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THE CHANGING NATURE OF THE BIOETHICS MOVEMENT

SANDRA H. JOHNSON*

INTRODUCTION

The thirtieth anniversary of bioethics has sparked several histories.¹ Variouslly described as a movement,² or a new discipline,³ or the intersection of traditional disciplines such as law, medicine, and philosophy,⁴ bioethics has largely enjoyed a life of reasoned debate as befits the "principlism"⁵ that has thus far dominated this area of study. The debate has been concentrated among professionals, taking place within professional and academic literature, within professional and

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1. See, e.g., Albert R. Jonsen, *The Birth of Bioethics*, HASTINGS CENTER REP., NOV.-DEC. 1993, at S1 (including papers presented at a "thirtieth anniversary" celebration); Albert R. Jonsen, *Theological Ethics, Moral Philosophy, Public Discourse*, 4 KENNEDY INST. ETHICS J. 1 (1994) (describing the historic roles of theology and philosophy in the development of public moral discourse); John C. Fletcher, *The Bioethics Movement and Hospital Ethics Committees*, 50 MD. L. REV. 859, 866 (1991) (offering a historical perspective on the bioethics movement); Jay Katz, *"Ethics and Clinical Research" Revisited: A Tribute to Henry K. Beecher*, HASTINGS CENTER REP., SEPT.-OCT. 1993, at 31 (providing a personal history); George J. Annas, *Ethics Committees: From Ethical Comfort to Ethical Cover*, HASTINGS CENTER REP., MAY-JUNE 1991, at 18 (providing a short history of ethics committees). See generally DAVID J. ROTHMAN, *STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING* (1991).

2. See e.g., Edmund D. Pellegrino et al., *Future Directions in Clinical Ethics*, 2 J. CLINICAL ETHICS 5, 5 (1991) ("We have chosen to make projections for the next two decades—a period roughly equal to the entire history of the modern biomedical ethics movement in America."); ROTHMAN, *supra* note 1, at 243; Jonsen, *supra* note 1, at S2 (discussing the characterization of bioethics as a movement).

3. See Barbara C. Thorton et al., *Education: Expanding the Circle of Participants*, HASTINGS CENTER REP., JAN.-FEB. 1993, at 26 (referring to bioethics as a discipline).

4. See, e.g., K. Danner Clouser, *Bioethics and Philosophy*, HASTINGS CENTER REP., NOV.-DEC. 1993, at S10 (noting that other disciplines approach moral problems from their own perspectives).

5. "Principlism" describes an approach to ethical reasoning that first specifies and then analyzes in application principles of ethical behavior. See generally TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* (1983). Principles commonly identified in relation to bioethics include autonomy, beneficence, truth-telling, and justice. *Id.* Principlism's dominance is often attributed to the 1976 book *Principles of Biomedical Ethics*, authored by Tom L. Beauchamp and James F. Childress. But see Tom L. Beauchamp, *The Principles Approach*, HASTINGS CENTER REP., NOV.-DEC. 1993, at S9 (identifying the Belmont Report, produced by the National Commission for the Protection of Human Subjects, as an earlier and more influential principlist statement).

scholarly commissions,⁶ and within institutional ethics committees and review boards, both dominated by the professionals who are to be guided by them.⁷

Legislation addressing bioethics has not controlled the development of the law during most of these first decades. Despite their calls for legislative assistance,⁸ courts, as opposed to legislatures, thus far have had the most apparent and dominant influence on the substantive law.

Although the media covers bioethics generously,⁹ seldom have decisionmaking and policymaking escaped the confines of ultimate professional control. While questions of biomedical ethics are no longer the province of physicians alone, the methods established to deal with such questions rarely involve the participation of the general public, patients, or subjects.¹⁰ To the extent that physicians may no longer make the most difficult treatment decisions alone, institutional ethics committees have stepped in to share in the decisionmaking.¹¹ Institutional review boards decide questions concerning human experimentation.¹² Because bioethics is essentially a movement towards personal choice and autonomy¹³ and driven, if not created, by public

6. The roles of bioethics commissions are discussed in George J. Annas, *Will the Real Bioethics (Commission) Please Stand Up?*, HASTINGS CENTER REP., Jan.-Feb. 1994, at 19, and in Alexander M. Capron, *Is It Time to Clone a Bioethics Commission?*, HASTINGS CENTER REP., Jan.-Feb. 1994, at 29.

7. For a recent critique of the professional domination of institutional review boards, see Jay Katz, *Human Experimentation and Human Rights*, 38 ST. LOUIS U. L.J. 7 (1993). For a critique of the lack of attention to procedures respectful of the patient's role, see Susan M. Wolf, *Ethics Committees and Due Process: Nesting Rights in a Community of Caring*, 50 MD. L. REV. 798 (1991).

