

A “PRINCIPLED RESOLUTION”: THE FULCRUM FOR BIOETHICS MEDIATION

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The concept of a “principled resolution” is the foundation for bioethics mediation.¹ This article presents the core bioethical principles that support the creation of principled resolutions as fulcrums for resolving disagreements in the healthcare setting. These disputes may arise among medical providers, between medical providers and patients, or among members of a patient’s family and can be managed or resolved by bioethics mediation using the conceptual tool of a principled resolution.

I

THE FOUNDATION

A. Bioethics Fundamentals: The Foundation for Principled Resolutions

Bioethics is a body of scholarship produced by philosophers, lawyers, judges, medical-care providers, and theologians who, in a lively set of dialogues over the last four decades, have identified shared values and legal rules that provide the basis for the normative principles and precepts of modern medicine.² These normative statements have been derived from benchmark ethical theory, largely propounded by John Stuart Mill and Immanuel Kant, which deals with interlocking ideas about morality and human behavior. These now arcane writings were modernized by the new field of bioethics in response to the development of the modern healthcare enterprise.³ Issues of care related to increasingly powerful medical technology that could maintain organ function

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1. NANCY NEVELOFF DUBLER & CAROL B. LIEBMAN, *BIOETHICS MEDIATION: A GUIDE TO SHAPING SHARED SOLUTIONS*, REVISED AND EXPANDED EDITION 14–15 (2011).

2. *See generally* TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* (5th ed. 2001); ALBERT R. JONSEN, MARK SIEGLER & WILLIAM J. WINSLAD, *CLINICAL ETHICS: A PRACTICAL APPROACH TO ETHICS DECISIONS IN CLINICAL MEDICINE* (6th ed. 2006); BERNARD LO, *RESOLVING ETHICAL DILEMMAS: A GUIDE FOR CLINICIANS* (4th ed. 2009); LINDA FARBER POST, JEFFREY BLUSTEIN & NANCY DUBLER, *HANDBOOK FOR HEALTH CARE ETHICS COMMITTEES* (2007).

3. *See generally* BEAUCHAMP & CHILDRESS, *supra* note 2.

beyond the existence of an integrated, relational person led to questions of withdrawing and withholding treatment from such patients and, under pressure from the field of solid-organ transplantation, to the development of criteria for the determination of brain death.⁴ Surrogate parenting, stem cell research, feminist ethics, ethics of disability, racial discrimination in healthcare, and other evolving issues have all demanded a contemporary exploration of emerging medical issues in light of established principles and shared societal commitments.⁵

Bioethics involves a set of ethical tenets that support the therapeutic relationship and give rise to physician and caregiver obligations. These include patient autonomy (supporting and facilitating the capable patient's exercise of self-determination), beneficence (promoting the patient's best interest and well-being and protecting the patient from harm), non-maleficence (avoiding doing harm to the patient), and distributive justice (allocating fairly the benefits and burdens of healthcare delivery).⁶ Finally, bioethics is about legal rules that have been created by courts and legislative bodies at the federal and state levels.⁷ These rules have recognized and responded to the evolving standards of care in medicine and defined the outer boundaries of a spectrum of possible behaviors from which a principled resolution is selected.⁸

B. Introduction to the Notion of the Principled Resolution

Congress; state legislatures; federal and state courts; and scholars in law, medicine, and philosophy have all addressed the process of how patients, family members, and medical professionals allocate decision-making authority and responsibility in the clinical-medicine setting.⁹ The rules are crisp and clear; the implementation, affected as it is by emotion, fear, and misunderstanding, can be messy.¹⁰

A principled resolution is a "consensus that identifies a plan that falls within clearly accepted ethical principles, legal stipulations, and moral rules defined by ethical discourse, legislatures, and courts, and that facilitates a clear plan for future intervention."¹¹ In 2005 Carol Leibman¹² and I were first struggling with

4. See generally *id.*; N.Y. STATE TASK FORCE ON LIFE AND THE LAW, WHEN OTHERS MUST CHOOSE: DECIDING FOR PATIENTS WITHOUT CAPACITY (1992); N.Y. STATE TASK FORCE ON LIFE AND THE LAW, THE DETERMINATION OF DEATH (2d ed. 1986).

5. See generally TOM L. BEAUCHAMP & LEROY WALTERS, CONTEMPORARY ISSUES IN BIOETHICS (6th ed. 2003); N.Y. STATE TASK FORCE ON LIFE AND THE LAW, SURROGATE PARENTING, ANALYSIS AND RECOMMENDATIONS FOR PUBLIC POLICY (1988).

6. See BEAUCHAMP & CHILDRESS, *supra* note 2, at 57.

7. See generally JERRY MENIKOFF, LAW AND BIOETHICS: AN INTRODUCTION (2001).

8. See generally DUBLER & LIEBMAN, *supra* note 1.

9. See, e.g., BEAUCHAMP & CHILDRESS, *supra* note 2; JONSEN, SIEGLER & WINSLAD, *supra* note 2; LO, *supra* note 2; POST, BLUSTEIN & DUBLER, *supra* note 2.

10. See, e.g., Arthur L. Caplan & Edward J. Bergman, *Beyond Schiavo*, 18 J. CLINICAL ETHICS 340, 340 (2007).

11. DUBLER & LIEBMAN, *supra* note 1, at 14.

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the tensions among three competing factors: (1) the stringent limits imposed by law on medical providers and institutions,¹³ (2) the powerful decision-making authority permitted to individual patients and families in medical decision-making, and (3) the power imbalances that infuse the operations of the modern hospital and medical center. The notion of a principled resolution combines the strengths of a mediative process that levels the playing field with legal norms and ethical conventions, and uses both as support for forging a consensus. A principled resolution reflects the deep and thorough support in the law and in society for decisions of patients and families, especially when these decisions contest the juggernaut of modern, institutionalized medical care.

II

THE PRACTICE OF APPLIED BIOETHICS

A. Applying Bioethics: The Practice of Clinical-Ethics Consultation (CEC)

Bioethics emerged as a distinct voice, largely in the 1970s and 1980s, in discussions about the allocation of decision-making authority and responsibility in medicine. It developed as the technical abilities of medicine to support organ function and address illness and disease expanded without concomitant agreement regarding who decides within what limits these new technical abilities should operate. Before the mid-twentieth century, medicine could diagnose and comfort, but could rarely cure. But after World War II, when antibiotics became available, intensive care units were created, antipsychotic drugs were developed, and resuscitation was widely integrated into care, there was the need to designate and empower those who could consent to or refuse care because there were real choices to be made. As the technical abilities of medicine expanded and access to healthcare reached more patients with the passage of Medicare and Medicaid, who decides, based on what standards, and with what sort of appeal and review became increasingly important.¹⁴ If decisions needed to be made, who should make them and how?

