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## Families and Futility: Forestalling Demands for Futile Treatment

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A few years ago, an article by Helft, Siegler, and Lantos in the *New England Journal of Medicine* chronicled the rise and fall of the futility movement.<sup>1</sup> The concept of futility was largely unrecognized 20 years ago; 10 years ago, futility was hotly debated; now it attracts little attention. However, the *problem* of futility has not gone away. "Futile treatment in hospitals is still very much an issue, yet doctors today are no more empowered to declare futility unilaterally than they were 15 years ago."<sup>2</sup> Delivering futile treatment remains as demoralizing as it ever was. And the problem of futile treatment takes on a special urgency in a climate of unrelenting cost-containment pressures — What care could be less cost worthy? What care could we more legitimately refuse to give?

Moreover, the problem of futility will only get worse. Medical progress will enable us to sustain some form of life for ever longer periods. New, even more expensive treatments will come into use, exacerbating cost-containment problems. Patients and families will become better informed about the "miracle treatments" available or promised soon. We must not give up on some kind of attempt to deal with the problem of demands for futile treatments.

### POLICY VERSUS DISCUSSION

Helft, Siegler, and Lantos explain the two main approaches to the problem of futile treatment. The *unilateral declarations* approach aims to empower physicians to not offer or to refuse to deliver futile treatments. This approach obviously runs the risk of arbitrary refusals of care — refusals that are motivated, perhaps subconsciously, by the values or attitudes of the individual physician. The second and more popular approach has been *hospital futility policies*. These policies state that a hospital — or group of hospitals — will not deliver futile treatments, and outline procedures for declaring treatment to be futile. Futility policies are often difficult to put into place. One administrator killed the fledgling effort to create a futility policy for his hospital by proclaiming, "This hospital is not about to become the 'futility hospital' in this area!" But even when they are in place, futility policies may still fail to protect physicians and hospitals from demands for futile treatment. I recently asked a hospital ethics committee for an example of one of their policies that is not working, and was greeted with a chorus of, "the futility policy!" And this in a metropolitan area in which all hospitals had worked together for a year to formulate and adopt a common policy on futile treatment.

Both of these familiar approaches are deeply flawed. They contain similar defects, and carry the seeds of their own failure within them. Both infuriate patients and families who do not share the physician's conviction that the treatment is, indeed, not worth continuing. Both approaches are unilateral and strike families as blatant assertions of the power of the hospital to have its way. Both are predictably sources of rage and a sense of betrayal, so both are sources of bad publicity and potential lawsuits. The hostility predictably generated by these approaches is surely one reason for the failure of hospital futility policies and the decline of the entire futility movement.

Both approaches to the problem have assumed that demands for futile treatment are both intractable and irrational. The care *is* futile, after all, and discussion and negotiation have already been tried, without success. This assumption about demands for futile treatment tends to harden both sides into their respective positions. On one side, it fuels anger and hostility as it becomes evident to patients and families that they are being perceived and treated as obstinately irrational. Nobody sees themselves that way; nobody likes to be treated that way. On the other side, having labeled requests for futile treatment *irrational* and *intractable*, physicians are freed from any responsibility to probe for the sources and roots of demands for futile treatment. There is then no point in trying to treat anything more than the symptom — the demand itself. The power to issue unilateral declarations of futility — either by physicians or by a hospital committee — seems to be the only solution. If demands for futile treatment can be rendered inefficacious, the *hospital's* problem is solved. That's all one could hope for in response to an irrational and intractable demand.

