched medically ill and community controls, those doing poorly are not identifiable by common demographic characteristics. Rather, the group's poorer over-all performance is influenced by a minority of thought-disordered individuals who suffer conceptual disorganization and unusual thoughts. Indeed, there is considerable overlap in the competence of medical and psychiatric patients.

The MacArthur Adjudicative Competence Study (Hoge et al. 1997), assessing competencies relevant to the judicial process demonstrates similar findings: it is the characteristics of decision-making (i.e., conceptual disorganization) rather than diagnosis that predispose subjects to incompetence. Here, too, there is considerable overlap between mentally ill and control subjects.

Recent applications of the MacArthur assessment instruments to subjects entering research protocols, a related area of medical competence, demonstrate the capacity of patients with major depression to

perform competently (Appelbaum et al. 1999). And among thought-disordered subjects entering research, concerted education efforts reverse poor initial performances on competence assessments (Carpenter et al. 2000). Overall, there is evidence that even persons with significant cognitive impairment retain substantial decision-making capabilities.

### *SUPPORT FROM BIOETHICS AND THE LAW*

Competence research is not alone in supporting decision-making criteria that are blind to a patient's diagnosis. As early as 1982, the President's Commission for the Study of Ethical Problems in Medical and Biomedical and Behavioral Research endorsed an individual's *functioning* in arriving at a decision as the appropriate focus of competence assessment (President's Commission 1982). The Commission explicitly rejected use of common "status" standards such as age or diagnosis for determining competence. Simply being diagnosed with an illness affecting mentation was deemed insufficient for ascribing incompetence.

Indeed, this endorsement of autonomous decision-making across all diagnoses has been echoed in the law. The movement supporting the right to refuse treatment among civilly committed patients exemplifies the recognition that mental illness does not signify global incompetence. Historically, civil commitment for a mental illness and some combination of dangerousness or helplessness was sufficient to permit forced treatment. However, landmark cases (e.g., *Rogers v. Commissioner* in Massachusetts, 1983) eventually carved out protections for specific competencies that were supported in the basic bioethics literature (Buchanan and Brock 1989; Beauchamp and Childress 2001). Under contemporary informed consent doctrine, competence is specific to the task being assessed, with clinicians avoiding findings of general incompetence because of the potential loss of basic human rights. In most jurisdictions, islands of competence among civilly committed persons are now specifically protected by the due process of law, from the drawing up of wills to the management of personal funds.

This support for focussed competence assessments that value reasoning over diagnosis should have special significance for patients whose wishes are improperly discounted at the end of life. In fact, this conceptual approach is now a valuable weapon for overcoming stereotypes in terminal illness as well as in psychiatry.

*RESEARCH ON SUICIDE RISK ASSESSMENT: THE NEED  
TO CONDUCT DIFFICULT DISCUSSIONS*

In addition to providing empirical research on specific competence to make treatment decisions, psychiatry has provided data on discussions that many consider potentially de-stabilizing. The most prevalent and dramatic of these is the assessment of suicide risk. Because suicide is perennially a top-ten killer of U.S. citizens, psychiatry has undertaken the study of its risk factors, assessment, and treatment. The major psychiatric disorders from major depression and bipolar disorder to schizophrenia and even panic disorder, carry lifetime suicide prevalences of 10 to 20%. Increasing age combined with chronic or terminal medical conditions only increases the relative risk (Moscicki 1997; Candilis 1998; Shuster and Stern 1991).

Psychiatrists know to raise this difficult topic among both medically and psychiatrically ill patients because of observations that the majority of suicide victims have recently visited their physicians, that the elderly are more reticent about suicidal urges, and that physical illnesses compound the risk of suicide. The established co-morbidity of medical and psychiatric conditions in completed suicide and the finding that suicide in general hospital patients is often precipitated by disruption of the patient-treater relationship strengthens the justification for initiating rather than avoiding these sensitive discussions (Moscicki 1997; Candilis 1998; Shuster and Stern 1991).

Similarly, at the end of life there is considerable evidence that those requesting assisted suicide and euthanasia are motivated by dread or despair. "No patients have become more estranged from medicine than those who become suicidal in response to terminal illness," writes Herbert Hendin in an eloquent discourse on the reversible reasons for requesting death (Hendin 1998). Ganzini et al., in reporting on Oregon's experience with assisted suicide, have reported that up to 20% of those requesting lethal prescriptions are depressed (Ganzini et al. 2000). Oregon's practitioners are particularly sensitive to the motivations of this population, recently describing a group of patients requesting assisted suicide who may *not* have received lethal prescriptions because of their mood state (Ganzini et al. 2002). Lifting the treatable depressions that accompany many terminal illnesses, attenuating neuropsychiatric symptoms or side-effects of medications, and overcoming the psychosocial pressures that lead to family disarray all require detailed communication (Wanzer et al. 1989). Physicians studying terminal illness have long taught that hopelessness about the future can be assuaged by as-

surances that the patient will not be abandoned and by discussions of what to expect and how to manage symptoms. Avoiding discussions of psychic or physical pain for fear of precipitating emotional instability consequently undermines both psychiatric and medical treatment.

