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## Mediating Bioethical Disputes

Diane E. Hoffmann

University of Maryland School of Law, [dhoffmann@law.umaryland.edu](mailto:dhoffmann@law.umaryland.edu)

Naomi Karp

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# Mediating Bioethical Disputes

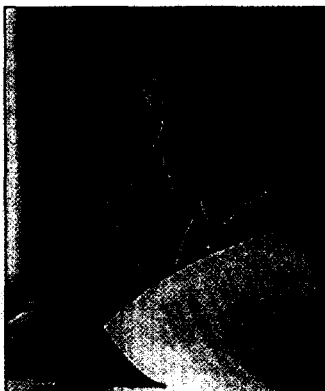
by Diane E. Hoffman and Naomi Karp

The process of health care decision making by and on behalf of patients presents complex challenges. Technological advances, skyrocketing costs, hierarchical staffing patterns, intensive government oversight, the litigation boom, ethnic diversity, and competing religious and moral beliefs about life and death all complicate the process. In some cases, these issues create conflicts between health care providers, patients, and family members over what types of care or treatment the patient should receive. Hospitals and nursing homes have been occupied for over a decade with how to resolve these "bioethical" disputes where the values and interests of one party are at odds with those of another. The most dramatic of these cases involve ending life support for a patient who is terminally ill, in a persistent vegetative state, or chronically ill with a progressively fatal condition that severely affects the patient's quality of life.

In some instances, courts have been asked to clarify who has the authority to make health care treatment decisions for an incapacitated patient and what guidelines should inform these decisions. States have also passed laws attempting to clarify who has decision-making authority in these cases. All states now have statutes specifically authorizing health care powers of attorney or permitting the appointment of a proxy; 48 jurisdictions have laws on living wills, and many have health care consent measures authorizing surrogates to make some or all health care decisions.

## How are Bioethics Disputes Resolved Now?

Most experts agree that litigation is the least effective way to resolve bioethical disputes. Wishing to avoid the burdens of going to court, health care institutions have sought ways to resolve these disputes in-house, by establishing ethics committees, for example. These committees are usually multidisciplinary, including physicians, nurses, social workers, and other health care providers. In some



cases, the committees include a lawyer, bioethicist, or member of the local community. Health care providers, patients, or their families come to the committees when they have an ethical dilemma about the care of a patient, or there is a dispute between the parties over the best course of treatment for the patient. Approximately 60% of hospitals with over 200 beds and about 30% of nursing homes have ethics committees in place.

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Ethics committees struggle with the best way to handle these cases. Some act as advisors or consultants; others act as quasi-adjudicatory bodies, recommending courses of treatment for the patients. In arriving at a recommendation, committee members consider the medical facts and the legal, ethical, familial, and social issues involved in the case. Committee members typically rely on the principles of bioethics—autonomy, nonmaleficance, beneficence, and justice—along with the relevant legal standards, in coming up with their recommendation.

## The Approach of Ethics Committees

Frequently dissatisfied with their role as decision-makers, or more accurately, recommendation-makers, some commit-

tees have begun to explore alternative methods for resolving bioethical disputes, including mediation. Recent conferences for ethics committee members have included workshops on mediation. Demonstration projects are being conducted on using mediation to resolve bioethics disputes. Some mediation training centers are expanding to include bioethics conflicts. Mediation has even appealed to some lawyers as an alternative

to litigation of these disputes.

## Mediation Demonstration Projects in the Health Care Setting

Demonstration projects are underway to test the use of mediation in a variety of health care institutions. In the acute care setting, a project at Montefiore and Beth Israel Medical Centers in New York, sponsored by the United Hospital Fund, investigated whether disagreements among patients, family, and staff over treatment decisions might be resolved sensitively, fairly, and expeditiously through mediation. Funded by the United

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Hospital Fund in 1992-93, the project trained hospital staff members—including bioethics consultants, a physician, a senior nurse administrator, hospital counsel, a risk manager, and a patient representative—in mediation. Project members then applied these skills to cases they encountered on the job. Participants met monthly to "debrief" about their experiences and to develop a model for mediating bioethical disputes in hospitals.

A second demonstration project, begun in 1994 and sponsored by the ABA with funding from the AARP Andrus Foundation and The Commonwealth Fund, is testing the use of mediation to resolve care disputes in nursing homes. The project involves approximately 25 facilities in the Washington, D.C. area that have ethics committees. Members of these committees were trained in dispute resolution, bioethical principles, and nursing home law. They are teamed with "mediator mentors," highly experienced volunteer mediators who know little about the long-term care world. These teams of mediator trainees and mentors are co-mediating care disputes arising in participating facilities. The project's designers hope that the co-mediation model will blend the substantive expertise of the in-house mediators with the mediation skills and neutrality of the mediator mentors.

