

Medical Futility

Mary Jane Shevlin, BSN, MA, CPHRM, CPHQ
Princeton Insurance Healthcare Risk Consultant

A 75-year-old patient with irreversible respiratory disease is in the intensive care unit where repeated efforts to wean him from ventilator support have been unsuccessful. There is general agreement among the healthcare team that he could not survive outside of an intensive care setting, and the family insists that the physician "fix" it.

Medical futility is a subject of constant debate among healthcare providers particularly when the care to the patient is over a long protracted period of time, involves tremendous consumption of resources and there is no perceived improvement in the clinical condition of the patient. It remains a very complex and emotional issue that continues to be a challenge to the healthcare providers particularly because reaching public consensus is elusive.

As this debate continues, many experts advise against the use of the term "futile care." From the family's perspectives, care is never futile. The term "medically futile" refers to a situation in which the treatments or interventions can no longer achieve beneficial ends and are considered pointless; but who defines what constitutes beneficial ends? Today the determination of medical futility is made by the physician and is typically a result of the combined ethics, values, morals, experience and perspectives of the physician. From the physician's perspective, medical futility is described as proposed therapy that should not be performed because it will not improve the patient's medical condition or won't achieve a "legitimate goal of medical treatment."

In the best case scenario, when death is imminent and the family has accepted the inevitable, consensus is reached between physician and patient/family. A mutual decision is reached to forego "heroic measures," and other life-sustaining interventions, ensuring everybody is at peace with the decision.



What if the patient or family requests an intervention that the physician or healthcare team considers futile?

In the above situation, it is important to encourage the patient/family/proxy to explain their rationale. This ongoing discussion may elicit concerns around specific issues, such as cultural outlook regarding health, medical treatment and death. It also provides an opportunity to clarify any misunderstandings and have a handle on what is acceptable for each patient and family. For some, the goals of care may be being comfortable, pain-free but not "drugged-up" and maintain some "control over their care"; for another it may be the wish to survive for the next two weeks to see a daughter or son get married.

The role of the physician in all of this is really to communicate to the family or the patient the possible outcomes and to bring out their preferences. During the 2002 American College of Surgeons Symposium on medical futility, Dr. Timothy Pawlik spoke about the nature of the patient-physician relationship. He believes it is a fiduciary one wherein physicians are expected to serve the best interests of their patients over their own self-interests. Oftentimes, the patient and family members look to the physician for direction particularly when medical intervention involves complicated technology in an accelerated pace such as in the intensive care units. It is also a place where heroic measures are often exercised to support life not where care is withheld or withdrawn. However, it is in these settings where conflicts regarding medical futility may start.

Texas tackles medical futility with a model

While the national debate about medical futility and end of life care and conflict continue, Texas provides a model policy. The decision and judgment regarding medical futility is placed in the hands of the physician who is

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Vice President of Healthcare Risk Services
Tom Snyder x5852

Manager, Healthcare Risk Services
Phyllis DeCola x5897

Phone: 609.452.9404

www.RiskReviewOnline.com

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guided by his medical experience with input from trained ethics experts.

The Texas Advance Directives Act of 1999 is also known as the Texas Futile Care Law.¹ The statute reserves the determination of what treatments are futile to the medical personnel treating the individual patient. The law provides for a multidisciplinary approach in the event of a disagreement between the medical personnel and family members to resolve the dispute. If a difference of opinion arises, an ethics consultation is called, and the family must be given 48 hours to be involved in the consultation process. In addition, they are also provided a written report of the findings of the ethics review process. If the ethics committee fails to have the parties reach an agreement, and the medical personnel want to stop medical treatments, the family has ten days to find another facility that is willing to offer the treatments and have the patient transferred there. After ten days, if plans to transfer the patient have not been made and the family has not received a legal extension, the medical facility can withdraw care.

This new Texas Advance Directives Act apparently has been used numerous times to address this often difficult situation in the state and is reported to bring benefits to patients, families, physicians and healthcare institutions. This law provides full legal immunity to the medical personnel, if the process as stated in the law is strictly adhered to. It has provided not only a "legal safe harbor" but also a "moral safe harbor" by providing a process of consultation with parties who are not involved with the treatment of the patient.

In the absence of a state law in New Jersey that addresses such conflicts between the patient/family and the medical providers, physicians have considered such options as offering the patient/family a transfer to either another physician or facility. Transfers appear to be a satisfactory compromise that helps the current physician or provider avoid inappropriate treatment and allows the patient to get the treatment that he or she wants. Although this option exists, it is often difficult for the patient/family/proxy to find a new provider or facility. There is a great reluctance in accepting a conflict-ridden case. Another option is to access the bioethics committee of the hospital. The bioethics committee is largely composed of multidisciplinary practitioners who can provide consultation and opinion. However, the role of the committee is advisory and therefore not binding.

