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Some Special Issues

Several special issues are central to decisions to forgo life-sustaining treatment. These include the distinction some health care professionals draw between stopping and not starting treatment, the moral significance of intentions, and euthanasia. Decisions about artificial nutrition and hydration also touch upon important values.

These issues help to define the ethical duties of health care professionals and the parameters of surrogate authority. They arise in many sensitive cases, in which medical and personal judgments about treatment benefits, intentions, and responsibilities may dramatically affect decisions at the end of life. In our pluralistic society, the diversity of beliefs about some of these issues poses additional challenges for public policy.

A. Withdrawing and Withholding Treatment

Health care professionals often distinguish between withholding treatment and withdrawing treatment after it has been initiated. As a result, health care professionals and facilities are sometimes willing to honor decisions by patients or family members not to start treatment, but will not allow them to refuse treatment once it has begun.[1] Another consequence of the distinction is that physicians may discuss decisions to withdraw treatment with patients and surrogates, but may decide to withhold treatment without consulting the patient or family.

Underlying the distinction is an understanding by some health care professionals that withholding treatment is an omission while withdrawing treatment is a positive action and is therefore more cul-

[1]See, e.g., President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* (Washington: U.S. Government Printing Office, 1983), 73-75; T. L. Beauchamp and J. F. Childress, *Principles of Biomedical Ethics*, 3d ed. (New York: Oxford University Press, 1989), 147-50; and R. F. Weir, *Abating Treatment with Critically Ill Patients: Ethical and Legal Limits to the Medical Prolongation of Life* (New York: Oxford University Press, 1989), 147-48, 401-3.

pable. Some regard the distinction as harshly as that between "letting die" and "killing."[2] Some professionals may also believe that actions to remove treatment have graver legal consequences.

Over the past decades, a consensus has emerged in the bioethics literature that withdrawing and withholding treatment should not be morally distinguished.[3] As often characterized, withdrawing life-sustaining treatment in response to the request of a patient or surrogate is best seen as allowing rather than causing the patient's death; the underlying disease, not the removal of treatment, remains the cause of death.

The Task Force shares the widely articulated belief that withholding and withdrawing treatment are morally equivalent. Whether treatment is stopped or never initiated, all relevant moral factors are the same, including health care professionals' duty to respect the patient's wishes, the consequences, the intentions, the cause of death, and the potential for abuse. Hence, if a patient is dying of cancer, either withholding or removing a respirator allows the disease to take its natural course; neither the omission nor the withdrawal of treatment causes the patient's death.[4]

The Task Force's 1988 study of health care facilities examined whether facilities would oppose, on religious or moral grounds,

[2]President's Commission, 73-74; L. Baer, "Nontreatment of Some Severe Strokes," *Annals of Neurology* 4 (1978): 381-82. Some Jewish authorities argue that from the perspective of traditional Jewish law, the physician's obligations in approaching a decision to withhold or withdraw treatment may be distinct in some cases. See, e.g., F. Rosner and M. D. Tendler, *Practical Medical Halacha*, 3d ed. (Hoboken, N.J.: Association of Orthodox Jewish Scientists in association with Ktav, 1990), 54. Others, though, argue that any such distinction should not be decisive. "At the outset, the physician should connect the support systems of respiration or circulation; he should not decline to do so on the grounds that this may be prolonging death. He must give the patient every chance for life. Having connected the systems conditionally, however, he may remove them if he then determines that their function was not prolongation of life but of death." D. M. Feldman, *Health and Medicine in the Jewish Tradition* (New York: Crossroad, 1986), 95. See also I. Jakobovits, *Jewish Medical Ethics*, 2d ed. (New York: Bloch, 1975), 121-25, 275-76.

[3]See, e.g., President's Commission, 73-77; American Medical Association, Council on Ethical and Judicial Affairs, *Current Opinions* (Chicago: American Medical Association, 1989), sec. 2.20, p. 13; P. Ramsey, *The Patient as Person* (New Haven: Yale University Press, 1970), 121.

[4]See Weir, 310-17. A different case would be presented if an otherwise healthy patient is left untreated (deliberately or negligently) and dies. In this type of situation, either the withholding or withdrawal of standard therapy would be considered a contributing cause of death from a moral and legal perspective.

decisions to either withhold or withdraw life-sustaining treatment. In a majority of the cases presented, respondents distinguished between decisions to withhold and to withdraw treatment. For example, facilities were more likely to have a religious or moral objection to withdrawing treatment than to withholding treatment.[5] Anecdotal evidence and public discussion of decisions about life-sustaining treatment in the State suggest that the distinction between not starting and stopping treatment is widespread in health care facilities.

The Task Force urges all health care facilities to review their policies and practices for decisions about life-sustaining treatment, and to abandon distinctions based solely on the difference of whether or not treatment has already been started. The distinction cannot be supported on moral grounds. It also contravenes New York legal principles specified in judicial decisions and statutes. Neither the common law right to refuse treatment nor the authority of a duly appointed health care agent turns on whether treatment has been initiated for patients. The relevant legal benchmark is the patient's consent or, for health care agents, the agent's authority and duty to promote the patient's wishes whenever possible and otherwise to decide in accord with the patient's interests. The liability of health care providers for withholding or withdrawing treatment does not depend on the distinction, but on the duty to provide the treatment and the validity of any consent that may be required to stop or not to start treatment.

Those who adhere to the distinction should recognize that it may prompt poor medical practice in some cases. For certain patients, a trial period of treatment may yield clinical information about the efficacy of the treatment or the patient's willingness to accept the burdens that treatment imposes. For example, physicians may not know how a sick newborn will respond to a respirator. An elderly patient may wish to experience dependence on a gastrostomy tube before deciding about long-term treatment. If parents, other surrogates, or patients are told that, once initiated, treatment is irreversible, they will in some cases opt not to start. In an emergency, the distinction places even greater pressure on the difficult, emotionally charged choices that must be made in the immediate aftermath of an unexpected injury or illness.

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[5]The survey explicitly instructed facilities to disregard concerns about liability as a basis for refusing to honor decisions to forgo treatment. In actual practice, legal considerations may drive many decisions to continue or to forgo life-sustaining treatment. New York State Task Force on Life and the Law, survey data. See appendix E.

The Task Force recognizes that the distinction between not starting treatment and stopping has proven tenacious, persisting now for many years despite a broadly articulated consensus that rejects the distinction on moral grounds. At the least, health care professionals should recognize that they have neither the moral nor the legal right to refuse to honor a decision to stop treatment by a competent patient or duly authorized health care agent, unless they have specific grounds for doing so, such as the patient's incapacity to decide or bad faith by the agent. The same would hold true for surrogate decisions under the proposed legislation. If health care professionals do not want to participate in removing treatment on grounds of conscience, they need not participate, but they must inform the health care facility and the patient or person deciding for the patient and cooperate in transferring care of the patient.

B. The Moral Significance of Intentions

For some treatment decisions, a surrogate's choice to relieve pain may conflict with the value of preserving or extending life. For example, a potentially beneficial treatment such as heart surgery or chemotherapy may carry a high risk of mortality. Likewise, effective doses of pain medication for a terminally ill patient may depress respiration and risk hastening a patient's death. In such cases involving conflicting values and obligations, some commentators distinguish intended consequences from those consequences that are not intended but can be foreseen.[6]

This distinction is supported by Roman Catholic teaching, as well as other religious and secular traditions, and is often expressed in terms of "the principle of double effect." An action with both good and evil effects is permitted if the action is not intrinsically wrong, the agent intends only the good and not the evil effect, the evil effect is not the

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[6]The *Ethical and Religious Directives for Catholic Health Facilities* states that "it is not euthanasia to give a dying person sedatives and analgesics for the alleviation of pain, when such a measure is judged necessary, even though they may deprive the patient of the use of reason, or shorten his life." National Conference of Catholic Bishops (St. Louis: Catholic Health Association of the United States, 1975), 13-14, par. 29. See similarly the Vatican's 1980 "Declaration on Euthanasia," in President's Commission, 304-5.

A Jewish *Compendium on Medical Ethics* agrees that "relief of pain is adequate reason to assure palliation therapy, even with attendant risk." D. M. Feldman and F. Rosner, ed., 6th ed. (New York: Federation of Jewish Philanthropies, 1984). See similarly Jakobovits, 276.

means to the good effect, and a favorable balance exists between the good and evil effects.[7]

Under this analysis, a decision to provide pain medication in the case of the terminally ill patient described above would be ethically acceptable. The administration of medication is not intrinsically wrong, and is intended to alleviate the patient's pain, although the risk of death could be anticipated. Respiratory failure and the patient's death are not intended, nor are they necessary to relieve pain. In addition, in certain cases, such as when the patient is terminally ill and in pain, the good achieved would outweigh the risk of harm.

