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**Foregoing Life - Sustaining
Treatment**

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INTRODUCTION

Chapter 7 described the various, interrelated factors that help produce an environment in which excessive intensive care unit (ICU) care is sometimes provided. The ICU treatment imperative is now being moderated by two relatively recent developments.

First, there has been increasing recognition of the emotional torment for the patient, the family, physician, and the hospital staff, of seemingly endless ICU stays that ultimately end with the death of the patient (243,247,278). A growing humanistic concern for the patient and his family supports the need to preserve the dignity of a dying patient, and may require earlier cessation of active life-support (18).

Second, there has been a growing recognition that the high costs of treating the most severely ill ICU patients may be too high, particularly if they obviously limit the resources available to treat moderately sick patients who are more likely to benefit from intensive care (54,247).

These two developments were explicitly recognized by experts in critical care medicine at the Critical Care Consensus Development Conference convened by the National Institutes of Health (NIH). The Consensus statement on Critical Care Medicine concludes:

It is not medically appropriate to devote limited ICU resources to patients without reasonable prospect of significant recovery when patients who need those services, and who have a significant prospect of recovery from acute] y life-threatening disease or injury, are being turned away for want of capacity. It is inappropriate to maintain ICU management of a patient whose prognosis has resolved to one of persistent vegetative state, and is similarly inappropriate to employ ICU resources where no purpose will be served but a prolongation of the natural process of death (176).

The NIH statement is significant not only because it recognizes the futility of ICU care in some situations but also because it acknowledges that ICU care is, in fact, already being rationed to some extent.

A full discussion of the difficult medical, ethical, and legal issues involved in deciding to forego life-sustaining treatment either because of the desire to permit death with dignity or because of a need to ration ICU resources is clearly beyond the scope of this case study. Readers are referred to the recently published report on this subject by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (191). In this chapter, a few issues of particular relevance to ICUs are briefly discussed.

THE NATURAL PROCESS OF DEATH

ICUs are uniquely capable of interfering with the natural process of death, since respirators and other ICU technologies are able to sustain vital functions long after the patient has any chance of recovery. As a consequence of these lifesaving technologies and the moral considerations involved in their use, many people today die "ICU deaths" rather than natural deaths (135). For ex-

ample, once a patient has been placed on a respirator, death may occur only when the physician steps in and discontinues its use. Indeed, some ICUs are developing policies and procedures for "terminal weaning" off of a respirator, which provide for the withdrawal of a respirator in a humane and efficient manner for the acknowledged purpose of permitting the patient to die (94).

As chapter 7 pointed out, in some situations, such as when the patient's prognosis and wishes concerning treatment are not initially known, there may be greater moral justification for permitting a death by withdrawing life-sustaining treatment, than for passively allowing death to occur by withholding ICU care in the first place. The ability of ICU technologies to intervene in the natural death process is also evident in patients suffering from a severe, debilitating, chronic illness who can survive their acute illness but who can never improve beyond their original unsatisfactory functional status.

In the past, pneumonia was known as "the old man's friend," because it often provided a rela-

tively quick and painless death for those facing years of disability (170). Medical technology, however, has largely removed this escape hatch. As a result, extremely elderly patients and patients with a severe chronic illness frequently survive their ICU stays, often at a great expense, only to be restored, at best, to their previous state of ill health. Similarly, patients who suffer a devastating injury and illness that in the past would have been fatal are now frequently saved by excellent medical skills and modern ICU technology, only to exist in a permanent state of profound physical or mental impairment (51).

FUNDAMENTAL ETHICAL, MORAL, AND LEGAL CONSIDERATIONS

For certain categories of patients, there has been considerable discussion in medical circles about the extent to which physicians and hospitals should be obligated initially to provide and then to continue ICU care. Many ICU physicians have taken the position, for example, that a necessary prerequisite to admission to an ICU is the potential salvageability of the patient (51,176,200,238). Some feel that in cases where the patient is clearly moribund and has no chance of improving, the physician's duty is to make the patient comfortable and not to impose intensive care (51,152). Although patients' families may attempt to pressure physicians into using the ICU, the physician and the institution probably would be on safe legal ground in denying such care, assuming the facts of the case sustain their position and that the decisionmaking process was reasonable (51).

