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ARTICLES

END-OF-LIFE DECISION MAKING: WHAT WE DON'T KNOW, WE MAKE UP; WHAT WE DO KNOW, WE IGNORE

SANDRA H. JOHNSON*

INTRODUCTION

Imagine that well-structured empirical studies consistently indicated that doctors do not tell patients what tests they are performing or why;¹ imagine that doctors can frame the information they provide patients and quite successfully generate the physician-desired consent or refusal of the treatment;² and imagine that only about half of patients recall being informed of serious risks of interventions, such as the risk of death.³ Now, imagine one more thing: that outcome studies indicate that survival rates do not vary according to whether the physician informed the patient of significant risks, benefits and alternatives of treatment.⁴

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1. Lori B. Andrews, *Past as Prologue: Sobering Thoughts on Genetic Enthusiasm*, 27 SETON HALL L. REV. 893, 904 (1997) (describing practice of clinical genetic testing without disclosure to patients); Thomas Koenig & Michael Rustad, *His and Her Tort Reform: Gender Injustice in Disguise*, 70 WASH. L. REV. 1, 69-70 (1995) (detailing cases in which physician failed to inform female patients that certain surgical procedures would be done).

2. See, e.g., Theresa M. Marteau, *Framing of Information: Its Influence Upon Decisions of Doctors and Patients*, 28 BRIT. J. SOC. PSYCHOL. 89, 93 (1989) (stating that options framed positively were more likely to be chosen than similar options framed negatively); David Orentlicher, *The Illusion of Patient Choice in End-of-Life Decisions*, 267 JAMA 2101 (1992) (stating that patient preferences regarding treatment options are often shaped by their physician's values); Cathy J. Jones, *Autonomy and Informed Consent in Medical Decisionmaking: Toward a New Self-Fulfilling Prophecy*, 47 WASH. & LEE L. REV. 379 (1990) (describing bias in information provided).

3. See, e.g., Terence C. Wade, *Patients May Not Recall Disclosure of Risk of Death: Implications for Informed Consent*, 30 MED. SCI. L. 259, 260 (1990) (discussing a study of patients' failure to recall disclosure of the risk of death). But see Alan Meisel & Mark Kuczewski, *Legal and Ethical Myths About Informed Consent*, 156 ARCHIVES INTERNAL MED. 2521, 2524 (1996) (arguing that recall is not the equivalent of understanding and that understanding at the point of decision making is the critical issue).

4. Informed consent has not been proven to affect survival rates. However, it has been

If good empirical data revealed all of this about actual practice, what response would be most appropriate? Would we abandon the ethical and legal duty of informed consent as impractical and unworkable and require only that the doctor make treatment choices in the patient's best interest? Should we?

A serious challenge to the law and public policy supporting a requirement of informed consent has not yet materialized,⁵ even though all but one of the data statements described above are authentic. Repeatedly, empirical studies have cast doubt on the practicality and performance of informed consent,⁶ but the place of that value in law and ethics has not yet collapsed, and may never collapse, in response to the data.⁷

To what extent should data on actual practices determine public policy and legal and ethical standards in health care decision making? A first-level response to this question is whether the particular study has produced accurate and verifiable results and, assuming that the research was itself well-designed and that the data are solid, whether the results are being used within the boundaries and limitations of the study's design. All statistical evidence generates these questions. In fact, the conference at which the papers in this Symposium issue of the *Indiana Law Review* were originally presented was entitled *Lies, Damn Lies and Statistics?: How Empirical Research Shapes Health Law and Policy*.⁸ The conference title quoted Mark Twain's identification of "three kinds of lies;"⁹ but, in addition to providing a catchy title for a conference,¹⁰ Twain's cutting

associated with other effects. See, e.g., Wendy Levinson et al., *Physician-Patient Communication: The Relationship With Malpractice Claims Among Primary Care Physicians and Surgeons*, 277 JAMA 553 (1997) (discussing patient dissatisfaction and litigation resulting from breakdowns in physician-patient communications). In a substantial analysis of informed consent, Peter Schuck observed that studies on the costs of informed consent are lacking, but that there are reports of other positive outcomes including: achieving better results, decreased likelihood of malpractice claims, and enhanced perception of competence and control by the patient. Peter Schuck, *Rethinking Informed Consent*, 103 YALE L.J. 899, 943 (1994).

5. Schuck, *supra* note 4, at 902-03.

6. Meisel & Kuczewski, *supra* note 3, at 2521-22.

7. Schuck, *supra* note 4, at 902-03. In reference to this debate, Schuck identified three different versions of informed consent doctrine: the "letter and spirit of the doctrine" ("law in books"); the law as imagined or caricatured by some doctors ("law in the mind"); and the doctrine as actually practiced ("law in action"). *Id.* at 903. Schuck noted that commentators fall into two groups—the idealists and the realists—and that these groups talk past each other in discussions of informed consent. *Id.* at 903-04.

8. Symposium, *Lies, Damn Lies and Statistics?: How Empirical Research Shapes Health Law and Policy*, 31 IND. L. REV. 9 (1998).

9. MARK TWAIN, MARK TWAIN'S OWN AUTOBIOGRAPHY 185 (Univ. of Wis. Press 1990). In his autobiography, Twain quoted English politician and historian Benjamin Disraeli, who stated that "there [are] three kinds of lies: 'lies, damned lies, and statistics.'" *Morningstar, Inc. v. Pilgrim Group, Inc.*, 29 Cal. Rptr. 2d 547, 553 (Cal. Ct. App. 1994).

10. Twain's original statement may have been closed with an ironic exclamation point, of course; surely not by a question mark. The addition of the exclamation is a slight offense, however,

critique of quantitative empirical research, at a minimum, identifies the skepticism and skill with which empirical research in bioethics should be analyzed.

This data-checking inquiry is not in itself an adequate response especially for any enterprise that sets standards of conduct, which includes both law and bioethics. Even well-designed statistically valid data requires interpretation.

When verifiable data on current practices clash with well-established normative standards, empirical research commonly appears to be appreciated only narrowly. The data may be construed, for example, to reveal only implementation or enforcement problems, while marginalizing the empirical challenge and leaving the core values and norms intact. Thus, it stimulates a call for more education, or greater "commitment," or stronger enforcement, rather than altering the normative standards.

In rare instances, empirical research may trigger radical calls for overthrowing the basic principles and paradigms that underlie established ethical and legal duties. One of the most notable occasions which prompted such a challenge occurred following investigation into actual practices in human experimentation, exposing evidence that medical researchers in the U.S. performed experiments on human beings in secret and without disclosure to their subjects.¹¹ In such a case, empirical research on actual behavior is seen as revealing an inadequacy in basic norms.¹²

As an applied ethics, bioethics must struggle with context. Empirical research tests whether ethical and legal standards "fit" the health care setting.¹³ Bioethics, however, shares with law a fundamental tension in the essential norm-setting function between maintaining desired norms despite sometimes frequent violation and assuring that standards are realistic and rest on a substantial practice of voluntary compliance.

The controversy over the appropriate role of empirical research in law has persisted for over a century. Coincidentally, the Center's conference on

and the prominence accorded this commentary attests to the integrity of the groundbreaking empirical research conducted by the Indiana University School of Law—Indianapolis Center for Law and Health.

11. DAVID J. ROTHMAN, *STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING* 3 (1991).

12. In health law, these occasions arise in the unusual case in which the courts depart from the standard of the profession and establish a judicial standard of professional duty. The classic case is *Helling v. Carey*, 519 P.2d 981 (Wash. 1974). In informed consent doctrine, at least half of the states hold the physician to the standard of the profession rather than to the patient's expectations. BARRY R. FURROW ET AL., *HEALTH LAW* § 6-10(a) (1995). In cases involving the withdrawal of life-sustaining treatment, many of the earliest cases attempted to harmonize their stated legal rule allowing termination of treatment with the ethical standards of medical practice even though the practice of withdrawal was still controversial. See, e.g., *In re Quinlan*, 355 A.2d 647, 664-69 (N.J. 1976).

13. Susan M. Wolf, *Shifting Paradigms in Bioethics and Health Law: The Rise of a New Pragmatism*, 20 AM. J.L. & MED. 395, 403-04, 409-10 (1994).

empirical research took place shortly after the centennial celebrations of the publication of Oliver Wendell Holmes' essay, *The Path of the Law*, in the *Harvard Law Review*.¹⁴ In his essay, Holmes claimed: "For the rational study of the law, the black-letter man may be the man of the present, but the man of the future is the man of statistics . . ." ¹⁵ Holmes was not merely predicting the influence of statistics,¹⁶ which had Twain lamenting only a few decades later, he was speaking prescriptively. Holmes argued that the law *should* be designed so that its actual effects take precedence over arguments based solely on morality or history or philosophy.¹⁷

Holmes used the criminal law to illustrate his point that the impact of the law is the true test of the law,¹⁸ but he might have used "law and bioethics" had it existed a century ago. Both fields, even more so than many other fields of law, are often viewed as embodying society's moral character,¹⁹ or at least society's declaration of the correct ordering of civilized communities.²⁰ Both criminal law and bioethics bear the mark of notions of the good and the natural order of things.

Holmes said the following about crime and punishment:

What have we better than a blind guess to show that the criminal law in its present form does more good than harm? . . . Does punishment deter?

14. Oliver Wendell Holmes, *The Path of the Law*, 10 HARV. L. REV. 457 (1897), reprinted in 110 HARV. L. REV. 991 (1997).

15. *Id.* at 1001.

16. Holmes' insight has proven largely true in the influence of several significant movements, including Legal Realism, Law and Society, Law and Economics, and Critical Legal Studies, which all emerge from an empirically-based analysis of the law. Each of these schools challenge what law is and what matters in law. Martha Minow, *The Path as Prologue*, 110 HARV. L. REV. 1023, 1023-25 (1997).

17. Robert W. Gordon, *The Path of the Lawyer*, 110 HARV. L. REV. 1013, 1013-14 (1997).

18. Holmes, *supra* note 14, at 1001-02.

19. See 136 CONG. REC. 12,251, at 12,260 (1990) (statement of Sen. Grassley) ("In a country that cherishes a separation between the state and any officially sanctioned religious practice, the criminal law is one of the few available institutions through which society can make a moral statement . . ."); Sissela Bok, *At the Juncture of Theory and Practice: Remarks on Receiving the Henry Knowles Beecher Award*, 26 HASTINGS CTR. REP. 5 (May-June 1996); Thomas P. Griesa, *There Is No Case for Legalizing Drugs*, WALL ST. J., Aug 10, 1993, at A14 ("We should bear in mind that the foundational fact about the criminal law is that it is a moral judgment."); George F. Will, *The Sting of Shame*, WASH. POST, Feb. 1, 1996, at A21 ("[T]he criminal law's expressive function is to articulate society's moral condemnation.")

20. See 136 CONG. REC. 11,224, at 11,250 (1990) (statement of Sen. Hatch) ("Through the imposition of just punishment, civilized society expresses its outrage and sense of revulsion toward those who, by contravening its laws, have not only inflicted injury upon discrete individuals, but also weakened the bonds that hold communities together.") (quoting Stephen J. Markman & Paul G. Cassell, Comment, *Protecting the Innocent: A Response to the Bedau-Radcliff Study*, 4 STAN. L. REV. 121, 157 (1988)); Edmund D. Pellegrino, *The Metamorphosis of Medical Ethics: A 30-Year Retrospective*, 269 JAMA 1158 (1993).

Do we deal with criminals on proper principles? . . . If the typical criminal is a degenerate, . . . it is idle to talk of deterring him by the classical method of imprisonment. . . . If, on the other hand, crime, like normal human conduct, is mainly a matter of imitation, punishment fairly may be expected to help to keep it out of fashion.²¹

The calculation advocated by Holmes' century-old essay does not yet, and probably never will, determine the outcome of public controversies over criminal law. Arguments over whether the lack of deterrent effect is relevant to the use of the death penalty²² and the effect of "three-strikes" sentencing²³ evidence the continuing struggle over the purpose of criminal law and punishment. Continuing disputes over the causes and prevention of crime also illustrate the intractability of answering Holmes' apparently empirical social inquiries.²⁴ Current debates in the law of bioethics have a similarly complex relationship with facts and values; rationality and irrationality; moral aspiration and consequentialist accounting; intuition and evidence.

