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Schiavo: The Road Not Taken

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Schiavo: The Road Not Taken

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INTRODUCTION

In this Article, I want to focus on the “anti-*Schiavo*,” not the case as it occurred, but the far more common situation in which the horror and the farce, if not the underlying tragedy, might be avoided by a different legal and social structure.

Imagine the following “variant *Schiavo*.” We still have a young woman in Florida who has suffered a tragic medical event that placed her in a persistent vegetative state (“PVS”). We still lack an advanced directive or a person whom the patient has designated as her healthcare surrogate. We still have a husband who believes that, under these circumstances, his wife would not have wanted to continue artificial nutri-

* Professor of Law, University of Miami School of Law. Many thanks to Kathy Cerminara, Michael Fischl, Leslie Francis, Clark Freshman, Ken Goodman, Patrick Gudridge, and Lili Levi for their suggestions, even the ones I did not follow. Thanks also for the invaluable work of my research assistant, Ashley Bruce.

tion and hydration. We still have parents who believe their daughter would want to fight to continue her life under all circumstances. And, finally, we are still subject to the same Florida law that designates the husband as the person who can decide, or petition a court to decide, that artificial nutrition and hydration should be withdrawn consistent with clear evidence of the patient's wishes.¹ What we do not have is the extreme, unmitigated hostility and distrust within the family and the intervention of others with ideological axes to grind that made the *Schiavo* case so much more than a family tragedy.

If we could imagine this variant *Schiavo*, we could also imagine a step in resolving the family dispute that never occurred in the real *Schiavo*: the intervention of a bioethics consultation.² After briefly setting out the relevant facts and background rules, I describe the bioethics consultation process and examine how it might provide a better avenue for reaching a decision and avoiding litigation in this and many other cases.

Finally, I consider the challenge that such an approach might entail an unacceptable cost to the patient's interests and wishes. There is no doubt that the costs of the litigation process are high for all the relevant parties. Although it is a closer question, I conclude that the costs of avoiding litigation, and thus not getting the "right" substantive outcome, are relatively low in this particular subset of end-of-life healthcare situations. In the real *Schiavo* case, the Second District Court of Appeal said, "[i]t may be unfortunate that when families cannot agree, the best forum we can offer for this private, personal decision is a public courtroom and the best decision-maker we can provide is a judge with no prior knowledge of the ward."³ I suggest that we can and should do better; one way of doing so is to provide a process to bring the relevant parties to consensus and keep them out of court.

This Article focuses on the relationship between bioethics consultations/mediations and adjudication. There is, however, a third forum for dealing with these issues: at the bedside among patient, proxy, family, and healthcare professionals without any outside intervention. No doubt most end-of-life issues are resolved in this manner and never come to anyone else's attention. However, such informality involves the risk of

1. Although I use this as the paradigmatic case, I intend to extend the discussion of bioethics alternatives to a range of situations in which the patient is not currently competent to make her own healthcare decisions and where the issue is whether to withhold or withdraw lifesaving medical treatment. As indicated later, our willingness to employ certain strategies to encourage settlement and avoid litigation should vary among these cases, depending on the extent to which we have reliable evidence of the once-competent patient's wishes.

2. I sometimes refer to the process upon which I focus as a consultation/mediation. Unless the context indicates otherwise, the term "bioethics consultation" has the same referent. See *infra* Part III for a discussion of bioethics consultations' functions and processes.

3. *In re Guardianship of Schiavo*, 851 So. 2d 182, 187 (Fla. 2d Dist. Ct. App. 2003).

inadequate communication, so that a decision may be based on a misunderstanding of the relevant facts or inappropriately reflect the power dynamics among the parties.⁴ It thus may lead to an ethically inappropriate outcome or unneeded litigation. A bioethics consultation can often avoid both of these outcomes.⁵ While such a process should not be obligatory, for the same reasons that adjudication should not be obligatory, it should be readily available whenever any of the participants wish to invoke it.

The Article concludes with some modest policy proposals that might enhance the effectiveness and the use of such processes.

I. THE FACTS

Without reprising the *Schiavo* case's convoluted history, it is useful to briefly lay out those facts that are most relevant to the issues discussed in this Article.⁶ Terri Schiavo was a twenty-six-year-old married woman⁷ when she suffered cardiac arrest in 1990, during which she was anoxic for several minutes. She emerged from her coma, but did not recover consciousness, instead entering a PVS.⁸ For several years her

4. See *infra* Part V.

5. Cf. John A. Robertson, *Committees as Decision Makers: Alternative Structures and Responsibilities*, in INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING 85, 88 (Ronald E. Cranford & A. Edward Doudera eds., 1984) [hereinafter INSTITUTIONAL ETHICS COMMITTEES] (arguing that "it is important to have an in-house forum for resolving disputes rather than to have resolution accomplished, for instance, by fiat of the most senior member of the medical team"); David Orentlicher, *The Limitations of Legislation*, 53 MD. L. REV. 1255, 1282 (1994) (raising the concern that physicians are "more likely to base treatment decisions on their own values rather than the patient's values"). See generally John J. Paris, *The Decision to Withdraw Life-Sustaining Treatment and the Potential Role of an IEC: The Case of People v. Barber and Nejdil*, in INSTITUTIONAL ETHICS COMMITTEES, *supra* (discussing the role a bioethics consultation might have provided in giving voice to a nurse's concerns and perhaps avoiding the prosecution of two physicians for murder for withdrawing artificial nutrition and hydration from an irreversibly brain-damaged patient).

As discussed *infra* Part III-IV, imposing a formal bioethics process does not eliminate these risks. The issue, however, is not if any process is perfect, but which is, on the whole, most likely to advance patients' desires and interests, properly understood.

6. See generally Kathy Cerminara & Kenneth Goodman, *Schiavo Case Resources, Key Events in the Case of Theresa Marie Schiavo* (2006), <http://www.miami.edu/ethics2/schiavo/timeline.htm> (outlining the events of this case, including the numerous judicial opinions generated).

7. Unsurprisingly, as a healthy young woman, she had never executed any advance directive.

8. See generally JAY WOLFSON, A REPORT TO GOVERNOR JEB BUSH AND THE 6TH JUDICIAL CIRCUIT IN THE MATTER OF THERESA MARIE SCHIAVO 8 (2003), available at <http://abstractappeal.com/schiavo/WolfsonReport.pdf>. Situations like this are, ironically, a consequence of the rapid improvements in medical care over the last half-century; only when there are treatments that permit survival in such circumstances need we decide if they should be withheld or withdrawn.

While I later acknowledge the disputes that arose in *Schiavo* and might arise in similar cases regarding the accurate diagnosis, I assume here that the medical testimony, as credited by the

husband and mother worked assiduously to provide her the best possible care, including a range of therapies that they hoped would improve her condition.⁹

By 1993, however, relationships between Terri Schiavo's husband, Michael, and her parents, Robert and Mary Schindler, had drastically deteriorated.¹⁰ Sometime before 1998, her husband was persuaded that he should seek to withdraw the percutaneous endoscopic gastrostomy tube that provided her nutrition and hydration – a decision that would lead to her death.¹¹ He petitioned the court to authorize such a withdrawal, arguing that she was in a PVS, that her condition would never improve, and that she had expressed to him and members of his family that she would not want continued treatment in that situation.¹² Her parents ultimately disagreed with all of these claims and additionally responded that, given Michael's changed situation,¹³ he should not be recognized as her guardian.

After extensive and increasingly hostile litigation, the feeding tube was withdrawn and Terri Schiavo passed away on March 31, 2005.¹⁴ The hostility among her family members has not abated.¹⁵ One thing all participants could surely agree on is that there should have been a better way to resolve such a tragic situation.

II. THE BACKGROUND LEGAL RULES

The background rules for resolving end-of-life disputes among or between the patient, the patient's family, the proxy (if any), and the patient's healthcare professionals vary among jurisdictions in both the substantive criteria and the procedural requirements that must be met before implementing a decision to withhold or withdraw life-sustaining

court, and as confirmed by the autopsy, correctly classified Terri Schiavo's condition. See, e.g., Jacob Goldstein & Noah Bierman, *Autopsy: Schiavo Damage 'Massive,'* MIAMI HERALD, June 16, 2005, at 1A.

9. See generally WOLFSON, *supra* note 8.

10. *Id.* at 8-10.

11. *Id.* at 11.

12. *In re Guardianship of Schiavo*, No. 90-2908GD-003, 2000 WL 34546715, at *2 (Fla. 6th Cir. Ct. Feb. 11, 2000).

13. He had developed a romantic relationship with another woman with whom he eventually had two children. See WOLFSON, *supra* note 8, at 14; see also MICHAEL SCHIAVO WITH MICHAEL HIRSH, *TERRI: THE TRUTH* (2006); cf. *In re Guardianship of Kowalski*, 478 N.W.2d 790, 796 (Minn. Ct. App. 1991) (rejecting parents' argument that Sharon Kowalski's lesbian lover's views should be disregarded since she had had other sexual relations subsequent to Kowalski's accident and noting that it "is not uncommon for spouses to make changes in their personal lives while maintaining their commitment to the injured person").

14. Cerminara & Goodman, *supra* note 6.

15. See generally SCHIAVO WITH HIRSH, *supra* note 13; MARY SCHINDLER ET AL., *A LIFE THAT MATTERS: THE LEGACY OF TERRI SCHIAVO – A LESSON FOR US ALL* (2006).

care.¹⁶ Since the variant *Schiavo*, like the situation of Terri Schiavo herself, occurs in Florida, Florida law applies.¹⁷

In the absence of an advance directive or a surrogate whom the patient has previously designated, the husband would be the legal proxy decisionmaker.¹⁸ He could choose to continue medical care (including artificial nutrition and hydration) and other family members would have no legal basis upon which to force a different decision.¹⁹ Alternatively, if the husband wished to discontinue medical treatment, he could legally seek to do so.²⁰ If he were seeking to withdraw life-prolonging procedures, he would need to conclude two things: first, he “must be satisfied

16. See generally ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* (3d ed. 2004 & Supp. 2005).

17. See generally § 765, FLA. STAT. (2006). A future federal statute might preempt these rules; none has yet done so.

18. § 765.401, FLA. STAT. (2006). In *Schiavo*, Michael Schiavo had previously been appointed her guardian; as such, he in effect occupied both the first and second statuses in the statutory hierarchy. See § 765.401(1)(a)-(b). The statutory hierarchy reflects the state’s default assumption regarding whom a no-longer-competent patient would have chosen. As with intestate succession, the spouse is first, followed by children, parents, and then siblings. Cf. §§ 732.102-.103, FLA. STAT. (2006).

Note that the determination is entirely formal. It does not turn on the quality of the relationship or whether the facts show that this is a “real” marriage. The proxy’s authority, as set out in the statutory hierarchy, however, can be challenged by facts specifically indicating that that person will not or cannot act consistent with the statutory criteria. Thus, the Florida courts properly rejected Terri Schiavo’s parents’ attempts to have her husband displaced as proxy because he was cohabiting with another woman. See Kathy L. Cerminara, *Tracking the Storm*, 35 STETSON L. REV. 147, 159 (2005); Katharine B. Silbaugh, *The Practice of Marriage*, 20 WIS. WOMEN’S L.J. 189, 211-14 (2005) (noting that the continued formal marriage status made irrelevant facts that suggested there was no longer a functional marriage between Michael and Terri Schiavo).

19. This decision, like the decision to withdraw treatment, must be based on what Michael reasonably believed Terri Schiavo would have wanted for herself, or if that were unknowable, her best interest. § 765.401(2)-(3). If the husband and parents’ positions had been reversed, however, it appears that there would have been no proper basis for litigation. See Lois Shepherd, *Terri Schiavo: Unsettling the Settled*, 37 LOY. U. CHI. L.J. 297, 314 (2006).

However, the healthcare facility or a financially responsible entity might impose significant pressure, including seeking to have the patient transferred to another facility, if they deemed continued care medically futile. Cf. TEX. HEALTH & SAFETY CODE ANN. § 166.046(3)(e) (2003) (authorizing a healthcare facility, if it follows certain procedural requirements, to discontinue life-sustaining treatment they deem “inappropriate” even if the patient or family requests that it continue). Some scholars have argued that any treatment for a patient in a PVS should be deemed futile, since “[m]ere biologic life . . . is not a life worth sustaining.” DAVID ORENTLICHER, *MATTERS OF LIFE AND DEATH: MAKING MORAL THEORY WORK IN MEDICAL ETHICS AND THE LAW* 133 (2001) (describing the positions expressed in Lawrence J. Schneiderman et al., *Medical Futility: Its Meaning and Ethical Implications*, 112 ANNALS INTERNAL MED. 949 (1990), and George J. Annas, *The “Right to Die” in America: Sloganeering from Quinlan and Cruzan to Quill and Kevorkian*, 34 DUQ. L. REV. 875, 887 (1996)).

20. His authority derives from chapter 765, Florida Statutes. The Florida legislature adopted this statute in response to the Florida Supreme Court’s decision in *In re Guardianship of Browning*, 568 So. 2d 4, 13 (1990), which found a right to do so in the Florida constitution’s right of privacy. See art. I, § 23, FLA. CONST.

that” his wife “has an end-stage condition, . . . is in a persistent vegetative state, or [that her] physical condition is terminal”;²¹ and second, that there is clear and convincing evidence – based on what she did and said while competent – to support his decision to withdraw medical care,²² a criteria denominated as “substituted judgment.” Alternatively, if there were insufficient evidence to meet this latter standard, the treatment could still be withdrawn if withdrawal were determined to be in her best interests.²³

Florida law quite clearly defines who can authorize to authorize withdrawal of treatment.²⁴ Since the proxy, when exercising substituted judgment, is not authorized to exercise his own judgment, but in effect, to channel the patient’s wishes, the statute permits other interested parties to challenge the choice in a court of law.²⁵ In effect, the *Schiavo* litigation demonstrates that, if the family members do not agree, there is a significant likelihood of a hostile, public, and internecine battle, with the additional possibility of political and interest group intervention, which introduces parochial agendas and will very likely overlay the tragedy with farce.²⁶

21. §§ 765.401(3), 765.305, FLA. STAT. (2006).

22. See § 765.401(3). Substituted judgment has been defined as requiring the proxy “to attempt to make decisions according to the substituted judgment standard – choosing as the incompetent individual would choose in the circumstances were he or she competent.” ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* 112 (1989); see also Norman L. Cantor, *Twenty-Five Years After Quinlan: A Review of the Jurisprudence of Death and Dying*, 29 J.L. MED. & ETHICS 182, 191 (2001) (advising that the proxy should “replicate what the now-incompetent patient would have chosen if somehow miraculously competent and aware of all the circumstances confronting him or her”).

23. § 765.401. The Florida Legislature did not add the “patient’s best interest” alternative until 2001, after the *Schiavo* controversy had already begun. See § 765.401(3); *In re Guardianship of Schiavo*, 916 So. 2d 814, 819 n.3 (Fla. 2d Dist. Ct. App. 2005). Note that no court authorization is required. The Florida statutes specifically provide civil and criminal immunity to healthcare facilities and providers who withdraw medical treatment in accordance with the chapter’s provisions. § 765.109, FLA. STAT. (2006). In effect, Florida has chosen, in most situations, to designate private parties to make this decision rather than requiring the approval of state actors.

Many such decisions are made every year without any judicial review, where all the relevant parties have agreed on the appropriateness of doing so. See generally JANET L. DOLGIN & LOIS SHEPHERD, *BIOETHICS AND THE LAW* 741 (2005).

24. § 765.401.

25. Section 765.105, Florida Statutes, allows a challenger to argue that one or more of the statutory criteria has not been met or that the proxy has neglected his or duties or abused his or her powers. § 765.401. The procedure in *Schiavo* was somewhat different than those described in the text. Since Michael Schiavo recognized that the Schindlers were certain to challenge any decision to withdraw artificial nutrition and hydration, he instead petitioned the court in his role as his wife’s guardian to authorize the withdrawal, thus the decision in the first instance was made by the trial judge rather than the statutory proxy. See *In re Guardianship of Schiavo*, 780 So. 2d 176, 179 (Fla. 2d Dist. Ct. App. 2001).

26. See KARL MARX, *THE EIGHTEENTH BRUMAIRE OF LOUIS BONAPARTE* (1852) (noting that “upon the stage of universal history, all great events and personalities reappear in one fashion or

The Florida statutes are silent on the processes that may precede any litigation except in a narrow situation that did not arise here.²⁷ In any case where there are family members available to participate in decisionmaking, the law does not require the participation of a bioethics committee. In *Schiavo* itself, bioethics processes, which might have avoided litigation, or at least decreased the litigation's hostility, remained unused. In the following section, I describe the structure of bioethics committees, the various processes they may employ to deal with end-of-life dilemmas, and the role that a bioethics consultant may play in determining outcomes.

III. THE BIOETHICS CONSULTATION PROCESS

Healthcare facilities frequently have some institutional structure to provide bioethics input.²⁸ One such structure is a bioethics committee.²⁹ Bioethics committees are typically comprised of a range of people with relevant expertise. At least at larger institutions, these committees typically include people who are not institutional employees.³⁰ The commit-

another . . . on the first occasion, they appear as tragedy; on the second, as farce"). In this case, tragedy and farce seem to have been operating, at least in part, concurrently.

27. Where "no family or friends are available or willing to serve as a proxy to make healthcare decisions for [the patient]," the court appoints a guardian. In that situation, the statute calls for a consultation among the guardian, the treating physician, and the hospital ethics committee to determine if the statutory criteria for treatment withdrawal are met. § 765.404, FLA. STAT. (2006).

28. Those institutions that wish to be accredited by the Joint Commission on Accreditation of Health Care Organizations ("JCAHO") must have some mechanism to address ethical issues. FLA. BIOETHICS NETWORK, GUIDELINES FOR ETHICS COMMITTEES: REPORT OF THE COMMITTEE ON ETHICS COMMITTEE STANDARDS 3 (1996) [hereinafter FLA. BIOETHICS NETWORK]. Over eighty percent of all hospitals had such mechanisms in place by 2003. Mark P. Aulisio, *Meeting the Need: Ethics Consultation in Health Care Today*, in ETHICS CONSULTATION: FROM THEORY TO PRACTICE 4 (Mark P. Aulisio et al. eds., 2003). These bioethics mechanisms are a relatively recent phenomenon, most post-dating the call for more bioethical consideration of end-of-life issues in *Quinlan* and in the report of the PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMED. & BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 164 (1983) [hereinafter PRESIDENT'S COMM'N, DECIDING TO FOREGO]. See also Susan M. Wolf, *Ethics Committees and Due Process: Nesting Rights in a Community of Caring*, 50 MD. L. REV 798, 798-99 (1991).

29. The earlier sources refer to committees and describe structures like the one set out in this text paragraph. See, e.g., Wolf, *supra* note 28, at 798-99. See generally INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING, *supra* note 5.

30. See Alexander Morgan Capron, *Decision Review: A Problematic Task*, in INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING, *supra* note 5, at 174, 181 (noting among the values of a diverse membership: reducing "the tendency to take the committee's task as essentially a technical one, which it is not" and preventing committees from becoming captive to the views of any one profession or social group). Among the individuals on the committees at some of the larger hospitals in South Florida are physicians, nurses, risk managers, genetic counselors, clergy, ethicists, and public representatives. See Glenn McGee et al., *A National Study of Ethics Committees*, 1 AM. J. BIOETHICS 60, 62 (2001). Providing a healthcare facility's attorney or risk manager a voting role in a bioethics committee is problematic; he or she certainly

tees can provide a variety of services to the facility, including the development of healthcare policy and the education of physicians and other staff on bioethical issues.³¹ Committees also respond to ethical questions that arise in particular clinical situations.³² The bioethicists are typically called in when the primary players have doubts or disagreements about the proper course of action. One of the most significant roles for bioethics committees or consultants is "to resolve disputes among staff members, and between staff and patients and their families, over non-treatment decisions."³³ End-of-life situations are a paradigmatic case.

While the bioethics committee is the appropriate body for carrying out policy development and educational functions, case-specific review can be carried out through a variety of structures.³⁴ I first describe the structure in which the committee itself serves as the mechanism for consultation and the provision of a recommendation or determination. I suggest, however, in light of some of the problems associated with that structure, that a consultation/mediation process is a preferable mechanism for dealing with these issues.

cannot ethically take on a consultant/mediator role. See FLA. BIOETHICS NETWORK, *supra* note 28, at 7.

