handbook

FOR HEALTH CARE ETHICS COMMITTEES

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CONTENTS

PREFACE

Anyone who has been paying attention to health care—patient, family member, professional care provider, policy maker, or interested observer—appreciates the profound changes during the past decades. Major advances in scientific knowledge, clinical skill, and technology have been paralleled by significant developments in how health care decisions are made and implemented. Decision making that used to be confined to the patient and family doctor now includes a whole cast of additional players, including consulting clinicians, relatives, health care proxy agents, risk managers, attorneys, judges, ethicists, organizational administrators, insurers, and other interested parties.

Among the most effective and valued resources in the health care decision-making process is you—the institutional ethics committee. As medicine becomes more complex, fiscal and bureaucratic pressures mount, and governmental regulations expand, clinicians and administrators increasingly look to you for analysis and guidance in resolving health care problems. Depending on the size and needs of the institution, the ethics committee typically serves as moral analyst, information clearing house, dispute mediator, educator, policy reviewer, and clinical consultant. The importance and scope of these responsibilities suggest that committees should be familiar and comfortable with bioethical theory and analysis, clinical consultation skills, institutional policies, legal precedents, organizational function, and resource allocation.

At this point, you have every right to say, "Are you kidding? Our committee is made up of clinicians and administrators who volunteer our time because we are interested in the ethical issues in health care. But it's all we can do to keep up with what we need to know to meet our clinical and administrative responsibilities. Don't ask us to take a course in bioethics."

Your very legitimate concern is what prompted this book—a handbook, not a textbook—that distills the important information and presents a basic foundation of bioethical theory and its practical application in clinical and organizational settings. Bioethics raises complex questions that require essays rather than short answers, and we have packed a great deal into this volume, including theory, vignettes, discussion questions, and suggested strategies. To make the material more accessible and useful, we have provided illustrative cases and ethical analyses to explain how the principles and

concepts apply to what you do. The book is divided into the following sections, each of which addresses one or more ethics committee functions:

- an eight-chapter ethics curriculum, organized according to the issues that ethics committees typically address
- an introduction to clinical ethics consultation, including examples of clinical cases raising ethical issues that trigger requests for consultation by an ad hoc group and/or review by the full committee
- examples of memoranda, guidelines, and protocols that can be generated and discussed by ethics committees
- examples of institutional policies that would be drafted or reviewed by ethics committees
- an example of an institutional code of ethics
- summaries of key legal cases in bioethics
- a transcript demonstrating how an ethics committee would address a difficult issue referred for its consideration

This handbook grew out of the twenty-seven-year history of the Montefiore Medical Center Bioethics Committee and Consultation Service and the frequent requests from other committees to share what we have learned. While the examples are drawn largely from the Montefiore experience, our goal is to provide information and suggestions that can be adapted to the needs of a wide range of committees. In the pages that follow, we talk to the members of both well-established and newly formed ethics committees in large academic medical centers, small community hospitals, nursing homes, and other care-providing agencies. We hope that this resource will stimulate your committee, inform its deliberations, and enhance its contribution to the care delivered in your institution.

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This handbook owes its existence and utility to numerous individuals and groups, whose invaluable contributions must be acknowledged. Because the book's inspiration is drawn from our collective experience at Montefiore Medical Center, most of those who were so helpful are part of that remarkable institution.

First and most important is the Montefiore Medical Center Bioethics Committee. Since its establishment in the mid-1980s, this multidisciplinary body has steadily increased the scope of both its membership and agenda, developing a considerable body of knowledge and skill in clinical and organizational ethics. The committee's eagerness to address new, sometimes controversial issues, its willingness to revisit previous recommendations in light of recent developments, and its determination to be actively involved in education, consultation, and policy review have made it a respected and routinely accessed institutional resource. This handbook reflects the considerable experience and insights of the Montefiore Bioethics Committee, which we hope your committee will find useful.

The effectiveness of an ethics committee depends in large part on whether it is marginalized or fully integrated into the functioning of the institution. The Montefiore administrative and clinical leadership has historically demonstrated support and respect for the Bioethics Committee, encouraging its robust role throughout the medical center. The collaborative relationship with the offices of the medical director, nursing, social work, legal affairs, and risk management has contributed significantly to the practical application of ethics described in this book. Medical Directors Dr. Brian Currie and Dr. Gary Kalkut, Director of Clinical Affairs Lynn Richmond, and Associate Legal Counsel Mary Scranton deserve special gratitude for their assistance in shaping the manuscript. Drs. David Hoenig, Martin Levy, Grace Minamoto, and Albert Sauberman provided important feedback on draft chapters that were piloted in their resident training programs. Dr. Kalmon D. Post read and reread the manuscript through its numerous incarnations and contributed valuable clinical insights. Maria denBoer provided meticulous manuscript review and editing, and Kim Johnson carefully guided the manuscript through production editing. Our extraordinary editor, Wendy Harris, shepherded the book from first draft to finished product with skill, support, tact, attention to detail, and surpassing patience.

