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ARTICLES

A Jurisprudence of Dysfunction: On the Role of “Normal Species Functioning” in Disability Analysis

Ani B. Satz, Ph.D., J.D.*

INTRODUCTION

The Americans with Disabilities Act (ADA) was signed into law by President George H. W. Bush on July 26, 1990. After twenty years of struggle and compromise by civil rights and disability advocacy groups, the legislation was hailed as a victory. The Act established civil rights protection for disabled persons in the workplace and in the provision of services (most notably transportation services) and public accommodation. The Act sought to “provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities . . . [via] clear, strong, consistent, enforceable standards.”¹

Fifteen years later, the Act is widely recognized as a failure. Judicial construction of the eligibility requirements of the Act severely undermines disability protections. In 1999, the United States Supreme Court, in opposition to

* Assistant Professor of Law, Emory University. The author wishes to thank the Harvard Health Policy Society; the Yale Bioethics Forum; the Princeton Center for Human Values; the National Endowment for the Humanities Workshop on Justice, Disability, and Equality; the Health Law Teachers Workshop; and the following individuals: Howard E. Abrams, Robert Ahdieh, Anita Bernstein, Jules Coleman, Martha A. Fineman, Ann Hubbard, Marc Miller, Michael Perry, Mathias Risse, Charles Shanor, Robert Schapiro, Anita Silvers, Peter Singer, Michael Stein, Timothy Terrell, and anonymous reviewers. I offer this piece in memory of my friend, colleague, and former law school classmate, Rosemary Quigley, who was one of the most capable people I have ever known.

1. Americans with Disabilities Act (ADA) of 1990, 42 U.S.C. §§ 12101(b)(1)-(2) (2000). *See generally* 42 U.S.C. §§ 12101-12213 (2000).

the Equal Employment Opportunity Commission (EEOC) and Department of Justice (DOJ) guidelines at the time, held that plaintiffs' eligibility for disability protections must be determined after measures to mitigate disability are employed.² The definition of disability, "a physical or mental impairment that substantially limits one . . . of the major life activities,"³ has met other judicial bars with regard to the interpretation of "substantial" and "major life activity."⁴

Thousands of articles have been written in the last few years lamenting the enervation of the ADA and suggesting remedies such as amending the Act to broaden the definition of disability,⁵ issuing regulations to enumerate a list of covered disabilities,⁶ overruling opinions that create high bars for eligibility under "substantial"⁷ or that look to a narrow range of major life activities,⁸ and reinstating the old EEOC and DOJ guidelines to consider litigants in a pre-mitigated state.⁹ Most recently, in a piece about the future of disability law,

2. *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999); *see also* *Albertson's, Inc. v. Kirkingburg*, 527 U.S. 555 (1999); *Murphy v. United Parcel Serv.*, 527 U.S. 516 (1999).

3. 42 U.S.C. § 12102(2) (2000).

4. *See, e.g., Toyota Motor Mfg., Ky. v. Williams*, 534 U.S. 184, 197 (2002).

5. *See, e.g.,* Claudia Center & Andrew J. Imparato, *Redefining "Disability" Discrimination: A Proposal to Restore Civil Rights Protections for All Workers*, 14 STAN. L. & POL'Y REV. 321 (2003); Chai R. Feldblum, *Definition of Disability Under Federal Anti-Discrimination Law: What Happened? Why? And What Can We Do About It?*, 21 BERKELEY J. EMP. & LAB. L. 91, 163-64 (2000) (arguing that the ADA should prohibit discrimination on the basis of "impairment," a broader category than "disability"); Barbara A. Lee, *A Decade of the Americans with Disabilities Act: Judicial Outcomes and Unresolved Problems*, 42 INDUS. REL. 11 (2003); Steven S. Locke, *The Incredible Shrinking Protected Class: Redefining the Scope of Disability Under the Americans with Disabilities Act*, 68 U. COLO. L. REV. 107 (1997); Arlene B. Mayerson, *Restoring Regard for the "Regarded As" Prong: Giving Effect to Congressional Intent*, 42 VILL. L. REV. 587 (1997); *see also* NAT'L COUNCIL ON DISABILITY, *RIGHTING THE ADA*, at § II(b) (Dec. 1, 2004), available at www.ncd.gov/newsroom/publications/2004/righting_ada.htm.

6. *See, e.g.,* Catherine J. Lanctot, *Ad Hoc Decision Making and Per Se Prejudice: How Individualizing the Determination of "Disability" Undermines the ADA*, 42 VILL. L. REV. 327 (1997); Wendy E. Parmet, *Individual Rights and Class Discrimination: The Fallacy of an Individualized Determination of Disability*, 9 TEMP. POL. & CIV. RTS. L. REV. 283, 301 (2000).

7. *See, e.g.,* Robert L. Burgdorf, Jr., *"Substantially Limited" Protection from Disability Discrimination: The Special Treatment Model and Misconstructions of the Definition of Disability*, 42 VILL. L. REV. 409 (1997); Lisa Eichhorn, *Applying the ADA to Mitigating Measures Cases: A Choice of Statutory Evils*, 31 ARIZ. ST. L.J. 1071 (1999); Feldblum, *supra* note 5, at 162.

8. *See, e.g.,* Feldblum, *supra* note 5, at 162-63; Ann Hubbard, *Meaningful Lives and Major Life Activities*, 55 ALA. L. REV. 997 (2004); Bonnie Poitras Tucker, *The Supreme Court's Definition of Disability Under the ADA: A Return to the Dark Ages*, 52 ALA. L. REV. 321 (2000).

9. *See, e.g.,* Debra Burke & Malcom Abel, *Ameliorating Medication and ADA Protection: Use It and Lose It or Refuse It and Lose It?* 38 AM. BUS. L.J. 785 (2001); Feldblum, *supra* note 5, at

leading disability scholar Sam Bagenstos, perhaps out of frustration with the rigid pronouncements that have become judicial construction of the ADA, argues that a return to a social welfare model is necessary to provide the disabled with the opportunities, services, and access they need.¹⁰ Given the gradual whittling of the Act, disability scholars and advocates were not surprised to learn some years ago that approximately ninety-four percent of disabled plaintiffs who pursue litigation lose in initial judicial proceedings, and eighty-four percent fail on appeal; this is comparable to the failure rate of prisoner civil rights claims, which is about eighty-six percent.¹¹

Perhaps the greatest judicial threat to the Act—and the subject of this Article—has yet to enter academic discussion. This Article examines the proper role of normal species functioning with regard to disability analysis. It proposes general inquiries for disability analysis and considers the Supreme Court's application of the role of normal species functioning to each inquiry. The Court's failure to consider properly the role of normal species functioning has profoundly impacted American disability law by creating divergent outcomes in the application of established Supreme Court tests and by undermining protections for persons with disabilities. In addition, it forces reliance on conceptions of disability that may embrace stereotypes or inaccurate assessments of abilities, resulting in the isolation and unemployment of disabled workers Congress sought

162; Vicki J. Limas, *Of One Legged Marathoners and Legally Blind Pilots: Disabling the ADA on a Case-By-Case Basis*, 35 TULSA L.J. 505, 539, 544 (2000); Wendy E. Parmet, *Plain Meaning and Mitigating Measures: Judicial Interpretations of the Meaning of Disability*, 21 BERKELEY J. EMP. & LAB. L. 53, 55, 88 (2000); Rebecca Hanner White, *Deference and Disability Discrimination*, 99 MICH. L. REV. 532, 553 (2000).

10. Samuel R. Bagenstos, *The Future of Disability Law*, 114 YALE L.J. 1 (2004). Bagenstos argues that the civil rights paradigm of disability discrimination should be abandoned in favor of a return to a welfare-based model eschewed by advocates of the ADA, in order to give force to the issues facing the disabled and to account for the withering reach of the ADA. This Article seeks to propose a new framework for disability analysis that continues to embrace the text of the ADA and give effect to disability protections as a matter of civil right thereunder. While it is clear that some issues facing the disabled (and other Americans, for that matter), such as access to health care and certain types of accommodations, are best addressed by social welfare schemes that seek distributive justice rather than formal justice, Bagenstos errs by excising disability discrimination from the civil rights context.

11. Ruth Colker, *The Americans with Disabilities Act: A Windfall for Defendants*, 34 HARV. C.R.-C.L. L. REV. 99, 100 (1999). This does not account for settlements and other informal agreements. In addition, the fact that most plaintiffs lose their cases does not mean that the ADA is unsuccessful in upholding a civil right but only that the right could be more robust. The ADA serves as a statement of government that discrimination against disabled persons is a violation of civil right and functions to discourage some acts of such discrimination. I am grateful to Charles Shanor for this point.

to avoid.

This Article will reference two different models of functioning: the normal species functioning model and the alternative modes of functioning model. Briefly stated, the normal species functioning model considers deviation from functioning that is normal for our species to be disabling. The alternative modes of functioning model does not look to a particular type of functioning but assesses functional outcomes to determine whether a certain level of functioning is disabling. For example, reading with one's eyes is normal species functioning, while using one's fingers to read Braille is an alternative mode of functioning. Supreme Court jurisprudence can be understood to appeal to both of these models: Alternative functioning is considered when determining whether someone is disabled under the ADA, and normal species functioning informs reasonable accommodation under the Act. This Article urges the Court to consider directly the role of functioning and to employ these two models in the opposite fashion, adopting what this Article terms Functioning-Based Disability Analysis. Under Functioning-Based Disability Analysis, the Court should consider normal species functioning when deciding eligibility for protection under the Act and alternative modes of functioning when determining reasonable accommodation.

To help clarify the differences between the normal species functioning model and the alternative modes of functioning model consider the following hypothetical:

Hannah, an employee of a software development company, was born with partial upper arms. She is able to type using upper arm prostheses, but she finds wearing them painful and typing with them inefficient; it is also difficult to hold the telephone or items on her desk while wearing them. She prefers to use her "fleshy feet"¹² to type as well as to grasp and manipulate objects.¹³

Under a normal species functioning model, Hannah is disabled because she does not have full-length arms. She is entitled to resources and an accommodation to further normal functioning, where "normal functioning" means typing with her upper arms. Under an alternative modes of functioning model, Hannah is disabled because her functioning is impaired in her work environment and not because she is missing part of her arms. She is entitled to a remedy, and it need not support normal functioning. Thus, her employer may offer to adapt her office to enable her to type with her fleshy feet.

12. "Fleshy feet" distinguishes Hannah's feet from prosthetic feet. Ani B. Satz & Anita Silvers, *Disability and Biotechnology*, in *ENCYCLOPEDIA OF ETHICAL, LEGAL, AND POLICY ISSUES IN BIOTECHNOLOGY* 173, 185 (Thomas J. Murray & Maxwell J. Mehlman eds., 2000).

13. This example is adapted from one in Satz & Silvers, *supra* note 12, at 183.

This example of Hannah and the software company, and the role of normal species functioning in disability analysis more generally, also speaks to an overarching tension in disability law: the tension between civil rights and social welfare models. Generally speaking, a civil rights model grounds a right to equality of participation for disabled persons as a protected class.¹⁴ Under this model, others have concomitant duties to adjust, within certain parameters, places of employment, public accommodation, services, and transit, in order to decrease isolation and enable greater participation of disabled persons in society. The duties supported by this right entitle Hannah to a remedy if her rights are violated, though they do not speak to the nature of her remedy. Accommodation under a civil rights model need not support any particular manner of functioning, so long as steps are taken to promote equality in the workplace. Indeed, the ADA does not specify the manner of functioning that should be supported. In other words, the Act, a civil rights mandate, does not require employers to accommodate atypical modes of functioning, such as Hannah's fleshy feet. A social welfare model, on the other hand, is redistributive. It seeks to better the position of the disadvantaged through resource allocation.¹⁵ Under a social welfare model, Hannah may be recognized as disadvantaged by her manner of functioning and entitled to resources to facilitate typing using her feet. A social welfare model would not, though, confer rights on Hannah based upon her disability *per se*. Under a social welfare model, she is entitled to resources because she is disadvantaged in a particular population by the manner in which she functions; others who are disadvantaged—whether disabled or not—have similar entitlement. The civil rights model, by contrast, recognizes a history of discrimination against the disabled and affords disabled individuals, as members of a protected class, rights addressing such discrimination in a variety of contexts.

This Article contends that a parallel blending of the models of functioning at one level, and of the civil rights and social welfare models at a higher level, is the future of American disability law. This Article examines a discrete and integral part of this view, namely, the role of normal species functioning in disability analysis. Part I of the Article provides background to the ADA and Supreme Court jurisprudence interpreting the Act. Part II provides an introduction to two models of functioning: the normal species and alternative modes of functioning models. Philosophical development of these models is useful for understanding

14. Congress intended to protect disabled individuals as a matter of civil right in a manner similar to race, gender, religion, and national origin.

15. For an excellent discussion of providing accommodations as a matter of justice, see Michael Ashley Stein, *Same Struggle, Different Difference: ADA Accommodations as Antidiscrimination*, 153 U. PA. L. REV. 579 (2004).

the proper role of functioning in disability analysis. The normal species functioning model determines eligibility and entitlement to resources based upon deviation from normal functioning and supports accommodation that furthers normal functioning. The alternative modes of functioning model supports normal as well as alternative modes of functioning; it is discussed as a more promising means to determine the nature of accommodation. Part III discusses how the Court currently employs the normal species and alternative modes of functioning models. Part IV proposes a model for Functioning-Based Disability Analysis. A three-prong test for disability analysis is offered to facilitate proper consideration of normal species functioning. Functioning-Based Disability Analysis considers deviation from the normal species functioning baseline when determining whether someone is disabled and entitled to a remedy under the Act but considers normal as well as alternative modes of functioning in making accommodations. The Article concludes by offering some insights into the use of Functioning-Based Disability Analysis as a means to resolve the tension between the civil rights and social welfare models of disability law.

I. DISABILITY LAW IN 2005

Prior to explaining different models for contemplating functioning, it is necessary to discuss the basic provisions of the ADA and judicial construction of the Act. The ADA contains an eligibility test for disability protections. This test, known as the disability threshold test, requires that a plaintiff be a “qualified individual with a disability.”¹⁶ Under Titles II and III, a qualified individual with a disability must have a disability and be discriminated against on the basis of it.¹⁷ In addition, Title I requires that the individual be able to perform the “essential functions” of a job “with or without reasonable accommodation”; this is known as the essential functions test.¹⁸

Under each title, an individual is first assessed for disability. An individual is “disabled” if she has “a physical or mental impairment that substantially limits one or more of the major life activities . . . a record of such an impairment; or [is] being regarded as having such an impairment.”¹⁹ Determination of disability entails an “individualized inquiry,” meaning that the facts pertaining to the alleged disability in each case are analyzed under established statutory tests, and generalizations cannot be made for a given condition nor can a condition be considered a *per se* disability.²⁰ In addition, disability is assessed from a post-

16. 42 U.S.C. §§ 12111(8), 12132, 12182 (2000).

17. 42 U.S.C. §§ 12132, 12182.

18. 42 U.S.C. § 12111(8).

19. 42 U.S.C. § 12102(2) (2000).

20. *Id.*; *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 483 (1999). *But see* *U.S. Airways, Inc.*

mitigated state, that is, after ameliorative drugs or devices are employed.²¹

The definition of disability is broken into three parts by the Supreme Court. An individual must have: (1) a physical or mental impairment that (2) substantially (3) limits a major life activity. The Supreme Court has closely followed the EEOC regulations for physical or mental impairment, which require an organic defect causing a disease, disorder, condition, or other biological anomaly.²² The most contentious aspect of the physical impairment part of the threshold test is determination of the point at which the organic defect becomes an impairment. While one must typically be mildly to strongly symptomatic to be covered under the Act, the Supreme Court has recognized an individual with asymptomatic AIDS as having a physical impairment.²³ Coverage of mental impairments is generally limited; ADA protection of individuals with mental impairments that do not result from an organic defect is even more restricted.²⁴

The requirement that a disability be a “substantial” limitation of a major life activity has been interpreted in such a way that it has become a significant hurdle to recovery under the Act. The Court has followed the EEOC regulations, which state that in order to be substantially limited in a major life activity, an individual must be “unable to perform . . . [or] [s]ignificantly restricted as to the condition, manner or duration under which [she] can perform a particular major life activity

v. Barnett, 535 U.S. 391, 403 (2001) (“The statute does not require proof on a case-by-case basis that a seniority system should prevail. . . . because it would not be reasonable in the run of cases that the assignment in question trump the rules of a seniority system.”).

21. *Sutton*, 527 U.S. 471; *see also* *Albertson’s, Inc. v. Kirkingburg*, 527 U.S. 555 (1999); *Murphy v. United Parcel Serv.*, 527 U.S. 516 (1999). These mitigating measures are typically employed by the individual to facilitate daily functioning.

22. 29 C.F.R. §§ 1630.2(h)(1)-(2) (2005) (“Physical or mental impairment means: (1) Any physiological disorder, or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genito-urinary, hemic and lymphatic, skin, and endocrine; or (2) Any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.”).

23. *Bragdon v. Abbott*, 524 U.S. 624 (1998).

24. *See, e.g.*, *Carroll v. Xerox Corp.*, 294 F.3d 231 (1st Cir. 2002) (finding an individual with anxiety and workplace stress is not disabled); *Emerson v. N. States Power Co.*, 256 F.3d 506 (7th Cir. 2001) (finding an individual with anxiety attacks is unable to fulfill the essential function of handling emergency calls); *Gaul v. Lucent Techs., Inc.*, 134 F.3d 576 (3d Cir. 1998) (finding an individual with workplace stress and depression is not disabled); *Guerra v. Garratt*, 564 N.W.2d 121 (Mich. Ct. App. 1997) (finding an individual suffering from repressed memories is not disabled); *Mundo v. Sanus Health Plan*, 966 F. Supp. 171 (E.D.N.Y. 1997) (finding an individual with workplace stress is not disabled); *DeWitt v. Carsten*, 941 F. Supp. 1232 (N.D. Ga. 1996) (finding an individual with anxiety and workplace stress is not disabled).

as compared to . . . the average person in the general population.”²⁵ This determination is made by considering “[t]he nature and severity of the impairment; [t]he duration or expected duration of the impairment; and [t]he permanent or long term impact, or the expected permanent or long term impact of or resulting from the impairment.”²⁶ In four of the last five Supreme Court opinions addressing “substantially,” the Court found that the plaintiffs were not disabled.²⁷

The set of major life activities recognized by the Court is small. The EEOC issued regulations for Title I that list examples of major life activities, including “caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.”²⁸ This list encapsulates the major life activities recognized by most courts. The Supreme Court has also recognized the major life activity of reproduction,²⁹ and currently there is a circuit split over whether interacting with others is a major life activity.³⁰

Most recently, in 2002, the Court decided *Toyota Motor Manufacturing*,

25. 29 C.F.R. § 1630.2(j) (2005); *see also* *Toyota Motor Mfg., Ky. v. Williams*, 534 U.S. 184, 195-96 (2002); *Kirkingburg*, 527 U.S. at 565 (requiring a “significant restriction,” not just a “difference”).

26. 29 C.F.R. §§ 1630.2(j)(2)(i)-(iii) (2005).

27. *Compare Toyota*, 534 U.S. 184 (finding that a plaintiff is not “substantially limit[ed]” in a major life activity and is ineligible for disability protections under Title I), *Kirkingburg*, 527 U.S. 555 (same), *Murphy v. United Parcel Serv.*, 527 U.S. 516 (1999) (same), and *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999) (same), *with Bragdon*, 524 U.S. 624 (finding the plaintiff is “substantially limit[ed]” in a major life activity and eligible for disability protections under Title III).

28. 29 C.F.R. § 1630.2(i) (2005).

29. *Bragdon*, 524 U.S. at 639.

30. *Compare Soileau v. Guildford of Me., Inc.*, 105 F.3d 12 (1st Cir. 1997) (holding that interacting with others should not be a major life activity) *with* *Jacques v. DiMarzio*, 386 F.3d 192 (2d Cir. 2004) (finding that a plaintiff with bipolar disorder was not substantially limited in the major life activity of interacting with others), *and* *McAlindin v. County of San Diego*, 192 F.3d 1226 (9th Cir. 1999) (recognizing that interacting with others is a major life activity). Several other courts have declined to address directly the issue of whether interacting with others is a major life activity but have held that plaintiffs were not “substantially limited” in interacting with others. *See, e.g.*, *Rohan v. Networks Presentations*, 375 F.3d 266, 274 (4th Cir. 2004); *Heisler v. Metro Council*, 339 F.3d 622, 628 (8th Cir. 2003); *MX Group, Inc. v. City of Covington*, 293 F.3d 326, 337 (6th Cir. 2002); *Steele v. Thiokol Corp.*, 241 F.3d 1248, 1254-55 (10th Cir. 2001). For a scholarly account of this issue, see Wendy F. Hensel, *Interacting with Others: A Major Life Activity Under the Americans with Disabilities Act?*, 2002 WIS. L. REV. 1139 (2002). Disability law scholar Ann Hubbard has suggested that “belonging” should also be recognized as a major life activity. *See* Ann Hubbard, *The Major Life Activity of Belonging*, 39 WAKE FOREST L. REV. 217 (2004); *see also* Ann Hubbard, *Meaningful Lives and Major Life Activities*, 55 ALA. L. REV. 997 (2004).

Kentucky v. Williams, which held that the test for a major life activity is whether the activity is “of central importance to most people’s daily lives.”³¹ In *Toyota*, the Court applied this test narrowly and found that the manual task particular to Williams’s job, namely, “repetitive work with hands and arms extended at or above shoulder level[] for extended periods of time,” was not an activity that is of central importance to most people’s daily lives.³² The Court then turned to other activities in Williams’s life to determine that she was impaired in some household manual tasks but not those of central importance to most people in daily living.³³ In finding Williams could not establish impairment in work-related or other household manual tasks, the Court set a high hurdle for establishing a substantial impairment of a major life activity.

Even if a plaintiff is able to demonstrate that she is disabled under the ADA, a plaintiff suing under Title I must show that she is able to fulfill the “essential functions” of her job “with or without reasonable accommodation” in order to be a qualified individual with a disability.³⁴ The essential functions requirement places the plaintiff in a predicament under current Supreme Court precedent: It is difficult to prove disability in a post-mitigated state under the Act, but if one appears too disabled, one may be deemed unable to fulfill the essential functions of one’s job and ineligible for disability protections. In the last four Title I cases decided by the Court, plaintiffs were determined to be both not disabled under the Act and too impaired to meet employers’ job requirements.³⁵

Nevertheless, some plaintiffs manage to establish eligibility for protections under the Act. Under current judicial construction of the Act, if an individual is a qualified individual with a disability, she is entitled to a remedy with no further

31. *Toyota*, 534 U.S. at 197-98.

32. *Id.* at 201 (citation omitted).

33. *Id.* at 202 (“[S]he could still brush her teeth, wash her face, bathe, tend her flower garden, fix breakfast, do laundry, and pick up around the house . . . her medical conditions caused her to avoid sweeping, to quit dancing, to occasionally seek help dressing, and to reduce how often she plays with her children, gardens, and drives long distances.”).

34. The plain language allows employers much discretion in determining the essential functions of a job: “[C]onsideration shall be given to the employer’s judgment as to what functions of a job are essential, and if an employer has prepared a written description before advertising or interviewing applicants for the job, this description shall be considered evidence of the essential functions of the job.” 42 U.S.C. § 12111(8) (2000). The regulations add, in part, that a function may be essential if the position exists to perform that function, a limited number of employees can perform it, or the employee was hired to perform that function because of expertise or ability to do so. 29 C.F.R. §§ 1630.2(n)(2)(ii)-(iii) (2005).

35. *Toyota*, 534 U.S. 184; *Albertson’s, Inc. v. Kirkingburg*, 527 U.S. 555 (1999); *Murphy v. United Parcel Serv.*, 527 U.S. 516 (1999); *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999).

analysis. That remedy may include an accommodation.³⁶ For Title I, in a post-hiring context, this may include:

(A) making existing facilities used by employees readily accessible to and usable by individuals with disabilities; and (B) job restructuring, part-time or modified work schedules, reassignment to a vacant position, acquisition or modification of equipment or devices, appropriate adjustment or modifications or examinations, training materials or policies, the provision of qualified readers or interpreters, and other similar accommodations for individuals with disabilities.³⁷

For Title II, the remedy may entail access to services, including publicly operated mass transit. Title III requires access to places of “public accommodation,” encompassing a wide variety of venues from zoos to doctors’ offices as well as transportation services provided by private entities.³⁸

While the statute does not require it, the EEOC has encouraged an “interactive process” in which an employer and employee work together to determine an employee’s accommodation.³⁹ This process is adopted in some circuits.⁴⁰ Even with an interactive process, the employer, by statute, is only required to make one reasonable accommodation.⁴¹ The offered accommodation might not be what the employee prefers.⁴² An employee may reject an offered

36. Other equitable relief and civil penalties are also possible. 42 U.S.C. § 1981(a) (2000); 29 U.S.C. § 794(a) (2000).

37. 42 U.S.C. §§ 12111(9)-(10) (2000). In pre-hiring situations, an individual cannot be denied an employment opportunity because of the need for a reasonable accommodation. 42 U.S.C. § 12111(8); *see also* 29 C.F.R. § 1630.9(b) (2005).

38. 42 U.S.C. § 12181(7) (2000).

39. 29 C.F.R. §§ 1630.2(o)(3), 1630.9 (2005). Much remains unresolved about the effect of the reasonable accommodation provision. Some argue that it may be cost shifting (to the employer), cost avoidance (by the employer), or cost sharing (between the employer and employee). *See* Elizabeth A. Pendo, *Disability, Doctors and Dollars: Distinguishing the Three Faces of Reasonable Accommodation*, 35 U.C. DAVIS L. REV. 1175 (2002).

40. *See* Conneen v. MBNA Am. Bank, N.A., 334 F.3d 318, 333 (3d Cir. 2003); *Humphrey v. Mem’l Hosps. Ass’n*, 239 F.3d 1128, 1137 (9th Cir. 2001); *Lovejoy-Wilson v. NOCO Motor Fuel, Inc.*, 263 F.3d 208 (2d Cir. 2001); *Beck v. Univ. of Wis.*, 75 F.3d 1130, 1135 (7th Cir. 1996); *Garcia-Ayala v. Lederle Parenterals, Inc.*, 212 F.3d 638 (1st Cir. 1996) (stating that accommodation is required only in some cases); *Taylor v. Principal Fin. Group*, 93 F.3d 155, 165 (5th Cir. 1996).

41. 42 U.S.C. § 12111(10) (2000) (discussing “the” or “an,” meaning one, accommodation); *see also* 29 C.F.R. § 1630 app. sec. 1630.9, at 375-77 (2005) (discussing “a,” meaning one, reasonable accommodation).

42. 29 C.F.R. § 1630 app. sec. 1630.9, at 377 (“If more than one of these accommodations will enable the individual to perform the essential functions or if the individual would prefer to provide his or her own accommodation, the preference of the individual with a disability should be given

accommodation, but the employer is not required to make an alternative one, even if the employee is no longer able to fulfill the essential functions of her job.⁴³

The Act provides employers (or other entities under Titles II and III) two affirmative defenses for failing to make a reasonable accommodation: “undue hardship”⁴⁴ and “direct threat.”⁴⁵ It is unlawful to fail to make a reasonable accommodation for a disabled employee, “unless such covered entity can demonstrate that the accommodation would impose an undue hardship on the operation of the business.”⁴⁶ “Undue hardship” is defined as “significant difficulty or expense,” in light of a number of factors including cost, the resources and number of employees of the covered entity or facilities involved in the accommodation, and the impact of the accommodation upon the facilities making it.⁴⁷ This determination is subject to substantial judicial discretion, with little guidance from the EEOC; the Interpretative Guidance issued by the agency states merely that an employer should not be forced to provide an accommodation that is “unduly costly.”⁴⁸ In addition, an employer need not provide an accommodation for an employee that poses a “direct threat to the health or safety of other[s].”⁴⁹

Recovery under the ADA in 2005 is akin to a complex trifecta; plaintiffs must succeed at three levels. First, the ADA includes restrictions on disability protections, namely, the eligibility requirement of the disability threshold test, the essential functions requirement of Title I, and the undue hardship and direct threat defenses. Second, the Supreme Court has narrowly construed the language of the Act in interpreting these requirements and by requiring that a plaintiff be assessed in a post-mitigated state. This Article addresses a third limitation to recovery: improper use of a baseline of normal species functioning to determine eligibility for protection, entitlement to remedy, and the nature of remedy. We will return to this limitation in Part III. First it is necessary to examine the different models for conceptualizing functioning.

primary consideration. However, the employer providing the accommodation has the ultimate discretion to choose between effective accommodations, and may choose the less expensive accommodation or the accommodation that is easier for it to provide.”).

43. 29 C.F.R. § 1630.9(d) (2005).

44. 42 U.S.C. § 12112(b)(5)(A) (2000).

45. 42 U.S.C. § 12113(b) (2000).

46. 42 U.S.C. § 12112(b)(5)(A).

47. 42 U.S.C. § 12111(10) (2000).

48. 29 C.F.R. § 1630 app. sec. 1630.2(p), at 371 (2005).

49. 42 U.S.C. § 12113(b); *see also* *Bragdon v. Abbott*, 524 U.S. 624, 649 (1998) (holding that a direct threat is one that poses a “significant risk” to others and is based upon “medical or other objective evidence”).

II. CONCEPTUALIZING FUNCTIONING

A. *Normal Species Functioning*

Normal species functioning, or species-typical functioning, is a concept that originated in the field of biology, most notably in the work of Christopher Boorse in the 1970s.⁵⁰ It is used to describe both functioning that benefits the survival of the species, which may not be expressed by a majority of species members, and functioning that is exhibited by a majority of members of a species, regardless of whether it serves the genetic fitness of the organism.⁵¹ The latter concept of normal species functioning was used over a decade later by philosopher Norman Daniels, in *Just Health Care*⁵² and in supporting works, to address the just distribution of health care services. Normal species functioning provides a baseline for distinguishing basic from non-basic health care services. Services that are aimed at preventing deviation from or restoring, in whole or in part, normal functioning, are considered basic health care services, while services that merely support long-term disability are not. Daniels argues that distributive justice requires access to the former but not the latter range of services.

Today, normal species functioning is the dominant philosophical paradigm for the just distribution of health care services. Recent legal scholarship suggests that normal species functioning is useful in determining both level of impairment and the protections and compensation that impairments may require.⁵³

50. See, e.g., Christopher Boorse, *Health as a Theoretical Concept*, 44 PHIL. SCI. 542 (1977); Christopher Boorse, *On the Distinction Between Disease and Illness*, 1 PHIL. & PUB. AFF. 49 (1975) [hereinafter Boorse, *On the Distinction*]; Christopher Boorse, *What a Theory of Mental Health Should Be*, 6 J. THEORY SOC. BEHAV. 61 (1976); see also Christopher Boorse, *Concepts of Health*, in HEALTH CARE ETHICS: AN INTRODUCTION 359-93 (Donald VanDeVeer & Tom Regan eds., 1987).