### *DEVELOPING THE RIGHT TOOLS*

Although some progress has been made in applying the findings of psychiatric research to the end of life, significant work remains. Calls for more focussed attention to the competence of end-of-life treatment choices, for example, have been based on the observation that orientation tests and scores on the Mini-Mental State Examination still serve as approximations of decision-making capacity (Walker et al. 1998, Chochinov et al. 1999). This approach, which misses the point of assessing specific competence against an established ethical or legal standard (e.g., understanding information, manipulating information rationally) is slowly being addressed in some circles.

Holzer et al., for example, find that executive function may be a better capacity measure than global cognitive functioning (Holzer et al. 1997). A standardized competence assessment for learning disabled patients offers clinical vignettes and correlation to verbal and memory ability (Arscott et al. 1999). An approach in geriatric patients uses clinical vignettes and a comparison to the clinical assessment of seasoned competence evaluators (Fazel et al. 1999). The Hopkins Competence Assessment Tool offers a clinical vignette that correlates to the assessment of a forensic psychiatrist (Janofsky et al. 1992).

But the most appropriate tool for end-of-life care would appear to be a combination of treatment-specific information and competence assessment that can be applied in *any* situation. It is uncertain whether narrow clinical vignettes translate to specific medical problems faced by patients at the end of life, and even more uncertain whether approaches based on population norms (e.g., verbal/memory tests) have overcome early methodologic objections. The statistical frequency model of normed testing, for example, generally ignores the affective component of competence and may be influenced by the hidden values of testing and interpreting population norms (Kopelman 1990). Instruments that do not assess understanding of a specific intervention or are limited by use of an unarticulated expert standard are likewise incomplete. The need for a standardized tool that is short, easily applicable, specific to the intervention offered, and testable against all rele-

vant competence standards persists in the end of life as it had in psychiatry.

Similar uncertainty surrounds knowledge of patient preferences. Widespread physician reluctance to discuss topics such as advance directives (Layson et al. 1994) leads to a need for empirical data on who is likely to complete such instruments and under what conditions. There is little data on the discussions that do take place, with some commentators worrying that discussions are not documented even when they are held (Lo et al. 1986). The failure of directives to reach the medical record is a well-known corollary to these breakdowns in communication (Morrison and Olson 1995). Might there be a strategy for standardizing these discussions and assuring that preferences remain accessible now that patient surveys and experience with difficult discussions favor their use?

Vague language in living wills and similar instruments underscores this question. Do the clinical vignettes and broad language that characterize these documents translate into specific, recognizable choices? Or does too much rely on interpretation after the fact? These are the same testable questions raised by imprecise competence assessments, and are just as answerable by research that draws on psychiatry's experience in holding difficult discussions.

End-of-life scholars appear to favor combining scenario and treatment-specific choices (such as the Medical Directive) as well as using values histories to clarify residual ambiguity (Emanuel 1993; Alpert et al. 1996; Lambert et al. 1990). Since these approaches have not yet been tested in combination, might it be possible to expand and monitor current preference discussions in a controlled fashion?

We believe we can answer some of these questions through the project "End-of-Life Care for Persons with Serious Mental Illness," a Robert Wood Johnson-funded collaboration of the Massachusetts Department of Mental Health, the University of Massachusetts Medical School, and the New Hampshire Dartmouth Psychiatric Research Center.

By focusing both on the perception of presumed incompetence and the avoidance of difficult discussions within a "case-managed" system—that is, one in which caseworkers refer individual patients for appropriate assessment—we hope to expand the current experience of end-of-life discussions. Case-management offers the kind of scrutiny that can identify the strengths and weaknesses of a systematic approach and provide immediate feedback on how to improve the model. We believe that the use of standardized instruments under this kind of over-



sight can identify problems, guide discussions, assure access to patient preferences, and generate high rates of compliance with patient wishes. Practitioners who subsequently adopt this methodology will be informed by the experience of seasoned case-managers in real-life settings. Moreover, by working with seriously mentally ill persons—a population faced by stereotyping and barriers to good care—we hope to explode the myths that have undermined end-of-life care for all populations.

### *THE MACARTHUR COMPETENCE ASSESSMENT TOOL—PROXY (MACCAT-P)*

To test the hypothesis of presumed incompetence we have developed a brief competence assessment tool derived from the MacArthur study instruments. This semi-structured interview presents information on the selection of a healthcare proxy and assesses understanding, reasoning, appreciation, and ability to make a choice. Choosing a healthcare proxy provides a minimal standard against which all patient populations can be compared and is a representation of a common occurrence in end-of-life care: the involvement of family or friends in medical decision-making. It is also the only advance directive recognized by law in our state.

