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TREATMENT REFUSALS FOR THE CRITICALLY AND TERMINALLY ILL: PROPOSED RULES FOR THE FAMILY, THE PHYSICIAN, AND THE STATE

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In the decade following the landmark decision of *In re Quinlan*,¹ questions surrounding the cessation of medical treatment for the critically and terminally ill have continued to generate controversy and confusion. "Death with dignity" has become an important and popular concept,² but a consensus on how to achieve it has eluded us. Recent news articles report the uncertainties felt by medical practitioners about the legalities and ethics of withholding or withdrawing treatment.³ Inconsistent practices exist from hospital to hospital, and, within the same hospital, from doctor to doctor. Avoiding the risk of legal liability has sometimes taken precedence over compassionate,

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1. 70 N.J. 10, 355 A.2d 647 (1976), *cert. denied*, 429 U.S. 933 (1976).

2. As Samuel Gorovitz observes:

A death can occur too soon or too late. Further, there is the question of how it will come about. There are dyings that are slow and agonizing and dyings that are gentle and graceful It seems reasonable that if death is impending, one should want to exert some influence on the mode of one's dying. Just as one wants to be able to influence the major events that shape and constitute a life at earlier stages, one may want to avoid the indignity of having to witness and endure a final stage not as an effective agent, but merely a deteriorating object.

GOROVITZ, DOCTORS' DILEMMAS: MORAL CONFLICT AND MEDICAL CARE 153 (1982) [hereinafter cited as GOROVITZ].

According to a 1981 Harris poll, by a margin of 78% to 19%, the majority of Americans think that "a patient with a terminal disease ought to be able to tell his doctor to let him die rather than to extend his life when no cure is in sight." By 73% to 23%, Americans believe that the family of a terminally ill irreversibly comatose person ought to be able to tell doctors to remove all life-support services and let the patient die. And a majority of Americans, by a 56-41 percent margin, even accept the notion that the terminally ill should be able "to tell the doctor to put him out of his misery," an apparent reference to active euthanasia. 39 THE HARRIS SURVEY (1981).

3. See Kleiman, *Uncertainty Clouds Care of the Dying*, N.Y. Times, Jan. 18, 1985, at B1, col. 1; Sullivan, *State Officials Drafting a Bill on Withholding Life Support*, N.Y. Times, Sept. 17, 1984, at A1, col. 1; Kleiman, *Doctors Ask, Who Lives? When to Die?* N.Y. Times, Jan. 16, 1985, at B1, col. 1.

humane medical care.⁴

Despite current uncertainties in the law, consensus has emerged on some major points. First, there is widespread agreement among courts today that individuals in our society have the right to refuse medical treatment.⁵ This right is paramount to the interests of the state in preserving life and preventing suicide, and to any interest of medical professionals in providing maximal care.⁶

Second, there is general agreement that incompetent patients who are unable to make such decisions for themselves preserve the right to refuse treatment.⁷ In the words of the Supreme Judicial Court of Massachusetts, the right "must extend to the case of an incompetent, as well as a competent, patient because the value of human dignity extends to both."⁸ Since incompetents are unable to assert the right, some means must be found to allow others to assert it effectively on their behalf.

Further common ground exists with respect to the appropriateness of exercising the treatment refusal right of an incompetent who is in a permanent vegetative state.⁹ Most of the court decisions in this area, starting with the case of Karen Ann Quinlan, deal with individuals in this extreme condition. Persons in this state function only on a "vegetative" level, with their bodies capable of maintaining body temperature, blood pressure, heart rate, and other biological functions not requiring conscious con-

4. See *supra*, note 3.

5. See, e.g., *In re Eichner*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266, *cert. denied*, 454 U.S. 858 (1981). The medical profession's interest had sometimes been given considerable weight in the past, see, e.g., *U.S. v. George*, 239 F. Supp. 752 (D. Conn. 1965), but changing norms in the medical profession and a societal rejection of maximal care as an unwarranted burden on dying patients has destroyed its former power. Compare *In re Quinlan*, 70 N.J. 10, 355 A.2d 646 (doctors oppose stopping treatment) with *In re Torres*, 357 N.W.2d 332 (Minn. 1984) (doctors support stopping treatment). The only interest that may override the individual's right to decline treatment is the societal interest in the welfare of minor children of that individual. See *In re Winthrop Hospital*, ____ Misc.2d ____, 490 N.Y.S.2d 996 (Sup. Ct. Nassau Co. 1985) (court grants order permitting blood transfusion should surgeon deem it necessary to save religious objector's life when religious objector is mother of infant).

6. See *supra*, note 5.

7. See *In re Torres*, 357 N.W.2d 332 and cases collected therein at 339.

8. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 745, 370 N.E.2d 417, 427 (1977).

9. See cases collected in *In re Torres*, 357 N.W.2d at 339.

trol.¹⁰ When patients in this condition have previously expressed a wish not to be maintained on respirators or other artificial life support systems, courts have required that those wishes be respected.¹¹ Legislatures in many states also support this result in "Living Will" or "Natural Death" statutes.¹² Even if no prior expression of intent was made, courts have authorized the withholding or withdrawing of life support equipment from irreversibly vegetative patients when asked to do so by the patient's family or guardian.¹³ This result is also approved of by the American Medical Association¹⁴ and the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research¹⁵ (hereinafter the President's Commission).

Certain areas of disagreement have arisen, however, concerning the procedures by which decisions to stop treatment are to be made. Controverted questions involve the precise roles that physicians, families, courts, and district attorneys should play in this type of decisionmaking. Other questions have yet to receive widespread legal attention, particularly those posed by incompetent persons who are severely ill, but not irreversibly comatose or permanently vegetative.¹⁶ Under what circumstances,

10. The patient may, without consciousness, make motions such as chewing and eye blinking, and even have a sleep/wake cycle, but there is no cognitive function at all. The condition is usually brought on by lack of oxygen to the brain, which destroys all areas of the brain except the brain stem within three to five minutes. Technically the victim is not "terminally ill" since the vegetative state can continue for an indefinite time extending over many years. The longest known vegetative state lasted 37 years. R. Cranford, *Brain Death and the Persistent Vegetative State*, in *LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS* 63-76 (Doudera and Peters eds. 1982) [hereinafter cited as *LEGAL AND ETHICAL ASPECTS*]; *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (expert medical testimony).

11. *E.g.*, *In re Eichner*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266; *In re Bludworth*, 452 So.2d 921 (Fla. 1984).

12. *E.g.*, CAL. NATURAL DEATH ACT, CAL. HEALTH & SAFETY CODE § 7185 *et. seq.* (West 1985).

13. *E.g.*, *In re Colyer*, 99 Wash.2d 114, 660 P.2d 738 (Wash. 1983); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647.

14. Statement by the Judicial Council, A.M.A. (1982), *reprinted in* President's Commission, *infra* note 15, at 299.

15. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS* 181-83 (1983) [hereinafter cited as *PRESIDENT'S COMMISSION*].

16. Only four cases involving such situations have reached the highest state courts: *In*

and by whom, are decisions to be made to withhold or withdraw life sustaining treatment from these individuals? This article will explore these issues and recommend appropriate decision-making roles for the various participants. The particular circumstances addressed are those in which (1) severely, irreversibly ill patients are incapable of making their own decisions, and (2) one or more family members exist who care about such patients' welfare and who are willing to be involved in decisionmaking on their behalf.

While some of today's treatment/nontreatment decisions may be relatively new ones posed by the availability of modern medical techniques, the basic problems they raise are not without precedent. Past experience, coupled with a close examination of the human values, ethics, and cultural forces at work today, offer some guidelines to resolve the decisionmaking dilemmas we face. The law, as one major cultural element which can influence behavior, is a special focus here, but it is well to remember that legal rules alone can not dictate the course of complex human interactions. If, as will be discussed here, good decisionmaking is dependent upon the careful development of information, genuine communication among the people involved, personal choices among moral and philosophical values, and the presence of human sensitivity and empathy, then rules of law, however well thought out, can play only a supportive role in the real-life dramas we are considering.

LEGITIMACY OF NON-TREATMENT DECISIONS

Decisions not to treat severely ill, incompetent persons are generally acceptable on three grounds. First, as a matter of self-determination, if the individual has previously expressed a desire to refuse treatment in specified medical circumstances, and those circumstances later arise, the previously expressed wishes should be followed. This is illustrated by the well-known case of Brother Fox,¹⁷ a member of a Catholic order who enjoyed good

re Conroy, 98 N.J. 321, 486 A.2d 1209 (1985); In re Storar, 52 N.Y.2d 363, 426 N.E.2d 64, 438 N.Y.S.2d 266, *cert. denied*, 454 U.S. 858 (1981); In re Spring, 380 Mass. 629, 405 N.E.2d 115 (1980); Superintendent of Belchertown State School v. Saikewicz, 373 Mass. 728, 370 N.E.2d 417. In time the proliferation of these cases may make Quinlan-type situations of persons in permanent vegetative states seem like easy cases.

17. In re Eichner, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266.

health until he was 83 years of age.¹⁸ After undergoing surgery for a hernia, he experienced cardiac arrest, suffered substantial brain damage as result of oxygen deprivation, and went into a coma.¹⁹ He was quickly put on a mechanical respirator, but it became clear that the coma was irreversible.²⁰ Based upon Brother Fox's own statements prior to his hospitalization, indicating he did not want such "extraordinary business" done for him should he ever be in an irreversible state like that of Karen Ann Quinlan, the New York Court of Appeals ruled that life support systems should be withdrawn.²¹ While this case involved an individual in a permanent vegetative state, the same principle of respect for self-determined treatment refusals applies with equal force to persons in non-vegetative conditions.

The second ground for withholding treatment from incompetent patients is the desire not to prolong the act of dying. Individuals described as "on the threshold of death" can be artificially suspended there by machines that keep minimal biological functions going. The patient in *Leach v. Akron General Medical Center*²² was suffering from the progressive and fatal disease amyotrophic lateral sclerosis (also known as "Lou Gehrig's disease").²³ The disease had progressed to the point that the patient was described by the court as "semi-comatose," irreversibly brain damaged, and without "hope of regaining cognitive or sapient powers."²⁴ The judge appropriately concluded that there existed "no possible benefit to the State . . . in extending minimal life" and authorized the disconnection of mechanical life supports.²⁵ While the patient in this case had expressed her wish while competent not to be artificially maintained in such a condition, the court's observation that society should not insist on medical intervention to prolong dying applies equally to similarly ill persons who have not previously expressed their desires concerning treatment. Courts in various states have so held.²⁶

18. *Id.* at 371, 420 N.E.2d at 67, 438 N.Y.S.2d at 269.

19. *Id.*

20. *Id.*

21. *Id.* at 379-80, 420 N.E.2d at 68, 438 N.Y.S.2d at 270.

22. 68 Ohio Misc. 1, 426 N.E.2d 809 (Ohio Comm. Pleas 1980).

23. *Id.* at 5, 426 N.E.2d at 812.

24. *Id.*

25. *Id.* at 12, 426 N.E.2d at 816.

26. *E.g.*, *In re Dinnerstein*, 6 Mass. App. Ct. 466, 380 N.E.2d 134 (1978); *In re L.H.R.*,

Another common intervention at what otherwise would be the moment of dying is cardio-pulmonary resuscitation (CPR). While many individuals are benefitted by CPR, its benefits are less clear when it forestalls the death of a patient who is in the final stages of terminal illness. Medical professional organizations accept the validity of orders not to resuscitate certain patients,²⁷ and the one case addressing this issue found orders not to resuscitate appropriate for the hopelessly ill patient whose death is imminent.²⁸ Rejection of emergency resuscitation is consistent with rejection of respirators and other life support interventions, and the acceptability of the latter logically mandates acceptance of do-not-resuscitate orders. When the condition of a critically, incurably ill patient is deteriorating, and death is inevitably expected, aggressive and violent²⁹ resuscitation efforts should not be required.

The final ground upon which treatment refusals can be justified, humane concern for the victim of critical illness, presents more difficulty. We may know little of the wishes of the patient (as is common in a society where death is frequently not talked about) and death may not be imminent, yet certain situations still seem to call for withholding or discontinuing aggressive medical treatment.

Medical professionals acknowledge that they have terminated treatment of very ill persons on humane grounds. One neurosurgeon writes: "Many physicians have let patients die. These actions were right and humane in order to stop the needless prolongation of agony. We have refrained from ordering medication to support blood pressure. We have stopped antibiotics to control fatal infections"³⁰ This has been done with

253 Ga. 439, 321 S.E.2d 716 (1984); *In re Hamlin*, 102 Wash.2d 810, 689 P.2d 1372 (1984).

27. See, e.g., *Standards for Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC)*, 227 J. A.M.A. 837, 864 (1974); other medical guidelines for issuing "do not resuscitate" orders are provided in App. A-F in *LEGAL AND ETHICAL ASPECTS*, *supra* note 10.

28. *In re Dinnerstein*, 6 Mass. App. Ct. at 475-76, 380 N.E.2d at 139.

29. See *id.* at 468-469, 380 N.E.2d at 135-36. The court noted that "[m]any of these procedures (used in CPR) are obviously highly intrusive, and some are violent in nature. The defibrillator, for example, causes violent (and painful) muscle contractions which, in a patient suffering (as this patient is) from osteoporosis, may cause fracture of vertebrae or other bones. Such fractures, in turn, cause pain, which may be extreme."

30. HEIPETZ, *THE RIGHT TO DIE: A NEUROSURGEON SPEAKS OF DEATH WITH CANDOR* 5

the concurrence of families for many years.³¹ Recent surveys indicate that the majority of doctors now accept the idea of passive euthanasia, i.e., ceasing to treat some hopelessly ill patients.³²

Humane concerns encompass the desire not to inflict needless pain and suffering, and the desire to preserve the patient's human dignity. Avoidance of pain and suffering is a widely accepted goal in our culture, and provides a strong incentive to avoid treatments which are themselves painful, or which prolong the life of a critically ill person who suffers constant pain while he remains alive. It is understandably a commonly agreed upon important factor in many decisions to stop treatment.³³

Humane concerns about preserving human dignity are pervasive in cases, statutes and medical literature.³⁴ The term "dignity" seems to encompass a cluster of concerns. They can be categorized as concerns for the individual's privacy, independence, bodily integrity and self-control, emotional equilibrium, and need for meaning and purpose in life. Medical treatments which diminish these life qualities are experienced by many in our culture as extremely burdensome.³⁵

(1975); See D. MAGUIRE, *DEATH BY CHOICE* 38-40 (2d ed. 1984) [hereinafter cited as D. MAGUIRE].

