A Preventive Ethics Approach to Counseling Patients About Clinical Futility in the Primary Care Setting

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Given the current themes of futility and managed care in medicine and bioethics, the primary care setting needs to account for how to address futility. We argue for applying the concept of clinical futility to primary care medicine. A preventive ethics approach directs the primary care physician to explain and counsel against futile interventions, with a negotiation strategy for circumstances of disagreement. These efforts will require primary care physicians to concentrate their efforts on education, negotiation, and enhanced trust in their patient relationships. Using a preventive ethics approach in these circumstances, the physician can better protect the interests of the patient by avoiding nonbeneficial interventions, especially those that also are potentially harmful. *Arch Fam Med. 1996;5:589-592*

Editor's Note: The suggestions for approaching a request for something that is perceived to be futile are good, but I would like to comment specifically on the preemptive preventive discussion of futility suggested by the authors.

I agree that talking about futility and end-of-life issues well in advance is a great idea, and I hope that I can do more of this with my patients. In practice, I have found it difficult. When is the appropriate time to do this? Is it by age (ie, they've turned 65), when a new diagnosis is discovered (ie, they now have heart disease), or at the annual prevention checkup? Finding the time to engage in conversations that may become lengthy also is problematic.

My suggested solution is sometimes to do this type of counseling individually and personally, but more often to disseminate the issues to patients as groups—through patient education newsletters, handout materials, or the press. I predict, however, that neither individual nor group contact will fully resolve America's issues of futility, because our society has many tolerated but conflicting views on the subject.

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During the past decade, the concept of futility has become prominent in the medical and bioethics literature. This developing body of literature can be applied in the primary care setting to develop a preventive ethics approach for discussing futile interventions with patients, including interventions that may be required on an urgent basis in the hospital setting.

Recent literature has focused on several important issues, such as the definition of futility, the reliability of determining an intervention as futile, and the connection between futility and rationing.[1-11] The purview of this article does not extend to a discussion on the rationing of monies or resources to people based on a legitimate claim of benefit.[12] Instead, we focus on the clinical challenge of responding to requests for futile interventions to primary care physicians.

A TIMELINE OF FUTILITY

During the past decade, literature about how physicians should deal with requests for nonbeneficial treatment has been a topic of discussion in medicine and bioethics. In 1986, Brett and McCullough[13] examined this topic in terms of the ethical concepts of autonomy, beneficence, and physician integrity. They maintained that physicians are not obliged to provide to patients therapies that physicians believe lack benefit for patients (ie, if an intervention has no potential "modicum of benefit" for the patient), and underscore the primary care physician's obligations in their case studies and analyses.

Since 1986, many authors have reflected on the concept of futility, with the

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tertiary care setting as their point of reference.[1-11] As a consequence, few discussions of futility and counseling patients about futility have taken place in the primary care setting. Healey[14] more broadly applies the notion of "shared decision-making" in the physician-patient relationship in his analysis of futility. Prendergast,[15] when discussing futile interventions, observes that "where the evidence is clear and convincing, autonomy is irrelevant," yet concedes that the physician-patient relationship should be "cooperative, not competitive." Truog et al[16] emphasize communication between patient and physician to attempt to compare, and perhaps compromise on, respective goals. The shared theme of enhanced communication, while not explicitly attributed to primary care by Healey and Truog, surely applies to it.

The concept of futility is far more complex than the physician merely judging a treatment as nonbeneficial. We will not address physiological futility, in which a consensus of scientific evidence states that a therapy has no possible physiological benefit (eg, cardiopulmonary resuscitation on a patient who died 20 minutes ago). Instead, we concentrate on interventions judged by the physician to be futile because they have a high probability of failure (ie, <1 success in 100 attempts) and are deemed not to possess clinical benefit to the patient based on reasonable clinical judgment and reliable empirical evidence.[17] Examples of futility would be an asymptomatic patient who uses tobacco and wants a chest radiograph to prove that he or she does not have cancer, a teenaged girl who desires a mammogram to rule out cancer when her physician palpates no lump but only glandular tissue, or an elderly patient with advanced pancreatic cancer who is receiving palliative care at home but wants an ambulance called and, if needed, cardiopulmonary resuscitation should he arrest. A preventive ethics approach to clinical futility emphasizes the physician's responsibility to discourage patients from the use of these interventions and to negotiate with patients about demands for clinically futile management.[18] This responsibility increases when the futile intervention also may cause iatrogenic harm directly (eg, with futile invasive, hospital-based interventions) or result in subsequent invasive workups that can cause harm (eg, futile outpatient interventions).

Patients come to their physicians with their own sense of values and beliefs about their health care. Patients' concerns, fears, and curiosity about pursuing a specific intervention may result in queries based on "peace of mind" or other reasons. Furthermore, in the managed care setting, the patient may want to discover the boundaries of what he or she can request. In all these circumstances, the primary care physician should serve as a resource of information and guidance about the prudent, ethically justified avoidance of futile interventions. The literature on futility supports discouraging the use of interventions reliably judged futile in the outpatient and inpatient settings.

