

While hospital ethics committees

have grown in number and visibility over the past decade, important questions about their proper role and method of functioning remain unanswered. One such question concerns the appropriate degree of access to and participation in hospital ethics committees (HECs) by patients and their families. At first glance, this may appear to be a relatively straightforward matter: surely patients and families should have ready access to and play significant roles in HEC deliberations. On closer inspection, however, this issue is complicated by the striking lack of clarity regarding what access means (or should mean). For example, can access objectives be satisfied simply by making HECs available to patients or families who request case review, or must specific efforts be undertaken to include patients and their families in these deliberations? Such questions point to fundamental difficulties about the purposes and functions of hospital ethics committees. Because the access issue brings into focus a range of questions about HECs, it is likely to become one of the more important second-generation challenges facing them.

Treatments of the access issue heretofore have tended to focus on pragmatic concerns such as notification, reporting of results, and analysis of group process. In addition, many discussions assume that patient rights are the primary consideration. We argue that there is an important but seldom appreciated relationship between pragmatic concerns and theoretical analysis of the access issue. Considering this relationship leads us to reject a reductionistic patient rights approach, because it oversimplifies the complex practical concerns that make the access problem compelling in the first place. George J. Agich is professor of medical humanities and psychiatry and director, Values in Medicine Program, School of Medicine, Southern Illinois University, Springfield, Illinois. Stuart J. Youngner is associate professor of medicine, psychiatry, and biomedical ethics, School of Medicine, Case Western University, Cleveland, Ohio.

## For Experts Only? Access to Hospital Ethics Committees

by George J. Agich and Stuart J. Youngner

How closely involved with hospital ethics committees should patients and their families become? Should they routinely have access to committees, or be empowered to initiate consultations? To what extent should they be informed of the content or outcome of committee deliberations? Seeing ethics committees as the locus of competing responsibilities allows us to respond to the questions posed by a patient rights model and to acknowledge more the complex moral dynamics of clinical medicine.

a central substantive principle in their deliberations, it need not always be the major determinant of ethics committee procedure. In reaching this conclusion we point to the need to complement the rights-based analysis of access by a more comprehensive consideration of responsibility in health care.

### Ethics Committee Functions

The problem of access is complicated by ambiguity in the accepted understanding of what hospital ethics committees are all about. The literature distinguishes, for example, the following very different functions: providing ethical advice and analysis, counselling, determining prognosis, peer review, quality assurance, resource allocation and rationing, risk management, and patient advocacy. The issue of access obviously undergoes marked mutation depending on which of these different functions is envisioned. Even when the range of committee functions is reduced to the three generally accepted major activities of education, policy formation, and case review, problems remain. For present purposes, we set the first two functions to one side and focus instead on case review, a more innovative and potentially disruptive function that brings the issue of patient

and family involvement into sharpest focus.

Case review is actually a complex family of functions that can be categorized along a number of axes, including, for example, a temporal one: we may distinguish between retrospective and concurrent review. Further, case review can be categorized according to whether (a) the *review is* required or optional, and (b) the *recommendation is* required or optional, yielding the optional/optional, optional/mandatory, mandatory/optional, mandatory/mandatory matrix.<sup>1</sup> Our analysis of the case review focuses on the optional/optional model since it seems to predominate in hospitals today.

Even with this restriction, the term *case review is* unclear; at least two types need to be distinguished: administrative case review and clinical ethics consultation.<sup>2</sup> Administrative case review involves consideration and discussion of actual ongoing patient care conflicts and dilemmas that are brought to the committee; they are reviewed by the committee and an "official" report or recommendation offered. In such review the committee meets usually as a whole, in a conference room or somewhere apart from the patient care setting, and "hears" the case presented by physicians, nurses, and other care givers

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or family. Typically, there is no independent gathering of evidence, review of medical records, or independent interviewing of all interested parties by the committee.

The second type of case review is ethics consultation. Consultation involves a different role and process from administrative review, one that is more congenial to current clinical practice, yet potentially problematic as well.<sup>4</sup> The ethics consultant functions as an independent professional in the clinical setting. This role accords the consultant independence of judgment and imposes the duty to review records, gather information, and make independent assessments of the nature of the problems involved. Clinical consultations might be carried out either by individuals or small consultation teams. Difficulties in scheduling meetings of full committees frequently necessitate such an approach, even when an administrative review model is preferred.

