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Memento . . . Life Imitates Art: The Request for an Ethics Consultation

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The resident called the ethics consult service with a request that someone guide them through an unusual problem: Who should consent to or refuse treatment in the case of a patient who has an aggressive lung cancer but who also has short-term memory loss?

Thoughts of the film *Memento* come to mind, in which the main character, Leonard Shelby, spends the entire movie trying to identify his wife's murderer.¹ Although the character in the film can recall details before his wife's death, he has complete recent memory loss. The film is a masterful enactment of a man trying desperately to cue himself into his recent past through a variety of techniques. Our patient, Mr. G, like the film character, had lost virtually all of his recent past.

THE FIRST ETHICS CONSULT

In reviewing the medical record, Mr. G, a 58-year-old White male, had first been admitted after crashing his truck. It was determined that he had had a seizure at that time, although it was unclear if this was the cause or the result of the accident. He was released from the hospital but came back two weeks later with more seizures and mental status changes. During the diagnostic work-up that followed, an incidental finding on a computed tomography (CT) of his chest became crucial. Mr. G was found to have a very aggressive type of tumor, which can be treated early on, with a 15 percent rate of cure. The down side was that the chemotherapy regime would be very burdensome with expected side-effects of nausea, vomiting, fatigue, and hair loss. As this type of disease progresses, the impact of therapy becomes less potentially beneficial.

When this was first found, Mr. G's brother was brought into the conversation, as Mr. G had appointed him as his healthcare agent (proxy) upon admission.² He was asked to make a decision about starting chemotherapy. Based on his knowledge of his brother's values and given the poor prognosis, he declined the chemotherapy. Because the medical team was unsure who should be making the decision, they asked for input from the ethicist.

The ethics consultant met with the patient and found him to be appropriate but with virtually no ability to recall what had been said an hour earlier. According to his care team, the patient had been told repeatedly that he had cancer, yet when the consultant visited him, he had no recollection of this whatsoever. In fact, he was unsure of why he had been in the hospital for two months (unrelated insurance/placement issues). The consultant asked whether the patient would choose chemotherapy in a theoretical situation, to which the

patient replied that he would have to think about it. The consultant recommended that the proxy be the decision maker as the patient's ability to recall his condition impaired his ability to give fully informed consent about any treatment.

THE SECOND CONSULT

Mr. G had a number of adult children from whom he had been estranged. When he was hospitalized, they were notified and began to visit. Their relationship with their uncle, the proxy, was distrustful, and they began to question his decision to withhold therapy. When they visited their father, he seemed quite lucid and capable of decision making, so one daughter called the ethics service. This time a different ethicist was on call, and he felt uncomfortable leaving Mr. G out of the decision-making process since the patient was so lucid in the moment.

ETHICS GROUP REVIEW

The entire service convened (five consultants) to review the case. Questions raised in the group discussion included: What is the reason for the patient's memory loss and the prognosis for recovery of memory? What are the burdens and benefits of treatment for his cancer? Is his brother a true proxy, speaking in "his voice"? Did the patient appoint his proxy under duress? What reasons does the proxy have for withholding therapy? Has the patient been asked repeatedly about his thoughts on therapy? Is he consistent in his replies? Do the burdens of proposed therapy take on additional weight due to the fact that he will not be able to remember why he is having the symptoms? What is his current baseline in terms of symptoms? Is his current physical condition impairing his quality of life?

The oncologist was called during this meeting to address specific questions regarding the type of cancer, staging, therapy, and prognosis. Since a decision had been reached not to pursue active treatment, a thorough staging had not taken place since the initial diagnosis two months prior. The oncologist stated that if caught early, this cancer had a 15 percent curative rate and a 60 percent rate of response that would extend the patient's life, but likely only for about one year. However, because it was such an aggressive type of cancer, the two-month delay would necessitate staging now with the likelihood of further disease and worse prognosis. The chemotherapeutic regime would be rigorous with significant side-effects as mentioned earlier.