Moreover, institutional changes will continue to put pressure on primary care physicians to control resources. The primary care physician is likely to be thrust into the role of supervising the use of resources in various managed care strategies. Informing the patient that something is futile may be perceived by the patient as a conflict based on power, money, trust, and hope.[19,20] Responding reactively to these ethical conflicts about futility taxes the time, energy, and goodwill of all involved parties.

DEFINING THE PRIMARY CARE PHYSICIAN'S ROLE

Primary care physicians should address their responsibilities in discussing issues of futility with their patients. In particular, primary care physicians should not postpone discussions of hospital-based interventions until they are rushed and the patient's decision-making capacity is reduced. Given the opportunities to see patients over time, primary care physicians are well positioned to discuss futility prospectively. Doukas and Brody[21] postulated 3 assumptions about the nature of primary care that have a bearing on circumstances of futile intervention: primary care physicians (1) "are primarily patient advocates and only secondarily advocates for various specific forms of medical therapy," (2) "have the opportunity to know the patient well over time and to become familiar with the patient's preferences and values regarding life prolongation and therapeutic interventions," and (3) "are prevention-minded."

This article introduces to primary care a new dimension of prevention-mindedness: practicing preventive ethics.[22-26] Preventive ethics provides the clinical tools for prospective discussions of futility with primary care patients. Preventive ethics involves the use of informed consent and other forms of communication with patients, such as negotiation and respectful persuasion, to anticipate and prevent ethical problems and conflict in the care of patients. For example, the discussion of advance directives in the primary care setting can prevent ethical problems such as unwanted admission to the intensive care unit, or not knowing the now-incompetent patient's values and preferences about aggressive response to life-threatening events.[27] So, too, frank discussion in the primary care setting of futile interventions is an essential part of a preventive ethics approach to futility.

RESPONDING TO REQUESTS FOR FUTILE PRIMARY CARE INTERVENTIONS

A preventive ethics approach to futility in the primary care setting involves 2 main strategies: explanation of, and counseling against, futile interventions; and a negotiated response on requests for futile interventions.

For the first strategy, some authors have proposed that physicians not communicate information to patients when an intervention is judged futile (eg, cardiopulmonary resuscitation).[18,28] Primary care physicians should not risk a potential breach of trust concerning interventions, especially when the physician believes that the patient or the family may have considered or even expected them.[29] In these cases, the patient or the family may not fully appreciate the frequent and nontrivial iatrogenic burdens of these interventions and the physician's justifiable concern to avoid them. For example, false-positive diagnostic results can cause stress and lead to invasive tests. Admission to a critical care unit always involves risk of iatrogenic harm. To help protect patients from the potential harm of futile invasive interventions, the primary care physician should take a preventive ethics posture

of counseling against these interventions. Failure to take this approach means that the primary care physician risks subjecting patients to iatrogenic harm. Having learned early about them and hearing the physician's recommendation against them, the patient may elect to forgo the futile interventions.

For the second strategy, primary care physicians are well equipped in knowledge and practice to decide reliably matters of clinical futility, including appropriate referral to secondary and tertiary care. When these interventions are judged to be clinically futile and when the patient still prefers them, the primary care physician should use negotiation and respectful persuasion against referral of a patient. The physician should explain to the patient that economic considerations do not enter these judgments and the recommendations based on them.

How can the primary care physician put these elements of preventive ethics into a coherent clinical strategy? In a 5-step preventive ethics approach to counseling patients about futile interventions (that also would be applicable to the tertiary setting), we attempt to structure an intervention.

Step 1

When patients request futile interventions, explore the request. Does the patient have mistaken or poorly informed beliefs that could be corrected by diligent and considerate education? Does the patient have other psychosocial concerns, historical incidents influencing his or her views, or other values underlying his or her request? If so, the physician should elicit these concerns and discuss them with the patient. The physician should help the patient to express his or her values (by asking, "What is important to you in making this request?") and work with the patient to see if alternatives other than futile intervention will support and advance those values. Using an instrument such as the Values History to better understand the patient's health-related and other values can help to redirect requests for futile intervention.[30,31]

Step 2

If the request remains unaltered after exploration, the next step is to negotiate with the patient. Point out to the patient the nature of the evidence or reliable clinical judgment that the intervention is futile. When notable morbidities are associated with the intervention (especially hospital-based interventions), these should be pointed out and the patient invited to think about those morbidities in terms of the values expressed in step 1. Tell the patient that inpatient diagnostic tests may detect an abnormality of unknown clinical significance. This can induce stress and lead to more, perhaps invasive workups, and the patient should be invited to reflect on these hidden "costs" of futile diagnostic interventions.

When the risk of morbidity from the intervention is high, ask the patient if he or she really thinks it is worth it to go for a very small chance of success that, with high probability, may result in significant morbidity. Ask the patient to reconsider.

Step 3

If step 2 fails, try respectful persuasion, ie, persuasion based on the patient's expressed values.[32] Refer to values expressed by the patient in step 1 and alternatives other than futile intervention that are consistent with them. Based on the sense of the patient's values and considered, reliable clinical judgment of available alternatives, recommend a trial of intervention for one of them. Invite the patient to participate in defining the rules for evaluating and stopping the trial, especially in cases of probable mounting morbidity.