Administrative case review mimics the legal process without explicitly providing for the same kinds of protections—for example, rules of evidence, avoidance of hearsay, and due process. Such *internal* (to the institution) review nonetheless could ameliorate rather than exacerbate the conflictual and adversarial tendencies that problem cases engender. While the potential for resolving conflict is undoubtedly one of the more significant factors underlying the acceptance of ethics committees, there are also problems associated with administrative case review, it can implicitly give recommendations the status of binding decisions,<sup>5</sup> and families may find its more formal and impersonal mechanisms daunting.

Ethics consultation is not without problems either. First, the dearth of individuals with experience and train-

sometimes be strength in numbers, we believe that the consultative team may engender a diffusion of responsibility that could lessen rather than enhance the effectiveness of ethics consultation. Second, confusion over the process of ethics consultation has been amplified by defining the clinical nature of ethics consultation in such away as to permit, or indeed require, only physicians to engage in the interactions (such as a physical examination, ordering of tests, and differential diagnosis) stipulated as necessary.<sup>5</sup> To be sure, advocates of ethics consultation must confront the process, skills, and requisite qualifications for the consultative approach; a strategy of either simply increasing the numbers of individuals involved as away to gain "interdisciplinary" coverage<sup>9</sup> or of presuming that ethics consultation insofar as it is clinical properly belongs to physicians raises a host of contentious questions. The important point for present purposes is that the question of patient and family access to case review is complicated by the basic ambiguity in and uncertainty about the function and process of case review itself. We can, nonetheless, distinguish at least the following six general aspects of the patient and family access issue.

#### Types of Access

Knowledge of Committees' Existence and Functions. Knowing of the existence and purpose of a committee seems to be the most fundamental element of access, yet the appropriate mechanism for getting this knowledge to patients and their families is far from settled.<sup>10</sup> Several alternatives seem obvious: all patients and families could be informed routinely on admission, or other methods could be developed for universal dissemination of information, such as distributing brochures or videotaped segments for in-house television where available, or use of local media. Information could be

shared only with persons in special care areas, such as intensive care units, where contested decisions such as limiting life-sustaining interventions are more likely. Or patients and families might be informed only at the discretion of the patient's physician, nurse, or social worker. A corollary concern involves whether patients and families should be informed of the committee's existence or of its *functions*, specifically the case review function. If information on the latter is included, should detailed information regarding the availability of consultation services, including named individuals and phone numbers, and charges, if any, be included? The question of charges is a particularly sticky point that obviously affects access, but perhaps opens other even more difficult and fundamental problems about case review.

Awareness of Specific Committee Meetings or Consultations. Should the patient and the family always be informed about any committee meeting or consultation? Should they never be informed? Should there be specific guidelines spelling out the conditions for informing? Should the decision be left to the discretion of the primary physician or other health professionals, or reserved to the committee, its chairman, or the ethics consultant? Informing patients and families about the existence of committees or about specific consultations or meetings raises immediate questions about the remaining four types of involvement and control.

Consent for Specific Case Review to Occur. Must ethics committees obtain consent from patients and families before a case review can be undertaken? Is consent mandatory in all cases or are there situations in which committees can and should proceed despite patient or family wishes to the contrary? Of course, if patients and families are not even informed that a committee exists, how it operates, or that a case review is planned, it is easier both to avoid obtaining consent and to meet without permission.

Convening the Committee or Initiating a Case Review. Should patients and their families be empowered to convene meetings of the ethics committee or to institute ethics consultations? One answer, of course, is that under no circumstances should patients or their

families be allowed to trigger a meeting or consultation. Even if one takes a more liberal stand, however, many questions remain. For example, should patient and family requests for meetings or case review be granted automatically, or should they be "screened" and evaluated on a case-by-case basis? If there is some degree of screening, who should do it and according to what criteria? Further questions include: To whom should the patient or family make the request? Should they have direct access to the ethics committee, its chairman, or consultation service, or should requests be conveyed by the primary physician? Could requests be channeled through other staff such as nurses, social workers, ministers, administrators, or patient advocates? Should each of these persons have discretionary power to screen requests? If yes, what criteria should they employ?

Attendance at Ethics Committee Meetings and Direct Involvement in Ethics Consultations. Should patients and families have the right to attend meetings or participate in case review? Should patients or families ever be required to attend meetings? If patients or families do attend, is it acceptable to conduct a portion of the meeting without them? In the case of consultations, should the patient always be involved directly and should all interested family members be involved or only those who are legitimate surrogates?