THE THIRD CONSULT

A third ethicist became actively involved after the group meeting. She spoke to the neurologist whose chart notes reflected a poor prognosis for regaining memory, although the etiology of the loss was unclear. There was a suggestion that brain metastases could be involved, but again, with the earlier decision not to be aggressive, the neurologist had no updated knowledge of the case, since he had not been involved for many weeks. When the attending hospitalist was queried, her response was to suggest that the ethics consultant speak directly with the neurology service, which, as mentioned, had not been involved for some time. Oncology had signed off the case as well, and again the hospitalist was not clear about treatment options as she had only recently encountered the patient. The ethical issues of fragmented care of a complex patient are worrisome, but are topics for other articles.

VISITING THE PATIENT

The patient's room was easy to locate on the cancer floor because there was a large sign posted saying "G's room." This was to help the patient to find his room, if and when he wandered. A similar sign was posted over his bed, across from a wall of family photos.

The patient was quietly lying in bed when the ethicist, Ms P, introduced herself as a member of the ethics team who was there to assist Mr. G in making decisions, or at least making sure that we were respecting his

wishes. He was asked about his living situation (couldn't remember), his designation of his brother as proxy (which he confirmed), and he was asked to identify persons (family members) in the photos (which he did without difficulty). Mr. G stated that he thought he was in the hospital but that he had no idea why. It was explained that his problems were twofold: (1) severe memory loss and (2) some newly diagnosed cancer. He readily acknowledged that he had a problem with memory but was shocked to hear that he had cancer. When asked about cancer treatments, he appropriately asked about side-effects. He was told that they would be nausea, vomiting, and hair loss, to which he shook his head. When pressed about whether he thought he might be interested in treatment, he said that it was a lot to think about.

LATER THAT SAME DAY

Ms P returned to the patient's room and asked if he remembered meeting her in the morning. He responded that she looked familiar, but he did not recall a morning visit. She again introduced herself and said that she was back to speak further about his wishes for treatment. He asked treatment for what? She gently said cancer. He again seemed shocked, asked if it was the bad kind, and when it was acknowledged that it was in his lungs, he began to cry. He then asked if he was being treated and was told no, that his brother did not think that he would want treatment. He said I have always said I didn't want to go through all of that. It's really about the quality of life and who wants to go through all of that? Ms P asked if he still felt that way, and he replied yes.

THE NEXT MORNING

Ms P made her final visit to Mr. G the next morning, since his daughter had requested a meeting to share her and her sisters' concerns about the treatment decisions. When Ms P approached the room, Mr. G was playing a card game with his granddaughter, very interactive and comfortable. She again introduced herself, and Mr. G again thought she looked vaguely familiar, agreeing to let his daughter ask questions and speak with the ethicist alone. The daughter told the tale of estrangement from the father, and more recently from the uncle who was thought to be withholding information from the daughters. The discussions of the day before were shared, and the daughter agreed with the plan to forego chemotherapy. After checking with the patient, permission was documented that medical information could be shared with the daughters.

DISCUSSION

Respect for patient's autonomy underpins decision making for healthcare in the United States. We expect patients to be informed about what is going on with their diagnosis and to consent or not to a proposed plan of care. However, when there is doubt about the patient's capacity to make such a decision, a thorough assessment is needed to evaluate this ability. One would be looking for a confirmation that he or she could understand the benefits, risks, and alternatives of any proposal and then be able to make a choice based on his or her values. In Mr. G's case, his inability to remember his diagnosis made the team question his ability to consent to a treatment that he could not foresee or appreciate in terms of benefits and risks.

