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# LAW AND BIOETHICS

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“Law and bioethics” differs in several important ways from the other “law and . . .” topics discussed in this collection. To begin, “bioethics” itself is less easily defined than the familiar disciplines that populate the land of academic legal hybrids. In the first section of this Essay, we describe the domain of bioethics. Next, we compare “law and bioethics” with other “law and . . .” topics as a means of understanding the ways in which the law has shaped bioethics and bioethics has come into legal studies. Finally, we examine legal and ethical issues in certain end-of-life cases, a topic familiar to students of bioethics but perhaps of interest to lawyers who are curious about what the field is all about.

## I. BIOETHICS

Bioethics is said to be the field that addresses the ethical problems posed by modern medicine and biotechnology.<sup>1</sup> But it is not a single, distinct academic discipline. As Daniel Callahan noted twenty years ago and as remains true today: “Most of its practitioners have wandered into the field from somewhere else, more or less inventing it as they go.”<sup>2</sup> Indeed, one of the strengths of the field is that it is interdisciplinary and has been since its origins, drawing people not only from medicine, philosophy, theology, and law but also from nursing, medical history, medical anthropology, medical sociology, and related fields. At a conference last fall on “The Birth of Bioethics,” the speakers—who were chosen as “pioneers” because they had published articles in the field prior to 1976—consisted of fourteen physicians, twelve philosophers, eight theologians, four lawyers, and five from other fields such as medical sociology and history of medicine, with several holding degrees in more than one field.

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1. John D. Arras, *Nancy Rhoden: Exploring the Dark Side of Biomedical Technology*, 68 N.C. L. REV. 835, 835 (1990).

2. Daniel Callahan, *Bioethics as a Discipline*, 1 HASTINGS CENTER STUD. 66, 68 (1973).

### A. *When Did the Field Originate?*

An argument can be made on more than parochial grounds that the University of Washington's celebration of "The Birth of Bioethics" was perfectly timed—the conference was held on the thirtieth anniversary of the November 1962 publication of Shana Alexander's widely cited *Life* article on the "God Committee."<sup>3</sup> This group of seven laypersons was charged with deciding which patients at Swedish Hospital in Seattle, where chronic hemodialysis was developed, would have access to the still scarce kidney machines—and also which patients, lacking this treatment, would die.<sup>4</sup> The kidney dialysis story typifies much of bioethics in that it raises problems or dilemmas that arise from the successes of biomedicine. Indeed, until the recent past, with the frustrations of the AIDS epidemic, much of bioethics seemed to be generated by the enormous powers of medicine that began to emerge so clearly by the 1960s—in resuscitation and intensive care, behavior modification, reproductive techniques, and a host of other high-tech, high-cost diagnostic and treatment modalities. In a phrase, bioethics has dealt with the problems of success, not failure.

Other observers might suggest that the principles and many of the issues that are central to bioethics originated earlier than the 1960s, most prominently in the standards for research with human subjects embodied in the "Nuremberg Code" articulated in 1945 by three American jurists in the course of passing judgment on the physicians who experimented on prisoners in the Nazi concentration camps.<sup>5</sup> Still others might argue that the many threads that make up bioethics did not really come together until the late 1960s with, for example, the founding in 1969 in Hastings-on-Hudson, New York, of the Institute of Society, Ethics and the Life Sciences—now formally known by its nickname, The Hastings Center. Dispute even arises over where and by whom the word "bioethics" was first used to describe the field—either Sargent Shriver or Van Rensselaer Potter.<sup>6</sup>

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3. Shana Alexander, *They Decide Who Lives, Who Dies*, LIFE, Nov. 9, 1962, at 102.

4. *Id.* at 106.

5. See generally JAY KATZ, EXPERIMENTATION WITH HUMAN BEINGS 292-306 (1972); *Medical Case*, in 1-2 TRIALS OF WAR CRIMINALS BEFORE THE NUERNBERG MILITARY TRIBUNALS (1949).

6. Warren Reich described these alternative theories in his address at the Birth of Bioethics Conference, on September 23, 1992, in Seattle, Washington, drawing on the recollections of the Honorable Sargent Shriver and on Van Rensselaer Potter's book on bioethics. It is thought that Sargent Shriver suggested the term to Andre Hellegers, M.D., in 1971 while Dr. Hellegers was organizing the Kennedy Institute of Ethics at Georgetown University, which included a Center on Bioethics. Dr. Potter coined the term "bioethics" to describe the joining together of biological knowledge and human values to create public policy that would ensure the survival of the quality of life on earth. See VAN RENSSELAER POTTER, BIOETHICS:

At the very least it is clear that by the 1970s, scholars and practitioners from a wide range of fields were working together in a domain that was no longer adequately described as medical ethics. Beyond mere concerns of medical etiquette—for example, whether it is proper for a physician to refer a patient to a practitioner who lacks a medical degree—medical ethics had been oriented, in effect, to the question: “What would the conscientious, moral physician do under the circumstances?” Bioethics was premised on the recognition that ethically acceptable solutions to the dilemmas posed by modern medicine—from crafting the rules that would guide human research to deciding when human life begins and ends to allocating life-saving resources—could be derived only from a more broadly based analysis, and a more generally legitimated decision-making mechanism than the choices made by individual physicians, however conscientious.