By tradition and habits of practice, physicians made the majority of decisions based on judgments regarding what was in the best interest of the patient. But litigation sharpening the doctrine of “informed consent” demonstrated that individuals—whose values, personal history, wants, and individual notions of the good life were defeated by physicians’ choices—wanted to decide for

13. See generally John J. Paris, *Court Intervention and the Diminution of Parents’ Rights: The Case of Brother Joseph Fox*, 303 NEW ENG. J. MED. 876 (1980).

14. See generally DAVID J. ROTHMAN, STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING (Aldine Transaction 2003) (1991); Nancy Neveloff Dubler, *The Legal Aspects of End-of-Life Decision Making*, in CHALLENGES OF AN AGING SOCIETY: ETHICAL DILEMMAS, POLITICAL ISSUES 20 (Rachel A. Pruchno & Michael A. Smyer eds., 2007).

themselves.¹⁵ At the same time, healthcare institutions realized that the documentation in an informed-consent form, which did not necessarily indicate a robust discussion or a process of engagement between physician and patient, might be protective in later litigation because it could indicate that the patient had knowingly assumed the risk of the intervention. From these factors the simulacrum of dialogue developed regarding who decides.

On closer inspection, however, if one directed a clinical ethics consultation service, as I did from 1978 to 2008,¹⁶ the landscape looked distinctly askew. Most patients and family members were deeply intimidated by the culture and operation of medicine. As the first mentor in mediation to the Montefiore Clinical Ethics-Consultation Service stated, “Doctors speak doctor; nurses speak nurse; and no one speaks patient or family.”¹⁷ The terms and conditions of medicine were confusing, the sights and smells were off-putting, the fear of a bad outcome was ever present, and the impression of the “unstoppable” of care was overwhelming. Clinical-ethics (CE) consultants wondered how to counter all of these seemingly inevitable aspects of highly technological, highly impenetrable, institutional healthcare delivery.

Concurrent with the growth of bioethics scholarship was the development of institutional ethics committees. These developed largely in hospitals, but also in long-term-care facilities and occasionally in home-care agencies. They addressed actual cases and the dilemmas that emerged in trying to adjust the perceived duties and obligations of healthcare providers and healthcare institutions to the values, wishes, wants, and desires of patients, and—even more—of family members on behalf of incapacitated patients. In 1992, the Joint Commission on the Accreditation of Hospital Organizations created a new standard that required all institutions to have the capacity to address ethical issues.¹⁸ After that, ethics committees became the norm of institutional healthcare practice.

At the outset these committees addressed education, policy development, and case consultation. The last generally consisted of a retrospective analysis of case situations in which certain practice decisions seemed to be at odds with the concerns and values of the patient and family. Early on, committees would address the issue of a patient who wanted to refuse treatment and accept death, which was seen to be in conflict with the physician’s obligation to support life. Gradually courts and commentators agreed upon a set of rules and norms that set parameters for case resolution. They include the following precepts:

15. See, e.g., *Canterbury v. Spence*, 464 F.2d 772, 782–84 (D.C. Cir. 1969); *Salgo v. Leland Stanford Jr. Univ. Bd. of Trs.*, 317 P.2d 170, 181 (Cal. Ct. App. 1957).

16. Division of Bioethics, Montefiore Medical Center, Bronx, New York.

17. Leonard Marcus, Dir. of the Program for Health Care Negotiation and Conflict Resolution, Harvard Univ. School of Pub. Health, Remarks at the Montefiore Medical Center Mediation Training (Spring 1991).

18. JOINT COMM’N ON ACCREDITATION OF HEALTHCARE ORGS., ACCREDITATION MANUAL FOR HOSPITALS (1992 ed., 1991).

1. Competent adult patients have the right to consent to or to refuse care even if the result of that refusal is death;¹⁹
2. Patients who are not capable of making decisions may execute an advance directive, such as a living will or a durable power of attorney for healthcare decision-making, to extend their values and wishes beyond their ability to insist on an outcome;²⁰
3. If the patient has not executed an advance directive, state law will determine which persons have what degree of authority to decide for the patient;²¹
4. Children are entitled to decisions made in support of their “best interest”;²²
5. Death may be preferable to extending the process of dying in children and incompetent patients;²³
6. Neonates and adolescents present complex circumstances in which the parents, pediatricians, patients (in the case of adolescents), advocates, and the state may all offer positions legally and morally demanding cognizance.

These sorts of developing principles and norms became the basis for ethics committees branching out to intervene prospectively into developing cases. Thus came the growth of CEC services, as independent services or as a function of a subcommittee of the ethics committee.²⁴ But what was the framework for this intervention? Joan McIver Gibson in New Mexico experimented with the ethics committee’s ability to mediate differences.²⁵ But committees are unwieldy and of uncertain dynamics. Much to be preferred are trained professionals, who are knowledgeable about medicine, relevant law, and regulations that govern the doctor–patient encounter, and who are also trained with the skills and interventions of a mediator.

Of greatest concern was the *non-self-executing* nature of the rules regarding the allocation of medical decision-making authority. These were excellent rules for courts and scholarly articles. However, in the guts of the hospital, on the wards, in the clinics, and in difficult and fraught situations, hardly anyone knew

19. POST, BLUSTEIN & DUBLER, *supra* note 2, at 288 (citing *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 306 (Cal. Ct. App. 1986)).

20. *Id.* at 291 (citing *Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261 (1990)).

21. *Id.*

22. *Id.* at 294 (citing *Custody of a Minor*, 379 N.E.2d 1053 (Mass. 1978)).

23. *Id.* at 290 (citing *In re Conroy*, 486 A.2d 1209 (N.J. 1985)).

24. Nancy Neveloff Dubler et al., *Charting the Future: Credentialing, Privileging, Quality, and Evaluation in Clinical Ethics Consultation*, HASTINGS CENTER REP., Nov.–Dec. 2009, at 23, 31; see also POST, BLUSTEIN & DUBLER, *supra* note 2, at 1.

25. See generally Mary Beth West & Joan McIver Gibson, *Facilitating Medical Ethics Case Review: What Ethics Committees Can Learn from Mediation and Facilitation Techniques*, 1 CAMBRIDGE Q. HEALTHCARE ETHICS 63 (1992).

them; how were they to become the real bases for decisions made in the course of clinical care?²⁶

CE consultants engage in various tasks in the course of their work as they confront misunderstandings, disagreements, disputes, and full-blown conflict in the course of helping to set the specific course for the care of a sick and debilitated patient.²⁷ Sometimes CE consultants merely clarify the protocols that govern medical decision-making—for example, the rules that are relevant to selecting and empowering family members to choose a course of care for a relative who is not capable of making decisions. Many times they clarify the issues and help the parties see the options and choices. Always, they teach about the law, medicine, and ethics and how these interact in a patient-care setting.