51. See, e.g., Boorse, *On the Distinction*, *supra* note 50, at 57.

52. NORMAN DANIELS, *JUST HEALTH CARE* (1985).

53. A Lexis search on August 15, 2005, revealed thirty-seven articles invoking Daniels's philosophical theory to inform legal analysis about just compensation. See, e.g., Adrienne Ash, *Disability Equality and Prenatal Genetic Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315 (2003); Troyen A. Brennan, *An Ethical Perspective of Health Care Insurance Reform*, 19 AM. J.L. MED. & ETHICS 37, 47-55 (1993); Melissa Cole, *The Mitigation Expectation and the Sutton Court's Closing of Disabilities*, 43 HOW. L.J. 499 (2000); Laura E. Cunningham, *National Health Insurance and the Medical Deduction*, 50 TAX L. REV. 237 (1995); Einer Elhauge, *Allocating Health Care Morally*, 82 CAL. L. REV. 1449, 1468-69 (1994); John A. Flippen, *The Early and Periodic Screening, Diagnostic, and Treatment Program and Managed Medicaid Mental Health Care: The Need to Reevaluate the EPSDT in the Managed Care Era*, 50 VAND. L. REV. 683 (1997); Sharona Hoffman, *A Proposal for Federal Legislation to Address Health Insurance*

Unfortunately, much of this literature misconstrues Daniels's theory, so it is necessary to begin with a fairly detailed discussion of his framework.⁵⁴

In *Just Health Care*, Daniels presents a contractarian theory derived from John Rawls's *A Theory of Justice*, arguing for the distribution of health care resources according to a baseline of functioning considered normal for the human

Coverage for Experimental and Investigational Treatments, 78 OR. L. REV. 203 (1999); Sharon Hoffman, *Unmanaged Care: Towards Moral Fairness in Health Care Coverage*, 78 IND. L.J. 659 (2003); Jill R. Horwitz, *Why We Need the Independent Sector: The Behavior, Law, and Ethics of Not-for-Profit Hospitals*, 50 UCLA L. REV. 1345 (2003); Paul E. Kalb, *Defining an "Adequate" Package of Health Care Benefits*, 140 U. PA. L. REV. 1987 (1992); Russell Korobkin, *Determining Health Care Rights from Behind a Veil of Ignorance*, 1998 U. ILL. L. REV. 801 (1998); Mark E. Meaney, *A Deliberative Model of Corporate Medical Management*, 28 J.L. MED. & ETHICS 125 (2000); Maxwell J. Mehlman, *How Will We Regulate Genetic Enhancement?*, 34 WAKE FOREST L. REV. 671 (1999); Maxwell J. Mehlman, *The Law of Above Averages: Leveling the New Genetic Enhancement Playing Field*, 85 IOWA L. REV. 517 (2000); E. Haavi Morreim, *Quality of Life: Erosions and Opportunities Under Managed Care*, 28 J.L. MED. & ETHICS 144 (2000); E. Haavi Morreim, *Playing Doctor: Corporate Medical Practice and Medical Malpractice*, 32 U. MICH. J.L. REFORM 939 (1999); David Orentlicher, *Destructuring Disability: Rationing of Health Care and Unfair Discrimination Against the Sick*, 31 HARV. C.R.-C.L. L. REV. 49 (1996); Pendo, *supra* note 39; Katherine T. Pratt, *Inconceivable? Deducting the Costs of Fertility Treatment*, 89 CORNELL L. REV. 1121 (2004); Eric Rakowski, *Who Should Pay for Bad Genes?*, 90 CAL. L. REV. 1345, 1354-56 (2002); Ted Schrecker, *Private Health Care for Canada: North of the Border, an Idea Whose Time Shouldn't Come?*, 26 J.L. MED. & ETHICS 138 (1998); Michael H. Shapiro, *Does Technological Enhancement of Human Traits Threaten Human Equality and Democracy?*, 39 SAN DIEGO L. REV. 769 (2002); Michael H. Shapiro, *The Impact of Genetic Enhancement on Equality*, 34 WAKE FOREST L. REV. 561 (1999); Michael H. Shapiro, *The Technology of Perfection: Performance Enhancement and the Control of Attributes*, 65 S. CAL. L. REV. 11 (1991); Rory Weiner, *Universal Health Insurance Under State Equal Protection Law*, 23 W. NEW ENG. L. REV. 327 (2002).

54. See, e.g., Brennan, *supra* note 53, at 47 (discussing health care as a "Rawlsian primary social good" when Daniels specifically rejects this idea and presents only a conditional extension of Rawls's fair equality of opportunity principle, see DANIELS, *supra* note 52, at 43-48); Elhauge, *supra* note 53, at 1468-69 (misunderstanding the connection between normal species functioning and the normal opportunity range by suggesting pain that does not prevent one from achieving life goals would fail to be considered a deviation from normal functioning); Pratt, *supra* note 53, at 1162 (referring to Daniels's theory as one of "explicit rationing" when it instead embraces one of allocation of resources over a lifetime); Rakowski, *supra* note 53, at 1354-55 (failing to understand Daniels's treatment versus enhancement distinction); Weiner, *supra* note 53, at 337, 345-46 (misunderstanding the "normal opportunity range" as "the range of life plans otherwise open to a person but for his unmet health care needs" when it speaks well beyond health needs, that Daniels's theory recognizes impairment to normal species functioning may limit more than health, and that Daniels's account of the elderly adjusts for natural changes in the normal opportunity range).

species.⁵⁵ Under Daniels's theory, resources are distributed to support normal species functioning.⁵⁶ Most succinctly stated, normal species functioning is *the level of functioning typically associated with "membership [in] a natural species," where non-species-typical functioning is the result of biological defect.*⁵⁷ Daniels interprets normal functioning as functioning without disease, though his theory could apply to biological impairments that are not diseases but affect normal species functioning.⁵⁸

Daniels argues that normal species functioning requires the provision of health care services that support a normal opportunity range.⁵⁹ The normal opportunity range allows individuals to pursue reasonable life plans and goals relative to individual "skills and talents."⁶⁰ Thus, one must have a disease (or biological defect) that impacts this range in order to be entitled to health care services. The range includes health care services that contribute to basic health

55. DANIELS, *supra* note 52, at 26-58. More specifically, Daniels extends a weak, conditional version of the second part of Rawls's second principle of justice, the fair equality of opportunity principle, to health care aimed at supporting normal species functioning. Rawls's principle, which states that "social and economic inequalities are to be arranged so that they are . . . attached to offices and positions open to all under conditions of fair equality of opportunity," is applied to health care by Daniels on the basis that health care is a special good that directly affects opportunity. JOHN RAWLS, *A THEORY OF JUSTICE* 72 (1971). Daniels's theory is an extension of fair equality of opportunity because, like Rawls's theory, it supports more than a formal, or negative notion of equality of opportunity. Fair equality of opportunity under Rawls and Daniels seeks to correct for detrimental influences rather than just remove barriers to equality of opportunity. This Article assumes that a sound principle of justice includes fair equality of opportunity and that Daniels presents an acceptable extension of fair equality of opportunity without presupposing acceptance of *A Theory of Justice*.

56. DANIELS, *supra* note 52, at 26-28.

57. *Id.* (citation omitted) ("The basic idea is that health is the absence of disease, and diseases . . . include deformities and disabilities that result from trauma . . ."). Of course our conception of what is "normal" is, to some extent, the product of our evolutionary history and social environment. This does not affect the value of the baseline but rather cautions one generally against overstating the connection between disease and disability. See PHILIP KITCHER, *THE LIVES TO COME* 213 (1996). Our evolutionary history entails development of culture and the capacity for reflective choice, and this weakens the relationship between natural selection and what humans view as valuable. That is, our evolutionary history demonstrates that there are social elements to preferred modes of functioning. Focusing on normal species functioning, then, may entrench subjective views about functioning without considering the benefits that other modes of functioning may offer. See *id.*

58. DANIELS, *supra* note 52, at 28.

59. *Id.* at 32-35.

60. *Id.*

care needs.⁶¹

According to Daniels, to support the normal opportunity range the basic tier of health care required by the biomedical model (and concomitantly distributive justice) is that which is necessary to support normal species functioning. He considers the impact of different types of health care institutions upon normal functioning in order to inform his conception of basic health care. Candidate levels of institutions are those that:

- (1) *Prevent disease*; maintain the health of those who are functionally normal through preventative care,
- (2) *Cure disease*; restore the health of those who are ill to normal functioning by providing “medical and rehabilitative services,”
- (3) *Compensate for disease*; maintain those with mild chronic ailments, disability, or age-related health needs by bringing them closer to normal functioning with “social support” and “extended medical services,” and
- (4) *Support disease*; provide “health care and related social services” for the severely disabled or seriously chronically ill individuals who cannot be brought closer to normal functioning by providing palliative or other care.⁶²

Daniels argues that normal species functioning requires the provision of health care services to prevent illness, restore health, or compensate for loss of health. As a result, distributive justice requires the services of the first three levels of health care institutions listed above. Supporting disease (that is, providing health care or social services for the severely disabled or chronically ill) is not aimed at preserving opportunity for functional normality and may exceed the bounds of justice.⁶³

Daniels’s model is a medical model, as it focuses upon the presence or absence of disease (or biological defect) to determine entitlement to resources. Normal species functioning, based upon the absence of disease, is used as the

61. *Id.* at 19-45. While Daniels assumes a strict biomedical model of health care needs (that is, disease alone is believed to impede the normal opportunity range) he utilizes a broad conception of personal medical services and other social services that operate to support this model of distributive justice. *Id.* at 28-32. Daniels identifies the broad range of services that meet these needs as: “(1) [a]dequate nutrition, shelter, (2) [s]anitary, safe, unpolluted living and working conditions, (3) [e]xercise, rest, and some other features of life-style, (4) [p]reventative, curative, and rehabilitative personal medical services, [and] (5) [n]on-medical personal and social support services.” *Id.* at 32.

62. *Id.* at 48.

63. *Id.* at 48. It seems, however, that services provided by fourth-tier institutions would preserve some aspects of normal opportunity. Health care for a severely mentally disabled person may afford her the opportunity to enjoy music, touch, friendship, or love. Even palliative care may allow a dying person the opportunity to prepare psychologically for death.

natural and relevant baseline for functioning in this context. An individual is entitled to resources to prevent movement from, or back towards, this manner of functioning. Daniels limits entitlement where resources would only support, rather than improve, disease. While the environment may cause deviation from normal functioning, Daniels's model, as a medical model, is concerned with ameliorating or preventing biological defects of individuals to promote normal opportunity rather than altering the environment, so long as pollution is controlled and other basic needs, such as sanitation, are accounted for.⁶⁴

In addition, Daniels gives preference to prevention over restoration and restoration over compensation in order to restore normal species functioning: "It is preferable to prevent than to have to cure, and to cure than to have to compensate for loss of functioning."⁶⁵ By "compensation," Daniels means services to manage disease and possibly disability. For example, cochlear implants might be made available to a deaf child in order to restore hearing instead of a voucher for a school for the deaf that teaches American Sign Language as a social support to compensate for loss of hearing.⁶⁶

The example of the deaf child illustrates why Daniels's normal species functioning model, though focused upon health care, is relevant to disability analysis. First, under Daniels's framework, a deaf child has an impaired health state, or is disabled, due to her hearing deficit, which is the product of disease or biological defect. This impairment prevents her from operating in a manner typical for our species. Second, the child is entitled to resources to bring her as close as possible to normal functioning. Third, applying Daniels's model to the nature of the entitlement, any remedy or accommodation will prioritize the restoration of normal species functioning over accommodation that supports

64. *Id.* at 32.

65. *Id.* at 48. It is important to note that Daniels does not give *moral priority* to one level of health care institutions over another, since the first three levels together support equality of opportunity. Nevertheless, an inherent preference for restoration over compensation underscores the inability of his model to consider alternative modes of functioning to support equality of opportunity.

66. Cochlear implants are the subject of much controversy in the medical ethics literature, as there is evidence to suggest that the implants are not very effective, and, as a result, a deaf child who undergoes the procedure may be unable to enter the hearing world in a meaningful way. See, e.g., National Association of the Deaf, Cochlear Implants: NAD Position Statement (Oct. 6, 2000), available at <http://www.nad.org/site/pp.asp?c=foINKQMBF&b=138140>; see also Satz & Silvers, *supra* note 12, at 173. Children with the implants may feel trapped between the hearing world and the deaf community. *Id.* What is clear is that, without the implant, the child will be a member of the deaf community, which is itself rich in history, culture, and tradition. Nevertheless, in Daniels's terms, Sign language is not morally equivalent to a cochlear implant. See Dena Davis, *Genetic Dilemmas and the Child's Right to an Open Future*, 27 HASTINGS CTR. REP. 7, 12 (1997).

alternative modes of functioning. The deaf child is entitled to health care services, such as a cochlear implant, to bring her as close as possible to hearing. Alternative modes of functioning, such as American Sign Language, would not be considered, as they would fail to restore her to a manner of functioning that is normal for our species.

In sum, under the normal species functioning model, if an individual does not function in a manner that is normal for our species due to biological disease (or defect), she is disabled.⁶⁷ In addition, the normal species functioning baseline only supports remedies that facilitate functioning that is normal for our species; alternative, effective modes of functioning are not considered. The model seeks to eliminate or ameliorate disease or defect by altering the disabled person rather than the environment. In other words, disability is understood to be of biological rather than social ontology.

Under the normal species functioning model, only an individual who has a disease that impairs normal functioning is presumed to be entitled to resources to restore normal functioning. The prevention or elimination of impairment of normal species functioning is valued over compensation and support for disability by means of various accommodations or mitigating measures that may facilitate alternative modes of functioning. Laws embracing the normal species functioning model recognize an individual that deviates from normal functioning as disabled and direct resources toward preventing deviation from, maintaining, and restoring normal species functioning, instead of accommodating alternative forms of functioning that may not be normal for the species.

Thus, being able to answer the questions of when and how normal functioning matters to disability analysis is vital to understanding whether someone is disabled and what legal protections are owed. Before progressing further, however, it is necessary to consider what the normal species functioning model does not take into account. Again, philosophical works are of assistance. It has long been recognized by philosophers who write about disability that the normal species functioning model does not contemplate effective, alternative modes of functioning.⁶⁸ Normal species functioning is concerned only with manner or mode of functioning and does not look to functional outcomes. For

67. The implications of considering an individual disabled who functions effectively in an atypical manner will be addressed in Subsection IV.B.1. An individual may also function atypically but in a manner that is *more* effective than normal functioning. For example, if Einstein's brain functioned atypically, he would not be disabled because his normal functioning range would fail to be impaired.

68. See, e.g., Anita Silvers, *Formal Justice*, in *DISABILITY, DIFFERENCE, DISCRIMINATION* 13-145 (Anita Silvers et al. eds., 1998); Ron Amundson, *Biological Normality and the ADA*, in *AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS* 102-10 (Leslie Pickering Francis & Anita Silvers eds., 2000).

example, a normal species functioning approach would view walking to the street corner as a desired manner of functioning but not wheeling to the corner, even though both may bring about the same outcome.

B. *Alternative Modes of Functioning*

In *Harrison Bergeron*, Kurt Vonnegut provides an extreme view of social equality, where citizens' talents and attributes are equalized to the lowest common denominator.⁶⁹ As dictated by the Handicapper General, the attractive must wear sacks over their heads, the slender weights on their bodies, and the intelligent thought-scrambling devices.⁷⁰ Disabilities are socially constructed in order to equalize abilities across a given population. Obviously, disability anti-discrimination laws do not seek to equalize abilities but to make the opportunities of those with impaired functioning more equal to those without disabilities. Nevertheless, Vonnegut poignantly raises the question of whether promoting equality requires changing the individual or society.

Unlike proponents of the normal species functioning model, advocates for alternative modes of functioning believe that it is not the individual functioning atypically who should be changed; rather, society should adapt to that individual's method of atypical functioning. This is an expression of a social model of disability. Such models generally stand for the proposition that disability is the result of a hostile social environment rather than impairment of normal biology. There is a spectrum of social disability, of course. It is useful here to invoke a concept I develop elsewhere between *categorical* and *relative* disability.⁷¹ A disability is *categorical* if no reasonable adjustment in one's social environment—such as installing elevators and ramps, providing traffic crossings with audible signals, making reading materials available in Braille, or lowering door handles—further enables functionality.⁷² A disability is *relative*, or not categorical, if social adjustment enables functionality.⁷³ The greater the degree of social construction of a disability, the less categorical a disability becomes. Stated another way, the ability to function depends upon how hostile or accommodating the environment is to someone with a particular disability.

Social models of disability, regardless of where the disabilities they encompass fall on the spectrum, are based upon two premises: a right to participation in certain social endeavors (such as education, work, and travel) and

69. KURT VONNEGUT, *Harrison Bergeron*, in WELCOME TO THE MONKEY HOUSE 7 (1968).

70. *Id.*

71. Ani B. Satz, Testing Access: Toward a Theory of Entitlement to Genetic Testing 286-93 (June 30, 2001) (unpublished Ph.D. dissertation, Monash University) (on file with author).

72. *Id.* at 286.

73. *Id.* at 286-87.

a right to particular outcomes from functioning (as distinguished from modes of functioning) within certain environments.⁷⁴ Both the medical model embraced by the normal species functioning baseline and the alternative modes of functioning supported by the social model (hereinafter the alternative modes of functioning model) may promote a right to participation; this is, in fact, the purpose of Daniels's normal opportunity range. The latter premise is what distinguishes the alternative modes of functioning model from the normal species functioning model.⁷⁵ As Anita Silvers and Ron Amundson argue, the alternative modes of functioning model opposes promoting one type of functioning over others, or what they term "functional determinism."⁷⁶ The alternative modes of functioning model looks to results.

It is necessary to separate the question about whether the alternative modes of functioning model should be used to determine whether someone is disabled from the question about whether she is entitled to a remedy, and, if so, what the nature of that remedy should be. Under the alternative modes of functioning model, an individual is disabled if she is unable to function to a particular degree due to a certain social environment. She may be entitled to a remedy depending upon available external resources and her own ability to mitigate her socially constructed disability. Those who are disabled by a particular environment may be entitled to accommodation that results in changes to that environment: structures, work schedules, etc. These accommodations may support manners of functioning that are effective, though not normal for our species.

Since mitigation and resources play a role under the normal species functioning model as well, the key differences between the two models lie with determining whether an individual is disabled and the nature of accommodation. The conception of disability under the alternative modes of functioning model is controversial, since it may greatly expand the protected class. For this reason, many reject the notion that a disability can be entirely socially created; they argue that a disability must have a biological component. Elucidation of the categorical and relative spectrum is useful here. To use an oft-cited example attributed to Silvers, placing a food dish for a Dachshund on the kitchen counter and a food dish for a Great Dane on the kitchen floor would impair their ability to eat; the Dachshund may in fact starve.⁷⁷ Adjusting the dogs' environment by

74. For an excellent discussion of the distinction between the social and medical models see Silvers, *supra* note 68, at 59-85, 94-95. See also Amundson, *supra* note 68, at 102-06.

75. One could be concerned with functional outcomes but embrace a biological approach. This would, however, collapse into the normal species functioning model. I am discussing the alternative modes of functioning model of disability as an outcome-based approach that supports functioning other than species-typical functioning.

76. Amundson, *supra* note 68, at 102-10; Silvers, *supra* note 68, at 13-145.

77. Silvers, *supra* note 68, at 127.

switching the food bowls would enable both to eat with ease. This is an example of an entirely socially created disability, or a relative disability. Similarly, parents of children of short stature have argued that their children should have access to Human Growth Hormone because, in some parts of western society, short stature is disabling.⁷⁸

On the other end of the spectrum are diseases or other biological conditions that result in an extremely low level of basic functioning and are categorically disabling, as no amount of social accommodation would facilitate less impairment to functioning. Some cases include the genetic diseases Lesch-Nyan syndrome, Tay-Sachs disease, and Duchenne muscular dystrophy, where one or more major life functions are seriously affected at birth or during early childhood.⁷⁹

Impairments that fall in the middle of the spectrum are more difficult to assess for the social construction of disability. Here internal assessments about one's ability to function weigh heavily in determining whether a disability is socially constructed. Some individuals with carpal tunnel syndrome, for example, may believe that with requisite social supports they are able to function fully in society. Others with the same condition, with or without the social supports, may view themselves as disabled, though perhaps less so than someone with Tay-Sachs disease or another systemically degenerative disease. In some cases, disabling conditions are considered enriching or beneficial, based upon social structure, and are desired.⁸⁰

If conditions and diseases in the middle of the spectrum contain a biological element, the alternative modes of functioning model could be recast as one that measures deviation from normal functioning just as easily as one that measures socially induced impairment. Arguably for cases that do not involve complete social impairment, the alternative modes of functioning model does not add much in terms of contemplating who is disabled. At most it serves as a reminder that not every disease that impairs normal species functioning should be considered categorically disabling or eradicated: What is relevant is the degree of impairment of functioning, and this may depend, in part, upon environment.

78. These individuals may be inspired by studies correlating height to adult income. *See, e.g.,* Haakon E. Meyer & Randi Selmer, *Income, Education Level and Body Height*, 26 ANNALS HUM. BIOLOGY 219-27 (1999).

79. This assumes, of course, that no treatments for these conditions are developed.

80. Consider the arguments of some deaf individuals that being deaf enables one to participate in the rich culture and traditions of the deaf community. *See supra* note 66 and accompanying text. Similarly, being born with achondroplasia (dwarfism) may be advantageous in terms of child birthing and rearing as well as parent-child bonding when the parents are also achondroplastic dwarfs.

In the accommodation context, a person is already determined to be disabled and entitled to a remedy, and the sole question is what mode of functioning should be supported to attain a given outcome. The normal species model supports only normal functioning. The alternative modes of functioning model eschews this functional determinism by considering accommodation that supports various methods of functioning to reach an outcome. A warehouse worker with a back problem, for example, may lift heavy objects with a mechanical device instead of wearing a back brace. The environment is adapted to the person instead of adapting the person to the environment. It is in this context that the alternative modes of functioning model holds much promise. We will return to this matter in Section IV.B.

C. Manner of Functioning Versus Functional Outcomes

Often the normal species and alternative modes of functioning models are confused. As Silvers and others correctly argue, using normal species functioning as a baseline may confuse three different categories of actions, each of which has varying implications for how one views disability: “standardizing biological states,” promoting familiar modes of functioning, and striving for particular outcomes.⁸¹ Standardizing biological states involves accommodations that allow individuals to function in biologically similar ways to other individuals. In other words, the mode of functioning is emphasized over the result of functioning. An individual might undergo particular surgery or drug treatment to enable her body to function in a similar way to most individuals’ bodies, such as separating webbed fingers or toes so that each digit functions independently.⁸²

Promoting familiar or normal modes of functioning entails accommodations that allow individuals to execute functions in ways that are most familiar, while not necessarily involving biological standardization. Encouraging, though not requiring, Hannah the computer programmer to use upper arm prostheses rather than her fleshy feet to type is an example. Obviously there may be overlap between the first two categories that Silvers presents, if biological standardization is involved in promoting familiar modes of functioning. If, for example, after learning that Hannah is more efficient and physically comfortable typing with her feet, the employer only allows office modifications to support typing with her artificial limbs, the accommodation moves toward biological standardization.

The important difference, though, is between Silvers’s first two categories and her third. The first two emphasize a manner or mode of functioning, the third

81. See Satz & Silvers, *supra* note 12, at 183.

82. I am grateful to Anita Silvers for this example.

functional outcomes. Silvers rightly argues that normal species functioning looks to manner or mode of functioning rather than functional outcomes. An alternative modes of functioning approach does not require any particular mode of functioning, only a certain functional result.

Instruments commonly used in other contexts to measure loss of functioning confuse functional outcomes with manner of functioning.⁸³ Consider one health status index, which measures “physical activity” and “mobility.”⁸⁴ According to the index, a person who walks without assistance is given four points for physical activity and five points for mobility for being able to use public transportation without special accommodation.⁸⁵ An individual employing a tool of assist to walk is given three and four points, respectively (assuming assistance is needed to board transportation).⁸⁶ A person using a wheelchair scores two points for physical activity.⁸⁷ Her mobility ranking is three points if she needs assistance leaving her home and boarding public transit, and the sidewalks outside of her house are not wheelchair accessible.⁸⁸ She could score as high as five points if modifications are made to her home, outside environment, and public transport.⁸⁹

The index assumes that one is less able to travel using a wheelchair than walking upright (two versus four points on the physical activity scale). However, those who wheel may travel just as effectively, if not more so, than those who walk. The mobility scale defines disability relative to social states that do not foster alternative modes of functioning, such as public mechanisms of transportation missing equipment for wheelchair use and sidewalks that step

83. These include Activities of Daily Living scales, which are found most notably in the *American Medical Association Guides to the Evaluation of Permanent Impairment (AMA Guides)* and some health status indexes. The purpose of these scales is to provide physicians with guides for measuring impairment. While they are not intended for use in estimating damages, the *AMA Guides* are used in over forty state workers compensation programs for this purpose. Gené Stephens Connolly, *Hidden Illness, Chronic Pain: The Problems of Treatment and Recognition of Fibromyalgia in the Medical Community*, 5 DEPAUL J. HEALTH CARE L. 111, 115 (2002). These guides are also widely criticized for embedded stereotypes about relevant tasks. Ellen Smith Pryor argues that the examples in the *AMA Guides* are blatantly stereotypical, focusing on mopping, shopping, cooking, and child rearing for women and sports for men. Ellen Smith Pryor, *Flawed Promises: A Critical Evaluation of The American Medical Association's GUIDES TO THE EVALUATION OF PERMANENT IMPAIRMENT*, 103 HARV. L. REV. 964, 967-75 (1990) (book review).

84. See DAN W. BROCK, *LIFE AND DEATH* 303 (1993); see also Amundson, *supra* note 68, at 107 (discussing this particular index as ignoring level of functioning).

85. See sources cited *supra* note 84.

86. See sources cited *supra* note 84.

87. See sources cited *supra* note 84.

88. See sources cited *supra* note 84.

89. See sources cited *supra* note 84.

down to the street instead of slope. Simply adding curb cuts and ramps to buses and trains would change an individual's mobility ranking, for then those who wheel and those who walk would score the same (five) points.

Confusing functional outcomes with manner of functioning undervalues effective, alternative modes of functioning that attain the same functional result as normal modes of functioning. As a result, accommodation may be diverted to standardizing biological states or promoting familiar modes of functioning as opposed to enabling functional outcomes. Careful attention must be paid to the purpose of disability inquiries in order to determine whether it is the manner (normal species functioning model) or the outcome of functioning (alternative modes of functioning model) that is at stake. The Supreme Court has failed to examine disability inquiries with full appreciation of this distinction and its consequences.

III. FUNCTIONING AND SUPREME COURT JURISPRUDENCE

It is uncontroversial that judicial construction of the ADA limits disability protections. Nevertheless, established Supreme Court tests are not what severely restrict coverage under the Act. The Court's undirected and improper use of normal functioning to inform disability analysis is what prevents most protection, both at the disability threshold stage (which the Court currently interprets as including eligibility for remedy) and with regard to accommodation.⁹⁰

When normal functioning informs disability analysis, an individual is not disabled or entitled to a remedy if she functions in a manner or mode that is normal for our species. An individual may be disabled and entitled to a remedy if she functions in a non-species-typical way. For example, a secretary who is less efficient than other workers because she takes breaks throughout the day to monitor her blood sugar and give herself insulin for diabetes may be disabled and eligible for relief. A secretary who takes the same number of breaks and maintains an identical work schedule due to a preference for a more relaxed work day would not be considered disabled and entitled to a remedy. If normal functioning fails to inform disability analysis, the manner or mode of functioning no longer matters, and the Court looks to functional outcomes. If the secretary with diabetes functions effectively with a self-adjusted schedule by working longer hours, she may not be considered disabled or entitled to a remedy. Thus, looking to functional outcomes rather than normal species functioning, the two

90. Recall that in the last five Supreme Court opinions addressing "substantially" as part of the "substantial impairment of a major life activity" test, four plaintiffs were found not to be disabled. See *supra* note 27 and accompanying text. In addition, "major life activity" has been narrowly construed. See *supra* notes 28-33 and accompanying text.

secretaries might be treated the same.

Under the plain language of the ADA, if an individual is found to be disabled under the Act, she may be entitled to accommodation; the nature of accommodation also varies depending upon whether normal species functioning is considered relevant. If normal species functioning informs accommodation, only species-typical modes of functioning will be supported. Alternative modes of functioning are supported by analysis that looks to functional outcomes.

In the disability threshold context, the Supreme Court has in all but one case failed to invoke normal species functioning in determining whether an individual is entitled to protection under the ADA. In other words, normal species functioning is not considered when determining whether an individual has a substantial impairment of a major life activity. When the Court fails to consider normal species functioning, an individual who functions effectively in a non-species-typical manner is not disabled. When the Court considers normal species functioning, an individual who functions atypically is disabled.

In *Bragdon v. Abbott*, a Title III public accommodation case, the Court held that reproduction is a major life activity, finding that an HIV infected woman could not reproduce in a normal fashion.⁹¹ In an opinion authored by Justice Kennedy in which Justices Stevens, Souter, Ginsberg, and Breyer joined, the Court found that Abbott could not reproduce normally because she posed about a twenty percent risk of infecting her partner, and there was an eight percent risk of perinatal transmission.⁹² In reaching its decision, the Court relied, in part, on an agency opinion authored by the Office of Legal Counsel of the DOJ, stating, “HIV-infected individuals cannot, whether they are male or female, engage in the act of procreation with the normal expectation of bringing forth a healthy child.”⁹³ Chief Justice Rehnquist (joined by Justices Scalia, Thomas, and O’Connor, in part), dissented on the ground that Abbott did not establish that she was substantially limited in a major life activity, and that opinion refers to major life activities as those that “are repetitively performed and essential in the day-to-day existence of a normally functioning individual.”⁹⁴ Thus, both the majority and the dissent appeal to normal functioning to determine elements of the definition of disability.

91. 524 U.S. 624, 641 (1998). The majority opinion also engages in a lengthy discussion of HIV, or presymptomatic AIDS, to determine that it is Abbott’s low CD4/CD8 counts that result in biological impairment. *Id.* at 633-38. Variation from species normality typically plays a role in the Court’s determination of the “physical or mental impairment” component of the disability threshold test. See *infra* Subsection IV.B.1.

92. *Bragdon*, 524 U.S. at 639-40.

93. *Id.* at 642-43 (citations omitted).

94. *Id.* at 660.

One year later, in a trilogy of cases decided by the Court, normal functioning is deemed irrelevant to determining eligibility under the disability threshold test. Compare *Bragdon* with *Albertson's, Inc. v. Kirkingburg*, a case involving a truck driver with monocular vision suing under Title I for employment termination. Justice Souter, joined by Justices Kennedy and Ginsburg and the dissenters in *Bragdon*, found that deviation from normal functioning did not indicate disability; Kirkingburg was not disabled, despite monocular vision. The Court specifically rejected the Ninth Circuit's appeal to normal species functioning:

The Ninth Circuit concluded that 'the manner in which [Kirkingburg] sees differs significantly from the manner in which most people see' because, 'to put it in its simplest terms [he] sees using only one eye; most people see using two.' The Ninth Circuit majority also relied on a recent Eighth Circuit decision, whose holding it characterized in similar terms: 'It was enough to warrant a finding of disability . . . that the plaintiff could see out of only one eye: the *manner* in which he performed the major life activity of seeing was different.' . . . But in several respects the Ninth Circuit was too quick to find a disability By transforming 'significant restriction' into 'difference,' the court undercut the fundamental statutory requirement that only impairments causing 'substantial limitations' in individuals' ability to perform major life activities constitute disabilities.⁹⁵

The effect of attributing different roles to normal species functioning in disability threshold analysis is illustrated by these two cases. In *Bragdon*, the Court is concerned with normal functioning because Abbott could not reproduce in a manner that is normal for our species; she was therefore limited in the major life activity of reproduction. The Court did not, for example, consider means of assisted reproduction available to Abbott, such as artificial insemination (with drug treatment), to lessen substantially the risk of perinatal HIV transmission and to avoid the risk to her partner altogether. Nevertheless, in *Kirkingburg*, the Court found that the plaintiff was not disabled, even though he failed to see in a manner that is typical for our species.⁹⁶ Here, it is not the manner of functioning that matters, but functional outcome, that is, whether Kirkingburg was substantially limited in functioning despite his impairment. The Court, citing *Sutton v. United Air Lines, Inc.*⁹⁷ another case in the trilogy, found that Kirkingburg's abilities must be assessed after mitigating measures for his monocular vision.⁹⁸ The Court then reasoned that since Kirkingburg's brain compensated for the vision defect, he was functional in a non-species-typical

95. *Albertson's, Inc. v. Kirkingburg*, 527 U.S. 555, 563-65 (1999).

96. *Id.* at 563-67.

97. 527 U.S. 471 (1999).

98. *Kirkingburg*, 527 U.S. at 565-66.

manner.⁹⁹

The Court's position in *Kirkingburg* on functional outcomes is mirrored in the other two cases forming the Court's 1999 trilogy, with support from the same justices: *Sutton*,¹⁰⁰ involving twin sister pilots with severe myopia who used special eye glasses to see, and *Murphy v. United Parcel Service*,¹⁰¹ pertaining to a mechanic who took drugs to manage severe hypertension. The language about functional outcomes is also followed in *Toyota Motor Manufacturing, Kentucky v. Williams*, where Justice O'Connor wrote for a unanimous court, holding that a woman with severe carpal tunnel syndrome who was able to perform certain manual household tasks was not disabled.¹⁰²

These cases illustrate the effect of considering normal species functioning in disability analysis. In *Bragdon*, deviation from normal reproductive functioning grounds the Court's finding that Abbott was impaired in the major life activity of reproduction and entitled to disability protections. Failing to invoke this baseline in *Kirkingburg*, *Sutton*, *Murphy*, and *Toyota* limits protections for persons with disabilities. In each of these cases, the plaintiff does not function in a manner that is normal for the species but mitigates or compensates for impairment, personally or with medical aids, and is found to be lacking a substantial impairment of a major life activity. Similar outcomes are found in Supreme Court jurisprudence under the precursor to the ADA, the Rehabilitation Act,¹⁰³ and in lower court ADA jurisprudence.¹⁰⁴

To draw out the second component to the problem, it is necessary to return to the hypothetical in the introduction about Hannah the computer programmer. Recall that Hannah would like office modifications to allow her to type with her fleshy feet. Suppose her employer fears that this would make other employees

99. *Id.*

100. *Sutton*, 527 U.S. 471.

101. 527 U.S. at 519-21 (1999) (affirming the lower court's holding that "petitioner's hypertension is not a disability because his doctor had testified that when petitioner is medicated, he 'functions normally doing everyday activity that an everyday person does'").

102. 534 U.S. 184 (2002).