Faced with the limited mechanisms with which to handle medical futility disputes, bioethicists recommend that physicians take a proactive approach and encourage individuals to engage in advance care planning. This type of planning moves beyond developing a living will and/or establishing a power of attorney for healthcare decisions.

Advance care planning

The best time to hold discussions about end-of-life care with patients particularly those with chronic conditions is before the patient becomes "terminally ill". It is beneficial to bring in the family /proxy in these discussions

so everybody gains a better understanding of the patient's personal treatment preferences under certain situations. It may also provide the physician an opportunity to discuss the patient's as well as the family's concerns or fears and reconcile their differences about end-of-life care.

Typically, advance care planning involves preparing for end-of-life issues and ideally includes the completion of a living will, a **durable power of attorney for healthcare** (DPAHC), and specific **end-of-life treatment preferences** (ELTP). A living will is a written statement of a patient's wish about the type

of care to have or not to have, or to withhold or withdraw life-sustaining treatment if they became terminally ill. Currently, these provisions vary from state to state. In New Jersey, under the N.J. Stat § 26:2H-53, (New Jersey Advance Directives for Healthcare Act) the advance directive/living will becomes operational when the patient no longer has the ability to make decisions about his/her health care

The important difference, however, between a living will and a DPAHC is that the living will gives instructions about end-of-life care preferences *without* appointing a healthcare representative. In contrast, a DPAHC is a legal document that allows individuals to designate a person to make medical decisions for them if they are unable to do so. The DPAHC is less specific than a living will and applies to all situations in which patients are incompetent and unable to make their own decisions.²

End of Life Treatment Preferences (ELTP)

Making the decision regarding ELTP is always difficult; however, an early understanding of the patient's preferences and treatment goals eventually spares everyone the difficult task of

second guessing the patient's wishes. The decision on the goal of treatment, options, and alternatives and how aggressive the treatment should be are discussed with the patient and the family/proxy. Addressing these preferences before an acute event then eliminates the stress and emotional burden that are associated with the illness and makes the family feel comfortable and confident that they have carried out the preferences of their loved one. This fosters shared end-of life decision making.³

Prior to talking with a family/proxy, it is critical that the physician and healthcare team agree with the information and how it will be provided so that the family is not confused by different options and opinions. The options should always include alternatives including a choice of palliative or comfort care, and a reminder to the family/patient that refusing a medical intervention does not mean that no care or no further treatment will be given. It is also important to inform the patient and family that palliative care is a form of treatment.

When discussing palliative care in the context of ELTP, it may be helpful to provide the family/proxy with information about resources, such as hospice care or chaplain services. It is essential to reiterate that the goal of treatment is comprehensive care focused on comfort and optimizing the

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quality of remaining life.

Do Not Resuscitate (DNR) or Allow Natural Death (AND)

The 1990 Patient Self Determination Act (PSDA) has encouraged physicians and hospitals to ask patients about their advance directive and establish whether the patient requests a do-not-resuscitate (DNR) order. The act requires Medicare and Medicaid providers to give adult individuals information regarding their right to direct their own health care decisions, the right to accept or refuse medical treatment as well as the right to prepare an advance directive. This regulation provided the impetus for discussing and clarifying patient's treatment preferences in the event of a catastrophic illness. It is almost two decades after the enactment of the PSDA and hopefully physicians and other healthcare providers are more comfortable in discussing end-of-life treatment preferences.

Today, a new trend is emerging for healthcare providers to encourage patients to declare an acceptance of natural death (Allow Natural Death, AND) when medical interventions are deemed medically futile. It is allowing nature in essence to take its own course. Increasingly, these decisions are being noted on charts within all healthcare settings, i.e., hospitals, nursing homes, hospice and home health settings.

The concept of "AND" is gaining acceptance in health care and seemed to be the preferred term. Proponents of the term "AND" suggest that it is a more positive and compassionate approach to death and dying while "DNR" as a terminology has a negative connotation which occasionally can be construed as "do not treat". The National Hospice and Palliative Care Organization has developed criteria (CARING)⁴ to identify patients who might benefit from a palliative approach to care.

As in any of these situations, a frank discussion of death and end of life issues should be initiated when the patient is still well enough to make his or her preferences known to the physician and his/her family. ❖

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Resources:

¹Robert L. Fine, MD. Medical Futility and the Texas Advance Directives of 1999. Baylor University Medical Center Proceedings Vol.13, No2 April 2000; 13:144-147

²<http://www.nia.nih.gov/HealthInformation/Publications/LongDistanceCaregiving/chapter19.htm>

³Syndney M Dy; Gary Shapiro: Beyond Futility: Good Shared End-of-Life Decision-Making Takes Ongoing Discussions, Realistic Goals Oncology. Vol. 22. No.8 July 1, 2008

⁴National Hospice and Palliative Care Organization website: www.nhpco.org ❖