CEC is an intervention in which a trained clinical-ethics professional

- responds in a timely fashion to the request for a CEC from any member of the medical-care team, the patient, or a family member;
- reviews the patient's medical record;
- either interviews relevant medical stakeholders or gathers the clinical-care team and other consultants to discuss the case;
- visits the patient and family whenever possible;
- as a preliminary matter, identifies the ethical issues at play and any sources of conflict;
- involves the patient or family with care providers to promote communication, explore options, and seek consensus, when appropriate;
- employs expert discussion of bioethical principles, practices, and norms and uses reason, facilitation, negotiation, or mediation to seek a common judgment regarding a plan of care going forward;
- attends to the social, psychological, and spiritual issues that are often at play in disagreements about the proper course of care;
- triggers a further process with hospital medical leaders or a bioethics committee to resolve the situation, if a resolution is not reached;
- follows up with a patient and family after the initial consultation (although this feature of CEC varies, since in some systems follow-up is a task solely for the medical team);
- records the process and substance of the consultation, including the consultant's recommendations and their justification, as part of the patient's medical record;
- reviews the consultation with others on the CEC service as a basic level of evaluation and peer review; and
- utilizes a formal and rigorous quality-improvement process.²⁸

26. Arthur S. Slutsky & Leonard D. Hudson, *Care of an Unresponsive Patient with a Poor Prognosis*, 360 NEW ENG. J. MED. 527, 528–29 (2009).

27. Dubler et al., *supra* note 24, at 25.

28. *Id.*

The most challenging situations CE consultants face, however, are those in which a subset of care providers and family members have faced off over the divide of a demented or debilitated patient, a neonate, or an adolescent, and are locked in combat over what is the proper course of treatment for this patient. In some instances, the staff and family are interpreting the values, history, explicit wishes, and life patterns of the patient. In others, they may be struggling with what is in the best interest of the patient and whether the notion of best interest includes the option of death. In these cases, the CE consultant must be prepared to engage in bioethics mediation designed to focus and sharpen the usual tasks of consultation and to arrive at a consensus that permits care to go forward.

CE consultants address some of the most divisive and contentious issues in American society.²⁹ CEC is a service within the hospital that, when difficult decisions must be made, “provides an additional resource and a conduit for complex communication among patients, their families (including relatives, significant others, close friends, and appointed surrogates), and the care team.”³⁰

CEC deals with life and death decisions pitting the family members’ needs to feel that “everything that can be done has been done” against the medical team’s perception that comfort is the only appropriate medical plan for a patient who is in the process of dying. Alternatively, CEC may involve medical providers who urge aggressive care opposing family members who feel that “the patient has suffered enough.” CE consultants also address situations in which family members clash with hospital policy. Consider, for example, the increasing tendency of intensive-care units (ICUs) to have policies dictating the discharge of patients to less-monitored beds whenever they are no longer benefiting from enhanced, carefully calibrated interventions. Although family members know that transfer signals a diminished chance for patient survival, this policy is based on the fact that ICU beds are a scarce resource that must be allocated fairly to those in need.³¹

Conflict is inevitable in modern American healthcare institutions.³² All healthcare is economically stressed, overburdened by underinsured and uninsured patients, overloaded with expensive technology, and under suspicion by patients and family members who have previously been excluded from care due to poverty or race. Just consider contemporary discussions about abortion,

29. Gordon DuVal et al., *What Triggers Requests for Ethics Consultations?*, 27 J. MED. ETHICS. i24, i27 (2001) (finding conflict and emotionally based triggers prompt ethical consultation more frequently than cognitive-based dilemmas).

30. Dubler et al., *supra* note 24, at 23.

31. POST, BLUSTEIN & DUBLER, *supra* note 2, at 192.

32. See, e.g., Slutsky & Hudson, *supra*, note 26, at 527; see also Atul Gawande, *Letting Go: What Should Medicine Do When It Can't Save Your Life?*, NEW YORKER, Aug. 2, 2010, at 33, available at http://www.newyorker.com/reporting/2010/08/02/100802fa_fact_gawande (discussing differences in perspective and views on care among providers, patients, and family members when patients are dying).

the care of Terri Schiavo,³³ or the treatment of imperiled newborns and the likelihood of these topics to import emotion into discourse.

B. From Clinical-Ethics Consultation to Bioethics Mediation

Montefiore Medical Center was at the forefront of developing a prospective CEC service.³⁴ Physicians, social workers, nurses, and others would call the CEC service, staffed by a philosopher and a lawyer, whenever they faced an “ethical dilemma.” As the service matured, the medical-care staff realized that, in addition to specialized knowledge of philosophy and law, these consultants brought an added value to the discussion of clinical matters that were in the process of escalating toward a seeming impasse; they brought the notion of “neutral turf”—a unique voice in these difficult clinical situations. This voice was the result of several unique aspects of the CEC.

First, the role of CEC was to harmonize conflicting obligations and values. CE consultants were committed to support shared decisions that honored the patient’s autonomy, the family’s reflection of patient values, and the clinical team’s obligations to promote the patient’s well-being. As a champion of the interests of both sides, the CE consultant was able to garner the trust and participation of both clinical teams and families. Second, CE consultants were naïve to the prior developments in the case. This meant that they were not responsible for an outcome—almost always negative—since no one calls for help when all is moving along smoothly. Third, CE consultants needed to hear the narrative, even after reading the chart, to understand what had really happened. This “fresh” lens allowed all parties to hear each other with more complete, current information, and often learn missing pieces of information. Fourth, CE consultants had no history of conflict with the care providers, patient, or family in this case. Thus, they were invested in neither the stakeholders’ solutions nor their positions and could present a new frame for discussion. Because of these four characteristics of the CE consultants’ work, CEC provided a variety of neutral turf for discussion and decision.

Neutral turf is what mediators bring to a dispute: distance from the parties and the issues, specific skills in managing conflicts, and a process for directing difficult conversations.³⁵ Thus began an odyssey toward the creation of bioethics mediation directed at understanding and managing situations of conflict as a specific set of skills for CEC.

33. See George J. Annas, “Culture of Life” Politics at the Bedside—The Case of Terri Schiavo, 352 *NEW ENG. J. MED.* 1710 (2005); Lawrence O. Gostin, *Ethics, the Constitution, and the Dying Process: The Case of Theresa Marie Schiavo*, 293 *J. AM. MED. ASS’N* 2403, 2403 (2005).