However, the assumption that demands for futile treatment are both intractable and irrational should be questioned and tested. Also, instead of just asking how a physician or hospital can respond to demands for futile treatment, we should ask how we might work to reduce the incidence of such demands. This would give rise to a third approach to the futility problem, an approach that would be dialogic, piecemeal, and case-by-case. A case-by-case approach obviously lacks the sweeping generality of a policy. As such, it does not hold out the promise of dealing with all requests for futile treatment. Some of the most frustrating and intractable cases will remain. However, this is the only approach that attempts to deal with both the hospital's problem and the patient's or family's problem, and thus holds the promise of resolving the problem of demands for futile treatment in a way that does not generate anger and ill will. Besides, the idea that a hospital policy would sweep away all the problems of futile treatment has proven illusory anyway. A *reduction* in futile treatment is perhaps the only realistic hope for *any approach* to the problem of futility.<sup>3</sup>

Helft, Siegler, and Lantos also conclude that "talking with patients and families should remain the focus of our efforts."<sup>4</sup> But without greater clarity about the nature and goals of this discussion, it remains unclear how their recommendation would differ from the discussions already taking place between patients or families, and physicians or hospital staff. I will argue that a *talking with patients and families* approach cannot succeed without moving beyond three simplifying assumptions that undergird much hospital care in the United States today, because these assumptions help to fuel demands for futile treatment. The approach I will advocate is compatible with hospital futility policies. Where they exist, futility policies can provide support and backup when dialogue fails. But they should not be our focus and we should usually, I believe, acknowledge our own failure when a futility policy is invoked.

I will focus on requests or demands by *families* for futile treatment. These are the most common and also the most troubling cases. They are the most common because patients are normally no longer competent by the time treatments have been determined to be futile. Cases of an alert, oriented patient who desperately wants her life prolonged — even if it is only existence in an intensive care unit — are much less common but also less troubling. Such patients create understanding and command sympathy. None of us wants to die. Demands by *families* for futile treatment are much more common, and are much more troubling because they raise ethical questions about whether the requested treatment even represents the wishes of the patient. The agendas of the proxy deciders seem so clearly in play in most of these cases.

## COMING CLEAN: CONFLICTING VALUES AND IATROGENIC SOURCES

We might begin by at least "coming clean." Many of the treatments we deem futile do prolong life. In fact, that is precisely what distinguishes futile treatment from ineffective or impossible treatment. But the life they prolong is unconscious or semiconscious life, life in the twilight of senility, or life confined to an ICU. There *may* be a consensus among physicians that prolonging life under these conditions is not an appropriate goal for medicine. But this is a value judgment that many people do not share. When the clash over demands for "futile" treatment represents this kind of value conflict, we should forthrightly admit as much. In such cases, we will be able to make progress with families only by acknowledging the basic conflict of values. Attempts to paper over the conflict with a declaration of futility will rightly bear the opprobrium of disingenuousness. Moreover, in cases in which there is a conflict of values, the demand for futile treatment is not simply irrational. It is not irrational to believe that human life in any form must be respected and preserved. Perhaps this belief is somehow deeply antithetical to the proper practice of medicine, but it is not clear why this should be so. Given a conflict of basic values, mediation efforts seem to be called for, not a unilateral assertion of the power to withhold or withdraw treatment.

We should also acknowledge the extent to which the problem of futile treatment is an *iatrogenic* problem, at least in the slightly expanded sense that includes problems caused by healthcare institutions. We should, for example, acknowledge that families have been given false hopes, both by the healthcare industry at large and often by their physicians as well. On the national level, we muster financial support for medical research by promising miracles. The media and various fund-raising campaigns spread these reports to a very interested public. "We're closing in on a killer!" a billboard on the way into my hometown proclaims. *The killer is leukemia and the cure is at hand!* Physicians may understand that we are a long way from understanding, let alone being able to cure, many of today's "killer diseases." Physicians also know that even if a cure were discovered tomorrow, it would not be widely available soon enough to help most patients who are dying today. But hopes are generated in the public. The billboard has been announcing for about a year now that they're closing in on this killer. So surely they must have it cornered by now. If we can somehow keep our daughter alive a little longer, they will have eliminated this killer and she will be cured!

There is little an individual physician or hospital can do to roll back unrealistic expectations. But the American Medical Association or the American Hospital Association could make substantial contributions to the reduction of demands for futile treatment by promoting a more realistic social assessment of the power — and also the drawbacks — of modern medicine. But it is in the interest of neither to do so. Nor are there any public education campaigns that proclaim, "Caring families don't let their loved ones die in an ICU!" Demands for futile treatment could be seen as the price we pay for having generated and profited from unrealistic expectations of modern medicine and medical science.

