

# Ethics Committees and Due Process: Nesting Rights in a Community of Caring

Susan M. Wolf

Follow this and additional works at: <http://digitalcommons.law.umaryland.edu/mlr>



Part of the [Health Law Commons](#)

---

### Recommended Citation

Susan M. Wolf, *Ethics Committees and Due Process: Nesting Rights in a Community of Caring*, 50 Md. L. Rev. 798 (1991)

Available at: <http://digitalcommons.law.umaryland.edu/mlr/vol50/iss3/7>

This Conference is brought to you for free and open access by the Academic Journals at DigitalCommons@UM Carey Law. It has been accepted for inclusion in Maryland Law Review by an authorized administrator of DigitalCommons@UM Carey Law. For more information, please contact [smccarty@law.umaryland.edu](mailto:smccarty@law.umaryland.edu).

## ETHICS COMMITTEES AND DUE PROCESS: NESTING RIGHTS IN A COMMUNITY OF CARING

SUSAN M. WOLF\*

In 1976 the New Jersey Supreme Court decided the case of Karen Ann Quinlan.<sup>1</sup> Fifteen years later, it is hard to remember what a momentous decision that was, the first from an appellate court on the right of a patient to refuse life-sustaining treatment, the so-called "right to die." The *Quinlan* court was clearly impressed by the gravity of the ethical and legal problems involved. Thanks to advances in medical technology, patients, families, caregivers, and courts now faced difficult life and death decisions, and with growing frequency. Yet there was no common agreement on how the decisionmaking process should proceed.

Searching for guidance on how to shape that process, the court turned to an unlikely source. The court uncovered a short and obscure article written by a pediatrician in the *Baylor Law Review*.<sup>2</sup> Quoting the author at length, the judges seized upon her suggestion: "an Ethics Committee . . . to review the individual circumstances of ethical dilemma[s] and . . . provide[] . . . assistance and safeguards for patients and their medical caretakers."<sup>3</sup> Thus was born what many now call the "ethics committee movement."

Ethics committees pre-dated *Quinlan*, but it was this decision that gave them their first prominence. By the time the President's Commission on biomedical ethics issued its seminal report on forgoing life-sustaining treatment seven years later,<sup>4</sup> ethics committees

---

\* Associate for Law, The Hastings Center, Briarcliff Manor, New York, and Adjunct Associate Professor, New York University School of Law. I would like to thank Daniel Callahan, Cynthia Cohen, Ronald Cranford, Jay Katz, Ingo Keilitz, Ruth Macklin, Karen Rothenberg, Julie Rothstein, and Fenella Rouse for helpful comments at various stages in the preparation of this article, and The Greenwall Foundation for its support. DeLona Norton provided invaluable secretarial assistance. My debt to Robert Cover is continuing and profound.

1. See *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976).

2. Teel, *The Physician's Dilemma: A Doctor's View: What the Law Should Be*, 27 BAYLOR L. REV. 6 (1975).

3. 70 N.J. at 49, 355 A.2d at 668 (quoting Teel, *supra* note 2, at 8-9).

4. See PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT (1983) [hereinafter PRESIDENT'S COMMISSION, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT]. I follow the common practice and refer to the commission as the "President's Commission."

had proliferated somewhat, but as yet a tiny fraction of hospitals<sup>5</sup> had them. The Commission reported that only one percent of hospitals possessed such a committee.<sup>6</sup> Even restricting the analysis to larger institutions, those over two hundred beds, the number was still less than five percent.<sup>7</sup>

Today all of that has changed. Ethics committees have spread substantially,<sup>8</sup> to the point that well over half of American hospitals have such a committee.<sup>9</sup> An extensive literature on these committees has arisen, complete with articles, books, and guidelines.<sup>10</sup>

5. Most ethics committees exist within hospitals rather than nursing homes or other types of health care institutions. See Zweibel & Cassel, *Ethics Committees in Nursing Homes: Applying the Hospital Experience*, HASTINGS CENTER REP., Aug.-Sept. 1988, at 23. Consequently, this article focuses on ethics committees within hospitals. However, the arguments I make in this article would also apply to ethics committees in other health care institutions such as nursing homes, perhaps with even greater force. In comparing hospital patients and nursing home residents, Zweibel and Cassel suggest that there is a "need for greater efforts to protect the rights of . . . residents." *Id.* at 24.

6. PRESIDENT'S COMMISSION, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 4, at 446.

7. *Id.*

8. See Hoffmann, *Regulating Ethics Committees in Health Care Institutions—Is It Time?*, 50 MD. L. REV. 746, 746 (1991) (reciting data on the spread of ethics committees); see also Cohen, *Birth of a Network*, HASTINGS CENTER REP., Feb.-Mar. 1988, at 11 ("In 1982, only one percent of American hospitals had established these committees; today, over 60 percent of hospitals with 200 beds or more have them.").

9. See Hoffmann, *supra* note 8, at 746; Cohen, *supra* note 8, at 11.

10. I could not possibly cite all that has emerged. However, some of the most prominent and influential discussions of ethics committees have occurred in the following sources, cited roughly in the order in which they appeared: Levine, *Hospital Ethics Committees: A Guarded Prognosis*, HASTINGS CENTER REP., June 1977, at 25; Veatch, *Hospital Ethics Committees: Is There a Role?*, HASTINGS CENTER REP., June 1977, at 22; Cohen, *Interdisciplinary Consultation on the Care of the Critically Ill and Dying: The Role of One Hospital Ethics Committee*, 10 CRITICAL CARE MED. 776 (1982); PRESIDENT'S COMMISSION, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 4; INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING (R. Cranford & A. Doudera eds. 1984) [hereinafter INSTITUTIONAL ETHICS COMMITTEES]; Robertson, *Ethics Committees in Hospitals: Alternative Structures and Responsibilities*, 10 Quality Rev. Bull. 6 (Jan. 1984); Youngner, Coulton, Juknialis & Jackson, *Patients' Attitudes Toward Hospital Ethics Committees*, 12 LAW, MED. & HEALTH CARE 21 (1984); Levine, *Questions and (Some Very Tentative) Answers about Hospital Ethics Committees*, HASTINGS CENTER REP., June 1984, at 9; Cranford, Hester & Ashley, *Institutional Ethics Committees: Issues of Confidentiality and Immunity*, 13 LAW, MED. & HEALTH CARE 52 (1985); Capron, *Legal Perspectives on Institutional Ethics Committees*, 11 J. C.U.L. 417 (1985); Fost & Cranford, *Hospital Ethics Committees: Administrative Aspects*, 253 J. A.M.A. 2687 (1985); Rosner, *Hospital Medical Ethics Committees: A Review of Their Development*, 253 J. A.M.A. 2693 (1985); J. ROSS, C. BAYLEY, V. MICHEL & D. PUGH, HANDBOOK FOR HOSPITAL ETHICS COMMITTEES (1986) [hereinafter HANDBOOK]; Siegler, *Ethics Committees: Decisions by Bureaucracy*, HASTINGS CENTER REP., June 1986, at 22; Lo, *Behind Closed Doors: Promises and Pitfalls of Ethics Committees*, 317 NEW ENG. J. MED. 46 (1987); Merritt, *The Tort Liability of Hospital Ethics Committees*, 60 S. CAL. L. REV. 1239 (1987); R. MACKLIN & R. KUPFER, HOSPITAL ETHICS COMMITTEES: MANUAL FOR A TRAINING PROGRAM (Albert Einstein College of Medicine, Mar. 1988). In addition, professional societies have is-

There are even journals specializing in the problems of ethics committees.<sup>11</sup>

A number of legislatures and courts have embraced ethics committees as well. The State of Maryland requires ethics committees by statute.<sup>12</sup> The federal "Baby Doe" regulatory scheme encourages them in order to review treatment decisions for infants.<sup>13</sup> Other legislative proposals have contemplated or mandated their use.<sup>14</sup> Various judicial decisions have also encouraged resort to ethics committees.<sup>15</sup> Indeed, some courts have taken cognizance of

sued guidelines on ethics committees. See Judicial Council, American Medical Association, *Guidelines for Ethics Committees in Health Care Institutions*, 253 J. A.M.A. 2698 (1985) [hereinafter AMA Guidelines]; AMERICAN NURSES' ASSOCIATION COMMITTEE ON ETHICS, *GUIDELINES FOR NURSES' PARTICIPATION AND LEADERSHIP IN INSTITUTIONAL ETHICAL REVIEW PROCESSES* (American Nurses' Association 1985); AMERICAN HOSPITAL ASSOCIATION, *GUIDELINES: HOSPITAL COMMITTEES ON BIOMEDICAL ETHICS* (1984) [hereinafter AHA Guidelines]. In preparing the above list, and generally in doing research for this article, I was greatly aided by two resources developed at The Hastings Center. One is a packet of materials entitled "Ethics Committees: Core Resources," which includes a number of articles and the *Handbook* listed above. The second is a bibliography also included in those materials. See Swenson, Gauri, Posner & Nolan, *A Selected, Annotated Bibliography of Ethics Committees* (Hastings Center 1988). The *Hastings Center Report* now publishes a regular section devoted to ethics committees, edited by Cynthia Cohen with Thomasine Kushner. See, e.g., *Ethics Committees*, HASTINGS CENTER REP., Sept.-Oct. 1990, at 33.

11. See, e.g., HOSP. ETHICS COMMITTEE Q; J. CLINICAL ETHICS.

12. See MD. HEALTH-GEN. CODE ANN. §§ 19-370 to -374 (1990 & Supp. 1990).

13. See HHS Model Guidelines for Health Care Providers to Establish Infant Care Review Committees, originally published at 50 Fed. Reg. 14,893 (1985), as authorized by amendments to the federal Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101-17 (1988) [hereinafter HHS Model Guidelines]. This article, however, focuses on general ethics committees rather than the more specialized infant care review committees (ICRCs), which have been created in some institutions in order to advise on treatment decisions for newborn and infant patients pursuant to the federal "Baby Doe" statutory and regulatory scheme. Though there are some comparative references to infant care review committees *infra*, the ground rules and procedures for those committees raise somewhat different process issues because the elaborate federal "Baby Doe" scheme recommends specific procedures and standards for the committees.

14. The proposed Senate version of the now-enacted Patient Self-Determination Act would have mandated the creation of ethics committees in health care institutions receiving Medicare or Medicaid funding. See S. 1766, 101st Cong., 1st Sess., 135 CONG. REC. 13,566-74 (Oct. 17, 1989), *passed as amended in Omnibus Budget Reconciliation Act of 1990*, Pub. L. No. 101-508, § 4206 (to be codified at 42 U.S.C. §§ 1819, 1833, 1877 and 1891). The Maryland State Bar Association has proposed that the state adopt legislation permitting ethics committee determinations to substitute for judicial review in some cases. See Hoffmann, *supra* note 8, at 750.

15. That encouragement began with the *Quinlan* requirement that the parties in that case gain the approval of an ethics committee before discontinuing mechanical ventilation of the patient. See *In re Quinlan*, 70 N.J. 10, 54, 355 A.2d 647, 671, *cert. denied*, 429 U.S. 922 (1976). Since then, other courts have commented on the utility of ethics committee consultation, with more or less approval. See *Severns v. Wilmington Medical Center*, 421 A.2d 1334, 1341-44 (Del. 1980); *In re Spring*, 380 Mass. 629, 635, 405

prior ethics committee determinations in deciding cases about the termination of life-sustaining treatment.<sup>16</sup>

As ethics committees have become increasingly common, and indeed sometimes a mandated feature of the hospital landscape, they have become increasingly powerful. Over time, many individual committees have gained in stature and acceptance, wielding greater and greater influence.<sup>17</sup> In some spheres of ethics committee activity this is not a problem. Typically, an ethics committee is a multidisciplinary group, including but not limited to health care professionals, that is convened within the institution to address ethical issues in patient care.<sup>18</sup> Committees do this in several ways—by leading educational programs, drafting institutional policy on issues such as the use of “do not resuscitate” orders, and analyzing ethical problems in past medical cases. However, by far the most problematic activity in which committees engage is to address ethical issues in ongoing cases involving current patients. Performing this function means that a committee is consulted in active treatment disputes. When the physician and the patient or the patient’s family<sup>19</sup> disagree, the physician (or far more rarely, the patient or family) may well take the case to the ethics committee.

---

N.E.2d 115, 120 (1980); *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 758-59, 370 N.E.2d 417, 434 (1977); *In re Torres*, 357 N.W.2d 332, 338-39 (Minn. 1984).

16. See *Spring*, 380 Mass. at 635, 405 N.E.2d at 120; *Saikewicz*, 373 Mass. at 758-59, 370 N.E.2d at 434; *Torres*, 357 N.W.2d at 338-39; see also Wolf, *Ethics Committees in the Courts*, HASTINGS CENTER REP., June 1986, at 12.

17. See Ritchie, *When It's Not Really Optional*, HASTINGS CENTER REP. Aug.-Sept. 1988, at 25 (“Initially, ethics committees tended to be informal groups. . . . Today’s ethics committees are more likely . . . to have official status within the institution. . . . [T]hey often command greater notice and their recommendations may be seen as more binding.”).

18. Cf. OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, *LIFE-SUSTAINING TECHNOLOGIES AND THE ELDERLY* 444 (1987) (defining an ethics committee as “[c]onsultative committee in a hospital or other institution whose role is to analyze ethical dilemmas and to advise and educate health care providers, patients, and families regarding difficult treatment decisions”); Cranford & Doudera, *The Emergence of Institutional Ethics Committees*, in INSTITUTIONAL ETHICS COMMITTEES, *supra* note 10, at 5 (defining an ethics committee as “a multidisciplinary group of health care professionals within a health care institution that has been specifically established to address the ethical dilemmas that occur within the institution”). In this article, I have deliberately not defined ethics committees as advisory bodies because I argue that one of the most important questions to be asked about these committees is whether they are indeed purely advisory or in fact wield greater power.

19. Throughout this article, I use the term “family” broadly to refer not just to the patient’s kin by birth, upbringing, or marriage, but to those who are the patient’s intimates. An appointed surrogate decisionmaker for the patient, who may be in none of these categories, may also become involved in a dispute over the patient’s care.

Many have lauded committees for their capacity to perform this function, advising on current cases and resolving disputes. The Maryland statute, the federal "Baby Doe" guidelines, the court cases taking note of these committees, and the great bulk of the scholarship and commentary on ethics committees all give their endorsement. Accordingly, great numbers of ethics committees are busily performing concurrent case review.<sup>20</sup>

They do so wielding substantial and growing influence. What the ethics committee advises can carry decisive weight. Moreover, many disputes will never make it into court; the committee will serve as the forum of last resort. Even when a case does make it to court, the committee's prior determination may exert substantial influence. As noted above, some judges have considered the prior committee determination, and have even suggested that courts should accord such a determination some deference.<sup>21</sup>

All of this comes at a time when the courts are attempting to sort out the basic legal rights involved, most notably in the *Cruzan* case decided by the Supreme Court last year.<sup>22</sup> In that case most of the Justices suggested that at least a competent patient's treatment decision would enjoy constitutional protection.<sup>23</sup> Thus, in conducting concurrent case review, ethics committees may often be dealing with constitutionally protected rights.

Given the fact that ethics committees have proliferated substan-

---

20. The terms "concurrent case review" or "prospective case review" are often used to distinguish review of an ongoing case from the retrospective review of a completed case undertaken for the purposes of ethics committee self-education. See, e.g., HANDBOOK, *supra* note 10, at 58; Bayley & Cranford, *Ethics Committees: What We Have Learned*, in MAKING CHOICES: ETHICS ISSUES FOR HEALTH CARE PROFESSIONALS 193, 195 (E. Friedman ed. 1986).

21. See Wolf, *Ethics Committees in the Courts*, *supra* note 16.

22. See *Cruzan v. Director, Missouri Dep't of Health*, 110 S. Ct. 2841 (1990).

23. Justice Rehnquist, writing for the majority in *Cruzan*, conceded that a competent patient refusing unwanted treatment asserts a constitutionally protected liberty interest. See *id.* at 2851. However, Justice Scalia's concurrence indicated that he did not join in this view. See *id.* at 2859 (Scalia, J., concurring). Nonetheless, the four dissenting Justices clearly did agree that a competent patient's treatment refusal enjoys constitutional protection. See *id.* at 2863 (Brennan, Marshall, and Blackmun, JJ., dissenting); *id.* at 2878 (Stevens, J., dissenting). Indeed, they would have gone further, to find the treatment refusal by Nancy Cruzan's parents on their incompetent daughter's behalf constitutionally protected as well. Thus, a majority of the Court has indicated that at least competent patients refusing treatment are asserting a constitutionally protected right. In addition, Justice O'Connor in her concurrence suggested that when a patient has appointed a proxy decisionmaker, through a mechanism such as a durable power of attorney, treatment refusals by that proxy might enjoy constitutional protection as well. See *id.* at 2856 (O'Connor, J., concurring). The logic of the dissents indicates that the four dissenters would join her in this.

tially, have been embraced by statute, regulation, and the courts, and are capable of wielding substantial power in a domain of protected rights, one might expect to see these committees according at least the rudiments of due process. That expectation, however, would be sorely disappointed. Most of these committees accord nothing resembling due process. All indications are that most fail even to give the patient notice and an opportunity to be heard,<sup>24</sup> much less other tools a patient might need to participate effectively in the ethics committee's proceedings.<sup>25</sup> The Maryland statute of-

---

24. See, e.g., Hoffmann, *supra* note 8, at 765 n.109; Hoffmann, *Does Legislating Hospital Ethics Committees Make a Difference?: A Study of Hospital Ethics Committees in Maryland, the District of Columbia, and Virginia* 38 (1991) (to be published in forthcoming issue of LAW, MED. & HEALTH CARE) (unpublished manuscript on file at the *Maryland Law Review*); Youngner, Coulton, Juknialis & Jackson, *supra* note 10, at 24; Youngner, Jackson, Coulton, Juknialis & Smith, *A National Survey of Hospital Ethics Committees*, 11 CRITICAL CARE MED. 902, 904 (1983) [hereinafter *A National Survey*]; *infra* note 105 and accompanying text.