31. See THOMAS L. HAFEMEISTER & PAULA L. HANNAFORD, RESOLVING DISPUTES OVER LIFE-SUSTAINING TREATMENT: A HEALTH CARE PROVIDER'S GUIDE 72-73 (1996); see also McGee, *supra* note 30, at 62. In addition, the committees should have a mechanism to review and learn from case consultations. See AM. SOC'Y FOR BIOETHICS & HUMANITIES, CORE COMPETENCIES FOR HEALTH CARE ETHICS CONSULTATION 27-28 (1998) [hereinafter ASBH].

32. While this was once the "least utilized and most controversial function of an ethics committee," Aulisio, *supra* note 28, at 4, it has become a standard part of such committees' work. See also McGee, *supra* note 30, at 60.

33. Robertson, *supra* note 5, at 88. They may also be legitimately called upon when the immediate parties do not disagree but seek confirmation from a more disinterested body that their decision is appropriate. See generally Diane E. Hoffmann, *Mediating Life and Death Decisions*, 36 ARIZ. L. REV. 821 (1994). While I discuss here a bioethics committee's role as a litigation alternative, in many situations, an informed, legally and ethically appropriate consensus decision can be reached at the bedside among the family, surrogate, and healthcare professionals involved in the patient's care. See generally Charity Scott, *Mediating Life and Death*, 11 DISP. RESOL. MAG. 23 (2004) (reviewing NANCY N. DUBLER & CAROL B. LIEBMAN, BIOETHICS MEDIATION: A GUIDE TO SHAPING SHARED SOLUTIONS (2004)). The participants should be aware of risks, and, as indicated below, a court might at times be unwilling to entertain a case in which no consultation has occurred. It would, however, seem overly intrusive and bureaucratic to require a formal bioethics process in every case. But see PRESIDENT'S COMM'N, DECIDING TO FOREGO, *supra* note 28, at 164 (suggesting that a bioethics committee should review all decisions regarding withdrawal of lifesaving medical treatment from incompetent patients to ensure they are within an acceptable ethical range).

34. For an overview of several different structures, see Cynda Rushton, Stuart J. Youngner & Joy Skeel, *Models for Ethics Consultation: Individual, Team, or Committee?*, in ETHICS CONSULTATION: FROM THEORY TO PRACTICE, *supra* note 28, at 88, and John C. Fletcher & Kathryn L. Moseley, *The Structure and Process of Ethics Consultation Services*, in ETHICS CONSULTATION: FROM THEORY TO PRACTICE, *supra* note 28, at 96.

Particularly when bioethics committees were first developed, they sometimes appeared overly deferential to physicians, accommodating their general resistance to any review of their actions.³⁵ The committees only acted at the request of healthcare professionals, typically the attending physician. Neither the patient, nor the surrogate, nor the family could invoke the process. Frequently none of these laypersons were notified, and they might not even have known that a bioethics committee was reviewing the case.³⁶ At the end of the process, the committee recommended to the physician what was ethically appropriate.³⁷ While this decision was not formally binding, it carried great weight with the institution and often with any court that might later review the physician's decision. Professor Wolf rightly criticized this system's denial of the patient and family's rights; she called instead for a system that provided them due process and helped facilitate, rather than impede, the patient's right – either directly or through surrogates or family – to exercise her autonomous treatment choice.³⁸ The directive, physician-centered approach is far less common, though it has not entirely disappeared.³⁹

At or near the other end of the continuum of possible approaches to bioethics review is the bioethics consultation/mediation process. Here, the patient, proxy, and family's roles are recognized and supported, and the consultant/mediator's role is to facilitate a decision among the direct

35. One way of doing so was to minimize any committee role in determining ethically appropriate care for particular patients and to focus instead on educational tasks. See, e.g., Norman Fost & Ronald E. Cranford, *Hospital Ethics Committees* 253 JAMA 2687, 2688 (1985). Another was to make the committee's role subservient to the treating physician. See JOHN LA PUMA & DAVID SCHIEDERMAYER, *ETHICS CONSULTATION: A PRACTICAL GUIDE* 8-11, 52-53 (1994); Robertson, *supra* note 5, at 90 (discounting a physician's concern with interference since "the physician is not obligated to follow the committee's advice").

A similar deference to doctors can be seen in assumptions that doctors, rather than family, should play a primary role in selecting a healthcare surrogate where none has been previously designated by the patient. See *John F. Kennedy Mem'l Hosp., Inc. v. Bludworth*, 452 So. 2d 921, 926 (1984) (suggesting that "[d]octors, in consultation with close family members are in the best position to make" end-of-life decisions); PRESIDENT'S COMM'N, *DECIDING TO FOREGO*, *supra* note 28, at 127 (expressing the idea that the healthcare practitioner should play a role in selecting an appropriate surrogate from among the patients' various family members). This trend to prioritize doctors' decisional importance, rather than the family's, is striking, though it parallels Justice Blackmun's approach to the abortion issue in *Roe v. Wade*, 410 U.S. 113 (1973).

36. See LA PUMA & SCHIEDERMAYER, *supra* note 35, at 12-13 (providing reasons for seeing the patient and implicitly responding to resistances to doing so, but stating that the consulted bioethicist need not see the patient if the healthcare professional "wants only an educational primer").

37. The healthcare professionals were seen as the "client," who could request the review and to whom the committee reported. See, e.g., John A. Robertson, *Committees as Decision Makers: Alternative Structures and Responsibilities*, in *INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING*, *supra* note 5, at 85, 87-89 (describing the operation of such a model).

38. See generally Wolf, *supra* note 28.

39. McGee, *supra* note 30, at 61, notes that five percent of the ethics committees surveyed indicated that they sometimes issued binding decisions.

participants rather than to impose his or her own view of the ethically correct outcome. There are a wide range of possible structures for carrying out a consultation/mediation.⁴⁰ The body entrusted to carry out the process might be the institution's bioethics committee, a subset thereof, or even a single person. The intervention might take place at different stages; it might be relatively active or passive, and the persons who can invoke it or participate in it might vary. The outcome might vary as well, taking the form of a decision, recommendation, or facilitation of a decision by the direct participants.⁴¹

Those engaged in the bioethics process must individually or collectively possess certain skills and knowledge.⁴² They must have sufficient knowledge of medical concepts and terminology to understand, and to ensure that the lay participants understand, the relevant medical context.⁴³ The participants should also know the specific policies that their institution has adopted and should have at least a general understanding of the legal framework within which they are operating.⁴⁴ Moreover,

40. See generally Fletcher & Moseley, *supra* note 34; Rushton et al., *supra* note 34. Some structures seem to fit more naturally with some tasks. For example, when the group is asked to review a physician's decision or issue their own determination of the ethically appropriate action, the committee as a whole will bring a greater range of expertise and views to that task. On the other hand, an individual or a small group is better suited to listen, facilitate communication, and, if possible, bring all the participants to consensus. LA PUMA & SCHIEDERMAYER, *supra* note 35, at 100-02 (describing one system in which the consultant and committee take on distinct but mutually supportive roles).

41. See Nancy N. Dubler & Carol B. Liebman, *Bioethics: Mediating Conflict in the Hospital Environment*, 59 DISP. RESOL. J. 32, 36 (2004) ("One of the greatest advantages of using the mediation process in bioethics disputes is that the process is flexible. The general structure of mediation can be adapted and altered to fit the needs of the participants. But the starting point is always the same: respect for the patient, the family and the care providers, as well as an impartial stance regarding what should be the outcome in any particular case."). Other commentators have described an approach in which a single consultant works with the attending physician, patient, and others at the bedside and formulates a specific recommendation or set of recommendations, which are communicated to the attending physician and included in the medical record, without any separate role for a bioethics committee. See generally LA PUMA & SCHIEDERMAYER, *supra* note 35.

42. ASBH, *supra* note 31, at 15-18 (delineating those competencies, both skills and knowledge, that all participants in the process must possess and those that at least some must possess).

43. Scholars dispute how crucial it is that an ethics consultant be a clinician. Compare John La Puma & Stephen E. Toulmin, *Ethics Consultants and Ethics Committees*, 149 ARCHIVES INTERNAL MED. 1109, 1110 (1989) (arguing that the consultant should be a clinician, which they define as someone who "understands a particular patient's history, personal situation, and medical illness sufficiently well to help in managing the illness. A clinician is an experienced professional who attends and becomes involved with individual patients regularly"), with ASBH, *supra* note 31, at 11-12 (indicating that consultants who are lawyers or philosophers might need "to acquire basic knowledge of the clinical context"). While there is value in having a trained clinician/physician as part of a group, if a consultant/mediator is a clinician/physician there is a risk that the family may defer too easily to what they perceive as his or her views.

44. ASBH, *supra* note 31, at 5.

they must also remember that neither law nor institutional policies are determinative of ethically acceptable outcomes.⁴⁵

Perhaps most important, the bioethicists must possess both an adequate knowledge of general bioethics principles and the ability to apply them. There are four basic principles that inform bioethical decision-making: (1) patient autonomy; (2) beneficence; (3) nonmaleficence; and (4) social or distributive justice.⁴⁶ In the context of decisions on particular cases, patient autonomy is generally assumed to be of paramount importance.⁴⁷ Where the patient's views have not been clearly expressed, however, the other values may properly have a greater role.⁴⁸

The consultant should also have the requisite interpersonal skills to facilitate the needed communication among the parties.⁴⁹ These skills can be learned and consultants should engage in continuing study to maintain and enhance their relevant knowledge and skills.

As noted earlier, hospitals vary regarding who can invoke a bioethics process; almost all of them authorize any healthcare professional involved in the patient's care to invoke the process, although it is most commonly the attending physician who does so.⁵⁰ Many of those

45. That law and ethics are distinct is a truism; if a citation were necessary, it could simply be "*cf.* the debates over abortion or stem-cell research."

46. See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 12 (3d ed. 1989). I collapse nonmaleficence into beneficence, creating three principles, following BUCHANAN & BROCK, *supra* note 22, at 87, who describe the three basic ethical values in this context as "respect for individual self-determination" (autonomy), "concern for the individual's well-being" (nonmaleficence and beneficence), and "distributive justice." *Id.*

47. See MEISEL & CERMINARA, *supra* note 16, at 4-7; H. TRISTRAM ENGELHARDT, JR., *THE FOUNDATIONS OF BIOETHICS* 122-23 (2d ed. 1996). But see Carl E. Schneider, *After Autonomy*, 41 WAKE FOREST L. REV. 411, 413 (2006) (criticizing the dominant bioethics approach as elevating autonomy over beneficence and social justice, particularly in light of the difficulty of implementing the autonomy principle in the real world). See generally Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 TEX. L. REV. 1823 (2003) (stressing the importance of beneficence and social justice concerns in decisions over withdrawal of lifesaving medical treatment). Some writers have noted that the current structure makes it difficult to recognize openly the resource limitations that might be relevant to treatment withholding issues if social justice were acknowledged as a legitimate criterion. See *infra* Part VII and accompanying footnotes (discussing the various claims scholars have made regarding the ethically appropriate criteria to guide end-of-life decisionmaking). See generally George J. Alexander, *Death by Directive*, 28 SANTA CLARA L. REV. 67 (1988).

48. The law, too, permits consideration of the patient's best interest (beneficence) where the patient's actual wishes cannot be known with sufficient clarity. See, e.g., § 765.401(2) FLA. STAT. (2006).

49. See, e.g., DUBLER & LIEBMAN, *supra* note 33, at 35-39.

50. LA PUMA & SCHIEDERMAYER, *supra* note 35, at 3; John A. McClung et al., *Evaluation of a Medical Ethics Consultation Service: Opinions of Patients and Health Care Providers*, 100 AM. J. MED. 456, 456 (1996). Indeed, Buchanan suggests that one of bioethics structures' significant roles is to provide healthcare professionals a means of challenging a surrogate's decision as inconsistent with the healthcare professional's view of the patient's best interests. Allen E. Buchanan, *Limitations on the Family's Right to Decide for the Incompetent Patient*, in

who have written about bioethics committees – and particularly those who discuss the desirability of a consultation/mediation process – urge that all healthcare facilities adopt the practice of permitting the patient or a family member to call for a consultation.⁵¹ Ideally the facility should engage in outreach to ensure that patients and families are aware of the availability of bioethics consultations.⁵²

Once a consultation has been requested, the question arises of who should participate. It is fundamental that the patient, if competent, be permitted to do so.⁵³ Furthermore, even patients who are not fully competent to make a treatment decision should be included to the maximum extent possible whenever they have some cognitive capacity.⁵⁴ If there is a legal guardian or a patient-appointed surrogate, that person should participate.⁵⁵ The healthcare personnel involved in caring for the patient are also necessary participants.⁵⁶

If the consultation/mediation is to achieve its goals, scholars all

INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING, *supra* note 5, at 209, 211-16.

51. HAFEMEISTER & HANNAFORD, *supra* note 31, at 79-80; Fletcher & Moseley, *supra* note 34, at 99. In contrast to the earlier study by Youngner (Stuart Youngner et al., *A National Survey of Hospital Ethics Committees*, 11 CRITICAL CARE MED. 902 (1983)), McGee et al. found in 2001 that over ninety percent of responding hospitals permitted patients, family members, nurses, and hospital staff as well as physicians to request a consultation. See McGee, *supra* note 30, at 62.

52. FLA. BIOETHICS NETWORK, *supra* note 28, at 19.

53. See, e.g., Glenn Cohen, *Negotiating Death: ADR and End of Life Decision-Making*, 9 HARV. NEGOT. L. REV. 253, 296 (2004). Ordinarily, the consultation cannot proceed without a competent patient's consent. The healthcare providers might, however, seek ethics guidance on certain questions that are essentially medical in nature without the patient's approval, if they do so without identifying the specific patient involved. This exception, however, never includes decisions whether to withdraw life-sustaining treatment.

Bioethics committees (in contrast to consultants) should and ordinarily do involve the patient or family in their clinical case review processes. Again, when they do not, because they are acting only as a source of advice to the healthcare personnel, it is crucial that this role be cabined and any such advice not be accorded special weight in a dispute with the patient or family. Cf. Wolf, *supra* note 28, at 822-24.

54. Greg A. Sachs & Mark Siegler, *Guidelines for Decision Making When the Patient Is Incompetent*, 6 J. CRITICAL ILLNESS 348, 348-49 (1991) (noting that the issue is not legal competency, but more concrete and specific capacities to understand and communicate); see also HAFEMEISTER & HANNAFORD, *supra* note 31, at 81-83; cf. *In re Guardianship of Kowalski*, 478 N.W.2d 790, 793 (Minn. Ct. App. 1991) (taking into consideration the patient's expressed wishes regarding future care, although she was severely disabled and not legally competent). This caveat is, of course, inapplicable to patients in a coma or a PVS.

55. See Robert M. Veatch, *Advice and Consent*, HASTINGS CTR. REP., Jan.-Feb. 1989, at 20 (arguing that discussion in the absence of the surrogate or patient is "unacceptable").

56. As one author notes, the consultant should particularly seek to involve the nurses. Unlike attending physicians, nurses frequently provide: (1) insight into treatment's impact on the patient's day-to-day experiences; (2) advocacy for consideration of the patient's physical condition; and (3) an ability to communicate more comfortably with the family. See Bernard Lo, *Behind Closed Doors*, 317 NEW ENG. J. MED. 46 (1987).

assume or assert that the patient's family should be included.⁵⁷ Two questions then arise: who should count as family and, thus, as participants, and, more fundamentally, why should family members have this role? The literature on bioethics processes and end-of-life decisionmaking sometimes speaks of "the family" in broad terms, neither carefully parsing particular relationships nor limiting the concept to legally defined relationships. For example, one pair of authors has stated that "the appropriate presumption is that the family . . . is to be the principal decision-maker."⁵⁸ While *formal* family status matters legally, most patients want their close family members included, which for them may be defined *functionally*. By not limiting the process to the legal surrogate, the bioethics consultation can bring in "whomever the individual is most closely associated with."⁵⁹ One scholar suggests a definition of family for this purpose as those who self-identify and become involved at the hospital.⁶⁰

Why involve the family rather than merely the legal surrogate in the consultation process? First, family members are the people who are most likely to have knowledge about the patient's values and preferences and to be concerned about advancing her welfare – in part because family is a place where many people find or construct meaning in their lives. Different family members may bring different perspectives and knowledge of different facts, all of which reflect aspects of the patient's

57. *Id.* Some of the earlier, more physician-deferent literature, when discussing a bioethics committee process, suggested a more limited role for patient and family. See Fost & Cranford, *supra* note 35, at 2869 (family should be permitted to participate in discussions "when they insist upon it"). See generally LA PUMA & SCHIEDERMAYER, *supra* note 35.

58. BUCHANAN & BROCK, *supra* note 22, at 136; see also Steven A. Newman, *Treatment Refusals for the Critically and Terminally Ill: Proposed Rules for the Family, the Physician and the State*, 3 N.Y.L. SCH. HUM. RTS. ANN. 35, 49-50 (1986) (stressing the need for engaging the family).

59. BUCHANAN & BROCK, *supra* note 22, at 136.

60. HAFEMEISTER & HANNAFORD, *supra* note 31, at 56; see also Jacqueline J. Glover, *Should Families Make Health Care Decisions?*, 53 MD. L. REV. 1158, 1160 (1994) (suggesting that the boundaries of family should be defined by "those relationships that are long-term and characterized by such things as interdependence, dedication, caring, and self-sacrifice"). Those recognized as the surrogate are statutorily defined in a way that privileges formal family relationships. An expanded definition of "family," however, could encompass those whom the individual patient thinks of as her intimates or her "real family." These may include extended family, functional kin, or intimates who are not so recognized by law, regardless of sexual orientation. A consultant need not be as concerned with drawing precise boundaries as a judge who must decide who has the right to participate in litigation.

In a situation unlike *Schiavo*, where the end-of-life problem arises relatively abruptly – for example, after an accident with major head injuries – a balance should be sought between the need, if any, for rapid decisionmaking and the desirability of notifying and involving all close family members, if possible. In a *Schiavo* situation, however, there is no time constraint, and thus the consultant should work with those present to determine what other family members the patient would wish to have involved and should then invite them to participate.

own history and views. Thus, including them is likely to make for a better decision in terms of the underlying criteria of furthering the patient's autonomy and welfare.⁶¹ Second, "most Americans want the decisions about their care, upon their incapacity, to be made for them by family and physician, rather than by strangers or by the government."⁶² Such an inclusive process is consistent with most patients' expectations.⁶³ In a study of competent elderly patients, many indicated that they wanted their spouses or adult children to serve as their surrogates, but they also wanted the surrogate to make treatment decisions *together with* other close family members.⁶⁴ Finally, bringing a full range of family members into the process can enhance the outcome's acceptability and deter litigation.

Having determined that a consultation will occur, and who the participants will be, the next issue is what will happen during the consultation. The ultimate goal is to bring the parties to a consensus, if possible, regarding an appropriate resolution. The process of getting there may take various forms: the consultant can seek to bring all the interested parties into a single discussion or engage in a series of consultations with different "players."⁶⁵ Similarly, there is no fixed rule about where to hold the discussions or the degree of formality.

The process should reflect the somewhat hybrid nature of a consultation/mediation. While the process resembles a mediation in some ways, particularly the consultant/mediator's relatively non-directive role,

61. Duncan Joseph Moore, *Medical Surrogacy Mediation: Expanding Patient, Family, and Physician Rights and Reformulating the Virginia Health Care Decisions Act*, 10 VA. J. SOC. POL'Y & L. 410, 435-36 (2003).

62. *In re Guardianship of Lawrance*, 579 N.E.2d 32, 39 (Ind. 1991).

63. There are people who do not wish to have some or all of their family members, including those who would be recognized as the surrogate under governing statutes, participate in deciding whether they should continue to receive lifesaving medical treatment. It would, however, be legally problematic for the healthcare professionals or consultant to exclude those whom the law includes. Those who desire such exclusion can do so by clearly expressing these wishes – either as part of an advance directive or, if they retain some communicative capacity, at the time the issue is under consideration. When the patient seeks to exclude someone who is not the legally recognized proxy, her wishes should ordinarily be honored. Without such direct evidence, consultants might sensibly hesitate to exclude family members from the process, although a judge might decide to prefer the positions articulated by non-kin intimates over those of legal family based on sufficiently clear evidence of the patient's views and life choices. See James A. Becker, Note, *Healthcare Surrogacy Laws: Implications for Gay and Lesbian Families*, 35 U. LOUISVILLE J. FAM. L. 97, 112-14 (1996) (discussing the court's preference in *In re Guardianship of Kowalski*, 478 N.W.2d 790 (Minn. Ct. App. 1991), for Kowalski's long-term lesbian lover rather than her father as guardian).