Several people contributed their considerable expertise by writing selected portions of the handbook. Dr. Tia Powell, executive director of the New York State Task Force on Life and the Law, co-authored the introduction on the nature and functioning of ethics committees, which provides the context for the book. Dr. Kenneth Berkowitz, chief, Ethics Consultation Service, Veterans Administration National Center for Ethics in Health Care, co-authored chapter 9, "Approaches to Ethics Consultation," in part II. Dr. Jack Kilcullen, surgical critical care attending at Washington Hospital Center and former member of the Montefiore Bioethics Committee, wrote "Allocating Critical Care Resources: Keeping the Teeth in ICU Triage," which appears in part III. Research assistants Dr. Kiyoshi Kinjo, Katharine Michi Ettinger, and Margot Eves were enormously helpful in gathering and organizing material. Several institutions generously shared their policies for comparison in parts IV and VI, including The Cleveland Clinic, Hennepin County Medical Center, Lenox Hill Hospital, Long Island Jewish Medical Center, The Methodist Hospital, Montefiore Medical Center, Mount Sinai Medical Center, Oregon Health and Science University, University of California at San Diego Healthcare, and Wyckoff Heights Medical Center.

Finally, this book would not have been possible without the encouragement, critical commentary, and general forbearance of our families.

Introduction: The Nature and Functioning of Ethics Committees

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Ethics committees vary from institution to institution along every significant dimension, including the number and qualifications of members, types of activities performed, the visibility of those activities, and perceived quality and usefulness. Across the country, some committees flourish while others fail to thrive. New committees, as well as those of long duration, can assess and change a variety of factors that may improve their chances of survival and add to their success in supporting the ethical practice of health care at their institutions.

FUNCTIONS

Traditionally, ethics committees have addressed some or all of three functions: education, policy development, and consultation. These functions are discussed in later chapters; here, we focus on the committee's obligation to define for itself which of these activities it will take on. In each of the three domains, the responsible committee members should clarify their goals and assess how they might attain them more effectively. For instance, if the ethics committee will provide ethics education, the committee should define its goals for education. A discussion aimed at improving educational efforts might focus on questions like the following: Toward whom should education be directed and in what format? Do committee members have sufficient expertise to teach ethics? Can they improve their knowledge base through continuing ethics education? If the hospital is affiliated with a medical school, are ethics committee members involved in teaching students? If not, can those who do teach students join the committee and lend their expertise to other groups within the institution? Are teaching activities geared to the needs of the institution? For instance, have members met with various groups, such as nursing, outpatient clinics, and the Emergency Department to see if they have a troubling case or other specific request for ethics teaching? Is there a set of basic topics in ethics for which the committee can offer instruction? Are there helpful articles and other prepared materials to distribute as part of the educational effort? Do teachers routinely provide evaluation forms so that they can learn which topics and instructors are well received and useful?

Similarly, the committee should assess its goals for policy development. If other

groups also handle policy development, the ethics committee might collaborate in some cases or take over development of policies in others, depending on the policy in question. For instance, the ethics committee might serve as consultant to colleagues in palliative care for policies on pain control at the end of life, but might have primary responsibility for revising a policy on do-not-resuscitate orders. The ethics committee should not attempt to duplicate work that is already handled well elsewhere, particularly in the domain of policy development. Rather, designated committee members can reach out to other divisions within the institution so that ethics expertise may be incorporated into policies throughout all hospital departments.

ETHICS CONSULTATIONS AND COMMITTEES

Clinical ethics consultation is a particularly challenging function and is handled differently at different institutions. In some cases, consultation is handled by a subgroup of the ethics committee, while in other facilities an entirely separate group or individual provides consultation (Fox, 2002). If the ethics committee will take primary responsibility for ethics consultation, it needs to provide requisite training and support for consultants. This book provides a curriculum for such training; consultants may also wish to consider some of the training programs that are now emerging across the country.

MEMBERSHIP

The committee should examine whether its membership reflects sufficient diversity to represent the whole institution. While some early ethics committees were constituted entirely of physicians, a committee with such a limited range of members is unlikely to be an effective resource to the entire institution. For instance, a committee composed only of doctors is not best qualified to understand, support, and provide ethics expertise for nurses, social workers, and other health professionals. These distinct health professions adhere to specific codes of ethics and confront dilemmas that can differ from those that physicians face. Thus, allied health professionals will be represented on a well-designed ethics committee. Some committees, though by no means all, include community representatives as a way of bringing the patient's voice into the committee's deliberations. Community members who participate in clinical discussions regarding patient information must offer the same guarantee of confidentiality as health professionals.