Unrealistic expectations and false hopes are also generated within the hospital, as has often been pointed out. Some of this is the result of the specialized reports from the various specialists involved in a particular case. After all, if Dad's lungs are better, it seems only logical to conclude that *he* must be better, too. Treatments are often tried that have only a small chance of producing the hoped-for result. Near-futile treatment is routinely delivered with words of encouragement. Treatments are also tried that don't have a clear time frame, a time when the treatment ends, and we will learn whether it has worked. Bad news is often not presented clearly enough, often enough, and in simple enough terms so that it gets through to families.

There are also important issues of time that surround all of this. Too often, families are expected to turn completely around, in a day or two, from a hopeful and cautiously optimistic stance to agreeing to withdraw all life-prolonging treatments. Frustration over a family's inability to change direction then develops, and this frustration can easily harden into a confrontation over futile treatments.

Finally, we should also acknowledge that we — our health care systems — have contributed to situations in which caring for a chronically ill loved one is the sole source of meaning in the caregiver's life. We happily externalize the costs — both financial and personal — of chronic care, arguing that home care is best for the patient, which effectively reduces the family to a "patient-support system." We thereby create lives

for family caregivers that include no time or energy for anything but struggling to deliver the care we require. Careers are destroyed, friends fall away, hobbies and other leisure interests are extinguished. None of this bothers most physicians and bioethicists, for we are single-mindedly pursuing what is best *for the patient*. Then we react with shock and horror when family caregivers cling to their loved one because she or he is the only remaining source of meaning in their lives. We forget that medicine created and bioethics sanctioned these lives that no longer contain anything but caring for their loved one.

## ASSUMPTIONS OF MEDICINE AND BIOETHICS

We can address many of these iatrogenic sources of demands for futile treatments within the normal paradigm of hospital medicine. But exposing and treating the deeper roots will require that we move beyond three traditional, simplifying assumptions of medicine and bioethics. These three assumptions are interrelated, but they can be teased apart conceptually. Like all simplifying assumptions, they persist because they work — most of the time they simplify situations, and focus healthcare professionals on the most salient features of the cases before them. But as with all simplifications, they ignore features of cases that sometimes become pivotal. Then our simplifying assumptions turn against us, and misdirect attention and create rather than resolve problems. Demands for futile treatment are partly generated, I contend, by three simplifying assumptions of modern medicine and modern bioethics.

1. *Medical treatment decisions should serve the interests of the individual patient.* By implication, the interests of others — the patient's family, other patients, insurers, the hospital, and physicians themselves — are simply to be ignored whenever they conflict with the interests of the patient. Except, perhaps, in situations that involve rationing medical resources. This patient-centered ethics of medicine is ancient, going back at least as far as the Hippocratic Oath. It continues to the present day, and has received the imprimatur of contemporary bioethicists. Unswerving fidelity to the interests of patients serves as a healthy reminder that patients are vulnerable, that medicine is a caring profession and not just another business, and that the interests of vulnerable — and often disvalued — patients are not to be routinely sacrificed to some greater, common good.

But as I have argued in this journal and elsewhere, a patient-centered ethics of treatment decisions is mistaken, because the interests of patients sometimes conflict with legitimate interests of others.<sup>5</sup> The interests of other members of the patient's family (at least) cannot ethically be ignored. Indeed, sometimes the interests of a patient's family should take precedence over the interests of a patient. Sometimes a family has more at stake in treatment decisions than a patient.

Two consequences of this simplifying assumption are germane to demands for futile treatment. (1) As mentioned above, if only the interests of the patient are considered, this implicitly reduces the rest of the family to a "patient-support system." As mentioned above, this contributes to situations in which the family ends up with nothing to give meaning to their lives except providing care for their loved one. We need to ask more seriously and more routinely, What is too much to ask of patients' families? We need more often to give them permission to refuse to deliver care. (2) This patient-centered ethics of medicine tempts — even urges — us to ignore the impending family crisis created by an accident, a catastrophic illness, or impending demise of a loved one. Medicine is about caring for the sick, period. The family needs to work out their own solution to the demise of a loved one. That is not a medical problem, for the patient is by then deceased and the case is closed.<sup>6</sup> But sometimes we pay a very large price for ignoring the family crises that serious illnesses cause, as they give rise to demands for futile treatment.

