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Bioethics Review Committees

The Task Force believes that treatment decisions for patients without decision-making capacity should generally be made by family members or others close to the patient, in consultation with physicians and other health care professionals. By and large, decisions made in accord with the proposed law will be private bedside decisions by those closest to the patient. In some circumstances, however, additional review or consultation will be necessary. In particular, consultation and review should be available if conflict arises or if surrogates wish to forgo life-sustaining treatment on behalf of patients who are not terminally ill or permanently unconscious, but who may be severely and chronically ill.

The Task Force proposes that multidisciplinary committees based in health care facilities, referred to as "bioethics review committees," would best fulfill these functions. In addition, the Task Force proposes that the review committees should also be authorized to review and approve proposed treatment decisions for patients without family or others to serve as surrogates and for emancipated minors.[1]

Establishing Bioethics Review Committees

The Task Force recommends that each health care facility should establish a bioethics review committee or participate in a review committee that serves more than one facility.[2] While these committees would share some of the characteristics of ethics committees, the authority of the review committees would be greater than that generally exercised by ethics committees.[3]

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[1]See chapter 10 for discussion of policies proposed for patients without surrogates and chapter 8, 132-35, for policies for emancipated minors.

[2]Facilities may also establish or participate in more than one review committee. For example, a large hospital might choose to establish separate review committees for infants or for other groups of patients.

[3]See chapter 1 for discussion of ethics committees.

The Task Force's recommendations for review committees draw not only upon the experience of ethics committees, but also upon institutional review boards (IRBs). Federal regulations mandate that IRBs review proposals for federally funded research involving human subjects.[4] New York State law requires a similar review procedure for any research with human subjects not covered by federal regulations.[5] Federal regulations set minimal standards for the composition of IRBs and specify criteria that IRBs must consider in their evaluations. IRBs have the power to approve, require modifications in, or disapprove any research activities they consider.

Under the Task Force's proposal, bioethics review committees would be mandated by state law and, like IRBs, would have to meet certain requirements. Review committees would be distinguished from IRBs most clearly in that review committees would consider treatment decisions for particular patients, while IRBs examine research programs as a whole. State law would frame the review committees' function and operation, but would be less specific than the regulations governing IRBs.

Bioethics review committees would also share some characteristics of surrogate committees for the mentally disabled established under Article 80 of New York's Mental Hygiene Law. Under Article 80, multidisciplinary committees make treatment decisions for mental hygiene facility residents who lack available surrogates. Bioethics review committees would also be multidisciplinary committees charged to promote the interests of vulnerable patients. However, under Article 80, the committees decide only for patients who have no natural surrogate, while the committees proposed by the Task Force would review certain decisions by family members or other surrogates.[6]

In developing its recommendations, the Task Force also examined the role the courts might and should play in surrogate decisions. It

[4] 45 C.F.R.§ 46 (1991). See L. H. Glantz, "Contrasting Institutional Review Boards with Institutional Ethics Committees," in *Institutional Ethics Committees and Health Care Decision Making*, ed. R. E. Cranford and A. E. Doudera (Ann Arbor: Health Administration Press, 1984), 129-37.

[5] N.Y. Pub. Health Law § 2444 (McKinney 1985).

[6] Another major difference is that bioethics review committees would be facility-based, while Article 80 committees are organized by the State of New York Commission on Quality of Care for the Mentally Disabled and operate as quasi-judicial authorities, independent of any health care or mental hygiene facility. The Task Force's proposal for bioethics review committees would not encompass decisions for patients covered by Article 80. See chapters 2 and 10 for further discussion of Article 80 committees.

concluded that the courts should always remain available as an alternative for those who do not want to participate in a facility-based process, and as a last resort for disputes or cases that cannot be resolved at the health care facility. The Task Force believes, however, that courts should not be the avenue of first resort, either as the sole alternative to address conflict or as the primary decision maker on behalf of all patients who are neither terminally ill nor permanently unconscious.[7] The courts would be overwhelmed by this responsibility, and patients would be ill-served by the delays and demands of the judicial process. This approach would also intrude unnecessarily on the privacy of the family unit and relationships.

Membership

The membership of the review committee should be diverse, in order to provide a range of experience and expertise and to ensure that a variety of perspectives inform committee deliberation. The composition of review committees will vary with the type and size of institution and the sorts of cases reviewed most often. The Task Force proposes that review committees should consist of at least five individuals; at many institutions, committees will be much larger.

Mandatory Members

Each review committee should include at least one physician; one registered nurse; one certified social worker or other person with training or expertise in providing psychosocial services to patients; one individual with training or expertise in bioethics, moral philosophy, or theology; and one lay community member unaffiliated with the facility. In long-term care facilities, at least one representative of the residents' council and one advocate for elderly or nursing home residents should participate on the committee. In addition, the Task Force encourages nursing home committees to include either a member of the bioethics review committee at an acute care hospital with which the nursing

[7] As observed in a report on guidelines for state court decisions authorizing the withholding of life-sustaining treatment, "The court should not be used as a clearinghouse for the rendering of medical decisions which are best made by the patient and family and the physician of the patient. A trial court must protect itself from inappropriate involvement in a life-sustaining medical treatment case and should decline jurisdiction if there is no justifiable controversy." National Center for State Courts, *Guidelines for State Court Decision Making in Authorizing or Withholding Life-Sustaining Medical Treatment* (Williamsburg, Va.: National Center for State Courts, 1991), 36. The guidelines were prepared by a council that advised the National Center for State Courts. Sol Wachtler, Chief Judge of the New York Court of Appeals, served as vice-chairman of the council. See also J. Kaye, "Staking Out the Law," *Mount Sinai Journal of Medicine* 58 (1991): 369-74.

home is affiliated or to participate in a review committee that serves more than one nursing home.[8]

Most committees will have more than one physician, representing different specialties and experience. The scientific and technical knowledge of physicians, as well as their clinical experience in caring for patients, is essential to committee deliberations. As the committee considers individual cases, it should begin by clarifying the medical facts, including the patient's diagnosis and prognosis, and treatment alternatives.

Nurses, like physicians, bring both clinical knowledge and experience with patients to committee discussion. Nurses spend extensive time with patients, caring for their personal and medical needs. Although nurses cannot serve on the committee when it considers a case involving one of their patients, this experience still informs their professional perspective. As suggested by a study of New York's DNR law, nurses may be more likely than many physicians to regard the promotion of patient rights as part of their professional mission.[9]

Social workers and other persons with training or expertise in providing psychosocial services to patients also have a vital role in committee discussion, especially concerning the personal, social, and psychological dimensions of each case. They can help to clarify the preferences of patients and the roles and views of family members and others close to the patient. Information about social support and resources available to the patient and family may be critical in some cases.

Review committees should also include at least one individual with training or expertise in bioethics, moral philosophy, or moral theology. These individuals bring skill and experience in identifying ethical

[8]New York State Department of Health regulations require each long-term care facility to maintain a transfer agreement with one or more general hospitals as required to meet the medical needs of residents. N.Y. Comp. Codes R. & Regs. tit. 10, § 415.26(g) (1991).

[9]Robert Baker et al. report that critical-care nursing directors surveyed "see themselves as having special obligations to protect the individual's right to self-determination." Thirty-seven percent of nursing directors providing written comments reported a need to advocate for patients' rights when physicians fail to discuss DNR orders. Only 3% of hematologists and oncologists surveyed explicitly mentioned patients' rights. R. Baker et al., "Legal and Professional Enforcement of Bioethical Reform: A Comparative Study of the 1988 New York 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).

problems and analyzing critically the ethical claims and interests of all involved in the case.[10] They can assist the committee to develop clear principles to guide decision making. Ethicists and chaplains may also be well versed in the literature on medical ethics and have experience applying ethical principles in the context of medical cases.

In many facilities, individuals with training or expertise in bioethics, philosophy, or theology will be members of the clergy. In addition to their contribution in evaluating ethical problems, clergypersons, including chaplains, may assist the committee to address religious issues that may be critical for some patients. A clergyperson can help identify the patient's religious values and ensure that the personal and religious views of all concerned are respected.

This responsibility must be approached with sensitivity to the religious and moral diversity likely to be encountered in health care facilities throughout New York State. A member of the clergy must be careful not to promote decisions based on his or her own religious convictions when these diverge from the patient's religious or moral outlook. Even if the patient and clergyperson share the same religious affiliation, their interpretations of that tradition may differ.

The Task Force recommends that review committees also include at least one community member who is not otherwise affiliated with the institution. These individuals should not participate as a "community representative" in the sense of promoting the interests of a group outside the institution, but rather should provide an independent perspective in advocating for patients. These individuals may notice practices and patterns that those affiliated with the facility might overlook or take for granted. They also add to the accountability and credibility of the committee. Their independence distances them from potential conflicts of interest, and enhances their freedom to take positions differing from those of facility administrators or others in a position of authority at the facility.

In acute care hospitals, the lay community member could be an individual who has recognized expertise or demonstrated interest in patient welfare or individual rights. Members of civic organizations and groups that advocate for the elderly or for patients generally could serve as the lay community member.[11] Committees that review cases

[10]Some philosophers might have little interest in resolving particular cases, focusing their concerns on abstract theory. They would be less likely than other philosophers to seek to participate on a review committee or to contribute fruitfully to its deliberations.

[11]The diversity of organizations whose members might volunteer for this

involving newborns might include the parent of a disabled child, an adult with a congenital disability, or a special education teacher. Retired physicians, nurses, judges, university professors, and others might also be willing to serve on the committee. In order to assure the availability of volunteer community members, several individuals could be selected.

In long-term care facilities, the lay community member should be an advocate for persons in long-term care or the elderly. This person could be a representative from the New York State Long Term Care Ombudsman Program. The Ombudsman Program, administered by the New York State Office of the Aging, provides advocacy services for older residents of long-term care facilities. The program relies on trained volunteers as well as state staff to receive, investigate, and resolve complaints. The lay community member might also be a member of a not-for-profit organization that has as part of its mission advocacy for long-term care residents or the elderly, such as the Nursing Home Community Coalition or the state chapter of the American Association of Retired Persons.

The Task Force recognizes that the participation of lay community members raises potential problems. These individuals may be unfamiliar with the clinical setting in general and the facility in particular, making it difficult for them to understand and contribute to committee discussion. They also may be intimidated or ignored by other committee members. Some commentators have expressed concern that patient confidentiality might be compromised by the participation of an individual unaffiliated with the institution, especially one who might not be sensitive to legal requirements or professional standards of confidentiality. Some individuals might be more devoted to general social goals or a personal agenda than to the wishes and interests of individual patients. Finally, some committee members might feel that the participation of a community representative lessens their own responsibility as an advocate for the patient.[12]

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responsibility is suggested by the many organizations that supported enactment of New York's health care proxy law. Among the measure's proponents were the National Organization of Women-New York State, the Association of the Bar of the City of New York, the New York Civil Liberties Union, the Lutheran Office of Governmental Ministry, the Gay Men's Health Crisis Center, the Junior League of Long Island, Citizen Action of New York, the Episcopal Diocese of New York, and the League of Women Voters.

[12]Some commentators assert that the participation of an individual unaffiliated with the institution may complicate liability concerns; the legal protection proposed for committee members and others addresses this concern.

Despite these difficulties, the Task Force believes that the participation of lay community members who are not affiliated with the facility adds to committee deliberation and on balance makes an essential contribution. An individual unaffiliated with the institution can bring a critical independent perspective. The individual will also enhance the committee's accountability and public trust in the committee process.

In long-term care facilities, committees should also include at least one member of the residents' council. Required in all facilities by New York State Department of Health regulations, residents' councils are designed to provide a forum for resident participation in devising facility programs and policies.[13] A member of the council can provide insight about treatment alternatives from the perspective of a patient at the facility. In addition, the resident can help to ensure that the patient's interests in each case are fully explored.

Additional Members

The participation of more than one individual from some of the above categories will generally enhance committee deliberation. Facilities can increase the expertise or perspectives available to the committee by inviting individuals affiliated with another health care facility or local institution such as a university to join the committee. Including individuals from another facility is especially important for nursing homes, which often have a more centralized administration than hospitals and may lack the independent viewpoints that coexist in many hospitals. The Task Force encourages committees in long-term care facilities to participate in a committee with another nursing home. When a single bioethics review committee serves more than one long-term care facility, the perspectives of members from different facilities are likely to enrich committee deliberation, and help guard against excessive deference to any one committee member or point of view.

Establishing a review committee with another facility may not be feasible for some nursing homes, particularly those in rural areas. Committees that serve a single nursing home, as well as others, should seek to include a health care professional from the acute care facility with which the nursing home is affiliated. This individual would provide an informed and independent perspective. The nursing home review committee would especially benefit from the experience of a member of the hospital review committee; the hospital committee's policies,

[13]See N.Y. Comp. Codes R. & Regs. tit. 10, § 415.26(b)(8) (1991), mandating residents' councils.

decisions in particular cases, and procedures could serve as a resource for the nursing home.

Review committees at both general hospitals and long-term care facilities may also be strengthened by other individuals from within the facility. For example, facilities that have a patient representative or patient-advocate program should consider appointing individuals from the program.

Attorneys can be a valuable resource for a committee. In addition to their familiarity with the law, lawyers are trained to identify principles and distinguish cases. They can help the committee apply relevant legal doctrines and assure that like cases are treated alike. Lawyers can also serve as an independent source of authority or opinion for a committee that might otherwise be dominated by one individual. Finally, lawyers can assist the committee to find a common ground between the interests of the patient and the legal concerns of the facility. However, if an attorney or risk manager participates on a review committee, special care must be devoted to clarifying his or her role. Facility counsel and risk managers often define their responsibility as finding the "safest" alternative, rather than as identifying a range of treatment options supported by existing case law and statutes. This focus on the institution may conflict with the committee's principal role of protecting patients. Without participating on the committee, attorneys or risk managers can still fulfill their traditional function by advising the facility once the committee has developed its recommendations.

A facility administrator can provide an overall perspective of the institution, as well as familiarity with institutional policies and resources. In some cases, administrative arrangements, like transferring care of the patient to another physician or different nurse on duty, might resolve the conflict. Like all other committee members, administrators who serve on a committee must accept the patient's needs as the committee's primary concern.