A more difficult situation arises when a patient is terminally or irreparably ill, but is considered to have a chance of surviving the present acute deterioration (51). In such situations, the fundamental decision on whether to use life-sustaining technology should, if possible, be made by the patients after they have been fully informed of their options and understand their implications (191). A terminally ill patient's right to forego or discontinue life-sustaining treatment has been established, and is usually protected by the con-

stitutional right to privacy (191). An immediate problem is that the term "terminal" is not a standard technical term with clear and precise criteria for its definition (12). Physicians may not agree on when an illness is terminal, and some do not even use the term.

In addition, as noted in chapter 7, critically ill patients are frequently not competent to make an informed decision. This is particularly true of ICU patients who suffer subtle alterations of consciousness and develop psychological reactions to their illness or to the ICU itself. If the patient's incapacity to consent is temporary, the decision to forego the use of life-sustaining treatment may have to be postponed. If the condition is permanent, however, the question arises as to who should make the decision on the patient's behalf and on what basis (151).

The President's Commission recommended that when a patient lacks the capacity to make a decision—a common ICU occurrence—a surrogate decisionmaker should be designated. Ordinarily, this will be the patient's next-of-kin (191). Problems arise when family members disagree, are themselves incapable of good decisionmaking, or demonstrate family interests that conflict with the patient's interest (191). In many instances, an incapacitated patient may have no family or even

close friends who can act as a surrogate on making decisions about life-sustaining treatment.

At times, there maybe a fundamental disagreement between physicians and the patient's next-of-kin on the appropriate treatment for an incompetent, seriously ill patient. When such disagreements cannot be resolved through discussion or through a hospital-based forum such as an ethics committee, *or* when the patient is a ward of the State, the issue may have to be resolved in court. Sometimes, a physician may agree with a surrogate's decision to forego life-sustaining treatment, but, nevertheless, seek a judicial ruling for fear of criminal prosecution or civil liability (191). It should be emphasized that cases which mandate specific procedures for determining whether to continue medical treatment for an incapacitated patient have been decided by State courts. Therefore, these court-ordered remedies, which sometimes have differed in significant ways, apply only to the State in which the case was brought, unless courts in other States specifically adopt the same analysis. A discussion of the decisionmaking procedures mandated or approved by the courts in situations where a patient cannot choose for himself is beyond the scope of this case study.

It should be noted, moreover, that there is legal confusion even over when a patient ought to be considered terminally ill and over what constitutes "medical" treatment. A New Jersey appeals court, for example, overruled a trial judge's decision that would have permitted removal of a life-sustaining feeding tube from an 84-year-old woman considered to be terminally ill but not facing imminent death (241). The appeals court found that removal of a feeding tube would have inflicted new suffering from dehydration and starvation on the patient. The court found that the State has a "substantial and overriding" interest in preserving the lives of patients who are not moribund. It also seems to have found a legal difference between "nourishment" and "medical treatment." "We hold only that when nutrition will continue the life of a patient who is neither comatose, brain dead, nor vegetative, and whose death is not irreversibly imminent, its discontinuance cannot be permitted on the theory of a patient's right to privacy, or,

indeed, on any other basis." ¹ A New Jersey Supreme Court review of this finding is pending.