31. See, *In re Storar*, 52 N.Y.2d 363, 385 n.3, 420 N.E.2d 64, 75-76 n.3, 438 N.Y.S.2d 266, 277-78 n.3 (sources cited in dissent of Jones, J.).

32. *Id.* This does not mean that all doctors who believe in letting people die necessarily act on their beliefs. See *infra* text accompanying notes 102-58.

33. What is less understandable is the apparent practice of many physicians of not providing sufficient pain medication for dying patients. One writer, a psychiatrist who observed the routine undermedication for pain in a burn clinic, suggests that unconscious psychological needs of health care providers lead them to these inadequate prescribing practices. His rational attempts to inform the medical staff of pain medications available, their efficiency, and the low risk of untoward side effects, failed to change physician behavior. Perry, *The Undermedication of Pain: A Psychoanalytic Perspective*, BULL. A. PSYCHOANALYTIC MED. 77 (June 1983). A leading medical journal devoted an editorial to this widespread problem, urging doctors to alleviate pain more effectively when they could. Angel, *The Quality of Mercy*, 306 NEW ENG. J. MED. 98 (1982). See also, *MDs Urged to Alter Prescribing Patterns for Dying Cancer Patients in Pain*, Am. Med. News, Feb. 18, 1983, p. 5.

34. *E.g.*, *In re Torres*, 357 N.W.2d 332; CAL. NATURAL DEATH ACT, CAL. HEALTH & SAFETY CODE § 7185 *et seq.* (West 1985).

35. Forcing stressful, invasive, or undignified treatments on hopelessly ill patients arouses intense feelings of anger and bitterness on the part of caring family members. For three compelling examples, see Crawshaw, *Technical Zeal or Therapeutic Purpose—How to Decide*, 250 J. A.M.A. 1857 (1983); Walter, *A Little Music*, PENNSYLVANIA GAZETTE 16 (April 1983); Ferber, *I Cried, but Not for Irma*, READER'S DIG. 92 (April 1976).

Irreversibly, severely ill patients often are subject to significant losses of personal dignity. Disease itself is one source of this loss; the most extreme case, that of the permanent vegetative state, deprives the individual of meaningful existence and of any independence or conscious self-control over body or mind.

For very ill persons in non-vegetative physical states, extensive losses of the various aspects of dignity result from the combination of physical condition and medical treatment. Privacy is lost with repeated visits of technicians tending machines or with the constant handling and monitoring of intensive care. A helpless dependence on others develops when basic hygiene and fundamental body function are beyond one's own physical or mental capacity. Bodily integrity and self-control may be lost to invasive tests and procedures and to inserted tubes and catheters. Emotional equilibrium may be upset not only by one's illness, but by the pain, fear, isolation and anxiety caused by hospitalization and by stressful treatment regimens.

What impairs the meaningfulness of life is a more philosophical question, perhaps, than the rest. In states approaching the vegetative, there is virtually undetectable cognitive, emotional or sensory functioning; there is minimal interaction with the environment. Some physical movement may exist but it lacks any thought or emotion associated with it. At this extreme, life certainly has lost meaning. Generally describing the point at which life loses meaning is much more problematic. One physician suggests that meaningful life involves "not mere biological existence of several organs but totally integrated functional existence at a rational human level."³⁶ Another suggests, "for life to be meaningful, there must be sufficient cerebral function to enable the person to appreciate it, and there must be freedom from unendurable pain or suffering of other kinds."³⁷ The emphasis on rationality in the first statement reflects a high value on mental soundness and intelligence (not surprising in a professional) but may be too weighted toward cognitive ability for many of us to accept. The second doctor's emphasis on "appreci-

36. Collins, *Limits of Medical Responsibility in Prolonging Life*, 206 J. A.M.A. 389 (1968).

37. Lewis, *Machine Medicine and Its Relation to the Fatally Ill*, 206 J. A.M.A. 387 (1968).

ation" of life has much appeal but provokes many questions about just what is meant.

My point here is not to delve into the philosophical meaning of life but to indicate its varieties of expression, and the differences in meaning life holds for each of us. The differences are inevitable in a social system that values freedom of thought, and they pose a choice in the medical treatment context now under consideration. Should the meaningfulness of life be a factor to consider in these matters, or does its variety of forms of expression and belief indicate it is best left out of the calculus of decision?

I suggest this difficult concept must remain among the decisionmaker's array of relevant factors. Whether we can define it precisely or not, the issue is nevertheless of fundamental importance to us. No doubt law, medicine, and morality would be simpler without such issues. But disregarding difficult questions distorts decisionmaking, it does not improve it. Moreover, attempting to delete a fundamental value from its rightful place does not drive it away, but rather underground, where it influences decisions in unconscious and unexamined ways.

In dealing with all of the dignity concerns previously identified, it is apparent we are dealing with aspects of the quality of life. Assessing the quality of another's life, for the purpose of deciding whether to withhold medical treatments, is staunchly resisted by some observers.³⁸ But to refuse to consider severely diminished quality of life in medical decisionmaking for the very ill again distorts the decisionmaking process by leaving out something of great importance. Consider the case of a patient described in one medical journal,³⁹ who is severely demented.⁴⁰ She is confined to a wheelchair.⁴¹ She rarely utters a word, and has negligible interactions with other human beings.⁴² She is

38. The New York Court of Appeals has been the most adamant on this point, declaring that no one may decide that "the patient's quality of life has declined to a point where treatment should be withheld and the patient should be allowed to die." *People v. Eulo*, 63 N.Y.2d 341, 357, 472 N.E.2d 286, 296, 482 N.Y.S.2d 436, 446 (1984).

39. Lo and Dornbrand, *Sounding Board: Guiding the Hand that Feeds—Caring for the Demented Elderly*, 311 NEW ENG. J. MED. 402 (1984).

40. *Id.*

41. *Id.*

42. *Id.*

kept in diapers because of incontinence.⁴³ A time comes when she eventually stops eating, rejecting all offers of food.⁴⁴ Doctors and family wonder whether a feeding tube should be inserted.⁴⁵ If they do, and the woman pulls it out, must she then be tied down, as demented patients often are?⁴⁶ Of course, we would want more information about the severity of her physical problems, her prognosis, her values prior to the onset of dementia. But the concern for her freedom from forcible restraint, her bodily integrity, her independence and privacy, and the meaningfulness of life to her, in short, her dignity, are unavoidable and of great significance. Such concerns are not reducible to precise terms, their weight on the decisionmaking scale is not subject to exact calculation. Some decisionmaker must take them into account, along with several other variables, and that decisionmaker must be vested with the wide discretion necessary to make such a complex, multi-factor decision. That decisionmaker, it is suggested, should be the patient's family, for the reasons discussed in the following section.

THE FAMILY AS DECISIONMAKER

Despite the problematic nature of choosing anyone to make critical decisions for another human being, I suggest that here the solution, for the vast majority of cases, is the designation of the family as decisionmaker for critically or terminally ill incompetent patients.⁴⁷ In some situations the family will be inappropriate or incapable of deciding, and other means of decision will have to be arranged.⁴⁸ But in the usual run of events, the family will be able to reach a decision that is within the range of acceptability, and in such cases its decision should be followed.

The justifications for family decisionmaking derive from experience, custom and tradition, and from certain values which are fundamental in our society.

43. *Id.*

44. *Id.*

45. *Id.*

46. *Id.* at 403.

47. This presumes that the patient has not previously designated a specific person to make medical decisions for him in the event of incompetency. Such a designation is an expression of the patient's right to self-determination, and should be respected. See CAL. CIV. CODE § 2500 *et seq.* (West 1985); 20 PA. CONS. STAT. ANN. § 5602 (Purdon 1975).

48. *E.g.*, when there is irreconcilable conflict among family members, when family members are ill-motivated, or when family members evince no interest in the patient.

Experience shows that families commonly exhibit the greatest degree of concern about the welfare of ailing family members. It is they who come to the hospital and involve themselves in the sick person's care and comfort. Competent patients usually actively solicit the advice and counsel of family members in decisionmaking.⁴⁹ Family members routinely ask questions of the medical staff about the patient's condition and prognosis; one study found they frequently asked more questions than patients themselves did.⁵⁰ Family members, in fact, commonly act as advocates for patients in the hospital, looking out for their comfort, care, and best interests.⁵¹ Decisionmaking by the family on behalf of incompetent, ill members is a matter of tradition in American society. A study performed for the Presidential Commission investigating health care practices in the United States found that when a patient was incompetent "a family member was automatically enlisted to make a proxy decision."⁵² A 1973 statement of the American Medical Association concerning the withdrawal of life support systems similarly maintained that the decision is that "of the patient and/or his immediate family. The advice and judgment of the physician should be freely available to the patient and/or his immediate family."⁵³ For comatose patients, doctors look to the closest relative for major decisionmaking.⁵⁴ Unfortunately, doctors follow the same custom with family members that they do with competent patients: they present only their recommended treatment for approval or disapproval, not the full range of treatment options available.⁵⁵ For some treatments, they don't bother seeking permission from anyone.⁵⁶

49. Lidz and Meisel, *Informed Consent and the Structure of Medical Care*, in 2 MAKING HEALTH CARE DECISIONS 317, 363 (1982) [hereinafter cited as Lidz and Meisel].

50. *Id.* at 396-97.

51. D. WALTON, ETHICS OF WITHDRAWAL OF LIFE-SUPPORT SYSTEMS 147 (1983) [hereinafter cited as D. WALTON]; Gold, *When Someone Dies in the Hospital*, AGING, June-July 1984, at 18.

52. Lidz and Meisel, *supra* note 49, at 362.

53. Branson and Casebeer, *Obscuring the Role of the Physician*, HASTINGS CTR. REP., 8 (Feb. 1976).

54. Lidz and Meisel, *supra* note 49, at 358.

55. *Id.* at 359.

56. *Id.* at 367. The problems posed by these physician practices are considered *infra* text accompanying notes 102-158.

The law reflects this family-oriented tradition as well. Generally speaking, families make decisions for incompetent members.⁵⁷ The courts will not substitute their own "best interests" judgment for that of the family, absent a showing of bad motives or significant deleterious effect on the incompetent.⁵⁸ This tradition informs several of the right to refuse treatment cases as well. The *Quinlan* decision authorized Karen Ann's father to make the decision to disconnect his daughter from a respirator.⁵⁹ A California court, dismissing murder charges against two doctors who disconnected a respirator in accordance with the wishes of the patient's family, noted that the patient's wife was the proper surrogate decisionmaker for her comatose husband.⁶⁰ The few statutes that exist on the subject of withholding or withdrawing life sustaining treatment also support the role of the family as surrogate decisionmaker,⁶¹ but the handful of recent cases are divided on the matter.⁶²

Family members have a unique knowledge of the patient which is vital to any decision on his or her behalf. For patients who were formerly competent but now are not, their closest relations will know their life style, values, medical attitudes, and general world view.⁶³ Sometimes they will know specifically what the patient, when competent, felt about mechanical life-support

57. See, e.g., *In re Barbara C.*, 101 A.D.2d 137, 474 N.Y.S.2d 799 (2d Dept. 1984) (abortion decision for retarded 25 year old made by her father), *appeal dismissed*, 64 N.Y.2d 866, 476 N.E.2d 994, 487 N.Y.S.2d 549, (1985); *Matter of Hofbauer*, 47 N.Y.2d 648, 393 N.E.2d 1009, 419 N.Y.S.2d 936, (1979) (unorthodox laetrile treatment chosen for a child with cancer); *In re Roll*, 117 N.J. Super. 122, 283 A.2d 764 (1971).

58. *Id.*

59. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647.

60. *Barber v. Super. Ct. of Cal.*, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484 (1983).

61. N.C. GEN. STAT. §§ 90-322 (1983); OR. REV. STAT. § 97.083 (1983); VA. CODE § 54-325.8:6 (1984).

62. Compare *In re Blutworth*, 452 So. 2d 921, with *In re Spring*, 380 Mass. 629, 405 N.E.2d 115 (court cannot authorize family to make decision) and *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (court rejects mother's decision for treatment refusal). I suggest that *Spring* and *Storar* are wrong on this point.

63. Benjamin Cardozo observed:

We are reminded by William James in a telling page of his lectures on Pragmatism that every one of us has in truth an underlying philosophy of life, even those of us to whom the names and the notions of philosophy are unknown or anathema. There is in each of us a stream of tendency, whether you choose to call it philosophy or not, which gives coherence and direction to thought and action.

B. CARDOZO, *THE NATURE OF THE JUDICIAL PROCESS* 12 (1921).

and other techniques to prolong life in case of incurable illness.⁶⁴ In other cases, they will know of some statements which bear upon the specific question of treatment/nontreatment that later arises, but which are not clearly conclusive.⁶⁵

But even if no prior specific statements were made, in the context of the individual's entire prior mental life, including his or her philosophical, religious and moral views, life goals, values about the purpose of life and the way it should be lived, and attitudes toward sickness, medical procedures, suffering and death, that individual's likely treatment/nontreatment preferences can be discovered. Family members are most familiar with this entire life context. Articulating such knowledge is a formidable task, requiring a literary skill beyond the capacity of many, perhaps most, families. But the family's knowledge exists nevertheless, intuitively felt by them and available as an important decisionmaking tool.⁶⁶

The family's knowledge of the life of the incompetent person will usually be extensive, or in any event much deeper than that possessed by hospital staff doctors, attending physicians (especially in this society of mobile individuals and ever fewer family practitioners), guardians ad litem, or judges. This is particularly important in the context of medical decisionmaking for the severely ill, where the physical condition of the patient may deteriorate rapidly, or where clinical crises (fevers, infections) may arise without advance notice. In these circumstances time is a major constraint. Treatment/nontreatment decisions must be made within the time available. Involved family members are both readily accessible and possessed of enough knowledge about the patient to make the necessary decision. Courts are too

64. *E.g.*, In re Lydia Hall Hospital, 116 Misc.2d 477, 455 N.Y.S.2d 706 (N.Y. Sup. Ct. 1982). Even with treatment directives such as living wills, interpretation issues may arise. *See*, R. Steinbeck & B. Lo, *Decision Making for Incompetent Patients by Designated Proxy*, 310 NEW ENG. J. MED. 1598 (1984).