34. The first consultation service in Montefiore Medical Center began in 1978.

35. DUBLER & LIEBMAN, *supra* note 1, at xiv, 13.

C. Bioethics Mediation

Bioethics mediation is one of the tools of CEC, a subspecialty of bioethics, and an example of applied ethics in which a trained professional, generally a physician, nurse, social worker, lawyer, or philosopher, acts as a consultant to the medical team to address discomforts about care planning and the implementation of previously forged care agreements.³⁶

In bioethics mediation, a principled resolution reflects a clinical plan of action agreed upon by relevant stakeholders and chosen from among multiple morally permissible options that fall within the spectrum of acceptable clinical, ethical, and legal outcomes. Bioethics conflict is almost always about the “proper” or “appropriate” plan for future care.³⁷ The parties generally include the attending physician, other members of the healthcare team, and some advocate for the patient.³⁸ This advocate can be a family member or friend. Sometimes the patient is alone without family, such as an “unbefriended elderly” or “unrepresented patient.”³⁹ The mediation is largely with non-patient advocates because capacitated adult patients have the legal right to accept or reject medical alternatives even if their decisions are thought to be wrong by others.⁴⁰ Thus, bioethics mediation often addresses situations in which the adult patient is allegedly incapacitated, is clearly incapacitated, or is a minor or an otherwise legally compromised person.⁴¹

The bioethics mediator is always neutral to the particular case, but is likely to be known to the medical staff.⁴² Indeed, case-mediation requests often come from satisfied repeat users of the service. One of the differences between bioethics mediation and other sorts of mediation is that the mediator is generally a member of the CEC team, giving her access to the healthcare institution, the right to intervene in the case, and the power to write a note in the medical chart, which is the legal record of the patient’s care.⁴³ In the chart note, the bioethics mediator notes the principled resolution as the consensus reached and, therefore, the CE recommendation. In general, the physician, who has the legal authority and responsibility for the patient’s care, will be a part of the mediation; thus committed to the consensus, she will write any orders as needed to effectuate the resolution.

36. AM. SOC’Y FOR BIOETHICS & HUMANITIES, TASK FORCE ON STANDARDS FOR BIOETHICS CONSULTATION 3 (2010) (noting that clinical ethics consultants and consultation are referred to as “health care ethics” consultants).

37. Dubler et al, *supra* note 24, at 26.

38. *Id.*

39. See Naomi Karp & Erica Wood, *Incapacitated and Alone: Healthcare Decision Making for Unbefriended Older People*, 31 HUM. RTS. 20, 20 (2004) (noting that the unrepresented patient is preferable because the patient may also be a younger, isolated, and perhaps mentally-ill person).

40. LO, *supra* note 2, at 83; POST, BLUSTEIN & DUBLER, *supra* note 2, at 89–90.

41. DUBLER & LIEBMAN, *supra* note 1, at 17, 141.

42. *Id.* at 23.

43. Dubler et al., *supra* note 24, at 26–27.

The bioethics mediator recognizes that there are always multiple options for the plan of care.⁴⁴ This may be in distinct contrast to the medical providers who more often tend to see only the best plan. This is not surprising because physicians are trained to evaluate medical data and act to reach the optimum goal. It goes counter to training, instinct, and paternalistic habits to see non-medical factors as relevant and valid. Even as physicians and practitioners began increasingly to recognize that medical choices reflect personal values and history, they still jockeyed to maintain control of the decision-making process. They did so out of the lofty motive to do what is in the “best interest” of the patient and the not-so-elevated characteristic of having no real experience in sharing power. The mediator helps the parties to maximize options either by defining actually distinct end points or by introducing new timetables that better permit the accumulation of data.⁴⁵ Thus the bioethics mediator plays the crucial role of opening space and time for considering other factors.⁴⁶

Consider the following vignette of a large, loving, and chaotic family (let us say) from Bosnia in which the healthcare proxy, the oldest son, is decompensating at the imminent death of his mom and is drinking heavily. He has had a number of clashes with the nursing staff in the ICU; some of the staff are merely wary and some are actively scared of him. The mediator and the attending physician have tried to move the family, all seventeen of them who are present, to accept the fact that mom is dying. The oldest son (the healthcare proxy) finally explodes and demands that the physician give mom a special tonic she used to take when she lived at home. Left to her own devices, the physician is likely to reject this out of hand. Nothing has prepared her for the experience of providing an unknown substance to a dying patient. However, the mediator has been at this for some time and says the following:

How lucky is your mom to have family who love her so much, are willing to spend so much time and effort to make her better. Now, I hear the doctor saying that this tonic is unlikely to help your mom, that she is dying and beyond the help of any medicine. However, it might be possible for the pharmacy to analyze this tonic and if they agree that it could not harm her, we might be able to give it to the patient.

By stroking, repeating, and reinforcing, the bioethics mediator has bought some time, supported the family (or at least the oldest son), deflected the annoyance and punitive reaction of the physician, and, with a bit of luck and a call on the “favor bank” at the pharmacy, would make this action possible. Her logic, from the bioethics perspective, is simple:

The patient was given the tonic at home as her family believed that it would help cure her ailment. She is now dying and cannot be discharged home where the family could continue with old remedies. But, as the patient is dying, the potential that this tonic will actively harm her is limited. Receiving the tonic supports the patient's and the family's beliefs and their explanatory model of illness, and it offers the son and family a sense of peace that they supported her well-being.

44. DUBLER & LIEBMAN, *supra* note 1, at 72–74.

45. *Id.* at 69.

46. *Id.* at 69–70.

Now, this person is an obtunded, ventilator-dependent, dying patient: what harm could this tonic possibly cause? The bioethics mediator’s action on behalf of the family changes the power structure, unpacks the enmity between staff and family, and calms the oldest son. In bioethics mediation the process is part of the product.

Bioethics mediation stands in the tradition of mediation in that it searches for consensus in chaos. The type of mediation described in the paragraph above is somewhat similar to the idea of the “permanent umpire”—a selected and fixed arbitrator who would give instant mediation and assist in ongoing dispute resolution. Bioethics mediation is a sort of hybrid between traditional mediation and the presence of a “permanent umpire.”⁴⁷

Bioethics mediation is distinct from other sorts of mediation because of the following factors:

- The bioethics mediator is generally employed by the hospital.
- The bioethics mediator and members of the treatment team are repeat players.
- The bioethics mediator provides information, enforces norms, and ensures that resolutions fall within medical “best practice” guidelines.
- Deciding not to reach a resolution is not an option.
- The playing field is usually uneven for patients and their families.
- Confidentiality is limited to information not relevant to patient care.
- Time is of the essence.
- Bioethics mediations involve life-and-death issues.
- Facts play a different role.
- The person with the greatest stake in the dispute, the patient, is often not at the table.
- There may be a sequence of separate, prior meetings in addition to the group mediation.
- Bioethics mediations are almost always multiparty events.
- The parties usually do not sign an agreement to mediate.
- The physical setting may not be in the mediator’s control.
- Bioethics mediators are often involved in following up on implementation of the agreement.
- All participants in a bioethics mediation have a common interest in the well-being of the patient.⁴⁸

These factors demand that the mediator be aware of the constraints on her behavior as she seeks to forge a principled resolution. In addition, the difference between traditional mediation and bioethics mediation requires attention to certain special features: First, bioethics may be an area for co-mediation,

47. William H. McPherson, *Grievance Mediation Under Collective Bargaining*, 9 INDUS. & LAB. REL. REV. 200, 201–02 (1956).