Training

The Task Force recognizes the importance of preparation and education for review committee members. Those without a medical background should gain familiarity with the clinical setting. Physicians and other health care professionals must be educated about the right of patients to decide about treatment, and the authority granted to family members and other surrogates under the law. The ethical premises underlying state policies and laws should be examined. Com-

mittee members must also develop a sense of the committee's role within the institution and its mandate under state law.

Education must be not only a central focus of the committee's early activity but an ongoing concern for committee members. Training is especially important for lay community members; they may have little background in medical decisions and must speak with an independent voice on the committee. The Task Force urges that an educational program should be developed for lay committee members, especially in the early stages of the committee's work.[14]

The program should focus on the standards and procedures embodied in the law, the ethical principles underlying the law, and basic facts about hospital services and organization. Modest financial and personal resources will be required for this purpose. While institutions and professional organizations should contribute to this effort, funding should also be provided by state government or by grants from the private sector. Training programs designed for surrogate decision-making committees for the mentally disabled under Article 80 of New York's Mental Hygiene Law could serve as a model. A study of that program found a high level of satisfaction with the training of committee members.[15]

Beyond any particular training provided, the ability of a committee to function well will hinge on intangible factors that cannot be regulated or mandated. Those factors include the tone established by the committee chairperson, the dedication of those who participate, and the support extended by the facility to the committee. At a minimum, each committee member must respect the contributions of members with different areas of expertise and be committed to promoting the wishes and interests of the patients whose cases are reviewed.

Procedures

Facilities should adopt a written policy governing committee functions, composition, and procedures. This policy should contain procedures for responding promptly to a request for a case consideration, informing appropriate persons of the case, and providing them with

[14]See, e.g., J. W. Ross, *Handbook for Hospital Ethics Committees* (Chicago: American Hospital Publishing, 1986), 49-50; B. Hosford, *Bioethics Committees: The Health Provider's Guide* (Rockville, Md.: Aspen Systems, 1986), 153-59; R. Macklin and R. B. Kupfer, *Hospital Ethics Committees: Manual for a Training Program* (Bronx, N.Y.: Albert Einstein College of Medicine, 1988).

[15]M. Gold and L. Torian, "The Surrogate Decision Making Program: Final Evaluation Report." January 29, 1988, 20, 70.

access to the committee. It should also specify the circumstances that would trigger the committee's participation or review.

The committee should inform the patient, when possible, the surrogate and involved family members, the attending physician, the facility, and other appropriate individuals of a pending case review, and provide information about the committee's procedures and function. These individuals should also be promptly informed of any decision or recommendation by the committee and should have the opportunity to present their concerns and views to the committee.

Patients and surrogates should also be allowed to bring a person with them to the meeting to assist them in understanding the issues discussed or in presenting their views. This person may be a family member, lawyer, member of the clergy, or simply a close friend. Especially for those who may be intimidated by the process, this is an important option.

While all persons connected with a case may present information to the review committee, health care professionals should not participate as committee members in a case that concerns them directly. For example, physicians caring for the patient whose case is under consideration should present their views to the committee in the same manner as individuals involved with the case, but should not otherwise participate in committee deliberations. This policy will facilitate frank discussion among committee members and enhance the fairness of committee review.

A quorum of the full committee should review surrogate decisions to withdraw or withhold life-sustaining treatment from a patient who is neither terminally ill nor permanently unconscious, or a decision to withhold or withdraw life-sustaining treatment from an emancipated minor or a patient without a surrogate. At a minimum, the proposed requirements for committee membership should be met: at least five members with the professional and other qualifications for committee composition should be present. A health care facility should identify the number of individuals that constitute a quorum of the committee. The presence of a quorum would help assure that cases are treated in a consistent manner and that principles or precedents reflected in the decisions are embraced by the review committee as a whole, not just by a few members.

The facility should make reasonable efforts to inform all committee members of the pending consideration of these sensitive cases. Decisions reviewed by the committee should not be implemented until the committee informs the patient, the surrogate and family members,

the facility, the attending physician, and other appropriate persons of the committee's recommendation. In these cases, the committee should also provide the surrogate and other appropriate individuals with a written statement of the reasons for approving or disapproving the decision to forgo life-sustaining treatment.

In general, facilities should maintain written records of committee decisions. The records will contribute to the continuity of the committee's activities, enabling the committee to examine its previous recommendations and to modify its decisions or procedures where appropriate. Maintaining records will also contribute to the committee's accountability.

Except for cases mentioned above when a quorum of the committee should always be present, committees should be allowed to delegate the review of cases to subcommittees. The full committee may be unable to consider every case, because of the frequency of decisions requiring review or the urgency of a particular case. Particularly in situations of conflict between family members or among members of the health care team, a subcommittee may be able to address the issues as well as a larger group and in a more timely way. Except for dispute mediation, which would not require any fixed number of individuals, at least three review committee members, including at least one physician, should participate in each case. Subcommittees should routinely report their activities to the review committee to maintain accountability and to allow the full committee to identify any patterns in subcommittee review that seem problematic.

Functions

Education and Policy Review

In addition to case consultation and review, bioethics review committees could undertake other responsibilities as authorized by the facilities they serve. Review committees could naturally fulfill other roles associated with ethics committees, such as education and policy development. In addition to their intrinsic importance, these activities generally strengthen the ability of committees to engage in case consultation and review. For facilities that already have ethics committees, those committees would probably provide the basis for or serve as the bioethics review committee.

Responding to Conflict or Requests for Consultation

Conflict among family members and others close to the patient will inevitably arise in some cases. For example, the children of an elderly

patient may disagree about which course of treatment would best accord with the patient's wishes and interests. In other cases, the surrogate and the physician or other health care professionals may disagree about the course of treatment.

The Task Force recommends that review committees should be available for consultation and advice upon the request of persons involved with the case. In addition, it proposes that committees should seek to resolve cases whether a decision to provide treatment or a decision to withdraw or withhold treatment triggers the conflict. When disagreements arise between or among the physician or other health care professionals caring for the patient, family members, other persons on the surrogate list, or the facility, they should be brought to the committee. For example, the committee should consider any of the following cases:

- A physician objects to a surrogate's decision to discontinue life-sustaining treatment and refers the matter to a review committee rather than implement the decision or transfer the patient's care to another physician.
- A close family member (or other individual on the surrogate list) objects to a surrogate's decision to provide life-sustaining treatment for a dying patient.
- A parent objects to another parent's or guardian's decision to refuse life-sustaining treatment for a minor child, or a minor refuses life-sustaining treatment despite the objection of a parent or guardian.
- An attending physician and other health care professionals disagree about surgery for a patient who has no surrogate.

In these types of cases, the most appropriate role for the committee may be dispute mediation. The committee may be able to resolve a conflict by improving communication among those involved or exploring alternative courses of action. The committee should also identify disputes that arise because a proposed course of treatment conflicts with the substituted judgment and best interests standards or with the medical predicates for surrogate decisions.

Reviewing Sensitive Treatment Decisions

The Task Force believes that three kinds of cases are so sensitive that they should be reviewed routinely by a bioethics review committee, even in the absence of disagreement among those close to the patient

and health care professionals: when a surrogate decides that life-sustaining treatment should be withdrawn or withheld for a patient who is neither terminally ill nor permanently unconscious; when a decision is made to forgo life-sustaining treatment for a patient without a surrogate; and when an emancipated minor wishes to forgo life-sustaining treatment. These types of cases present difficult treatment decisions for patients who are extremely vulnerable.[16]

Under the Task Force's proposal, decisions by family members or other surrogates to forgo life-sustaining treatment for patients who are neither terminally ill nor permanently unconscious would not be authorized unless reviewed and approved by the committee or by a court. Committee review and approval would not change the fact that the surrogate and physician remain the decision makers, although it does establish a constraint on their authority. In essence, the committee should function in these sensitive cases to confirm that the decision-making standards have been met and that a surrogate's decision is made in good faith. For emancipated minors, the committee can serve as an advocate, assuring that health care professionals have explored the options for available care and informed the minor fully. For minors as well as surrogates, the committee can also determine whether the choice falls within a range of acceptable alternatives.

The review committee may enhance the surrogate's or minor's decision by seeking additional medical information, clarifying available alternatives, and raising issues that might have been overlooked in previous discussions. The committee should also issue a recommendation about the surrogate's or minor's decision, presenting a statement of the reasons for its recommendation. The statement may persuade the surrogate or minor to accept the committee's recommendation. The statement of reasons would also provide a basis for the surrogate, minor, or attending physician to respond to the committee or to challenge the committee's position. Surrogates, minors, or physicians acting on behalf of their patients can also bypass the committee altogether and seek judicial approval of the decision.

Extending Legal Protection

The Task Force proposes that individuals who serve on bioethics committees in good faith in accord with the proposed legislation should

[16]The special role of the committees for patients without surrogates and the policies proposed for emancipated minor patients are discussed fully in other chapters of this report. See chapters 8 and 10.

be protected from liability.[17] It is appropriate to extend this legal protection. It is also essential to encourage individuals to serve on the committees. Given the authority vested in the committees, the potential for liability would be more real than when ethics committees perform a purely consultative role, as they do now. Fears of liability, if unaddressed, would not only discourage persons from participating on committees, but would also would inhibit free and open discussion among committee members.

The Task Force proposes that individuals should be granted legal protection for actions taken in good faith as a member of or consultant to a review committee or as a participant in a review committee meeting. The protection proposed is broad but not unlimited; it would not encompass either activities outside the scope of committee duties or actions taken in deliberate disregard of the standards and requirements of the proposed legislation.[18] For example, committee members who place the interests of the health care facility ahead of those of the patient whose case is considered would not be protected from liability.

This proposed protection from liability resembles protections afforded under New York law to participants in other health care committees that also function to improve patient care. For example, persons who participate in good faith in dispute mediation under the DNR law are protected from civil liability, criminal prosecution, and professional misconduct sanctions.[19] Likewise, if a person's participation on a facility's quality assurance committee meets a good faith standard, New York law extends immunity from any action for civil damages or other relief as a result of the activity.[20]

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[17]The law firm of Kalkines, Arky, Zall & Bernstein provided the Task Force with a legal analysis of New York law and the law in other states relating to the confidentiality and immunity protections extended to ethics committees. That analysis of existing law informed the Task Force's judgments presented in this chapter.

[18]Although few states have statutes on hospital ethics committees, of those that do, almost all provide liability protection. See, e.g., Section 19-374 of the Maryland Health-General Code, providing immunity for advice provided in good faith; Section 37-2-201 of the Montana Code, providing immunity for any action taken within the scope of the functions of the committee, if without malice and in the reasonable belief that it is warranted by the facts; and Section 663-1.7 of the Hawaii Revised Statutes, providing immunity for acts done in the furtherance of the purpose for which the committee was established, if done without malice and within the authority of the particular member.

[19]N.Y. Pub. Health Law § 2974(3) (McKinney Supp. 1992).

[20]N.Y. Pub. Health Law § 2805-j(2) (McKinney Supp. 1992).

Maintaining Confidentiality

Confidentiality for committee deliberations is also crucial to foster committee activity and to protect the privacy of patients whose cases are reviewed. The Task Force recommends that internal committee discussions and records should remain confidential, except for the cases and circumstances specified below.[21] As a general matter, neither the proceedings nor the records of the committee should be released by committee members, consultants, or others privy to such information, nor should the information be accessible to others for use in legal proceedings or government agency investigations. Under this standard, minutes, memoranda, or other written materials prepared for the committee would be kept confidential. Internal committee deliberations and views expressed at committee meetings would also remain private. This confidentiality should be accomplished in two ways. Committee members, consultants, and others with access to these materials and discussions should have a duty to maintain confidentiality. Also, persons external to the committee process, such as individuals who bring a legal action against a physician or the facility, generally should be unable to gain access to documents and discussions by means of subpoenas or other methods.

This confidentiality protection should be subject to two important exceptions. First, committee records and proceedings that address the withdrawal or withholding of life-sustaining treatment from a patient without a surrogate, an emancipated minor patient, or any patient who is neither terminally ill nor permanently unconscious, should be subject to review by the New York State Department of Health. The nature of these sensitive treatment decisions calls for greater oversight and openness about the decision-making process. Also, confidentiality protections should not prevent the patient, the surrogate, other persons on the surrogate list, or the parent or guardian of a minor patient from speaking about the committee proceedings to which they have access, if they choose to do so. For example, a spouse acting as the surrogate for her husband should not be constrained from describing

[21] See A. Meisel, *The Right to Die* (New York: John Wiley and Sons, 1989), 485 (§ 15.9), emphasizing the importance of ethics-committee confidentiality: "Ethics committees do not merely discuss issues of ethics, law and medicine, but they are also concerned with equally if not more delicate issues, such as errors in professional judgment, personality clashes, professional misconduct, and quality of care. Without a vow of confidentiality to which all ethics committee members subscribe, the functioning of ethics committees can only suffer; individuals may be reluctant to serve or to participate fully and health care professionals may be reluctant to bring cases to the committee or to be forthcoming with the committee."

the comments made by committee members during any part of a review committee meeting she attended.

Policies preserving the confidentiality of committee proceedings are also important to protect the privacy of patients. In order for the bioethics review committee to perform its function, committee members, consultants, and others must have access to relevant medical records and information. This access entails a duty to respect the patient's privacy and the confidentiality ordinarily accorded medical information.[22] Any patient-specific information should be disclosed only to the extent strictly necessary to accomplish the purposes of the surrogate decision-making proposal or as otherwise provided by law.[23] For example, the committee should be permitted to inform appropriate persons of a pending case, but should only give individuals the medical information necessary to foster decision making under the standards of the proposal. The patient's privacy should remain of utmost concern.

Health care facilities or the committees themselves should make special efforts to explain the confidentiality requirements to community members and long-term care residents who serve on the committees. These individuals, like others on the committee, should have a clear legal duty to respect the patient's privacy, but may not be familiar with the confidentiality that extends to medical information.