8. See, e.g., *Satz v. Perlmutter*, 362 So. 2d 160, 164 (Fla. Dist. Ct. App. 1978) (noting that the Florida legislature has failed to adopt suitable legislation in the area of refusal of medical treatment), *aff'd*, 379 So. 2d 359 (Fla. 1980).

9. See generally Linda Roach Monroe, *How Can We Trust Science if Findings Change Daily?*, MIAMI HERALD, Oct. 18, 1992, at 1J; Diane Lore, *Media Provide Key That Opens Money Chests*, THE STATE, Jan. 28, 1992, at 1D.

10. There are, of course, exceptions—including, for example, the recent referenda on assisted suicide in Washington and California. For a discussion of the Washington and California referenda, see Maria T. CeloCruz, *Aid-In-Dying: Should We Decriminalize Physician Assisted Suicide and Physician Committed Euthanasia?*, 18 AM. J.L. & MED. 369 (1992). For a discussion of the California assisted suicide referendum, see Leslie Berkman, *O.C. in Middle of 'Death With Dignity' Debate*, L.A. TIMES, Oct. 4, 1992, at A1; Paul Jacobs & Virginia Ellis, *Prop. 165 and Right-to-Die Measure Trail*, L.A. TIMES, Nov. 4, 1992, at A1.

11. See Annas, *supra* note 1, at 18-19.

12. *Id.*

13. See, e.g., Daniel Callahan, *Why America Accepted Bioethics*, HASTINGS CENTER REP., Nov.-Dec. 1993, at S8; ROTHMAN, *supra* note 1, at 243.

interest in the work of doctors and scientists,¹⁴ it is remarkable that bioethics continues to be so professionally dominated.

Marking the stages of intellectual history is a risky business especially when attempted in such close proximity to the events studied. One of the interesting aspects of the new bioethics histories, for example, is their disagreement over the movement's birthdate. Some argue that bioethics came into being with the publication of the *Life* magazine article on Seattle's "God Committee";¹⁵ others claim that Henry Beecher's exposé on experimentation sparked the movement;¹⁶ still others maintain that the *Quinlan* case¹⁷ or other events¹⁸ mark the birthdate of bioethics. Despite the hazards, classifying developments by stages can be a functional method for analyzing change.

I. QUINLAN TO CRUZAN

The New Jersey Supreme Court's decision in *Quinlan* is best known for establishing that withdrawal of medical treatment, even when death is expected to result, is legally permissible under some circumstances.¹⁹ It is also known for being the midwife of ethics com-

14. See, e.g., Arthur L. Caplan, *What Bioethics Brought to the Public*, HASTINGS CENTER REP., Nov.-Dec. 1993, at S14; see also Robert M. Veatch, *From Forgoing Life Support to Aid-in-Dying*, HASTINGS CENTER REP., Nov.-Dec. 1993, at S7 (noting that the *Quinlan* case "became the symbol of the fact that the debate over decisions to cease life support was going public" and beyond interdisciplinary professional study groups and projects).

15. Shana Alexander, *They Decide Who Lives, Who Dies*, LIFE, Nov. 1962, at 103. Albert Jonsen, among others, identified the publication date of Alexander's article as the birthdate of the bioethics movement. See, e.g., Jonsen, *supra* note 1, at S1 (discussing the *Life* article's impact on bioethics). But see Judith P. Swazey, *But Was It Bioethics?*, HASTINGS CENTER REP., Nov.-Dec. 1993, at S5-6 (arguing that the *Life* article occurred in "the pre-bioethics era").

16. Henry K. Beecher, *Ethics and Clinical Research*, 274 NEW ENG. J. MED. 1354-60 (1966). David Rothman identified the publication of Beecher's article as a critical point in the development of bioethics. ROTHMAN, *supra* note 1, at 3. Jay Katz describes his and Beecher's work in human experimentation as existing prior to the "flowering" of the field of bioethics. Katz, *supra* note 1, at 31.

17. *In re Quinlan*, 355 A.2d 647 (N.J.), cert. denied sub nom. Garger v. New Jersey, 429 U.S. 922 (1976); see, e.g., Jonsen, *supra* note 1, at S3 (acknowledging that some consider the date *Quinlan* was decided as the bioethics movement's birthdate).

18. See, e.g., Warren T. Reich, *How Bioethics Got Its Name*, HASTINGS CENTER REP., Nov.-Dec. 1993, at S6 (marking the coining of the term "bioethics" as the birthdate of the field); Stanley J. Reiser, *View the Third*, HASTINGS CENTER REP., Nov.-Dec. 1993, at S13-14 (identifying the letter of Pope Pius XII concerning the use of ventilators, published in 1957, as the "beginning of the modern biomedical ethics movement").