103. *See, e.g., Se. Cmty. Coll. v. Davis*, 442 U.S. 397, 409-10, 413 n.12 (1979) (holding that a nursing college under section 504 of the Rehabilitation Act was not required to accommodate a student with a serious hearing impairment who could participate in the normal clinical training program by using an assistant).

104. *Compare* *Rooney v. Koch Air, LLC*, 410 F.3d 376 (7th Cir. 2005), *Wong v. Regents of Univ. of Cal.*, 410 F.3d 1052 (9th Cir. 2005), *Genthe v. Quebecor World Lincoln*, 383 F.3d 713 (8th Cir. 2004), *and* *Calef v. Gillette Co.*, 322 F.3d 75 (1st Cir. 2003), *with* *Rohan v. Networks Presentations, LLC*, 375 F.3d 266 (4th Cir. 2004), *Rosbach v. Miami*, 371 F.3d 1354 (11th Cir. 2004), *Giordano v. New York*, 274 F.3d 740 (2d Cir. 2001), *and* *Talk v. Delta Airlines, Inc.*, 165 F.3d 1021 (5th Cir. 1999).

and clients uncomfortable and prefers to alter her office to enable Hannah to use her upper arm prostheses. Remember that under current agency and judicial construction of the Act, regardless of whether the employer is willing to engage the employee in an interactive process, the employer retains the right to determine the nature of the accommodation, so long as it is reasonable.¹⁰⁵ Arguably, office adjustments to accommodate upper arm prostheses would be reasonable, even if the employee would not be quite as happy or efficient in the workplace as a result.

Thus, under current construction of the ADA, an employer may determine the manner in which an employee functions in the workplace. While it is largely an empirical matter whether employers, over the years, will choose to support normal or alternative modes of functioning, the EEOC's recommended process is not required by the Court. Given the history of oppression of individuals who function in atypical ways and recent, though sparse, relevant jurisprudence about accommodation, there is a valid concern that employers will choose to make reasonable accommodations that further only species-typical functioning.¹⁰⁶

Generally speaking, the Court has very narrowly construed the reasonable accommodation mandate of Title I.¹⁰⁷ In *US Airways, Inc. v. Barnett*,¹⁰⁸ the Court held that a mail room job provided as a reasonable accommodation to a disabled employee could be offered to a nondisabled employee under the company's seniority system, even if no other accommodation was available to the disabled employee. Due to the seniority system, the position was not "vacant" for accommodation purposes.¹⁰⁹ While the holding in this case may be limited to collectively bargained seniority systems, the Court's narrow construction of the reasonable accommodation mandate does not inspire hope that accommodations supporting non-species-typical modes of functioning will be provided to

105. *See supra* Part I.

106. This may result from ignorance of non-species typical alternatives or from a desire to "normalize" disabled employees. The accommodation provision is concerned with outcomes, that is, employing disabled individuals who are able to fulfill the essential functions of their job regardless of how they do so, for example, by constructing buildings that allow disabled individuals access whether they walk, wheel, scoot, etc.

107. To date, the Supreme Court has so narrowly construed the disability threshold test that few cases have made it through to reasonable accommodation analysis. Further, since the Court groups the inquiry of whether someone is disabled with whether they are entitled to a remedy, analysis surrounding whether accommodations should be made, and if so, what they should be, is often muddled with disability eligibility questions, making it difficult to determine how courts approach reasonable accommodation.

108. 535 U.S. 391 (2002).

109. *Id.* at 399, 403.

employees under Title I.¹¹⁰ Further, the nature of accommodation is discussed only in passing in non-employment contexts by the Court, where language suggests a preference for normal modes of functioning.¹¹¹

Thus, there are two parts to the problem of how a baseline of normal functioning is used under current law. Lack of use under the disability threshold test excludes persons with disabilities from protection under the ADA. Use under the accommodation mandate may not speak to preferred, more efficient non-species-typical modes of functioning and further stigmatization of individuals who function in atypical ways by regarding such methods of functioning as ineffective or inferior.

IV. FUNCTIONING-BASED DISABILITY ANALYSIS

Functioning-Based Disability Analysis suggests that in order to consider properly the role of normal species functioning in disability analysis and to overcome the problems discussed in Part III, it is necessary to separate disability inquiries about eligibility, entitlement, and the nature of accommodation. One must then consider whether normal species functioning should inform each inquiry. Philosophical understanding of normal functioning helps clarify relevant factors and suggests that the normal species functioning baseline should be applied to questions of eligibility and entitlement but not to determine the nature of accommodation.

A. *Proposed General Disability Inquiries*

Inquiries about disability status, entitlement, and the nature of

110. The dissent, authored by Justice Scalia, with whom Justice Thomas joins, even more narrowly construes reasonable accommodation by stating the accommodation should not be made, as the majority suggests, to “accommodat[e]” the disabled employee,” but rather to “accommodat[e] . . . the known ‘physical or mental limitations’ of the employee.” *Id.* at 413 (emphasis removed). In other words, Scalia would like to limit accommodations to those that mitigate the impairment itself rather than workplace obstacles. Such accommodations may not support alternative modes of functioning. As addressed *supra* in Part II, accommodation that seeks to change the individual usually supports normal species functioning.

111. See *PGA Tour v. Martin*, 532 U.S. 661, 671-72, 683 (2001) (discussing, under Title III, how a golf cart accommodation enables a disabled golfer to function closer to the typical walking golfer); *Olmstead v. L.C.*, 527 U.S. 581, 608-11 (1999) (Kennedy, J., concurring) (explaining that, under Title II, community-based treatment or more normal, integrated treatment for the mentally ill as advocated by the majority may not serve the needs of some severely mentally disabled individuals who require more assistance and supervision).

accommodation are distinct factual questions.¹¹² While they must be separated in order to clarify the proper role of normal species functioning, the exact wording of the inquires is not important. This Article offers three general inquiries as a guide for the courts.

The three general inquiries this Article proposes for Functioning-Based Disability Analysis are:

- (Q1) Is person X disabled?
- (Q2) If person X is disabled, is she entitled to resources?
- (Q3) If person X is disabled, and she is entitled to resources, how should those resources be used?

This analysis may take on a slightly different shape if a plaintiff is seeking injunctive relief rather than an accommodation. In these instances, Q2 and Q3 may be read to speak generally to a remedy rather than to resources. “Remedy” may also apply to resource claims.

Under established Supreme Court tests, Q1 is akin to the disability threshold test. That is, a person is disabled if she has a substantial impairment of a major life activity, a record of such a disability, or is regarded as disabled. While it is important to emphasize that this question contains three important sub-queries, namely, (1) whether a disability is a physical or mental impairment and (2) whether it “substantially limits” (3) a major life activity, this Article argues that the normal species functioning baseline should be applied in a similar manner to each of these elements.

Under current Supreme Court jurisprudence, if an individual is considered disabled and discriminated against on the basis of her disability, she is entitled to resources, unless one of the two affirmative defenses is relevant (undue hardship or direct threat) or, under Title I, the worker cannot fulfill the essential functions of her job. Q2 separates this finding from the disability threshold test (Q1) and is thereby a departure from current judicial construction of the ADA. Q1 and Q2 are two distinct inquiries. An individual may be disabled under the Act yet not entitled to an accommodation if she functions in an unimpaired fashion in a given situation, assuming that there is no other disability-based discrimination.

The second stage of disability analysis is where courts should assess mitigating measures. Currently the Court considers mitigating measures at the stage this Article calls Q1, categorizing most plaintiffs as not disabled and denying them protection under the Act. Nevertheless, these individuals are often considered too impaired by their employers to work. This is the case where there are perceived safety concerns about functioning, even when they do not arise to

112. I am grateful to Jules Coleman for his insights on this matter. Broader exploration of Coleman’s related works in torts warrants examination elsewhere.

the level of direct threat.¹¹³

Q3 aligns with the reasonable accommodation mandate of the ADA. Under the language of the Act, the nature of accommodation is to be determined by the entity under scrutiny; under Title I, this would be the employer, Title II the service provider, and Title III the place of public accommodation. Under Title I, an employer may engage an employee in an interactive process in order to determine a preferred accommodation, though this is not required by the Act and adopted in only some judicial circuits.¹¹⁴

B. Proper Consideration of Normal Species Functioning

In this Section, the application of the normal species functioning baseline is examined with respect to each disability inquiry. This Article argues that the normal species functioning baseline should be applied to the first and second inquiries (Q1 and Q2) but not to the third (Q3). Legal and philosophical discussion of functioning helps explain why the normal species functioning baseline should be applied to inquiries about whether a person is disabled and entitled to an accommodation under law but not to determine the nature of accommodation.¹¹⁵

1. Definition of Disability

Q1 encompasses the disability threshold test, that is, whether an individual has: (1) a physical or mental impairment that (2) substantially limits (3) a major life activity. The application of the baseline must be assessed with regard to each element of the disability threshold test; this Article argues that it should be applied to all three parts. Applying the normal species functioning baseline to the disability threshold test (Q1):

Those who function effectively in a manner that is normal for our species are not disabled, while those who function effectively but in a non-species-typical manner (due to disease or biological defect) are disabled.

Application of the normal species functioning baseline to “a physical or

113. *Albertson's, Inc. v. Kirkingburg*, 527 U.S. 555 (1999); *Murphy v. United Parcel Serv.*, 527 U.S. 516 (1999); *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999).

114. See *supra* note 40 and accompanying text.

115. Functioning-Based Disability Analysis also bears on the non-functional prongs of the ADA, that is, protections that stem from having a record or history of a disability or being regarded as having a disability. For the reasons discussed *infra*, normal species functioning should be applied to inquiries about whether an individual is disabled and entitled to a remedy but not to the nature of accommodation.

mental impairment” is strongly supported by the EEOC regulations and the legislative history of the ADA. This statutory requirement is interpreted by the EEOC and Congress to assume a medical model of disability, impliedly rejecting a social, or alternative functioning model. The EEOC interprets the phrase to mean “any physiological disorder, or condition, cosmetic disfigurement, or anatomical loss” to a major body system or “[a]ny mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.”¹¹⁶ These categories, taken directly from a House Report, all stem from biological defect or anomaly.¹¹⁷ The same report further states that “environmental, cultural, and economic disadvantages are not in themselves covered.”¹¹⁸ Courts have almost uniformly interpreted this aspect of the disability threshold test to invoke a medical model of disability.¹¹⁹

The normal species functioning baseline allows distinctions to be drawn between individuals seeking accommodations for various needs. It provides a rough measure for promoting equality among the disabled by promoting a normal opportunity range. While a more expansive category might be desired, it raises the problems discussed in Section II.B, most notably, difficulty in limiting the protected class. In *Sutton*, the Court assumes the number of Americans in the protected class to be roughly forty-three million.¹²⁰ While it is disputed that this number, taken from the Preamble of the ADA,¹²¹ was intended to establish a ceiling, the alternative modes of functioning model would exceed substantially this number by allowing any individual, with or without biological defect and disabled by their environment, to be a potential member of the protected class.¹²²

116. 29 C.F.R. §§ 1630.2(h)(1)-(2) (2005).

117. H.R. Rep. No. 101-485, pt. 2, at 51 (1990).

118. *Id.* at 51-52.

119. As noted in Part I, it remains unclear whether courts will extend mental impairment to include conditions of uncertain biological origin or social cause. See *supra* note 24 and accompanying text.

120. *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 484 (1999).

121. 42 U.S.C. § 12101(a)(1) (2000) (stating that “[s]ome 43,000,000 Americans have one or more physical or mental disabilities, and this number is increasing as the population as a whole is growing older”).

122. *Sutton*, 527 U.S. at 494 (Ginsburg, J., concurring); *id.* at 495 (Stevens, J., dissenting); see also Feldblum, *supra* note 5, at 154 (“I can attest that the decision to reference 43 million Americans with disabilities in the findings of the ADA was made by one staff person and endorsed by three disability rights advocates, that the decision took about ten minutes to make, and that its implications for the definition of disability were never considered by these individuals. Moreover, it was my sense during passage of the ADA that this finding was never considered by any Member of Congress, either on its own merits or as related to the definition of disability.”).

This would arguably fly in the face of what Congress intended. Invoking the normal species functioning baseline at the first stage of disability analysis would limit the protected class, as disability would be measured relative to a biological baseline of what is normal for our species.

There is a question, though, as to whether the normal species functioning baseline should be applied to “substantially limits” and “major life activity,” given the social influences on what one recognizes as significant life activities and a “substantial limit[ation]” of those activities. The plain language of the statute is not helpful here, and the EEOC Regulations and Congressional Record seem to reject an alternative modes of functioning approach. The EEOC regulations define “a substantial impairment of a major life activity” with reference to “the average person in the general population.”¹²³ In this context, “substantially” and “major life activity” are not separated. This aligns with Congress’s account of “a substantial impairment of a major life activity”: “A person is considered an individual with a disability for purposes of the first prong of the definition when the individual’s important life activities are restricted as to the conditions, manner, or duration under which they can be performed in comparison to *most people*.”¹²⁴ It is left largely to the courts to determine the role of social influence upon “substantially” as separate from “major life activity.”

It is here that the Supreme Court abandons the medical model in part. In the 1999 trilogy, the Court finds no substantial impairment in three different contexts, due to the individual’s ability to mitigate a particular disability. Eligibility for disability protections is assessed not according to the degree of biological impairment as compared to the rest of the species but only after tools of assist and other mitigating measures are employed. This appears to look to the alternative modes of functioning model, or to functional outcomes. There is a strong argument to be made, though, that the Court does not intend to invoke the alternative modes of functioning model at this stage and is simply engaging in its mitigation analysis too early. As argued in Section IV.A, consideration of mitigating measures should come into play at the next level of inquiry, the question whether someone is entitled to resources. Because the Court combines these inquiries, the analysis is confused. Further indication that the Court may not wish to look to the alternative modes of functioning model at the disability threshold stage is that, when contemplating the meaning of “major life activity,”

123. 29 C.F.R. § 1630.2(j)(1)(i) (2005). An individual with a substantial impairment of a major life activity is “significantly restricted as to the condition, manner or duration under which [she] can perform a particular major life activity as compared to the condition, manner, or duration under which the *average person* in the general population can perform that same major life activity.” *Id.* at § 1630.2(j)(1)(ii) (emphasis added).

124. H.R. Rep. No. 101-485, pt. 2, at 52 (1990) (emphasis added).

it returns to speaking of a biological majority. In *Toyota Motor Manufacturing, Kentucky v. Williams*, the Court interprets major life activities to be those that are of “central importance to *most* people’s daily lives.”¹²⁵ Thus, current regulations and statutory and common law give us no reason to invoke the alternative modes of functioning model at this level of disability analysis.

Applying the alternative modes of functioning model at the level of “substantial” and “major life activity” is problematic for the same reasons it is troublesome to apply it to “the physical or mental impairment” prong. Put simply, it is too difficult to know who to exclude from the class of disabled individuals when sorting through distributive justice claims, if major life activities are not defined relative to a majority of our species. Applying the alternative modes of functioning model to “substantial” would also likely encounter the difficulty that individuals who are particularly creative in overcoming impairments, or who are very resilient or able to work harder for the same level of functioning, would not be considered disabled. These individuals would not be entitled to a remedy unless they are no longer able to compensate for their disability, holding them hostage to their self-mitigating measures.

On the other hand, individuals who function effectively in atypical ways may resent being characterized as disabled. Under the current judicial construction of the ADA, where the question of disability and entitlement to resources are considered together as a threshold matter, this view is understandable. Characterizing someone as disabled sends the message that she is entitled to resources, presumably based upon need. This may be offensive to an individual who believes herself to be self-sufficient. Treating the inquiries separately undercuts this concern. Under the proposed scheme, taking offense would require an objection to the formal protections afforded the disabled as a protected class, protections an individual need not invoke.¹²⁶

2. *Entitlement to Resources*

Currently the Court does not separate Q2 from Q1, though these are distinct factual inquiries.¹²⁷ Applying the normal species functioning baseline to Q2:

Those who function in a species-typical fashion are not entitled to resources. Conversely, those who function in a non-species-typical way (due to disease or biological defect) may have claims to resources.

125. *Toyota Motor Mfg., Ky. v. Williams*, 534 U.S. 184, 187 (2002) (emphasis added).

126. Objections to membership in a protected class do not arise in other civil rights contexts, such as race and gender. Obviously, however, in these contexts eligibility for protection does not involve impaired capacities.

127. See *supra* Section IV.A.

Resource claims are limited depending upon available public or private resources as well as, under current judicial construction of the Act, the ability of an individual to mitigate her disability. The defenses of undue burden and direct threat also may affect claims to resources. While resource availability is inherently a social constraint, it pertains not to entitlement to a remedy (or to the alternative modes of functioning model) but rather to the availability of a remedy. Consideration of mitigating measures, though, does pertain to entitlement to a remedy and invokes models of functioning. The Court looks to functional outcomes (the alternative modes of functioning model) when considering mitigation rather than the manner of functioning to determine entitlement to resources. Thus, under current law, when mitigating measures are considered, an individual who does not function in a manner that is normal for the species may have a *lesser* claim to resources because of an ability to function effectively in an atypical manner.

Applying the normal species functioning model to resource claims without considering mitigation allows resource distribution to those who function in atypical ways. Applying the model to resource claims when mitigation is considered, an individual may still be entitled to resources to promote her normal opportunity range. This would likely be the case in instances of partial or difficult mitigation of disability, situations involving those who are hyper-vulnerable to changes in their environments, or circumstances where company policies label workers as safety risks on the basis of disability, even though there is no or limited risk after mitigation. Under current jurisprudence, the latter two categories of individuals are not protected. In order to sue, hyper-vulnerable individuals are forced to wait until changes in their environment render them disabled. In its famous trilogy of cases, the Court finds the plaintiffs not disabled after mitigation but unable to meet the safety requirements of their employers; it is unclear, though, whether these safety precautions are reasonable or a source of disability discrimination in themselves.

Under current judicial construction of the ADA, one could not adopt the alternative modes of functioning model in response to Q2 without also adopting it for at least one of the prongs of the statutory definition of disability encompassed by Q1, as discussed above. This Article rejects the alternative modes of functioning model at Q1.¹²⁸ Nevertheless, it is worth noting that if one were to adopt the alternative modes of functioning model for Q1 and Q2, the same arguments about over-inclusiveness and under-inclusiveness would apply. It is difficult to know where to draw lines, as a matter of justice as well as practice, around a class of disabled individuals whose disabilities are believed to be wholly or mostly a matter of social construction. Further, those individuals

128. See *supra* Subsection IV.B.1.

who exert much effort to overcome impairments would encounter a significant hurdle at the remedy stage if they appeared to be functioning effectively, assuming they could even establish a “substantial” disability under Q1. This is a much higher hurdle to establish disability than the one faced under the normal species functioning approach, even taking into account mitigating measures.

One problem with looking to normal functioning in the context of remedy is an individual who functions in an atypical manner is entitled to resources even if she functions to the same level without resources as someone who functions in a species-typical fashion. Arguably, this is in keeping with the spirit of the ADA, which only seeks to protect individuals who are disabled under the statutory definition of disability or who are discriminated against on the basis of being regarded as disabled under this definition. Individuals disadvantaged for other reasons were excluded by Congress.¹²⁹ It is important to remember that the civil rights grounded in the ADA need not give rise to an accommodation. This is recognized in the statutory definition of “qualified individual with a disability” under Title I, which states that if an individual is disabled, she is qualified for employment, so long as she can fulfill the essential functions of her job “with or without reasonable accommodation.”¹³⁰

3. *Nature of Accommodation*

Applying the normal species functioning baseline to Q3:

Resources must support species-typical ways of functioning. If the normal species functioning baseline is not applied to Q3, disabled persons may be accommodated in a manner that best supports preferred and more effective modes of functioning, regardless of whether these modes of functioning are normal for the species.

Legal, moral, and policy arguments support the conclusion that a person with a disability should determine her own accommodation.

a. *Essential Functions Test*

As already discussed, the interactive process advocated by the EEOC strongly supports, though does not require, that a disabled employee be able to choose her own accommodation.¹³¹ In addition, Congress, courts, and the EEOC have already embraced the idea of functional outcomes versus manner of functioning in the essential functions context. The essential functions test of Title

129. H.R. Rep. No. 101-485, pt. 2, at 51-52 (1990).

130. 42 U.S.C. § 12111(8) (emphasis added).

131. See *supra* notes 39-43 and accompanying text.

I, which requires that a qualified individual with a disability be able to fulfill the essential functions of her job “with or without reasonable accommodation,” is interpreted by the EEOC to mean that an employee must be able to obtain a certain functional result.¹³² The clearest articulation of this view is found in the EEOC’s Technical Assistance Manual, which states that:

In identifying an essential function to determine if an individual with a disability is qualified, the employer should *focus on the purpose of the function and the result* to be accomplished, *rather than the manner* in which the function presently is performed. An individual with a disability may be qualified to perform the function if an accommodation would enable this person to perform the job in a different way, and the accommodation does not impose an undue hardship. Although it may be essential that a function be performed, frequently it is not essential that it be performed in a particular way.¹³³

Similarly, the Technical Assistance Manual states that formal job analysis to identify the essential functions of a job must “take into account the fact that people with disabilities often can perform essential functions using other skills and abilities [than those specifically enumerated in the analysis].”¹³⁴ It continues, “[t]he job analysis may contain information on the manner in which a job currently is performed, but should not conclude that ability to perform the job in that manner is an essential function, unless there is no other way to perform the function without causing undue hardship.”¹³⁵ In making accommodations, employers should focus upon ways in which an individual might fulfill an essential job function rather than the manner in which they currently do so.¹³⁶ The Technical Assistance Manual provides three examples of atypical functioning fulfilling essential functions: developing computer programs directly on the computer rather than by hand, listening to audiotapes to learn technical manuals rather than reading them, and using tools of assist to lift cartons into truck-trailers rather than lifting them by hand.¹³⁷

The Congressional Record also supports the proposition that the essential

132. 42 U.S.C. § 12111(8) (2000).

133. EEOC, A TECHNICAL ASSISTANCE MANUAL ON THE EMPLOYMENT PROVISIONS (TITLE I) OF THE AMERICAN’S WITH DISABILITIES ACT § 2.3(a) (1992) (emphasis added).

134. *Id.* at § 2.3(b).

135. *Id.*

136. *Id.* at § 3.5 (“In considering an accommodation, the focus should be on the abilities and limitations of the individual . . . on ways that [a] person might be able to do the job function, not on the nature of her disability or how persons with this kind of disability generally might be able to perform the job.”).

137. *Id.* at § 2.3(b).

functions test is concerned with functional outcomes rather than the mode of functioning. The distinction was made by Representative Fish when he introduced amendments to the bill that became the ADA. He stated:

The essential function requirement focuses on the desired result rather than the means of accomplishing it. For example, in one case under the Rehabilitation Act, the employer required each employee to be able to perform the job with both arms. *Prewitt v. U.S. Postal Service*, 662 F.2d 292 (5th Cir. 1981). The plaintiff was unable to do this because his disability resulted in limited mobility in his left arm. The court found that the essential function of the job was the ability to lift and carry mail which the employee had proven that he could do, not the ability to use both arms. Moreover, the court found that the employer was required to adapt the work environment to determine whether the employee with the disability could perform the essential requirements of the job with reasonable adaptations.

Likewise, in a job requiring the use of a computer, the essential function is the ability to access, input, and retrieve information from the computer. It is not essential that the person be able to use the keyboard or visually read the computer screen, if the provision of adaptive equipment or software would enable the person with the disability—for example, impaired vision or limited hand control—to control the computer and access the information. The relevant question would be whether the acquisition of the equipment would be a reasonable accommodation, given the factors to be considered in making that determination.¹³⁸

This passage is cited by the Third Circuit in *Skerski v. Time Warner Cable Co.*, for a similar proposition, namely, that the requirement of a job detailing a method of performance may not be an essential function if the task it targets may be accomplished in an atypical way.¹³⁹ In addition, at least two other circuits have acknowledged that accommodations for atypical functioning may allow an individual to fulfill the essential functions of her job. In *Gillon v. Fallon Ambulance Services*, the First Circuit found that a woman missing part of one arm due to a genetic defect was able to serve as an emergency medical technician

138. 136 CONG. REC. 11,451 (daily ed. May 22, 1990) (statement of Rep. Fish) (emphasis added).

139. *Skerski v. Time Warner Cable Co.*, 257 F.3d 273, 280-81 (3d Cir. 2001). In *Skerski*, a cable installer technician who suffered anxiety attacks at high elevations requested the use of a bucket truck to reach cable wires. The court remanded the case on the grounds that there were genuine issues of material fact as to whether climbing was a physical task job requirement but not an essential function, and, if so, whether the defendant's reassignment of Skerski to a warehouse position was a reasonable accommodation. *Id.* at 280-86.

with a partner to aid in lifting and carrying adults on stretchers.¹⁴⁰ Similarly, the Eighth Circuit, in *Fenney v. Dakota, Minnesota, & Eastern Railroad Co.*, acknowledged that a “long call” procedure of advance warning allowed a man who lost his thumb and part of a finger and damaged his right arm to be an on-call locomotive engineer by affording him sufficient time to report to work.¹⁴¹

b. Philosophical Argument from Moral Equivalence

Particular philosophical perspectives also lend support for the argument that accommodation to restore or promote normal species functioning should not be given priority over accommodation of alternative modes of functioning. There is a philosophical argument to be made about the moral equivalence between “treatment” (that is, amelioration of a defect to normal functioning) and other forms of compensation. If treatment to further normal species functioning is morally equivalent to other forms of compensation that support alternative modes of functioning, failing to provide compensation for these alternative forms of functioning may be unjust.

The literature on the moral equivalence of treatment and prevention is of some assistance in understanding the moral distinction between compensation, via facilitating alternative modes of functioning, and treatment or prevention offered to preserve normal species functioning. Treatment, after all, is not always fully restorative and may be used as a form of compensation to support alternative modes of functioning. In fact, treatments may be provided for the purpose of producing only marginal benefits for individuals with disabling conditions. There are, of course, limitations to this analogy, insofar as treatment may bring one back to normal species functioning, and compensation is understood to try to restore one to functionality in society, possibly outside of what is normal for the species.

As part of the treatment/prevention debate, philosopher Paul Menzel argues that treatment has a qualified moral priority over prevention.¹⁴² This is so, in part, because rational people may choose to avoid the greatest risk to their life by spending more in high-risk situations, that is, on treatment when they are sick, than in low-risk situations, such as prevention when they are well. This priority is

140. 283 F.3d 11 (1st Cir. 2003).

141. 327 F.3d 707, 710 (8th Cir. 2003) (allowing Plaintiff time to “bathe, dress, shave, prepare a meal, and drive himself to work on time”).

142. PAUL T. MENZEL, *MEDICAL COSTS, MORAL CHOICES: A PHILOSOPHY OF HEALTH CARE ECONOMICS IN AMERICA* 151-83 (1983). Menzel is concerned with the emphasis of treatment over prevention in the allocation of medical resources. His conclusion is useful to the present discussion for understanding the priority of treatment (and by analogy compensation) relative to prevention of deviation from normal species functioning.

limited under a hypothetical choice situation, where individuals consider what is fair at the beginning of their lives, as well as a willingness-to-pay argument in circumstances where treatment is understood to make a less significant reduction to the high risk.¹⁴³ Treatment may also be prioritized over prevention on the ground that those who are currently sick (a case could be made for individuals symptomatic as well as those asymptomatic for disabling disease or conditions) would fail to benefit from prevention and therefore would not consent to the moral equivalency between treatment and prevention. One exception to the priority of treatment over prevention, as Menzel notes, is for situations where prevention actually enables the subject's ability to consent to the moral equivalence between treatment and prevention.¹⁴⁴ In other words, prevention allows an individual the capacity to consent. In these cases, prevention should be morally equivalent to treatment for the condition at stake.¹⁴⁵

Menzel's interpretation of the qualified moral priority of treatment over prevention is of relevance to discussing compensation of alternative modes of functioning versus prevention of deviation from normal species functioning. This is so because an analogy may be made between treatment and compensation, as compensation may be the outcome when treatment does not specifically reduce high risk (though here the risk is to functioning and is not necessarily as threatening).¹⁴⁶ In these instances, prevention may have priority over compensation, were it not for the fact that those with disabling diseases or conditions are already affected. Given this factor, and with specific reference to the neonatal context, Menzel argues that prevention and treatment in this context are morally equivalent. He states:

[I]n assessing the importance of preventing congenital, chronically disabling diseases for future persons . . . the claim for prevention is as weighty as the claim for treatment of those in the present generation whom these disease afflict, and in any case, it is weightier than the claim to prevent other, equally cost-effective, preventable diseases which do not preclude their victims from sometimes having a rational self-interest in a policy of equivalence. The

143. *Id.* at 171.

144. *Id.* at 175, 179. Menzel argues that this is a question of justice and not self-interest. He compares it to a veto of moral priority when one is not sick, and argues that this veto is unjustified because it is based upon self-interest, presumably because the individual would desire priority for treatment if the tables were turned. It seems, however, that in both cases the parties are self-interested, though perhaps for stronger reasons in the first (i.e., when the person is sick) than in the second (i.e., when the individual is not yet sick). Regardless, a compelling interest may be enough to sustain the qualification.

145. *Id.* at 178-79.

146. This may present difficulties for the analogy regarding some of the finer points of Menzel's analysis, but the basic idea still stands.

practical implications are immensely important. For example, treatment of defective newborns may properly take priority over many types of prevention, but it should not take priority over prevention of future, similar, neonatal defects. An appeal to a local health-planning council to expand a neonatal intensive-care unit, for example, should not be granted until equal-marginal-benefit-producing funds are devoted to educational programs to prevent future birth defects.¹⁴⁷

This has several implications for the analogy between treatment/prevention in the health care context and compensation/prevention for alternative modes of functioning in the disability context. If, to continue Menzel's example, the fetus is understood to have moral status, there are obvious limits to drawing an analogy between educational programs to prevent future birth defects, with respect to such practices as smoking and drinking during pregnancy, and preventing birth defects through prenatal testing and selective abortion. If the fetus does not possess moral status, however, one could argue that there is no morally relevant difference between prevention and compensation with respect to discrimination against the disabled. In this instance of moral equivalency, it seems that both treatment of disabled newborns as well as prevention of disabled births would be supported, so the claim to prenatal testing and selective abortion has equal force to the claim to material supports to raise disabled children.¹⁴⁸

Making an analogy to Menzel's thesis in this manner, one could extend the moral equivalency argument to compensation for disabilities outside of the prenatal and neonatal context. This approach might lend support for funding for compensatory medical care that seeks to support alternative modes of functioning, rather than prioritizing accommodation that strives to normalize individuals by preventing deviations from normal species functioning. *Ceteris paribus*, extending the argument from moral equivalency in this manner lends tremendous weight to the voices of disabled individuals who prefer non-species-typical modes of functioning. The discussion now turns briefly to other theories of distributive justice that support distributing resources to facilitate non-species-typical modes of functioning.

147. MENZEL, *supra* note 142, at 177-78 (emphasis omitted).

148. If this analogy holds, there is no relevant moral difference between bringing an affected fetus or the "next child" (the next, hypothetical child, non-rigidly defined) to term. Although Menzel does not adopt the theory that Rawls presents in *A Theory of Justice*, *supra* note 55, if one was to apply this argument to Rawls, this would assume that the original contractors know of their existence and would not give treatment moral priority over prevention in an effort to preserve themselves. Further discussion of this point, however, is outside of the scope of this Article.

c. *Additional Arguments from Justice*

The dominant theories of just distribution, Rawlsian contractarianism (from which Daniels's theory of normal species functioning is derived) and consequentialist schemes, also provide some support for distributing resources to aid alternative modes of functioning. Stated very generally, Rawls is concerned with just procedure of distribution (pure procedural justice), and consequentialists are concerned with best outcomes. The arguments are only very superficially surveyed here.

To begin, the notion of hypothetical consent used by Menzel could be applied to choice behind Rawls's veil of ignorance, where individuals do not know their lot in life. In general, however, accommodating alternative modes of functioning under Rawlsian contractarianism is more difficult than under consequentialist schemes. This is because it is unclear what the difference principle, the conception that resources should be distributed to benefit the least advantaged, provides for individuals with disabilities.¹⁴⁹ In addition, Rawls's discussion of primary goods, the basic social goods that are distributed, takes little note of the diversity of needs between individuals.¹⁵⁰ Since Rawls places emphasis on normal functioning by assuming that individuals are normal and fully functioning over a lifetime, an extension of his principles to a theory of the just distribution of health care services would likely use normal functioning as a baseline, as does Daniels's theory.¹⁵¹ Further, as recognized by Ronald Dworkin, Robert Nozick, and Thomas Nagel, there is a social conscription of natural assets

149. As recognized by philosophically-minded Harvard economist Amartya Sen, "hard cases do exist, and to take disabilities, or special health needs, or physical or mental defects, as morally irrelevant [sic], or to leave them out for fear of making a mistake, may guarantee that the *opposite* mistake will be made." Amartya Sen, *Equality of What?*, in CHOICE, WELFARE, AND MEASUREMENT 353, 366 (1982).