Mandating Committees

The growing presence of interdisciplinary ethics committees in hospitals and nursing homes in New York State attests to their value and acceptance.[24] Nonetheless, the Task Force recognizes that man-

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[22]The common law and state and federal statutes and regulations, as well as the constitutional right of informational privacy, impose duties of patient confidentiality upon health care providers. Private accreditating bodies, such as the Joint Commission on the Accreditation of Healthcare Organizations, also require providers to respect patient confidences. See, e.g., M. C. Macdonald, K. C. Meyer, and B. Essig, *Health Care Law: A Practical Guide* (New York: Matthew Bender, 1989), chapter 19, for a full discussion about medical information and confidentiality.

[23]Otherwise confidential medical information may be subject to release to governmental agencies pursuant to laws governing, for example, child abuse and neglect. See, e.g., N.Y. Soc. Serv. Law §§ 411 to 428 (McKinney 1983 & Supp. 1992) ("Child Protective Services").

[24]A 1988 Task Force survey of New York health care facilities found that 51% of responding hospitals had an ethics committee, and an additional 6% were in the process of developing one. A lower percentage of nursing homes (27%) had established a committee. However, this represented an increase of 14% over the number of nursing homes that had an ethics committee in a 1986 Task Force survey.

dating bioethics review committees would constitute a major policy shift. In general, the committees that exist today in hospitals and nursing homes in New York State are voluntary, not mandated by legislation.[25] Indeed, only the state of Maryland has affirmatively required facility-based ethics committee.[26] Also, unlike the purely advisory function fulfilled by existing ethics committees, bioethics review committees would have the authority to approve or disapprove certain proposed decisions to forgo life-sustaining treatment.

Some individuals have cautioned against requiring health care facilities to establish ethics committees. Concerns have been raised about mandating committees that lack a clear role and specific guidelines. Some have suggested that even when committees are purely advisory, they violate patients' rights because they do not accord patients and those close to them adequate information, notice, or access.[27]

The Task Force's proposal addresses many of these concerns. It not only requires facilities to establish review committees, but delineates the functions of the committees and sets minimum standards for their composition and process. Many of the proposed procedures are designed to make the committee process open and accessible. The committees would be required to function according to a written policy and to consider and respond to health care matters presented by patients, a person on the list of potential surrogates, health care providers, or an authorized state agency. They must also inform patients and those close to them that a matter is under consideration and tell them about the committee's function and procedures. Moreover, the proposed decision-making process, including the participation of committees, represents an alternative for patients and their family members. It would not prevent them from bypassing the committee altogether and seeking judicial intervention at any time.

See discussion of ethics committees, chapter 1 and appendix E.

[25]One important exception concerns level III perinatal care programs, which are required to establish an infant bioethical review committee. These committees are authorized to provide guidance to family and staff, to ensure that parents are given medical information and that decisions by competent parents to continue life-sustaining treatment are implemented, and to intervene when parents lack decisional capacity or make a decision "manifestly against the infant's best interests." N.Y. Comp. Codes R. & Regs., tit. 10, § 405.21(h)(3)(ii)(1989).

[26]See Sections 19-370 to 19-374 of the Maryland Health-General Code.

[27]See, for example, the symposium in the *Maryland Law Review* on hospital ethics committees and the law. *Maryland Law Review* 50 (1991): 742-919.

The Task Force believes that review committees are the best available option for meeting the identified needs and gaps in the current decision-making process for incapacitated patients. Undoubtedly, some facilities will be better prepared than others to establish committees able to meet their responsibilities under the law. Nonetheless, in all hospitals and nursing homes, the committees will offer a greater degree of openness and scrutiny for the decisions they are charged to review.

Recommendation

The Task Force recommends that each health care facility should establish one or more bioethics review committees or participate in a review committee that serves more than one facility. Each review committee should include at least one physician; one registered nurse; one certified social worker or other person with training or expertise in providing psychosocial services to patients; one individual with training or expertise in bioethics, moral philosophy, or theology; and one lay community member unaffiliated with the facility. In long-term care, the community member should be a representative of the Long-Term Care Ombudsman Program or of a not-for-profit organization that promotes the rights and interests of the elderly or nursing home residents as part of its mission. Review committees at long-term care facilities should also include at least one representative of the residents' council. Long-term care facilities should be encouraged, but not required, to include either a member of the bioethics review committee at the acute care hospital with which the facility is affiliated or representatives of more than one long-term care facility in a review committee serving more than one facility.

Facilities should adopt a written policy governing committee functions, composition, and procedures. This policy should include procedures for responding promptly to a request for case consideration and should permit persons connected with a case to present their views to the committee. The proceedings and records of the review committee should generally be kept confidential. All committee members have a duty to respect the confidentiality of patient information.

Review committees should be consulted in the event of conflict between and among health care professionals, family members, and others close to the patient or the facility. Committees should also review and be authorized to approve decisions to forgo life-sustaining treatment by emancipated minors and for patients who are neither terminally ill nor permanently unconscious, even in the absence of

conflict. In both types of cases, review committees should determine whether the decision satisfies the standards for surrogate decisions and should issue a recommendation. Review committees should also review and be authorized to approve recommendations to forgo life-sustaining treatment for patients who do not have a family member or friend willing and able to serve as surrogate.

See Appendix A, proposed legislation, Section 11.

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Deciding for Adults Without Surrogates

Every day, hospitals, nursing homes, and health care professionals face the formidable problem of how treatment decisions should be made for patients who lack capacity and have no family members or close friends to act as "natural" surrogates. These individuals are among New York's most vulnerable patients: elderly nursing home residents without involved family members, AIDS patients predeceased by loved ones, drug abusers, and homeless persons estranged from relatives and companions.

Family members and close friends play a critical role as surrogates for incapacitated patients by promoting the patient's values and preferences, and assessing the proposed course of treatment. This balance, and the dialogue about treatment it entails, are not available for individuals without natural surrogates.[1]

Many physicians and health care facilities now make decisions for isolated patients, including decisions to forgo life-sustaining treatment, without review or consultation. Other providers, more wary of the absence of legal authority for such decisions, find themselves paralyzed, unable to give isolated patients the same timely care that other patients receive, or to stop treatment that they believe imposes an excessive burden on the patient.

In rare cases, a health care facility or public official seeks a court order authorizing treatment, or a committee or guardian of the person has been appointed and decides about treatment. More often, the expenses and delays associated with court proceedings are avoided.

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[1] An incapacitated patient who lacks a family member or close friend to make treatment decisions, but has a court-appointed committee of the person, or guardian of the person for a mentally retarded or developmentally disabled person, would not lack a surrogate decision maker under the Task Force's proposal. These court-appointed individuals are included as the first potential surrogates on the Task Force's proposed surrogate list. See chapter 6.

Sometimes health care professionals wait until a patient's condition deteriorates and major medical interventions are authorized under the emergency exception to the requirement of informed consent.[2] Other times, a patient receives treatment, but health care providers proceed without a clear legal substitute for patient or family consent. In either case, decisions are routinely made on an informal basis, without prospective or retrospective review.

Existing informal practices for deciding about treatment for isolated patients do not adequately protect these patients' interests. Nor, in all cases, are the practices supported by established legal principles. The Task Force proposes a decision-making process for this patient population that seeks to facilitate their access to needed treatment and to permit the discontinuation of life-sustaining measures in accord with publicly approved standards and procedures.

In devising its recommendations, the Task Force examined policies in other states to identify precedents and possible models. Remarkably few exist. Apart from traditional guardianship proceedings and the availability of a court order to authorize treatment decisions, most states have no explicit policies for deciding on behalf of patients without a surrogate.

Oregon and North Carolina are exceptions. Both states authorize the patient's physician to make decisions for incapacitated patients who have no surrogate, including decisions to forgo life-sustaining treatment.[3] The Task Force concluded that this process is not sufficient to preserve the interests of incapacitated patients, especially for decisions to withdraw or withhold life-sustaining treatment. Unless treatment is futile, as narrowly defined and understood, decisions to forgo life-sustaining treatment involve judgments that are principally social and ethical, not medical.[4] Physicians acting alone should not be empowered to decide for isolated patients.

The Task Force considered three decisional paradigms for isolated patients: a judicial model, a nonjudicial system centered outside of health care facilities, and a facility-based approach. The Task Force concluded that hospitals and nursing homes are the appropriate locus for decision making so long as decisions are made in accord with publicly accepted standards and are open to public scrutiny.

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[2]N.Y. Pub. Health Law § 2805-d (McKinney 1985 & Supp. 1992).

[3]N.C. Gen. Stat. § 90-322(b) (1989); Or. Rev. Stat. § 127.635(3) (1990).

[4]See below, chapter 14 on medical futility.

Alternative Approaches

Relying on the Courts

The Task Force considered, and rejected, mandating court review in all cases or requiring a court-appointed legal guardian for each isolated patient. It determined that the disadvantages of a judicial model outweigh the advantages. Under the Task Force's proposal, the courts will remain an important alternative for those who seek the judicial appointment of a guardian or for any case challenging decisions made on behalf of an isolated patient.

The judicial process entails a high degree of public accountability and our society's most extensive due process protections, including important fact-finding powers. Judicial decisions must satisfy societal requirements for the particular case and in terms of the decision's role as precedent. Judicial proceedings also provide a neutral forum and an impartial decision maker. However, court proceedings are often cumbersome and time-consuming. They are almost always adversarial and public. As such, they are at odds with the timely, private, and collegial model of medical decision making.

It is also unclear that court decisions would be qualitatively better than decisions reached at the facility level, subject to publicly approved standards. In cases about treatment decisions, judges tend to defer to physicians' recommendations.[5] Judges are at a disadvantage, as compared with health care professionals and others who are close to the treatment setting and patient, have ready access to medical expertise, and can respond to the patient's changing medical needs. Under the Task Force's proposal, the courts will remain an important forum for deciding disputes and controversies that are not resolved within health care facilities. The courts, however, cannot be expected to evaluate and monitor treatment plans for all patients without surrogates in New York State.

This approach is supported by the guidelines on life-sustaining treatment cases prepared for state court judges. The commentary that

[5]See commentary for guidelines for state court judges on life-sustaining treatment cases, acknowledging that judges are inexperienced at handling these cases and tend to defer to medical authority. National Center for State Courts, *Guidelines for State Court Decision Making in Authorizing or Withholding Life-Sustaining Medical Treatment* (Williamsburg, Va.: National Center for state Courts, 1991), 36, n. 61. As explained by Judge Judith S. Kaye, "it may be difficult — perhaps more so than in other litigation — to replicate in the courtroom the critical reality that may become evident over time at the bedside." "Staking Out the Law," *Mount Sinai Journal of Medicine* 58 (1991): 372.

accompanies the guidelines notes that most "guardianship petitions filed with the court do not appear to raise complex issues of law or facts, thereby adding to the costs and delays in what might otherwise be relatively simple decision-making. Courts lack the personnel and resources to develop, calculate and monitor complex plans for services."[6]

Nonjudicial Models

The Task Force considered several alternatives for a nonjudicial system centered outside of health care facilities that could make decisions on behalf of isolated patients. Under one approach, a public guardianship program would assume responsibility for treatment decisions. Some states currently rely upon public guardians to decide about treatment for isolated patients.[7] However, the experience of these efforts suggests that their effectiveness is too often hampered by chronic underfunding.[8] The Task Force concluded that the cost of creating a sufficiently large public guardianship program in New York State would be inordinate. The Task Force also has strong reservations about relying on public guardianship because such a program would essentially vest a small office or one individual with both broad policy-making authority and responsibility for thousands of cases.[9]

Another approach would rely on committees similar to surrogate decision-making committees for the mentally disabled established by

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[6]Ibid., 36-37.

[7]See 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), 130.

[8]Ibid.

[9]In New Jersey, the courts mandated a role for the State Ombudsman's Office in cases where life-sustaining treatment is withheld or withdrawn from an elderly, incompetent nursing home patient. *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985) and *In re Peter*, 108 N.J. 365, 529 A.2d 419 (1987). In 1989, the Ombudsman informed all New Jersey nursing homes that every proposal to forgo life-sustaining treatment from an elderly nursing home resident would be considered "a possible case of patient abuse," and that all such proposals must be reported to the Ombudsman's Office. The policy was widely rejected by both health care professionals and advocates for patients, leading ultimately to the Ombudsman's resignation. See "Controversial Patient Abuse Policy Chills NJ Nursing Home Decisions," *Medical Ethics Advisor* 5 (1989): 8; "NJ Hospital Association Sues Ombudsman Over 'Abuse' Guidelines," *Medical Ethics Advisor* 5 (1989): 38.

Article 80 of New York's Mental Hygiene Law.[10] Under Article 80, multidisciplinary committees decide about treatment for mentally ill and developmentally disabled individuals who reside in mental hygiene facilities and lack natural surrogates. Article 80 committees are organized and operated by the New York State Commission on Quality of Care for the Mentally Disabled. The committees function as quasi-judicial authorities, independent of any health care or mental hygiene facility.

Article 80 committees have provided a responsible and important forum for decisions for the special patient population they serve, helping to ensure that patients are not denied needed treatment because of the expense and delay of obtaining court approval. The program has been recognized as a model for decisions on behalf of the institutionalized mentally ill and developmentally disabled. It is unlikely, however, that the system could be expanded successfully to make decisions for all isolated patients in New York State. The interdisciplinary panels that function as decision makers under the Article 80 program are comprised of volunteers. Given the volume of cases that would arise if the program's jurisdiction were expanded to encompass all persons without surrogates in general hospitals and nursing homes, administration of the program would be unwieldy. The Task Force also believes that such an extensive system could not depend principally on donated service.[11] The lack of adequate resources for a statewide program represents another significant hurdle. Sufficient resources to

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[10]See N.Y. Mental Hyg. Law Article 80 (McKinney 1988 & Supp. 1992); M. Gold and L. Torian, "The Surrogate Decision Making Program: Final Evaluation Report," January 29, 1988; C. J. Sundram, "Informed Consent for Major Medical Treatment of Mentally Disabled People: A New Approach," *New England Journal of Medicine* 318 (1988): 1368-73.