Access to Reports and Recommendations. Should patients and families be informed about the content and outcome of committee deliberations or a consultation report? If yes, a host of questions (similar to those asked above) arise. Should the committee, its chairman, or the primary physician communicate the report or recommendations directly to the patient or family? What type of information should be shared just the committee's advice, recommendations, and conclusions, or the reasoning supporting these, including disagreements within the committee or between the committee and the primary physician? Finally, should the report or recommendations be given verbally or in writing?

As these questions suggest, there is a wide range of patient and family access to ethics committees. For example, a committee that accorded maximal ac-

cess and control would inform all patients and families of the committee's existence and *modus operandi*. Such a committee would imaginatively seek to disseminate information about the committee and its services broadly. Patients or families could convene the committee or initiate a consultation directly and automatically; there would be no screening by health professionals. If health professionals wanted the committee to meet, they would have to inform patients and be required to obtain their permission as well. Patients and families could participate fully in the entire meeting and expect to receive in writing any committee recommendations, including disagreements among committee members.

A committee that accorded minimal access and involvement would not inform patients and families about the committee's existence and function. Neither patients nor families would be able to convene the committee without the physician's assent; health professionals would have no obligation either to tell patients and families about specific committee meetings, or obtain their permission to meet. Patients and families would be routinely excluded from the review process and would receive recommendations or reports only at the direction of, and in a form decided by, their primary physician.

Clearly, within these extremes there is room for considerable variation, such as informing the patient or family that a meeting is to occur, but not inviting or permitting them to attend. Specific variations will reflect not only isolated consideration of the question of patient access, but the political and sociological realities of the institutional setting, as well as its conception of and commitment to ideals of patient care and professional responsibilities. These realities point to the moral and political complexities of medical decisionmaking in modern hospitals that need to be considered in addressing the question of patient and family access to ethics committees.

#### Access: Theoretical and Practical Aspects

Given the complexities discussed above, it is not surprising that the access question has received a varied treatment. In a 1985 review article on ad-

ministrative aspects of ethics committees, Norman Fost and Ronald Cranford clearly recognize that "the most controversial question confronting an institution considering formation of an ethics committee is the definition of access and jurisdiction." After establishing the desirability of involving patients and families in critical care decisions, and then asking if such involvement should include direct discussions with the ethics committee, whom they identify as "a group of strangers," they conclude,

In some cases it will be appropriate for relatives to join the discussion (e.g., when they insist on it), but that should not preclude the group having an opportunity to discuss the issues among themselves, free of the inhibition that would accompany the presence of patients or relatives. In other cases, family involvement may be unnecessary and/or unwanted by the family. If the primary function of the group is to be advisory to the attending physician, apologies should not be needed for the physician's desire to have a free and uninhibited consultation. A flexible policy would be to invite family members to present their views but not require it. (p. 2689)

Fost and Cranford do acknowledge the importance of patient and family wishes, resources, and religious orientation, but question whether this information needs to be presented directly by them. They also note the cardinal importance of the legal right of self-determination when competent patients are the subject of discussion, but note that it is unclear whether explicit permission is necessary from the patient or family before physicians can consult with the HEC. Remarkably the legal duty regarding confidentiality, they counsel that "it would seem prudent, if not required by law, to obtain permission from the patient or family" (p. 2690). On the specific point of patient access, they insist that it is in part a "political issue" and offer a pragmatic proposal rather than a moral analysis by suggesting that the problem be "resolved within the personalities and traditions of each hospital" (p. 2690).

On this view, the access question is conceived primarily in terms of the



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physician's need for consultation, which is constrained, especially in the case of the competent patient, by the legal rights of self-determination and confidentiality. Nevertheless, the discussion stresses that the issue of access is mainly pragmatic. Case review is conceived primarily as administrative review, but a consultative model is acknowledged as a necessity owing to inevitable unavailability of a majority of committee members. For the most part, the question of access is seen as practical, but constrained by a theoretical acceptance of patients' rights.

Others have more explicitly and unambiguously called for greater patient and family involvement. Invoking images of secrecy or relying heavily on rights language, they have raised the specter of ethics committees serving the paternalistic, self-interested, or narrow values of physicians (or institutions) at the expense of patients' privacy and freedom to control the decisionmaking process.

