Guidelines for Infant Bioethics Committees

BACKGROUND

In recent years a widespread public debate has developed on issues surrounding the care and treatment of critically ill infants. One aspect of this debate concerns the procedures that should be available to ensure that difficult treatment decisions regarding such infants are always made in the most effective manner possible. The American Academy of Pediatrics believes that hospital-based “infant bioethics committees,” consisting of both physicians and nonphysicians, can provide consultation and review, ensuring sensitive treatment decisions made in a reasoned, informed, and caring manner. Infant bioethics committees can provide education, develop and recommend institutional policies, and offer consultation to providers and families facing a range of ethical problems or questions about medical treatment of infants. The Academy urges all hospitals to establish such committees either on their own or in conjunction with other hospitals. This document is intended to assist those individuals and institutions who elect to engage in this process.

The American Academy of Pediatrics has been involved in discussion of ethical issues surrounding the care and treatment of critically ill infants since 1982. In 1983, the US Department of Health and Human Services published regulations on this issue, establishing federal law enforcement activities which were intrusive into patient care. The Academy successfully challenged that rule in court. Subsequently, the Department of Health and Human Services issued regulations in the Federal Register (effective Feb 13, 1984, but currently in litigation) that, among other things, endorse the concept of infant review committees as suggested in comments that had been submitted by the American Academy of Pediatrics.

The Academy's recommendation that parents and physicians consult with an institutional ethics committee when decisions are contemplated to forego life-sustaining treatment is consistent with the conclusions of the President's Commission for the Study of Ethical Problems in medicine and biomedical and behavioral research set forth in the report entitled Deciding to Forego Life-Sustaining Treatment (US Government Printing Office, Washington, DC, 1983). As the Commission's report points out, institutional ethics committees have been established by a number of hospitals in recent years. Their use has been recommended by health care professionals, ethicists, and many others, including the American Society of Law and Medicine. Although experience with this approach in the context of seriously ill infants is relatively limited, much can be learned from the experience of those institutions that have developed multidisciplinary ethics committees to address the needs of their general patient populations.

The following guidelines are suggestions developed by a task force of the American Academy of Pediatrics comprised of Academy members knowledgeable about ethics committees as well as consultants from other organizations and disciplines. In light of the wide diversity of institutions that would consider establishing infant bioethics committees, the task force has prepared guidelines for a model committee which may, of course, be tailored to the needs of each institution. The Academy expects that each hospital will structure its own committee in a manner consonant with other committees of that hospital and responsive to the overall needs of the institution and the community. Over time, the scope and functions of such committees will undoubtedly evolve, and the range of ethical issues that they address will expand.

As hospitals develop more experience with these committees, the Academy would appreciate receiving comments on their experience in order to supplement these guidelines by incorporating the benefits of this experience.

INTRODUCTION

The American Academy of Pediatrics recommends that the governing body, in consultation with the medical staff and administration, of each hospital that provides care for infants give serious
consideration to the role an Infant Bioethics Committee may play in aiding decision making about the care of seriously ill infants. (For purposes of these guidelines, an infant is any person less than 2 years old.) Such a committee would serve the purposes of: (1) providing an educational resource for hospital personnel and families of seriously ill infants; (2) recommending institutional guidelines and policies concerning ethical principles in the care of infants; and (3) offering consultation and review on treatment decisions regarding critically ill infants, especially when the foregoing of life-sustaining treatment is being considered.

In designing a process that is appropriate for its circumstances, the hospital should consider: (1) the relationship of an infant bioethics committee to other existing processes for decision making of the hospital (including other ethics committees); (2) whether the process should include a standing hospital committee, a procedure for empaneling ad hoc committees as need arises, or a group of advisors; and (3) the possibility of cooperating with other institutions in establishing a joint committee, especially when the hospital does not treat enough critically ill infants to justify a separate committee.

FUNCTIONS

In the context of ethical issues involving the care of infants, the Infant Bioethics Committee should perform the following four functions:

Education

The committee should educate hospital personnel and families about the means available within the hospital and in the community to assist them in making good decisions about treatment, about relevant ethical principles, literature and resources, and about community services for disabled persons.