The debate over the relative influence of aspiration and practice, though an old debate both in law and ethics, is being pressed now in bioethics because of the recent emergence of a body of substantial empirical research on the operation of bioethics in practice. The most extensive empirical examination of bioethics "at the bedside" to date is also the most recent. From 1989 to 1994, the Robert Wood Johnson Foundation funded an ambitious study of care for patients

21. Holmes, *supra* note 14, at 1002.

22. See generally MICHAEL L. RADELET & MARGARET VANDIVER, CAPITAL PUNISHMENT IN AMERICA (1988); Walter Berns et al., *The Death Penalty: A Philosophical and Theological Perspective*, 30 J. MARSHALL L. REV. 463 (1997); William J. Bowers et al., *A New Look at Public Opinion on Capital Punishment: What Citizens and Legislators Prefer*, 22 AM. J. CRIM. L. 77 (1994); Stephen B. Bright, *The Death Penalty as the Answer to Crime: Costly, Counterproductive and Corrupting*, 36 SANTA CLARA L. REV. 1069 (1996); Walter L. Gordon, III, *Death Penalty: National Disaster Visits California*, 33 SANTA CLARA L. REV. 283 (1993); Jordan Steiker, *Essay, The Long Road Up From Barbarism: Thurgood Marshall and the Death Penalty*, 71 TEX. L. REV. 1131 (1993).

23. See generally Meredith McClain, Note, *"Three Strikes and You're Out": The Solution to the Repeat Offender Problem?*, 20 SETON HALL LEGIS. J. 97 (1996); Mark W. Owens, Legislative Note, *California's Three Strikes Law: Desperate Times Require Desperate Measures—But Will It Work?*, 26 PAC. L.J. 881 (1995); Ilene M. Shinbein, Note, *"Three-Strikes and You're Out": A Good Political Slogan to Reduce Crime, But a Failure in Its Application*, 22 NEW ENG. J. ON CRIM. & CIV. CONFINEMENT 175 (1996); Victor S. Sze, Comment, *A Tale of Three Strikes: Slogan Triumphs Over Substance as Our Bumper-Sticker Mentality Comes Home to Roost*, 28 LOY. L.A. L. REV. 1047 (1995).

24. See generally Stephen Kinsella, *A Libertarian Theory of Punishment and Rights*, 30 LOY. L.A. L. REV. 607 (1997); Richard Lowell Nygaard, *Essay, On the Philosophy of Sentencing: Or, Why Punish?*, 5 WIDENER J. PUB. L. 237 (1996); Thomas J. Philipson & Richard A. Posner, *The Economic Epidemiology of Crime*, 39 J.L. & ECON. 405 (1996); Negley K. Teeters, *Fundamentals of Crime Prevention*, FED. PROBATION, Sept. 1995, at 63.

hospitalized with life-threatening conditions.²⁵ *SUPPORT*, which is discussed later in this Article, tested the actual operation of informed consent, patient autonomy, and compliance of physicians with patient or surrogate choice in medical treatment decision making, among other events in the treatment of these patients.²⁶

SUPPORT contrasts with another type of influential study of bioethics, one with a longer history. In 1978, Congress established the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.²⁷ The President's Commission studied bioethics from the position of logic and values and clinical experience, though largely intuitive or anecdotal experience and rarely empirical.²⁸ The President's Commission produced a document that provided the foundation for the development of the law and principles of bioethics regarding life-sustaining treatment decisions.²⁹ This document, *Deciding to Forego Life-Sustaining Treatment*,³⁰ has been cited as persuasive in no fewer than thirty-five appellate judicial opinions resolving end-of-life treatment issues.³¹ In the nearly twenty years that passed between the President's Commission and *SUPPORT*, the basic principles of bioethics, especially as they were captured in law, remained grounded primarily in the "head work" of the Commission and its progeny.³²

Although empirical research is a relative latecomer to bioethics, data on practices relating to medical ethics have already produced sometimes troubling questions concerning the gap between normative principles, including those adopted by the President's Commission, and reality. For example, are the basic values of American bioethics and the legal framework of health care decision making culture-bound and culturally exclusive of large numbers of U.S. patients?³³ Are surrogate decision makers, including family members, "reliable"

25. The *SUPPORT* Principal Investigators, *A Controlled Trial to Impede Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)*, 274 JAMA 1591 (1995) [hereinafter *SUPPORT*].

26. *Id.*

27. 42 U.S.C. § 300 (1978).

28. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT* (Comm. Print 1983).

29. *Id.*

30. *Id.*

31. *See, e.g.*, Thor v. Superior Court, 855 P.2d 375, 381 (Cal. 1993); Care & Protection of Beth, 587 N.E.2d 1377, 1380 (Mass. 1992); *In re Moorehouse*, 593 A.2d 1256, 1261 (N.J. Super. Ct. App. Div. 1991); *In re Fiori*, 673 A.2d 905, 912 (Pa. 1996); *In re Guardianship of L.W.*, 482 N.W.2d 60, 70-73 (Wis. 1992).

32. Similar efforts to guide the development of standards and practices in bioethics include much of the work of the Hastings Center, a private bioethics organization that has produced the influential Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying (1987), among other documents, and The New York State Task Force on Life and Law.

33. *See, e.g.*, Leslie Blackhall et al., *Ethnicity and Attitudes Toward Patient Autonomy*, 274

in their understanding of the principal's preferences concerning medical treatment?³⁴ Even if a patient executes an advance directive, is the patient's doctor likely to comply with the document in directing medical treatment decisions?³⁵ Each of these questions has been studied empirically, and it is from such studies that an increasingly more robust body of empirical research in bioethics has formed.

There has not been a clear transition of authority in bioethics between the approach exemplified by the President's Commission of 1978 and the inquiry represented by the 1995 report of the *SUPPORT* results, however. Each form of bioethics "study," philosophical and empirical, continues to influence the area. Neither has achieved a commanding presence. Even increased and more powerful empirical research will not overtake the philosophical arm of bioethics, however, because the tension between the "is" and the "ought," between the real and the ideal, is inherent in any normative work that seeks to carry an authority in practice.

This Article examines how the debate over the appropriate source of legal and ethical norms in medicine has been played out publicly in recent judicial decisions regarding the legalization of physician-assisted suicide. It begins with an analysis of the Ninth Circuit's majority opinion in *Compassion in Dying v. Washington*.³⁶ It goes on to examine the results of *SUPPORT* and responses to those results. The Ninth Circuit opinion illustrates the use of empirical research and the framing of core questions in factual terms in efforts to change the law of bioethics. Responses to *SUPPORT* illustrate the persistence of basic principles in the face of substantially challenging empirical research.

I. *COMPASSION IN DYING V. WASHINGTON*

The Ninth and Second Circuit Courts of Appeals issued startling decisions in 1996. The courts' decisions in *Compassion in Dying v. Washington*³⁷ and in *Quill v. Vacco*³⁸ were startling simply because two federal appellate courts recognized a new constitutional right, an exceptional result in itself in light of the constitutional jurisprudence of this decade. The United States Supreme Court granted *certiorari* in both of those cases³⁹ and heard oral arguments in January

JAMA 820 (1995); Sheila T. Murphy et al., *Ethnicity and Advance Care Directives*, 24 J.L. MED. & ETHICS 108 (1996).

34. See, e.g., P.M. Layde et al., *Surrogates' Predictions of Seriously Ill Patients' Resuscitation Preferences*, 4 ARCHIVES FAMILY MED. 518 (1995).

35. See, e.g., Marion Danis et al., *A Prospective Study of Advance Directives for Life-Sustaining Care*, 324 NEW ENG. J. MED. 882 (1991).

36. 79 F.3d 790 (9th Cir. 1996), *rev'd sub nom.* *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997).

37. *Id.*

38. 80 F.3d 716 (2d Cir. 1996), *rev'd*, 117 S. Ct. 2293 (1997).

39. *Compassion in Dying*, 79 F.3d at 790, *cert. granted sub nom.* *Washington v. Glucksberg*, 117 S. Ct. 37 (1996); *Quill*, 80 F.3d at 716, *cert. granted*, 117 S. Ct. 36 (1996).

1997. The course of the oral arguments foreshadowed the outcome of the cases and, as was thereafter generally expected, the Supreme Court reversed both circuit court decisions.⁴⁰ There was no dissent, but five justices joined in concurring opinions.⁴¹

The drama of a U.S. Supreme Court ruling on the legal status of assisted suicide concluded somewhat anti-climactically. The Court neither recognized a new or expanded right to die nor declared that the U.S. Constitution prohibited the states from recognizing or creating such a right within their own authority.⁴² Justice Stevens' concurring opinion indicated he does not believe that the Court's decision closes the door on later consideration of a federal constitutional right to physician-assisted suicide under different circumstances.⁴³ Despite Stevens' opinion, the focus now moves to the states. State courts,⁴⁴ state legislatures,⁴⁵ and popular referenda/initiatives⁴⁶ are the arenas for the next round in the controversy over legalization of assisted suicide. As the arena shifts, the major points of argument reflected in these judicial opinions are likely to be repeated.

This Article focuses on the Ninth Circuit's majority opinion and only less so on the Supreme Court's majority opinion, although a note on the contrast between the two is appropriate. Although the Supreme Court authoritatively reversed the Ninth Circuit, the Supreme Court carried an easier burden than did the Ninth Circuit and than will the state courts and state legislatures. The Supreme Court did not take on the substantial burden of establishing a legal right in the face of great controversy. Nor did it have to justify institutionalizing the status quo under significant challenge. The Court's decision intentionally left the ultimate question of legalization open and would not close the door on the

40. *Glucksberg*, 117 S. Ct. at 2258; *Quill*, 117 S. Ct. at 2293.

41. See *Glucksberg*, 117 S. Ct. at 2275 (Souter, J., concurring in judgments); *Washington v. Glucksberg*, 117 S. Ct. 2302, 2303 (1997) (O'Connor, J., concurring in judgments); *Id.* at 2304 (Stevens, J., concurring in judgments); *Id.* at 2310 (Ginsburg, J., concurring in judgments); *Id.* (Breyer, J., concurring in judgments).

42. *Glucksberg*, 117 S. Ct. at 2258.

43. Justice Stevens specifically stated that "there are situations in which an interest in hastening death is legitimate . . . I am also convinced that there are times when it is entitled to constitutional protection." *Glucksberg*, 117 S. Ct. at 2305. He remained open to the possibility that "an individual plaintiff seeking to hasten her death, or a doctor whose assistance was sought, could prevail in a more particularized challenge." *Id.* at 2309.

44. See, e.g., *Krischer v. McIver*, 697 So. 2d 97 (Fla. 1997) (After the Supreme Court's decision, the Florida Supreme Court held that the Florida Constitution did not include a right to physician assistance in death.).

45. See, e.g., S. 653, 89th Leg., Reg. Sess. (Mich. 1997); Henriette Campagne, *Lawmakers Take Up Assisted Suicide Issue*, MASS. LAW. WKLY., June 30, 1997, at 27.

46. Oregon is the only state that has approved the legalization of physician-assisted suicide, but the referendum vote is currently being challenged in the Oregon state courts. OR. REV. STAT. §§ 127.800-.897 (1996). The "Death with Dignity Act" will be sent back to the Oregon voters in November 1997. Richard Carelli, *Court Unanimously Rules Against Doctor-Assisted Suicides*, DET. FREE PRESS (June 27, 1997) <<http://www.freep.com>>.

matter.⁴⁷ Consistent with the jurisprudence of the Rehnquist Court, the Supreme Court simply endorsed the state's authority either to maintain or to change the law largely without constraint from the federal courts.⁴⁸ The Rehnquist opinion relied on historical state law prohibitions against aiding and abetting suicide⁴⁹ and accorded great deference to the state's assessment of potential harms under the rational basis test.⁵⁰ The Ninth Circuit, without the deference exercised by the Supreme Court, more substantively addressed arguments for and against legalization.⁵¹ Therefore, the structure of its responses is most likely to reappear on the state level in the ensuing debate.

