

ARE FUTILITY POLICIES THE ANSWER?

Caregivers Must Improve Communication with Patients and Their Families

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Should hospitals develop policies to deal with requests for what is often termed "futile treatment"?* This question has been around almost as long as the futility debate itself. S. Y. Tan, MD; Bradley Chun, MD; and Edward Kim, MD, in their article "Creating a Medical Futility Policy" (p. 14), answer this question in the affirmative. They not only argue in favor of developing a futility policy, they also detail the process they (and others) undertook in developing such a policy for their own health care facility and present the policy itself. Although the authors recognize at least some of the risks in having a futility policy, they believe these are outweighed by the benefits, which they cite throughout their article.

We agree with Dr. Tan and his colleagues regarding the benefits and risks of hospital futility policies and even concur that such policies can serve a useful function, though in a limited number of cases. Yet, despite our overall positive impression of these policies, we do have some concerns. Chief among them is that futility policies can easily become the dominant mind-set and mechanism for addressing conflict in end-of-life decision making. This is particularly true when such policies are not situated within a broader vision of and more comprehensive approach to end-of-life care. If and when this occurs, futility policies might actually cause more harm than good by breeding mistrust of caregivers, robbing

the dying patient and family of precious time, and exacerbating the already adversarial environment in health care. To prevent this from happening, futility policies should be one aspect of a larger effort aimed at enhancing communication and preventing conflicts from arising in the first place. By themselves, such policies cannot adequately address the root causes and issues underlying requests for futile treatment.

In what follows, we wish to discuss elements of a more preventive approach to managing so-called futility cases. We outline three general strategies (by no means exhaustive) that focus primarily on familial requests for futile treatment. We realize, of course, that at times such requests come from patients themselves. In using the term "families," we wish to include surrogates and legal guardians.

ENHANCE COMMUNICATION

One of the major contributing factors to family requests for futile treatment is inadequate communication between the family and caregivers. The possible difficulties here are several. At times, a pattern of regular communication between the family and the patient's physician is not established from the outset. This leaves family members feeling that they do not know what is happening and that they have no input into or control over the plan of care for their loved one. They feel "in the dark" because they are not receiving the information they need and want. Because their questions are not being adequately answered, they may be "chasing" the physician or other caregivers in order to try to obtain information. This may rather quickly contribute to a sense of marginalization. Families feel like bystanders rather than participants or collaborators in charting a course of care consistent with their loved one's wishes and values. In time, usu-



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*We do not necessarily like the term "futile treatment," given the definitional issues and baggage surrounding it. We prefer the more descriptive term "nonbeneficial treatment." However, since futile treatment is used in the accompanying article by Drs. Tan, Chun, and Kim and is the one most often employed in discussions of the topic, we will use it throughout our article.

ally a very short time, this lack of communication and participation breeds frustration and anger and, on occasion, a desire to seize control.

Poor communication between caregivers and families creates fertile ground for requests for futile treatment to arise. In some instances, these requests may be a somewhat desperate attempt on the part of family members to assert them-

selves and regain some control of and authority over the situation. In other instances, the lack of communication prevents the family from understanding their loved one's situation and precludes them from keeping pace with the actual course of his or her condition. Consequently, they have neither the necessary factual understanding nor the psychological preparation to hear, much less accept, a physician's suggestion of "withdrawal of treatment" or "limitation of treatment." They are not ready cognitively or emotionally for what is being recommended. They may well be thinking: "How can this be? Things really can't be this bad. We want everything done!"

Such situations are also often complicated when the family is given conflicting information by the various caregivers. Physicians, and even nurses, caring for the patient may vary in their assessment of the patient's condition, the course of his or her disease, possible remaining interventions, and the likelihood of an intervention's success. Conflicting information not only creates confusion, it also creates doubt. In the face of doubt about the seriousness of the patient's condition, the course of his or her disease, or the possibility that some treatment might still be beneficial, families will often opt for the most positive interpretation, the one that offers some glimmer of hope, and insist on continuing an aggressive course of treatment.

Better communication between caregivers and families would likely go a long way toward reducing the instances of requests for futile treatment. What might "better communication" entail? First, it would entail keeping families informed and involved early and throughout the course of their loved one's illness. Doing so would necessitate regular and ongoing communication with family members, enabling them to participate in some way and to some degree in determining the

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plan of care for their loved one. This undoubtedly requires time. However, time invested along the way will be time saved by averting crises and conflicts.

Second, it is critical that families receive adequate information in easily understandable terms and are relatively clear about the *implications* of that information for their loved one and his or her treatment options.