25. Throughout this article I refer to patients' rights and the need to provide procedural protections to patients. However, when a patient lacks decisional capacity, a family member or other surrogate typically exercises the patient's rights on her behalf. See generally A. BUCHANAN & D. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* (1989). The fact that a surrogate is exercising the patient's rights in no way diminishes the necessity for due process. The arguments I offer in the text for according procedural protections would apply as well to the surrogate voicing the patient's preferences or otherwise attempting to safeguard the patient's best interests. Thus my claims concerning patients throughout this article apply both to patients with decisional capacity, and patients without capacity who instead have a family member or other surrogate speaking for them. I and others have made clear in past work the necessity of a surrogate for all patients who lack capacity. See, e.g., THE HASTINGS CENTER, *GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING* 24-26 [hereinafter *GUIDELINES*]. For a powerful argument in favor of broad decisional authority on the part of the patient's family, see Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375 (1988).

In some treatment disputes, of course, the disagreement is over whether the family or other purported surrogate is actually the appropriate representative for the patient. One might argue that in such cases the patient's right to participate in committee proceedings cannot be the basis for the purported surrogate's participation, because the precise question is whether the latter should be permitted to exercise the rights of the former. However, Rhoden suggests that the burden should rest on the medical caregivers to overcome a presumption in favor of family decisionmaking. This suggests that until the family is unseated as surrogate, they do indeed exercise the patient's rights. Indeed, in many circumstances that "unseating" will not be within the powers of an ethics committee or a medical institution, but will require going to court for a formal adjudication of who the patient's surrogate should be.

In any case, even when the dispute before an ethics committee focuses on the authority of purported surrogates, it is difficult to see how the committee could fully understand the dispute and properly protect the patient's rights and interests without the participation of the would-be surrogates.

Finally, even when a family's authority to speak for a patient is in doubt, there may often be no one on the scene who is *better* able to reconstruct the patient's treatment preferences and ascertain what treatment course is in her interests. Though someone

fers some procedural protection, but hardly enough.<sup>26</sup> The federal "Baby Doe" committee guidelines offer even less.<sup>27</sup>

Even more remarkably, there is no hue and cry. Instead, there is a widespread sense that ethics committees are fine as they are, without the cumbersome requirements of due process.<sup>28</sup> This article explores why this is so—the roots of that complacency. It is ultimately an argument for restructuring the ethics committee process by embracing a broad concept of due process, one grounded not only in law but also in ethics and what I call below the "transformative obligations" of ethics committees.

Part I begins by taking a long step back from the details of process to ask first what beliefs about ethics committees have allowed them to escape the requirements of due process. I identify an accepted gospel, a mythology about ethics committees. According to this set of beliefs, ethics committees are in their infancy and so should be free to experiment as they see fit in designing their procedures. The second belief is that these committees are purely advisory and wield no decisionmaking power of their own. The third is that ethics committees promote the interests of patients anyway, without any need for due process. Part I rejects all three claims and debunks the mythology by showing that ethics committees are increasingly widespread and entrenched, sometimes wield determinative power in treatment disputes, and can greatly disadvantage patients.

Having rejected the usual description of ethics committees, Part II then explores the question of how to describe them properly, in order to ground the formulation of a suitable ethics committee process. This section examines the literature on committee process and finds a dichotomy in scholars' writings about ethics committees. Committees are often depicted as support mechanisms for physicians and other hospital caregivers. Ethics committee consultation is thus likened to the consultation of medical committees or expert

---

else may ultimately take over the role of surrogate, the family's information and assessments will remain highly relevant. This, too, argues for their participation in ethics committee proceedings.

26. See MD. HEALTH-GEN. CODE ANN. § 19-370 to -374 (1990 & Supp. 1990), discussed *infra* in text accompanying notes 158-169.

27. See HHS Model Guidelines, *supra* note 13.

28. There certainly are exceptions to this. For example, see Hoffmann, *supra* note 8, at 785-90 (arguing that if ethics committees become mandated by legislation, they should be held to certain standards). Other commentators who have advocated that ethics committees be held to some kind of standards include S. ELIAS & G. ANNAS, REPRODUCTIVE GENETICS AND THE LAW, ch. 7 (1987), and Veatch, *Advice and Consent*, HASTINGS CENTER REP., Jan.-Feb. 1989, at 20, 20-22.



medical colleagues. This view yields a model of process that is informal, focuses most immediately on the needs of caregivers, and offers no procedural protections to the patient. I label this model the Consultation Model. On the other hand, some scholars liken ethics committees to courts. In this view, ethics committee process must be more formal, the focus is on patients' rights, and the committee must afford procedural protections. I label this model the Adjudicatory Model. Part II argues that, in fact, the dichotomy between the caregiver-focused Consultation Model and the patient-focused Adjudicatory Model is too sharp. Ethics committees have drawn on both models. Indeed, committees can flip back and forth. The result is that the committees end up being rather like one of those baffling prints by M.C. Escher, that one minute seems to show a flock of birds in flight, and the next minute a school of fish swimming in the opposite direction.<sup>29</sup> There is a shifting duality—one minute fish and the next minute fowl—and a consequent elusiveness to the identity of ethics committees. That poses real dangers, especially for patients and their families, who may not be included at all in the committees's process. This dangerous double identity reflects the fact that we are still in the midst of a struggle between traditional physician paternalism and a newer effort to recognize patients' rights. The proliferation of ethics committees has been part of an attempt to revolutionize medical relationships by shifting decisional power to the patient, but it is a revolution that so far is incomplete and swamped in ambivalence. The double-identity is also rooted in the related ambivalence of our language, the dual discourse that we speak about clinical decisionmaking. On the one hand we speak the language of rights and self-determination, in both ethics and law. On the other hand, we speak the language of protective community and caring. It is thus no accident that in talking about ethics committees we are trapped in ambivalence and double-speak.

Then, what to do? Part III of the article pursues reconstruction. It argues that the first step in constructing a sound process is to recognize that committees' foremost obligation is to serve and protect the patient. This mandates due process. I argue for due process not only in fulfillment of the committee's legal obligations, but also its ethical and transformative ones. Part III then suggests a process. The challenge is to find procedures that will protect not

---

29. See D. SCHATTSCHEIDER, *VISIONS OF SYMMETRY: NOTEBOOKS, PERIODIC DRAWINGS, AND RELATED WORK OF M.C. ESCHER* 215 (1990).

only the patient's rights and self-determination, but also her relationships to medical personnel and continued connection to professional and medical caregiving. To accomplish this, Part III suggests that ethics committees afford due process in their own case consultations. More than that, they should become the leading proponents of due process in the clinical setting, instigating a process of innovation and change within that culture. The idea is to domesticate due process, to make it not the lawyerly enemy of the physician, but the tool to guarantee that the patient is heard. In this way due process becomes the protector not only of rights, but of relationships. The goal is not to alienate the caregivers from their patient, but to cement them to her through a process that allows for conflict and rights. By embracing due process, ethics committees can become true advocates for patients' rights, rights that are nested in a community of caregiving.

### I. DEBUNKING THE REIGNING MYTHOLOGY

There is an accepted gospel on ethics committees that rationalizes the absence of due process in committee deliberations. The standard set of beliefs provides that ethics committees are still in their infancy and thus should be permitted to experiment with different forms and processes rather than be held to any definite set of expectations. In any case, it is further argued, these committees are purely advisory with no decisionmaking power of their own. The attending physician remains fully responsible for the patient, and the courthouse door remains wide open. Consequently, individual ethics committees may do whatever they think best, since whatever the committee does takes nothing away from the physician's accountability or the court's availability. Finally, for those who might still harbor doubts, the ultimate reassurance has been that ethics committees promote ethical decisionmaking and thus are good for patients.

In this section I reject all three basic tenets of the reigning mythology on ethics committees. However, one important caveat is in order. Certainly there are some ethics committees that are still in their infancy, some that are purely advisory and whose advice may indeed be rejected, and some that are good for patients. This section nonetheless rejects these propositions as accurate generalizations about ethics committees, and as a reliable basis on which to absolve committees of the responsibility to accord due process.

### A. *The Myth of Infancy*

For an awfully long time now, people have been saying that ethics committees are in their infancy and should be free to experiment. At some point, though, infancy gives way to adolescence, and some sort of expectations are in order.<sup>30</sup> We have reached that point with ethics committees. They have proliferated enormously, and now are a common feature of hospitals.

That ethics committees are no longer some kind of novel experiment is borne out by the fact that today ethics committees are mandated or recognized by statutory schemes, legislative proposals, and court decisions. In addition to the Maryland statute and the federal "Baby Doe" framework already mentioned,<sup>31</sup> a Hawaii statute recognizes ethics committees, confers immunity on committee members, and provides that one ethics committee function is to "make decisions regarding ethical questions, including decisions on life-sustaining therapy."<sup>32</sup> New York State's legislation governing "do not resuscitate" orders, while not mandating ethics committees, does require that institutions maintain a "dispute mediation mechanism,"<sup>33</sup> a requirement that might well be fulfilled by using an ethics committee. The proposed Senate version of the "Patient Self-Determination Act" that was recently enacted by Congress would have required Medicare and Medicaid providers to establish ethics committees.<sup>34</sup> A Maryland State Bar Association proposal suggests allowing ethics committee deliberations to substitute for judicial review in some cases.<sup>35</sup> In addition to all of these statutory proposals and schemes, various courts beginning with *Quinlan* have suggested or required the use of ethics committees.<sup>36</sup>

At what point is it appropriate to levy expectations on ethics committees? It is when they become entrenched, and begin to wield influence. Before that time, the committee is a curiosity, something

---

30. For another author who has become impatient with the language of "infancy" and has traded it for the language of "adolescence," see Cohen, *The Adolescence of Ethics Committees*, HASTINGS CENTER REP., Mar.-Apr. 1990, at 29. But see Merritt, *Assessing the Risk of Legal Liability for Ethics Committees*, HASTINGS CENTER REP., Feb.-Mar. 1988, at 13, 14 ("[e]thics committees are still in their infancy"); Merritt, *supra* note 10, at 1241 (same).

31. See *supra* notes 12-13 and accompanying text.

32. HAW. REV. STAT. § 663-1.7 (1988 & Supp. 1990).

33. N.Y. PUB. HEALTH LAW § 2972 (McKinney Supp. 1991).

34. See S. 1766, 101st Cong., 1st Sess., 135 CONG. REC. 13,566-74 (1989); see also Hoffmann, *supra* note 8, at 749 nn. 12-14.

35. See Hoffmann, *supra* note 8, at 750.

36. See cases cited *supra* note 15; Wolf, *Ethics Committees in the Courts*, *supra* note 16.

new to try, and the committee is readily challenged and criticized. It is genuinely in the process of being shaped, assessed, and reshaped, as a prelude to settling down and becoming institutionalized.

By now, many and perhaps most committees are no longer in that preliminary phase, but instead have settled into routines. They are institutionalized and entrenched. Indeed, some are mandated by the law. No one will readily uproot them. They are here to stay.<sup>37</sup>

At this point, the sheer difficulty of challenging ethics committee processes imposes upon the committee a responsibility to assure that those processes meet at least some minimum standard. The committee can no longer do as it pleases; it has institutional functions to perform. If those functions involve review of ongoing cases and dispute resolution, then the committee must take steps to ensure that its procedures are suitable and protect the vulnerable parties. The claim of infancy thus cannot be used to absolve committees of procedural obligations.

### B. *The Myth that Committees are Purely Advisory*

It is amazing how long the claim has persisted that ethics committees are purely advisory, given that the President's Commission reported data to the contrary eight years ago. The Commission's survey of ethics committees revealed that over thirty percent classified making treatment decisions as one of the committee's actual functions, in contrast to merely providing counsel, support, and review.<sup>38</sup> Yet commentators are only now beginning to recognize that ethics committees are not purely advisory.<sup>39</sup>

It is difficult to generalize about the amount of influence that ethics committees actually wield. With apologies to Gertrude Stein, an ethics committee is not an ethics committee is not an ethics committee. They vary substantially.<sup>40</sup> Some are merely shadow com-

---

37. See *supra* notes 8-11 and accompanying text.

38. PRESIDENT'S COMMISSION, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 4, at 164, 451.

39. See Merritt, *supra* note 10, at 1248-49, 1271-75; Ritchie, *supra* note 17, at 25 (recognizing that ethics committee recommendations exert varying degrees of influence, ranging "from truly optional to nearly mandatory"); Moreno, *Institutional Ethics Committees: Proceed with Caution*, 50 MD. L. REV. 895-99 (1991). Merritt actually argues "It is possible that in some . . . cases, final decisionmaking authority should . . . rest with the committee." Merritt, *supra* note 10, at 1249 (emphasis added). One commentator who did focus relatively early on the Commission's data and the potential for committees to become actual decisionmakers is Mark Siegler. See Siegler, *supra* note 10, at 22-23.

40. See, e.g., Cohen, *The Social Transformation of Some American Ethics Committees*, HASTINGS CENTER REP., Sept.-Oct. 1989, at 21.

mittees that hardly ever meet and wield no power at all.<sup>41</sup> In fact, few people may even know of the committee's existence. On the other hand, some committees are very well known, consulted often, and enormously influential.<sup>42</sup>

Despite this variation, when someone does consult a functioning committee in a difficult case, the committee's conclusions may have a substantial impact.<sup>43</sup> For example, in a case in which the attending physician and the family of an incompetent patient disagree over a treatment choice—a common scenario for ethics committee consultation—committee support for the physician's recommendation is likely to seem a nearly insuperable obstacle to the family. There will be many families convinced simply to stop fighting at that point. The committee's advice may have such a psychological impact on the disputants and carry so much weight within the institution that the advice is determinative.

In addition, limitations on the family's resources may make the committee's advice the last word. This is particularly so for families without the financial means to trigger judicial review. For these, the position taken by the hospital may determine the treatment course. The theoretical availability of judicial review is of no practical help.<sup>44</sup>

Finally, it is difficult to maintain that ethics committees are purely advisory when courts themselves have on occasion taken cognizance of committee determinations. Committee determinations can have an impact on subsequent court proceedings. Some courts have indicated that ethics committee determinations may be received as evidence.<sup>45</sup> Indeed, a close reading of these opinions indicates that not only may the determination be received into evidence, but it may also be accorded some degree of deference by the

---

41. See Hoffmann, *supra* note 8, at 757, 758.

42. See *id.* at 757-58.

43. Ritchie has come to parallel conclusions: "The institutional force of some [ethics committee] recommendations is so strong that they are, in effect, mandatory." Ritchie, *supra* note 17, at 25.

44. Cf. Lantos, Miles & Cassel, *The Linares Affair*, 17 LAW, MED. & HEALTH CARE 308, 314 (1989) (reporting on a case in which "the hospital requested that the family obtain a court order to withdraw the respirator, a request that this family was ill-equipped and financially unable to undertake"; rather than go to court, a family member removed the patient's ventilator while holding health care personnel at bay with a gun).

45. See Wolf, *Ethics Committees in the Courts*, *supra* note 16, at 13-14 (citing *In re Torres*, 357 N.W.2d 332 (Minn. 1984); *In re Spring*, 380 Mass. 629, 405 N.E.2d 115 (1980); and *Superintendent of Belchertown v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977)—cases indicating that ethics committee determinations may be received as evidence in court and may be accorded some degree of deference by the judge).

court.<sup>46</sup> In some unreported cases as well, judges have sought the opinion of the ethics committee.<sup>47</sup> All of this means that the committee's determination may have an impact on the court proceedings, whether the court takes cognizance explicitly and on the record or *sub rosa*.<sup>48</sup>

Indeed, some of the proponents of ethics committees have sought such influence for them.<sup>49</sup> One article, for example, suggests that ethics committees adjust the way they operate so as to enhance the chances that a court will give substantial weight to the committee's conclusions: "[L]ike an appeals court reviewing a lower court's transcript, a court which can see that the [institutional ethics committee] promoted good decision-making practices is more likely to endorse the recommendation of that committee."<sup>50</sup> Another article states, "It is predicted that most ethics committees will make recommendations in particular cases and that the courts will respect them."<sup>51</sup>

In view of all of these ambitions and realities, it seems disingenuous to maintain nonetheless that ethics committees are purely advisory mechanisms and so relieve them of due process require-

---

46. I am grateful to Jay Katz for suggesting to me that the risk of judicial deference to ethics committee determinations is heightened by the long history of judicial deference to physicians generally. See generally J. KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 83 (1984). Courts have often used a professional judgment standard, regarding physicians themselves as the best arbiters of what constitutes proper medical practice. See *id.* But see *Canterbury v. Spence*, 464 F.2d 772, cert. denied, 409 U.S. 1064 (1972) (a landmark opinion limiting deference). Thus courts may fall into the trap of seeing ethics committees as the best arbiters of what constitutes an appropriate treatment decision. Cf. Delgado & McAllen, *Moralist as Expert Witness*, 63 B.U.L. REV. 869 (1982) (detailing risks of misguided deference to the testimony of expert ethicists).

47. See Wolf, *supra* note 16, at 15 n.5. Diane Hoffmann also discusses courts' willingness to take ethics committee decisions into consideration. See Hoffmann, *supra* note 8, at 780.