In addition to differing on the level of deference required, the Supreme Court's and the Ninth Circuit's majority opinions differed on the sources they relied upon as persuasive. To the extent that the Rehnquist opinion did engage the arguments for and against legalization substantively, it relied largely on the report of the New York State Task Force on Life and the Law.⁵² In this, the Rehnquist opinion resembled state court decisions of the last two decades which relied heavily on the recommendations of the President's Commission to recognize a right to refuse or forego life-sustaining treatment.⁵³

In contrast, in major parts of its majority opinion, the Ninth Circuit addressed the question of the legal status of assisted suicide with more of an emphasis on empirical evidence and its relevance for resolving public policy and legal issues. In other parts of its decision, the Court of Appeals made assumptions about professional behavior that make the question of legalization appear to rest on empirically verifiable facts. The Ninth Circuit's opinion is quite revealing in its treatment of arguments that rely on apparently empirically-based or empirically verifiable assertions, a point that is especially pertinent to the question presented by this special issue of the *Indiana Law Review*.

This critical analysis of the impact of "empiricalism" on the Ninth Circuit's decision is not intended to illustrate deficiencies unique to that opinion. An examination of the earlier Ninth Circuit opinion written for a panel of the Ninth Circuit by Judge John Noonan⁵⁴ and vacated by the Court of Appeals *en banc* in *Compassion in Dying*, for example, would likely yield a similar critique even though Judge Noonan's opinion reached a result opposite to that of the later majority. No matter the side, arguments for and against legalization of assisted suicide, to the extent they engage the substantive issues, present similar questions regarding the availability, reliability and relevance of empirical data on public and professional opinion, current practices, and anticipated risks and

47. *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997).

48. *See id.* at 2275.

49. *Id.* at 2262-65.

50. *Id.* at 2271-75.

51. *Compassion in Dying v. Washington*, 79 F.3d 790, 816-39 (9th Cir. 1996).

52. *Glucksberg*, 117 S. Ct. at 2272-75.

53. *See supra* notes 27-32 and accompanying text.

54. *Compassion in Dying v. Washington*, 49 F.3d 586 (9th Cir. 1995), *vacated en banc*, 79 F.3d 790 (9th Cir. 1996), *rev'd sub nom.* *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997).

benefits of the rejection or maintenance of the current legal status of assisted suicide.

The debate over physician-assisted suicide embraces many arguments. Three of several identifiable arguments in this debate are:

(1) The majority of Americans appear to indicate some support for physician-assisted death,⁵⁵ and therefore: law must change to reflect public opinion and actual practice;⁵⁶ or current law actually does accurately reflect society's "real" opinion concerning legalization,⁵⁷ if majority views are even relevant to the question.⁵⁸

(2) The participation of doctors in the process of assistance in suicide, as compared to the participation of family members for example, alters the nature of the act: participation of doctors contributes to the safety of the process;⁵⁹ or the participation of doctors merely "medicalizes" or "white coats" the act so that it appears to be safer, more normal, and more acceptable.⁶⁰

(3) Particular "vulnerable" populations may be affected differently by the legalization of assisted suicide: legalization will not harm these populations and may remedy the special suffering faced by vulnerable populations;⁶¹ or legalization presents a special danger within a system that already victimizes certain identifiable populations.⁶²

55. See James A. Tulsky et al., *A Middle Ground on Physician-Assisted Suicide*, 5 CAMBRIDGE Q. HEALTHCARE ETHICS 33, 34 (1995) (focusing also on the consistent refusal to indict, prosecute or convict physicians who aid in death); see also David Orentlicher, *Physician Participation in Assisted Suicide*, 262 JAMA 1844 (1989).

56. See, e.g., Catherine L. Bjorck, *Physician-Assisted Suicide: Whose Life Is It Anyway*, 47 SMUL. REV. 371, 372 (1994) (arguing that opinion surveys, suicide statistics and public concern demand legalization of physician-assisted suicide).

57. Brief of the United States Catholic Conference et al. as Amici Curiae in Support of Petitioners at 8 n.1, *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997) (No. 96-110); see also Stephanie Graboyes-Russo, *Too Costly to Live: The Moral Hazards of a Decision in Washington v. Glucksberg and Vacco v. Quill*, 51 U. MIAMI L. REV. 907, 915-16 (1997) (arguing that polls only reflect attitudes toward dying with dignity not toward physician-assisted suicide).

58. Edmund D. Pellegrino, *The Limitation of Empirical Research in Ethics*, 6 J. CLINICAL ETHICS 161, 162 (1995); see also Ruth Shalit, *When We Were Philosopher-Kings: The Rise of the Medical Ethicist*, NEW REPUBLIC, April 28, 1997, at 24 (criticizing bioethicists and the "place of ethical expertise in a liberal democracy").

59. See, e.g., Lori D. Pritchard Clark, *Rx: Dosage of Legislative Reform to Accommodate Legalized Physician-Assisted Suicide*, 23 CAP. U. L. REV. 689, 705 (1994).

60. See John M. Dolan, *Is Physician-Assisted Suicide Possible?*, 35 DUQ. L. REV. 355, 392-93 (1996); see also George J. Annas, *Physician-Assisted Suicide—Michigan's Temporary Solution*, 20 OHIO N.U. L. REV. 561, 569 (1994) (arguing that physicians should not sacrifice their ethics to further the goals of the state).

61. Brief of Council for Secular Humanism and International Academy of Humanism as Amici Curiae in Support of Respondent at 9-10, *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997) (No. 96-110).

62. See, e.g., Alexander M. Capron, *Legalizing Physician-Aided Death*, 5 CAMBRIDGE Q.

Each of these three mirror-image points either relies on empirical data or suggests that empirical data will be relevant to the resolution of the dispute over the legalization of physician-assisted suicide. For example, the Ninth Circuit majority opinion in *Compassion in Dying* used public opinion polls as relevant evidence supporting judicial recognition of a constitutional right to physician-assisted suicide.⁶³ The court relied on the protective role of physicians as an essential characteristic of the legal right it recognized.⁶⁴ Further, the court rejected most claims that a legal right to assistance in suicide will operate in unacceptable population-specific patterns and argued that the availability of legalized physician assistance in suicide may address the particular needs of some persons within these groups.⁶⁵

A. Opinion Polls

The Ninth Circuit described broad public support for the legalization of physician-assisted suicide. The court began its discussion of public opinion by observing that “[p]olls have repeatedly shown that a large majority of Americans—sometimes nearing 90%—fully endorse recent legal changes granting terminally ill patients, and sometimes their families, the prerogative to accelerate their death by refusing or terminating treatment.”⁶⁶ The court further reported that “[o]ther polls indicate that a majority of Americans favor doctor-assisted suicide for the terminally ill,”⁶⁷ and described an April 1990 Roper poll that found “64% of Americans believed that the terminally ill should have the right to request and receive physician aid-in-dying.”⁶⁸ The court also described “another national poll” that showed “nearly two out of three Americans favor doctor-assisted suicide and euthanasia for terminally ill patients who request it”⁶⁹ and stated that a 1994 Harris poll found “73% of Americans favor legalizing physician-assisted suicide.”⁷⁰

HEALTHCARE ETHICS 10, 19-20 (1996) (discussing the particular vulnerability women); Marshall B. Knapp, *Old Folks on the Slippery Slope: Elderly Patients and Physician-Assisted Suicide*, 35 DUQ. L. REV. 443, 444 (1996) (arguing that the elderly are a particularly vulnerable group susceptible to influence on physician-assisted suicide by family members and physicians because they may believe themselves a burden to their family or society).

63. See discussion *infra* Part I.A.

64. See discussion *infra* Part I.B.

65. See discussion *infra* Part I.C.

66. *Compassion in Dying v. Washington*, 79 F.3d 790, 810 (9th Cir. 1995) (citing Sanford H. Kadish, *Letting Patients Die: Legal and Moral Reflections*, 80 CAL. L. REV. 857, 860 & n.16 (1992)).

67. *Id.*

68. *Id.* (citing Robert L. Risely, *Voluntary Active Euthanasia: The Next Frontier, Impact on the Indigent*, 8 ISSUES IN L. & MED. 361, 365 (1992)).

69. *Id.* (quoting Kadish, *supra* note 66, at 861 n.22).

70. *Id.* (citing David Cannella, *Physician-Aided Suicide Fight Rages in Several States: Issue Expected to Go to Supreme Court*, ARIZ. REPUBLIC, May 13, 1995, at A22).

In the same paragraph with its recitation of the results of public opinion polls, the court also described the voting margins on the physician-assisted suicide referenda and state initiatives in Oregon, California, and Washington.⁷¹ In the defendant state, Washington, the proposed legislation produced only 46% affirmative votes;⁷² however, in Oregon, proposed legislation to legalize physician-assisted suicide had passed with 51% of voters approving the referendum.⁷³

The court concluded its description of public opinion, including the results of the California, Washington and Oregon initiatives on legalization of assisted suicide, by concluding that "there is unquestionably growing popular support for permitting doctors to provide assistance to terminally ill patients who wish to hasten their deaths."⁷⁴ The opinion implied that the degree of public support for legalization is relevant to its resolution of the constitutional issue.⁷⁵ Growing approval could be used to indicate that its holding that there is a constitutional right to assistance in suicide reflects mainstream thought.

The Ninth Circuit's use of public opinion polls concerning physician-assisted suicide raises at least two issues that are specific to the suicide debate. First, although the Ninth Circuit considered public opinion to be relevant to the recognition of a liberty interest in physician assistance in death, it did not confront the gap between public opinion polls and the results of public votes on the issue to that point. Second, the court did not recognize that studies of both public and professional attitudes and practices relating to aid in dying are confounded by the transformation occurring in the language of end-of-life decisions.

The court described the results of the three public initiatives/referenda in the same paragraph as it discussed public opinion polls and concluded that the electoral results provide evidence of growing public support for legalization of assisted suicide. The court's reliance on the failed referendum in Washington state, the defendant in *Compassion in Dying*, as support for its holding that there is a constitutional right to assistance in suicide is curious. The court interpreted the clearly negative vote in Washington as positive support of its own position.⁷⁶

The Ninth Circuit decision used evidence of public opinion polls to support its rejection of the results of a direct vote on the statute at issue in the case.⁷⁷ Public referenda may be irrelevant to any particular individual civil liberty,⁷⁸ of

71. *Id.*

72. *Id.*

73. *Id.*

74. *Id.* In November 1997, Oregon voters voted not to repeal their earlier affirmative vote on assisted suicide.

75. *Id.* at 811.

76. *Id.* at 810.

77. *Id.*

78. For a discussion of the role of popular votes on bioethical issues, see Judith F. Daar, *Direct Democracy and Bioethical Choices: Voting Life and Death at the Ballot Box*, 28 U. MICH. J.L. REFORM 799 (1995).

course, and the Ninth Circuit certainly did view access to physician-assisted death as a liberty interest that reached the most intimate decisions.⁷⁹ The Ninth Circuit, however, argued that public opinion polls were relevant to the recognition of this right. The court reviewed the jurisprudence on “fundamental rights” and noted the consistent effort to assure that the recognition of fundamental rights did not emerge only from the “imposition of the Justices’ own choice of values.”⁸⁰ The use of public opinion polls in constitutional adjudication is controversial. Generally, public opinion polls have not been persuasive when courts were dealing with issues of fundamental constitutional rights. Opinion polls have been labeled as being too uncertain because they are based on temporary opinions which are continually swayed by political activists.⁸¹ The United States Supreme Court, considering a death penalty case, believed that opinion polls were inconclusive because the people had not voted on the issue through referendum or through their representatives in the legislature, which the court believed would be done if a position was truly popular.⁸² Recently, a current Supreme Court Justice has spoken on the issue and submitted that the Federal Judiciary was given Article III protections (life tenure and salary protection) under the United States Constitution so that it could decide fundamental constitutional issues independent of such things as opinion polls.⁸³

Despite its own discussion of public opinion, the Ninth Circuit finally specifically rejected both majority and minority control of this issue: “[N]either the state nor the majority of the people in a state can impose its will upon the individual” in this matter.⁸⁴ The court rejected arguments that the issue should be left to state elections, citing legal conflicts that may arise if some states legalized assisted death and others did not.⁸⁵

Commentators have offered other reasons for rejecting the Washington and California votes as invalid indicators of public sentiment. For example, after the failed initiatives in California and Washington, commentators charged that the vote did not reflect the actual will of the majority because certain groups overwhelmed the proponents of legalization in terms of money spent on the campaign.⁸⁶ Others implied that certain “outside” groups heavily influenced the

79. *Compassion in Dying*, 79 F.3d at 812-13.