64. Dallas M. High, *All in the Family: Extended Autonomy and Expectations in Surrogate Health Care Decision-Making*, 28 GERONTOLOGIST 46, 49-50 (1988) (emphasis supplied).

65. For example, DUBLER & LIEBMAN, *supra* note 33, at 52, 55-56, suggest a meeting at an early stage with the healthcare team to learn the medical facts and to help determine which healthcare professionals ought to participate in later discussions with the family.

it also differs significantly from classic mediation. The person for whom the outcome is most important, the patient, often cannot participate. The mediator/consultant has a continuing relationship with the healthcare personnel, while patients and families are unlikely to participate in such a process more than once.⁶⁶ Deciding not to decide is not an option.⁶⁷ This hybridity requires awareness of the ways in which the advantages and disadvantages of consultation/mediation may counter or reinforce each other.

Substantively, these discussions should focus on obtaining and sharing, first, the needed information about the patient's condition, prognosis, and treatment options, and then information about the patient's wishes and values. This involves facilitating discussions among and between the healthcare personnel, the patient, proxy, and family. Each of those discussions can present challenges.

As to the medical facts, the attending physician and other healthcare professionals will be the most knowledgeable. In the simplest case, these people agree, and the facts are clear. The consultant/mediator may nonetheless have to play an active role in ensuring that the medical facts are presented to the lay participants in a way they can understand. This requires recognizing and responding to both the patient/family's lack of familiarity with medical concepts and terminology and the situation's emotional intensity, which may make it difficult for the participants to hear and understand.⁶⁸ Sometimes what seem to be irrevocable conflicts among some or all of the participants have "their origins in misperceptions, misunderstandings, and miscommunication," which may be resolved by a trained bioethics consultant's intervention.⁶⁹

In many situations, however, even where the healthcare professionals are in agreement, they do not know, or at least know with a great deal of certainty, what the medical facts are. They may agree that a particular treatment is unlikely to improve the patient's condition, or even what the probabilities of success are. But probabilistic facts may be especially difficult to communicate to patients and their families, who might find it extraordinarily difficult to integrate such facts into the task

66. Thus, the healthcare professionals may possess some undeserved procedural advantages that accrue to "repeat players" in litigation and arbitration. See, e.g., Marc Galanter, *Why the "Haves" Come Out Ahead: Speculations on the Limits of Legal Change*, 9 LAW & SOC'Y REV. 95, 97 (1974); Carrie Menkel-Meadow, *Do the "Haves" Come Out Ahead in Alternative Judicial Systems?: Repeat Players in ADR*, 15 OHIO ST. J. ON DISP. RESOL. 19, 20 (1999).

67. These are among a long list of distinctions set out in DUBLER & LIEBMAN, *supra* note 33, at 21-31.

68. Nancy N. Dubler, *Heroic Care Cases: When Difficult Decisions About Care Are Near, Mediation Can Help Bridge Communications Gap*, 5 DISP. RESOL. MAG. 7, 8 (1999).

69. Sachs & Siegler, *supra* note 54, at 356; see also Dubler, *supra* note 68, at 7; Lo, *supra* note 56, at 2.

of choosing whether to withhold or withdraw treatment.⁷⁰ Nonetheless, since “treatment decisions for the severely, hopelessly ill turn not merely on medical data but on moral and ethical values” as well, the degree of medical certainty must be clearly communicated if patient, proxy, and family are effectively to make choices.⁷¹ Finally, the healthcare professionals may disagree about the patient’s diagnosis, prognosis, or treatment options. Despite the hopes of the proponents of evidence-based medicine, most clinical medicine cannot be reduced to irrefutable answers determined by computers.⁷² In such situations, patient and family may already have heard conflicting stories from different members of the treatment team. Compounding the problem of unclear communication, healthcare professionals are naturally discomforted when they are unable to determine the medically “correct” answer and may either avoid difficult conversations or assert greater confidence and precision in their diagnosis or prognosis than is warranted.⁷³ A skilled consultant/mediator must attempt to overcome these difficulties so that the parties can reach a common understanding of what they do or do not know.⁷⁴ One of the most important roles for the bioethics consultant during this process is to help the parties share their knowledge, so that the decision will reflect, as best as possible, the correct “facts.”⁷⁵

The consultant/mediator must also work with the lay participants to help them sufficiently understand the medical situation. The bioethicist should recognize the complex interrelationship between facts and values. Patients and family members often perceive the medical facts through a scrim of their values and goals. As Dr. Cranford once noted, for example, people’s religious or moral views on when artificial nutrition and hydration is appropriate may affect their willingness to accept the healthcare professionals’ presentation of the medical facts regarding

70. See Sachs & Siegler, *supra* note 54, at 349.

71. Newman, *supra* note 58, at 59; see also Ben A. Rich, *Prognostication in Clinical Medicine: Prophecy or Professional Responsibility?*, 23 J. LEGAL MED. 297, 358 (2002).

72. Cf. Cynthia D. Mulrow & Kathleen N. Lohr, *Proof and Policy from Medical Research Evidence*, 26 HEALTH POL., POL’Y & L. 249, 249-50 (2001).

73. See KENNETH W. GOODMAN, *ETHICS AND EVIDENCE-BASED MEDICINE: FALLIBILITY AND RESPONSIBILITY IN CLINICAL SCIENCE* 131 (2003) (“[i]f uncertainty is an unavoidable part of clinical practice, then it becomes deceptive not to acknowledge” that to patients).

74. The consultant/mediator should assist the healthcare professionals to communicate effectively and to recognize when they are not being heard or understood. In one study of consultations, one-third of the patients or families thought that the consultation had not been helpful in facilitating communication, while the healthcare personnel rarely perceived this as a problem. McClung et al., *supra* note 50, at 456.

75. Getting the medical facts right at this stage is particularly valuable since the alternative, if the dispute ends up in court, is having them determined by a judge, almost certainly without medical training.

the patient's condition.⁷⁶

The role of the patient and family is not merely to hear and understand what the healthcare professionals say. In determining the patient's values and wishes, and in choosing what course to take, the patient, proxy, and family should play the lead role, with the healthcare professionals in a supportive one.⁷⁷ To ensure that this happens, the consultant must be aware of the dynamics and structure of the consultation process. The parties are differently situated in terms of their relevant knowledge, and various structural and personal attributes give them more or less power in this setting.⁷⁸ In particular, the healthcare personnel may too easily dominate the discussion and impose their values as to the correct outcome. Generally, the healthcare personnel are more familiar with the language of bioethics and medicine; they are less emotionally distraught; they are more advantaged by class, gender, and ethnicity than patient or family; and physicians tend to expect and receive a degree of deference from patients and families in their interactions.⁷⁹ Consultant/mediators must use their training and insight to recognize and counter these dynamics.⁸⁰ They must ensure that the patient's and family's voices are effectively heard and that deference to physicians is limited to those issues as to which it is ethically appropriate.⁸¹

76. Ronald Cranford, *Facts, Lies and Videotapes: The Permanent Vegetative State and the Sad Case of Terri Schiavo*, 33 J.L. MED. & ETHICS 363, 364 (2005) ("These witnesses who stated that Ms. Jobes was able to respond to requests or commands were not giving false testimony under oath. Their sincere opposition to the withholding of nutrition in any patient . . . have [sic] caused them to see signs of intelligence where no such intelligence exists." (quoting *In re Jobes*, 510 A.2d 133 (N.J. 1986))); see also Dubler, *supra* note 68, at 7.

77. DUBLER & LIEBMAN, *supra* note 33, at 28-29; Hoffmann, *supra* note 33, at 859; Newman, *supra* note 58, at 48-49. The process described here thus differs somewhat from the consultation process set out in LA PUMA & SCHIEDERMAYER, *supra* note 35, at 17. Those authors call for the attending physician to lead the meeting among the family "since he or she is primarily responsible for the patient's care" and seem comfortable with a form of shared decisionmaking that will reflect, *inter alia*, "the doctor's personal value system." *Id.* at 42.

78. See generally PHYLLIS BECK KRITEK, *NEGOTIATING AT AN UNEVEN TABLE: DEVELOPING MORAL COURAGE IN RESOLVING OUR CONFLICTS* (2d ed. 2002) (explicating the various ways in which people can exercise dominance or power over others and techniques to recognize and combat these facts); Cohen, *supra* note 53.

79. "The power imbalance in a hospital setting comes from many sources: the difference in level of knowledge and expertise between most patients and the treatment team, the highly technical and unfamiliar physical setting, and the imperfectly allied interests of the patient and the treatment team members." Dubler & Liebman, *supra* note 41, at 36; see also DUBLER & LIEBMAN, *supra* note 33, at 11.

80. See, e.g., KRITEK, *supra* note 78, at 36 (recognizing the untoward tendency for physician preferences to prevail). For example, physicians may resist a process that treats family and proxy as their equals. The mediator should acknowledge this discomfort without yielding to a dynamic that reinforces patterns of domination and deference.

81. See Orentlicher, *supra* note 5, at 1282 (discussing the conflict between patient and physician values, with the latter often dominating). LA PUMA & SCHIEDERMAYER, *supra* note 35, at 18-19, correctly note that where the patient is able to articulate his or her goals, these goals –

Difficulties in ensuring a productive dialogue, in which everyone can effectively participate, might also arise as a result of family dynamics. The consultant should be able to recognize and manage interpersonal dynamics within a family in conflict. Sometimes those intrafamily conflicts reflect long-standing issues. What might at first appear to be disagreements about what should be done, or what a patient would want done, regarding the continuance or withdrawal of medical treatment could instead be a displacement of issues in a long-running family drama.⁸² Some people never reconcile themselves to what they perceive as the unworthy and inappropriate person their child has married. In *Schiavo*, for example, by the time the case was litigated, the conflict had permeated the entire relationship between Michael Schiavo and his in-laws. It could be traced back at least as far as their disagreements over the appropriate allocation of the malpractice lawsuit settlement Terri Schiavo received in 1993.⁸³ In such situations, the bioethicist's job is more difficult.⁸⁴ Nonetheless, he or she may be able to persuade the family members to focus on the immediate issues of the patient's condition, wishes, and best interest, while setting aside their broader disputes.

There are also difficulties that can arise from different communicative styles and personalities within the family. Some participants may be more assertive or less concerned with ensuring that everyone is heard and that relationships remain civil; absent a countering response by the mediator, they may dominate the discussion.⁸⁵ Other participants may

rather than any conflicting family wishes – should be implemented. In that situation, the consultant should seek to focus the family on the patient's wishes. The consultant must also, however, be sensitive to acknowledging his own limitations: it is not necessarily true that consultants (or judges or mediators) will be better than the family at accurately identifying the patient's goals. This is a particular risk where the consultant does not make a sufficient effort to listen to the family. Cf. Fletcher & Moseley, *supra* note 34, at 109 (noting that in one case the consultant dealt only with the medical personnel, not the competent patient who was seeking withdrawal of artificial nutrition and hydration, and "strongly [took] sides in an ethics controversy with two morally acceptable options").

82. HAFEMEISTER & HANNAFORD, *supra* note 31, at 86; Hoffmann, *supra* note 33, at 837-38; see also George J. Annas, "Culture of Life" Politics at the Bedside – The Case of Terri Schiavo, 352 NEW ENG. J. MED. 1710, 1714 (2005) ("Decision making near the end of life . . . can exacerbate unresolved family feuds . . .").

83. WOLFSON, *supra* note 8, at 9-10. One rather suspects, though nothing in the record so states, that the money was not the only point of contention. It is impossible to reconstruct, through the increasingly hardening positions, if there had ever been a time during this psychodrama when the family relationships were civil enough to permit an effective bioethics intervention.

84. The bioethicist will thus need to be particularly aware of whether some family members are seeking to implement extraneous agendas that conflict with the patient's wishes. If so, he or she needs to avoid decisions that may unethically resolve intrafamily conflicts at the expense of patient autonomy.

85. LA PUMA & SCHIEDERMAYER, *supra* note 35, at 19. Women are more frequently concerned with maintaining relationships and are, thus, often disadvantaged in a process where the

disagree but be afraid to say so. The mediator must be able to distinguish between those who seek only to win and those who seek solutions to conflict.⁸⁶ He or she must also be aware of the emotional nature of the issues and emotion's effect on the communication process. People confronting a loved one's illness or death may respond with grief, withdrawal, and anger; a whole gamut of emotions that others may perceive as "inappropriate."⁸⁷ The consultant/mediator must recognize and seek to overcome the desire of some healthcare or lay participants to restrict the issues, or the language in which the issues are discussed, in ways that silence others.⁸⁸ Ideally, the process will be designed to ensure that all the participants have, and view themselves as having, a voice in the process.⁸⁹

To ensure that the discussion and the ensuing decision fairly reflect the participants' voices and focus on the patient's wishes insofar as those can be discovered, the consultant/mediator must be sensitive to his or her role. While he or she is not a member of the healthcare team, the consultant/mediator is chosen by, and perhaps is an employee of, the healthcare institution. The consultant/mediator must make every effort to be, and to be seen as, a neutral party rather than as another voice of the institution or the medical profession.⁹⁰

Once the participants have developed a common knowledge base regarding the patient's condition, values, and wishes, a decision should, ideally, be reached regarding the continuance or withdrawal of lifesaving medical treatment. There is debate in the literature over what role the consultant should play in reaching that decision. There are a variety of possible roles, ranging from authoritarian to purely facilitative.⁹¹ At one extreme, the consultant is authorized to determine and impose the

mediator is entirely neutral. This effectively reinforces, rather than counters, the "uneven table." See Martha Fineman, *Dominant Discourse, Professional Language, and Legal Change in Child Custody Decisionmaking*, 101 HARV. L. REV. 727, 730 (1988); Trina Grillo, *The Mediation Alternative: Process Dangers for Women*, 100 YALE L.J. 1545, 1556 (1991).

86. KRITEK, *supra* note 78, at 258-60.

87. Cf. Grillo, *supra* note 85, at 1572-73 (women's anger in child custody mediations is sometimes seen as inappropriate by mediators and the women themselves may obscure their true feelings and desires in the attempt to persuade the mediator that they are "good people").

88. KRITEK, *supra* note 78, at 36-37, 216-17; Grillo, *supra* note 85, 1572-73.

89. Dubler, *supra* note 68, at 8; Wolf, *supra* note 28, at 856-58; cf. Grillo, *supra* note 85, at 1550 (noting the importance of allowing people to speak in their "authentic voices").

90. ASBH, *supra* note 31, at 29; HAFEMEISTER & HANNAFORD, *supra* note 31, at 80; cf. Grillo, *supra* note 85, at 1587 (warning of the need for a mediator to be aware of, and to struggle against, her own inevitable particularity).

91. ASBH, *supra* note 31, at 5, uses this terminology. While the text focuses on the range of positions that scholars have advocated and ethics committees have adopted, the law may play a role here in defining what ethics consultants or committees may do, or at least what role would insulate the decision from undue judicial oversight. See Annas, *supra* note 19, at 885 (suggesting that courts do not fully trust families but do not want to decide for themselves). Ethics

right outcome.⁹² Similar, but less extreme, is the view that the ethics consultant should offer expert advice, which would carry a strong presumptive force.⁹³ Another position would allow the ethics body to formulate a recommendation, but would leave the decision in the healthcare professionals' hands.⁹⁴ At the other extreme, the consultant's role could be entirely facilitative (i.e., to "identif[y] and analyz[e] the nature of the value uncertainty and facilitat[e] the building of consensus" without injecting his or her own views).⁹⁵ A committee or consultant might adopt different roles in different situations – sometimes providing a specific opinion of the most ethically correct answer, sometimes indicating the range of ethically permissible outcomes, and sometimes facilitating the decision by others. When committees or consultants act in this fashion, it is important that they clearly distinguish which role they are taking in each particular instance. Professor Wolf raises concerns about role confusion, both by the committee and by others, including judges, who are influenced by what the committee does. She concludes that the only way to avoid this risk is to require that the committee always follow the same due process protective model.⁹⁶ Another way to minimize this problem would be to assign different roles to different entities: a consultant/mediator could help the participants develop a range of ethi-

committees with fairly directive authority are one means of screening the court from ultimate authority while not giving it to the family.

92. See Aulisio, *supra* note 28, at 10 (defining the "authoritarian" approach). None of the examined sources advocated this position. See, e.g., FLA. BIOETHICS NETWORK, *supra* note 28, at 18 (explicitly rejecting the idea that ethics committees should make binding decisions); see also George J. Agich & Stuart J. Youngner, *For Experts Only? Access to Hospital Ethics Committees*, HASTINGS CTR. REP., Sept.-Oct. 1991, at 17 (noting the theoretical possibilities of mandatory or optional invocation of the consultative process and mandatory or optional acceptance of the ethics committee's recommendation). Some bioethics committees have, however, followed a mandatory approach, pressing for one outcome when others are ethically permissible and excluding the patient's proxy from process. See Fletcher & Moseley, *supra* note 34, at 109-12 (discussing activities of bioethicists in the *Bouvia* and *Baby K* cases).

93. See, e.g., Agich & Youngner, *supra* note 92, at 21 (indicating that an ethics committee's purpose is "to assure a morally sound solution to practical conflicts, dilemmas, or problems in clinical care"); Ruth Macklin, *Consultative Roles and Responsibilities*, in INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING, *supra* note 5, at 158 (suggesting that the ethics committee's role is "to assist in efforts to arrive at morally right solutions to hard choices in clinical decisions"). This view tends to support the position that courts should ordinarily defer to the conclusions of an ethics committee. See Lo, *supra* note 56, at 46 (critiqued in Wolf, *supra* note 28, at 810).

94. Unsurprisingly, this was the recommendation of the AMA. See AMERICAN MEDICAL ASSOCIATION, GUIDELINES FOR ETHICS COMMITTEES IN HEALTH CARE INSTITUTIONS § 1 (1984) [hereinafter AMA GUIDELINES].

95. ASBH, *supra* note 31, at 6; see also DUBLER & LIEBMAN, *supra* note 33, at 8 (defining mediation as a "private, voluntary, informal process in which an impartial third person facilitates a negotiation between people in conflict and helps them find solutions that meet their interests and needs").

96. See Wolf, *supra* note 28, at 858.

cally appropriate outcomes, while the bioethics committee, if asked, could provide its own view on the ethics of a particular proposed action.

Most contemporary scholars suggest a role that is closer to the facilitative end of the spectrum, but tempered by the authority and obligation to invoke ethical and other constraints as needed.⁹⁷ This reflects, in part, the bioethical understanding that respecting patient autonomy is a core value and that the patient, surrogate, and family are best situated to assess what outcome best advances the patient's autonomy. It also embodies a recognition that in most of these situations of tragic choice, there is more than one morally acceptable outcome.

Thus, the most crucial ethical role for the consultant may be to ensure an adequately informed and thoughtful process, rather than to guide the parties to a particular outcome.⁹⁸ The consultant/mediator should be sensitive to the effects of religious, cultural, and ethnic identities, which may be associated with distinct views regarding end-of-life decisionmaking.⁹⁹ For example, where the patient and family have particular views on the value of life or the meaning of suffering, those views should be taken into account even if the consultant and healthcare personnel would not have adopted similar views for themselves.¹⁰⁰ Reasonable minds could differ over the value of continuing the life of a person who is severely disabled, subjected to severe incursions on his or her dignity, and in pain that cannot be fully ameliorated by palliative care. In such situations, it is the patient's values – as expressed by those who knew her best – that should be followed.¹⁰¹

The consultant/mediator's role is not, however, simply to facilitate

97. See, e.g., ASBH, *supra* note 31, at 6-8; DUBLER & LIEBMAN, *supra* note 33, at 36-37; Jonathan Moreno, *Can Ethics Consultation Be Saved?*, in *ETHICS CONSULTATION: FROM THEORY TO PRACTICE*, *supra* note 28, at 23-24.

98. While it is important not to impose a particular outcome, a good consultant/mediator can help develop an array of acceptable outcomes and, where possible, find those which create value rather than simply claiming value for one particular party. See KRTEK, *supra* note 78, at 258-61; Carrie Menkel-Meadow, *Whose Dispute Is It Anyway?: A Philosophical and Democratic Defense of Settlement (In Some Cases)*, 83 GEO. L.J. 2663, 2672-74 (1995).