48. There is, or should be, significant concern about unreported contact between judges and ethics committees or ethics committee personnel. One obvious danger is that the judge may base her ultimate decision on opinions, statements, or conclusions that have not been documented on the record and open to challenge by the parties. But an additional danger is that the judge may attribute unwarranted and inappropriate weight to the advice of those supposedly expert in moral matters. See Delgado & McAllen, *supra* note 46, at 898-99.

49. This set of ambitions is quite evident in the ethics committee literature. See, e.g., Bayley & Cranford, *supra* note 20, at 193; see also Cranford, Hester & Ashley, *supra* note 10, at 53, 59.

50. Cranford, Hester & Ashley, *supra* note 10, at 53.

51. Lo, *supra* note 10, at 46; see also Bayley & Cranford, *supra* note 20, at 198 ("We expect that courts will increasingly rely on recommendations from ethics committees . . .").

ments.<sup>52</sup> That permits the committee to operate in an unbridled fashion, subject to no governing process standards. Shielded by protests that it lacks decisionmaking power, the committee may actually wield enormous power. At the clinical level, the committee may effectively have the last word; in litigated cases, the committee may have a substantial influence over court disposition.

### C. *The Myth That Committees are Good for Patients*

There is an extremely widespread presumption that ethics committees are good for patients. Commentators seldom even feel the need to state it explicitly. After all, ethics committees are meant to promote ethical decisionmaking, and ethically correct treatment decisions will assign priority to the patient's good. Occasionally a commentator does manage to articulate the presumption explicitly, as when one states, "Institutional ethics committees serve the needs of patients."<sup>53</sup> Indeed, the President's Commission recommends committees because they can serve those needs.<sup>54</sup> Others have gone further, arguing that the only proper purpose of an ethics committee, when consulting on real cases, is patient protection. Ruth Macklin has articulated this forcefully: "The rights and welfare of patients should take precedence over other, competing concerns, however relevant and important: the risk of medicolegal liability for the hospital and its personnel; the autonomy and authority of physicians in the institution; conscientious moral objections by nurses or other staff . . . ."<sup>55</sup>

Yet even a cursory look at the facts about ethics committees will cast grave doubts on a claim that ethics committees do protect patients' rights and interests. A survey published in 1984 showed that most patients did not even know about the existence of these ethics committees.<sup>56</sup> Another survey published around the same time by the same group revealed that most committees did not permit the

---

52. Cf. PRESIDENT'S COMMISSION, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 4, at 168 ("[I]f a major advantage of institutional ethics committees is that they will provide an alternative to court review in most cases, careful attention must be paid to the acceptability of the committees within existing legal structures.").

53. Wikler, *Institutional Agendas and Ethics Committees*, HASTINGS CENTER REP., Sept.-Oct. 1989, at 21.

54. PRESIDENT'S COMMISSION, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 4, at 5.

55. Macklin, *Consultative Roles and Responsibilities*, in INSTITUTIONAL ETHICS COMMITTEES, *supra* note 10, at 158.

56. See Youngner, Coulton, Juknialis & Jackson, *supra* note 10, at 24.

patient to attend the committee's meeting.<sup>57</sup> Nor did most committees permit a patient to trigger an ethics committee consultation.<sup>58</sup>

Instead, what the researchers found is that physicians and other health care professionals controlled all aspects of committee functioning. Most members of ethics committees were physicians, with some committees comprised entirely of physicians.<sup>59</sup> All committees surveyed allowed the physician in charge of the case to trigger committee consultation and to attend the committee's meeting.<sup>60</sup> The researchers concluded that "[t]he composition and function of committees . . . would not allay many of the concerns of patients' rights advocates about patient representation and control. Committees were clearly dominated by physicians and other health professionals."<sup>61</sup> Other authors since have reinforced the conclusion by adding to the roster of concerns. The patient may receive no notice that her case is going before the committee,<sup>62</sup> and may not be asked for her permission before confidential information about the case is shared with the committee.<sup>63</sup>

Of course, one might argue that all of this is no problem. If physicians and patients have identical interests and physicians can be counted upon to champion those interests, then a committee dominated by physicians will seek the patient's good even if patients themselves are entirely excluded. However, the proposition that physicians and patients have identical interests has been widely rejected.<sup>64</sup>

Traditionally physicians have indeed undertaken to act for the benefit of their patients.<sup>65</sup> But one of the major tasks of modern medical ethics has been to discredit the idea that what the physician thinks will benefit the patient is necessarily the same as what the patient thinks. The physician, for example, may want to try an aggressive therapy to improve the patient's condition. The patient, however, may wish to reject it, feeling that she has had enough. The physician and patient will often see a treatment choice in different

---

57. See Youngner, Jackson, Coulton, Juknialis & Smith, *A National Survey*, *supra* note 24, at 904.

58. *See id.*

59. *Id.* at 903.

60. *See id.* at 904.

61. *Id.*

62. *See infra* note 105 and accompanying text.

63. *See* PRESIDENT'S COMMISSION, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 4, at 167-68; *infra* note 170.

64. *See* J. KATZ, *supra* note 46, at 99-100; *infra* text accompanying note 115; GUIDELINES, *supra* note 25, at 9.

65. *See* J. KATZ, *supra* note 46, at 4.



terms. The physician is likely to concentrate on medical effectiveness, while the patient is likely to concentrate on whether the prospective benefits of treatment outweigh the physical, psychological, and other burdens to her.

The consensus in law and ethics has been that it is the patient, not the physician, who ultimately has the right to determine whether treatment is utilized or foregone. In law, this concept is manifested in the fundamental requirement of informed consent.<sup>66</sup> In ethics, this notion of the patient's right to decide flows from the principle of autonomy or self-determination. Thus, it is extremely troubling that ethics committees would claim to serve the needs and interests of patients and yet exclude them from the committee room. At best it seems that ethics committees serve the needs of patients as physicians understand those needs. Yet what is likely to trigger ethics committee consultation is precisely a conflict between the patient (or her surrogate) and the physician. Consequently, the committee is hearing only the physician's perspective. Moreover, the treating physician, as well as the health care professionals on the committee, inevitably will bring into the room their own needs—as persons, professionals, and members of the health care institution. When the committee is dominated by health care professionals, hears only from other health care professionals, and excludes the patient herself, it certainly appears that the committee is serving the needs of the health care professionals, not the patient.<sup>67</sup>

Thus when a case comes before the committee in which there is disagreement between physician and patient, it is not at all clear that the committee will function so as to protect the patient. Certainly some committees have done so. Yet there is no general assurance that committees will, and the evidence is overwhelming that the voices and needs of health care professionals may well dominate instead.

## II. IDENTIFYING THE REIGNING AMBIVALENCE

Thus far I have argued that the dominant set of beliefs about

---

66. See *infra* notes 93-94 and accompanying text.

67. There is much in the literature that confirms this. A group from Massachusetts General Hospital in Boston, reporting on the benefits of their ethics committee, listed, "above all, maximizing support for the responsible physician." *Optimum Care for Hopelessly Ill Patients: A Report of the Clinical Care Committee of the Massachusetts General Hospital*, 295 *NEW ENG. J. MED.* 362, 364 (1976). Subsequent commentators have gone even further. Cynthia Cohen reports, "The structure of some committees has been designed to protect institutional interests . . ." Cohen, *supra* note 40, at 21.

ethics committees is false—in fact, committees are no longer in their infancy, they have sought and can wield determinative power in treatment disputes, and they can harm the interests and rights of patients. Once the myth of the advisory and harmless committee has been dispelled, and the potential power of these committees is clear, then what procedural standards should be imposed? In order to answer that question, it is necessary to articulate the proper function of ethics committees.

Part II scrutinizes and critiques the two visions usually offered of what ethics committee functions and process should be. The first section of Part II identifies these two alternative models. The second section claims that ethics committees flip back and forth between these two models, displaying features of each. The third section argues that this double identity is dangerous for patients. The last section seeks the roots of this double identity and finds them in a persistent ambivalence about shifting power away from caregivers to patients, and in the difficulty of combining attention to rights with the task of sustaining caregiving.

#### A. *The Two Models*

Those who write about ethics committees have offered two fundamentally different views of these committees. According to one vision, ethics committees should be consultative bodies providing ethical advice to caregivers. This vision likens ethics committees either to other hospital committees that also advise caregivers or to individual medical professionals providing a consultation.<sup>68</sup> On the basis of either analogy, the appropriate committee process is depicted as informal, with no procedural protections for patients. Indeed, there may be no effort to include patients at all. Because this vision prescribes for ethics committees a function and process like that pursued when other hospital committees or individuals are consulted, I label this the Consultation Model.<sup>69</sup> This model focuses on

---

68. See, e.g., Veatch, *supra* note 28, at 20, 21 (discussing the fact that others analogize use of an ethics committee to intrahospital consultation or to tissue and quality assurance committees); Fleetwood, Arnold & Baron, *Giving Answers or Raising Questions?: The Problematic Role of Institutional Ethics Committees*, 15 J. MED. ETHICS 137, 138 (1989) (likening committees to individual colleagues, whom treating physicians often consult about their cases); Merritt, *supra* note 10, at 1243 (“most committees serve as consultative bodies with whom the attending physician may discuss current ethical dilemmas as in the treatment of specific patients” (footnote omitted)).

69. I am not arguing that ethics committees are identical to other kinds of hospital committees. Commentators have noted some of the differences. See, e.g., Merritt, *supra* note 10, at 1258-63; Cranford, Hester & Ashley, *supra* note 10, at 58. I am arguing that

servicing caregivers and sustaining their delivery of care.

The other vision of ethics committee function and process focuses on their capacity to resolve disputes and on the power they wield. Instead of analogizing ethics committees to other hospital committees or to consultants, this vision likens them to courts. Thus, the appropriate committee process is depicted as court-like, providing procedural protections to safeguard patients' rights. Indeed, some versions of this model would remove the committee from the hospital altogether, in order to ensure its independence of judgment. Because this vision prescribes for committees a function and process like that of adjudicatory bodies, I call this the Adjudicatory Model. This model focuses on resolving disputes in a way that protects patients' rights.

I label these "models," but I am discussing something more than simply abstract outlines of what these committees could be. These two different models are alternative mind sets or gestalts. Thus, in identifying these two models, I am trying to perform a kind of archeology, digging deeper than the usual discussion of ethics committees to explore two fundamentally different approaches.

1. *The Consultation Model.*—The Consultation Model is familiar to caregivers, whether it is manifest in the work of committees or individual consultants. Hospitals are full of committees. Indeed, some of these committees sit to perform a function in some ways quite similar to that of ethics committees—they sit to review hard cases. These committees are intended to be collegial arenas in which caregivers can bring difficult cases for review, feedback, and advice. Patients and families play no part in these meetings, unless a patient is viewed in order literally to flesh out the problem. Ordinarily, patients and their families would not even be aware that the patient's case was being reviewed. In fact, review might not occur until after a patient's death. That is consistent, though, with the purposes of this model—staff education, staff support, guidance for tough cases, and quality control.

The Consultation Model in its key features operates similarly when the consultant is an individual. It is quite common for a patient's attending physician to enlist the services of another professional as a consultant. The consultant may be another physician with more specialized knowledge in a relevant area, or a non-physi-

---

there are some similarities, and most important, that medical personnel often *see* ethics committees as being like other committees (whether rightly or wrongly) and construct ethics committee processes accordingly.

cian professional with other expertise. Again, the process typically excludes the patient or involves her only minimally. The consultant may need to perform a physical examination of the patient or ask her a few questions. But the person to whom the consultant reports is the physician who requested the consult. The consultant supplements the physician's expertise, providing guidance and advice.

Ethics committees could operate as these committees and consultants do. In the privacy of the committee, staff members could seek advice and support from their colleagues on difficult cases.<sup>70</sup> Under this model, the committee would function as helpmate to the staff; patients and their surrogates would play no role at all. Indeed, they would often have no idea the case was before the committee.<sup>71</sup>

John Robertson has laid out the process details of this model. He calls this type of committee "optional/optional," meaning that the physician has the option of consulting the committee and the option of following its advice. According to Robertson, this kind of committee exists to help physicians, nurses, and others with ethical problems.<sup>72</sup> Robertson lays out the committee process corresponding to this function, an informal process providing no procedural protections for the patient:

As an optional/optional advisory body, the committee's proceedings need not be formal . . . [N]othing written need be submitted, and no records need to be kept. There is no reason for this procedure to be public or open because it is simply an advisory mechanism for members of the health care team. Nor would a committee . . . have to notify the patient, much less get his or her permission to

---

70. Merritt describes in detail this vision of the ethics committee as servant to the physician rather than the patient:

Some ethics committees . . . may view their "clients" as the doctors who consult them, rather than the patients affected by their advice. These committees may perceive their role as helping doctors manage the risks of medical practice rather than furthering the interests of patients. The physicians, too, may view themselves, rather than the patient, as the committee's client.

Merritt, *supra* note 10, at 1284 (footnotes omitted). Merritt goes on to say that "if the committee's role . . . extends to helping physicians avoid 'unethical' as well as technically unlawful conduct, the primary constituency of the committee is arguably the physicians who request the committee's aid, not the patients who are ultimately affected by the decisions." *Id.* at 1284 n.172.

71. *Cf.* Fost & Cranford, *supra* note 10, at 2689 ("If the primary function of the [ethics committee] 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.").

72. Robertson, *Committees as Decision Makers: Alternative Structures and Responsibilities*, in *INSTITUTIONAL ETHICS COMMITTEES*, *supra* note 10, at 87.

consider the case . . . .<sup>73</sup>

Thus the envisioned process accords no notice to the patient and no opportunity to participate in the committee's proceedings. Instead, the health care professionals are all free to act as they do when physicians seek medical consultations and the advice of other hospital committees.

2. *The Adjudicatory Model.*—Ethics committees might, however, operate using a very different model. Under the Adjudicatory Model the committee operates something like a court. This is far less familiar to caregivers than the Consultation Model approach. The Adjudicatory Model emphasizes the committee's role in resolving disputes between patients and caregivers. Indeed, under this model the committee may go so far as to decide between the warring positions. Thus the patient must be involved in the committee's proceedings and her rights protected.

John Robertson lays out a version of this contrasting model as well, what he calls the "mandatory/mandatory" committee:

[T]he form and procedures of a mandatory ethics committee will differ in some important respects from those of the optional/optional committee. When the committee is optional/optional, it functions as a consultant. It is there to facilitate the physician's independent moral inquiry. However, when it becomes mandatory, the committee functions more like a decision maker . . . .<sup>74</sup>

Thus the committee acting under this model is obliged to give the patient notice and an opportunity to be heard. Indeed, Robertson goes so far in depicting a court-like model that he concludes the committee's proceedings should be open to public scrutiny.<sup>75</sup>

George Annas is even more explicit in making the analogy between a committee that is proceeding pursuant to this model and a court:

[I]f the ethics committee is to make a decision about whether a [patient] is to be treated or not, the committee must meet the requirements of basic due process. The ethics committee would have to act like an administrative agency that is set up to make decisions usually made by the

---

73. *Id.* at 89.

74. *Id.* at 93.

75. *See id.*

courts.<sup>76</sup>

Thus Annas raises the possibility that committees following this model might be constitutionally obligated to accord all the procedural protections a court would give.

In developing this Adjudicatory Model, both Robertson and Annas hinge a great deal on the single fact that the committee's recommendation is binding; it is this that provokes them to require due process protections. But others have articulated versions of this model without strictly requiring that. Bernard Lo advocates many procedural due process protections simply because ethics committees are seeking to serve as an alternative to the courts in performing a dispute resolution function.<sup>77</sup>

Thus the Adjudicatory Model focuses on the committee's role in resolving treatment disputes between patient and caregiver. Whether or not the committee's determination is binding strictly speaking, the committee is seen as having an obligation to discharge its functions fairly. Under this model the patient participates directly in the committee's proceedings. The committee undertakes an obligation to protect that patient's rights. Whereas the Consultation Model emphasizes support of caregivers, the Adjudicatory Model emphasizes the protection of patients' rights.

These models offer two very different pictures of process, and an ethics committee could pursue either one.<sup>78</sup> To illustrate how

---

76. Annas, *Legal Aspects of Ethics Committees*, in INSTITUTIONAL ETHICS COMMITTEES, *supra* note 10, at 56.

77. See Lo, *supra* note 10, at 47. After enumerating procedural protections provided by the "legal system," Lo states:

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. *Id.*

78. Judith Wilson Ross argues as well that there are alternative models for ethics committee case consultations. Ross, *Why Cases Sometimes Go Wrong*, HASTINGS CENTER REP., Jan.-Feb. 1989, at 22. However, she identifies three, rather than two models: consultation comparable to a medical consultation, case review in a fashion "indebted to the legal system," and education fashioned on a "counseling model." Her first and third models come closest to my Consultation Model. Under both her first and third models the committee is giving advice rather than determining the matter, and Ross is clear that under the first model the committee is serving the primary physician. Neither her first nor third model involves any attention to procedural niceties. She contrasts both with the model "indebted to the legal system," which has clear affinity with my Adjudicatory Model.

