

KNOCK KNOCK ... WHO'S THERE?

*Incorporating Patient-centered
Spirituality Into Ethics Consultations*

BY DANIEL J. BRESSLER, MD

“Who is the person at the center of this medical process?” This question inevitably arises when I am called to assist the treatment team in handling a “biomedical-ethics” dilemma. The “what” of the person is well-documented in the chart: the H&P, the consultants’ reports, the lab and imaging results, and the pretty pictures of ugly diseases from the pathology department. The so-called “social history,” as recorded in the initial interview, usually lists such things as health habits (smoking, drinking, and drug use), marital status, and possibly present or pre-retirement occupation. The patient’s religion may be listed, along with the basic demographic information, just under their Social Security number and home address. “CTHLC” means Catholic, “JWSH” means Jewish, “PRTNST” Protestant, “MSLM” Muslim, etc., just as “DR” means drive and “CA” California. All this seems to answer the “what” questions but — at least from the perspective of a bioethical consultation — adds only the smallest amount to the “who” questions.

Who a person is can often best be answered by understanding his or her spirituality. I am using this overworked term — spirituality — to represent the realm of human identity that addresses itself to questions that are beyond the reach of quantitative agreement. It is about beliefs and thus, by this definition, about things that cannot be proven by facts. It is the source of the questions that are addressed by the founders and adherents of religion, philosophers, and also by writers, poets, filmmakers, and singers when they dive deep. The questions are, and always will be: Where did I come from? Where do I go after I die? What constitutes a good life? What constitutes a good death? One could call these questions “existential” or “philosophical,” but I think “spiritual” is both more specific and, in most contexts, less intimidating. Thus spirituality is the door on which we have to knock to find out who is there.

The answers to these questions end up being more useful to the demands of an ethics dilemma than do the typical denominational labels. Being a “religious Baptist” may indicate where a person spends his Sunday mornings, but not necessarily whether he wants to be defibrillated a third time. Knowing that that woman is a “practicing Hindu” often tells us little about whether or not she will choose to have her husband taken off pressors in light of a grim prognosis.

Sometimes I hear complaints that the treatment team delves insufficiently into the deeper aspects of a person’s spirituality. In their concern for the details of the technical and biological, the doctors, nurses, and ancillary personnel are said to give short shrift to the spiritual dimensions. To me, in the absence of a crisis that triggers such deeper investigation, this focus on the biological and technical facts seems

perfectly appropriate. When the goals of therapy are clear, when everyone is in agreement as to what should and should not be done, when progress is being made and “everyone is on the same page,” there seems to be no need to dig down to spiritual layers. It must also be said, however, that such straightforward circumstances rarely elicit the need for an ethics consultation.

Most consultations involve some stage of the dying process. And because, as Hamlet noted, death is that “undiscovered country from whose bourn no traveler returns,” we are, all of us, forced onto our spirituality for an answer as to what it means to be dead, i.e., “where we go after our final discharge.” Here is where we must start to dig down to the patient’s core beliefs for a way of taking into account one key factor (but obviously not the only factor) in guiding decisions. We must turn to beliefs in part because death sends us no reliable dispatches. We also know from this side of the divide (the land of the living) that dying, whatever our faith, is an almost universally frightening prospect. As one philosopher notes, the gap between being and nonbeing is infinite; the fear, for almost all of us, is the possibility of oblivion. And even for the most devout there is the sadness of not seeing those they love again in this life.

The sheer number of permutations of bioethical conflicts is an outgrowth of the multicultural nature of American society. There is no single or unifying spiritual foundation as one goes around the circle of the stakeholders: patient, patient’s family, treatment team members, clergy, and ancillary personnel. The conflict that triggered the consult may be as much from inside the family as elsewhere. It’s not much of a confabulation to recount the story of the atheist patient struggling to decide on code status between his bouts of septicemic delirium while his Evangelical Christian twin sister and estranged Catholic wife exchange angry glances in the ICU waiting room, each presenting their perspective to the Vietnamese Buddhist senior resident and Jewish ICU Attending.

