

Jeffrey P. Spike, "Memory Identity and Capacity," *The Journal of Clinical Ethics* 18, no. 3 (Fall 2007): 252-5.

Memory Identity and Capacity

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The situation of Mr. G described in "Memento . . . Life Imitates Art," a case in this issue of *The Journal of Clinical Ethics*, raises questions with which every ethics consultant must wrestle. It is an interesting case because it combines classic issues with some new twists. When one first reads it, the case includes the very types of prognoses that can make good decision making perplexing even for physicians. Is a 15 percent chance for a cure a good chance? Many people would think a 5 percent chance for a cure is small, and close to negligible when you factor in the amount of suffering that one must endure during treatment. Many of the same people might think 20 percent chance for a cure is a different matter, and worth the gamble. But 15 percent is confusing: high enough to be tempting, but low enough to make one worry about regretting the decision if you turn out (as is likely) to be in the other 85 percent. And that is before factoring in the question of whether extending life by a year is worth it, if much of that time would be spent with the typical and predictable symptoms suffered from chemotherapy. Is that extra year a benefit or a burden?

What makes Mr. G's case worthy of being singled out, however, is that it simultaneously raises another issue, one just as important to the successful practice of ethics consultation, but far less appreciated. After 10 years in the practice of hospital-based clinical ethics consultation, I reviewed my many cases and discovered that capacity issues are just as common as end-of-life issues. By my estimate, each is at least part of a legitimate ethics consult 80 percent of the time. As with Mr. G, both often appear together. And as is so often the case, what makes the situation so ethically difficult is the overlay of the issue of capacity upon the (end-of-life) consequences. It places the case at the intersection of two ethical planes, one deontological and the other utilitarian.

Clinical ethics is of course an amalgam, a mix of ethics, law, and medicine. Ethics, as a branch of philosophy, has had a lot to say about the importance of memory to personal identity. The vital importance of memory to personal identity has become widely accepted (if not universal) in philosophy, since the near-universal rejection of dualism and the existence of the soul in the late eighteenth century. Without a substantial soul, only memory seemed able to explain what makes a person the same person at different times. From this interdependent relationship, it would be natural to assume that a loss of memory means a loss of personal identity, and thus a person would lack capacity to make "their own" decisions. This seemingly natural series of links involves many assumptions, however, and some of them do not hold up.

There is not a one-to-one relationship of memory to capacity, and in fact a patient may have capacity despite very compromised memory.¹ The active involvement of at least three different ethics consultants in

Mr. G's case certainly shows the difficulty he presented. One important lesson that might be drawn from his case is that to consider capacity as all-or-nothing is often a mistake, and one that can create additional problems. When one consultant decided to turn to a family member who was the proxy chosen by the patient, it raised doubts in the minds of some other family members. This is a common problem.

Consultants should avoid ever appearing to leave the patient out of the conversation, unless the patient has asked to not be involved. Thus good practice means often having conversations with the proxy in the presence of the patient, or at least telling the patient the decision that was made after meeting with the proxy. I counsel this approach even when a patient is in a coma, so the proxy doesn't feel guilt afterwards, as though he or she had deceived the patient.

The case before us is even more interesting because of the ability of the patient to participate in conversation. In a recent review chapter on decision-making capacity, I discussed another case that raised some of the same issues.²

THE CASE OF MRS. BENSE

Mrs. Bense is a 75-year-old widow with advanced vascular dementia and end-stage congestive heart failure. She listens to a description of the benefits and burdens of having a do not attempt resuscitation (DNAR) order, and when her physician recommends it, she agrees. But the next day she has no memory of the discussion, so her physician repeats the consent process, and she again agrees. Her physician wonders if she can have capacity when her memory is so compromised.

ANALYSIS

The analysis of this type of case reinforces the value of including, as a component to the definition of capacity, that the patient makes a decision *consistent with her or his past choices*. This is a way to test for authenticity of belief. The ethical goal is to have a patient make autonomous choices, or choices that reflect his or her personality and represent the patient's core values or deeply held beliefs.

Including the criterion of consistency over time to our assessment of capacity has at least two advantages: (1) it helps to identify decisions made in a state of panic or anxiety that the patient may later regret, and (2) it emphasizes the link between the concepts of decision-making capacity and surrogate decision making, since surrogates of incapacitated patients are expected to make decisions that are consistent with those the patient made when capacitated.