John Robertson elucidated a now famous four-way scheme for classifying ethics committees in an article in 1984. See Robertson, *supra* note 72; see also text *infra* pp. 816-17. He focused first on whether ethics committee review was optional or mandatory, and second on whether following the ethics committee's recommendation was optional

different they are, consider a hypothetical case that might well come before an ethics committee. Say that a patient with amyotrophic lateral sclerosis (ALS), an inevitably fatal disease characterized by neuromuscular degeneration, and commonly called "Lou Gehrig's Disease," is approaching the point of needing mechanical ventilation to compensate for failing respiratory capacity. The patient wants to refuse the ventilator and any other life-sustaining treatment, to allow the disease to take its course. The physician, however, resists. She insists that the patient could live for years more if the patient were willing to become respirator dependent. Efforts to resolve the conflict in conversation between patient and doctor fail. This is actually quite typical of the sorts of cases that go before ethics committees. Many of those cases concern disputes over the refusal of life-sustaining treatment. Indeed, a number of the litigated cases concerning the termination of treatment have dealt specifically with patients who have ALS and wish to refuse mechanical ventilation.<sup>79</sup>

The ethics committee's consideration of the case will look quite different, depending on whether the committee is pursuing the Consultation Model or the Adjudicatory Model. In purest form, adherence to the Consultation Model would mean that the ethics committee was functioning essentially as an in-house advisor to the institution's staff. Thus the treating physician would bring the case to the committee for review. The patient might not even be aware of this, would have no opportunity to consent to the process, and might well never know the conclusions reached. This whole process would operate for the benefit of the primary caregiver, in her efforts to deliver good patient care. It also might function to protect other staff and the caregiving institution as a whole.

Pursuit of the Adjudicatory Model would be quite a different process. The committee would focus on resolving the dispute between patient and caregiver. The committee's pre-eminent concern

---

or mandatory. Consequently, he generated four possible designs for an ethics committee: optional/optional, optional/mandatory, mandatory/optional, and mandatory/mandatory.

Although Ross generates three models and Robertson four, this article focuses on two alternatives. This is grounded in my claim that historically there have been two alternative pictures that have dominated the thinking about ethics committees. Robertson's article in fact bears this out. Although he identifies four distinct ways committees could be set up by a hospital, when he describes how they would work and what their procedures would be, he actually describes two models, which correspond to my Consultation Model and Adjudicatory Model. I quote Robertson at length in the text describing the two. See *supra* pp. 816-17.

79. See, e.g., *In re Farrell*, 108 N.J. 335, 529 A.2d 404 (1987).

would need to be how to do that properly, in a way sufficiently protective of the patient. The patient would obviously have to know that her case was coming before the committee. She would also have to be able to participate. Finally, she would have to be able to challenge the committee's process and substantive decision. These necessities would dictate at least some, if not all of the procedural protections that Robertson and Annas enumerate.

From the point of view of the patient, there is a stark contrast between these two models. The contrast is less pronounced from the caregiver's standpoint. Under either model the physician would be well aware of and an active participant in the committee process. It is the patient's participation that is affected radically.

### *B. Where Ethics Committees Stand—A Double Identity*

If ethics committees can pursue either a Consultation Model advising caregivers or an Adjudicatory Model resolving disputes, which is it they do pursue? I suggest that they partake of both, pursuing sometimes one, and sometimes the other. Indeed, a single committee can alternate between the two. One minute the members will see the group as a committee advising caregivers; the next minute they will see it as a body resolving or actually deciding treatment disputes. A close look at ethics committees shows that they have no single clear identity, but rather have a double identity, with the capacity to alternate. As suggested above, it is rather like an Escher print—one minute fish and the next minute fowl.

This double identity is evident in a number of ways. First, ethics committees serve two sets of masters. They sit to advise their own hospital staff on difficult cases, that is, to serve their colleagues and institution. Yet they also may claim to serve the patient by attending to her needs and interests. Thus, in keeping with the Consultation Model, the ethics committee's foremost concern is sometimes the physician or other troubled caregiver. Yet in keeping with the Adjudicatory Model, the foremost concern at other times is the patient. The scholarly literature reflects this schizophrenia.<sup>80</sup> It lauds the ethics committee as a safe place in which caregivers can seek advice and support,<sup>81</sup> even suggesting that committee deliberations be shielded from public view and their records be beyond sub-

---

80. See, e.g., Wikler, *supra* note 53, at 21 ("Institutional ethics committees serve the needs of patients. They also help doctors and nurses . . ."); Cranford & Doudera, *supra* note 18, at 13 ("The committee . . . [serves] as a resource . . . for staff and families.").

81. See, e.g., Fost & Cranford, *supra* note 10, at 2689; *infra* note 70.



poena and discovery.<sup>82</sup> Yet the literature also praises committees for their capacity to act as defenders of patients' rights and interests.<sup>83</sup> Realistically, a committee cannot simultaneously serve patients above all and clinicians above all.<sup>84</sup> Usually, the ethics committee is consulted precisely because there is a conflict between what the physician wants and what the patient or her surrogate wants. Thus the committee must serve primarily the needs of one or the other.<sup>85</sup> Some committees may habitually favor one pattern; others may alternate between the two.<sup>86</sup>

Matters are similarly confused when you examine not whom the committee serves, but what power it is wielding. Sometimes committees seem to be merely providing advice, and sometimes they seem to be actually resolving treatment disputes. As noted above, committees often claim they are purely advisory. Nonetheless they may seek to exercise enormous and even determinative influence over the final treatment decision. Even though the language of "advisory" dominates, to the point that Maryland's statute *labels* them "advisory committee[s],"<sup>87</sup> references to ethics committees as actual decisionmakers keep bobbing up here and there like a buoy that no one can keep submerged underwater too long.<sup>88</sup>

Similarly, confusion reigns when you look at the committee's method of operation. One minute the committee is operating like other hospital committees or individual consultants, advising and educating hospital staff. The next minute the committee is talking patients' rights and may even be *de facto* adjudicating disputes. Yet as committees pursue one or the other vision, or indeed alternate, there is no sign they clearly declare it or even mark the shift. Both processes are going on with the same people, sitting in the same

---

82. See *Fost & Cranford, supra* note 10, at 2689-90.

83. See, e.g., *Bayley & Cranford, supra* note 20, at 196.

84. Jonathan Moreno makes a similar point in asking: "What counts as an excellent ethics committee? . . . One that is viewed by health care providers as friendly and supportive of their problems or one that is seen by patients as friendly and supportive of their problems?" Moreno, *supra* note 39, at 897.

85. *Cf. Annas, supra* note 76, at 52 (The "primary function [of committees] is usually either to protect the institution (and the people who work at the institution) or to protect patients. We have seen both kinds, although the ones designed to protect institutions are more prevalent.").

86. *Cf. Ross, supra* note 78, at 23 (enumerating three models and observing that ethics committees may alternate or mix them).

87. MD. HEALTH-GEN. CODE ANN. § 19-370(c) (1990 & Supp. 1990).

88. See, e.g., HAW. REV. STAT. § 663-1.7 (1988 & Supp. 1990); PRESIDENT'S COMMISSION, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 4, at 164 ("[E]thics committees might be actual decisionmakers. The Commission's study revealed that . . . slightly more than 30% classified this as an actual function." (footnotes omitted)).

meeting room, with no discernable shift in gear. Thus, they may not alter their processes. The committee serving as advisor to caregivers and according no procedural protections to patients may then seek to resolve a treatment dispute, but do so without switching gears into a procedural mode that accords due process. Judith Wilson Ross makes a similar point: "Individuals or entire committees may use one of these models for one case, another for a second case. Or they may mix them in a single discussion. Furthermore, the term identifying the model being used may not reflect what is actually being done."<sup>89</sup> Some might praise this as flexibility, exciting experimentation by a phenomenon in its infancy. I argue that it is dangerous.

### C. *The Dangers of a Double Identity*

Because of this double identity of ethics committees, and their ability to alternate, patients face serious problems in dealing with ethics committees. Patients will never know precisely where they stand. The committee may talk as if it serves patients, but the reality may be something else again. The committee may not yet have sorted out the confusion involved in claiming to serve both patients and caregivers. Indeed, the committee may be laboring under the delusion that serving caregivers is serving patients, that their interests are identical. Thus the committee actually may not serve patients, but serve caregivers instead. Yet the patient may not realize that, and may rely on assurances that the committee serves her interests.

Moreover, the committee may claim that it is purely advisory, and thereby discourage the patient from demanding full participation and procedural protections. Yet the committee may wield substantial and even decisive power. It may actually be the patient's forum of last resort, or a significant influence on subsequent litigation.

Finally, the committee may talk the language of "rights" but actually give none.<sup>90</sup> Committees will inevitably spend a great deal

---

89. See Ross, *supra* note 78, at 23.

90. For an exceedingly insightful treatment of the gap between the rhetoric of patients' rights and practice, see J. KATZ, *supra* note 46. On a much smaller scale, I discussed this gap in analyzing Frederick Wiseman's film "Near Death," a nearly six-hour documentary showing the practice in one hospital's medical intensive care unit. See Wolf, "Near Death"—*In the Moment of Decision*, 322 NEW ENG. J. MED. 208 (1990); see also Wolf, *Trying Not to Talk Forever: A Tool for Change*, 15 LAW, MED. & HEALTH CARE 248 (1987/1988).

of time discussing patients' rights. These are, after all, ethics committees and there is tremendous consensus that medical ethics demands respect for those rights. Ethics committees may even proclaim their mission to be protection of patients' rights.<sup>91</sup> Yet at the same time the committee may accord no procedural protections at all, not even notice and a chance to participate in the committee's proceedings. Instead, the committee members may believe they can adequately comprehend the patient's position and protect her rights without her participation.

There is real danger to the patient here. Most patients are in the hospital because they are sick or disabled. Having come to the hospital seeking help, support, and care, they are vulnerable and in need. Now a committee comprised mostly or entirely of caregivers assures the patient that she has nothing to fear from them, that her welfare is their uppermost concern. She has every reason to believe them. She probably has no prior experience with that or any other ethics committee. Moreover, since the committee is a part of the health care institution caring for her, she will have substantial motivation not to make demands that may antagonize the committee members. There will be strong incentives to accept and go along with whatever the committee tells her.<sup>92</sup>

The patient who does "go along" will be failing to insist on the protections of the Adjudicatory Model. In truth, she is in a poor position to recognize the need for those protections and demand them. We cannot expect the patient, the most vulnerable and least powerful actor in this whole drama, to spot the inconsistencies in the script and insist that it be rewritten. She is not in control.

The danger to the patient is all the greater because the committee members themselves may sincerely not see the danger they are posing to the patient. They may truly believe the committee is serving patients, but may actually first and foremost be serving the needs of caregivers. Moreover, committee members may believe the committee is simply advisory, but may labor to determine the outcome of disputed treatment decisions, and may even strive to affect subsequent judicial disposition. Finally, the committee may believe the committee is acting to protect patients' rights, but fail to accord even the rudimentary protections of notice and the chance to

---

91. Cf. Macklin, *supra* note 55, at 158 (arguing that ethics committees should recognize that their "primary responsibility is to protect the rights and welfare of patients").

92. Cf. Wolf, *Conflict Between Doctor and Patient*, 16 LAW, MED. & HEALTH CARE 197, 201 (1988) ("The patient . . . being the more dependent, may feel that any disagreement with or challenge to the physician is forbidden.").

be heard. It is the committee's well-meaning sincerity that may blind it to the problem.

*D. The Roots of this Double Identity: The Reigning Ambivalence*

It is no accident that ethics committees are trapped in a kind of double-identity, partaking of both the Consultation Model and the Adjudicatory Model. Nor is the attendant confusion in the minds of patients, surrogates, and committee members themselves fortuitous. It reflects a broader history of reform, of which committees are a part. The rise of patients' rights, both in law and ethics, instigated a revolution not yet completed. The double-identity of ethics committees graphically demonstrates a transition still in progress, a revolution in the throes, with all the ambivalence one might expect. Because of this history, there is in the world of clinical decisionmaking (as in many other realms) a very troubled effort under way to reconcile the reforming language of patient rights and autonomy with the language of caring and community.

Efforts to reform the doctor/patient relationship and to shift the locus of decisionmaking power away from physicians to their patients significantly predate the rise of ethics committees. Probably the line most cited in medical jurisprudence in support of patients' rights was written by Justice Cardozo in 1914: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body."<sup>93</sup> Jay Katz has traced the subsequent development of the doctrine of "informed consent"—the notion that physicians have affirmative obligations to disclose information to their patients and to seek the patient's consent for treatment.<sup>94</sup> Parallel with these legal developments, modern biomedical ethics arose as a serious field of endeavor and as a reforming movement. While the case law was giving birth to "informed consent" in a period Katz dates as 1957-72,<sup>95</sup> works such as Paul Ramsey's *The Patient as Person* were beginning to appear.<sup>96</sup> Both law and ethics began to demand transformation in medical relationships, rejecting the traditional approach of physician-knows-best in favor of patients' rights to make treatment decisions.

It is no exaggeration to call this revolutionary. Katz has

---

93. *Schloendorff v. Society of New York Hosp.*, 211 N.Y. 125, 129, 105 N.E. 92, 93 (1914).

94. See J. KATZ, *supra* note 46, at 48-84.

95. See *id.* at 49.

96. P. RAMSEY, *THE PATIENT AS PERSON* (1970).

demonstrated that physician paternalism<sup>97</sup> and silence were built into the long history of medicine. Now physicians were being asked to yield information and surrender decisionmaking authority. Moreover, they were asked to hand all of this over to the very person they had been laboring to shield from the truth and the weight of decision—the patient.

It was unreasonable to think that this revolution would happen easily. In fact, there has been great resistance to this change. Physician resistance, while not complete by any means, has manifested itself in numerous ways. Most recently it has erupted in new attempts to carve out areas—such as the realm of “futile treatment”—in which physicians claim to be entitled to make treatment decisions without the patient’s involvement.<sup>98</sup>

---

97. I have opted to use the traditional term “paternalism” in this article rather than the gender-neutral “parentalism.” One could argue that the latter is the proper term, since certainly female physicians can demonstrate the “doctor-knows-best” approach that typifies traditional paternalism. Yet the traditional roles of dominant physician and submissive patient may in part be a product of the historical fact that most doctors have been men and most patients women. Thus it may be very important to retain a gendered term to refer to this tradition of domination. I am indebted to Susan Sherwin for bringing home to me the notion that the patient’s traditional role may be fundamentally gendered. Sherwin, oral presentation, Hastings Center Project Meeting on “Feminism & Bioethics: Beyond Reproduction,” Nov. 1990. See generally Sherwin, *Feminist and Medical Ethics: Two Different Approaches to Contextual Ethics*, 4 HYPATIA 57 (1989). See also B. EHRENREICH & D. ENGLISH, *FOR HER OWN GOOD: 150 YEARS OF THE EXPERTS’ ADVICE TO WOMEN* (1989); S. FISHER, *IN THE PATIENT’S BEST INTEREST: WOMEN AND THE POLITICS OF MEDICAL DECISIONS* (1988); A.D. TODD, *INTIMATE ADVERSARIES: CULTURAL CONFLICT BETWEEN DOCTORS AND WOMEN PATIENTS* (1989). Cf. Miles & August, *Courts, Gender and “The Right to Die,”* 18 LAW, MED. & HEALTH CARE 85, 85 (1990) (concluding that judges’ views on patients in “right to die” cases are fundamentally gendered).

98. See Wolf, *Conflict Between Doctor and Patient*, *supra* note 92, at 198 (“There are newer manifestations too of the strong urge to let physicians off the hook—to enable them to avoid at least some areas of conversation and confrontation with their patients. One good example is the recent debate over the notion of futility.”). For more on the futility debate, see, e.g., Lantos, Singer, Walker, Gramelspacher, Shapiro, Sanchez-Gonzales, Stocking, Miles & Siegler, *The Illusion of Futility in Clinical Practice*, 87 AM. J. MED. 81 (1989); Youngner, *Who Defines Futility?*, 260 J. A.M.A. 2094 (1988). For the recent eruption of the futility debate in the courts, see Belkin, *As Family Protests, Hospital Seeks an End to Woman’s Life Support*, N.Y. Times, Jan. 10, 1991, at A1, col. 1 (in order to avoid giving “futile” medical care, a hospital plans to go to court).

Katz illuminates the deeper dynamic:

Treatment decisions are extremely complex and require a . . . sustained dialogue, one in which patients are viewed as participants in medical decisions affecting their lives. This is not the view of most physicians, who believe instead that patients are too ignorant to make decisions on their own behalf, that disclosure increases patients’ fears and reinforces ‘foolish’ decisions, and that informing them about the uncertainties of medical interventions in many instances seriously undermines faith so essential to the success of therapy. Therefore, physicians asserted that they must be the ultimate decision makers.

Ethics committees are themselves an outgrowth of the revolutionary attempt to bring modern medical ethics into the clinic and recognize patients' rights. The idea that a group of people would scrutinize the ethics of treatment decisions, and possibly criticize the attending physician, was itself a blow to absolute physician authority. In fact, articles on ethics committees anticipated and tried to respond to physician resentment.<sup>99</sup> Thus the mere existence of these committees was revolutionary.

Beyond that, the substantive ethical principles these committees were supposed to apply promoted patients' rights. By the time the *Quinlan* decision gave ethics committees their first major endorsement in 1976,<sup>100</sup> and certainly by the time the President's Commission on biomedical ethics offered its qualified endorsement of ethics committees in 1983,<sup>101</sup> there was widespread agreement on the basic ethical principles that should guide treatment decisions. This was especially true in the realm of decisions about whether to forgo life-sustaining treatment.<sup>102</sup> Consensus has been particularly strong in that domain probably because it has been the focus of the most concentrated work in modern biomedical ethics and the subject of a great many judicial decisions. Cases about life-sustaining treatment have consistently dominated the agendas of ethics committees, so these committees have been operating in an area in which a consensus has been achieved that embraces ethical principles protecting patients' rights to decide.

