Limiting Technology in the Process of Negotiating Death

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Death is a negotiated event; it happens by design. Whereas accident or negligence may occasionally intervene as an independent cause, 70% of the 1.3 million Americans who die in health care institutions do so after a decision has been made and implemented to forego some or all forms of medical treatment. One can only assume that this percentage has increased during the last decade as technological advances increasingly permit support of single organ function at the expense of integrated conscious existence.

Two powerful forces in health care evolved in the 1990s to affect the course and conduct of medicine at the end of life. Both are reflected, although not presented in sufficiently sharp focus, in the series of essays collected in the thoughtful volume, Managing Death in the Intensive Care Unit: The Transition from Cure to Comfort, edited by J. Randall Curtis and Gordon D. Rubenfeld. First, death has re-emerged as an acceptable outcome of medical practice, even in the intensive care unit, for patients whose prognosis is hopeless. Second, financial disincentives for long-term hospital stays must make us wary of determining the prognosis of hopelessness too easily. Capitated systems and prospective payment mechanisms provide incentives for shortened lengths of stay. This financial fact of life must not be permitted to contaminate decisions about death.

These evolutions, one clinical and one economic, have combined to force health care organizations and institutions to reevaluate their practices and protocols for managing patients at the end of life and especially in expensive intensive care units. In the aggregate, the results may be beneficial to patients and families as new perceptions and practices

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limit the endless process of dying that had become the norm in many health care centers. But not surprisingly, dangers of discrimination, creation of levels of care linked to layered reimbursement, and unnecessarily hastened deaths lurk in newly found perceptions of palliative and hospice care.

Most of the chapters in this book are well conceptualized and clearly written, and some provide valuable tools for professionals seeking to offer appropriate and compassionate care to patients and their families. Both physicians and nurses provide data, algorithms, and scripts to assist intensive care unit (ICU) staff in providing compassionate care. Having recently attended a working group of clinicians and clergy where physicians were virtually begging for scripts to follow in the uncomfortable arena of spiritual values, I find that many chapters provide clearly useful and practical guidelines that address how to speak to, evaluate, and treat the dying patient in pain, and how to approach and support the family.

Nonetheless, there are certain micro- and macro-ethical themes addressed in the book that require more explicit development. If staff members are to be able to negotiate effectively between and among the parties who must cooperate in order to permit a “good” death, they must have the perceptions and skills to assess, evaluate, and manage conflict. Misunderstandings, disagreements, and disputes are inevitable in the context of life and death decisions when individual history and preference must combine with present prognosis according to principles of probability. Techniques of mediation and negotiation can facilitate a dynamic process that reflects, but is independent of, ethical principles of individual choice.

Nowhere is this point more evident than in the various discussions of the notion of “futility” that emerge in multiple chapters. As in many discussions, futility is conceptualized by all of the authors as a binary mode—either care is futile or non-futile. Yet, I would argue that except for those rare instances in which the cases reported in the medical literature demonstrate “no possible benefit,” the notion of futility exists somewhere on a sliding scale of benefit and burden. But what it more commonly reflects is the fact that communication between the surrogates and the physician has broken down. The term futility is a trump card played by the physician to deny requested care and to end the discussion. What is needed at that point is not the blunt instrument of physician-exercised power—the doctrine of futility—but rather a nuanced process to bring the family to recognize the scant possibility of benefit and burdens of continued care. In such circumstances, techniques of mediation that set the stage, level the playing field, invite discussion, identify positions, and
seek consensus among conflicting conceptions of a good care plan will be far more helpful than asserting and insisting on physician power to decide—the essence of the futility discussion. In pursuit of that consensus, time-limited trials and variations in ICU visitation rules may provide the redress of medical power that makes agreement possible. As death reflects more of a negotiated process rather than a discrete event, collaboration and negotiation will need to replace the raw exercise of power that appealing to “futility” represents.

When examining the likely effects of easier access to death for patients, families, medicine, and society, a microanalysis that focuses on forging a patient-care plan must be accompanied by a macroanalysis emphasizing more global themes. These themes include differential access to care, the problem of the uninsured and underinsured, the wise stewardship of scarce institutional resources, corporate contracting arrangements that search out cost-effective care, and the ever-present dangers of racism and discrimination in provision of services. This analysis should take place in the context of the principle that ICU care is, and should remain, a scarce resource whose use is restricted to those patients whose prior health status and level of function can be restored. This is so because limitation of health care expenditures is an ethical and not merely an economic issue. If we, as a society, are to have effective public education, infrastructure, cultural institutions, and other indicia of a good society, then we must limit the costs of medicine.

