els and may also relieve symptoms, such as headache, related to the mass effect of the tumor.¹²

Somatostatin was initially proposed as a treatment for acromegaly, since it normally reduces growth hormone levels. However, the very short half-life of somatostatin made it unsatisfactory for therapeutic use. In contrast, the long-acting somatostatin analogue SMS 201-995 has proved valuable in patients with acromegaly that is refractory to surgery, bromocriptine, and other forms of therapy. The series of Comi et al.1 extends the indications for this long-acting somatostatin analogue to patients with thyrotropin-secreting pituitary tumors. Although this condition is relatively rare, somatostatin analogues offer the hope of reducing thyrotropin levels when these patients have not responded to other forms of treatment. The need for multiple daily injections may ultimately be overcome with the development of an oral form of the drug¹³ and of different analogues of somatostatin.

The treatment of patients with pituitary tumors can be simple when one therapy is highly successful. However, management of these tumors often requires the combined or sequential use of multiple forms of therapy. The reports on SMS 201-995 in this issue are a welcome indication that additional medical treatment will soon be available for patients with thyrotropinsecreting pituitary tumors. Drug therapy already offers an effective form of treatment for patients with prolactinomas. The day when medical therapy alone can be used for patients with more difficult conditions, such as Cushing's disease, acromegaly, and thyrotropin-producing tumors, is not yet here but seems to be drawing closer.

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SOUNDING BOARD BEHIND CLOSED DOORS Promises and Pitfalls of Ethics Committees

HOSPITAL ethics committees have been hailed as providing a promising way to resolve ethical dilemmas in patient care. Although ethics committees may have various tasks, such as confirming prognoses, educating care givers, or developing hospital policies, their most innovative role is making recommendations in individual cases.¹⁻⁵ This role has been supported by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, the American Medical Association, and the American Hospital Association. Strictly speaking, such recommendations are not binding, but they undoubtedly carry great weight, especially if they are cogently justified.⁶ It is predicted that most ethics committees will make recommendations in particular cases³ and that the courts will respect them.³

Ethics committees may offer an attractive alternative to the courts.³⁻⁵ The judicial system may be too slow for clinical decisions.^{7,8} Moreover, the adversarial judicial process may polarize physicians, patients, and families,⁹ whereas ethics committees may reconcile divergent views. The 1986 New York State Task Force on Life and the Law encouraged resolving patient care dilemmas at the hospital level, rather than turning to the courts, and suggested that ethics committees might mediate such disagreements.¹⁰

Although I support ethics committees, several questions trouble me. First, are these committees ethical? The goals and procedures of some committees may conflict with established ethical principles. Second, is agreement by committees always desirable? Group dynamics may lead to flawed information, reasoning, or recommendations. Third, are these committees effective? Like other medical innovations, they need to be rigorously evaluated.

GOALS AND PROCEDURES OF ETHICS COMMITTEES

The very name suggests that ethics committees base their recommendations on ethical principles and rational deliberation, rather than on mere custom, political power, or self-interest. A consensus on medical decision making has emerged in the medical literature, court decisions, and reports of the President's Commission.^{1,7,8,11,12} According to this consensus, competent patients should give informed consent or refusal to the recommendations of physicians. Care givers need not accede to patient requests for treat-

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ments, however, if there are no medical indications. In cases in which patients are incompetent, decisions should be based on their previously expressed preferences or, if such preferences are unclear or unknown, on their best interests. The goals of some ethics committees, however, may conflict with these ethical guidelines. Goals vary substantially among committees.^{1-3,13-15} Some do not have explicit goals. One committee has said, "We have never formally stated in writing the exact purpose or purposes of our committee but have decided to proceed in an informal manner. . . . We felt that to formalize our objectives might be counterproductive to the work of our committee."¹⁴ But as ethics committees mature, and especially as they wish to serve as alternatives to the courts, they need to define their goals more clearly. Some so-called ethics committees have as goals confirming prognoses, providing emotional support for care givers, or reducing legal liability for physicians or hospitals.^{1-3,13-15} One hospital administrator has even suggested that the ethics committee be used as a public relations "tool" for justifying unpopular decisions to discontinue unprofitable services.¹⁶ Although committees on quality assurance, staff support, risk management, or public relations are important, there is little reason for patients, their surrogates, or the public to accept their recommendations about patient care.