150. RAWLS, *supra* note 55, at 440-46. Primary goods include the social bases of self-respect, rights and liberties, powers and opportunities, and income and wealth. These goods are considered primary because they are necessary for the fulfillment of all rational life plans. They avoid commitment to specific ways of life that a "thick theory of the good" would entail, and, as a result, are understood to represent Rawls's "thin theory of the good." Rawls's contractors seek to maximize the amounts of primary goods available to citizens, though the concern is with pure procedural justice rather than just outcomes.

151. See John Rawls, *Social Unity and Primary Goods*, in UTILITARIANISM AND BEYOND 159, 168 (Amartya Sen & Bernard Williams eds., 1982) (Individuals are "normally active and fully cooperating members of society over a complete life"). Nevertheless, it might be possible to extend Rawls's principles and adopt a baseline of functional output that is blind to one's mode of functioning.

in Rawls in the sense that natural assets are treated as if they belong to society.¹⁵² As a result, Rawls's theory leans toward a common mode of functioning, such that natural assets can be measured across society. This makes it more difficult to accommodate non-species-typical modes of functioning, though Rawlsian contractarianism provides some support for atypical functioning, as is evident through Daniels's conditional extension of the fair equality of opportunity principle, encompassing the distribution of health care resources to compensate individuals who cannot be brought back to normal functioning.

Consequentialist theory offers direct consideration of alternative modes of functioning, although the distribution of resources for such purposes meets other constraints. Consider the theory of basic capability equality proffered by Amartya Sen.¹⁵³ Stated very generally, Sen argues that "units" called capabilities are to be maximized across populations. These units comprise sets (capability sets) that reflect the actual functionings available to an individual. Pertinent to present purposes, this means that capability sets are defined relative to a person's ability (or disability). In other words, capabilities for functioning of that individual are accounted for directly. A person may choose to maximize her well-being by choosing a capability set with a particular level of functioning. It is possible that this level of functioning could be achieved by mechanisms normal for the species as well as those that fall outside of normal species functioning. If other individuals in that society value the same level of functioning, it may be equalized across the population considered, though there may be various means of attaining it.

Similarly, any mode of functioning that contributes to utility will be valued under a utilitarian consequentialist scheme, regardless of whether it is normal for the species. Utilitarianism, the theory of the greatest good for the greatest number, does meet some challenges in considering alternative modes of

152. Robert Nozick, *ANARCHY, STATE, AND UTOPIA* 183-231 (1974); Ronald Dworkin, *The Original Position*, in *READING RAWLS: CRITICAL STUDIES ON RAWLS' A THEORY OF JUSTICE*, 16-53 (Norman Daniels ed., 1989); Thomas Nagel, *Rawls on Justice*, in *READING RAWLS: CRITICAL STUDIES ON RAWLS' A THEORY OF JUSTICE*, *supra*, at 1-16.

153. See, e.g., AMARTYA SEN, *COMMODITIES AND CAPABILITIES* (1999); AMARTYA SEN, *INEQUALITY REEXAMINED* (1992); Amartya Sen, *Capability and Well-being*, in *THE QUALITY OF LIFE* 30-53 (Martha Nussbaum & Amartya Sen eds., 1993); Amartya Sen, *Equality of What?*, in *LIBERTY, EQUALITY, AND LAW: SELECTED TANNER LECTURES ON MORAL PHILOSOPHY* 138 (Sterling M. McMurrin ed., 1987 [hereinafter Sen, *Equality of What?*]); Amartya Sen, *On the Foundations of Welfare Economics: Utility, Capability and Practical Reason*, in *ETHICS, RATIONALITY AND ECONOMIC BEHAVIOR* 50 (Francesco Farina et al. eds., 1996); Amartya Sen, *The Standard of Living: Lecture I, Concepts and Critiques* and *The Standard of Living: Lecture II, Lives and Capabilities*, in *THE STANDARD OF LIVING* (Geoffrey Hawthorn ed., 1987); Amartya Sen, *Well-being, Agency, and Freedom: The Dewey Lectures 1984*, 82 *J. PHIL.* 169 (1985).

functioning but is not undermined in this regard. For utilitarianism, there is a classic pure distribution problem. The disabled, who experience high satisfaction in their lives despite their disability, have weaker claims than those individuals without disabilities who live unhappy lives. This assumes, though, that accommodation addressing disability fails to increase sufficiently the happiness of the “happy disabled” to justify entitlement, but resources increase sufficiently the happiness of the “unhappy able-bodied” for this purpose, which may not be the case.¹⁵⁴

Another commonly invoked argument against utilitarian or cost-utility approaches is that they create a situation of “double jeopardy” for individuals who develop serious illness or disability.¹⁵⁵ It is viewed as double jeopardy in the sense that these individuals, often through “brute luck,”¹⁵⁶ experience illness or disability and then subsequently have a lesser claim to resources as a result of those conditions. What this position reveals, though, is the tension between looking at distributive justice over a lifetime, as opposed to viewing it during certain periods of time.¹⁵⁷ If the premise of justice over a lifetime is accepted, this form of double jeopardy does not constitute unjust treatment. The sick or disabled are offered an equal chance for treatment or resources over a lifetime.¹⁵⁸

In sum, there seem to be strong normative reasons for considering alternative modes of functioning when compensating persons with disabilities. These justifications are derivative of dominant theories of distributive justice, with consequentialist frameworks offering the strongest support. As discussed in Subsection IV.3.b, justification may also be derived from the moral equivalency thesis of treatment and prevention. To fail to consider alternative modes of functioning emphasizes manner of functioning rather than functional outcomes and may reject valuable and preferred modes of functioning for persons with disabilities.

154. Sen, *Equality of What?*, *supra* note 153, at 365. I am unable within the confines of this Article to address all of the possible defenses that a utilitarian may have to such a standard critique. See J. J. C. SMART & BERNARD WILLIAMS, *UTILITARIANISM: FOR AND AGAINST* (1973).

155. JOHN MCKIE ET AL., *THE ALLOCATION OF HEALTH CARE RESOURCES: AN ETHICAL EVALUATION OF THE “QALY” APPROACH* 99-116 (1998).

156. “Brute luck” refers to risks that are not the product of “deliberate” choice, such as one’s genetic composition or disabling condition or illness (assuming that one did not deliberately choose to place oneself in peril). Ronald Dworkin, *Equality of Resources*, in *SOVEREIGN VIRTUE: THE THEORY AND PRACTICE OF EQUALITY* 73-74 (2000).

157. MCKIE ET AL., *supra* note 155, at 99-116.

158. This may not adequately address the situation of individuals born with serious disabilities or illnesses. Some cost-utility measurements, such as Quality Adjusted Life Years, however, take into account the length of remaining life in determining entitlement to resources and may mitigate this problem for individuals who experience long-term disability.

4. *Alternative Modes of Functioning and Accommodation Revisited*

There are a number of reasons it may be important to account for the social element of disability, or alternative functioning, in making accommodations. First, the alternative modes of functioning model supports non-species-typical modes of functioning that may allow disabled persons to function in a manner that is preferred and more efficient. At a minimum, the alternative modes of functioning model would stress an interactive process between an employer and employee that considers non-species-typical accommodation. At a maximum, it would require the employer to provide preferred, non-species-typical accommodation, so long as it is reasonable and does not create an undue hardship or direct threat under the terms of the ADA. Recent work in the area of accommodation suggests both that accommodations are economically efficient and that supporting alternative modes of functioning is not more costly than supporting normal modes of functioning.¹⁵⁹

The alternative model of accommodation would also provide greater protection to individuals with biological defects who currently function well in society or at work but may be highly susceptible to changes in their environments. A diabetic's hidden disability may require a certain work schedule that allows for regular blood sugar tests and insulin as well as the ability to keep food and insulin in the workplace and eat meals at regular times.¹⁶⁰ A shift in workplace or a new schedule imposed by a management change could easily disrupt the ability of the worker to control her diabetes.¹⁶¹ Failing to consider the social aspects of disability places such individuals on the brink of functional impairment by requiring them to wait for a workplace change in order to have their interests considered.¹⁶² A person with such hyper-sensitivities may not, if forced to sue, be entitled to disability protection under current judicial construction of the ADA, since her condition may be self-controlled in certain environments. The alternative modes of functioning model as applied to accommodation would encourage a dialogue between individuals and employers before environmental changes, in hopes of avoiding later conflicts, accommodation requests after expenditures to alter environments, or litigation.

159. Michael Ashley Stein, *The Law and Economics of Disability Accommodations*, 53 DUKE L.J. 79 (2003).

160. Anita Silvers, *The Unprotected: Constructing Disability in the Context of Antidiscrimination Law*, in AMERICANS WITH DISABILITIES: EXPLORING IMPLICATIONS OF THE LAW FOR INDIVIDUALS AND INSTITUTIONS, *supra* note 68, at 134.

161. *Id.* at 134-35.

162. As Silvers aptly states, "[p]eople whose impairments make them extraordinarily vulnerable to being made dysfunctional by seemingly innocuous alterations in their environments are substantially limited simply in virtue of their hypervulnerability." *Id.* at 135.

By advocating an alternative modes of functioning model for the accommodation stage of disability analysis, focus is placed on functional outcomes rather than modes of functioning. As discussed with regard to the health status index in Section II.C, there are some health policy models that purport to look to functional outcomes. These models often confuse manner of functioning with functional outcomes, however.¹⁶³

CONCLUSION

This Article examines a discrete part of the problem with American disability law today. It argues that the Supreme Court's failure to consider properly the role of normal species functioning has severely enervated protections for the disabled and frustrated the purpose of the ADA. Part of the trouble is attributable to the Court confusing three distinct levels of disability analysis: eligibility for disability protections, entitlement to resources, and the nature of accommodation. This Article proposes a three-part disability analysis distinguishing these considerations that allows one to consider, with regard to each inquiry, the role of normal species functioning. Philosophical works about the normal species functioning and alternative modes of functioning models help clarify the application of normal species functioning to these three inquiries and established Supreme Court tests.

Proper consideration of normal species functioning leads to what this Article terms Functioning-Based Disability Analysis. There is philosophical and legal support for the application of the normal species functioning baseline to all three

163. Other relevant health indexes include the Disability-Adjusted Life Year (DALY) approach, which assesses overall quality of well-being not merely functionality, and the International Classification of Functioning, Disability and Health (ICF), which seeks to weigh the physical and social aspects of disability as distinguished from handicap and impairment. See WHO, WORLD HEALTH REPORT 2003: SHAPING THE FUTURE (2003); WHO, TOWARDS A COMMON LANGUAGE FOR FUNCTIONING, DISABILITY, AND HEALTH (2002), available at <http://www3.who.int/icf/beginners.htm> (defining "impairment" and "handicap" in a manner that embraces a social model); see also Dan Wikler & Richard Cash, *Ethical Issues in Global Public Health*, in GLOBAL PUBLIC HEALTH: A NEW ERA 226 (Robert Beaglehole ed., 2003). The latter holds promise as a means for conceptualizing disability and disability accommodations, though its vague definitions of key concepts and myriad of classifications do not provide the flexibility of the ADA's disability threshold test or hold promise for judicial economy. See Rob Imrie, *Demystifying Disability: A Review of the International Classification of Functioning, Disability, and Health*, 26 SOC. OF HEALTH & ILLNESS 287 (2004); Teresa Magalhaes & Claude Hamonet, *Handicap Assessment: Setting the Grounds for an Effective Intervention*, 20 MED. & L. 153, 153-59 (2001); see also WHO, ICF Checklist, available at <http://www3.who.int/icf/checklist/icf-checklist.pdf> (last visited Sept. 5, 2005) (providing a fifteen page abbreviated checklist for assessing the functioning of an individual).

levels of the disability threshold inquiry. There is similar support for the application of the normal species functioning baseline to the question of entitlement to resources. When determining the nature of remedy, or accommodation, however, the normal species functioning model fails to consider more efficient, alternative methods of functioning that may not be typical for our species. A strong case can be made that the disabled should be able to choose the nature of their accommodation as a matter of justice. Regulations and case law from the essential functions context provide additional support.

This Article examines the elements of disability analysis at its most concrete level and the role of normal functioning at a more abstract level. It is necessary to move between these two levels of abstraction to locate exactly what is wrong with American disability law today. As current Supreme Court jurisprudence indicates, it is extremely difficult to assess the role of normal species functioning when the levels of disability analysis are conflated. Similarly, it is not possible to answer the questions raised at each level of analysis without direct consideration of whether it is relevant that some individuals function effectively in a manner that is different from most of our species.

This understanding of disability analysis and functioning is an integral part of disability law reform. Only after understanding the levels of disability inquiry and the role of functioning as applied to each is it possible to see resolution to the over-arching tension between the civil rights and social welfare models of disability law. This takes one to yet a higher, though vital level of abstraction, to which this Article ultimately speaks.

The relevance of functioning to each level of disability analysis casts light on whether disability law should embrace a civil rights or social welfare model. Normative and legal claims support applying normal species functioning to the questions of whether an individual is disabled and entitled to a remedy. Applying the normal species functioning model in this way supports the civil rights model of disability law. The normal species functioning model furthers, as a matter of justice, an individual's normal opportunity range. This promotes equality of participation in civil society for a protected class of persons, namely, those who do not function in a manner that is normal for our species.

When it comes to allowing a disabled individual to determine the nature of the accommodation that would be most effective for her, the normal species functioning model, the civil rights model, and the law as it stands, stop short. The civil rights model is silent on manner of functioning, so long as equality of participation is promoted. Under this model, like the normal species functioning model, a firm need not support alternative modes of functioning. Arguments from particular philosophical perspectives and law support the alternative modes of functioning model for determining the nature of accommodation. The alternative modes of functioning model, which is a social model, looks to

functional outcomes within certain environments as opposed to the manner of functioning. Similarly, a social welfare model has the flexibility to redistribute resources to those most in need with functional impairments, regardless of manner of functioning. Thus, while the civil rights model gives broad rights to the disabled in a variety of contexts, the social welfare model responds to certain kinds of functioning disadvantages, creating an entitlement to resources that may support alternative modes of functioning. Hannah should be able to use her fleshy feet.

“Conscience Clauses” or “Unconscionable Clauses”: Personal Beliefs Versus Professional Responsibilities

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In 2002, a University of Wisconsin student brought a prescription for Loestrin to pharmacist Neil Noesen, who was working in a local community pharmacy in Menomonie, Wisconsin. Noesen refused to fill the prescription, citing his “conscientious objection to participation in refilling a contraceptive order.”¹ He failed to ask the student whether she had any medical conditions that might make pregnancy dangerous.² He also refused to inform her of any other local pharmacies that were capable of filling the prescription.³ When the student, on her own, located another pharmacy, Noesen refused to transfer the prescription, claiming that doing so would “induce another to do a morally wrong or sinful act pursuant to the doctrines of the Roman Catholic Church.”⁴ As a result, the student was unable to take her medication as prescribed and risked pregnancy.⁵

Pharmacists in a number of other states—including California, Georgia, Illinois, Louisiana, Massachusetts, New Hampshire, North Carolina, Ohio, Texas, and Washington—have also refused to fill similar prescriptions.⁶ Some pharmacists will only dispense birth control pills to married women; others

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1. Protection of Conscience Project, Police Used To Intimidate Objecting Pharmacist: Statement of Neil Noesen, pharmD (cand.) (Nov. 20, 2003), <http://www.consciencelaws.org/Repression-Conscience/Conscience-Repression-33.htm>.

2. Disciplinary Proceeding Against Neil T. Noesen, 01 P.H.M. 080, slip op. at 16 (Wis. Pharm. Examining Bd. Feb. 28, 2005) (proposed final decision & order), *aff'd*, Noesen v. Wis. Dep’t of Reg. & Licensing Pharm. Examining Bd., No. 05CV212 (Wis. Cir. Ct. Feb. 3, 2006).

3. *Id.* at 5.

4. *Id.* at 5.

5. *Id.* at 20. Indeed, the student later became pregnant as the result of one missed dose of her contraceptive medication. *Id.*

6. Rob Stein, *Pharmacists’ Rights at Front of New Debate; Because of Beliefs, Some Refuse To Fill Birth Control Prescriptions*, WASH. POST, Mar. 28, 2005, at A1.

refuse to provide the pills to anyone, mistakenly believing emergency contraception to be an abortifacient;⁷ still others, like Noesen, “hold prescriptions hostage” so that women are unable to take the prescriptions to other pharmacies.⁸

While much recent publicity has been directed at pharmacists who have refused to fill prescriptions, for many years other health care professionals have been quietly refusing to provide patients with medical care they believe violates their personal beliefs. In 2004, a physician and nurse midwife in rural Pennsylvania, citing their religious beliefs, refused to recommend an abortion to a thirty-two-year-old woman who was nearly twenty weeks pregnant and suffering from an infection of her amniotic fluid—withstanding the fact that an abortion was the preferred medical therapy to avoid the spread of the infection.⁹ Prioritizing their personal moral objections to abortion over the patient’s health, these professionals ignored the standard that traditionally has guided health care providers in performing their professional responsibilities.¹⁰

7. Unlike abortion, which terminates a pregnancy, contraception prevents pregnancy by inhibiting fertilization and ovulation.

8. Stein, *supra* note 6; see also ACLU REPROD. FREEDOM PROJECT, RELIGIOUS REFUSALS AND REPRODUCTIVE RIGHTS (2002), available at <http://www.aclu.org/FilesPDFs/ACF911.pdf>; Tresa Baldas, *Fighting Refusal To Treat*, NAT’L L.J., Feb. 7, 2005, at 17; Monica Davey & Pam Belluck, *Pharmacies Balk on After-Sex Pill and Widen Fight*, N.Y. TIMES, Apr. 19, 2005, at A1. Some commentators argue in favor of expanding pharmacists’ rights to refuse. See, e.g., Donald W. Herbe, Note, *The Right To Refuse: A Call for Adequate Protection of a Pharmacist’s Right To Refuse Facilitation of Abortion and Emergency Contraception*, 17 J.L. & HEALTH 77 (2002-2003); Melanie Hunter, *Pro-Life Group Files Suit Against Walgreens for Pharmacists’ Firings*, CYBERCAST NEWS SERVICE, Jan. 27, 2006, <http://www.cnsnews.com/MainSearch/Search.html> (search “Pro-Life Group Files Suit Against Walgreens”). Other commentators argue against pharmacists’ abilities “to impose personal beliefs on others.” Mary K. Collins, *Conscience Clauses and Oral Contraceptives: Conscientious Objection or Calculated Obstruction?*, 15 ANNALS HEALTH L. 37 (2006).

9. *Thomas v. Abdul-Malak*, No. 02-1374 (W.D. Pa. July 29, 2004) (on file with author).

10. Many other cases have been reported in which health care providers concluded that providing a certain type of care would violate their personal moral codes. See, e.g., Brietta R. Clark, *When Free Exercise Exemptions Undermine Religious Liberty and the Liberty of Conscience: A Case Study of the Catholic Hospital Conflict*, 82 OR. L. REV. 625, 626-27 (2003) (describing a case in which a physician personally paid for a car to transport his patient to another hospital when her own hospital refused to provide a necessary abortion because the woman’s life was not imminently in danger). Other examples include cancer patients who sought information about harvesting an egg or sperm, but faced providers unwilling to talk about the procedure, pregnant patients being denied sterilization at religious hospitals, and providers denying pain medications in end-of life situations. See, e.g., Baldas, *supra* note 8; Florence A. Ruderman, *Prescription for Injustice*, N.Y. TIMES, Sept. 1, 2005, at A23 (describing a pharmacist’s refusal to

Consequently, the woman suffered septic shock, was transferred to the hospital's intensive care unit, and required a total hysterectomy.¹¹

The potential adverse effects on patient care caused by health professionals' refusals to provide health services, as evidenced by the unwanted pregnancy of the University of Wisconsin student who was unable to obtain her prescription for birth control pills, did not deter the Wisconsin legislature from proposing Assembly and Senate bills to explicitly permit pharmacists to refuse to distribute medication that they believe will cause an abortion—even if that belief is not medically supportable.¹² Nor did concern for the ability of patients to obtain necessary medical care prevent the Wisconsin legislature from passing a new law that would give health care professionals, including pharmacists specifically, broader ability to refuse to participate in a wide variety of medical procedures.¹³

Previously enacted Wisconsin statutes allow health care professionals to opt out of performing abortions and sterilizations. Assembly Bill 207, introduced in March 2005, would have extended those refusal rights not only to participating in procedures that involve embryonic stem cells, but also to withholding or withdrawing nutrition or hydration from individuals who are not terminally ill, such as patients in permanently vegetative states.¹⁴ Governor Jim Doyle vetoed the proposed law, refusing to permit such an expansion of health care professionals' rights of refusal. In justifying his veto, he announced that the law would “put[] a doctor's political views ahead of the best interests of patients,” and therefore “ought to be called the ‘unconscionable clause.’”¹⁵

Governor Doyle's veto, however, runs against the tide of protective legislation enacted over the past thirty-five years that permits health care professionals and institutions to refuse to participate in certain medical procedures. For example, some state laws do not expressly require physicians to

fill pain medication for a terminally ill patient).

11. *Abdul-Malek*, No. 02-1374.

12. A.B. 285, 97th Leg., Reg. Sess. (Wis. 2005); S.B. 155, 97th Leg., Reg. Sess. (Wis. 2005). These bills—neither of which were scheduled for a vote—would also permit pharmacists to refuse to dispense a drug if “the pharmacist believes that the drug . . . would be used for the purpose of . . . [c]ausing the death of any person,” but only “if the pharmacist consults with the practitioner who prescribed the drug . . . before the pharmacist makes the refusal”; no such condition is attached to the refusal to dispense medication that the pharmacist believes “would be used for the purpose of . . . [c]ausing an abortion.” Wis. A.B. 285; Wis. S.B. 155; *see also* H.B. 1383, 104th Gen. Assemb., Reg. Sess. (Tenn. 2005); S.B. 76, 104th Gen. Assemb., Reg. Sess. (Tenn. 2005) (permitting pharmacists to refuse to dispense any medicines that violate their moral principles).

13. A.B. 207, 97th Leg., Gen. Sess. (Wis. 2005) (vetoed).

14. *Id.* at § 3(b)(7).

15. Jim Doyle, Veto Statement (October 14, 2005), <http://www.wisgov.state.wi.us/docview.asp?docid=5111>. The governor vetoed a similar bill in 2004.

participate in abortions, even when abortion is necessary to save the woman's life and even if no other physician is available.¹⁶ Several states permit pharmacists to refuse to fill prescriptions for contraceptives if doing so would conflict with the pharmacist's personal or moral beliefs.¹⁷ Some states permit nurses to refuse to participate in terminating the life support of a terminally ill patient, regardless of the patient's and patient's family's wishes, if the nurse believes that participating in such procedures would violate her religious beliefs.¹⁸ In fact, in some states, *any kind* of health care provider may refuse to provide *any kind* of health service based on her personal beliefs.¹⁹

Emergency contraception has been a particularly controversial subject for state legislatures and governors.²⁰ The controversy surrounds whether the pill

16. See, e.g., N.J. STAT. ANN. § 2A:65A-1 (West 2006); OR. REV. STAT. ANN. § 435.485 (West 2003).

17. See, e.g., ARK. CODE ANN. § 20-16-304(5) (West 2005) ("religious or conscientious objection"); FLA. STAT. ANN. § 381.0051(6) (West 2005) ("religious reasons"); ME. REV. STAT. ANN. tit. 22, § 1903(4) (2005) ("religious or conscientious objection"); TENN. CODE ANN. § 68-34-104(5) (2005) ("religious or conscientious objection"); W. VA. CODE ANN. § 16-2B-4 (West 2006) ("personal religious beliefs"); WYO. STAT. ANN. § 42-5-101(d) (2005) ("personal or religious beliefs"); cf. GA. CODE ANN. § 49-7-6 (2005) (permitting refusal due to "personal religious beliefs," but authorizing agency directors "to reassign the duties of any such employees in order to carry out this chapter effectively"); OR. REV. STAT. ANN. § 435.225 (West 2003) (permitting refusal if a procedure is contrary to employee's "personal or religious beliefs," but requiring that employee to "notify the immediate supervisor in writing of such refusal in order that arrangements may be made for eligible persons to obtain such information and services from another employee").

18. See, e.g., ALASKA STAT. § 13.52.060(e) (2005); 20 PA. CONS. STAT. ANN. § 5409(b) (West 2005); W. VA. CODE ANN. § 16-30-12(b) (West 2006).

19. See, e.g., 745 ILL. COMP. STAT. ANN. 70/3 (West 2006); MISS. CODE ANN. § 41-107-3(1) (2005); MISS. CODE ANN. § 41-107-5(1) (2005). But see Doyle, *supra* note 15.

20. State legislatures in Alaska, California, Hawaii, Maine, New Hampshire, New Mexico, and Washington have all passed bills requiring hospital emergency rooms to make emergency contraception available to rape survivors and to allow pharmacists to dispense emergency contraception through a collaborative agreement with a physician. NARAL Pro-Choice Massachusetts, Emergency Contraception Bill (Sept. 15, 2005), <http://www.prochoicemass.org/s10issues/200309292.shtml>. In Massachusetts, the state legislature overrode Governor Mitt Romney's veto of a bill requiring all hospitals to dispense emergency contraception to rape victims. Although the state public health commissioner originally interpreted the law not to apply to private hospitals, *Massachusetts To Exempt Private Hospitals from Emergency Contraception Laws*, NEWS TARGET, Dec. 18, 2005, <http://www.newstarget.com/z015976.html>, Governor Romney's administration eventually overturned that interpretation. On February 15, 2006, the *New York Times* reported that the Massachusetts state pharmacy board ruled that Wal-Mart pharmacies were required under state law to stock and dispense emergency contraception. Katie Zezima, *Massachusetts: Contraceptives Must Be Stocked*, N.Y. TIMES, Feb. 15, 2006, at A20; see also

should be available in hospital emergency rooms for administration to rape victims. As a practical matter, emergency contraception, or the “morning-after pill,” must be dispensed to women within seventy-two hours of unprotected sexual intercourse in order to prevent a pregnancy.²¹ Some state legislatures have passed laws that specifically permit hospitals or pharmacists that hold religious or moral objections to refuse to dispense the medication,²² while others have enacted laws requiring all hospitals, including religious hospitals, to dispense the drug.²³ The relationships between state legislatures and state governors are being severely tested as governors veto these bills, some on the basis that the State should not interfere with the physician-patient relationship²⁴ and others on the basis that the State should not interfere with the rights of religious hospitals.²⁵

Some may challenge the appropriateness of state-licensed hospitals refusing to provide emergency contraception to rape victims. Others may question the professionalism of the pharmacist who refused to dispense birth control pills and the physician and nurse who refused to provide the medical treatment necessary to preserve their patient’s reproductive capacity. Nevertheless, since the early 1970s, the U.S. Congress and most state legislatures have widely accepted the ability of health care professionals and institutions to refuse to perform their

Doyle, *supra* note 15; Janet Napolitano, Veto Statement (Apr. 13, 2005), <http://www.governor.state.az.us/press/2005/0504/veto%20letter%20HB%202541.pdf> (vetoing H.B. 2541, which would have permitted “pharmacies and health care institutions to refuse to sell lawfully prescribed health care products and services”); Bill Owens, Veto Statement (Apr. 5, 2005), <http://www.colorado.gov/governor/press/april05/1042.html> (vetoing H.B. 05-1042, which would have required “all hospitals to provide [rape] victims information about the availability of emergency contraception”).

21. E-Medicine Consumer Health, Emergency Contraception, http://www.emedicinehealth.com/emergency_contraception/article_em.htm (last visited Apr. 6, 2006).

22. *See, e.g.*, H.B. 2541, 47th Leg., 1st Reg. Sess. (Ariz. 2005) (permitting pharmacists to refuse to provide emergency contraception if doing so conflicts with their moral or religious beliefs). The bill was vetoed by Governor Napolitano on April 5, 2005. Napolitano, *supra* note 20; *cf.* A.B. 21, 2005-2006 Leg., Reg. Sess. (Cal. 2005) (requiring pharmacies to find ways to fill prescriptions when an individual pharmacist refuses to provide medication on moral or religious grounds).

23. *See, e.g.*, H.B. 05-1042, 65th Leg., 1st Reg. Sess. (Colo. 2005) (requiring hospitals to tell rape victims about the availability of emergency contraception). Governor Bill Owens vetoed the bill. Owens, *supra* note 20. At the federal level, Senator Lautenberg (D-NJ), Representatives Carolyn Malone (D-NY), and Debbie Wasserman-Schultz (D-FL) recently introduced the Access to Legal Pharmaceuticals Act, H.R. 1652, 109th Cong. (2005), that would allow individual pharmacists to refuse to fill a prescription, but only if another pharmacist at the same pharmacy would fill it.

24. *See, e.g.*, Napolitano, *supra* note 20.

25. *See, e.g.*, Owens, *supra* note 20.

professional responsibilities because of their personal moral or religious beliefs. On the federal level, Congress passed the Hyde-Weldon Amendment in 2004, which requires federal funds to be disbursed only to federal agencies that honor so-called conscience clauses; as a condition of federal funding, agencies must allow the institutions, insurers, health care facilities, and individual health care providers that they fund to refuse to provide, pay for, provide coverage for, or refer for abortions.²⁶ Unlike the majority of conscience clauses that have proliferated in the past thirty years, the Hyde-Weldon Amendment is so broadly drafted that it does not limit a health care provider's objection to personal belief or conscience. Rather, any reason for refusal will suffice. The Amendment even permits health care providers to refuse to provide, pay for, or even refer patients for abortions when the abortion is necessary to save the life of the mother.²⁷

As overreaching as the Hyde-Weldon Amendment is, it is merely the latest in a series of federal and state laws that allow health care providers, institutions, and insurers to refuse to provide medical care to patients.²⁸ Various professional associations also have incorporated provisions into their official Codes of Ethics that allow their members to decline to perform particular procedures or provide certain services on the basis of their personal beliefs.²⁹ Until 2005, the Joint

26. Consolidated Appropriations Act of 2005, Pub. L. No. 108-447, Division F, Title V, § 508(d), 118 Stat. 2809 (2004). The Hyde-Weldon Amendment is modeled after the Abortion Non-Discrimination Act of 2003. H.R. 3664, 108th Cong. (2003); S. 1397, 108th Cong. (2003). The House of Representatives passed a version of this bill in 2002. H.R. 4691, 107th Cong. (2002). The Senate, however, did not consider the measure at that time. Rather, the substance of the bill was incorporated into the Hyde-Weldon Amendment to the Fiscal Year 2005 Appropriations Act. Thus, the measure must be attached to subsequent appropriations acts in order to remain in effect. Nat'l Family Planning & Reprod. Health Ass'n, Federal "Refusal Clause" Signed into Law by President Bush as Part of Omnibus Spending Bill (Dec. 8, 2004), <http://www.nfprha.org/pac/factsheets/anda.asp>.

27. The law is the subject of lawsuits both by the State of California and the National Family Planning and Reproductive Health Association. The State of California contends that the Hyde-Weldon Amendment prevents California from enforcing its own laws regarding medically necessary abortions. Steven Ertelt, *Lawsuit Against Abortion Conscience Clause Can Continue, Judge Rules*, LIFE NEWS.COM, June 29, 2005, <http://www.lifenews.com/net1408.html>. The National Family Planning and Reproductive Health Association has filed suit on the basis that the Hyde-Weldon Amendment contradicts Title X's requirement that information regarding abortion be provided to patients. Nat'l Family Planning & Reprod. Health Ass'n, Press Release: NFPRHA Argues that New Federal Refusal Clause Threatens Women's Reproductive Health, Urges Judge To Enjoin Law (Jan. 5, 2005), <http://www.nfprha.org/media/index.asp?ID=33>.

28. See Lynn D. Wardle, *Protecting the Rights of Conscience of Health Care Providers*, 14 J. LEGAL MED. 177, 178 (1993) ("Forty-four states and the United States presently [as of 1993] have some kind of statutory conscience clause.").

