As a critical care nurse, you know how deeply affecting it can be to care for a patient whose medical treatment is considered futile. These patient situations aren’t just psychologically and emotionally challenging; they also can be intellectually challenging as you deliberate the ethics of withdrawing treatment, search for ways to communicate the concept and treatment modalities to others, and try to help the patient, family, and caregivers find peace. On the flip side, providing inappropriate or death-prolonging interventions and thwarting true comfort and dignity for the dying is ethically demoralizing. This also is a causative factor in moral distress and burnout for nurses.1-3

A hot button

Futility as a concept has been widely debated in the literature, but the definitions often refer to patients in either (or both) of these situations:
- medical treatment has become more burdensome than therapeutic, therapies are no longer of benefit to the patient, the likelihood of survival is nil, the patient’s quality of life is profoundly negatively affected, or the patient is imminently dying
- the goals of healing are no longer achievable.4

Dilemmas over medical futility occur more frequently now as a result of the patient rights movement of the 1980s and 1990s.5 As the patient or his surrogate assert their autonomy, they may seem to go against what the physician and nurse consider good for the patient. They may pursue care despite all medical indications that the patient isn’t benefiting from treatment or is sustaining multiple complications as a result of the original disease or its treatment.

The futility issue is of particular concern to physically or mentally disabled patients, who fear that they could lose decision-making autonomy to healthcare providers and institutions.6 Another issue is the allocation of scarce medical resources. However, because scarcity addresses decisions between patients (and not the benefit or lack of treatment for an individual patient), it’s universally decried as an inappropriate rationale for futility decisions.7

Reality check

Why do families pursue futile care against the advice of clinicians? Nurses in critical care say the primary reasons are cultural or religious factors and misperceptions regarding “the reality, complications, and limitations of ICU care.”8

You know the importance of ascertaining the philosophical, spiritual, and religious backgrounds of patients and families. This information provides perspective on the patient and family’s rationales for healthcare decisions. For example, if the family firmly believes in miracles of faith, waiting for God’s will is paramount.

When a futile situation occurs, most ethics committee consults are requested by physicians, but 20% of the time, nurses are the ones who call cases of futility to the attention of ethics committees.9

Many strategies to avoid or limit medical futility have been successful, including having early and regular team communication with the families of those who can’t voice their wishes, using rapid response teams to avoid patient transfer to critical care, using defined trials of therapy with time limits, having access to a clinical ethicist, and in the rare case of an impasse, taking the decision out of the hands of family members.8

Taking families out of a gridlocked decision-making process is just what Texas did when it amended its advance directives act in 1999. The amended act lets physicians and hospital ethics committees, faced with intractable differences between families and the medical team, engage in due process to handle these rare futility cases.10-12

Here’s how it works: After the patient’s care is declared futile by the physicians, the ethics committee reviews the case; if they agree, the family
is given 10 days to find alternate sources of treatment. The family is given a list of healthcare providers and groups that are willing to help with the transfer. If, after 10 days, the family hasn’t been able to transfer the patient, the hospital has no further obligation to continue futile treatment. The Texas act remains a source of legal challenge, confrontation and debate even now.

What can you do?
In many cases, the suggestions mentioned earlier for dealing with medical futility aren’t sufficient or won’t work. For example, families who lack healthcare familiarity and literacy may be unable to have the kind of discussions that are pivotal to decision making. Despite your efforts to educate the family and provide clear information, it may take days and weeks of discussion, and much repetition, until they understand the situation. Gathering the various healthcare professionals and working families for conferences is often difficult and may be impossible.

You can take some steps on the front end of illness, before futile situations occur. You can speak at civic meetings, in places of worship, and in schools to educate the public about advance directives and the limits of medicine. When you care for a chronically ill patient, encourage him to complete an advance directive as part of the regular assessment package.

Making such decisions a part of the usual healthcare dialogue would go a long way toward helping us honor the actual wishes of the person who is the focus of our care. This also would create a new and sustainable culture of openness about the limits of healthcare and would help minimize confrontation, ethical dilemmas, and emotional turmoil for all.

REFERENCES

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