This process is, in part, an attempt to help families understand the patient's current situation and possible future developments. A clear understanding of the latter may be especially helpful in preparing family members psychologically for possible eventualities, thus facilitating a more realistic understanding of their loved one's condition and more appropriate treatment choices, should these eventualities arise. Psychological preparation for what could occur in the course of the patient's disease helps minimize the shock factor as well as impulsive reactions to what had not been foreseen or even implicitly or explicitly denied.

Third, it is critical that all involved in a given case be clear about the goals of treatment throughout the course of the patient's disease. Clarity (and agreement) about goals also involves an assessment of whether those goals are realistic and potentially attainable. Only when there is clarity and agreement about goals of treatment can there be a meaningful discussion of possible *therapeutic interventions*. Requests for futile treatment arise out of a lack of common understanding concerning what may be achievable goals for the patient and which interventions might help achieve those goals. Needless to say, determining treatment goals is an ongoing process. Goals will change (at least to some degree) with the patient's condition. Periodic review by all parties is therefore essential.

Finally, great care should be taken in deciding how treatment options are presented to families. Too often it is in the manner of a "buffet." All or most treatment options are laid out, and families are invited to choose what they wish. Questions like "Do you want us to do everything?" or "What do you want us to do?" are invitations to conflict. There is no medical, legal, or moral requirement to offer families every conceivable

treatment option. Only treatment options that are medically appropriate and that offer hope of benefit to the patient should be offered. To do otherwise would seem to be an abdication of professional responsibility on the part of physicians, who have the training and experience to judge which modalities are likely to be of benefit to the patient. The "buffet" approach is confusing to families and paves the way for unrealistic and unreasonable requests.

These considerations surely do not exhaust the components of good communication between caregivers and families, but they do highlight some of the elements that are critical to avoiding or at least diminishing instances of requests for futile treatment. A major challenge still ahead—and one that cannot be addressed here—is *how* to improve communication between caregivers and families. There are, however, programs (e.g., Northwestern University Medical School's Education for Physicians on End-of-life Care [EPEC]) and print resources (e.g., JAMA's "Perspectives on Care at the Close of Life" issue [November 15, 2000] and Robert Buckman's *How to Break Bad News: A Guide for Health Care Professionals* [Johns Hopkins University Press, Baltimore, 1992]) that could be helpful in improving communication skills.

ONE CONVERSATIONAL PROCESS

At times, making use of a defined process for having important conversations can also be helpful. One such process follows.*

Establish the Setting It is important that the attending physician, having first ensured comfort and privacy for their conversation, sit down with the family (and the patient if he or she can be involved). The physician may introduce the issue by saying something like: "I'd like to talk to you about possible health care decisions that might need to be made in the future."

Determine the Level of Understanding The attending physician might ask open-ended questions to find out what the family (and the patient) knows and understands about the patient's diagnosis and prognosis. The physician might consider asking this question: "What do you understand about your loved one's (or 'your' in the case of the patient) health situation?" The physician should fill in any gaps in their understanding in clear and easy-to-comprehend terms and give them time to

absorb any new information.

Clarify Values and Hopes It would then be important for the physician to talk to the family (and, of course, the patient if he or she is present for the discussion) about the patient's deeply held values and hopes for the future, perhaps by asking questions such as: "What makes life meaningful to your loved one (or 'you' in the case of the patient)?" "What does your loved one (What do you) value most about life?" "What conditions would your loved one (you) not want to live in?" "What is an acceptable quality of life for your loved one (you)?" "What does your loved one (What do you) expect for the future?" Most families (and patients) will take this opportunity to share their thoughts about living and dying. If the attending physician notices a sharp division between what he or she thinks is reasonable and what the family (and/or patient) thinks is reasonable with regard to treatment, he or she should now express those concerns and clarify any misconceptions.

Discuss Shifting Goals of Treatment The attending physician should, in language they can understand, share with the family (and/or the patient) his or her thoughts about the lack of benefit regarding the treatment in question. The physician should be firm yet compassionate in stating the reasons why he or she thinks the treatment would not promote the patient's overall best interest and is not, therefore, a viable option. Also, the physician should point out the care options available to the patient (palliative care and hospice care), and be sure to inform the family (and/or patient) that limiting treatment does not mean abandoning appropriate care designed to promote comfort, dignity, and emotional and spiritual support. Emphasis might be placed on what can and will be done rather than on what will *not* be done. The phrase "There's nothing more we can do" should probably never be used in this type of conversation.

