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Medical Futility in Intensive Care

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What should be done when patients and families demand futile care? Recent advances in American law and ethics now provide a pathway for resolving these conflicts.

Introduction

Many of the ethical and legal conundrums in intensive care medicine centre around patient rights, and two of the most difficult concern the rights of patients to refuse treatment, and the rights of patients to demand treatment. Europe and North America have taken very different approaches to these problems. In Europe, physicians have traditionally been empowered to make these decisions on behalf of the patients under their care. In contrast, the North American approach has been to cede much of this authority to patients and families.

Through the 1970s and 1980s, North America developed a strong ethical and legal consensus that gives patients a virtually unlimited right to refuse any medical treatment, even when physicians strongly believe the treatment is in the patient's best interest and should be administered. Only over the last 15 to 20 years has the debate moved on to the question of when, if ever, patients have a right to demand treatments that physicians believe to be futile. Since European standards seem to be moving away from physician paternalism and more toward patient-centred decision making, Europeans may have an interest in knowing how the debate over medical futility has developed in North American ethics and law. The issue can be examined from several different perspectives (Lantos 1994).

Power

At its root, the futility debate is most fundamentally about power. Who has the power to say "no" when patients demand treatments that physicians regard as futile? Physicians argue that only they have the knowledge and expertise to make these decisions, whereas patients insist that these decisions are laden with values that fall outside of the authority of the medical profession, such as deciding what chance of success is "worth it," or how great a price is "too much."

Trust

Closely related to issues of power are questions of trust. Futility judgments often concern life and death decisions. Why should patients and families trust physicians with these decisions? Indeed, a review of the futility cases that come to hospital ethics committees would show that many of them arise in situations where trust has broken down in the physician-patient relationship. Furthermore, patients can point to data indicating that physicians are poor predictors of survival from intensive care, and even worse at predicting the quality of life of survivors (Frick et al. 2003). Not surprisingly, therefore, conflicts between physicians and patients over potentially futile life-sustaining treatments are often complicated by a lack of trust.

Money

From another perspective, some insist that the futility debate is fuelled by a drive to save money. After all, if a patient with metastatic cancer insists on taking high dose Vitamin C in the absence of any evidence of effectiveness, few physicians would object, since the drug is cheap and easy to provide. On the other hand, if that patient insists upon treatment with high dose chemotherapy and a bone marrow transplant when there is no evidence of effectiveness, then physicians are likely to refuse, insisting that the treatment is futile and should not be provided.

Many physicians believe that a great deal of money could be saved by refusing to provide futile treatments. The data, however, indicate otherwise. Several articles, in both the adult and paediatric ICU literature, (Goh and Mok 2001; Halevy et al. 1996; Sachdeva et al. 1996) support the view that "The frequency of futile interventions appears to be low unless one is willing to accept a definition that includes patients who could survive for many months... this suggests that concepts of futility will not play a major role in cost containment" (Halevy et al. 1996).

Integrity

On the basis of the above considerations, the futility debate could be described as a power-play by physicians to exert their authority over patients and families, in a context where patients do not trust physicians to make these decisions and where data indicate that physicians are not deserving of that trust. Furthermore, data show that allowing physicians to act on these decisions will not save a significant amount of money. Some have therefore concluded that the futility debate is dead, and that physicians should never be given the power to unilaterally refuse to provide treatments (Helft et al. 2000). This conclusion fails to account, however, for the fact that physicians are often motivated by the highest ideals in insisting that certain treatments not be provided. Certainly physicians must often inflict pain and suffering on patients as a necessary price for making them well. But when the treatments have little chance of benefiting the patient, persisting with invasive and aggressive treatments that can only harm the patient strikes many physicians as profoundly wrong and unethical. On this view, while futility determinations must be made cautiously and with a full realization of the ways that power, trust, and money may enter into the calculus of decisionmaking, there may be a small number of circumstances where such determinations are legitimate and indeed necessary to maintain standards of professional integrity.

Diagnosing Futility

If, as suggested above, futility determinations can sometimes be ethical, how should the diagnosis be made? The first suggestions called for diagnostic standards, such as claiming a treatment to be futile if it had failed in the last 100 attempts, or if it would only sustain survival in an ICU or a state of permanent unconsciousness (Schneiderman et al. 1990). Some hospitals actually adopted standards like these into policy, but unfortunately they found that such standards were exceedingly difficult to apply in actual cases, where the "messy" mix of circumstances, context, and details made definitive black-and-white conclusions highly suspect.

A breakthrough came in the late 1990s, when a variety of hospitals and organizations perceived that while it may be impossible to devise a workable "definition" of futility, it might be possible to create a "procedure" for evaluating specific situations that could be both fair to patients while also identifying cases where treatment was futile and should not be provided (Plows et al. 1999). All of these protocols share certain features, such as a process based upon deliberation by a multidisciplinary committee which includes community involvement, with formal opportunities for both the physicians and the patient or family to present their views about whether the treatment should be provided. Early experience with these hospital policies has been very favourable.

Legislative Developments

One problem with hospital based futility policies has been that they lack the force of law. On the basis of their encouraging early track record, however, several states have created legislation that recognizes a procedural approach to futility determinations. Baylor University recently published its experience with the law in Texas (Fine and Mayo 2003). In the 2 years after the law came into effect, 47 futility cases came before the ethics committee. In 43 of these cases, the committee affirmed the consensus of the clinical team that further treatment was futile and should not be provided. In these cases, 37 families acceded to the decision and agreed to withdrawal of treatment, whereas six families refused to accept the decision. Of these 6 families, 3 agreed within a few days of receiving the report, 2 patients died during the 10 day waiting period required by the law, and 1 died awaiting transfer to an alternate provider. Most importantly, none of the families went to court in an attempt to overturn the judgment of the committee.

As an interesting aside, the authors noted that even families who vigorously argued for maintenance of life sustaining treatments sometimes seemed relieved by the process. In other words, their data suggest that there may be some families who can never bring themselves to agree with a decision to limit life-sustaining treatment, but who will not object, if the decision is made for them. In the next several years, more states are likely to follow Texas and adopt futility legislation. While some might see this as a return to the traditional European approach of paternalistic physician decision-making, this would be an overly simplistic interpretation. The practice that is developing in North American ethics and law does recognize physician determinations of futility, but surrounds that determination with a process explicitly designed to respect and defend the rights of patients and families.

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