65. *See* In re Quinlan, 70 N.J. 10, 355 A.2d 647. The New Jersey Supreme Court later realized it was wrong not to consider such statements. *See also* In re Conroy, 98 N.J. 321, 486 A.2d 1209.

66. For those who distrust family decision making because it may involve unarticulated, intuitive thinking, consider Cardozo's observation about the process of judicial decision making: "Much of the process has been unconscious or nearly so. The ends to which courts have addressed themselves, the reasons and motives that have guided them, have often been vaguely felt, intuitively or almost intuitively apprehended, seldom explicitly avowed." B. CARDOZO, *THE NATURE OF THE JUDICIAL PROCESS* 117 (1921).

inaccessible and slow, and doctors are too busy to spend time inquiring into the patient's life, philosophy, and value preferences.⁶⁷ Only the family, immersed in and constantly thinking about its fateful decision, will devote the necessary time and possess the necessary information about the patient. With the medical data provided by attending doctors, they are uniquely placed to make treatment/nontreatment decisions.

Family knowledge is also an important element in decision-making for patients who were never competent prior to their illness, but in a somewhat different way. The never-competent patient, such as the severely mentally retarded individuals in the *Storar*⁶⁸ and *Saikewicz*⁶⁹ litigations, never had the ability to form the value preferences which treatment/nontreatment decisions require.⁷⁰

Knowledge about the patient nevertheless comes into play as a vital element in decisionmaking on his behalf. It is a different kind of knowledge, however, a knowledge of the patient's feelings, and of the way he experiences events. Certain treatments, for example, may engender feelings of fear, isolation, or disorientation. They may involve pain and discomfort, or require physical restraint and handling by others. How one experiences these things is unique, varying from person to person. A significant bodily invasion may not terribly bother one person, while a lesser invasion may be extremely distressing to another. This is true for competent patients as well as incompetent ones, and it is why knowledge about the particular individual, even the never-competent one, is so vital. Family members, assuming of

67. For further discussion see *infra* notes 102 to 114 (doctors) and 188 to 196 (courts).

68. In re *Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266.

69. Superintendent of Belchertown State School v. *Saikewicz*, 373 Mass. 728, 370 N.E.2d 417.

70. Because of this, the "substituted judgment" test enunciated in *Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 is impossible to carry out. The court noted "the decision in cases such as this should be that which would be made by the incompetent person, if that person were competent . . ." *Id.* at 752, 370 N.E.2d at 431. The test, as applied to persons who never were competent, misconstrues the nature of decisionmaking itself. When several options exist, each plausibly supportable, with its own risks, benefits, and burdens, then personal value preferences must exist to determine what the particular individual would want done. The individual who, like Mr. *Saikewicz*, could not comprehend the very notion of death could not form any values about adopting a course of nontreatment that might shorten his life.

course that they are involved with the patient,⁷¹ are best placed to witness and understand what their never-competent relative is feeling and experiencing. The family's conclusions, particularly about the relative burdens of treatment/nontreatment options, are therefore of great significance.⁷²

Fundamental societal values also support making the family the primary decisionmaker in treatment/nontreatment decisions for incompetent, critically ill persons. The family is from time to time proclaimed to be the foundation on which society is built.⁷³ Whether it is or not, it is certainly our most enduring, fundamental social unit, with profound meaning and significance to the individual and to society.⁷⁴

The family has been a resilient, hardy institution surviving through and adjusting to a variety of social, political and economic upheavals. It has been recognized in law in numerous ways as a basis for personal and property rights and obligations. Fundamental constitutional rights spring from the value placed on the intimate relationships of family life.⁷⁵ Under the Constitution there exists a "private realm of family life which the state cannot enter."⁷⁶

These legal doctrines reflect the fact that we view family self-governance as a highly prized value in American life. Its protected status under the Due Process Clause evidences concern that majorities not regulate family decisionmaking in its most intimate and sensitive functions. Responding to a severely incapacitating, irreversible illness of a member of the family unit is one of these functions. The impending death, permanent loss of consciousness, or near-complete mental and physical incapac-

71. In *Saikewicz*, two sisters were informed of his condition and of the hearing "but they preferred not to attend or otherwise become involved." *Id.* at 731, 370 N.E.2d at 420.

72. In *re* *Quinlan*, 70 N.J. 10, 53, 355 A.2d 647, 664.

73. See, e.g., *Maynard v. Hill*, 125 U.S. 190, 211 (1888).

74. "Thus the importance of the familial relationship, to the individuals involved and to the society, stems from the emotional attachments that derive from the intimacy of daily association, and from the role it plays in 'promot[ing] a way of life' through the instruction of children, *Wisconsin v. Yoder*, 406 U.S. 205, 231-233 (1972), as well as from the fact of blood relationship." *Smith v. O.F.F.E.R.*, 431 U.S. 816, 844 (1977).

75. "[F]reedom of personal choice in matters of . . . family life is one of the liberties protected by the Due Process Clause of the Fourteenth Amendment." *Cleveland Bd. of Educ. v. LaFleur*, 414 U.S. 632, 639-40 (1974).

76. *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944).

tation of a parent, spouse, or child is one of the most emotionally intense experiences of family life. Dealing with such events requires family members to gather their emotional strength, to seek solace from trusted intimates, and to bring their personal moral, philosophical or religious convictions to bear for guidance and comfort. By necessity, the experience must be shared with the strangers⁷⁷ who render care for the ill, but it is one that is otherwise entitled to a respectful and decent privacy.

It might be argued that the value of family privacy and autonomy must give way to some individual right of the family member, in the context of decisionmaking that may have the effect of shortening the individual's life.⁷⁸ But in the case of incompetent patients, their individual right to decide must be exercised by someone else, and to look to the individual's own network of intimate human connection is the most compelling alternative open to us. A law that focuses only on the individual, viewing him as a lone, solitary being, fails to recognize a vital aspect of living. When individuals living in a mass society are fortunate enough to be part of a small, supportive human community, the law should promote and respect that community.

A final basic value that lends support to family decision-making is our culturally shared moral principle that those who bear the burdens of a decision have a major claim to making it.⁷⁹ In reporting on decisionmaking at the Yale-New Haven Hospital, in the tragic situations presented by severely malformed and impaired infants, physicians Raymond Duff and A.G.M. Campbell wrote:⁸⁰

Since families primarily must live with and are most affected by the decisions, it therefore appears that society and the health professions should provide only general guidelines for decision making. Moreover, since variations between situations are so great, and the situations

77. With the disappearance of the family doctor, and the advent of medical specialists and health care teams composed of technicians, nurses, and hospital staff interns and residents, it can be said that caregivers nowadays are frequently "strangers."

78. Nesbitt, *Terminating Life Support for Mentally Retarded, Critically Ill Patients*, 3 J. LEGAL MED. 245, 263-64 (1982) [hereinafter cited as Nesbitt].

79. GOROVITZ, *supra* note 2, ch. 13.

80. Duff and Campbell, *Moral and Ethical Dilemmas in the Special Care Nursery*, 289 NEW ENG. J. MED. 890 (1973) [hereinafter cited as *Moral and Ethical Dilemmas*].

themselves so complex, it follows that much latitude in decision making should be expected and tolerated. Otherwise, the rules of society or the policies most convenient for medical technologists may become cruel masters of human beings instead of their servants.⁸¹

In sum, selecting the family as primary decisionmaker recognizes its unique knowledge and involvement, its preferred status in American legal and medical tradition, and its rightful claims to privacy and self-governance in its most intimate and difficult functions.

Difficulties in Family Decisionmaking

Choosing the family as decisionmaker is not without its difficulties. Family members are subject to conflicting emotions. They may feel guilt if they don't ask doctors to "do everything possible." Their own need for the patient's survival may lead them to urge inappropriate treatment.⁸² Deciding to withdraw treatment, even when that seems the most reasonable course, might be too emotionally traumatizing to the family.⁸³ As one observer put it, "Families [may look] for miracles instead of death."⁸⁴ Alternatively, family members may become weary with the prolonged illness of the patient, and consciously or not, wish for the relief that death would bring.⁸⁵ Chronic critical illness can place substantial psychological, emotional and financial burdens upon family members and may cause physical stress and exhaustion as well.⁸⁶

These emotional difficulties are part of the familial experience of sickness and death. They are not sufficient to disqualify the family from decisionmaking for several reasons. First, they can be dealt with, often with the help of doctors and nurses attending the patient. Some doctors attempt to allay the guilt feelings of the family by taking the initiative in suggesting treatment termination, and allowing the family, if it wishes, to

81. *Id.* at 894.

82. Lidz and Meisel, *supra* note 49, at 464.

83. D. MAGUIRE, *supra* note 30, at 158.

84. R. DUFF & A. HOLLINGSHEAD, *SICKNESS AND SOCIETY* 319 (1968) [hereinafter cited as DUFF & HOLLINGSHEAD].

85. D. MAGUIRE, *supra* note 30, at 158.

86. DUFF & HOLLINGSHEAD, *supra* note 84, at 377-78; Ferber, *supra* note 35.

perceive the decision as one in which they acquiesced, rather than one which they actively demanded.⁸⁷ As to the need for relief that death might bring, it is likely to be consciously fought against and to be counteracted by the need to hold onto the family member. In practice, there appears to be no evidence that patients are being denied treatment prematurely.⁸⁸

The emotional involvement with the patient that close family members feel can play a positive, even essential role in decisionmaking for the incompetent patient. Gorovitz, in his book *Doctor's Dilemmas*, stresses the importance to the decisionmaking process of having an emotional understanding of the illness and its effects.⁸⁹ He describes a discussion among medical students concerning treatment and nontreatment options for a 3-year old child in a vegetative coma.⁹⁰ The discussion changes markedly in tone and character after the students actually see the patient whose treatment they are talking about. Gorovitz reports the "shallowness of discussion that is wholly detached from emotional impact and the attendant stresses of the situation in question."⁹¹ Of course, the emotional shock of sudden or tragic medical developments can impair decisionmaking, as Gorovitz notes.⁹² But even if initially overcome with paralyzing grief, people have means of marshaling their decisionmaking resources.⁹³ At that point, their emotional involvement is not the enemy of reason, but an essential adjunct to it. Emotional reactions lead us to the knowledge of what is important in the human scale of values. Sensitivity, empathy, and compassion inspire a more profound understanding of the patient's situation, and are as essential to this type of decisionmaking as is "pure" rational thinking. Family members bring these critical emotional elements into their considerations.

87. *Moral and Ethical Dilemmas*, *supra* note 80, at 891; D. WALTON, *supra* note 51, at 214-15 (1983).

88. Accounts in scholarly journals and in the press indicate that overly aggressive treatment is the true problem. See articles *supra* notes 3, 35, 36, 37. Dr. Ronald Cranford, a nationally recognized expert in this area, has said that "overtreatment is rampant in hospitals." INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING 233 (Cranford and Doudera eds. 1984).

89. GOROVITZ, *supra* note 2, at 197.

90. *Id.*

91. *Id.*

92. *Id.*

93. See articles cited *supra* note 35.

Another problem presented by families is the potential for stalemate. Disagreement is a complication which inevitably exists when a unit composed of more than one individual is recognized as decisionmaker. But the family unit is one which regularly functions with some degree of discord, and it usually develops some mode of dealing with it. It is thus quite possible for the family to be substituted for the incompetent patient, and to reach decisions. Disagreement may not exist, or it may be resolved by some other family practice. As an example, consider one family, known to the author, faced with the question of whether to continue the wife/mother on a mechanical respirator. The adult children disagreed among themselves about disconnection, with most favoring it. The husband/father opposed disconnection. The "family decision" was to continue the mechanical support, based not on complete agreement, but on deference to the wishes of the husband/father. The irreversibly comatose patient received respirator support for a year and a half before she died in the coma.

Some commentators cite a potential conflict of interest arising from family members' stake in the inheritance they will receive from their ill relative.⁹⁴ In the literature, however, it is significant to note that this concern is never documented with actual examples. The conflict of interest seems more theoretical than real, a problem more common to mystery novels and television dramas than to real life experience.

Another objection to family decisionmaking is the difficulty of identifying who is "the family." The New York Court of Appeals complained that "family" was an unbounded "open-ended" concept that reaches "to the limits of the family tree"⁹⁵ as if this posed a major obstacle in most cases. One way to identify the pertinent individuals is to specify them by their relationship to the patient. The Virginia statute on withdrawing life support for the terminally ill, for example, lists a patient's spouse, adult children, and parents (in that order of priority) as surrogate decisionmakers, with a catchall phrase "the nearest living relative" as a last resort.⁹⁶

94. D. MAGUIRE, *supra* note 30, at 158.

95. In re Storar, 52 N.Y.2d 363, 370, n.2, 420 N.E.2d 64, 67, n.2, 438 N.Y.S.2d 266, 269, n.2.

96. VA. CODE § 54-325.8:6 (1985 Supp.). The code gives highest priority to a judicially

Another method is to leave the term "family" as the identifying term, without specific elaboration. There is nothing in the medical literature indicating that it is difficult to identify family members, and AMA guidelines use the term "family," apparently believing further elaboration to be unnecessary.⁹⁷ In the usual hospital settings, concerned family members identify themselves and are routinely involved with physicians, nurses, and the patient. Of course, if close relatives refuse to be involved, then they should not be decisionmakers, and if non-relatives who are close intimates of the patient wish to be involved, they should be. It is possible, of course, that in some instances some line-drawing will have to be done, but this does not arise in the generality of cases and when it does, a court proceeding to name a guardian for decisionmaking for the patient will take care of the problem.

Another possible objection to family decisionmaking in this area is that the family may take its own self-interests into account. I do not believe this is a valid criticism, so long as the family has genuine concern for the welfare of the patient. A family may be subject to crushing burdens when catastrophic illness strikes one of its members. The illness may be a source of great torment and place great stress on the functioning of the family, even to the point of endangering its own viability as a unit.⁹⁸ Hospital bills may threaten financial ruin for the remaining members. The expenses associated with intensive care and high technology medicine are notoriously high, and not all is covered by the current patchwork system of health insurance.⁹⁹ Such burdens on the family are not wholly irrelevant to decisionmak-

appointed guardian if one exists, and to any person specifically designated in writing by the patient.