The California appellate court decision in the criminal case of *People v. Nejdil and Barber*, in which homicide charges were brought against physicians who withdrew nutrition in the form of intravenous fluids and nasogastric feedings from a comatose patient, significantly departs from the reasoning used by the New Jersey Appeals Court in the case cited above. The California case did not distinguish between "ordinary" and "extraordinary" care and instead defined the concept of "proportionate treatment." The court wrote:

Proportionate treatment is that which . . . has at least a reasonable chance of providing benefits to the patient, which benefits outweigh the burdens attendant to the treatment. Thus, even if a proposed course of treatment might be extremely painful or intrusive, it would still be proportionate treatment if the prognosis was for complete cure or significant improvement in the patient's condition.²

The reasoning of the New Jersey Appeals Court decision, which has been appealed to the State Supreme Court, and that of the California Appeals Court would appear to be irreconcilable. Thus, considerable legal uncertainty remains over precisely which medical therapies, if any, are considered routine or ordinary and in which clinical situations they must be provided. Treatments might be considered mandatory for some patients but not for others. Weaning a terminal patient who is brain dead off a respirator would appear to be permissible, for example, but removing a feeding tube or intravenous line might not. Likewise, physicians might be legally required to provide different treatment for patients who are seriously ill and have no chance for sustained recovery than for patients who are permanently comatose or who face imminent death.

¹See *In re Conroy*, 188 N.J. Super. 523, 532 (ch. Div. 1983).

²See *Neil Leonard Barber, Robert Joseph Nejdil v. Superior Court of the State of California for the County of Los Angeles*; Court of Appeals of the State of California, Second Appellate District, Civil No. 60350; Oct. 12, 1983.

The use of life-sustaining technology has also been questioned for the patient who is not terminally ill but who finds the quality of life unacceptable and without any reasonable chance for improvement (51,225). Judgments about quality of life obviously reflect the values and biases of the person making the judgment (152) and therefore are relevant only if they represent the views of the patient (148). While some courts have ventured into this area (26), there is much less legal precedent on which to guide physicians about the obligation to provide ICU care for such patients, particularly where the patients are incompetent to decide for themselves (170). Because it took years for even the current level of consensus to develop regarding the possibility of foregoing care for terminally ill patients, one should expect a similar evolutionary process on the issue of foregoing life-sustaining care for those with an unacceptable quality of life.

Beginning with the enactment of the California Natural Death Act in 1976, 15 States and the District of Columbia have enacted statutory au-

thorization for competent individuals to write an "advance directive" which directs their physicians to forego life-sustaining treatment under circumstances in which they are both incompetent and suffering from a terminal condition (273). A "proxy directive" designates a surrogate of the patient's choice to make decisions for the patient if he or she is unable to do so; it maybe accompanied by an "instruction directive" which specifies the type of care the person wants to receive. In addition, 42 States have enacted "durable power of attorney" statutes, which provide authority to appoint a proxy to act after a person becomes incompetent. Although developed in the context of property law, these statutes may be used to provide legal authority for an advance directive.

There are a number of unresolved issues about how advance directives should be drafted, given legal effect, and used in clinical practice. Nevertheless, the President's Commission recommended their use as a way of honoring patient self-determination (191).

PROCEDURES FOR REVIEW OF DECISIONMAKING

The models of decisionmaking procedures for incompetent patients derived from court opinions are quite different. The New Jersey Supreme Court in the *Quinlan*³ case invoked the presence of hospital "ethics committees" to provide consultation to an incompetent patient's guardian and specifically rejected judicial review of such decisions (191). By contrast, the Supreme Judicial Court of Massachusetts in the *Saikewicz*⁴ case appeared to explicitly reject the New Jersey method of decisionmaking and instead has established judicial review of these decisions as the rule rather than the exception (191). However, in followup decisions, the Massachusetts court has seemingly modified its *Saikewicz* opinion such that only certain categories of cases would appear to require judicial review, such as when the family or the family and doctors are in disagreement or when

the physicians needs, but cannot otherwise obtain, consent to a course of treatment when the patient is a ward of the State (272).

The President's Commission recommended that resorting to courts should be reserved for occasions when adjudication is clearly required by State law or when concerned parties have disagreements over matters of substantial importance that they cannot resolve. The Commission stated that ethics committees and other institutional responses can function more rapidly and sensitively than judicial review (191).

