



Scholl Institute of Bioethics

Bioethics Review

Vol 15 No 3

The Scholl Institute of Bioethics is a nonprofit, Judeo-Christian organization that addresses bioethical issues including euthanasia, physician-assisted-suicide, the withholding or withdrawing of food and water from non-dying patients, brain death, organ transplantation, genetic engineering, and the rights of disabled or mentally ill persons.

PATIENT AUTONOMY? DON'T BE TOO SURE

By Germaine Wensley RN

A recently developed protocol, futile care, may directly impact your life by posing a threat to your patient autonomy. Let me explain why.

When patients enter a medical facility, they usually expect that they or their surrogate will have full autonomy over care decisions, right? In the latter half of the twentieth century, greater recognition of patient autonomy led to that expectation. It gave patients the right to make decisions about their health care including the right to refuse recommended treatment even if death were hastened because of it, or even against the better judgment of their health care provider. Today's public is well aware of miracles that can happen with the right care because of medical technologies and capabilities never dreamed of in the past. "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 is compromised is significant," according to Dr. Kenneth Prager.¹

Health care decisions increasingly cause conflict and tension among physicians, patients and families because of the medical advances, and it appears that physician autonomy rather than patient autonomy is beginning to take center stage. This change was motivated by an increase in requests from patients for treatments deemed by the medical profession to be ineffective as well as costly. Nancy S. Jecker PhD explains this attitude from a physician's perspective, "Although the ethical requirement to respect patient autonomy entitles a patient to choose from among medically acceptable treatment options (or to reject all options), it does not entitle patients to receive whatever treatments they want. Instead, the obligations of physicians are limited to offering treatments that are consistent with professional standards of care and that confer benefit to the patient."²

Your health care decisions could be revoked.

But from a patient's point of view when a loved one is seriously ill, it becomes personal and emotional. To be denied care that you believe is desperately needed for your survival or that of your loved one is traumatic to say the least. How did we come to disregard patient autonomy?

As conflict increased between physicians and patients or their advocates over care, a protocol called futile care or medical futility began to emerge. It was quietly adopted by some internal hospital policies as well as some physicians' thinking.

What is futile care? Definitions are many and varied, and no particular one prevails. Futile care is not a strictly medical judgment but more a value judgment, and the definition seems to depend somewhat on who is doing the defining.

"In clinical practice, especially in the care of patients at the end of life, any intervention that will not improve a patient's health, well-being, comfort, or prognosis" is one medical dictionary's definition.³ An article in *Oncology Journal* states "If one considers that the goal of medical care is to achieve a benefit above a

certain minimal threshold, then futile care could be defined as care that fails to achieve that benefit. The sticking point, then, is not one's definition of futility, but one's definition of benefit. That is why the application of the word "futility" in discussions of medical care is considered ethically hazardous, especially when the values of the physician are incongruous with those of his or her patient."⁴

Attorney and bioethicist Wesley J. Smith writes extensively about the dangers in some interpretations of futile care. Metaphorically, he says, it means doctors are putting signs above the intensive care unit, similar to what you might see in a restaurant: 'We reserve the right to refuse service.' He describes futile care in this way: "When a patient reaches a certain predefined stage of age, illness, or injury, any further treatment other than comfort care shall be deemed "futile" and shall therefore be withheld, regardless of the desires of the patient or family. The personal values and morals of the patient are no longer relevant. End of story, and often end of life."⁵

“Medical futility has been conceptualized as a power struggle for decisional authority between physicians and patients/surrogates,” observes J.L. Bernat M.D.⁶ This policy remains ethically controversial for several reasons. For one, physicians and hospitals frequently assert their authority to deny life-preserving measures by working through hospital ethics committees. If this group says that a certain procedure or care will not be approved in that hospital, even if you find a doctor willing to provide the care, he won’t be able to carry it out there. For another, medical futility determination is often based solely on the physician’s perception, not necessarily the patient or advocate’s view. Cost containment also enters in. Healthcare providers may claim that a treatment is futile without truly knowing the relevant outcome because their focus may be on the financial burden. It’s not always unreasonable to hope that a patient may survive a futile care diagnosis.