48. DUBLER & LIEBMAN, *supra* note 1, at 21–22.

especially with lawyer mediators, because lawyers may be inadequately trained to be mediators in a setting that requires sensitivity, empathy, patience, love, and the ability to absorb powerful feelings and direct difficult conversations; linking with a social worker or nurse may provide the empathy that must accompany analysis. Second, there is a special need for subject-matter expertise for bioethics mediators because of their role in translating the ethical and legal norms of medical practice for the family and the medical staff. The mediator is not just mediating, but harmonizing these norms within the culture and practice of the particular medical institution and the facts of the case at hand. Finally, there may also be certain questions about the perceived neutrality of a mediator who is both employed by the hospital and a repeat player. The use of an outsider might provide a better, more neutral reality but would be difficult to accomplish given the risk-averse nature of medical institutions, the fact that the healthcare chart is a legal record that can only be added to by approved staff, and the need for the mediator to understand the conventions of the setting and the specifics of the conflict.

Bioethics mediation is the progeny of bioethics as a field of scholarship combined with the skills and perspectives of mediation. It uses those skills, however, within the framework of case law and regulation,⁴⁹ much as child-custody mediation uses the notion of the child's best interest against which to measure the appropriateness of adult agreements.

D. Applying the Notion of a Principled Resolution in Bioethics Mediation

As noted above, bioethics mediation is constrained by case law, statutes, and regulations that have defined the interests, rights, and duties of the parties involved in healthcare delivery scenarios. For example, the modern notion of "informed consent," so central to the empowerment of patients in the context of their care, has its origins in a New York opinion stating that

[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages. This is true except in cases of emergency where the patient is unconscious and where it is necessary to operate before consent can be obtained.⁵⁰

Two important and well-accepted medical, ethical, and legal rules emerged from this opening discussion and from subsequent cases and statutes. First, adults who are decisionally capable have the right to decide what care they would like to receive and those interventions they wish to refuse. Second, in the emergency room (ER)—where time is of the essence, the capacity of patients to understand and process information is not clear, and some interventions may be necessary emergently to save a life—individual consent is not a prerequisite to a lifesaving or health-preserving intervention.

49. *Id.* at 23, 24.

50. *Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 129–30 (1914).

Were there to be a disagreement in the ER, for example, in which a wife argued that lifesaving surgery could not be performed on her unconscious husband without his consent or approval, it would be improper for the medical staff and the wife to reach a consensus that the husband should be permitted to die because he could not give his explicit informed consent for the surgery or other intervention. The allocation of decision-making authority in the ER states that the informed consent of the patient is explicitly excluded as a precondition to care.⁵¹ The parties could not, as part of a mediated settlement, abrogate that well-grounded legal rule and ethical precept.

Sadly, however, most scenarios are not this clear and crisp. Perhaps the patient in the ER had chronic obstructive pulmonary disease (COPD) and had been in a steep decline at home. Furthermore, suppose he had been quite clear with his wife that he did not want her to call for an ambulance if he had breathing difficulties because he was ready to die at home. Suppose further that the wife was desperate for her husband to keep on living, and over his objection and with her contrary knowledge, called for an ambulance. Would it then be fair for the ethics of the ER to prevail? But, how would the ER know of the patient's conflicting values? Would it then be wrong for ER staff to intubate the patient in an effort to save his life?

So, too, a decisionally capable hospital patient who is refusing a second above-the-knee amputation, having experienced one amputation previously, could not be forced to have the amputation even if his wife and healthcare team reached a consensus that this intervention was in his best interest. On the other hand, assume that the patient is of diminished and fluctuating capacity—as is often the reality. He is sometimes clear and consistent, but other times much less so. He also seems ambivalent about death and is questioning whether the gangrenous leg will really kill him if left attached. What then? If he is not “of sound mind,” does he lose all of his rights? Can we take his statements that are made in windows of lucidity and use them to support a consistent, continuous plan of care when he is confused and disoriented? If we are to consider what is in his “best interest,” are we bound to take his statements when capacitated into account? How can that be done consistent with obligations and responsibilities to protect his life and honor his person? Can it ever be in the “best interest” of a person to be dead? Ferreting out the medical facts, the status of the patient in regard to decision-making, the possible consequences of various options for interventions, and how all of these elements fit within the legal rules and ethical stipulations always requires discussion and often demands mediation.

In bioethics mediation, the process is critical. Mediation brings all of the parties together and requires them to talk and hear each other. Talking to and about the patient with the entire healthcare team present often uncovers statements that would not necessarily be available otherwise. Perhaps there was

51. James G. Adams & Joel Wegener, *Acting Without Asking: An Ethical Analysis of the Food and Drug Administration Waiver of Informed Consent for Emergency Research*, 33 ANNALS EMERGENCY MED. 218, 220 (1999).

a discussion with a nurse in the quiet of the night when the patient talked about his hopes and fears, wishes and desires. Mediation creates a forum to illuminate these decisions at times when the patient's values and preferences are cloudy. It carves time and space from the always-moving and always-acting medical world of changing players and creates a moment in which contemplation, and not action, counts.

Not only are bioethics-mediation interventions constrained by the notion of the principled resolution, they are, in addition, time consuming and counter to decades of medical tradition that, despite case law and statutes to the contrary, still privilege the opinions of medical providers in the process of reaching decisions. This is the case for a myriad of reasons including the following:

1. Physicians do know more about medicine than most patients and family members, and most often want to do the right thing either to make the patient better or end her suffering;
2. Family members do not "speak medicine" and are often uncertain about the meaning of terms and the weight of facts presented;
3. Situations are confusing or uncertain and it may not be clear what is actually happening to the patient and what is in her best interest;
4. Power imbalances are endemic to medicine and reflect the education, skill, and experience of providers and the funding arrangements that increasingly limit their time to talk with patients and family members;
5. Distances created by education, culture, ethnicity, religious beliefs, and poverty invade the discussions and make patients and family members shy about revealing their values and preferences because they are uncertain that these will be well-received and respected; and finally,
6. The language of the American healthcare system assumes that healthcare is a commodity to be bought and sold and not a right to be enjoyed.

As long as this last point remains the case, and even the Obama plan assumes that subsidies will permit those without resources to "buy" adequate healthcare, then there will always be a "buyer beware" element to the doctor-patient and doctor-family interaction; this will add edges to the discussion and tend to augment what might be seen as conflicting agendas. So, "as long as health care is viewed as a product to be bought and sold, even the most well-intentioned reformers will someday soon have to come to grips with health care rationing, if not by wealth then by some other criteria."⁵² Enough has been

52. James Ridgeway, *Meet the Real Death Panels: Should Geezers Like Me Give Up Life-Prolonging Treatments To Cut Health Care Costs?*, MOTHER JONES (July-Aug. 2010), <http://motherjones.com/politics/2010/07/health-care-rationing-death-panels>.

spoken and written about the costs of care—especially about the costs of care at the end of life—that patients and, even more to the point, family members are aware that monies not spent on this patient will be available for other patients and for the institution. They know this and they fear it. Will the healthcare system skimp on care for their loved one so that it will be available to another, “more deserving” patient?

In the end, however, the notion of a principled resolution only assumes form in the context of real cases. Bioethics is about stories: consider the following case examples, taken from real cases by the practitioners who were responsible for crafting care plans. In each of these actual cases, culled from various Northeastern academic teaching hospitals as preparation for various workshops, consider how the care team might proceed with mediation; in what setting; with what care providers, family members, and others; and how the discussion might be constrained by the notion of a principled resolution.

