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Beyond Schiavo

Arthur L. Caplan and Edward J. Bergman

Arthur L. Caplan, PhD, is Director of the Center for Bioethics and Chair of the Department of Medical Ethics at the University of Pennsylvania School of Medicine, Philadelphia, caplan@mail.med.upenn.edu.

Edward J. Bergman, JD, is Director of Mediation Services at the Center for Bioethics at the University of Pennsylvania and a Lecturer in the Department of Legal Studies and Business Ethics at the Wharton School of Business of the University of Pennsylvania, ejb@gear3.net. ©2007 by *The Journal of Clinical Ethics*. All rights reserved.

In the aftermath of the *Schiavo* case, commentators continue to focus on the rights and wrongs that characterized this tragic high-profile saga from its inception.¹ Far less attention has been devoted to the lack of effective mechanisms by which differences between patients, surrogates, families, and healthcare providers can be addressed with dignity, a modicum of privacy, and the hope of consensual resolution.

Over the past 20 years, bioethicists and dispute-resolution professionals have begun to explore the use of bioethics mediation as a means of processing the especially painful class of disputes in which families disagree with one another, or with doctors, about the care of those who cannot communicate.² One salient characteristic of these controversies is the fact that each participant, whatever his or her role, invariably lays claim to the same concern — the best interests of the patient. While the patient's interest can be a stand-in for participants' fears and anxieties — a spouse's dread of being alone or a physician's discomfort with losing a patient — their positions are rarely a by-product of malice or ill will. None of these "stakeholders"³ may be conversant with the language of bioethics, but they may, nonetheless, be unwitting advocates of sound bioethical principles.

For example, a wife pleading for adherence to her husband's long-stated preference for death over respirator-dependent life is also an advocate for the principle of patient autonomy.⁴ A son who asks that his father be afforded every means available to medical science for the cure of his disease evidences a commitment to the principle of bene-ficence,⁵ or the duty of a physician to help the patient. A physician who states that a patient's condition is futile and concludes that heroic interventions will engender needless suffering is an advocate for non-mal-eficence⁶ or the duty to do no harm. Finally, family members who argue that, for religious, cultural, or personal reasons, they cannot abide death absent every attempt to preserve life, embody the bioethical principal that healthcare decisions must be made in the context of the individual's total life and value system so that family concerns, religious beliefs, and cultural norms (among other factors) must be given weight so long as the patient is not, in consequence, allowed to suffer unreasonably.⁷

What these examples reveal is the frequency with which end-of-life-disputes are not ethical controversies susceptible of definitive answers reached through ethical reasoning. Abstract principles articulated as dispositive by designated "experts" fail to capture, and arguably to respect, the unique and complex nature of

each such individual decision-making process.⁸ These are profoundly human conflicts in which each of the participants can be seen as a proponent of a particular balancing of ethical principles in the context of relationships, personal history, and competing value systems. Some commentators, emphasizing the role of narrative in clinical ethics, posit that patients themselves are the true ethicists whose moral choices unfold as the product of life stories that embody the meaning and ethics of ordinary life reflected in the sufferers' individual experience.⁹

Hospital ethics committees perform ethics consultations for individual cases in addition to their role in the formulation of institutional policies.¹⁰ Many observers agree that, whether by virtue of insufficient training and experience, procedures focused on producing a single, ethical imperative rather than a range of acceptable options, or reducing clinical ethics to decision by majority, or, worse, decision making driven by fear of legal liability, ethics committees have not always fulfilled the needs of acutely distressed individuals for assistance in end-of-life decision making.¹¹

A secondary concern is that some ethics committees, whatever their shortcomings, receive only a minuscule number of consultation referrals in relation to the number of events that might benefit from outside intervention.¹² Disputes in this realm encompass strained relationships, personality differences, cultural considerations, communication and information issues, and the need for a forum that can help empower those persons on the disadvantaged side of a dramatic imbalance of power.