### B. *A Multitude of Methods*

Bioethics is hard to describe not only because it is not a clearcut discipline but because it lacks a single, accepted methodology. Philosopher-bioethicists use the methods of philosophy and theologian-bioethicists use the methods of theology, at least when writing. But when bioethicists consult in hospitals, exactly what are they doing?—especially if the “bioethicist” is a physician or lawyer and not a moral philosopher or theologian. Although it has been suggested that bioethics rescued moral philosophy,<sup>7</sup> bioethics is not simply applied ethics. First, it is fundamentally interdisciplinary and draws on a variety of understandings of biology and the practice of medicine.<sup>8</sup> Second, as Barry Hoffmaster has recently argued, it deals with practical problems in light of their circumstances and contexts, whereas moral philosophers traditionally disclaim any special ability to say what is the right thing to do—although they are willing to say what counts as a good moral reason.<sup>9</sup>

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BRIDGE TO THE FUTURE (1971). Chapter one of his book is titled “Bioethics, The Science of Survival.” *Id.* at 1. This is obviously a quite different use of the term than the one that has become familiar. Dr. Potter was primarily concerned with the environment rather than with medicine and biotechnology. *Id.* at 2.

7. Stephen Toulmin, *How Medicine Saved the Life of Ethics*, 25 *PERSP. BIOLOGY & MED.* 736 (1982).

8. For example, one of us, V.M., is trained as a family therapist, and has found that both in teaching bioethics and in case consultation, she draws heavily on both the theory and methods of that field.

9. Barry Hoffmaster, *Can Ethnography Save the Life of Medical Ethics?*, 35 *SOC. SCI. & MED.* 1421 (1992).

In the last few years, considerable discussion has taken place concerning bioethics methodology—largely in the philosophical rather than the legal literature, but still important to any understanding of law and bioethics. Bioethics has traditionally been focused on mid-level ethical principles such as autonomy, beneficence, justice, and nonmaleficence.<sup>10</sup> Argumentation at this level is necessary because general agreement is lacking on a moral theory that would resolve bioethical dilemmas. But the appeal to mid-level principles has proved no more successful since most dilemmas arise precisely when conflict occurs among ethical principles, none of which have an unchallenged claim of priority.<sup>11</sup>

In their 1988 book, *The Abuse of Casuistry*,<sup>12</sup> Albert Jonsen and Stephen Toulmin challenge this principle-based theory. Drawing on their experiences as, respectively, a member of and a consultant to the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in the mid-1970s, the authors assert that agreement on the solution to bioethical problems comes not by deductive reasoning from general rules or principles, but rather from a “shared perception of what was *specifically* at stake in particular kinds of human situations.”<sup>13</sup> Jonsen and Toulmin thus promote casuistry—“the analysis and classification of ‘cases’ and ‘circumstances’ ”<sup>14</sup>— as the appropriate methodology for bioethics, based on the claim that “*moral knowledge is essentially particular* so that sound resolutions of moral problems must always be rooted in a concrete understanding of specific cases and circumstances.”<sup>15</sup> Readily recognizable examples of good and evil, and right and wrong, provide paradigmatic examples that can then be applied to new and more complex cases. Jonsen and Toulmin note that philosopher John Arras calls this the common-law ethics model,<sup>16</sup> and of course it is a model that probably seems eminently reasonable from the perspective of lawyers who use it every day.

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10. These four principles are often referred to as the “Georgetown Mantra” because they have been repeatedly articulated by scholars from the Kennedy Institute at Georgetown University. See generally THOMAS BEAUCHAMP & JAMES CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* (3d ed. 1989) (describing ethical principles that serve as basis of analysis in field of bioethics).

11. A key reference work for physicians actually states that the principle of autonomy has priority, but offers no justification for this contention. ALBERT R. JONSEN ET AL., *CLINICAL ETHICS: A PRACTICAL APPROACH TO ETHICAL DECISIONS IN CLINICAL MEDICINE* (2d ed. 1992).

12. ALBERT R. JONSEN & STEPHEN TOULMIN, *THE ABUSE OF CASUISTRY: A HISTORY OF MORAL REASONING* (1988).

13. *Id.* at 18.

14. *Id.* at 11.

15. *Id.* at 330.

