

The Pressure to Withhold or Withdraw Life-sustaining Therapy from Critically Ill Patients in the United States

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Physicians and nurses sometimes exert pressure on the families of critically ill patients to withhold or withdraw life-sustaining therapy from them. This pressure may stem from prognostic, professional, social, and economic factors. Although the pressure to limit life support may be appropriate in some circumstances, in others it is not justified. The pressure also may damage communications and cause resentment. If communications cannot be improved, and if the pressure cannot be relieved, a due process approach to conflict resolution that involves other parties may be required.

Keywords: end-of-life care; withholding and withdrawal of life-sustaining therapy; ICU rationing; triage

Intensive care unit (ICU) admission is eagerly sought by most patients, families, and clinicians. All parties usually are hopeful when the admission begins, and little is said about the limits of medicine or the possibility of failure. Yet, when patients do not improve or actually worsen, the increasing likelihood of their in-hospital death or, at best, severe disability after discharge brings to the fore the question of whether life-sustaining therapy should be withheld or withdrawn. Families may ask this question for patients who cannot speak for themselves, but more commonly it is physicians and nurses who do so. The occasion often is a family meeting, where physicians discuss the patients' poor prognoses and recommend limiting life support (1).

Meetings such as this reach the resolution sought by clinicians if the families accept the prognoses offered them and agree with a transition from restorative to palliative treatment—that is, from treatment that is undertaken primarily to keep patients alive and restore them to health to treatment whose purpose is to comfort them while dying. But this resolution may not be achieved if the families are not ready to accept the prognoses and insist that restorative care be continued. Even when families accept the prognoses, they may disagree with what physicians and nurses consider the proper goals of treatment. In some situations in which they encounter disagreement, clinicians may continue life-sustaining therapy even when they consider it contrary to the patients' best interests (2). In others, they may withhold or withdraw therapy they consider futile without the families' knowledge or despite their objections (3). In still others,

they may exert pressure on families to remove life support from their loved ones.

Kaufman (4) observed the course of over 100 critically ill patients who died, and many more who did not, at three community hospitals in California. The anthropologist found that ICU physicians and nurses usually left final decisions about withholding or withdrawing life-sustaining therapy in the hands of families when patients could not articulate their wishes. Kaufman also noted that families generally agreed with recommendations to limit life support when clinicians convinced them that death was imminent. Furthermore, physicians and nurses acknowledged that families "needed time to adjust" to the fact that their loved ones were dying. Nevertheless, the clinicians often "became exasperated" when the families did not "choose" to withhold or withdraw life-sustaining therapy after a few hours or days. This exasperation was brought to bear at meetings in which the pressure on families to "decide" to remove life support could be "palpable." Families responded to the pressure in a number of ways, including arguing, withdrawing emotionally, or becoming unavailable after the meetings so that decisions could not be made.

The pressure to limit life support and family responses to it have been mentioned in the medical (5, 6) and nursing (7) literature, although they have not been the focus of investigations. Physicians and nurses may not be aware of the pressure some of them exert or appreciate how strong it can seem to family members. We have prepared this perspective to make the pressure more understandable and to stimulate research about it. We explore several possible factors—prognostic, professional, social, and economic—that may underlie the pressure to withhold or withdraw life-sustaining therapy, and how families may deal with it. We also discuss when the pressure is justified and potentially helpful and, when it is not, how the pressure can be relieved. Finally, we describe how resolution can be accomplished when families and clinicians disagree about patients' prognosis, treatment goals, or both. Although our discussion may be relevant to ICUs in other countries, we restrict it to the United States because laws and ethical norms differ around the world (8), and space limitations preclude cross-cultural comparisons.

PROGNOSTIC FACTORS

Despite extensive experience with critically ill patients and the availability of prognostic scoring systems, prognostication generally remains imprecise in the ICU. As a result, for the majority of critically ill patients, physicians cannot say in absolute terms that the patients will die or will have poor functional outcomes (9). Analysis of family meetings reveals that physicians rarely speak in absolutes when discussing prognoses with families and frequently do not explicitly discuss the patients' chances for short-term survival (10). Clinicians frequently consider life support inappropriate unless the likelihood of survival is higher

(Received in original form September 30, 2006; accepted in final form March 21, 2007)

Supported by a career development award from the NIH Roadmap K12 (HD049077) (to D.B.W.).

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Am J Respir Crit Care Med Vol 175, pp 1104–1108, 2007

Originally Published in Press as DOI: 10.1164/rccm.200609-1397CP on March 22, 2007
Internet address: www.atsjournals.org

than at least a few percentage points (11). On the other hand, an even lower likelihood is satisfactory to many patients and families.

