Choosing the Right Medical Treatment at the End of Life

Thaddeus Mason Pope

On November 30, 2010, the University of Maryland and the Maryland Healthcare Ethics Committee Network (MHECN) hosted an all-day conference at the University of Maryland Medical Center titled "Medical Futility and Maryland Law." It was attended by over 200 healthcare professionals, including physicians, nurses, social workers, chaplains, risk managers, lawyers, and others. A video of the conference is available on the law school's website: www.law.maryland.edu/faculty/conferences/detail.html?conf=104. The topic of this conference is, and should be, of interest to Maryland seniors.

Medical futility typically refers to a type of conflict over end-of-life medical treatment, usually the type of treatment provided in a hospital's intensive care unit. In these disputes the patient almost never has capacity (sometimes referred to as competence) to understand and make treatment decisions. So, healthcare decisions are made by the patient's substitute decision makers: whether patient-appointed, court-appointed, or default. The paradigmatic medical futility dispute is one in which the surrogate requests aggressive treatment interventions for an imminently dying or catastrophically chronically critically ill patient. But that patient's providers consider such treatment to be medically ineffective and/or ethically inappropriate.

For example, patients over age 85 undergoing in-hospital cardiopulmonary resuscitation (CPR) have only a 6% chance of surviving to hospital discharge. Those with pre-existing co-morbidities are even less likely to survive. And many of the very few that do survive have significantly poorer neurological and functional states than they did before cardiac arrest. In short, physicians are reluctant to pound on a patient's chest, break ribs, and otherwise cause suffering and burdens, when there is no corresponding benefit to be gained. When death is unavoidable and continued life-sustaining interventions can only make death more uncomfortable, providers frequently determine that palliative care (which focuses on the relief of pain, symptoms and stress of serious illness) is most appropriate.

Fortunately, the vast majority of medical futility disputes are resolved through good communication. When the treatment team meets with the patient's family (often on several occasions) and carefully explains the prognosis, they almost always reach consensus. Still, in a small but significant subset of cases, conflict remains intractable. The conference focused primarily upon these intractable cases.

The 1993 Maryland Health Care Decisions Act (HCDA) provides that life-sustaining medical treatment (such as dialysis, a ventilator, artificial nutrition and hydration) may be withheld or withdrawn from incapacitated patients only with the consent of an authorized decision maker, except in two circumstances: (1) where treatment is "medically ineffective" and/or (2) where treatment is "ethically inappropriate." But the statute defines these terms in such a narrow way that these exceptions do not apply to most futility disputes. Furthermore, even when these exceptions do apply, the statute still requires providers to continue complying with treatment decisions unless or until the patient is transferred to another provider or facility. Since such transfers are almost never found, the statute effectively requires providers to comply with surrogate requests for aggressive curative treatment that they consider non-beneficial, burdensome, and even cruel.

This deleterious effect of the statute has been measured and confirmed. In 2010, the MHECN conducted a survey of medical and legal professionals in nearly fifty Maryland hospitals. Survey respondents felt that the HCDA does not sufficiently empower them to resist inappropriate treatment demands. Indeed, providers often feel as though they are torturing the patient. Still, they usually comply with surrogate decisions for such treatment due to fear of litigation. In short, the "medically ineffective" and "ethically inappropriate" provisions in HCDA do not provide an adequate mechanism for resolving intractable medical futility disputes.

Still, a separate HCDA provision is of some use. When a surrogate makes a treatment decision that clearly contradicts what the patient would have wanted, the provider need not comply with that decision. The HCDA provides: "Any person authorized to make health care decisions for another under this section shall base those decisions on the wishes of the patient and, if the wishes of the patient are unknown or unclear, on the patient's best interest." In other words, surrogates must make decisions that reflect the patient's values, preferences, or best interests. Otherwise, they act outside the scope of their authority. Surrogates who are not faithful agents can and should be replaced.

While effective and functional in some cases, surrogate replacement is hardly a complete solution to medical futility disputes. Most patients have not completed any advance care planning. Of the 34% of Marylanders who have completed advance directives, those directives are usually unavailable when needed. And even when available, those directives usually fail to speak to the patient's current clinical circumstances. In short, there is often no evidence of patient preferences. Consequently, it is impossible to demonstrate any contradiction between those preferences and surrogate decisions. While we know, statistically, that few of us would want to live in an extremely compromised condition, particularly if cognitively unaware, providers often do not know what any particular patient is

willing to live with. In such cases, there are rarely grounds to replace a surrogate requesting treatment that providers determine is inappropriate.

In the afternoon sessions, the November 30th conference turned from educating the participants to soliciting their ideas and suggestions. Most participants seemed to agree that revisions to the Maryland HCDA are in order. Providers need to be able to "stand up" for their patients. The tough work is designing a dispute resolution mechanism that can act with the real-time speed these cases demand, yet include sufficient safeguards to ensure due process protections like neutral and unbiased adjudication. Proposed "futility" provisions to the Maryland HCDA would primarily affect Maryland seniors. You should be engaged in this earnest and profound debate.

Thaddeus Mason Pope is a law professor at Widener University in Wilmington, Delaware, where he writes and speaks on end-of-life medical-legal issues. www.thaddeuspope.com