16. *Id.*

However, as Kevin Wildes notes, it is not clear how paradigms are selected in the Jonsen-Toulmin model.<sup>17</sup> In the medieval practice of casuistry, the paradigms were set in "the disciplinary matrix of Catholic confessional practice"<sup>18</sup> and made sense within that moral tradition. Wildes doubts any basis exists for assuming a common morality today as a matrix for paradigm bioethics cases. "The conceptual question for contemporary bioethics . . . is determining who is the moral authority today."<sup>19</sup> He argues that the legitimacy of the Jonsen-Toulmin model is undermined because they "do not take moral pluralism seriously."<sup>20</sup>

The problem of moral pluralism plagues every effort to settle on a satisfactory methodology for bioethics. Tackling this problem directly, H. Tristram Engelhardt asserts that we meet as "moral strangers"—people who do not "share enough of a concrete morality to allow the common discovery of the basis for the correct resolution of a moral controversy."<sup>21</sup> This accounts for the centrality of individuals in bioethics theories. However, even though people lack a shared moral community,<sup>22</sup> they can still "establish a procedural ethic, based on respect of the freedom of the moral agents involved, even without establishing the correctness of any particular moral sense."<sup>23</sup>

This tilt toward procedure over substance is familiar—and comfortable—for many lawyers in the liberal, democratic tradition, but some lawyers working in bioethics have nonetheless rejected it. George Annas has reacted strongly to suggestions that bioethics should concentrate on acceptable decision-making processes rather than substantive rules. He recognizes the frustrating nature of the task of defining the latter but says "it nonetheless strikes me as one that is worthy of law and social policy, and the only one that can hope to prevent medical law (and medical ethics) from becoming no more than simply the arbitrary exercise of power."<sup>24</sup> But this point is not made in disregard of the problem of moral pluralism. In fact, Annas ends the introduction to his most recent

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17. Kevin W. Wildes, S.J., *The Priesthood of Bioethics and the Return of Casuistry*, 18 J. MED. & PHIL. 33, 40 (1993).

18. *Id.* at 39.

19. *Id.* at 44.

20. *Id.* at 45.

21. H. TRISTRAM ENGELHARDT, JR., *BIOETHICS AND SECULAR HUMANISM* at xiv (1991).

22. *Id.* at 135-36.

23. H. TRISTRAM ENGELHARDT, JR., *THE FOUNDATIONS OF BIOETHICS* 45 (1986).

24. GEORGE J. ANNAS, *JUDGING MEDICINE* at xiii (1988).

book with this quotation from Joseph Campbell: "Lawyers and law are what hold us together. There is no ethos."<sup>25</sup>

## II. LAW AND BIOETHICS

### A. *Is It Just Health Care Law?*

The issues of domain and methods are even more interesting when the question is enlarged beyond "what is bioethics?" to "what is law and bioethics?" For example, when law firms offer bioethics consultation as part of the services they provide, what does this mean?<sup>26</sup> If the expertise being offered is not strictly legal, what is it? And if it is strictly legal, how does it differ from the rest of health law practice so as to justify having a name of its own?

In other words, does "law and bioethics" really just refer to a subject area *within* law like sports law or entertainment law so that it should rightly be called bioethics law and not be classified with the "law and . . ." topics? An argument can be made for considering bioethics as simply a subset of health care law that deals with medical decision making, genetic and reproductive technology, human subjects research, and the like. In fact, health law casebooks today typically include chapters or sections on bioethics.

But this view does not fully capture the means by which bioethics is generally taught. Long before "health law" emerged as a field separate from forensic medicine, courses dealing with bioethics were being taught at law schools,<sup>27</sup> although the first casebook with the title *Bioethics and Law* was not published until 1981.<sup>28</sup> A sense of what sets the field apart can be seen in that casebook, in which the first two chapters describe "the new biology" and recount the dilemmas engendered by modern medicine and biotechnology, and in which the third chapter, "Managing the Dilemmas: Ethical Theories," begins: "Virtually all of the dilemmas and governance problems raised in the preceding chapters pose both legal

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25. GEORGE J. ANNAS, STANDARD OF CARE: THE LAW OF AMERICAN BIOETHICS 12 (1993).

26. See, e.g., ARENT FOX KINTNER PLOTKIN & KAHN, LEGAL CONSULTING SERVICES IN THE FIELD OF BIOETHICS (undated advertising brochure) (on file with *Loyola of Los Angeles Law Review*).

27. For example, Jay Katz, M.D., taught courses on "Experimentation with Human Beings" and "Catastrophic Diseases" at Yale Law School from the mid-1960s, and one of us, A.M.C., who had taught with Dr. Katz, published (in photocopy form) several editions of a casebook on "Law and the Life Sciences" that were used at Columbia, Pennsylvania, and Yale Universities beginning in 1973. This material eventually became one foundation for JUDITH AREEN ET AL., LAW, SCIENCE, AND MEDICINE (1984).