Thus the very existence of ethics committees and the ethical

---

J. KATZ, *supra* note 46, at 83. It is worth noting that Katz himself is a physician.

99. See, e.g., Lo, *supra* note 10, at 48 ("The committee may feel attacked by various groups [including] attending physicians who fear that their power is being usurped . . . ."); Fost & Cranford, *supra* note 10, at 2690 ("At present, most physicians appear unlikely to consult such a group of their own volition . . . . This resistance suggests that hospitals should initially establish a policy of voluntary consultation, with no decision-making authority in the committee.").

100. See *In re Quinlan*, 70 N.J. 10, 50, 355 A.2d 647, 669, *cert. denied*, 429 U.S. 922 (1976).

101. See PRESIDENT'S COMMISSION, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 4, at 160-70.

102. See *id.* (setting forth the basic principles); see also GUIDELINES, *supra* note 25 (a later formulation). Despite the widespread agreement, there has always been controversy on some points. For example, there historically has been significant controversy on whether termination of artificial nutrition and hydration should be governed by the same ethical principles as the termination of other life-sustaining treatments such as ventilators. That controversy has gradually been resolved in favor of governing all decisions about whether to utilize life-sustaining treatment by the same basic principles. The ethical controversy was substantially quieted by the pronouncement in *Cruzan* that the same legal principles govern, whether the treatment in question is artificial nutrition and hydration or another life-sustaining intervention. See 110 S. Ct. 2841, 2852 (1990).

principles they were meant to apply were pro-patient. Yet from the start ethics committees have been mired in the same ambivalence that has attended the rest of this attempted revolution in health care. As others have recognized,<sup>103</sup> the so-called "ethics committee" demanded by the *Quinlan* court was really to be a committee of physicians convened merely to confirm the patient's prognosis. Committees have continued to be physician dominated ever since. As noted above, research in the early 1980s showed that most ethics committee members were physicians, that most committees would not permit patients to bring cases to the committee, nor would most committees permit patients to attend meetings.<sup>104</sup> Debates raged in the literature about whether a patient should even be told that her case was being considered by the committee, much less asked for consent before confidential information was shared with this group of strangers.<sup>105</sup> Physician control was so pronounced that some commentators declared forthrightly that the true purpose of ethics committees was to serve the interests and needs of physicians.<sup>106</sup> Indeed, one commentator suggested that ethics committees were not physician-dominated enough. He maintained that only clinicians should perform ethical consultations on clinical cases; consultation by a committee whose membership included non-clinicians was suspect.<sup>107</sup>

Ethics committees thus have always been a battleground on which traditional physician paternalism and control have gone head to head with the newer commitment to patients' rights. To this day the battle remains unresolved. That is the root of ethics committees' double identity. They spring from modern medical ethics and its commitment to patients' rights, but have been thoroughly dominated and shaped by physicians. Thus it is no surprise that the very ambivalence that many (if not most) physicians feel toward ceding decisional authority to patients is played out in the ethics committee. This is all the more predictable because the very cases that come to the ethics committee are the hard cases, the ones in which there is some dispute between the doctor and patient or patient's

---

103. See, e.g., PRESIDENT'S COMMISSION, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 4, at 162.

104. See *supra* notes 56-61 and accompanying text.

105. See, e.g., Veatch, *The Ethics of Institutional Ethics Committees*, in INSTITUTIONAL ETHICS COMMITTEES, *supra* note 10, at 36; Robertson, *supra* note 72, at 89.

106. See, e.g., *supra* note 70; Fost & Cranford, *supra* note 10, at 2689 ("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.").

107. See Siegler, *supra* note 10, at 22.

surrogate. Thus the committee is presented with a polarized choice between physician and patient. That is not to say that committees never take the patient's side; they sometimes do. It is merely to say that the setup is guaranteed to activate whatever ambivalence or hostility committee members feel toward patients' rights and authority.

So far I have found the roots of committees' double identity in their history, as part of a revolution not yet completed. But there is another part of the root system, connected yet distinct. It is the fact that all of us, not just physicians, speak a kind of double discourse about medical decisionmaking. On the one hand, in both ethics and law we speak the language of rights, and emphasize autonomy and self-determination. This is the language of reform. The attempted transformation in medical relationships, the effort to shift power from doctor to patient, has hinged on the recognition of legal and moral rights belonging to the patient. "Patient autonomy" has been the battle cry.<sup>108</sup>

At the same time there has been a whole different language used to talk about clinical relationships—the language of caregiving. This language emphasizes the connectedness of physician and patient; it eschews what is seen as the adversarial and isolating language of rights. There is a long tradition behind this approach. It has roots in the traditional physician paternalism that Katz traces from Hippocratic sources and into this century.<sup>109</sup> This ancient approach sees the physician as guardian of the patient's well-being as

---

108. Indeed, the emphasis on patient autonomy has been so great that there has been a backlash. Some within the field of medical ethics have claimed that there has been an over-emphasis leading to distortion in ethical analysis. See, e.g., Callahan, *Autonomy: A Moral Good, Not a Moral Obsession*, HASTINGS CENTER REP., Oct. 1984, at 42; *Questioning Autonomy in Health Care Decision Making*, 9 ETHICAL CURRENTS 1 (Nov. 1986) (newsletter) (on file at *Maryland Law Review*). Among physicians there has been a different sort of negative reaction, less grounded in philosophy. Some physicians have rejected the idea of patient decisional authority outright. Others have claimed that health care personnel themselves have rights that may be violated if patients are given too much authority. Such a claim was made in *In re Jobs*, 108 N.J. 394, 529 A.2d 434 (1987). In that case, an entire health care institution refused to effectuate a family's decision on the patient's behalf to terminate artificial nutrition and hydration. The institution asserted that it had a policy against withdrawing artificial nutrition. The court nonetheless ruled that the staff was obligated to respect the treatment refusal. *Id.* at 425-26, 529 A.2d at 450. However, the court relied on the fact that the health care institution had given no notice when the patient was first admitted that the staff would refuse to terminate this form of life-sustaining treatment. *Id.* at 425, 529 A.2d at 450. The court thus left open the possibility that if a patient or her surrogate were so notified upon admission, the staff could successfully assert the claimed right.

109. See J. KATZ, *supra* note 46, at 1-29.



understood by the physician, rather than seeing the physician as bound to respect the patient's rights as asserted by the patient. The emphasis is on physician beneficence rather than patient autonomy. This tradition is actually premised on an assumption of deep connectedness between doctor and patient. The physician is presumed to know what is best for the patient, and without even discussing it with her explicitly.<sup>110</sup> The Hippocratic Oath actually admonishes physicians to avoid revealing to the patient a diagnosis or prognosis, and Katz points to the long history of physician silence that has followed.<sup>111</sup> Even today we still see the suggestion that physicians are so connected to their patients that they simply know what the patient wants, without the need for explicit conversation.<sup>112</sup> Indeed, some people still argue that physicians ought to avoid discussing troubling diagnoses or prognoses with their patients,<sup>113</sup> even though polls commissioned by the President's Commission and published in the early 1980s showed that people want to hear the truth, even if it is dire.<sup>114</sup>

One of the great contributions of Katz's work in *The Silent World of Doctor and Patient* is to expose the assumption of doctor/patient connectedness in traditional physician paternalism:

[P]hysicians have tried to justify their preference for trust in silence rather than in conversation on [a] dangerous belief: that physicians and patients have an identity of interest in medical matters. In this view no conflict exists between them; one can decide for the other . . . .

. . . .

The belief that doctors can act on behalf of patients denies the existence of inevitable conflict. Physicians' and patients' separate identities become obliterated. They col-

110. See *id.* at 2 & *passim*.

111. See *id.* at 4-7 & *passim*.

112. In the realm of decisionmaking about "do not resuscitate" orders, a groundbreaking study, much cited ever since, demonstrated that physicians were unlikely to talk to their patients about resuscitation, yet frequently formed opinions anyway about the patient's resuscitative preferences. The study went on to show that physicians were wrong in their intuition of the patient's preference a substantial amount of the time. See Bedell & Delbanco, *Choices About Cardiopulmonary Resuscitation in the Hospital: When Do Physicians Talk with Patients?*, 310 NEW ENG. J. MED. 1089 (1984).

113. See, e.g., Cantwell, *Final Plans*, N.Y. Times, Sept. 22, 1987, at A34, col. 1 ("[D]ealing with a death sentence is another matter. Some people prefer not to hear from others what they have already told themselves.").

114. See PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *MAKING HEALTH CARE DECISIONS* 75 (1982).

lapse into one identity and one single authoritative voice emerges—the physician's.<sup>115</sup>

Thus the ancient tradition of physician paternalism that the patients' rights movement of the mid-20th century endeavored to overthrow was grounded in an assumption of profound connection between doctor and patient. Indeed, contemporary critics of the patients' rights movement have accused it of destroying the doctor/patient relationship, turning the doctor and patient into adversaries.<sup>116</sup> The patient is depicted as a stranded and lonely decisionmaker, deprived of the physician's wisdom and protection.<sup>117</sup>

Just as the revolution in the doctor/patient relationship remains incomplete, so the two types of discourse about that relationship continue—the rights-based one emphasizing patient autonomy, and the paternalism-based one emphasizing physician beneficence and connectedness to the patient. They are separate strands that weave their way through the literature in a tangled fashion. There is, for example, a literature investigating the process of medical decision-making and what allocation of decisionmaking roles patients want.<sup>118</sup> This literature is a product of the patients' rights movement, insofar as it is asking patients the fundamental question of who should decide what in the medical interaction. Yet all too often articles end up retreating from the full implication of patients' rights by talking about whether there should be patient "involvement" or "participation" in the treatment decision, not whether the patient should control the treatment decision by having the final say.<sup>119</sup> In-

115. J. KATZ, *supra* note 46, at 98-100.

116. See, e.g., Ladd, *Legalism and Medical Ethics*, in CONTEMPORARY ISSUES IN BIOMEDICAL ETHICS 1, 18-19, 29 (J. Davis, B. Hoffmaster, S. Shorten eds. 1978); Robertson, *The Rights of Doctors*, BIOETHICS NORTHWEST, Spring 1976, at 6; Thomasma, *Beyond Medical Paternalism and Patient Autonomy: A Model of Physician Conscience for the Physician-Patient Relationship*, 98 ARCHIVES INTERNAL MED. 243, 245 (1983).

117. See, e.g., Callahan, *supra* note 108, at 41; Burt, *The Limits of Law in Regulating Health Care Decisions*, HASTINGS CENTER REP., Dec. 1977, at 29, 32.

118. See, e.g., Strull, Lo & Charles, *Do Patients Want to Participate in Medical Decision Making?*, 252 J. A.M.A. 2990 (1984); M. Haug & B. Lavin, CONSUMERISM IN MEDICINE: CHALLENGING PHYSICIAN AUTHORITY (1983); cf. Smedira, Evans, Grais, Cohen, Lo, Cooke, Schecter, Fink, Epstein-Jaffe, May & Luce, *Withholding and Withdrawal of Life-Support from the Critically Ill*, 322 NEW ENG. J. MED. 309, 312 (1990) (asking families).

119. See, e.g., Angell, *Respecting the Autonomy of Competent Patients*, 310 NEW ENG. J. MED. 1115, 1116 (1984) ("Without information [the patient] cannot participate in decisions." (emphasis added)); Farber, Bowman, Major & Greene, *Cardiopulmonary Resuscitation (CPR): Patient Factors and Decision Making*, 144 ARCHIVES INTERNAL MED. 2229, 2229 (1984) ("Although most physicians would agree that patients or their families should be involved in the decision . . . , the real potential for their contribution is questionable." (emphasis added)).

volvement or participation in a decision is, after all, not the same thing as control over the decisional outcome.

“Rights” and “autonomy” talk thus exists side by side with a kind of caregiving talk that emphasizes beneficence and doctor/patient connectedness. The tension between a rights-oriented perspective and one grounded in human connection and interdependency pervades many literatures and fields of endeavor today.<sup>120</sup> Thus, it should come as no surprise that the way we talk and think about ethics committees reveals the same tension. On the one hand, they are presented as patient-protective rights enforcers; on the other hand, as groups serving clinicians by offering consultation and support. To date, these warring perspectives are completely intertwined with one another. Few people have carefully separated them.

The result is that ethics committees are mired in a confusion and double-speak that endangers patients. Committees claim to serve patients and protect their rights, but pursue processes that in fact serve caregivers, affording patients no rights at all.

### III. WHERE TO FROM HERE—THE ROLE OF DUE PROCESS

Ethics committees are a due process wasteland. There is no indication that committees regularly offer patients any of the basic procedural protections such as notice, an opportunity to be heard, a chance to confront those in opposition, receipt of a written determination and a statement of reasons, and an opportunity to challenge that determination. Ethics committees may seek the decisive power of the Adjudicatory Model, while using the processes of the Consultation Model. This is the worst of both worlds—the committee wields great influence over the treatment decision but accords no protections for the patient’s rights.

This Part argues that committees must protect patients’ rights and so must accord due process. Committees should indeed be merely advisory—legally and ethically, the patient possesses the binding decisional authority, and there is no basis for committee pre-emption of this prerogative. Committees should nonetheless offer procedural protections because of their potential influence and full range of obligations. Without giving the patient notice and an opportunity to be heard, the committee is merely talking rights without granting any. Section A argues that this is unacceptable.

---

120. Feminist writers in particular are struggling actively with this tension. See generally C. GILLIGAN, *IN A DIFFERENT VOICE* (1982); N. NODDINGS, *CARING* (1984).

Ethics committees have legal, ethical, and what I call "transformative" obligations to protect patients' rights. For too long we have permitted committees to serve only caregivers, and allowed ambivalence to reign about true recognition for patients' rights. That has to change. Committees must accord due process when consulting on current cases.

Section B spells out what process is due. It begins with an analysis of the procedural requirements imposed by the Maryland law, the one existing statute dictating how committees should operate.<sup>121</sup> I argue that although the statute is a step in the right direction, more process is necessary to guarantee full patient participation.

Finally, the last section argues that a committee embracing due process is performing a vital mission within the hospital. By providing due process protections in its own proceedings, the committee moves caregivers from a history of dominance and ambivalence about patients' rights, toward an era in which patients' rights become a reality. Due process is not a tool to defeat caregiving. Caregivers and their concerns will remain in the committee room inescapably. But the patient will be in the room as well, and protection of her rights will be the committee's priority. Thus due process becomes a tool for protecting patients' rights in the context of caregiving. By according due process in its own proceedings, and by championing a form of due process more broadly within the health care institution, the committee can fulfill the progressive mission of nesting rights in a community of care.

#### *A. The Necessity of Due Process*

For too long we have tolerated the muddle described in previous sections: the persistence of a false mythology lulling many into believing that an ethics committee could advise on a current case without assuring patient involvement in the proceedings. Ethics committees could simply pursue the Consultation Model, serving the needs of health care professionals, and according the patient no notice, opportunity to be heard, and other means of participation.

Yet while the false mythology and the use of a Consultation Model have quieted due process concerns,<sup>122</sup> in fact committees

---

121. See *infra* note 155.

122. As a 1975 student Note remarked, "There has been almost no discussion of due process in the medical area." Note, *Due Process in the Allocation of Scarce Lifesaving Medical Resources*, 84 YALE L.J. 1734, 1734 n.4 (1975). That state of affairs has hardly changed since.

have become increasingly entrenched, exercising greater and greater power over the fate of real patients. As I have detailed above, committees and their proponents have sought to amass substantial power for ethics committees. The literature shows committees claiming the power to make treatment decisions, shows ethics committee proponents judging a committee's maturity and success by its degree of influence over those treatment decisions, and shows the proponents even urging that courts defer to ethics committee determinations. Ethics committees may have rested on the Consultation Model in assuring themselves that no particular process was due, but they have sought the power and influence of the Adjudicatory Model.

Even when an ethics committee does not deliberately seek to wield great influence over the outcome of treatment disputes, others may give the committee that sort of influence. As suggested above, patients, surrogates, and caregivers may simply give the committee's conclusion determinative weight. In any case, the patient or surrogate may not be able to pursue the matter in court. Finally, the court may give committee conclusions great weight, whether the committee wants that or not.

All of this should suggest that dismissing due process as irrelevant simply because the committee declares itself to be advising rather than determining the outcome of treatment disputes is wrong-headed. It is wrong because, as elaborated above, there is no simple dichotomy, but a range of influence the committee may exercise. It is also wrong because the committee may decide to be simply advisory, but in fact wield determinative power.

Because of the actual influence ethics committees can exert over the patient's fate—indeed, her life and death—committees must accord procedural due process to the patient whenever the committee consults on an ongoing case. I analyze below the legal, ethical, and “transformative” roots of this due process obligation. But it is important to clarify here exactly what committee activities require due process.<sup>123</sup>

The due process obligation should attach whenever an ethics

---

123. John Fletcher agrees that ethics committees should accord due process. See Fletcher, *The Bioethics Movement and Hospital Ethics Committees*, 50 MD. L. REV. 859, 860 (1991). Yet he maintains that the committee can serve the doctor at one minute, and the patient at another. See *id.* at 860-61. However, I reject that contention. Fletcher also advocates establishing an “institutional ethics program.” See *id.* at 860. He argues that what I seek can be obtained within that framework. See *id.* Yet, Fletcher's proposal to create “programs,” by itself, does not solve the due process problem that concerns me.

committee becomes involved in an ongoing clinical case in a way that has the potential to exert significant influence over treatment decisions. This is a very broad standard. It means that it is almost never appropriate for a committee to serve as private consultant to the health care professional in a case.<sup>124</sup> Indeed, there should be a presumption in favor of the committee according due process whenever it is consulted in an ongoing case.<sup>125</sup>

There will be many hostile to this suggestion, who believe that caregivers should have access to an ethics committee without patient involvement.<sup>126</sup> As noted above, there are those who have argued that the primary mission of ethics committees—or at least an important part of their mission—is to serve medical personnel. I reject that squarely. Because of the actual power that ethics committees can wield, their primary mission must be patient protection rather than service to health care professionals. Serving the needs of health care professionals cannot be the dominant mission for committees performing dispute resolution in ongoing cases. Because these committees actually exercise power in disputes over what will

---

124. I say “almost never” because it does seem conceivable that there is a narrow category of questions a clinician could ask of an ethics committee without triggering the need for committee due process. For example, if the clinician wanted to use the committee as a sounding board in order to make sure that she had collected all medical and nonmedical information needed to work with a patient toward a treatment decision, or to make sure that the roster of information she was presenting to the patient was complete, that might not trigger the due process requirement. The exception to the due process obligation would be based on the fact that the committee would be advising the clinician on how to participate adequately in the initial decisionmaking process. If the primary decisional process between doctor and patient then erupts in dispute, or founders on some ethically controversial point, committee involvement will require patient participation and due process protections.