For example, a substantial proportion of chronically ill patients would consent to prolonged mechanical ventilation in the ICU for merely a 1% chance of leaving the ICU alive (12). Furthermore, 70% of patients who survived ICU admission, and the families of nonsurvivors, would be willing to undergo admission again to achieve even another month of survival (13). Although this high level of willingness has been documented only in a single study from one institution, a recent survey (14) by the California HealthCare Foundation has demonstrated that 44% of adult African Americans, 44% of Latinos, 28% of Asian-Americans, and 14% of non-Hispanic whites believe that “everything possible should be done in all circumstances to save a life.”

Prognostic uncertainty is often coupled with uncertainty of what patients would want when their prognosis is poor. Families rarely have had detailed discussions about end-of-life issues with patients before ICU admission, so they usually must guess what the patients’ preferences would be in the event of unlikely survival from critical illness. Given their uncertainty about the patients’ wishes, some families understandably request life support. There is a conservative position, similar to that taken by the U.S. Supreme Court in its *Cruzan* (15) decision that allows states to require the continuation of life-sustaining therapy when death is the alternative and patients’ wishes are not fully known.

In some circumstances, families consciously or unconsciously rely on their own preferences for continued restorative treatment in the absence of patient directives. Clinicians may realize how family preferences influence decisions made for family members and argue, at least among themselves, that families are incapable of speaking objectively for their loved ones or representing their best interests. To date, studies (16, 17) of substituted judgment among the families of terminally ill patients in the United States have shown that family decisions are reasonably concordant with what patients want, particularly if the two parties have discussed end-of-life issues beforehand. Physicians have been no better than family members in predicting patient choices in these investigations. Furthermore, even if surrogacy on the part of families is imperfect, most patients interviewed by investigators in the United States would prefer that family members make medical decisions for them in consultation with clinicians if they become incapacitated (18).

A study (19) of self-reported preferences and responses to clinical vignettes has demonstrated that most physicians prefer to withhold or withdraw life-sustaining therapy resulting in delayed, rather than immediate death when confronted with prognostic uncertainty. Nevertheless, we wonder if aversion to such uncertainty might not influence some clinicians to seek rapid resolution at the end of life. These physicians and nurses may reach a point at which they consider certain patients beyond the point of regaining health or living for a long period, and rather than focus on a small chance of survival, their attention may be captured entirely by the high likelihood of death. This cognitive mechanism may help ease the emotional difficulty of facing the death of patients to whom the clinicians are attached. Unfortunately, such detachment may deprive dying patients of attention and upset their families (1).

PROFESSIONAL FACTORS

Despite the ascendance of autonomy in biomedical ethics, many physicians and nurses owe their strongest allegiance to the long-standing ethical principles of beneficence and nonmaleficence (20). As a result, they may feel compromised when requested to provide restorative treatment, with all its potentially adverse

side effects, to ICU patients for whom they judge such treatment to be unlikely to prolong life appreciably or to improve its quality, however quality is defined. They also may resent families who insist on treatment if it does not constitute benefit in the clinicians’ eyes.

Many physicians and nurses are drawn to the ICU because of the order and structure of the environment and the focus on life-sustaining measures found therein. Because of this, they may derive limited professional gratification from treating patients who are unlikely to be returned to health. At the same time, they also may feel a sense of loss, if not guilt, when patients are dying. “We’re not good at taking care of corpses,” a nurse said to us about a deeply comatose, elderly, head-injured patient whose family insisted on continued restorative care.

SOCIAL FACTORS

Many critical care physicians and nurses consider themselves stewards of health care resources, implicitly entrusted by society to use these resources wisely (21). This self-perceived social role, therefore, is threatened when they are asked to perform interventions they consider unwise from both a medical and economic point of view. ICU physician and nursing directors responding to a recent survey (22) of bedside rationing said not only that little rationing actually occurred in their institutions but that more rationing was desirable. Behind this response probably lay the beliefs that too much money is directed toward dying patients, and that the money should be used instead for other health care purposes.

Although these beliefs are understandable, there is little evidence that health care costs can be reduced appreciably by limiting intensive care at the end of life (23). Even if such a reduction could be accomplished, it is not clear that the money saved would be redirected within health care rather than to other priorities. Furthermore, despite their perceptions, physicians and nurses do not have a legal mandate to limit life support on the grounds of cost containment in the United States. Instead, a commentator (24) argued in 1984, they are required “to do everything that they believe may benefit each patient without regard to costs or other social considerations.” Although clinicians might seem to have a say in what constitutes benefit in this argument, the final word is given to patients—and, by extension, their families—because they, and not society, are “the doctor’s master.”