My sister-in-law Anne, a brilliant, successful, business woman in her 60s is a case in point. She was hospitalized for treatment of acute cellulitis when septicemia set in, and she lapsed into a coma. After two months in ICU on a ventilator, feeding tube, and IVs, we were called in to the hospital for a family meeting to discuss her condition. By this time she was curled up into a fetal position. We were told she was in multi-organ failure, brain dead, and all treatment needed to be stopped since her liver failure and lung failure equaled death. Her HMO was also getting concerned about the rising costs. The physician who called the meeting happened to mention that her blood was full of toxins, and my husband (her brother) picked up on that. He requested that she have kidney dialysis started. At his insistence, the physician very reluctantly agreed to try it. We were fortunate that the doctor complied because within three days of starting kidney dialysis, Anne began to wake up! Then came the question of removal of the ventilator. Survival would be impossible if the ventilator were suddenly discontinued. So Anne was transferred to a specialty hospital where she was slowly weaned off the ventilator. Kidney dialysis was also discontinued as her kidneys started to work on their own. Eventually this “brain dead” woman went back to her full time job, as intelligent and capable as ever.

It appears that patient autonomy, in this technical age with the advent of futility care policies, is no longer a guarantee that your wishes will be met. When someone falls into the “futile” category, family members often find hospitals pressuring them for permission to end the patient’s life - and sometimes taking the family to court if they refuse.⁷

A majority of states have weighed in on the side of medical futility, and therefore don’t provide effective protection for patient autonomy. “The laws of all but twelve states may allow doctors and hospitals to disregard advance directives when they call for treatment, food, or fluids. The result being that if you want life-saving treatment - or even food and fluids - in most states you can’t be assured your desires will be honored, even if you make them clear in a valid advance directive.”⁸

That may be the reason Wesley Smith suggests that it could be coming to the point where patients and their families may want to have a lawyer on call when a loved one needs hospitalized. “To be sure, we are not yet close to imposing the explicit duty to die, but we cannot be passive. If a loved one is threatened with a futile-care imposition, we have to fight in the courts, if necessary, to protect their lives, rather than surrender—to doctors or faceless bioethics committees—the intimate decision about when to struggle on and when to let nature take its course.”^{9,10}

The public needs to be aware that, since futility care protocols have emerged, an individual’s autonomy for healthcare decisions could be revoked. Being informed is being forewarned. Losing the freedom to make your own medical decisions may very well mean you have lost everything. Lawrence R. Huntoon M.D., PhD. advises “If you’re a sick patient and want to live, you had better hope for a doctor who is able to play the ‘bureaucratic game’ well and who can tweak your quality of life score high enough so that the bureaucrats won’t demand your termination.”¹¹ If you or a loved one needs to be admitted to a medical facility it would be prudent to ask if the facility has a medical futility policy, and ask for a copy of it so you can know what you are up against. The problem, however, is that the institution may feel they don’t have to produce it. Might that mean patient autonomy is not acknowledged there?

NOTES

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8. “Will Your Advance Directive Be Followed?,” A REPORT BY THE ROBERT POWELL CENTER FOR MEDICAL ETHICS Originally issued April 2005, updated July 2015.
9. Smith, Wesley, “The Futile-Care Revolution: Killing Them Softly,” National Right to Life News Today, September 30, 2013.
10. Wesley J. Smith, “Futile Care Theory: Assisted Suicide’s First Cousin,” Human Life Review, August 18, 2008.
11. Huntoon, Lawrence R. MD, PhD, “Futility of Care Guidelines and The Killing Fields of the Future,” Medical Sentinel, Volume 4, No. 6, November/December 1999.

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