The Benefits of a North Carolina Policy for Determining Inappropriate or Futile Medical Care

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Editorial Note: Readers of the Journal will recall that in the July/August issue of 2004 (Volume 65, Number 4), we chose the topical theme of “New Directions in End-of-Life and Palliative Care.” Reaction to this issue has been very positive, but a number of additional issues have been raised in North Carolina and around the country, which are worthy of our consideration. The commentary that follows summarizes an effort by some of the leadership in our state’s medical profession to address one of these matters and is presented here as a policy change proposal for further discussion and debate.

Intractable conflicts sometimes develop among patients or their surrogates and clinicians where protracted negotiations and discussions fail to result in a course of action tolerable to everyone. In 1999, Texas passed the first legislation to deal with such disputes. The legislation tries to honor patients’ or their surrogates’ rights and values, but is also based upon a notion of professional integrity, respecting the fact that physicians are the most skilled in determining appropriateness and inappropriateness in medical care. Individual physicians or institutions do not have immunity from civil or criminal liability in making decisions against the patients’ or surrogates’ wishes unless they go through multi-stepped procedures involving a medical staff or ethics committee. Patients or their surrogates may avoid or abort this process by seeking other caregivers or turning to the courts. This due process policy has proved successful in helping to solve entrenched disputes among clinicians, patients, and families. North Carolina should adopt a policy using this portion of the Texas law as a model.

The Problem

Conflicts sometimes develop among patients or their surrogates and clinicians about the appropriate medical course to follow. Many conflicts are resolved with patience, better communication, and education. Nurses, social workers, patient representatives, chaplains, and other representatives along with physicians can help clarify options and prognoses in a way that fosters general agreement about what courses of action are acceptable for the patient. There are times, however, when protracted negotiations and discussions end in irreconcilable differences, and no course of action seems tolerable to everyone. At times these disagreements may reflect deep-seated views about the meaning of life or duties to vulnerable people. In what follows, we focus on the subset of these intractable disputes where requests by families or patients are judged to be inappropriate by all, or almost all, clinicians.

Three Options for Resolving Conflict over Courses of Treatment

In these rare cases where irreconcilable differences remain, and no courses of action seem acceptable to everyone, clinicians...
are left with three choices. First, they can acquiesce to the patient’s or their surrogate’s continued demands, such as to sustain life when all or almost all clinicians believe such support is not medically appropriate as judged by current practice standards. This response, however, tramples the clinician’s own ethical and value judgments and undercuts the integrity of professional medical practice standards. Many clinicians have been critical of this stance, arguing it unreasonably defers to patients or families.1,2

Second, clinicians may choose to respond by returning to a form of medical paternalism, imposing their clinical judgment on patients and families. These challenging situations arise in the context of medical treatment, and as such, estimates about treatment that is futile, useless, unsafe, or inappropriate should be understood in the context of medical science. These circumstances make practice guidelines particularly important in assessing reasonable expectations, probable effects of treatments, and why clinicians, as a group using these guidelines, are the best judge of what medical care is appropriate. Nonetheless, this recommended return to unilateral decision-making by physicians tramples patients’ and families’ choice and has been repeatedly rejected by policy makers and the courts, so for a great variety of reasons, this option seems unlikely to prevail.

Third, in response to sustained disagreements, Texas has turned to procedural justice, developing a due process method to solve intractable conflicts concerning what care is medically inappropriate. This solution has many advantages. It avoids the pitfalls of both medical paternalism and of ignoring practice guidelines. In addition, it ensures that the views of families or patients are not crushed by those in authority. In our view, a policy for North Carolina based on the Texas law offers the best way to deal with this type of entrenched legal or moral dispute.3

**Due Process as a Way to Resolve Disputes**

The publication of the report, “Medical Futility and End-of-Life Care,” by the American Medical Association’s (AMA) Council on Ethical and Judicial Affairs in March 1999 was an important step toward resolution of such disagreements by a due-process method.4 The report recommends using an open and fair process for considering futility cases with joint decision-making by the physician and the patient or surrogate, use of consultants and ethics committees, and attempts to transfer patients to other physicians within the institution or at another institution if the conflict between the patient or surrogate and physician about how to proceed cannot be resolved. In an unresolved conflict, the Council proposes, “if transfer is not possible because no physician and no institution can be found to follow the patient’s and/or proxy’s wishes, it may be because the request is considered offensive to medical ethics and professional standards in the eyes of the majority of the healthcare profession. In such a case, by ethics standards, the intervention in question need not be provided, although the legal ramifications of this course of action are uncertain.”5 It further recommends that “health care institutions, whether large or small, adopt a policy on medical futility, and that polices on medical futility use a fair process approach such as that presented above.”6

The AMA’s Council on Ethical and Judicial Affairs recognizes that irreconcilable conflicts about how to proceed with end-of-life care are sufficiently frequent that their resolution should be addressed. Further, the AMA proposes that clinicians, patients, and patient surrogates should resolve their conflicts with an open and fair process mechanism. The last step in the AMA’s due process mechanism, which states that it is ethical to unilaterally cease futile interventions, is problematic because the legal implications are unclear. Uncertainty about the legal implications of acting against the patient’s or surrogate’s wishes often prevents physicians from taking that step, despite agreement among all or almost all clinicians.