28. MICHAEL H. SHAPIRO & ROY G. SPECE, JR., BIOETHICS AND LAW (1981).

and ethical issues, and thus we are required to deal with 'law and bioethics.'"<sup>29</sup> What follows is a twenty page discussion of ethical theory. Similarly in *Law, Science and Medicine*, Section C of the first chapter, entitled "Values and Uncertainty,"<sup>30</sup> includes an eighteen-page excerpt from an article by philosopher Tom L. Beauchamp, *Ethical Theory and Bioethics*.<sup>31</sup> Thus, when legal academicians teach courses in this field, they consider grounding in ethical theory central to an understanding of the subject.

From this one might conclude that law and bioethics is a subset of law and philosophy.<sup>32</sup> But such a characterization would also do the field an injustice because attention is usually not focused on mastering philosophical concepts for their own sake but as they relate to understanding society's appropriate responses to developments that deeply affect people's lives and relationships. Indeed, while law and bioethics courses originally relied heavily on nonlegal materials,<sup>33</sup> the flood of cases, statutes, and regulations in recent years makes casebooks in this field now look more like those in traditional fields. This deluge also makes law and bioethics of greater interest to legal practitioners.<sup>34</sup>

29. *Id.* at 72.

30. AREEN ET AL., *supra* note 27, at 114.

31. Tom L. Beauchamp, *Ethical Theory and Bioethics*, in TOM L. BEAUCHAMP & LEROY WALTERS, *CONTEMPORARY ISSUES IN BIOETHICS* 1, 4-11, 13-24, 26-31 (2d ed. 1982), reprinted in AREEN ET AL., *supra* note 27, at 131-48.

32. Indeed, the author of the Essay on law and philosophy in this collection, Professor Leslie Pickering Francis, does work in bioethics.

33. This is exemplified by the fact that

[w]hen I began teaching "Law and the Life Sciences," most of my course materials were either from other disciplines, such as sociology and philosophy, or were cases and statutes that did not deal directly with the life sciences but from which I could draw analogies by examining the possible application of rules in contracts, criminal law, constitutional law, or administrative law. For example, we asked, what would come out of applying Erving Goffman's work on "total institutions" to the hospital—not just mental institutions but ordinary hospitals? What legal structures would then be appropriate?

Alexander M. Capron, *A "Bioethics" Approach to Teaching Health Law*, 38 J. LEGAL EDUC. 505, 506 (1988).

34. Although now there are many opportunities to practice in the specialized field of bioethics, this was not always the case. For example,

[i]n the early 1970s students would say, "I am very interested in what you're doing, but where can you recommend that I look for a job after I graduate?" . . . Because there were no firms specializing in "bioethics," even such landmark cases as *In re Quinlan* were usually litigated by lawyers who had no special preparation. Since then opportunities have expanded, and anyone teaching a bioethics approach to the health care field today can assure students that there are many ways the material will be relevant in legal practice. Partners at general practice firms—and even more, at health law firms—now recognize the need for people whose experience goes beyond reimbursement issues to encompass the philosophical and social subtleties in bioethics cases.

*Id.* at 506-07 (footnote omitted).



B. *How Does It Differ from Other "Law and . . ." Disciplines?*

Bioethics and law are entangled in ways that set them apart from the other "law and . . ." fields. First, it cannot be said that law has shaped most of the other "law and . . ." disciplines—such as anthropology, history, language, literature, sociology, theology, or even the natural sciences—in any significant way. But a leading bioethicist-lawyer has argued that "American law, not philosophy or medicine, is primarily responsible for the agenda, development and current state of American bioethics."<sup>35</sup> For example, it is hard to separate the ethical principle of autonomy in the bioethics literature from the legal expression of that principle as "privacy" or "liberty" in the context of judicial decisions on informed consent or the right to refuse treatment. Indeed, the nonlawyers doing bioethics in the late 1960s and early 1970s often grounded their advocacy for a transformation of the physician-patient relationship on the rules developed by courts in the early informed consent cases.<sup>36</sup> Likewise, the principles and procedures developed by medical associations and the federal government to ensure respect for the rights and interests of human beings in biomedical research<sup>37</sup> drew on the decision of the American judges at the Nuremberg Tribunal in sentencing the Nazi concentration camp doctors.

Reciprocally, bioethics has shaped the law through the introduction of concepts like proportionality<sup>38</sup> or the elaboration of concepts such as personhood. Furthermore, lawyers and courts have been forced to tackle bioethical dilemmas. For example, the limited availability of dialysis machines in the early 1960s led to an increasingly visible struggle with the problem of choosing the "most worthy" to receive treatment. The spectacle of patients dying for lack of access to a successful therapy proved too much for Congress, prompting its decision in 1972 to fund all end-

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35. ANNAS, *supra* note 24, at 3.