19. *Quinlan*, 355 A.2d at 671-72.

mittees,²⁰ although the current role for such committees is significantly broader than the specific charge by the court in *Quinlan*.²¹

Studying the *Quinlan* court's decision from the perspective of current controversies in bioethics is like going back to the future. For example, in *Quinlan*, the court discussed at length whether Karen Quinlan, who was in what is now called a persistent vegetative state, was actually dead or alive.²² At the time that *Quinlan* was decided, anyone involved in teaching lawyers, doctors, or other health care professionals about the law of life-sustaining treatment knew that the first task was to make clear that Karen Quinlan was not dead according to contemporary medical and legal norms. During this period, the determination of death statutes were recent developments in most states.²³ Soon after *Quinlan*, whole-brain death was widely adopted as the appropriate legal standard for the determination of death and seemed firmly established.²⁴ Currently, however, the legal standard for the determination of death is once again a controversial topic. Some argue that irreversible cessation of higher brain function, which occurs in the persistent vegetative state, constitutes death.²⁵ Others contend that anencephaly also should be included in the legal definition of death.²⁶ At least two states now require accommodation of religious objections to the whole-brain death standard.²⁷ Under this

20. See Annas, *supra* note 1, at 18-19.

21. The *Quinlan* court, relying upon a proposal made in a law review article, directed Karen Quinlan's physicians to consult with the hospital's Ethics Committee. *Quinlan*, 355 A.2d at 668-69 (citing Karen Teel, *The Physician's Dilemma. A Doctor's View: What The Law Should Be*, 27 BAYLOR L. REV. 6, 8-9 (1975)). If the Committee agreed that there was no reasonable possibility of Quinlan's emerging from the coma, treatment could be withdrawn without the threat of civil or criminal liability. *Id.* at 671-72.

22. *Id.* at 652-55.

23. Promulgation of whole brain death statutes occurred after publication of the *Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death: A Definition of Irreversible Coma*, 205 JAMA 85 (1968). For a review of early statutory efforts, see Alexander M. Capron & Leon R. Kass, *A Statutory Definition of the Standards for Determining Human Death: An Appraisal and a Proposal*, 121 U. PA. L. REV. 87 (1972).

24. For a discussion of the adoption of brain death legislation, see BARRY R. FURROW ET AL., *BIOETHICS: HEALTH CARE LAW AND ETHICS* 193-200 (1991).

25. See, e.g., Robert M. Veatch, *The Impending Collapse of the Whole-Brain Definition of Death*, HASTINGS CENTER REP., July-Aug. 1993, at 18 (discussing the difficulties inherent in a "whole-brain oriented" definition of death).

26. See, e.g., *In re T.A.C.P.*, 609 So. 2d 588, 594-95 (Fla. 1992) (considering and rejecting the claim that an anencephalic infant with some brain stem function was brain dead).

27. N.J. STAT. ANN. § 26:6A-5 (West Supp. 1993) requires the physician to use cardio-respiratory criteria, as opposed to neurological criteria, to determine death if the physician has reason to believe, based on information in the patient's record or provided by someone familiar with the patient's religious beliefs, that using the neurological criteria would violate the patient's religious beliefs. New York public health regulations also require phy-

standard, the question of whether or not one is dead, in certain circumstances, becomes a matter of personal choice.

The *Quinlan* court also reviewed the admissibility of statements made by Karen Quinlan prior to her injury relating to her treatment preferences.²⁸ The court recounted that, while she was competent, Quinlan had verbalized "her distaste for continuance of life by extraordinary medical procedures, under circumstances not unlike those of the present case."²⁹ Although the court did not overturn the trial court's admission of the statements, the court voiced its skepticism: "[W]e agree with the . . . trial court that such statements, since they were remote and impersonal, lacked significant probative weight."³⁰ This early skepticism concerning a patient's prior statements is noteworthy, in light of the recent critiques of the substituted judgment standard and its basis in the autonomy of the individual.³¹

Quinlan, and the long line of cases up to the point of *Cruzan*, established a legal framework for decisionmaking concerning life-sustaining treatment. This framework allowed discontinuation or withholding of medical treatment when justified under either a substituted judgment standard (generally relying, though not always, on some evidence of the formerly competent patient's putative choice) or under the best interests standard (balancing the benefits and burdens of treatment if evidence of the patient's choice was lacking).³²

Despite the *Quinlan* court's early skepticism, a patient's prior statements concerning treatment preferences were routinely given preferential consideration after *Quinlan*.³³ In cases in which evidence of the patient's choice was lacking, and in which the courts relied on

sicians to accommodate individual preferences when determining whether death has occurred. See Charlotte K. Goldberg, *Choosing Life After Death: Respecting Religious Beliefs and Moral Convictions in Near Death Decisions*, 39 SYRACUSE L. REV. 1197, 1201 & n.25 (1988).