If the previously mentioned argument is correct—and many believe it still is—families are not unreasonable when they request therapies that offer only a small chance of benefit, and the physicians’ desire to refuse these therapies is ethically questionable. Distributive justice requires that physicians and nurses educate their professions and the public about the proper allocation of health care resources (20). It also allows that clinicians ration scarce medical resources, such as mechanical ventilators or ICU beds, in situations, such as a mass disaster or an avian influenza epidemic, requiring triage (25, 26, and White DB, Luce JM, Lo B. Triage of patients with respiratory failure during an avian influenza epidemic: ethical challenges and unanswered questions. Unpublished manuscript). Nevertheless, removing life support from one patient to benefit another can rarely be justified in the name of triage in our country, where ventilators and ICU beds usually are available. Furthermore, bedside rationing of life-sustaining therapy on the basis of abstract utilitarian principles or to prevent eventual health care resource shortages will only be widely acceptable when American society agrees that such rationing is necessary (27).

In the United States, the legal justification for withholding or withdrawing life-sustaining therapy is the patients’ right to

accept or refuse medical interventions, not the clinicians' belief that the interventions are nonbeneficial or futile (28). Nevertheless, despite the lack of consensus about what constitutes futility, this term is commonly invoked to support not only recommendations to withhold or withdraw life-sustaining therapy but also to challenge families who reject such recommendations (29). Such invocation suggests that many physicians and nurses consider family refusals of their recommendations an affront to their professional authority, and that they want futility to serve as a legal rule.

When clinicians and health care facilities have asked U.S. courts to sanction their challenges to families before actually removing life support, the courts traditionally have refused to do so, as in the *Baby K* (30) and *Wanglie* (31) cases, without facing the futility issue head on. At the same time, physicians and hospitals have not been punished after withholding and withdrawing life-sustaining therapy over family objections, as seen in *Gilgunn* (32). These cases remind us that judges seem unwilling to decide life-and-death issues and would prefer that clinicians and families do so. Furthermore, when cases are brought to the legal system, the speed of deliberations is slow, which may partially explain some clinicians' reluctance to involve the courts in the first place. These last two observations suggest the desirability of an extrajudicial process to resolve physician-family futility-based disputes, as discussed later in this perspective.

ECONOMIC FACTORS

Although the hospital once provided a place for patients and families to wait for death, prolonged waiting is no longer acceptable in most acute-care facilities. Instead, many hospital staff want "to move patients through the system," according to Kaufman (4), so that the hospital can function efficiently and stay in the business of caring for as many patients as possible. Hospital efficiency and longevity are advanced if patients are assigned to the "appropriate level of care" and labor costs are decreased, and if lengths of stay are reduced so that Diagnosis Related Group (DRG) payments are maximized. In addition, clinicians may want to make beds available for other critically ill patients, especially when ICU occupancy is high. These desires, increasingly pervasive as hospitals consolidate and beds become even scarcer, are thwarted when withholding or withdrawing life-sustaining therapy is delayed.

Physicians practicing in a fee-for-service capacity are poorly reimbursed for the time they spend in family meetings and have little financial incentive to participate in them. On the other hand, they do not gain financially if their patients die sooner rather than later, even if, and despite claims to the contrary, the patients participate in managed care (33). Salaried physicians also are not rewarded by hastening death, and, like them, nurses are paid for the hours they work, not according to the time their patients die. Thus, there is no reason to believe that clinicians profit from pressuring families to limit life support, or that the possibility of profiting contributes to the pressure. Yet, physicians and nurses alike are influenced by the pace of modern hospital practice, and families may interpret their urgency to resolve these issues as being motivated economically.

On their side, families rarely are financially accountable for the cost of hospital admission, regardless of its length, and they need not be responsive to the imperatives of a DRG. Most families in the United States have high expectations about medical care in general and intensive care in particular. If they are new to the country, the families may not understand why they are asked to limit life-sustaining therapy; if they have been here for generations, they still may resent being rushed when they

believe that the death of their loved ones may result when such therapy is withheld or withdrawn. Such resentment may be particularly strong if the families, by virtue of their ethnicity or socioeconomic status, are philosophically opposed to removing life support and have had limited access to medical services previously (34, 35). Coupled with their suspicion of clinicians' motives, it may translate into an insistence on providing life-sustaining therapy despite recommendations to the contrary.

WHEN IS THE PRESSURE APPROPRIATE?

Whatever its origins, an inclination on the part of physicians and nurses to resolve end-of-life issues relatively quickly may be appropriate in certain circumstances. Some interventions may be physically harmful and others painful despite analgesia and sedation, and clinicians rightfully may object that the principles of beneficence and nonmaleficence are violated by them. Moreover, some therapies truly are futile under even the strictest definition of the term—for example, mechanical ventilation for patients with bone marrow transplants and hemodynamic instability in the setting of hepatic or renal failure (36), and cardiopulmonary resuscitation for patients with multiorgan failure already receiving vasopressors at high doses (37)—and physicians are not obligated to provide them. Strong pressure to withdraw life-sustaining therapy also is justified when families report that patients would refuse such therapy but the families cannot bring themselves to authorize withdrawal. And it may be appropriate when family members are divided as to the advisability of removing life support and resolution can only be reached by requesting a consensus forthwith.

