Encountering Diversity: Medical Ethics and Pluralism

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ABSTRACT: An emerging issue in medical ethics is how to respond to the growing religious and ethnic diversity seen in American hospitals. This fictionalized account of a clinical case uses narrative ethics to explore decisions at the end of life in a pluralistic society. The author maintains that it is the rights secured for patients and their families by secular bioethics and its inherent respect for pluralism that allow for cultural and religious differences.

One Friday night several years ago, a Hassid met an unaffiliated young Jewish physican in the corridors of the hospital. Dressed in hospital whites, the resident was a study in contrast with his co-religionist dressed in black. To the surprise of the Hassid, the young physician said, "Good Shabbos." Thus began a relationship which would have implications for the doctor and the Hassid, whose 82-year old father lay in a room down the hall dying of inoperable lung cancer, suffering from end stage chronic obstructive lung disease.

"You're Jewish?" asked the Hassid glancing at the doctor's name tag. "Yes," said resident. "My name is Sephardic." "Oh." "Are you Mr. Friedman's son?" "Yes." "Good. I'm just coming on the case. I'll be his resident for the next five weeks." The young doctor introduced himself and they shook hands." "How is your father doing? When I saw him a hour ago he was having some difficulty breathing. I ordered a change in his inhalers and asked the nurse to give him a treatment. I was just coming back around to check on him." "Thank you. He's doing a little better, but he still is not able to talk."

The resident and the Hassid walked back to Mr. Friedman's room and the resident listened to his lungs. They were still obstructed, but the recent treatment had made things a little better. Though gratified that the patient was more comfortable, the resident knew that the situation was extremely grave. A decision would soon have to be made about Mr. Friedman, as to whether he

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would go down to the intensive care unit and be placed on a respirator or if they would try to keep him comfortable and let nature take its course. As the resident placed his stethoscope in his pocket, he asked the patient's son if they could go outside and talk.

The resident felt in his own heart as a doctor and a Jew that placing Mr. Friedman on a ventilator at such a late stage in his illness would place a terrible burden upon him and do little more than prolong the dying process. The ventilator would also cause the patient some discomfort. In addition, being in an ICU bed would limit the time that the patient could be with his family. He asked the son to consider these choices because his father did not have the capacity to participate in these decisions.

The doctor shared these views with Mr. Friedman's son and waited for the inevitable response.

"You know, doctor, we value life. Its worth is infinite. Each breath is of infinite worth because it is a piece of infinity. Besides, I cannot make such a decision." "But, you're his only child and closest relative. Who else can make this decision?" "My Rabbi." "Yes, of course. Will you speak with him and tell him what we spoke about? I am sure he is a learned man and that he will help you."

To the resident's surprise, the patient's son agreed to raise these issues with the Rabbi. Again they went over his father's prognosis, what might be accomplished by a transfer to the Intensive Care Unit, and at what cost.

They agreed to meet Saturday evening and discuss things further. For the young doctor, the time before that meeting was a reflection on the different worlds that he and the Hassid inhabited. They were both Jews, yet lived very different lives. Still, there was a bond and a closeness that Shabbos evening when they greeted each other and spoke as Jews about the dying patient who was also the stricken father. He was glad they could communicate across the cultural divide that has fractionalized modern American Judaism. He was pleased that their common history had bound them closely enough to allow them to work together on the patient's behalf.

Later, as he checked the computer for his patient's labs, the resident was glad he had had this discussion with the patient's son. He had seen too many times when end-of-life issues were not brought to the attention of families and patients. He knew how these omissions often led to treatment decisions which proved futile and burdensome. He had learned from reading the work of the medical ethicist Lawrence Schneiderman to distinguish the effect of these treatment decisions from their hoped for benefits to patients.¹ ICU care may produce a physiologic effect like raising the blood pressure or increasing the amount of oxygen in the blood stream. But the resident had seen how these physiological effects do not always result in benefit to the patient as a whole.

Thinking about the son's response the resident decided that whatever the Rabbi counselled, at least he had given the patient's family the medical information it would need to make decisions about care rendered at the end of life. The decision was now out of the hands of doctors who did not know the patient; it rested comfortably in the hands of his son. With the counsel of his Rabbi and the father's doctors, he had all the information he would need to make these value-laden decisions for himself.

Although it struck the doctor as ironic that the son would take this newfound authority and give it to the Rabbi, he was pleased that the decision would be reflective of the patient's values and beliefs and not imposed from without.

Only in America, the resident thought as he continued his rounds. Next to the old Hassidic Jew was a Chinese woman with liver cancer. A midwestern college kid was down the hall recovering from a bone marrow transplant. The patients each had their own religious and secular beliefs and personal and cultural views on issues at the end of life. A prevailing state, religious, or institutional ideology circumscribing the choices they could make could not satisfy them all and would be burdensome to most.