This type of case is distinct from the intentional termination of life by lethal overdose. Active euthanasia relieves suffering by a deliberate action with the primary intention of ending the patient's life. In contrast, palliative medication in the case above may risk hastening death, but it is not intended to cause death.[8]

This distinction between intended and foreseen consequences has been criticized as irrelevant, especially as expressed in the doctrine of double effect. Some argue that if consequences, actions and all other factors are the same, it makes no difference whether the patient's death is intended or not. Critics note problems in applying the distinction to actual cases, in which it is often difficult to discern exactly what a physician or others intended, and what counts as a means or a side effect. Some emphasize that those who act are responsible for all consequences of their actions that can be anticipated.[9]

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[7]See, e.g., Beauchamp and Childress, 127-28. Evaluation of the balance of good and evil effects is classically phrased in terms of proportionality. Most instances of causing unintended but foreseeable deaths would be judged morally wrong on this basis because the negative effect of the patient's death would outweigh any good effects. Various formulations of the principle (or doctrine) of double effect have been developed by philosophers and moral theologians. Recent essays on this topic may be found in *Journal of Medicine and Philosophy* 16, no. 5 (1991): 465-585.

[8]Some commentators also distinguish between intended and foreseen consequences when decisions are made to forgo life-sustaining treatment. They accept the withholding or withdrawal of treatment with the intention to alleviate burdensome treatment. However, they oppose the denial of treatment intended to lead to the patient's death, as passive euthanasia. W. E. May et al., "Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons," *Issues in Law and Medicine* 3 (1987): 204, 207-9.

[9]President's Commission, 77-82; Beauchamp and Childress, 130-34; A. R. Jonsen, M. Siegler, and W. J. Winslade, *Clinical Ethics*, 2d ed. (New York: Macmillan, 1982), 120-21.

Several commentators, while criticizing the intended/foreseen distinction and the doctrine of double effect, acknowledge that intentions may be a significant factor in moral deliberation. For example, they note that many medical interventions, intended to cure the patient or relieve pain, entail some finite risk to life. Society has granted physicians the authority to evaluate risks and benefits, to recommend a course of treatment, and to implement treatments chosen by a patient or surrogate in pursuit of accepted medical goals. While potentially risky interventions intended to cure the patient or relieve pain are within the scope of the physician's professional role, actions that are intended directly to cause death fall outside the physician's special authority. Commentators argue that allowing physicians to act with the intention of causing death raises problems for the way physicians view themselves and the practice of medicine and poses dangers of abuse for society as a whole.[10]

Some members of the Task Force embrace the principle of double effect. Others stress that intention is one, but not the primary, factor in determining the moral acceptability of providing pain relief; they believe that the decision should focus on the overall risks and benefits of the treatment. All agree that health care professionals have a duty to offer effective pain relief to patients when necessary, in accord with sound medical judgment and the most advanced approaches available.

Pain relief is of vital, and often overwhelming, importance to patients. Of the many disabilities and discomforts associated with illness and the dying process, patients often fear the experience of pain most. The popularity of the book *Final Exit*, instructing people how to kill themselves, attests to the public's anxiety about a lingering, painful death. This fear can be attributed, in part, to the medical profession's recognized failure to make adequate pain relief available to patients facing painful terminal or chronic illness. As characterized by an editorial in the *New England Journal of Medicine*, pain relief for hospital patients is "regularly and systematically inadequate."[11]

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[10] President's Commission, 77-82. See also E. Y. Waldenberg, *Tzitz Eliezer*, vol. 13, no. 87; discussed in B. A. Brody, "A Historical Introduction to Jewish Casuistry on Suicide and Euthanasia," in *Suicide and Euthanasia*, ed. B. A. Brody (Dordrecht: Kluwer Academic Press, 1989), 73.

[11] M. Angell, "The Quality of Mercy," *New England Journal of Medicine* 306 (1982): 98-99. See also K. M. Foley "The Relationship of Pain and Symptom Management to Patient Requests for Physician-Assisted Suicide," *Journal of Pain and Symptom Management* 6 (1991): 289-97; "Will Doctors Hear the Wake-Up Call?" *American Medical News*, December 9, 1991, 3; D. M. Gianelli, "Euthanasia Opponents Urge

Various reasons have been offered to explain why physicians fail to provide sufficient pain relief, including lack of training in advanced pain relief techniques, patients' reluctance to complain, physicians' failure to acknowledge patients' pain, and physicians' fear of side effects, including addiction and the possibility that pain medication will hasten the patient's death. Studies have shown, however, that concerns about addiction or hastening death from pain medication are not supported by medical evidence; patients receiving medication for chronic pain generally do not become addicted or suffer serious or fatal respiratory distress. The rare case when aggressive analgesia would pose significant risks should be resolved through careful discussion between the patient or surrogate and health care professionals. When the goals of prolonging life and alleviating suffering conflict, the values of the patient should generally be decisive.[12]

C. Deciding about Artificial Nutrition and Hydration

Throughout the public deliberation leading up to passage of New York's health care proxy law, decisions about artificial nutrition and hydration generated the most extensive debate. The Task Force recognizes that as the legislature considers its proposal for surrogate decisions, policies on these measures will once again receive close scrutiny.

The term "artificial nutrition and hydration" refers generally to the provision of food and water through tubes inserted in the patient's veins, nose and throat, stomach, or intestine. Artificial feeding is used to supplement nutritional intake or to provide total nutritional support on a short-term or long-term basis. As long-term measures, artificial nutrition and hydration are usually provided through a tube inserted in the nose and esophagus or surgically inserted into the stomach or a portion of the small intestine.[13] While such nutritional support is

Pain-Control Education." *American Medical News*, January 20, 1992, 9.

[12]See American Medical Association, *Current Opinions*, sec. 2.20, p. 13. See Bioethics Committee, Montefiore Medical Center, "Ethical Issues in Pain Control" (Bronx, N. Y., 1991), for a helpful and comprehensive summary of medical and ethical issues.

[13]U.S. Congress, Office of Technology Assessment, *Life-Sustaining Technologies and the Elderly*, OTA-BA-306 (Washington: U.S. Government Printing Office, 1987), 275-93; C. M. Lewis, *Nutrition and Nutritional Therapy in Nursing*, (Norwalk, Ct.: Appleton Century-Crofts, 1986). Total parenteral nutrition (TPN) is another means of artificial feeding that involves the provision of nourishment through a central venous catheter. The risks and high cost of TPN, however, make tube feeding the

usually highly effective, potential complications, including the risk of serious infection, are numerous and vary according to the feeding method chosen.[14]

The issue of withdrawing artificial nutrition and hydration arises most frequently for patients who have permanently lost consciousness. It is also considered for some patients who are irreversibly ill and do not tolerate the procedure well.[15] If artificial nutrition and hydration as well as other nursing and medical care are provided to patients who have permanently lost consciousness, their vital bodily functions may be maintained for many years.[16] Karen Ann Quinlan, for example, lived for 10 years following removal of the artificial respirator that assisted her breathing. When artificial nutrition and hydration are withdrawn, patients usually die within a period of time ranging from two to ten days.[17]

Existing medical opinion suggests that patients who have permanently lost consciousness do not experience pain or discomfort

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treatment of choice for most patients who can process food in some portion of their gastrointestinal tract. See C. H. Bastian and R. H. Driscoll, "Enteral Tube Feeding at Home," in *Clinical Nutrition*, vol. 1, *Enteral and Tube Feeding*, ed. J. L. Rombeau and D. M. Caldwell (Philadelphia: W. B. Saunders Co., 1984), 494-512; S. A. Chrysomilides and M. V. Kaminiski, "Home Enteral and Parenteral Nutritional Support: A Comparison," *American Journal of Clinical Nutrition* 34 (1981): 2271-75.

[14]Tube feeding, especially among the elderly, can be continued for long periods but is associated with a high frequency of complications. For a detailed discussion of the potential complications and side effects associated with different methods of providing artificial nutrition and hydration, see M. Bernard and L. Forman, "Complications and Their Prevention," in *Clinical Nutrition*, vol. 1, 542-69; Office of Technology Assessment, 280-86; J. O. Ciocon et al., "Tube Feeding in Elderly Patients," *Archives of Internal Medicine* 148 (1988): 429-43.

[15]J. Lynn and J. F. Childress, "Must Patients Always Be Given Food and Water?" *Hastings Center Report* 13, no. 4 (1983): 17-21; P. Schmitz and M. O'Brien, "Observations on Nutrition and Hydration in Dying Cancer Patients," in *By No Extraordinary Means: The Choice to Forgo Life-Sustaining Food and Water*, ed. J. Lynn (Bloomington: Indiana University Press, 1986), 29-38; H. Brody and M. B. Noel, "Dietitians' Role in Decisions to Withhold Nutrition and Hydration," *Journal of the American Dietetic Association* 91 (1991): 580-85.

[16]In one recorded case, the patient survived in a permanently unconscious state for 37 years; in another, for 18 years. President's Commission, 181-82.