97. See AMA statement quoted *supra* text accompanying note 53.

98. See *supra*, note 80. Duff and Campbell noted the extensive damage done to some families where the severe illness was suffered by newborns. 289 NEW ENG. J. MED. at 891, 892. (1973). Families of older patients may also be shattered by the experience. Malcolm, *For Doctors and Patients, Decisions on Death*, N.Y. Times, Dec. 23, 1984, § 1, at 1.

99. The President's Commission estimated that 16% of Americans have no health insurance at all. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL BEHAVIORAL RESEARCH, 1 SECURING ACCESS TO HEALTH CARE: THE ETHICAL IMPLICATIONS OF DIFFERENCES IN THE AVAILABILITY OF HEALTH SERVICES 92-93 (1983). The court in *In re Dinnerstein*, 6 Mass. App. Ct. 466, 467 n.1, 380 N.E.2d 134, 135 n.1, noted that Medicare stops payment for custodial care of incurable victims of Alzheimer's disease.

ing, because (1) the patient himself would, if competent, be likely to care about the welfare of the family, (2) the family welfare is entitled to some concern also, for its own sake, as long as the patient's interests are of primary concern and (3) all decisionmakers in fact take such matters into account as unavoidable aspects of the entire tragic event unfolding before them. Courts, physicians and family, for example, think about the enormous costs of high technology treatments.¹⁰⁰ If financial costs cannot be openly discussed and considered, they will then become a "hidden" element that nevertheless has its influence.¹⁰¹

Objections to a general rule of family decisionmaking must be considered not only on their own, but in comparison to objections to alternate decisionmakers such as physicians and courts. The following sections will discuss the appropriate roles of both doctors and courts in the process of decisionmaking for incompetent, critically ill persons.

THE ROLE OF THE PHYSICIAN

Current Practices

In formulating the appropriate role for the physician in treatment/nontreatment decisions, it is important to examine some of the current characteristics of medical practice. Much of the study of physician practice focuses on the doctor-patient relationship. When patients are incompetent, however, it appears that doctors deal with families in much the same way as they do with competent patients.¹⁰²

Doctors are essential to the treatment decisionmaking process, since they have vital information on which any decision

100. See, e.g., *Leach v. Akron Gen. Med. Ctr.*, 68 Ohio Misc. 1, 2, 426 N.E.2d 809, 810 (notes \$500/day cost involved in maintaining hopeless patient); Wanzer *supra* note 145, at 957 (physicians state, "financial ruin of the patient's family . . . should be weighed in the decision-making process, although the patient's welfare obviously remains paramount"); Walter, *supra* note 35, at 22 (father's hospital bill of \$47,795 for 37 days attached to respirator against daughter's wishes; additional doctor bills exceed \$14,000); Malcolm, *Family Seeks a Mercy Death Accord*, N.Y. Times, May 12, 1985, sec. 1, at 20, col. 1. (hospital care for man in a permanent vegetative state costs \$150,000 a year).

101. Kleiman, *Changing Way of Death: Some Agonizing Choices*, N.Y. Times, Jan. 14, 1985, sec. 1, at 1, col. 1.

102. See Lidz and Meisel, *supra* note 49.

must be based. For anyone else to participate in decisionmaking (including patients themselves), doctors must share their knowledge. To the extent they refuse to do so, they ensure that they will control the decisionmaking process. Many common practices in current medical care combine to place just such control in the doctors' hands. In particular, the brevity of doctor-patient or doctor-family interactions, the limited information that doctors convey, the way they present information, and the practice of masking the uncertainties of medical diagnosis, of choice of treatment, and of prognosis, tend to leave patients and families with little, if any, opportunity to make decisions.

In theory, competent patients are entitled to make their own health care choices under the informed consent doctrine.¹⁰³ Medical practice, however, has transformed the notion of informed consent into a brief and sparse exchange that fails to transmit much vital information. A study incorporated into the Presidential Commission's report revealed that hospital patients, when they are competent, are usually not told anything about tests and procedures which physicians consider "routine."¹⁰⁴ Patients are often not told when various tests have been ordered, what the tests involve, or even what they are for. The same information vacuum exists for medications prescribed, drawing of blood, x-rays, and other matters that are "routine" for the professional though not for the patient.¹⁰⁵

When physicians do communicate with patients and families, they see the exchange as one whose primary function is to convey the decision the physician *has already made* concerning treatment.¹⁰⁶ These communications are marked by a brevity which devalues the importance of discussion and deprives the patient and family of a significant role in decisionmaking.¹⁰⁷ Use of medical jargon often further limits the layperson's ability to

103. See Miller, *Informed Consent*: 1, 244 J. A.M.A. 2100 (1980).

104. Lidz and Meisel, *supra* note 49, at 393.

105. *Id.*

106. *Id.* at 399-400.

107. See KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (1984) [hereinafter cited as KATZ]. Critically ill patients and their families need time for discussion, not only to make informed decisions, but to feel supported in their struggle and to exercise some control over their disrupted and disorganized lives. Cassileth, *Care of the Terminally Ill Patient and Family*, DEL. MED. J. 482 (1983) [hereinafter cited as Cassileth].

extract useful information from the brief visit.¹⁰⁸ Doctors schedule themselves to see many patients quickly, and allot little time for discussion with any of them.¹⁰⁹ This lack of time helps to structure the physician-patient-family interchange as a one-way, take-it-or-leave-it recommendation. All too often, after discussion with the doctor, a patient and his family remain uneducated about such vital matters as treatment alternatives which exist, their relative risks and benefits, their potential negative side effects, the nature of the treatment procedure chosen, and expectations about pain the treatment may cause.¹¹⁰

Another matter that is usually never fully disclosed, despite its importance, is medical uncertainty. The treatment recommendation offered by the physician is often made with bland reassurances, confidence, and certainty, despite the lack of certainty that may exist in either the physician's own mind or within the profession generally.¹¹¹ The air of certainty commonly adopted is rationalized as therapeutic for the patient, but in fact it may more often be explained as a way physicians deny, relieve or hide their own anxieties, and as a product of medical training that inappropriately disregards uncertainty.¹¹² The discomfort caused by uncertainty may be a source of stress and conflict among caregivers, and may lead doctors to make hasty decisions which don't take the true uncertainty of the patient's condition into account.¹¹³ As for patients, pat reassurances make many "feel disregarded, ignored, patronized and dismissed."¹¹⁴

Instead of talking with patients and families, some doctors rely upon "tacit" understandings or assumed knowledge of their patients.¹¹⁵ Topics which doctors feel are difficult to discuss—such as whether a "Do Not Resuscitate" order should be

108. Corless, *Physicians and Nurses: Roles and Responsibilities in Caring for the Critically Ill Patient*, in *LEGAL AND ETHICAL ASPECTS*, *supra* note 10, at 271-72.

109. *Id.* See also Kassirer, *Adding Insult to Injury: Usurping Patients' Prerogatives*, 308 *NEW ENG. J. MED.* 898, 900 (1983) [hereinafter cited as Kassirer].

110. Lidz and Meisel, *supra* note 49.

111. KATZ, *supra* note 107, at 165-206.

112. *Id.* at 184-88, 225.

113. Cassem, *Consulation to Continue or Stop Treatment Measures in Irreversible Illness*, 10 *ADV. PSYCHOSOMATIC MED.* 119, 127 (1980).

114. KATZ, *supra* note 107, at 210. See also Gold, *supra* note 51, at 20.

115. *E.g.*, Van Scoy-Mosher, *An Oncologist's Case for No-Code Orders*, in *LEGAL AND ETHICAL ASPECTS* *supra* note 10, at 16-17; Levine, *Disconnection: The Clinician's View*, *HASTINGS CTR. REP.* 11 (Feb. 1976).

issued—are simply skipped over entirely. A study done at a prestigious university teaching hospital found that most physicians, including those who said they believed in talking with patients about their desires concerning resuscitation, did not in fact discuss the issue with patients or their families.¹¹⁶ Patients, interestingly, did not find the issue too difficult to discuss with the researchers, and the study found that doctors' assumptions about what patients wanted was often incorrect.¹¹⁷ The result, of course, was to infringe upon the right of the patient to make his own decisions.

A more subtle undermining of patient autonomy also transpires in the doctor-patient relationship. In addition to depriving patients of information necessary to intelligent decision making, many physicians deprive them of the self-confidence needed to make important decisions. This occurs when physicians act as if 1) the patient is incapable of understanding anything medical, and 2) the patient is acting appropriately in regarding the doctor as an omnipotent authority figure. The latter is a commonplace, irrational fantasy for very ill persons, a child-like wish to have someone take care of them and make everything come out all right. In psychological terms, this might be called an infantile transference phenomenon.¹¹⁸ Physicians may rationalize their dominating stance with patients by saying that it is what the patients themselves want, referring to this irrational transference effect. But co-existing with irrational wishes are patients' other thoughts and desires, in particular, the desire to know what is wrong with them, and the desire to "control their own lives during illness just as they do during health."¹¹⁹ Physicians could tailor their behavior to reinforce and encourage this set of desires in their patients, instead of the more infantile, less rational desires. Their contrary behavior may reflect more on their own unconscious needs (e.g. the narcissistic desire to take power, to act the hero or to fight Death) than on the true

116. Bedell & Delbanco, *Choices About Cardiopulmonary Resuscitation in the Hospital—When Do Physicians Talk with Patients?* 310 NEW ENG. J. MED. 1089 (1984).

117. *Id.* at 1091. This was particularly true for patients who did not want resuscitation. Eight patients told researchers they opposed resuscitation. Of the sixteen doctors involved with the care of these patients, only one accurately assessed the patients' desires.

118. KATZ, *supra* note 107, at 211-12.

119. *Id.* at 209.

needs and desires of most patients.¹²⁰

Some physicians do practice medicine in such a way as to make patients and families truly informed decision making agents. Dr. Jerome Kassirer, in an article entitled *Adding Insult To Injury: Usurping Patients' Prerogatives*, advises his colleagues to "set aside their image of themselves as making life-and-death decisions alone and undertake instead the less glamorous and more time-consuming process of exploring options and outcomes with the patient."¹²¹ Nevertheless, Kassirer sees physician-imposed decisions as widespread.¹²² The tradition of paternalism and professional dominance is still very much alive in the medical profession.

Criticism of Physician Practices

When doctors provide little or no information on treatment options, they maintain excessive control over decisionmaking.¹²³ This is objectionable because treatment decisions for the severely, hopelessly ill turn not merely on medical data but on moral and ethical values.¹²⁴ The value to a dying or severely ill patient of aggressive medical treatment is a matter of personal judgment. For human beings, health is an important value, but it is one among many values, and it is not always the most important one. The case of Rosaria Candura, a 77-year old woman who refused a medically-indicated operation to amputate her leg illustrates this point.¹²⁵ Although doctors tried to persuade her to undergo the operation, without which she risked dying, and her daughter sought a court order to declare her incompetent, the patient had her own non-medical reasons for refusing the

120. *Id.* at 15, 131-41, 148-49.

121. Kassirer concludes: "The sick suffer enough. We must avoid adding insult to injury by denying them a proper role in determining their future." Kassirer, *supra* note 109, at 900-901.

122. *Id.*

123. *Moral and Ethical Dilemmas*, *supra* note 80, at 894; Hilfiker, *Allowing the Debilitated to Die: Facing Our Ethical Choices*, 308 NEW ENG. J. MED. 716 (1983) [hereinafter cited as Hilfiker].

124. D. WALTON, *supra* note 51, at 174, D. MAGUIRE, *supra* note 30 at 150, VEATCH, DEATH, DYING AND THE BIOLOGICAL REVOLUTION (1976); McNeil, Weichselbaum, & Pauker, *Speech and Survival: Tradeoffs between Quality and Quantity of Life in Laryngeal Cancer*, 305 NEW ENG. J. MED. 982 (1981).

125. *Lane v. Candura*, 6 Mass. App. Ct. 377, 376 N.E.2d 1232 (1978).

treatment.¹²⁶ These reasons, as described by the court, were that "she has been unhappy since the death of her husband, that she does not wish to be a burden to her children, that she does not believe that the operation will cure her, that she does not wish to live as an invalid or in a nursing home, and that she does not fear death but welcomes it."¹²⁷ The court refused to conclude that her thinking demonstrated her incompetence to make her own decision, and held that she had the right to refuse the recommended treatment.¹²⁸

Mrs. Candura did not choose to maximize health values, in the face of other values which were more important to her. Even when health values are most important, there may be room for value choices. Consider the alternatives of surgery and radiation therapy posed by some cases of lung cancer. As of 1978, surgery offered a better chance for five year survival than did radiation, but surgery was associated with some risk of peri-operative mortality.¹²⁹ Doctors generally favored taking the risk of surgery to increase the odds of greater longevity. But when patients' attitudes were studied, medical researchers found that some were much more risk-averse than doctors, i.e., there were patients who did not want to take the risk of early death posed by surgery, preferring instead the prospect of assured life for at least a few months. The researchers, all physicians, concluded that:

[T]he highly risk-averse patients should receive radiation therapy, which has no associated operative mortality, rather than surgical extirpation, which has an operative mortality, even though surgical therapy appears significantly better on the basis of five-year-survival data. This analysis is based on the premise that it is the patients' own attitudes that should prevail because, after all, it is the patient who suffers the risks and achieves the gains. However, in contemporary medicine the attitudes most frequently used are those of physicians; doctors are generally more risk seeking than patients, perhaps because

126. *Id.* at 378, 376 N.E.2d at 1234.

127. *Id.*

128. *Id.* at 379, 376 N.E.2d at 1236.

129. B. McNeil, R. Weichselbaum, and S. Pauker, *Fallacy of the Five-Year Survival in Lung Cancer* 299 *NEW ENG. J. MED.* 1397 (1978).

of age and perhaps because the consequences of the decision may be felt less immediately by them than by the patient.¹³⁰

In this situation, physicians who recommend surgery and neglect to discuss radiation as an alternative are clearly allowing their own values to supersede those of the patient.

When physicians inject their own values into decisionmaking for others, they may feel they are acting out of purely altruistic motives. This is the justification generally offered in defense of medical paternalism.¹³¹ What must not be overlooked, however, is that physicians' values are shaped not only by altruism, but also at times by self-interest, by professional bias, and by personal needs, all of which may be at odds with the best interests of the patient.