125. Fletcher discusses the fact that ethics committee case consultation is sometimes conducted not by the plenary committee, but by a sub-group, a single designated individual, or a group of individuals whom the committee asks to intervene. See Fletcher, *supra* note 123, at 878. Whenever anyone acts on the ethics committee's behalf in consulting on an ongoing case, the potential exists for decisively influencing the treatment outcome, for inspiring judicial deference, and for offering what is in effect the forum of last resort. Thus, due process obligations would still obtain. However, precisely what procedural protections those obligations would require may vary depending on exactly what group or individual performs the consultation and whether the patient can subsequently trigger plenary committee review. Spelling out all of the possible variations is beyond the scope of this article. The point is that the committee as a whole has a responsibility to ensure that whatever mechanism it uses fulfills the committee's responsibility to accord due process.

126. Fletcher suggests that many physicians will prefer “traditional” consultation to meeting with a full committee. See Fletcher, *supra* note 123, at 879. This is undoubtedly true. But I am arguing that it is the job of the ethics committee to break down physician resistance to involving patients directly in the process of resolving treatment disputes. See *infra* pp. 853-54.

happen to individual patients, the committees cannot properly take as their mission simply supporting the physician or other professional. To adopt that mission would turn these committees into a kind of kangaroo court, a mechanism for backing the powerful parties—the health care professionals. Even though the committee might occasionally admonish an individual professional, its ultimate goal would be to support that camp.

This is an unacceptable use of ethics committees. When a committee becomes involved in an ongoing case, the person whose fate is on the line is not the physician, but the patient. It is the patient whose body, whose life and death, whose entire well-being is at issue. Moreover, it is the patient not the physician whose basic legal and moral rights are at stake. In the common case, for example, in which the patient seeks to refuse life-sustaining treatment, the patient may be asserting a constitutionally protected liberty interest, other constitutional rights, and a common-law right to be free of unwanted bodily invasion. Moreover, in ethical terms the patient will be asserting fundamental rights of autonomy and self-determination.

Rarely, if ever, will the health care professional be asserting any right of similar magnitude. In any event, there is tremendous agreement both in law and ethics that patients' rights and interests should govern treatment decisions. Thus, treatment must be evaluated by asking whether it serves the patient's interests, and the patient is the one who has the final say. Consequently, if an ethics committee involving itself in a treatment dispute is to act in keeping with the prevailing legal and ethical consensus, the committee must regard patients' rights and interests as its primary concern.

One might agree with this proposition, and nonetheless fail to impose due process obligations on committees. As noted above, Ruth Macklin maintains that the committee, though faced with a host of caregiver and institutional concerns, must give the patient's rights and welfare precedence.<sup>127</sup> Yet she suggests that committees may nonetheless act as consultants to caregivers.<sup>128</sup> In other words, committees can champion the rights and welfare of patients without having the patient in the room. Nor is Macklin alone. Others maintain that the committee's process need not afford patients full participation or even notice—so long as the committee's conclusion is

---

127. See Macklin, *supra* note 55, at 158.

128. See *id.* at 159-62.

advisory rather than binding.<sup>129</sup> Thus I must show that even when the committee's determination is advisory, the committee must accord due process to fulfill its mission of protecting patients' rights.

A number of commentators have conceded that were the committee's determination to be binding, the committee would be obligated to ensure patient participation and provide procedural protections.<sup>130</sup> Yet I join with the majority of authorities who have maintained that committees should render only advisory determinations. After all, it is the patient who possesses binding decisional authority, as long as she has decisionmaking capacity; if she lacks capacity, a surrogate exercises decisional authority for her. There is no basis in law or ethics for committee pre-emption of the patient or surrogate.

It may seem odd, then, that I would relegate the committee to rendering non-binding decisions and yet demand due process. Yet as I have argued, even a committee whose determination is formally non-binding may in fact exercise tremendous power. Furthermore, it may serve as the forum of last resort, even if technically the courthouse door remains open. I argue that these facts of life mandate that committees accord due process in order to fulfill the full range of their obligations.

The obligation to accord due process, I suggest, springs from three different roots—from law, ethics, and the historic role of committees in transforming medical relationships so as to empower patients. It may seem unusual at first blush to suggest roots outside the law for process obligations. After all, "due process" is a phrase that comes to us from constitutional law. I do indeed argue that in some health care settings and some situations, committees labor under a legal obligation to accord due process. However, the argument below is more far-reaching than that. Even when the law would not strictly impose these process obligations, committees have an ethical obligation to accord due process because of the power they may exercise over the resolution of treatment disputes. There is no way to exercise power over treatment decisions so as to fulfill the mission of giving patients' interests and rights priority, without allowing the patient to articulate her interests and safeguard her rights. Finally, I suggest that the obligation to accord due process is also grounded in the historical transformation of which ethics committees are a part. An ethics committee cannot empower pa-

---

129. See, e.g., Robertson, *supra* note 72.

130. See *supra* pp. 817-18; *supra* notes 74-76.



tients and give them a voice, while excluding them from the committee's process and rendering them silent.

1. *Legal Grounds for Due Process.*—In treatment disputes coming before committees, patients will often have constitutionally protected rights at stake. Many cases that come before these committees concern the so-called "right to die," and the Supreme Court recently made it clear in *Cruzan* that these cases involve constitutionally protected rights.<sup>131</sup> In addition, some state courts in deciding termination of treatment cases have found relevant protections in their state constitutions.<sup>132</sup> Moreover, some of the disputes that come before ethics committees may involve constitutionally protected rights other than the right to refuse life-sustaining treatment, such as the right to refuse psychotropic medication<sup>133</sup> or abortion rights.<sup>134</sup>

Because the constitutional mandate of due process applies to state action,<sup>135</sup> committees in public health care institutions dealing with rights protected by the Constitution will labor under this requirement. It will also apply in whatever additional circumstances support a finding of state action. But the mandate to provide due process should apply more broadly. Committees within private institutions may find their determinations accorded judicial deference in subsequent litigation, as indicated above.<sup>136</sup> The court may formally acknowledge that deference in its opinion, or may never acknowledge it at all. Thus the committee may, in effect, exercise substantial influence over the judicial resolution of litigated cases. If judges are free to defer to the ethics committee's conclusions, then committees should be obligated to ensure full patient participation in the committee process. Otherwise, the wrong the committee does in excluding the patient is compounded by the court's subsequent reliance on the committee's judgment. Although the patient presumably will have the opportunity in court to challenge the committee's judgment, any judicial tendency to defer to the eth-

---

131. See *supra* note 23.

132. See, e.g., *Rasmussen v. Fleming*, 154 Ariz. 207, 741 P.2d 674 (1987) (basing the right to refuse treatment on both federal and state constitutions, as well as the common law); *McKay v. Bergstedt*, 801 P.2d 617 (Nev. 1990) (same).

133. See generally *Washington v. Harper*, 110 S. Ct. 1028 (1990).

134. See *Webster v. Reproductive Health Servs.*, 492 U.S. 490 (1989); *Roe v. Wade*, 410 U.S. 113 (1973).

135. The fourteenth amendment provides in pertinent part, "No state shall . . . deprive any person of life, liberty, or property, without due process of law . . ." U.S. CONST. amend. XIV, § 1 (emphasis added).

136. See *Wolf*, *supra* note 16, at 13-14.

ics committee's conclusions may make that challenge a difficult uphill battle.

Finally, any proposal that ethics committee proceedings substitute for judicial review must require that committees accord due process. There have been many such proposals.<sup>137</sup> Indeed, Alan Meisel has written that "The primary judicial (and regulatory) impetus for ethics committees has been to substitute for judicial review of decisions about life-sustaining treatment, or some components of the decision making process . . . ."<sup>138</sup> Most authorities do not recommend that an ethics committee determination formally preclude judicial review. Nonetheless, they do suggest that more cases be resolved by the committees, without subsequent judicial review. As suggested above, many patients and families lack the wherewithal to take their case to court in any event. Thus, whether by design or due to lack of patient resources, the ethics committee will often serve as the forum of last resort. This too imposes on committees due process obligations. Judges, other authorities, and ethics committees themselves, cannot seek to substitute the committee's processes for judicial ones and then tolerate a committee process that precludes patient participation.<sup>139</sup>

I do not mean to suggest that ethics committee review should actually be permitted to preclude judicial review. The courthouse door must remain open. Ethics committees engage primarily in ethical analysis, not the enforcement of legal rights. Nothing in the history or design of ethics committees would equip them to serve as the ultimate guardian of those rights. An ethics committee may not even include a lawyer. Moreover, these committees are predominantly staffed by employees of the health care institution, and so cannot provide the independent review of a court. Even if several health care institutions within a community were to create a joint committee, it would probably be dominated by health care professionals employed at the cooperating institutions. Thus the court must always remain available. Yet those who advocate using com-

---

137. See, e.g., A. MEISEL, *THE RIGHT TO DIE* 474-75 (1989) (as quoted in text *infra*); Lo, *supra* note 10, at 46 ("Ethics committees may offer an attractive alternative to the courts. . . . The judicial system may be too slow for clinical decisions.").

138. A. MEISEL, *supra* note 137, at 474-75 (footnote omitted).

139. Cf. PRESIDENT'S COMMISSION, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT*, *supra* note 4, at 168 ("[I]f a major advantage of institutional ethics committees is that they will provide an alternative to court review in most cases, careful attention must be paid to the acceptability of the committees within existing legal structures."); Lo, *supra* note 10, at 47 ("[F]or 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.").

mittees instead of courts simply show once again that there is pressure from many sources to use ethics committees as the decisive forum. This means that patients cannot be excluded. As the frequent, and often intended forum of last resort, committees must accord due process.

2. *Ethical Grounds for Due Process.*—Committees should also recognize an ethical obligation to accord due process. That ethical obligation is grounded, first of all, in the fact that a patient involved in a treatment dispute has fundamental moral rights at stake. The dispute may take one of several forms, and the precise rights at stake will vary depending on what is in dispute. But usually the patient's right to autonomy or self-determination will be at issue.<sup>140</sup> For example, if the competent patient and her physician are in disagreement about the proper treatment course, then the patient's autonomy is certainly at stake. Her right to govern her own body, to exert the authority of a self-governing competent adult, and to meet death as she chooses (in the case, for example, of a patient refusing life-sustaining treatment) are all on the line. If, however, the dispute is about whether she is competent to decide, then her authority to exercise rights on her behalf is at stake. Again the patient's autonomy is in jeopardy, but in a different way.<sup>141</sup>

The correlate of the patient's right to self-determination is others' obligation to respect her autonomous choices. As Beauchamp and Childress have carefully explained, this requires not only an attitude of respect, but also a certain kind of action.

To respect an autonomous agent is, first, to recognize that

---

140. For an influential explication of autonomy in biomedical ethics, see T. BEAUCHAMP & J. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 67-119 (3d ed. 1989).

141. The argument is more complex in the case of a patient who lacks decisional capacity. If that patient while formerly competent left treatment instructions (for example, in a living will or another form of advance directive), then most commentators would agree that those instructions represent an exercise of patient autonomy or self-determination. The more difficult case is the patient who failed to leave instructions or who has never been competent. In those cases, the courts, beginning with *Quinlan*, have nonetheless reasoned that incompetent patients are rights-bearers whose rights must be exercised by a surrogate. See, e.g., *Quinlan*, 70 N.J. at 41, 355 A.2d at 664. Yet some commentators have challenged this, arguing that it makes no sense to talk about an incompetent patient's right of self-determination when that person never exercised the right while previously competent. See, e.g., Rhoden, *supra* note 25, at 385-88. For the purposes of my argument in text that ethics committees have ethical obligations to ensure patient or surrogate participation, one can reject the rights analysis for this category of patients (even though the courts have embraced it), and nonetheless find a committee obligation based on the ethical duty to protect patient welfare and prevent harm.

person's capacities and perspectives, including his or her right to hold views, to make choices, and to take actions based on personal values and beliefs. But respect involves more than taking an attitude. It involves treating agents so as to allow or enable them to act autonomously.<sup>142</sup>

The duty of respect for persons, here articulated as a duty of respect for autonomous agents,<sup>143</sup> is at the core of modern biomedical ethics. That is because the value of self-determination or autonomy is either the central value or one of the central values in theories of medical ethics, depending on which theory you use.<sup>144</sup>

Most theories of medical ethics embrace autonomy in the usual sense of self-governance given it by the tradition of liberal individualism. However, I do not mean to use the concept of autonomy uncritically here. Others have criticized the liberal formulation of autonomy for resting on the fiction of isolated selves whose boundaries must be preserved in order to keep others out and so remain self-governing.<sup>145</sup> Of course, this version of autonomy has almost no relevance to ill patients in a medical setting. Such people are quite dependent on others, including their medical caregivers, for support, advice, and health care, among other things. Moreover, patients are dependent on caregivers to create the circumstances under which a patient can even make a decision about treatment. Caregivers must supply information, interpretation, and support for the patient's exercise of authority. Indeed, the patient may not even know she *has* decisional authority until the caregiver tells her. Thus, autonomy in a health care setting requires support from the caregiving context.

How does all of this relate to ethics committees? First, ethics committees are supposed to understand, apply, and advocate ethical principles within their health care institutions. As Robert Veatch argues, an ethics committee "must have in place, and must consciously orient to a set of general ethical principles that will guide its actions and shape its decision making."<sup>146</sup> Yet any plausible set of ethical principles in medicine, at least in the second half of the 20th

---

142. T. BEAUCHAMP & J. CHILDRESS, *supra* note 140, at 71.

143. See THE NATIONAL COMMISSION FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIOR RESEARCH, U.S. DEP'T OF HEALTH, EDUCATION AND WELFARE, THE BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH (1978).

144. See A. BUCHANAN & D. BROCK, *supra* note 25, at 41-47.

145. See, e.g., Nedelsky, *Reconceiving Autonomy: Sources, Thoughts and Possibilities*, 1 YALE J.L. FEMINISM 7, 10 (1989).

146. See Veatch, *supra* note 105, at 37.

century, will centrally include the principle of respect for persons and value of patient autonomy. Thus an ethics committee will have to embrace the principle of respect for persons and the committee will have to accord such respect in its own actions.

There is a second source as well for the committee's obligation to accord respect for persons. It is the fact that the committee is the creature of a broader health care institution with institutional obligations toward its patients.<sup>147</sup> Those obligations must include the fundamental obligation of respect for persons. An institution that tramples on its patients, according their exercise of self-determination no respect, cannot be rendering good patient care. Moreover, there is an institutional responsibility to ensure that individual clinicians practice in a way that fulfills their individual obligations to respect patient self-determination. Thus the ethics committee as a creature of the institution must accord respect to patient self-determination, and must act in a way that prompts the treating physician and other professionals involved in the patient's case to accord that same respect.

Finally, health care professionals on the ethics committee will have their own individual obligations to show this same respect toward the patient. They do not cast off their professional obligations at the door to the committee room. Moreover, health care professionals have this obligation toward any patients with whom they come into contact, not just those within their medical care. Thus a physician is not free to do something to another physician's patient that violates the patient's right of self-determination.

Thus on several grounds the ethics committee incurs ethical obligations, and those obligations include maintaining, demonstrating, and promoting respect for patients and their self-determination. This is an ethical ground for a duty of due process. The committee cannot show respect for the patient and her self-determination if the committee reaches a judgment about a dispute over her treatment with no notice to her and no chance for her to participate. Indeed, such action would show disrespect for her. It would substantively erode her right of self-determination. The committee failing to accord due process would set itself up as a separate decisionmaker rather than respecting the patient's role as the key decisionmaker. Finally, according no due process would demonstrate to the treating

---

147. Cf. Merritt, *supra* note 10, at 1272 ("Ethics committees may have . . . —as a part of the hospital structure—at least an indirect relationship with the patient and a duty to serve the patient's interests.").

clinicians that the patient need not be present, much less be heard, while the proper treatment course is being decided. This would undermine the commitment of those clinicians to show respect for the patient's self-determination in their own treatment of her.

There are additional ethical grounds for a duty of due process. They need not detain us at such length because again they derive from the fact that the ethics committee is a creature of the broader health care institution, is composed at least in part of health care professionals, and directly affects both the individual patient and her treating clinicians. Thus an ethics committee, being a creature of the health care institution and comprised of health care professionals, incurs the institution's and professionals' obligations of beneficence and non-maleficence.<sup>148</sup> In other words, the committee must act to promote the well-being of patients and avoid harm to them. To exclude the patient from the process of determining her care, and to consider overriding the patient without listening to her, is certainly to harm the patient's interests.

