Decision-Making During Grave Illness: How to Show Respect for the Person

Modern American biomedical ethics is centered on a standard paradigm. Well-informed patients should make autonomous choices about their own health care. The legal and ethical foundations are solidly established, and the language of “rights” dominates much of public discourse. Emphasis on rights has led to strong protections for individual decision-making. Patients who are unable to make good decisions reliably, however, such as those with severe cognitive impairment or psychiatric illness can be irretrievably harmed by a thoughtless insistence or self-determination.

Clinicians recognize that some patients simply cannot comprehend or manipulate the information necessary to make a meaningful decision. However, clinicians also recognize that many patients, particularly those who are sick and elderly, operate in a gray area. Prevalence of chronic cognitive impairment rises with age. Acute illness could cause transient disturbance of cognition, more commonly among even the well elderly. Chronic polypharmacy, exacerbated by increased contact with prescribers during acute illness, can also produce unpredictable impairment of decision-making capacity.

Clinicians who take care of sick, elderly patients face a vexing challenge. When is a patient so impaired that the decisions she makes should not be honored? In this issue, Ganzini and colleagues discuss 10 myths about decision-making capacity. These myths were identified from survey results of two professional societies and chairs of Veterans Affairs Medical Centers’ ethics committees. Instrument, respondents, responses, and analysis are not described. Several of these myths deserve special accent.

Myth 4, that capacity is “all-or-nothing,” is frequently assumed by housestaff, who could ask for a global “assessment of competency” when caring for a confused person. A person could be competent to play pinochle but not poker, or tennis but not table tennis. A patient could be able to specify meal preferences but not to decide about neurosurgery for deep, solitary brain metastasis or the proper management of severe, two-vessel coronary artery disease. If a clinician is asked, “Do you think this patient is competent?” the proper first reply should be a question: “Competent to do what?”

Myths 2, 3, 5, 6, and 8 converge on a common theme, the “status definition” of capacity. In very limited situations, a person’s status defines the person as incapable. The most common example is youth. Below a certain age, a child simply is defined to be incompetent to make business contracts. As the authors point out, status definition of incapacity can only rarely be applied to a conscious adult. Patients who disagree with their physicians are not presumed to lack capacity (myth 2), and conversely, those who agree are not presumed to have it (myth 3). Simply knowing that a patient has cognitive impairment (myth 5) or psychiatric disorder (myth 8), has previously been determined to lack capacity (myth 6), or even has been involuntarily committed (myth 9) does not by itself prove a person’s incapacity.

In most situations, the clinician’s evaluation of the patient’s capacity to make a particular decision evolves during a discussion about that decision. As the authors note in their discussion of myth 3, the standards for assessing capacity could vary according to what is at stake. A patient’s decision to agree to an IV will be judged by a different standard than their decision to refuse antibiotics for endocarditis. For many decisions, however, risks and benefits are not so sharply outlined. Also, for many, assigning values to risks and benefits is intensely personal. Idiosyncratic and compelling value systems, religion is the most common and accepted example, could by definition defy logical analysis.

I would like to propose an 11th myth for emphasis: “The neuropsychiatric equivalent of a biopsy can objectively determine whether a patient has the capacity to make a given decision.” This too is false and commonly believed. Subjective judgment will always remain an element of capacity determination. When a clinician cannot clearly distinguish how her values and the patient’s should be balanced, appeal to a neutral third-party referee is needed. The authors suggest, variously, legal or psychiatric staff and the ethics committee as potential referees. I believe the work of these referees should be seen more as brokering a good decision than as discovering whether the patient “really” has capacity. (Legal, psychiatric, and ethics workers each operate, of course, within their own professional world view.)

Finally, I believe an important “meta myth” could be stated: “When a decision must be made for a frail, seriously ill, elderly patient, a physician’s best action is to determine whether the patient has capacity, and if so to ask the patient to make the decision.” On one hand, this myth fits well with a lawyerly, contractual, “consenting adults” model of transactions. How better to show respect for persons than to respect...
their autonomy. On the other hand, patients nearing death could face decisions that are terrifying, mystifying, and tragic. What many patients want when gravely ill is for someone to take care of them. They would prefer this to a rights-based formulaic approach. Should they be encouraged to be fully educated about the many ways in which they are sick, their many possible future sufferings, the likelihoods of near-term death, and then expected to steer a course through this unimaginable landscape?

The authors refer to this meta myth in the first sentence of text: Clinicians are obligated to involve patients “to the degree they desire” in medical decision-making. Although their intent was clearly to address a more particular question, I believe a broader background of decision-making for the ill and dying helps to locate more clearly the meaning and importance of capacity and informed consent.

In conclusion, Ganzini and colleagues present 10 myths that they identified as important based on survey results. Most of the myths reflect clinicians’ attempts to shortcut the very difficult work of determining capacity. Status definitions of incapacity rarely work; if you want to know whether a patient can “get it,” you usually have to go and talk to her. Two additional points were likely inaccessible to survey methodology. Determining whether a patient has capacity is often, perhaps almost always, a decision rather than a discovery. Also, in many cases, the consenting-adults standard paradigm fails. A physician bearing a menu of options is not what a gravely ill person with or without capacity wants nor is it the optimal strategy to show respect for persons.

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