28. *In re Quinlan*, 355 A.2d 647, 653 (N.J.), cert. denied sub nom. Garger v. New Jersey, 429 U.S. 922 (1976).

29. *Id.*

30. *Id.*

31. See, e.g., *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988) (en banc), *aff'd sub nom. Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990); *Mack v. Mack*, 329 Md. 188, 618 A.2d 744 (1993).

32. See, e.g., THE HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING (1987); GUIDELINES FOR STATE COURT DECISIONMAKING IN LIFE-SUSTAINING MEDICAL TREATMENT CASES (1993).

33. It might be said that the Massachusetts Supreme Court case *Superintendent of Belchertown State Sch. v. Saikewicz*, 728 N.E.2d 417 (Mass. 1977), with its reliance on a substituted judgment standard in allowing treatment to be foregone for a severely mentally retarded adult, actually influenced the courts in other states on this point more significantly than the earlier and more well-known *Quinlan* case.

the best interests of the patient, the presence or absence of pain was often a determining factor.³⁴ The role of the family varied, with some courts viewing the family primarily as a source of evidence about the choices of the patient and other courts according it more substantial deference.³⁵ While it was most common to require clear and convincing evidence of the formerly competent patient's choice, there was significant variation in the courts' views of what constituted clear and convincing evidence.³⁶ There was no variation, however, in the view that advocacy of nontreatment bore the burden of proof. In addition, the courts were consistent in concluding that the "state's interests" in these cases did not require life-sustaining medical treatment for incompetent terminally ill, seriously debilitated or permanently unconscious patients.³⁷

Legislation enacted during this early post-*Quinlan* period focused almost entirely on enabling individuals to memorialize their treatment choices in a legal instrument. This paralleled the courts' preference for evidence of the patient's choice. The first form of these documents, the living will, was of limited use: the vast majority of persons would not use such documents; and they were simply inadequate in responding to the range of medical conditions under which surrogate decisionmaking is required or to the range of treatment decisions that arise. Such legislation did confirm, however, that nontreatment was legally permissible under certain circumstances, and for its time, that was a significant supplement to the case law.

II. AFTER *CRUZAN*

The *Cruzan*³⁸ decision marks a turning point with respect to legislation concerning life-sustaining treatment. Although it would be an overstatement to say that *Cruzan* caused a shift in the legislation, it certainly influenced its timing. *Cruzan*, with its contemporary

34. See, e.g., *In re Conroy*, 486 A.2d 1209 (N.J. 1985), establishing a "pure-objective test" that, in the absence of evidence of the patient's choice, would allow withdrawal of treatment in cases where the patient was experiencing pain.

35. For a discussion of the role of family members and the standards to be used for family and other surrogates, see *Guidelines for State Court Decision Making in Life-Sustaining Medical Treatment Cases* (2d ed. 1993) at 71-81. See also *In re Jobes*, 529 A.2d 434, 451 (N.J. 1987) ("Our legal system cannot replace the more intimate struggle that must be borne by the patient, those caring for the patient, and those who care about the patient.").

36. See discussion of burden of proof in BARRY R. FURROW ET AL., *BIOETHICS, HEALTH CARE LAW AND ETHICS* 301-02 (1991).

37. See, e.g., *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417 (1977).

38. *Cruzan v. Harmon*, 760 S.W.2d 408 (Mo. 1988), *aff'd sub nom. Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990).

*O'Connor*³⁹ in New York,⁴⁰ were the first high-profile cases to reject the family's unanimous decision to discontinue treatment for a previously competent adult, breaking the custom developed after *Quinlan*.⁴¹ Obviously, *Cruzan* stands apart as the first case concerning the refusal of life-sustaining treatment to be reviewed by the United States Supreme Court, after nearly fifteen years of case law in the state and federal courts. Both the Missouri Supreme Court and United States Supreme Court decisions in *Cruzan* helped shape the landscape of state legislation concerning life-sustaining treatment.

The majority opinion of the Missouri Supreme Court rebelled against the generally accepted legal framework for the withdrawal of life-sustaining medical treatment. It rejected the notion of unqualified autonomy for incompetent patients in regard to treatment decisions,⁴² the characterization of medically provided nutrition and hydration as medical treatment,⁴³ and any preferential decisionmaking role for the patient's family.⁴⁴ The court asserted that Missouri's state interest was distinct from other states' interests. Missouri's interest required life-sustaining medical treatment, especially nutrition and hydration, for patients in a persistent vegetative state who had not left formal instructions regarding treatment choices.⁴⁵

The United States Supreme Court affirmed this decision, though the Court reduced the Missouri opinion to the least radical proposition; that is, that Missouri required clear and convincing evidence of the patient's treatment choices. The Chief Justice's decision in *Cruzan* appears to be a work of compromise designed to attract the votes needed to form a majority on the result. A key vote apparently belonged to Justice O'Connor, who wrote her own concurring opinion to emphasize some points reserved by the Rehnquist opinion, includ-

39. *In re Westchester County Medical Ctr.*, 531 N.E.2d 607 (N.Y. 1988).