[17]Conversation with Fred Plum, M.D., Chairman, Dept. of Neurology, Cornell-New York Hospital Medical Center, April 15, 1987.

following the withdrawal of artificial nutrition and hydration.[18] For some permanently unconscious patients, however, the provision of artificial nutrition and hydration leads to numerous complications. Less information is available about the experience of greatly debilitated patients or those suffering from severe illness who are in the end stage of the dying process. Available information, however, suggests that these patients appear to experience little, if any, discomfort when routine comfort measures are provided.[19] Finally, in some cases, the provision of artificial nutrition and hydration very close to the time of death may increase the patient's discomfort. Some patients are more likely to experience pulmonary edema, nausea, and mental confusion when artificial nutrition and hydration are maintained in the last stages of the dying process.[20]

Ethical Considerations

Discussions about artificial nutrition and hydration often center on whether these measures should be distinguished from other treatment on medical or clinical grounds. Some insist that artificial nutrition and hydration constitute "basic care" rather than medical treatment. They describe nutrition and hydration, whether provided directly or by artificial means, as universal needs, not just as needs of the sick. Artificial nutrition and hydration are not administered in order to cure or control disease, but rather to sustain the patient's life. While some patients require assistance to receive nutrition and hydration, dependence

[18]Patients who are permanently unconscious have lost all thought, sensation, and awareness. This includes patients in a persistent vegetative state, patients who are totally unresponsive following brain injury or hypoxia, and patients at the end stage of certain degenerative neurological conditions. See President's Commission, 177. See also Brief for Amicus Curiae American Academy of Neurology, 10-29; *Brophy v. New England Sinai Hospital*, 398 Mass. 417, 497 N.E.2d 626(1986).

[19]Schmitz and O'Brien, 29-38; P. Schmitz, "The Process of Dying with and without Feeding and Fluids by Tube," *Law, Medicine and Health Care* 19 (1991): 23-26; J. A. Billings, "Comfort Measures for the Terminally Ill: Is Dehydration Painful?" *Journal of the American Geriatrics Society* 33 (1985): 808-10. Billings reports that the only troubling and commonly encountered symptoms that can be attributed to dehydration in terminally ill patients are thirst and dry mouth. He suggests that these symptoms can be relieved by small amounts of oral fluid or by keeping the patient's mouth moist with water, ice chips, or artificial saliva. A study by Ciocon et al. that examined the complications of tube feeding, indicated that patients frequently experienced problems of agitation, extubation, and aspiration pneumonia. Weight loss was common among patients who had been tube fed for more than six months. See also "Terminal Dehydration," *Lancet* no. 8476 (1986): 306; D. J. Oliver, "Terminal Dehydration," (letter) *Lancet* no. 8403 (1984): 631.

[20]Lynn and Childress, 19.

on others for the provision of nutrition is an accepted part of the human condition.[21]

Some commentators also emphasize the symbolic and affective meanings associated with providing nutrition and hydration and the effects upon society of allowing persons to die by starvation or dehydration.[22] A practice of forgoing artificial nutrition and hydration could undermine the self-image of health care professionals as well as the trust of patients.[23]

Perhaps the strongest concerns about forgoing artificial nutrition and hydration are that such procedures intentionally cause death, at least in some cases. Commentators point out that while death does not always occur after the withdrawal of other treatments such as artificial respiration, death is inevitable if nutrition and hydration are withheld. Lack of nutrition and hydration become the cause of death.[24]

Some commentators argue that the certainty of death following the forgoing of nutrition makes the intention of death inescapable, especially for patients who are not terminally ill. Some assert that artificial nutrition and hydration should be withheld or withdrawn only when the measures are absolutely futile or when the aim is to avoid burdens caused by the treatment itself. It is wrong, though, to withhold nutrition and hydration from patients simply because others regard their lives as

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[21]G. Meilaender, "On Removing Food and Water: Against the Stream," *Hastings Center Report* 14, no. 6 (1984), 11-13; P. Derr, "Why Food and Fluids Can Never Be Denied," *Hastings Center Report* 16, no. 1 (1986), 28-30; W. B. Smith "Is a Decision to Forgo Tube Feeding for Another a Decision to Kill?" *Issues in Law and Medicine* 6 (1991): 388-90.

[22]As stated by A. J. Weisbard and M. Siegler: "Although the techniques for providing such supports may be medical, and thus logically associated with other medical interventions, the underlying obligations of providing food and drink to those who hunger or thirst transcend the medical context, summoning up deep human responses of caring, of nurturing, of human connectedness, and of human community." "On Killing Patients with Kindness: An Appeal for Caution," in *By No Extraordinary Means*, 112.

[23]D. Callahan, "On Feeding the Dying," *Hastings Center Report* 13, no. 5 (1983): 22; D. Callahan, "Feeding the Dying Elderly," *Generations* 10, no. 2 (1985): 15-17; Derr, 29-30; Smith, 391.

[24]"Deliberately to deny food and water to such innocent human beings in order to bring about their death is homicide, for it is the adoption by choice of a proposal to kill them by starvation and dehydration." May et al., 207. See also Weisbard and Siegler, 111-112; Derr, 28-29; Meilaender, 12; B. A. Brody, "Ethical Questions Raised by the Persistent Vegetative Patient," *Hastings Center Report* 18, no. 1 (1988): 35.

valueless.[25] Withholding nutrition on that basis is regarded as the intentional achievement of death or deliberate killing. Some commentators warn of the dangers of abuse, and the consequences to society, of a widespread practice of decisions to forgo artificial nutrition and hydration.[26]

In contrast, others argue that artificial nutrition and hydration should not be distinguished from other medical treatments. This position is reflected in statements by the American Medical Association's Council on Ethical and Judicial Affairs and the New York Academy of Medicine, recent court decisions, and other public commentary.[27] Advocates of this position maintain that, like other treatments and in contrast to ordinary feeding, artificial nutrition and hydration are not universal needs for all persons, but interventions in response to an underlying disease or condition. While nutrition and hydration provided without medical intervention are basic needs, air is an equally basic need; providing air by artificial respiration is properly understood as medical treatment. Artificial nutrition and hydration require the assistance of medical personnel, entail risks, discomfort and complications for the patient, and in some cases require surgery.[28]

Responding to concerns about the symbolic significance of nutrition and hydration, commentators emphasize the differences between medical nutrition and hydration on the one hand and food and water on the other. Starvation is repugnant because it causes suffering, but when artificial nutrition and hydration are appropriately forgone, the

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[25]May et al., 206.

[26]As stated by Daniel Callahan: "A denial of nutrition and hydration may in the long run become the only effective way to make certain that a large number of biologically tenacious patients actually die. Given the increasingly large pool of superannuated, chronically ill, physically marginal elderly, it could well become the nontreatment of choice." Callahan, "On Feeding," 22. See also Meilaender, 12; May et. al., 207; Derr, 29-30; R. M. Veatch, *Death, Dying and the Biological Revolution*, 2d ed. (New Haven: Yale University Press, 1989): 84-85.

[27]American Medical Association, Council on Ethical and Judicial Affairs, "Withholding or Withdrawing Life Prolonging Medical Treatment," March 14, 1986; "Statement of the Joint Subcommittee on the Care of the Terminally Ill of the Committee on Public Health and the Committee on Medicine in Society," approved by the Council of the New York Academy of Medicine, April 22, 1987. See also, Weir, 409-10; Lynn and Childress, 17-21; G. J. Annas, "Do Feeding Tubes Have More Rights than Patients?" *Hastings Center Report* 16, no. 1 (1986): 26-28; S. Wanzer et al., "The Physician's Responsibility Toward Hopelessly Ill Patients," *New England Journal of Medicine* 310 (1984): 955-59.

[28]Annas, 28-30; Lynn and Childress, 17-19; Weir, 409-13.

patient's suffering diminishes. Some commentators argue that the interests of particular patients cannot be sacrificed in order to maintain a general symbol. It is further claimed that people can clearly differentiate the withholding and withdrawal of artificial nutrition and hydration from allowing the poor to starve to death.[29]

Commentators assert that forgoing artificial nutrition and hydration remains essentially similar to forgoing other types of life-sustaining treatment and differs crucially from intentional and active killing. While death is certain in some cases following the withdrawal of artificial nutrition and hydration, death may also be certain when other life-sustaining treatments are withdrawn. From this perspective, the abatement of artificial nutrition is no more the cause of death than the discontinuance of artificial respiration or antibiotics. In all of these cases, the cause of death remains the disease or injury that brought about the need for life-sustaining treatment.[30]

Additionally, forgoing artificial nutrition and hydration remains the refusal of treatment. Among those who reject the distinction between artificial nutrition and hydration and other treatment, some advocate that, like other treatment, artificial nutrition and hydration cannot and should not be imposed over the wishes of a competent patient.[31] Others focus on the standard of proportionality and maintain that a competent patient may appropriately refuse artificial nutrition and hydration when the burden of treatment outweighs the benefits it offers the patient.[32] Under either analysis, the symbolic importance of providing

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[29]Lynn and Childress, 20-21; J. F. Childress, "When Is It Morally Justifiable to Discontinue Medical Nutrition and Hydration," in *By No Extraordinary Means*, 74-76; Veatch, 84. Some commentators also suggest that words like "kill" or "starve" obscure rather than advance meaningful discussion. As stated by Dennis Brodeur, "'Starvation' and 'murder' are morally charged words that conjure up deliberate, and by definition, immoral actions. These words do not suggest moral dialogue. Rather they present moral conclusions. When discussing respirators, for example, the moral question is not asked: 'Can we turn off a ventilator and suffocate a person to death?'" Brodeur, "Is a Decision to Forgo Tube Feeding a Decision to Kill?" *Issues in Law and Medicine* 6 (1991): 397.