III

CASES FOR CONTEMPLATION⁵³

A. Emergency Intubation of an Adult Patient

1. Fact Pattern

A gentleman with thyroid cancer presented to the ER with stridor (a wheezing sound on breathing in), respiratory distress, and impending airway compromise. The patient needed emergency fiber-optic intubation or an awake tracheotomy. The patient repeatedly stated that he did not want to be intubated and on a ventilator for a sustained amount of time. He agreed to a tracheotomy. Due to invasion of the thyroid cancer and collapse of the trachea, the tracheotomy did not succeed. The patient desaturated (had less oxygen in his blood) on the table, became unresponsive, and the healthcare team was still unable to place a tracheotomy tube. The attending physician made the decision to intubate the patient in an attempt to save his life.

2. Analysis

What might be a principled resolution in this case? First assume that this patient came to the ER alone because there is no mention of family in the narrative, and there surely would have been if any family members had been present. A best guess is that in this case, the ER staff would have made a STAT (immediate) call to the CEC service because the staff would have been divided on the propriety of intubating the patient. Some would have argued that he had

53. The following fact patterns were submitted anonymously by various providers over the years in the course of the author conducting bioethics mediation seminars. They were saved with no notation regarding physician, author, or institution.

distinctly refused intubation. Others would have pointed out that he had not refused all intubation, but only intubation *for a sustained amount of time*.

The CE consultant would have discussed the case with the referring physician, likely the fellow in the ER, asked a few questions, and asked that, if possible, one of the surgical attendings or fellows be present to discuss the possibilities of treatment for this sort of tumor. She would then go to the ER where she would gather the team and hear the medical facts, and the diagnosis and prognosis or as much as could be determined in the ER. Most discussions of “medical facts” in the ER consist of educated guesses, as the specific tests that indicate prognosis are generally not available. She would ask the ER fellow to present the case and suggest a resolution, and would solicit all arguments to the contrary. The ensuing discussion would place the medical discussions in the context of the legal consensus that capable patients have the right to make decisions, and the ethical consensus that lifesaving actions in the ER are justified. She would point out that the language of this patient is empowering because he did not reject intubation outright, but rather rejected intubation “for a sustained amount of time.” The crux of the debate focused on whether this sort of patient was likely to regain capacity or whether he would be ventilator dependent forever. Some argued that due to the dimensions of his tumor, placing him on a ventilator would render him permanently dependent because the tumor would make it impossible to breathe independently. Others were more optimistic.

As the case developed, the intubation was successful and the patient was transferred to the ICU and placed on the ventilator. After he was eventually taken off sedation, the reason for intubation was explained at length to the patient and he understood. He later underwent a successful tracheotomy and thyroidectomy.

B. Neonatal Intubation and Treatment

1. Fact Pattern

A full-term, three-kilogram black male was born as a first child to a dedicated mother and father of simple means and limited educational background. The child was diagnosed via prenatal ultrasound with Larsen’s syndrome, which is characterized by joint dislocations, clubfeet, cervical instability with risks of paralysis, microcephaly, and bronchomalacia associated with premature death from pulmonary failure. The literature is full of case reports describing morbidity and mortality attributed to Larsen’s syndrome, but information about typical life quality and duration is elusive. A precedent for pregnancy termination following the diagnosis of Larsen’s syndrome does exist.⁵⁴

54. Martina Doren, Helga Rehder & Wolfgang Holzgreve, *Prenatal Diagnosis and Obstetric Management of Larsen’s Syndrome in a Patient with an Unrecognized Family History of the Disease*, 46 GYNECOLOGIC & OBSTETRIC INVESTIGATION 274, 275 (1998).

At birth the patient was transferred to the neonatal intensive-care unit (NICU). He had inspiratory stridor and cyanosis (a bluish discoloration of the skin or mucous membranes). He was also noted to have clubfeet and dislocations at every elbow, knee, and hip joint. Oxygen saturation could be maintained with tight mask ventilation, positive pressure, an oral airway, and neck extension; but it was clear the patient would not survive more than an hour without endotracheal intubation.

This child was intubated and failed extubation twice. Otolaryngology was consulted and it diagnosed laryngomalacia (onset, at or soon after birth, of a harsh respiratory sound mostly audible during inspiration). Despite reports of this disorder dating back to the mid-nineteenth century, specific etiology and pathogenesis remain nebulous. Analysis of findings in thirty infants indicates there are often associated manifestations of delayed development in neuromuscular control. Associated findings include gastroesophageal reflux, obstructive and central apnea, hypotonia, failure to thrive, and pneumonitis.⁵⁵ The laryngomalacia was too severe for surgical remedy, so the family was offered and accepted a tracheotomy. At the one-month follow-up, the patient remains ventilator dependent because of bronchomalacia (excessive collapsibility of bronchi).⁵⁶ Consultants have predicted he will never walk. Tracheotomy removal will be difficult.

These were the questions posed by the providers, [part of the fact pattern] who indicated that there were disagreements among the staff on virtually all of the questions:

Should the parents be engaged in a discussion about quality of life and the consequences of intubation versus no intubation? Whose responsibility is it to initiate this discussion? How could discussions such as this be held throughout our country in an unbiased and uniform fashion, when individuals have such divergent views about life and choice? Once the patient is intubated and there is time for contemplation, is there any possibility of revisiting the same question, or is it ethically wrong to withdraw airway support, especially from a child? Does a family's educational background have any bearing on the questions that should be raised? Should healthcare providers use their training and background to educate families about likely outcomes and introduce the option of withdrawing support, or does that expose them to accusations of elitism, malpractice, or even homicide? In this world of finite resources, do healthcare providers have any obligation to control healthcare costs by putting a value on life? Has the healthcare system done the patient and the family a service in the support it provided? Has it done a service for society? Are some outcomes worse than death?

55. Judson R. Belmont & Kenneth Grundfast, *Congenital Laryngeal Stridor (Laryngomalacia): Etiologic Factors and Associated Disorders*, 93 ANNALS OTOLARYNGOLOGY, RHINOLOGY & LARYNGOLOGY 430, 435–36 (1984).

56. Mizuki Nishino et al., *Excessive Collapsibility of Bronchi in Bronchiectasis: Evaluation on Volumetric Expiratory High-Resolution*, 30 J. COMPUTER ASSISTED TOMOGRAPHY 474, 474 (2006).