As was noted earlier, relatively few hospitals have such ethics committees, and those in existence serve various functions, ranging from formulating policy and guidelines and serving as a forum for considering difficult ethical problems, to consulting on prognosis in individual cases and, finally, to reviewing or even making treatment decisions (191). Because of the lack of general experience with ethics committees, the Commission

³*In re Quinlan*, 70 N.J. 10, 355A. 2d 647, 699, cert. denied, 429 U.S. 422 (1976).

⁴*Superintendent of Belchertown State School v. Saikewicz*, 370 N.E. 2d 417, 434-3s (Mass. 1977).

called for additional evaluation of various forms of formal and informal institutionally based committees before general adoption in all hospitals (191).

It should be noted that over the past 15 years, Institutional Review Boards (IRBs) have been set up to review in advance the ethical considerations of specific research involving human subjects. Although initially controversial, IRBs are now generally accepted in the biomedical research community (191).

RATIONING ICU CARE

Up to now, discussion of withholding and withdrawing ICU care has focused primarily on the perceived or actual interests of the patient. However, the NIH panel has acknowledged the fact that patients who might benefit from treatment in an ICU are denied admission because beds are occupied by patients who do not have a reasonable prospect of “significant” recovery. Early analysts recognized that a few individuals consumed a dramatically disproportionate share of ICU resources and suggested that those resources be increased so as to avoid difficult choices about access (162). The President’s Commission advised against limitations on access to life-sustaining care as an initial part of any cost-containment strategy (191). It argued, instead, that the first step should be the control of “small ticket” tests and treatments, such as routine blood test and X-rays, which are believed by some to be less cost effective than more dramatic forms of therapy (153), and which can be discussed in relatively dispassionate terms. Unfortunately, because marginal costs of ancillary services are much less than average costs, cutbacks on these services are not likely to have a major impact on hospital costs (1).

In addition, the care of a typical high-cost ICU patient is, to a large extent, an accumulation of small ticket items. While some efficiencies in ICU care can be achieved (227), the fact remains that the decision to initiate and continue ICU care for patients for whom recovery is unlikely, but possible, is one of the major causes of the increasing proportion of the Nation’s health costs accounted

for by ICUs. Despite current efforts to make health care more efficient, it seems clear that further attempts at cost-containment will encounter the reality that a large amount of medical care is consumed by patients with highly unfavorable prognoses (219).

“It is a basic tenet of our society that we will not give up a life to save dollars, even a great many dollars” (111). Yet, to some extent, this “lifesaving imperative” is a myth, since society’s devotion to saving lives is greatest where the threat is to identifiable individuals, such as trapped miners or the victims of catastrophic disease. Society, however, accepts the loss of many “statistical” lives (111), whether from the results of toxic waste or inadequate preventive health care.

Physicians usually follow the same lifesaving imperative. Many health professionals, lawyers, and philosophers have warned that while society may choose to limit medical treatments for economic reasons, it is not appropriate for physicians to do it for individual patients (17,83,152,266). They argue that the doctor-patient relationship requires an absolute commitment to do everything possible for the individual patient, regardless of the effect on society’s resources.

However, most physicians by training and practice accept the fact that there are limits to the resources that society can expend on any one individual, and in some circumstances they act as society’s agent in balancing the needs of their patient against the needs of other patients and so-

ciety as a whole. For example, a patient with intractable gastrointestinal hemorrhage does not receive limitless supplies of blood (152). At some point, a physician makes a decision, sometimes implicitly, that society's interest in having a supply of blood available for the community outweighs the patient's need for continued transfusions. The threshold for the decision to discontinue transfusions obviously varies, depending on factors such as the patient's underlying medical problem, age, and perceived life expectancy and the physician's point of view.

In less dire circumstances, physicians commonly weigh the value of a marginal benefit to their patients against the general cost to society. An example is the support of preventive health screening based on population-related, cost-effectiveness data. For instance, differences in the recommended intervals for screening for cervical cancer through use of the PAP test (103) are essentially based on different views of how many missed cases are acceptable on a cost-effectiveness calculation. Physicians who choose one standard over others do so with an implicit acceptance that there is some level of risk that is acceptable for an individual patient.