After clarifying goals, committees can establish procedures. Ethics committees must decide who can refer cases or attend meetings. Many committees limit participation by patients and families. According to a 1982 survey, only 25 percent of ethics committees that reviewed cases allowed patients to bring cases to the committee. Only 19 percent of committees allowed patients to attend meetings, whereas 44 percent allowed family members to do so.¹⁷ Limiting access to committee proceedings may seem desirable. It may be sound political strategy to overcome initial resistance to the ethics committee within the hospital. For example, attending physicians may fear that their authority will be undermined if patients, families, or nurses can ask the committee to review cases. Restricting access may also facilitate frank discussions by care givers and committee members about sensitive topics. In addition, discussions with other health professionals may help physicians to clarify their thinking before they talk to patients or families.

Restricted discussions, however, may not be accepted by patients, families, and society. Patients or surrogates who disagree with physicians are unlikely to regard the committee as impartial if they may not convene the committee or present their views directly, whereas physicians may do so. Disagreements that reach ethics committees usually involve important personal issues — even questions of life and death. In such vital decisions, patients and their proxies are not likely to accept recommendations by a committee whose members they have not met or that seems to meet behind closed doors. The composition of ethics committees may not reassure patients that their wishes and interests are represented. Typically, most members of ethics committees are physicians, who may assess the importance of medical problems or the risks and benefits of treatment differently from patients.^{18,19} Patients or surrogates who disagree with the committee's recommendations may say that the composition of the committee was biased against them.

Some committees meet with patients or family members who take the initiative and request meetings. But people who need the most help in expressing their preferences or interests may be the least likely to request a meeting. They may be cognitively impaired or unable to navigate the medical system, or there may be cultural, language, or educational barriers. Hence, it is desirable for the committee to take steps to inform patients, as well as care givers, of its work. Such information is particularly important if the committee can review a case without the consent of the parties. Mandatory review has been recommended, for example, when withholding life-sustaining treatment from neonates or from incompetent adults without surrogates is being considered.²⁰ A pamphlet about the committee might be distributed when patients are admitted. Patients or surrogates who are concerned that committee discussions or recommendations may invade their privacy can then express those concerns in advance. Before the committee discusses a case, it should inform patients or surrogates and invite them to participate in the deliberations.

Most ethics committees also restrict the access of nurses. The 1982 survey found that only 31 percent of committees allowed nurses to present cases, and only 50 percent allowed nurses to attend meetings.¹⁷ But it may be advisable to increase the access of nurses. Nurses have close contact with patients and families and may take the role of patient advocates.²¹ They may raise previously overlooked issues, contribute new information, or express the questions and viewpoints of patients and families. Disagreements by nurses with physicians' orders often indicate a need to reconsider decisions.²²

Because ethics committees are touted as an alternative to the courts, it may be useful to compare their safeguards with those in legal procedures.²³ The legal system notifies parties of the proceedings, allows them to give evidence, and ensures representation for patients. If the patient is incompetent, the court may appoint a guardian ad litem to represent the interests of the patient or to argue for continuing treatment. Moreover, parties are notified of the decision and the reasons for it, so that the decision can be reviewed or appealed. Ethics committees that make recommendations may not need safeguards that are as elaborate as those in a legal system that makes binding decisions. But for ethics committees to be accepted as a quicker and less acrimonious alternative to the courts, they must be perceived to be as fair as the courts.

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In order for ethics committees to assist in decision making, their recommendations and the reasons for them must be known by all parties. In addition to communicating with the patient or surrogate and the attending physician, a representative of the committee might write a note in the medical record, so that nurses, consultants, and physicians understand the committee's recommendation and reasoning. Ethics committees, however, may seem reluctant to allow their recommendations to be reviewed. Some committees do not note their recommendations and reasoning in the medical record. In addition, articles about ethics committees discuss how to reduce the liability of individual committee mem-that is, from being subpoenaed in civil suits.20,24 Such apparent secrecy may evoke the suspicion that the committee is more concerned with protecting physicians, the hospital, or itself than with helping patients.

PITFALLS OF COMMITTEE DISCUSSIONS

Pressures on ethics committees to reach agreement may lead to recommendations that are ethically questionable. Agreement or even consensus does not confer infallibility. For example, in the 1960s, hospital committees selected patients with chronic renal failure for treatment with life-prolonging dialysis machines, which were limited in number. When it was disclosed that criteria of social worth were implicitly applied, these committee decisions were criticized as being unfair and discriminatory.²⁵

In some circumstances, committees may impair rather than improve decision making. Political scientists and psychologists have shown that committees may inadvertently pressure members to reach consensus, avoid controversial issues, underestimate risks and objections, or fail to consider alternatives or to search for additional information.^{26,27} In other words, committees may not serve their intended function of considering diverse viewpoints and arguments. Such undesirable qualities of committee discussions, which have been called "groupthink," may lead to grave errors in judgment.