Professional bias in medical decisionmaking for the critically ill takes many forms. Some doctors believe death is the enemy of professional medicine, and that it must always be fought aggressively, lest the physician feel a sense of failure or defeat.¹³² This attitude fosters a dehumanized, "machine medicine" mentality, which supplants sensitive and humane care for the severely ill.¹³³ Some doctors favor medical technology simply "because it is there."¹³⁴ Young doctors may rely upon technology to hide their inexperience.¹³⁵ Others may opt for aggressive treatment because the patient offers the physician a chance to hone his skills. A medical administrator observes that "many physicians feel that they are not fully actualized in their practice if [they are] not using the complete complement of technological tools at their disposal."¹³⁶ Along the same lines, Gorovitz notes

130. *Id.* Professor Katz also concludes that physicians value the highest statistical chance of longevity above all else, and won't let patients decide for other values. KATZ, *supra* note 107, at 97.

131. *Id.* at 89.

132. GOROVITZ, *supra* note 2, at 20; Brooks, *Withholding Treatment and Orders Not to Resuscitate*, in LEGAL AND ETHICAL ASPECTS, *supra* note 10, at 105; Hanratty, *Care of the Dying Patient*, 103 J. ROYAL SOC. HEALTH 1 (1983).

133. Lewis, *supra* note 37.

134. Van Scoy-Mosher, *supra* note 115, at 16.

135. N. COUSINS, *THE HEALING HEART: ANTIDOTES TO PANIC AND HELPLESSNESS* (1984).

136. S. Weiss, *The Health Care Team: Changing Perceptions of Roles and Responsibilities in Caring for the Critically Ill Patient*, in LEGAL AND ETHICAL ASPECTS, *supra* note 10, at 264.

that doctors with state-of-the-art skills want to use them, and may derive aesthetic satisfaction when they do.¹³⁷ He reports the case of a doctor practicing certain medical procedures on a comatose patient, who could not be expected to benefit from the procedures and whose family would get the bill for them.¹³⁸ Other such accounts exist, e.g., of a hospital resident permitting a new intern to repeatedly resuscitate a dying infant, in order to let the intern practice his skills.¹³⁹

A variety of personal, professional and institutional interests may affect decisionmaking by physicians, including research agendas, personal views on ethics, and professional training opportunities. Consider this account by Duff and Campbell of reasons physicians in a university teaching hospital's intensive care nursery gave for aggressively treating severely defective newborns:

There was a feeling that to "give up" was disloyal to the cause of the profession. Since major research, teaching and patient-care efforts were being made, professionals expected to discover, transmit and apply knowledge and skills; patients and families were supposed to co-operate fully even if they were not always grateful. Some physicians recognized that the wishes of families went against their own, but they were resolute. They commonly agreed that if they were the parents of very defective children, withholding treatment would be most desirable for them. However, they argued that aggressive management was indicated for others. Some believed that allowing death as a management option was euthanasia and must be stopped for fear of setting a "poor ethical example" or for fear of personal prosecution or damage to their clinical departments or to the medical center as a whole. Alexander's report on Nazi Germany was cited in some cases as providing justification for pressing the effort to combat disease. Some persons were concerned about the loss through death of "teaching material." They feared the

137. GOROVITZ, *supra* note 2, at 17, 21-22.

138. *Id.*

139. Towers, *Ethical and Legal Responsibilities of the Physician Toward the Dying Newborn*, in *LEGAL AND ETHICAL ASPECTS*, *supra* note 10, at 234.

training of professionals for the care of defective children in the future and the advancing of the state of the art would be compromised. Some parents who became aware of this concern thought their children should not become experimental subjects.¹⁴⁰

As this excerpt shows, the bias toward research and experimental medicine in teaching hospitals sometimes introduces a conflict of interest that goes totally unrecognized by doctors. In such environments, the sick person may be seen as "a *datum* among *data*,"¹⁴¹ rather than as an individual entitled to respectful care.

The need to cover mistakes also surfaces in physician behavior. Duff and Hollingshead, investigating general medical practice at a university teaching hospital, report: "When a physician made a mistake in diagnosing a patient's illness he faced a question, perhaps a fatal one for the patient, of importance to his self-respect and for his practice: Should he tell the patient and the patient's family the truth, or should he evade the issue and bluff his way through to the end?"¹⁴² Human nature being what it is, some doctors choose to evade and bluff.¹⁴³ Others aware of physician mistakes may also have self-interests to protect. Winslow reports the experience of a nurse "present when a surgical resident botched a tracheotomy and severed the patient's carotid artery. The patient bled to death. The nurse decided that for the sake of other patients she should report the resident. But the medical director cautioned the nurse not to pursue the matter unless she hired an attorney. As the nurse put it: 'Dr. X kills the patient and I need a lawyer.'"¹⁴⁴

Another element of self-interest that affects doctors in making treatment decisions is the fear of legal liability. This "often interferes with the physician's ability to make the best choice for the patient," writes a group of prominent physicians from the

140. *Moral and Ethical Dilemmas*, *supra* note 80, at 892.

141. The phrase is from D. MAGUIRE, *DEATH BY CHOICE* 152 (2d ed. 1984). See generally J. KATZ AND A. CAPRON, *CATASTROPHIC DISEASES: WHO DECIDES WHAT?* (1975).

142. R. DUFF AND A. HOLLINGSHEAD, *SICKNESS AND SOCIETY* 314 (1968).

143. *Id.*

144. Winslow, *From Loyalty to Advocacy: A New Metaphor for Nursing*, *HASTINGS CTR. REP.* 32, 38 (June, 1984).

nation's leading hospitals and medical schools.¹⁴⁵ An example is described by an oncologist who issued a "no-code" order (an order not to resuscitate in case of cardio-respiratory failure) on a patient.¹⁴⁶ A surgeon involved with the care of the patient, fearing liability, cancelled the order during his hospital rounds.¹⁴⁷ Thus it happened that the no-code order was issued every morning and cancelled every afternoon.¹⁴⁸ By chance, the patient died while the no-code order was in effect.¹⁴⁹ In fairness, it should be noted that hospital lawyers contribute to physicians' liability fears, by exaggerating legal risks and offering advice that minimizes such risks without concern for the benefit and humane care of the patient.¹⁵⁰

Finally, it is important to recognize that medicine, like other occupations, fulfills the personal needs of those who choose it as their work, and those needs can motivate, sometimes unconsciously, medical behavior. Katz speaks of the need of many physicians to feel dominant and in control.¹⁵¹ They refuse to treat laypersons as adults, and insist on relationships with patients that resemble parent-child relations.¹⁵² Others see in medical training the fulfillment of a need to "command all situations."¹⁵³ Doctors react to patients not only rationally but emotionally. Their unconscious reactions may cause them to make errors in diagnosis,¹⁵⁴ to undermedicate patients in severe pain,¹⁵⁵ and to withdraw from patients whom they cannot save but who still need their attention and support.¹⁵⁶ Further, they are at the top of the socio-economic ladder, and they may feel

145. Wanzer, Adelstein, Cranford, Federman, Hook, Moertel, Safar, Stone, Taussig & Van Eys, *The Physician's Responsibility Toward Hopelessly Ill Patients*, 310 NEW ENG. J. MED. 955, 957 (1984) [hereinafter cited as Wanzer].

146. Van Scoy-Mosher, *supra* note 115, at 16.

147. *Id.*

148. *Id.*

149. *Id.*

150. Annas, *Reconciling Quinlan and Saikewicz: Decision Making for the Terminally Ill Incompetent*, in LEGAL AND ETHICAL ASPECTS, *supra* note 10, at 40-41; Wanzer, *supra* note 145, at 956.

151. Katz, *supra* note 107, at 148-49.

152. *Id.* at 142-46.

153. Towers, *supra* note 139, at 234.

154. Dinsdale, *Delays and Slips in Medical Diagnosis*, 27 PERSP. IN BIOL. & MED. 213 (1984).

155. See Perry, *supra* note 33; Angel, *supra* note 33.

156. Cassileth, *supra* note 107, at 483; Gold, *supra* note 51.

uncomfortable with, or even disdainful of those from a different social class, and these feelings too may affect their medical judgments.¹⁵⁷

Of course, not all physicians exhibit all the self-interested behaviors discussed above. But it would be wrong to assume physicians act only out of altruistic motives in their medical practice. There is a constant tension in medical practice between altruism and self-interest.¹⁵⁸ When values come into play in medical treatment decisions, as they inevitably do, the physician's choices should not be assumed to be superior to those of the patient or the patient's family.

Suggested Role of the Physician

The proper role for the physician is broad enough, even without ultimate decisionmaking authority. The key components of an appropriate role for the physician are delineated below.

1. Application of medical skills and judgment

Medicine is still an art as well as a science. Great skill and wise judgment are required in making an accurate diagnosis, in reducing pain, in ascertaining the level of cognitive, sensory and emotional functioning the patient is experiencing, and in predicting the future course of an illness. The complexities multiply when, as is common, the patient suffers from a variety of physical ailments, somatic changes must be followed and assessed, and the physician must identify the risks and benefits of multiple treatment possibilities. The uncertainties that pervade medical practice increase the stress on doctors in performing these tasks, as do unrealistic expectations and demands of patients and families. The doctor's judgment and medical skill necessarily remains a key part of any decisionmaking scheme.

2. Communication of information

Doctors usually share their knowledge of the patient's diagnosis, level of functioning, and prognosis with the family. In ad-

157. Eisenberg, *Sociologic Influences on Decision-Making by Clinicians*, 90 ANNALS OF INTERNAL MED. 957 (1979); DUFF & HOLLINGSHEAD, *supra* note 84, at 118-19, 126-27, 133, 366-67.

158. Jonsen, *Watching the Doctor*, 308 NEW ENG. J. MED. 1531 (1983).

dition, they must become accustomed to sharing (1) their knowledge of treatment and nontreatment options available, with the potential risks, burdens, and benefits attendant upon each, and (2) their uncertainty, if it exists, about all of these matters.

The law's vision of informed consent, which has been allowed to atrophy in practice,¹⁵⁹ needs revitalization. To breathe new life into it, three steps need to be taken. The first is to identify the disclosures that are required by reference to the patient's (or family's) needs, rather than to the standards and norms of the medical profession. The latter became the basis of disclosure in the early formulation of the doctrine¹⁶⁰ but, since the 1970's several states have adopted a "patient needs" approach.¹⁶¹ The second step is to require disclosure of all treatment options, not just the single option recommended by the doctor. Some courts are now requiring this expanded form of disclosure, but many do not.¹⁶²

The third necessary step is to include the notion of "informed refusal" in the informed consent doctrine. This is particularly important when patients are critically, irreversibly ill, because *not* accepting treatment often becomes a reasonable option. Further, if death is expected, families may want to accept some treatments and reject others, in order to choose what one thoughtful observer, M. Pabst Battin, calls "the least worst death."¹⁶³ Professor Battin explains:

[I]n almost any terminal condition, death can occur in various ways, and there are many possible outcomes of the patient's present condition. The patient who is dying of emphysema could die of respiratory failure, but could also die of cardiac arrest or untreated pulmonary infec-

159. PRESIDENT'S COMMISSION, *supra* note 15 at 105-06; KATZ, *supra* note 107, at 82-84.

160. Nathanson v. Kline, 186 Kan. 393, 350 P.2d 1093 (1960); DiFilippo v. Preston, 173 A.2d 333 (Del. 1961). See Meisel, *The Expansion of Liability for Medical Accidents: From Negligence to Strict Liability by Way of Informed Consent*, 56 NEB. L. REV. 51 (1977).

161. *E.g.*, Cobbs v. Grant, 8 Cal.3d 229, 104 Cal. Rptr. 505, 502 P.2d 1 (1972); Canterbury v. Spence, 464 F.2d 772 (D.C. Cir. 1972). See discussion of these two standards in Miller, *Informed Consent: I*, 244 J. A.M.A. 2100 (1980).

162. Cases on both sides of the issue are collected in Annot., 38 A.L.R. 4th 900 (1985).

163. Battin, *The Least Worst Death*, HASTINGS CTR. REP., 13 (April 1983) [hereinafter cited as Battin].

tion. The patient who is suffering from bowel cancer could die of peritonitis following rupture of the bowel, but could also die of dehydration, of pulmonary infection, of acid-base imbalance, of electrolyte deficiency, or of an arrhythmia. . . . Infection and cancer, for instance, are old friends; there is increased frequency of infection in the immuno-compromised host. Other secondary conditions, like dehydration or metabolic derangement, may set in. Of course certain conditions typically occur a little earlier, others a little later, in the ordinary course of a terminal disease, and some are a matter of chance. The critical point is that certain conditions will produce a death that is more comfortable, more decent, more predictable, and more permitting of conscious and peaceful experience than others. Some are better, if the patient has to die at all, and some are worse. Which mode of death claims the patient depends in part on circumstance and in part on the physician's response to conditions that occur. . . . But though it is crucial in making a genuinely informed decision, the patient's right to information about the risks and outcomes of alternative kinds of refusal has not yet been recognized. So, for instance, in order to make a genuinely informed choice, the bowel cancer patient with concomitant infection will need to know about the outcomes of each of the principal options: accepting both bowel surgery and antibiotics; accepting antibiotics but not surgery; accepting surgery but not antibiotics; or accepting neither. The case may of course be more complex, but the principle remains: To recognize the patients's right to autonomous choice in matters concerning the treatment of his own body, the physician must provide information about all the legal options open to him, not just information sufficient to choose between accepting or rejecting a single proposed procedure.¹⁶⁴

When the patient is unable to make decisions for himself, the family should receive the necessary information about all treatment/nontreatment alternatives.¹⁶⁵

164. *Id.* at 15-16.

165. *See supra*, text accompanying notes 47-81.

Some courts have adopted the notion that the refusal of treatment should be as informed as the consent to treatment. In *Truman v. Thomas*,¹⁶⁶ the California Supreme Court considered the case of a physician who failed to warn a woman of the risks involved in refusing a pap smear.¹⁶⁷ The Court ruled that the physician could be held liable when, lacking the appropriate information, the woman refused the diagnostic procedure, and later died of cervical cancer.¹⁶⁸ A New York court ruled similarly in the case of a woman whose doctor recommended surgery for what he told his patient was a "pinched nerve" in her right foot.¹⁶⁹ The doctor did not tell her that he didn't know what was causing the pinched nerve.¹⁷⁰ The woman refused the surgery, and later had to have her leg partially amputated when it was discovered that a malignant tumor was causing the foot problem.¹⁷¹ The court ruled a jury could properly find the defendant doctor negligent for failing to advise her that a tumor might be present and that surgery was needed to find out for sure.¹⁷² It is worth noting that here the doctor failed to disclose his uncertainty about the patient's condition. The case demonstrates the importance of sharing medical uncertainties as well as medical knowledge possessed by physicians.