The instrument, or MacCAT-P (MacArthur Competence Assessment Tool—Proxy), educates patients in the various components of choosing a proxy: the nature of the appointment, its futurity, reversibility, burden, and the like. (See sample questions in Appendix 1.) Because of its easy readability it can be used by any patient population considering end-of-life decisions. Information is divulged part-by-part with numerous repetitions if necessary so that information disclosure is offered in the fashion recommended by prior consent research (Appelbaum and Grisso 1995, 1995a; Grisso et al. 1995). Competence of thought-disordered patients with medical conditions—patients among whom deficits are likely to be observed—is then tested against a matched community sample.

Prior experience does predict that a difference in abilities will exist, but it also predicts that a considerable overlap will exist with community controls, that common demographics will not be predictive of incompetence, and that educational efforts will serve to improve poor results. Pilot data and experience with our first subjects support the capacity of our seriously ill subjects to complete this 20-minute tool.

The tolerability of the MacCAT-P, like that of its predecessors, speaks not only to the ease of competence assessment but also to the tolerability of difficult discussions. Facilitating end-of-life discussions is critical to these patients not only because they remain at risk for perceived incompetence and exclusion from treatment decisions, but also because of premature death and inadequate access to healthcare. Numerous studies have identified the poor access to care and excess mortality of persons with co-morbid psychiatric and medical conditions (Dembling et al. 1999; Black et al. 1985). Using tools that are easily tolerable should facilitate discussions among even those patients facing the greatest pressures of ill health and miscommunication. If the tools are acceptable in this population, the hope is that they can be used with confidence in any patient group discussing end-of-life care.

#### *THE HEALTHCARE PREFERENCES QUESTIONNAIRE (HCPQ)*

A second tool for easing difficult discussions is a companion healthcare preferences survey that will ultimately be incorporated into the case-management record. Case-managers will track this tool, as well as the MacCAT-P, as patients endure exacerbations of illness and ultimate decline. The companion tool not only offers the treatment-specific scenarios supported by general end-of-life scholarship but also adds a values history. Incorporation of spiritual and religious elements, and inclusion of specific probes of interview distress make this tool the most comprehensive one tested to date. Based on the widely disseminated American Health Decisions template (American Health Decisions 1997), this preferences survey rates health status, frequency of treatment, and opinion on common ventilator-withdrawal and psychiatric restraint vignettes. Incorporation of simple outcome measures like health status and healthcare utilization will strengthen comparisons with community controls and offer generalization to non-mentally ill groups. (See sample questions in Appendix 2.)

#### *TOWARD A STANDARDIZED APPROACH TO END-OF-LIFE DISCUSSIONS*

Monitoring the progress of this population—encumbered as it is by most of the challenges experienced by patients at the end of life—

should eventually allow us to ascertain whether the barriers of presumed incompetence and avoidance of difficult discussions can be overcome in a systematic fashion. If simple survey instruments can guide end-of-life discussions as they have competence discussions, physicians should ultimately be able to determine both the competence and content of patient preferences in a practical manner. Drawing on the experience of suicide risk assessment, physicians and patients may finally have the confidence to discuss as difficult a topic as end-of-life care.

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### APPENDIX 1: SAMPLE QUESTIONS, MACCAT-P

Nature of the problem: “Before you get medical treatment, you and your doctor usually have the chance to talk about what you want.

But, if you’re in an accident or too sick and confused to think clearly, it’s hard for your doctor to know what you want.”

“Do you have any questions about what I just said?”

“Can you tell me your understanding of what I just said?”

Selecting a health care proxy: “One way to help doctors know what you want if you’re too sick or confused to tell them, is to choose someone else to make medical decisions for you. You can do this by filling out a form ahead of time. The person you choose to make medical decisions for you is called your ‘health care proxy.’”

“Do you have any questions about what I just said?”

“Can you tell me your understanding of what I just said?”

Bringing a proxy into effect: “Doctors ask your health care proxy to make a decision *only if they think you’re not able* to make the decision yourself.”

“Do you have any questions about what I just said?”

“Can you tell me your understanding of what I just said?”

## APPENDIX 2. SAMPLE QUESTIONS, HEALTHCARE PREFERENCES QUESTIONNAIRE

Do you have specific wishes about what medical treatment, such as breathing machines or feeding tubes, you would want if you were not able to make medical decisions for yourself?

Please tell me what healthcare decisions you think you would be the most concerned about others making for you if you were unable to make your own choices during a serious illness or at the end of your life.

If a person is too sick to make decisions about her care and has not given written instructions for her care in advance, should someone else make medical care decisions for her?

Is there any reason that someone else should NOT make decisions for patients in situations like the ones we have discussed?

Do you have spiritual or religious beliefs that would influence your decisions if you found yourself in either of the imaginary situations I have read with you?

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