Unless a participant is incompetent, ill-informed of the medical or contextual facts,¹³ or possessed of motives that prove inconsistent with his or her claimed commitment to the patient's best interests, one stated treatment preference is often not more, or less, ethical than another.¹⁴ While such conflicts are often subjected to traditional ethical analysis, the mediation process is well-suited to fleshing out the existence of disparate elements that may be driving a dispute.¹⁵

A number of commentators have characterized the ideal physician-patient relationship as patterned on a negotiation model.¹⁶ If such is the case, it appears logical that mediation, a form of assisted negotiation, be utilized when the unassisted physician-patient negotiation has gone awry. Genuine differences frequently exist between rational individuals in possession of the same facts and devoid of ulterior motives. Ideological battles waged in the media, as in the *Schiavo* case, foster public perception of family members as saints and sinners, seeking judicial validation of their asserted monopolies over decision making or simply righteousness. What actually occurred in *Schiavo*, and occurs in similar cases, is a failure of the patient's most significant others to reach consensus on a course of action. In such cases the court must determine, not which preference is ethically or even legally correct, but which individual is legally empowered to make a decision in the absence of agreement, and, in some instances (dependent upon the statutory and case law of the jurisdiction), whether mandated criteria have been applied by the decision maker.¹⁷

In the majority of cases, a responsible agreement that does not violate the right of a patient to choose (either in an express writing or by clear evidence of intent as defined by the law of the jurisdiction) and does not impose unnecessary suffering on the patient will be viewed as benign by both legal and bioethical criteria. Parenthetically, such agreements are unlikely to be attacked by third parties unless a legitimately interested party has been excluded from the process. What may be needed and useful in many situations is a form of bioethics mediation to resolve disputes or to prevent them from emerging.

Mediation of end-of-life-disputes is not a simple task. Talent, skill,¹⁸ and training¹⁹ are required of the bioethics mediator. Models for the effective use of neutrals in clinical settings are only in their infancy. Resources must be dedicated to the development of this specialized field — to professional training, scholarship, credentialing, criteria for success, and public awareness.

The unique aspects of bioethics mediation place special demands on the mediator. Neutrality and the perception of neutrality are jeopardized by the frequent status, to date, of bioethics mediators as employees of hospitals where cases are being considered.²⁰ Alternative provider options should be developed and studied. When the mediator is connected to the hospital, an exploration of steps to diminish the threat to neutrality should be undertaken. When the mediator is independent of the hospital, questions nonetheless persist

regarding the plausibility of neutrality when the mediator is charged with enforcing legal and ethical norms as constraints on the parties' self-determination.²¹

Patients and families are at the extreme end of a power imbalance in disputes with healthcare professionals who are versed in a vast and complex scientific literature. Lay participants are further handicapped by the psychological and physical debilitation associated with the illness or injury from which they suffer. Parties to a bioethics mediation are rarely represented by legal counsel. Hence, the mediator plays a significant role as communicator and translator of otherwise opaque information in the service of leveling the playing field.

But the mediator is not the patient's personal representative. The beneficial aspects of the mediator's possession of subject matter expertise in various aspects of medicine, beyond an understanding of legal and bioethical norms, seem evident. How and where this education is to be provided and what constitutes a reasonable, measurable standard of expertise has yet to be determined.

Confidentiality, a signature element of the mediation process in most non-bioethical healthcare contexts,²² is subject to inherent limitations in bioethics mediation because the patient's chart must remain accessible to subsequent healthcare providers who are not parties to the mediation.²³ State laws differ with respect to the privileged nature of mediation communications and when these may be discoverable.²⁴ To what extent, if any, should the mediation be charted? Will this have a chilling effect on candor within the process? If so, can these effects be minimized?

While all of these obstacles to the application of classical mediation paradigms in the healthcare arena are daunting, capitulation to such challenges denies stakeholders in the dispute a previously nonexistent forum in which they are given a voice, access to comprehensible explanations, an outlet for catharsis, and an arena in which to express dissent. Bioethics mediation confers similar benefits upon members of the healthcare team who may or may not have decision-making power in the event of nonagreement.

Since it is triggered by crisis, bioethics mediation inevitably demands an outcome. If mediation is unsuccessful, decisions will be made by those empowered to act, with or without unanimity amongst the stakeholders. If the less-empowered stakeholders disagree, they can appeal to the hospital administration or petition a court of law for intervention in accordance with the substantive and procedural requirements of the jurisdiction. While much commercial mediation is also conducted in the shadow of the law,²⁵ so that failure to reach a consensual resolution also leads to a litigated rather than negotiated outcome, many disputes outside the healthcare sphere can remain in suspense for years until the pressure for resolution becomes acute. The implications of this distinction for the conduct of bioethics mediation have not been fully explored. Commentators in the realm of international relations have postulated that crisis negotiations in a diplomatic context possess unique dynamics.²⁶ Experience may demonstrate that special crises are applicable in end-of-life disputes.