One case makes clear, in the context of a critically ill person with a short life expectancy, that informed refusal is a part of the doctrine of informed consent. This is the case of *In re Conroy*,¹⁷³ in which an 84-year old woman suffered from multiple severe disorders and exhibited only minimal cognitive, sensory, or emotional functioning.¹⁷⁴ The court, in considering whether artificial means of feeding and hydration had to be continued, stated:

The doctrine of informed consent presupposes that the patient has the information necessary to evaluate the

166. 27 Cal. 3d 285, 611 P.2d 902, 165 Cal. Rptr. 308 (1980).

167. *Id.*

168. *Id.*

169. *Crisher v. Spak*, 122 Misc.2d 355, 471 N.Y.S.2d 741 (1983).

170. *Id.*

171. *Id.*

172. *Id.*

173. 98 N.J. 321, 486 A.2d 1209.

174. *Id.* at 347, 486 A.2d at 1222.

risks and benefits of all the available options The patient's ability to control his bodily integrity through informed consent is significant only when one recognizes that this right also encompasses a right to informed refusal.¹⁷⁵

Revitalizing the legal doctrine of informed consent along the lines suggested here will not, in itself, guarantee a change in doctors' customs and practices. Other changes—in professional attitudes, in medical school training, and, perhaps most important, in public insistence on improved patterns of communication on the part of doctors—will be necessary before informed consent and informed refusal become firmly established features of medical life. But there are signs that these changes are developing.¹⁷⁶ The law should foster these developments by adding its own weight on the side of genuine informational sharing among doctors, patients and families.

3. *Providing compassionate support to the patient and family*

Caring doctors have always been part of the ideal in medicine. It is of obvious importance in care of the severely ill. Without belaboring the point, I suggest three ways in which physicians might act to come closer to the ideal. First, they must learn how to convey information in an empathetic way that preserves honesty and maximal clarity of thought. This is not easy, as the experience of doctors on a burn unit shows:

It took many months before we could shed a "we know best" defense and actually ask the patient what he

175. *Id.*

176. The public, for example, has become aroused over specific medical issues such as the safety of the childhood pertussis vaccine. A citizens' group is lobbying for state laws mandating specific physician disclosures of vaccine risks and benefits, and has achieved its first success in Maryland. See MD. ANN. CODE §§ 18-328 to 18-332 (Supp. 1985). The citizens' group is the Dissatisfied Parents Together of Vienna, Virginia, see, *Maryland Passes First DPT Reform Law In U.S.*, DISSATISFIED PARENTS TOGETHER NEWS, Fall 1984, at 1.

Physician attitudes have at least been subject to scrutiny and criticism by some within the profession. See articles by Kassirer, *supra* note 109; Imbus and Zawacki, *infra* note 177; Bedell and Delbanco, *supra* note 116; and Moral and Ethical Dilemmas, *supra* note 80. Medical school training is beginning to include attention to doctor-patient communication, ethics, and humane care. See Hechinger, *Medical Text Revives Lost Skill: Compassion*, N.Y. Times, July 31, 1984, at C5, col. 1.

wanted on admission when he was most competent to decide. Our approach seems obvious and right to us now; the first few times were agonizing. Our words seemed clumsy and awkward. If we had acted individually, without colleague support, the plan would probably have reverted rapidly to denial, or even worse, to a paternalistic decision making for the patient.¹⁷⁷

Patients and families, these doctors found, reacted well to their efforts at open and compassionate communication:

The very frequent question—"Am I going to die?"—is answered truthfully by the statement, "We cannot predict the future. We can only say that, to our knowledge, no one in the past of your age and with your size of burn has ever survived this injury, either with or without maximal treatment." At this point, those who interpret this diagnosis of a burn without precedent of survival as an indication to avoid heroic measures typically become quite peaceful. Regularly, they then try to live their lives completely and fully to the end, saying things that they must say to those important to them, making proper plans, preparations and apologies and, in general, obtaining what Kavanaugh refers to as "permission to die." These patients receive only ordinary medical measures and sufficient amounts of pain medication to assure comfort after their choice is made explicit. Fluid resuscitation is discontinued, they are admitted to a private room, and visiting hours become unlimited. An experienced nurse and, frequently, a chaplain are in constant attendance, using their expertise to comfort and sustain the patient and his family, chiefly by their continued presence and willingness to listen.¹⁷⁸

Second, doctors must stay involved with the hopelessly ill patient and his family, and resist the temptation to avoid them and withdraw all attention. Withdrawal is regularly observed,

177. Imbus & Zawacki, *Autonomy for Burned Patients When Survival is Unprecedented*, 297 NEW ENG. J. MED. 308, 310 (1977) [hereinafter cited as Imbus & Zawacki].

178. *Id.* at 309.

and engenders patient despair and family bitterness.¹⁷⁹ Third, doctors can help families to make difficult decisions about treatment withdrawal. This requires at least some familiarity with the ethics of such decisions, with the common emotional responses of people facing them, and with techniques used successfully by others to allay guilt and other emotional blocks to sound decisionmaking.¹⁸⁰ Some of these matters may be better handled by others on the health care team,¹⁸¹ but the physician, as the leading health professional in the eyes of patients and families, can not disclaim all responsibility for them.

4. *Screening out abusive family decisions*

Although judging by the extensive literature in the field, families rarely press for treatment refusals without reason or for ill motives, the possibility of abusive decisionmaking by families must be taken into account. I suggest that health professionals are the most appropriate and best situated people to insure that patients are not victimized by abusive family decisionmaking. They are best situated to do so because any decision about medical options must be implemented by them. If a family directs the physician to disconnect from a respirator a person whose loss of consciousness is not irreversible, for example, it would be an obvious abuse to do so. As a professional, a doctor has an obligation not to engage in abusive treatment of patients, so assigning the role to physicians of "screening out" abusive family decisions about treatment refusal is not an unusual or unexpected burden. In other contexts, the law has looked to physicians to prevent abuse. In *Parham v. J.R.*,¹⁸² for example, the Court looked to medical professionals to prevent improper attempts by parents to commit their children to state mental institutions.¹⁸³ The Court rejected arguments that only adversary proceedings could screen out abusive family decisions.¹⁸⁴

179. See *supra* note 156.

180. E.g., *Moral and Ethical Dilemmas*, *supra* note 80, at 891.

181. See Cassileth, *supra* note 107.

182. 442 U.S. 584 (1979).

183. *Id.*

184. *Id.* at 597. One need not agree with the Supreme Court's application of this point to *Parham* facts. Parents attempting to institutionalize their children are voluntarily initiating a family separation, and psychological evidence exists suggesting that par-

*Landeros v. Flood*¹⁸⁵ held that doctors may also be required to diagnose some forms of child abuse and to prevent further abuse by keeping a battered child in the hospital rather than returning the child to its abusive custodians.¹⁸⁶ These cases illustrate the law's recognition that in medical situations, doctors normally should and do act to prevent ill-motivated family members from using health professionals to assist in the abuse of another family member.

The doctor's "screening out" role, it should be noted, is a limited one. It does not empower a physician to challenge a family's decisionmaking authority unless the family's decisions are clearly beyond reasonable bounds or motivated by malice or ill-will. The function of preventing abuse is not intended to permit professionals to substitute their own judgments for those of families in the usual situation, but to block abusive judgments in the rare situation.

THE ROLE OF COURTS

As dilemmas develop in a complex society, and notions of "rights" expand, more frequent resort to courts for all manner of problem solving can be expected.¹⁸⁷ Before accepting this reliance on the judicial process in the treatment/nontreatment context, however, it is important to consider the drawbacks of court involvement in these matters. These drawbacks suggest that judicial resolution is neither inevitable nor desirable in the large majority of treatment withdrawal decisions.

Delay

The law's delay is an old complaint and one of great importance in the medical decisionmaking context. It is a common-

ents sometimes seek to characterize a child as the problem to avoid facing their own substantial emotional problems. See, e.g., NAPIER & WHITAKER, *THE FAMILY CRUCIBLE*, (1978). In these circumstances, the medical experts' "screening" may not be reliable enough. In the case of a hopelessly ill family member, any separation is brought on by involuntary illness, and the psychological evidence that family members act upon improper motives is absent.

185. 17 Cal. 3d 399, 551 P.2d 389, 131 Cal. Rptr. 69 (1976).

186. *Id.*

187. Friedman, *Exposed Nerves: Some Thoughts on Our Changing Legal Culture*, 17 SUFFOLK U.L. REV. 529 (1983).

place occurrence in the withdrawal-of-treatment cases that have been brought to court that the patient dies during the time it takes for the trial court and the appellate review process to work.¹⁸⁸ In the case of *Earl Spring*, the Supreme Judicial Court of Massachusetts noted that the case was still unresolved a year after it began.¹⁸⁹ The court urged greater dispatch in the future, but litigation realities—the need to investigate the facts, prepare testimony, do legal research, and prepare arguments at each level of the trial-appellate process, with all lawyers and judges involved needing time to familiarize themselves with the case—hamper speedy decisionmaking.

Changing Facts

Severe illness is not a static phenomenon. Physical symptoms and functioning can change rapidly. One physician has described the “kaliedoscope of symptoms” that occurs in the chronically ill that require treatment/nontreatment decisions.¹⁹⁰ The severely ill patient also frequently suffers from multiple diseases, which fluctuate in their intensities and in their effects on bodily and mental functions.¹⁹¹ Even where only a single disease is present, physical changes occur which call for new evaluation of treatment choices and goals. Moreover, when clinical crises arise, they must be addressed on the spot.

Courts that have dealt with persons in the persistent vegetative state (most of the reported cases) may not appreciate the variability of other conditions. When speed, flexibility of response, and continual re-assessment are necessary, the shortcomings of the judicial process are apparent. A medical practitioner engaged in the care of chronically ill and severely debilitated individuals observes: “the facts are that these decisions usually need to be made quickly (within hours or days), repeatedly (options with respect to quality of life, prognosis, and treatment may vary from day to day), and with a considerable degree of medical expertise.”¹⁹²

188. See, e.g., *In re Eichner* and *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (reported together); *In re Hamlin*, 102 Wash.2d 810, 689 P.2d 1372.

189. *In re Spring*, 380 Mass. 629, 641, 405 N.E.2d 115, 123.

190. Hanratty, *supra* note 132, at 2.

191. Battin, *supra* note 163, at 15.

192. Hilfiker, *supra* note 123, at 718. The author concluded that it was “ridiculous”

Burdensomeness

Court proceedings are a great burden for the families of the severely ill, especially so since they are already under great stress. The process is exhausting, expensive, and intimidating. Karen Ann Quinlan's father, who eventually won the right to direct discontinuation of respirator support for his comatose daughter, was quoted as saying, "that was terrifying having to go to court."¹⁹³

The delay occasioned by court involvement increases uncertainty and anxiety, and keeps the family in limbo. The delay may also mean additional and substantial hospital expenses, physician expenses and treatment costs, all of which presumably continue at maximal levels while the matter is pending in court. Running up the medical bill is unfair to the family that has carefully and agonizingly reached its own decision to stop treatment, but must wait weeks, months, or more for court approval.

The stress of adversary proceedings is well known. Benjamin Cardozo wrote that lawsuits are "catastrophic experiences" for most people.¹⁹⁴ Learned Hand said "[A]s a litigant I should dread a lawsuit beyond almost anything else short of sickness and death."¹⁹⁵ In treatment refusal cases, courts will often appoint a guardian ad litem specifically charged with the task of presenting all arguments in favor of treatment.¹⁹⁶ Thus adversariness is assured, along with the trepidation, exposure, confrontation, and loss of autonomy that the family as litigants experience.

to believe the courts could act promptly enough in these matters. *Id.* See also Dunn, *Who "Pulls the Plug": The Practical Effect of the Saikewicz Decision*, 6 MEDICOLEGAL NEWS 6 (1978) [hereinafter cited as Dunn].

193. Norman, *Our Towns: The Quinlans and the Latest Right to Die Ruling*, N.Y. Times, Jan. 24, 1985, at B4, col. 4.

194. CARDOZO, *THE NATURE OF THE JUDICIAL PROCESS* 128 (1921).

195. Learned Hand, *Address Delivered Before the Association of the Bar of the City of New York*, 3 LECTURES ON LEGAL TOPICS 89, 105 (1926).

196. See, e.g., *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 756, 370 N.E.2d 417, 433. This role for the guardian ad litem encourages appeals, further delaying the proceeding.

Loss of Privacy and Autonomy

A lawsuit brings a private issue into a public forum. For the issue under discussion here, legal proceedings bring strangers, in the form of lawyers and judges, into a most private matter of family life. The most personal of emotions—grief, love, sorrow, regret—go on display in the courtroom. Since these cases often attract the attention of the media, the family may be besieged by reporters and subject to even wider privacy invasions.¹⁹⁷

In addition, the involvement of legal professionals brings with it a more subtle, but very significant, sense of loss. This is a loss of control, which laypeople experience when professionals make their searching inquiries and tell their clients what to do, in an atmosphere familiar to the professional but alien and disorienting to the non-professional. In such circumstances, the family is likely to feel that the professionals have taken control. In a society where family autonomy is a basic value, this consequence of court involvement is a serious negative element.

Chilling Effect

If asserting the right of an incompetent patient to forego medical treatment means going through the distress and trauma of legal proceedings, it is possible that those closest to the incompetent patient will be influenced not to assert the right.¹⁹⁸ Burdening the exercise of a right with adversarial procedural requirements will deter some, and for them the right is rendered a nullity.¹⁹⁹ The deterrent effect of required court procedures has been recognized by two courts considering withdrawal of life support from patients in the vegetative state.²⁰⁰ There is no reason to suppose the effect on the family is any less when the

197. Bayley, *Who Should Decide?*, in *LEGAL AND ETHICAL ASPECTS*, *supra* note 10, at 7.

198. Rosoff describes a situation in which the family of an irreversibly vegetative patient requested removal of life support systems. Hospital representatives, fearing liability, said "We'd like to do this. Why don't you bring a lawsuit against the hospital." The family could not afford the expense and did not want the publicity of a lawsuit. The hospital refused to act. Five months passed before the patient died. The medical bill was \$110,000, of which Medicare paid \$80,000. Rosoff, *Living Wills and Natural Death Acts*, in *LEGAL AND ETHICAL ASPECTS*, *supra* note 10, at 186-87.