[30]Lynn and Childress, 20; Weir, 413-14.

[31]Annas, 27; Childress; D. Brock and J. Lynn, "The Competent Patient Who Decides Not to Take Nutrition and Hydration," in *By No Extraordinary Means*, 202-15.

[32]See G. Kelly, "The Duty of Using Artificial Means of Preserving Life," *Theological Studies* 11 (1950): 203-20; J. J. Walter, "Food and Water: An Ethical Burden," *Commonweal* 113 (1986): 616-19. This approach has been espoused by some within the Roman Catholic tradition, although debate continues about the

nutrition and hydration does not outweigh other considerations: either the patient's right to self-determination or, under the proportionality standard, the patient's interest in the appropriate course of medical treatment.[33]

Proposed Policy for Surrogate Decisions

Members of the Task Force hold diverse views on many issues posed by decisions to forgo artificial nutrition and hydration. They concur,

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implications of Catholic teaching for decisions about artificial nutrition and hydration. In a statement of guidelines for legislation on life-sustaining treatment, the United States Bishops' Committee on Pro-Life activities urged that laws about life-sustaining treatment should establish a strong presumption in favor of providing artificial nutrition and hydration, but it recognized that "Laws dealing with medical treatment may have to take account of exceptional circumstances, when even means for providing nourishment may become too ineffective or burdensome to be obligatory." "The Rights of the Terminally Ill," *Origins* 16 (1986): 222-24. Commentators within the Roman Catholic tradition generally agree with this statement and the principles articulated in the Vatican's 1980 "Declaration on Euthanasia," but they vary in their interpretation of these guidelines.

Msgr. William B. Smith, for example, argues that in most cases, artificial nutrition and hydration represent basic care that should be provided to conserve and sustain life. He further notes the symbolic significance of providing life-sustaining measures. "Supporting life . . . does benefit that person even if only minimally because it expresses love of that person (neighbor). One benefit is care of the comatose rather than their abandonment. And this maintains human solidarity which affirms their dignity as persons and our dignity as personal caregivers." Smith, 391, 385-94.

Within the Catholic tradition, others argue that commitment to the intrinsic value of human life is compatible with the forgoing of "disproportionately burdensome" treatment in a broader range of cases. A joint statement of 16 of the 18 Texas Catholic bishops and the Texas Conference of Catholic Health Facilities states that permanently unconscious patients, while human persons with inherent dignity, suffer from a lethal pathology. "The morally appropriate forgoing or withdrawing of artificial nutrition and hydration from a permanently unconscious person is not abandoning that person. Rather, it is accepting the fact that the person has come to the end of his or her pilgrimage and should not be impeded from taking the final step. The forgoing or withdrawing of artificial nutrition and hydration should only occur after there has been sufficient deliberation based upon the best medical and personal information available." "On Withdrawing Artificial Nutrition and Hydration," *Origins* 20 (1990): 53-55.

See also Joseph Cardinal Bernadin, "Context for and Moral Principles Guiding Catholic Conference of Illinois' Position on Senate Bill 2213," address to a meeting of the Pro-Life Department, Catholic Conference of Illinois, September 11, 1990; Brodeur, 395-406; Kelly, 203-20; and the discussion in New York State Task Force on Life and the Law, *Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent* (New York: New York State Task Force on Life and the Law, 1987), 43-44.

[33]Brock and Lynn, 202-15; Annas, 26-28.

however, on two basic recommendations for public policy. First, decisions about artificial nutrition and hydration are highly sensitive, requiring caution and careful attention to the personal and medical circumstances of each particular patient. Second, legislative provisions for these measures that differ from the policies proposed for other decisions about life-sustaining treatment are not needed to address these concerns.

While court cases have found that no legal distinction can be drawn between artificial nutrition and hydration and other life-sustaining treatments, a diversity of opinion prevails about the measures. Some individuals in our society distinguish artificial nutrition and hydration on personal, religious, and moral grounds and would want the measures provided, unless they are futile or themselves cause physical harm. Others firmly reject that distinction and would frame their treatment wishes accordingly.

Many people, perhaps most, do not think about their wishes in relation to artificial nutrition and hydration or other particular treatments; they concentrate on the outcomes of treatment. For example, many individuals may not even know that artificial nutrition and hydration, along with treatments such as antibiotics, are used to sustain the lives of patients who are permanently unconscious, although they may have strongly held views about whether they would want to live under such circumstances.[34]

Policies for surrogate decisions must accommodate these diverse views and understandings of artificial nutrition and hydration. Our social and religious pluralism does not lend itself to a single resolution of this personal question. Instead, those who act as surrogates should devote special efforts to ascertaining the patient's own preferences and values.

Public policies should also take into account the fact that individuals dependent on artificial nutrition and hydration are often frail and

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[34]The case of Helga Wanglie, for instance, turned on her general desire to have her life sustained as long as possible, not on her specific wishes or beliefs about artificial nutrition and hydration. See discussion above, chapter 14, 195. Likewise, in the case of Nancy Cruzan, her parents did not assert that Nancy had particular views about artificial nutrition and hydration but that she would not have wanted to survive in a state of unconsciousness. *Cruzan v. Director, Mo. Dep't of Health*, 110 S. Ct. 2841 (1990). Indeed, the fact that most people do not focus on or talk specifically about artificial nutrition and hydration or other treatments highlights the failing of the clear and convincing evidence standard; people generally think about their future treatment in terms of outcomes, not interventions.

vulnerable. They have lost many of the qualities and abilities commonly prized in our society, such as their self-reliance and the ability to communicate. They depend on others, often strangers or heavily burdened family members, for care that is demanding and expensive. Decisions to forgo artificial nutrition and hydration for these individuals would potentially affect thousands of nursing home residents.

The Task Force's proposal includes substantive and procedural standards to protect the interests of patients requiring surrogate decisions, especially for decisions about life-sustaining treatment. While policies are needed to prevent inappropriate decisions to forgo artificial nutrition and hydration, decisions to forgo other life-sustaining treatments, such as antibiotics, pose similar risks and can also be wrongful. The Task Force believes that the safeguards it has proposed for decisions about other life-sustaining treatments are appropriate and sufficient for decisions about artificial nutrition and hydration.

The Task Force did not distinguish artificial nutrition and hydration from other life-sustaining measures in its proposed legislation for the health care proxy law, although it did acknowledge special social concerns raised by artificial nutrition and hydration in its accompanying report.[35] Ultimately, the legislature decided that decisions to forgo these measures should meet an additional requirement, beyond those proposed for treatment decisions generally. It chose to require reasonable knowledge by the agent of the patient's wishes to forgo these measures.[36]

Under the Task Force's proposal, the authority conferred upon a surrogate would be far more constrained than the authority granted to health care agents. Medical circumstances define the limits of the surrogate's authority to forgo life-sustaining treatment. Only if the patient is terminally ill or permanently unconscious and treatment would be an excessive burden can the surrogate decide, in conjunction with the physician, to forgo artificial nutrition and hydration. In any other medical circumstance, decisions to forgo these measures or other life-sustaining treatment, would require approval by a bioethics review committee, or by a court. Records of committee decisions would then be available for review. These requirements assure heightened scrutiny of the decisions likely to pose the greatest danger of abuse.

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[35]Task Force, 36-40.

[36]N.Y. Pub. Health Law § 2982(2) (McKinney Supp. 1992).

Furthermore, decisions by a surrogate may be more readily challenged than those by a health care agent. In general, the agent has the same authority to make decisions as the patient would have had if capable. While agents must act in good faith and decide in a manner consistent with the patient's wishes and interests, their decisions can only be challenged in court. In contrast, health care professionals caring for the patient, as well as family members and others on the list of potential surrogates, can challenge decisions made by surrogates that they believe violate the proposed decision-making standards. Conflicts that cannot otherwise be resolved must be considered by a bioethics review committee.[37]

In the context of the proxy law, the requirement for reasonable knowledge of the patient's wishes regarding artificial nutrition and hydration represents a more appropriate safeguard than a similar requirement for surrogate decisions. Adults who create a proxy are informed that they should communicate their wishes about artificial nutrition and hydration to the agent; the proxy form and instructions prepared by the New York State Department of Health specify this information.[38] Patients who have not appointed an agent, however, are not likely to know or to have ever been told about the importance of articulating their preferences concerning these measures.

For patients whose wishes are not known, and for children and adults who never had the ability to formulate and express their own values and preferences, the health care proxy law would not provide the basis to forgo artificial nutrition and hydration under any circumstances. Almost all commentators agree that, in at least some cases, decisions to forgo these measures are mandated by consideration of the patient's best interests. For example, most would agree that artificial nutrition and hydration should be withheld or withdrawn when the measures cause additional suffering to a dying patient by increasing edema, nausea, and abdominal pain.[39]

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[37] See chapter 9.