Policy Development

The committee should develop and recommend hospital policies and guidelines that define ethical principles for conduct within the hospital's activities.

Prospective Review

The committee should provide consultation and review in cases where the foregoing of life-sustaining treatment is under consideration, helping to resolve disagreements among families and health care providers.

Retrospective Review

The committee should review medical records retrospectively when life-sustaining treatment has been foregone to determine the appropriateness of hospital policies and whether these policies are being followed.

STRUCTURE

The precise organizational relationship of the Infant Bioethics Committee—whether a committee of the governing body, of the medical staff, or otherwise—will depend upon a number of factors, such as hospital bylaws and state law on confidentiality and discoverability of hospital records. One committee may serve several hospitals as part of a collective effort among the hospitals.

Appropriate clerical, legal, and fiscal support should be provided to the committee so that it can fulfill its obligations.

MEMBERSHIP

Although the precise membership of the committee will depend on institutional needs and resources, it is important that the committee include members from various disciplines. A multidisciplinary approach is recommended so that the committee will have sufficient expertise to supply and evaluate all pertinent information, and because representation of viewpoints of the community is desirable to contribute to better decisions.

An effort should be made to ensure that the committee has at least the following expertise available to it through members or advisors: medical, psychosocial, human service resources, nursing, social work, and familiarity with issues affecting disabled persons, legal and ethical. The committee may wish to identify and have available other areas of expertise.

The committee size should be large enough to represent diversity, but not so large as to hinder candid discussions and deliberations. The following is a suggested list of “core” committee members: practicing physician; pediatrician knowledgeable about the nursery; nurse; hospital administrator; parent of a disabled child, representative of a disability group, or developmental disability expert; social worker; member of the hospital’s pastoral care program or other clergy; lawyer; lay community member; and person trained in ethics or philosophy.

JURISDICTION

The Infant Bioethics Committee should not supplant other existing means within the institution for reaching good decisions about the care of criti-
cally ill infants. The processes of consultation and review established by the committee should seek to assure that all decisions, whenever possible, have had the benefit of prior appropriate consultations and discussion in patient care conferences. This is particularly important when there is disagreement between the family members and/or the health care providers. The clarification that such processes provide may allow resolution on factual grounds of what may have seemed initially to be ethical disputes.

PROCEDURES AND FUNCTIONS

At the time the governing board decides to establish an Infant Bioethics Committee, decisions should be made as to how the members will be appointed and how the chairperson and vice-chairperson will be selected.

The committee should establish procedures about how often it will meet, attendance of alternates or substitutes, quorum requirements, and the like. It is anticipated that regular meetings will be needed for the committee to carry out its functions in educating hospital staff, infants’ families, and the community; in recommending to the hospital’s governing board policies for the care of critically ill infants; and in retrospective review. The committee may find it helpful to draw on the extensive literature and published policies on issues such as orders not to resuscitate and appropriate treatment of permanently unconscious patients. (See, for example, the report of the President’s Commission on Deciding to Forego Life-Sustaining Treatment, Appendices G-1, and Cranford RE, Duodera AE (eds): Institutional Ethics Committees and Health Care Decision Making, Section III, Guidelines. Ann Arbor, MI, Health Administration Press, 1984.)

In addition, the committee should meet at the call of the chairperson to review individual cases. It should be recognized that there will be fewer occasions for such special meetings as the committee’s policies and expectations become better known and understood within the institution.

Educational Functions

The committee shall act as a resource to the hospital staff, to families of infants, and to the community, as feasible, for information on ethical principles involved in medical decision making and about issues surrounding the treatment of critically ill infants and programs for disabled persons and their families.

Each hospital shall be expected to see that the existence and functions of the Infant Bioethics Committee are well known, including policies, procedures, and the method of contacting the committee.

