

Virtual Mentor

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ETHICS CASE

Invoking Shared Beliefs in End-of-Life Decision Making

Commentary by William J. Hogan, Jr., MD, and Juan R. Velez, MD

Mr. Getty's polycythemia vera had progressed dramatically over the last few months, even as he slowly regained function from his recent stroke. Mr. Getty had expressed more than once—emphatically—that he didn't want to do hospice at home. This meant that, when the time came, Dr. Burks, his longtime physician, would oversee his care in the several-hundred bed hospital a few miles away. The doctor had been able to persuade Mr. Getty to allow him to visit him at home every month or so, a rare concession on the part of the old cattle rancher.

Mr. Getty's wife stood at the door and swung it open as the doctor approached. He smiled. "Where's the young man?"

"None here!" came a voice from the other room. Dr. Burks and Mrs. Getty moved from the kitchen into the room in back, where Mr. Getty sat in an armchair in front of the television. He reached across for the remote and turned off the set. Dr. Burks reached down and shook his hand, then pressed his shoulder. For a moment the two men held each other in silent regard.

"How are your sores?"

"They hurt."

Dr. Burks listened to his heart, looked closely at his fingernails and hands for signs of bruising. He sat on the chair Mrs. Getty had set for him and crossed his legs.

"Looking all right, Mr. Getty," he said, opening his briefcase.

"Jan, grab those papers, will you?" said Mr. Getty. When she returned, the doctor took them into his hands and flipped through them. "Great, OK, advance directives..."

On the last page was a brief checklist. Suddenly the doctor was conscious of the print his wet finger was making on the page.

"Everything OK, Doc?" Mr. Getty looked at him.

"Uh, yes. Fine." But really he felt cold. Dr. Burks looked again. "Are you sure about this part?" he asked, pointing to the middle of the page.

Mr. Getty waved his hand in dismissal, or absolution. “Ah, I’m an old man, doc. I don’t want to be a burden on anyone. If it’s my time, it’s my time.”

The doctor stole a look over to his patient’s wife. She sat in the chair listening, then met his gaze. For a flash Dr. Burks was back at the bedside of his dying grandfather, feeding him ice cubes. Dr. Burks had been much younger then; his family had decided to withdraw his grandfather’s feeding tube for reasons he’d long since forgotten. Even in his obtunded state, far past coherence, his grandfather had lunged for the cubes, sucked on them desperately with noisy gulps. Dr. Burks looked down again and read through the conditions listed on the page: “...or (c) a minimally conscious condition in which I am permanently unable to make decisions or express my wishes...” His eyes lingered on the blue check mark next to the option, in that clinical language to which he had never grown accustomed: I do not want artificial nutrition and hydration.

Almost automatically, he finished the exam, shook Mr. Getty’s hand, and exchanged a few more kind words. He slipped the copy of the document into his briefcase. Mrs. Getty walked him to the door. “You know, Dr. Burks, you have been such a blessing for us,” she said. “I don’t know what we would do without you. And even if he doesn’t say it—” she glanced with a kind smile to the other room, then pressed closer, “it means so much to Dan that you’ll be the one there for him if anything happens.”

As he drove, the radio low, his mind lingered over the documents in his briefcase. He became more and more certain that it was a directive with which he could not comply.

Commentary

Dr. Burks was saddened by his patient’s remarks, yet it occurred to him that their conversation about his wishes for his care at the end of his life had just begun. As he made the trip back to his office, he considered his options: continue his care of Mr. Getty, follow the specifics of his advance directive, and so violate his moral principles, or tell Mr. Getty that in conscience he could not in every circumstance withhold nutrition and hydration from a patient and so had to recuse himself from his patient’s care. Burks had already ruled out the former and did not want to pursue the latter until he was certain he and Mr. Getty really could not agree. In fact, Burks realized there was a third option: initiate a dialogue with Mr. Getty, his wife, and his children, to explore their fears regarding suffering and incapacitation at the end of life. He would then share with them his thoughts on advance directives, the provision of nutrition and hydration, and the role of a physician’s conscience in his or her care of a patient.

While he had had this kind of conversation before with patients of different faith traditions and varying intensity of religious practice, this was different; he and Mr. Getty shared the same faith and moral tradition. Dr. Burks, in accord with Catholic moral teaching, considered the provision of nutrition and hydration not medical

treatment, but ordinary, humane care that should be given to patients unless its administration posed particular hardships and failed to provide any benefit. Usually the cost and effort involved are proportionate to the benefit foreseen, i.e., protecting a person from the discomfort of hunger and dehydration. If death were not imminent due to deteriorating clinical status, the cause of his death would be dehydration. And if depriving the patient of this ordinary care led to his death, it would constitute euthanasia [1, 2].