[38] See appendix D.

[39] See May et al., 208-9; Schmitz and O'Brien, 29-30. Joseph Cardinal Bernadin writes: "It does not seem justified to argue, as some have, that unless a person has given explicit delegation regarding nutrition and hydration, no other party is able to make decisions in this regard." He suggests that surrogate decision makers should be authorized to decide to forgo artificial nutrition and hydration based on a calculus of benefits and burdens for the particular patient, with safeguards to prevent abuse. "Context," p. 19 of manuscript.

Ideally, adults will sign a health care proxy or provide guidance about their wishes. Our laws must also recognize decisions to withhold or withdraw artificial nutrition and hydration for those patients whose wishes cannot be identified or who never were able to formulate their own values and preferences.

D. Euthanasia

In its report recommending the health care proxy law, the Task Force urged that existing New York laws prohibiting the taking of human life should not be modified and that euthanasia, understood as direct measures intended to cause a patient's death, should remain illegal. The Task Force recognized that euthanasia would provide a less painful, prolonged dying process for certain patients, but it concluded that compassion for these patients could not justify a change in public policy that would allow one human being intentionally to kill another.[41]

Since the Task Force issued that broad statement, national events have focused debate on the narrower question of physician-assisted suicide. In 1990 and 1991, Dr. Jack Kevorkian helped patients to die using suicide devices that he invented.[42] In the March 7, 1991, issue of the *New England Journal of Medicine,* Dr. Timothy Quill described the case of Diane, a patient with leukemia who committed suicide using barbiturates prescribed by Dr. Quill. In August of that year, the New York State Board of Professional Medical Conduct decided not to refer Dr. Quill's case for misconduct charges. It distinguished Quill's actions from those of Kevorkian, stating that it "does not condone so-called assisted suicide, which remains a crime under New York law." The Board called upon the Task Force to examine the social and ethical issues posed when physicians assist a competent adult to commit

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[41]The Task Force's full statement is found in *Life-Sustaining Treatment*, 40-42. As proposed by the Task Force, the health care proxy law granted agents the same, but no greater, legal authority than that extended to competent adults, thereby incorporating existing legal prohibitions against assisted suicide and homicide into the proxy law. As enacted, the proxy law expressly states that it is not intended to permit or promote suicide, assisted suicide, or euthanasia. N.Y. Pub. Health Law § 2989(3) (McKinney Supp. 1992).

[42]L. Belkin, "Doctor Tells of First Death Using His Suicide Device," *New York Times*, June 6, 1990, sec. A, p. 1; M. Williams, "Dr. Kevorkian's Future Without a License Is Uncertain," *American Medical News*, December 9, 1991, 9. In 1991, Washington State voters considered and defeated a referendum initiative that would have allowed physicians to provide "aid-in-dying" when requested by terminally ill patients. This provision would have legalized physician-assisted suicide as well as direct active euthanasia.

suicide, suggesting that both patients and physicians need guidance.[42] The Task Force has agreed to assume this charge and will address these issues in a future report.

The Task Force's recommendations in this report do not encompass decisions by adults with decision-making capacity, but decisions by others on behalf of those unable to decide. Few commentators have proposed that active measures such as a lethal injection should be used to end the life of a person without the capacity to make an informed request to have his or her life ended, although some have argued that honoring the requests of competent adults will extend inevitably to substitute consent for the incapacitated.

In proposing public policy for surrogate decisions, the Task Force affirms the position expressed in the health care proxy report; the Task Force does not recommend any change in current New York State law prohibiting active measures to cause a patient's death. It again distinguishes active measures such as lethal injection from legitimate, reasoned decisions to withdraw or withhold treatment made in accord with appropriate standards.

The Task Force's proposal addresses the need for policies to provide sound, responsible decisions for patients who cannot decide for themselves. It is not intended either as a step on the road to assisted suicide or as a vehicle to extend the authority of family members beyond the traditional boundaries established by consent to provide treatment or not to treat. The Task Force proposes that the legislation on surrogate decisions should, like the health care proxy law, state that the law is not intended to permit or promote euthanasia, assisted suicide, or suicide.

Recommendation

The Task Force believes that withholding and withdrawing treatment are morally equivalent and should not be distinguished. The proposed legislation would grant surrogates the authority to consent equally to the withholding or withdrawal of treatment, under the same standards. The Task Force urges health care facilities to review their policies and practices about life-sustaining treatment and to abandon distinctions solely based on the difference of whether or not treatment has already been started.

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[42]New York State, Board for Professional Medical Conduct, "Dr. Timothy Quill," August 16, 1991; T. E. Quill, "Death with Dignity: A Case of Individualized Decision-Making," *New England Journal of Medicine* 324 (1991): 691-94.

Health care professionals have a duty to offer aggressive pain relief to patients when necessary, in accord with sound medical judgment and the most advanced approaches available. The provision of pain medication is ethically acceptable, even when such treatment may hasten the patient's death, if the medication is intended to alleviate pain, not to cause death, and is provided in such a way that the benefits of the treatment outweigh the risks. The Task Force urges health care professionals and facilities to accord pain control a higher priority in medical practice and education.

Decisions about artificial nutrition and hydration are highly sensitive, requiring caution and careful attention to the personal and medical circumstances of each particular patient. Surrogates should make special efforts to identify patients' wishes about artificial nutrition and hydration, but legislative provisions distinct from the policies proposed for other life-sustaining treatments are not necessary. The safeguards proposed for decisions about other life-sustaining treatments are appropriate and sufficient for decisions about artificial nutrition and hydration.

The Task Force's proposal responds to the need for policies that provide a sound, responsible decision-making process for patients who lack capacity. The proposed legislation is not intended to permit or promote suicide, assisted suicide, or euthanasia. Nor does the Task Force recommend any change in current New York State law that prohibits active measures to cause a patient's death.

See Appendix A, proposed legislation, Section 15(3).

16

Merging the DNR Law with Policies for Surrogate Decisions

The Task Force first approached the issue of surrogate decision making in the context of decisions about cardiopulmonary resuscitation (CPR) and the issuance of DNR orders. Based on recommendations by the Task Force, New York's DNR law was enacted in 1987 and amended in 1991.[1]

The Task Force addressed decisions about CPR apart from other treatment decisions because problems and confusion about the legality of DNR orders appeared to be widespread. Equally significant, a broader societal consensus existed about surrogate decisions for CPR than for other life-sustaining measures.[2]

The DNR law has achieved important goals. It granted surrogates clear authority to decide about CPR for incapacitated patients, removed the secrecy that had surrounded the decision about CPR in many hospitals and nursing homes, and reinforced the right of adult patients with decision-making capacity to decide for themselves. One ancillary but significant benefit of the law is that it has served as a testing ground for policies on surrogate decisions. The proposed surrogate decision-making legislation encompasses the basic principles and procedures established in the DNR law, with some modifications to accommodate the broad range of decisions covered and to reflect experience and insight gained from the DNR law.

The Task Force recommends that the DNR law should be integrated with the proposed legislation, with specific policies for DNR orders retained where appropriate. For the most part, separate policies for CPR and other treatments are not necessary. In addition, the existence

[1]N.Y. Pub. Health Law Article 29-B (McKinney Supp. 1992).

[2]New York State Task Force on Life and the Law, *Do Not Resuscitate Orders*, 2d ed. (New York: New York State Task Force on Life and the Law, 1988), 6-8; T. E. Miller, "Do-Not-Resucitate Orders: Public Policy and Patient Autonomy," *Law, Medicine and Health Care* 17 (1989): 245-54.

of two laws and sets of policies would be unworkable for health care professionals.

In the clinical setting, decisions about CPR are best made in the context of an overall plan about the course of the patient's care. The patient's wishes and needs for CPR should be explored in relation to other treatments. Combining CPR decisions with discussions about other treatment is also likely to minimize misunderstandings and the tendency to equate a DNR order with an order "not to treat."

Building on the DNR Law

Many of the basic policies in the surrogate proposal are drawn from New York's DNR law: the list of surrogate decision makers, reliance on the patient's wishes and interests to guide surrogate decisions, and the establishment of a facility-based determination of patient incapacity, subject to judicial review when necessary. The standard for incapacity, like the standard in the health care proxy law, potentially addresses the capacity for all treatment decisions, not just decisions about CPR. A definition of "best interests" has been added to provide further guidance for surrogates and health care professionals.

The conditions under which surrogates may decline life-sustaining treatment are more rigorous under this proposal than under the DNR law, to reflect and address the broad scope of treatments covered by the proposal. In addition to the mediation process established under the DNR law to resolve conflict, this proposal recommends a more formal committee structure authorized to review decisions under specified circumstances.

The Task Force proposes that certain policies in the DNR law should be retained for decisions about CPR, but should not be extended to other treatment decisions. Specifically, the Task Force recommends that the therapeutic exception should apply to decisions for CPR but not to decisions about other life-sustaining treatment. Under the DNR law, physicians may seek consent to a DNR order from a surrogate even if the patient has the capacity to decide, if two physicians determine that discussing CPR with the patient would cause therapeutic harm, defined in the law as "severe and immediate" injury.[3] Inclusion of the exception in the DNR law was the subject of considerable debate within the Task Force and by the public at large.[4]

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[3]N.Y. Pub. Health Law § 2964(3) (McKinney Supp. 1992).