36. The notion that to be valid, consent must be preceded by a physician's disclosure of information about what was proposed to be done to a patient was first articulated in *Salgo v. Leland Stanford Jr. Univ. Bd. of Trustees*, 154 Cal. App. 2d 560, 317 P.2d 170 (1957).

37. KATZ, *supra* note 5, at 312-21, 845-46 (discussing Declaration of Helsinki and other ethical standards governing biomedical research on human subjects).

38. The notion from Catholic doctrine that otherwise binding obligations become optional when they create burdens that are disproportionate to their benefits first entered bioethics law in the famous New Jersey Supreme Court decision *In re Quinlan*, 355 A.2d 647 (N.J.), *cert. denied*, 429 U.S. 922 (1976), which involved a patient whose wishes were unknown but might be derived from her Catholic faith. In time, however, this concept progressed from that particular context—of a Catholic patient—to a generally applicable concept useful in judging not only a patient's obligations to accept treatment but families' and professionals' obligations to offer treatment.

stage renal disease treatment through the Medicare program.<sup>39</sup> This arguably premature and poorly considered legislative response is an example of the law reacting to the development of new medical technology. The rapid development of biomedical technology has probably made this reactive posture inevitable, though a central task of law and bioethics scholarship has been to anticipate needed social responses to biomedical developments.

The existence of many litigated bioethics cases is a characteristic of this field that distinguishes it from most of the other "law and . . ." topics. Most of the others are academic disciplines rather than applied or practical fields, whereas bioethicists as a regular matter see their theories tested in both court cases and legislation. The field grew out of the practical realities of the physician-patient relationship, biomedical research, and the behavior of health care institutions.

Bioethicists have also had a role in the formation of public policy that is atypical of participants in the other "law and . . ." fields, except perhaps law and economics. Three national commissions, as well as myriad other governmental bodies at the state and federal levels, have dealt with the ethical and social issues raised by research with human subjects, medical technology and health care.<sup>40</sup>

### C. *What Is Taught and Published?*

One way to trace the history of a "law and . . ." field is to look at the legal curriculum as it is described through the course categories mentioned in the American Association of Law Schools (AALS) *Directory of Law Teachers*. In the 1960s, the index to courses listed simply Law and Medicine, described as including Health Law and Psychiatry and the Law. In the 1974-1975 directory, Law and Medicine was changed to include only Health Law, while Law and Psychiatry was listed separately. Law and Medicine was then expanded to include Forensic Medicine in 1976-1977, and Bioethics a decade later. The following year, 1987-1988, Health Care Law gained a separate listing. Law and Science has also had a listing, at least since the 1960s.

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39. Social Security Amendments of 1972, Pub. L. No. 92-603, § 299I, 86 Stat. 1329, 1463-64 (codified at 42 U.S.C. § 426-1 (1988)).

40. These commissions were the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1974-1978; the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1980-1983; and the Biomedical Ethics Advisory Committee, 1987-1990. One of us, A.M.C., has served as consultant to the first commission, executive director of the second, and chair of the third.

But the AALS directory information turns out not to reflect what was really being taught. For example, one of us, A.M.C., started teaching a bioethics course called "Law and the Life Sciences" in 1972-1973 at Pennsylvania, having taught other courses in this area the previous two years at Yale. Similarly, our colleague Michael Shapiro began teaching a course at University of Southern California in 1969 called "Law and Technology" that covered issues in bioethics and environmental law. But it took nearly twenty years for bioethics to be recognized with so much as a subheading in the AALS directory.

Another indicator of the development of law and bioethics might be the listings in the *Index to Legal Periodicals (Index)*. "Medical Jurisprudence" is a longstanding category in the *Index*. In the 1964-1967 cumulative index, most of the entries in this category relate to medical malpractice, medical evidence, law and psychiatry, and the like. There are a few articles on consent to or refusal of medical treatment and one entitled *The Legal Rights of the Unborn Child*,<sup>41</sup> which might be thought of as falling in law and bioethics territory. However, by the 1967-1970 edition, the *Index* listed many articles that dealt with bioethics including abortion, organ transplants, the definition of death, experimentation with human subjects, and refusal of life-sustaining treatment. Additionally, there were several law review symposia on bioethics issues.<sup>42</sup> Thus, the *Index* would place the birth of bioethics as a field of academic legal writing in the late 1960s, which is consistent with the time of the first law school courses and the founding of the Hastings Center and the Kennedy Institute. Despite this, however, the *Index* has never had a subject heading of "bioethics," although since 1987-1988 it has listed "Medical Ethics," which seems odd in that medical ethics seems less connected with law than bioethics. The literature of law and bioethics is not just found in law reviews, or for that matter just in scholarly journals of other disciplines such as philosophy, but appears also in medical and health policy journals and in bioethics publications, most notably the *Hastings Center Report* and *The Journal of Law, Medicine & Ethics*.