Technological advances in medicine will inevitably continue at a remarkable rate. Our ability to sustain life at various suboptimal levels will surely increase commensurately, rendering end-of-life disputes even more commonplace than at present. While a diversity of views on such delicate topics is inevitable, and reflects the complexity of life itself, participants in this most personal and definitive act of decision making must be afforded an appropriate forum in which to engage such profound issues with clarity and respect.

The politicization of the Schiavo family's painful and acrimonious struggle over the fate of their wife and child²⁷ clearly manifests society's failure to invest in processes that facilitate constructive dialogue for reconciliation of divergent, emotionally charged perspectives on life-and-death issues. This failure carries potentially damaging consequences for an increasing number of families. We believe the time has come for bioethicists and individuals associated with hospital ethics committees to invest in the development of bioethics mediation. We owe that to the vast number of people who now, or inevitably will, face awesome confrontations with mortality in hospital settings. Bioethics mediation carries the promise of a significant contribution to a pressing issue in American healthcare in a manner that complements existing skills and infrastructure while greatly expanding the opportunity for consensual resolution of a significant class of disputes.

NOTES

1. A.L. Caplan, J.J. McCartney, and D.A. Sisti, ed., *The Case of Terri Schiavo: Ethics at the End of Life* (New York: Prometheus Books, 2006).

2. N.N. Dubler, "Mediation & Managed Care," *Journal of the American Geriatrics Society* 46, no. 359 (1998) (proposing a bioethics mediation model in the managed-care context); see also R.J. Wagener, "Introducing Medication to Hospital Ethics," *California Law* (December 1992): 69 (noting the formation of a center specializing in bioethics mediation); see also M.B. West and J.M. Gibson, "Facilitating Medical Ethics Case Review, What Ethics Committees Can Learn from Mediation and Facilitation Techniques," in *Bioethics: An Introduction to the History, Methods, and Practice*, ed. N. Jecker, A.R. Jonsen, and R.A. Pearlman (Sudbury, Mass.: Jones & Bartlett, 1999), 293-99; see also Y. Craig, "Patient Decision-making: Medical Ethics and Mediation," *Journal of Medical Ethics* 22 (1996): 164-7; see also J.M. Gibson, "Mediation for Ethics Committees: A Promising Process," *Generations* 18, no. 4 (1994): 58-60.

3. B. Gray, *Collaboration: Finding Common Ground for Multiparty Problems* (San Francisco, Calif.: Jossey-Bass, 1989), 5, 14-5, 62-6, 168-9, 261-64.

4. T.L. Beachamp and J.F. Childress, *Principles of Biomedical Ethics*, 5th ed. (New York: Oxford University Press, 2001).

5. Beauchamp and Childress, see note 4 above.

6. Beauchamp and Childress, see note 4 above.

7. A.R. Jonsen, M. Siegler, and W.J. Winslade, "Introduction," in *Clinical Ethics*, 5th ed. (New York: McGraw Hill, 2002), 2-11.

8. K.D. Clouser and B. Gert, "A Critique of Principlism," in Jecker, Jonsen, and Pearlman, *Bioethics: An Introduction to the History, Methods, and Practice*, see note 2 above, pp. 147-57.

9. See, e.g., R. Charon and M. Montello, ed., *Stories Matter: The Role of Narrative in Medical Ethics* (New York: Routledge, 2002).

10. D.E. Hoffman, "Mediating Life and Death Decisions," *Arizona Law Review* 36 (1994): 821, 822-3, 842-8 (explaining how ethics committees arose to provide a multi-disciplinary approach to assist families with difficult cases); see also J. McIver, "Mediation for Ethics Committees: A Promising Process," *Generations* 94 (1994): 58.

11. See E. Fox and R.A. Pearlman, "Ethics Consultation in United States Hospitals: A National Survey," *American Journal of Bioethics* 7, no. 2 (2007): 13-25; Hoffman, "Mediating Life & Death Decisions," see note 10 above (naming structural, process, and substantive concerns associated with ethics committees); A. Fiester, "The Failure of the Consult Model: Why 'Mediation' Should Replace 'Consultation'," *American Journal of Bioethics* 7, no. 2 (2007): 31-2.