29. See, e.g., AM. MED. ASS'N, H-295.896, CONSCIENCE CLAUSE: FINAL REPORT, available at

Commission on the Accreditation of Healthcare Organizations required hospitals to adopt policies allowing staff members to refuse to participate in certain types of health care.³⁰ Some hospitals have entered into agreements with their staffs acknowledging staff members' rights to refuse to participate in certain types of

<http://www.ama-assn.org> (search "H-295.896"; then follow "Policy Finder - American Medical Association: H-295.896") (last visited March 10, 2006) (requiring medical schools to have "mechanisms in place that permit students to be excused from activities that violate the students' religious or ethical beliefs"); Lois Snyder & Cathy Leffler (for the Ethics and Human Rights Comm., Am. College of Physicians), *Ethics Manual, Fifth Edition*, 142 ANNALS OF INTERNAL MED. 560, 564, 571 (2005) (stating that physicians who object to abortion, sterilization, contraception, or other reproductive services are "not obligated to recommend, perform, or prescribe them," although they are obligated to "transfer care as along as the health of the patient is not compromised," but at the same time recognizing that "[t]he physician's first and primary duty is to the patient" and "[t]he physician's professional role is to make recommendations on the basis of their medical merit and to pursue options that comport with the patient's unique background and preferences"); cf. AM. NURSES ASS'N, CODE OF ETHICS FOR NURSES WITH INTERPRETIVE STATEMENTS Provision 5.4 (2001), available at http://www.nursingworld.org/ethics/code/protected_nwcoe303.htm ("Where a particular treatment, intervention, activity, or practice is morally objectionable to the nurse, whether intrinsically so or because it is inappropriate for the specific patient, or where it may jeopardize both patients and nursing practice, the nurse is justified in refusing to participate on moral grounds. Such grounds exclude personal preference, prejudice, convenience, or arbitrariness. Conscientious objection may not insulate the nurse against formal or informal penalty."). Additionally, the American Pharmacists Association has addressed the refusal rights of its members. The Code of Ethics for Pharmacists affirms that "[a] pharmacist places concern for the well-being of the patient at the center of professional practice." AM. PHARM. ASS'N, CODE OF ETHICS FOR PHARMACISTS (1994), <http://www.apha.org> (follow "Pharmacy Practice" hyperlink; then follow "Code of Ethics" hyperlink under "Pharmacy Practice Resources"). However, in reaction to the legalization of physician assisted suicide in Oregon, the American Pharmacists Association adopted an additional policy stating: "APhA recognizes the individual pharmacist's right to exercise conscientious refusal and supports the establishment of systems to ensure [the] patient's access to legally prescribed therapy without compromising the pharmacist's right of conscientious refusal." *Freedom of Conscience for Small Pharmacies: Hearing Before the H. Small Business Comm.*, 109th Cong. (2005) (statement of Linda Garrelts MacLean, Clinical Assistant Professor of Pharmacotherapy, Washington State University on behalf of the American Pharmacists Association), available at <http://www.house.gov/smbiz/hearings/databaseDrivenHearingsSystem/displayTestimony.asp?hearingIdDateFormat=050725&testimonyId=380>.

30. JOINT COMM'N FOR THE ACCREDITATION OF HEALTHCARE ORGS., COMPREHENSIVE ACCREDITATION MANUAL FOR HOSPITALS: THE OFFICIAL HANDBOOK, at CK-30 (2005) (modifying this standard from one in which the refusal rights of health care workers are emphasized to one which focuses on the needs of patients, suggesting a possible change in focus). This standard previously stated: "The hospital addresses a staff member's request not to participate in any aspect of patient care." *Id.* In 2005, this standard was modified to read: "The hospital follows ethical behavior in its care, treatment, and services and business practices." *Id.* at RI-8.

treatment. Perhaps most notably, St. Vincent's Hospital in Santa Fe, New Mexico, entered into an agreement which allows nurses to "conscientiously object to circumcision."³¹

In addition to circumcisions, nurses and physicians have refused to participate in sterilizations,³² abortions,³³ withdrawal of life support,³⁴ and artificial insemination³⁵ on grounds that these procedures conflict with their religious or moral beliefs. The types of prescriptions that pharmacists have refused to provide include not only contraception and emergency contraception, but even pain-killers for terminally ill patients.³⁶

Against the recent tide of legislation and commentary promoting the expansion of so-called conscience clauses,³⁷ a few scholars have argued in favor of restricting the ability of health care providers who serve the public from refusing to provide certain types of care.³⁸ However, even those commentators

31. St. Vincent Hospital, Memorandum of Understanding for Circumcision Procedure (Jan. 31, 1995), <http://www.consciencelaws.org/Conscience-Policies-Papers/PPPMedicalInst.html#MEMORANDUM%20OF%20UNDERSTANDING%20for%20CIRCUMCISION%20PROCEDURE>.

32. *E.g.*, Taylor v. St. Vincent's Hosp., 369 F. Supp. 948 (D. Mont. 1973) (involving a Catholic hospital that refused to allow a patient to undergo a sterilization procedure at the time she was having a Caesarian section), *aff'd*, 523 F.2d 75 (9th Cir. 1975).

33. *E.g.*, Valley Hosp. Ass'n v. Mat-su Coal. for Choice, 948 P. 2d 963 (Alaska 1997) (involving a hospital that refused to allow elective abortions to be performed at its facility).

34. *E.g.*, Bartling v. Glendale Adventist Med. Ctr., 209 Cal. Rptr. 220 (Ct. App. 1984) (involving a hospital that refused to disconnect a mechanical respirator at the patient's request); *In re Jobes*, 529 A.2d 434 (N.J. 1987) (involving a nursing home that refused to remove a feeding tube from a patient in a vegetative state at the request of her husband); see discussion *infra* Part III.

35. *E.g.*, N. Coast Women's Care Med. Group, Inc. v. Superior Court, No. D045438, 2006 WL 618767 (Cal. Ct. App. Mar. 14, 2006).

36. Baldas, *supra* note 8, at 17.

37. See, *e.g.*, Bryan A. Dykes, *Proposed Rights of Conscience Legislation: Expanding To Include Pharmacists and Other Health Care Providers*, 36 GA. L. REV. 565 (2002); Donald W. Herbe, *supra* note 8; Maureen Kramlich, *Coercing Conscience: The Effort To Mandate Abortion as a Standard of Care*, 4 NAT'L CATHOLIC BIOETHICS Q. 29 (2004); Mark S. Latkovic, *Pro-Life Nurses and Cooperation in Abortion: Ordinary Care or Extraordinary Intervention?*, 4 NAT'L CATHOLIC BIOETHICS Q. 89 (2004); Irene Prior Loftus, *I Have a Conscience, Too: The Plight of Medical Personnel Confronting the Right To Die*, 65 NOTRE DAME L. REV. 699 (1990); Staci D. Lowell, *Striking a Balance: Finding a Place for Religious Conscience Clauses in Contraceptive Equity Legislation*, 52 CLEV. ST. L. REV. 441 (2005); Nikolas T. Nikas, *Law and Public Policy To Protect Health-Care Rights of Conscience*, 4 NAT'L CATHOLIC BIOETHICS Q. 41 (2004); Wardle, *supra* note 28; Carol Hogan, *Conscience Clauses and the Challenge of Cooperation in a Pluralistic Society*, CAL. CATHOLIC CONF., Feb. 2003, available at <http://www.cacatholic.org/rfconscience.html>. See generally Protection of Conscience Project, www.consciencelaws.org (last visited Mar. 23, 2006).

38. See, *e.g.*, William W. Bassett, *Private Religious Hospitals: Limitations upon Autonomous*

who argue against the expansion of refusal clauses generally do not question the right of individual health care professionals to refuse to participate in care to which they object on the basis of their personal consciences.³⁹ Rather, those commentators endorse the autonomous right of individual health care professionals to refuse to provide care based on their religious or moral beliefs. At least one commentator has suggested that the physician's right to assert her personal autonomy in the form of her personal conscience—quite aside from professional ethics—is at least as important as the patient's autonomous right to choose her medical treatment.⁴⁰

This Article argues that, while health care professionals should be encouraged to refuse to participate in treatment that violates the generally accepted professional standards of practice applicable to their professions, the monopolistic state-granted licenses that medical professionals receive should preclude these professionals from injecting their personal beliefs into their professional practices. Such a distinction must be made between *professional* integrity based on prevailing medical ethics and *personal* morality in order not only to protect patient access to medical care, but also to implement health care professionals' fiduciary obligations to their patients. The provision of medically indicated health care should be the health care professional's primary responsibility, subordinating personal religious or moral beliefs to the needs of patients.⁴¹ Recognizing this principle will reinforce patient trust in health care

Moral Choices in Reproductive Medicine, 17 J. CONTEMP. HEALTH L. & POL'Y 455 (2001); Susan Berke Fogel & Lourdes A. Rivera, *Saving Roe Is Not Enough: When Religion Controls Healthcare*, 31 FORDHAM URB. L.J. 725 (2004) [hereinafter Fogel & Rivera, *Saving Roe is Not Enough*]; Sylvia A. Law, *Silent No More: Physicians' Legal and Ethical Obligations to Patients Seeking Abortions*, 21 N.Y.U. REV. L. & SOC. CHANGE 279 (1994-1995); Louis-Jacques Van Bogaert, *The Limits of Conscientious Objection to Abortion in the Developing World*, 2 DEVELOPING WORLD BIOETHICS 131 (2002); Susan Berke Fogel & Lourdes A. Rivera, *Religious Beliefs and Healthcare Necessities: Can They Coexist?*, HUM. RTS. MAG., Summer 2003, at 2, available at <http://www.abanet.org/irr/hr/spring03/religiousbeliefs.html>.

39. See, e.g., Bassett, *supra* note 38, at 456 (arguing that while the refusal rights of individual health care professionals should be secured, health care institutions should be able to refuse only if patients can choose their providers freely).

40. Edmund D. Pellegrino, *Patient and Physician Autonomy: Conflicting Rights and Obligations in the Physician-Patient Relationship*, 10 J. CONTEMP. HEALTH L. & POL'Y 47, 58 (1994) ("The physician-patient relationship is a moral equation with reciprocal rights and obligations. Today, that equation is becoming unbalanced as patient autonomy is elevated to the status of a trumping principle, morally as well as legally. For some, this even implies or includes overriding the physician's values, his discretionary latitude in clinical decisions, and in some cases, even his rights of conscience.").

41. In arguing against the acceptance of physician-assisted suicide, the Supreme Court has acknowledged that "[t]he patient's trust in the doctor's whole-hearted devotion to his best interests

professionals and the integrity of the health care system.

The expected standard of care for health professionals should be to place patients' interests above their own. The patient's autonomous expression of her interests should set the course for medical decision-making, guided by the health care professional's advice. The professional's advice should derive from both clinical evidence and professional ethics. The personal religious or moral beliefs of the health care professional should not play a role in this process.

The wave of legislatively enacted refusal clauses condoning the practice of refusing to participate in the delivery of health care should be abated. Professional schools should teach, institutional policies should encourage, and professional codes of ethics should confirm that health care professionals are professionally obligated to provide patients with requested care—so long as it is not medically contra-indicated, prohibited from the standpoint of professional ethics, or illegal. Disfavoring medical professionals from injecting their personal moral judgments into their clinical decision-making will reinforce the health care professional's fiduciary duty to her patients and bolster the trust placed in her by her patients who should be able to assume that the professional's primary interest is in promoting their health.

This approach does not mean that there is no room for medical professionals to raise issues of personal conscience in refusing to provide medically indicated care, but it does mean that circumstances in which conscientious objection based on personal beliefs is considered acceptable should be rare. To ensure the rarity of their invocation, health care professionals should be admonished that conscientious objections based on personal beliefs, as opposed to professional ethics, will entail consequences. Most severely, where conscientious objection adversely impacts a patient's health, the professional might be subject to reprimand, transfer, or termination.⁴² The Nurses Code of Ethics recognizes this possibility when it states: "[c]onscientious objection may not insulate the nurse against formal or informal penalty."⁴³ When a professional represents herself as a

will be hard to sustain [if physician-assisted suicide is permitted]." *Washington v. Glucksberg*, 521 U.S. 702, 731 (1997) (*Assisted Suicide in the United States: Hearing Before the Subcomm. on the Constitution of the H. Comm. on the Judiciary*, 104th Cong. 355-56 (1996) (statement of Dr. Leon R. Kass)). A similar argument can be put forth against the physician who, in refusing to provide treatment based upon her personal moral code, places her own personal interests ahead of those of the patient, thus violating the patient's trust in the physician's devotion to her best interests.

42. See, e.g., WIS. ADMIN. CODE § Phar 10.03(2) (West 2006) (defining "unprofessional conduct" as "[e]ngaging in any pharmacy practice which constitutes a danger to the health, welfare, or safety of patient or public, including but not limited to, practicing in a manner which substantially departs from the standard of care ordinarily exercised by a pharmacist *which harmed or could have harmed a patient . . .*") (emphasis added).

43. AM. NURSES ASS'N, *supra* note 29, at Provision 5.4.

provider of certain services, she has a responsibility to provide that care without reference to her personal beliefs. This is especially true for medical professionals who, by virtue of their state-granted licenses, hold a monopoly on the type of care they provide.

This Article reviews the history of “conscience” or “refusal” clauses in federal and state laws, as well as their treatment by various courts. Part I highlights the expansion of refusal clauses and the distinctions various clauses make in their coverage. Part II reviews the case law involving both institutions and individuals who have refused to provide care. While both federal and state legislatures are increasingly sympathetic to the passage of broad refusal clauses, courts have been somewhat less lenient in their interpretation of these and related laws. Part III discusses the concurrent and at times opposing movement toward enhanced patient autonomy. In the context of medical decision-making, courts have generally not condoned health care professionals’ prerogatives to advance their values over their patient’s desires. Part IV elaborates on some of the compromises that have been proposed to address potential conflicts between patients’ exercise of their decision-making autonomy and their access to health care, on the one hand, and the health care provider’s personal beliefs, on the other. Part V finds none of these so-called compromises satisfactory. It suggests that the proliferation of these clauses undermines patient autonomy, threatens patient access to care, and subverts patients’ trust in their health care professionals. Rather than being guided by their personal moral judgments, health care professionals should be guided by those ethics that comprise the standard of care of their professions. Part VI argues against the wholesale acceptance of conscience or refusal clauses, positing that the medical needs of the patient should eclipse the personal morality of the treating health care professional. The opportunity for conscientious objection on the basis of the health care professional’s personal morals should be discouraged. Due to the monopolistic nature of health care professionals’ state-granted licenses, these professionals should be obligated to provide requested medical care that is not medically contraindicated, is not outside generally accepted medical or professional ethics, and is not illegal.

I. EXPANSION OF REFUSAL CLAUSES

Refusal clauses first began to proliferate at the state and federal levels following the Supreme Court’s decision in *Roe v. Wade*.⁴⁴ Initially, such clauses granted the rights of health care providers to refuse to participate in abortion and sterilization. However, over the past thirty-five years, refusal clauses have

44. 410 U.S. 113 (1973).

expanded to cover a broader range of entities and types of procedures. While early refusal clauses applied only to direct providers of care and health care institutions,⁴⁵ more recent clauses often extend to indirect providers of care, including payers.⁴⁶ Recent refusal clauses extend far beyond abortion and sterilization to include, in some cases, all types of health services.⁴⁷

The Church Amendment, enacted in 1973, was the first federally mandated conscience clause.⁴⁸ The Amendment prohibited a court or public official from using certain federal funds⁴⁹ to require any individual or institution to perform or assist in performing abortions or sterilization procedures, if doing so would violate the individual's or institution's religious or moral beliefs.⁵⁰ It also prohibited certain federally funded institutions from discriminating in admission for internships and residencies against any health care professional on the basis of her refusal to participate in an abortion or sterilization procedure contrary to her religious or moral beliefs.⁵¹ Finally, it extended protection of the health care professional's right to refuse beyond abortion and sterilization to *all health services* funded through the Department of Health and Human Services (DHHS), specifying that no individuals participating in programs and research activities funded through DHHS "shall be required to perform or assist in the performance of any part of a health service program . . . if his performance or assistance in the performance of such part of such programs . . . would be contrary to his religious beliefs or moral convictions."⁵²

45. See, e.g., OR. REV. STAT. ANN. § 435.485 (West 2005) (effective 1969) ("No physician is required to give advice with respect to or participate in any termination of a pregnancy if the refusal to do so is based on an election not to give such advice or to participate in such terminations and the physician so advises the patient.").

46. E.g., MISS. CODE ANN. § 41-107-9 (West 2004) ("A health care payer has the right to decline to pay, and no health care payer shall be required to pay for or arrange for the payment of a health care service that violates its conscience."); see also ARK. CODE ANN. §§ 20-16-304(4)-(5) (West 2005) (extending the right of refusal explicitly to pharmacists who object to providing contraceptives).

47. See, e.g., 745 ILL. COMP. STAT. ANN. 70/1 (West 2005); MISS. CODE ANN. § 41-107-3 (West 2004). The state of Washington was ahead of this trend; it enacted a similarly broad statute in 1995. WASH. REV. CODE ANN. § 70.47.160 (West 2006) (effective 1995).

48. Health Programs Extension Act of 1973, Pub. L. No. 93-45, § 401(b), 87 Stat. 91 (codified as amended at 42 U.S.C. § 300a-7 (2000)).

49. *Id.* ("[T]he Public Health Service Act [42 U.S.C. § 201 et seq.], the Community Mental Health Centers Act [42 U.S.C. § 2689 et seq.], or the Developmental Disabilities Services and Facilities Construction Act [42 U.S.C. § 6000 et seq.] . . .").

50. 42 U.S.C. § 300a-7(b).

51. 42 U.S.C. § 300a-7(e).

52. 42 U.S.C. § 300a-7(d).

Enacted in response both to *Roe*, which effectively required all states to permit non-therapeutic abortions, and to *Taylor v. St. Vincent's Hospital*,⁵³ in which a Catholic hospital was compelled to perform a tubal ligation in violation of Catholic directives, the Church Amendment set the course for subsequent legislation at both the state and federal levels. Although some states had refusal statutes in place that addressed “therapeutic abortions”⁵⁴ before *Roe* was decided,⁵⁵ there was a flurry of legislative activity after *Roe*, with state legislatures creating rights of refusal for both health care professionals and institutions to permit them not to participate in now-legalized abortions.⁵⁶ Some statutes were limited to abortion,⁵⁷ but others included rights of refusal for both abortion and sterilization procedures.⁵⁸ While most permitted both health care institutions and individuals to refuse to participate in abortions, some gave

53. 369 F. Supp. 948 (D. Mont. 1973), *aff'd*, 523 F.2d 75 (9th Cir. 1975). The plaintiffs sued the hospital under 42 U.S.C. § 1983 and 28 U.S.C. § 1343, claiming that the hospital, due to its receipt of Hill Burton funds (i.e., funds provided for hospital construction under Title VI of the Public Health Service Act, 42 U.S.C. § 291 (2000)), had acted under the color of state law when it deprived them of their right to have tubal ligation surgery at the hospital. The district court initially ruled that the hospital’s receipt of federal funds was sufficient to make the hospital a state actor for the purpose of the suit. However, the district court dissolved the injunction following Congress’s adoption of the Church Amendment, which “[b]y its plain language . . . prohibits any court from finding that a hospital which receives Hill-Burton funds is acting under color of state law.” *Taylor*, 369 F. Supp. at 950.

54. “Therapeutic abortions” were abortions that were considered medically necessary to preserve the health or life of the pregnant woman. Hospitals often established boards to determine whether an abortion was “therapeutic.”

55. *E.g.*, OR. REV. STAT. ANN. § 435.485 (West 2003) (enacted 1969) (“(1) No physician is required to give advice with respect to or participate in any termination of a pregnancy if the refusal to do so is based on an election not to give such advice or to participate in such terminations and the physician advises the patient . . . (2) No hospital employee or member of the hospital medical staff is required to participate in any termination of a pregnancy if the employee or staff member notifies the hospital of the election not to participate in such terminations.”); N.M. STAT. ANN. § 30-5-2 (West 2005) (enacted 1969) (stating that hospitals are not required to admit patients “for the purposes of performing an abortion,” nor is a “person who is a member of, or associated with, the staff of a hospital, or any employee of a hospital . . . who objects to the justified medical termination on moral or religious grounds” required to participate in the procedure).

56. *E.g.*, ARIZ. REV. STAT. ANN. § 36-2151 (West 2005) (enacted 1973); N.J. STAT. ANN. § 2A:65A-1 (West 2005) (enacted 1974); N.J. STAT. ANN. § 2A:65A-2 (West 2005) (enacted 1974); NEV. REV. STAT. ANN. § 632.475 (West 2005) (enacted 1973); UTAH CODE ANN. § 76-7-306(2) (West 2005) (enacted 1974).

57. *E.g.*, MICH. COMP. LAWS ANN. § 333.20182 (West 2006); NEV. REV. STAT. ANN. § 632.475 (West 2005).

58. *E.g.*, N.J. STAT. ANN. § 2A:65A-1 (West 2005); R.I. GEN. LAWS § 23-17-11 (2005).

special protection to “private or denominational” institutions.⁵⁹

In 1981, Congress again addressed the issue of the right to refuse to participate in certain types of medical care, expanding that right to cover health insurers. As part of its appropriations bill for the District of Columbia, Congress specified that any legislation regarding contraceptive coverage by health insurance plans must contain a “conscience clause” that “provides exceptions for religious beliefs and moral convictions.”⁶⁰

As the number of state refusal clauses in the area of reproductive services continued to increase after 1973, the right of health care providers to refuse to participate in other types of services began to appear after 1976. In that year, the New Jersey Supreme Court decided the case of *In Re Quinlan*, in which the parents of Karen Quinlan, a young woman in a persistent vegetative state, petitioned the court to authorize the removal of the respirator upon which she appeared to depend to breathe.⁶¹ In response to public pressure triggered by this well-publicized case, state legislatures began passing “Natural Death Acts,” which permitted people to prepare living wills through which they could provide medical direction to their care providers in the event that they were not able to express their wishes at the relevant time. Since 1976, all states have enacted some form of advance directive legislation, whether in the form of living wills, durable powers of attorney, or health care proxies;⁶² virtually all of these statutes contain clauses that permit health care professionals to disregard a patient’s or

59. IND. CODE ANN. § 16-34-1-3 (West 2005); *see also* UTAH CODE ANN. § 76-7-306(2) (West 2005).

60. Consolidated Appropriations Resolution, 2003, Division C, Title III, Pub. L. No. 108-7, 117 Stat. 11, 126-27 (2003).

61. *In re Quinlan*, 355 A.2d 647 (N.J. 1976). In fact, Karen lived for ten years after the respirator was removed. Ascension Health: Healthcare Ethics, Quinlan, Karen Ann (2005), <http://www.ascensionhealth.org/ethics/public/cases/case21.asp>. Ten “living will” statutes were enacted between 1976 through 1980 and twenty-nine were enacted between 1981 and 1986. SOCIETY FOR THE RIGHT TO DIE, HANDBOOK OF LIVING WILL LAWS 5 (1987). Other states waited to enact “living will” legislation until the U.S. Supreme Court decided the case of Nancy Cruzan, in which the parents of a young woman in a persistent vegetative state petitioned the court to authorize the removal of the woman’s artificial nutrition and hydration. *Cruzan v. Mo. Dep’t of Health*, 497 U.S. 261 (1990). In her concurring opinion in *Cruzan*, Justice Sandra Day O’Connor specifically encouraged the use of various types of advance directives as “a valuable additional safeguard of the patient’s interest in directing his medical care.” *Cruzan*, 497 U.S. at 291-92 (O’Connor, J., concurring).

62. *See Advance Directives by State*, WALL ST. J., March 22, 2005, *available at* http://online.wsj.com/public/article/SB111144394604885495-4MQpLbfZZSZWMXQ4BdPaL0_1d0k_20050421.html?mod=tff_main_tff_top.

family's wishes due to the health care professionals' personal beliefs.⁶³

As the 1990s progressed, Congress began to focus again on ways to accommodate health care providers who refused to perform various reproductive services. In 1991, Congress adopted the Coats Amendment, which prohibits the government from "discriminating" against medical residency programs or other entities that lose accreditation because they fail to provide or require training in abortion services.⁶⁴ In 1997, Congress extended "conscience protections" to cover Medicaid and Medicare managed care plans, enabling them to refuse to "provide, reimburse for, or provide coverage of a counseling or referral service if the . . . organization offering the plan . . . objects to the provision of such service on moral or religious grounds"⁶⁵ Two years later, after a long battle, Congress agreed to require health plans that insure federal employees to cover prescription contraception; however, Congress explicitly exempted religiously affiliated health plans from this requirement.⁶⁶ Other conscience clauses proscribe "discrimination" against individuals in specified government-funded health plans that refuse to provide contraceptives due to their "religious beliefs or moral convictions,"⁶⁷ or against organizations funded under various international health funding programs that limit the types of treatment they provide based on

63. See, e.g., ALASKA STAT. § 13.52.060(e) (2004) (providing that "[a] health care provider may decline to comply with an individual instruction or a health care decision for reasons of conscience"); N.H. REV. STAT. ANN. § 137-H:6(I) (2005) (providing that a physician is not required to comply with an advance directive if, "because of his personal beliefs or conscience, [he] is unable to comply"); W. VA. CODE § 16-30-12(b) (2005) (providing that no individual health care provider is required to comply with a patient's health care decision if it is "contrary to the individual provider's sincerely held religious beliefs or sincerely held moral convictions"). Very few states do not require unwilling providers to make transfer arrangements. Among that small number are Michigan, which has no Natural Death Act; Minnesota, which establishes explicitly that an unwilling provider need not transfer the patient unless the patient becomes mentally incapacitated and unable to seek transfer, MINN. STAT. ANN. § 145B.06 (West 2005); North Carolina, which interprets N.C. GEN. STAT. § 90-321 (2005) not to require an unwilling institution to transfer a patient, Advisory Opinion: Institutional Objections to Advance Directives, 1996 WL 925107 (May 23, 1996); and Washington, which is silent on the issue of transfer, WASH. REV. CODE ANN. §§ 43.70.480, 70.122.060 (West 2006).

64. 42 U.S.C. § 238(n) (2000) (effective 1996); see also Abortion Non-Discrimination Act of 2005, S. 1983, 109th Cong. (2005) (extending the non-discrimination provision of the Coats amendment beyond the training and licensing of physicians to insurers, other health professionals, facilities, organizations, and plans).

65. 42 U.S.C. § 1395w-22(j)(3)(b) (2000).

66. Consolidated Appropriations Resolution, 2003, Division E, Title II, Pub. L. No. 108-7, 117 Stat. 11, 163 (2003).

67. Consolidated Appropriations Resolution, 2003, Division J, Title VI, § 635(c), Pub. L. No. 108-7, 117 Stat. 11, 472 (2003).

their “religious or conscientious commitment” or “religious or moral objection.”⁶⁸

Currently, virtually all states have legislated refusal clauses that excuse health care professionals or institutions from providing medical care under specified circumstances.⁶⁹ Among the types of treatments and services covered are: abortion,⁷⁰ contraception,⁷¹ insurance to cover contraception,⁷² family planning services or referrals,⁷³ sterilization,⁷⁴ assisted reproduction,⁷⁵ human cloning,⁷⁶ fetal experimentation,⁷⁷ euthanasia,⁷⁸ and termination of life support.⁷⁹

68. United States Leadership Against HIV/AIDS, Tuberculosis, and Malaria Act of 2003, Pub. L. No. 108-25, 117 Stat. 711, 733 (2003); Consolidated Appropriations Resolution, 2003, Division E, Title II.

69. See GUTTMACHER INSTITUTE, STATE POLICIES IN BRIEF: REFUSING TO PROVIDE HEALTH SERVICES (2006), available at http://www.guttmacher.org/pubs/spib_RPHS.pdf (listing all federal and state laws allowing nonparticipation in reproductive health care as of Mar. 1, 2006). Forty-six states allow some health care providers to refuse to provide abortion services; all permit individual health care providers to refuse to provide abortion services; forty-three states allow institutions to refuse to provide abortion services (fifteen states limit the exemption to private or denominational institutions, and one state allows only religious health care entities to refuse to provide abortion services); thirteen states allow some health care providers to refuse to provide services related to contraception (eight states allow individual health care providers to refuse to provide contraceptive-related services; four states explicitly permit pharmacists to refuse to dispense contraceptives; four additional states have broad refusal clauses that may apply to pharmacists); ten states allow health care institutions to refuse to provide services related to contraception (six states limit the exemption to private entities, and one state limits it to religious entities); seventeen states allow some health care providers to refuse to provide sterilization services (sixteen states allow individual providers to refuse to provide sterilization services, and fifteen states allow institutions to refuse to provide sterilization services; four limit the exemption to private entities). *Id.*

70. *See id.*

71. *E.g.*, ARK. CODE ANN. § 20-16-304(5) (West 2005); FLA. STAT. ANN. § 381.0051(6) (West 2005); GA. CODE ANN. § 49-7-6 (2005); ME. REV. STAT. ANN. tit. 22, § 1903(4) (2005); OR. REV. STAT. ANN. § 435.225 (West 2003); TENN. CODE ANN. § 68-34-104(5) (2005); W. VA. CODE ANN. § 16-2B-4 (West 2006); WYO. STAT. ANN. § 42-5-101(d) (2005); *see also* GUTTMACHER INSTITUTE, *supra* note 69.

72. *E.g.*, HAW. REV. STAT. § 431:10A-116.7(a)(4)(b) (2004).

73. *See* NARAL PRO-CHOICE AMERICA FOUNDATION, REFUSAL CLAUSES: DANGEROUS FOR WOMEN'S HEALTH (2006), available at <http://www.prochoiceamerica.org/assets/files/Abortion-Access-to-Abortion-Refusal-Clauses-Refusal-Clauses-Dangerous.pdf>.

74. *See* GUTTMACHER INSTITUTE, *supra* note 69.

75. *See, e.g.*, H.B. 5085, 2005 Gen. Assem., Jan. Sess. (R.I. 2005).

76. *Id.*

77. *Id.*

78. *Id.*; *see also* N.J. STAT. ANN. § 30:11-9 (West 2006) (“Nothing in this act . . . shall give the licensing authority or agency herein provided for the power or authority to require any hospital to

Proponents of expanding the coverage of conscience clauses advocate the application of these clauses to many other procedures, including autopsies, organ transplants, blood transfusions, medical experimentation, and physician-assisted suicide.⁸⁰ Participation in human embryonic stem cell research has already been included in the most recently proposed refusal clauses.⁸¹ Within the past three years, at least two states have enacted far-reaching refusal statutes that define “health care” or “health care services” so broadly as to cover virtually all types of treatment,⁸² and at least three additional state legislatures have proposed similarly far-reaching statutes.⁸³

All refusal statutes, as currently enacted, apply to health care providers who provide direct care to patients.⁸⁴ Many also permit institutions to refuse to

practice or permit sterilization of human beings, euthanasia, birth control or any other similar practice contrary to the dogmatic or moral beliefs of any well established religious body or denomination”); S.D. CODIFIED LAWS § 36-11-70 (2005) (“No pharmacist may be required to dispense medication if there is reason to believe that the medication would be used to . . . [c]ause the death of any person by means of an assisted suicide, euthanasia, or mercy killing.”).

79. See, e.g., N.H. REV. STAT. ANN. § 137-H:6(II) (2005); W.VA. CODE § 16-30-12 (2005).

80. Wardle, *supra* note 28, at 177, 181.

81. See, e.g., H.B. 5085, 2005 Gen. Assem., Jan. Sess. (R.I. 2005).

82. See, e.g., 745 ILL. COMP. STAT. ANN. 70/3 (West 2006) (defining “[h]ealth care” to include “any phase of patient care, including but not limited to, testing; diagnosis; prognosis; ancillary research; instructions; family planning, counseling, referrals, or any other advice in connection with the use or procurement of contraceptives and sterilization or abortion procedures; medication; or surgery or other care or treatment rendered by a physician or physicians, nurses, paraprofessionals or health care facility, intended for the physical, emotional, and mental well-being of persons”); MISS. CODE ANN. § 41-107-3(1) (2005) (defining “Health Care Service” to be “any phase of patient medical care, treatment or procedure, including, but not limited to, the following: patient referral, counseling, therapy, testing, diagnosis or prognosis, research, instruction, prescribing, dispensing or administering any device, drug, or medication, surgery, or any other care or treatment rendered by health care providers or health care institutions.”); see also N.Y. EDUC. LAW § 6527(4)(c) (McKinney 2006) (permitting physicians employed by certain insurers or hospitals to refuse “to perform an act constituting the practice of medicine to which he is conscientiously opposed by reason of religious training and belief”); WASH. REV. CODE ANN. § 70.47.160 (West 2006) (“No individual health care provider, religiously sponsored health carrier, or health care facility may be required by law or contract in any circumstances to participate in the provision of or payment for a specific service if they object to so doing for reason of conscience or religion. No person may be discriminated against in employment or professional privileges because of such objection.”).

83. E.g., H.B. 4741, 93d Leg., 1st Reg. Sess. (Mich. 2005); H. 5085, 2005 Gen. Assem., Jan. Sess. (R.I. 2005); A.B. 207, 97th Leg., Gen. Sess. (Wis. 2005) (vetoed by Governor Jim Doyle on October 14, 2005. Doyle, *supra* note 15).