Ethnic and cultural diversity is also important within the committee membership, because a significant number of consults stem from differences in religious practices and cultural expectations. For example, patients and family members from many cultures fear that full disclosure of a cancer diagnosis will rob patients of all hope (Powell, 2006). An ethics committee member from the same community serves as an educational resource to colleagues and as a helpful liaison to patients, professionals, and the committee.

As much as an effective committee requires diversity of representation, it also needs stability of membership. A frequently changing membership decreases the ease with which colleagues can identify those with ethics expertise. Moreover, the committee cannot build upon the experience and continued training of its membership if it is constantly changing. Committees with a high rate of turnover (or a significant proportion of no-show members) should view this as a sign of failure to thrive; busy professionals will not devote their time to a group that accomplishes little or whose work is of poor quality. In contrast, committees known for effective and skillful work enjoy a flow of volunteers seeking to join. Poor meeting attendance and a high drop-out rate signal the immediate need for intervention. The committee needs to address frankly every aspect of its functioning, from who chairs meetings and how effectively they are run, to whether the committee's goals are clear, realistic, useful, and adequately met.

The committee membership should be diverse in terms of whom it represents, but also must include a broad range of skills and knowledge. The American Society for Bioethics and Humanities produced a valuable report in 1998 entitled *Core Competencies for Health Care Ethics Consultation*, which is required reading for any ethics consultation service. Though specifically geared to the task of ethics consultation, these core competencies are also a useful benchmark for ethics committees that provide education and policy development. The skills and knowledge described need not all be present in the same individual. In fact, a great benefit of the committee structure is that collective expertise can surpass that of any one person. Some of the skills noted in *Core Competencies* are the abilities to identify and analyze values conflict, facilitate meetings, listen and communicate well, and elicit the moral views of others. Necessary knowledge areas are quite broad and include moral reasoning, bioethics issues, institutional policies, relevant health law, and beliefs and perspectives of staff and patients. Committees that function at a high level monitor their strengths and gaps in expertise and skill, and address those gaps by adding skilled members and/or encouraging continuing education for individual members and the group as a whole. In addition to ongoing educational efforts for members, a committee can also devise an orientation manual and a set of educational expectations for new members. Such a manual might include a list of useful reference works and journals in medical ethics, as well as copies of relevant institutional policies. Mentorship by a senior committee member to whom questions may be addressed, and information about continuing education opportunities would also be valuable. Providing a useful orientation for members new to the committee can be particularly helpful to those committees that have suffered from high turnover or low interest. Sitting through a series of meetings without having a clear role or understanding of the goals can lead new members to drift away instead of staying and contributing to the success of the committee.

EXPERTISE IN ETHICS

Ethics committees perform a unique function within a health care institution by virtue of the fact that they possess expertise in the area of ethics, an expertise that other bodies in the organization generally lack. Doubts may be raised, however, about whether there is such a thing as ethics "expertise" and, hence, whether any individual or group can possess it. The notion of expertise in ethics is not particularly fashionable these days in a culture like ours where relativism, or at least what passes for relativism, is in the ascendance and traditional views of legitimacy and authority are called into question. The notion of expertise in ethics also smacks of elitism, whereas it seems to be a hallmark of our democratic society that everyone is entitled to her own opinion about right and wrong. It is critical, therefore, to characterize accurately the sort of ethics expertise that ethics committees can offer.

As already noted, the expertise at issue here involves several components. Knowledge of general ethical concepts and principles and some understanding of ethical theory are important requirements, but not all committee members need have extensive philosophical training in ethics. Every committee, however, should have among its members an ethicist with at least some formal background in this area who is conversant with the relevant ethics literature and can educate other committee members in the fundamentals of ethics. In addition to familiarity with principles and concepts, committee members should be able to distinguish issues about which there is consensus in the literature from those that are controversial, to think about ethical problems in a critical and analytic fashion, and to be sensitive to and knowledgeable about cultural differences and power asymmetries in clinical practice. Clearly, there is much that committee members have to learn and, for this reason, committee self-education cannot be a one-time effort but must be an ongoing process.

Skills are also important ingredients of the ethics expertise that ethics committees possess, and they too require practice and continual honing. These include the following: the ability to communicate effectively and teach others; the ability to facilitate discussion and mediation of ethical conflicts; and, as a foundation for the rest, skill at discerning the existence and nature of particular ethical problems and dilemmas.