[11]From May 1986 to July 1991, Article 80 committees considered 168 major medical treatment cases from the downstate areas of Bronx, Kings, Richmond, and Rockland counties. CQC, *Surrogate Project Report (May 1986 - July 1991)* (July 15, 1991) (available from CQC), 1. The number of cases would increase exponentially if the program covered all incapacitated patients statewide. Not only would the number of patients covered expand enormously, but their need for decisions would be dramatically higher. Unlike mental health facilities, which are homes for many individuals, patients admitted to an acute care facility are admitted to receive major medical treatment.

serve Article 80's existing target population, the residents of mental hygiene facilities, are not available.[12]

Finally, decisions by a committee outside the hospital or nursing home might not substantially improve decisions reached at the facility level. For example, data on the Article 80 program show that the committees have followed physician recommendations in all but a few cases.[13]

The Task Force Proposal: Deciding Within Health Care Facilities

The Task Force recommends that a facility-based procedure should be developed to make health care decisions for isolated, incapacitated individuals. The decision-making process should vary depending upon the nature of the treatment decision presented, with more serious decisions triggering more extensive review. The Task Force proposes three distinct processes for decisions depending on whether the decision involves routine treatment, major medical treatment, or a decision to forgo life-sustaining measures.

As with all patients, the decision-making procedures should be initiated only if health care professionals determine that the patient lacks capacity. If the patient objects to the determination of incapacity or to any treatment decisions made thereafter, the patient's objection or decision should prevail unless a court determines otherwise.

Physicians and facilities that now make treatment decisions for isolated patients without consultation or review may regard the proposed procedures as burdensome. However, the Task Force believes that many health care providers will welcome the policies as a vehicle to improve decision making by creating a clear, workable system. The policies also resolve the dilemma that confronts health care providers who care for isolated patients: the clear professional obligation to care for these patients and the inadequate legal basis for obtaining consent to treatment short of judicial intervention.

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[12] In 1990 the New York Legislature authorized expansion of the Article 80 program beyond the geographic areas where it functioned as a demonstration project, but public funds have not yet been appropriated to finance this expansion.

[13] CQC, 3.

The Decision-Making Standard

The Task Force proposes that the decision-making standards for isolated patients should be the same as those recommended for patients with surrogates. Treatment decisions should, to the extent possible, reflect the patient's health care wishes, preferences, and values. If these are not reasonably known, decisions should be made in accord with the patient's best interests. Decisions should not be based on a facility's or health care provider's financial or administrative concerns, although the Task Force does not intend by this to suggest that hospitals or nursing homes should be required to expand their existing equipment and facilities solely to provide treatments to isolated patients beyond the treatments provided to other patients.

In order to promote decisions based on patient preferences, hospitals and nursing homes should identify patients who appear to have no natural surrogate. As far as practicable, facilities should elicit these patients' preferences about the goals of treatment and pending health care decisions. The results of this discussion should be recorded in the medical record and should guide treatment decisions if the patient loses capacity. Health care providers should also make reasonable efforts to determine whether a patient who appears to have no involved family members or friends has appointed a health care agent or can identify a potential surrogate.[14]

Routine Treatment

Some medical procedures, such as drawing blood for tests or providing medication for high blood pressure, are minimally invasive, involve little or no risk to the patient, and are clearly beneficial. For procedures of this kind, physicians generally do not obtain a specific consent from the patient or others. Such treatments could be characterized as "routine." They involve judgments that are primarily medical in quality, although they may touch upon personal preferences or value judgments at the margin. In general, the greatest risks are posed when routine treatment is delayed or denied, not when it is provided.

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[14] A University of New Mexico project has developed, tested, and disseminated a "values history" document, designed to record isolated patient's health care wishes and to become a part of the admissions and medical record. See "Values History Project Confronts Questions Before Crisis Occurs," *Medical Ethics Advisor* 5 (1989): 155; P. Lambert, J. M. Gibson, and P. Nathanson, "The Values History: An Innovation in Surrogate Medical Decision-Making," *Law, Medicine and Health Care* 18 (1990): 202-12.

The Task Force proposes that the attending physician should be authorized to decide about routine medical treatment for patients without surrogates, a proposal that would bring existing law into line with existing practice. This policy would facilitate access to routine treatments for isolated patients without presenting a risk of serious harm.

Routine medical treatment should be defined as any routine health care, such as the administration of medication, the extraction of bodily fluids for analysis, or dental care performed with a local anesthetic, for which physicians do not ordinarily seek specific consent. This definition recognizes that some medication, as well as the extraction of bodily fluids for diagnostic purposes, such as a spinal tap or the removal of fluid from the pleural space surrounding the lungs, may involve serious risks. For this reason, physicians do not perform these tests without specific consent. In addition, some treatments are appropriately considered routine if intended for short-term use, but are invasive and burdensome if used for prolonged periods. For example, a nasogastric tube would be routine if needed for a brief period following recovery from surgery, but should be considered a judgment about major medical treatment if provided as a long-term solution to a permanent medical condition. The Task Force proposes that the concept of routine treatment should encompass consideration of the intended or actual duration of the treatment.

Major Medical Treatment

Apart from treatments that might be considered routine, most medical interventions are invasive. Many carry potential risks and entail the loss of privacy and autonomy. In each case, these burdens should be assessed in light of the benefits and overall goals of treatment. The Task Force proposes that decisions about treatments considered "major medical treatments" should be made by the attending physician in consultation with others.

Decisions about major medical treatment require substantial medical judgment but also incorporate important nonmedical considerations. One patient with a serious heart condition may choose a surgical intervention, while another favors long-term medication. The reasons may be more personal than medical. The deliberative process about major medical treatment is informed by individual judgments or attitudes about pain, disfigurement, disability, and risk. The value-laden nature of these decisions, as well as the greater risks and burdens imposed by major medical interventions, call for input beyond a unilateral decision by the attending physician.

The Task Force proposes that major medical treatment should be defined as any treatment, service, or procedure to diagnose or treat an individual's physical or mental condition: (i) where a general anesthetic is used; (ii) which involves any significant risk; (iii) which involves any significant invasion of bodily integrity requiring an incision, producing substantial pain, discomfort, or debilitation, or having a significant recovery period; or (iv) which involves a significant period of chemical or physical restraint.[15] Thus, for example, if the administration of medication involves serious risks, such as a course of cancer chemotherapy, the medication should be considered major medical treatment.

In deciding about major medical treatment, the attending physician should consult with the staff, such as the nurses, social workers, and nurses aids, who care for and know the patient best. Particularly in nursing homes, the attending physician may be far more distant from the patient than nurses and social workers who have regular, daily contact with the patient. These members of the health care team may be an important repository of information about the patient's preferences, personal needs, and values.

In nursing homes, the personnel consulted would most likely be members of the resident's interdisciplinary care team, the individuals responsible under New York State regulations for developing and implementing the resident's plan of care.[16] Although state regulations do not establish similar teams in hospitals, physicians should identify the nurses and others who have had regular contact with the patient. These professionals can help assure that physicians consider the personal dimension of the decisions and the patient's own preferences. If any of the individuals consulted by the attending physician conclude that the physician's decision does not reflect the patient's preferences or best interests, they should bring the case to the attention of the facility's bioethics review committee.

The Task Force also proposes prospective review and confirmation of the physician's medical judgment before decisions about major

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[15]This definition is similar to and drawn from the definition of major medical treatment in Article 80 of the Mental Hygiene Law. N.Y. Mental Hyg. Law § 80.03(a) (McKinney Supp. 1992)

[16]N.Y. Comp. Codes R. & Regs. tit. 10, § 415.11 (1991). Pursuant to this regulation, the members of the interdisciplinary care team must include "the attending physician, a registered professional nurse with responsibility for the resident, and other appropriate staff in disciplines as determined by the resident's needs." § 415.11(c)(2)(ii).

medical treatment are authorized and carried out for patients without a surrogate. Specifically, a second physician, designated by the hospital or nursing home, should evaluate the attending physician's recommendation. The second physician should examine the patient's diagnosis, prognosis, and treatment alternatives, as in an ordinary second opinion. In essence, this opinion gives isolated patients the benefit of the second opinion that many individuals pursue before undertaking surgery or other major interventions. The review also creates a check on the practice of allowing physicians to authorize unilaterally the often costly services for which they will be remunerated. If an unresolved difference of opinion arises between the attending and the confirming physician, the case should be brought to the bioethics review committee, which should issue a recommendation.

As defined by the Task Force, treatment involving any significant period of chemical or physical restraint would also be included in the category of major medical treatment. Both types of restraints can be extremely coercive, denying patients their dignity and the most basic human freedoms of thought and movement. Restraints may also impose significant medical risks.[17] New York State Department of Health regulations establish specific, detailed safeguards for the use of restraints in nursing homes.[18] Those safeguards, including the prohibition against using restraints for purposes of discipline or staff convenience, establish criteria and a process for decisions about restraints. The regulations require that the patient, or a person authorized to consent on the patient's behalf, provide consent before physical restraints may be administered, except in an emergency. The Task Force recommends that the attending physician should seek the consultation and confirmation needed for other major medical treatments before prescribing or authorizing physical or chemical restraints for a significant time period.

Forgoing Life-Sustaining Treatment

Decisions to forgo treatment that might prolong the patient's life present the greatest risk of harm from a wrongful choice and require the most profound judgments about the benefits and burdens treatment affords. These decisions pose more serious risks than decisions to provide major medical treatment that are also value-laden and

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[17] See the discussion above, chapter 1, 14.

[18] N.Y. Comp. Codes R. & Regs. tit. 10, § 415.4 (1991). The proposed legislation would not eliminate or diminish these safeguards but would provide a mechanism for consent within the framework established by the regulations.

subjective. For example, a decision to amputate a leg to prevent a deadly case of gangrene is an intensely personal choice; some patients would rather die than live without a limb. But the decision to provide a major medical treatment differs fundamentally from the refusal of the same treatment. The patient's continued life is the expected outcome of one, while the patient's death is the likely result of the other. The Task Force proposes that decisions to withhold or withdraw life-sustaining treatment should be subject to the closest scrutiny.

The treatments characterized as life-sustaining should not be restricted to those, such as dialysis or the artificial respirator, that are ordinarily included in this category. The Task Force recommends that life-sustaining treatment should be understood more expansively as any treatment or procedure without which the patient will die within a relatively short time, as determined by the attending physician, to a reasonable degree of medical certainty. Under this formulation, whether a particular treatment choice constitutes a decision to forgo life-sustaining treatment turns on the consequences of the treatment decision, not on the type of treatment. Returning to the case above, for example, a decision not to undergo a leg amputation, where the result will be death from gangrene within a relatively short period of time, would be considered a decision to forgo life-sustaining treatment. In contrast, the amputation, if provided, would be classified as major medical treatment. Likewise, if a patient would be likely to die within a relatively short time unless antibiotics are provided, a decision to refuse the antibiotics would be a judgment to forgo life-sustaining treatment, while a decision to provide antibiotics to cure an acute condition would constitute a decision about routine treatment.

Decisions to forgo life-sustaining treatment for isolated patients should be made in a process that draws upon the physician's medical judgment, a second medical opinion, the knowledge of other facility staff who have cared for the patient, and full consideration and approval of the decision by the bioethics review committee. The decision-making process will ordinarily begin with the attending physician. The attending physician should consult with health care personnel to gather all available medical and personal information about the patient. In developing a recommendation, the physician should also determine whether continued treatment would be an excessive burden to the patient in light of the substituted judgment and best interests standards. A second physician, designated by the facility, should review the attending physician's diagnosis and prognosis.

The committee's review should focus on these questions: Is the physician's recommendation to forgo life-sustaining treatment consistent with the patient-centered standards for surrogate decisions? Would treatment be an excessive burden for the patient? Does the decision comport with available knowledge about the patient's wishes, or if the patient's wishes are not reasonably known, the patient's best interests? Committee review should differ from the review that would take place for patients with a surrogate. The committee not only must decide whether the physician's recommendation meets the proposed standards and falls within the range of acceptable decisions but, in effect, acts as the decision maker. The committee should evaluate the physician's recommendation as a patient or surrogate ordinarily would, engaging in a discussion with the attending physician and others to ensure that its judgment is informed by the relevant medical and personal information available.

For some patients at the end stage of the dying process, physicians may recommend that all interventions to prolong the patient's life should stop and that the goal of treatment should be solely to care for the patient with palliative measures to ease pain and discomfort. In these cases, not just one but several technologies to sustain life may be withdrawn or withheld over time.[19] Physicians effectively are making a judgment about the overall course of care, not just individual treatments. Physicians should not have to seek committee review of each discrete treatment decision as it arises but should instead be able to obtain review of the decision to provide only palliative care. This option should be available for all patients, and is especially important to avoid unnecessary delay for patients without a surrogate.

The Task Force recommends that a hospital review committee considering a decision to forgo life-sustaining treatment for an isolated patient who has been transferred from a nursing home should consult with the nursing home staff that have known the patient. The potential to improve the quality of decision making at the hospital outweighs the administrative burden of this requirement. Members of the nursing home staff may spend years caring for residents who lack family or close friends and may come to know these residents well. If a nursing home resident is transferred to a hospital during his or her final illness,

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[19]Many hospitals, for example, have long had policies establishing different levels of care, including "palliative care only." See, for example, S. H. Miles and C. F. Gomez, *Protocols for Elective Use of Life-Sustaining Treatments* (New York: Springer Publishing Company, 1989).

the knowledge of the nursing home staff should be available as a resource for decisions at the hospital.

The full review committee, not just a subcommittee, should consider decisions to withdraw or withhold life-sustaining treatment for patients who have no surrogate. At a minimum, at least five committee members who meet the categories of membership required for any bioethics review committee, as well as a quorum of the entire committee, should participate in reviewing decisions to forgo life-sustaining treatment for these patients. In the unusual case that a review committee approves a decision that violates the decision-making standards or required procedures, members of the committee should inform the facility administration. Members should also be authorized to seek judicial intervention based on a good faith belief that the treatment decision and the committee's recommendation do not satisfy the standards and procedures set forth by the law.