99. Cf. Haripriya M. Mannan, *Death as Defined by Hinduism*, 15 ST. LOUIS U. PUB. L. REV. 423, 425-27 (1996) (explaining Hindu views of religiously permitted self-willed death and consequences of the death of the physical body).

100. Interview with Professor Stephen Sapp, Univ. of Miami Dep't of Religious Studies, in Coral Gables, Fla. (Oct. 11, 2006). For a discussion on the importance of acknowledging religion's role in shaping the views of patients and families, see Kathleen M. Boozang, *An Intimate Passing: Restoring the Role of Family and Religion in Dying*, 58 U. PITT. L. REV. 549 (1997). The consultant/mediator must be aware of his own values so he can work to avoid imposing them. Cf. Grillo, *supra* note 85, at 1592-93 (warning that mediators should not impose their own view of what fairness requires but, instead, allow the parties to come to their own views within the range of those that are legally acceptable).

101. See Wolf, *supra* note 28, at 839-42.

any decision; it is to facilitate a decision that is morally acceptable.¹⁰² The consultant should seek to derail an unethical decision¹⁰³ by exercising what might be called constrained deference. Some of these constraints are ethical. There may also be different, though often overlapping, constraints, based in institutional policy or law.¹⁰⁴ It is important to recognize that the law does not require that the consultation process' outcome be identical to one that a court could have imposed.¹⁰⁵

A decision may raise ethical warning signals if, for example, it seems to impose substantial suffering on the patient without a clear indication that this is the patient's wish. Such warning signals may also arise if there is reason to believe that the family members are acting based on their own concerns, distinct from those they believe the patient had or has. In such situations, the consultant/mediator should seek to shift the process to one that will lead to morally acceptable outcomes.¹⁰⁶ If this cannot be done, the consultant/mediator can encourage the parties to participate in alternative, more directive processes, and "[a]s a last resort, involved parties may turn to the courts."¹⁰⁷

102. Aulisio, *supra* note 28, at 13.

103. Cf. Fletcher & Moseley, *supra* note 34, at 103-04 (consultants should provide decisionmakers information on morally acceptable options). Even Dubler and Liebman, who strongly advocate a largely mediative process, note that the mediator may have to shift to a more directive role if the process appears to be "leading to an ethically unsupportable outcome." DUBLER & LIEBMAN, *supra* note 33, at 13.

104. For example, if the healthcare facility has a religious identity, this may constrain the decisions that may be implemented at that institution. The consultant should make the parties aware of this, but should also assure them of the institution's obligation to seek to facilitate, if needed, the transfer of the patient to an institution without such constraints. See AMA GUIDELINES, *supra* note 94, § 4. The institution's attorney or risk manager has a role, distinct from that of the bioethics consultant, in ensuring that these constraints are followed.

105. In general, even when a private decision reached by the concerned parties is subject to court approval, that decision may embody terms that a judge could not impose. For example, where it is impractical to provide the funds generated by a class settlement directly to the class members, the settlement agreement can provide that the sum defendants pay will go to a fund to benefit the class members' interests. However, a judge could not *sua sponte* impose such a term. See, e.g., *Eisen v. Carlisle & Jacquelin*, 479 F.2d 1005, 1012 (1973), *aff'd on other grounds*, 417 U.S. 156 (1974). Similarly, the parties to a dissolution of marriage in Florida can agree that support will be provided for the children's college education and that agreement can be memorialized in an enforceable judgment, though the court cannot order such post-majority support. *Holmes v. Holmes*, 384 So. 2d 1295, 1296 (Fla. 2d Dist. Ct. App. 1980). Hoffmann, *supra* note 33, at 870, suggests that a consultant/mediator must reject a solution if it is contrary to state law. While this is true in one sense, it is wrong insofar as it suggests that the law limits the consensual, consultative process outcomes to those available to a court.

106. See, e.g., Aulisio, *supra* note 28, at 13-14 (explaining that part of the consultant's job is to ensure that the decision reached by the family and medical personnel falls within the range of morally acceptable options set by the guiding bioethical principles).

107. ASBH, *supra* note 31, at 8.

IV. THE LITIGATION ALTERNATIVE

The consultant/mediator must recognize the consultative process' limits. Patients with communicative capacity, close family members, or even healthcare professionals may choose not to participate. People may be unwilling to accept undisputed relevant facts or may legitimately disagree about what those facts are and, thus, about what should be done. They may have irreconcilable ethical views about the appropriate outcome, even in light of undisputed facts. In such situations, court intervention may be unavoidable. Note, however, that court processes need not, and ought not, be invoked absent such a dispute.¹⁰⁸ In particular, the costs of litigation should not be endured simply because the healthcare facility, though agreeing substantively with the proposed outcome, seeks judicial intervention to protect itself against the possibility of civil or criminal liability.¹⁰⁹

In Florida, family members, the healthcare facility, the attending physician, or "any other interested person who may reasonably be expected to be directly affected by the surrogate or proxy's decision" can file a lawsuit to challenge such a decision.¹¹⁰ The healthcare professionals might legitimately bring a challenge if they thought the surrogate's decision were contrary to the patient's clear wishes, if there were a dispute between parties with equal claim to speak for the patient,¹¹¹ if there were specific reason to think the surrogate was acting with an improper motive,¹¹² or if the treatment demanded was medically futile.¹¹³

108. This is clearly the rule in Florida, and courts in several other jurisdictions have also called for it. See, e.g., *In re Spring*, 405 N.E.2d 115, 122 (Mass. 1980); *In re Jobes*, 529 A.2d 434, 449 (N.J. 1987); *In re Nemser*, 273 N.Y.S.2d 624, 631 (N.Y. Sup. Ct. 1966).

109. As Sachs & Siegler, *supra* note 54, at 353, point out, "the fears of criminal and civil liability [for withholding treatment] are enormously out of proportion to the actual risks Almost all court cases of note have involved patients and families suing for the discontinuation of treatment, *not* suing because treatment was stopped inappropriately."

110. § 765.105, FLA. STAT. (2006). On any plausible interpretation, the category in quotations in the text would not include the governor, the legislature, the president, or a non-profit organization with an ideological agenda. These entities had a role in the *Schiavo* case only because those who were statutorily authorized had chosen to bring the case to the courts.

111. Cf. *In re Doe*, 418 S.E.2d 3, 4 (Ga. 1992); *Couture v. Couture*, 549 N.E.2d 571, 572 (Ohio Ct. App. 1989) (medical facility took the case to court for a legal determination of the correct cause of action because patient's parents had different views of what was in the patient's best interest).

112. *John F. Kennedy Mem'l Hosp. v. Blutworth*, 452 So. 2d 921, 926-27 (Fla. 1984). Since close family will typically be the patient's chosen heirs, this cannot be sufficient to create a cognizable conflict. But cf. Aaron N. Krupp, *Health Care Surrogate Statutes: Ethics Pitfalls Threaten the Interests of Incompetent Patients*, 101 W. VA. L. REV. 99, 111-14 (1998) (suggesting that monetary benefit from patient's death should require court intervention).

113. Ronald E. Cranford, *Helga Wanglie's Ventilator*, HASTINGS CTR. REP., July-Aug. 1991, at 23-24 (approvingly describing a situation where a facility sought court permission to refuse to

The patient's family is the other major category of persons who are specifically authorized to seek judicial intervention. Judicial intervention is appropriate when there is "unresolvable disagreement among competent adult members of the family about the correct decision."¹¹⁴ The relevant Florida statute identifies the bases that must be stated in such a petition.¹¹⁵ Other family members may disagree with the proxy's assessment of the patient's medical condition and prognosis; they may believe that there is insufficient evidence that the patient wished to have treatment withdrawn. A family conflict, however, should not be considered irresolvable until significant efforts have been made to resolve it outside the courtroom.¹¹⁶

Court intervention is also authorized (and necessary) when there is evidence of wrongful motives or patient abuse.¹¹⁷ If the participants seem prepared to concur in a decision that raises these concerns, the bioethics consultant can use his or her knowledge and authority to deem such a decision as outside the ethically acceptable range; and if necessary, can encourage the healthcare facility to seek judicial intervention.

Even where litigation occurs, the bioethics consultation is often

provide what they deemed futile services); see also *In re Doe*, 418 S.E.2d at 3, 4. Where "futility" is simply a value judgment regarding quality of life, there is reason to question whether the healthcare professionals should be able to challenge the surrogate or family's choice. Boozang criticizes Cranford on this ground. See generally Boozang, *supra* note 100. Professor David Orentlicher notes the confusion engendered by the use of the term "futility" both for situations in which this is in fact a medical concept, to be determined by healthcare professionals, and those which embody moral-political judgments about the cost of the intervention relative to the expected limited length and quality of life. ORENTLICHER, *supra* note 19, at 144; see also Barbara A. Noah, *Politicizing the End of Life: Lessons from the Schiavo Controversy*, 59 U. MIAMI L. REV. 107, 128-31 (2004) (distinguishing between medical futility and ethical futility or resource allocation).

114. 1 PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMED. & BEHAVIORAL RESEARCH, MAKING HEALTH CARE DECISIONS 183 (1982) [hereinafter PRESIDENT'S COMM'N, MAKING HEALTH CARE DECISIONS]. As the court in *Jobes* noted, "[o]f course, if there is a dispute among the members of a patient's family, the guardian and the physicians, any interested party can invoke judicial aid to ensure that the guidelines we have established are properly followed and that the patient is protected." *In re Jobes*, 529 A.2d 434, 449 (N.J. 1987); cf. Annas, *supra* note 82, at 1714 (noting that when there is disagreement among participants, "the involvement of outside experts, including consultants, ethics committees, risk managers, lawyers, and even courts, may become inevitable").

115. See § 765.105, FLA. STAT. (2006). These statutory bases, of course, overlap only in part with the motivations that might lie behind the decision to invoke the judicial process.

116. See HAFEMEISTER & HANNAFORD, *supra* note 31, at 102-03 (resort to courts is needed when "the parties appear to have become irrevocably deadlocked"). See generally DUBLER & LIEBMAN, *supra* note 33 (promoting bioethics mediation, in part, as a means to reduce risk of litigation).

117. *John F. Kennedy Mem'l Hosp. v. Bludworth*, 452 So. 2d 921, 926-27 (Fla. 1984); see also 1 PRESIDENT'S COMM'N, MAKING HEALTH CARE DECISIONS, *supra* note 114, at 183 (noting that the decision of the surrogate/family member can be challenged if there is "evidence of physical or psychological abuse or neglect of the patient by the family, evidence of bias against the patient's interests due to conflicting interests, or evidence that the family intends to disregard the patient's advance directive").

beneficial. The bioethicist's prior involvement may clarify positions, narrow the range of dispute, and perhaps lower the temperature of the conflict. If litigation occurs, however, the court should independently decide the matter based on the relevant legal standards. Even where the consultation/mediation process is as sensitive to due process as it should be, the fact that a consultant/mediator found a particular outcome morally acceptable (or even more morally acceptable than any alternative) is not a determination entitled to judicial deference. The consultant's role is to decide what is ethical; the judge's role is to decide the quite distinct issue of what is legal.¹¹⁸

If such consultations resolve many disputes, improve the decisional climate – even in disputes that cannot be resolved – and rarely lead to a worse outcome than would have occurred in their absence, then it would be reasonable to expend at least a moderate amount of resources to increase the frequency and quality of such processes.

V. AN (UNFORTUNATELY) HYPOTHETICAL SCENARIO

We know that in the real *Schiavo* case, Michael Schiavo and the Schindler family were in conflict on five distinct relevant questions. These comprised three factual issues: (1) Was Terri Schiavo in a PVS? (2) What was her prognosis? And, (3) what were her treatment preferences? The conflict also included one conceptual issue: (4) was her feeding tube a medical treatment or ordinary nourishment? Finally, there was a values question: (5) what was the value of continued life in her then-current state?¹¹⁹ Given these disagreements, even an advance directive would not have avoided the ensuing dispute. We also know that in the *Schiavo* case, the level of distrust, fueled to some unascertainable extent by the legal strangers who later became involved, ultimately made reconciliation or even civility impossible.¹²⁰

As Professor Dresser noted, and as this Article elaborates, “*Schiavo* demonstrates the need for mediation and other dispute resolution procedures to address family disagreements over life-sustaining treatment.”¹²¹ Let us imagine what might have happened if a bioethical intervention

118. See Wolf, *supra* note 28, at 838. Unfortunately, as Wolf notes, some courts do seem inappropriately to defer to the outcome of a bioethics process. *Id.*; see also *In re Spring*, 405 N.E.2d 115, 122 (Mass. 1980) (“[T]he concurrence of qualified consultants may be highly persuasive on issues of good faith and good medical practice.”). This may be understandable since judges are reluctant to take full responsibility for determining the outcome in such difficult situations. See Annas, *supra* note 19, at 885. But to quote former President Nixon, “that would be wrong.”

119. Rebecca Dresser, *Schiavo: A Hard Case Makes Questionable Law*, HASTINGS CTR. REP., May-June 2004, at 8-9.

120. See WOLFSON, *supra* note 8, at 33 n.1.

121. Dresser, *supra* note 119, at 9.

had been offered to the family as soon as the healthcare professionals realized that a disagreement was developing over any of these issues and before positions became so entrenched that hostility seemed almost a goal rather than an undesired byproduct.

A bioethics consultant/mediator who was called in at a sufficiently early stage might have helped the participants communicate about, and possibly agree upon, the factual issues in dispute.¹²² The different positions regarding the medical questions may have stemmed from different understandings of what a PVS is and the characteristics of someone in such a state.¹²³ Many people doubtless found it hard to understand that a PVS is distinct from a coma – that people in a PVS can open and close their eyes, move their bodies, and vocalize, as Terri Schiavo did.¹²⁴ Imagine how much harder it would be for a loving family member to accept this in light of the intense desire to believe that a loved one's condition is not hopeless and that his or her vocalizations are, at some level, an attempt to communicate.¹²⁵ This is, I suggest, particularly likely for parents to whom the helpless patient may evoke the remembered infant whose wordless vocalizations were similarly seen as communicative and harbingers of the infant's growing consciousness of herself and the world around her. The consultant/mediator's knowledge and communication skills might have helped the parents accept the bitter fact that a PVS patient is non-sentient. Alternatively, in conjunction

122. Cf. Lynne Sims-Taylor, Note & Comment, *Reasoned Compassion in a More Humane Forum: A Proposal to Use ADR to Resolve Medical Treatment Decisions*, 9 OHIO ST. J. ON DISP. RESOL. 333, 364 (1994) (suggesting that healthcare professionals who recognize that a conflict exists within the family should invoke a process of bioethics mediation).

123. Note, however, that views on facts are not always "independent variables." The Schindlers seem to have once agreed that Terri Schiavo was in a PVS, but shifted their ground as hostility grew and, perhaps, as the implications of that position for their claim that artificial nutrition and hydration be continued became clearer. See WOLFSON, *supra* note 8, at 33 n.1. Under Florida law, a court can authorize withdrawal of life-sustaining treatment for someone in a PVS, but cannot legally do so if the patient is minimally conscious or in some other severely disabled state not specified in the statute. See § 765.404, FLA. STAT. (2006). In effect, the value question of which kinds of conditions permit the withdrawal of treatment has been answered by the legislature, leaving to the parties or court on this point only the factual characterization.

124. See Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State*, 330 NEW ENG. J. MED. 1499, 1499-1508, 1572-79 (1994) (on the characteristics of a PVS). One of the key diagnostic tools is the inability to engage in "sustained visual pursuit." *Id.* at 1500. The brief moments, highlighted on the widely distributed video clip, in which Terri's eyes appeared to follow a balloon, did not meet this criterion. See Cranford, *supra* note 76, at 366. Similarly, although it seems counterintuitive to those of us without medical training, swallowing saliva is a reflexive behavior and can occur although the person, like Terri Schiavo, lacks the cognitive capacity required to swallow food and water. See WOLFSON, *supra* note 8, at 27-28.

125. See Lori A. Roscoe, Hana Osman & William E. Haley, *Implications of the Schiavo Case for Understanding Family Caregiving Issues at the End of Life*, 30 DEATH STUDIES 149, 156 (2006) (describing how family members frequently misinterpret the reflex activities of patients in a PVS as evidence of cognition or emotional response to the observer).

with the medical personnel, a bioethics consultant could have helped the husband understand (if the facts had warranted) that the patient likely had some minimal consciousness and that he might be projecting through his own pain a belief that her condition was more dire than it actually was.

In terms of the patient's expressed wishes, the bioethicist might have helped the family members accept that each was, in good faith, basing his or her views on what he or she recalled the patient as having once said, on more general understandings of what the patient's beliefs and views were on life and death, or on the relative importance of quality of life versus life itself. Most importantly, the consultant might have brought them to understand that, at least in the absence of a clear, formally articulated advance directive, there is frequently evidence that points in more than one direction and that each of them may have been reading the same congeries of fact through a different lens.¹²⁶

The consultant/mediator might have helped the family members understand that they should try their best to understand what *the patient* believed in regard to the value of continued life in her current state. They could have agreed to disagree on their own views, without finding the other family members' views outside the range of ethical legitimacy.¹²⁷ They might have agreed that the patient, who never faced the question with the salience that all of them were now experiencing, likely did not have as clearly or fully developed a decisional viewpoint as any of them now did.¹²⁸

The consultant/mediator might have helped the participants understand that the characterization of feeding tubes is not a factual question about which the disagreeing family members were intransigently wrong. Rather, it is a frame that inevitably reflects one's moral views about what is acceptable.¹²⁹ The consultant might also have helped the parents

126. The consultant might also have helped them understand how these lenses were the product of their own values and histories, only partly shared by Terri Schiavo.

127. M. Gregg Bloche, *Managing Conflict at the End of Life*, 352 NEW ENG. J. MED. 2371, 2371 (2005). Bloche advocates a non-litigated process precisely because it encourages a conversation about these end-of-life issues among patients, family members, and others. *Id.*

128. Tom Preston & Michael Kelly, *A Medical Ethics Assessment of the Case of Terri Schiavo*, 30 DEATH STUDIES 121, 127 (2006) ("[N]o one can be absolutely certain what Terri would have wanted, or how much thought she gave before her injury to what would have been for her a remote and hypothetical matter."); cf. Mack v. Mack, 618 A.2d 744, 761 (Md. 1993) (McAuliffe, J., dissenting) (noting that it would be rare for healthy young adults to have any settled, articulated views on what should happen if they were to be in a PVS).

129. Many caregivers and members of the general public construe nutrition and hydration as a form of basic care, like keeping the patient clean and turning her to prevent bedsores, rather than as medical treatment. See DOLGIN & SHEPHERD, *supra* note 23, at 750-51; Joanne Lynn & James F. Childress, *Must Patients Always Be Given Food and Water?*, HASTINGS CTR. REP., Oct. 1983, at 17; see also JOHN KEOWN, EUTHANASIA, ETHICS AND PUBLIC POLICY 215 (2002).

understand – without demanding that they agree with the ethical legitimacy of the position – that Florida law classifies artificial nutrition and hydration as a form of medical treatment and allows withdrawal under certain circumstances, including those that the husband was asserting were true.¹³⁰

Of course, there is no guarantee that at the end of this process the hypothetical family would have concurred on an outcome that all found minimally acceptable, nor is there any guarantee what that outcome might have been. For instance, using the *Schiavo* parties as an example, the Schindlers might have agreed to permit Michael to have the feeding tube withdrawn. Alternatively, Michael might have been persuaded to delay doing so. They might have agreed to a waiting period or additional tests to enhance the chances of an agreement on the underlying medical facts.¹³¹ Finally, the dispute might have continued unresolved and been brought to court. Even in that situation, however, a good faith guided communication process might have mitigated hostilities or induced the parties to keep this a relatively private intrafamily dispute.

VI. THE PROCESS VALUES OF A NON-ADJUDICATIVE APPROACH

The use of a bioethics consultation process has many potential benefits as compared to litigation. I focus at this point on the benefits; in the next section I will examine the extent to which the use of this process as a substitute for litigation might undermine our confidence that the “right” substantive outcome has been reached.

First, the bioethics consultative process is better designed to be iterative. The participants can reach a tentative outcome, which they can alter in response to changes in the underlying facts, such as an unexpected improvement in the patient’s condition in response to a new treatment. While parties can return to court when facts change, the litigation

130. See also *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261, 288-89 (1990) (O’Connor, J., concurring) (noting that artificial nutrition and hydration are constitutionally equivalent to medical treatment); *id.* at 307-08 (Brennan, J., dissenting) (asserting that artificial nutrition and hydration are considered medical treatment by the medical profession and the federal government). Some state statutes, however, do not so treat it, but require greater procedural protections. See Cerminara, *supra* note 18, at 171-73.