2. *Death is a medical problem, a medical crisis.* This is normally a reasonable assumption. We love life and cling to it; we want to live. Medicine is sometimes what enables us to do so. Many Americans also believe that we have an obligation to live, even if we don't want to. But if we see medicine as an enterprise devoted to saving lives, *every* impending death is turned into a medical crisis. This is a deeply damaging oversimplification. And it fuels demands for futile treatment that will, after all, ward off death. In our medicalization of death, we have radically misidentified the kind of a crisis that death is.

The death of a patient is normally a crisis for doctors and other health professionals, as it represents the failure of an intense effort to preserve life. For *doctors*, death may, indeed, normally be a medical crisis. Impending death is often also a crisis for the dying patient. But for the patient, it is not a *medical* crisis, although it may be foretold and marked by medical indicators. Death is not bad primarily because of its physical symptoms — because it is painful, or because it is accompanied by nausea or dyspnea. The dying person may have suffered much greater physical discomfort before. The pain or nausea could be easily, even cheerfully borne if it would be followed by recovery and a return to healthy life. If death is a crisis for the patient, it is a crisis because it is *the end of the patient*, or at least the end of the patient's existence as we know it. Secondly, chronic illness or death may also be a crisis for the patient due to awareness of the possibilities for the future that are going to be lost. But all this is an existential, or, as I prefer to call it, a *spiritual crisis*, not a medical crisis.<sup>7</sup> A *spiritual crisis* is, by my definition, a challenge to someone's fundamental values, commitments, and the basic beliefs that have shaped the person's life.

The crisis of death can be resolved only by deep acceptance of our finitude and by activities that are appropriate to a life that will not last forever. The solution to the problem of unfulfilled potential and unfinished business is not an attempt to employ medical means to live longer and longer. It is a call to live differently *now*. Without this kind of deep reorientation, we will not complete unfinished business nor realize unfulfilled potential even if we survive the present health crisis. And even if we live much longer, we will never do and experience everything we would like. We need to make our peace with that. Medicine is distorted and held captive by our deep cultural inability to accept our finitude.

However this may be, it is all arguably somewhat beside the point. For in the cases we are concerned with here — those that lead to proxy requests for futile treatments — we need to recognize that death is not a crisis *for the patient* at all. Sometimes, of course, death is not even a bad thing for the patient, because it brings to a merciful end a long period of suffering. In many other cases, death is not a crisis for the patient because, through loss or lack of mental capacities, she does not have a sense of self as an enduring entity. Death poses no problems for one who has no conception of death or no recognition of self. (This is why animals presumably do not bemoan the fact that they will die.) Death can be a crisis for the patient only if the patient is able to appreciate that it is the patient who is alive, that the patient's life is the life that is threatened. Infants, small children, and the senile have no such sense of self. Without awareness of self, it is not even clear that a shorter run of relatively pleasant moments is worse than a longer run of them. *Shorter* and *longer* are impositions of other, quite different points of view than many incompetent patients are capable of.

The kinds of deaths that lead to proxy demands for futile treatment are, then, *spiritual* crises. But they are normally spiritual crises for the patient's *family*, not for the patient. In the cases in which proxy requests for futile treatment arise, death is usually no longer a crisis of any kind for the patient. With this observation, we move to a third simplifying assumption.

3. *The job of doctors and hospitals is to deliver medical care to patients, not to address the spiritual needs of their families.* In some ways, this assumption is a combination of the first two. Doctors and hospitals are focused on patients, on providing for their medical needs by prolonging life and restoring health. When health can be fully restored, this is almost always a useful assumption. It focuses and directs activities appropriately. But as patients develop chronic or fatal illnesses and begin to fail, medicine is brought face-to-face with the fact that the needs of these persons cannot be so neatly divided into the medical and the nonmedical, and also that the lives of patients are deeply interwoven with the lives of their loved ones. This inseparability of the lives of those who are close is increased and underlined by the facts of vulnerability and dependence.

