

Virtual Mentor

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ETHICS CASE

When Physicians and Surrogates Disagree about Futility

Commentary by Kenneth Prager, MD

Mrs. Smith was 46 when she suffered a cardiac arrest at home. Her 20-year-old daughter was with her at the time and called 911. Mrs. Smith was resuscitated by the paramedics and rushed to the nearest hospital, but had suffered severe loss of oxygen to the brain during the episode. She was admitted to the intensive care unit (ICU) and required intubation and mechanical ventilation. An EKG revealed that Mrs. Smith had long QT syndrome, which her daughter said had never been diagnosed. Her daughter insisted that “everything be done” for her mother.

After 2 months in the ICU, Mrs. Smith’s brain functioning had not returned or shown improvement; she had not awakened or been conscious of where she was or who was in the room. Mrs. Smith’s care had been complicated by infections from the intravenous lines into and from her body, kidney failure and the need for dialysis, and worsening heart function that required an intra-aortic balloon pump. Her physicians judged that further treatment would be futile; it was highly unlikely that Mrs. Smith would leave the hospital alive, or, if she did, it was likely that she would return within days or weeks. Mrs. Smith was too sick to be placed in an outpatient center and remained in the medical ICU.

The medical team, treating complication upon complication, believed they were not helping Mrs. Smith heal in any way. They felt that continuing aggressive treatment violated medicine’s fundamental “first-do-no-harm” precept. When end-of-life care measures such as comfort care, withdrawing treatments, or assigning do-not-resuscitate status to Mrs. Smith were suggested, her daughter became extremely upset, saying “My mom gave me life, how can I take hers away?” At one point her daughter broke down and said, “I would rather visit my mom in the hospital than in the graveyard.”

Commentary

The tragic case of Mrs. Smith illustrates an all-too-common ethical dilemma facing doctors in ICUs throughout the country. Seeing the daughter visit her mother daily, stroking her hair and kissing her, only the most hard-hearted individual could fail to be moved and feel empathy for this young woman whose most beloved person is lying unresponsive in an ICU bed with no chance of recovery.

And yet...

Medical technology has advanced to the point where it is getting more and more difficult to die in an ICU. We have machines that can replace failing hearts, lungs, kidneys, and the gastrointestinal tract. More potent antibiotics can treat myriad infectious agents. Sophisticated monitors enable physicians to maintain physiologic homeostasis in the most unstable of patients. These interventions are a godsend when they can help patients recover from devastating illnesses and injuries. But the flip side is that they can prolong the dying process for weeks or months in patients with no hope of recovery. The human and material resources expended can be enormous, and the emotional effect on clinicians who feel their professionalism compromised is significant.

The problem of what many would consider the misuse of sophisticated medical technology to prolong suffering and the dying process will almost certainly get worse as the tidal wave of baby boomers advances into old age in the next 2 decades, and the development of ever-more-powerful and -expensive medical technology continues. As the sad case of Mrs. Smith illustrates, there are no easy answers to this ethical dilemma, and both sides have compelling arguments.

“Medical Futility”

Not infrequently one reads in the medical record of a patient like Mrs. Smith: “further treatment is medically futile.” Although the statement makes a powerful declaration, implying that further treatment is inappropriate and even misguided, the statement is meaningless out of context. An action cannot be considered futile unless its goal is clearly stated. Continued ICU treatment of Mrs. Smith is indeed futile if its goal is to have her recover mentally and physically. If the goal of continued ICU treatment, however, is to keep her alive as long as possible, such treatment is anything but futile. From the viewpoint of the physicians who have in mind restoring the patient to a state of consciousness and medical stability, treatment is futile; from the daughter’s viewpoint it is extremely effective in realizing her goal of keeping her mother alive as long as possible.

Ethical Issues: Multiple Perspectives

From the perspective of Mrs. Smith’s daughter, patient autonomy is clearly an issue. When patients or their surrogates exercise autonomy by asking that treatments be limited and even that life support be withdrawn, physicians are unlikely to object, assuming that the reasons for these requests are reasonable. However, when patients exercise that same right of autonomy to make what are often perceived as unreasonable demands for “futile” interventions, physicians react differently. Patient autonomy must be respected not only when patients wish to limit their end-of-life care in accordance with a physician’s recommendations but also when they do not. Defining “reasonable” and “futile” is often difficult, based on values that may not be shared between physicians and their patients. This can lead to anger, distrust, misunderstanding, and failures of communication between the medical staff and families.

The point of view of physicians is very different. When physicians are asked by patients or their families to provide aggressive treatment in situations deemed futile for meaningful recovery, they often feel that they are violating the ethical mandate to avoid maleficence by contributing to their patients' suffering and violating their dignity. Clinicians "may feel distress at the lack of trust from the family and the fact that the family is not willing to follow their recommendations for withholding or withdrawing life support" [1]. In addition, physicians in these situations develop "feelings of distaste and even repugnance that administering such treatments without reasonable prospect of success amounts to the infliction of physical abuse on dying...people" [1].

In many cases, such as that of Mrs. Smith, however, there is no evidence that the patient *is* suffering. Such patients are often totally unaware of their surroundings because of brain damage or are sedated and narcotized for the sole purpose of sparing them the suffering that physicians invoke as a reason to withhold further treatment.