As a result of the *Schiavo* controversy, the Starvation and Dehydration of Persons with Disabilities Prevention Act was introduced in the Florida Legislature. It would have distinguished artificial nutrition and hydration from other forms of medical treatment, allowing discontinuance for a currently non-competent patient only if she had explicitly requested this in writing. See Cerminara, *supra* note 18, at 171-73. A similar bill was introduced during the 2006 session. Although neither passed, such legislation may be reintroduced in the future. Interview with Raquel Rodriguez, Counsel to Governor Jeb Bush, in Miami, Fla. (May 10, 2006).

131. Perhaps at this earlier stage, when there was less hostility, Jay Wolfson’s proposal that the parties agree to have Terri Schiavo undergo “swallowing tests,” and the consequences that would follow from the tests’ results, might have been accepted. See WOLFSON, *supra* note 8, at 37.

process – which drives the participants to take firm and sharply dichotomous positions – makes this more difficult.¹³²

Second, the consultative process is less complex, less intimidating, and less costly. As the *Jobes* court noted, in criticizing a requirement that every treatment-withdrawal decision be judicially approved, “[t]he mere prospect of a cumbersome, intrusive and expensive court proceeding, during such an emotional and upsetting period in the lives of a patient and his or her loved ones, would undoubtedly deter many persons from deciding to discontinue treatment.”¹³³ Speed, low cost, and simplicity are of particular value in many end-of-life situations since the alternative is a “judicial proceeding [that] . . . may . . . prolong the physical suffering of the patient and aggravate the distress of a family already confronting the emotional and financial pressures of coping with a serious illness.”¹³⁴ In light of these process advantages, it seems almost gratuitously cruel to require a judicial process when there is no genuine dispute or substantive concern over the legitimacy of the outcome desired by all of the parties.¹³⁵

Third, the consultant-guided process may be better at identifying and elucidating the range of potentially relevant facts and feelings.¹³⁶ A

132. Cohen, *supra* note 53, at 308 (“Traditionally, litigation occurs with two parties, each on one side of the ‘v.’”).

133. *In re Jobes*, 529 A.2d 434, 449 (1987); see also John F. Kennedy Mem’l Hosp. v. Bludworth, 452 So. 2d 921, 925 (Fla. 1984) (warning that process to implement right to refuse treatment “must not be so cumbersome so as to effectually eliminate it”). The Florida Supreme Court reiterated this point in *In re Guardianship of Browning*, 568 So. 2d 4, 15 (Fla. 1990).

134. Mark Fowler, Note, *Appointing an Agent to Make Medical Treatment Choices*, 84 COLUM. L. REV. 985, 995 (1984); see also BUCHANAN & BROCK, *supra* note 22, at 140-41; Stewart G. Pollack, *Life and Death Decisions: Who Makes Them and by What Standards?*, 41 RUTGERS L. REV. 505, 536 (1989) (“[N]o matter how expedited, judicial intervention in this complex and sensitive area may take too long.” (quoting *In re Farrell*, 529 A.2d 404, 415 (1987))).

135. *Cf. In re Spring*, 405 N.E.2d 115, 122 (Mass. 1980) (affirming trial court decision to allow treatment withdrawal where the medical testimony indicated the patient was in great discomfort with no significant hope of improvement and where the judge relied on “the opinion of the ward’s wife of fifty-five years [which] was corroborated by that of the son, and there was every indication that there was a close relationship within the family group, that the wife and son had only the best interests of the ward at heart, and that they were best informed as to his likely attitude”).

136. See Menkel-Meadow, *supra* note 98, at 2669-70 (noting the value of non-adjudicative processes in allowing for emotional catharsis); cf. ROBERT A. BURT, *TAKING CARE OF STRANGERS: THE RULE OF LAW IN DOCTOR-PATIENT RELATIONS* 167 (1979) (stressing the need to acknowledge the complex, painful situation in which all the participants have some responsibility for the decision, rather than seeking to avoid responsibility by projecting the decision entirely on some other person or entity). In a consultation/mediation, the parties can acknowledge that they are considering congeries of facts that might be denominated as substituted judgment, best interests, quality of life, and/or effect on others, while a court will often, in effect, obscure what is in fact happening. See Rebecca S. Dresser & John A. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach*, 17 L. MED. & HEALTH CARE 234 (1989); Thomas G. Gutheil & Paul S. Appelbaum, *Substituted Judgment: Best Interests in Disguise*, HASTINGS CTR. REP., June 1983, at 8-9.

judicial hearing in which all participants seek the same outcome is merely a choreographed formality. Where there is conflict, the evidence is structured by each party to advance a predetermined outcome. By contrast, in a well-run ethics consultation the participants are less likely to be locked into conflicting positions, carefully limited to be internally coherent. The comparative advantage of the consultant-guided process is particularly strong where the relevant facts are unavoidably indeterminate. This is frequently the case regarding the underlying medical facts. Indeterminacy is even more likely when trying to ascertain a now-incompetent patient's views, values, and current interests.¹³⁷

Perhaps most importantly, the goals of a bioethics consultation, unlike litigation, include seeking consensus and reducing the hostility level among the participants.¹³⁸ It can sometimes avoid preliminary wrangling over who should be the proxy decisionmaker by bringing the parties to agreement on the substantive outcome.¹³⁹ It can help create a mutual acknowledgment that other family members have the same ultimate goals of enhancing the patient's autonomy and welfare, even if they disagree about what decision best advances those goals.¹⁴⁰

Consensus and lack of hostility among the family are not only valu-

137. For example, we often have no way of knowing with certainty if the responses of a severely cognitively impaired patient indicate that she feels pain in the same way that we understand pain, yet this might be central to a determination of the patient's wishes or best interests. Interview with Professor Stephen Sapp, Univ. of Miami Dep't of Religious Studies, in Coral Gables, Fla. (May 10, 2006); cf. *In re Conroy*, 486 A.2d 1209, 1217 (N.J. 1985) (noting that it was unclear from the evidence whether Conroy was experiencing pain). A judge may well conclude that she has to "decide" the facts in the course of determining whether a particular outcome is legal; a bioethics process requires that such questions be discussed, but not necessarily answered.

138. "[S]olutions crafted by the parties to a conflict come with a sense of shared ownership that dampens discord." Bloche, *supra* note 127, at 2372; see also Menkel-Meadow, *supra* note 98, at 2674 (non-adjudicated processes facilitate the maintenance of relationships among the parties to a dispute).

139. The avoidance of a dispute over whether, for example, the mother or father should serve as surrogate may itself help create such consensus. Similarly, patients can participate as much as possible under the circumstances without any formal competency determination.

140. In a private process, it is also more likely that the parties can acknowledge that they are facing a "tragic choice." And, by keeping the decision out of the public eye, they may avoid the often irresolvable, destructive, public debate that we saw in *Schiavo*. The surrogate's decisionmaking power, together with that of healthcare professionals and other family members, can be seen as analogous to that of the jury, which Calabresi and Bobbitt refer to as "the irresponsible agency" that usefully obscures tragic choices. GUIDO CALABRESI & PHILIP BOBBITT, *TRAGIC CHOICES* 57 (1978). See generally ORENTLICHER, *supra* note 19, at 3 (discussing the application of Calabresi and Bobbitt's work to end-of-life issues). Pollack, *supra* note 134, at 538, makes a similar point when he suggests that the increased use of, and deference to, private decisions facilitated by bioethics committees, can be seen as a form of judicial deregulation. Some scholars disagree, arguing that litigation "provides the health care community and society with an opportunity to explore publicly the issues associated with life-saving medical treatment," HAFEMEISTER & HANNAFORD, *supra* note 31, at 102.

able to the family; these qualities of the consultative process also enhance the welfare of patients. Part of what we seek to achieve in end-of-life decisionmaking is to advance those values we would want recognized if we were in the patient's position. Surely avoiding the kind of internecine family battle that the *Schiavo* case became is one of them. Even in the not uncommon situation where a man and his in-laws do not get along, the wife/daughter – with loyalties and affection for all of them – would ordinarily not want to see that relationship irreparably damaged.¹⁴¹

Finally, if the dispute can be resolved in this alternative forum, it will remain more private since neither the media nor outside groups will likely have access.¹⁴² We could avoid the media feeding frenzy and political rhetoric that plagued the *Schiavo* story. The participants in a bioethics consultation are the healthcare professionals, the family, the proxy, and the patient. There is no role for others, whatever ideological interest they might have in the outcome. Based on overwhelming survey results, we can confidently assume that Terri Schiavo would not have wanted her tragedy to become grist for other people's agendas.¹⁴³

VII. THE SUBSTANTIVE ACCEPTABILITY OF A NON-ADJUDICATIVE PROCESS

The more difficult question is what the relationship is likely to be between (1) the outcome that the participants reached collectively in such non-adjudicative processes and (2) the outcome that would be correct under the relevant legal standard. The latter typically uses patient autonomy as its fundamental criterion, limited only by a relatively high burden of proof to withdraw life support (a burden presumptively met when there is a relevant advance directive).¹⁴⁴ Yet, at least where the

141. See Bloche, *supra* note 127, at 2373 (quoting the local Catholic bishop, Robert Lynch, who said that "[t]he legacy of Terri's situation should not be that of those who love her the most loathing the actions of one another").

142. In one case where the family and guardian chose privacy, the nursing home allowed right-to-life advocates to enter and interview the patient. The result was a \$2.58 million judgment against the facility for invasion of privacy. See PRESIDENT'S COMM'N, DECIDING TO FOREGO, *supra* note 28, at 93 n.3.

143. *Schiavo* is the most widely publicized, but not the first, end-of-life case in which special-interest groups sought to hijack the judicial process, with or without the assistance of certain family members. Cf. *In re Lawrance*, 579 N.E.2d 32, 44 (Ind. 1991) (where healthcare facility and family of patient in a PVS agreed to withdraw artificial nutrition and hydration, it was error for trial court to appoint a representative of ideological groups opposed to such withdrawals as guardian to represent the patient's interests); *Gilmore v. Finn*, 527 S.E.2d 426, 453, 457-58 (Va. 2000) (even after the family members resolved their dispute regarding the withdrawal of artificial nutrition and hydration, the governor of Virginia continued to litigate (unsuccessfully) to prevent this).

144. See *In re Guardianship of Browning*, 568 So. 2d 4, 13 (Fla. 1990). Where there is

patient is incompetent to participate, as with the case of a PVS patient, we seemingly have chosen to follow the consensus among a group of which the patient was not a part. To what extent should that trouble us?

In some contexts, we may be concerned about non-litigated solutions even where all the parties to the particular dispute fully participate, because significant public values are implicated and may be given short shrift by the parties.¹⁴⁵ I do not believe that is the situation here. Within the limits set by the Constitution, the larger issue of when medical care should be withheld and death hastened is appropriate for public discussion and for legislative consideration.¹⁴⁶ However, the application of those criteria to particular cases can be insulated both from these larger ideological or political agendas and from the intervention of those without knowledge of, and concern for, the individual patient.

Other, more specific considerations may caution us against allowing the participants' consensus to dictate a decision that will, in fact or in law, be final. Where the patient has made her¹⁴⁷ wishes relatively clear in an advance directive, and by executing such a document has dictated that her wishes be followed, that determination should carry almost determinative weight, regardless of the contrary views of health-care professionals and family members.¹⁴⁸ On the other hand, where there is no advance directive, a consensus reached by the participants should ordinarily be conclusive.

A. *Where There Is an Advance Directive*

Where the patient has made a sufficiently clear and serious indication of what she wishes to happen, then the substantive value of recog-

insufficient evidence of the patient's wishes to use the autonomy criterion, the decision is to be based on the patient's best interest. *Id.*

145. See Owen M. Fiss, *Against Settlement*, 93 YALE L.J. 1073, 1075, 1085 (1984) (problematizing use of ADR and settlement in contexts of conflicts involving public law values).

146. Some commentators have called for a strong constitutional right to withdrawal of treatment for both competent and incompetent patients. However, in the context of patients not currently competent, this may be an area where the constitutional framework should generally be designed to facilitate and enhance democratic decisionmaking rather than preempt it. See generally STEPHEN BREYER, *ACTIVE LIBERTY: INTERPRETING OUR DEMOCRATIC CONSTITUTION* (2005); JOHN HART ELY, *DEMOCRACY AND DISTRUST: A THEORY OF JUDICIAL REVIEW* (1980).

147. To avoid grammatical clumsiness, the patient shall be referred to hereafter as "she," a pronoun chosen in honor of the women – Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo – whose cases have formed the law and public attitudes about end-of-life care.

148. See Wendy E. Parmet, Terri and Katrina: A Population-Based Perspective on the Constitutional Right to Reject Treatment 9 n.33 (May 2006) (unpublished manuscript, Northeastern University School of Law Research Paper No. 01-2006), available at <http://ssrn.com/abstract=905873> (noting that the four dissenters and Justice O'Connor in her concurring opinion in *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261 (1990), all "believed that a competent individual had a constitutionally-protected right to reject life-sustaining treatment").

nizing her autonomy and implementing her views is paramount. The Oregon Death with Dignity Act provides a clear example.¹⁴⁹ The procedures therein are well-designed to ensure that the patient is competent and not acting out of psychological impairment.¹⁵⁰ Once those determinations are made, the patient's wishes should be implemented. The high value people place on autonomy and control is demonstrated by the response to the Oregon statute: significant numbers of patients have requested and obtained life-ending drugs and then, knowing they were available, chosen not to use them.¹⁵¹

Families have no independent role in this process; healthcare professionals' only role is to ensure that protective criteria are met before facilitating the patient's wishes. Nonetheless, some are concerned that the patient's expressed wishes may inappropriately incorporate pressure by family members or healthcare professionals, actual or perceived, to end her life prematurely and reduce the family's suffering or the drain on medical resources.¹⁵² Such concerns are not entirely frivolous but, if accepted, would undermine the concepts of consent and autonomy themselves – a path inherently in conflict with the bases of both bioethics and American jurisprudence.¹⁵³

149. OR. REV. STAT. §§ 127.800-127.897 (2006). Although the Supreme Court rejected the claim that there was a constitutional right to physician-assisted suicide in *Washington v. Glucksberg*, 521 U.S. 702, 735 (1997), it also rejected the attempt of Attorney General Gonzales to derail the Oregon system through a rule that would have held that physicians who provided drugs to patients pursuant to the Act violated the Federal Controlled Substances Act. See *Gonzales v. Oregon*, 126 S. Ct. 904, 913-14, 925 (2006).

150. See *Gonzales*, 126 S. Ct. at 912.

151. See, for example, KATRINA HEDBERG, OREGON'S DEATH WITH DIGNITY ACT: THREE YEARS OF LEGALIZED PHYSICIAN-ASSISTED SUICIDE 9 (2001), which reports that one-third of the recipients died from causes other than use of the drugs (cited in Brief for the Patient-Respondents at 36-37, *Gonzales v. Oregon*, 126 S. Ct. 904 (2006) (No. 04-623), 2005 WL 1749169).

152. These concerns have been raised within American legal scholarship as early as 1958 – see Yale Kamisar, *Some Non-Religious Views Against Proposed "Mercy-Killing" Legislation*, 42 MINN. L. REV. 969, 990-93 (1958) – and were one of the factors that led the Supreme Court to reject a constitutional right to die. See *Washington v. Glucksberg*, 521 U.S. 702, 752-760 (1997) (Souter, J., concurring). However, recent research, made possible by the Oregon experiment, suggests little reason for concern. The patients choosing physician-assisted suicide generally are better educated, and all have some form of health insurance. There is no evidence that pressure from others was a "primary motivating influence." Brief for the Patient-Respondents, *supra* note 151, at 36; see also L. Ganzini & S. K. Dobscha, *Clarifying Distinctions Between Contemplating and Completing Physician-Assisted Suicide*, 15 J. CLINICAL ETHICS 119, 121 (2004) (concluding that "these data do not support a slippery slope of increasing death-hastening acts").

153. The presumption of free will/autonomy is perhaps clearest in criminal law since punishment necessarily rests on a belief that the wrongdoer can be blamed for his harmful acts. See Sanford H. Kadish, *Complicity, Cause and Blame: A Study in the Interpretation of Doctrine*, 73 CAL. L. REV. 323, 326 (1985). Compare the outcry over Catherine MacKinnon's view that women lack sufficient free will under contemporary conditions to give free consent to sexual activities in, for example, CATHERINE A. MACKINNON, *FEMINISM UNMODIFIED: DISCOURSES ON LIFE AND LAW* (1987), and discussions of MacKinnon's work in, for example, Lucinda M. Finley,

Substantially greater concerns regarding the reality of autonomy could be raised in the case of a no-longer-competent patient where life-preserving treatment is withheld in accordance with previously expressed wishes in a living will or via a chosen healthcare surrogate. Even if we knew with absolute certainty what the patient, when competent, wanted to happen in the particular situation she now faces, there is the conceptual problem that the patient *is no longer that person*. The medical condition has changed both her capacities and her needs, and it may also have changed her desires.¹⁵⁴ This is not an insignificant problem. Advocates for the disabled note that studies seem to suggest that persons with quite limited cognitive and physical capacity to control or even interact with their environment find significant subjective pleasure in those activities and experiences that remain open to them.¹⁵⁵ Should someone in that situation be denied life-preserving treatment because she, when still without such impairments, clearly indicated that she “would not want to live that way”?

I find this problem poignant and painful, though unlike some other scholars¹⁵⁶ I ultimately conclude that implementing the autonomous wishes of the then-competent patient, rather than her current best interest (presumably as assessed by physician and family) is the proper course.¹⁵⁷ Most of us who write and think about these issues are intel-

The Nature of Domination and the Nature of Women: Reflections on Feminism Unmodified, 82 Nw. U. L. REV. 352 (1988), Patricia A. Cain, *Feminism and the Limits of Equality*, 24 GA. L. REV. 803 (1990), and Jeanne L. Schroeder, *Abduction from the Seraglio: Feminist Methodologies and the Logic of Imagination*, 70 TEX. L. REV. 109 (1991).

154. Dresser, *supra* note 47, at 1823, 1833-37; see also RONALD DWORKIN, *LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA, AND INDIVIDUAL FREEDOM* 199-237 (1993).

155. There “is some empirical evidence that healthy patients underestimate the quality of life that comes with having a disabling condition.” Orentlicher, *supra* note 5, at 1294.

156. ALAN JACQUES & GRAHAM A. JACKSON, *UNDERSTANDING DEMENTIA* 286 (3d ed. 2000); Dresser & Robertson, *supra* note 136, at 234.

157. See JACQUES & JACKSON, *supra* note 156, at 287-300. If we were to conduct a best interest test here, the medical personnel would play a large role since the kinds of knowledge that the family possesses would be less significant than in a substituted-judgment situation. By definition, we are not seeking to implement the person's previously expressed wishes, and there is no reason to impute to the severely cognitively impaired any current concern regarding the effect of their treatment on the lives of other family members except insofar as it might affect the caretaking or emotional support for the patient herself.

Agnieszka Jaworska, *Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value*, 28 PHIL. & PUB. AFF. 105 (1999), persuasively argues that many persons with significant loss of cognitive capacity nonetheless retain some of the critical interests they previously had. They value certain activities and ways of being, not merely for their immediate experiential pleasure but because they express people's sense of who they are – in other words, their values and not merely their desires. Insofar as that is true, the person retains some capacity for autonomy, and our respect for autonomy requires us to “take seriously his current wishes.” This would raise serious issues for a position that would permit withdrawal of lifesaving medical treatment because the person, in his current position, lacks sufficient “meaning and purpose in [his] life,” even absent an advance directive. Newman, *supra* note 58, at 41. It is less problematic

lectuals. For us generally and for me specifically, cognitive capacities are central to self. I can imagine myself living a satisfactory, if more circumscribed life even with very substantial limits on my physical capacities and comfort. I can, at some level, identify with Helen Keller or Steven Hawking and see their lives as ones I could live with satisfaction. But, I have repeatedly said, and fully believe, that I absolutely do not want to live with advanced Alzheimer's. I remember my mother, who spent her last few years in the Alzheimer's unit of a nursing home, and have asked my children to do everything legally possible, and more if they can do so without legal risk to themselves, to end my existence before I reach that stage. In part, I suppose, I lack the moral imagination to see myself as a person enjoying a life whose highlights consist of the taste of ice cream a nurse's aide spoons into my mouth and the feel of a blanket my fingers compulsively caress.