Physicians in health maintenance organizations (HMOs) may practice a somewhat different style of medicine, based on the reality of a fixed pool of resources. HMOs face "either-or" choices and must decide whether particular treatments, such as for catastrophic diseases, are better investments than others, such as for prenatal care (111). While

the constraint of limited resources is imposed externally, HMO physicians, perhaps unconsciously, may alter their decisionmaking for individual patients in accordance with the reality of limited resources. While the HMO may exclude or limit certain benefits explicitly in its contract with subscribers, it also counts on physicians to practice "cost-effective" medicine, often at a small but measurable risk to certain individual patients (22).

The clear bias in ICU decisionmaking is to initiate and continue ICU care even when it is extremely unlikely that the patient will benefit from such care. Nevertheless, because of limited ICU resources, decisions are made every day to curtail the care provided to individual ICU patients and to restrict access to ICUs. In public hospitals, difficult decisions to ration limited ICU beds have become commonplace (186). Even in nonpublic hospitals, rationing of ICU resources has occurred, particularly where there has been a shortage of nurses (220,230).

Up to now, shortages in ICU capacity to treat patients who might benefit from intensive care have resulted primarily from internal hospital decisions on allocation of beds and other resources between the ICU and general floors, and not from external economic restraints. As discussed in chapter 6, that will no longer be the case, however, under the Medicare's DRG hospital payment system. In the next few years, therefore, much more attention will have to be given to how ICU care should be rationed.

EXPLICIT OR IMPLICIT RATIONING OF ICU CARE?

Explicit Rationing

Provision of ICU care can involve both explicit and implicit forms of rationing. Explicit rationing of medical care generally involves direct administrative decisions on such issues as exclusion of certain types of services from insurance coverage, limitations on the availability of specific methods of care, preauthorized and concurrent review and approval for expensive treatments and

procedures, required intervals between provision of specified services, and limitations on total benefits (159). In the context of the ICU, explicit rationing might include the establishment of medical criteria for treatment based on predictors of outcome for ICU care as they become available. In addition to predominately medical considerations, factors such as life expectancy, family role, and social contribution could also be formally considered (196), although the experience of al-

locating rare renal dialysis machines and selecting patients for kidney transplants in the 1960s on the basis of social factors was nearly intolerable to those involved (2,14) and might not be acceptable to society.

The ethical considerations of how to decide who should receive lifesaving treatment and who should not has received attention by bioethicists (13). It is relevant here to note that to avoid explicit rationing for lifesaving treatments, health planners and policymakers have tended either to approve facilities or financing mechanisms that will assure treatment for nearly everyone with a particular illness, e.g. end-stage renal disease, or they make a decision not to facilitate treatment for anyone suffering from a certain condition, e.g. patients needing heart transplants (111) except perhaps on an experimental basis (122). Since ICUs are not disease-specific, explicit rationing on the basis of disease would not seem to be an appropriate means of limiting ICU care.

Explicit rationing of ICU care might also include limits on covered benefits beyond a certain amount, or in certain clinical situations, where patients could have to bear the costs of ICU care directly. Currently, most patients have insurance coverage for most ICU costs. Many without coverage have been subsidized. In public hospitals, rationing of limited ICU beds has been based largely on a combination of medical factors, such as likelihood of successful intervention, and demographic factors, such as age, and not on considerations of ability to pay (186). There is the real question of whether society would tolerate explicit denial of “life and death” ICU care on the basis of insurance coverage or personal wealth. In recent years, Congress has considered several proposals for national health insurance that would extend coverage to everyone for catastrophic illness in order to avoid denial of care on the one hand and the possibility of extreme financial hardship and bankruptcy on the other (72).

Implicit Rationing

Implicit rationing involves limitations on the resources available to health care providers, such as fixed budgets and restrictions on sites of care or hospital beds (159). These limitations are im-

PLICIT because they do not specify what services should be provided to whom or what assessments physicians should make. Instead, they achieve their effect by placing greater pressures on physicians and hospitals to make hard allocation choices. Simple reliance on the price mechanism can also be a rationing device, since everyone’s ability to pay is limited at some point; for almost all *resources* in our society, price does “ration” access to goods and services. Cost-based payment for insured medical services has been a notable exception. The new DRG payment system for Medicare is a form of implicit rationing since the total payments allowed under the system are fixed, regardless of the level of services provided.