The committee should issue a statement of reasons for its decision, and unlike cases where the committee acts in an advisory manner, committee records of decisions about life-sustaining treatment should be subject to review by the New York State Department of Health. These procedures will afford openness and accountability for these sensitive decisions.

Treatment Without Medical Benefit

The Task Force identified a narrow category of decisions that, like a decision about routine treatment, call for judgments and evaluations that are primarily medical in character. During the final days and hours of the dying process, many treatments offer no benefit for the patient. For some patients, treatments are continued in the final days of their dying process for the benefit of grieving family members who have not reconciled themselves to the patient's death. In rare cases, treatment to prolong the patient's life even at the end stage of the dying process corresponds to the patient's preferences. The Task Force recommends that decisions to forgo such treatments for patients in this condition who have no family members or others to act as surrogate should not require review by a bioethics review committee. Like all health care decisions, these decisions should accord with the patient's wishes or, if these cannot be ascertained, with the patient's interests.

The attending physician should determine whether the patient will die within a short time period even if treatment is provided. This finding should be made in accordance with accepted medical standards and to a reasonable degree of medical certainty. In light of the vulnerability

of isolated patients, a second physician should be consulted and confirmation of the attending physician's decision should be required. This second opinion will minimize the risk of error and the likelihood that physicians will rely upon an expansive or value-laden notion of futility in making these judgments. Unresolved differences of opinion between the attending physician and the consulting physician should be referred to the bioethics review committee for prospective review. Committee review of decisions for all patients who are imminently dying is not necessary and is likely to result in the provision of unnecessary, harmful treatment.

Recommendation

The Task Force recommends that a process based in health care facilities should be created to decide about treatment for adult patients who lack capacity and have no available surrogate. The process should provide an alternative for making decisions, but should not preclude health care professionals or other appropriate parties from seeking a court appointed guardian or judicial approval for a recommended course of treatment or for a particular treatment decision.

Decisions should conform to the patient-centered standards proposed for patients with surrogates, including, when applicable, the standards for withholding or withdrawing life-sustaining treatment. To facilitate decisions based on patient preferences, facilities should identify patients without involved family or friends and elicit their treatment wishes or the name of a surrogate if possible.

The attending physician should decide about routine medical treatment. A decision to provide major medical treatment should be authorized if the attending physician makes a recommendation, in consultation with other health care personnel directly involved in the patient's care, and a second physician concurs in the recommendation. The bioethics review committee should review disputes that arise among health care personnel about the decision.

A decision to forgo life-sustaining treatment should be authorized if (i) the attending physician recommends the withdrawal or withholding of treatment, in consultation with other health care personnel directly involved in the patient's care; (ii) a second physician concurs in the recommendation; and (iii) the bioethics review committee approves the recommendation. The review committee should issue a statement of its reasons for approving or disapproving the recommendation, and committee records concerning the decision should be

subject to review by the New York State Department of Health. If a general hospital patient has been transferred from a nursing home, a representative of the review committee should consult with nursing home personnel who cared for the patient.

A decision to forgo treatment should also be authorized if the attending physician determines, in accord with accepted medical standards and to a reasonable degree of medical certainty, that the patient will die within a short time even if treatment is provided, and a second physician concurs in this medical determination. The bioethics review committee should review the case if the attending physician and the physician consulted disagree about the imminence of the patient's death or other clinical judgments.

See Appendix A, proposed legislation, Section 7.

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Patients with Mental Disabilities

Each year, more than 500,000 persons receive treatment for mental illness in New York State. Approximately 25 percent are cared for in residential facilities.[1] Residential treatment is provided in diverse settings: state-operated psychiatric centers, psychiatric units in general hospitals, private psychiatric hospitals, community residences, family care homes, residential care centers, and special facilities for children.

More than 68,300 individuals receive services provided, funded, or certified by the Office of Mental Retardation and Developmental Disabilities.[2] These individuals have a broad range of chronic conditions that arise prenatally or in childhood and that substantially impair an individual's intellectual functioning or adaptive behavior. Conditions commonly identified as developmental disabilities include autism, cerebral palsy, epilepsy, mental retardation, and muscular dystrophy. The most profoundly impaired developmentally disabled persons usually reside in state-operated facilities that provide total care. Persons with the mildest impairments often live independently or with their families. Some reside in group homes. Fewer than 8,000 individuals still reside in developmental centers. Another 24,000 live in various types of community-based residential services. Most developmentally disabled persons live independently or with their families.[3]

Residents of Mental Health Facilities

Existing state statutes, as well as constitutional principles and regulations, guide and constrain decisions for the mentally disabled and, in particular, for residents of mental hygiene facilities. State laws authorize health care decisions by a court-appointed committee or

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[1]New York State, Office of Mental Health, *Annual Report*, 1987, 29-32.

[2]New York State, Office of Mental Retardation and Developmental Disabilities, *The Community Challenge*, July 1991, p. 49, fig. 3-15.

[3]New York State, Governor Mario Cuomo, *Message to the Legislature*, January 9, 1991, 55.

guardian.[4] Regulations issued by the Office of Mental Retardation and Developmental Disabilities and the Office of Mental Health allow family members and others on a list of potential surrogates to consent to proposed medical treatments for residents of mental hygiene facilities.[5] Treatments such as psychotropic medication are covered by specific regulations.[6] In addition, Article 80 of the Mental Hygiene Law establishes quasi-judicial committees to decide about major medical treatment for incapable residents of mental hygiene facilities who lack an available surrogate.[7]

The Task Force's current proposal does not encompass surrogate decisions for residents of mental hygiene facilities, except for decisions authorized by court order. Policies for mental hygiene residents must rest on a careful understanding and assessment of relevant state statutes, judicial decisions, and constitutional law. The special needs and concerns of mental hygiene residents must also be explored in relation to the particular problems presented by long-term care for mental illness.

The Task Force will deliberate about guidelines for surrogate decisions on behalf of mental health facility residents, in conjunction with those most concerned about the residents, including the appropriate executive agencies of state government and advocates for the mentally disabled. It does not believe that these policies must necessarily be considered and debated at the same time as the broader surrogate proposal.[8]

Currently, decisions about CPR for mental hygiene facility residents at certain facilities and in hospitals are governed by New York's DNR law. The Task Force proposes that these policies should remain in place until they are merged with comprehensive policies for surrogate decisions.

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[4]See discussion above, chapter 2, 38-39.

[5]See, e.g,. N.Y. Comp. Codes R. & Regs. tit. 14, § § 527(9)(b)(2)(i) and 633 (11)(a)(1)(iii)(b) (1991).

[6]E.g., N.Y. Comp. Codes R. & Regs. tit. 14, § 527(8)(c)(2)(ii)(1991).

[7]Article 80 committees are discussed in Chapters 2, 9, and 10.

[8]The Task Force took this same approach in relation to decisions about CPR, proposing policies for general hospitals and nursing homes and then turning to the more complex questions presented in mental hygiene facilities. When the legislature passed the DNR law in July 1988, policies for the mental hygiene facilities had already been incorporated.

At this time, the Task Force recommends one crucial change in state law on surrogate decisions for residents of mental hygiene facilities. Current New York law provides no legal foundation for decisions to forgo life-sustaining treatment for patients who do not have, and never possessed, the capacity to decide for themselves. Existing law requires clear and convincing evidence of a wish to forgo treatment. This standard is unattainable for those without the capacity to formulate such wishes. It is also inhumane, substituting a legal imperative to treat in all cases for a judgment about the limitations and benefits of modern medical technology for each patient.

The Task Force proposes that courts should be empowered to authorize decisions to forgo life-sustaining treatment for residents of mental hygiene facilities, as for all other individuals in New York State. The courts should assess the decisions under the substituted judgment and best interests standards embodied in the proposed legislation.[9]

The Mentally Disabled in the Community

Many individuals who are mentally disabled do not reside in mental health facilities – they live at home or in group homes. In New York City, a high percentage of the homeless are mentally ill. These individuals are routinely treated in hospitals, but are not covered by the same laws or regulations that apply to mental hygiene facility residents transferred to a hospital. The Task Force recommends that these individuals should be covered by the proposed surrogate policies, with special requirements for determining their capacity to decide about treatment.

Under this approach, the decision-making process for mentally disabled individuals in hospitals will depend on whether or not the individual has been transferred from a mental hygiene facility. Existing law and policies already distinguish the mentally disabled on this basis. In contrast to the body of statutes and regulations that apply to decisions for mental hygiene facility residents, a vacuum exists for individuals admitted to hospitals and nursing homes whose mental disability is recognized in the course of caring for them. The Task Force believes that these individuals are extremely vulnerable at present. They will be better served by the general surrogate policies proposed,

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[9]The majority of state courts in the country evaluate and authorize surrogate decisions relying on standards similar to those in the proposed legislation. See chapter 2, 35-36.

with special procedures for determining capacity, than by existing practice.

The DNR and health care proxy laws incorporate specific requirements for determining incapacity for patients who are mentally disabled.[10] Both require the participation of physicians or psychologists with specialized expertise and training to determine that a patient lacks decision-making capacity due to mental illness or developmental disability. Persons without the necessary expertise may err in two directions. They may too readily presume that persons are incapable because of their disability, or conversely, they may not appreciate the limitations of patients who appear lucid and capable.

The Task Force recommends similar requirements for surrogate decisions. A determination that a patient lacks capacity due to mental illness or developmental disability should require the participation of a health care professional who has specialized training or experience in diagnosing or treating mental illness or developmental disability of the same or similar nature.

Recommendation

Surrogate policies for residents of mental hygiene facilities raise complex legal, ethical, and social questions. The Task Force will recommend policies for these patients after examining existing New York law and policies and the particular problems presented for surrogate decisions by long-term mental illness. At this time, the Task Force proposes that at least one forum, the courts, should be authorized to approve decisions to withdraw or withhold treatment for residents of mental hygiene facilities, subject to standards in the proposed legislation. In addition, the DNR law should remain in effect for residents of mental hygiene facilities until comprehensive surrogate legislation is adopted.

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[10]The fact that an individual has a mental illness or developmental disability does not in itself establish that the individual lacks capacity to make health care decisions. In many cases, a mental disability affects some mental abilities without undermining others. For example, persons who are schizophrenic or have other serious mental disorders may be fully capable of making some or all health care decisions. A. Stone, "Informed Consent: Special Problems for Psychiatry," *Hospital and Community Psychiatry* 30 (1979): 326; S. Reiser, "Refusing Treatment for Mental Illness: Historical and Ethical Dimensions," *American Journal of Psychiatry* 137 (1980): 331. See N.Y. Pub. Health Law §§ 2963(3) and 2983(1) (McKinney Supp. 1992). New York's highest court has upheld the right of persons in mental health facilities to make treatment decisions unless the person has been determined to lack capacity by a judicial finding. *Rivers v. Katz*, 67 N.Y.2d 485, 504 N.Y.S.2d 74 (1986).

Mentally disabled individuals who are patients in a general hospital and have not been transferred from a mental hygiene facility are not covered by many of the same laws and regulations that apply to residents of mental hygiene facilities. The policies proposed for surrogate decisions generally should apply to these patients, with special requirements for determining incapacity.

See Appendix A, proposed legislation, Sections 2(2), 3(3), and 16(2).

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The Obligations of Health Care Professionals

Under the Task Force's proposal, physicians and other health care professionals have specific obligations, including the duty to determine incapacity and diagnose the medical conditions under which surrogates may decide to forgo life-sustaining treatment.[1] Health care professionals also have more general responsibilities to the surrogate, arising from their primary duty to care for the patient.

Talking to Patients

The availability of surrogate decisions for patients who have lost capacity does not diminish the duty of physicians to discuss treatment alternatives with the patient directly whenever possible. Physicians who have an ongoing relationship with patients should ask them about their wishes and values regarding treatment and encourage them to discuss their preferences with family members. Even if patients opt not to provide specific advance instructions, physicians can greatly enhance surrogate decisions and diminish the burden of decision making by engaging the patient in a dialogue about the goals of treatment.[2]

For patients with chronic and progressive diseases, physicians can often anticipate that the patient may lose decision-making capacity and that certain treatment choices are likely to arise. With these patients in particular, the physician should discuss treatment options and suggest that they appoint a health care agent or decide in advance about a course of treatment. Nurses and other health care professionals often play a critical role in this dialogue, encouraging both physicians and

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[1] See above, chapters 5 and 7.

[2] As discussed above in chapter 1, studies have consistently shown that patients want to discuss treatment alternatives, including life-sustaining treatment, and many expect their physician to initiate the conversation.

patients to start the conversation and assisting patients when necessary.[3]

Although some individuals who lack decision-making abilities are not able to communicate at all, others can converse on some level about their condition and care. Indeed, they often have questions and concerns and may have important information to offer. The existence of a surrogate does not relieve health care professionals of the obligation to communicate with the patient to the extent possible.

Patients should also be encouraged, if able, to make nonmedical decisions about their care. Allowing a patient to decide, for example, whether to take two injections at once or at separate times, expresses respect for the patient and may enhance a sense of control. It also reinforces the decision-making abilities of patients who may be able to regain capacity, or of minors who may come to develop such capacity.

Communicating with Surrogates

When a patient lacks capacity and a surrogate begins to decide about treatment on the patient's behalf, the obligations of health care professionals to care for the patient remain undiminished. However, the patient's loss of capacity triggers the surrogate's authority and responsibility to decide about treatment. Health care professionals must relate to and communicate with the surrogate accordingly. The physician must provide information to the surrogate, frame treatment options, and contribute an independent perspective in promoting the patient's wishes and interests.

The physician should provide a complete and straightforward explanation of the relevant medical circumstances to the surrogate. That explanation should include a discussion of the risks and benefits of any proposed treatment, as well as information about available alternatives. While the physician's recommendation about proposed treatment is an integral part of medical care, that recommendation should be distinguished from a clear statement of the medical facts necessary for the surrogate to make an informed judgment.

[3]In a recent study of New York's DNR law, 37% of critical care nursing directors offering comments reported that they frequently urge physicians to initiate discussions about DNR orders with their patients, despite physician reluctance. 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).