Robert Veatch, for example, argues: "If the patient or surrogate is really the key decisionmaker, then discussions of patients' cases without their participation and consent is unacceptable."<sup>12</sup> Veatch appeals to the principle of confidentiality. The requirement of confidentiality outweighs the obligation of beneficence, and therapeutic privilege is specifically rejected as a permissible exception. Furthermore, he rejects the notion that consultation with ethics committees can be viewed like other more "routine" medical consultations or reports to tissue or quality assurance committees. Case review by an ethics committee is importantly different from other medical consultations, because in typical medical consultations, he claims, "there is no reason why a patient might object and every reason to expect that the patient would want the consultation" (p. 21). In the case of tissue and quality assurance committees, he notes that a release may have been signed by the patient permitting disclosure as required for insurance reimbursement or by law. It is very dif-

ferent with ethics committee reviews, however, where "enough patients and surrogates believe in their right and duty to make their own decisions that no one can presume they would prefer that their case be discussed without their approval" (p. 21).

Bernard Lo too advises against limiting patients' and families' access, and appropriately questions the enthusiasm that has driven the ethics committee movement in recent years. He notes with concern that many ethics committees do not permit patients to bring cases for review.<sup>14</sup> Committees not only restrict access of patients and families, but of nurses and other health professionals as well. In light of his concern about the negative aspects of HECs, he suggests several criteria for evaluating both the process by which committees review cases and the results of their deliberations: first, patients and their surrogates should have ready access to HECs, second, recommendations by the committee and the reasons for them should be available to the parties in each case; third, recommendations by ethics committees and actual decisions by physicians should be consistent with the widespread ethical and legal consensus that has emerged on many issues; fourth, parties in disagreements should be satisfied with the process of review and the recommendations made; and finally, ethics committees that make recommendations in particular cases should have internal systems of review (p. 49).

These authors helpfully call attention to some of the pitfalls associated with patient and family access to ethics committees. In so doing, they help disentangle from hard practical realities the enthusiastic and positive rhetoric frequently associated with the ethics committee movement, but by conceptualizing the access question in terms of patient rights, a truncated picture of the issue is presented. To be sure, Lo is primarily concerned to sound a cautionary note, one with

mitted to the legalistic understanding of patient rights, though this commitment has rather different implications in each treatment. While Fost and Cranford note the importance of the patient's legal rights of self-determination and confidentiality, they nonetheless propose a "flexible policy" that accepts situations in which it is appropriate for patients or families to participate in case discussions, namely when they insist on it, but also situations in which patient or family participation is not required, such as when the primary focus of the review is to advise the physician. Their goal is to accommodate the practical realities of HEC review and clinical medicine within constraints imposed by patient rights without, it seems to us, acknowledging that their pragmatic accommodation lacks explicit justification.

Veatch is specifically concerned to undercut the case-review function by a stringent interpretation of patient autonomy and confidentiality. He claims that patients' and surrogates' belief "in their right and duty to make their own decisions" invalidates the notion of presumed consent for their care givers to consult with an ethics committee. He seems to equate presuming consent for case review with leaving patients and families out of the decisionmaking process entirely. Even if many or most patients and surrogates want to control decisions about their care, it can hardly be concluded that they would object to their physician's consulting an ethics committee. That is an empirical question for which there is little or no data. Just as he does when he claims that patients do not normally object to medical consultations, Veatch confuses empirical matters, about which there are hardly any reliable data, with normative questions such as whether patients should be asked to consent for even routine medical consultations. Furthermore, Veatch's emphasis on confidentiality leads him to argue that without the express consent of the patient, the committee cannot be consulted "even when a clinician is attempting to obtain assistance in presenting the moral and medical options to the patient."

Veatch's analysis hinges on a narrow adversarial and legalistic conception of patient rights. Exceptions to his rigorous view of confidentiality could

occur only "if there were a law requiring or authorising disclosure" and, even then, "such a law would be plausible only if the disclosure were made in a context of public due process and accountability." Correlatively, committee members "should be chosen by public mechanisms." In Veatch's account, there are but two alternatives—a rigid adherence to the principle of confidentiality, or a public (and thus assuredly adversarial) resolution of the questions by legal mandate. Veatch leaves little room for good will or trust within the institutional context.