199. See *Parham v. J.R.*, 442 U.S. 584 (1979).

200. *In re Colyer*, 99 Wash.2d 114, 660 P.2d 738; *In re Bludsworth*, 452 So.2d 921.

stricken family member is in a dire condition short of the vegetative state.

Courts Have No Special Competence To Make These Decisions

For those instances in which stopping treatment is not beyond the bounds of society's widely shared sense of morality, judges can not claim any particular competence to make treatment/nontreatment decisions for others. Such decisions require a moral, philosophical, or religious set of values; without these it is impossible to determine whether the benefits of treatment outweigh the burdens.²⁰¹ Government officials, including judges, should not be selecting among competing, acceptable moral philosophies.²⁰² Moral diversity on the issue of treatment refusal exists in the society at large. The government, in a free society, ought to respect that diversity.

These objections, compelling as they are, would be unavailing if it could be shown that court intervention was absolutely necessary to protect the interests of patients and society. But there is nothing in our experience to date to indicate that decisions for non-treatment are being made precipitously, or that private decisionmaking is producing unacceptable results.²⁰³ As Judge Jones of the New York Court of Appeals, dissenting in *In re Storar*, wrote, there is "no empirical evidence that society or its individual members have suffered significantly in consequence of the absence of judicial oversight."²⁰⁴

Indeed, there is some cause to think that judicial interventions, when attempted, have failed to improve the quality of decisionmaking. In addition to lacking an appropriate source of values to apply, judges also are poorly situated to find and interpret the facts. To resolve cases, judges depend upon facts and their proof. But the "facts" in these matters are subject to

201. See *supra* text accompanying notes 124-30.

202. Abram & Wolf, *Public Involvement in Medical Ethics: A Model for Government Action*, 310 NEW ENG. J. MED. 627 (1984). Cf. *Roe v. Wade*, 410 U.S. 113, 159 (1973): "When those trained in the respective disciplines of medicine, philosophy, and theology are unable to arrive at any consensus [on the question of when life begins], the judiciary, at this point in the development of man's knowledge, is not in a position to speculate as to the answer."

203. See *supra* note 88.

204. 52 N.Y.2d 363, 386. 420 N.E.2d 64, 76, 438 N.Y.S.2d 266, 278.

widely varying interpretation. For example, the facts of the *Storar* case in the lower court²⁰⁵ offered a grim picture of Mr. Storar's life. John Storar, a mentally retarded man dying of bladder cancer, began receiving substantial blood transfusions every eight days, until his mother refused to consent to further transfusions.²⁰⁶ Mr. Storar, in the lower court, is portrayed as a man whose physical condition is severely and steadily deteriorating; he rarely ventures outside his room; he is subject to extreme pain, which will increase as his cancer unavoidably spreads.²⁰⁷ The transfusions can not save his life, they cause him great distress, he dreads and cannot understand them, and in significant ways they make his suffering worse.²⁰⁸ With or without them, he will die in a matter of months.²⁰⁹ His mother does not want to subject him to them and thereby prolong his intense pain and suffering.²¹⁰ She is very protective of and close to her son.²¹¹

In the Court of Appeals, John Storar's life sounds quite different. He is said to be more energetic after transfusions; he is feeding himself, showering, taking walks and running; he even engages in some "mischievous" behavior.²¹² With the transfusions, the Court says, he is "essentially the same as he was before."²¹³ The trial court judge saw Mr. Storar suffering greatly. The appellate court saw him enjoying life, with some occasional distress. The difference is disturbing to one's faith in judicial factfinding. In part the problem may stem from the difficulty in knowing what the incompetent patient is experiencing. To know this requires an empathy with the patient that comes with intimacy and involvement with him over time. John Storar's mother had this sort of intimacy and involvement. The trial judge recognized this: "Mrs. Storar, over her son's lifetime, has come to understand his wants and needs and is acutely sensitive to his best interests. . . . She is closer to feeling what John is feeling than

205. In re *Storar*, 106 Misc.2d 880, 433 N.Y.S.2d 388 (Sup. Ct. 1980).

206. *Id.*

207. *Id.*

208. *Id.*

209. *Id.*

210. *Id.*

211. *Id.* at 882-84, 433 N.Y.S.2d at 391-93.

212. In re *Storar*, 52 N.Y.2d 363, 374, 420 N.E.2d 64, 69, 438 N.Y.S.2d 266, 271.

213. *Id.* at 381, 420 N.E.2d at 73, 438 N.Y.S.2d at 275.

anyone else."²¹⁴ The appeals court rejected Mrs. Storar's assessment and substituted its own. I suggest that Mrs. Storar's sense of the facts of her son's experience of pain and suffering is greater and more reliable than any court's, most especially an appellate court working from a printed record.

The judicial orientation toward provable facts leads some courts to inappropriately delimit their factual inquiry. Certain facts which are subject to proof are given undue prominence, e.g., the degree of invasiveness of a proposed treatment. To an irreversibly comatose patient, this fact is of little significance, but a Connecticut court looking for objective data made much of this fact in justifying its decision.²¹⁵ In another case, the New Jersey Supreme Court selected out the existence of severe pain as the most critical fact in deciding on the appropriateness of continuing medical treatment.²¹⁶ The focus on pain failed to allow other humane values to play their proper role in decision-making for a severely debilitated, elderly woman in an extreme condition bordering on the vegetative.²¹⁷

Court interventions also make matters worse when judges devise special procedural rules for these situations. An Ohio court, for example, after authorizing a husband to direct the disconnection of a mechanical respirator from his chronically vegetative wife, required that notice be given to the county coroner and county prosecutor, so that they could send representatives to witness the act of disconnection.²¹⁸ A more needless, offensive presence at such a time is difficult to imagine. Another court insisted that formal legal guardianship proceedings be instituted in all treatment refusal cases.²¹⁹ It rescinded this requirement one year later.²²⁰

In its first major case on the subject, the Massachusetts Supreme Judicial Court appeared to say that all instances of with-

214. 106 Misc.2d at 885, 433 N.Y.S.2d at 393.

215. *Foody v. Manchester Memorial Hospital*, 40 Conn. Supp. 127, 482 A.2d 713 (Conn. Super. Ct. 1984).

216. *In re Conroy*, 98 N.J. 321, 367, 486 A.2d 1209, 1232-33.

217. The dissenter in *Conroy* adopted this view. *Id.* at 374-76, 486 A.2d at 1244-50. See Annas, *When Procedures Limit Rights: From Quinlan to Conroy*, HASTINGS CTR. REP. 24 (April 1985).

218. *Leach v. Akron Gen. Med. Ctr.*, 68 Ohio Misc. 1, 8, 426 N.E.2d 809, 816.

219. *In re Colyer*, 99 Wash.2d 114, 119-21, 660 P.2d 738, 746-49.

220. *In re Hamlin*, 102 Wash.2d 810, 812, 689 P.2d 1372, 1377.

drawal of life support treatment had to be submitted to and decided by judges.²²¹ Later it modified this position, after generating confusion and chaos in tertiary care hospitals all over the country.²²² In New York, an appellate court came up with an elaborate procedure that would have involved as many as six doctors, five attorneys and a judge, for all proposed withdrawals of treatment.²²³ Fortunately, the ruling was reversed by the Court of Appeals.²²⁴

The overuse of procedure by these courts appears to be the legal profession's counterpart to medicine's tendency to over-treat. Doing nothing seems difficult for professionals, but it is sometimes the wisest course. As a Florida appellate court has said: "We must remember that the conscience of society in these matters is not something relegated to the exclusive jurisdiction of the court."²²⁵

The care of incompetents has always been left to the family, and the government has not intervened, absent evidence of abuse. It is submitted that this tradition, and the fundamental values underlying it,²²⁶ should extend to family decisionmaking for the severely ill. When there is a willing family decisionmaker available, resort to the courts is appropriate in only the most limited circumstances, e.g., when there is irreconcilable conflict among family members or clear evidence of wrongful motives, or a strong basis for believing that the choice selected is beyond any reasonable bounds. It is not appropriate when the family has made a plausible choice (even if others might have chosen differently), or when hospitals merely seek the legal comfort of a court order.²²⁷

221. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 755-59, 370 N.E.2d 417, 433-34.

222. *In re Spring*, 380 Mass. 629, 636-41, 405 N.E.2d 115, 120-23. The chaos and confusion is recounted in Dunn, *supra* note 192. The protest from the medical community was so vigorous that Justice Liacos, author of the Saikewicz opinion, took the unusual step of defending the decision before a conference of health professionals. See Liacos, *Dilemmas of Dying*, in *LEGAL AND ETHICAL ASPECTS*, *supra* note 10, at 149.

223. *In re Eichner*, 73 A.D.2d 431, *rev'd*, 52 N.Y.2d 363 (1981).

224. *In re Eichner*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981).

225. *In re Guardianship of Barry*, 445 So.2d 365, 372 (Fla. App. 1984).

226. See *supra* text accompanying notes 52-62.

227. Hospitals could be prevented from bringing cases by denying them standing in these matters. See, e.g., *In re Storar*, 52 N.Y.2d 363, 373-74 n.3, 420 N.E.2d 64, 69 n.3, 438 N.Y.S.2d 266, 271 n.3.

ETHICS COMMITTEES

Interest in the creation of hospital ethics committees has grown enormously in recent years.²²⁸ The basic notion is to put together a group of people that would participate in the process of deciding questions relating to withdrawal of treatment for the critically ill, particularly where incompetent patients are involved. Major questions about such committees abound, including when these committees would function, how they would be constituted, and whether they would be a advisory body or a decisionmaking body. These issues, and many more, are being addressed in articles and conferences now, and in some cases in experimental programs in hospitals.²²⁹

With so many possibilities open, it is impossible to assess the value of ethics committees in general. Potentially, a body specifically designed to consider and advise on the ethical, psychological, social and legal aspects of care of the hopelessly ill can raise the consciousness of those who now refuse to acknowledge the true problems of this area of medical care. Withdrawal, avoidance and denial are all too common human reactions to difficult situations. A committee can focus attention and bring information and insight to bear on complex, value-laden, and emotionally difficult matters.

While the formation of ethics committees holds some promise, it is too soon for courts or legislatures to endorse their use. First, committees may function in such a way as to add to a patient's or family's problems. Patient autonomy may suffer at the hands of a committee run in a bureaucratic manner, or constituted of hospital personnel who see their role as protective of the institution rather than the patient. Committees composed largely of physicians may increase the problem of professional dominance that already exists in medical settings. Families forced by hospital rules to go before an ethics committee may feel intimidated, be uncomfortable baring their problems before a group of strangers, or generally feel their privacy and independence threatened and compromised. Busy committee members

228. Malcolm, *Hospital Panels Consider Key Ethics Issues*, N.Y. Times, Nov. 4, 1984, at 1, col. 4.

229. See, INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING (Cranford and Doudera eds. 1984).

may not devote the necessary time to committee work, which should include their own self-education in current moral, medical, psychological, and social thought on the issue.²³⁰

Ethics committees, if indeed they are to be part of the solution to dilemmas of medical decisionmaking and not part of the problem, must find their way carefully and cautiously. These committees exist in a minority of hospitals, and are in the earliest stages of development.²³¹ Considerably more experience with them is needed before their role in decisionmaking for the critically ill incompetent patient can be firmly established. For the present, courts are best advised not to require their use.²³²

THE ROLE OF THE CRIMINAL LAW

The question of choosing not to treat critically or terminally ill persons is complicated by the role that criminal law plays in this area. Prosecutions of doctors for terminating life support in hopeless cases are extremely rare.²³³ But the possibility of criminal prosecution was indelibly imprinted on physicians' minds when a Los Angeles prosecutor charged two California doctors with murder when they disconnected a deeply comatose man from a respirator.²³⁴ The doctors did so at the request of the family, after medical tests indicated the patient had suffered severe brain damage and was in a permanent vegetative state.²³⁵ The murder charges were rejected by a magistrate, reinstated by a superior court judge, and finally dismissed by an appellate

230. For more detailed discussions of the advantages and disadvantages of ethics committees, see, Levine, *Questions and (Some Very Tentative) Answers about Hospital Ethics Committees*, HASTINGS CTR. REP., 9 (June 1984), Levine, *Hospital Ethics Committees: A Guarded Prognosis*, HASTINGS CTR. REP., 25 (June 1977); Veatch, *The Ethics of Institutional Ethics Committees*, in INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING, *supra* note 229, at 35.

231. McCormack, *Ethics Committees: Promise or Peril?*, 12 L., MED. & HEALTH CARE 150 (1984); Youngner, Coulton, Juknialis and Jackson, *Patients' Attitudes Toward Hospital Ethics Committees*, 12 L., MED. AND HEALTH CARE 21, 22 (1984).

232. The Georgia Supreme Court in *In re L.H.R.*, 253 Ga. 439, 321 S.E.2d 716 (1984); and the Washington Supreme Court in *In re Colyer*, 99 Wash.2d 114, 660 P.2d 738, both adopted this position.

233. Ginnex, *A Prosecutor's View on Criminal Liability for Withholding Medical Care: The Myth and the Reality*, in LEGAL AND ETHICAL ASPECTS *supra* note 10.

234. Barber v. Super. Ct. of Cal., 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484.

235. *Id.*

court.²³⁶ The publicity the case received was vast and it generated insecurity and fear throughout the medical profession.²³⁷ The *Barber* case showed that an indictment could happen. The fact that it was ultimately dismissed on appeal in California did not provide any guarantee that similar charges would not be brought elsewhere, since the question of what behavior constitutes murder is a matter of individual state law. Moreover, prosecutors throughout the nation have other state criminal laws to draw upon, such as criminal negligence, aiding a suicide, and endangering the welfare of an incompetent person.²³⁸

Prosecutors are also visible in these matters because of the practice of courts, when considering applications by patients or their families to disconnect life support systems, of seeking the involvement of the local district attorney.²³⁹ At other times, reports of a grand jury investigation may indicate to medical professionals that a local prosecutor is paying attention to their conduct.²⁴⁰ Occasionally, prosecutors will speak at conferences of health professionals, airing their views about when murder, manslaughter, or other criminal charges *might* be brought.²⁴¹

One result of this is that the fear of criminal action seriously impairs sound treatment/nontreatment decisionmaking for the critically and terminally ill. Hospitals insist on court orders to protect themselves, even when family members and physicians agree on the futility of treatment.²⁴² At times, even competent patients with terminal illnesses who direct cessation of treatment are forced to go to court by fearful health professionals.²⁴³ Prominent doctors have felt it necessary to urge their col-

236. *Id.*

237. See Flaherty, *A Right to Die? The Premier Privacy Issue of the 1980's*, Nat'l L.J., Jan. 14, 1985, at 1, col. 1; Towers, *Irreversible Coma and Withdrawal of Life Support: Is it Murder if the IV line is Disconnected?*, 8 J. MED. ETHICS 203 (1982).