CAPACITY VERSUS COMPETENCE

The appointment of the patient's proxy was undertaken when he was first admitted, and he reconfirmed this on multiple separate occasions. Because capacity is, by nature, task specific, the staff were comfortable that the patient did have the capacity to complete this appointment, as it seemed logical and consistent. He was also not globally incompetent, as a demented or unconscious patient would be. The criteria needed to ensure decision making regarding chemotherapy was more complex and sophisticated than appointing a proxy, and this was the source of the struggle between beneficence (trying to do right by the patient) and respect for the patient's autonomy (incorporating him into the decision.)

CONFLICT ABOUT TREATMENT

The patient's adult daughters were notified when he was admitted. They visited and brought a number of pictures to display, as well as their children, in an attempt to reconcile after years of minimal contact. In the moment, Mr. G seemed very lucid and appropriate. They did recognize his amnesia, but were concerned that their uncle might be making decisions that he could make himself. The proxy was adamant that he would not want any further work-up or treatment.

Because Mr. G's prognosis for recovery was not good, in spite of some uncertainty regarding staging, and because the burdens related to the therapy would not be understood by the patient in light of their potential benefit, much of the team felt comfortable withholding chemotherapy. Commenting on the burdens of treatment, one person noted, every day he wakes up sick and vomiting, it will be like a nightmare because he has no clue why he feels this way. Even when he is told, he cannot retain the information. This was the view of the proxy as well.

The other side of the argument supported further staging just in case Mr. G's prognosis would be better than originally thought. Therapy could possibly benefit him by giving him more time. His current quality of life was hampered by his memory, but his breathing was not yet a problem. Because he was able to enjoy his family's visits immensely and repair past breaks with his family, why not buy as much time as possible? He was not physically uncomfortable as yet. These were strong arguments on both sides, but which would be more consistent with Mr. G's individual values?

WHAT IS THE "RIGHT" DECISION?

Based on the patient's responses — "I'd have to think about that; that's a lot to consider" — one could argue that he might have considered therapy, but counterbalancing that were his comments: "My brother is saying what I have always said: 'What good is it if you don't have a quality of life?'. I still feel that way."

One of the particularly difficult aspects of this case was the heart-wrenching response each time the patient was told he had cancer. He was always shocked, and even cried. Repeating the diagnosis to ask him yet again what he might do began to feel cruel to the consultant. In the end, most of those concerned seemed to feel comfortable allowing his proxy to make decisions. The daughters were also given permission, by the patient, to access his medical information, which solved the trust issue with their uncle. Mr. G was ultimately discharged to a supportive facility where he would be cared for with the goal of comfort-care.

FINAL QUESTIONS THAT LINGER

Was this the right choice for Mr. G? Staging had not been ordered because of the decision to withhold treatment. What if he could have been in the small percentage of patients who would have responded? What if his prognosis had not been so poor? Would we have pushed harder for treatment? Would we have been more willing to accept his choice if he said yes to treatment, without involving a surrogate? Was he asked often enough to provide a consistent pattern? Did the discomfort of the consultant in repeatedly bringing up an unpleasant subject play out in protecting the patient or did it short-change him?

SUMMARY

This was a troublesome case, without complete consensus about the right thing to do. It seemed there were arguments on both sides: those who thought that the goal of comfort care without treatment was most consistent with his wishes, versus those who thought the additional testing and treatment might have produced a net benefit in spite of the burdens. Ultimately, the patient was placed in a facility with a do-not-resuscitate (DNR) order in effect and a plan for comfort care. He may live a few months or more. We all hope that whatever time he has is spent free of pain and symptoms, and that he is able to live a life of quality consistent with his wishes.

The main story line is consistent with actual events; however, there have been changes in terms of gender, disease, and relationships that have been included to protect the anonymity of the patient.

CONFIDENTIALITY

The names, genders, and family dynamics in this case have been disguised to maintain the confidentiality of the patient.

NOTES

1. J. Nolan and C. Nolan, *Memento* (Burbank, Calif.: New Market Capital Group, 2000).
2. NY State Proxy Law, 1991, Public Health Law article 29-c (2980-2994).