Analysis of the access issue is thus frequently structured by reliance on the theory of patient rights to trump other concerns. Such reliance not only uncritically assumes a legalistic model of the ethics of medical care, but effectively precludes any realistic case-review role. Veatch's treatment of the issue in terms of confidentiality is paradigmatic in this regard, but acceptance of the fundamental nature of patient rights is evident in Lo's analysis as well as in Fost and Cranford's treatment. Both of these latter discussions, however, signal the practical realities of IHEC functioning that deserve more explicit theoretical attention. On our view, a legalistic treatment of the access issue understandably fails to provide an adequate account of the practical alternatives associated with the problem. Even if physicians should not consult with ethics committees without patient or family consent, it is important to be clear how this prohibition plays into other aspects of the access issue that, in turn, have implications for the underlying concept of the nature and purpose of ethics committees.

Discussion of the access issue is thus caught between the Scylla of the patient care that occasions the need for case review and the Charybdis of commitment to a legalistic theory of patient rights that accords the patient and family full involvement with—indeed control over—case review. Few commentators attentive to the realities of patient care and the positive prospects associated with HECs, however, seem willing to insist that patients or families should have exclusive access or complete control over access, even when they grant the importance of patient rights.<sup>6</sup> Why? In part, this reluctance may stem from the failure of commen-

tators to come to terms with the real complexity of the access question. As a result, lip service is paid to patient rights without fully embracing the implications of such a theory for the access question. In this regard, Veatch's view that patient rights require nothing less than complete control by patients is important for honestly drawing out the implications of the model. Helpful suggestions such as those offered by Lo as well as Fost and Cranford seem without justification if the framework is defined by a legalistic theory of rights. This dilemma points to the need to reexamine the theoretical framework in terms of which the question of access is posed.

#### Being Responsible versus

#### Having Rights

Many problems come to the attention of ethics committees not because rights are being violated or morally repugnant decisions are being made,

and punishments on individuals and institutions by the state; second, an internal, moral dimension that concerns the accountability of individuals for their actions as well as the consequence of choice; and third, a comprehensive dimension that captures the social and cultural context and significance of human action.<sup>7</sup> Historically, responsibility is a product of modern thought that brings together two ancient philosophical themes: accountability for one's beliefs and actions and the imputability of moral praise or blame. Originally these concerns developed separately, but by the end of the seventeenth century, the languages of natural law and of duties provided a common vocabulary for addressing concrete problems of [ethics.la](#)

Responsibility brings considerations of justice, in which political and legal matters are primary, together with considerations of duty that focus on the nature of moral agency; and it does so

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but because of genuine existential confusion and frustration. Many problems grow out of poor communication and its attendant misunderstandings and suspicions. They grow out of personal incompatibilities among and between patients, families, and health professionals. They grow from Angst, as all concerned attempt to cope with the ultimate paradox presented by medical technology: a simultaneous loss yet illusion of control in the face of critical illness and death. In this context ethics committees should not be restricted by a rigorist model of patient rights. Instead, the guiding ethical concept should allow such ambiguous and perilous situations to be confronted realistically and constructively.

The concept of responsibility includes three dimensions that make it particularly well-suited to this purpose: first, an external, legal dimension that concerns the imposition of penalties

by directing attention to the concrete context of human action. Responsibility is thus a complex notion that nonetheless indicates the kind of concern one person ought to have for another's welfare in light of the specific relationship between them and concrete circumstances. As a result, attending to responsibility involves considering the way ethical principles practically inform the actual context of action; it necessarily involves taking seriously moral judgment the attitudes and needs of involved parties—as well as the specific interpersonal relationships that make action, choice, and deliberation an ethically complex dynamic.

The importance of this concept becomes clear when we reflect on the central purpose of HEC case [review.to](#) assure a morally sound solution to practical conflicts, dilemmas, or problems in clinical care.<sup>19</sup> Such a purpose is consistent with the goals of preserving patient

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rights and well-being, but not slavish to them; it establishes a role for HEC members that institutionally empowers them to act in ways that are usually-for bureaucratic, interpersonal, or professional reasons-otherwise unavailable. Hospitals undoubtedly have various reasons for creating ethics committees, but the essential purpose is to respond to a range of recurrent needs.