Ethics committees may fall victim to groupthink. First, these committees may reach consensus too easily, by not adequately considering patients' preferences. Despite the ideal of informed consent, patients are often not involved in decisions about their care.²⁸⁻³⁰ Second, committees may accept secondhand information uncritically. Physicians appreciate that medical consultants should take new histories, examine patients, and review x-ray films and scans.^{31,32} Similarly, an ethics committee should scrutinize information about the medical situation and the patient's preferences. Conclusions and inferences, rather than primary data, may be presented. For instance, patients may be described as "terminal" or "hopelessly ill," or it may be reported that an incompetent patient would not want "heroic care." Since such phrases are ambiguous and potentially misleading, committees should require and, if necessary, seek out more specific information. Third, ethics committees may overlook imaginative means of resolving disagreements. Disputes over patient care are not always caused by conflicts of ethical principles or obligations. They may also result from misunderstandings, stress, or lack of attention to the details of care.²² Despite stalemates over conflicting ethical principles or duties, agreements on particular recommendations for patient care may be possible.³³

Ethics committees should appreciate that they work under conditions that predispose them to groupthink. A rapid recommendation may be needed despite uncertain information and conflicting values and interests. Such clinical urgency may press the committee to reach agreement. The committee may feel attacked by various groups: attending physicians who fear that their power is being usurped, nurses who think that they are given unreasonable orders, administrators who wish to control costs, or risk managers who want to avoid legal difficulties. If committee chairpeople are forceful leaders who control discussions, they may unintentionally discourage frank debate and disagreement. Tendencies toward groupthink may be reinforced if access to the committee is limited.

Ethics committees that recognize the dangers of groupthink can take steps to avoid them. First, committees can guard against premature agreement. The chairperson may explicitly ask that doubts and objections be expressed or may appoint members to make the case against the majority. Second, committees can scrutinize any secondhand information they receive. To understand the patient's preferences, the committee might talk with the patient or proxy directly, invite the patient or surrogate to participate in some discussions, or assign a committee member to act as a patient advocate. Third, the committee can look for innovative ways to settle disputes. Improved communication may resolve disagreements. Families, nurses, or house staff may accept the attending physician's decisions after they hear the reasons for it and have an opportunity to ask questions. Alternatively, a compromise may be negotiated.³⁴ For example, a patient who threatens to sign out of a cardiac care unit may agree to further treatment if he or she is given more control over the timing of the administration of medications and nursing care and if one physician and one nurse take responsibility for answering his or her questions.

EVALUATING ETHICS COMMITTEES

Ultimately, the question of whether ethics committees are useful is an empirical one. Before consulting ethics committees can be considered to be a standard decision-making procedure rather than a promising innovation, they need to be evaluated. Because enthusiastic anecdotes about innovations may not be confirmed in controlled trials, pleas have been made

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to evaluate new technological procedures, such as angioplasty, before they are accepted and put into wide use.³⁵ Institutional innovations should also be evaluated, even if they seem to be obviously beneficial. For instance, hospices were expected to provide more humane and less expensive care for patients with terminal illnesses. Controlled studies, however, suggest that hospice care may not differ substantially from current conventional care and may be more expensive.³⁶⁻³⁸

As in any evaluation, deciding on clinically meaningful outcomes and designing unbiased studies require thought and planning. I suggest several criteria for evaluating both the process by which ethics committees review cases and the results of their deliberations. First, patients and their surrogates should have access to the ethics committees. Specifically, they should be able to ask the committees to review their cases and to meet with the committees if they desire. Second, recommendations by the committee and the reasons for them should be available to the parties in each case. Generally, a note in the medical record would be required. Third, recommendations by ethics committees and actual decisions by attending physicians should be consistent with ethical and legal guidelines. The gold standard should be the widespread ethical consensus that has emerged on many issues.³⁹ Evaluations might focus on whether ethics committees reduce discrepancies between this consensus and actual decisions by physicians. For instance, studies indicate that care givers often fail to discuss management options with patients or the surro-gates of incompetent patients.²⁸⁻³⁰ Ethics committees should recommend such discussions when appropriate. If their recommendations have an effect on care givers, fewer decisions will be made without such discussions with patients or their surrogates. Committees should also increase informed refusals of care by patients. Moreover, committees should decrease decisions based on ambiguous or uncorroborated secondhand information about the indications for treatment or about patient preferences. Fourth, parties in disagreements should be satisfied with the process of review and with the recommendations of the ethics committee. Although the degree of satisfaction of care givers with ethics consultations has been studied,⁴⁰ it is also important to determine the reactions of patients or their surrogates. Finally, ethics committees that make recommendations should have their own internal systems of review, to ensure that the suggested criteria are met.