### **Attraction of Mediation to Ethics Committees**

Mediation may be attractive to ethics committees for a number of reasons. Perhaps first and foremost is its attention to context. Ethics committees seem uncomfortable with the rigidity of legal standards and prefer the more flexible principles of bioethics. For example, many ethics committee members would not want to have to base a decision about an incapacitated patient's health care treatment solely on "clear and convincing evidence" of the patient's wishes, as required by law in a number of states. Instead, they would prefer to evaluate all relevant evidence, including the views of those closest to the patient. Another attraction mediation may hold for members of ethics committees who are primarily health care providers is its emphasis on relationships and communication rather than rule-based decision making. Finally, ethics committees may be attracted to mediation because it shifts the responsibility for making a potentially life-or-death decision to the parties most affected by it.

### **Appropriateness of Mediation for Bioethics Disputes**

Whether mediation will ultimately be workable in the case of bioethics disputes will depend on whether the parties to the dispute are motivated to "negotiate" with one another over the course of treatment

for a patient. In the health care setting, where one of the parties to the dispute is often a physician, this may be a stumbling block. While physicians may want to avoid a court proceeding, they may also prefer the process that ethics committees traditionally follow in dealing with these issues: the committee speaks briefly with the physician, gets the medical facts, talks to the other relevant parties, and comes to a recommendation on its own. The physician may wish to avoid the confrontation often involved in mediation and the relatively time-consuming bargaining process. Moreover, physicians may not trust the validity of a mediated resolution and instead may want the approval of some officially recognized body, such as the ethics committee, before proceeding with some intervention or withdrawal of life support.

In contrast to the physicians, family members of an incapacitated patient may prefer mediation to the more common processes of ethics committees, as mediation would give them more control over the outcome. Whether mediation is appropriate for family disputes, however, may depend on the dynamics of the particular family. If there is a danger of significant power imbalances within the family, mediation may not be appropriate. In addition, mediation may not be appropriate when one or more of the parties, typically a family member, views life as sacred and not to be terminated under any circumstances.

Even if it were possible to get the parties to a bioethical dispute to agree to participate in a mediation session, there is still a question of the appropriateness of the technique for some of these disputes, especially those that may involve the life or death of the patient. Of particular concern is the "competency" of the parties to engage in a bargaining process. As we have learned from divorce mediation, parties under a great deal of stress may be viewed as temporarily "incompetent" to participate in a mediation session. Such could often be the view of family members going through the emotionally difficult ordeal of caring for a relative during a terminal illness or a long, chronic, debilitating disease, such as Alzheimer's.

The issue of power imbalances is also of concern in these disputes, not only among family members but between family members and physicians. Physicians typically have the upper hand in these disputes. They control the resources used to care for the patient; they write the orders

as to how the patient is to be treated; and they have the medical knowledge about the patient's disease and prognosis that will enable them to bargain more effectively about the course of treatment for the patient. For these reasons, family members are at a significant disadvantage. They may also be intimidated by the physician and be reluctant to question his or her authority and expertise. In order for mediation to work in these disputes, the mediator must be alert to the physician-patient-family member dynamics and must empower those at a disadvantage.

### **A Negotiated Agreement versus An Ethics Committee Recommendation**

Perhaps the most difficult question to answer in determining whether mediation is appropriate for bioethical disputes is whether bioethical conflicts are "private" or "public" disputes. For the most serious of these disputes—those involving the life or death of the patient—society clearly has an interest in the outcome. Virtually every state has laws recognizing a competent individual's right to refuse life-sustaining treatment. This right is also constitutionally protected. States have also recognized the validity of living wills and durable powers of attorney for health care, allowing the wishes of competent patients to be honored when they become incapacitated. And states have recognized family members as appropriate decision-makers in the absence of such documents. To the extent that mediation might lead to a legally valid surrogate, such as a family member, unknowingly to cede rights that they would otherwise be required to exercise regarding the care of a patient, it would appear to violate state law and public policy, as well as constitutional principles.

While this issue can be dealt with by informing participants prior to mediation about their legal rights to make a decision, there is still a question as to whether we feel comfortable with the parties coming to an agreement that may be inconsistent with established norms. In most cases, the relevant bioethical and legal norms require that a decision about the course of treatment for an incapacitated patient be made consistent with what the patient would have wanted, if that can be discerned, and, if not, in accordance with their "best interests." Often we do not know what the patient would have wanted and must resort to the "best

interests" analysis. In this regard, it is difficult to determine whether a mediated agreement is appropriate, because the patient's "best interests" are often indeterminate.