40. The New York Court of Appeals, in one of its first cases on life-sustaining treatment, drew different lines on life-sustaining treatment. In *In re Storar*, 420 N.E.2d 64 (N.Y. 1981), the court ordered treatment for a severely mentally retarded adult over the request of his mother. Storar had bladder cancer, and the blood transfusions at issue would not cure the cancer but would maintain his blood level during his remaining months of life. The court rejected a substituted judgment standard for the never-competent patient and ordered this "life-saving" treatment.

41. For a comparison and analysis of the New York and Missouri cases, see Sandra H. Johnson, *From Medicalization to Legalization to Politicization: O'Connor, Cruzan and Refusal of Treatment in the 1990s*, 21 CONN. L. REV. 685 (1989).

42. *Cruzan*, 760 S.W.2d at 419-22.

43. *Id.* at 423.

44. *Id.* at 425-26.

45. *Id.* at 426.

ing a possible constitutionally protected status for patient-designated proxies.⁴⁶

The tentativeness of the United States Supreme Court majority opinion has limited its influence on subsequent cases. In fact, neither the analysis developed by the Missouri Supreme Court nor that of the United States Supreme Court has altered the course of the case law regarding life-sustaining treatment in any significant way thus far. With only a rare exception,⁴⁷ the cases occurring after *Cruzan* continued to allow withdrawal of life-sustaining treatment based either on the familiar substituted judgment or best interests standards.⁴⁸

The significance of *Cruzan* is in the legislation that it spawned. On the federal level, Senators from Missouri and New York cosponsored the Patient Self-Determination Act (PSDA).⁴⁹ The PSDA requires covered health care providers to ask patients whether they have advance directives.⁵⁰

The most significant legislative activity, however, has occurred at the state level. As discussed more extensively in this symposium, after *Cruzan*, several states enacted legislation providing for the durable power of attorney for health care, which allows competent adults to designate a proxy decisionmaker for health care decisions. Although some states had adopted such statutes prior to *Cruzan*,⁵¹ the *Cruzan* Court's rejection of the family's unanimous treatment choice and Jus-

46. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 289 (1990) (O'Connor, J., concurring).

47. *Mack v. Mack*, 329 Md. 188, 618 A.2d 744 (1993). See also Karen L. Goldmeier, Comment, *The Right to Refuse Life-Sustaining Medical Treatment: Recent Changes in Maryland Law*, 53 MD. L. REV. 1306 (1994).

48. This is true even in Missouri. On remand, the probate court in *Cruzan* ordered treatment discontinued based on the submission of more evidence of conversations concerning treatment preferences with the patient prior to her injury. In addition, the Missouri Court of Appeals has held that the Missouri *Cruzan* decision is to be limited to the provision of nutrition and hydration and that the best interests standard allows for the refusal of cardiopulmonary resuscitation by a surrogate. *In re Warren*, 858 S.W.2d 263 (Mo. App. 1993). See also *In re L.W.*, 482 N.W.2d 60 (Wis. 1992); *In re Doe*, 583 N.W.2d 1263 (Mass.), cert. denied sub nom. *Doe v. Gross*, 112 S. Ct. 1512 (1992).

49. Omnibus Budget Reconciliation Act of 1990, P.L. No. 101-508, § 4751, 104 Stat. 1388-204 (1990) (codified as amended in scattered sections of 42 U.S.C. (1988 & Supp. IV 1992)).

50. For a discussion of the operation of the PSDA, see *The Patient Self-Determination Act*, 2 J. CLINICAL ETHICS 172 (1991); Special Section: *Practicing the PSDA*, HASTINGS CENTER REP., Sept.-Oct. 1991, at 172-212.

51. See, e.g., CAL. CIV. CODE §§ 2430-2444 (West 1993 & Supp. 1994) (originally enacted in 1983); COLO. REV. STAT. ANN. § 15-14-501 (West 1989 & Supp. 1993) (originally enacted in 1973 and amended to specifically include medical decisionmaking in 1983). Statutory durable powers of attorney not designed specifically for health care decisions were being used for health care decisionmaking. See Mark Fowler, Note, *Appointing an Agent to Make Medical Treatment Choices*, 84 COLUM. L. REV. 985, 1015-25 (1984) (discussing the enactment

tice O'Connor's invitation in her concurring opinion,⁵² prompted many more states to enact durable power of attorney legislation.⁵³

The durable power of attorney or patient-designated proxy represents a decided improvement over the living will.⁵⁴ But only a minority of people execute durable powers of attorney or other advance directives.