The scope of ethics committee functioning should not be dictated by an uncritical and exclusive adherence to a patient rights model. Unlike rights, moral decisions based on responsibility involve judgment. Discussion, reflection, and problem-solving are essential components of the exercise of this judgment, whereas rights normally do not require or even permit consideration of matters other than those related to the status of the right itself and an individual's ability to do what the right requires. Responsibility becomes especially important whenever there is an antecedent inequality between the parties as far as their needs and abilities are concerned. Responsibility relationships, therefore, define social roles that aim to enhance the well-being of the weaker party. As a consequence of this point, responsibility relationships are dynamic; they change and develop over time as the needs and abilities of the involved persons develop and their conditions change. Rights, however, exist in abstraction from any particular relationship and are determined before interactions occur or the decisionmaking process starts.<sup>2</sup> On the responsibility model, the committee of necessity and unavoidably has to exercise judgment in light of the concrete circumstances of the particular case.

In fact, the circumstances that engender requests for case review are not so readily reducible to the model of patient rights for at least three important reasons. First, confusion and communicative dislocations owing to the ambiguity and emotionally charged nature of decisionmaking, especially in

contexts of critical care, are the most common occasions for case review. Second, conflicts are of many types: conflicts of choice, conscience, means or methods, and value. Only some of these conflicts are properly defined in terms of rights. Third, patient rights may themselves conflict, so some ordering is always necessary. The right to confidentiality, for example, might prevent concerned health professionals from enlisting the aid of an HEC in having a patient's right to an informed refusal of treatment respected by the attending physician and family. Clearly, a decision must be made regarding which of these rights is more fundamental.

Instead of the analytically reductive and practically barren model of patient rights, the concept of responsibility affords a more appropriate model for treating the question of patient and family access to hospital ethics committees. When committees see their role as balancing conflicting responsibilities, they are in a better position to decide access on a case-by-case basis. On the responsibility model, elements such as the inequalities of parties to health care, the importance of attitudes, and the dynamic character of care-giving relations come to the fore. That is why many experienced commentators such as Fost and Cranford as well as the American Hospital Association, its Special Committee on Biomedical Ethics, and The Hastings Center either explicitly allow ethics committees or their chairpersons to limit patient and family access or call for-but importantly do not themselves provide-specific procedures or rules." These commentators recognize the need for discretion in determining access, but also see the need for guidelines. However, rigid rules for patient and family access, such as those provided by Veatch's reading of **confidentiality**, oversimplify the complex ethical reality of clinical medicine. Such a reductive

but without a framework to justify allowing committees discretion or judgmental latitude. The model of responsibility fills this gap by helping us see how the novel-albeit complex-role of HECs creates a unique responsibility relationship that imposes an obligation to exercise the associated authority or power to pursue morally sound outcomes. Judgment occupies a central place in this process of enacting the HEC role.

The exercise of moral judgment is a developed skill that involves education and cultivation. While the exercise of judgment is not reducible to the application of rules or algorithms, there are consensus norms that serve in their stead, as Lo correctly pointed out<sup>22</sup> Good judgment does not make one an expert in the widely criticized sense of the engineering model of applied ethics, but confers an authority based on experience in making sound and practically successful judgments. Responsibility thus affords a different and more comprehensive way to assess and understand clinical ethics and the functions and purposes of ethics committees than does the rights model. Importantly, responsibility serves these ends by complementing rather than competing with rights.

Rights language is appropriate for contexts in which moral relationships have broken down, in which moral relationships cannot be assumed to exist, or in which genuine moral conflict exists." When these circumstances occur, responsibility itself requires appeal to rights to protect patients. If hospitals were correctly viewed only in these terms, then ethics committees would be about as useful as they might be in the midst of anarchy or civil war. In such circumstances the patient advocate, bodyguard, or attorney would be the appropriate ally. Hospitals, however, are not adequately viewed in these terms. Rather, they are places where, in general, well intentioned and capable health professionals do their best to fulfill the goal of delivering the best medical care they can in a highly organized and bureaucratically structured institutional setting. Patients and families for their part typically trust physicians and other caregivers and are more concerned about achieving the best possible medical outcome than they are about protecting and asserting their abstract "rights." Responsibility for

promoting and maintaining trust and appropriate clinical goals is, therefore, a central feature of the ethical practice of medicine. The concept of responsibility requires that the myriad factors that influence and complicate human action in the practice of medicine be considered; it also helps identify and

c the issues associated with the question of patient and family access to case review.