The condition of consistency over time also comports well with the ethical methodology of narrative ethics. Narrative ethics holds that a human life is best seen as a story: it has a beginning, middle, and end, with each stage growing naturally out of earlier stages, and with identifiable threads woven through it that hold it together, such as the subject's personality, memories, values, goals, and social network. Memory is important, but is not the only source of strength with which to weave a life tapestry. At the edges one's story quite often frays. Judging someone to have capacity is then saying that the person ought to remain in charge of his or her life story, and have the right to decide its ending.

The cases of Mrs. Bense and of Mr. G demonstrate the potential importance of considering consistency over time. When physicians and ethicists discovered that the two patients had no memory of discussions the day before, they wisely repeated the entire informed-consent process. But when the patients made the same decisions again, it was appreciated that retaining the information wasn't necessary for the decision to be authentic and autonomous. Consistency sufficed for the team to be comfortable that the patients' choices represented their core values.

A fourth interesting consequence of adding consistency to the criteria for capacity is that the experts about consistency would be the persons who have best known the patient over time. Thus a capacity assessment in controversial cases will often have to include a family member, friend, or long-term careprovider

who has known the patient well for an extended period of time (that is, since the patient indisputedly had capacity). Such expertise can be more important in cases of this type than a psychiatric opinion.

This appreciation of the limited importance of memory is also a reminder of a well-known yet easily overlooked fact about capacity assessment. The commonly used Folstein mini-mental state test does not assess capacity, and using it for that purpose is a mistake.³ Folstein is designed to assess dementia, and is validated for that purpose. But it was never intended to be used to assess capacity. As a result, I would argue that a reference to a Folstein score in a psychiatry note responding to a request for a capacity evaluation is more of an indicator of confusion on the part of the consultant than the patient. Mrs. Bense and Mr. G would probably score less than a 15 on the Folstein, but were rightly judged to have capacity to refuse potentially life-sustaining treatment. (Interestingly, a patient can also score a perfect 30 on the Folstein and lack capacity, such as in cases of fixed false beliefs. The point is the same: the Folstein simply does not test for capacity.)

It is now a commonplace that any clinician should be able to assess capacity, and it does not require a psychiatric evaluation. I would add that any clinical ethicist is also a clinician while in that role, and must be able to have his or her own independent judgment of a patient's capacity. Capacity is one of the core issues in ethics consultation, and to feel that it lies in the domain of expertise of others would render ethics consultants nearly powerless in many of their consults. Some ethicists may fear this means having to have a clinical degree. But I do not mean anything of the sort.

Assessing capacity is not a technical skill requiring years of training, although it is a judgment requiring experienced, excellent communications skills and a finely tuned ear. Indeed it is more likely to be the technicians who find it hardest to do, because there is no physiological test, blood work, or scan that can replace good judgment.

What is needed for capacity assessment is a well-documented half-hour conversation with a patient about his or her illness and all of the reasonable treatment options. If the patient understands the options, makes a choice, and understands the consequences, then a note documenting those facts in the chart is adequate to determine that the patient has capacity and to legally justify orders crafted to achieve the patient's goals. It will be helpful if the note quotes verbatim a few of the questions asked of the patient and the patient's replies. These can prove enormously helpful to the staff and the family later in the hospitalization, should the patient lose capacity. The role of the family in this case is then limited to helping us to assess that Mr. G has the capacity to make this decision himself.

CONFIDENTIALITY

While based on a true case, many details in the story of Mrs. Bense have been left out, and others changed, to assure that no one can easily identify the patient.

NOTES

1. J.P. Spike, "Personhood and a Paradox about Capacity," in *Personhood in Healthcare*, ed. D. Thomasma and D. Weisstaub (Dordrecht, the Netherlands: Kluwer Academic Publishers, 2001); J.P. Spike, "Capacity is Not in Your Head," in *Variables of Moral Capacity*, ed. D. Thomasma and D. Weisstaub (Dordrecht, the Netherlands: Kluwer Academic Publishers, 2004); J.P. Spike, "Narrative Unity and the Unraveling of Personal Identity: Dialysis, Dementia, Stroke, and Advance Directives," *The Journal of Clinical Ethics* 11, no. 4 (Winter 2000): 367-72.

2. J.P. Spike, "Assessment of Decision-Making Capacity," in *Reichel's Care of the Elderly*, 6th ed. (Cambridge, U.K.: Cambridge University Press, forthcoming).

3. M.F. Folstein, S.E. Folstein, and P.R. McHugh, "Mini-mental state: a practical method for grading the cognitive state of patients for the clinician," *Journal of Psychiatric Research* 12 (1975): 189.