84. Advance directive statutes tend to focus on physicians. See, e.g., IOWA CODE § 144A.8 (West 2005). Abortion refusal laws, conversely, often include other direct providers. See, e.g., CAL.

provide certain types of medical treatment.⁸⁵ Moreover, some more recently adopted provisions expand coverage to include health care providers not originally envisioned, such as pharmacists.⁸⁶ In doing so, legislators are extending the protection beyond *direct* providers of care to include *indirect* providers of care. Pharmacists are often considered *indirect* providers of care because they do not have prescriptive authority; rather, they are the “middlemen” dispensing medications that have been prescribed by physicians.⁸⁷ Finally, many recently enacted statutes have extended coverage beyond both direct and indirect providers of care to embrace the insurance companies that pay for care.⁸⁸

This expansion raises questions regarding how far removed from direct care

HEALTH & SAFETY CODE § 123420(a) (West 2006) (“a physician, a registered nurse, a licensed vocational nurse, or any other person employed or with staff privileges at a hospital, facility, or clinic [may refuse] to directly participate in the induction or performance of an abortion . . .”); MINN. STAT. ANN. § 145.42 (West 2006) (providing that “[n]o physician, nurse or other person who refuses to perform or assist in the performance of an abortion”).

85. Some statutes limit institutional refusal rights to private and denominational institutions. *E.g.*, S.C. CODE ANN. § 44-41-40 (2005) (providing that “[n]o private or nongovernmental hospital or clinic shall be required to admit any patient for the purpose of terminating a pregnancy”); TENN. CODE ANN. § 68-34-104(5) (2005) (providing that “[n]o private institution . . . shall be prohibited from refusing to provide contraceptive procedures . . . when such refusal is based upon religious or conscientious objection, and no such institution, employee, agent, or physician shall be held liable for such refusal”); *see also* Wardle, *supra* note 28, at 182-85 (describing the coverage of institutions in state conscience clauses).

86. *See, e.g.*, ARK. CODE ANN. § 20-16-304(4)-(5) (2006) (permitting pharmacists to refuse to furnish “any contraceptive procedures, supplies or information”); MISS. CODE ANN. § 41-107-3(b), -3(c), -5(1) (West 2005) (permitting pharmacists and pharmacies not to participate in any health care service if they object on religious, moral, or ethical principles); S.D. CODIFIED LAWS § 36-11-70 (2006) (permitting pharmacist not to dispense drugs that might result in abortion, euthanasia, suicide, or mercy-killing); *see also* S.B. 1485, 47th Leg., 1st Reg. Sess. (Ariz. 2005) (permitting pharmacies and pharmacists not to participate in abortions, contraception, emergency contraception, or sterilizations on “moral or religious grounds”); Baldas, *supra* note 8 (reporting that, in 2004, fourteen states introduced thirty-seven bills to permit pharmacists and other health care providers not only to refuse to participate in abortions, but also to refuse to dispense emergency contraception or other drugs on the basis of personal “moral” objections).

87. This may explain the American Medical Association’s support of legislation that requires pharmacists to fill valid prescriptions or to refer patients immediately to other pharmacies that will do so. *AMA Passes Resolution Saying Pharmacists Should Be Required To Fill All Prescriptions or Provide Immediate Referrals*, KAISER FAM. FOUND.: DAILY REP. (June 21, 2005), http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=30867.

88. *E.g.*, Hyde-Weldon Amendment, Consolidated Appropriations Act 2005, Pub. L. No. 108-447, Division F, Title V § 508(d), 118 Stat. 2809 (2004); MISS. CODE ANN. § 41-107-3 (2005) (enacting the most extensive refusal clause that has been adopted to date, covering a wide variety of health care providers, institutions, and payers).

an individual may be to qualify for protection under a refusal clause. As one commentator inquired:

What if receptionists refused to make an appointment or refused to give the physician a telephone message because they did not approve of something? The pharmacist might refuse to fill a prescription, the cashier might refuse to sell the prescribed item, or the driver of the distributor's delivery truck might refuse to transport it.⁸⁹

There have already been cases by clerks who refused to file information about abortion,⁹⁰ a county health department employee who refused to translate into Spanish information about abortion options,⁹¹ and an emergency medical technician who refused to drive a woman to an abortion clinic.⁹²

Some of these refusal statutes require the objecting health care professional to notify her employer of her objection to participating in a particular medical treatment.⁹³ However, the states disagree as to whether written notice is required,⁹⁴ or whether oral notification will suffice.⁹⁵ In the case of abortion, no state requires notice to be provided at any specific time in advance of the health care professional's refusal,⁹⁶ although some states do require health plans to provide advance notice to patients about services they do not cover in order to give patients an opportunity to choose their insurer based upon such knowledge.⁹⁷ Regarding end-of-life care, some statutes require that institutions

89. Wolffe Nadoolman, *Correspondence*, 353 NEW ENG. J. MED. 1301, 1302 (2005).

90. *Spellacy v. Tri-County Hospital*, No. 77-1788, 1978 WL 3437 (Pa. Ct. Com. Pl. Mar. 23, 1978), *aff'd*, 395 A.2d 998 (Pa. Super. Ct. 1978).

91. *Moncivaiz v. DeKalb County*, No. 03 C 50226, 2004 WL 539994 (N.D.Ill. Mar. 12, 2004).

92. *Adamson v. Superior Ambulance Service*, No. 04C 3247 (N.D. Ill. filed May 7, 2004).

93. *E.g.*, NEV. REV. STAT. ANN. § 632.475 (2005).

94. *See, e.g., id.*; R.I. GEN. LAWS § 23-17-11 (2005); *see also* H.B. 4741 § 5, 93d Leg., 1st Reg. Sess. (Mich. 2005).

95. *See, e.g.*, OR. REV. STAT. § 435.485(2) (2006) (individual must merely "notif[y]" employer of her objection).

96. *But see* H.B. 4741 § 6, 93d Leg., 1st Reg. Sess. (Mich. 2005) (covering all medical services, and requiring the objecting health care provider to "assert his or her conscientious objection": (a) "[u]pon being offered employment," (b) "[a]t the time the health care provider adopts an ethical, moral, or religious belief system that conflicts with participation in a health care service," or (c) "[w]ithin 24 hours after he or she is asked or has received notice that he or she is scheduled to participate in a health care service to which he or she conscientiously objects").

97. For example, in California, health insurers, including managed care organizations, are required to post information in their provider directories informing their members that some providers do not offer a full range of reproductive health services, listing the specific services that may not be available, and providing a toll-free number where consumers call to obtain more

have written policies in place regarding objections, but require no similar documentation for individual health care providers.⁹⁸ Most statutes require institutions and individual health care providers to provide “timely” or “prompt” communication of their refusal policies to patients or their surrogates.⁹⁹ Meanwhile, some states either impose no notification requirement at all or impose no time requirements.¹⁰⁰ This means that patients may find themselves in health care institutions or under the care of health care professionals who object to the type of care they desire, without ever having received any advance notification of the positions of these health care providers. Although the Patient Self-Determination Act¹⁰¹ and the regulations promulgated pursuant to that Act¹⁰²

information about how to access such services. CAL. HEALTH & SAFETY CODE § 1363.02 (West 2000 & Supp. 2004); CAL. INS. CODE § 10604.1 (West 1988 & Supp. 2004); CAL. WELF. & INST. CODE § 14016.8 (West 2001). In Washington state, health carriers are required to: “(i) provide written notice to enrollees, upon enrollment with the plan, listing services that the carrier refuses to cover for reason of conscience or religion; (ii) provide written information describing how an enrollee may directly access services in an expeditious manner; and (iii) ensure that enrollees refused services under this section have prompt access to the information developed pursuant to (b)(ii) of this subsection.” WASH. REV. CODE. § 48.43.065(b) (2006). *See generally* Fogel & Rivera, *Saving Roe is Not Enough*, *supra* note 38, at 740-42.

98. *E.g.*, ME. REV. STAT. ANN. tit. 18-A, § 5-807(e) (2005) (noting that “[a] health-care provider may decline to comply with an individual instruction or health-care decision if the instruction or decision appears not to be in compliance with this Act or for reasons of conscience. A health-care institution may decline to comply with an individual instruction or health-care decision if the instruction or decision . . . is contrary to a policy of the institution that is expressly based on reasons of conscience”); *cf.* 20 PA. CONS. STAT. ANN. § 5409(b) (2005) (permitting a health care provider’s employer to require that her refusal be expressed in writing).

99. *See, e.g.*, ALASKA STAT. § 13.52.060(e-g) (2005); DEL. CODE ANN. tit.16 § 2508(e) (2005); HAW. REV. STAT. ANN. § 327E-7(e) (LexisNexis 2004); ME. REV. STAT. ANN. tit. 18, §5-807 (2005); N.H. REV. STAT. ANN. § 137-H:6(I) (2005); N.M. STAT. ANN. § 24-7A-7(E) (West 2005); 20 PA. CONS. STAT. ANN. § 5409(a) (2005) (requiring the attending physician or health care provider to “promptly” inform the patient); W. VA. CODE § 16-30-12(b)(2) (2005) (requiring the individual health care provider to “promptly inform” the health care decision-maker). *But see* N.Y. PUB. HEALTH LAW § 2984(3)(a) (McKinney 2006) (requiring private hospitals to inform patients or health care agents of conscience-based refusals prior to or upon admission, if reasonably possible).

100. *See, e.g.*, IND. CODE ANN. § 16-36-4-13 (West 2005) (imposing no requirement on the physician to inform the patient of her objections); TENN. CODE ANN. § 32-11-108(a) (West 2005) (imposing no time requirements for notification).

101. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, § 4206, 104 Stat 1388 (1990) (codified as amended in relevant part at 42 U.S.C. 1395cc(f) (2000)) (requiring health care facilities to provide patients with written information about their rights under state law to refuse medical treatment). Regulations promulgated pursuant to the Act require institutions to inform patients of any written policies that limit the institution’s willingness to comply with a patient’s wishes, including a clarification of “any differences between institution-wide conscience objections

do require health care institutions to provide written information to patients about their written policies, “including a clear and precise statement of limitation if the provider cannot implement an advance directive on the basis of conscience,”¹⁰³ the notice is generally provided to a patient only at the time of admission,¹⁰⁴ often too late for a patient preparing to undergo urgent surgery to choose another provider. Even when the patient is “on notice” that a health care institution objects to a certain type of care because of religion-based policies, the patient may not be in a position to obtain care elsewhere. This is the case when a patient is brought to a hospital emergency room by ambulance. This situation may also occur when patients, either as a result of their employment relationships or because they are poor, are involuntarily placed into managed care programs that restrict the facilities from which they may seek covered care. Finally, patients seeking routine treatment are unlikely to base their hospital choice on the hospital’s position regarding a procedure that the patient assumes she will not encounter. For example, a patient entering a hospital for a routine appendectomy may not anticipate an “adverse medical event” that renders her permanently unconscious, thereby triggering the need for enforcement of her advance directive.

Unlike abortion refusal statutes, advance directive statutes usually require individuals and institutions to cooperate in facilitating the transfer of the patient to an institution that will comply with a patient’s wishes.¹⁰⁵ However, some of these statutes leave arrangements for the transfer up to the patient’s surrogate, rather than the objecting health care professional or institution.¹⁰⁶ In many cases,

and those that may be raised by individual physicians.” Final Regulations Promulgated Pursuant to the Patient Self-Determination Act, 42 C.F.R. § 489.102(a)(1)(ii)(A) (2006).

102. 42 C.F.R. § 489.102.

103. 42 C.F.R. § 489.102(a)(1)(ii).

104. 42 C.F.R. § 489.102(b). In the case of home health agencies and personal care services, notice must be provided “in advance of the individual coming under the care of the institution.” 42 C.F.R. § 489.102(b)(3).

105. *E.g.*, N.H. REV. STAT. ANN. § 137-H:6(II) (2005); W. VA. CODE ANN. § 16-30-12(b)(2) (West 2005). *But see* MINN. STAT. ANN. § 145B.06 (West 2005); WASH. REV. CODE ANN. §§ 70.122.060 (West 2006); Advisory Opinion: Institutional Objections to Advance Directives, 1996 WL 925107 (N.C. Attorney Gen. May 23, 1996) (interpreting N.C. GEN. STAT. § 90-321 (2005) as not requiring an unwilling institution to transfer a patient).

106. *E.g.*, W. VA. CODE § 16-30-12(b)(2) (2005) (“[T]he medical power of attorney representative or surrogate decision maker shall have responsibility for arranging the transfer of the person . . .”); 755 ILL. COMP. STAT. ANN. 35/3(d) (West 2006) (stating that “it is the patient’s responsibility to initiate the transfer to another physician,” but that, if the patient is unable to do so, the physician must notify the patient’s surrogate so that the surrogate can make transfer arrangements). However, Illinois’ broad Health Care Right of Conscience Act specifically excuses

transferring a terminally ill patient to another institution or even another physician within the same institution can be a difficult, if not impossible, task for health care professionals, let alone family members. The New Jersey Supreme Court acknowledged this in the case of *In re Jobes*, in which the nursing home where the patient resided wanted to discharge her rather than comply with the wishes of her family to withdraw her artificial nutrition. The court wrote, "it would be extremely difficult, perhaps impossible, to find another facility that would accept Mrs. Jobes as a patient."¹⁰⁷ Presumably, this is because few institutions would accept an unfamiliar patient for the sole purpose of withdrawing life support. Personal and professional relationships among physicians also often make it uncomfortable to transfer the care of patients within a hospital.

Finally, transferring a patient at such a late stage in treatment is unduly stressful for both the patient and her family. The Superior Court of New Jersey considered this issue in *In re Requena*,¹⁰⁸ when it required a hospital to comply with a patient's request that her artificial nutrition be withdrawn, rather than transfer her to a willing hospital seventeen miles away. The court wrote:

The subverting of hospital policy and offending the sensibilities of hospital administrators and staff were reasonably determined . . . to be subordinate to the psychological harm to be visited upon Mrs. Requena at this time . . . Mrs. Requena . . . finds assurance in the familiar surroundings and the familiar nursing and professional personnel who have been taking care of her . . . [M]oving her from St. Clare's . . . would be a hard psychological and emotional blow to her.¹⁰⁹

When the medical treatment involved is controversial, such as abortion, it may be difficult to find other willing providers in a convenient location.¹¹⁰ Where timing is crucial, for example, in the case of emergency contraception, transferring a patient to another willing provider might delay the administration of the drug to the point that it is no longer effective. Moreover, some health care providers would object not only to participating in a transfer, but even to

health care providers of all types from "perform[ing] assist[ing], counsel[ing], suggest[ing], recommend[ing], refer[ring] or participat[ing] in any way in any form of medical practice or health care service that is contrary to his or her conscience." 745 ILL. COMP. STAT. ANN. 70/6 (West 2006). Presumably, this would include participating in the transfer of a patient to a willing provider.

107. *In re Jobes*, 529 A.2d 434, 450 (N.J. 1987); see also George Annas, *Transferring the Ethical Hot Potato*, 17 HASTINGS CENTER REP. 20 (1987) (criticizing hospitals for engaging in "ethical dumping," that is, transferring patients whose treatment choices they find objectionable).

108. *In re Requena*, 517 A.2d 869 (N.J. Super. Ct. App. Div. 1986).

109. *Id.* at 870.

110. See discussion *infra* Part IV.

informing a patient of the availability of such services elsewhere. This was the case in *Brownfield v. Daniel Freeman Marina Hospital*,¹¹¹ in which the police brought a patient to the emergency room at a Catholic Hospital after having been raped. Although the patient's mother inquired about the "morning-after pill," the hospital refused to provide information concerning this treatment; moreover, it failed to inform the patient that if she wished to receive emergency contraception, she would have to contact another health provider within the required time period.¹¹²

Refusal statutes also differ in how they address situations in which a patient might suffer adverse consequences if she does not receive prompt medical attention. Some statutes contain emergency exceptions;¹¹³ that is, they do not permit health care providers to exercise their refusal rights in emergencies. Others do not address situations in which other health care professionals are unavailable to provide the medically necessary care.¹¹⁴ Statutes that do provide for emergency exceptions often do not define "emergency" or provide extremely limited definitions.¹¹⁵ Other states address the emergency issue in a round-about way by limiting the immunity of the refusing health care provider to situations that do not result in serious injury or death to a patient.¹¹⁶

111. 256 Cal. Rptr. 240 (Ct. App. 1989).

112. *Id.* at 242.

113. *E.g.*, NEV. REV. STAT. ANN. § 632.475 (West 2005).

114. *See, e.g.*, 745 ILL. COMP. STAT. ANN. 70/1-14 (West 2006) (providing for no emergency exceptions and appearing to supersede earlier requirements at 745 ILL. COMP. STAT. 70/6, 70/9 that did not relieve health care providers from providing care against their consciences if they had legal obligations to provide "emergency medical care").

115. *See, e.g.*, KY. REV. STAT. ANN. § 311.800(1) (West 2005) (prohibiting the performance of abortions in publicly owned health care facilities "except to save the life of the pregnant woman"); OKLA. STAT. ANN. tit. 63, § 1-741 (West 2005) (permitting health care providers to refuse to provide medical procedures in connection with an abortion "except when the aftercare involves emergency medical procedure which are necessary to protect the life of the patient"). *But see* H.B. 4741, 93d Leg., 1st Reg. Sess. § 9 (Mich. 2005) (providing a clearer definition of "emergency," refusing to excuse objecting health care professionals from providing treatment in the following circumstances: "(a) A patient's condition, in the reasonable medical judgment of an attending physician or medical director, requires immediate action and no other qualified health care provider is available to provide that health care service. (b) In the event of a public health emergency").

116. *See, e.g.*, MD. CODE ANN. HEALTH-GEN. § 20-214(d) (West 2005) (permitting non-referral, but specifying liability may arise if the failure to refer "would reasonably be determined as: (1) [t]he cause of death or serious physical injury or serious long-lasting injury to the patient; and (2) [o]therwise contrary to the standards of medical care"); OKLA. STAT. ANN. tit. 63, § 1-741 (West 2005) (providing that the immunities granted by the law "shall not include medical procedures in which a woman is in the process of the spontaneous, inevitable abortion of an unborn child, the death of the child is imminent, and the procedures are necessary to prevent the death of the

Many of these statutes provide civil and criminal immunity to objecting health care providers¹¹⁷ and prohibit employers from disciplining¹¹⁸ or discriminating against these health care providers in employment.¹¹⁹ Illinois law provides for the award of treble damages, plus the costs of suit and attorney's fees, for violations of its refusal statute.¹²⁰ The Pennsylvania statute further requires all facilities offering abortions—except for those devoted exclusively to abortion services—to post a notice entitled “Right of Conscience” for the “exclusive purpose of informing medical personnel, employees, agents and students of such facilities of their rights” under the law.¹²¹ Failure to post an adequate notice may result in a civil penalty of up to \$5,000.¹²² Yet, Pennsylvania does not require hospitals or individual providers to notify their prospective patients of their objections, so a patient might not realize when seeking an abortion that the provider is unwilling to provide the service sought.

The most significant difference among the various refusal statutes pertains to the beliefs that may be invoked to justify a refusal to provide medical treatment. At least one state, West Virginia, authorizes individuals and institutional providers to refuse to comply with a patient's wishes regarding end-of-life care only on the basis of “sincerely held religious beliefs” or “sincerely held moral convictions.”¹²³ However, West Virginia appears to be in a very small minority. Many state refusal statutes, especially those regarding abortions and related services, do not even require a health care provider to explain her reasons for refusing to participate in treatment.¹²⁴ The Hyde-Weldon Amendment, along with several state statutes, adopts this approach. For example, New Jersey's abortion refusal statute states simply: “[n]o person shall be required to perform or assist in the performance of an abortion or sterilization.”¹²⁵ No reason must be given.¹²⁶

mother”).

117. *E.g.*, 745 ILL. COMP. STAT. ANN. 70/4 (West 2006); MISS. CODE ANN. § 41-107-5(2) (West 2005); MO. ANN. STAT. § 197.032 (West 2005).

118. *E.g.*, MICH. COMP. LAWS ANN. § 333.20182 (West 2006).

119. *E.g.*, 745 ILL. COMP. STAT. ANN. 70/5 (West 2006); MISS. CODE ANN. § 41-107-5(3) (West 2005); MO. ANN. STAT. § 197.032(3) (West 2005) (“Any person who shall deny or discriminate against another for refusal to perform or participate in an abortion shall be liable to the party injured in an action at law, suit in equity or other redress.”).

120. 745 ILL. COMP. STAT. ANN. 70/12 (West 2006).

121. 18 PA. CONS. STAT. ANN. § 3213(f)(1) (West 2005).

122. § 3213(f)(2).

123. W. VA. CODE ANN. § 16-30-12 (West 2005).

124. *See generally* Rachel Benson Gold & Adam Sonfield, *Refusing To Participate in Health Care: A Continuing Debate*, GUTTMACHER REP. ON PUB. POL'Y, Feb. 2000, at 8, available at <http://www.guttmacher.org/pubs/tgr/03/1/gr030108.pdf>.

125. N.J. STAT. ANN. § 2A:65A-1 (West 2006); *see also* ALASKA STAT. § 18.16.010(b) (2004)

South Carolina's abortion refusal statute requires a "physician, nurse, technician or other employee of a hospital, clinic or physician to advise the hospital, clinic or employing physician in writing that he objects to performing, assisting or otherwise participating in such procedure."¹²⁷ However, it states specifically that "[s]uch notice will suffice without specification of the reason therefor."¹²⁸

As of 1993, more than one-third of jurisdictions in the United States that had enacted conscience clauses failed to state what the acceptable grounds for conscientious objection were.¹²⁹ Lynn Wardle argues that these statutes "irrefutably assume" that the refusal to participate in certain medical treatments is based on conscientious objection.¹³⁰ However, some of these provisions are drafted so broadly that they would equally protect the right of a health care professional to refuse to participate in a medical treatment because the procedure was scheduled too early in the morning or because the procedure was controversial. Thus, their categorization as "conscience" clauses, rather than as pure refusal clauses, is questionable.

Those statutes that do specify that a health care professional's refusal to participate in the provision of certain health services must be based on her personal beliefs are often ambiguously drafted. Among the phrases used are "moral, ethical or religious basis,"¹³¹ "moral or religious grounds,"¹³² "personal beliefs or conscience,"¹³³ "sincerely held religious beliefs or sincerely held moral convictions,"¹³⁴ "reasons of conscience"¹³⁵ and "contrary to the conscience."¹³⁶

(providing that "[n]othing in this section requires a hospital or person to participate in an abortion"); OR. REV. STAT. ANN. § 435.485 (West 2003) ("(1) No physician is required to give advice with respect to or participate in any termination of a pregnancy if the refusal to do so is based on an election not to give such advice or to participate in such terminations and the physician so advises the patient. (2) No hospital employee or member of the hospital medical staff is required to participate in any termination of a pregnancy if the employee or staff member notifies the hospital of the election not to participate in such terminations."); Wardle, *supra* note 28, at 179.

126. *But see* H.B. 4741, 93d Leg., 1st Reg. Sess. § 5(2) (Mich. 2005) ("A health care provider shall notify his or her employer in writing of a conscientious objection The written notice shall be given directly to his or her supervisor and shall include a statement explaining his or her conscientious objection and the health care service or services to which he or she specifically objects to providing or participating in under this act.").

127. S.C. CODE ANN. § 44-41-50(a) (2005).

128. *Id.*

129. Wardle, *supra* note 28, at 196.

130. *Id.* at 197.

131. *E.g.*, NEV. REV. STAT. ANN. § 632.475 (West 2005).

132. *E.g.*, N.M. STAT. ANN. § 30-5-2 (West 2005).

133. *E.g.*, N.H. REV. STAT. § 137-H:6 (2005).

134. *E.g.*, W. VA. CODE § 16-30-12 (West 2005).

135. *E.g.*, ALASKA STAT. § 13.52.060(3) (2005); ME. REV. STAT. ANN. tit. 18, § 5-807(e) (2006).

The refusal bar is set very low, permitting health care providers to refuse to participate in a procedure with only vague justifications.

While most states do not set forth any statutory definitions of the terms they use, the two most comprehensive and most recently passed refusal clauses do provide a detailed definition of “conscience.” The Illinois Health Care Right of Conscience Act defines “conscience” as “a sincerely held set of moral convictions arising from belief in and relation to God or which, though not so derived, obtains from a place in the life of its possessor parallel to that filled by a deity among adherents to religious faiths.”¹³⁷ The Mississippi statute defines “conscience” as follows:

the religious, moral or ethical principles held by a health care provider, the health care institution or health care payer. . . . a health care institution or health care payer’s conscience shall be determined by reference to its existing or proposed religious, moral or ethical guidelines, mission statement, constitution, bylaws, articles of incorporation, regulations or other relevant documents.¹³⁸

While the Illinois statute limits the definition of conscience to quasi-religious moral convictions, Mississippi references religious, moral, and *ethical* principles; however, it is not clear whether the legislature intended to refer to *professional* or *personal* ethical principles, which is a crucial distinction. Furthermore, although some statutes (at least in the case of refusals to comply with a patient’s wishes concerning life support) require institutions to have specific written policies that define their positions, no refusal statutes require the individual health care professional to provide in-depth justification of her position either to the health care professional’s employer or to the patient seeking treatment.¹³⁹ Requiring health care professionals to support their objections with detailed justification is not the answer, however. This Article maintains that refusals for reasons other than those based on commonly accepted medical standards should be discouraged whether or not they are supported with a detailed explanation.

It is not clear whether state refusal clauses are sufficiently broad to protect the rights of health care professionals not only to refuse to participate in

136. *E.g.*, 745 ILL. COMP. STAT. ANN. 70/4 (West 2006).

137. 745 ILL. COMP. STAT. ANN. 70/3(e) (West 2006); *see also* 18 PA. CONS. STAT. ANN. § 3203 (West 2005) (adopting substantively the same language).

138. MISS. CODE ANN. § 41-107-3(h) (West 2005).

139. *But see* H.B. 4741, 93d Leg., 1st Reg. Sess. § 5(2) (Mich. 2005) (requiring a health care provider to “notify his or her employer in writing of a conscientious objection,” which shall include “a statement explaining his or her conscientious objection and the health care service or services to which he or she specifically objects to providing or participating in under this act”).

particular procedures, but also to refuse on the basis of their religious beliefs to treat particular groups of patients, such as homosexuals.¹⁴⁰ For example, may a physician refuse to perform artificial insemination for a lesbian simply because it is against her moral beliefs for lesbians to raise children?¹⁴¹ May she refuse to treat a homosexual with AIDS because she frowns on his sexual activities? What about the conservative Muslim orthopedist who prefers not to treat the sports injury of a female athlete, on the basis that under his interpretation of Islam women should not participate in athletics? Or the physician who refuses to deliver the ninth baby of a patient on Medicaid because she does not believe poor people should have babies? How about the pediatrician who refuses to treat sexually active teenagers because of her “religious convictions”?¹⁴²

Legislatures have only recently begun to address this type of selectivity based on the status of the patient rather than on the type of procedure requested.¹⁴³ While these statutes represent a laudable effort in discouraging health care professionals from discriminating against classes of individuals, none of them is comprehensive in its list of protected groups. For example, while Mississippi’s statute prohibits discrimination on the basis of a patient’s race, color, national origin, ethnicity, sex, religion, creed, or sexual orientation,¹⁴⁴ it does not prohibit discrimination against many other groups, including, for example, unmarried persons. Pending legislation in Michigan offers a fairly comprehensive list: “religion, race, color, national origin, age, gender, height, weight, familial status, marital status, participation in high-risk activities, past or

140. However, professional ethics may discourage refusals on these bases. *See, e.g.*, Snyder & Leffler, *supra* note 29, at 565 (stating specifically that “[t]he denial of appropriate care to a class of patients for any reason, including disease state, is unethical”).

141. *See, e.g.*, N. Coast Women’s Care Med. Group, Inc. v. Superior Court, No. D045438, 2006 WL 618767 (Cal. Ct. App. Mar. 14, 2006); John C. Fletcher, *Artificial Insemination in Lesbians, Ethical Considerations*, 145 ARCHIVES OF INTERNAL MED. 419, 420 (1985) (showing no reluctance in asserting his values in medical decision-making when he argues that since there is “no evidence of concrete harm to such children thus far . . . a physician can act ethically to help a lesbian couple with [artificial insemination] if the partners show a prevailing pattern of responsibility”). *See generally* James W. Jones et al., *Ethics of Refusal To Treat Patients as a Social Statement*, 40 J. VASCULAR SURGERY 1057, 1058 (2004).

142. *See, e.g.*, American Health Lawyers Association, Credentialing and Peer Review Listserve (Feb. 24, 2006) (on file with author) (reporting a case involving a physician refusing to treat sexually active teenagers because of “religious convictions”).

143. *E.g.*, MISS. CODE ANN. § 41-107-5(1) (West 2005) (“Rights of Conscience. A health care provider has the right not to participate, and no health care provider shall be required to participate in a health care service that violates his or her conscience. However, this subsection does not allow a health care provider to refuse to participate in a health care service regarding a patient because of the patient’s race, color, national origin, ethnicity, sex, religion, creed or sexual orientation.”).

144. *Id.*

present medical disease or condition, sexual orientation, employment status, insurance coverage, ability to pay, or method of payment.”¹⁴⁵ However, the apparent inclusiveness of this list suggests that other categories may need to be added in the future. For example, does “gender” or “sexual orientation” cover transgendered individuals? In fact, it is probably impossible to compile an exhaustive list of all the possible groups that might face discrimination, thus limiting the attempted protection afforded by this type of provision.

As the foregoing demonstrates, most states have refusal clauses that can be exercised by both individual and institutional direct health care providers in the context of specified medical procedures. However, the most recently enacted refusal clauses may be invoked by all types of medical providers and payers and may be applied to all kinds of health care services. As Wardle correctly points out in arguing for an expansion of conscience clauses, there is every reason to believe that, as technological innovations increase and health care professionals become more religiously and ethnically diverse, the number of health care professionals who object to participating in certain medical services will also increase.¹⁴⁶ We already see some evidence of the expansion of refusal clauses to include new technologies in pending legislation in Rhode Island, which specifically includes human cloning and human embryonic stem cell research among the health care services in which health care professionals need not participate.¹⁴⁷ Before the technique of artificial insemination became generally available, the issue as to whether it was morally appropriate to provide the procedure to a lesbian never arose. As new technologies develop, it is likely that at least *some* health care providers may object to the application of *some* technology to *some* patient on the basis of *some* religious or moral belief. As certain health care providers object to certain treatments, patients may be forced to choose their health care provider not according to the provider’s professional abilities, but according to her religious and moral beliefs. One commentator suggests that this may lead to a “balkanization of medicine, whereby patients will go only to doctors of their own sect, who prescribe only for pharmacists of that sect, and refer only to specialists of that sect.”¹⁴⁸

145. H.B. 4741, 93d Leg., 1st Reg. Sess. § 9(1)(d) (Mich. 2005).

146. Wardle, *supra* note 28, at 181.

147. H. 5085, 2005 Gen. Assem., Jan. Sess. (R.I. 2005).

148. Nadoolman, *supra* note 89, at 1302. The beginning of “balkanization” can be seen in Susannah Meadows, *Halfway to Heaven: A Catholic Millionaire’s Dream Town Draws Fire*, NEWSWEEK, Feb. 27, 2006, at 39, which describes a Catholic millionaire’s attempt to build a community in southwestern Florida that represents his conservative values. He has asked that pharmacies in the community not carry contraceptives. Naples Community Hospital, which plans to open a clinic in the town, has agreed not to provide birth control to students, although it will provide the pill to the general public. *Id.*

On the contrary, this Article contends that continued expansion of the coverage and breadth of health care professionals' refusal rights will increasingly threaten patient access to medical care. Broader statutes create a slippery slope, in which an increasing number of medical procedures fall into the category of being morally objectionable to some health care professionals, and there is little reason to think that such expansion will abate. As a result, institutions may find it increasingly difficult to provide care and more patients will be denied access to care. If the medical professional is subsequently viewed as placing her self-interest before the patient's best interest, her status, as well as the status of the medical profession writ large, will be detrimentally affected.

II. JUDICIAL TREATMENT OF CONSCIENCE CLAUSES: THE DISPARITY BETWEEN INSTITUTIONAL AND INDIVIDUAL REFUSALS

While state and federal legislators generally have been sympathetic to the introduction of broad-based legislation to expand the refusal rights of health care professionals, the courts have been somewhat less willing to grant such blanket protection, particularly to institutional actors.¹⁴⁹ Courts have been relatively unsympathetic to institutional refusals in two ways. When courts have characterized institutions as public or quasi-public, they have been less willing to permit the institution to refuse to provide requested care.¹⁵⁰ In other cases, courts have interpreted laws so narrowly as to preclude protection for the institution.¹⁵¹

149. See Wardle, *supra* note 28, at 199; Katherine A. White, Note, *Crisis of Conscience: Reconciling Religious Health Care Providers' Beliefs and Patients' Rights*, 51 STAN. L. REV. 1703, 1709-11 (1999).