That said, forcing the issue may sometimes be harmful to families who disagree with recommendations to withhold or withdraw life-sustaining therapy, be they divided or unified. It also may harm physicians or nurses by influencing families to bring suit against them, particularly if the clinicians have limited life support unilaterally. Winning such a suit would require that plaintiffs prove that physicians and nurses have acted below the standard of care as determined by medical experts, which may be difficult (29). Nevertheless, before taking unilateral action, physicians and nurses should remind themselves that prognostication is imperfect and that some patients will survive if their treatment is continued at families' insistence. In addition, clinicians should appreciate that some families are satisfied when their loved ones live only a few days longer, or if they survive with severe disabilities.

RESOLVING CONFLICTS

Most families accept physicians' recommendations to limit life-sustaining therapy because they agree that critically ill patients are likely to die and do not want death to be prolonged, or because they believe that the patients' quality of life would be marginal after discharge (4, 11, 38, 39). Yet, acceptance may require time, so clinicians are advised to temper the rush to resolution with consideration of some families' needs for a slower decision-making pace. True communication requires that all parties understand their respective positions and the factors responsible for them. It may be improved by beginning family meetings shortly after ICU admission, having them led or at least coordinated by attending physicians, discussing the possibility that interventions may not be successful from the outset, determining specific therapeutic goals and expectations, and establishing clinical "milestones" indicative of treatment success or failure (40).

At these and subsequent meetings, allowing family members more time to speak, addressing their emotional issues, obtaining second opinions, and affirming key principles of biomedical

ethics and nonabandonment of patients may improve communication, especially in situations that have been identified in advance as being at high risk of conflict (41–43). Finally, consultation with ethics committees has been shown to reduce hospital and ICU length of stay and life-sustaining therapy in patients who ultimately did not survive until discharge (44).

When resolution cannot be reached in patients whose further care is deemed futile by physicians, a due process approach to conflict resolution has been recommended by the Council on Ethical and Judicial Affairs of the American Medical Association (45). This approach initially requires joint decision making by clinicians and families at the bedside. Third-party consultants then are asked to facilitate if agreement cannot be reached; if it cannot, an ethics committee or other institutional group becomes involved. If the committee agrees with the families' position but physicians remain unpersuaded, patients may be transferred to other physicians within the institution. On the other hand, if the committee supports the physicians' position but families are unpersuaded, patients may be transferred to physicians at other facilities. If transfer cannot be accomplished, life-sustaining therapy may be withheld or withdrawn.

Based on a multiinstitutional policy developed in Houston (46), this due process approach was incorporated into the Texas Advance Directives Act in 1999 (47). Like the American Medical Association guidelines, the Texas statute recognizes the absence of a universal definition of futility, reserving that determination to ethics committees while allowing patients to be transferred to other facilities that are willing to provide treatment and presumably have a different notion of futility. As of 2003, experience with the due process approach at one institution indicated that, of the five cases pursued through this approach, three families agreed to withdraw life-sustaining therapy shortly after receiving the ethics committee report, two patients died without alternative physicians having been located, and one patient died awaiting transfer after an alternative physician had been found (48).

The ethical appropriateness of the due process approach contained in the Texas Advance Directives Act has not been agreed upon widely, and its constitutionality has not been determined to date. One troublesome aspect of the approach is its reliance on institutional ethics committees, which may not always represent families' interests adequately. Nevertheless, the approach has the advantage of removing families and physicians who are at odds to a higher, but nonjudicial, body without actually involving the legal system. It also requires that time be spent in end-of-life deliberations, thereby decreasing the pressure to speed resolution. If nothing else, this aspect of the due process approach should provide comfort for families who resent the pressure as much as being asked to remove life support from their loved ones.

CONCLUSIONS

That Texas has imbedded the due process approach in its Advance Directives Act should remind us that disagreements between families and clinicians on end-of-life care are commonplace in the United States. Such disagreements are likely to increase in the future as the population ages, more technologies become available to sustain life, and concern about the proper use of these technologies intensifies in the ICU. Concurrently, pressure on the part of physicians and nurses to limit life support also may intensify. Clinicians should understand the sources of this pressure and its potential impact on families, and should apply it only when appropriate. Otherwise, communication between both parties may suffer, and a due process approach to resolve disagreements increasingly will be required.

Conflict of Interest Statement: Neither author has a financial relationship with a commercial entity that has an interest in the subject of this manuscript.

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