In summary, the promise that ethics committees will resolve dilemmas about patient care and avoid legal disputes needs to be examined critically. If recommendations by ethics committees are to be accepted by patients, families, society, and the courts, the wishes and interests of patients must be represented and ethical guidelines must be followed. Committees can take active steps to reduce the risk of groupthink. Empirical studies may indicate what kinds of committees improve decisions relating to patient care and in which clinical circumstances.

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MULTIPLE SCLEROSIS IN TWINS

To the Editor: Ebers and coworkers have made a valuable contribution in reporting concordance rates for multiple sclerosis among twins registered at 10 multiple sclerosis clinics across Canada (Dec. 25 issue).¹ On the basis of a higher concordance rate found in monozygotic twin pairs, the authors conclude there is a "major genetic component in susceptibility to multiple sclerosis."

In assessing the relative contribution of genetic and environmental factors in the light of concordance rates in twins, it may be instructive to compare the rates for multiple sclerosis with rates for paralytic polio in a population-based twin study (Table 1).²

| Table 1. Twin Studies of Multiple Sc | clerosis and Paralytic Polio. |
|--------------------------------------|-------------------------------|
|--------------------------------------|-------------------------------|

| | MONOZYGOTIC TWINS | | | DIZYGOTIC TWINS | | |
|--|-------------------|-----------------|-------------------|-----------------|-----------------|-------------------|
| | CON- CORDANT | DIS- CORDANT | % CON- CORDANT | CON- CORDANT | DIS- CORDANT | % CON- CORDANT |
| Multiple sclerosis $(n = 70)$ (Ebers ¹ 1986) | | | | | | |
| By clinical evaluation | 7 | 20 | 25.9 | 1 | 42 | 2.3 |
| With magnetic imaging | 9 | 18 | 33.3 | 1 | 42 | 2.3 |
| Paralytic polio (n = 47) (Herndon ² 1951) | 5 | 9 | 35.7 | 2 | 31 | 6.0 |

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One inference to be drawn from the similar concordance rates in these two disorders is that, just as genetic factors are likely to play a part in paralytic polio,^{3,4} so environmental factors are likely to play a part in multiple sclerosis.⁵

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To the Editor: The study by Ebers et al. estimates the concordance ratio for multiple sclerosis at 25.9 percent among monozygotic twins. This finding and the results of studies of migrants^{1,2} suggest the presence of environmental factors that alter the expression of the disease in genetically susceptible persons. This quantity penetrance — although not equivalent to the monozygotic concordance ratio, can be inferred from it. For example, if a disease is expressed in 50 percent of susceptible persons, we would expect a concordance ratio of 33 percent (in one fourth of the pairs both members will be affected, and in half the pairs only one member will be affected). Similarly, a concordance ratio of 25.9 percent corresponds to a penetrance of 41 percent.

It should be noted that the concordance ratio is not necessarily a fixed estimate, but may vary with the prevalence of disease in a population. Where penetrance is influenced by environmental factors, the concordance ratio will be similarly affected. The best indicator of the frequency of the environmental factors in a region is the disease prevalence, and therefore we would expect a higher concordance ratio in regions of high prevalence. Unfortunately, the studies cited in Table 2 of the Ebers paper are drawn from populations with roughly similar prevalences of multiple sclerosis and do not permit the testing of this prediction.

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- Alter MA, Leowenson R, Kahana E. Migrants and multiple sclerosis. Neurology 1977; 27:341.

To the Editor: Ebers et al. proclaim unacceptable bias "inherent" in the study of twin volunteers, believe their sample of twins with multiple sclerosis to be both population-based and representative, and interpret their findings to emphasize further a genetic cause. None of these conclusions are justified.

Allegations of bias must be specific. This one is not supported by the only evidence provided, a citation¹ appropriate to neither multiple sclerosis nor twin concordance. In that study, healthy students had no particular motivation to volunteer, the outcome was not a lifelong disabling condition but a "soft" psychometric test score, and the finding (unequal variance between but not within twin pairs by zygosity) would imply no bias in concordance.

The ascertainment of Ebers et al. was not really population-based; the clinics serve