2. Analysis

This is a particularly interesting case because it is difficult to articulate what the principled resolution might be. Neonatal care has been the subject of much case law in various states, and has been the subject for medical and legal guidelines and rancorous debate surrounding both of these processes. Consider some of the statements that might undergird a principled resolution:

1. Goals seek to maintain a focus upon the best interests of the child. In determining the best interests of the child, the parents generally are considered to be the spokespersons; hence, healthcare providers usually seek their opinions, discern their values, and consider their goals.⁵⁷
2. The aim of guidelines should not be to dictate medical care but to facilitate decision-making and perhaps give consistency to the process in which difficult decision-making takes place. An end result may be that families are empowered in decision-making; however, certainly all parties involved in these decisions for critically ill newborns should benefit from enhanced communication and clearly defined goals.
3. In many specific healthcare environments, a concept of the good must be refined to reflect the peculiarities of the patients, their conditions, the available treatment alternatives, the values placed upon those alternatives by relevant parties, the likely outcomes of treatment or non-treatment, and the influences of external considerations. In the NICU, as elsewhere, goods that are pursued include health, prevention or elimination of disease or morbidity (including side effects of treatment), relief of unnecessary pain or suffering, and the prolongation of life.⁵⁸

The law in regard to neonates was articulated through a series of cases culminating in congressional action following the Baby Doe⁵⁹ case in Stony Brook, New York.

In response to growing interest in these difficult decisions, in 1984–1985, the U.S. Congress amended the federal child abuse law specifically to make each state's child protection agency responsible for overseeing the withholding and withdrawing of medically indicated treatments from neonates. The law details the physician's responsibility to use reasonable medical judgment to make recommendations for care of critically ill neonates. Furthermore, the federal regulations strongly urge the formation of infant care review committees (which the American Academy of

57. See Brian S. Carter & Steven R. Leutner, *The Ethics of Withholding/Withdrawing Nutrition in the Newborn*, 27 SEMINARS PERINATOLOGY 480, 482–85 (2003) (eloquently describing the process of parents “negotiating” the child’s best interest).

58. Phoebe A. Haddon, *Baby Doe Cases: Compromise and Moral Dilemma*, 34 EMORY L.J. 545, 585–88 (1985); Brian S. Carter, *Ethical Issues in Neonatal Care*, WEBMD (July 16, 2009), <http://emedicine.medscape.com/article/978997-overview>.

59. POST, BLUSTEIN & DUBLER, *supra* note 2, at 293–99.

Pediatrics calls infant bioethics committees) to facilitate decision review and to assist in the interaction among physicians, the family, the hospital, and the state.⁶⁰

The amendment to the federal child-abuse law and subsequent regulations applying it to neonatal treatment states that

“withholding of medically indicated treatment” means the failure to respond to an infant’s life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which in the treating physician’s reasonable medical judgment will be most likely to be effective in ameliorating or correcting all such conditions. Exceptions to the requirement to provide treatment may be made only in cases in which one of the following applies:

(i) The infant is chronically and irreversibly comatose.

(ii) The provision of such treatment would merely prolong dying or not be effective in ameliorating or correcting all of the infant’s life-threatening conditions or otherwise be futile in terms of the survival of the infant.

(iii) The provision of such treatment would be virtually futile in terms of the survival of the infant and the *treatment itself under such circumstances would be inhumane*.⁶¹

Add to this complexity that every infant-bioethics committee establishes its own rules for evaluating the statements and perspectives of the family and care providers who come together in these cases. Thus, the infant-bioethics review committee at Montefiore Medical Center—the Albert Einstein College of Medicine had the following rule: If the medical problem was easily fixable and intervening was uncontroversial (for example, fixing an esophageal blockage on a baby with Down syndrome), the committee would recommend the intervention regardless of the parents’ wishes; if the medical problem was complex, intractable, and not subject to treatment (for example, fixing the body of a baby whose gut was born external to the body—gastroschisis⁶²), the committee would recommend against the intervention regardless of the parents’ wishes; and, in the vast majority of cases where nothing is clear or precise, the values, beliefs, and wishes of the parents would control. So what might be the parameters of a principled resolution in this case, and what process could be used to arrive at a consensus?

In thinking about a principled resolution, consider how you might proceed, strategically and as a mediator, if the parents wanted “all possible care” and the care team had decided that this baby’s life would be an experience of ongoing suffering.

The case seems to require

1. gathering all of the care team and trying to clarify the prognosis—exactly how long this baby is likely to survive (assuming that this calculation is not possible, might he be ventilator dependent?);

60. Alan R. Fleischman, *Neonatal Care*, in THE HASTINGS CENTER BIOETHICS BRIEFING BOOK 121, 123 (Mary Crowley ed., 2008).

61. 45 C.F.R. § 1340.15(b)(2) (2008) (emphasis added).

62. Kim Hayes et al., *G.I. Anomalies in Pediatric and Newborn Care*, SURFNEON.COM (Nov. 16, 2005), <http://www.surfneon.com/nu/gi.html>.

2. surfacing disagreements about the prognosis among members of the medical team, and deciding how to convey uncertainty if that is a factor;
3. determining the “medical facts” while taking into account that although medical facts “have the ring of scientific objectivity, . . . determining what counts as a medical fact is a matter of selection and interpretation, and that process reflects normative assumptions”;⁶³
4. finding a comfortable room and sitting down with the parents and a subset of the team so that the parents can talk about themselves and their family situation, their church and their beliefs, their experience and fears, and their wants and desires for this baby;
5. discussing the medical facts and the notion that continued care may not be a clear path for this baby;
6. figuring out if there are any milestones that could help to move the understanding of the medical facts, for example another attempt at intubation in a few days;
7. giving permission for the ineffable option of letting this baby die;
8. assuming the burden of that decision without disempowering the parents;
9. assuring that all involved family members and clergy are invited to the next meeting; and
10. scheduling a follow-up meeting to review all of the matters again.

C. Parental Intervention in Adolescent-Patient Treatment

1. Fact Pattern

Larissa is a sixteen-year-old girl with longstanding lung disease of undetermined origin, for which she has been admitted several times over the past three years. Her treatment on each of her admissions has been similar: She comes in with an exacerbation of her lung condition, receives steroids, does fairly well, and is discharged. On this last admission, however, she was found to have renal failure, for which she has begun to receive dialysis. Her doctor is not certain how long she will require it—possibly for the rest of her life.

Larissa’s mother is characterized as somewhat suspicious of conventional medicine, and under the circumstances, this is not unreasonable. She has sought out alternative treatments with an osteopathic physician from whom Larissa has received high-dose intravenous hydrogen peroxide and vitamin C. Larissa received a week of infusions just prior to her latest admission to the hospital.

63. DUBLER & LIEBMAN, *supra* note 1, at 47–48.

There is a definite possibility that Larissa’s renal failure is due to the treatments she has received from the osteopathic doctor, but at this point this is only speculative. There is no definitive evidence that her renal condition is caused by these alternative treatments. However, the physicians treating her were in complete agreement that going forward, the treatments must be stopped because, at this point, they will likely make Larissa’s renal condition worse.

Everyone in the treatment team stated that there is no evidence that the mom wants to hurt her child: the mom’s unhappiness with the care her daughter has received is understandable, given that no cause for her lung problem has yet been found. Larissa’s mom is in a state of shock, having just learned that Larissa has this new and serious renal problem. It would be counterproductive and unfair to assign blame to the mom for her daughter’s condition. Yet there may be a number of treatments that could make the renal condition worse, and all of them should be monitored carefully or stopped completely—including, but not limited to, the treatments she has been receiving from the osteopathic physician.