**The Texas Advance Directive Act of 1999**3

Near the time of the AMA Council’s report, a group of hospitals in Houston, Texas, working together through a joint ethics committee, formulated a “multi-institution collaborative policy on medical futility,”5 which subsequently became the basis for state-wide Texas legislation.6 The cooperation of individuals from a broad spectrum of political views led to the creation and successful application of this legislation, which now provides a legislatively-sanctioned, nonjudicial, fair-process mechanism for resolving end-of-life conflicts.3 The legislation offers a mechanism to discontinue medically inappropriate care after appropriate efforts have been made to resolve the ethical conflict existing between the treating physician and the patient or surrogate. Contrasting with the AMA Council’s recommendation to withhold certain medical treatment based on medical futility, Texas law bases this recommendation on medical inappropriateness. The legislation is based upon a notion of professional integrity and respects the fact that physicians are the most skilled in determining medical appropriateness and inappropriateness. However, it does not allow an individual physician to have a legal safe harbor in deciding to withhold or withdraw treatment against the patient’s or surrogate’s wishes without going through a hospital committee—either a medical staff committee or an ethics committee. Typically, these committees have chaplains, medical ethicists, community representatives, and administrators, as well as doctors and nurses. Committees may find they agree with the patient or surrogate and not the attending physician. In any case, the patient or surrogate can turn to the courts if they lack confidence in the process or the impartiality of the committee. The law further recognizes that clinicians sometimes disagree and encourages transfers of patients to physicians who share the values of the patients or their proxies.

The law5 developed in Texas and signed by then Governor George W. Bush in 1999, offers a procedure for granting immunity from civil or criminal liability for attending physicians and institutions who wish to refuse to honor patients’ requests, advance directives, or surrogates’ requests made on behalf of patients. The law stipulates that first, such decisions must be reviewed by an ethics or medical committee to which the attending physician does not belong, and second, the patients “...shall be given life sustaining treatment during the review.” (This and the following quotes are from §166.046.)6 In what follows, we offer a brief summary of the steps that must be taken:
(1) The patient or surrogate “shall be informed of the committee review process not less than 48 hours before the meeting…” and must be given information about the process and hospital policy.
(2) The patient or surrogate must be invited to participate in the meeting and given a “copy of the registry list of health-care providers and referral groups” that may be willing to take over their care or that of their relative.
(3) The physician and the patient or surrogate must receive a written explanation of the committee’s decision.
(4) If the ethics or medical committee agrees that the care requested by the patient or surrogate is inappropriate, they should work together to find another physician or institution willing to provide the care sought by the patient or surrogate.
(5) If after 10 days from the time of the committee’s decision and notification of the patient or surrogate, the committee does not find an institution or clinician willing to care for the patient, the institution and attending physician are no longer obligated to provide therapy that has been determined to be medically inappropriate.
(6) A court may extend this time beyond 10 days if a preponderance of evidence shows that another physician or institution may soon be found to consider accepting transfer.
(7) Where no extension is sought by the patient or surrogate and none granted by the courts, clinicians and institutions are permitted to withhold or withdraw treatments they judge to be inappropriate, and they are immune from civil and criminal prosecution.

Does It Work?

The Texas legislation was the first of its kind in the United States and appears to be successful.\(^7\) First, it acknowledges the values and interests of both clinicians and patients or their surrogates. For the patient or surrogate, the legislation does not permit a paternalistic or unilateral decision to withdraw therapy by a single physician or institution against the patient’s or surrogate’s wishes. Such support can only be withdrawn if it is morally troublesome, not only to the physician, but to members of the review committee. Furthermore, the treatment can only be withdrawn or withheld if no other physician can be found (including at another hospital) who is willing to provide the support the patient or surrogate desires. Thus, a very high community standard of inappropriate care is used in an open process that determines medically inappropriate care. Second, the legislation, through the open process it provides, makes it legal for physicians to discontinue treatment and have assurance that they are not making a decision that will be questioned by their colleagues or other healthcare peers. The legislation also provides a legal safe harbor for the physicians and institutions in that both are provided immunity from civil or criminal liability if they follow the process provided.

A recent report from MD Anderson Hospital in Texas shows the benefits of the Texas legislation. After the Texas legislation passed, the number of referrals to the hospital ethics committee to evaluate end-of-life care decisions increased significantly because the physicians believed that making such referrals was no longer a futile exercise.\(^7\) Also, in that hospital, a number of cases were taken through the review process and care was unilaterally discontinued when the review committee concurred with the physician that continuing or providing certain care was not appropriate. Although not all patients or their surrogates were pleased with the process, many of them did feel relieved and accepted the committee’s recommendations once the decision to discontinue life support was taken off their shoulders.\(^7\) The physicians were also relieved that they were no longer required to provide care that they believed violated their ethical principle to “do no harm” and that was also against their medical judgment and the professional standards of care. It is also possible the review committee may support the views of the patient or surrogate, but arguably there are benefits to the patient or surrogate even if they do not. They have a full airing of their concerns and are provided written responses from the review committee. In addition, they have the opportunity to find other clinicians or institutions that would support their views. They can also turn to the courts at any time if they believe the process is unfair or the committee is not impartial. Finally, there is a benefit of avoiding unsafe and medically inappropriate interventions.

We believe a consensus might exist among clinicians, state representatives in the legislature, and citizens of North Carolina to implement a law similar to that passed in Texas. This law would address the relatively rare, but extremely troubling demands by patients or their surrogates for care, which all, or almost all clinicians, regard to be inappropriate given patients’ medical conditions. NC Med J

REFERENCES