Formulating a Care Plan

The physician and surrogate should discuss the patient's overall course of care on an ongoing basis. Together they should formulate a comprehensive care plan based on treatment objectives that are appropriate in light of the patient's medical condition, as well as his or her wishes and preferences. Each patient's plan should be carefully tailored to reflect the medical and personal circumstances of that patient and should be reviewed regularly. The care plan offers a valuable framework for communication between the surrogate and health care professionals and allows for a coordinated course of treatment.

The comprehensive care plan also provides the context for particular treatment decisions. Physicians should seek the surrogate's consent whenever significant health care decisions arise. These decisions include the provision of major medical treatments, decisions not to provide treatments that could offer significant benefits to the patient, decisions among medically acceptable alternatives that entail differing risks and benefits, and decisions to withdraw or withhold life-sustaining treatment.

When patients have no surrogate, they do not have the benefit provided by two independent perspectives, that of the surrogate and the physician. A care plan may be even more important for these patients to assure that the overall goals of treatment have been identified and that decisions are not made by default. As discussed in Chapter Ten, health care professionals have special obligations for these patients.

Responding to Surrogate Decisions

The Task Force's proposal would grant surrogates the legal authority to make health care decisions following specified guidelines and procedures. Physicians and other health care professionals must honor surrogate decisions made in accord with these policies, unless they take steps to challenge the surrogate's decision or transfer the patient's care.

Disagreements between physicians and surrogates are bound to arise. In some cases, a surrogate may opt for a combination of treatments that would be inconsistent with good medical practice or insist on a treatment decision that a physician believes would harm the patient. In these and other circumstances, health care professionals may conclude that the surrogate's decision violates the proposed

standards, either because the surrogate is seriously mistaken or because the surrogate is acting in bad faith.

Whenever disagreement arises, the health care professional should discuss the matter with the surrogate. An unsound decision by a surrogate may well be changed by a conversation with a physician or other health care professionals. If the surrogate is not persuaded, physicians and other health care professionals have a professional, ethical, and legal obligation to challenge the surrogate's decision. The physician or any other health care professional responsible for the patient's care may ask the facility's bioethics review committee to consider the case. The attending physician must also refer a disagreement about life-sustaining treatment among the patient's family members or other potential surrogates to the review committee, if the dispute cannot be otherwise resolved.

In some cases, physicians or other health care professionals may believe that the surrogate's decision, although consistent with the proposed decision-making standards, violates their own religious beliefs or sincerely held moral convictions. When this occurs, health care professionals have the same obligations they would have if it were a patient's decision to which they objected. Health care professionals should inform the surrogate of their beliefs and cooperate in transferring care of the patient to another health care professional.[4]

Managing the Withdrawal or Withholding of Life-Sustaining Treatment

Physicians and other health care professionals must ensure that treatment orders are understood and communicated to all health care professionals responsible for the patient's care. A decision to withhold one life-sustaining treatment should not be interpreted as a decision not to provide other treatments. Too often, for example, a DNR order is interpreted as a "do not treat" order, denying patients with a DNR order the option to decide about other medical treatments.[5] As a result,

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[4]See chapter 13, discussing conscience objections of health care providers and facilities.

[5]Numerous studies as well as personal observations indicate that such misunderstanding of DNR orders is widespread. C. Joseph and W. Wanlass report: "When nursing home patients are transferred to the hospital, we have sometimes found that hospital staff: (1) express reluctance about admitting acutely ill DNR patients after emergency department evaluation, (2) are reluctant to offer surgery to patients with a DNR order, (3) require reversal of the DNR order prior to any

patients or surrogates who would otherwise refuse resuscitation may be unwilling to consent to a DNR order because of fears that the patient will be abandoned. In some cases, the same considerations that lead to a DNR order would suggest other measures to limit aggressive treatment. In other cases, CPR may be ineffective, but antibiotics or other life-sustaining procedures would offer clear benefits. Physicians should engage surrogates in a dialogue about specific life-sustaining measures. A decision to forgo one or more forms of life-sustaining treatment must not be viewed as a signal to abandon the patient.[6]

Physicians should also review any orders or plan to forgo life-sustaining treatment, in accord with good medical practice. The Task Force recommends that hospitals and nursing homes should prepare written guidelines for this review. In addition to periodic review, physicians should note any change in the patient's condition that might prompt reconsideration of the decision to forgo treatment and should cancel the decision when appropriate.

Health care professionals also have an obligation to convey complete and accurate medical information whenever a patient is transferred from their care. If the patient is transferred to another health care facility, the transferring facility should assure that any orders or plan to withhold or withdraw life-sustaining treatment, such as a DNR order, accompany the patient. The order should remain effective at the receiving facility until the patient is examined by an attending physician, who must either reissue the order or cancel it and inform the person who consented to the order and the facility staff directly responsible for the patient's care.

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surgery, and (4) deny admission to the intensive care unit for patients who have a DNR order." "DNR Orders," *Journal of the American Geriatrics Society* 39 (1991): 1142. Baker et al. found that over 40% of health care professionals surveyed in New York reported that a DNR order is interpreted as a signal to withhold life-sustaining measures other than CPR. Similar responses to DNR orders are documented by, e.g., H. L. Lipton, "Do-Not-Resuscitate Decisions in a Community Hospital: Incidence, Implications, and Outcomes," *Journal of the American Medical Association* 256 (1986): 1168; and D. R. Berlowitz, S. V. B. Wikling, and M. A. Moskowitz, "Do-Not-Resucitate Orders at a Chronic Care Hospital," *Journal of the American Geriatrics Society* 39 (1991): 476.

[6]As eloquently stated by ethicist Paul Ramsey: "Desertion is more choking than death, and more feared. The chief problem of the dying is how not to die alone. To care, if only to care, for the dying is, therefore, a medical-moral imperative: it is a requirement of us all in exhibiting faithfulness to all who bear a human countenance." *The Patient as Person* (New Haven: Yale University Press, 1970), 134.

These proposed policies are identical to those now embodied in New York's DNR law.[7] They are designed to ensure continuity of care and to avoid the necessity of obtaining a new consent for decisions to forgo treatment when patients are transferred. The policies also recognize that physicians at the receiving facility may identify legitimate reasons for canceling the order and that they cannot in any event be bound by an order or plan of care entered by a physician at another facility.

Protection from Liability

In recent years, concerns about liability have asserted greater influence over the practice of medicine. While health care professionals must be aware of their legal responsibilities, fear of criminal and civil liability can distort the decision-making process by displacing patient care as the pivotal focus of the decision.[8]

Protecting health care professionals and facilities from liability in appropriate cases, while beneficial for providers, also confers tangible benefits for patients. Equally important, health care professionals and facilities should not be forced to choose, as they must now in some cases, between appropriate medical treatment for their patients and the risk of civil or criminal liability.

The Task Force believes that health care professionals and facilities who honor in good faith treatment decisions made by surrogates and others in accord with the policies proposed, should be protected from criminal sanctions, civil liability, and professional penalties. This protection, however, should extend only to claims based on the professional's good faith reliance on a surrogate's decision. For example, physicians should be required to obtain informed consent from a surrogate, as they would from a patient. Moreover, all health care

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[7]N.Y. Pub. Health Law § 2971 (McKinney Supp. 1992). In 1991, this provision was amended to underscore the fact that physicians need not obtain a new consent to enter the DNR order at the receiving facility. Instead, if they do not reissue the order, they must inform the person, patient or surrogate, who consented to the order.

[8]For example, the Harvard Medical Practice Study Group conducted a series of physician surveys, which revealed that the overall perceived risk of being sued in a given year was 20%, approximately 3 times the actual risk of being sued. Physicians who perceived themselves to be at greater risk of suit said that in the past 10 years they had ordered more tests and procedures and reduced their practice scope more than had their colleagues with less perceived risk. "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, 9-10.

professionals should remain obligated to provide medical treatment in accordance with applicable standards of care. Thus, a physician would not be protected from liability if he or she failed to meet applicable standards of skill and care in making the medical diagnoses required by the legislation or in carrying out the surrogate's decisions.

Recommendation

Physicians and other health care professionals should assist patients to plan in advance by choosing a health care agent, and discussing their treatment values and preferences, and decisions. Once the patient has lost decision-making capacity, the physician should communicate effectively with the surrogate, enabling him or her to make an informed decision on the patient's behalf.

The physician and surrogate, in conjunction with other health care professionals, should formulate a care plan based on treatment objectives that are appropriate in light of the patient's medical condition as well as his or her wishes and preferences. Physicians should review an order or plan to forgo life-sustaining treatment in accord with accepted medical standards and facility guidelines for this review. If the patient is transferred from one facility to another, an order or plan to forgo treatment should remain effective unless canceled.

Health care professionals and facilities that honor surrogate decisions in good faith in accord with the standards proposed, should be protected from civil and criminal liability and from penalties for professional misconduct.

See Appendix A, proposed legislation, Sections 6, 9, 10, and 13.

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Responding to Conscience Objections

In some cases, treatment choices by patients or surrogates conflict with the moral, religious, or professional convictions of those who provide health care, including physicians and nurses. Health care facilities may also object to honoring certain treatment decisions because of religious or moral principles embraced by the facility.

Generally, professionals or facilities object on grounds of religious or moral conscience to decisions about life-sustaining treatment. Initially, conscience objections focused on withdrawing artificial respiration. Currently, objections are more likely to arise in response to decisions about artificial nutrition and hydration.

In the past several years, a different kind of conscience case has also emerged. Health care professionals and facilities have begun to object on grounds of professional or moral conviction to decisions to continue life-sustaining treatment that they regard as futile or not medically indicated. These objections reflect a judgment that the provision of treatment would violate the provider's professional integrity and commitment to the patient.[1]

Objections by Health Care Professionals

Physicians are not legally required to honor a treatment decision that contravenes their religious, moral, or professional convictions.[2]

[1]See chapter 14 for discussion of medical futility.

[2]New York law formally recognizes that physicians do not engage in unprofessional conduct if they refuse to perform an act that constitutes medical practice because of their religious belief or training. N.Y. Educ. Law § 6527(4)(c) (McKinney 1985). Explicit legal protection extends to all health care professionals for decisions not to honor a DNR order. N.Y. Comp. Codes R. & Regs. tit. 10, §§ 405.43(e)(2)(v) and 405.43(f)(6)(v) (1988). Section 79-i of the New York Civil Rights Law bars facilities from discriminating against employees who refuse to participate in an abortion because it violates their moral or religious beliefs. (McKinney 1976).

Instead, physicians may withdraw from the case and transfer care of the patient to another physician willing to honor the patient's or surrogate's decision. Physicians may not simply abandon patients; they remain responsible for a patient's care until transfer to another physician has occurred.[3] Special legal protection exists for health care professionals who decide not to assist or perform an abortion.[4]

Under New York's health care proxy law, health care professionals may refuse to honor a decision by an appointed health care agent on grounds of religious or moral belief, provided the professional would object to the same decision if made by the patient when competent. Professionals must inform the agent and the health care facility promptly of their objection and cooperate in transferring the care of the patient to another professional.[5]

The Task Force believes that individual health care professionals should not be legally obligated to carry out decisions that contravene their religious or moral convictions. This respect for individual convictions should extend to decisions to provide treatment as well as decisions to refuse. The Task Force recommends that a policy similar to the policy in the health care proxy law should be adopted for individual conscience objections to surrogate decisions.

A health care professional should be required to inform the surrogate and the facility promptly of an objection and should cooperate in transferring care of the patient to another health care professional. The burden of effecting the transfer should rest on the facility, recognizing that for some professionals responsibility for carrying out the transfer would also violate their convictions.

In cases involving claims by individuals seeking to exercise their First Amendment right to free exercise of religious belief, the courts have consistently examined the sincerity of the individual's religious beliefs, but not the content of the beliefs.[6] The Task Force endorses this

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[3]See, e.g., *Shapira v. United Medical Service, Inc.*, 15 N.Y.2d 200, 213-14, 257 N.Y.S.2d 150 (1965).

[4]See above at note 2, N.Y. Educ. Law § 6527(4)(c), N.Y. Civ. Rights Law § 79-i.

[5]N.Y. Pub. Health Law § 2984(4) (McKinney Supp. 1992).

[6]See, e.g., *United States v. Ballard*, 322 U.S. 78 (1944); *Int'l Soc'y for Krishna Consciousness, Inc. v. Barber*, 650 F.2d 430 (2d Cir. 1981); *Sherr v. Northport-East Northport Union Free School Dist.*, 672 F. Supp. 81, 94 (E.D.N.Y. 1987). The health care proxy law requires that moral convictions must be "sincerely held" but does not impose the same requirement on religious convictions. Consistent with First Amendment principles, the courts are likely to conduct the inquiry of sincerity in a

approach for conscience objections on religious or moral grounds by health care providers. Refusals on grounds of conscience should be based on clearly articulated and sincerely held moral or religious convictions; they should not be used to mask other personal interests, such as the desire to avoid a situation that the physician or other health care professionals may find difficult or demanding.

The Task Force does not propose restricting conscience objections to cases when the health care professional would object if the same decision had been made by a patient. That provision in the proxy law reflects the special status of decisions made by a health care agent, selected by the patient and explicitly authorized to decide on his or her behalf.

Objections by Health Care Facilities

Like principles underlying First Amendment protection for religious belief, conscience objections in the health care context are premised on the notion that individuals cannot be forced to engage in conduct that violates personal, religious, or moral beliefs. However, questions about how institutions "hold" beliefs, and how those beliefs are identified, are complex. Institutions do not have the same personal rights as individuals, although some legal commentators have argued that institutions can be understood to hold beliefs as an aggregate of the individuals that belong to the institution. Institutions may also be seen to have a sense of integrity or mission that reflects a particular moral or religious vision.[7]

In New York State, both the courts and the legislature have addressed the right of institutions to object on grounds of conscience to treatment decisions. Court cases involving decisions to withdraw life-sustaining treatment have yielded diverse precedents. Two decisions — *Delio v. Westchester County Medical Center* and *Elbaum v. Grace Plaza of Great Neck, Inc.* — illustrate the diverse approaches adopted by New York courts.

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contested case. In any event, the Task Force believes that convictions that are not "sincerely held" should not be protected.