Respond to Deeper Needs This is an extremely trying situation for the family (and/or patient). Along with providing medical information, the attending physician should be attentive to and respond to the psychosocial and spiritual needs of the family (and/or patient). He or she would be well advised to seek help from pastoral care and/or social services to provide assistance in addressing the family's (and/or patient's) emotional and spiritual needs.

Devise a Care Plan If agreement is reached with the family (and/or patient), the attending physician should establish a care plan that is attentive to the patient's values and to the family's (and/or patient's) emotional and spiritual needs. It is absolutely critical that the attending physician

* This process is based on suggestions for discussing do-not-resuscitate (DNR) orders in Charles F. von Gunten and David E. Weissman, "Discussing DNR Orders in the Clinical Setting: Part 1," *Midwest Ethics Committee Network Newsletter*, September-October 2000, pp. 1-2.

maintain lines of communication with the family (and/or patient) throughout the dying process and continually update and comfort them. In fact, the physician should be present as much as possible and keep company with the patient and the family as the patient approaches death.

COUNSELING AND SUPPORT

A well-known and essential component of good communication is attentive listening. This element becomes even more critical as tensions begin to arise between caregivers and families (and/or patients) over requests for futile treatment. Most often, there is something behind these requests, and by identifying what that "something" is, it is often possible to defuse the situation and reorient goals of treatment in a more appropriate direction. Families request futile treatment for various reasons. Sometimes the reasons are rather straightforward: inadequate information about or understanding of the patient's medical condition and prognosis; insufficient time to process a change in the patient's condition and the consequent need to shift goals of treatment (caregivers often come to this realization much more quickly than do patients and families); unrealistic hopes in the possibilities of medicine; mistrust of the health care system or the patient's caregivers; a desire to gain some control over the situation; or a genuine belief (though probably mistaken) that the treatment in question will be of some benefit. Patients make requests for nonbeneficial treatment for many of the same reasons that families do. In addition, however, they might make these requests because they are afraid of dying or have unfinished business, perhaps relational, financial, or spiritual.

At other times, familial requests for futile treatment are more complex and difficult to address. These may include (but are not limited to) the following: denial of the situation; an inability to let go and to face the future without their loved one; guilt for some past neglect that results in trying to do everything now in compensation; concerns about future financial well-being or inheritance; some particular understanding of God's will as it relates to human decisions about life, suffering, and death; hope for a miracle; misconceptions or beliefs about the moral permissibility of withdrawing treatment; or even anger toward their loved one and a desire to make their loved one atone for past transgressions. The point here is not to list every reason but rather to highlight some of the motivating factors that lie beneath the surface of requests for futile treatment.

Because of the emotionally charged nature of many of these underlying causes of requests to do everything, it is generally helpful to involve the pastoral care or social services departments (or, in

some cases, psychiatry) to help identify and process the issues. People in these disciplines are skilled in doing this. In addition, they may be viewed by the family as more neutral and thus able to bring a fresh pair of eyes, a different approach, and new insights to the situation. Such people offer the hope of breaking the impasse, actual or impending, by addressing the real issues behind unreasonable requests.

OFFER A POSITIVE ALTERNATIVE

Our language concerning end-of-life issues is often unsettling to patients and families. Such expressions as "terminating treatment" or, worse, "withdrawing care" or "There's nothing more we can do" engender the fear of giving up on and abandoning the patient. It is no wonder, in the face of such expressions, that families demand that everything be done. They are not about to let medical professionals give up on their loved ones.

It might well be more constructive to speak of "shifting goals of treatment from trying to cure to providing comfort." Families need to understand that there comes a point in every illness where medicine reaches its limits and the illness gets the upper hand. At that point, what is called for is not further aggressive treatment aimed at staving off death, but rather aggressive measures aimed at providing physical, psychosocial, and spiritual comfort. The emphasis should be on what *will* be done rather than on what *will not* be done. This, of course, assumes that the facility is prepared to offer good palliative care or to transfer the patient to a reputable hospice program. Often, demands to do everything begin to dissipate when families understand that aggressive palliative measures will be initiated and will be more beneficial to the patient than continued aggressive efforts at curing.

AVOIDING CRISES IS THE GOAL

The considerations just discussed are intended to prevent requests for futile treatment from arising. They suggest an agenda much more comprehensive than the development of a futility policy alone. Until we enhance communication among caregivers and patients and their families, better utilize social and spiritual support services for those approaching the mystery of death, and make a smoother transition from aggressive treatment to palliative or hospice care, requests for futile treatment will continue and increase in number. The mere formulation of a futility policy will not change this fact; it can only better equip us for dealing with a crisis situation that is already out of control. Despite the merit of such policies, the goal should be to *avoid* these crises to the greatest degree possible. □

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