Nonetheless, I think this disjuncture between the experiential lives of the severely cognitively disabled and their prior non-disabled selves is an insufficient reason not to follow the clearly expressed and relevant wishes of the earlier self.¹⁵⁸ A commitment to autonomy, including the ability to bind ourselves now to something in the future, like Ulysses at the wheel, is one of the significant strands of our jurisprudence.¹⁵⁹ And,

for my view, which would privilege the person's prior wishes in an advance directive, insofar as we ensure that patients, if they retain some communicative capacity, be part of the dialogue over medical care choices and that their current views then be "taken seriously." See *In re Martin*, 538 N.W.2d 399, 413 (Mich. 1995) (refusing to apply rules of deference to determinations of treating physician, hospital ethics committee, and guardian to withdraw lifesaving treatment where patient retained some ability to communicate); *Conservatorship of Wendland v. Wendland*, 28 P.3d 151 (Cal. 2001) (same). Even Jaworska, who focuses on persons who still have some significant cognitive capacities and ability to communicate their wishes, concludes that family and caretakers need not necessarily defer to the person's current wishes if they are internally inconsistent or conflict with prior autonomous choices because of defects in current reasoning capacity. Jaworska, *supra*, at 137-38.

158. It is also worth noting that in a study of older Americans, those with more serious health conditions were more willing to accept treatments despite the risk of pain or significant physical disability post-treatment. However, a large percentage of all respondents would reject treatment likely to lead to an outcome of severe cognitive disability. Terri R. Fried et al., *Prospective Study of Health Status Preferences and Changes in Preferences over Time in Older Adults*, ARCHIVES INTERNAL MED., Apr. 24, 2006, at 890.

159. While some contract scholars see autonomy as the dominant value, see, for example, CHARLES FRIED, *CONTRACT AS PROMISE: A THEORY OF CONTRACTUAL OBLIGATION* (1981), others stress the importance of competing values such as community, see, for example, GRANT GILMORE, *THE DEATH OF CONTRACT* (Ronald K.L. Collins ed., 1974), and Duncan Kennedy, *Form and Substance in Private Law Adjudication*, 89 HARV. L. REV. 1685, 1733 (1976). In the particular context of end-of-life decisionmaking, I suggest that autonomy is appropriately privileged where the patient has made her wishes clear, while values of community are of greater significance in the absence of advance directives.

Dresser's rejection of autonomy on the view that the earlier, competent person is so different that she has no ethical claim to bind the later, incompetent person is rejected by BUCHANAN & BROCK, *supra* note 22, at 157-59, who argue that the later self is either sufficiently similar or, in

without disrespecting the interests of the disabled, I believe the concerns of the earlier, competent person, reflecting a carefully considered determination, should trump the possibly divergent views of the person who is no longer competent (at least when that current person's medical condition is as severe as is necessary to trigger current law regarding withdrawal of artificial nutrition and hydration for a non-competent patient).¹⁶⁰

Nevertheless, this still leaves the question of whether and when a living will or the appointment of a healthcare surrogate provides us with sufficient certainty regarding what this person would want to happen when the triggering condition later arises. Unfortunately, we are typically far less certain than we might wish.

First, a living will is an imperfect instrument because it is essentially impossible to anticipate the many and various conditions and prognoses that may be in our future and to indicate with precision and clarity what medical responses we might want for each.¹⁶¹ Consider the difficulties of informed consent generally. Even with a trained professional guiding the discussion and choices, structured by an existing medical condition and a relatively limited set of treatment options, it is not always possible to adequately predict the possible outcomes so that the patient may, with full knowledge, choose a course of action.¹⁶² As Jay Katz noted, the tension between our visions of articulated informed consent, implementing patient control and based on full disclosure, on the one hand, and all the legal, medical, and human realities that constrain such decisionmaking on the other, "is the central problem of informed consent."¹⁶³ In the context of advance directives, the possible situations to which the document might apply are far greater, and the prognoses

the case of extreme cognitive incapacity, so radically different that it should not be denominated a self at all.

160. Under section 765.302, Florida Statutes, and section 765.306, Florida Statutes, the patient must be terminal, in an end-stage condition, or in a PVS. See also BUCHANAN & BROCK, *supra* note 22, at 109 (arguing for strong deference to the performative act of an advance directive, particularly since "[a]mong the candidates for preeminent objective goods, self-determination and a life of conscious purposeful activity or at the very least one in which pleasures outweigh pains and disabilities are much more plausible than biological life as such").

I do not reach in this Article the more difficult question of when substituted judgment, based on relevant choices in an advance directive, might be used to refuse life-sustaining treatment for a patient, such as one who had suffered a severe stroke, who is incapable of participating in care decisions yet retains some cognitive capacity and is not in a terminal condition.

161. Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, HASTINGS CTR. REP., Mar.-Apr. 2004, at 30.

162. Cf. Judith H. Hibbard et al., *Informing Consumer Decisions in Health Care: Implications from Decision-Making Research*, MILBANK Q., Sept. 1997, at 395 (noting limits on human capacity to process complex arrays of information).

163. Jay Katz, *Informed Consent – A Fairy Tale? Law's Vision*, 39 U. PITT. L. REV. 137, 139 (1977).

and treatment options harder to imagine, given the near certainty of changes in medical knowledge and practices over time.¹⁶⁴ For example, the concepts and boundaries of PVS and coma have changed over time; by the time my younger colleagues' advance directives come into play, the set of categories and their boundaries will likely be different than they are today.

In fact, most people who use living wills work from one of a small number of forms provided by non-profit or professional organizations.¹⁶⁵ These necessarily paint with a broad brush. Some interpretation is frequently needed to apply the terms of a living will to a situation that fits only imperfectly into the language of the form the patient found, read, and signed. If people try to avoid this with an individualized document, they may still fail to anticipate the specific situation in which they eventually find themselves.¹⁶⁶ Any document will become misleading if people's preferences change, but they may neglect to update the advance directive. Moreover, the document may be unavailable at the time it is needed, or worse yet, it might not even be followed.¹⁶⁷

164. See, e.g., BUCHANAN & BROCK, *supra* note 22, at 104-07; Dresser, *supra* note 47, at 1830-31; Orentlicher, *supra* note 5, at 1294; cf. Hibbard et al., *supra* note 162, at 400 (noting that a "person in good health cannot always foresee what his or her needs or values might be during an illness").

This is a problem in part because some healthcare professionals and courts insist on a greater degree of specificity in advance directives than those who execute them desire. Nikki Ayers Hawkins et al., *Micromanaging Death: Process Preferences, Values, and Goals in End-of-Life Medical Decision Making*, 45 GERONTOLOGIST 107, 108 (2005).

When an advance directive is executed close to the time when it will become operative, such as one done at the relevant hospital admission pursuant to the information provided under the Patient Self-Determination Act of 1990, 42 U.S.C. § 1395cc(f) (2007), these problems are lessened. Of course, this will not apply in a *Schiavo*-like situation where the patient is unconscious before the hospital admission or even when the patient's cognitive capacities are substantially reduced by the triggering event, such as a stroke.

165. Some of the organizations and the Web sites from which such documents can be obtained are: (1) the Florida Attorney General (see Fla. Bar & Fla. Med. Ass'n, *Suggested Form of a Living Will*, *Florida Statutes Section 765.303*, <http://www.myfloridalegal.com/LivingWill.pdf> (last visited Apr. 2, 2007)); (2) Caring Connections (see Advance Directives – Download – Caring Connections, <http://www.caringinfo.org/i4a/pages/Index.cfm?pageid=3425> (last visited Apr. 2, 2007)); and (3) the American Bar Association (see AARP, AM. BAR ASS'N COMM'N ON LEGAL PROBLEMS OF THE ELDERLY & AM. MED. ASS'N, SHAPE YOUR HEALTHCARE FUTURE WITH HEALTH CARE ADVANCE DIRECTIVES (1995), available at <http://www.abanet.org/lawinfo/adb.pdf>).

166. After discussing all these problems with living wills as currently executed, Pope indirectly undermines the possibility of fully eliminating them by proposing that advance care planning be done in the doctor's office over several visits and "include family, friends, clergy, or lawyers in the discussion" – a staggeringly impractical proposal for all but a tiny percentage of the cases where some kind of advance directive is desirable. See Thaddeus Mason Pope, *The Maladaptation of Miranda to Advance Directives: A Critique of the Implementation of the Patient Self-Determination Act*, 9 HEALTH MATRIX 139, 153 (1999). A similarly idealistic, impractical vision of the advance directive process can be seen in Douglas K. Martin, Linda L. Emanuel & Peter A. Singer, *Planning for the End of Life*, 356 LANCET 1672 (2000).

167. Fagerlin & Schneider, *supra* note 161, at 33-36; Kenneth W. Goodman, *Persistent*

These problems can be avoided by the use of a healthcare surrogate, rather than a living will.¹⁶⁸ The patient will choose someone she knows and trusts to understand her views on the issues of end-of-life care.¹⁶⁹ The patient will, one hopes, have discussed those views in detail with the surrogate before or after choosing him for that role.¹⁷⁰ The surrogate will know the patient's history and her philosophy of life well enough to fill in the interstices of those specific conversations and instructions. The surrogate will be available at the time the healthcare situation arises. The healthcare professionals can communicate the actual situation, prognosis, and treatment options to the surrogate, just as they would have to the patient herself if she were still competent. The surrogate can then choose what the patient would have wished.

Unfortunately, studies of healthcare surrogates tend to undermine this rosy picture. A number of studies have examined potential patients and the people they had chosen as a surrogate, the people they said they would choose, or the relatives (most typically spouses or adult children) whom, experience indicates, people in particular family constellations generally choose (the "putative surrogate").¹⁷¹ The potential patient and the putative surrogate were presented with the same scenario and asked to indicate the healthcare option they would choose for the potential patient. In comparing the choices people made for themselves and those of their surrogates, they agreed between sixty and seventy percent of the time, a better correlation than between people and their physicians, but less than the potential patients had predicted.¹⁷² Not infrequently, the

Legislative State: Law, Education, and the Well-Intentioned Healthcare Ethics Committee, 13 HEC F. 32, 37 (2001) (some healthcare facilities are inappropriately reluctant to follow non-standard living wills); Joanne Lynn, *Why I Don't Have a Living Will*, 19 MED. & HEALTH CARE 101, 101-04 (1991).

168. The problem of patient's choice being ignored can still arise. Deference to the choice of a patient-selected surrogate was not always even seen as appropriate. Cf. 1 PRESIDENT'S COMM'N, MAKING HEALTH CARE DECISIONS, *supra* note 114, at 164 (promoting surrogate decisionmaking, but then asserting that healthcare professionals should be able to challenge the surrogate's choice "on the ground that it is not based on the patient's best interests or on a reasonable interpretation of the patient's instructions").

169. 2 PRESIDENT'S COMM'N, MAKING HEALTH CARE DECISIONS, *supra* note 114, at 240 (indicating that patients are likely to select a family member as their surrogate).

170. Having used "she" for the patient, I use masculine pronouns – "he," "him," etc. – for the surrogate to avoid confusion.

171. Dallas M. High and Howard B. Turner indicate that patients want to have a spouse or an adult child serve as surrogate, but do not want to execute advance directives unless they do not have such close relatives available to speak for them. Dallas M. High & Howard B. Turner, *Surrogate Decision-Making: The Elderly's Familial Expectations*, 8 THEORETICAL MED. 303, 307 (1987). See generally Ezekiel J. Emanuel & Linda L. Emanuel, *Proxy Decision Making for Incompetent Patients: An Ethical & Empirical Analysis*, 267 JAMA 2067 (1992).

172. Jan Hare, Clara Pratt & Carrie Nelson, *Agreement Between Patients and Their Self-Selected Surrogates on Difficult Medical Decisions*, 152 ARCHIVES INTERNAL MED. 1049 (1992); Allison B. Seckler et al., *Substituted Judgment: How Accurate Are Proxy Predictions?*, 115

surrogate will choose to withdraw medical treatment when the patient would have wanted it to continue or vice versa.¹⁷³ One study asked participants the *reasons* for their decision: surrogates were more likely to list the patient's pain level as crucial, and patients were more likely to consider the burden on their families and the time left to live.¹⁷⁴ In the real world, such disagreements, or even a conflict of interest that fosters doubt regarding the surrogate's capacity to know and choose consistent with the patient's wishes, are unlikely to be discovered, since "the range of acceptable practices is so broad that the absence of explicit statements of patients' preferences makes it difficult to discern such conflicts."¹⁷⁵

This would be troubling if patients expect the surrogate to channel the patient's own wishes. However, one study suggested that a "majority . . . of terminally ill patients would select their surrogate's treatment decision rather than the treatment outlined in their own advance directives."¹⁷⁶ Patients' stated reasons included trust in the surrogate's judgment and concern for the surrogate's own interests.

Despite the predictable gaps between what the decision would be if the decisionmaker could know with certainty what the patient wants and the decision embodied in a living will or made by a designated proxy, it still seems likely that following the latter significantly – though imperfectly – enhances patient autonomy.¹⁷⁷ Where the patient has explicitly

ANNALS INTERNAL MED. 92 (1991). Professor Doukas proposes that people and their chosen surrogates engage in a complex process of detailed discussion leading to a guidance document he denominates a "family covenant." David John Doukas, "Family" in *Advance Care Planning: The Family Covenant in the Wake of Terri Schiavo*, 33 J.L. MED. & ETHICS 372 (2005). This idea is, I believe, as impractical as Pope's analogous effort to reform the process for living wills. See Pope, *supra* note 166, at 153.

173. Rebecca S. Allen & John L. Shuster, *The Role of Proxies in Treatment Decisions*, 20 BEHAV. SCI. & L. 235, 241 (2002) (the best predictor of the proxy's choice is what he would choose for himself); William E. Haley et al., *Family Issues in End-of-Life Decision Making and End-of-Life Care*, 46 AM. BEHAV. SCI. 284 (2002); Orentlicher, *supra* note 5, at 1268-69 (citing various studies and concluding that there is evidence both that surrogates underpredict and overpredict the patient's desired level of care).

174. Hare, *supra* note 172, at 1051, 1053.

175. Emanuel & Emanuel, *supra* note 171, at 2068.

176. Haley, *supra* note 173, at 290; see also Christina M. Puchalski et al., *Patients Who Want Their Family and Physician to Make Resuscitation Decisions for Them: Observations from SUPPORT and HELP*, 48 J. AM. GERIATRICS SOC'Y S84 (2000) (most older Americans studied preferred to let their family member or physician decide whether to issue a do-not-resuscitate order, rather than being bound by their own previously stated preference, particularly if they had chosen the family member as their surrogate); Peter B. Terry et al., *End-of-Life Decision Making: When Patients and Surrogates Disagree*, 10 J. CLINICAL ETHICS 286, 288-89 (1999) (seriously ill patients preferred to have their surrogate's treatment choice followed rather than their own advance directive, especially where the patient chose the surrogate).

177. In *Cruzan v. Director, Missouri Department of Health*, 497 U.S. 261, 289 (1990), Justice O'Connor indicated in her concurrence that courts should grant greater deference to a chosen surrogate's decision than that of a legally designated substitute. Even Chief Justice Rehnquist suggested that the constitutional issue might have been decided differently if there were sufficient

sought to make her wishes clear, autonomy values are central and displace conflicting values of intrafamily harmony or other interests extrinsic to the patient's autonomy. Part of family values is the recognition that the interests of certain family members, such as those who are extremely ill, may trump the conflicting values of other family members.¹⁷⁸ While we can and should work to improve advance directives' availability, accuracy, and completeness, this objective is not inconsistent with implementing, as best we can, the wishes embodied in whatever documentation exists.¹⁷⁹

We should acknowledge that this rule of high deference is designed to make people, while competent, feel comfortable that they have the authority to make these decisions for themselves and to know that their wishes will govern what happens to them when they are no longer competent.¹⁸⁰ That comfort is provided by following the living will or the surrogate's directives, which are the best evidence we have of the patient's wishes when competent. Perhaps we should take some comfort from the fact that most people who use living wills are unaware of the research described above and thus probably believe that their wishes are clear and will be followed. Meanwhile, those who choose surrogates may recognize (and even want) the surrogate to take the whole context into account or may seek to turn decisionmaking responsibility over to the surrogate, although such attitudes do not fit easily within a simplistic vision of "patient autonomy." The patient's autonomous choice may be, in a sense, to "choose in accordance with the surrogate's view of the patient's best interests, rather than the surrogate's view of the patient's preferences."¹⁸¹

Even in this situation, while the patient's choice to have treatment withdrawn should be determinative, there should be some limited flexi-

evidence that the patient had chosen to have the decision made for her by a surrogate she had selected. *Id.* at 287 n.12. See generally DOLGIN & SHEPHERD, *supra* note 23, at 743-49.

178. But cf. John Hardwig, *What About the Family?* (*Patient Autonomy, Medical Ethics and the Family*), HASTINGS CTR. REP., Mar.-Apr. 1990, at 6 ("[T]he seriously ill may have a right to special consideration, and the family of an ill person may have a duty to make sacrifices to respond to a member's illness. . . . [But] there are limits to the right to special treatment by virtue of illness.").

179. See generally Allen & Shuster, *supra* note 173, in which the authors summarize the literature demonstrating limitations in the current advance planning processes, but conclude that the response should be new modalities to improve those processes and make them more effectively available to a broader range of people.

180. See BUCHANAN & BROCK, *supra* note 22, at 154 (arguing that "law and medical practice ought to regard valid advance directives as having nearly the same force as a competent patient's contemporaneous choice, because attempts to limit the authority of advance directives would in practice lead to their being ignored by paternalistic physicians or families, thus robbing them of their value").

181. Orentlicher, *supra* note 5, at 1280; see *infra* notes 191-208 and accompanying text.

bility at the margins. When we are reasonably certain that a family member or members have a long-term, intimate, and loving relationship with the patient, their concerns should not always be entirely irrelevant unless the family member can recast them as expressing the patient's own, autonomous wishes. A loving spouse or adult child who has long been the patient's caretaker may have difficulty accepting that the patient's condition is terminal or that no further treatment can provide the patient a quality of life sufficient to meet her formerly expressed minimum expectations. Assume that the patient's express prior statements are silent regarding her wishes to consider the impact on the family member, but that all the evidence about their relationship and our knowledge of how most people live their lives embedded in a web of care and concern would suggest that the patient would want that family member's concerns to be taken into account. It does not seem to intrude unnecessarily upon patients' autonomy to delay the withdrawal of treatment for a limited period of time to allow family members to reconcile themselves to the situation and to let go.¹⁸²

B. *In the Absence of an Advance Directive*

A different analysis is called for when the decision to seek treatment withdrawal is made by a proxy selected by a legal default rule rather than by the patient herself. In this case, the proxy's assertion that his request is merely implementing the patient's wishes lacks the indicia of reliability or serious consideration inherent in an advance directive situation. In turn, we have less reason to think that a judge, following the proxy's recommendation, will reflect the patient's choice, and thus further "patient autonomy." This weakness is compounded by the nature of court processes, which are an imperfect instrument to determine the patient's wishes. They are less capable than a consultant-guided discussion of taking into account a rich understanding of what a patient would want, including the impact of the choice on the family.¹⁸³ Studies suggest that a more nuanced view of patient autonomy than courts can readily acknowledge is more likely to lead to an outcome

182. See Lois Shepherd, *Shattering the Neutral Surrogate Myth in End-of-Life Decisionmaking: Terri Schiavo and Her Family*, 35 CUMB. L. REV. 575, 585-88 (2004) (criticizing the decision of the court in Hanford Pinette's case to enforce his living will and end lifesaving medical treatment without any accommodation for the concerns of his wife of fifty-three years). Similarly, in an end-of-life situation for a child with an extremely poor prognosis, the most ethical, legally permissible outcome would permit parents who had chosen not to continue care a reasonable period to process the situation before the decision to remove life-sustaining medical treatment is implemented.