Within some boundaries, however, there is latitude to come up with a range of alternatives that might be in the patient's best interests. The problem is defining those boundaries. If one party proposes something clearly outside accepted societal norms—such as child neglect or assisted suicide—it would be incumbent upon the mediator to identify such solutions as untenable and halt the process if the negotiation continues to move in that direction. Within the broad confines of the law and accepted ethical principles, however, it would be hard to argue that a mediated solution could not meet established norms of a patient's best interests.

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### **The Appropriate Mediation Model**

If mediation is to be applied to bioethics disputes, some thought must also be given to the appropriate mediation model. Is the "traditional" mediation model appropriate, where the parties meet face-to-face with a single neutral, who makes no value judgments and does not review an agreement for consistency with established legal or ethical norms? Or is some modification to the model in order, incorporating additional safeguards for the parties and techniques that will

increase the likelihood that an agreement is within ethical and legal boundaries?

The demonstration project at Montefiore and Beth Israel Medical Centers in New York struggled with these and other thorny questions, such as: Who should mediate, an ethics committee member or an individual such as a bioethics consultant? Must the mediator be a stranger to the institution, or can a staff member serve as mediator? Are there certain staff members (e.g., risk managers, hospital counsel) who can never be sufficiently neutral to mediate? Must the process adhere to a formal mediation framework, or is an informal, flexible mediative approach more realistic in the hospital setting? Is it even possible to get all of the parties together in one place at one time? Can a level playing field be reached so that the patient (or patient's family) can be on an equal footing with the institution and its staff? Do patients or their surrogates need advocates in the process?

The ABA demonstration project in the nursing home setting is also raising some tough questions for the implementers. Although some of the issues are the same as those that arose in the acute care setting, new issues have been raised because of the uniqueness of the long-term care setting. Residents generally remain in nursing homes a lot longer than most hospital stays, and thus the parties to a care dispute will likely deal with each other over an extended period of time. Moreover, care disputes are often less crisis-oriented and more ongoing, covering diet, medication, use of restraints, hospital transfers, and other aspects of care plans, as well as end-of-life questions of artificial nutrition and hydration, life support systems, and resuscitation. Both of these factors make mediation appropriate for long-term care issues. Even so, many specific questions remain: Which care disputes are appropriate for mediation? Can a more formal mediation model than the approach used in the Montefiore project work in the nursing home setting? Can ethics committee members, most of whom are nursing home staff, serve as neutral and effective mediators? Can nursing home residents bargain on an equal footing with facilities and/or their staff members? What supports may be needed to enhance the ability of residents to participate effectively in mediation? Who will determine whether the resident can understand the mediation process and the resulting agreement? If a resident

lacks capacity to mediate and/or make health care decisions, can a surrogate mediate on the resident's behalf? If so, who is an appropriate surrogate and how will that be determined?

Alternative mediation models that might be appropriate for bioethics disputes include: (1) having a neutral party serve as the mediator but having ethics committee members participate as "experts" on medical and ethical issues; (2) having a neutral party serve as mediator but having members of the ethics committee review the agreement for consistency with relevant ethical and legal norms, (3) having a member of the ethics committee serve as an "activist" mediator who educates the parties to the mediation process. Each of these approaches has some strengths and drawbacks. In some ways they represent a combination of a traditional mediation model with a traditional ethics committee consultation process. This may make them more useful in the health care setting.

### **Conclusion**

More attention must be paid to these issues before mediation can be fully embraced in bioethics disputes. Mediation offers some promise to health care ethics committees struggling with how best to resolve these difficult conflicts, but ethics committees should proceed with caution. In particular, serious discussion must focus on what types of bioethical disputes are appropriate for mediation and which model of mediation is best suited for the dispute. The facts of each dispute must be analyzed carefully to make this determination.

*Naomi Karp is an attorney on the staff of the ABA Commission on Legal Problems of the Elderly. She is a project director of the Commission's current project on mediating care disputes in nursing homes, and served as a consultant to the United Hospital Fund's project on mediating bioethical disputes in the acute care setting.*

*Diane Hoffmann, Assistant Professor of Law. A.B., 1976, Duke University; M.S., 1980, J.D., 1986, Harvard University. As Assistant Professor Diane Hoffmann was instrumental in the passage of Maryland's Health Care Decisions Act.*