As for the physicians' claim that they are depriving hopelessly ill patients on life support of their dignity, this is a question for families to decide; different people have different notions of human dignity based on individual, cultural, and religious values that may not be shared by the treating physicians. "Families live with memories of the death of a loved one for years; certainly their religious, cultural, and personal preferences during that process should be honored, or at least tolerated, whenever possible" [2].

Physicians often cite the waste of costly medical resources as ethical justification for withholding life support technology from ICU patients who are clearly dying. However this argument loses force when monetary analysis of the savings to be had from withholding treatment from such patients fails to show that a dent would be made in the \$2.7 trillion U.S. medical budget. "Even if life support were consistently denied to patients whose situations met common definitions of futility, the monetary savings would be trivial" [3].

Is Legislation the Answer?

Physicians have been grappling with the issue of so-called medical futility for decades [4]. Not only has there never been an agreed-upon definition of this term, but only one state, Texas, has enacted legislation allowing physicians to unilaterally withhold or withdraw treatment in such cases with legal protection [5]. That there is not a consensus on how to define or deal with this issue, either in the medical community or in state legislatures, attests to its complexity and sensitivity. Legislators are understandably loath to grant physicians the power to make life-and-death decisions for patients against the wishes of their families. In addition, the U.S. population's diverse views and values on all matters, including death and dying, make it virtually impossible to create a national policy that would be acceptable to the vast majority of Americans. Lastly, the "can-do" attitude of Americans facing all sorts of challenges has given rise to an approach to sickness that some wags have

characterized as an American belief that “death is an option,” to be combated if one chooses, rather than an inevitability.

The absence of consensus on medical futility does not mean there is no appropriate way for physicians to handle this problem. They should do so with empathy, expert clinical judgment, skillful communication, and patience. This approach does not always enable physicians to persuade families to see things their way. But it is our only resource.

What is clearly *not* ethically acceptable is for physicians to withhold, withdraw, or in other ways modify their treatment of a hopelessly ill patient without the knowledge (and, except in Texas, consent) of the patient’s family. This is unacceptable deception. This does not mean that every conceivable intervention must be offered. On the one hand, it would be wrong to withhold from the family the fact that their loved one is developing renal failure in an attempt to avoid the question of dialysis; on the other hand, dialysis need not be offered if the clinical situation makes such an intervention medically inappropriate. This is a nuanced area and, once again, the definition of “inappropriate” might differ in the eyes of physicians and family. How to phrase this information is a skill that experienced and empathic physicians should learn. Optimally, the physician can take the burden of deciding against dialysis off the shoulders of the family, if they allow it.

Finally, there are many different scenarios that fall within the overall category “futility.” In the case of Mrs. Smith, the patient was not suffering, her daughter was sincerely involved in her care, and one can easily empathize with her desire to hold on to her mother as long as possible. But supposing Mrs. Smith had a daughter who was estranged, who flew in from afar to see her mother once, demanded that “everything” be done to keep her mother alive as long as possible, then left and was unreachable while complications kept recurring? Supposing Mrs. Smith had a huge and deep sacral decubitus, winced every time her wound was changed, developed severe anasarca, required multiple courses of pressors and antibiotics for recurrent episodes of sepsis, and was completing her fourth month in the ICU?

Clearly the latter two scenarios would try the patience and empathy of the most saintly physician—and rightly so. There is always the possibility of legal recourse, although most hospitals are loath to invest the time and expense to use this approach. There is no easy answer for cases in which the family seems not to be acting in good faith or in which patient suffering appears to be uncontrollable. But these cases are relatively uncommon and would not seem to warrant legislation giving physicians unilateral power to withhold or withdraw treatment *in all* cases of perceived futility.

The Future of EOL Decision Making

The coming decades will present formidable ethical challenges concerning hopelessly ill patients being kept alive at their families’ insistence with ever more sophisticated, powerful, and expensive technologies. The context in which these

challenges will play out has evolved as the role and the authority of the physician has changed. Eric Wold summed up this evolution nicely:

With medical information much more readily available through the internet and other media sources, physicians' authority and, similarly, the respect with which we are viewed by the public may have less to do with our clinical judgment...and more to do with our ability to participate in medical decision making as one voice among many. Although some may mourn the day when physicians were held in such esteem that they could consider unilaterally denying care, such regret misses the point of larger social changes that go to the very heart of the way in which physicians' authority is constructed. The better question is not, "What do doctors think is appropriate," but simply, "How can doctors share their wisdom?" [6].

References

1. Curtis JR, Burt RA, Why are critical care clinicians so powerfully distressed by family demands for futile care? *J Crit Care*. 2003;18(1):23.
2. Truog R. Treating medical futility in Texas. *N Engl J Med*. 2007;357(1):3.
3. Truog, 2.
4. Helft PR, Siegler M, Lantos J, The rise and fall of the futility movement. *New Engl J Med*. 2000;343(4):293.
5. Texas Health and Safety Code, sec 166.046, Texas Advance Directives Act, 1999.
6. Wold E. Letter to the Editor. *New Engl J Med*. 2000;342:1576.
<http://www.nejm.org/doi/full/10.1056/NEJM200011233432116> Accessed October 25, 2013.

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