An ethics consult can also be called when there seems to be too few voices rather than too many. This is particularly true when a patient is both unable to communicate and there is no reasonable person who can speak for him. The so-called “unrepresented” or “unbefriended” patient has no durable power of attorney for healthcare, no family, no one who knows him well enough to express his wishes, and, usually, no advance directives. The treatment team may be at the crossroads of a big decision. For both legal and ethical reasons, they do not want to get caught in the trap of just talking among themselves. The ethics committee can, among other entities, speak on behalf of the patient, discerning what they can about both what he would want, given the circumstances,

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and what are ethically acceptable clinical pathways, given the medical facts.

Ethics consults are triggered by the realization of one or more fundamental tensions between the principal players in the clinical drama. One common scenario is a conflict as to whether treatment should be directed at cure or palliation. Although it is always our intention as physicians to relieve suffering, sometimes our treatments actually cause acute pain, presumably in service to a higher good. We drain an abscess, amputate a numb but infected diabetic limb, cardiovert asymptomatic atrial fibrillation, and intubate a patient in pleasant hypercapneic narcosis all with the therapeutic justification of short-term pain for long-term cure. When the possibility of long-term cure becomes less and less likely, the pain-for-gain tradeoff starts to look ambivalent at best, and inhumane at worst.

The concept of hope often emerges in these medical dramas. Hope can be empowering when it, for example, allows a patient and her family to look beyond the grimness of current circumstances to see a way toward healing. Hope can be a distraction if it becomes a placeholder for denial or delusion. While it's true that one should never take away someone's hope, one role we play in ethics consults is to clarify the object of that hope. What, in fact, are the goals

of the therapy at this point? Pulling on that string leads us, again, to address such patient-centered spirituality questions as: What constitutes a good life and a good death? Hope is sometimes a fuzzy concept kept, deliberately or not, in a realm separate from measurability and likelihoods. How do statistical chances of survival mix with hope? How do you combine the conflicting results of a nuclear brain scan and EEG with the conflicting spiritual beliefs about eternity of a patient and his spouse? Such is the challenge of an ethics consult: forming a meaningful conversational bridge between the "spiritual/philosophical who" and the "factual/statistical what."

There are usually two undiscussed "elephants in the room" when dealing with an ethics consultation. The first "elephant" is the fear of legal repercussions. There is always a chance that an action or inaction by the treatment team (when in conflict with the wishes of someone else — patient, spouse, friend, a disgruntled treatment team member, etc., etc.) will lead to the subpoena of records and the entire disturbing process known as a malpractice lawsuit. The second "elephant" is that of justification of resource allocation — i.e., how do we deal with the fact that there are always more critically ill patients than there are ICU beds, more patients with bleed-

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ing and coagulopathy than there are units of fresh, frozen plasma in the blood bank, and more sick people than there are dollars to pay for their care? In some sense we are always robbing Peter to pay Paul. As Donald Berwick, Obama's new head of the Centers for Medicare and Medicaid Services, along with many others, has pointed out, we are already and always rationing but simply calling it by another name. My own experience at Scripps Mercy has been that, in conversation with families and physicians, nurses and lawyers, the direct appeal to law and money is not useful. Instead, returning to the spiritual themes allows a tacit and unthreatening way of weaving these themes into a conversation. "Do you think of your dad as a generous person?" "What are your sister's beliefs about the afterlife?" "How did Mom look on other peoples' children?" Such conversations do not eradicate these unruly elephants but can render them more docile.

What constitutes a "successful" ethics consultation? Is it (pick as many as you like):

1. a peaceful death?
2. an agreed decision to continue pressors, ventilatory support, transfusions, triple antibiotic therapy, dialysis, and proceed with the additional amputation?
3. the absence of a lawsuit?

4. the opportunity for the estranged son to come say his last farewells?

As you might guess, the variety of possible clinical outcomes is wide. Rather than a specific technical outcome (death, weaning from vent, transfer to a long-term acute facility, etc.), the outcomes are better characterized using emotional and social terms. I would say, whenever possible, we seek to create the opportunity for there to be some element of closure and acceptance among all the stakeholders in those cases when the patient dies in the hospital. We also seek to promote a vision on the part of the treatment team of being "of service." Sometimes there are storybook endings worthy of a Hollywood movie; sometimes there are endings filled with bitterness and frustration, worthy of a bad soap opera. In the final analysis, the ethics consultation is best seen not as a narrowly defined problem to be solved but as a messy process to be guided. At the center of that process is the spirituality of the patient, the layers of beliefs and identities that exist on the other side of the door labeled "Who's there?" **SDP**

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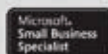


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