[4]Task Force, 26-27, 66-68. See also C. Rogers, Testimony on behalf of Medical

Since the law has become effective, some physicians have urged that it should contain a broad therapeutic exception because the discussion of CPR can be traumatic for some patients.[5] The Task Force rejected this proposal in considering amendments to the DNR law and continues to believe that broadening the exception is unwise. Studies have consistently shown that many patients are eager to discuss CPR, while many physicians often opt not to do so.[6] Given the reluctance of physicians to discuss CPR with their patients, an expansive therapeutic exception would seriously diminish the right and opportunity for patients to participate in decisions about CPR.

Although narrowly drawn, the therapeutic exception in the DNR law should not apply to other life-sustaining treatments. Consent to a DNR order entails an advance decision that will be relevant only if an intervening event arises — the patient suffers cardiopulmonary arrest. In contrast, for other life-sustaining treatments, the withholding of treatment is contemporaneous, not future oriented, and the harm of withdrawing or withholding treatment is immediate. The Task Force believes that the potential harm caused by excluding the patient from the decision-making process would in virtually all cases outweigh the potential harm of a discussion.

In discussing the issue of medical futility in this report, the Task Force also underscored the importance of the patient-physician dialogue. Guidelines on the DNR law from the Health Department clarify that physicians are not obligated to provide medically futile CPR, but they must inform patients, the health care agent, or a surrogate before entering an order on grounds of futility.[7] The Task Force recommends that this requirement of informing patients, agents, or

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Society of New York State, New York State, Assembly and Senate Health Committees, *Public Hearing on Legislation Regarding the Issuance of Do Not Resusciate Orders*, New York, February 12, 1987, 227; J. Linville, Testimony on behalf of Health and Hospitals Corporation, *Public Hearings*, 176.

[5]F. Rosner, "Must We Always Offer the Option of CPR: The Law in New York," *Journal of the American Medical Association* 260: (1988): 3129; P. Swender, "Reflections on the New York DNR Law," *New York State Journal of Medicine* 89 (1989): 57-58.

[6]See chapter 1, 8-9, for discussion of studies.

[7]New York State Department of Health, Medical Society of the State of New York, and Hospital Association of New York State, *Do Not Resuscitate Orders: Questions and Answers for Health Care Professionals* (Albany: New York State Department of Health, 1990), 20.

surrogates should remain explicit for DNR orders, either in legislation, regulation, or guidance from the department.

Based on recommendations by the Task Force and the Department of Health, the legislature amended the DNR law in 1991 to establish policies for honoring DNR orders for patients cared for at home or in other community settings.[8] The law requires emergency medical services (EMS) personnel to honor DNR orders issued by physicians based on consent by the patient, an appointed health care agent, or a surrogate identified under the provisions of the DNR law. The policies were devised in response to concerns expressed by physicians, patient advocates, and EMS representatives that existing laws and practices did not adequately protect decisions to withhold CPR for terminally ill patients cared for in the community.

The problems posed by other treatment decisions in outpatient settings appear less urgent, in part because CPR is one of the more common, and most invasive, life-saving treatments provided by EMS. The Task Force proposes that policies for DNR orders in community settings should be retained, but should not encompass other treatments. Reliance on advance decisions in an emergency, and the process of surrogate decision making, are more complex and more varied for patients in the community than in a health care facility. The Task Force recommends that New York State, as it did with DNR orders, should implement surrogate decision-making policies in health care facilities first and then turn to identified problems for patients at home and in other community settings.

New York's DNR law also covers decisions in certain mental health facilities. As discussed in Chapter 11, the Task Force recognizes the special issues raised by surrogate decisions in these facilities and the considerable body of statutes and regulations that currently governs many surrogate decisions for residents of mental health facilities. It proposes that the DNR law should continue to apply to these facilities, until such time as comprehensive surrogate policies for mental health facilities are enacted.

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[8] N.Y. Pub. Health Law § 2977 (McKinney Supp. 1992). These policies cover CPR decisions for patients in a wide variety of settings including, for example, individuals living at home, with or without home care support, those living in a group home, and prisoners.

Recommendation

The DNR law should be merged with broader surrogate decision-making legislation, with specific policies retained for DNR orders where appropriate. Specifically, the therapeutic exception to consent to forgo treatment, the duty to inform patients or surrogates of a DNR order entered on grounds of futility, and policies for patients in community settings should be retained for DNR orders, but should not be extended to other treatment decisions.

See Appendix B, Policies for DNR Orders: Existing Law.

17

Promoting Surrogate Decisions

While some aspects of the law governing life-sustaining treatment remain unclear or undeveloped in New York State, judicial decisions, statutes, and regulations have accorded patients, and those authorized to decide for them, certain basic rights.[1] The impact of these rights is undermined when health care providers misunderstand or misconstrue the laws governing treatment decisions. In addition to complying with ethical and professional standards for good medical practice, providers owe a duty to patients and surrogates to understand and abide by the law.

Bridging the Gap Between Theory and Practice

Educating Health Care Professionals

Confusion about the law on treatment decisions appears to be widespread among health care professionals in New York State. A 1990 study assessing New York's law governing DNR orders revealed that two years after the law's passage, a significant percentage of physicians misunderstood some of the law's basic requirements.[2] Important common law principles are also not well understood. For example, many health care professionals believe that New York law establishes a right to withhold life-sustaining treatment, such as an artificial respirator, but not the right to have treatment stopped once it has begun, a right clearly recognized by judicial decisions.[3]

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[1]See discussion, chapter 2.

[2]R. Baker et al., "Legal and Professional Enforcement of Bioethical Reform: A Comparative Study of the 1988 NY and JCAHO DNR Reforms," in *Legislating Medical Ethics: A Study of New York's DNR Law*, ed. R. Baker and M. Strosberg, Philosophy and Medicine Series (Dordrecht: Kluwer Academic Publishers, forthcoming).

[3]See discussion, chapter 2.

A broad educational effort is essential to clarify misconceptions about the law on treatment decisions and the legal obligations and protections afforded health care professionals. The Task Force urges health care lawyers and administrators to create a process by which medical professionals can be educated and advised on a regular basis about the law on decisions about life-sustaining treatment and health care more generally. In addition, associations representing health care facilities and professionals, as well as patient advocacy groups, should continue their support for this educational effort.

Health care organizations have already undertaken cooperative educational efforts, as evidenced by recent publications describing New York's health care proxy and DNR laws.[4] New federal and state mandates have also prompted public and professional education about the rights of patients and families to make health care decisions.[5] Future educational initiatives should build on past efforts and seek new avenues to inform physicians about the laws that are critical to them and to their patients.[6]

Available Remedies

Health care professionals and facilities are understandably cautious in framing policies and responding to individual decisions about life-sustaining treatment. In addition, some legal doctrines such as the requirement of clear and convincing evidence of a patient's wishes call

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[4]For example, the 1991 guidebook on the health care proxy law was prepared by the New York State Department of Health and the Task Force, in consultation with the Association of the Bar of the City of New York, the Greater New York Hospital Association, the Hospital Association of New York State, the Medical Society of the State of New York, the New York Academy of Medicine, and the New York State Nurses Association.

[5]See, e.g., the Patient Self-Determination Act of 1990, §§ 4206 and 4751 of the Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, codified at 42 U.S.C. §§ 1395cc(f), 1396a(a)(57), 1396a(a)(58), and 1396a(w)(1), requiring Medicare and Medicaid providers to educate patients and their families, staff, and the community about advance directives; and N.Y. Pub. Health Law § 2992 (McKinney Supp. 1992), requiring hospitals and nursing homes to educate patients and their families and staff about New York's health care proxy law.

[6]Professional organizations such as the Hospital Association of New York State hold regular educational conferences for their members. In general, these conferences are well attended by social workers, nurses, and administrators, but rarely attended by physicians. While studies of the DNR law suggest that other hospital staff, especially nurses, may prod physicians to comply with the law, including the duty to honor patients' decisions about treatment, lack of understanding or ignorance of the law by physicians imposes obvious burdens on patients.

for hard judgments. It appears, however, that some physicians and facilities do not struggle to apply the law in good faith, but allow concerns about liability to preclude a reasonable or informed legal judgment. This undue caution penalizes patients and those deciding on their behalf.