One major topic in legal scholarship can legitimately be said to be part of the law and bioethics literature: abortion. Although much of the literature on abortion would be classified as straight constitutional law

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41. Richard P. Byrne, *The Legal Rights of the Unborn Child*, 41 L.A. B. BULL. 24 (1965).

42. INDEX TO LEGAL PERIODICALS (1967-70 ed.) (listing Symposium, *Reflections on the New Biology*, 15 UCLA L. REV. 267 (1968); *The Medical, Moral and Legal Implications of Recent Medical Advances: A Symposium*, 13 VILL. L. REV. 732 (1968); Symposium, *Medical Progress and the Law*, 32 LAW & CONTEMP. PROBS. 561 (1967)).

analysis, an emerging feminist approach<sup>43</sup> is greatly influenced by Carol Gilligan's work,<sup>44</sup> which focuses on *moral* development and the ways in which women and men resolve moral dilemmas. Given the concern with how to conceptualize values, it is not surprising that the work of Gilligan and other feminist moral theorists, such as Nel Noddings,<sup>45</sup> has begun to show up in the law and bioethics literature. This influence is felt not only in the subjects dealing directly with women—such as abortion, maternal-fetal issues, and reproductive technology—but also in less obvious places like the literature on ethics committees.<sup>46</sup> In fact, one might have expected this influence to have appeared earlier than it did because the subject matter of bioethics is largely the relationship between patients and health *caregivers*. These relationships would appear to lend themselves to an analysis grounded in concepts of relationship and connection that have been central to feminist analysis—in contrast to the dominant analytic framework of bioethics which has been that of patient autonomy and rights.

#### D. *Too Much Rights Talk?*

For better or worse, law has had a major effect on the way bioethics is conceptualized and the language in which it is discussed. In large part because of lawyers—particularly those who think in terms of constitutional law, as Paul Armstrong did when he argued in the New Jersey courts on behalf of the Quinlan family in 1975-1976—bioethics issues have been framed in the language of competing rights, whether the issue is abortion, the so-called maternal-fetal conflict, surrogate motherhood, or the refusal of life-sustaining medical treatment. An amicus brief filed in *Webster v. Reproductive Health Services*<sup>47</sup> on behalf of an ad hoc group, Bioethicists for Privacy,<sup>48</sup> argued that *Roe v. Wade*<sup>49</sup> should not be overruled because the right of privacy it articulated was generally important to protecting the physician-patient relationship.

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43. See, e.g., Pamela S. Karlan & Daniel R. Ortiz, *In a Diffident Voice: Relational Feminism, Abortion Rights, and the Feminist Legal Agenda*, 87 NW. U. L. REV. 858 (1993).

44. CAROL GILLIGAN, *IN A DIFFERENT VOICE* (1982).

45. NEL NODDINGS, *CARING: A FEMININE APPROACH TO ETHICS AND MORAL EDUCATION* (1984).

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

47. 492 U.S. 490 (1989).

48. Brief for Bioethicists for Privacy as Amicus Curiae Supporting Appellees at 11-13, *Webster v. Reproductive Health Servs.*, 492 U.S. 490 (1989) (No. 88-605).

49. 410 U.S. 113 (1973).

The issues in bioethics are some of the most sensitive and most divisive confronted by our society. We resort to "rights" when non-adversarial solutions seem impossible. As Ronald Dworkin notes, "The concept of rights . . . has its most natural use when a political society is divided, and appeals to cooperation or a common goal are pointless."<sup>50</sup> With the sharp divisions that exist in American society over bioethics issues and the tendency to take them to court, the formulation of ideas in terms of rights is thus not surprising. But this is not to say that legal commentators on bioethics are all attached to rights language and analysis. Many resist over-legalizing the field and recognize that the caregiver-patient relationship is ideally characterized as intimate and collaborative. Indeed, one central concern for law and bioethics is to discern the limits of law as a mechanism to structure concepts and relationships in health care. In doing this it draws on the traditions of medicine as well as the insights of philosophy, theology, anthropology, and the like.

Prior to the development of modern medical technology, the relationship between physician and patient was paternalistic—with the theory being that the doctor would do what was best for the patient, and the reality being that the doctor could not greatly affect the course of illness. With the increasing effectiveness of medical interventions, physicians began to possess some real power to influence their patients' futures, and that power became the subject of disputes concerning how it was to be distributed in the physician-patient relationship. Legal commentators suggested—and most bioethicists embraced—redefinition of that relationship in terms of patients' rights.<sup>51</sup> The dominant place of patients' rights in law and bioethics theory dismays many health care professionals who lament the adversarial tone that they feel the law has introduced into the practice of medicine. There may be a legitimate complaint here, but physicians have historically denied that they are making anything but medical decisions for patients. It has taken bioethicists to point out that once alternative treatments are available, the choice between them is usually based on value judgments, not medical judgments, and doctors have no special expertise that justifies their values taking precedence over the patient's values. Law and bioethics literature has addressed the problem of the power imbalance between a vulnerable ill person and a physician who has control of all the information needed for decision making. As critical race theory has also made clear, rights are crucial to deal with power inequality even where our preference would be to conceive of rela-

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50. RONALD DWORBIN, TAKING RIGHTS SERIOUSLY 184 (1977).