Case review offers a way to attend to the ethical quandaries of the many parties involved in the care of a single patient in order to promote understanding of the complexity that comprises the moral universe of clinical medicine and to devise morally sound solutions. A patient rights model unfortunately impedes, if not prevents, dealing with these concerns. Rights language has a peremptory ring that trumps other relevant moral considerations. So, if a committee meets without asking the permission of a patient or family, it violates rights by meeting "behind closed doors" and "violates" confidentiality. Rights language relies on an abstract, adversarial, and impersonal conception of human relationships. It assumes that the paradigm human relationship is one between strangers, hence there is little or no room for caring, discussion, negotiation, reflection, or trust. The anxiety, apprehension, confusion, fear, and helplessness engendered by critical illness are conveniently removed from consideration by the essentially abstract character of the patient rights model. Consideration of responsibility, however, restores the hard concreteness of clinical ethical problems. It enables us to confront situations that are ambiguous and potential areas of conflict, recognizing that relationships between patients and health professionals can change from utter dependency and helplessness in some situations to mutual respect and trust in others. It focuses attention on the processes of action, interaction, communication, and decisionmaking at times of great emotional and existential stress.

#### Advantages of the Consultative Model of Case Review

Our analysis thus far leads to three major conclusions: first, the consultative model of case review is preferable

to the administrative; second, while patient and family involvement should be encouraged, exceptions should be permitted if they are justified explicitly; and third, an individual consultant model is preferable to a group consultation approach, all things being equal.

The maximum level of patient and family control called for by Veatch and others seems unwise and impractical. Health care institutions would not likely embrace such committees and it is doubtful that they would be used with any frequency by health professionals or even patients and families. Furthermore, such a model involves a truncated and overly simplistic view of the ethical issues involved in medicine as well as of the kinds of dilemmas that engender requests for case review in the first place. A purely paternalistic approach seems equally unacceptable. Even well-meaning health

For these reasons, a better model for case review is the consultative model. The consultative model is less formal and more open-ended, hence it affords multiple avenues and opportunities (often private) for interaction with patients and families. A consultant is not as restricted to rendering an opinion on the basis of limited information presented in the course of one meeting. Instead, the consultant has the latitude, indeed the obligation, to pursue points that need clarification and to render an opinion only upon satisfactory completion of the consultative investigation. One notable advantage of this approach is that it focuses attention on the contextual character of case review and highlights the ethical nature of the ethics consultant's own role. Ethics consultants should be allowed latitude of judgment in discharging their duties to serve the

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cannot be counted on to represent patient interests effectively. A model that severely limits patient and family involvement is more likely to diminish both patient rights and well-being.

Of the two operational models for case review discussed above, the administrative model seems more vulnerable to the abuses of paternalism than the consultative model. Administrative review is more formal, and, thus, more likely to be taken as binding. Representations about patient or family views as well as the "facts" in the case necessarily tend to be secondhand. Discussions usually take place far from the bedside and at one time, leaving little opportunity for reflection or revisiting issues after new information has come to light. Administrative review inevitably takes place in the presence of many persons, some of whom may be strangers, unequal in power, shy by nature, or otherwise indisposed to discuss deeply personal or conflictual issues in such a setting.

best interests of patients and families, while, at the same time, acknowledging and indeed nurturing their autonomy.

#### Justified Exceptions to Patient and Family Involvement

In any hospital to which they are admitted, patients and families should routinely be informed about the existence of an ethics committee and how it could prove helpful to them. If they can meet with the committee or request an ethics consultation, they should be routinely informed of this right and the procedures by which to exercise it. To presume their knowledge in these matters is at best naive. To keep such information from patients and families intentionally can quite reasonably be considered deceitful and implies a fear or lack of trust of the very people the hospital and its professions are meant to serve.

Whether or not patients and families can convene the committee directly

Hospitals are places where, in general, well-intentioned and capable health professionals do their best to fulfill the goal of delivering the best medical care they can. Responsibility for promoting and maintaining trust and appropriate clinical goals is a central feature of the ethical practice of medicine.

may be less important than how their direct care gives view the committee's role. After all, if the physicians, nurses, and social workers think the committee is threatening or ineffectual, it is unlikely that patients or families will choose to access it. Even if patients and families do not have a right to trigger committee review, we think that responsible committees will maximize their access, especially when conflict is present or the issues at stake are serious.