183. While it is possible that this patient, though not having executed a living will or proxy designation, did not want the concerns of her family considered, a bioethics consultant is as well situated as a judge to elicit any evidence of this.

consistent with what people usually want in this kind of situation.¹⁸⁴

I have already described the potential disjuncture between what the patient had earlier indicated she would later want and what she actually would want now. This problem is far more severe in the absence of an advance directive. The court may lack effective access to relevant information regarding what the patient wants, as this is often hard to articulate in the formal categories required by the rules of evidence and the relevant substantive legal categories. Professor Jecker has argued convincingly that the law's demand for cognizable evidence, especially when it is combined with a requirement that the evidence be clear and convincing, "effectively dismantles any effort to locate remnants of patients' values through intimate contacts and piece them into meaningful patterns."¹⁸⁵

When the evidence consists of specific statements that the patient is claimed to have made, there may be reasons to doubt its reliability. Consider the evidence in *Schiavo* itself. The husband produced his own testimony and that of members of his family that – in the context of the terminal illnesses of Terri Schiavo's grandmother and grandmother-in-law and a television movie about an end-of-life situation – Terri Schiavo had stated that she would not want to live like that.¹⁸⁶ Her parents believed that their daughter's views were different and that, like them, she would have followed Catholic doctrine and refused the withdrawal

184. In addition, since we are less certain of the patient's wishes absent an advance directive it may be appropriate to give greater weight to her current best interest. See BUCHANAN & BROCK, *supra* note 22, at 119-20.

185. Nancy S. Jecker, *The Role of Intimate Others in Medical Decision Making*, 30 GERONTOLOGIST 65, 67 (1990); see also Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 377 (1988) (noting that families' judgments of what patients would want are often "highly intuitive – based on love and intimacy, not specific statements or actions"). Justice Brennan, dissenting in *Cruzan*, stressed the value of testimony from the family that the Missouri court had discounted because it was not a reporting of specific statements Nancy Cruzan had made, but the family's assessment based on their general knowledge of their daughter or sister regarding what she would have wanted. See *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 322 (1990) (Brennan, J., dissenting) ("[T]hey were certain that Nancy would want to discontinue artificial nutrition and hydration . . ."). While there are good reasons to allow such intuitive knowledge into the decisionmaking process, there are at least equally compelling reasons to forbid its introduction, or court reliance upon it, in the law in general. See, e.g., *Florida v. Rodriguez*, 469 U.S. 1, 5 (1984) (per curiam) (stating that the Fourth Amendment requires that police have reasonable, articulable suspicion, not merely intuitions based on their experience, to permit a frisk); *Terry v. Ohio*, 392 U.S. 1, 21-22 (1968).

186. See *In re Guardianship of Schiavo*, No. 90-2908GD-003, 2000 WL 34546715, at *6 (Fla. 6th Cir. Ct. Feb. 11, 2000); SCHIAVO WITH HIRSH, *supra* note 13, at 139, 145, 159. Some of the testimony would cover the situation in which Terri Schiavo found herself, but was likely not intended to be taken to its literal conclusion. For example, her husband said she would not have wanted to live in a way that would "be a burden to anybody," but surely she was not calling for the withdrawal of any lifesaving treatment if she were permanently wheelchair-bound. *Id.*

of artificial nutrition and hydration.¹⁸⁷ The judge's decision concerning the patient's beliefs necessarily relied upon hearsay, a form of evidence we frequently are hesitant to fully credit.¹⁸⁸ Not atypically, the statements may have been offhand or evoked by particular emotional situations. We know how polls can be manipulated; should it matter what the television movie's embedded viewpoint was? Further, even more than in the situation of construing a living will, we must extrapolate comments such as these, evoked by particular and often readily distinguishable factual situations, to Terri Schiavo's wishes in regard to her actual condition and the specific issue whether artificial nutrition and hydration should be withdrawn.¹⁸⁹ Even if each witness testified to what he or she honestly remembered the patient as having said, and even if each witness's testimony was fully consistent with what the witness believed the patient wanted, the witnesses are likely (as they were here) to be family members or close friends whose perceptions and memories are likely colored by their own beliefs about what they want for the patient and, thus, believe the patient must have wanted for herself.¹⁹⁰

We do know that Judge Greer believed the husband's witnesses and found he had shown by clear and convincing evidence that Terri Schiavo would have wanted the feeding tube withdrawn.¹⁹¹ But this is a situation where evidence is frequently less than clear. And it is difficult for the judge, like the witnesses, to put aside personal values or beliefs

187. See SCHINDLER ET AL., *supra* note 15, at 183 (describing Terri as "a devout and pious Catholic"); *id.* at 70-72 (noting that Terri had been upset that Karen Ann Quinlan was taken off life support).

188. In *Cruzan*, Chief Justice Rehnquist noted the analogy of withdrawal of lifesaving medical treatment to situations such as the appropriate distribution of the deceased's estate in which we often refuse to admit such oral testimony at all. *Cruzan*, 497 U.S. at 284.

189. *Cf. In re Martin*, 538 N.W.2d 399, 411 (Mich. 1995) (rejecting argument for treatment withdrawal because the patient "is not suffering from the type of incapacitation referenced in his expression of a desire not to continue life-sustaining medical treatment"). More generally, the *Conroy* court indicated that in assessing claims of what the patient said she wanted, the court should consider the claims' "probative value [which] . . . may vary depending on the remoteness, consistency, and thoughtfulness of the prior statements or actions and the maturity of the person at the time." *In re Conroy*, 486 A.2d 1209, 1230 (N.J. 1985). One might draw an analogy between (1) the difference between using an advance directive and oral statements such as Terri's and (2) the difference between applying a rule from a statute that may not have anticipated the precise situation and finding a rule from scattered dicta in cases with different facts.

190. It is apparent that Michael's brother and sister-in-law supported the withdrawal of treatment; even if their reporting was entirely accurate, Terri may have been agreeing with them rather than articulating her own, independently developed views.

191. "[W]e cannot gainsay the findings of the court" though "no one can be absolutely certain what Terri would have wanted, or how much thought she gave before her injury to what would have been for her a remote and hypothetical matter." Preston & Kelly, *supra* note 128, at 127; *cf. Shepherd*, *supra* note 182, at 580-81 (conceding that it is difficult to know with sufficient certainty what Terri Schiavo would have wanted but approving the court's decision since there should be a strong presumption against continuing care for a patient in a PVS).

about what most people would want in assessing the evidence. If we imagine Professor Cantor as a judge, he might readily credit even fragmentary evidence and thus find that the patient would want to avoid a horrific situation that the guardian had posited as possible: that she might be aware of her situation yet unable to hear, see, speak, or interact.¹⁹² But a Judge Ashcroft or Gonzales,¹⁹³ each with a strong belief in the value of human life, might be far more skeptical of Michael Schiavo's witnesses, concurring with the majority in *Cruzan* that "there is no automatic assurance that the view of close family members will necessarily be the same as the patient's would have been had she been confronted with the prospect of her situation while competent."¹⁹⁴ Indeed, the evidence presented in *Cruzan* – Nancy Cruzan's statement during a "somewhat serious conversation with a housemate friend that if sick or injured she would not wish to continue her life unless she could live at least halfway normally"¹⁹⁵ – seems at least as specific as the evidence in *Schiavo*. In *Cruzan*, however, the Missouri Supreme Court determined that this statement did not meet the requisite evidentiary standard.¹⁹⁶

192. WOLFSON, *supra* note 8, at 4 (referring to "Hypothesis III"). Professor Cantor has written numerous articles advocating a standard that would facilitate withdrawing medical treatment from those with extremely low quality-of-life prognoses. See, e.g., Norman L. Cantor, *Discarding Substituted Judgment*, 48 RUTGERS L. REV. 1193, 1197 (1996) [hereinafter Cantor, *Discarding Substituted Judgment*]; Norman L. Cantor, *On Kamisar, Killing and the Future of Physician Assisted Death*, 102 MICH. L. REV. 1793, 1842 (2004) [hereinafter Cantor, *On Kamisar*]; Cantor, *supra* note 22, at 193. Justice Brennan appears to adopt a similar orientation in *Cruzan*, repeatedly referring to Nancy Cruzan's condition as one that many would find "an ignoble end" or "humiliating." *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 310-11 (1990) (Brennan, J., dissenting).

193. As Attorneys General, both John Ashcroft and Alberto Gonzales advocated for positions advancing a "culture of life" against claims for physician-assisted suicide or abortion. See, e.g., *Gonzales v. Oregon*, 126 S. Ct. 904, 924 (2006) ("The Government contends ordinary usage of [the words 'medical' or 'medicine'] ineluctably refers to a healing or curative art, which by these terms cannot embrace the intentional hastening of a patient's death."); *Oregon v. Ashcroft*, 368 F.3d 1118, 1123 (9th Cir. 2004) ("With a change of administrations came a change of perspectives. On November 9, 2001, newly appointed Attorney General John Ashcroft reversed the position of his predecessor and issued the Directive at issue here. The Ashcroft Directive proclaims that physician assisted suicide serves no 'legitimate medical purpose' . . . and that specific conduct authorized by Oregon's Death With Dignity Act 'may render [a practitioner's] registration . . . inconsistent with the public interest and therefore subject to possible suspension or revocation.'").

194. *Cruzan*, 497 U.S. at 286.

195. *Id.* at 268.

196. *Cruzan v. Harmon*, 760 S.W.2d 408, 424 (Mo. 1988). The difference here is one of legal standards rather than sufficiency of evidence: while the standard in both Florida and Missouri is "clear and convincing," the Missouri courts frame the issue as requiring evidence of statements about the specific situation facing the patient, while Florida accepts statements evidencing a more general orientation toward withdrawal of treatment. Noah, *supra* note 113, at 111-12; cf. *In re Jobes*, 529 A.2d 434, 444 (N.J. 1987) (allowing a decision to withdraw treatment, absent any explicit evidence of the patient's wishes, based on "his or her relevant philosophical, theological, and ethical values").

Perhaps most importantly, the private bioethics consultation/mediation can assess the effect that the decision would have on families, an effect that the patient, if competent, would likely also have taken into account.¹⁹⁷ A fundamental dilemma that many scholars have recognized is that the law seemingly demands that the family, as surrogate decisionmakers, take into account only the patient's wishes and interests as opposed to their own. Yet the two sets of wishes and interests cannot be fully disentangled. The problem is not simply that families are often incapable of separating them; rather, it is that these issues are inextricably intertwined for most of us.¹⁹⁸ When I think about myself as someone facing an end-of-life situation or as someone in a PVS, one of my concerns is to advance my family's interests. I do not want them to suffer by seeing me in this condition (even if I myself will be unable to experience pain or indignity). I do not want my care to drain my family's resources, which I would want available for other needs. Indeed, one reason people execute living wills is to avoid imposing the painful process of choice on their loved ones, just as some people make their own funeral arrangements not merely to ensure that the funeral process coincides with their wishes, but also to relieve their family from the stress and burden of having to do so upon their death.

What if we accept as a background presumption that most people are both liberals and communitarians: they want the freedom to advance their own individual goals, but they also recognize and value family connections. Where a patient has not indicated that she would want liberal individualism alone to be the guiding principle for end-of-life decision-making, we may best advance her interests and presumed wishes by encouraging the family to decide on her behalf.¹⁹⁹ This is most clearly so when the family is in agreement. When the patient is permanently incompetent to decide for herself and the choice is within the range of ethical acceptability, we should not force the family to defend its choice

197. See Glover, *supra* note 60, at 1168; Jecker, *supra* note 185, at 66; Rhoden, *supra* note 185, at 440.

198. An AARP survey showed that over two-thirds of respondents indicated that among their significant concerns regarding end-of-life situations was that they not be a burden to family and friends. See AARP NORTH CAROLINA END OF LIFE SURVEY: AFRICAN AMERICAN MEMBERS 12 (2003), available at http://assets.aarp.org/rgcenter/health/nc_eol_aa.pdf. This point has been extensively examined in the literature. See, e.g., DOLGIN & SHEPHERD, *supra* note 23, at 743-49; Rhoden, *supra* note 185, at 402. As Justice Brennan pointed out in *Cruzan*, a patient may wish to avoid "visiting a prolonged and anguished vigil on [her] parents, spouse, and children." *Cruzan*, 497 U.S. 261 at 311 (Brennan, J., dissenting).

199. James L. Nelson, *Taking Families Seriously*, HASTINGS CTR. REP., July-Aug. 1992, at 6, 11-12; cf. Jennifer Nedelsky, *Reconceiving Autonomy: Sources, Thoughts and Possibilities*, 1 YALE J.L. & FEMINISM 7, 10 (1989) (suggesting that autonomy, properly reconceptualized, recognizes that people are not atomistic; rather values are "shaped by . . . the relationships that are a part of one's life").

to a judge. This can also be true when the ultimate agreement among the family is the result of a complex discussion process, often conducted with the aid of an outsider trained to facilitate their discourse and rooted in shared concern for the patient's wellbeing.

When we take the issue to court, these communitarian, familial concerns cannot be a genuine part of the decisionmaking process.²⁰⁰ We ask the court and witnesses to assume that the patient considers only her own interests. In discussing the *Quinlan* case, Professor Burt stated that "[i]f Karen were determined to be utterly self-centered in her deliberations, disdainful of the consequences to others in pursuit only of her most selfishly conceived interests, continuation of the life-support apparatus would be the most rational course for her."²⁰¹ Legal criteria seemingly call on a court to assess what patient A would want according to a matrix that does not allow the court to recognize fully the kind of person patient A was. At the same time, these legal criteria obscure the ways in which these impossible demands are elided as witnesses craft their testimony in light of the criteria. The testimony implicitly reflects the witness' understanding of what patient A, as a wife, mother, or sister, would have wanted, and it takes into account what the husband, son, or brother who testifies believes (and believes that patient A believes) is best for patient A, but the witness cannot do so explicitly.²⁰²

In contrast to the adjudicative process, the consultant-guided process encourages a discussion in which the parties to an end-of-life dispute can recognize the tragic choice they collectively face,²⁰³ articulate their values, and ideally develop a solution that accords with the particularized congeries of values that are most significant to the patient and to them.²⁰⁴ Both the process and the outcome are more consistent with what most people would want when they are in patient A's position.

200. Cf. Pollack, *supra* note 134, at 518, 523 (suggesting that courts engage in legal fictions to obscure the fact that they rely on evidence of much more than the patient's wishes, narrowly construed).

201. BURT, *supra* note 136, at 151.

202. Pollack notes that although the substituted judgment and best interest tests are often stated separately, "the tests should be viewed not as a dichotomy, but as a continuum of subjective and objective information about the patient that will support a reliable decision." Pollack, *supra* note 134, at 518. To insist that the family may only testify to a subset of the concerns that they and the patient share, as the legal rules often do, is to make the process dishonest. The familial concerns will be part of the process, even if not articulated as such. See Newman, *supra* note 58, at 54-55 (discussing some of the familial concerns).

203. Unlike substituted judgment, which Dresser & Robertson, *supra* note 136, at 240, criticize as avoiding the acknowledgement of tragic choices, this process allows the participants to face the tragic choice without any *a priori* ranking of the values that should inform it.

204. See DUBLER & LIEBMAN, *supra* note 33, at 9-12 (praising bioethics mediation for its role in developing norms within the community formed around the end-of-life choice for this patient); cf. Cohen, *supra* note 53, at 279 (stressing the value of the consultative process in encouraging a dialogue among the parties); Pollack, *supra* note 134, at 536-38.

Studies consistently show that people, perhaps especially the ill or elderly, who are overrepresented among the populations likely to face end-of-life issues, deeply value the relationships they have with their families and their families' interests.²⁰⁵ People want a process that defers to their family's decisions because they believe that the family is best situated to know what they would want, or because they view the family's harmonious collaboration in deciding the issue as valuable in and of itself.²⁰⁶

The failure to appoint a surrogate or to make an advance directive may be the result of insufficient knowledge or connection to the legal system or of psychological unwillingness to think about one's own physical deterioration or death. However, the lack of an advance directive may instead reflect, at some level, a preference not to decide, but rather to choose to have one's family do so.²⁰⁷ "[S]urely some . . . patients prefer family choice *over* the opportunity to make [their] own choices in advance," despite the risk that the choice would be different than the one they would themselves have made.²⁰⁸

C. *Other Reasons to Prefer Consultation to Adjudication*

I have suggested here a particular view of the criteria that should guide end-of-life decisionmaking. But if we recognize that there is an essentially irresolvable dispute on this question, that fact provides another reason to avoid litigation where possible. A judicial process must be guided by some predefined decisional criteria if it is to be recognized as "law." The scholars who have written on the subject of end-of-life decisionmaking, and the courts that have ruled upon such issues, have proffered a variety of approaches a decisionmaker might follow when there is no clear and specific advance directive.

First, they propose a number of different substantive decisional criteria. Some seemingly focus only on substituted judgment²⁰⁹ or on substituted judgment as the preferred criterion, but with the patient's best

205. See discussion *supra* note 198.

206. See, e.g., MEISEL & CERMINARA, *supra* note 16, at 3-52, -53; Boozang, *supra* note 100, at 552; High & Turner, *supra* note 171, at 316. Like views on appropriate end-of-life treatment choices, views on who should make this decision and the role of family are culturally inflected. One study indicated that Mexican and Filipinos are more likely than Euro-Americans to value a family-centered decisionmaking model. Cf. Terry et al., *supra* note 176, at 291.

207. See Allen & Shuster, *supra* note 173, at 243 (patients may "choose to abdicate decision-making responsibility to physicians or familial proxies").

208. DOLGIN & SHEPHERD, *supra* note 23, at 759.

209. See, e.g., MEISEL & CERMINARA, *supra* note 16, at 4-7 (describing substituted judgment standard in the context of the hierarchy of standards).

interest a permissible alternative criterion,²¹⁰ at least when there is insufficient evidence of the patient's wishes.²¹¹ Others propose that the patient's current best interest is ordinarily the proper criterion when she is permanently incompetent.²¹²

Second, insofar as substituted judgment is used, scholars and jurists vary in how the criterion should be defined. Should it consist solely of what the patient would want if she were thinking only of her own interests?²¹³ Or should it include the patient's concern for the impact of the decision on her family?²¹⁴ If the latter may be considered, how certain must it be that this patient wished to take this impact into account? Should there be a strong default presumption that people consider familial impact in making end-of-life decisions?²¹⁵ Should the decisionmaker apply a rule that people ought to take familial impact into account and, thus, include these concerns at least absent clear evidence that this patient was unusually self-centered?²¹⁶

210. Buchanan, *supra* note 50, at 214-15, suggests that substituted judgment, unlike an advance directive, can be ethically limited by the patient's interests.

211. § 765.401(2), FLA. STAT. (2006); *In re Conroy*, 486 A.2d 1209, 1231-32 (N.J. 1985); 1 PRESIDENT'S COMM'N, MAKING HEALTH CARE DECISIONS, *supra* note 114, at 180-81.

212. See, e.g., Dresser & Robertson, *supra* note 136, at 236, 240 (rejecting rule that previously competent patient's autonomy should be dominant criteria in favor of promoting the then-existing patient's best interest). Some commentators stress the importance of avoiding the indignity of invasive treatment. While this might have been the patient's clearly articulated prior view, it is often asserted as an aspect of her current best interest as most people would understand it, even in situations where the patient herself no longer possesses the cognitive capacity to experience indignity. See Cantor, *On Kamisar*, *supra* note 192, at 1840; Rebecca Dresser, *Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 ARIZ. L. REV. 373, 374 (1986). But see DOLGIN & SHEPHERD, *supra* note 23, at 747-48 (questioning whether indignity should only factor into the decision insofar as the patient has the capacity to experience indignity).

213. See 1 PRESIDENT'S COMM'N, MAKING HEALTH CARE DECISIONS, *supra* note 114, at 180 (calling for a stringent evidentiary standard to demonstrate that people would disregard their self-interest in order to reduce the burden on their families); cf. John A. Robertson, *Assessing Quality of Life: A Response to Professor Kamisar*, 25 GA. L. REV. 1243, 1250-51 (1991).

214. See, e.g., Boozang, *supra* note 100, at 549; Cantor, *supra* note 22, at 192 (noting that most people would want the effect on family to be considered); Dresser & Robertson, *supra* note 136, at 240 (authors would allow consideration of the impact on the family, but as a secondary concern vis-à-vis the patient's current best interest); Glover, *supra* note 60, at 1165.

215. See *In re Jobes*, 529 A.2d 434, 444 n.10 (1987) (noting that people care about the impact on their families and any evidence of this can be considered as part of substituted judgment). The Schiavo judge accepted that the effect on the family was part of what Terri Schiavo would have considered, though there was no reference to any particular statement from her supporting this conclusion. See *In re Guardianship of Schiavo*, 780 So. 2d 176, 180 (Fla. 2d Dist. Ct. App. 2001).