51. See George J. Annas & Joseph M. Healey, Jr., *The Patient Rights Advocate: Redefining the Doctor-Patient Relationship in the Hospital Context*, 27 VAND. L. REV. 243, 245 (1974).

tionships in terms of caring and connection. This tension has been a recurring theme in law and bioethics, as we hope to make clear by exploring one of the most contentious areas in the field, decision making about treatment—especially life-sustaining—for persons who lack present decision-making capacity.

### III. AN ILLUSTRATION: LIFE SUPPORT FOR NONCOMPETENT PATIENTS

Decision making for noncompetent persons has been the subject of numerous state laws providing for advance directives for health care, as well as the federal Patient Self-Determination Act.<sup>52</sup> Additionally, countless cases from *In re Quinlan*<sup>53</sup> to *Cruzan v. Director, Missouri Department of Health*<sup>54</sup> are part of the growing body of law in this area. It is not surprising, then, that this issue has provoked substantial law review literature as well. The reigning assumption of statutes, cases, and articles is that individual autonomy is the central principle. Ideally, every person would write his or her wishes for future care in an advance directive or otherwise communicate them to family members or an appointed agent. Legislators and courts have expressed virtually no reservations about this model. In fact, though the *Cruzan* court was unwilling to give constitutional protection to family decision making on behalf of incompetent patients, it indicated in dictum that a competent patient's decision to forgo life-prolonging treatment could not be overruled by the state.<sup>55</sup> Justice O'Connor went further and—reflecting state statutes and cases—suggested that the choice made by a duly appointed health care agent would enjoy the same constitutional protection.<sup>56</sup>

Yet a review of the literature tells a much more interesting story. The conversation among bioethics scholars has reflected differences in the way people imagine their control over the course of their lives. Although grounded in the need for a way to decide legal cases, the discussion is dominated by philosophical and psychological rather than legal concepts.

In 1986 Rebecca Dresser published an article which was, as she put it, "a critique of the legal principles currently governing decisions on life-

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52. Patient Self-Determination Act of 1990, Pub. L. No. 101-508, 104 Stat. 1388-115 (codified as amended in scattered sections of 42 U.S.C.).

53. 355 A.2d 647 (N.J.), *cert. denied*, 429 U.S. 922 (1976).

54. 497 U.S. 261 (1990).

55. *Id.* at 278.

56. *Id.* at 289 (O'Connor, J., concurring).

sustaining treatment for incompetent patients.”<sup>57</sup> She identified the predominant view as one that sees the best treatment decision as one that is most consistent with a patient’s “formerly articulated beliefs, values, and goals”<sup>58</sup> because this preserves the patient’s right of self-determination. Yet this focus on past preferences relies on a simple, but not necessarily correct, assumption: “If we can identify what the formerly competent patient once wanted, we will know what she would want in her present incompetent state.”<sup>59</sup> This assumption may not hold up because people may change their views about what constitutes an acceptable life in the face of illness or disability; relying on earlier statements might not “maximize their current interests as incompetent patients.”<sup>60</sup> The theory of personal identity put forth by philosopher Derek Parfit suggests that a person may not in fact be the same person throughout his or her life in the absence of psychological continuity from one time to another.<sup>61</sup> Instead of attempting to discover the past preferences of a formerly competent person who has now become a new incompetent person, Dresser proposed determining the patient’s present best interests through discovery of “how these patients actually experience their lives.”<sup>62</sup>

The major counter arguments to the Dresser critique were first put forward by the late Nancy Rhoden.<sup>63</sup> She advocated a presumption in favor of decision making by close family members in situations where an incompetent patient has not expressed his or her wishes when competent. Rhoden did not, however, adopt the rationale for family decision making first articulated by the New Jersey Supreme Court in *Quinlan*—namely, that the right of the patient to decide has not been extinguished merely because the patient is incapable of exercising it; the right will instead be

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57. Rebecca Dresser, *Life, Death and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 ARIZ. L. REV. 373, 374 (1986).

58. *Id.* at 375.

59. *Id.* at 379.

60. *Id.*

61. *Id.* at 380-81.

62. *Id.* at 390. This challenge to the general view—and its legislative manifestation in advance directive statutes—was continued in subsequent publications. See Rebecca Dresser, *Relitigating Life and Death*, 51 OHIO ST. L.J. 425 (1990); Rebecca S. Dresser & John A. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach*, 17 LAW MED. & HEALTH CARE 234 (1989).

63. Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375 (1988) [hereinafter Rhoden, *Litigating Life and Death*]. Two subsequent articles were also written at least partially in response to Dresser. See Nancy K. Rhoden, *How Should We View the Incompetent?*, 17 LAW MED. & HEALTH CARE 264 (1989); Nancy K. Rhoden, *The Limits of Legal Objectivity*, 68 N.C. L. REV. 845 (1990) [hereinafter Rhoden, *The Limits of Legal Objectivity*].

exercised by the family member as surrogate decision maker.<sup>64</sup> Rhoden's preference for family choice, as she puts it, "can be gleaned from history, from society's respect for the family, and from the fact that family decisionmaking best embodies patient preferences."<sup>65</sup> On the assumption that physicians tend to favor continued treatment of critically ill patients and courts tend to defer to physician judgments, her proposal would shift the burden of proof to the physician to show that the family's choice was unreasonable.<sup>66</sup>

Rhoden's focus on *who* will make the treatment decision rather than on how substantively the decision will be made is the opposite of Dresser's. However, Rhoden also responded directly to Dresser, arguing that patients' clear prior directives should be followed since "a competent person who makes a living will does so because she sees her interests and values as continuing in time."<sup>67</sup> Rhoden points out that Derek Parfit's view, upon which Dresser relies, "conflicts with the ordinary social, moral and legal ways in which we view persons."<sup>68</sup> Even if one does not accept Parfit's extreme view on personal identity, Rhoden claims that Dresser "makes a serious mistake by insisting on viewing a person only in a highly restricted slice of time."<sup>69</sup> Instead, Rhoden draws on Ronald Dworkin's defense of advance directives, in which he "notes that we can think of a demented person either as she is in the present only, or as a person who has become demented, a view that takes into account the larger context of her life."<sup>70</sup>

We have obviously vastly oversimplified the conversation between Dresser and Rhoden, a conversation that has included lawyers John Robertson and Norman Cantor and philosophers Allan Buchanan and Dan Brock. These writers have all to one degree or another found the reasoning of the courts about decision making for incompetent patients unsatisfactory and have tried to offer alternative approaches that draw on

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64. See *In re Quinlan*, 355 A.2d 647, 664 (N.J.), *cert. denied*, 429 U.S. 922 (1976). In fact, Nancy Rhoden objects to attributing a right to incompetent patients that they lack all capacity to exercise. Rhoden, *Litigating Life and Death*, *supra* note 63, at 388.

65. Rhoden, *Litigating Life and Death*, *supra* note 63, at 437.

66. *Id.* at 441.

67. *Id.* at 410. She elaborates on this in a later article where she says: "Prior directives are the tools for projecting one's moral and spiritual values into the future." Rhoden, *The Limits of Legal Objectivity*, *supra* note 63, at 858.

68. Rhoden, *Litigating Life and Death*, *supra* note 63, at 414.

69. *Id.* at 415.

70. *Id.* (citing Ronald Dworkin, *Autonomy and the Demented Self*, 64 *MILBANK Q.* 4, 4 (Supp. 2 1986)).



philosophical theory as well as the realities of medical practice.<sup>71</sup> Still further dimensions have been added by the explorations of psychoanalytically oriented scholars such as Robert Burt and Jay Katz, both of whom delve into the psychology of the caregiver-patient relationship and its relationship to the law.<sup>72</sup>

The ongoing nature of this particular debate on law and bioethics can be seen in the recent suggestion by philosopher Jeffrey Blustein that the characteristics of families identified by Rhoden as justifying a presumption in favor of family decision making for incompetent patients "also provide good reasons for family involvement in the competent patients' thinking about choices."<sup>73</sup> Blustein, however, does not suggest changing legal rules to mandate or even facilitate such involvement, but rather, recommends changes in medical practice.<sup>74</sup> Yet his reliance on Rhoden's article is a reminder of the absence of a sharp boundary between legal and nonlegal bioethics literature, and of the ways in which the practical problems of clinical medicine, the findings of biology and psychology, the insights of philosophy, and further contributions from other disciplines combine with legal doctrine and theory to make "law and bioethics" a particularly rich and complex field.

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71. See, e.g., ALLEN W. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* (1989); Norman L. Cantor, *Prospective Autonomy: On the Limits of Shaping One's Postcompetence Medical Fate*, 8 J. CONTEMP. HEALTH L. & POL'Y 13 (1992); John A. Robertson, *Cruzan and the Constitutional Status of Nontreatment Decisions for Incompetent Patients*, 25 GA. L. REV. 1139 (1991).

72. ROBERT A. BURT, *TAKING CARE OF STRANGERS* (1979); JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (1984).

73. Jeffrey Blustein, *The Family in Medical Decisionmaking*, HASTINGS CENTER REP., May-June 1993, at 6, 12.

74. See *id.*