In light of this public resistance to advance directives, several states have enacted legislation that represents a third stage (after living wills and designated proxies) in legislation addressing decisions about life sustaining treatment. These more recent surrogate consent statutes authorize specific parties to make health care decisions for incompetent patients in the absence of advance directives.⁵⁵

The *Cruzan* decision demonstrated that a family's authority to make medical treatment decisions for an incompetent family member was legally insecure and required specific legal recognition. The surrogate-consent statutes specifically authorize what some claim always to have been the actual practice in health care institutions before *Cruzan*.⁵⁶

III. BEYOND *CRUZAN*

There are clear signs that point to significant change in the field of bioethics. Three substantial changes include: (1) a shift in the basic paradigm; (2) an increase in public debate, political compromise, and direct democracy; and (3) the reassertion of both physician and

of durable power of attorney legislation and its use in delegating medical decisionmaking responsibilities).

52. See *supra* note 46 and accompanying text.

53. See, e.g., Catherine J. Barrie, *Legislative History of Missouri Senate Bill 148, Durable Power of Attorney for Health Care*, 11 ST. LOUIS U. PUB. L. REV. 453, 454 (1992).

54. For a further delineation of this position, see Susan R. Martyn & Lynn B. Jacobs, *Legislating Advance Directives for the Terminally Ill: The Living Will and Durable Power of Attorney*, 63 NEB. L. REV. 779 (1984); Fowler, *supra* note 51, at 1000-05; Sandra H. Johnson, *Sequential Domination, Autonomy and Living Wills*, 9 W. NEW ENG. L. REV. 113, 133-34 (1987).

55. See, e.g., ARK. CODE ANN., § 20-17-214 (Michie 1991); CONN. GEN. STAT. ANN. § 19a-571 (West Supp. 1994); LA. REV. STAT. ANN. § 40:1299.58.5 (West 1992); N.M. STAT. ANN. § 24-7-8.1 (Michie Supp. 1991); OR. REV. STAT. § 127.635 (1990); TEX. CIV. PRAC. & REM. CODE ANN. § 135.00 (West Supp. 1994); UTAH CODE ANN. § 75-2-1107 (1993); VA. CODE ANN. § 54.1-2986 (Michie 1991 & Supp. 1993).

56. See, e.g., Judith Areen, *The Legal Status of Consent Obtained from Families of Adult Patients to Withhold or Withdraw Treatment*, 258 JAMA 229, 234 (1987). The President's Commission recommended deference to the family as the norm. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT: A REPORT ON THE ETHICAL, MEDICAL, AND LEGAL ISSUES IN TREATMENT DECISIONS* 127-28 (1983).

social control over decisionmaking, especially in regard to treatment decisions with noticeable allocative effects.

The dominant paradigm in the first two decades of bioethics was "principlism."⁵⁷ Principlism provided a framework and a vocabulary that were quite compatible with judicial decisionmaking. This paradigm is criticized, however, for being unduly limiting and abstract.⁵⁸ It also is criticized for its emphasis on patients' autonomy.⁵⁹ Clearly the advance directive legislation⁶⁰ emerges from adherence to an autonomy theory, although the cases have often included a consideration of the best interests of the patient.⁶¹

Other paradigms for bioethics have been gaining strength.⁶² For example, studies regarding the impact of culture on decisionmaking call into question the broad acceptance of autonomy-based principles.⁶³ Similarly, the communitarian paradigm has shifted the focus from the autonomy of the individual to the community.⁶⁴ Finally, there is growing concern regarding medical decisions based on rights alone, rather than in conjunction with "moral principles."⁶⁵

The marriage of political action and bioethics has also expanded the forum for bioethics. Bioethics has always been at the forefront of broad public interest. Increasingly, bioethics has involved political ac-

57. See *supra* note 5 (discussing principlism).

58. For example, as a key part of the "rationalist" approach to ethics, principlism is subject to criticism for excluding emotions. See, e.g., Sidney Callahan, *The Role of Emotion in Ethical Decisionmaking*, HASTINGS CENTER REP., June-July 1988, at 9.

59. See Symposium, *Autonomy—Paternalism—Community*, HASTINGS CENTER REP., Oct. 1984, at 5 (discussing the claims of the community versus the autonomous rights of the individual); see also JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (1984); Jay Katz, *On Touching "The Happy Isles": Reflections about Past, Future, and Present*, 17 LAW, MED. & HEALTH CARE 110 (1989) (urging a broader conceptualization of autonomy).

60. See *supra* note 53 and accompanying text.

61. See, e.g., *supra* notes 11-12 and accompanying text (describing the use of an ethics committee to decide whether to withdraw life sustaining support).