Other forms of payment limits could also require rationing. Indeed, because many people lack insurance altogether or have less than full-cost, open-ended coverage, implicit rationing occurs for many medical services today, particularly non-hospital care. It would be possible to limit total social spending on ICUs (or anything else) through the implicit rationing device of patient cost-sharing, which does not require administrative decisions. Such price-based allocation of resources can be troublesome, however, when applied to catastrophic medical care for a variety of reasons (see 111).

The cost of care for the sickest patients in the ICU is currently being subsidized to a great extent by those who are not as ill, and by the hospital. DRG fixed payments, which are not adjusted according to the severity of the illness, will often make high-cost Medicare ICU patients significant financial “losers” for the hospital. In this situation, physicians will likely feel institutional pressures not only to alter the style of ICU care they provide to reduce costs, but also to reconsider the thresholds for withholding and withdrawing ICU care from specific individuals. In addition, hospitals may limit or even reduce the number of ICU beds, thus reducing access for patients who would have received higher cost ICU care. This form of implicit rationing of ICU care raises a number of questions:

- **What protections will patients require to avoid arbitrary decisionmaking to limit care?** Will certain categories of patients, such as the elderly, the retarded, or otherwise chronically

dependent persons who might benefit from ICU care, be systematically excluded on purely economic considerations?

- **Will the potential threats of criminal prosecution and malpractice suits act as a sufficient countervailing force to the new incentives that DRGs will bring?** More specifically, will there be a fundamental conflict between traditional malpractice standards and new norms of practice that may involve limiting care more strictly? Malpractice law has traditionally judged the behavior of medical care providers almost exclusively by the customary practice of their peers, rather than by an independently determined standard of socially appropriate care (22). Malpractice law generally does not recognize varying styles of care to suit varying available resources. It remains to be seen whether courts will recognize limited available resources as a factor in determining negligence. In fact, hospitals and physicians may have new incentives not to treat very sick ICU-type patients in the first place, not only because of the directly negative economic consequences, but also because it may place them in legal jeopardy under existing malpractice standards. Once care has been initiated, the primary responsibility of the provider is to meet a high standard of care that may not be reimbursed sufficiently under the DRG payment scheme. Hospitals may decide systematically to avoid the responsibility in the first place by diverting and transferring patients elsewhere.
- **Will society tolerate different levels of ICU care based on willingness and ability to pay?** Medicare will prohibit hospitals for the most part from seeking direct payments from its patients above the allowable DRG payments

(Social Security Act Amendments of 1983, Public Law 98-21). Can a Medicare patient in a life or death situation be denied the continued ICU care he or she desires and is willing to pay for personally, primarily through private insurance, because Medicare prohibits patient payments above the DRG limit? If not, it is likely that different types of ICUs will develop, based largely on the ability to pay.

- **Finally, what procedures should be used to assist ICU decisionmaking in an era in which at least some patients become financial “losers” for the hospital?** A number of procedural safeguards have been proposed to protect the interest of patients who have insufficient capacity to make particular decisions on their own behalf, including: 1) naming an appropriate surrogate to act on the patient’s wishes or in the patient’s interest; 2) establishing administrative arrangements, such as ethics committees for review and consultation of different decisions; and 3) permitting advance directives, such as living wills, through which people designate someone to make health care decisions on their behalf, and/or give instructions about their care (191). While initially proposed in the context of protecting the interests of incompetent patients, these or other procedural safeguards also appear necessary to protect the interests of competent patients who might otherwise be rationed out of the ICU. ICU decisionmaking has been difficult when there was no theoretical conflict between the interests of patient, physician, and institution. Under a prospective payment system, patients, physicians, and hospitals may have different interests.