80. *Id.* at 803.

81. *Swann v. Charlotte-Mecklenburg Bd. of Educ.*, 318 F. Supp. 786, 793 (W.D.N.C. 1970).

82. *Stanford v. Kentucky*, 492 U.S. 361, 377 (1989).

83. Hon. Justice Clarence Thomas, *Judging*, 45 U. KAN. L. REV. 1, 4 (1996) (Justice Thomas argued that if judges allow their “decisions to be guided by popular sentiment and group rights and demands, then the Constitution will be nothing but a malleable, transparent barrier to majoritarian desires.”).

84. *Compassion in Dying*, 79 F.3d at 839.

85. *Id.* at 833 n.124.

86. Diane M. Gianelli, *Euthanasia Measures Fail, But Backers Vow to Renewed Push*, AM. MED. NEWS, Nov. 23, 1992, at 42; Susan Gilmore, *Will Foes’ Efforts Doom California’s Euthanasia Bill?*, SEATTLE TIMES, Oct. 24, 1992, at A14.

state-specific public debate.⁸⁷ Some advocates charged that opponents sensationally misrepresented the potential impact of the proposed legislation.⁸⁸ Others conceded that the legislation could have been rejected on the basis of specifics—the weakness of safeguards, for example—even though there may have been adequate support for more narrow legalization.⁸⁹ Still, some commentators have observed that pre-election polls may indicate that public support is strong enough to win as they did in Washington, but cannot indicate, until the actual vote, whether support is deep enough; that is, whether it will persist once arguments against the initially preferred position are offered or once an actual vote or other decision is required.⁹⁰

The second issue in the court's use of survey data concerning acceptance of physician-assisted suicide relates to the emerging problem of language in life-sustaining treatment issues. The suicide debate, like some other politicized bioethics issues,⁹¹ is plagued by jockeying over the names that will identify the advocate's position with virtue and caregiving and the opponent's position with evil and danger. In part, this is an unavoidable consequence of the politicization of the question: the battle takes place in snippets and slogans and has to appeal to emotion and intuition through association with familiar terms.

The language strategy may pay off politically. In 1993, in preparation for the referendum in Oregon, a survey was taken to test the impact of different terms.⁹² In that survey, 44% of respondents indicated that they would vote for a law allowing "physician-aided suicide"; 51% for "physician's aid in dying"; 55% for

87. Jim Simon, *National Groups, Huge Budgets Invade Former Turf of the Little Guy*, SEATTLE TIMES, Oct. 4, 1991, at A1.

88. Ellis E. Conklin, *Support for Initiative 119 Slipped Away in Final Hours*, SEATTLE POST-INTELLIGENCER, Nov. 7, 1991, at A9; Tom Paulson, *Death With Dignity Backers Accuse Foes of Distortion*, SEATTLE POST-INTELLIGENCER, Oct. 24, 1991, at B1.

89. Howard Breuer, *Act of Mercy Brings Legal Problems Santa Paula Man Probed in Ailing Wife's Suicide*, L.A. DAILY NEWS, Oct. 17, 1993, at TO1; B.D. Colen, *Campaign '92 Initiatives California is Voting on the Right to Die Act Would Legalize Some Forms of Mercy Killing*, NEWSDAY, Oct. 29, 1992, at 23.

90. See Ezekiel J. Emanuel, *Empirical Studies on Euthanasia and Assisted Suicide*, 6 J. CLINICAL ETHICS 158 (1995); Gianelli, *supra* note 86, at 42; Conklin, *supra* note 88, at A9. The Ninth Circuit commented that the Washington and California proposals "contained far fewer practical safeguards" than did the "carefully-crafted" referendum in Oregon. *Compassion in Dying*, 79 F.3d at 810. Later in its opinion, however, the court rejected a central restriction in the Oregon referendum. The court implied in dictum that restricting assisted suicide to prescription of medication which the patient would administer to himself or herself may itself be unconstitutional. *Id.* at 831-32.

91. Another example is the debate over "partial-birth abortions." See Kathleen A. Cassidy Goodman, *The Mutation of Choice*, 28 ST. MARY'S L.J. 635 (1997); Kim Painter, *Handling the Aftermath of the Decision to Abort*, USA TODAY, Aug. 18, 1977, at 6D; Richard Saltus, *Late-term Abortion at Issue Called Rare in Mass.*, BOSTON GLOBE, May 17, 1997, at A1.

92. Mark O'Keefe, *Doctor-Assisted Suicide Law Boils Down to a War of Words*, THE OREGONIAN, Dec. 1, 1994, at A1.

“euthanasia”; and nearly 66% for a terminally ill patient’s choice to “die with dignity.”⁹³ The survey revealed an increase of 50% in affirmative responses as between “physician-aided suicide” and “death with dignity” just by use of the different term.⁹⁴ Equally revealing is the difference between “physician-aided suicide” and “physician’s aid in dying”:⁹⁵ the difference between 44% and 51% is the difference between winning and losing an election. The Ninth Circuit’s use of polls asking about “aid in dying” as evidence of support for physician-assisted suicide demonstrates a lack of recognition of these language issues.⁹⁶

Although the term “physician-assisted suicide” connotes professional assistance to an individual engaging in an act, committing suicide, that is not itself illegal, proponents of legalization no longer rely on the assisted “suicide” concept or language. The campaign director for the 1992 California initiative reacted to the campaign’s victory in eliminating the word suicide from the ballot by stating that “the ballot language is worth a million bucks to us.”⁹⁷

The Oregon initiative itself provides that “Actions taken in accordance with this Act shall not . . . constitute suicide [or] assisted suicide.”⁹⁸ The Ninth Circuit explicitly challenged the use of the “s” word to describe the intervention⁹⁹ even though the opinion laboriously examined the historical treatment of suicide to prove that suicide was not always viewed as immoral or illegal.¹⁰⁰

The political power of language predictably has led advocates to search for a term for “assisted suicide” or “aid in dying” or “lethal intervention” that communicates a certain quality about the interaction of physician and patient. The language strategy will have an impact on the political process if politics holds true to form. But strategic language has produced a more substantial difficulty in this case. At a minimum, it has had an impact on the evaluation and meaning of empirical data describing current opinions and practices relating to end-of-life care. The poll discussed earlier,¹⁰¹ which tested only differences in the terms, illustrates how powerfully the terminology can affect the results of surveys probing this issue.

The political use of language is not the only difficulty here. Underneath the political currency lies a fundamental deconstruction of the ethical and legal framework established for decisions regarding care at end of life. An essential point in the debate over assisted suicide is whether there is any difference at all between actions that are currently illegal and those that are legal and widely accepted. Advocates for legalization of assisted suicide argue that withholding

93. *Id.*

94. *Id.*

95. *Id.*

96. *Compassion in Dying*, 79 F.3d at 810.

97. Paul Jacobs, *Prop. 161—A Matter of Life or Death at the Polling Place*, L.A. TIMES, Oct. 10, 1992, at 20.

98. OR. REV. STAT. § 127.880 (1996) (Oregon Death with Dignity Act § 3.14).

99. *Compassion in Dying*, 79 F.3d at 824.

100. *Id.* at 806-10.

101. See O’Keefe, *supra* note 92.

or foregoing life sustaining treatment (particularly nutrition and hydration, but also ventilator support and other interventions) is no different than providing lethal medication.¹⁰² Proponents of legalization also argue that administering medication to relieve pain, where the pain medication may foreseeably hasten the patient's death, is no different than providing a non-therapeutic lethal drug.¹⁰³ Withdrawal of medical treatment is legal within broadly circumscribed circumstances while providing or administering a lethal drug is not. Prescribing or administering pain medication therapeutically, even assuming that the medication may hasten death, which itself is a highly controversial point,¹⁰⁴ is not illegal.¹⁰⁵ Opponents of legalization argue that there is an ethical, historical, medical, and legal difference between aiding suicide and withdrawing treatment or treating pain.¹⁰⁶ The Ninth Circuit itself recognized that both withdrawal of treatment and provision of adequate pain relief are legal.¹⁰⁷ The Ninth Circuit adopted the argument that there is no legally significant difference between those actions and providing lethal medication, while the Supreme Court, in contrast, detailed the states' consistent adherence to legal distinctions between withdrawing treatment and medicating for pain on the one hand and providing lethal medication on the other.¹⁰⁸ The Rehnquist opinion and the concurring opinions further emphasized the legality of providing pain medication even where that medication may present the risk of an earlier death.¹⁰⁹

Establishing a distinction in legal and ethical character between withdrawal of treatment and euthanasia or assisting suicide was a critical point in the courts' initial legal recognition of a patient's right to refuse medical treatment.¹¹⁰

102. See, e.g., Brief of Julian W. Whitaker, M.D., as Amicus Curiae in Support of Respondents at 15, *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997) (Nos. 96-110, 95-1858) [hereinafter Whitaker]; Brief of Gay Men's Health Crisis and Lambda Legal Defense and Education Fund as Amicus Curiae in Support of Respondents at 24, *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997) (Nos. 96-110, 95-1858).

103. See Whitaker, *supra* note 102.

104. See, e.g., John Colin Partridge & Stephen N. Wall, *Analgesia for Dying Infants Whose Life Support is Withdrawn or Withheld*, PEDIATRICS, Jan. 1, 1997, at 76 (reporting a study indicating that average length of time between withdrawal of ventilator support and death was identical for infants receiving no pain medication and those receiving morphine and longer for those infants receiving a greater amount of morphine).

105. Yale Kamisar, *The "Right to Die": On Drawing (and Erasing) Lines*, 35 DUQ. L. REV. 481, 500 (1996).

106. Brief Amicus Curiae in Support of Petitioners at 3, *Vacco v. Quill*, 117 S. Ct. 2293 (1997) (No. 95-1858); Brief of the United States Catholic Conference et al. as Amici Curiae in Support of Petitioners at 4-5, *Vacco v. Quill*, 117 S. Ct. 2293 (1997) (No. 95-1858).

107. *Compassion in Dying v. Washington*, 79 F.3d 790, 827 (9th Cir. 1996).

108. *Washington v. Glucksberg*, 117 S. Ct. 2258, 2270 (1997).

109. *Id.* at 2270; *id.* at 2276 (Souter, J., concurring); *Washington v. Glucksberg*, 117 S. Ct. 2302, 2307 (O'Connor, J., concurring).

110. See, e.g., Alexander M. Capron, *Borrowed Lessons: The Role of Ethical Distinctions in Framing Law on Life-Sustaining Treatment*, 1984 ARIZ. ST. L.J. 647.