Many deaths — and almost all deaths that precipitate proxy requests for futile treatment — are deaths *in the family*. A death in the family is most often, as we have seen, a *spiritual* crisis and normally a crisis *for the family*, not for the patient. We will be unable to adequately address situations that threaten to harden into demands for futile treatment until we acknowledge as much. By contrast, the standard approach to requests for futile treatment is to insist that it is the proper role of hospitals and doctors to deliver medical care to

patients, that the need to sort out what are sometimes dismissively called the "psychodramas of patients' families" is not a justifiable use of medical resources. End of story.

Some of this is undoubtedly true — if death is not a crisis for the patient, and, indeed, is not a medical crisis at all, a medical response to a nonmedical problem seems inappropriate — perhaps even a perversion of medicine — costly and probably ineffective.<sup>8</sup> Here, as elsewhere in medicine, a patient-centered ethic fails us. We recognize that increasing debility and impending death are crises for the patient. Some physicians try to address the emotional and spiritual crises these problems pose for the patient. But we do not fully acknowledge in practice that this crisis is often at least as profound for the family as for the patient. Even if we recognize the family crisis that serious illness represents, we usually do little to address it. The family is not our patient.

We will not get to the root of demands for futile treatment nor will we be able to develop approaches that are likely to reduce the incidence of such demands if we end the story with the flat assertion that medical care should not be used to help families sort out their spiritual crises. Any preventive approach to the problem of futile treatment will have to attend to these issues. For it is precisely the "psychodramas" of families that give rise to proxy demands for futile treatment. An attempt to avoid dealing with them is doomed, as it will result in treating only the symptoms. What is needed is spiritual care for the family, not medical care for the patient. And except for cases of truly unforeseeable events (a car accident or massive stroke), it usually should have already been the focus of care for months, even years before the patient's terminal admission.

### THE NEEDS OF THE FAMILY

Time is required to come to terms with an impending death in the family. The loss of a loved one is itself a kind of death; the meaning and purpose that have sustained lives oriented around family are lost. The surviving family members must be reborn as new and very different selves before they can go on. Time is also required before the death for the human task of winding up unfinished business that families so often bring to end-of-life treatment decisions. "Thank you," "I love you," and "Good bye" need to be said, preferably while the patient is alert enough to appreciate them. Difficult tasks, such as burying old grievances, acknowledging guilt, and asking for and giving forgiveness, must be undertaken, again preferably while the patient is still aware enough to participate.

Even more difficult is coming to terms with the death of an infant or young child. Babies and young children are the very embodiment of promise and hope. We plan to take joy in their growth and development, not to watch them wither and die, or lie unconscious in a hospital bed. Many adults are also more emotionally involved with their children than with their parents. Parents have invested so much of themselves in their children, and we normally feel much more responsible for how their lives turn out. Finally, the death of a child — even an adult child — is "unnatural." Children are supposed to bury their parents, not the other way around. We are, then, on some level, emotionally prepared for the deaths of our parents; we are supposed to witness the deaths of our parents. Even the death of our partner, forsaken though it makes us feel, is more bearable than the death of our child.

Also, we all need hope. Perhaps we humans cannot live at all without hope, and certainly no one can thrive without it. But families need to be helped to relinquish one hope in favor of another. Families may hope against all odds that Mom's disease will miraculously reverse itself and she will return to lucidity, thanking everyone for the aggressive, life-prolonging treatment that pulled her through. This is a fragile hope, however. Regardless of how well fortified it may be against doubt, it will be shattered by subsequent events if treatment is indeed futile. Nor is it at all clear that the *family's* interests are well-served by treatments that allow it to cling to a hope for months, even years. The family members live in a kind of suspended animation, waiting for a recovery that will never come.