Dr. Burks reasoned that, when the wishes of a patient and a physician differ in significant moral decisions, both need to seek what is “morally right,” which at times does not coincide with one’s “wishes.” In his experience, when a physician and patient have the same moral framework it is easier to arrive at a shared judgment about the morality of a given medical action. Sometimes it will be up to the physician to point out what is morally right; at other times it will be the patient who makes the correct moral argument.

After thinking and praying a bit more about the situation, Dr. Burks collected some reading material he had previously given patients about advance directives and health care proxies (durable medical power of attorney), as well as on “ordinary” and “extraordinary” care (also known as “proportionate” and “disproportionate” care), especially as it related to nutrition and hydration—food and water—toward the end of life. He mailed this to Mr. and Mrs. Getty, along with a note that he looked forward to discussing these issues at his next visit.

Over the course of the next few weeks, Dr. Burks mentally prepared the topics he planned to address with Mr. Getty and his family:

- He would explore Mr. Getty’s fears regarding his physical deterioration as his polycythemia vera progressed. Dr. Burks wanted him to understand that his goal as Mr. Getty’s physician was to cure when possible, to always strive to ease his suffering, but not to unnecessarily prolong his life at all costs. Dr. Burks saw his role not as dictating what was to be done but rather as advising Mr. Getty of the best medical options. At the same time, he wanted Mr. Getty to know he could not comply with a patient’s wishes if they involved violating his moral commitment to never participate in ending a human life. For Dr. Burks, it was not a matter of his moral principles competing with his patient’s desires, but rather a challenge for both patient and physician to apply their shared understanding of the good to the specifics of the patient’s condition.
- Dr. Burks wanted Mr. Getty to consider the possible implications of his current desire to refuse nutrition and hydration were he to enter a minimally conscious state. He would tell Mr. Getty his memory of his own grandfather’s severe thirst and that provision of nutrition and hydration had been shown in a number of clinical situations to improve patients’ quality of life at its end [3]. In fact, the clinical scenarios in which nutrition and hydration cause harm are rare indeed. By referring to harm done when

excluding hydration of a patient and the rare occasions that a judicious use of fluids is harmful, the doctor can clarify the worries of a patient.

- Dr. Burks wanted Mr. Getty to consider replacing his advance directive with the naming of a health care proxy. Advance directives are by necessity very general statements that, given the multiplicity of clinical scenarios possible for any given patient, may or may not accurately reflect what the patient would have wanted in an unforeseen situation. As a result, implementation of an advance directive always requires *some person to interpret* the application of that directive to the specific clinical situation of the patient. Therefore, Dr. Burks considered the naming of a health care proxy very familiar with Mr. Getty's wishes, such as his wife, as a more appropriate and effective way to name the interpreter of his wishes were he to become mentally incapacitated. Dr. Burks would need to make it clear to Mrs. Getty that, if in the case of her husband's incapacity she asked for removal of fluids from her husband, he would only be able to do so if he considered that providing fluids would occasion Mr. Getty with a special burden.

Dr. Burks arranged his next visit to his patient's ranch for an evening so as to have more time to speak with Mr. and Mrs. Getty. They appreciated this gesture and the reading material and his explanation of his views regarding Mr. Getty's situation and options. Mr. Getty articulated his fear not only of pain, but of lingering for an extended period of time, unable to have some mobility and ability to communicate. He was reassured by his longstanding relationship with Dr. Burks and Dr. Burks' expression of his understanding of his role as a physician to cure when possible and alleviate suffering when curing is not possible. Mr. Getty understood that Dr. Burks had firm moral convictions regarding the care of dying patients and considered it unfair to oblige him to contradict those convictions [4].

At the conclusion of their visit, Mr. Getty expressed his willingness to reconsider his advance directive to refuse nutrition and hydration were he to enter a minimally conscious state, and to name his wife his health care proxy. Dr. Burks was reassured that he would not be required to compromise his conscience in his further care of Mr. Getty. Their open communication had helped both physician and patient appreciate the freedom and rights corresponding to their relationship. A physician is always free to decline to act in a way that violates the moral principles that he thinks are correct and binding. This freedom is protected by rights recognized in U.S. law, namely, the right to conscientious objection. A patient also has the right to choose his physician and to decline certain tests or treatments. This right has been recognized as patient autonomy and specifically as "informed consent" in all major ethics policy since the 1970s. Conflicts regarding moral decisions that arise in patient-doctor relationships can be resolved by a better understanding of the medical choices at play, the moral obligations of the two parties, or at times by a discontinuation of a given patient-doctor relationship.

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