[7]See, e.g., I. C. Lupu, "Free Exercise Exemption and Religious Institutions: The Case of Employment Discrimination," *Boston University Law Review* 67 (1987): 391-442; S. H. Miles, P. A. Singer, and M. Siegler, "Conflicts Between Patients' Wishes to Forgo Treatment and the Policies of Health Care Facilities," *New England Journal of Medicine* 321 (1989): 48-50; K. W. Wildes, "Institutional Integrity: Approval, Toleration and Holy War or Always True to You in My Fashion," *Journal of Medicine and Philosophy* 16 (1991): 211-20.

In *Delio*,[8] the court authorized the withdrawal of artificial nutrition and hydration from a permanently unconscious patient, but permitted the facility to decline, on conscience grounds, to terminate treatment at the facility. Instead, the court ordered the hospital to cooperate in transferring the patient to another facility where treatment could be discontinued.[9]

In *Elbaum*,[10] a facility also objected to the removal of a feeding tube from a permanently unconscious patient. In that case, the court upheld the family's request to withdraw artificial feeding and hydration from Ms. Elbaum and ordered the facility to carry out the decision within 10 days if it could not transfer the patient to a facility willing to honor the family's wishes. In reaching its decision, the court noted that the facility did not have a written policy against discontinuing artificial nutrition and hydration and that the facility had not informed the patient's family of the policy prior to admission or in a reasonable time thereafter.[11]

The legislature has also addressed the issue of conscience objections by health care facilities. New York's health care proxy law specifies the conditions under which facilities can object, on religious or moral grounds, to treatment decisions by a health care agent.[12] The proxy law recognizes that private facilities may object to an agent's decision if the facility would object to the same decision by the patient. Health care facilities must assert that the decision is "contrary to a formally adopted policy that is expressly based on religious beliefs or sincerely held moral convictions central to the facility's operating principles" and the hospital or nursing home would be permitted by law to refuse to honor the decision if made by the patient.[13] Facilities must also inform patients or the agent prior to or upon admission about their conscience policy. If a conflict arises, the facility must cooperate

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[8] 129 A.D.2d 1, 516 N.Y.S.2d 677 (2d Dep't 1987).

[9] Similar decisions from other states include *Brophy v. New England Sinai Hosp., Inc.*, 398 Mass. 417, 497 N.E.2d 626 (1986) and *In re Morrison*, 206 Cal. App. 3d 304, 253 Cal. Rptr. 530, 535 (1st Dist. 1988).

[10] 148 A.D.2d 244, 544 N.Y.S.2d 840 (2d Dep't 1989).

[11] Similar decisions from other states include *In re Jobes*, 108 N.J. 394, 529 A.2d 434 (1987) and *McConnell v. Beverly Enterprises*, 209 Conn. 692, 553 A.2d 596 (1989).

[12] N.Y. Pub. Health Law § 2984(3) (McKinney Supp. 1992). For a further discussion of the proxy law's provisions on institutional conscience objections see T. E. Miller, "Public Policy in the Wake of *Cruzan:* A Case Study of New York's Health Care Proxy Law," *Law, Medicine and Health Care* 18 (1990): 363-64.

[13] Ibid.

in transferring the patient to a facility willing to honor the decision. If no such facility is available or the transfer is not accomplished for other reasons, the facility must seek judicial relief.

The Task Force believes that significant respect should be accorded convictions identified by private health care facilities as fundamental or essential to their mission and continued operation. This respect acknowledges the personal commitments of the individuals that manage and work for the facility. It also allows a facility as a community of individuals to embrace a distinctive set of religious commitments or a particular moral vision that guides their collective enterprise. The same deference should not be extended to public institutions. Supported entirely by society at large, public health care institutions should be obligated to honor the full spectrum of choices recognized in our laws and public policies.

As with individual conscience objections, the Task Force suggests that policies for institutional conscience objections should be similar to policies currently embodied in New York's health care proxy law. Conscience objections should reflect a formally adopted policy expressly based on sincerely held religious beliefs or moral convictions central to the facility's operating principles.[14] Facilities should be obligated to inform patients or their surrogates about the policy in advance of admission whenever possible. The facility must also cooperate in transferring the patient to a facility willing to honor a decision to which it objects. In contrast to the proxy law, conscience objections should not be restricted to cases when the health care facility would object to the decision if it had been made directly by the patient.

For health care facilities operated or sponsored by religious communities, beliefs are defined by a body of authoritative teaching or religious doctrine, although the particularized facts of medical cases frequently call for an interpretation of general principles, and interpretations may differ. Moral convictions vary more widely and are not constrained or delineated by reference to one particular body of beliefs. Sincere moral convictions that are central to a facility's operation should be respected. The broad rubric of moral convictions, however, should not serve as a placeholder for policies motivated by concerns about liability or other administrative interests.

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[14] As with individual beliefs, the proxy law requires that moral, but not religious, beliefs must be "sincerely-held." Consistent with and drawn from First Amendment principles, the sincerely held requirement should apply equally to objections based on religious as well as on moral convictions.

The Task Force believes that recognizing the moral convictions of private facilities creates the potential for abuse, especially in New York State, where fears about liability often drive the decision-making process. The Task Force recommends that stringent standards and procedures should be applied in assessing the legitimacy of institutional conscience objections. Facilities generally have greater resources and access to legal counsel than individuals. A facility invoking conscience in refusing the request of a surrogate should therefore be responsible for initiating legal proceedings, if the dispute cannot otherwise be resolved. The facility should also bear the burden of showing that the surrogate's decision contravenes a formally adopted policy that is expressly based on sincerely held religious beliefs or on sincerely held moral convictions central to the facility's operating principles. In this inquiry, the actions of the facility in other cases and in response to other patients should be assessed carefully to determine if the stated conscience objection is consistent with the overall pattern of practices at the facility.

The right of facilities to refuse to honor a treatment decision on grounds of conscience must be balanced against the rights of patients or their surrogates to decide about treatment. Accommodating facility objections by transferring a patient to another institution can impose significant burdens on a patient and family. This is especially true for long-term care residents who may have lived in a facility for months or years and developed personal attachments to the institution, other residents, and the staff. In some instances, another facility willing to honor the resident's or surrogate's decision may not be available or accessible to the resident's family. In such cases, or if the transfer is not accomplished for other reasons, the facility should honor the surrogate's request or seek judicial relief.

Recommendation

Nothing in the Task Force's proposal should be construed to require a health care professional to carry out a treatment decision that contravenes the individual's sincerely held religious or moral convictions. In these cases, the health care professional should promptly inform the person who made the decision, and the facility, of his or her refusal to honor the decision. With the cooperation of the health care professional, the facility should then promptly transfer responsibility for the patient to another health care professional willing to honor the decision.

Nothing in the proposal should be construed to require a private hospital or nursing home to honor a health care decision if the decision is contrary to a formally adopted policy of the facility expressly based on sincerely held religious beliefs or sincerely held moral convictions central to the facility's operating principles. This provision applies only if the hospital or nursing home has informed the patient or family of the policy prior to or upon admission, if reasonably possible, and the patient is transferred promptly to another facility that is reasonably accessible under the circumstances and willing to honor the decision. If the patient's family is unable or unwilling to arrange such a transfer, a hospital or nursing home may intervene to facilitate such a transfer. If such a transfer is not effected, the facility must seek judicial relief or honor the decision.

See Appendix A, proposed legislation, Section 12.

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Medical Futility: Defining the Limits of the Duty to Treat

Increasingly, physicians and hospitals have asserted a right not to provide treatment they consider medically futile. Discussion of the duty of physicians to talk to patients or families about treatment they regard as futile, or to provide such treatment, often focuses on decisions about cardiopulmonary resuscitation. In New York, debate has centered on New York's law on DNR orders.

Recent cases have highlighted the significance of the issue for other treatments. For example, in a case reported in 1990, physicians refused to provide artificial respiration to assist the breathing of a severely handicapped, two-year-old girl. The girl's mother requested the treatment, but physicians asserted that the treatment would be futile and inconsistent with the child's best interests.[1] In the case of Helga Wanglie, an 86-year-old woman who was permanently unconscious, the Hennepin County Medical Center in Minneapolis sought a court order to discontinue artificial respiration. Physicians at the hospital maintained that treatment was medically futile because it could no longer serve the personal interests of a patient in Ms. Wanglie's condition. Ms. Wanglie's husband and children wanted treatment continued, stating that the patient had previously expressed the wish that "she did not want anything done to shorten or prematurely take her life."[2]

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[1]J. Paris, R. K. Crone, and F. Reardon, "Physicians' Refusal of Requested Treatment: The Case of Baby L," *New England Journal of Medicine* 322 (1990): 1012-15. Baby L suffered from extensive neurological impairment. The authors report that her care was transferred to another physician. Two years later, Baby L had survived and was living with her parents but required intensive home nursing care; she was blind, deaf, and quadriplegic, with the mental status of a three-month-old infant. Responses to this case are found in "Point-Counterpoint: Physicians' Refusal of Requested Treatment," *Journal of Perinatology* 10 (1990): 407-15.

[2]"Hospital Opposes Family, Seeks Termination of Treatment," *Medical Ethics Advisor* 7 (1991): 17-19; L. Belkin, "As Family Protests, Hospital Seeks an End to Woman's Life Support," *New York Times* January 10, 1991, sec. A, p. 1. On July 1, 1991, a

Defining Futility

Any discussion of medical futility is complicated by the diversity of physicians' understandings of the term. As noted by the Council on Ethical and Judicial Affairs of the American Medical Association: "The term *futility* does not express a discrete and identifiable quantity, but rather encompasses a range of probabilities and is likely to be interpreted in different ways by different physicians. Determinations of futility also may vary from one physician to another based on the perceived objectives of medical treatment and the criteria that are used to evaluate outcome."[3]

Some physicians use "futile" narrowly, considering treatments to be futile if they would be physiologically ineffective or would fail to postpone death, "by even a few minutes."[4] New York State's DNR law defines "medically futile" to mean that "cardiopulmonary resuscitation will be unsuccessful in restoring cardiac and respiratory function or that the patient will experience repeated arrest in a short time before death occurs."[5]

Many physicians embrace a broader, more elastic understanding of the term. Assessments of futility may represent a judgment that a given result is highly unlikely, even if not absolutely impossible. Commentators report that "some physicians may only invoke futility if the success rate is 0 percent, whereas others invoke futility for treatments with success rates as high as 13 percent."[6]

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court rejected a petition to appoint an independent conservator and designated Ms. Wanglie's husband, Oliver, as conservator. Helga Wanglie died three days later. For further discussion of the case, see A. M. Capron, "In Re Helga Wanglie," *Hastings Center Report* 21, no. 5 (1991): 26-28; S. H. Miles, "Informed Demand for 'Non-Beneficial' Medical Treatment," *New England Journal of Medicine* 325 (1991): 512-15. For further discussion of decisions about life-sustaining treatment for permanently unconscious patients, see above, chapter 3.

[3]"Guidelines for the Appropriate Use of Do-Not-Resuscitate Orders," *Journal of the American Medical Association* 265 (1991): 1870.

[4]S. J. Youngner, "Who Defines Futility?," *Journal of the American Medical Association* 260 (1988): 2094-95. See also "Point-Counterpoint," statements by A. R. Fleischman (407), and by R. H. Perelman and N. C. Fost (413).

[5]N.Y. Pub. Health Law § 2961 (McKinney Supp. 1992).

[6]J. D. Lantos et al., "The Illusion of Futility in Clinical Practice," *American Journal of Medicine* 87 (1989): 82. These authors argue that "futility cannot be defined with precision, but is simply the end of the spectrum of low-efficacy therapies." Others propose that a treatment should be regarded as futile if it has not worked in the last hundred cases. L. J. Schneiderman, N. S. Jecker, and A. R. Jonsen, "Medical Futility:

Some physicians might regard a treatment as futile if it could not preserve a patient's life for what they consider a significant length of time; for example, if CPR could prolong life for a few days or weeks but would not allow a patient to survive until discharge from the hospital.[7] Some broadly define treatment as futile if it cannot improve "the patient's prognosis, comfort, well-being, or general state of health. A treatment that fails to provide such a benefit – even though it produces a measurable effect – should be considered futile."[8]

Following this approach, a treatment might be seen as futile if it does not offer what physicians consider an acceptable quality of life. For example, in one survey, a majority of physicians agreed that for a severely demented patient with Alzheimer's disease, CPR would be "so clearly inappropriate or futile on medical grounds that physicians should be permitted to institute DNR status based on clinical judgment, without obtaining consent."[9]

The Significance of Futility

Underlying the debate about medical futility are basic assumptions about the ability of patients and family members to decide about treatment, the importance of their participation in treatment decisions, and the balance that should be struck between the authority of patients and the authority of physicians. Concerns about resource allocation have also fueled the futility debate.

Several approaches to futility have been proposed. Under one approach, physicians may decide not to provide a treatment on grounds of futility without informing the patient or family. Some agree that physicians have the authority to make decisions based on futility,

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Its Meaning and Ethical Implications," *Annals of Internal Medicine* 112 (1990): 951-52.

[7]See, e.g., American Medical Association, 1870.

[8]Schneiderman, Jecker, and Jonsen, 950. See also L. J. Blackhall, "Must We Always Use CPR?," *New England Journal of Medicine* 317 (1987): 1284; and the statement of Stanley J. Reiser, quoted in Belkin.

[9]N. Spritz, "Views of Our Membership Concerning the DNR Issue and the New York State DNR Law," 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). Seventy-seven percent of respondents agreed that physicians should be able to institute DNR status unilaterally based on futility in some cases, and 75% of that group believed that they should be able to do so for the patient with severe Alzheimer's disease.

but urge that they should discuss their decisions with the patient or surrogate. Others argue that the patient or surrogate should make most significant treatment decisions, even when futility is invoked, with the physician playing an advisory role.