Persuading health care professionals that there was a qualitative ethical difference between allowing a patient to die and killing a patient was also important in the effort to assure that withdrawal of life-sustaining treatment and effective pain management would be carried out.¹¹¹

Whether or not there is a “real” difference between withdrawing treatment or medicating for pain on the one hand and assisted suicide or euthanasia on the other, the suicide debate’s deconstruction of the legal and ethical underpinnings of the last two decades (and along with that foundation, the language) has made it difficult to communicate. A prominent example of this difficulty emerged from a recent survey of critical care nurses.¹¹² This survey was described as revealing that nineteen percent of the nurses had reported performing or participating in “euthanasia,” with the implication that the nurses had engaged in illegal or unethical behavior, that they had killed their patient.¹¹³ This was not just another incident where the media could be criticized for misunderstanding or hyperbole. The study’s principal investigator, Dr. David Asch, described his survey as supporting that finding.¹¹⁴

The publication of the survey elicited a strong response. Much of the negative reaction was heavily critical of the survey questions. Two questions in particular were controversial.

The survey asked whether the nurse respondent had ever performed actions “with the intent of causing or hastening that patient’s death—other than the withdrawal of life-sustaining treatment” and whether the nurse had ever given an “overdose of opiates.”¹¹⁵ Both of these questions alluded to the administration of medication to a person whose death is imminent or who is in the final stages of terminal illness. In response to the publication of the Asch study, nurse specialists, professional nursing organizations, and nurse researchers generally claimed that the questions asked on the survey were too ambiguous to generate a meaningful response.¹¹⁶

The question referring to an “overdose of opiates” is particularly problematical. “Overdose” implies that the pain medication was administered in an amount that was not required for the treatment of pain but that was instead

111. Graboyes-Russo, *supra* note 57, at 916-17.

112. David A. Asch, *The Role of Critical Care Nurses in Euthanasia and Assisted Suicide*, 334 NEW ENG. J. MED. 1374 (1996).

113. Barbara Reynolds, *Nurses, Physicians Should Not Play God*, USA TODAY, June 7, 1996, at 15A; *Are Nurses Angels of Death?*, TIMES UNION, June 1, 1996, at A6.

114. David A. Asch, *Promises and Pitfalls Along the Road to Empirical Scholarship in Bioethics*, 2 CENTER FOR BIOETHICS NEWSLETTER 1 (1996).

115. David A. Asch, *The Role of Critical Care Nurses in Euthanasia and Assisted Suicide*, 335 NEW ENG. J. MED. 971, 973-74 (1996) (Letter to the Editor).

116. Colleen Scanlon, *Euthanasia and Nursing Practice—Right Question, Wrong Answer*, 334 NEW ENG. J. MED. 1401 (1996); *see also* Patricia A. Dunn, *The Role of Critical Care Nurses in Euthanasia and Assisted Suicide*, 335 NEW ENG. J. MED. 971 (1996) (Letter to the Editor); Nancy L. Szaflarski & John M. Clochesy, *The Role of Critical Care Nurses in Euthanasia and Assisted Suicide*, 335 NEW ENG. J. MED. 971 (1996) (Letter to the Editor).

non-therapeutic. Current research on effective pain relief has clearly established that "standard" doses of opiates are meaningless for patients who have received these pain medications over some amount of time.¹¹⁷ Much larger doses of the drugs are both safe for such patients and are required for relief of pain.¹¹⁸ Such "overdoses" can be well tolerated by those patients often without the sedation side effect or other side effects. For minimally adequate treatment of pain in patients who have used prescribed pain medication previously, doctors *should* be prescribing and nurses administering "overdoses" of opiates and can prescribe an "overdose" without shortening the patient's life.¹¹⁹ If Asch intended to exclude these totally therapeutic, non-life-threatening "overdoses" from the reach of his question, he failed to do so. If he intended to include any case in which a "large" amount of opiates is provided, he has asked a question using a term that implies substandard care to describe acceptable medical or nursing care.

Asch responded to the criticism of his study:

[T]he term "euthanasia" is loaded. Those who believe that the term can refer properly only to activities that are immoral may also feel that it cannot apply to all the activities reported by the nurses. If there is a continuum of moral appropriateness represented here, it is not clear where the moral divide lies, whether there is a single divide, or whether that divide is shifting over time. The range of activities described by the nurses who participated in this study may reveal the inadequacy of the term "euthanasia" and the many professional and legal policies built on it.¹²⁰

Asch's response highlights the ambiguity of the term euthanasia but it also illustrates the difficulty of the context in which the debate over and studies of physician-assisted suicide are occurring. Whether or not the argument that there is no difference, other than the current legal distinction, between withdrawing treatment and medicating for pain on one hand and assisting in suicide on the other ultimately prevails, the "no distinction argument" has a direct impact on the meaningfulness of empirical studies on professional attitudes and practices. To the extent that such research may be used in judicial or legislative decision making, this problem has to be recognized specifically and with some sophistication.¹²¹

The "no distinction argument" could be having other broad and disturbing consequences. The desired outcome of the deconstruction of the current ethical and legal framework may be the expansion of medical options and the expansion of individual control over medical decisions, as well as the relief of suffering.

117. See, e.g., Russell K. Portenoy, *Opioid Therapy for Chronic Nonmalignant Pain: Clinicians' Perspective*, 24 J.L. MED. & ETHICS 296 (1996).

118. *Id.*

119. See, e.g., Szaflarski & Clochesy, *supra* note 116.

120. Asch, *supra* note 115, at 973.

121. For a critical analysis of survey data concerning physician attitudes toward euthanasia and assisted suicide, see Emanuel, *supra* note 90, at 158.

It is possible, however, that dismantling the legal and ethical framework for the treatment of pain could have an opposite effect. If medicating for pain relief becomes associated with physician-assisted suicide or euthanasia, adequate treatment for pain could take on all of the moral connotations of killing. Individual doctors and nurses who believe that it is immoral to “kill” a patient and who may already be anxious about providing adequate pain medication for their patients for fear of causing death, may become even more hesitant to provide medically required pain medication.¹²² This reaction would exacerbate the current shameful neglect of pain and cause increased and avoidable human suffering. Furthermore, legislators who want either to make assisted suicide and euthanasia illegal, or to legalize assisted suicide and euthanasia but only under tightly controlled circumstances, might establish standards that greatly restrict access to effective pain relief. For example, in the 1997 legislative session, a bill was filed in the Michigan legislature that would legalize physician-assisted suicide.¹²³ A section of that bill, however, provided: “A nonphysician . . . who administers [or] causes to be administered . . . medications . . . to an individual for use in a manner substantially likely to cause or hasten that individual’s death is guilty of a felony.”¹²⁴ This provision would prohibit nurses from administering pain medication to patients who are suffering severe pain if the medication carries the risk of hastening death. Doctors prescribe medication, but nurses ordinarily administer medications in a hospital setting. Nurses ordinarily attend patients at the end of life. Physicians are often not readily available to administer pain medication as needed. This proposed legislation, then, legalizes the use of medication to assist a death when certain restrictive circumstances are met but could make the use of pain medication illegal where the narrow circumstances of the statute are not met.

B. How Physicians Do and Will Behave

Both *Vacco v. Quill* and *Compassion in Dying* limited their holdings to assistance provided by physicians. The three state initiatives placed before voters in California, Washington and Oregon also legalized assistance in suicide only where it was to be provided by physicians.¹²⁵

Opponents, as well as some proponents, of legalization of assisted suicide have taken issue with the use of physicians to aid in death. Some opponents of legalization of assisted suicide argue that the involvement of physicians perverts the role of physician as healer and will irreparably damage the trust in the physician-patient relationship.¹²⁶ Other opponents of legalization argue that

122. Melissa L. Buchan & Susan W. Tolle, *Pain Relief for Dying Persons: Dealing with Physicians' Fears and Concerns*, 6 J. CLINICAL ETHICS 53, 57 (1995).

123. S. 653, 89th Leg., Reg. Sess. (Mich. 1997).

124. *Id.* § 5689.

125. *Washington v. Glucksberg*, 117 S. Ct. 2258, 2266 (1997); see also *Compassion in Dying v. Washington*, 79 F.3d 790, 810 (9th Cir. 1996).

126. Brief of the American Medical Association et al. as Amici Curiae in Support of

reliance on physicians as the centerpiece of the movement to legalize assistance in death is strategic to make the process appear to be an ordinary form of medical treatment.¹²⁷ Some proponents of legalization argue over whether doctors should have a monopoly over this work and whether other professionals, including nurses with prescribing authority or newly created categories of health care providers, would be better suited to the task.¹²⁸ Other proponents argue that the patient should be able to choose to have the assistance of family or friends instead of that of a professional stranger, and that legally requiring any professional intervention is an invasion of the privacy of the patient and gives too much control to physicians.¹²⁹

The Ninth Circuit emphasized the protective and tempering role of physicians in the provision of assistance in suicide. It viewed the participation of doctors as a safeguard against abuse:

We believe that most, if not all, doctors would not assist a terminally ill patient to hasten his death as long as there were any reasonable chance of alleviating the patient's suffering or enabling him to live under tolerable conditions. We also believe that physicians would not assist a patient to end his life if there were any significant doubt about the patient's true wishes. To do so would be contrary to the physicians' fundamental training, their conservative nature, and the ethics of their profession.¹³⁰

In this statement, the court attributes two priorities to physicians in the care of their patients at the end of life. First, the court alludes to doctors' commitment to relieving suffering and pain. Second, the court emphasizes physicians' adherence to the wishes of their patients. The court nests these priorities in medical education and medical ethics.

No one can know how physicians will behave if assistance through lethal intervention were legalized. It would seem likely that neither Jack Kervorkian nor Timothy Quill—the two most prominent physician-advocates of physician-assisted suicide—would represent the majority of physicians providing such assistance. There is empirical evidence, however, that examines physicians'

Petitioners, *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997) (No. 96-110); Brief of the Legal Center for Defense of Life, Inc. and the Pro-life Legal Defense Fund as Amici Curiae in Support of Petitioners, *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997) (No. 96-110).

127. Brief of the American Medical Association et al. as Amici Curiae in Support of Petitioners, *Vacco v. Quill*, 117 S. Ct. 2293 (1997) (No. 95-1858); Brief of the American Medical Association et al. as Amici Curiae in Support of Petitioners, *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997) (No. 96-110).

128. See, e.g., Annette E. Clark, *Autonomy and Death*, 71 TULANE L. REV. 45 (1996).

129. David C. Thomasma, *An Analysis of Arguments For and Against Euthanasia and Assisted Suicide: Part One*, 5 CAMBRIDGE Q. HEALTHCARE ETHICS 62, 66-67 (1996) (describing claims that there should be no "middle person" involved and evidence of physician paternalism in refusals to comply with euthanasia requests).

130. *Compassion in Dying*, 79 F.3d at 827.

behavior in their care of patients generally, particularly in their treatment of patients in pain, and in their compliance with patients' choices concerning medical treatment.

The Ninth Circuit's confidence in the medical commitment to providing effective pain relief through available means is not supported in currently available data. The medical capacity to relieve pain is greater than it has ever been. Effective pain management is medically available for cancer pain, for chronic nonmalignant pain, and for pain related to diseases at the end of life. Effective pain management is available in many forms, including controlled substances such as opioids, that do not cause addiction or serious mental impairment.¹³¹

Yet, pain continues to be seriously neglected and undertreated. Treatable but untreated pain is a widespread problem that cuts across many patient populations. Studies have repeatedly documented undertreatment of pain in U.S. health care. For example, the *SUPPORT* study of 9105 patients dying in five teaching hospitals found pain management lacking. *SUPPORT* reported that the surviving family members of fifty percent of the dying patients reported that the patients suffered moderate to severe pain half of the time.¹³² The very recent Institute of Medicine report on end-of-life care also identified undertreatment of pain as a major concern.¹³³ Seventy-five percent of cancer patients in one study reported suffering pain, with forty to fifty percent reporting moderate to severe pain and twenty-five to thirty percent reporting severe pain. This occurs even though ninety percent of cancer pain can be relieved through "relatively simple means."¹³⁴ Chronic nonmalignant pain has been described as an extremely prevalent problem.¹³⁵ Over two-thirds of nursing home residents experience serious chronic pain.¹³⁶ Moreover, the elderly, minorities, women, children, and those unable to speak for themselves due to disability bear the brunt of ineffective care and are undertreated at even higher rates than others.¹³⁷ Despite

131. See AGENCY FOR HEALTH CARE POLICY & RESEARCH, U.S. DEPT. OF HEALTH & HUMAN SERVICES, *MANAGEMENT OF CANCER PAIN: MANAGEMENT OF CANCER PAIN GUIDELINE PANEL* (1994) (Pub. No. 94-0592); AGENCY FOR HEALTH CARE POLICY & RESEARCH, U.S. DEPT. OF HEALTH & HUMAN SERVICES, *ACUTE PAIN MANAGEMENT: OPERATIVE OR MEDICAL PROCEDURES AND TRAUMA* (1992) (Pub. No. 92-0032).