For some physicians, risk managers, and hospital lawyers, the assessment of potential liability for honoring decisions to forgo life-sustaining treatment is one-sided; not only is the risk of liability for stopping treatment exaggerated, but the logical corollary in the equation, the risk of providing treatment without consent or in the face of an explicit refusal, appears to carry little, if any, weight.[7]

If treatment is provided without consent or following an explicit refusal, patients or those authorized to decide on their behalf may seek judicial redress for medical battery or for the violation of informed consent requirements or the constitutionally-based right to refuse medical treatment. Health care providers found liable may lose the right to collect a fee for the medical services rendered without consent,[8]

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[7]See R. Weir and L. Gostin, "Decisions to Abate Life-Sustaining Treatment for Nonautonomous Patients: Ethical Standards and Legal Liability for Physicians after Cruzan," *Journal of the American Medical Association* 264 (1991): 1846, 1847, 1852, arguing (1852) that the perception of risk felt by providers for decisions to forgo life-sustaining treatment is ungrounded in existing judicial precedents. See also, e.g., M. Kapp and B. Lo, "Legal Perceptions and Medical Decision Making," *Millbank Quarterly* 64 (1986): 163, 179. The authors observe, "[M]any attorneys and risk managers who advise medical professionals and institutions in life-sustaining situations err greatly on the side of legal conservatism, to the point where their caution in seeking absolute legal immunity before any action is taken wastes time, energy, and emotion in a way that is a disservice to both the client and affected patients and families."

[8]Existing law establishes that competent patients have no obligation to pay for treatment provided over their express objection. See *Shapira v. United Medical Service, Inc.* 15 N.Y.2d 200, 257 N.Y.S.2d 150 (1965). This same principle applies to the refusal of treatment by a health care agent that meets the standards of the health care proxy law. See N.Y. Pub. Health Law §§ 2982(1) and 2987. In *Grace Plaza of Great Neck, Inc. v. Elbaum*, N.Y.L.J., Jan. 19, 1990, at 26 (Sup. Ct., Nassau Co.), the trial court ruled that a nursing home could not collect fees of over $100,000 after providing life-sustaining treatment to a permanently unconscious patient over the objections of her husband that providing treatment would violate her clearly expressed wish. The nursing home appealed the ruling, arguing, in part, that the legal remedy of nonpayment should not apply because of the uncertainty of existing law on decisions to forgo treatment for incapacitated patients.

may pay monetary damages,[9] or may be held responsible for attorneys' fees.[10] Under Section 2801-d of the Public Health Law, residents of nursing homes may collect statutory damages, as well as punitive damages and attorneys' fees, when appropriate, for violation of their rights.

Nonetheless, patients or their family members rarely sue to enforce the right to refuse treatment.[11] It is possible that they are unaware of their rights or are too exhausted or emotionally drained by the patient's illness to pursue judicial relief. Generally, patients and surrogates also have limited access to the financial resources required for legal redress. Thus far, refusal of treatment cases have not generated large monetary outcomes in the form of damages or attorneys' fees.[12] As a result, few lawyers may be willing to take similar cases on a contingency-fee basis. Persons of moderate or low income, who depend upon such arrangements to gain access to the courts, cannot seek judicial intervention unless they find an attorney willing to take their case on a *pro bono* or reduced-fee basis.

The Task Force believes that the unlawful refusal to honor a decision to forgo life-sustaining treatment is a serious harm. Whether brought as a battery action or as a violation of the constitutional right to refuse

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[9] In two reported cases concerning the right to refuse life-sustaining treatment, the courts approved monetary settlements: In re A.C., 573 A.2d 1235 (D.C. App. 1990) and *Leach v. Shapiro*, 13 Ohio App. 3d 393, 496 N.E.2d 1047 (Ct. App. 1984).

[10] In at least three cases to date the courts have awarded attorneys' fees to patients who sued to enforce their right to refuse life-sustaining treatment. *Bouvia v. Glenchur*, 195 Cal. App. 3d 1075, 241 Cal. Rptr. 239 (1987); *Hoffmeister v. Coler*, 544 So. 2d 1067 (Fla. D.C. App. 1989); *Gray v. Romeo*, 709 F. Supp. 325 (D.R.I. 1989).

[11] See, for example, National Center for State Courts, *Guidelines for State Court Decision Making in Authorizing or Withholding Life-Sustaining Treatment*, 13 (1991), presenting data from a survey of state court judges indicating how rarely courts decide these cases. The low percentage of suits indicates little about the extent of the injury or harm. Indeed, it may say far more about the lack of accessible remedies. For example, the 1990 Harvard Medical Practice Study estimated that 8 times as many patients suffered an injury from negligence as filed a malpractice claim, and about 16 times as many patients suffered an injury from negligence as received compensation from the tort liability system. "Patients, Doctors, and Lawyers: Medical Injury, Malpractice Litigation, and Patient Compensation in New York," Report of the Harvard Medical Practice Study to the State of New York, 1990, 6.

[12] It appears that no reported case nationwide has resulted in monetary damages awarded after final judgment. Notes 9 and 10, above, indicate how few cases have resulted in monetary settlements or the award of attorneys' fees.

treatment, the harm to the patient should be assessed not only in terms of physical injury, but as a violation of the patient's dignity and person.

The Task Force deliberated about the possibility of specifying statutory damages or making the remedies under Section 2801-d of the Public Health Law available for hospital patients, as well as nursing home residents. Some of the members believe that replacing the clear and convincing evidence standard with policies allowing surrogate decisions under different standards, as proposed in the legislation, would address the underlying problem.[13] Others suggested that initial implementation of the legislation will necessarily entail an adjustment and some uncertainty on the part of providers about their obligations. Overall, however, many of the Task Force members remain concerned that patients and those close to them should not be left helpless when physicians or facilities unlawfully refuse to respect their rights.[14]

The Task Force members did not reach a resolution on the question of statutory remedies or damages for this harm. They agree, however, that as a matter of equity, any physician or health care facility that unlawfully refuses to honor an explicit request to withhold or withdraw treatment should not be entitled to compensation for the treatment provided in violation of the patient's right or the authorized decision of a health care agent or surrogate. Existing case law recognizes this principle for decisions by a patient.[15] The Task Force proposes that the legislation on surrogate decisions should provide that any physician or

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[13] In *Elbaum*, discussed above at note 8, the Grace Place nursing home asserted that its refusal to honor Murray Elbaum's decision on behalf of his wife was appropriate in light of the uncertainty of existing law and the difficulties of applying the clear and convincing evidence standard. Reply Brief for Plantiff-Appellant at 16-26, *Grace Plaza of Great Neck, Inc. v. Elbaum*, No. 90-01888 (N.Y. App. Div., 2d Dep't, dated Aug. 13, 1990). The proposed legislation would eliminate the clear and convincing evidence standard and drastically reduce legal uncertainty, although it would still require health care providers to exercise professional judgment in applying the standards set forth in the law.

[14] The fact that patients or their families can seek injunctive or other judicial relief offers little comfort for the vast majority of individuals. As argued by organizations that submitted an amicus brief in *Elbaum*, "Patients typically lack the physical capacity and they and their families typically lack the emotional and financial resources required to obtain court approval for what should be a self-executing right." Brief of Proposed Amici the Coalition of Institutionalized Aged and Disabled, Inc., Friends and Relatives of Institutionalized Aged, Inc., and the Nursing Home Community Coalition of New York State at 8-9, *Grace Plaza of Great Neck, Inc. v. Elbaum*, No. 90-01888 (N.Y. App. Div., 2d Dep't, dated July 18, 1990).

[15] See note 8.

facility that refuses to honor a surrogate's decision that accords with the standards of the legislation should not be entitled to compensation for treatment provided in violation of the statute. Consistent with the terms of the proposed legislation, health care providers may exercise a conscience objection to treatment decisions, challenge the surrogate's decision under standards set forth in the proposed legislation, and rely on procedures such as dispute mediation. But a physician or hospital that refuses to honor an authorized decision, not the patient or family member responsible for the patient's medical bills, should bear the financial burden of the provider's failure to comply with the decision-making process and standards in the statute. This relief should be available in addition to the remedies under existing law, including injunctive relief, damages for battery, and administrative penalties.

The actual cases that rely upon this remedy may be few. Many people are intimidated by the prospect of a judicial action and will simply not have the resources either to bring a suit against a physician or health care facility or to defend themselves in an action for nonpayment of medical bills. But explicit recognition of the remedy alone will prompt some physicians and facilities to weigh more carefully the consequences of treating a patient if the patient or a legally authorized representative expressly refuses treatment. In this regard, the proposed policy will lead to judgments that are more balanced, benefiting the patients and those close to them who lack the resources to pursue and preserve their rights.

Recommendation

Any physician or health care facility that refuses to honor a surrogate decision authorized by the proposed legislation should not be entitled to compensation for treatment provided in violation of the standards and decision-making process of the legislation. This remedy should not limit other rights or remedies under existing law, including administrative remedies.

See Appendix A, legislative proposal, Section 17.

Conclusion

Upon completing the proposal for health care proxy legislation in 1987, we began our deliberations on surrogate decisions. We recognized at the outset that patients without decision-making capacity who did not or could not leave advance guidance of their wishes present society with profound social and ethical questions. We also understood that any policies proposed would touch the lives of most New Yorkers. Virtually all of us, as a parent, spouse, sibling, or friend, will be called upon to act as surrogate for someone close to us or will have decisions made on our behalf.