62. For a discussion of other approaches, see generally Edmund D. Pellegrino, *The Metamorphosis of Medical Ethics: A 30-Year Retrospective*, 269 JAMA 1158 (1993) (describing a "metamorphosis in medical ethics" that began with the "Quiescent Period," and progressed to the "Period of Principlism," which was followed by a "Period of Antiprinciplism" and concluded with a "Period of Crisis").

63. See, e.g., *Special Section: Cultural Differences in Bioethics*, 4 J. CLINICAL ETHICS 134-42 (1993).

64. See, e.g., Jeffrey Blustein, *The Family in Medical Decisionmaking*, HASTINGS CENTER REP., May-June 1993, at 6 (discussing the conflict between autonomy and communitarianism).

65. See, e.g., John Ladd, *Legalism and Medical Ethics*, in *ETHICAL ISSUES IN MODERN MEDICINE* 65-69 (John Arras & Nancy Rhoden eds., 3d ed. 1989) (discussing the relationship between the legal and moral aspects of bioethics).

tion. The assisted suicide referenda in Washington⁶⁶ and California⁶⁷ are illustrative of such political exercises. Grassroots movements attempting to set standards for allocation decisions evidence a broader public base for bioethics.⁶⁸ Political action, coupled with increased public control over the prevailing norms in bioethics,⁶⁹ present significant challenges to "business as usual" in bioethics.

Finally, the question of health care allocation or rationing promises to expand bioethics beyond the focus on the individual medical treatment decision.⁷⁰ The *Quinlan-to-Cruzan* era addressed whether the discontinuation or withholding of treatment was legally permissible and whether a surrogate had the authority to make the treatment decision on behalf of an incompetent patient.⁷¹ This inquiry necessarily implicated the concern that surrogates might act too quickly or out of self-interest.⁷² In the light of this concern, the law presumed that treatment must continue unless the surrogate met a substantial burden of proving that an exception should be made.⁷³

The question facing the legal and medical communities at this time, however, is to what extent the decision to withhold or to continue treatment should remain a matter of personal choice.⁷⁴ The

66. Ballot Initiative 119 (1991) (referendum that would have legalized assisted suicide and euthanasia in Washington state).

67. Ballot Initiative 161 (1992) (referendum that would have legalized doctor-assisted suicide in California).

68. See, e.g., Bruce Jennings, *A Grassroots Movement in Bioethics*, HASTINGS CENTER REP., Special Supp., June/July 1988; Diane M. Gianelli, *One Community Looks for Consensus on "Futile Care,"* AM. MED. NEWS, Sept. 20, 1993, at 1.

69. Political action, political compromise, and public "control" are distinguishable from the "public moral discourse" described by Albert Jonsen and engaged in by bioethics commissions. Albert R. Jonsen, *Theological Ethics, Moral Philosophy, and Public Moral Discourse*, 4 KENNEDY INST. ETHICS J. 1, 3 (1994).

70. Bioethics has been criticized for concentrating on the physician-patient relationship and neglecting the larger community interest in furthering justice in health care decisionmaking. See Renee Fox, *Advance Medical Technology—Social and Ethical Implications*, 2 ANN. REV. SOC. 231-68 (1976).

71. See discussion *supra* Part I.

72. See Areen, *supra* note 56, at 232-33 (discussing the possibility that families may make decisions out of ignorance or bad faith).

73. See *supra* note 27.

74. See, e.g., *In re Conservatorship of Wanglie*, No. PX-91-283 (Minn. Dist. Ct., Hennepin Co., June 28, 1991) (Findings of Fact, Conclusions of Law, and Order) (deciding whether it was in the best interest of an elderly woman who is comatose, gravely ill, and ventilator-dependent to have her husband of 53 years or a stranger make her medical care decisions for her); *In re Baby "K"*, 16 F.3d 590 (4th Cir. 1994) (holding that under the Emergency Medical Treatment and Labor Act a hospital must provide emergency stabilizing treatment).

debate over medical futility⁷⁵ highlights the social element of medical treatment decisions and calls for some degree of social or physician control over such decisions. How the surrogate-consent statutes, confirming and strengthening the customary role of kith and kin in making treatment decisions for incompetents, will influence the legal issues presented by this powerful question remains to be seen. In light of the new pressures on health care allocation, the individual rights approach probably will not survive as the dominant legally recognized method for treatment decisionmaking. The challenge to bioethics is to move beyond the bedside and beyond the physician-patient dyad while maintaining the patient-centered moral aspect of treatment decisions.

Although legislatures have addressed some questions of access to medical care, they have not tackled the issues raised in this generation of allocation decisions. For instance, state statutes governing access to medical care have focused almost entirely on access to emergency treatment.⁷⁶ The federal Emergency Medical Treatment and Labor Act likewise protects only a limited right to emergency care.⁷⁷ The recent *Baby "K"*⁷⁸ case reveals the inadequacy of such legislation in light of the futility debate. Unfortunately, the federal antidiscrimination statutes⁷⁹ will not resolve the question of medical futility, although they do establish important minimum boundaries for rationing.