Policy Development Functions

The committee should develop and recommend for adoption by the hospital, institutional policies concerning foregoing of life-sustaining treatment for infants with life-threatening conditions and guidelines for decision making in other specific types of cases or diagnoses, eg, Down syndrome and myelomeningocele. It should also develop procedures to be followed in recurring circumstances such as brain death and parental refusal to consent to life-sustaining treatment.

In recommending these policies and guidelines, the committee should consult on issues involving disabled individuals with medical and other authorities, eg, neonatologists, pediatric surgeons, county and city agencies that provide services for the disabled, and disability advocacy organizations. The committee should also consult with appropriate committees of the medical staff to ensure that the committee policies and guidelines build on existing staff bylaws, rules, and procedures concerning consultations and staff membership requirements. When these policies and guidelines have been approved by the hospital, the committee should inform and educate hospital staff on the policies and guidelines it develops and should recommend the necessary measures to ensure that the policies and guidelines are properly implemented.

Consultative Functions (Prospective Review)

1. Discretionary Review. Because it should aim for an atmosphere of collaboration with those who face difficult decisions about the case of infants in the institution, the committee should make clear that it expects many (or even most) of the cases it reviews prospectively to arise in a voluntary context. In these cases, the committee may meet as a whole or may, by established procedures, delegate to certain members, as an ethics consultant team, the responsibility of consulting with the concerned parties. The scope of the committee’s discretionary review should include the following: (a) The committee may review the care of a hospitalized infant upon the request of any member of the hospital staff or member of the infant’s immediate family, when a serious ethical issue is presented by a decision about the infant’s care. (b) The committee may review any case of a hospitalized infant when serious ethical questions about the infant’s care have been raised by a public agency.

The presumption—especially early in a committee’s existence—should be that it will review all
cases in which there is serious disagreement among the staff responsible for the care of an infant or between the attending physician and the parents.

2. Mandatory Review. The committee should review all cases in which the attending physician and parents propose to forego life-sustaining treatment for an infant. Review is not mandatory when an infant is imminently dying. In doubtful cases, the presumption should be in favor of review. The attending physician should be responsible for notifying the committee of a case requiring mandatory review.

The committee may wish to specify certain diagnoses, such as Down syndrome or myelomeningocele, for which a decision to forego treatment will always be reviewed by the committee.

3. Requests for Review. Ordinarily, the attending physician should forward requests for review, or the need for mandatory review, to the committee, but others may do so if necessary. The person requesting review should contact the chairperson or other designated committee member or hospital official. Although not encouraged, requests for Infant Bioethics Committee review may be anonymous. In any case, the hospital should have procedures to keep confidential the identity of persons requesting committee review and to protect those persons from reprisal.

4. Initial Assessment. Following a request for committee review by any of the above routes, an assessment of the situation will be made by the committee chairperson or his or her designee, including contacting the family and the attending physician, before determining whether to convene a committee meeting. After review of relevant considerations, a preliminary decision should be made as to whether the request for committee review is appropriate or inappropriate. An inappropriate request is one that clearly does not raise serious ethical issues, e.g., because the infant in question is not a patient at the hospital, because the infant is not seriously ill, or because the decision alleged to have been made about treatment or nontreatment actually has not been made. The presumption should be toward review by the committee.

At the regularly scheduled meetings, the chairperson should report to the committee on any requests for committee review that were denied on the grounds that they were inappropriate.

If the chairperson considers the request appropriate, a committee meeting should be convened. If not, the request can receive administrative disposition by the chairperson, with a later report to the committee. The person requesting the review should be informed of the disposition of the request.

5. Invited Participants. When there is deemed sufficient reason to convene a special committee meeting to consult on a case, the committee generally should invite those persons with interest in the case to the appropriate parts of the meeting, but not necessarily at the same time. These persons include the parents (family) of the infant; the attending physician, nurse, senior staff person, consultants, house staff assigned to the infant, and others closely connected with the care of the infant; and the person requesting the meeting.

The parents (family) may, if they wish, bring their own support persons, e.g., clergy. The family and others invited to the meeting need not attend the meeting if they do not wish to or may be appropriately excused from the deliberative portions of the meeting.