Finally, the committee has an obligation to accord due process grounded in its duty to act fairly and in accordance with values of procedural justice. I have noted earlier that the value of procedural justice has gone under-appreciated in formal statements of the values underlying ethical medical care.<sup>149</sup> In part this is probably because medical ethics as a discipline grew up examining the dyadic relationship of doctor and patient, rather than how groups of professionals, committees, and even whole institutions should function. In the dyadic relationship of doctor and patient, procedural justice has less of a role than in the functioning of those groups. Yet as attention now turns to the ethical obligations of these groups, the dictates of procedural justice should receive more attention as well. Here the legal literature can provide useful analogies and analysis, since the values underlying procedure and the nature of procedural justice have received such extensive treatment there.<sup>150</sup> In the bioethics literature there are at least the beginnings of attention to problems of procedural justice.<sup>151</sup> One needs no elaborate theory of procedural justice to recognize that there is some fundamental duty of fairness. Because ethics committees deal with patients and their basic moral rights, it would seem that committees have a duty to develop a procedure that ensures the committee will do so fairly.

---

148. See, e.g., T. BEAUCHAMP & J. CHILDRESS, *supra* note 140, at 120-255.

149. See *supra* text accompanying notes 56-63.

150. See, e.g., R. COVER & O. FISS, *THE STRUCTURE OF PROCEDURE* (1979).

151. See, e.g., T. BEAUCHAMP & J. CHILDRESS, *supra* note 140, at 169-70.

This would suggest that a committee must deal with the rights and interests of patients seriously and deliberately. It is hard to imagine a principle of fairness and procedural justice that would permit a committee to become involved and exercise power in a treatment dispute without hearing from the patient herself. Moreover, a duty of procedural justice would suggest that a committee has an obligation to formulate rules, a set of regular procedures to be followed. Otherwise, there will be no guarantee of serious, deliberate, and fair consideration in an individual case. There also will be no assurance that cases will be treated comparably, in other words no assurance of fairness across cases as well as within a single case. Thus obligations of procedural justice also suggest that committees have a duty to accord due process both in handling the individual case and in formulating rules to govern procedure in the various cases that come before the committee.

3. *Transformative Grounds for Due Process.*—I have so far argued that the committee has legal and ethical obligations both to the individual patient and to the group of patients whose cases come before the committee, and that these obligations ground a duty to accord due process. But there is one other basis for that duty—the committee's transformative obligations not only to the individual patient and the group whose cases come to the committee, but also to the entire category of patients, present and future. Ethics committees have been embraced as part of a whole movement whose major ambition is the recognition of patients' rights, as I have described above. They have proliferated as part of a larger effort to transform doctor/patient relationships, shifting the locus of power from doctor to patient. True, ambivalence has set in, so that many committees now talk patients' rights while affirming physician authority. But committees were nonetheless embraced because of their transformative potential—committees could bring the modern medical ethics movement into the clinic, and help give birth to patients' rights.

The fact that ethics committees spring from this transformative vision, and do in fact have transformative potential, is itself another basis for committee due process obligations. Committees were a response to the realization that patients were a subordinated and oppressed group—those with the most at stake had the least power. Committees thus have an obligation to help alleviate the traditional subordination and oppression of patients, and instead to assist in the ongoing effort to empower patients. A committee that ignores patients and excludes them from its process is turning its back on

this obligation. It is reinforcing the traditional exclusion of patients from the process of determining their treatment, and is thwarting the empowerment of patients.

Committees have a transformative mission in one other sense as well. They can and should make the abstract ethical concept of autonomy a functioning reality in the health care setting. As noted above, the traditional idea of autonomy as exclusion of others in order to achieve self-governance has almost no applicability in medical settings.<sup>152</sup> Instead, we need a notion of autonomy that preserves the value of self-determination but recognizes that this is self-determination in the context of dependency. Jennifer Nedelsky has recently written about the need to reconceive autonomy generally along these lines.<sup>153</sup> She has also recognized the great role procedural due process can play in accomplishing this. Ethics committee experimentation with due process is the way to rebuild from the ground up a notion of autonomy that genuinely preserves patient self-determination, while recognizing the patient's dependence on caregiving.

### B. *What Kind of Process is Due?*

Ethics committees thus have due process obligations grounded in law, ethics, and the committees' transformative mission. It is heartening, then, to see the one state that requires ethics committees take due process seriously.<sup>154</sup> The Maryland statute requiring ethics committees mandates notice, the right to be heard, and the right to receive an explanation of the committee's determination.<sup>155</sup> While I will argue that this is not enough, it is important to understand what a step forward these Maryland process mandates are. The American Medical Association's and American Hospital Association's guidelines on ethics committees suggest hardly any procedural protections at all.<sup>156</sup> Moreover, it certainly seems that left to their own devices, ethics committees do not create process protections.<sup>157</sup>

To date, the Maryland statute is the major legislative effort to

---

152. See *supra* p. 840.

153. See Nedelsky, *supra* note 145.

154. See MD. HEALTH-GEN. CODE ANN. §§ 19-370 to -374 (1990 & Supp. 1990).

155. See *id.* § 19-374(b).

156. See AMA Guidelines, *supra* note 10; AHA Guidelines, *supra* note 10.

157. See *infra* text accompanying notes 56-63; *A National Survey*, *supra* note 24, at 904 (in the early 1980s, only 19% of ethics committees would allow patients to attend their meetings).



spell out good process for ethics committees.<sup>158</sup> Thus the Maryland statute is the key precedent for developing due process rules for ethics committees, and its process provisions deserve enumeration. This is rapidly done, however, because even in this ground-breaking statute, the process provisions are not numerous.

The most detailed process provisions in the statute concern the committee's process when it is advising on treatment options for patients with life-threatening conditions. In such cases the committee is obligated to notify the patient of her right to trigger the committee process as "petitioner,"<sup>159</sup> to meet with the committee,<sup>160</sup> and "[t]o receive an explanation of the . . . committee's advice."<sup>161</sup> In addition, there are others who must be notified that they hold the same rights: the patient's immediate family, her guardians, and anyone with power of attorney to make medical decisions for her.<sup>162</sup> It is not entirely clear from the wording of the statute whether one retains the rights to meet with the committee and receive an explanation even when someone else, such as the physician, acts as petitioner and triggers the committee process. However, we can construe the statute to be generous in its creation of rights, and assume that as long as someone triggers the committee process, the relevant patient, her family, guardians, and appointed proxy all have the rights. Finally, the statute also suggests that the committee must render its advice in writing, by stating that the "advice . . . shall

---

158. In addition to the Maryland statute, there has been one other significant governmental effort to describe good ethics committee process. However, this effort was aimed at a very specific kind of ethics committee—those operating within the "Baby Doe" statutory and regulatory framework created by the federal government in an attempt to encourage states to limit non-treatment decisions for imperiled newborns. The Department of Health and Human Services promulgated optional guidelines for "Infant Care Review Committees." See HHS Model Guidelines, *supra* note 13. The HHS guidelines do contain some procedural protections. First, the infant care review committee is supposed to take steps to see that the families of these infant patients know of the committee's existence, function, and availability. See § III. B. 1. Second, the patient's parent or guardian is among those who can request an emergency committee meeting. See § VI. A. 2. And finally, such meetings are supposed to "be open to the affected parties." See § VI. A. 4. However, less clear is the extent to which the full participation of the parents or guardian is guaranteed. Although the guidelines recommend an advocate for the infant, this is not an independent advocate but rather someone the committee chair appoints from among the committee's members. See § VI. A. 5. The guidelines also leave unclear the extent to which the family is entitled to an explanation of the committee's conclusions.

159. MD. HEALTH-GEN. CODE ANN. § 19-374(b)(1)(i) (1990 & Supp. 1990).

160. *Id.* § 19-374(b)(1)(ii).

161. *Id.* § 19-374(b)(1)(iii).

162. *Id.* § 19-374(b)(1).

become part of the patient's medical record."<sup>163</sup>

A separate section covers process generally, presumably when the question is not treatment options for a patient with a life-threatening condition.<sup>164</sup> Here the procedural protections are more limited. There is no mandated notice to the patient and the others. Nor is there a right to receive an explanation of the committee's advice. The statute only addresses the question of whether the patient and her family can meet with the committee.<sup>165</sup> The statute says that "the advisory committee, in appropriate cases, shall consult" them.<sup>166</sup> It does not clarify, however, what "in appropriate cases" means. This suggests that it is up to the committee itself to determine what constitutes an "appropriate" case. Thus the committee might decide not to consult with the patient or family at all. This section does provide one safeguard with greater bite: the person triggering the committee process, who may be the patient, is entitled to "be accompanied by any persons the petitioner desires."<sup>167</sup> Presumably this means the patient, if she is the petitioner, could bring her lawyer and anyone else.

There is one other relevant provision. Indirect protection is perhaps offered by the requirement that the health care institution "establish . . . [a] written procedure by which the . . . committee shall be convened."<sup>168</sup> It is not clear from the wording whether this document is supposed to specify the committee's procedures for case consultation. If so, however, such a document would at least provide the protection of a written set of rules.

The Maryland statute thus presents some quirks and definite gaps when it comes to providing procedural protections for the patient. First, there is no reason to bifurcate the procedural rules, giving one set of protections to patients with life-threatening conditions, and another to everyone else. All patients need both sets of protections enumerated in the statute: the right to trigger the proceedings, meet with the committee, and receive an explanation of the committee's determination; notice to the patient that she has those rights; plus the right to bring people with her when she

---

163. *Id.* § 19-374(d)(2).

164. *See id.* § 19-372.

165. *See id.* § 19-372(a)(3).

166. *Id.*

167. *Id.* § 19-372(b).

168. *Id.* § 19-371(2). However, the statutory language does not explicitly state whether this document must specify the committee's procedures regarding case consultation. An interpretation that it does would provide at least the protection of a written set of rules.

does trigger committee proceedings. However, the patient should have these rights whether or not she triggers the proceedings by acting as "petitioner." Whenever her case is being considered, she should be entitled to meet with the committee, bringing anyone with her, and be entitled as well to an explanation of the committee's determination.

Yet even this is not enough. Indeed, Paula Hollinger, the legislator who sponsored the bill that eventuated in this statute, has acknowledged that the statute leaves a great deal unspecified. In responding to the question of whether there are "specific procedures that these committees must follow when they review cases," she replied, "[t]he protocol for each committee is left to the individual hospital."<sup>169</sup>

What protections are missing from this statute? One protection that is a fundamental element of anything resembling due process is notice to the patient and her representatives that the committee intends to consider her case.<sup>170</sup> Strikingly, the wisdom of according even this very basic protection is debated in the literature.<sup>171</sup> Yet arguments against notice are untenable. Without notice, patients and their representatives have no way of challenging, correcting, participating in, or simply monitoring ethics committee consideration of the patient's case. The ethics committee can then simply shut the patient out of its process altogether. However, this would violate the committee's legal, ethical, and transformative obligations, as enumerated above. Omitting the fundamental requirement of notice is especially indefensible when one considers the great influence ethics committees often want and wield over treatment decisions, up to and including actual decisionmaking power.<sup>172</sup>

---

169. See Hollinger, *Hospital Ethics Committees Required by Law in Maryland*, HASTINGS CENTER REP., Jan.-Feb. 1989, at 23, 24.

170. I do not address the question of whether the patient should have the right to block ethics committee consideration of her case. However, there is a significant literature on this question. See, e.g., Veatch, *supra* note 105, at 36; Fost & Cranford, *supra* note 10, at 2689-90. The argument that the patient's approval should be required before the committee may evaluate her case is based on concerns about the confidentiality of patient information, not due process concerns. See Veatch, *supra* note 105, at 36 ("[C]onfidentiality is a right of the patient . . . . That means that committee members should have no access to information about a patient's case without the patient's approval . . . ." (citation omitted)). I am quite sympathetic to this claim, but discussion of it is beyond the scope of this article.

171. See, e.g., Robertson, *supra* note 72, at 89; Lo, *supra* note 10, at 47.

172. This points up a basic flaw in John Robertson's argument that no notice is required when consulting the committee is optional rather than mandatory and following the committee's recommendation is similarly optional rather than mandatory. See Robertson, *supra* note 72, at 89. The problem is that plenty of committees are set up that

It is important to recognize that notice, however, must mean more than simply notice to the patient that the committee intends to take up her case. It must also mean that the patient is notified of the procedures the committee will follow, and the procedural options she can exercise. Without that, the patient will be at the committee's mercy, unable to anticipate what will happen, to participate actively, and to mount challenges. Finally, before a case ever gets to this point, patients or their representatives should be routinely notified of the ethics committee's existence and functions. Absent such notice, patients may well not even realize that such a forum exists.

Moving beyond notice, you get into more debatable territory. There is, after all, no fixed content to due process; it depends on the function being served. The legal concept of due process, the cases tell us, hinges on "the probable value, if any, of . . . [the] procedural safeguards" in preventing erroneous deprivation of the individual's protected interest.<sup>173</sup> This is only the legal root and formula for due process. I have argued above that an ethics committee's due process obligations have other roots as well, in its ethical and transformative obligations.<sup>174</sup> But it useful to start with a consideration of what this legal formula recommends.

In an ethics committee's consideration of a case, this formula suggests safeguards on the basis of whether they will help prevent the committee from making a mistake in arriving at a conclusion. There are indeed many opportunities for ethics committees to make mistakes—in their understanding of the medical facts, facts about

---

way, but in reality exert substantial influence over the final treatment decision and, as I have argued in the text, serve as the actual forum of last resort. The committee may be designed to be what Robertson calls "optional/optional," and committee members may bemuse themselves that they are merely giving optional advice, but the actual power and effect of the committee may be much greater. Robertson makes two assumptions that I reject. He assumes that the intended committee functioning is the same as the actual committee functioning. Moreover, he assumes a simple dichotomy between committees whose recommendations are optional and those whose recommendations are mandatory, without recognizing that there is a spectrum. *Cf.* Ritchie, *supra* note 17, at 25 (arguing that there is a spectrum). A committee's recommendations need not be officially mandatory to exert a determinative influence over treatment decisions.

173. *Mathews v. Eldridge*, 424 U.S. 319, 335 (1976). The legal formula derived from *Mathews v. Eldridge* has been criticized for being excessively utilitarian and overly focused on questions of technique, rather than attending to the values underlying due process. See Mashaw, *The Supreme Court's Due Process Calculus for Administrative Adjudication in Mathews v. Eldridge: Three Factors in Search of a Theory of Value*, 44 U. CHI. L. REV. 28, 28-30, 46-59 (1976). This suggests that a proper legal theory of due process would probably incorporate some of the elements that I maintain are mandated by the committee's ethical due process obligations.

174. See *supra* pp. 839-44.

the patient's position or that of her family or representatives, and the relevant ethical principles. All three of these potential sources of error counsel procedures that will ensure participation in the committee's proceedings by the patient and her allies.

As to the first of these sources of error, the probability of the committee making mistakes about the medical facts soars if there is no one participating in the committee process with a stake in challenging the treating physician's presentation of those facts. Anyone who has ever sat on an ethics committee knows that it can be quite difficult to get to the bottom of the medical facts, but that sound ethical analysis depends on it.<sup>175</sup> Yet it is only the patient or her representative who has a direct stake in challenging the presentation of facts by the treating clinician. This suggests that the patient should be informed of what medical facts will be presented before the committee convenes. She should be able to consult with other health care personnel in an effort to understand those facts and prepare to challenge them. She should also have full access to any records on which those facts are based, typically her own medical records. Finally, at the committee's meeting, she must be able to contest the medical facts presented, asking other health care personnel of her choosing to offer different views. This would not relieve the ethics committee of its own responsibility to investigate and clarify the medical facts, particularly because not all patients will elect to exercise the right. It would merely assure that the patient is informed of the medical facts to be presented and is able to challenge them if she chooses.

In order to avert error of the second sort, error about the patient's views or those of her representatives, these people must be able to present their views directly to the committee. Second-hand reporting by the treating clinician involved in the dispute will not do, though I suspect it is a rather common practice.<sup>176</sup> Nor should second-hand reporting by any other health care professional, including mental health professionals involved in the case, be deemed sufficient. In any treatment dispute, the patient's views or those of her surrogate are critical. There is no substitute for allowing the disputants to speak for themselves.

Averting error of the third type is more difficult. The patient

---

175. Indeed, because proper evaluation of clinical data is difficult, yet critical to the case review process, one commentator has suggested that only trained clinicians assist in clinical ethical decisionmaking. See Siegler, *supra* note 10, at 24.

176. Cf. *A National Survey*, *supra* note 24, at 904 (reporting in the early 1980s that only 19% of ethics committees would allow patients to attend their meetings).

cannot be expected to develop an expertise in medical ethics. Indeed, ethics committees themselves often have trouble finding someone who can instruct them and help develop their own ethics expertise. Of course, that only makes it all the more important to consider ways in which the patient can challenge the committee's ethical conclusions. Two options present themselves. The first is simply to make it clear to the patient that she can consult with anyone she wishes, including anyone with an expertise in ethics, be they an ethicist, a health care professional, a member of the clergy, or an attorney. Moreover, the patient should be able to bring that person with her to the committee's proceedings and have that person make a presentation. The second way in which mistake may be averted is more familiar. It is to require the committee to render its conclusions in writing, together with a statement of reasons. Then the patient can review and evaluate the committee's reasoning. If she wishes to challenge it, she should be able to do so. The committee should be required to discuss with her and re-examine its conclusions.