2. Analysis

Treating an adolescent patient presents particular legal and ethical issues for medical providers. Adolescents do not have the right to consent to or refuse care that accrues to adults.⁶⁴ On the other hand, the ethics of adolescent care developed by the Society of Adolescent Medicine and the American Academy of Pediatrics dictate that the adolescent know the issues, diagnosis, and prognosis; participate in the decisions about care; and agree to the treatment or lack thereof.⁶⁵

“Constitutional rights do not mature and come into being magically only when one attains the state-defined age of majority. Minors, as well as adults, are protected by the Constitution, and possess constitutional rights.”⁶⁶ This case, *Planned Parenthood v. Danforth*, was decided in the context of rights to abortion, which are particularly sensitive in American society. But a right to live or die is almost as fraught with divergent meaning.⁶⁷

Most scholars agree that by the age of thirteen, adolescents have the moral capacities to weigh and measure some of the aspects of treatment. They have some ability to foresee consequences for themselves and others. What they are

64. See ROBERT S. LAWRENCE, JENNIFER APPLETON GOOTMAN & LESLIE J. SIM, NATIONAL RESEARCH COUNCIL AND INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES, *ADOLESCENT HEALTH SERVICES: MISSING OPPORTUNITIES* 180–81 (2009).

65. See generally AM. MED. ASS’N, *GUIDELINES FOR ADOLESCENT PREVENTIVE SERVICES: RECOMMENDATIONS MONOGRAPH* (1997).

66. *Planned Parenthood of Cent. Mo. v. Danforth*, 428 U.S. 52, 74 (1976); see also *O’Connor v. Pierson*, 426 F.3d 187, 201 (2d Cir. 2005) (holding that sensitive medical information is “of the most intimate kind” and the right to privacy includes the right to maintain medical confidentiality); *City of Akron v. Akron Ctr. for Reprod. Health*, 462 U.S. 416, 417 (1983) (holding that a state cannot make a blanket decision that all minors are too immature to consent to an abortion, or that an abortion may never be in the minor’s best interests without parental consent).

67. See Annas, *supra* note 33, at 1710.

lacking in general experience, some acquire through experience in the medical-care system through an odyssey in chronic illness.

The legal rule is generally stated as the following: All non-emergency healthcare requires consent before treatment can be provided.⁶⁸ When the patient is a minor child, a parent or legal guardian usually must consent to that child's medical treatment. There are some exceptions to this rule of course. For example, adult caregivers often may consent to medical treatment for children under their care, even when the caregiver does not have formal legal custody of the child. In addition, minors may consent to their own care when they meet certain status conditions, such as being married, or are seeking certain types of care, such as drug-abuse treatment.⁶⁹

Adolescents are that midway creation straddling childhood and adult responsibilities. And the emotional period of adolescence has been extended, at least for the middle class, as job opportunities decrease and the cost of independent living increases. Some scholars of adolescence maintain that it now extends into the early twenties.⁷⁰ Whatever its extent, the capacity of an adolescent to understand and appreciate the medical situation facing her, the risks and benefits of treatment, and the risk of refusing treatment is an ever-changing quotient during adolescence.

For this reason, the American Academy of Pediatrics has a guideline that states that "[t]he physician or health care professional should always seek consent or assent for medical care from the pediatric patient as appropriate for the patient's development, age, and understanding."⁷¹

Finally, consider this statement from the Department of Health and Human Services:

Laws that affect the minor's right to consent to medical care have been developed under the precedent of parental autonomy. In adolescents under the age of majority who receive health care services, the American Academy of Pediatrics has a long-standing policy statement encouraging physicians and parents to include adolescents in the decision-making process, but the parental autonomy and parental right to give consent for a minor is the standard.⁷²

For this case, consider what should be the process and how a principled resolution might be characterized. How might the process be constructed? Would the mom be required to give up her decision-making authority to the daughter? Can the patient assume this burden? Who would decide, based on what rules, with what empowerment of the patient, and with what protections for her?

68. *Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 129–30 (1914).

69. LAWRENCE, GOOTMAN & SIM, *supra* note 64, at 180.

70. *Id.* at 2 n.1.

71. Comm. on Pediatric Emergency Med., Am. Acad. of Pediatrics, *Consent for Emergency Medical Services for Children and Adolescents*, 111 PEDIATRICS 703, 705 (2003).

72. Ann Maradiegue, *Minor's Rights Versus Parental Rights: Review of Legal Issues in Adolescent Health Care*, 48 J. MIDWIFERY & WOMEN'S HEALTH 170, 171 (2003).

D. Religious Beliefs and Family Involvement

1. Fact Pattern

The patient is a fifty-four-year-old woman who first presented as a new patient for evaluation of a left-breast mass. She first noticed the mass four months ago and believed it was getting larger. On examination, she had a hard, one-centimeter nodule in the left breast. Urgent mammography and fine-needle aspiration were arranged and the nodule proved to be malignant. The patient was referred to surgery. She did not return to the internist for a visit scheduled postoperatively. One month later, the surgeon notified the internist that a lumpectomy was done showing tumor cells in the margin of the specimen. The patient was scheduled for definitive surgery, but did not appear on the day of the procedure and could not be reached. The internist reached the patient who stated that she understands her condition but believes that she does not need surgery.

The patient is a devout Christian and she is certain that God will cure her. After several telephone calls, she agreed to come to the office to discuss her situation in person. She was well groomed, fully oriented, and had understanding and insight about the choice she was making. She declined the doctor's request to contact members of her family or her church. After this visit, the patient stopped returning the doctor's calls. Putting herself in the place of a possible family member, the doctor worried that perhaps the patient's judgment was inappropriately affected by her religious preoccupations and the stress of a cancer diagnosis. She remained concerned that she should have notified family members or friends, over the patient's objections, to give them the opportunity to be involved in the patient's decision.

2. Analysis

Again, consider how the mediator should proceed and what might constitute a principled resolution. How should the process be constructed? Who should be present when the medical team meets to review the “medical facts”? What if the patient refuses to join the conversation? Does the responsibility of the medical staff end with the patient's refusal to appear? Could there be a mediation?

IV

CONCLUSION

As the American healthcare establishment becomes more complicated, which will necessarily be the case as the implementation of healthcare reform proceeds, hospitals and all other healthcare institutions will increasingly confront misunderstandings of the new regulations, disagreements and disputes over the fairness and justice of implementing the new law, and conflicts about the positions that institutions take in this evolving process. These conflicts will augment already-existing conflicts about who lives, who dies, and who decides.

The next years are likely to be somewhat chaotic even if ultimately greater health benefits and improved access to care accrue to more patients. In these times, institutions should consider bioethics mediators as a vibrant resource for managing change because they are an invaluable resource for forging principled resolutions.