There are widely accepted ethical (to say nothing of legal) principles that limit the options available for solution of ethical problems, and there is a consensus within the medical and ethics literature on particular issues. Even when ethics committees have to work through cases involving patients and families from different cultures, cultural sensitivity, not a relativism of ethical view, seems to be the appropriate response. Finally, there is no basis for the charge of elitism if it is understood that everyone on the committee can make a valuable contribution to the identification, analysis, and resolution of ethical issues.

LEADERSHIP

Committee leadership is of crucial importance in shaping the nature and success of the committee. The tenure of the committee chair should be long enough for both hospital leadership and other colleagues to identify the leader with the ethics committee and its work. Though some committees have adopted a rotating chair, this strategy has the disadvantage of diffusing authority and decreasing visibility. On the other hand, some chairs do not provide effective leadership and an effort to support term limits may be a way to bring new energy to such a committee. The ethics committee chair should be a person respected within the institution, as well as someone with ethics expertise, yet not every facility contains a person who fits this description ideally. Committees whose chair has great institutional credibility but limited formal training should be especially conscientious in continual self-education and efforts to enlist ethics professionals with formal training. A committee whose chair offers formal ethics expertise but limited clinical experience or institutional recognition must build collegial relationships with clinicians. A strong, knowledgeable, and well-respected committee chair is critical to ethics committee survival. The ethics committee chair functions as liaison between the committee and the rest of the institution. When the committee finds that a difficult recommendation is nonetheless the right one, a chair with strong collegial ties to leadership can help present the committee's views effectively. A committee chair who antagonizes colleagues with judgmental or arrogant pronouncements about what is and is not ethical undermines the work of the committee and may even cause its demise. In contrast, a chair who mediates conflict and addresses ethical tensions effectively and respectfully is an invaluable asset to the committee and the institution.

SECURING A FOOTHOLD

The ethics committee should be situated within the overall structure of hospital governance. Whether the committee reports to the medical board or directly to the hospital leadership, a clear reporting structure creates accountability for the ethics committee, as is appropriate for any workgroup in the institution. At the same time, the reporting structure shows the committee where it may turn when it requires additional support. That support may be financial, for example, funding for a lecture series, or it may be political, as when the committee wants to address a controversial topic like questionable billing practices in one hospital division.

An ethics committee will not flourish and may not even survive in a useful way unless it has the support of the institution, from both leadership and staff. Hospitals in which senior leaders are committed to ethics reflect that commitment in large and small ways throughout the institution. On the other hand, if a key leader—for instance,

the chair of a powerful department—doubts the value of ethics endeavors, the institution will follow that lead and ethics activities will be peripheral to the hospital's mission. New committees and those hoping to improve their efficacy need to examine their level of institutional support. Keeping in mind that hospital directors face extraordinary demands on their time, attention, and financial resources, the ethics committee may wish to consider ways in which support might be increased. Before approaching leadership to ask for support in terms of space, money, or other resources, the committee should define what it offers the institution in exchange for that support. An ethics committee that can show that its current or planned services are important and effective is far more likely to win initial or sustained support than a committee that can define neither its goals nor its accomplishments. The task of clearly defining goals and seeking more effective ways to attain them is a key aspect of earning and deserving support from hospital leadership. Ethics committees that assume that their name alone assures them of support are unlikely to flourish.

Support does not only come from above. A committee may enjoy strong backing from leadership but fail to win the respect of colleagues; such a committee will not thrive. Therefore, in addition to winning the confidence of the institution's leadership, the committee must gain a broad base of support from staff in different departments and roles. The best way to earn support, of course, is to provide a valuable service. A committee that actively seeks out ways in which it can be helpful and provides useful assistance in addressing ethical problems will enjoy the support of its lucky institution; an ethics committee that sits alone in the boardroom waiting for consults will fail. The delicate balance here is to avoid intruding while providing easy and broad access to ethics expertise. Some ethics committees and consultants make rounds with medical teams as a means of increasing visibility and offering real-time assistance. The benefit of this approach is that it brings ethics into the daily fabric of clinical care, which is where it should be. The liability is that many ethics dilemmas cannot be solved on the spot. Consultants must avoid the urge to please colleagues by providing quick answers that lack depth. For example, consultants who round with medical and surgical teams must have the confidence and experience to note when a situation requires a more lengthy and in-depth resolution process than can be provided during rounds.

In summary, ethics committees that flourish have several elements in common. Their goals are clearly defined, and continual efforts are made to improve the ways in which these goals are met. Membership is professionally and culturally diverse, and includes significant expertise in ethics. The committee seeks to build strong collegial relationships with both leadership and colleagues. Committees that provide effective ethics education, policy development, and consultation support the delivery of excellent health care at their institutions.

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