238. These laws were noted in *Severns v. Wilmington Med. Center*, 421 A.2d 1334, 1346 (Del. Super. Ct. 1980).

239. See, e.g., *In re Eichner* 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266, Leach v. Akron Gen. Med. Ctr., 68 Ohio Misc. 1, 426 N.E.2d 809.

240. See, e.g., Sullivan, *Hospital's Data Faulted in Care of Terminally Ill*, N.Y. Times, Mar. 21, 1984, at B1, col. 4.

241. See, e.g., Oakes, *A Prosecutor's View of Treatment Decisions*, LEGAL AND ETHICAL ASPECTS, *supra* note 10, at 194-99.

242. See *supra* notes 198 and 227.

243. E.g., *In re Lydia Hall Hospital*, 116 Misc. 2d 477, 455 N.Y.S.2d 706; *Patient May Refuse Life-Support Care*, N.Y. Times, Dec. 28, 1984, at A1, col. 1; Annas, *Prisoner*

leagues not to subordinate the best interests of their patients to their own self-interests in avoiding the threat of legal liability.²⁴⁴ While such sentiments express worthy ideals, doctors can not realistically be expected to put aside all concern for their own personal and professional lives, and the evidence is clear that they do not.

Examples of distorted medical decisionmaking abound. In some instances, doctors have refused to disconnect life support systems from persons who are brain-dead.²⁴⁵ At one New York hospital, officials insisted on court approval to disconnect a patient who previously clearly expressed her wish not to be artificially maintained in a vegetative state, despite clear legal precedent permitting doctors to do so without court authorization. When the court order was granted, the hospital, displaying the utmost in timidity and unprofessionalism, asked the court not to direct its personnel to perform the actual disconnection.²⁴⁶ Physicians and hospitals have adopted unusual and even bizarre practices to avoid accountability for nontreatment decisions. Orders not to resuscitate, for example, have not been written on the patient's chart. Instead, they are whispered, pencilled in on the chart and erased, written in code on a blackboard, or indicated by means of a purple "dot" affixed to papers in the patient's file.²⁴⁷ These practices increase the possibility of mistakes, such as occurred in the purple dot system, when a patient was not resuscitated even though no definite diagnosis had been made, and no prior notice of the nonresuscitation order was given to the patient or family.²⁴⁸ Such secretive practices, in ad-

in the ICU: The Tragedy of William Bartling, HASTINGS CTR. REP. 28 (Dec. 1984).

244. Wanzer, *supra* note 145, at 956.

245. *Woman, 44, Dies After Judge Allows a Halt to Life Support*, N.Y. Times, Sept. 1, 1984, at 26, col. 5; Annas, *Defining Death: There Ought to be a Law*, HASTINGS CTR. REP. 20, 21 (Feb. 1983).

246. *In re Moschella*, N.Y.L.J., May 22, 1984, at 12, col. 2 (Sup. Ct. Queens Cty. May 21, 1984).

247. Van Scoy-Mosher, *supra* note 115, at 15 (orders erased, whispered); Nicholson, *Secret Grade System for Cancer Patients at Top Hospital*, N.Y. Post, Mar. 26, 1984, at 3, col. 1 (blackboard code); N.Y. STATE DEPUTY ATTORNEY GENERAL FOR MEDICAID FRAUD CONTROL, REPORT OF THE SPECIAL JANUARY THIRD ADDITIONAL 1983 GRAND JURY CONCERNING "DO NOT RESUSCITATE" PROCEDURES AT A CERTAIN HOSPITAL IN QUEENS COUNTY 4, 12-16 (1983) [hereinafter cited as REPORT OF THE SPECIAL JANUARY THIRD GRAND JURY] (purple dot system).

248. REPORT OF THE SPECIAL JANUARY THIRD GRAND JURY, *supra* note 247, at 7.

dition to risking error, discourage doctors from speaking openly with families about nontreatment options and from obtaining their informed consent.

The untoward effects on decisionmaking for the severely ill might be worth the cost if a criminal act were truly being deterred. But the disconnection of life support systems by doctors acting at the behest of families should not be considered a criminal act, absent extraordinary circumstances (e.g., if doctors know the condition is curable). The *Barber* court dismissed the indictment against the accused surgeon and internist in part based upon a distinction between "omission" and "commission."²⁴⁹ Discontinuing the use of artificial respiration and feeding devices, the court concluded, was not an affirmative act of commission.²⁵⁰ The court reasoned:

Even though these life support devices are, to a degree, "self-propelled," each pulsation of the respirator or each drop of fluid introduced into the patient's body by intravenous feeding devices is comparable to a manually administered injection or item of medication. Hence "disconnecting" of the mechanical devices is comparable to withholding the manually administered injection or medication.²⁵¹

This reasoning, although it leads to the right result, is unsatisfactory. Other courts might rationally label the same conduct acts of "commission," by focusing on the positive action needed to stop the machines and to remove the tubes.²⁵² The decision should not hinge on labeling, but on basic notions of what we mean, and don't mean, by homicide.

Disconnection is not homicide, it is submitted, for the same reason that a request for cessation of treatment by a competent patient is not suicide. The Supreme Judicial Court of Massachusetts, rejecting the notion that a patient's refusal of lifesaving treatment was suicide, noted that "(1) in refusing treatment the patient may not have the specific intent to die, and (2) even if he did, to the extent that the cause of death was from natural

249. *Barber v. Super. Ct. of Cal.*, 147 Cal. App. 3d 1006, 1016, 195 Cal. Rptr. 484, 490.

250. *Id.*

251. *Id.*

252. See discussion in *In re Conroy*, 98 N.J. 321, 369-70, 486 A.2d 1209, 1234.

causes the patient did not set the death producing agent in motion with the intent of causing his own death."²⁵³ Similarly, when a family decides to stop treatment, based on a hopeless diagnosis, it is not their desire to kill, and if death seems inevitable, it is not their fault when it occurs.²⁵⁴

Since so few cases are actually brought, those which are seem random and capricious. Prosecutors who bring them are acting deviantly, in comparison to the vast majority of their colleagues. They may be politically motivated,²⁵⁵ or publicity seeking. Describing the activity of the prosecutor in the *Barber* case, medical writer Bernard Towers observed:

With each step in the case to date, the media coverage has become more intense. During the August flurry of activity the DDA [Deputy District Attorney] was everywhere to be seen and heard and read about. He must have devoted many hours to being in front of news cameras, microphones, and tape recorders.²⁵⁶

The elixir of mass media attention may well be intoxicating.²⁵⁷ Whatever the motive for bringing these cases, the freakish nature of them is another argument favoring de-criminalization of this area of medical decisionmaking. Courts in other contexts have disapproved of arbitrary and capricious uses of the criminal law.²⁵⁸ Our basic sense of fairness and justice is offended by infrequent prosecutions which have an air of randomness about them. This is especially so when the legal standards prosecutors employ are vague, ill-defined, or confused. Consider the following statements by three different prosecutors:

253. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 743 n.11, 370 N.E.2d 417, 426 n.11.

254. A literal reading of the homicide laws, without thought for their point and purpose, could produce a contrary conclusion (situation in which the family would be held culpable), but that simply highlights the need for sense and wisdom in statutory interpretation.

255. See *PRESIDENT'S COMMISSION* *supra* note 15, at 93 n.6; Vorenberg, *Decent Restraint on Prosecutorial Discretion*, 94 HARV. L. REV. 1521, 1558 (1981).

256. Towers, *supra* note 237, at 205.

257. Cf. Hurson, *The Trial of a Highly Publicized Case—A Prosecutor's View*, 16 AM. CRIM. L. REV. 473 (1979).

258. *E.g.*, *Furman v. Georgia*, 408 U.S. 238, 309-10 (1972) (Stewart, J., dissenting).

I do not believe that a no-code situation [i.e., a do-not-resuscitate order] will ever result in any type of prosecution. Withdrawal of life support, on the other hand, is not so clear. The withdrawal of hydration and nutrition may cause physicians to come within the concern of the prosecutor's office. The inevitability of death in those situations is so great that you must attribute an intent to kill to the withdrawal of hydration and nutrition.²⁵⁹

. . .

Personally I can understand when a physician, surrogate, or parent makes a treatment decision based on his or her view of the quality of the patient's life. . . . Yet while I understand that this issue will be considered in the normal treatment decisionmaking process, I am offended if quality of life considerations are allowed to enter into the courtroom and affect the court's decisionmaking process.²⁶⁰

. . .

[T]he criminal law prevents termination of treatment decisions from being made on "quality of life" assessments.²⁶¹

The first prosecutor broadly questions the "withdrawal of life support," making an exception for orders not to resuscitate. The basis for distinguishing such orders from other nontreatment decisions is left vague and unstated. What about discontinuing respirators, stopping powerful drug treatments, allowing pneumonia to go untreated in a patient dying of cancer, failing to give blood transfusions, kidney dialysis, and a host of other treatments to the hopelessly ill? Doctors must guess how such a prosecutor would react to all of these possibilities. Even if they could figure out this prosecutor's views, what about his counterpart in the next county?

This prosecutor also steps boldly into an ill-defined area of the law when he treats the withdrawal of nutrition and hydra-

259. Oakes, *supra* note 241, at 199.

260. Stein, *The Case of Phillip B: A Prosecutor's View*, in *LEGAL AND ETHICAL ASPECTS* *supra* note 10, at 202-03.

261. Nesbitt, *supra* note 78, at 247.

tion as homicide. The question of whether we must keep alive a permanently comatose patient, possibly for a decade, by medical efforts to intubate and feed is one open to debate.²⁶² Murder prosecutions, however, are inappropriate vehicles for resolving such public policy questions. They cannot provide a forum for public debate of such an issue, they subject the accused to the harsh ordeal of criminal accusation and defense, and they rudely publicize the grief and intensify the distress of the family involved.

The second and third prosecutors quoted above would use their offices to see that "quality of life" assessments do not enter into decisionmaking. One prosecutor does recognize it as an understandable element in the hospital but not in the courtroom, as if the basic question for decision changes with the physical surroundings. These prosecutors refuse to see that the severely low quality of life of people in extreme states of physical debilitation is what makes us think of terminating life support systems, not attempting to resuscitate, and otherwise not invoking the array of medical interventions at our command. These statements sweep so broadly, one might understand, if not excuse, the reluctance to withdraw life-support treatment from even a brain-dead person until a court gave its approval and removed the threat of criminal prosecution.²⁶³ Inevitably, doctors will think twice about discussing nontreatment options with families of critically ill, incompetent patients. Because of the chilling effect of the threat of criminal prosecution, treatment withdrawal may not even be presented to the family as an option.

The good faith decisions of families and physicians to withhold or withdraw medical treatments deserve protection from criminal prosecution. These decisions are not homicide according to any rational view of that term. A murder prosecution is

262. Two courts have stated that medical interventions to artificially feed a patient are not always required, and the withholding or withdrawal of these medical efforts should be considered on the same basis as rejection of any other life-supporting treatments. *Barber v. Super. Ct. of Cal.*, 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484; *In re Conroy*, 98 N.J. 321, 486 A.2d 1209. PRESIDENT'S COMMISSION, *supra* note 15, at 190, recommends that family and health professionals have the option to stop feeding permanently unconscious patients. *But see*, Meilaender, *On Removing Food and Water: Against the Stream*, HASTINGS CTR. REP. 11 (Dec. 1984).

263. *See supra* note 226.

surely not the proper forum for resolving the policy issues here under discussion. The few prosecutors who do involve themselves in these issues seem to make matters worse with their loose and confused remarks. The prosecutor's vast, virtually unreviewable discretion to bring criminal cases influences hospitals and physicians to make decisions which are self-protective and not in the best interests of patients. Courts and legislatures should act promptly to de-criminalize this sphere of medical decisionmaking.

CONCLUSION

I have suggested here that the family is entitled to make treatment/nontreatment decisions for irreversibly, severely incapacitated family members who cannot make their own medical decisions. This choice should be made with the cooperation of physicians who supply vital information on which these decisions must be based. Health professionals also should contribute, as part of humane care, their emotional support, sympathy, and understanding, helping to share the burdens that family members suffer. Decisions should not be rushed, and time for both discussion and reflection should be built in to the process. Decisionmaking should be private, i.e., without the participation of those outside the network of family, patient, and health care professionals directly involved in providing care to the patient. Exceptions to this privacy should be made only when the family fails to reach a decision (because of internal conflicts, for example) or when the decision is contrary to society's "widely shared ideals about human rights."²⁶⁴ Exceptions should not be based on a health provider's desire to usurp the decisionmaking function in order to substitute his or her own independent decision. A family's reasoned decision should receive support in the vast majority of cases. Health professionals who question the family's considered decision should examine their own motivations first.²⁶⁵ If they are genuinely satisfied that an exception is warranted, bringing in qualified outsiders (e.g., a hospital ethicist or

264. The phrase quoted is from Professor Tribe's discussion of rights of privacy and personhood in L. TRIBE, *AMERICAN CONSTITUTIONAL LAW* at 985-90 (1978).

265. Physicians themselves are "strongly influenced by their personal values and unconscious motivations." Wanzer, *supra* note 145, at 956.

ethics committee) is appropriate. The family should be told why its decision is being challenged and be given the opportunity to communicate its own reasons. Discussion may then provide a resolution. If it does not, as a last resort, civil court action is appropriate. In no event should good faith decisions to withhold or withdraw treatment be subject to criminal prosecution.

Placing the family at the center of medical decisionmaking for incompetent members affords respect for the family in its privacy, its control over its own destiny, and its assertion of moral and philosophical values. A check on unreasonable decisionmaking by families exists, but it is one to be employed sparingly, allowing latitude in decisionmaking to families who are concerned about the patient and who voluntarily participate in the decisionmaking process. This scheme of decision recognizes the vital role played by professionals, but as expert advisers, not as controllers of others' lives.