216. Glover, *supra* note 60, at 1166 ("The family is a necessary part of health care decisionmaking because the patient himself or herself should make decisions as a family member."); Hardwig, *supra* note 178, at 6 (implying that a patient's treatment decisions should not be made in isolation of their effects on the patient's family). Nelson argues that families are entities that have moral significance and collective values and thus they should be recognized "(at least oftentimes) [as] valuable in themselves," not just sources for determining and advancing the patient's ends. Nelson, *supra* note 199, at 7.

What relevance, if any, should the proxy's own views regarding the right outcome have? Some have recognized that appointed proxies often do not accurately predict what the patient would have chosen. Does this make deference to the proxy inappropriate or even illegitimate? Or should we nonetheless defer to the proxy's choice because the patient chose the proxy? Or should we so defer only if the patient was explicitly made aware of the frequency of patient-proxy disjunctures and nonetheless chose to appoint a proxy?²¹⁷

Some of these disputes are embedded in arguments over what "autonomy" means in the end-of-life context.²¹⁸ Some advocate that decisions reflect the obligation to advance autonomy, narrowly construed.²¹⁹ Those arguing for more inclusive criteria frequently state that they are still seeking to advance the patient's autonomy, but that autonomy, properly understood, includes the patient's choice to consider the impact on her family²²⁰ or to defer to the proxy's decisions.²²¹ Others construe autonomy narrowly, but argue that it should be tempered by other values.²²²

217. See, e.g., BUCHANAN & BROCK, *supra* note 22, at 101-02 (acknowledging that patients who assign proxies are leaving decisionmaking to the proxies absent explicit directives).

218. This dispute is sometimes articulated in the language of "specific autonomy," i.e., the desire that a person's *particular wishes* be followed versus "general autonomy," which can include a person's preference that his or her desired *process* be used for making treatment decisions.

219. See Pope, *supra* note 166, at 145-46 (asserting that people want to exercise specific autonomy and calling for a much more detailed process of constructing advance directives to further this goal).

220. Bruce Jennings, *The Liberal Neutrality of Living and Dying: Bioethics, Constitutional Law, and Political Theory in the American Right-to-Die Debate*, 16 J. CONTEMP. HEALTH L. & POL'Y 97, 102, 104, 119 (1999); cf. MARY SIMMERLING, CHOOSING TO BE HARMED: AUTONOMY AND ITS LIMITS IN LIVING ORGAN DONOR TRANSPLANTATION 111-16 (2005) (providing a persuasive critique of concepts of autonomy in the organ donor context that fail to recognize that decisions reflecting our concerns about familial impact can embody autonomy properly understood, since patients make their decisions within webs of intrafamily care and felt obligation); Nedelsky, *supra* note 199, at 12 (suggesting that what allows autonomy are our "relationships with parents, teachers, friends, loved ones"); Stephen Sapp, *Death on Whose Terms? Crossing the Great Divide Between Patient Autonomy and Family/Community* 18 (Mar. 24, 2003) (unpublished manuscript, on file with the University of Miami Law Review) ("[W]e might be doing violence to someone's autonomy by forcing that person to exercise it when he/she would rather let a trusted and loved family member make the decision.").

221. See Sapp, *supra* note 220, at 18; see also Hawkins et al., *supra* note 164, at 108 (noting that "there is accumulating evidence to suggest that patients may, in fact, have little desire to exert [the] type of specific control over end-of-life medical decisions" embodied in advance directives); Orentlicher, *supra* note 5, at 1280 ("The choice of a surrogate decisionmaker is just as much an exercise of autonomy as the giving of a specific treatment instruction. As long as people understand that their surrogates may not choose exactly as they would have, the exercise in autonomy is a meaningful one. The important point is that the patient has decided how the decision will be made.").

222. See Boozang, *supra* note 100, at 549; Jerry A. Menikoff et al., *Beyond Advance Directives – Health Care Surrogate Laws*, 327 NEW ENG. J. MED. 1165 (1992) (both arguing that a narrow

Finally, courts and commentators differ as to the specificity with which the patient's wishes must be expressed (i.e., the substantive standard) and the requisite degree of certainty that those were the patient's wishes (i.e., the burden of proof).²²³ Those who would impose a greater degree of specificity or a higher evidentiary burden or both are, in effect, imposing a relatively strong default rule as part of the legal requirements – whether that rule is to continue life-sustaining medical treatment because the state should choose life²²⁴ or to withhold it either because most people would not want to be kept alive in those circumstances²²⁵ or because of healthcare resource allocation concerns.²²⁶

Many of these positions can be articulately and persuasively presented. Neither logic, nor evidence, nor indisputable ethical principles can tell us which is “correct.” Yet, insofar as the decision is one delegated to judges, some rule must be chosen.²²⁷ Whichever it is, the

focus on autonomy wrongly excludes a meaningful role for families); Nelson, *supra* note 199, at 7 (communal values of family as an entity should be considered and the autonomy of the patient not “privileged”); Rhoden, *supra* note 185, at 377 (arguing that courts engage in a legal fiction of taking these broader considerations into account by construing as relevant to autonomy facts that do not really fit within that concept); *see also* Jennings, *supra* note 220, at 104 (rejecting focus on autonomy in favor of attending to the question of what constitutes “good dying”); Schneider, *supra* note 47, at 413; Susan M. Wolf, *Foreword: Bioethics – From Mirror to Window*, 15 ST. LOUIS U. PUB. L. REV. 183 (1996) (urging a reorientation of bioethics generally away from its privileging of autonomy over other values such as communitarianism or social justice). *See generally* Hardwig, *supra* note 178 (construing autonomy narrowly but stating that ethical consideration may require taking familial impact into account); Nelson, *supra* note 199 (values of family as an entity should be considered).

223. *See generally* MEISEL & CERMINARA, *supra* note 16, at 3-132 to -134 (explaining the importance of not conflating these two issues).

224. O. Carter Snead, *The (Surprising) Truth About Schiavo: A Defeat for the Cause of Autonomy*, 22 CONST. COMMENT. 383, 391 (2005); *see also* *In re Conroy*, 486 A.2d 1209, 1232 (N.J. 1985) (concluding that when there is not sufficiently clear evidence of the patient's wishes, treatment can be withdrawn only when “the net burdens of his prolonged life . . . markedly outweigh any physical pleasure, emotional enjoyment, or intellectual satisfaction that the patient may still be able to derive from life” (emphasis supplied)). *See generally* David F. Forte, *The Role of the Clear and Convincing Standard of Proof in Right to Die Cases*, 8 ISSUES L. & MED. 183 (1992) (describing the clear and convincing evidentiary standard's status as a due process requirement).

225. *See, e.g.*, Cantor, *On Kamisar*, *supra* note 192, at 1840.

226. *See, e.g.*, BUCHANAN & BROCK, *supra* note 22, at 194-96 (explaining that where patients are in a PVS, they have no quality of life and their prior wishes might be overridden by concerns for distributive justice). As Bloche notes, there are toxic effects when resource allocation issues appear as covert rationing rather than as an explicit national conversation over the “conflict between efforts to limit medical spending and insistence on all possibly beneficial care.” Bloche, *supra* note 127, at 2373.

227. Alternatively, the decisional rule can be one that simply authorizes the judge to decide after evaluating a laundry list of factors. *Cf.* § 61.13(3), FLA. STAT. (2006) (authorizing a judge to determine custody of children in their best interest, after evaluating twelve specific factors plus “[a]ny other fact considered by the court to be relevant”). Such almost-unfettered judicial discretion is less desirable than a decision reflecting the discretionary choice of those more closely involved.

decision will incorporate certain value judgments and reject others that many citizens strongly hold. And, it will do so on matters intensely important to the people involved. By instead adopting a rule of strong deference to the consultant-guided choice of the family, healthcare professionals, and proxy, we encourage norm building within a community created to deal with this tragic choice.²²⁸ We simultaneously minimize the number of occasions when the state must apply generalized, formalized, and yet contestable value choices.²²⁹

In situations where the patient has executed an advance directive or named a substitute decisionmaker, I concluded above that we should accept the role of litigation when necessary to ensure that her choices are respected even if those currently able to participate in decisionmaking would choose otherwise. That conclusion was based on the importance of autonomy.

Autonomy is less significant where there is no advance directive.²³⁰ Or, perhaps, more accurately, autonomy's meaning is different in this context and can also include the patient's wish to let others take the lead in making the relevant decision.²³¹ Thus, in that situation I believe we should accept the legitimacy of a decision that arises from the alternative dispute resolution processes discussed here, even if it might be different than what a court would have decided. The family's consensus choice is the best alternative among the limited range of outcomes. It is not much less likely to advance the patient's explicit views than a trial judge's

228. See DUBLER & LIEBMAN, *supra* note 33, at 8; see also Glover, *supra* note 60, at 1167 ("We need to shift the focus in our accounts of moral adjudication away from the moment of individual choice to the process of collective reflection on the goods at stake in the choice.") (quotations and internal citation omitted)).

229. In effect, I suggest here a melding of classical liberalism: that the state should not determine the content of the good life but instead provide a structure that allows individuals to develop and implement their own views and communitarianism since values are to be developed and implemented within concrete communities formed to deal with the dilemmas raised by end-of-life issues for particular patients. See Moreno, *supra* note 97, at 24. Some commentators, uncomfortable with the degree of deference to the consensus view suggested here, yet acknowledging the undesirability of requiring judicial oversight, propose a range of rather peculiar intermediate institutions to assume the decisionmaking role. See, e.g., Krupp, *supra* note 112, at 127-28 (decision to be made by an attorney provided by the facility after a mini-trial); Moore, *supra* note 61, at 443 (discussing the implementation of a panel of three doctors whom the healthcare facility appointed to help make surrogate decisions). See generally Amitai Etzioni, *A Communitarian Approach: A Viewpoint on the Study of the Legal, Ethical and Policy Considerations Raised by DNA Tests and Databases*, 34 J.L. MED. & ETHICS 214 (2006).

230. Emanuel and Emanuel recognize the same limitations on ensuring with certainty that the proxy's decision actually reflects the autonomous choice the patient would have made. They then conclude that since this is not in fact advancing autonomy, the determination should not necessarily be left in the family's hands, but should reflect "the articulation of some shared community standards for treating the incompetent, even if these are only procedural standards permitting the family power over the patient." Emanuel & Emanuel, *supra* note 171, at 2070.

231. Orentlicher, *supra* note 5, at 1279-80.

determination, and it is more likely to embody the patient's wishes and her best interest (at least as they are understood by those closest to her). Finally, the consultant-guided process is least likely to embody someone's view about "what people in general would want in that situation," which has a tendency to become, in effect, a question whether we as a society believe this is a life worth living.²³² Doubtless, with advances in medical care and skyrocketing medical costs, we are likely to have no choice but to confront that question. We should not do so in the context of deciding what to do about particular patients, however, but collectively, *legislatively*, and with the requisite thoughtful, painful honesty.

To be sure, the interposition of a bioethics consultation/mediation is not risk-free. The participants could ignore the patient's clear wishes. The physicians or others could exercise unwarranted dominance in imposing their views on others. The patient or surrogate's legal rights could be overridden. Illegitimate concerns could infect the decision. These dangers are real.²³³ The issue, however, is whether such dangers are sufficient to raise doubts about the legitimacy of encouraging such consultations. I believe the answer is no.

First, all these risks increase if a decision is made at the patient's bedside, without the intervention of a bioethics consultant/mediator. Second, even insofar as an adjudicative process would mitigate these harms,²³⁴ emotional and financial costs may deter people from going to court. Third, adjudication, in this context, suffers from many of the same dangers. The patient is not a party except, perhaps, through the legal fiction of a guardian *ad litem*. Healthcare professionals may still dominate the process by articulating their positions as based on irrefutable medical facts. While the family or the proxy may be able to bring in other medical experts to contest these assertions, a decisionmaker who lacks medical expertise may too readily defer to the views of the treating physicians. The interposition of attorneys may, but need not, create a more level playing field, while the legal process will almost certainly make it more difficult for participants to articulate concerns outside the

232. Thus I reject Justice Stevens' position in *Cruzan*, which calls for a rule that would have the state act so as to "give[] appropriate respect to [Nancy Cruzan's] own best interests," which, he suggests, is an objective standard that reflects his and the guardian's assessment of her quality of life, with little mention of her own desires. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 331 (1990) (Stevens, J., dissenting). Indeed, he later proposes a constitutional rule that would allow the withdrawal of life-sustaining medical treatment when it was concluded that it was in the patient's best interest, even in the absence of any indicia of her wishes, as where she had never confronted the issue or had always been incompetent. *Id.* at 350.

233. See, e.g., Hoffman, *supra* note 33, at 825; see also *supra* notes 76-80 and accompanying text. See generally KRTEK, *supra* note 78, at 18-19 (discussing power imbalances).

234. See Menkel-Meadow, *supra* note 98, at 2663-65 (discussing the importance of assessing the appropriateness of adjudication or alternative dispute resolution within the specific context).

narrow range of those that are deemed legally relevant. While the courthouse doors must always remain open, there is no reason to assume that the processes behind those doors will effectively eliminate the potential problems a consultation/mediation process might raise. Thus, we should not be concerned if, in most cases, no one brings the case to court.

RECOMMENDATIONS AND CONCLUSIONS

What might we learn from the above inquiry? First, bioethics interventions could be very valuable in *Schiavo*-like situations.

Without supplanting the triad of patient, family, and physician, ethics committees provide a forum to which the decision-makers can turn when confronted with the perplexing choices generated by the biotechnological revolution. The committee ensures that the interests of all parties, especially those of the incapacitated person, have been adequately represented, and that the decision reached lies within the ranges of permissible alternatives.²³⁵

There are a few modest steps that might be taken to make bioethics consultations more available and accessible. First, more hospitals and other healthcare facilities should provide trained consultant/mediators.²³⁶ While some mechanism for dealing with bioethics questions must exist in every JCAHO-accredited healthcare facility, that mechanism may be only a formal ethics committee with some or all of the drawbacks and limitations described above.²³⁷ JCAHO or state licensing boards should at least require hospitals to report on whether they have a consultation/mediation process available, how its availability is effectively communicated to patients, proxies, and families, how frequently it is invoked, and how successful it has been in resolving or reducing conflict.²³⁸ Such systems, or any form of structured bioethics process, may not be generally available in the kinds of skilled nursing facilities in which Terri Schiavo lived.²³⁹ Perhaps cooperating arrangements between these facilities and the larger hospitals in which the doctors who serve the facility have admitting privileges could be designed.

235. Pollack, *supra* note 134, at 538-39 (internal citations and quotations omitted).

236. *Cf. id.* at 538-39 (suggesting that hospitals create ethics committees to assist in decisionmaking).

237. *See supra* notes 34-38 and accompanying text.

238. The institution's bioethics committee could conduct this retrospective review. Ideally, the reports of these reviews, appropriately redacted to remove identifying data, could provide the basis for a more systematic empirical study of what processes are most appropriate and efficacious. Such a process would apply systems for quality improvement to bioethics similar to those that are increasingly used in regard to patient safety and quality of care. *See generally* TROYEN A. BRENNAN & DONALD M. BERWICK, *NEW RULES: REGULATION, MARKETS, AND THE QUALITY OF AMERICAN HEALTH CARE* (1996).

239. *See In re Conroy*, 486 A.2d 1209, 1236-42 (N.J. 1985).

Furthermore, since such consultations may be most effective if offered early, systems should be instituted to encourage facilities, social workers, and nurses to keep families apprised of this resource as soon as it appears that a tragic choice may arise.²⁴⁰

Second, if these kinds of consultations are a valuable aspect of end-of-life care, funding for the consultation's modest costs might be found through private health insurance, Medicare, or Medicaid. If we want physicians and nurses to take the time to engage in consultation/mediations, this should be recognized in our compensation systems, not discouraged by managed-care economics that make this time noncompensable.²⁴¹ We not only need healthcare professionals to participate in these processes, we also need them to learn how to do so effectively. Bioethics committees' educational role should ideally include helping these professionals develop the skills to communicate with patients, families, and each other – skills that would improve the dialogue both within and outside a consultation/mediation process.²⁴²

The foregoing proposals place significant demands on the members of bioethics committees as well as on the bioethics consultant/mediators. Institutions must take care in choosing people who will fill these roles and must provide them with support systems and access to continuing education.²⁴³ The people who fill these roles should be appropriately

240. See Bloche, *supra* note 127, at 2372-73; Dresser, *supra* note 119, at 8-9. The Patient Self-Determination Act might be revised to ensure that the information provided to newly admitted patients informs them of (1) these processes and (2) their right to invoke them. See generally Patient Self-Determination Act of 1990, 42 U.S.C. §§ 1395i-3, 1395l, 1395cc, 1395bbb (2006).

241. Cf. LA PUMA & SCHIEDERMAYER, *supra* note 35, at 76 (calling for a procedure or diagnostic billing code that would recognize ethics consultants' labors); Orentlicher, *supra* note 5, at 1303 (suggesting that reimbursement rules be rewritten to provide an incentive for physicians to spend time learning the patient's views); Rich, *supra* note 71, at 331 (noting managed care's impact on necessary physician-patient communication). The physician's contribution could be recognized by designating these mediations as a separate compensable procedure or by adjusting the compensation schedule for those healthcare situations particularly likely to lead to the invocation of consultations/mediations. Nurses' participation is also generally important, and the general problem of nursing shortages may adversely affect consultation/mediation.

242. See Dr. Nessa Coyle, Mem'l Sloan-Kettering Cancer Ctr., Remarks at the Brooklyn Law School David G. Trager Public Policy Symposium: End-of-Life Care: Bioethical Perspectives and Conflict Resolution (Feb. 8, 2007) (describing the clinical communication training program at Memorial Sloan-Kettering Cancer Center).

243. A number of writers have stressed the skills a good consultant/mediator must have and the concomitant necessity of communicating the need for attaining and maintaining these skills among healthcare personnel. See, e.g., ASBH, *supra* note 31, at 12-16; DUBLER & LIEBMAN, *supra* note 33, at 35-39. See generally ROBERT A. BARUCH BUSH & JOSEPH P. FOLGER, THE PROMISE OF MEDIATION: RESPONDING TO CONFLICT THROUGH EMPOWERMENT AND RECOGNITION (1994); KRITEK, *supra* note 78 (explaining the need for a similar set of skills and setting out exercises to develop them among negotiation participants); Leonard L. Riskin, *Mindfulness: Foundational Training for Dispute Resolution*, 54 J. LEGAL EDUC. 79 (2004).

recognized and rewarded for this important and difficult work.²⁴⁴ Governmental bodies, private health insurance companies, foundations, and healthcare facilities themselves should invest the needed resources.

While efforts should be made to encourage the use of such processes, they should not be mandatory.²⁴⁵ Many jurisdictions require that the parties to child custody disputes engage in mediation before they may fully litigate their disputes.²⁴⁶ That model should not be followed here. While it is appropriate to ask if a bioethics consultation/mediation has occurred, or if a dispute has been submitted to a bioethics committee, there should be no obligation to do so. A consultation/mediation that occurs after at least one participant has invoked a court's jurisdiction is unlikely to be productive.²⁴⁷

Bioethical consultation/mediation is not a panacea. I believe, however, that it would benefit people facing end-of-life decisions and their families, healthcare personnel and facilities, as well as the courts and society as a whole, if more cases were resolved via those processes. If this were to occur, fewer cases would risk becoming the ugly, public fight that *Schiavo* ultimately was.

244. See LA PUMA & SCHIEDERMAYER, *supra* note 35, at 73-77 (discussing different systems for compensating ethics consultants).

245. This mitigates the sorts of concerns Professors Grillo and Fineman have raised regarding mandatory mediation in family law. See generally Fineman, *supra* note 85, at 729-30; Grillo, *supra* note 85, at 1549.

246. See, e.g., CAL. FAM. CODE § 3170 (2006); OR. REV. STAT. § 107.179 (2006); Helen W. Gunnarsson, *New Rules Expedite Custody Cases: New Supreme Court Rules, Effective July 1, Are Designed to Coordinate, Streamline, and, Most Importantly, Speed the Resolution of Custody Cases*, 94 ILL. B.J. 166, 166 (2006); Jean R. Sternlight, *Separate and Not Equal: Integrating Civil Procedure and ADR in Legal Academia*, 80 NOTRE DAME L. REV. 681, 695 n.65 (citing N.C. GEN. STAT. § 50-13.1 (2003); NEV. 8TH JUD. CIR. R. 5.70).

247. The healthcare facility should, however, consider the frequency with which bioethics disputes arising at its facility result in litigation and what a high frequency might suggest about the need for reforming those processes.