The assumption of the appropriateness of scarcity leads me to contest one of the premises of this volume, that it presents the “state of the art in caring for dying patients in the ICU.” It may be that determining when a patient is dying is an ICU function, but this is only valid as the precursor to transfer from the ICU to a more appropriate level of care. No rule is absolute, but if the ICU remains a limited resource it must be used wisely by admitting those who can benefit and denying admission or transfer to those who cannot. Intensive care units need to save the lives of salvageable patients but do not necessarily need to manage the resulting deaths. Other sites and staffs in the hospital may be better at, and more cost-effectively situated for, end-of-life care. Nonetheless, ICUs must be better prepared for the eventuality that some proportion of patients will die in the units.

I would also disagree that “good end-of-life care is like an art: it is difficult to define, but you know it when you see it.” This book belies the statement. A good professional knowledge base, quality communication skills (rated as high as clinical skills by family members), and a willingness to face the modest benefit that continued care will likely provide, combine
to offer a basis for presentation of options and negotiation of a coordinated care plan. There are some artful elements, but many of the necessary techniques can be learned.

At the level of individual rights, a series of chapters in the book focus on the need for discussion with the patient, which is generally not possible when the person is in the ICU. As an alternative, the author discusses reliance on advance directives and family narratives. In these chapters, the author constructs pleas for a change in climate and perspective to emphasize truth telling. I would argue that if this is to occur, however, it must be accompanied by a new principle of “intellectual modesty.” Often there is no truth to tell; the doctor can only relay past data and fashion a prognosis in light of published studies. When those studies offer dire predictions, respect for the patient, compassion for the family, and regard for the integrity of medicine should combine to offer a realistic prognosis. Clinical exposure and discussion of medical uncertainty is the only fair way to prepare family members for the death of the patient.

However, there is another perception about families that receives little attention in any of these essays. While the notion that families need support is addressed, their need for protection is equally important. It is commonplace for ICU clinical staff to reach the decision that a patient is dying and take appropriate steps to avoid prolonging the process. Decisions to permit death are part of the regular business of diagnosis and prognosis within the realm of illness and disease. But family members have no comparable intellectual framework and no matching emotional distance. For them, the death of the patient will leave an unfillable void. Compassion for family members requires that medical staff shoulder the responsibility for the decision to permit death without disempowering families’ rights to make decisions. This is no easy matter. The legal rules, ethical principles, and medical conventions of decision making by family members preclude the medical team from usurping the decision. But compassion requires that medical staff absorb the burden of the decision so that the family does not perceive itself as the cause of the patient’s death; this is the artful part of end-of-life care.

One of the negative consequences of medical decision making in this litigious era is the insistence that if the patient or family have the right to decide, then they must shoulder the burden of the decision. This theme is evident in the risk-management notions of informed consent that emphasize the litany of risks over the balance of risks and benefits. In order to protect against the later possibility of legal liability, the locus of decision must be clearly separated from the medical professionals involved in care. That is a foolish consequence of our tort system and the litigious
society it encourages, and it is also a terrible basis for allocating the components of the decision-making process at the end-of-life. If institutions want to focus on liability for end-of-life care, they should be concerned about the fact that physicians who are not specialists in intensive care have half the success of intensivists in treating very sick patients. This provides powerful support for specially trained intensive care staff and a warning to institutions that permit community-based physicians to supervise the care of imperiled patients.13

But this sea change in medical perspective and the goals of physician communication will require a robust discussion within society, rather than a debate cloaked in the framework of court cases whose fact patterns often distort the discussion to force the narrative to conform to preexisting common law principles. This re-conceptualization of the debate began with the emergence of palliative care as a separate consulting discipline. The public discussion in the media of a “good” death has also contributed to this change. Reconstructing the grim reaper not as the enemy, but as a welcome friend, will take time and require reframing the goals of medicine.14 But it will require changes in “hospital culture, physician practices, and societal expectations” to really move practice.15

This book is another entry into the expanding discussion of end-of-life care. It applies to the ICU, but even more so to other medical staff who treat dying patients and support their families. It reflects the reality that medicine is adjusting its Olympian stance to the realities of chronic disease and the aging of the population. Patients and families have noticed that the SUPPORT study revealed that over 50% of patients die in moderate to severe pain, and that endless days in the ICU may extend dying, but may not reverse a declining quality of life.16 Medicine has acted as prince of the realm of death for the last fifty years. It has ushered in new techniques for treating illness. It must now learn to ease death as it previously enhanced life.
References


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7. Marin H. Kollef, Outcome Prediction in the ICU, in Managing Death, supra note 1, at 39.


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10. Sarah E. Shannon, Helping Families Prepare for and Cope with a Death in the ICU, in Managing Death, supra note 1, at 174.

11. See Malcolm Fisher, An International Perspective on Death in the ICU, in Managing Death, supra note 1, at 280, 282 for a discussion of the role that physicians play in managing death in New Zealand and Australia.


15. Kollef, supra note 7, at 44.

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