132. *SUPPORT*, *supra* note 25, at 1591.

133. INSTITUTE OF MEDICINE, *APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE* (Marilyn J. Field & Christine K. Cassel eds., 1997).

134. AGENCY FOR HEALTH CARE POLICY & RESEARCH, *supra* note 131 (referring generally to both articles).

135. Russell K. Portenoy, *Opioid Therapy for Chronic Nonmalignant Pain: A Review of the Critical Issues*, 11 *J. PAIN & SYMPTOM MGMT.* 203 (1996).

136. Bruce A. Ferrell et al., *Pain in the Nursing Home*, 38 *J. AM. GERIATRICS SOC.* 409 (1990).

137. B. S. Shapiro & B. R. Ferrell, *Pain in Children and the Frail Elderly*, in *APS BULLETIN* (Oct./Nov. 1992); Knox H. Todd et al., *Ethnicity as a Risk Factor for Inadequate Emergency Department Analgesia*, 269 *JAMA* 1537 (1993).

the development of effective pain management interventions and the overall human and financial cost of pain, pain is neglected and undertreated.

The Ninth Circuit also expresses remarkable confidence in doctors' interest in and commitment to following the patient's wishes concerning medical treatment at the end of life. The Ninth Circuit's confidence greatly exceeds what the empirical data would support.¹³⁸

In an important article published in the *Journal of the American Medical Association*, David Orentlicher, then writing for the Office of General Counsel of the AMA, and now co-director of Indiana University's Center for Law and Health, observes:

Over the past two decades a societal consensus has developed around the principle that decisions about life-sustaining treatment should be guided by patient self-determination. According to the President's Commission, the Hastings Center, the American Medical Association, and the U.S. Supreme Court, treatment decisions should be based on the values, goals and preferences of the patient.

While theory may emphasize the patient's values, empirical data suggest that other considerations may have a greater impact on decisions about life-sustaining treatment. *In particular, there is increasing evidence that physician values may be a more decisive factor than patient values in these decisions.*¹³⁹

Orentlicher supports his statement with a review of the empirical literature. For example, the authors of a study of compliance with advance directives concluded that the physicians in the cases studied actually provided undesired treatment and withheld desired treatment based on the *physician's* judgment of what was appropriate or beneficial to the patient. Orentlicher concludes that "patient's preferences were respected as long as the physicians thought that the patients' choices resulted in the best decisions."¹⁴⁰

Studies also consistently indicate that patients are greatly influenced by the manner in which the doctor presents treatment options. Orentlicher reviews studies indicating that patients are more likely to choose surgery when the probability of survival is presented rather than the probability of death,¹⁴¹ and

138. See JAY KATZ, *SILENT WORLD OF DOCTOR AND PATIENT* (1984). Katz presents the classic critique of informed consent as a legal requirement and as a professional practice. In his analysis of the legal requirement of informed consent, Katz calls informed consent a "fairy tale" and delineates why informed consent is unnatural to physicians and how the law's enforcement of the requirement is ineffective and half-hearted at best.

139. David Orentlicher, *The Illusion of Patient Choice in End-of-Life Decisions*, 267 *JAMA* 2101, 2101 (1992) (emphasis added) (citations omitted).

140. *Id.* (discussing Marion Danis et al., *A Prospective Study of Advance Directives for Life-Sustaining Care*, 324 *NEW ENG. J. MED.* 882 (1991)).

141. *Id.* at 2102 (discussing T. M. Marteau, *Framing of Information: Its Influence Upon Decisions of Doctors and Patients*, 28 *BR. J. SOC. PSYCH.* 89 (1989)).

that patients are more likely to choose treatment when the treatment is presented positively rather than negatively.¹⁴²

Orentlicher also reviews studies that indicate that physicians "are more inclined to talk with patients who are most like them"¹⁴³ and that physicians give both more time and more explanations of the course of treatment to patients who seem more intelligent and better educated.¹⁴⁴ Orentlicher concludes: "Ironically, physicians may become most aware of the preferences of patients who share their values. . . . Physicians may be less aware of the preferences of patients whose values diverge sharply from those of their physicians."¹⁴⁵

More recent research remains consistent with the research relied upon by Orentlicher in his 1992 article.¹⁴⁶ In particular, the results of the *SUPPORT* study of in-hospital end-of-life care, discussed later in this article, confirms Orentlicher's conclusions.¹⁴⁷

Empirical research on the medical neglect of pain and on non-compliance with patients' treatment choices at the end of life contradicts the Ninth Circuit's reliance on physicians as a safeguard in the administration of legalized physician-assisted suicide. The data actually support the proposition that physicians will not act as a guard against suicides undertaken because of neglected pain or without the complete understanding and consent of the patient.

Steven Miles calls for more study of the psychology of the physician-patient relationship in relation to physician-assisted suicide. He notes:

There is ample evidence that physicians often have difficulty responding therapeutically to chronically ill or dying patients. They often underdiagnose and undertreat pain or depression, either of which may be part of why a patient may choose to die. Chronically ill or dying patients have told how their physicians emotionally or physically withdrew from them. . . .

The intractability of these findings, despite years of calls for more sensitivity to the needs of dying persons and for better use of therapeutic information, implicates deep causes in the genesis of such mistreatment. . . . In this view, a physician tends to withdraw from dying patients, minimize pain, overlook clinical depression, and prematurely believe

142. *Id.* (discussing T.R. Malloy et al., *How Interventions Are Described Affects Patients' Decisions About Life-Sustaining Treatment*, in AMERICAN GERIATRIC SOCIETY/AMERICAN FEDERATION FOR AGING RESEARCH ANNUAL SCIENTIFIC MEETING, 1991 PROGRAM (Abstract A2)).

143. *Id.* at 2102.

144. *Id.*

145. *Id.*

146. See, e.g., Lawrence J. Schneiderman et al., *Do Physician's Own Preferences for Life-Sustaining Treatment Influence Their Perceptions of Patients' Preferences? A Second Look*, 6 CAMBRIDGE Q. HEALTHCARE ETHICS 131 (1997); Steven H. Miles, *Physicians and Their Patients' Suicides*, 271 JAMA 1786 (1994).

147. See discussion *infra* Part II.A.

patients have chosen to die as a result of the physician's own dread of death or disability or belief that a patient is as demoralized by his or her condition as the physician is. If this critique is correct, physicians are not bad, just human.¹⁴⁸

Descriptions of current medical practices do not necessarily predict future practices. The patterns described by Orentlicher and *SUPPORT* and others might be remedied in the future. The Ninth Circuit relies on current medical training and ethics as a source of constraint for physicians in assisting death, and the court anticipates a future in which medical training and ethics will continue to operate in that fashion and will continue to emphasize constraints or prohibitions on intervening to cause death. Opponents to legalization argue that legalization itself will change medical ethics and medical education in the most significant way.¹⁴⁹ Perhaps these contrasting visions of the future could be empirically tested, although problems in structuring such a study seem insurmountable.

Even if such an experiment could be structured, it is unlikely that the data would resolve the question of whether the legalization of physician-assisted suicide has a positive or negative impact on physician behavior and medical ethics. Proponents of legalization argue that physicians who now cannot aid a patient in suicide without committing a crime, abandon their patients and their own ethical duty to relieve suffering.¹⁵⁰ In this view, the ethical physician is one who is willing to care for the patient even to the point of ending that patient's life, and a society that respects an individual's choice to end his life is a better society. Opponents argue that the physician's ethical duty to the patient requires that the physician be fully committed to the well-being of the patient, including aggressively treating pain even to the point of the patient's unconsciousness, but that the doctor's duty requires refusing the patient's request for death. From this perspective, a society that allows physicians to kill patients upon request is a society that has abandoned caring for the ill, the dying and dependent.¹⁵¹ Empirical research could measure physicians' behavior pre- and post-legalization, but it cannot answer whether the behavior is more or less ethical than before.

The Ninth Circuit's confidence in physician practices in respecting their

148. Miles, *supra* note 146, at 1788-89.

149. Reply Brief for Petitioners, *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997) (No. 96-110); Brief of Family Research Council as Amicus Curiae in Support of Petitioners, *Washington v. Glucksberg*, 117 S. Ct. 2258 (1997) (Nos. 96-110, 95-1858).

150. Brief of the American Medical Student Association and a Coalition of Distinguished Medical Professionals as Amici Curiae in Support of Respondents, *Vacco v. Quill* 117 S. Ct. 2293 (1997) (Nos. 95-1858, 96-110); Brief of Amicus Curiae Bioethicists Supporting Respondents, *Vacco v. Quill* 117 S. Ct. 2293 (1997) (Nos. 95-1858, 96-110).

151. Brief of the American Medical Association et al. as Amicus Curiae in Support of Petitioners, *Vacco v. Quill*, 117 S. Ct. 2293 (1997) (No. 95-1858); Brief of the International Anti-Euthanasia Task Force in Support of Petitioners, *Vacco v. Quill*, 117 S. Ct. 2293 (1997) (Nos. 95-1858, 96-110).

patients' wishes concerning medical treatment and in treating patients in pain is clearly misplaced. Part of the Ninth Circuit's argument in favor of a right to physician-assisted death, however, is that withdrawal of life-sustaining treatment under the current legal framework itself presents risks of abuse.¹⁵² This observation could logically lead to restrictions on withdrawal of life-sustaining treatment just as much as it could lead to acceptance of the use of lethal drugs. The argument that there is no difference between the two can work both ways.

C. *At-Risk Populations*

Opponents to legalization of assisted suicide argue that legalization would place certain vulnerable populations at particular risk of involuntary, coerced, or simply desperate decisions for termination of life.¹⁵³ The groups that are often considered particularly vulnerable in the U.S. health care system include the poor, minorities, those disadvantaged by lack of access to adequate health care, the disabled and the elderly.¹⁵⁴ It is common practice for courts to identify particular groups as vulnerable and to construct legal rules designed to compensate for that vulnerability.

The Ninth Circuit reviewed arguments that these vulnerable populations will be at risk. However, the court of appeals rejected arguments that most of the vulnerable populations identified will be negatively affected by a change in the legal status of physician-assisted suicide. The court makes several different arguments on this point.

The court first addresses the argument that persons who do not have access to adequate health care will be threatened by the legalization of physician-assisted suicide:

The argument that disadvantaged persons will receive more medical services than the remainder of the population in one, and only one area—assisted suicide—is ludicrous on its face. So, too, is the argument that the poor and the minorities will rush to volunteer for physician-assisted suicide because of their inability to secure adequate medical treatment.¹⁵⁵

The Ninth Circuit is particularly harsh in its response to such arguments. It supports its conclusion with the experience of access to abortions, an instance where similar arguments about vulnerable populations have been made.¹⁵⁶ The court notes that public funding for abortions is very limited and that other factors

152. *Compassion in Dying v. Washington*, 79 F.3d 790, 817 (9th Cir. 1996).

153. Reply Brief for Petitioners Vacco and Pataki, *Vacco v. Quill*, 117 S. Ct. 2293 (1997) (No. 95-1858); Brief of the American Geriatrics Society as Amicus Curiae Urging Reversal of the Judgments Below, *Vacco v. Quill*, 117 S. Ct. 2293 (1997) (Nos. 95-1858, 96-110).

154. *Compassion in Dying*, 79 F.3d at 825.