These suggested procedural protections are motivated so far by the desire to avoid error, the linchpin of the legal due process calculus, as noted above.<sup>177</sup> Yet many of these protections do a good deal more than simply reduce the chance of error. They also help a committee fulfill its ethical obligations. The committee's obligation to act fairly mandates the patient's full participation in the committee's proceedings, as well as an opportunity to challenge the committee's conclusions. The committee's duty to demonstrate re-

---

177. See *supra* note 173 and accompanying text. *Mathews v. Eldridge* provides that in evaluating whether due process requires a given procedure, the "administrative burdens that the additional . . . procedural requirement would entail" is one factor that a court must consider. 424 U.S. 319, 334-35, 347-48 (1976) (citation omitted). Although providing notice, an opportunity for the patient to participate, and a written determination may somewhat inconvenience ethics committees, such burdens seem a small price to pay given the fact that, for all practical purposes, the committee's action may conclusively determine the outcome of a disputed treatment decision. Indeed, other commentators have maintained that committees ought to provide even more procedural protections, regardless of how administratively burdensome those may be. See, e.g., Annas, *supra* note 76, at 56-57 (arguing that when committees review treatment decisions for incompetent patients, the people involved must know the substantive and procedural rules, there must be provision for representation of the incompetent patient, and there must be a mechanism for appeal); Robertson, *supra* note 72, at 93 (asserting that if a committee exerts decisionmaking authority, "the patient has the right to notice and participation . . ." and committee "operations should . . . be open and available to public scrutiny"); Lo, *supra* note 10, at 47-48 (suggesting that an ethics committee inform patients of its work, give patients or surrogates notice before discussing a case, issue patients or surrogates invitations to participate in the committee deliberations, and communicate the committee's recommendations and reasons to all parties).

spect for persons requires no less. Finally, its obligation to promote the well-being of patients and avert harm to them mandates efforts to protect their rights and interests.

In addition to legal and ethical obligations, the transformative obligation of committees—their duty to assist in the recognition of patients' rights and empowerment of patients—offers particularly strong support for this set of procedural obligations. Indeed, anything less than a concerted effort to support the voice, participation, and authority of patients would violate this obligation. If committees are sincerely trying to transform health care relations and make patients' power and authority a reality, then the committee should see itself as accountable to the patient. After all, the legal and ethical consensus is that the patient has ultimate authority over whether to accept or reject medical treatment. Unless overruled by a court, it is the patient or her surrogate who has the right to say yes or no. More ethics committees should see themselves as trying to satisfy the patient that their procedures are open, fair, and thorough, and their conclusions sound. Commentators have argued that good ethics committee procedures can persuade higher authorities outside the health care institution to listen to the committee.<sup>178</sup> These commentators would have committees play to the wrong audience. The key person to persuade is the patient herself.

That yields the final element of my due process proposal: that ethics committees undertake an obligation to evaluate their own functioning and procedures periodically,<sup>179</sup> and perform the evaluation first and foremost from the patient's point of view.<sup>180</sup> The committee must examine whether it is fulfilling its obligations to patients. The key people to ask, though not the only ones, are patients themselves. The committee must ascertain whether all of

---

178. See, e.g., Cranford, Hester & Ashley, *supra* note 10, at 53 (“[C]ourts may give greater weight to [committee] recommendations where the committee process is open.” (footnote omitted)); Lo, *supra* note 10, at 47.

179. A literature has developed on the desirability of evaluating ethics committee performance, but there is no consensus on the criteria by which their performance should be judged. See, e.g., Allen, Moldow & Cranford, *Evaluating Ethics Committees*, HASTINGS CENTER REP., Sept.-Oct. 1989, at 23; PRESIDENT'S COMMISSION, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 4, at 170; Povar, *Evaluating Ethics Committees: What Do We Mean by Success?*, 50 MD. L. REV. 904 (1991).

180. Cf. Matsuda, *Looking to the Bottom: Critical Legal Studies and Reparations*, 22 HARV. C.R.-C.L. L. REV. 323, 324 (1987) (“[T]hose who have experienced discrimination speak with a special voice to which we should listen. Looking to the bottom—adopting the perspective of those who have seen and felt the falsity of the liberal promise—can assist critical scholars in the task of fathoming the phenomenology of law and defining the elements of justice.”).

these procedural protections in fact make full patient participation possible. The best way to find out is to ask patients who have been through the process.<sup>181</sup> Problems and obstacles that patients identify should cause the committee to consider further procedural innovation, beyond what I have proposed as a starting point.

### C. *Nesting Rights in a Community of Caring*

One might conclude that despite the procedural innovations I recommend, we should nonetheless give up on ethics committees. After all, if Katz is right and there is an inevitable conflict between the perspectives of doctors and patients,<sup>182</sup> then maybe asking physician-dominated committees to look out for patients' interests is like asking the proverbial fox to guard the chicken coop. Moreover, if the committee exists within a health care institution and is composed of members of that institution's staff, then the committee will never provide the independent judgment of a body such as a court.

Ethics committees will indeed never provide the independence of a court. Nor will committees ever be adequate guardians for patients' legal rights. That is why I have argued that use of an ethics committee should never preclude judicial review, and that courts should review litigated cases *de novo*, without deferring to a committee's prior determination. But all of that simply means that the committee's role must and should be different from the court's. The court's role is to be the ultimate arbiter of legal rights; that role requires independence from all parties. The committee's role, however, should be to help transform the decisional process at the institutional level into one that is ethically adequate and provides protection for patients' rights.

It is precisely by operating within rather than outside of the institution, that a committee can reform in-house practice. Resort to the committee becomes a part of the practice within the institution. If the ethics committee through the mechanism of due process is giving patients a voice and protecting patients' rights, then those patients need not force the decisional process outside of the institution into a court of law in order to be heard. They can be heard while the decisionmaking process is still occurring within the institu-

---

181. Youngner and his colleagues have reported an empirical study in which they asked patients questions about ethics committees and received fascinating responses, though the researchers did not focus on patients who had been through the ethics committee process themselves. See Youngner, Coulton, Juknialis & Jackson, *supra* note 10, at 22-23.

182. See J. KATZ, *supra* note 46, at 104-29.



tion, close to the bedside, without the delay, formality, and expense of judicial proceedings.

Thus ethics committees can perform a unique function, one the courts do not share. That function requires that ethics committees be part of the process for resolving disputes and handling treatment decisions within the institution. When the committee is part of the institution, then committee innovations to give patients voice and rights in the committee's processes necessarily alter institutional processes at the same time.

Moreover, by being part of the institution, the committee has a particularly strong vantage point from which to discover and address problems in practice within the institution but outside of the committee. The committee is in a position to go through the often slow and laborious process of changing the culture and practice around it. The committee may also have considerably more credibility and clout in certain quarters—say, among physicians—than outsiders would.

The hitch, of course, is that a committee comprised of physicians and other health care professionals from within the institution may be less likely to advocate change and to advance the process of according patients rights. As noted above, we may be asking the fox to guard the chicken coop. But the hard reality is that in medical relationships the fox *must* guard the chicken coop. The patient will always be the more vulnerable and in need. It is up to the treating clinician both to protect the patient's medical welfare and to create a caregiving relationship in which the patient can exercise decisional authority and assert her rights. There are others who can play important supporting and correcting roles, including courts. But in the final analysis, it is clinicians themselves who will exercise the greatest influence over the shape of clinical relationships and decisionmaking.

Consequently, it is precisely the task of the ethics committee to make the patient's participation and patient's rights a reality within the committee's own in-house, clinician-dominated process. By doing that, the committee both ensures patient participation and rights within its own piece of the broader institutional decisional process, and models for other clinicians within the institution a process that takes patients' rights and authority seriously. While other clinicians in their one-to-one relationships with patients will obviously not pursue the precise processes a full committee does, the committee will at least be demonstrating one approach to ensuring that the patient's voice is heard.

The committee's embrace of a broad concept of due process grounded in law, ethics, and a transformative mission, thus becomes a tool. It is a means to guarantee that the patient can participate, be heard, and assert her rights in the caregiving context. Due process literally brings the patient into the committee room and gives her a voice in the proceedings. It makes rights a reality in the caregiving context.

Committees, however, should do more than change their own procedures and thereby indirectly try to influence change in decisionmaking practices outside of the committee. Ethics committees should aggressively champion a broad concept of due process in the clinical setting. They should encourage all within the health care institution routinely to ask the question: are we pursuing decision-making processes that are fair and empowering to the patient?

Both in embracing due process within the committee and in becoming the institutional champion of due process more broadly, the committee will be playing a new role. For too long the ethical principles guiding medical relationships have been reduced to four: autonomy, nonmaleficence, beneficence, and justice.<sup>183</sup> One might think that the principle of justice incorporates a notion of due process. Instead, medical ethicists usually discuss justice in the context of allocation and rationing where the question is what distributive justice commands, rather than in relation to procedural rights.<sup>184</sup> That, of course, is not a mere oversight. It is a function of the historic ambivalence toward ceding patients full rights discussed above. Thus for the ethics committee to embrace and champion due process, the committee may well have to overcome considerable resistance, both within the committee itself and in the broader health care institution. Due process may be seen as some kind of unwelcome intruder from the world of law,<sup>185</sup> rather like a foreign

---

183. See, e.g., T. BEAUCHAMP & J. CHILDRESS, *supra* note 140. The widely read HANDBOOK FOR HOSPITAL ETHICS COMMITTEES counsels ethics committees that these are the principles they "should be concerned with in their work." HANDBOOK, *supra* note 10, at 12.

184. See, e.g., HANDBOOK, *supra* note 10, at 13 ("Justice has many aspects but in health care the aspect of concern is usually distributive justice . . ."). See also T. BEAUCHAMP & J. CHILDRESS, *supra* note 140, at 256-306. Beauchamp and Childress discuss procedural justice, but include it within their explanation of the principle of nonmaleficence. See *id.* at 169-70, 177.

185. I deliberately refer to the antagonism many physicians, nurses, and others in health care settings feel toward the law and lawyers. Anxiety about the law, and animosity towards people and things connected with the law, are important and interesting facts of life in health care settings. There is the beginning of a literature on this subject, and on the ways in which clinicians' feelings, beliefs, and attitudes about the law and

virus invading a previously healthy body. But the real root of resistance is likely to be not so much the origin of the notion, but the fact that it protects patients' rights. Many may see an ethics committee's embrace of due process and insistence on procedural protections for the patient in committee case consultations as too much attention to patients' rights, creating an adversarial relation between the patient and health care professionals. It may be seen as the triumph of patients over caregivers, rights over caring.

This is precisely why it is so important that ethics committees embrace due process and make it a routine part of their concerns. Ethics committees must reject the stark dichotomy of patients versus caregivers, rights versus caring. They must be the ones within their health care institutions working hardest to make patients' rights a functioning reality within medicine. That should be the basic mission of ethics committees. Fulfilling that mission means creating a robust respect for patients' rights, but doing it in a way that preserves the patient's relationships to caregiving health professionals. It means rejecting the dichotomy between caring and rights, and instead nesting those rights within a community of caring.

Most of this part of the article has been devoted to sketching what attention to rights would look like. That is because the history of medicine is a history of attention to caregiving instead. The struggle is to recognize patients' rights. But it is important to say what preserving caregiving relationships would look like in an era of attention to rights. Consider an ethics committee that is adopting my proposal, according due process to those patients whose cases come before the committee, and championing due process concerns in the broader institution. How does that committee also act to preserve caregiving relationships?

The committee must first recognize that disagreement and conflict between physicians or other caregivers and their patients does not by itself signify or excuse the end of the caregiving relationship. Consequently, when a dispute comes to the ethics committee or simply erupts in the broader institution, everyone should acknowl-

---

lawyers affect their practices. See, e.g., Johnson, *The Fear of Liability and the Use of Restraints in Nursing Homes*, 18 LAW, MED. & HEALTH CARE 263 (1990); Kapp & Lo, *Legal Perceptions and Medical Decision Making*, 64 MILBANK Q. 163 (Supp. 2) (1986).

The Education Development Center and The Hastings Center have addressed these problems in developing a training program for clinicians on termination of treatment issues. See generally DECISIONS NEAR THE END OF LIFE, MODULE 2: WORKING WITH THE LAW (1989) (magazine). Two relevant articles produced for that training program are Dubler, *The Law: Myths and Realities*, *id.* at 22, and an excerpt entitled *The Role of Law*, *id.* at 17 (drawn from GUIDELINES, *supra* note 25).

edge that the caregiving relationship is continuing. The professional is not relieved of her responsibility to maintain that relationship. But for the caregiver to be in disagreement and in relationship simultaneously, means to accept the fact that disagreement between caregiver and patient is not a sign of failure. In fact, it can be a sign that a truly adult collaboration is under way between two people who have different priorities and vantage points. I have written about this at greater length elsewhere.<sup>186</sup> There the starting point of my argument was Jay Katz's fundamental insight that conflict between doctors and patients is inevitable, because of the great difference in their values and perspectives.<sup>187</sup> Katz has argued that physicians have spent centuries avoiding conversation with their patients. This silence has suppressed the conflict, but it also means that physicians have failed to share information, have made all the decisions themselves, and have shut patients out of the decision-making process. The result, Katz maintained, is that patients have felt abandoned.<sup>188</sup>

Thus the ethics committee has an important role to play in persuading all that a good caregiving relationship includes exploring areas of disagreement and facing that disagreement squarely. Sometimes facing disagreement will mean going to the ethics committee. The ethics committee should let it be known that once a dispute is there, the committee will not keep the patient from the room, silence her voice, and thwart her participation. Instead, the committee will do all it can to enable the patient to participate fully and articulate her perspective. The committee will even enable the patient to discuss and challenge the committee's own conclusions.

In this way the committee refuses to collude in perpetuating the long history of silence that Katz condemns. The committee ensures that the patient is in the room, that the silence is broken, and that full dialogue ensues. Due process protections thus become a vehicle for creating an even fuller kind of caregiving relationship than before. This is a caregiving relationship based on uninhibited dialogue. The patient is no longer shut out and abandoned, as Katz depicts. Instead, the patient can participate fully; she is free to disagree.

Due process thus need not be the enemy of caregiving. At heart, due process is a way to make sure the patient can speak and

---

186. See Wolf, *Conflict Between Doctor and Patient*, *supra* note 92.

187. See J. KATZ, *supra* note 46, at 99-100.

188. See *id.* at 207-25.

be heard. That means that due process is indeed a revolutionary force. Ensuring that patients can speak and be heard breaks the long tradition of silence that left physicians the only ones with authority. Due process allows patients to enter into active partnership with their caregivers. It makes patients' rights and authority a functioning reality.

### CONCLUSION

Ethics committees have come of age. Many of these committees have been striving for recognition and influence within their health care institutions, and they have succeeded. Many proponents of ethics committees have worked hard to gain influence for these committees even beyond the institution, in courts of law. They too have succeeded. The result of all this success is that ethics committees wield real power over the fate of real patients.

Yet committees have thus far avoided taking responsibility for this power. Committees simultaneously seek power but offer assurances that they are merely advisory. They may exert a decisive influence over patients' legal and moral rights, yet routinely offer no protection for those rights. They claim to benefit patients while serving health care professionals.

These seeming contradictions tell a story. It is a story that began long ago when Hippocrates instructed physicians to perform their duties "concealing most things from the patient."<sup>189</sup> Patients have since lived with centuries of physician paternalism and silence.

This pattern might have continued undisturbed. Yet astonishingly, it did not. After centuries and centuries, in our own lifetimes the realization finally dawned that it is the patient's body, her fate, her life and death that are at stake. Thus her own personal values must govern treatment decisions. This was a founding insight of modern biomedical ethics. Nor did the law lag behind. Both ethics and law called for patients' rights.

We have been embroiled in tumult ever since. The revolution in medical relationships remains incomplete and embattled. In the clinic, ambivalence reigns.

Ethics committees were born of the movement for patients' rights. But they have grown up in the clinic. Those who have always held sway in the clinic, health care professionals and pre-eminently physicians, have controlled ethics committees too. Their

---

189. *See id.* at 4 (quoting 2 HIPPOCRATES, DECORUM 197 (W. Jones trans. 1967)).

ambivalence about patients' rights has fundamentally shaped these committees. Double messages and paradox abound.

Some will see the health care professionals as villains in this story and call for their defeat. That is not my purpose. Mine is to show both sides that form the coin, to hear both messages and the sound they form together, to see that the Escher print is both fish and fowl.

Ethics committees are destined to be the place where health care professionals and patients meet. Two different and often conflicting sets of interests will always be in that room. The necessity to protect the patient's rights will always sit right beside the desire to preserve caregiving relationships.

Some in that room will choose to see only one part of the picture, regarding all as a matter of patients' rights or all as a matter of professional caregiving. I advocate a fuller vision. Only then will we appreciate what to do.

Ethics committees must recognize that because they wield substantial power over the patient's fate, they have obligations toward that patient. They must pursue a process that is fair and fully protective of the patient's rights. In arriving at their conclusions, they must be attentive to the priority that both law and ethics assign to the patient's authority to make treatment decisions.

Yet that is not enough. The patient is entitled to more than rights; she is entitled to sensitive caregiving. The committee must honor her rights while supporting her caregiving relationships. When people are ill, rights and caregiving cannot be enemies. Patients need both. Rights give patients decisional authority in the context of options and support provided by caregivers. And caregiving depends on dialogue with the patient and respect for her right to decide.

By stepping into treatment disputes, ethics committees obligate themselves to honor patients' rights, while nesting these rights in a community of caring. To do this, ethics committees must embrace due process. They must ensure that the patient's voice is heard, that she can participate fully in treatment decisions, exercise her decisional authority, and challenge those who oppose her. Due process is the way to guarantee this. It ensures that both sides are in the room, collaborating and, if need be, struggling—both patient and caregiver.