At one extreme, some contend that physicians need not discuss treatments that they consider futile with a patient or family members. Responding to New York's DNR law, some physicians have urged that physicians should be granted unilateral authority to decide about CPR because severely ill patients or those close to them cannot make a rational choice. As stated by Dr. Kenneth Praeger, "Critically ill patients often cannot cope with the stress of discussing the possibility of their imminent death and of rationally weighing the pros and cons of CPR. They often have no idea of what the procedure involves and of the possible state to which they might be restored in the event of a 'successful resuscitation.'"[10]

Other physicians echoed these concerns about the DNR law, asserting that discussions about CPR cause therapeutic harm.[11] Some physicians asserted that doctors could know their patients' wishes and need not ask when they determine that CPR is not medically appropriate in their judgment.[12]

The Task Force rejects each of these arguments as a basis for granting physicians unilateral authority to decide about CPR or other treatments on the grounds of medical futility. The paternalistic notion that physicians should make decisions without consulting their patients because patients are incapable of making an informed or rational choice flies in the face of principles embraced in the past decade of discussion about medical advances.[13] It is also at odds with profes-

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[10]K. Praeger, "How CPR Can Threaten the Desperately Ill," *Wall Street Journal*, March 9, 1989, 16. See similarly D. J. Murphy, "Do-Not-Resuscitate-Orders: Time for Reappraisal in Long-term—Care Institutions," *Journal of the American Medical Association* 260 (1988): 2099. While Murphy acknowledges that discussion even about these decisions would provide some benefits to patients and family members, he suggests that "time would be better spent discussing other therapies and plans."

[11]F. Rosner, "Must We Always Offer the Option of CPR: The Law in New York," *Journal of the American Medical Association* 260 (1988): 3129.

[12]P. Swender, "Reflections on the New York Do-Not-Resuscitate Law," *New York State Journal of Medicine* 89 (1989): 57-58.

[13]Testifying about the therapeutic exception to consent at hearings on New York's DNR law on behalf of a coalition of organizations that advocate for nursing home residents, Nelly Peissachowitz stated: "The aged have, during their lifetime, faced traumatic experiences, they have suffered losses, but they have coped and they have

sional standards of practice.[14] This position should not be condoned or adopted in the context of policies about medical futility.

The fact that some patients facing imminent death may find it difficult to decide about CPR does not suggest their failure, but the failure of physicians to raise the issue at an earlier time. Indeed, Dr. Praeger's comments beg the question of why he, and other physicians, wait until their patients enter the last stages of the dying process before raising the question of CPR. Some patients might want to refuse the treatment earlier. As shown by many studies, most would appreciate the respect and control such a conversation accords.[15]

Studies have also shown that unless physicians ask patients about their treatment wishes, they fare no better than chance alone at estimating what their wishes might be. Surrogates are not always familiar with the patient's wishes, but are more likely than physicians to approximate the patient's choice.[16]

In addition, studies of the DNR law do not support either the assumption that patients and families make poor choices by routinely opting for futile treatment or that involving patients and families in the decision-making process will lead to more futile treatment. Studies of actual practices before and after implementation of the DNR law consistently show that the provision of CPR did not increase after the

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survived. Most of the aged have made, or are in the process of making, their own decision regarding disposal of their belongings. They've arranged for a burial place and have expressed their wishes regarding disposal of their remains. We know that many have donated their organs, they have executed their will and indicated whether they wish to be cremated or not. The same individuals, we feel, can be trusted to express their wishes should they be faced with cardi[a]c or respiratory arrest in ca[s]e of hopeless illness. The medical assumption of possible harm in raising this issue is really, at best, an assumption." N. A. Peissachowitz, Testimony on behalf of the Nursing Home Community Coalition of New York State, New York State, Assembly and Senate Health Committees, *Public Hearing on Legislation Regarding the Issuance of Do Not Resuscitate Orders*, New York, February 12, 1987, 125.

[14]As stated by the American Medical Association Council on Judicial and Ethical Affairs in its most recent guidelines on DNR orders (1871): "Patients who are at risk of cardiac or respiratory failure should be encouraged to express, in advance, their preferences regarding the use of CPR. These discussions should include a description of the procedures encompassed by CPR and, when possible, should occur in an outpatient setting when general treatment preferences are discussed, or as early as possible during hospitalization, when the patient is likely to be mentally alert."

[15]See chapter 1, 8-10, 15.

[16]See chapter 1, 6-8.

law was implemented.[17] The largest study conducted to date also found that the law did not significantly alter the medical condition of the patients for whom the orders were entered, with the sickest patients most likely to have DNR status before and after the law.[18]

Some of those who have advocated a medical futility exception to the duty to provide treatment, or to consult patients or surrogates about decisions, have explicitly urged that the need to ration medical care justifies this approach.[19] The Task Force agrees that our current health care system lacks coherent, equitable policies to allocate health care resources. It does not believe, however, that such allocation should or can be achieved by the judgments of individual physicians or that the concept of medical futility should be a placeholder for those rationing choices. Rationing by individual physicians cannot yield coherent, fair policy. The judgments of individual physicians about the quality of life achieved by treatment are likely to vary as much as the views of patients. Access to treatment will then depend on the personal, religious, and moral views of each doctor, under the broad rubric of "medical futility."

A final major force driving the debate about medical futility is the growing body of data available about the poor outcomes of treatment for patients in certain medical conditions. Based on this data, physicians are able to determine that for certain patients, such as those in the final stages of a terminal illness, certain treatments offer no hope of cure or improvement and limited, if any, chance for prolonging life.[20]

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[17]Based on anecdotal evidence, physicians and others have asserted that the DNR law increased futile CPR. No studies of the law support this claim. The studies do suggest, however, that physicians hostile to the notion of talking to patients or family members about CPR are most likely to report an increase in futile CPR. By their silence, some physicians effectively opt to impose CPR they deem futile on their patients.

[18]J. C. Ahronheim, S. Maheswaran, and C. Rosenberg, "Impact of Do-Not-Resuscitate Legislation on the Use of Cardiopulmonary Resuscitation in Three Teaching Hospitals," *New York State Journal of Medicine*, forthcoming. The authors stated that they undertook the study to confirm the "impression on the part of some of our colleagues that the DNR law was leading to an increase in the number of medically inappropriate resuscitations." They concluded that the study failed to confirm that observation. See similarly R. S. Kamer et al., "Effect of New York State's Do-Not-Resuscitate Legislation on In-Hospital Cardiopulmonary Resuscitation Practice," *American Journal of Medicine* 88 (1990): 108-11.

[19]See, e.g., Murphy, 2100. Others who agree that physicians should be able to withhold treatment based on futility insist that resource considerations must remain separate from the futility debate. Schneiderman, Jecker, and Jonsen, 953.

In light of this data, some commentators have argued that physicians should be able to decide not to provide treatment they judge to be futile, although they should first talk with the patient or surrogate. Most treatments impose risks and harms to patients. These commentators urge that physicians should be able to refrain from performing interventions when they determine that the risk of significant harm far exceeds potential benefits. Physicians and other health care professionals feel frustrated when forced to provide treatment that they deem futile. Health care professionals may also believe that providing such treatment violates their personal and professional integrity.[21]

Commentators have also argued that physicians should not "offer" treatments to patients or surrogates that they believe to be futile, because this falsely implies that the physician believes the treatment is a reasonable option. At the same time, some have noted that conversations between physicians and patients or surrogates, even about futile treatments, can provide important benefits and safeguards.[22] Discussion with patients and family members manifests respect for them, promotes trust in the patient-physician relationship, and gives patients and surrogates the opportunity to seek a second opinion or to transfer care of the patient.[23]

Asserting that judgments about futility of treatment for particular patients are often value-laden, some commentators emphasize that the patient's own wishes and values must play a central role in the decision-making process.[24] For patients who lack decision-making capacity,

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[20]See American Medical Association, 1868-69.

[21]Some physicians have recognized that the provision of "futile" treatment could be indicated by the duty to serve the best interests of the patient or by compassion in some cases, but assert that decisions about providing treatment on these grounds fall within the domain of professional authority. Schneiderman, Jecker, and Jonsen, 952-53; T. Tomlinson and H. Brody, "Futility and the Ethics of Resuscitation," *Journal of the American Medical Association* 264 (1990): 1277-79.

[22]As stated by Tomlinson and Brody (1279-80): "[The] goal in rejecting the consent process for futile CPR is to place the discussion in a meaningful context, not to avoid the emotional pain of discussing terminal illness with patients."

[23]Youngner, "Futility in Context," *Journal of the American Medical Association* 264 (1990): 1296. See also American Medical Association, 1871.

[24]As Stuart Youngner observes: "Living for five more days might give some patients the opportunity to say good-byes, to wait for the arrival of a loved one from another city, or to live to see the birth of a grandchild. For one patient, a life with extreme disability and pain might be quite tolerable; for another, it might be totally unacceptable. Risk takers might see a 3% chance as worth taking, while others might

family members and other surrogates are generally best able to articulate the patient's wishes through substituted judgment. Significant deference should be accorded surrogates' assessments of the best interests of patients as well.[25] At the least, patients and surrogates should participate in the decision-making process, so that the special values of the patient and family can be taken into account.[26]

Some are more adamant about the authority of the patient or surrogate. One physician urges that while a physician can explain why a DNR order seems appropriate, "it is up to the patient to decide whether to be resuscitated. . . . The physician's decision ought only to be that in his or her judgment there is no medical benefit, not that the patient will not be resuscitated."[27] A unilateral decision by the physician would violate the rights and dignity that physicians should accord their patients.

Many commentators note that defining the authority of physicians, patients, and surrogates to make treatment decisions based on futility raises important concerns for public policy. Some assert, however, that physicians may withhold treatment on the grounds of futility based on a clear consensus in the medical community that a treatment is futile or on a socially shared understanding that a treatment is unreasonable.[28]

The Task Force believes that neither patients nor those who decide on their behalf have, or should be granted, the right to insist on

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give more weight to the 97% chance of failure." "Who," 2095. See similarly Lantos et al., 82-84.

The American Medical Association "Guidelines" (1870-71) state that, unless CPR would be physiologically ineffective, "judgments of futility are appropriate only if the patient is the one to determine what is or is not of benefit, in keeping with his or her personal values and preferences."

[25]See, e.g., Fleischman, 407-8, and discussion above, chapters 1 and 3.

[26]Youngner, "Context," 1296.

[27]S. J. Farber, Letter on "Ethics of Life Support and Resuscitation," *New England Journal of Medicine* 318 (1988): 1757-58. Most of those who emphasize the role of the patient and family in assessing futility agree that it is appropriate for physicians to recommend a course of treatment and seek to persuade the patient or surrogate about the appropriate treatment choice.

[28]Schneiderman, Jecker, and Jonsen, 949, 952-33; Tomlinson and Brody, 1279; G. B. Avery, statement in "Point-Counterpoint," 410. These commentators acknowledge that if futility simply represents a vague appeal to physician discretion, it may be abused. They also warn that physicians should not "impose unsubstantiated claims of certainty" in assessing futility.

treatment that offers no physiological benefits in terms of cure, care, or the prolongation of life. At the same time, it has concluded that policies on medical futility must account for the diverse understandings of futility among physicians, the persistent reluctance of physicians to discuss end-of-life decisions with patients, and the importance of the dialogue between the physician and the patient or someone authorized to decide on the patient's behalf.

The Task Force proposes that legislation on surrogate decisions should recognize the limits of surrogate authority to insist upon treatment. This constraint on surrogate authority should be coextensive with the limits on the right of competent patients. Policies for surrogate decisions should provide that a request for treatment by a surrogate shall not create any greater duty to provide treatment than a request by a competent patient.

This policy creates no hard-and-fast rule about when treatment can be deemed futile; it recognizes that a societal consensus about the term, except in its strictest, most limited sense, has not yet developed and is still evolving. It also establishes that a determination that treatment is futile under appropriate standards constrains the choices of both competent adults and surrogates.

Physicians currently have no duty to provide treatment that is futile in the narrow sense of the term – treatment that will not achieve any identified medical benefit, including the prolongation of life. A broader definition that encompasses perhaps the last few days or possibly weeks of the dying process would have to await the consensus of society at large, not just physicians. The Task Force did not reach a consensus on whether the definition of futility should be broadened, and believes that such a consensus has not yet emerged.[29]

In all cases, however, the Task Force believes that a conversation between the physician and the patient or surrogate is crucial before the

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[29]Some Task Force members believe that physicians should provide any life-sustaining treatment that is not physiologically futile and that is requested by a surrogate in accord with decision-making standards. Other members feel that, after informing a patient or surrogate, physicians should be able to refuse to provide treatment that might extend the life of a dying patient by hours or days without any chance of cure. Task Force members agree that if a patient without decision-making capacity lacks a surrogate, and the attending physician and a second physician determine that the patient will die within a short time even if treatment is provided, a decision to withhold or withdraw treatment should not require review by a bioethics review committee. Like all health care decisions, this decision should accord with the patient's wishes or, if these cannot be ascertained, the patient's interests.

physician unilaterally withdraws or withholds life-sustaining treatment on grounds of futility. The conversation will shore up the trust between patient and physician; it will avoid the silence and secrecy that accompanied DNR decisions before the DNR law was enacted. The conversation also affords patients, or those deciding for them, an opportunity to seek a second opinion and to inquire about the physicians' assessment of futility. Given the expansive, variable notion of futility among physicians, this option is critical for individual cases and as an overall check upon reliance on futility as a basis to deny treatment according to the subjective judgments of each physician. Without this conversation, the futility concept would undoubtedly become, for some physicians, a way to avert conversations they find difficult and have long avoided.[30]

Recommendation

Neither patients nor surrogates have the right to insist on physiologically futile treatment. The Task Force proposes that legislation for surrogate decisions should recognize that a request for treatment by a surrogate should not create any greater duty to provide treatment than a request by a competent patient. In all cases, however, futility must be carefully defined, and the physician should talk with the patient or surrogate before treatment is withheld or withdrawn on grounds of medical futility. This conversation promotes good decision making, enhances trust, and allows the patient or surrogate an opportunity to seek a second opinion or inquire about the physician's assessment of futility.

See Appendix A, proposed legislation, Section 4(3)(a).

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[30]See T. E. Miller, "Do-Not-Resuscitate Orders: Public Policy and Patient Autonomy," *Law, Medicine and Health Care* 17 (1989):245-54.