150. See, e.g., *Doe v. Charleston Area Med. Ctr.*, 529 F.2d 638, 642-43 (4th Cir. 1975); *Wolfe v. Schoering*, 541 F.2d 523, 527 (6th Cir. 1976); *Valley Hosp. Ass'n v. Mat-su Coal. for Choice*, 948 P.2d 963, 972 (Alaska 1997); *Doe v. Bridgeton Hosp. Ass'n*, 366 A.2d 641, 645 (N.J. 1976). *But cf.* *Greco v. Orange Mem'l Hosp. Corp.*, 513 F.2d 873, 880-81 (5th Cir. 1975) (finding that hospital receipt of Hill-Burton grants, county funding of construction of the hospital facilities, lease of county property, requirement under the lease from the county that the hospital accept indigent patients, and benefits accruing to tax-exempt status were insufficient to transform the hospital into a state actor); *Taylor v. St. Vincent's Hosp.*, 523 F.2d 75 (9th Cir. 1975) (holding that the Church Amendment prohibits courts from finding that a hospital that receives Hill-Burton funds is acting under the color of state law for the purpose of deciding the applicability of the Civil Rights Statute of 1964, 42 U.S.C. § 1983 (1979)); *Doe v. Bellin Mem'l Hosp.*, 479 F.2d 756, 757 (7th Cir. 1973) (holding that the hospital's receipt of Hill-Burton grants and state funding, and the fact that the hospital was subject to state regulation, was insufficient to transform it into a state actor); *Jones v. E. Me. Med. Ctr.*, 448 F. Supp. 1156, 1162 (D. Me. 1978) (finding that the hospital's receipt of certain federal funds was insufficient to find "state action" under the Civil Rights Act of 1871 where there was no other state nexus).

151. *Catholic Charities of Sacramento v. Superior Court*, 85 P.3d 67 (Cal. 2004).

In contrast, courts have tended to protect the rights of individual health care professionals to refuse to participate in care, at least insofar as their refusals have applied to reproductive services;¹⁵² however, courts have been less likely to protect the rights of health care providers to refuse to participate in other kinds of care.¹⁵³

A. Institutional Refusals

Shortly after Congress enacted the Church Amendment, the Fourth Circuit established a comparably high bar for determining whether a health care provider's reasons for refusing to perform an abortion fell within the "moral or religious" language of the statute.¹⁵⁴ In this case, *Doe v. Charleston Area Medical Center*, a plaintiff brought suit under 42 U.S.C. § 1983 claiming that the private, nonprofit hospital violated her constitutional rights while acting under "color of state law" in enforcing its policy on abortions—i.e., not permitting the performance of abortions at its facility except where necessary to save the life of the pregnant woman.¹⁵⁵ The Fourth Circuit rejected the hospital's argument that the Church Amendment precluded the court from finding that the hospital was acting under the color of state law based on its receipt of Hill Burton funds.¹⁵⁶

The court found not only that the hospital's receipt of federal funds was in itself a sufficient nexus to make it a state actor for the purposes of Section 1983,¹⁵⁷ but it further concluded that the hospital's policy was based on its belief

152. See, e.g., *Ravenstahl v. Thomas Jefferson Hosp.*, No. 83-5790, 1985 WL 378 (E.D. Pa. Jan. 16, 1985) (abortion); *Kenny v. Ambulatory Ctr. of Miami*, 400 So. 2d 1262 (Fla. Dist. Ct. App. 1981) (abortion); *Larson v. Albany Med. Ctr.*, 676 N.Y.S.2d 293 (App. Div. 1998) (abortion); *Swanson v. St. John's Lutheran Hosp.*, 597 P.2d 702 (Mont. 1979) (sterilization). But see *Disciplinary Proceeding Against Neil T. Noesen*, 01 P.H.M. 080 (Wis. Pharm. Examining Bd. Feb. 28, 2005) (proposed final decision & order), *aff'd*, *Noesen v. Wis. Dep't of Reg. & Licensing Pharm. Examining Bd.*, No. 05CV212 (Wis. Cir. Ct. Feb. 3, 2006) (holdings by both the ALJ and Circuit Court that the pharmacist's religion-based right to refuse to provide pharmacy services was overridden by the patient's right to obtain her prescription for emergency contraception).

153. See, e.g., *Free v. Holy Cross Hosp.*, 505 N.E.2d 1188 (Ill. App. Ct. 1987) (involving a nurse objecting to the transfer of a patient); *Warthen v. Toms River Cmty. Mem'l Hosp.*, 488 A.2d 229 (N.J. Super. Ct. App. Div. 1985) (involving a nurse failing to administer kidney dialysis to terminally ill patient); *Farnam v. Crista Ministries*, 807 P.2d 830 (Wash. 1991) (involving removal of patient's artificial nutrition).

154. *Charleston Area Med. Ctr.*, 529 F.2d at 642-643.

155. *Id.* at 640.

156. Hill-Burton funds are federal funds disbursed under Title VI of the Public Health Service Act, 42 U.S.C. § 291 (2000), to assist public and nonprofit medical institutions in constructing or modernizing their facilities.

157. *Charleston Area Med. Ctr.*, 529 F.2d at 642-43. The Court noted, however, that the receipt

that the policy was required by the West Virginia criminal abortion statute, making the hospital a state actor when it enforced its policy.¹⁵⁸ The court found that the Church Amendment did not prevent it from concluding that the hospital's receipt of Hill Burton funds made the hospital a state actor, finding inadequate the hospital's passing reference in its supporting brief that its policy "is naturally related to the long existing Statute of West Virginia and *motivated thereby from a moral standpoint*."¹⁵⁹ The court found that this meager "attempt [by the hospital] to invoke a moral obligation falls short of an assertion that the policy rests upon moral and religious belief [as required to invoke the protections of the Church Amendment] rather than the West Virginia criminal statute."¹⁶⁰

Several subsequent state courts also characterized private hospitals as "quasi-public" institutions and therefore found that they could not refuse to perform constitutionally protected abortions.¹⁶¹ In 1976, the New Jersey Supreme Court in *Doe v. Bridgeton Hospital Ass'n*¹⁶² held that several private, nonprofit, nonsectarian hospitals were quasi-public institutions because they were nonprofit corporations organized to serve the public, received substantial financial support from federal and local governments and the public, benefited from tax exemptions, were available to the public, and because their properties were "devoted to a use in which the public has an interest and are subject to control for the common good."¹⁶³ As such, these hospitals could not refuse to permit their facilities to be used for first trimester abortions under the state's refusal statute, since to hold otherwise would constitute state action in violation of the federal constitutional right to an abortion during the first trimester.¹⁶⁴

Similarly, the Alaska Supreme Court concluded in 1997 that a hospital was a "quasi-public" institution on the grounds that it had a special relationship with

of Hill-Burton funds had been treated differently by other circuits.

158. *Id.* at 643 (holding that the Charleston Area Medical Center's anti-abortion policy based on West Virginia's criminal abortion statute involved the state sufficiently to constitute the policy "state action" under 42 U.S.C. § 1983). In other words, the court found that because the hospital policy "rests firmly upon what was thought to be the compulsion of state law . . . the hospital acted 'under color of law' when it refused to allow its facilities to be used by Doe for an abortion." *Id.* at 644.

159. *Id.* at 642 n.7 (emphasis added).

160. *Id.*

161. *See, e.g.,* Valley Hosp. Ass'n v. Mat-su Coal. for Choice, 948 P.2d 963, 972 (Alaska 1997); *Doe v. Bridgeton Hosp. Ass'n*, 366 A.2d 641, 645 (N.J. 1976). *But see* Greco v. Orange Mem'l Hosp. Corp., 513 F.2d 873, 880-81 (5th Cir. 1975); *Jones v. E. Me. Med. Ctr.*, 448 F. Supp. 1156, 1162 (N.D. Me. 1978).

162. 366 A.2d 641, 645 (N.J. 1976).

163. *Id.* at 645.

164. *Id.* at 647.

the state through the state's Certificate of Need program, received construction funds from state, local, and federal governments, and also received a significant portion of its operating funds from governmental sources;¹⁶⁵ as such, it could not abridge the plaintiff's right to abortion as protected under the Alaska Constitution.¹⁶⁶ The court rejected the hospital's reliance on the state's "conscience clause" which permitted hospitals to "decline to offer abortions for reasons of moral conscience,"¹⁶⁷ holding that constitutional rights "cannot be allowed to yield simply because of disagreement with them."¹⁶⁸

The Sixth Circuit, in a case challenging the constitutionality of various provisions of Kentucky's abortion statute, also distinguished the ability of "public" hospitals from "private" facilities to invoke Kentucky's "conscience clause," which permits hospitals, other health care facilities, and various health providers to refuse to participate in abortions for "ethical . . . moral, religious or professional reasons."¹⁶⁹ The court held that the conscience clause was not invalid when invoked by private hospitals, but "as applied to public hospitals, unconstitutionally interfered with the woman's constitutional right to abortion."¹⁷⁰

Like the Fourth Circuit in *Charleston*, other courts have rejected hospitals' arguments that they should not be obliged to offer certain health services by narrowly interpreting the applicable law. In 1989, a California appellate court interpreted the refusal clause in California's Therapeutic Abortion Act as not immunizing a Catholic hospital that refused to provide information about the "morning-after-pill" to a rape victim, concluding that the "morning-after-pill" was not an abortion.¹⁷¹ At least two state courts have narrowly interpreted the applicable refusal clauses invoked in actions brought before them, finding in each case that, since the refusal clause specifically referred only to abortions and sterilizations, it could not be invoked to justify the refusal of a health care institution to participate in other types of medical procedures like withdrawing

165. *Valley Hosp. Ass'n*, 948 P.2d at 972.

166. *Id.*

167. *Id.* at 971.

168. *Id.* at 972 (quoting *Brown v. Bd. of Educ.*, 349 U.S. 294, 300 (1955)).

169. *Wolfe v. Schoering*, 541 F.2d 523, 527 (6th Cir. 1976).

170. *Id.*

171. *Brownfield v. Daniel Freeman Marina Hosp.*, 256 Cal. Rptr. 240 (Ct. App. 1989). Whether the "morning-after pill," otherwise known as "emergency contraception," is in fact an abortifacient, is still being challenged by some religious health care providers. See generally NARAL PRO-CHOICE AMERICA, THE DIFFERENCE BETWEEN EMERGENCY CONTRACEPTION AND EARLY ABORTION OPTIONS (RU486) (2006), available at <http://www.prochoiceamerica.org/assets/files/Birth-Control-EC-EC-Mife-difference.pdf>.

artificial life support.¹⁷²

In the related area of state mandated contraceptive insurance coverage, the California Superior Court, in *Catholic Charities of Sacramento, Inc. v. Superior Court*,¹⁷³ denied Catholic Charities' petition for declaratory relief and to enjoin the application of California's Women's Contraception Equity Act, which would have required the organization to provide contraceptive insurance coverage to its employees. Narrowly interpreting the "religious employer" exemption under the statute, the court concluded that the exemption did not apply to a charitable corporation, like Catholic Charities: (1) for which the inculcation of religious values is not the purpose of the entity; (2) which serves people of all faiths; (3) which employs mainly non-Catholics; (4) which offers social services to the general public; and (5) which benefits from a federal tax exemption.¹⁷⁴

The contrast between judicial and legislative approaches is clear in *St. Agnes Hospital of Baltimore v. Riddick*,¹⁷⁵ in which the U.S. District Court for the District of Maryland held that a Catholic hospital was not exempt from providing or arranging for abortion, contraception, and sterilization training in its medical training program as required for accreditation.¹⁷⁶ However, the effect of the court's decision was vitiated when Congress passed the Coats Amendment,¹⁷⁷ which prevents the government from denying accreditation residency training programs that, for religious reasons, refuse to require, refer for, or arrange for abortion training.¹⁷⁸ Thus, like the Church Amendment, which was a reaction to a district court decision in *Taylor v. St. Vincent's Hospital*,¹⁷⁹ the Coats Amendment demonstrates how legislatures have taken steps to undermine the effect of the judicial decisions that limit the rights of health care providers to exercise refusal rights.

172. *Gray v. Romeo*, 697 F. Supp. 580, 589-90 (D.R.I. 1988) (holding that Rhode Island's conscience clause only covers abortion and sterilization); *Elbaum v. Grace Plaza of Great Neck, Inc.*, 544 N.Y.S.2d 840, 847 (App. Div. 1989) (rejecting the nursing home's reliance on the Church Amendment when it refused to withdraw a patient's artificial nutrition and hydration since it concluded that the Church Amendment only applies to abortion and sterilization); see also Wardle, *supra* note 28, at 202.

173. 85 P.3d 67 (Cal. 2004).

174. *Id.* at 94-95.

175. 748 F. Supp. 319 (D. Md. 1990).

176. *Id.* at 331-32.

177. 42 U.S.C. § 238n (2000) (effective Apr. 26, 1996).

178. 42 U.S.C. § 238n(b). Thus, physicians training in obstetrics and gynecology in certain religious hospitals will be certified without having the skills to provide comprehensive health care to their patients.

179. 523 F.2d 75, 76 & n.1 (9th Cir. 1975) (discussing the legislative history of the Church Amendment).

B. Individual Refusals

In the context of individual refusals, courts have tended to be comparatively more sympathetic to plaintiffs who refuse to participate in abortions and sterilizations¹⁸⁰ than those who refuse to participate in other medical services,¹⁸¹ and more sympathetic to refusals based on moral or religious beliefs¹⁸² than those based on professional ethical principles or public policy.¹⁸³ However, in the cases in which plaintiffs asserted that their refusal to participate in certain medical services arose from their professional ethics or public policy concerns, courts often have affirmed the validity of invoking a public policy justification even while finding that the facts in the cases before them failed to support such a justification.

Most cases in which courts have upheld the refusal rights of health care professionals have involved health care professionals who have been discharged

180. See, e.g., *Ravenstahl v. Thomas Jefferson Hosp.*, No. 83-5790, 1985 WL 378 (E.D. Pa. Jan. 16, 1985); *Kenny v. Ambulatory Ctr. of Miami*, 400 So. 2d 1262, 1267 (Fla. Dist. Ct. App. 1981); *Swanson v. St. John's Lutheran Hosp.*, 597 P.2d 702 (Mont. 1979) (finding for a nurse-anesthetist who sued her hospital employer claiming that she had been wrongly dismissed because she had asserted her rights under the state conscience statute, MONT. CODE ANN. § 50-5-502 to -505 (2005), to refuse to participate in sterilization); *Larson v. Albany Med. Ctr.*, 676 N.Y.S.2d 293 (App. Div. 1998) (finding for nurses who objected to participating in an abortion due to fetal death after they sued their medical center employer pursuant to N.Y. CIV. RIGHTS LAW § 79-I (McKinney 2006), which prohibits discrimination against individuals who refuse, due to conscience or religious beliefs, to participate in an abortion).

181. See, e.g., *Free v. Holy Cross Hosp.*, 505 N.E.2d 1188 (Ill. App. Ct. 1987) (finding against a nurse attempting to sue a hospital employer under Illinois Right of Conscience Act, 745 ILL. COMP. STATE ANN. 70/2 (West 2006), which permits health care providers to refuse to act in contravention to their consciences, after she was allegedly fired for objecting to the transfer of a patient); *Pierce v. Ortho Pharm. Corp.*, 417 A.2d 505 (N.J. 1980) (finding against a physician researcher at pharmaceutical company who filed a complaint for alleged wrongful discharge after she was fired for opposing continued research on a particular formulation of a drug, citing her interpretation of the Hippocratic Oath); *Warthen v. Toms River Cmty. Mem'l Hosp.*, 488 A.2d 229 (N.J. Super. Ct. App. Div. 1985) (finding against a nurse who sued her hospital employer alleging her discharge for failure to administer kidney dialysis to terminally ill patient violated public policy); *Farnam v. Crista Ministries*, 807 P.2d 830 (Wash. 1991) (finding against a nursing home employee who sued a nonprofit Christian organization claiming religious discrimination and wrongful discharge in violation of public policy allegedly based on the employee's reporting to public ombudsman removal of patient's artificial nutrition).

182. See, e.g., *Ravenstahl*, 1985 WL 378; *Kenny*, 400 So. 2d 1262; *Swanson*, 597 P.2d 702; *Larson*, 676 N.Y.S.2d 293.

183. See, e.g., *Free*, 505 N.E.2d 1188; *Pierce*, 417 A.2d 505; *Warthen*, 488 A.2d 229; *Farnam*, 807 P.2d 830.

from their employment or demoted due to their religion-based refusals to participate in abortions or sterilizations. Health care professionals have sued their employers asserting that their termination or demotion violated a state conscience clause,¹⁸⁴ a state or federal civil rights statute,¹⁸⁵ the First Amendment rights to freedom of religion and free expression of religion,¹⁸⁶ or public policy under the common law.¹⁸⁷ Although not specifically enacted with health care professionals in mind, the federal statute most frequently invoked by employees of health care institutions to protect their right of conscience is Title VII of the Civil Rights Act of 1964.¹⁸⁸ As amended in 1972, the Civil Rights Act requires employers to accommodate the religious beliefs of their employees unless such accommodation results in undue hardship for the employer.¹⁸⁹ Several plaintiffs have brought successful suits against their employers based on their employers' alleged refusal to accommodate satisfactorily the employee's religion-based refusals to participate in certain medical procedures.¹⁹⁰

184. See, e.g., *Moncivaiz v. DeKalb County*, No. 03 C 50226, 2004 WL 539994 (N.D. Ill. Mar. 12, 2004); *Free*, 505 N.E.2d 1188; *Swanson*, 597 P.2d 702; *Farnam*, 807 P.2d 830.

185. See, e.g., *Shelton v. Univ. of Med. & Dentistry of N.J.*, 223 F.3d 220 (3d Cir. 2000); *Ravenstahl*, 1985 WL 378; *Larson*, 676 N.Y.S.2d 293; *Spellacy v. Tri-County Hosp.*, No. 77-1788, 1978 WL 3437 (Pa. Ct. Com. Pl. 1978), *aff'd*, 395 A.2d 998 (Pa. Super. Ct. Mar. 23, 1978) (part-time admissions clerk, who refused to file any forms in connection with abortions or sterilizations, filed a Complaint in Equity against her hospital employer alleging that the hospital had violated a provision of the Pennsylvania Human Relations Act, 43 PA. CONS. STAT. ANN. § 955.2(a) (West 2005), which prohibits health care facilities from holding an employee liable for refusing to participate in abortions or sterilizations).

186. See, e.g., *Moncivaiz*, 2004 WL 539994 (addressing claims under 42 U.S.C. § 1983 for violations of the rights to freedom of speech and free exercise of religion under the First and Fourteenth Amendments and denial of equal protection under the Fourteenth Amendment); *Ravenstahl*, 1985 WL 378 (addressing claims based on the rights to freedom of religion, freedom of speech, due process, and equal protection under the U.S. Constitution).

187. See, e.g., *Pierce*, 417 A.2d 505; *Warthen*, 488 A.2d 229; *Farnam*, 807 P.2d 830.

188. 42 U.S.C. § 2000e-2 (2000) (enacted 1964).

189. *Id.*; 42 U.S.C. § 2000e(j) (2000).

190. See, e.g., *Moncivaiz*, 2004 WL 539994 (refusing to dismiss the claim of a part-time secretary that she was denied a promotion on the basis of her religious beliefs because she refused to translate abortion related materials); *Kenny v. Ambulatory Ctr. of Miami*, 400 So. 2d 1262, 1267 (Fla. Dist. Ct. App. 1981) (applying Title VII analysis when interpreting Florida's refusal statute and therefore requiring the reinstatement of a nurse who refused to participate in abortions). *But see*, e.g., *Shelton*, 223 F.3d at 228 (finding a hospital not liable to a nurse under Title VII of the Civil Rights Act of 1964, 42 U.S.C. §§ 2000e(j), 2000e2(a)(1) (2000), since the hospital had attempted to accommodate the nurse's religion-based objections); *Ravenstahl*, 1985 WL 378 (rejecting a nun-nurse's claims under the Civil Rights Acts of 1871 and 1964 that she was discriminated against for expressing her opposition to a late abortion, stating that "persons opposed

In *Swanson v. St. John's Lutheran Hospital*,¹⁹¹ the Montana Supreme Court permitted a nurse anesthetist to invoke the state's conscience clause to justify her refusal to participate in a sterilization procedure, notwithstanding the fact that she had participated in many previous sterilization procedures without objection and that she had not indicated at the time of her objection that her refusal was based on the "religious beliefs or moral convictions" required by the statute.¹⁹² The court found that there was "overwhelming evidence that all parties knew at the time why she was refusing to participate,"¹⁹³ that the Montana statute required the objecting health care professional to state her moral or religious objections only if requested, and that the hospital did not make such a request in this case. Therefore, the court concluded that the nurse's failure to state the reasons for her refusal at the time of the refusal was not determinative. The court found further that the nurse was not bound to state the "precise commandment, dogma, or tenet that leads to her refusal: [because t]he intent of the legislature in so providing is manifest: A person's conscience about sterilization need not be related to any particular religion, cult, or sect, but may be a part of the person's indefinable concept of the natural law, not easily explained in an A-B-C fashion."¹⁹⁴ Thus, this court set a very low bar for health care professionals who choose to refuse to participate in certain types of medical care: they need to provide only vague, "indefinable" justification for their refusals.

Likewise, a Florida appellate court in *Kenny v. Ambulatory Centre of Miami, Florida, Inc.*¹⁹⁵ did not focus on the substance of the religious beliefs of a nurse who sued an ambulatory care center after she was demoted for refusing to participate in abortions and other related birth control and sterilization operations. Rejecting the lower court's finding that the employer's decision was based on "fiscal necessity,"¹⁹⁶ and applying a federal Title VII analysis to Florida's civil rights statute, the court concluded that accommodating the nurse would not have created "undue hardship" for the clinic, and, thus, the nurse was entitled to reinstatement.¹⁹⁷

In four other cases, courts in Pennsylvania, New York, Illinois, and California found that employees of medical centers stated causes of action under

to abortion on moral, religious, or professional grounds do not constitute the kind of class, animus against which provides a basis for recovery under [42 U.S.C. § 1985 or 1986]]," although the court did conclude that the nurse had a cause of action under Title VII).

191. 597 P.2d 702 (Mont. 1979).

192. *Id.* at 704.

193. *Id.* at 710.

194. *Id.*

195. 400 So. 2d 1262.

196. *Id.* at 1263.

197. *Id.* at 1267.

referenced statutes for religious discrimination based upon their religious or moral positions against abortion. The U.S. District Court of Eastern Pennsylvania in *Ravenstahl v. Thomas Jefferson Hospital*¹⁹⁸ concluded that a nun-nurse who had been discharged for expressing her opposition to abortion stated a cause of action for religious discrimination under Title VII of the Civil Rights Act of 1964.¹⁹⁹ Likewise, a New York appellate court found that employees who alleged that their discharge was due to letters sent to their employer (a medical center) announcing their moral stance against abortion stated a sufficient cause of action for violation of New York's Civil Rights and Executive Laws, which made it an unlawful discriminatory practice to terminate employees because of their religious beliefs.²⁰⁰ The court concluded that the employees' "moral stance" constituted "an expression held with the strength of traditional religious conviction."²⁰¹ In *Moncivaiz v. DeKalb County*,²⁰² the court found that a part-time secretary stated a cause of action against the county under Title VII, 42 U.S.C. § 1983, and the Illinois Health Care Right of Conscience Act when she claimed that she did not receive a promotion after she refused, on the basis of her religious beliefs, to translate abortion-related information. Finally, in an unreported case, a federal jury in Riverside, California, ordered a county public health clinic to pay a born-again Christian nurse damages for back pay and emotional distress, concluding that the County had violated the nurse's constitutional right to free exercise of religion by firing her for refusing to give patients emergency contraception.²⁰³

In contrast, in the *Noesen* case, involving the Wisconsin pharmacist who refused to dispense birth control pills or to transfer the patient's prescription, both the administrative law judge and the circuit court judge concluded that the state's interest in assuring that professionals practice their professions in a competent manner and that patients have access to requested care outweighed the

198. No. 83-5790, 1985 WL 378 (E.D. Pa. Jan. 16, 1985).

199. *Id.* at *1. However, in granting the hospital's motion for partial summary judgment, the court rejected her claims under the Civil Rights Act of 1871 that the hospital had conspired to interfere with her civil rights, since it concluded not only that religion might not be the kind of immutable trait that defines a class that is protected by the Act, but also that "persons opposed to abortion on moral, religious, or professional grounds do not constitute the kind of class, animus against which provides a basis for recovery under [42 U.S.C. § 1985 or 1986]." *Id.* at *3.

200. *Larson v. Albany Med. Ctr.*, 676 N.Y.S.2d 293 (App. Div. 1998).

201. *Id.* at 296.

202. No. 03 C 50226, 2004 WL 539994 (N.D. Ill. Mar. 12, 2004).

203. Associated Press, Jury Sides with Nurse Fired for Refusing To Dispense 'Morning-After' Pills, First Amendment Center, May 29, 2002, <http://www.firstamendmentcenter.org/news.aspx?id=3839>.

pharmacist's constitutional rights to exercise his religion freely.²⁰⁴ The *Noesen* case is an exception, however, and may be explained by the context in which it was brought. Unlike the employment cases in which the "victim" was an employee penalized by her employer for refusing to participate in certain medical treatments, in *Noesen* the complainant was an injured patient who brought an action before a state professional licensing board.

Notwithstanding the *Noesen* case, courts in most reported cases involving employees who refused to participate in reproductive services have found in favor of the employee. Only where plaintiffs rejected their hospital-employers' extensive attempts to find alternative placements have courts held against plaintiffs who objected to participating in reproductive services based on their religious beliefs. In *Spellacy v. Tri-County Hospital*,²⁰⁵ a Pennsylvania court held that a part-time admissions clerk was not protected under the Pennsylvania abortion refusal statute when she refused to perform her clerical duties for patients who were scheduled to have abortions. The Pennsylvania statute protects physicians, nurses, staff members, and employees who state in writing their "objection to performing, participating in, or cooperating in abortion or sterilization on moral, religious or professional grounds."²⁰⁶ However, the court relied on specific language in Pennsylvania regulations that exclude from the definition of "cooperation" the activity of "functioning in ancillary services, such as . . . recordkeeping by clerical personnel."²⁰⁷ The court further concluded that even if there were a duty to accommodate the plaintiff's religious objections, the hospital had made extensive efforts to offer the plaintiff alternative employment, all of which had been rejected by the plaintiff.²⁰⁸

Similarly, in *Shelton v. University of Medicine & Dentistry of New Jersey*,²⁰⁹ the Third Circuit found that the hospital had satisfied its duty when it offered to transfer the nurse to a newborn intensive care unit. In that case, the plaintiff nurse brought a Title VII action against a state hospital alleging that the hospital failed to reasonably accommodate her religious beliefs when she repeatedly refused to participate in abortions, even in emergency situations. Although the court did acknowledge the nurse's sincere religious beliefs, it criticized her for "[h]er unwillingness to pursue an acceptable alternative nursing position . . . [which]

204. Disciplinary Proceeding Against Neil T. Noesen, 01 P.H.M. 080 (Wis. Pharm. Examining Bd. Feb. 28, 2005) (proposed final decision & order), *aff'd*, *Noesen v. Wis. Dep't of Reg. & Licensing Pharm. Examining Bd.*, No. 05CV212 (Wis. Cir. Ct. Feb. 3, 2006).

205. No. 77-1788, 1978 WL 3437 (Pa. Com. Pl. Mar. 23, 1978), *aff'd*, 395 A.2d 998 (Pa. Super. Ct. 1978).

206. 43 PA. STAT. ANN. § 955.2(a) (West 2005).

207. *Spellacy*, 1978 WL 3437, at *3.

208. *Id.* at *5.

209. 223 F.3d 220 (3d Cir. 2000).

undermines the cooperative approach to religious accommodation issues that Congress intended to foster.”²¹⁰

Where health care professionals have refused to participate in medical procedures or related activities other than abortion or contraception, they have generally based their objections on professional ethical or public policy concerns, rather than on religious beliefs—and courts have been much less sympathetic to their concerns.²¹¹ Interpreting the Illinois Right of Conscience Act narrowly to exclude objections based on ethical, as opposed to religious, concerns, an Illinois appellate court, in *Free v. Holy Cross Hospital*,²¹² refused to hold in favor of a discharged nurse. The nurse had been terminated after arguing against the allegedly premature discharge of a patient, based on her “ethical duty as a registered nurse not to engage in dishonorable, unethical or unprofessional conduct.”²¹³ Although the Illinois refusal statute prohibits discrimination against health care providers who refuse, “contrary to their conscience or conscientious convictions . . . to . . . deliver medical services and medical care,”²¹⁴ the court held: “[We] do not believe that the Act contemplates the protection of ethical concerns as opposed to sincerely held moral convictions arising from religious beliefs.”²¹⁵

Conversely, while the Illinois court found the *Free* nurse’s “ethical concerns,” as opposed to her “moral convictions,” to be unprotected by the state refusal statute, two New Jersey courts found “professional ethics,” as opposed to “personal morals,” to be the type of “public policy” that would justify a health care professional’s refusal to participate in an assigned task.²¹⁶ In these cases, the courts distinguished refusals based on “professional ethics,” which they concluded might in some cases constitute a public policy reason for upholding the discharged employee’s right to refuse, from refusals based on the “personal morals” of the plaintiff, which were not justifiable.

In *Pierce v. Ortho Pharmaceutical Corp.*,²¹⁷ a physician sued her employer, a pharmaceutical company, for discharging her after she refused to participate in research involving the use of saccharine in a medication to be provided to

210. *Id.* at 228.

211. *See, e.g.*, *Pierce v. Ortho Pharm. Corp.*, 417 A.2d 505 (N.J. 1980); *cf.* *Free v. Holy Cross Hosp.*, 505 N.E.2d 1188 (Ill. App. Ct. 1987); *Farnam v. Crista Ministries*, 807 P.2d 830 (Wash. 1991).

212. 505 N.E. 2d 1188.

213. *Id.* at 1190.

214. *Id.* (quoting 745 ILL. COMP. STAT. ANN. 70/2 (West 2006) (amended 1998)).

215. *Free*, 505 N.E.2d at 1190.

216. *Pierce v. Ortho Pharm. Corp.*, 417 A.2d 505, 512 (N.J. 1980); *Warthen v. Toms River Cmty. Mem’l Hosp.*, 488 A.2d 229, 233 (N.J. Super. Ct. App. Div. 1985).

217. 417 A.2d 505.

children and elderly persons. She based her refusal on her conclusion that the safety of saccharine was “controversial,” that her interpretation of the Hippocratic Oath prevented her from participating in such controversial research, and that her refusal was therefore justified under the “public policy” exception to the wrongful discharge doctrine.²¹⁸ Although the New Jersey court held in favor of the pharmaceutical company in this case, observing that there was no public policy (and no professional ethical code) against participating in research that is merely asserted to be “controversial,” the court noted that, in some cases, a professional code of ethics would constitute a public policy that would justify the physician’s refusal.²¹⁹ In the case before it, however, the court concluded that “an employee should not have the right to prevent his or her employer from pursuing its business because the employee perceives that a particular business decision violates the employee’s *personal morals*, as distinguished from the *recognized code of ethics* of the employee’s profession.”²²⁰ Furthermore, it observed that “[c]haos would result if a single doctor engaged in research were allowed to determine, according to his or her individual conscience, whether a project should continue.”²²¹

Following the decision in *Pierce*, the New Jersey Superior Court in *Warthen v. Toms River Community Memorial Hospital*²²² held that public policy did not preclude a hospital from discharging a nurse for refusing to administer kidney dialysis to a terminally ill double-amputee patient who on previous occasions had suffered from cardiac arrest and severe internal hemorrhaging during dialysis. The court rejected the nurse’s assertions that continuing to participate in this treatment violated the nursing code of ethics, which obligates nurses to “respect . . . human dignity.”²²³ Relying on *Pierce*, it warned against confusing reliance on “professional ethics” with reliance on “personal morals.”²²⁴ The court held that the nursing code provision “defines a standard of conduct beneficial only to the individual nurse and not to the public at large” since it would have allowed the nurse’s interpretation of “human dignity” to prevail at the expense of the patient’s life and the family’s wishes.²²⁵ It observed that a patient’s right not to have medical treatment terminated against his will is a public policy mandate that “clearly outweighs any policy favoring the right of a nurse to refuse to participate in treatments which he or she *personally* believes threatens human

218. *Id.* at 507-08.

219. *Id.* at 512.

220. *Id.* (emphasis added).

221. *Id.* at 514.

222. 488 A.2d 229 (N.J. Super. Ct. App. Div. 1985).

223. *Id.* at 233.