The young resident thought about this some more. If he had not been respectful of pluralism, a decision would have been imposed upon the patient which had little resemblance to the one they might have chosen. Curiously, he was most respectful of the patient's traditional beliefs by telling him of the rights which secular bioethics had secured for him. In our pluralist society one theological view, though prized by an individual group, can never be embraced as the exclusive religion. In America, Jewish doctors take care of Christian patients, Christian physicians attend to Jewish patients, to mention but some of the diverse possibilities. Here, where the enterprise of medical care and medical illness is equally shared by all religions and nationalities, we must respect pluralism. Indeed if one chooses to live in a theocratic community, it is a shared respect for pluralism that allows one to be different without being called deviant.

Difference counts and individuals have a right to make decisions about the care they receive. No one has a greater stake in these decisions than the patients themselves. This sentiment is articulated in the opinions of the great jurist Benjamin Cardozo. He wrote in 1914 that

Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages. This is true except in cases of emergency where the patient is unconscious and where it is necessary to operate before consent can be obtained.²

More recently, the Supreme Court decided in the Cruzan case that a competent adult patient has the constitutional right to refuse treatment and that refusals to accept artificial nutrition and hydration are no different from other interventions.³ These legal decisions follow from a decision-making hierarchy that instructs us to respect the choices individuals make for themselves and not to impose our own values upon others.⁴

This hierarchy starts with what the patient tells the physician or once told his or her doctor. This is called "expressed wishes." If we do not know just what the patient said, we try to reconstruct his or her beliefs through a process we call substituted judgment. Here we try to be true to the patient's philosophy and views. If we do not know what the patient said and cannot imagine what he or she might say, we are left with a "best interests standard." That is, what would a reasonable person do in the given situation.

A quick consideration will demonstrate that the best-interests standard is the most problematic. For example, if a patient were unconscious and we neither had knowledge of what was said nor knowledge of their beliefs, then the decision would have to reflect community standards.

Because community standards can vary, what is perceived as being in the patient's best interest may depend upon who is making the determination. For example, an unconscious pregnant woman who is transferred to a Catholic hospital in an emergency will likely receive obstetrical care that reflects Catholic teaching. In that hospital, the best-interests standard might favor the life of a fetus over the mother's. In a Jewish hospital it would be the life of the woman which is protected before the potential life of the fetus.

Resorting to a best-interests standard when considering this contentious point makes most decisions no more than an approximate fit. Unlike decisions which stem from articulated preferences, the best-interests standard does not accommodate individuals or individuality. In a liberal society, our individual personal and religious beliefs are protected when we value what patients articulate for themselves and do not try to impose a religious ideology upon them based on venue. Parochial institutions in a secular society, if they receive federal funds, have to respect a divergence of views under federal law if not American decency.

But even if we share the same religious beliefs, we may look at choices at the end of life differently. The work of Pearlman, Uhlmann, and Cain illustrates this point.⁵ They asked doctors, patients over 65 with chronic medical conditions, and their spouses about decisions to receive cardiac resuscitation under several scenarios.

First, would they want to receive resuscitation in their current health status? In this scenario, patients wanted to be resuscitated more than their doctors predicted but less than their spouses did. Suppose, however, the patients had a serious lung condition or suffered a stroke, what then? In this case the patients would want resuscitation more than their doctors predicted and not less. The spouses again were more likely to desire resuscitation for their husband and wife.

What does this tell us? Basically, that we view things differently and that we might make choices that do not represent the wishes of the patient if we fail to discuss these issues with them in the first place. Even well-intentioned doctors and spouses tend to misrepresent the wishes of patients because they fail to invoke the decision-making hierarchy just advanced. Instead they bring their own personal views to these decisions.

As the young resident was thinking about these issues, he planned for his upcoming meeting with Mr. Friedman's son. He decided that in the absence of clearly expressed wishes by the patient, he would encourage the son to make a decision that his father might have made. When they met later, they sat together in the quiet afforded by the solarium.

Without prompting, the son told the doctor, "My father never talked with me about his death and so I did not know what to do. I talked with the Rabbi. They were very close. At first we spoke about the value of my father's life, but I also told him what you said about the pain and the little time we'd have with father once he got into the intensive care unit." The doctor waited, and to his surprise, the son continued. "The Rebbe agreed with you. He said it would prolong the dying process and *halakically*—that is our law—it would be permissible for him not to go to the intensive care unit." The son wiped a tear from his eye, and said,"Thank you, doctor."

The Friedman family asked to take their father home so he could die with his family. With oxygen, inhalers, and high-dose steroids which would temporarily help his breathing, the old man was readied for discharge. Amidst his family and in familiar surroundings, his condition initially improved. He survived several days and then died with his son and grandchildren by his side.

The following year, Mr. Friedman's son moved to Israel and sent the young doctor *shmura matzoh* for his Passover seder.⁶ He also included a note that he had just had a son whom he had named Jacob after his father.

References

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- 6. Shmura matzoh is handmade matzoh that is prepared under strict Rabbinical supervision.