12. Fox and Pearlman, see note 11 above.

13. See e.g. D. Franklin, "Come Again? Good Medicine Requires Clarity," *New York Times*, 24 January 2006 (discussing problems of providing enough information to obtain patients' informed consent, particularly for those with low levels of literacy).

14. Hoffman, "Mediating Life & Death Decisions," see note 10 above (stating some ethics committees appear uncomfortable with trying to determine one ethical answer, believing a range of options are acceptable); Society for Health and Human Values — Society for Bioethics Consultation Task Force on Standards for Bioethics Consultation, *Core Competencies for Health Care Ethics Consultation* (Glenview, Ill.: American Society for Bioethics and Humanities, 1998), 7 (discussing the ethicist's role in helping families choose between more than one morally acceptable option).

15. See e.g. C.W. Moore, *The Mediation Process: Practical Strategies for Resolving Conflict*, chaps. 9 and 10 (San Francisco, Calif.: Jossey-Bass, 1996), 213-43; D. Golann, *Mediating Legal Disputes: Effective Strategies for Lawyers and Mediators*, chap. 2 (Boston: Little Brown, 1996), 39-59; Hoffman, "Mediating Life & Death Decisions," see note 10 above (noting this has led some to "refer to mediation as a more feminine approach to conflict resolution").

16. A. Lazare, *On Apology* (New York: Oxford University Press, 2004), 204; A. Lazare, *The Interview as a Clinical Negotiation*, in *The Medical Interview: Clinical Care, Education and Research*, ed. M. Lipkin, Jr., et al. (New York: Springer-Verlag, 1995), 60-2; see also J. Groopman, "Introduction," in *How Doctors Think* (New York: Houghton Mifflin, 2007), 1-26 (arguing that effective medical diagnosis is dependent on the artful employment of negotiation skills, e.g. "open-ended questioning" and "active listening"); see also P.W. Chen, *Final Exam*, chap. 8 (New York: Alfred A. Knopf, 2007), 166-8 (discussing important patient interview techniques).

17. See generally, J. Menikoff, *Law and Bioethics: An Introduction*, chaps. 10 and 11 (Washington, D.C.: Georgetown University Press, 2001), 241-355.

18. *Core Competencies for Health Care Ethics Consultation*, see note 14 above (asserting that ethicists need ethical assessment, processing, and interpersonal skills); see generally, N. Dubler and C. Liebman, *Bioethics Mediation* (New York: United Hospital Fund, 2004).

19. Dubler and Liebman, *Bioethics Mediation*, see note 18 above, pp. 16-21 (highlighting the areas in which an ethicist must be knowledgeable).

20. See generally L.J. Marcus et al., *Renegotiating Health Care* (San Francisco, Calif.: Josey-Bass, 1995), 327-8 (providing examples of neutrality issues associated with informal mediation by an employee of an institution); K. Gibson, "Mediation in the Medical Field: Is Neutral Intervention Possible?" *Hastings Center Report* 29, no. 5 (1999): 6-13; *Core Competencies for Health Care Ethics Consultation*, see note 14 above, p. 7 (discussing the importance and difficulty of maintaining constituent neutrality).

21. D. Perlman, "Mediation and Ethics Consultation: Towards a New Understanding of Impartiality," 2001, <http://www.abanet.org/dispute/essay/perlman.doc> (arguing that ethicists should not remain neutral in regards to moral norms, but only in regards to the parties); Hoffman, "Mediating Life and Death Decisions," see note 10 above, p. 821.

22. Gibson, "Mediation in the Medical Field," see note 20 above, p. 6 (explaining a working assumption for many mediators is that the mediation must remain confidential).

23. See e.g., Dubler and Liebman, *Bioethics Mediation*, note 18 above, pp. 26-7.

24. The discoverability of a patient's chart note containing references to a mediation process requires an analysis of each state's mediation statutes and court rules and the state's case law interpreting those sources.

25. See generally, E.J. Bergman and J.G. Bickerman, *Court-Annexed Mediation: Critical Perspectives on Selected State and Federal Programs* (Bethesda, Md.: Pike & Fischer, 1998).

26. See e.g. B. Starkey, M.A. Boyer, and J. Wilkenfield, *Negotiating a Complex World* (Lanham, Md.: Rowman & Littlefield, 1999), 83-5.

27. T.A. Shannon, "The Legacy of the Schiavo Case," in *The Case of Terri Schiavo: Ethics at the End of Life*, ed. Caplan, McCartney, and Sisti, see note 1 above, pp. 260-3.