The United States Supreme Court, in the case of Nancy Cruzan, affirmed that each state has the responsibility to fashion policies for surrogate decisions. Those policies must foster the wishes and interests of incapacitated patients. They must make it possible for family members and others close to the patient to decide about treatment in a way that expresses their caring, their compassion, and their affirmation of the values and life the patient chose for himself or herself. Public policy should also promote sound decisions for patients who have no natural surrogate to decide on their behalf.

The Task Force believes that the proposed legislation will achieve these goals. The legislation will also respond to the legal vacuum that surrounds many surrogate decisions today. Legal hurdles now deny some patients ready access to treatment. For others, treatment is determined by what is technologically possible, rather than by a judgment of what is humanly and medically desirable. Society should fulfill its responsibility to these individuals, and to those standing at their bedside.

Minority Report

J. David Bleich

The report of the Task Force and its proposals for legislation governing health care decision-making address two entirely distinct issues, each of which is deserving of examination, analysis and debate on its own merits. Linkage of the two can only lead to obfuscation of the issues and dereliction in candid confrontation of moral concerns.

The law, as it presently stands, does not permit a physician to treat a patient without the patient's consent. Next of kin have no formal standing to grant consent – or to withhold consent – even if the patient lacks decision-making capacity. Although, in theory, a physician has no right to treat without consent of the patient, in practice, this requirement does not serve to bar treatment of patients lacking decision-making capacity since, in cases of emergency or serious illness, the law presumes that, were the patient capable of giving consent, he or she would do so. Thus, in practice, such patients do receive treatment.

Since, in such circumstances, the consent of the patient is presumed as a matter of law, consent of next of kin is not required. Many, and probably most, physicians are under the impression that consent of next of kin is required, at least in situations in which next of kin are available, and hence, as a matter of practice, they seldom make treatment decisions without such consent. Although not legally required, it is probably prudent for physicians to seek such consent since, arguably, under estoppel doctrine next of kin who grant consent are effectively precluded from later claiming that the physician acted improperly. Formal establishment of authority to provide routine medical treatment in non-life-threatening situations is certainly a legal *desideratum*. Yet the Task Force recognizes that "[i]n practice, family members have long been accorded the right to consent to treatment" (Part II, Chapter Six). Thus the Task Force's justificatory statement in the preface to its report claiming that "existing law presents a hurdle for some patients in gaining access to needed treatment" and that "[i]ndividuals without

family available to consent to treatment are especially vulnerable" by its own admission must be taken *cum grano salis*.

This is not to say that problems do not exist. They do. They are more likely to arise, not in the context of a decision to treat or not to treat, but in the context of how to treat when a choice between different treatments is available. Consider the case of a patient lacking decision-making capacity afflicted with a malignant tumor. The tumor can be removed surgically, or it can be treated by means of chemotherapy or radiation. Since the condition is life-threatening, even under current law, the physician may treat the patient despite the absence of consent and, presumably, he may choose the mode of therapy as well. Although few physicians would make such a choice without consultation with, and the consent of, next of kin, much can be said for making such a procedure a legal requirement. Yet, doing so generates still another problem. What shall the physician do when members of the same surrogate class disagree? What shall the physician do when one child demands surgical excision while the other insists upon chemotherapy? Although Solomonic wisdom may be required to solve such dilemmas it is somewhat strange that the report of the Task Force does not explicitly address the issue of dispute resolution with regard to choice of treatment.

This lacuna is symptomatic of the fact that the real concern of the Task Force is not surrogate decision-making in the treatment of incompetent patients but the entirely different issue of surrogate decision-making regarding withholding of treatment and termination of life-support systems.

During recent years, there has been a steady, linear progression in the erosion of the value associated with preservation of human life in the mores of our society. There was a time when whether or not withholding nonhazardous treatment by a physician at the request of a patient would constitute manslaughter was a matter of serious consideration by legal scholars. Today, not only would the very suggestion be dismissed out of hand but the converse has become the accepted legal norm. The physician dares not preserve the life of his patient against the latter's wishes. Upon acceptance of the view that a patient can refuse even nonhazardous life-preserving therapy, attention focused upon withholding of artificial hydration and nutrition. Judicial decisions then established that refusal of artificial nutrition and hydration is to be equated with refusal of medical treatment and medical personnel who comply with such directives are not to be regarded as assisting in the patient's suicide. Legislation recommended by the Task

Force has been enacted making it possible for such decisions to be made not only by the patient himself but also by an agent designated by the patient. The present recommendation would not only enable a person specifically designated by the patient and explicitly charged with that responsibility to make a decision to allow the patient to die, but would, by operation of law, automatically grant such power to a surrogate in situations in which the patient cannot himself or herself make such decisions.

This recommendation marks a new ideological departure from previously accepted moral principles. In expressing earlier adopted moral positions, society was well aware of an often existing tension between two conflicting moral values, preservation of life and respect for personal autonomy. In retaining a prohibition against attempted suicide or assisting a suicide, society – at least for the present – continues to accord precedence to preservation of life over personal autonomy or "the right to die," at least in non-medical contexts. Acceptance of a patient's right to demand passive euthanasia does not deny the value of preservation of human life but instead reorders priorities in assigning precedence to patient autonomy. Granting the patient the right to delegate such decisions to a health-care proxy, it might be argued, is merely an extension of the exercise of individual autonomy. It is the patient who designates the health-care proxy and empowers the agent to authorize withholding or withdrawal of treatment. That the act of the agent is the act of the principal is well-established as a legal principle in other areas of human endeavor. It may be argued with some cogency that refusal to permit such delegation of authority would itself be a constraint upon a person's free choice to designate an agent.

Provision for surrogate decision-making by operation of law, rather than by designation of the patient, is not a victory of individual liberty over preservation of life. In the absence of the expressed or otherwise known desire of the patient there exists no conflict between two competing values, each of which is independently entitled to respect and protection. Permitting a surrogate to refuse life-sustaining treatment without the patient's authorization constitutes stark abnegation of preservation of life as a value in and of itself. The proposed limitations upon the powers of the surrogate are predicated upon quality of life considerations and clearly assume that not every human life is possessed of intrinsic value. Adoption of these proposals would constitute far more than a reordering of priorities; it would signify a renunciation of hitherto accepted values.

The gravity of this step dare not be minimized. There may be room for debate with regard to whether human life constitutes an absolute value or whether its acceptance as a value is to be qualified by a *ceteris paribus* clause. But, if so, one should be prepared to spell out in precise detail the conditions and circumstances in which life need not be preserved. In effect, such an exercise serves to establish values that may be granted precedence over preservation of life. A benefit-burden or best interests test falls short of doing so unless it spells out clearly and precisely what is to be recognized as a countervailing burden or as an adverse interest. Even among those willing to accept such a test in principle, there will assuredly be disagreement with regard to precisely which factors may be considered in subordination of human life. The present recommendations give the surrogate full decision-making powers and hence, in effect, permit him to assign zero value to human life in balancing preservation of life against other considerations.

It is readily acknowledged that these recommendations are limited to decisions made by a surrogate on behalf of a terminally ill patient, defined as a patient who is presumed to have a maximum longevity anticipation of six months, or on behalf of a patient judged to be permanently unconscious. Translated into value terms, the Task Force recommendations render virtually nugatory the moral significance of all but the final six months of the life of a patient incompetent with regard to independent decision-making. But there is nothing sacrosanct with regard to that time frame. Six months may readily be expanded to one year, two years or ten. After all, life itself is a terminal condition. Similarly, the Task Force's recommendations render nugatory the moral significance of the life of a permanently unconscious patient. Moreover, the distinction between the moral significance of the life of a permanently unconscious person and a person who is permanently insane is far from clear. If decisions to permit passive euthanasia may be made by a surrogate on behalf of the permanently unconscious, why may such decisions not be made on behalf of persons deemed to be permanently demented? Once it is accepted that life per se is no longer a transcendental value, may society not dispense with the surrogate and his services and determine by operation of law that life-sustaining treatment be withdrawn from any permanently unconscious or terminally ill patient incapable of independent decision-making or even from a non-terminally ill mentally incompetent person?

In an earlier minority report I wrote: "I fully concur in the recommendation that competent patients be accorded the opportunity to designate an agent for purposes of making health-care decisions — so

long as the proxy is designed to be only for the purpose of achieving a therapeutic result." I also fully concur in the recommendation that provisions be made for designation of a surrogate for purposes of making health-care decisions on behalf of incompetent patients — so long as the surrogate's decision-making authority is designed to be exercised for the purpose of preservation of life.

Designation of a surrogate is justifiable only for the purpose of weighing the pros and cons of alternatively available therapies or of weighing the risk-benefit factors inherent in a proposed treatment. Such decisions are predicated upon one prior assumption: the desired goal is cure or, *de minimis*, maximum prolongation of life. The decision itself is simply with regard to the means of achieving that end. Decisions for the withholding of potentially life-prolonging treatment are based upon an entirely different premise: they are designed to result in the patient's early demise.

Even in the extremely limited circumstances under which some ethicists might regard such a decision to be morally justified, it would be thoroughly unconscionable to sanction such a course of action without the patient's own fully informed consent. A decision to die is far too awesome a matter to be delegated to a proxy and certainly far too awesome a matter to be delegated to a self-appointed surrogate.