So families need to be helped to come to new hopes: to the hope that Mom will be granted a peaceful and pain-free death, that she knew she was loved, and that the unraveled fabric of the family can be reknit without the pivotal role Mom always played. Or, to the hope that the other members of the family will be

able to come through the loss of their daughter or sister relatively unscarred, that the family will be able to pull together instead of pulling apart in the face of this tragedy, that their faith in the goodness of life will not collapse under the weight of this loss, and that they will be able to give to each other the love and care they formerly devoted to her.

Failure to accomplish the human tasks surrounding death contributes to families' needs, which in turn fuel demands for futile treatment. Families must be encouraged not to postpone these difficult tasks and must be helped to avoid doing so. Once we acknowledge that family issues (such as guilt, loss of meaning, and an inability to envision how one will go on) often motivate requests for futile treatment, it becomes obvious that helping families to resolve such issues is one way to forestall requests for futile treatment.

Families also need help to distinguish — and to separate emotionally — withdrawal of life-prolonging treatments from abandonment, for abandonment of one's own parent or child is one of the worst things a person can do. In many medical settings, the opposite message is more commonly given. If the treatment team has not yet abandoned hope, families are often not really given permission to withhold treatment. This is evident in the *pro forma* consents to treatment that physicians extract from families. "Your daughter's blood gases are dropping, so she needs. . . ." Here the clear message is that if family members do not consent to treat this medical problem, they are not giving their own daughter the care she needs. We should not be surprised if family members, after weeks of being urged to equate caring for their loved one with consenting to high-tech, life-prolonging medical treatments, have difficulty separating withdrawing treatment from abandonment. Often, the distinction and possible conflict between care and more treatment should have been under discussion for a long time before the final hospitalization.

Yet quite often, the distinction and possible conflict between care and more treatment should have been under discussion for a long time before the final hospitalization. One young doctor said to other doctors on the team, "When I'm dying, if anyone does to me what we're doing to this guy, I'm gonna come back and get 'em." But this message is not usually conveyed to the nonmedical world. Families need our help to understand that transferring a loved one to an ICU, or persisting in high-tech rescue attempts, can be a form of abandonment. Even taking a dying loved one to the hospital sometimes can be abandonment. The ICU is certainly not the best place to die. Even hospitals are often not good places to die. We need to say that clearly and often to families, publicly and privately.

This is appropriate care for distraught families. The appropriate response to a guilty son's request that we "do everything for Dad" is not to prolong Dad's life in an unconscious state or an ICU. That much the futility movement has right. But it is also not appropriate to vilify the son for demanding inappropriate treatment. (Let he among us without unfinished business with his parents cast the first stone.) The appropriate response is to address the son's guilt, his concerns that he will now never be able to make things right, and his very human emotions connected with the death of his father. Even more appropriate would have been a phone call to the missing son months earlier, when the death of his father was foreseeable — if the son has anything he needs to say to his father, he had better say it soon, for in just a little while his father will no longer be able to hear what the son needs to say.

If we wish to forestall requests for futile treatment, hospitals should support grieving families. We could, for example, provide someone to talk with families, preferably someone with enough medical knowledge to help clear up misconceptions families might have about what they have been told. Family members could be encouraged to talk about what the patient has meant to them, about the complexities of their relationships with the patient, about the patient's role in the family, about the families' fears of having to go on without the patient, and so on. It might well take hours, but, given a sympathetic ear, one would expect the "irrational" hopes and fears to come out, the hidden agendas to begin to surface. When they come out, we can help families begin to deal with them. Even giving voice to these fears and agendas will sometimes be enough to help families get beyond them.

Such care is *preventive* care. It should normally be started weeks or months before requests for marginally useful treatment harden into demands for futile treatment. This is not always possible, as when an unforeseeable incident suddenly renders a member of the family permanently unconscious. But more often,

such supportive family care can be begun even before the family is able to acknowledge that Mom or Junior is dying. Indeed, there are family issues that can only be completely resolved if they are approached months before the patient dies. Forgiveness cannot be given by an unconscious mother; the terminal admission is far too late for a father to really be there for his dying son.

It may be objected that none of these measures address the heart of the problem — the sheer irrationality of some of these requests. Families persist in hopes for miracles and stubbornly refuse to face reality. But we will not know how *intractably* irrational such hopes are or how *irresolvably* hidden such agendas are until we at least attempt to address them.