155. *Id.*

156. *Id.*

converge to limit access even where there is an ability to pay.¹⁵⁷

One could argue that the case of abortion services is not strictly analogous to this case. Abortion services are more costly and require more institutional collaboration, in terms of space and equipment, than would a prescription for lethal medication. Although abortion might not be a totally effective analogy, there may be other analogous situations.

Whether or not abortion is analogous to assisted suicide, a focus on the anticipated utilization rate reduces the argument over whether legalization specially endangers those who are currently denied health care and the poor and minorities to an empirically verifiable question. A study could be constructed to monitor the provision of assisted death services in a way that would test the court's assumption about excess utilization by such groups. Structuring the study would be difficult unless the use of the service could be both tightly controlled and accurately recorded, but it still might be feasible.¹⁵⁸

Arguments based on inadequacies in the health care system include a further assertion that legalization of assisted suicide may undercut already weak public support for adequate health care, particularly for conditions that can trigger substantial costs with little or no hope for a return to health or substantially improved functioning. This concern reaches care for the dying and long-term care for the seriously debilitated elderly, among other situations.¹⁵⁹ This view argues that if the sometimes drawn-out "natural dying" process is viewed as a matter of personal choice, those who choose natural dying will have to bear the cost of that choice. The proposed regulation of assisted suicide in the Oregon initiative of 1994 attempts to respond to this problem and prohibits

[t]he sale, procurement, or issuance of any life, health, or accident insurance or annuity policy or the rate charged for any policy shall not be conditioned upon or affected by the making or rescinding of a request by a person, for medication to end his or her life in a humane and dignified manner.¹⁶⁰

Such regulation, however, cannot control the general level of insurance coverage or government payment for health care services for the dying, disabled or very dependent elderly.

Dissipation of public and private support for health care and supportive care for the dying and the debilitated elderly would be quite hard to measure. Such a change may operate glacially, and not be detectable for many years. This concern over withdrawal of financial support—whether public or private—is speculative, but so are assertions that legalization of assisted suicide will not

157. *Id.*

158. See *infra* text accompanying notes 164-65 (discussing various approaches to fairness).

159. See, e.g., Susan Kastner, *The Battle Between Generations Many of Today's Sandwich Generation, the Newly Naked Middle Class, Have Been Forced Back to Frequently Bitter Interdependence. Young Against Old, Old Against Young, Families Cloistered Together, and at Odds*, TORONTO STAR, April 22, 1996, at A15.

160. OR. REV. STAT. § 127.875 (1996).

have such an impact.

The Ninth Circuit also addresses concerns about discrimination against the disabled. At one point, the court opined that such discrimination is unlikely because “[o]rganizations representing the physically impaired are sufficiently active politically and sufficiently vigilant that they would soon put a halt to any effort to employ assisted suicide in a manner that affected their clients *unfairly*.”¹⁶¹ The court did not describe what it meant by unfair treatment.

The situation of the disabled quite clearly raises the issue of what constitutes discrimination against any population. Is it discriminatory to legalize assisted suicide by disabled persons; or is it discriminatory to “protect” such individuals by excluding them from choosing certain options any other individual may choose? The Ninth Circuit in *Compassion in Dying* responded in this fashion:

[s]eriously impaired individuals will, along with non-impaired individuals, be the beneficiaries of the liberty interest asserted here—and . . . if they are not afforded the option to control their own fate, they like many others will be compelled, against their will, to endure unusual and protracted suffering.¹⁶²

The court’s perception of assisted suicide as beneficial is a value judgment and is unlikely to be resolved empirically.

The Ninth Circuit offered fairness as a basis on which to resolve the conflict between risks to vulnerable populations generally and limitations on individual liberty: “The resolution that would be best for all, of course, would be to ensure that the practice of assisted suicide is conducted fairly and well, and that adequate safeguards sufficient to avoid the feared abuses are adopted and enforced.”¹⁶³ In this argument, legalization would allow regulation of assisted suicide and activate safeguards to prevent abuses.

The aspiration that the system be administered “fairly and well” appears to be a standard that can be performance-monitored. One common and well accepted method for monitoring the fairness of any allocation system is to examine patterns in utilization. In recent years, for example, many studies on health care delivery have produced statistics on the provision of certain medical interventions across populations.¹⁶⁴

Empirical studies on the incidence of assisted suicide across identified populations must operate on implied values of fairness: for example, that a

161. *Compassion in Dying*, 79 F.3d at 825 (emphasis added).

162. *Id.*

163. *Id.* at 825.

164. See, e.g., M.B. Hamel et al., *Seriously Ill Hospitalized Adults: Do We Spend Less on Older Patients?*, 44 J. AM. GERIATRICS SOC. 1043 (1996); Scott Burris, *Dental Discrimination Against the HIV-Infected: Empirical Data, Law and Public Policy*, 13 YALE J. ON REG. 1 (1996); Carol Jonann Bess, *Gender Bias in Health Care: A Life or Death Issue for Women with Coronary Heart Disease*, 6 HASTINGS WOMEN’S L.J. 41 (1995); David R. Williams & Chiguita Collins, *U.S. Socioeconomic and Racial Differences in Health: Patterns and Explanations*, 21 ANN. REV. SOC. 349 (1995).

distribution that is determined solely by race or gender would be “fair” or “unfair.” Empirical data standing alone cannot resolve the question of whether the system for assistance in death is operating “fairly.” The resolution of whether assisted death is administered fairly requires that the content of the notion of fairness be made more specific. If fairness is taken in its most common meaning of “treating like cases alike,” then the criteria for relevant similarities and differences need to be identified to provide the Ninth Circuit’s notion of fairness with some content. ~

It is not clear from the Ninth Circuit’s opinion, for example, how data that indicate a disproportionate representation of “seriously impaired individuals” among those choosing assisted suicide should be assessed. Would the data be interpreted as showing that assisted death was being administered fairly because it was reaching the people who could significantly benefit from the service, or would the data provide *prima facie* evidence of unfairness because of concerns that the disabled were not receiving adequate health care? The court’s observation that “seriously impaired individuals” will be among the beneficiaries of legalization indicates that the court would not view disproportionate representation of disabled persons among those receiving medical services to end their lives as a problem.

The influence of economic factors in the administration of physician-assisted suicide might also be studied. Hypothetically, data could indicate either that patients receiving physician aid in death were primarily from higher income groups or that uninsured patients were disproportionately represented. If assisted suicide patients were often uninsured, would that indicate unfairness in the system? If only higher income patients were using this service, would it indicate that there were financial or non-financial barriers, such as required consultations and psychiatric assessments, that unfairly excluded lower-income uninsured patients? The Ninth Circuit opinion directly addressed the issue of financial considerations. In response to arguments that the terminally ill might choose assisted suicide because of financial pressures from “astronomical medical bills” that “consume the life savings they planned to leave for their families” or that “worse yet, burden their families with debts they may never be able to satisfy,” the court stated that “[w]e are reluctant to say that, in a society in which the costs of protracted health care can be so exorbitant, it is improper for competent, terminally ill adults to take the economic welfare of their families and loved ones into consideration.”¹⁶⁵ It is fair to say that the Ninth Circuit would not consider a disproportionate representation of persons of lower economic status an indication of unfairness in the administration of physician-assisted death. In fact, the court, in rejecting fears that the poor and minorities would be at risk of abuse, stated that there “is far more reason to raise the opposite concern: . . . that the poor and the minorities . . . will not be afforded a fair opportunity to obtain . . . the assistance that would allow them to end their lives with a measure of dignity.”¹⁶⁶

165. *Compassion in Dying*, 79 F.3d at 826.

166. *Id.* at 825.

The court did not address race-based patterns separately from income-based patterns, although the two can operate separately on access to health care.¹⁶⁷ Nor did the court separately address gender, although gender differences in health care have been discussed in the context of life-sustaining treatment decisions and physician-assisted suicide.¹⁶⁸

II. THE STUDY TO UNDERSTAND PROGNoses AND PREFERENCES FOR OUTCOMES AND RISKS OF TREATMENTS (*SUPPORT*)

If money were no object, could we design an empirical study that would determine once and for all whether we should maintain our allegiance to the ideal of patient choice in medical treatment decision making at the end of life? And if we could design such a study, would it resolve the issue of whether patient choice will drive physician-assisted death or whether physicians will drive physician-assisted death?

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments,¹⁶⁹ commonly known as *SUPPORT*, was a very large and very ambitious empirical study of the principles of bioethics in practice and certainly the most massive to date. *SUPPORT*, funded by the Robert Wood Johnson Foundation for \$28 million,¹⁷⁰ studied the care of 9,105 patients admitted to five major medical centers in five states from June 1989 through January 1994. Eight co-principal investigators, with the advice of a ten-member national advisory committee, directed the efforts of over 150 professional staff engaged in the project.

Each of the over 9,000 patients was admitted to a participating hospital in the advanced stages of one of nine life-threatening or terminal illnesses. *SUPPORT* studied the care these patients received while in the hospital with a particular focus on resource utilization and on communication of and compliance with patient preferences. In their principal report on the project,¹⁷¹ the investigators clearly view the importance of the study in relation to the basic principals of bioethics, especially as they have come to be understood by clinicians and institutionalized by the law in end-of-life care. The investigators note that "professional organizations, the judiciary, consumer organizations, and a

167. See, e.g., Council on Ethical and Judicial Affairs, American Medical Association, *Black-White Disparities in Health Care*, 263 JAMA 2344 (1990); Vernellia R. Randall, *Racist Health Care: Reforming an Unjust Health Care System to Meet the Needs of African-Americans*, 3 HEALTH MATRIX 127 (1993).

168. Steven H. Miles & Allison August, *Courts, Gender and "The Right to Die,"* 18 L. MED. & HEALTH CARE 85 (1990); Nancy J. Osgood & Susan A. Eisenhandler, *Gender and Assisted and Acquiescent Suicide: A Suicidologist's Perspective*, 9 ISSUES L. & MED. 361 (1994).

169. *SUPPORT*, *supra* note 25, at 1591.

170. Steven A. Schroeder, Robert Wood Johnson Foundation, *President's Message, On Dying in America*, <<http://www.rwjf.org/library/annual/press1.htm>>.

171. The study produced many articles, but the principal report was published in the Journal of the American Medical Association. See *SUPPORT*, *supra* note 25.

president's commission have all advocated more emphasis on realistically forecasting outcomes of life-sustaining treatment and on improved communication between physician and patient."¹⁷² The investigators view *SUPPORT* as an empirical test of the operation of informed consent and compliance with patients' preferences. In addition, the study associated patient choice with the issue of resource consumption in hospital care for patients near the end of life.¹⁷³

The first years of *SUPPORT*, now known as Phase I, were conducted from June 1989 to June 1991. According to the investigators, Phase I revealed "shortfalls in patient-physician communication."¹⁷⁴ For example, of the 4,301 patients enrolled in the protocol in those years, 31% preferred that cardio-pulmonary resuscitation be withheld in the case of cardiac arrest, but fewer than half of the physicians treating these particular patients knew of their patients' preference to forego resuscitation.¹⁷⁵ For only 47% of all of the patients enrolled in Phase I could their physicians accurately report the patient's choice whether to accept or refuse resuscitation. Somewhat fewer than half of those patients who preferred not to undergo CPR had a written order (a "do-not-resuscitate order" or "DNR") which would allow CPR to be foregone should they arrest.¹⁷⁶ Because most hospitals require that CPR be performed unless there is a written order otherwise, the patients without such an order may have undergone unwanted resuscitative interventions if they had suffered an arrest.¹⁷⁷

Pain was undertreated. Twenty-two percent of the patients interviewed reported suffering moderate to severe pain at least half the time in the hospital. Surrogates or family members interviewed after a patient had died reported that half of all conscious patients who had died in the hospital experienced moderate to severe pain at least half of the time over the last three days of hospitalization.¹⁷⁸

The investigators reported that there was a substantial variation in these results among physician specialty groups and among the five medical centers. For example, the percentage of patients reporting moderate to severe pain ranged from a low of 12% in one institution to a high of 32% in another. Agreement on reports of DNR preferences varied by specialty from 8% for cardiologists and their patients to 24% for oncologists and their patients.¹⁷⁹

The study was monitored throughout its course. Early findings revealed these substantial problems in physician-patient communication, treatment decisions and outcomes. When doctors at the participating hospitals indicated

172. *Id.* at 1591.