In general, permission for case review should be obtained. This is especially important if the review follows administrative lines and yields an "official" report rather than simply providing a consultative review and recommendation. In the latter case, patient or family consent for an ethics consultation is not always necessary, though the consultant will obviously need to seek consent if patients and families are to be involved in the consultative process. However, in those cases in which the consultation focuses, for example, on breakdowns in communication between nursing or other staff and physicians or in which the focus involves value conflicts or moral dilemmas for health professionals, it is not clear that the consultation requires specific patient or family authorization. In these cases, we believe that peer review functions and education afford relevant precedents. While such exceptions violate the most rigorous (and outmoded) interpretation of the duty of confidentiality, they occur regularly and of necessity in the complex social reality of hospital-based medical care. However, we would hasten to add that our views depend upon a certain idealized understanding of the character and purposes of the ethics committee as well as the qualifications and competence of the ethics consultant. Admittedly, not all ethics committees function equally well and not all who claim to do ethics consultations

would meet our minimal expectations. Finally, there are circumstances in which health professionals could justify seeking case review without informing or obtaining prior patient or family consent. These expectations would include: first, a pressing need to protect the best interests of an incompetent patient or the autonomy of a competent one, second, the need to resolve conflict among the professional staff, or third, the need for emotional support, clarification of the problem, and social validation. Each of these circumstances should be justified cogently.

#### Advantages of an Individual Consultant Model

If ethics consultation (as opposed to administrative review) is the ideal type of case review, it strikes us that in most instances consultation is best performed by an individual rather than a group. Individual consultants have the advantage of greater flexibility with regard to time, direct access to the medical chart, the ability to communicate directly with key persons, and, finally, more visible and personal accountability to the important decision-makers—including the patient and family. In most instances, patients and families will experience greater comfort interacting with individuals rather than groups. Indeed, many, if not most, access problems will be resolved by a bedside (as opposed to conference room) consultation, because the former of necessity involves direct interaction with patient and family.

The relationship of the individual consultant to the committee should be complementary rather than competitive. The full committee could regularly review, in a retrospective fashion, the consultations performed by individual ethics consultants. This would have the advantage of educating the coo-

mittee and provide a quality control function for the consultants. If the consultant, health professional, or patient felt that a particular case was unusually complex or controversial, then full committee administrative review could occur. Under such a system the ethics consultant would have a great deal of discretion and flexibility on how to handle each case. Such discretionary authority is nothing new, however, as effective committee chairpersons exercise it regularly in "screening" the cases that come for full committee review.

The question of patient and family access to ethics committees turns out to involve basic questions about the nature and specific purposes of ethics committees. We have argued that some of these questions have been bypassed by both proponents and critics of ethics committees. As the case-review function lends prominence to ethics committees, these questions will need to be given greater attention than heretofore. In defending a responsibility-based model of committee functioning and a consultative model for case review, we have tried to take into account the complex clinical and political realities of hospitals as well as to reflect on the strengths and weaknesses of the experience of ethics committees to date. We believe that the nuanced issue of patient and family access is best handled by models of clinical ethics that afford room for judgment and flexibility in dealing with particular cases and circumstances.

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2. Judith Wilson Ross, "Why Cases Sometimes Go Wrong," *Hastings Center Report* 19, no. 1 (1989): 22-23, distinguishes a third type, namely counseling. We, however, regard counseling as a function more akin to what George J. Agich, "Clinical Ethics: A Role Theoretic Look" *Social Science and Medicine* 30 (1990): 389-99, has termed "witnessing" than consultation.
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min, "Ethics Consultants and Ethics Committees," *Archives of Internal Medicine* 149 (May 1989): 1109-12. La Puma and Toulmin distinguish clinical ethics consultants, ethics consultation services, and ethics committees conducting case review. For the moment, we treat individual ethics consultants and team consultation services as one stressing the consultative as opposed to administrative nature of the review involved, though we shall distinguish consultations performed by individuals from interdisciplinary team consultations.

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9. Ronald E. Cranford and J. C. Roberts, "Ethics Committees: None of Us Is as Smart as All of Us," *Michigan Hospitalist* 22 (December 1986): 14-16 and 31-34. Other potential problems include concerns that individual ethics consultants will speak, or be heard to speak, with the voice of the committee without a clear mandate to do so. Others have questioned the authority or validity of committee decisions. For example, Bernard Lo, "Behind Closed Doors," p. 48, warns about the dangers of "groupthink" and Jonathan D. Moreno, "Ethics by Committee: The Moral Authority of Consensus," *Journal of Medicine and Philosophy* 14 (November 1988): 411-32, and "What Means This Consensus? Ethics Committees and Philosophical Tradition," *Journal of Clinical Ethics* 1 (January 1990): 38-43, questions the status of consensus in committee decisionmaking.

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