And if it still seems that addressing the family crises surrounding the death of a loved one is no part of the work of medicine, then we should simply acknowledge that the problem of futile treatment is part of the price we pay for the medicalization of death and dying, for promoting an overly optimistic picture of the powers of medicine, and for focusing too exclusively on the medical needs of the patient.

But what about the costs of such care of families? In an era of cost-containment, ancillary services of all sorts are being cut or eliminated. Yet the very term *ancillary* evinces the deep commitment to the simplifying assumptions that exacerbate the problem of futile treatment. What, after all, is central to the care of the dying and what is ancillary to that? Moreover, the sort of family support I advocate might well turn out to be a cost-saving measure. ICU care is very expensive. If a hospital could avoid even a few weeks of uncompensated or under-compensated ICU care each year, it might actually save money through the provision of such family care. There is, of course, no way to bill for such care. Families are not even patients.

Granted, this approach will not resolve every request for futile treatment. But this is an approach that might well *reduce* the incidence of demands for futile treatment. Perhaps most importantly, spiritual care for families is the only approach to the problem of futility that offers even a chance of a healing process for the family, not merely a mechanism to treat the hospital's problem of futile treatments. As such, it is an approach that deserves full discussion and some serious "clinical trials."

## NOTES

1. P.R. Helft, M. Siegler, and J. Santos, "The Rise and Fall of the Futility Movement," *New England Journal of Medicine* 343, no. 4 (2000): 293-6.

2. *Ibid.*, 293.

3. There is also a fourth approach to the problem of futility that should at least be mentioned in passing. We could be more open about the fact that one of the main reasons healthcare professionals find futile treatment so demoralizing is that it is a simply horrible use of scarce medical resources, including themselves. Though we may legitimately claim that the futility problem is different from the problem of rationing healthcare resources, few physicians and nurses get too upset about requests for simple, relatively inexpensive treatments that don't work — antibiotics for viruses, large doses of vitamins to prevent cancer, alternative medicines used in conjunction with standard therapies, etc. If we honestly admitted that we ration healthcare all of the time, we could fold the futility problem into the problem of scarce, pooled healthcare resources. Then we could refuse to deliver futile treatment simply because there are much better uses of the available resources. "We do not prolong life we believe to be permanently unconscious because we believe it is much better to devote those medical resources to preserving the life of conscious patients." Although I believe this approach also has merit, I will focus in this article on approaching the problem of futility through talking with patients and families.

4. See note 2 above, p. 296.

5. J. Hardwig, "The Problem of Proxies with Interests of Their Own," *The Journal of Clinical Ethics* 4, no. 1 (Spring 1993): 20-7; J. Hardwig, "What About the Family?" *Hastings Center Report* 20, no. 2 (March-April 1990): 5-10; J. Hardwig, "SUPPORT and the Invisible Family," *Hastings Center Report* 25, no. 6 (November-December 1995): S23-5.

6. Hospice care is a noteworthy exception. Hospice continues to care for the "survivors" after the patient has died.

7. J. Hardwig, "Spiritual Issues at the End of Life: A Call for Discussion," *Hastings Center Report* 30, no. 2 (March-April 2000): 28-30.

8. Note that we happily pursue medical solutions to all kinds of nonmedical family problems without feeling any sense that medicine is thereby perverted. Think of cosmetic surgery, for example. If a husband's dislike of the crow's feet around the eyes of his 40-year-old wife is not an inappropriate reason to use medical resources, why is the spiritual crisis of a dying patient's husband not an equally appropriate use of them? We are faced with the difficult question of which nonmedical needs pervert medicine. The answer to this question cannot be that patients themselves pay for cosmetic surgery, for that would draw a connection between two problems that we have insisted are distinct — the problem of futility and the problem of scarce, pooled resources.

9. Needless to say, this is not an argument for converting ICUs into hospice units. But it may be a plea for returning ICUs to their proper mission of helping those who can be restored to a full-enough functioning to be discharged from the ICU.