173. *Id.* The study used total hospital resource consumption per case and the number of days spent in intensive care when the patient was on ventilator support or in a coma as indicators. *Id.*

174. *Id.* at 1592.

175. *Id.* at 1594.

176. *Id.*

177. *Id.*

178. *Id.*

179. *Id.*

an interest in trying to change the situation, the study was altered in an attempt to change these observed patterns at the participating hospitals. Meetings were held with the doctors and other participants to develop a plan for improving physician-patient and family communication and for bringing treatment decisions, such as the decision concerning resuscitation, in alignment with patient preferences and probable outcomes. The result of these meetings became Phase II of *SUPPORT*.¹⁸⁰

According to investigators, physicians participating in Phase I asserted that communication would improve if they could have access to more reliable and timely information and if project staff “would make it more efficient to have conversations.”¹⁸¹ In response to these ideas, the project designed an intervention to respond to the doctors’ expressed needs. In Phase II of the project, patients were divided into a control group and an intervention group.¹⁸² Patients and physicians in the intervention group received services from a *SUPPORT* nurse specifically focusing on providing information to the patient and family concerning treatment and prognosis and eliciting discussions with them concerning the patient’s or surrogate’s choices for treatment.¹⁸³ The patient’s physician had to approve before the *SUPPORT* nurse could work with any particular patient.¹⁸⁴

SUPPORT nurses worked with nearly all of the 2,652 patients enrolled in the intervention group of Phase II through a randomized process following hospital admission. Only 133 patients enrolled in the intervention group did not receive the *SUPPORT* intervention, and of these, 75 had died or were discharged on the day they were placed in the study.¹⁸⁵ The *SUPPORT* nurse intervened as seemed advisable in each case. The *SUPPORT* nurse talked directly with the patient or family about the patient’s prognosis in 84% of the cases; about pain in 77%; about likely outcomes of resuscitation in 63%; and about written advance directives in 73% of the cases.¹⁸⁶

A *SUPPORT* nurse discussed the patient’s choices and understanding of their medical condition with the patient’s doctor in “virtually all cases.” At least one written report of the patient’s or surrogate’s preferences was provided in 78% of the cases.¹⁸⁷ *SUPPORT* nurses also engaged in “time-consuming discussions, arranged meetings, provided information, supplied forms, and did anything else to encourage the patient and family to engage in an informed and collaborative decision-making process with a well-informed physician.”¹⁸⁸

SUPPORT also provided doctors in Phase II with information on the patient’s

180. *Id.* at 1592.

181. *Id.*

182. *Id.* at 1593.

183. *Id.* at 1592.

184. *Id.*

185. *Id.* at 1594.

186. *Id.*

187. *Id.*

188. *Id.*

prognosis. *SUPPORT* developed a prognostic model for predicting survival rates and outcomes for the types of patients involved in the study. For 94% of the patients in Phase II, physicians received at least one written prognosis evaluation, and this written evaluation was placed in the patient's medical record in 80% of the cases.¹⁸⁹

A. *The Results of SUPPORT*

The investigators reported on the results of Phase II: "In phase II of *SUPPORT*, improved information, enhanced conversation, and an explicit effort to encourage use of outcome data and preferences in decision making were completely ineffectual, despite the fact that the study had enough power to detect small effects."¹⁹⁰ In describing the detail that supported their conclusion, *SUPPORT* investigators reported that only 34% of the physicians acknowledged having received a report of patient preferences, although a written report was provided in 78% of the cases.¹⁹¹ Fifty-nine percent of the doctors acknowledged having received the prognosis report, even though a written report was given to the doctor in 94% of the cases and had been placed in the patient's medical record in 80% of the cases.¹⁹² Only 15% of the participating doctors reported having discussed the information on prognosis and preferences with their patients.¹⁹³ The prevalence and timing of written DNR orders was the same for the control and the intervention groups. The investigators reported that there was "a small association" of the intervention with improvement in patient-physician agreement on the patient's desires concerning resuscitation.¹⁹⁴ There was no change in the use of hospital resources or in the length of stay in the intensive care unit. There was an increase in reported untreated pain in the interviews conducted with patients themselves.¹⁹⁵ The intervention did not change the unadjusted proportion of patients or surrogates who reported having a discussion about CPR (37% of the control group and 40% of the intervention group), with 41% of those reporting that CPR had not been discussed stating that they would have liked to discuss the decision.¹⁹⁶

B. *Reactions to SUPPORT*

The President of the Robert Wood Johnson Foundation said that "the investigators were stunned" with the results of Phase II.¹⁹⁷ He reported that he was not surprised with the results, however, because of his own experiences as

189. *Id.* at 1595.

190. *Id.* at 1596.

191. *Id.* at 1595.

192. *Id.*

193. *Id.*

194. *Id.* at 1596.

195. *Id.*

196. *Id.*

197. Schroeder, *supra* note 170.

a physician and because of the "horror stories" told him by relatives and friends. The investigators themselves stated: "We are left with a troubling situation. The picture we describe of the care of seriously ill or dying persons is not attractive." They also described the ideal to which they compared the Phase II results: "One would certainly prefer to envision that, when confronted with life-threatening illness, the patient and family would be included in discussions, realistic estimates of outcome would be valued, pain would be treated, and dying would not be prolonged."¹⁹⁸ This was the investigators' vision of good care for the dying. But the investigators observed that "most patients and families indicated they were satisfied [with the care], no matter what happened to them."¹⁹⁹

The investigators offered their own advice for the appropriate response to the results of *SUPPORT*. They conclude their report by arguing that improved care for the dying and improved communication require "reexamination of our individual and collective commitment to these goals, more creative efforts at shaping the treatment process, and perhaps, more proactive and forceful attempts at change."²⁰⁰

The Robert Wood Johnson Foundation, which funded *SUPPORT*, took a "proactive" and "forceful" action in reaction to the results of *SUPPORT*. The Foundation established a national campaign to improve care of the dying. This "Last Acts" campaign is a nationwide multi-million-dollar effort to improve care of the dying through funded research, demonstration projects, consensus conferences, task forces, and media events. The Foundation also funded the first round of expert commentary on *SUPPORT*, published in the Hastings Center Report to coincide with the release of the results of Phase II.²⁰¹

C. Does *SUPPORT* Answer Our Questions?

SUPPORT has revealed a gap between behavior and normative expectations. Current normative expectations require that physicians talk with their patients or the patients' surrogates, about prognosis, treatment options and choices. The same norms expect that patients will participate in such discussions and perhaps will want to have such discussions. Norms requiring discussion include an expectation that physicians will account for, if not follow, the patients' treatment preferences. These are not new ethical and legal standards. They have provided the dominant ethical and legal framework for life-sustaining treatment decisions for the past two decades and for informed consent to treatment since at least the mid-1950s, if not earlier.²⁰²

198. *SUPPORT*, *supra* note 25, at 1597.

199. *Id.* at 1596.

200. *Id.* at 1597.

201. Schroeder, *supra* note 170.

202. Justice Cardozo's opinion in *Schloendorff v. Society of New York Hospital*, 105 N.E. 92 (1914), is often cited as the root of the right to refuse treatment. In that opinion, Cardozo stated: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body." *Id.* at 129. For one history and a critique of legal enforcement of informed consent,

Does *SUPPORT* tell us that patient choice concerning life-sustaining medical treatment is an ideal that should be abandoned? *SUPPORT* certainly reveals that the intervention used in Phase II to increase conversation and information did not improve the incidence of patient-physician communication substantially; that it only minimally improved the accuracy of physician knowledge of patient preferences; that it did not alter physician decisions concerning writing a DNR order or discharging a patient from an ICU; that it did not improve treatment for pain; and that the great majority of both physicians and surviving family members reported feeling satisfied that things went well. But many of those evaluating the *SUPPORT* results charge this failure to defects in the intervention itself: the intervention put an intermediary between the physician and the patient;²⁰³ the intervention used nurses instead of physicians as the stimulus for change;²⁰⁴ the intervention did not try to alter the organizational environment and incentives for maintaining current behaviors;²⁰⁵ the Project's prognosis model produced results no more accurate than physician judgment and so could not change decisions that would have been made by physicians without the model;²⁰⁶ and so on.

Some argue that another intervention designed differently could succeed²⁰⁷ and that the lesson of *SUPPORT* is that we must redouble our efforts to assure that behavior conforms to our ideals. In this view, *SUPPORT* is not the death knell for patient autonomy and informed consent in decisions concerning life-sustaining treatment; it is argued that more education and more commitment can change the patterns revealed by *SUPPORT*.

The more radical responses to *SUPPORT* have argued that *SUPPORT* is not groundbreaking. *SUPPORT* joins a great body of evidence and analysis that proves that informed consent, conversation and patient autonomy is ill-suited to decision making regarding medical interventions. Physicians simply will not talk with their patients, perhaps especially in terminal care, and will not yield control to the patients. Doctors may not be the only ones resistant to planning for death.²⁰⁸ Some argue that it is time to abandon the myth of individual patient

see KATZ, *supra* note 138. See also Schuck, *supra* note 4, at 900 (observing that the legal doctrine did not emerge in "relatively robust form" until 1957).

203. Ellen H. Moskowitz & James L. Nelson, *The Best Laid Plans*, 25 HASTINGS CTR. REP. S3 (1995).

204. *Id.*

205. Mildred Z. Solomon, *The Enormity of the Task: SUPPORT and Changing Practice*, 25 HASTINGS CTR. REP. S28 (1995).

206. On the reliability of the prognosis report as compared with the individual physicians' judgments, see Joanne Lynn et al., *Accurate Prognostications of Death: Opportunities and Challenges for Clinicians Caring for Patients at the End of Life*, 163 W.J. MED. 250 (1995); Bernard Lo, *Improving Care Near the End of Life: Why Is It So Hard?*, 274 JAMA 1634 (1995).

207. Bernard Lo, *End-of-Life Care After Termination of SUPPORT*, 25 HASTINGS CTR. REP. S6 (1995); Solomon, *supra* note 205.

208. Ellen Goodman, *The Conspiracy of Silence About Death is Too Strong*, BALTIMORE SUN, Dec. 1, 1995, at 27A (reporting on family and patient resistance); *Special Report: Critical*

autonomy, or consumer choice, and redesign the relationship between physician and patient along different and yet to be announced lines.²⁰⁹

CONCLUSION

While researchers design the “next *SUPPORT*” to further test the workability of patient choice in end-of-life care, legislatures and courts are being asked to regulate the area. Empirical research can certainly aid in this effort, but will not resolve the ultimate issues. Empirical research does not have the answers. It is likely that the studies will never be well-enough designed or the results conclusive enough to predict the direction and impact of change.

Furthermore, the tension between what is now and what should be cannot be resolved by the data. The best that can be hoped for is that assumptions are recognized for what they are rather than accepted with the confidence of fact and where empirical data do indicate patterns of behavior, those patterns are recognized rather than denied.

What we do not know we can make up, but we should all realize when that is being done. What we do know, as little as that may be, we cannot ignore. It would be a great loss, if advocacy for legalization of physician aid in dying or assisted suicide triggered the collapse of the social pact that allows us to stop aggressive treatment of terminally ill patients, vegetative patients, or patients for whom treatment causes pain without benefit. But it also seems foolhardy to legalize assisted death on the basis of a fantasy of physician commitment to patient choice in health care and to the provision of adequate pain relief.

Times for Critical Care: What About “Quality of Death,” MED. OUTCOMES & GUIDELINES ALERT, Nov. 30, 1995 (describing need for changing institutional culture rather than physician attitudes).

209. See, e.g., Eric G. Anderson, *Some New Lessons to Consider About Life—and Death*, AM. MED. NEWS, Aug. 5, 1996, at 35.