6. Plan of the Meeting. At the meeting, all concerned parties should have an opportunity to present their viewpoints and, as appropriate to the case, to hear the views of others. The first objective should be to elicit all pertinent facts and to clarify the issues raised by the case. The committee should then assess the alternative course(s) of treatment proposed or possible, with the objective of facilitating consensus about the interests of the infant. A collaborative atmosphere will usually remedy any deficiencies in the decision-making process so that the committee and all those concerned with the case can agree on an appropriate course of action. Every effort should be made to support the dignity and integrity of the family and health care providers involved in such decisions, as the interests of the infant are being defined.

7. Recommendations. The committee should recommend a course of action only when agreement cannot be reached among the committee, the family, and the health care providers, and when it concludes that one, or more, of the proposed course(s) of action is(are) based on clearly unreasonable premises about, or inappropriate evaluation of, the interests of the infant, e.g., failure to correct an uncomplicated intestinal obstruction in an infant with Down syndrome.

Regardless of committee recommendations, if the family wishes to continue life-sustaining treatment and the attending physician disagrees, the family's wishes should be carried out until they are officially removed from their position as the infant's guardian or until treatment is ceased pursuant to existing hospital policies and procedures.

With the above exception, when there continues to be substantive disagreement between the principal parties and the committee concerning the appropriate course of action, the committee should follow established procedures to report its conclusions to the hospital official(s) responsible for re-
porting such cases to the appropriate court and/or child protective agency. Because of the gravity of this step, the committee should establish procedures for documenting the degree of consensus about its recommendation through a formal vote, conducted in a manner that allows each committee member to express his or her conscientious conclusions free of coercion from the group process (such as by anonymous, written ballot). Only members of the committee should be allowed to vote. Such formal procedures for identifying committee recommendations should be limited to those situations in which a consensus cannot be achieved and in which members of the committee feel the proposed course of action is contrary to the interests of the infant.

While legal proceedings are being instituted, it is expected that every effort should be made to continue treatment, preserve the status quo, and prevent worsening of the infant’s condition, until such time as a course of action has been ordered by a person acting under the authority of the court.

The recommendations of the committee discussions should be promptly conveyed to the attending physician, who should see that an appropriate notation is made in the patient’s record. To avoid misunderstanding, especially in difficult cases, the attending physician may request the notation to be made by the committee.

Consultative Function (Retrospective Review)

The committee should adopt retrospective review procedures to determine whether cases that should come before the committee are being missed, to follow up on the outcome of the cases that have been referred to the committee, and to evaluate the effectiveness and acceptability of the policies that have been approved by the hospital.

In order to ensure that appropriate cases are being reviewed, some form of review of treatment of critically ill infants in the hospital should be performed. Examples of how this could be accomplished include reviewing the records of disabled infants born in, or admitted to, the hospital and reviewing the records of infants who have died in the hospital. A listing of all such cases should be regularly provided to the committee. The committee should have a procedure for determining whether to review every chart so listed, to review a randomly selected sample of charts, or to assign preliminary reviews to a subcommittee.

RECORD KEEPING

The committee should maintain records of all its deliberations and summary descriptions of specific cases considered and the disposition of those cases. Committee minutes should be approved by the committee before they become final. Records should be kept in accordance with institutional policies on confidentiality of medical information. Hospital counsel should clarify for the committee the circumstances under which records must be made available to governmental officials or other persons, as required by state law.

LEGAL ISSUES

Provision should be made for timely reporting by the committee to the hospital’s governing body through appropriate mechanisms. The advice of counsel should be sought about the responsibilities imposed by state law on hospital officials to see that certain treatment decisions are reported to designated governmental officials as possible instances of child neglect or abuse so that consideration may be given by a court to the appointment of an infant guardian.

It is unlikely that committee members will face civil or criminal liability for actions taken in the course of committee proceedings. Indeed, state law may provide committee members with immunity from any such civil and/or criminal liability. Nonetheless, hospitals should indemnify committee members from liability for their decisions. In any case, careful decisions made by the committee in good faith should minimize any chance of liability.

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