Step 4

If step 3 fails, 2 options are available to the primary care physician. The physician's first option is to propose a trial of the futile intervention, labeled as such, with mutually agreed-on stopping rules. Warn the patient that third-party payers may challenge authorization of the intervention and that a complete shift of economic risk to the patient may occur. Also, warn the patient that hospitals (eg, under diagnosis-related group conflicts of interest) may resist further hospitalization or admission to critical care.

Alternatively, if use of the intervention violates the physician's concept of beneficial treatment, inform the patient that one cannot provide this care oneself, and that one is concerned about the potential of harm of this intervention. While there is no iron-clad guarantee of the futility of the intervention, the physician's professional integrity does not require him or her to enlist in an intervention that he or she believes is counter to his or her personal and professional values. The physician can say that the patient may seek care from another physician for this intervention.

Step 5

If step 4 fails, an institutional ethics committee from a local hospital, nursing home, or home health agency could be called on to review the case to assess the quality of preventive ethics used to date, assess for overlooked alternative therapeutic options, and suggest new alternatives. Involvement by an ethics committee is predicated on existing institutional policy that supports this role for the committee, especially as more committees are willing to consult on cases from the community. If an ethics committee is unavailable, an alternate form of consultation could come from a thoughtful colleague who agrees to review the pertinent ethical elements of the case. The consultant(s) should review and critically assess in a timely manner the basis and reliability of the physician's futility judgment and make recommendations for reactivating steps 3 or 4. Steps 1 to 4 should then be tried one more time, incorporating the consultant(s) recommendations.

CLINICAL IMPLICATIONS OF A PREVENTIVE ETHICS APPROACH TO FUTILITY

The preventive ethics strategy we describe directs the primary care physician to work with patients to help them understand that these therapies are futile due to their lack of benefit and that they may even constitute a potential harm (and are therefore doubly not in the patient's best interest). These efforts will do more for the patient's peace of mind, we believe, than providing these interventions. Indeed, peace of mind can be placed at risk by futile interventions in the inpatient and outpatient settings. The physician should make a strong case

for the value of forgoing the requested futile intervention.

The main purpose of a preventive ethics approach to futility by the primary care physician is to help the primary care physician to do what he or she should be especially well suited for—discovering the patient's real problem.[21] Patients often come to their physician's office because of other psychosocial, historical, or value-laden problems that underlie the explicit reason for the visit. A patient may go to the physician because a close friend has died of a rare disease, and the patient wants nonbeneficial invasive and expensive modalities to screen for it. Reasons such as fear or anxiety can precipitate requests by hospitalized patients or their family members for interventions that are of no proven benefit. Primary care physicians can address these concerns without necessarily sanctioning futile testing or therapy. Patients or family members who persist in demanding futile interventions are a difficult problem for the primary care physician. The patient or the family may want "everything done" in a specific circumstance. The physician should assure the patient that all medically appropriate means requisite to the patient's care will be offered when they are expected to benefit the patient.

However, not all interactions about futility issues will have a negotiated settlement, especially when there is intransigence of one of the parties about what he or she considers beneficial. Because these disputes can result in calling on institutional guidelines and ethics committees to resolve them, health care institutions should develop institutional policies and practice guidelines for futility and medical interventions.[33,34] These policies should support counseling against futile interventions and place a reasonable burden of proof on physicians to support judgments of clinical futility rigorously and on patients and their families to justify requests for futile interventions after informed consent and negotiation have been tried and failed.

In the managed care setting, primary care physicians serve in the valuable role of limiting access to services in and beyond the primary care environment. The time-intensive efforts of preventive ethics may superficially seem to be in conflict with managed care practice, in which pressure is increasing on physicians to see more patients and time is at a premium. However, preventive ethics adds value to the physician-patient relationship by taking patients' requests for futile interventions and the patient's values and concerns seriously and not simply giving in to them. False respect for autonomy by blindly accepting any requested futile intervention or capricious overriding of autonomy by refusing futile interventions without explanation or negotiation is dehumanizing and undermines patient freedom. Moreover, preventive ethics may be cost beneficial. The offsetting benefit of enhanced communication may result in fewer referral requests and lower expenditures on nonbeneficial tests.

CONCLUSIONS

Primary care physicians should play a central role in setting standards of care, especially when legal institutions, payers, and managed care plans and their consultants surely will step in to fill the void when physicians fail to play this role.[35] The informed-consent process, including counseling against futile interventions, is an essential component of standard setting, followed by a clinical method of negotiation and respectful persuasion. Institutional policy, therefore, should support counseling against futile interventions followed by negotiation and persuasion against futile care, tests, and therapy. Primary care groups and managed care entities should develop preventive ethics policies to guide discussion of futile management for the outpatient setting, and institutional ethics committees should do so for the inpatient setting. It is essential that these policies include mechanisms of transfer of care and appeal for patients who persist in requesting futile interventions.

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