CONCLUSION: A DIRECTION FOR FUTURE SCHOLARSHIP

Almost all of the scholarship on the law of bioethics has concentrated entirely on statutory and case law, the most easily accessible sources of law, but clearly a limited universe.⁸⁰ Thoughtful critique of legislation and case law undoubtedly makes a contribution to the de-

75. The academic and professional literature on medical futility is already massive. For a good description of the issues and a variety of definitions of medical futility, see Symposium, *Medical Futility*, 20 LAW, MED. & HEALTH CARE 307 (1992).

76. See, e.g., N.Y. PUB. HEALTH LAW § 2805-b(1) (McKinney 1993); PA. STAT. ANN. tit. 35, § 449.8(a) (1993). For an excellent analysis of the duty to provide emergency treatment under state law, see Karen H. Rothenberg, *Who Cares?: The Evolution of the Legal Duty to Provide Emergency Care*, 26 Hous. L. Rev. 21 (1989).

77. 42 U.S.C. § 1395d(d) (1988).

78. *In re Baby "K"*, 16 F.3d 590 (4th Cir. 1994).

79. See, e.g., Title VI of the 1964 Civil Rights Act, 42 U.S.C. § 2000d (1988); the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1988 & Supp. IV 1992); and the Americans with Disabilities Act, 42 U.S.C. § 1201 (1988 & Supp. 1990).

80. There have been some notable exceptions to the focus on case law, including the controversy and action surrounding the *Baby Doe* regulations litigated in *Bowen v. American Hospital Ass'n*, 476 U.S. 610 (1986).

velopment of law in this area. Health care delivery is a highly regulated enterprise, however, whether it occurs in a private medical office or in state-licensed and federally reimbursed health care facilities. Statutory developments on the state level often produce state administrative regulations, a source of law that has in the past been difficult to research. Neglecting such administrative regulation, however, results in ignorance of the sources of law that have the most direct and effective influence on provider behavior.⁸¹ To the extent that bioethics provides a critique of the law and of attorneys advising health care providers, bioethics must analyze the *entire* legal environment, including rulemaking by administrative agencies and adjudication by professional and institutional licensure and certification agencies.

Moreover, if experience is any guide to the future, questions of rationing health care are more likely to be resolved within a bureaucracy rather than by courts or legislatures. Just as bioethics will move beyond the bedside, legal scholarship on bioethics must move beyond the confines of statutory and case law if it is to remain a relevant influence in medical treatment decisionmaking.

81. The most well-known example of deference to an administrative system is the role established for the New Jersey Ombudsman for the Institutionalized Elderly in *In re Conroy*, 486 A.2d 1209 (N.J. 1985). In *Conroy*, the Supreme Court of New Jersey required that the Office of the Ombudsman receive notification whenever a nursing home contemplates withdrawing life-sustaining treatment from an elderly, incompetent resident. To execute the court's mandate, the first ombudsman issued a letter to nursing homes announcing that his office would investigate every case in which life-sustaining treatment might be withheld and that facilities should hold in-service training to avoid "possible fines, professional censure and other serious penalties." Letter from Hector Rodriguez, Aug. 30, 1988. In a report to the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care, the ombudsman stated that those who desired to prevent the deterioration and death of the elderly would not oppose such an aggressive program. A subsequent ombudsman, in contrast to the first, promulgated rules that defined "abuse" as providing medical treatment after a competent resident has made a voluntary and informed choice to terminate treatment. Using the limited scope of judicial review traditionally accorded administrative rulemaking, a New Jersey appellate court upheld the definition in *Gleason v. Abrams*, 593 A.2d 1232 (N.J. Super. Ct. App. Div. 1991). Other illustrations of the impact and latitude enjoyed by administrative agencies exist. See, e.g., Clarence J. Sundram, *Informed Consent for Major Medical Treatment of Mentally Disabled People*, 318 NEW ENG. J. MED. 1368 (1988) (describing an administrative "surrogate decisionmaking committee," established in New York to make medical treatment decisions for incompetent patients for whom no other surrogate was available, which did not require clear and convincing evidence of the patient's choice); Rob Carson, *Rule Lets Aid Crews Defy Living Will*, TACOMA NEWS TRIB., Mar. 7, 1993, at B1; Carol M. Ostrom, *Health Dept. Will Stand Behind Tougher "No-CPR" Rules*, SEATTLE TIMES, Mar. 13, 1993, at A8 (describing the Washington state health department's restrictive regulations concerning the availability of "no-CPR" bracelets).