224. *Id.*

225. *Id.*

dignity.”²²⁶ Adopting the hospital’s argument, the court wrote: “It would be a virtual impossibility to administer a hospital if each nurse or member of the administration staff refused to carry out his or her duties based upon a *personal private belief* concerning the right to live”²²⁷

The Washington Supreme Court also distinguished between stances assumed by health care professionals that further their own personal goals from positions that promote the public good. In *Farnam v. Crista Ministries*,²²⁸ a nursing home employee sued her nonprofit Christian organization employer after she was fired for reporting to the state ombudsman the removal of a patient’s nasal gastric tube, which she believed was in violation of the organization’s Christian principles.²²⁹ To state a cause of action under Washington’s common law policy protecting whistleblowers, the court observed that “Farnam must have been seeking to ‘further the public good, and not merely private or proprietary interests.’”²³⁰ Since the removal of the naso-gastric tube was not illegal under state law, the court denied Farnam’s claim, concluding that “[w]hile the sincerity of Farnam’s belief is not questioned, her concern appears to be directed at urging Christian health care providers to adopt *her view* rather than furthering the public good.”²³¹

The *Shelton* court, in dicta, made a similar point with respect to public hospital employees. Citing *Rodriguez v. City of Chicago*,²³² in which the Seventh Circuit held that a police department had reasonably accommodated the religious objections of a police officer who refused to guard an abortion clinic, the Third Circuit noted:

It would seem unremarkable that public protectors such as police and firefighters *must be neutral* in providing their services. We would include public health care providers among such public protectors [W]e believe public trust and confidence requires that a public hospital’s health care practitioners—with professional obligations to care for the sick and injured—will provide

226. *Id.* at 234 (emphasis added).

227. *Id.* Whether the physician in *Pierce* and the nurse in *Warthen* were, in fact, relying on “personal morals” rather than “professional ethics” is debatable. The physician in *Pierce* referred specifically to a clause in the Hippocratic Oath which read: “I will prescribe regimen for the good of my patients according to my ability and my judgment and never do harm to anyone.” *Pierce v. Ortho Pharm. Corp.*, 417 A.2d 505, 513 (N.J. 1980). The nurse in *Warthen* referred to language regarding “human dignity” in the Nursing Code, *Warthen*, 488 A.2d at 233.

228. 807 P.2d 830 (Wash. 1991).

229. *Id.* at 832.

230. *Id.* at 836 (quoting *Dicomes v. State*, 782 P.2d 1002, 1008 (Wash. 1989)).

231. *Farnam*, 807 P.2d at 836 (emphasis added).

232. 156 F.3d 771 (7th Cir. 1998).

treatment in time of emergency.²³³

The *Rodriguez* court was concerned that the police officer's invocation of his personal religious views to justify his refusal to guard an abortion clinic would have a negative impact on public safety.²³⁴ Similarly, in *Kalman v. Grand Union Co.*,²³⁵ the court expressed concern about the public's safety. In that case, a pharmacist refused to leave un-staffed a pharmacy counter in a grocery store, contrary to the grocery store manager's instructions, because he said that both state law and his professional code of ethics required the pharmacy to be staffed at all hours during which the grocery store remained open. The court found that the pharmacy code's requirement and the public interest both supported having the pharmacy counter staffed at all times because leaving the counter un-staffed "would have exposed the public to the risk that dangerous drugs might be accessible to the public"²³⁶ Thus, the court remanded the case to determine whether the pharmacist's discharge had in fact resulted from his refusal to close the counter.²³⁷

The risk to the public of a physician's refusal to treat patients was also essential to the court's holding in *Fineman v. New Jersey Department of Human Services*.²³⁸ In that case, a physician brought an action against his employer under the New Jersey Conscientious Employee Protection Act (CEPA)²³⁹ after he was discharged from a nursing home for refusing to treat patients not assigned to him in order to "cover" for another physician who was on vacation. The physician had contended that taking responsibility for so many patients would violate his ethical responsibilities based on the Hippocratic Oath and the American Medical Association Principles of Medical Ethics.²⁴⁰ The court distinguished between expressing one's objections, which is protected by CEPA, and "overt acts such as refusal to give medical assistance,"²⁴¹ which are not protected by the law.

233. *Shelton v. Univ. of Med. & Dentistry of N.J.*, 223 F.3d 220, 228 (3d Cir. 2000) (emphasis added).

234. *Rodriguez*, 156 F.3d at 779-80.

235. 443 A.2d 728 (N.J. Super. Ct. App. Div. 1982).

236. *Id.* at 730.

237. *Id.* at 731.

238. 640 A.2d 1161 (N.J. Super. Ct. App. Div. 1994).

239. N.J. STAT. ANN. § 34:19-3(c)(3) (West 2006) ("An employer shall not take any retaliatory action against an employee because the employee . . . [o]bjects to, or refuses to participate in any activity, policy or practice which the employee reasonably believes . . . is incompatible with a clear mandate of public policy concerning the public health, safety or welfare or protection of the environment.").

240. *Fineman*, 640 A.2d at 1166.

241. *Id.* at 1170.

Moreover, the court observed:

When a professional employee merely raises an objection, the *consequences*, and therefore the necessary weighing of competing interests, are apt to differ materially from those produced when the objection is expressed by overt acts such as refusal to give medical assistance Given the advanced age of most residents, it can reasonably be assumed that [the] plaintiff's refusal to see or treat residents whose needs were brought to his attention by the nursing staff, could itself raise competing questions of medical ethics and responsibility.²⁴²

Thus, the court concluded that "a balancing of interests test [the physician's interpretation of his medical ethics as weighed against the health interests of the nursing home residents] could not here support an objectively reasonable determination that there was a clear ethical and legal mandate of public policy requiring a physician to refuse to treat patients in distress."²⁴³

The administrative law judge in *Noesen* engaged in the type of balancing test referred to in *Fineman*, but found herself in the position of weighing a health care professional's religious beliefs, as opposed to his professional ethics, against the potential harm to a patient.²⁴⁴ After hearing testimony from pharmacist experts about the appropriate standard of care for pharmacists and referencing the American Pharmacist Association's *Policy Committee Report on Conscience Clauses and the Pharmacist Code of Ethics*, Administrative Law Judge Baird concluded that Noesen had departed from the "standard of care ordinarily exercised by a pharmacist and which harmed or could have harmed the patient."²⁴⁵ In arriving at this conclusion, she pointed specifically to Noesen's failure to inform the managing pharmacist or pharmacy that he would not transfer a prescription for contraceptives, his refusal to advise the patient of her options in getting her prescription filled elsewhere, his failure to ask the patient if she had any medical conditions that might be adversely affected by a pregnancy, and his refusal to transfer the patient's prescription to another pharmacy.²⁴⁶ Baird observed that Noesen was more concerned with "satisfying his own personal

242. *Id.* (emphasis added).

243. *Id.* at 1171. The clarity of the public mandate was also an issue in *Birthisel v. Tri-Cities Health Services Corp.*, 424 S.E.2d 606 (W. Va. 1992), in which the court found that a Social Work Code of Ethics did not provide sufficiently specific guidance to justify a social worker's refusal to add information to the hospital's Master Treatment Plan in preparation for a visit from an accreditation team.

244. Disciplinary Proceeding Against Neil T. Noesen, 01 P.H.M. 080 (Wis. Pharm. Examining Bd. Feb. 28, 2005) (proposed final decision & order), *aff'd*, Noesen v. Wis. Dep't of Reg. & Licensing Pharm. Examining Bd., No. 05CV212 (Wis. Cir. Ct. Feb. 3, 2006).

245. *Id.* at 7.

246. *Id.* at 18-19.

moral code” than with the health interests of the patient.²⁴⁷ Among other penalties, Judge Baird ordered that Noesen’s license be restricted for two years and required him to attend ethics classes.²⁴⁸ In addition, she ordered him to submit to future employers a detailed notice of the procedures he refuses to perform, as well as the steps he will take to ensure a patient’s access to medication is not impeded by his refusal.²⁴⁹ Judge Baird’s decision was affirmed by the Barron County Circuit Court.²⁵⁰ The Circuit Court also addressed Noesen’s argument that the free exercise of religion protected by the First Amendment of the U.S. Constitution and Article 1, Section 8 of the Wisconsin State Constitution exempted him from complying with the requirements of the Wisconsin Pharmacy Code. Applying a compelling interest/least restrictive means test as required by the Wisconsin Constitution, the court found that the state had compelling interests “in ensuring that health care professionals practice in a competent manner”²⁵¹ as well as “in ensuring that patients are able to access the medications that have been prescribed to them.”²⁵²

In balancing the potential harm to the patient against the religious rights of the pharmacist, both Judge Baird and the appellate court in *Noesen* concluded that the state’s dual compelling interests in assuring that professionals perform their duties in a competent fashion and that patients receive their prescribed medication were sufficient to override the pharmacist’s right to freely exercise his religious beliefs. The *Noesen* case presents a promising approach toward limiting the effect of legislatively enacted refusal clauses—an approach that is consistent with the thesis of this Article. Since refusing to provide medically indicated treatment arguably violates the standard of care required by various state professional regulations, and thereby potentially endangers patient health, aggrieved patients might bring disciplinary actions against offending professionals before applicable state professional boards. Although *Noesen* did not address the issue of patient abandonment, aggrieved patients might make abandonment arguments in cases in which a health care professional has an ongoing relationship with a patient, arguing that the refusal to treat the patient constitutes an “abandonment” of the health care professional’s responsibility to her patients. Like the failure to satisfy the general standard of care required by health care professionals, patient abandonment also often constitutes “unprofessional conduct” under various states’ professional licensing

247. *Id.* at 7.

248. *Id.* at 7-8.

249. *Id.* at 7.

250. *Noesen v. Wis. Dep’t of Reg. & Licensing Pharm. Examining Bd.*, No. 05CV212, slip op. at 17 (Wis. Cir. Ct. Feb. 3, 2006).

251. *Id.* at 15.

252. *Id.* at 16.

regulations.²⁵³

Judge Baird and the appellate court in *Noesen* are in the minority in penalizing a health care professional for refusing to provide treatment to a patient on the basis of his religious beliefs. However, the *Noesen* courts are also in the minority in that they were confronted with a patient who was injured as a result of a health care professional's assertion of his refusal rights. In contrast, the courts in the employment cases faced discharged or demoted health care professionals as the aggrieved plaintiffs. Once injury to patients is at issue, it may be more difficult for courts to be sympathetic to the health care professional's assertion of her refusal rights.

Thus, with the *Noesen* case as a noted exception, most courts have tended to protect the rights of individual health care professionals to refuse to participate in medically indicated treatment on the basis of the health care professional's personal religious beliefs, even if such beliefs are "indefinable."²⁵⁴ This is especially true in cases in which the medical treatment involved is abortion.²⁵⁵ In contrast, courts generally have interpreted the common law public policy exception specifically to exclude reliance on personal beliefs, as opposed to professional ethics or the "public good." As the New Jersey courts have pointed out, allowing the personal religious or moral beliefs of each individual health care professional to determine whether she will practice her profession could potentially create chaos for health care administration and patient care.²⁵⁶ On the other hand, allowing a health care professional to object to participating in patient treatment because of generally accepted professional ethics is unlikely to have such ramifications simply because professional standards have been developed by consensus and, over time, these standards can easily be shared in

253. See, e.g., 49 PA. CODE § 16.61 (2006) (stating, in relevant part, that a physician commits "unprofessional conduct" when she "abandon[s] a patient. Abandonment occurs when a physician withdraws his services after a physician-patient relationship has been established, by failing to give notice to the patient of the physician's intention to withdraw in sufficient time to allow the patient to obtain necessary medical care").

254. *Swanson v. St. John's Lutheran Hosp.*, 597 P.2d 702, 710 (Mont. 1979).

255. In view of the fact that abortion is the only type of medical care that enjoys specific constitutional protection, this finding is paradoxical and suggests a failure to attribute sufficient weight to the state's interest in protecting the right to abortion in balancing this interest against the health care professional's religious or moral beliefs. The Alaska Supreme Court made this point in *Valley Hospital Ass'n v. Mat-su Coalition for Choice*, 948 P.2d 963 (Alaska 1997), in which it held against a quasi-public hospital that refused to permit abortions on the basis of its moral beliefs because "constitutional rights 'cannot be allowed to yield simply because of disagreement with them.'" *Id.* at 979 (quoting *Brown v. Bd. of Educ.*, 349 U.S. 294, 300 (1955)).

256. *Pierce v. Ortho Pharm. Corp.*, 417 A.2d 505, 514 (N.J. 1980); *Warthen v. Toms River Cmty. Mem'l Hosp.*, 488 A.2d 229, 234-5 (N.J. Super. Ct. App. Div. 1985).

advance with the public.

Focusing on the individual's rights of conscience, both refusal statutes and civil rights legislation generally do not consider the ramifications of the health care professional's refusal on patient care. In contrast, when courts have considered health care professionals' refusals in the context of public policy, the effects of the refusals have had a substantial influence on the courts' conclusions. The effects of refusal were central to the courts' holdings in *Kalman*, where the possibility of public access to dangerous drugs was considered an unacceptable public risk,²⁵⁷ and in *Noesen*, where harm to the public was made concrete by the injured plaintiff.²⁵⁸ In line with this reasoning by courts, this Article posits that, in considering the potential ramifications of the health care professional's refusal to provide care, there should be an affirmation of the general rule that the personal interests of health care professionals should not be permitted to prevail over the health needs of their patients.²⁵⁹

III. PROFESSIONALS' RIGHTS OF REFUSAL VERSUS PATIENT AUTONOMY

The trend toward expanding health care professionals' rights to refuse to participate in certain types of medical care has overlapped with an opposing trend toward increasing patients' rights to direct their own medical care. Since the end of World War II, there has been a trend toward respecting patients' autonomous decisions, notwithstanding the objections of physicians or medical institutions.²⁶⁰ Alan Meisel has called this trend toward "the assertion of citizen autonomy"²⁶¹ as reflected, in part, by the recognition of individual autonomy in the doctor-patient relationship, "the greatest revolution of twentieth century American society."²⁶²

Prior to the post-World War II period, most medical decisions were made by physicians with little input from patients. This model of medical decision-making

257. *Kalman v. Grand Union Co.*, 443 A.2d 728, 730 (N.J. Super. Ct. App. Div. 1982).

258. *Disciplinary Proceeding Against Neil T. Noesen*, 01 P.H.M. 080 (Wis. Pharm. Examining Bd. Feb. 28, 2005) (proposed final decision & order), *aff'd*, *Noesen v. Wis. Dep't of Reg. & Licensing Pharm. Examining Bd.*, No. 05CV212 (Wis. Cir. Ct. Feb. 3, 2006).

259. *See also Shelton v. Univ. of Med. & Dentistry of N.J.*, 223 F.3d 220, 228 (3d Cir. 2000) ("It would seem unremarkable that public protectors such as police and firefighters must be neutral in providing their services. We would include public health care providers among such public protectors . . . [W]e believe public trust and confidence requires that a public hospital's health care practitioners—with professional obligations to care for the sick and injured—will provide treatment in time of emergency.").

260. Alan Meisel, *Managed Care, Autonomy, and Decisionmaking at the End of Life*, 35 *HOUS. L. REV.* 1393 (1999).

261. *Id.* at 1397.

262. *Id.*

has been referred to as “medical paternalism” and has been defined as “an action taken by one person in the best interests of another without their consent.”²⁶³ This principle is illustrated by the case of *John F. Kennedy Memorial Hospital v. Heston*,²⁶⁴ in which the New Jersey Supreme Court held that a twenty-two year old woman’s physician was justified in ordering a life-saving blood transfusion over the patient’s surrogate’s religion-based objections. The court reached this ruling not only because the state had a compelling interest in the preservation of life, but also because permitting the physician to act otherwise would violate the professional standards of the medical staff. The court wrote:

Hospitals exist to aid the sick and the injured. The medical and nursing professions are consecrated to preserving life. That is their professional creed When the hospital and staff are . . . involuntary hosts and their interests are pitted against the belief of the patient, we think it reasonable to resolve the problem by permitting the hospital and its staff to pursue their functions according to their professional standards.²⁶⁵

However, beginning slowly in the post-World War I period and quickly following the World War II period,²⁶⁶ challenges to authority resulted in a trend

263. David C. Thomasma, *Beyond Medical Paternalism and Patient Autonomy: A Model of Physician Conscience for the Physician-Patient Relationship*, 98 ANNALS OF INTERNAL MED. 243, 244 (1983) (citing James F. Childress, *Paternalism and Health Care*, in MEDICAL RESPONSIBILITY: PATERNALISM, INFORMED CONSENT, AND EUTHANASIA 15, 18 (Wade L. Rovison & Michael S. Pritchard eds., 1979)). Thomasma provides the example of a physician who recommends a bypass operation to save a patient’s life, while the patient prefers medications over surgery. If the physician tries to talk the patient into the surgery “for his own good,” he is acting paternalistically. Thomasma, *supra*, at 246.

264. 279 A.2d 670 (N.J. 1971), *overruled in part by In re Conroy*, 486 A.2d 1209 (N.J. 1984) (overruled to the extent that the court attributed more weight to the physicians’ professional creed than to the competent patient’s privacy rights); *see also In re Application of the President and Directors of Georgetown College*, 331 F.2d 1000, 1009 (D.C. Cir. 1964) (ordering a hospital to administer a blood transfusion over the religious objections of a twenty-five year old woman in part because she had voluntarily sought medical attention and had exposed the hospital and its doctors to potential civil and criminal liability either for administering the transfusion or allowing her to die); *United States v. George*, 239 F. Supp. 752, 754 (D. Conn. 1965) (emphasizing that a patient should not be able to dictate a course of treatment that required his physicians to ignore their own conscience and to commit virtual malpractice).

265. *Heston*, 279 A.2d at 673.

266. The exposure of war-time atrocities after WWII resulted in a renewed interest in individual rights as exemplified by the Universal Declaration of Human Rights. *See* Universal Declaration of Human Rights, G.A. Res. 217A, at 71, U.N. GAOR, 3d Sess., 1st plen. mtg., U.N. Doc. A/810 (Dec. 12, 1948). Shocking revelations concerning abuses in medical research by the Nazis resulted in the Nuremberg Code, *The Nuremberg Code*, in 2 TRIALS OF WAR CRIMINALS BEFORE THE

of rejecting paternalism in various institutions (including unions, schools, and families)²⁶⁷ and placing enhanced value on the rights of the individual. As the result of the growing consumer and civil rights movements of the 1950s and 1960s, the emphasis among both medical ethicists and the courts began to center on a model of medical decision-making that emphasized patient autonomy and self-determination, rather than physicians' rights. In this model, it is the competent patient, not the physician, who ultimately makes decisions regarding her care, based on the physician's description of the relative risks, benefits, and alternatives available. This model is reflected in the doctrine of informed consent, which has become the "core principle of American bioethics."²⁶⁸

The law of informed consent originated in the oft-quoted statement by Judge Cardozo in the case of *Scholendorff v. Society of New York Hospital*: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body"²⁶⁹ Subsequent cases have affirmed the concept of informed consent and further delineated its legal requirements²⁷⁰ such that it is now generally accepted that physicians must obtain their patients' consent before treating them and that such consent is not valid unless it is "informed;" that is, unless the physician has disclosed to the patient the benefits, risks, and possible alternatives to treatment.²⁷¹

NUREMBERG MILITARY TRIBUNALS UNDER CONTROL COUNCIL LAW NO. 10, at 181-82 (1949), which emphasized the voluntary consent of individuals prior to their participation in research, and the subsequent development of the Belmont Report, NATIONAL INSTITUTES OF HEALTH, BELMONT REPORT: ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH (1979), available at <http://ohsr.od.nih.gov/guidelines/Belmont.html>. The Belmont Report emphasized the rights of individuals with decision-making capacity:

An autonomous person is an individual capable of deliberation about personal goals and of acting under the direction of such deliberation. To respect autonomy is to give weight to autonomous persons' considered opinions and choices while refraining from obstructing their actions unless they are clearly detrimental to others. To show lack of respect for an autonomous agent is to repudiate that person's considered judgments, to deny an individual the freedom to act on those considered judgments, or to withhold information necessary to make a considered judgment, when there are no compelling reasons to do so.

Id. at B(1). These concepts have been applied both by biomedical ethicists and the courts not only in research, but also in clinical contexts.

267. Meisel, *supra* note 260, at 1398.

268. *Id.* at 1399.

269. 105 N.E. 92, 93 (N.Y. 1914).

270. See, e.g., *Canterbury v. Spence*, 464 F. 2d 772, 780 (D.C. Cir. 1972).

271. See, e.g., Med. Care Availability & Reduction of Error Act of 2002, 40 PA. CONS. STAT. ANN. § 1303.504(b) (2005) (effective 2002) ("Consent is informed if the patient has been given a description of a procedure set forth in subsection (a) and the risks and alternatives that a reasonably

Just as individuals have the right to consent to treatment, they also have the right to refuse treatment.²⁷² That right has been tested and upheld, most often in cases in which a patient's life is threatened due to his refusal of life-sustaining or life-prolonging treatment.²⁷³ However, the patient's right to refuse treatment is not absolute. It is balanced against four state interests: the preservation of life, the protection of dependents, the prohibition against suicide, and the protection of the "integrity of medical professionals."²⁷⁴

In general, the "integrity of medical professionals" has not been afforded significant weight in these end-of-life cases because courts have concluded that recognizing the right of the patient to refuse life-prolonging treatment does not, in fact, compromise medical ethics. As the court noted in *Superintendent of Belchertown State School v. Saikewicz*:

Prevailing medical ethical practice does not, without exception, demand that all efforts toward life prolongation be made in all circumstances. Rather . . . the prevailing ethical practice seems to be to recognize that the dying are more often in need of comfort than treatment. Recognition of the right to refuse necessary treatment in appropriate circumstances is consistent with existing medical mores; such a doctrine does not threaten either the integrity of the medical profession, the proper role of hospitals in caring for such patients or the State's interest in protecting the same [I]f the doctrines of informed consent and right of privacy have as their foundations the right to bodily integrity . . . and control of one's own fate, then those rights are superior to the institutional considerations.²⁷⁵

As a result, most subsequent courts that have faced this issue have concluded that

prudent patient would require to make an informed decision as to that procedure. The physician shall be entitled to present evidence of the description of that procedure and those risks and alternatives that a physician acting in accordance with accepted medical standards of medical practice would provide.").

272. Meisel, *supra* note 260, at 1400.

273. See Martha Swartz, *The Patient Who Refuses Medical Treatment: A Dilemma for Hospitals and Physicians*, 11 AM. J.L. & MED. 147, 155-63 (1985).

274. *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 425 (Mass. 1977) (holding that a mentally incapacitated patient suffering from acute myeloblastic monocytic leukemia had the right, through his surrogates, to refuse chemotherapy).

275. *Id.* at 426-27; see also *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 303-04 (Ct. App. 1986) ("Where the performance of one duty [to sustain life] conflicts with the other [to relieve suffering], the choice of the patient . . . should prevail.") (quoting COUNCIL ON ETHICAL & JUDICIAL AFFAIRS, AM. MED. ASS'N, WITHHOLDING OR WITHDRAWING LIFE PROLONGING MEDICAL TREATMENT (1986)); Alan Meisel, *Refusing Treatment, Refusing To Talk and Refusing To Let Go: On Whose Terms Will Death Occur*, 17 L. MED. & ETHICS 221 (1989).

the patient's right to refuse life-prolonging treatment, based on her right to privacy, her liberty interests, or her right to self-determination, should prevail over objections based on outdated concepts regarding what constitutes prevailing medical ethics. As Alan Meisel, a legal authority on the right to die, points out, "[n]ot a single reported case—certainly not a right-to-die case in which the patient was terminally ill and would die relatively soon even if treatment were administered—has ever found this interest [medical integrity] to outweigh a patient's claim not to be treated."²⁷⁶

Even in cases in which health care providers raised religious objections to disconnecting a seriously ill patient's ventilator, courts have concluded that the physicians had a professional obligation to support the patient's wishes. For example, in *Bartling v. Glendale Adventist Medical Center*,²⁷⁷ a competent adult patient with serious, but not terminal, illnesses requested that his ventilator be withdrawn. The hospital submitted a declaration "to the effect that [Glendale Adventist] is a Christian, pro-life oriented hospital, the majority of whose doctors would view disconnecting a life-support system in a case such as this one as inconsistent with the healing orientation of physicians."²⁷⁸ However, while the court did "not doubt the sincerity of real parties' moral and ethical beliefs, or their sincere belief in the position they have taken in this case," it held that "if the right of the patient to self-determination as to his own medical treatment is to have any meaning at all, it must be paramount to the interest of the patient's hospital and doctors."²⁷⁹ Thus, the court held that the lower court erred in denying the patient's petition for a mandatory injunction.²⁸⁰

Chemotherapy and artificial ventilation are not the only types of treatment that courts have approved withdrawing, in compliance with a patient's wishes. Courts have also condoned the withdrawal of artificial nutrition and hydration

276. Alan Meisel, *supra* note 275, at 223-24; *see also Bouvia*, 225 Cal. Rptr. at 301 (declaring, in a case involving the right to refuse medical intervention, including nutrition, that the patient's "right to refuse medical treatment is basic and fundamental . . . Its exercise requires no one's approval. It is not merely one vote subject to being overridden by medical opinion."); *In re Guardianship of Browning*, 568 So. 2d 4, 14 (Fla. 1990) (noting that maintenance of the ethical integrity of the medical profession is the least significant of various State interests in a case involving the right to direct medical treatment). *But cf. McIver v. Krischer*, 697 So. 2d 97 (Fla. 1997) (reversing a lower court order of declaratory and injunctive relief and noting that the state has a compelling interest in maintaining the integrity of the medical profession in the context of a patient's request for a physician's assistance in committing suicide).

277. 209 Cal. Rptr. 220 (Ct. App. 1984).

278. *Id.* at 225.

279. *Id.* The patient's intervening death rendered the case moot, so no court order to transfer the patient was considered.

280. *Id.* at 226 & n.8.

upon a patient's or surrogate's request, even though there was at one time a controversy within the medical community about withholding care that was considered "ordinary," like artificial nutrition and hydration, as opposed to care that was considered "extraordinary," like ventilators.²⁸¹ For example, in *In re Jobes*,²⁸² a private nursing home opposed, on religious grounds, a patient representative's request for the removal of a terminally ill patient's feeding tube. The New Jersey Supreme Court held that the patient's privacy rights superseded the refusal rights of the institution and staff and declined to allow the nursing home to continue the patient's artificial feeding while the patient awaited transfer.²⁸³ One year earlier, in *In re Requena*,²⁸⁴ the New Jersey Superior Court had similarly required a Catholic medical center to comply with a patient's wishes to have her artificial feeding tube withdrawn, reasoning that "the subverting of hospital policy and offending the sensibilities of hospital administration and staff were reasonably determined . . . to be subordinate to the psychological harm to be visited upon Mrs. Requena at this time."²⁸⁵

281. The early end-of-life cases established a distinction between "extraordinary" care, e.g., ventilators, that are extremely invasive and "ordinary" care, e.g., naso-gastric feeding tubes, that are not very invasive and that provide "comfort care." See, e.g., *In re Quinlan*, 355 A.2d 647 (N.J. 1976). But see *Brophy v. New Eng. Sinai Hosp., Inc.*, 497 N.E.2d 626, 637 (Mass. 1986). The *Brophy* court took note of evolving standards within the medical ethical community when it concluded that its primary focus should be on the patient's "desires and experience of pain and enjoyment—not the type of treatment involved." *Id.* at 636. However, because it found that "[t]here is substantial disagreement in the medical community over the appropriate medical action," and more importantly, because the hospital was willing to transfer the patient to a willing institution, the court refused to order physicians, over their ethical objections, to discontinue the artificial nutrition and hydration of a terminally ill patient at the patient's guardian's request. *Id.* at 639.

282. 529 A.2d 434 (N.J. 1987).

283. *Id.* at 450-51.

284. 517 A.2d 869 (N.J. Super. Ct. App. Div. 1986); cf. *Brophy*, 497 N.E.2d at 638-40.

285. *In re Requena*, 517 A.2d. at 870; see also *Gray v. Romeo*, 697 F. Supp. 580, 591 (D.R.I. 1988); *Bartling*, 209 Cal. Rptr. 220 (Ct. App. 1984); *Elbaum v. Grace Plaza of Great Neck, Inc.*, 544 N.Y.S.2d 840, 848 (App. Div. 1989); *Wardle*, *supra* note 28, at 211-15; cf. *Brophy*, 497 N.E.2d 626; *Conservatorship of Morrison*, 253 Cal. Rptr. 530, 534 (Ct. App. 1988) (holding that a physician had the right to refuse on "personal moral grounds" to follow a patient's conservator's direction to remove a life-sustaining naso-gastric tube from a patient as long as the physician was willing to transfer the patient). The court in *Morrison* refrained from ruling on whether a physician could refuse to comply with a conservator's request if no physician were available who agreed to comply with the conservator's wishes, writing: "The issue of whether a court could compel physicians to act contrary to their ethical views is too profound for gratuitous discussion in a dictum." *Morrison*, 253 Cal. Rptr. at 535. The court uses the word "moral" interchangeably with the word "ethical," so that it is unclear whether the court is referring to the physician's personal moral beliefs or his interpretation of his profession's ethical guidelines.

Thus, in end-of-life cases, it is generally accepted within both the medical community and the judiciary that a patient's autonomous wishes should prevail over a health care provider's objections to terminating care. Moreover, courts have even found in favor of patients when physicians and institutions have asserted religion-based objections to terminating treatment.²⁸⁶ This is in contrast to cases involving health care professionals who object to participating in reproductive health care where courts often have been sympathetic to religion-based objections.²⁸⁷

Many commentators have concluded that while health care professionals may be required to respect a patient's right to *refuse* treatment, respect for patient autonomy cannot compel health care professionals affirmatively to *provide* treatment requested by patients, but to which the medical professional objects.²⁸⁸ These commentators point out that the law routinely distinguishes between honoring a patient's decision to refuse care and honoring a patient's decision to demand care.²⁸⁹ The President's Commission on Biomedical Ethics specifically declares, "[a]lthough competent patients . . . have the legal and ethical authority to forego some or all care, this does not mean that patients may insist on

286. See, e.g., *Bartling*, 209 Cal. Rptr. 220; *Jobes*, 529 A.2d 434.

287. See, e.g., *Ravenstahl v. Thomas Jefferson Hosp.*, No. 83-5790, 1985 WL 378 (E.D. Pa. Jan. 16, 1985); *Kenny v. Ambulatory Ctr. of Miami*, 400 So. 2d 1262, 1267 (Fla. Dist. Ct. App. 1981); *Larson v. Albany Med. Ctr.*, 676 N.Y.S.2d 293 (App. Div. 1998).

288. See, e.g., PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMEDICAL & BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT (1983) [hereinafter PRESIDENT'S COMM'N]; Eric M. Levine, *A New Predicament for Physicians: The Concept of Medical Futility, the Physician's Obligation To Render Inappropriate Treatment, and the Interplay of the Medical Standard of Care*, 9 J.L. & HEALTH 69 (1994-1995); James J. Murphy, *Beyond Autonomy: Judicial Restraint and the Legal Limits Necessary To Uphold the Hippocratic Tradition and Preserve the Ethical Integrity of the Medical Profession*, 9 J. CONTEMP. HEALTH L. & POL'Y 451 (1993).

289. *U.S. v. George*, 239 F. Supp. 752, 754 (D. Conn. 1965) ("[T]he doctor's conscience and professional oath must . . . be respected . . . [The patient in this case] sought to dictate to treating physicians a course of treatment amounting to medical malpractice The patient may knowingly decline treatment, but he may not demand mistreatment."); *In re Farrell*, 529 A.2d 404, 412 (N.J. 1987) (observing that "even as patients enjoy control over their medical treatment, health-care professionals remain bound to act in consonance with specific ethical criteria [A] patient has no right to compel a health-care provider to violate generally accepted professional standards"). *But see Jobes*, 529 A.2d at 450 (holding that a nursing home that had no formal policy against withdrawing artificial nutrition must comply with a family's wishes to withdraw artificial nutrition from a patient in a permanent vegetative state since the family "had no reason to believe that they were surrendering the right to choose among medical alternatives when they placed her in the nursing home").

particular treatments.”²⁹⁰ No medical association has recognized the right of patients to demand any treatment they want.²⁹¹ For example, a physician cannot, at a patient’s request, be compelled to prescribe antibiotics for a virus or to perform heart surgery when the physician believes that medication is likely to produce similar results with less risk.

However, a number of courts have refuted this position by ordering that medical professionals provide therapy that the health care professional considers “ineffective” or not beneficial to the patient. For example, in *In Re Wanglie*,²⁹² a Minnesota court rejected a hospital’s and physician’s argument that the care of a patient in a persistent vegetative state—dependent on a ventilator for breathing and a nasogastric tube for feeding—should be withdrawn because further care would be, according to the physicians, “non-beneficial” and “medically inappropriate.”²⁹³ The court concluded that the patient’s husband was the appropriate decision-maker, and, since he had not requested the termination of treatment, the physicians could not initiate a withdrawal order.²⁹⁴

Several commentators have pointed out that the treatment requested by the patient’s husband-conservator in the *Wanglie* case was not “medically futile” since it had the desired effect; that is, it maintained the patient’s life. Conversely, the patient’s physicians considered continued treatment to be “medically futile” in the sense that, in the physicians’ opinions, being kept alive would be of no benefit to the patient in light of her hopeless prognosis. This conclusion, these commentators suggest, was not scientifically based, but rather was based on the physician’s “values,” which conflicted with those of the patient’s conservator who believed that a “miracle” would save his wife.²⁹⁵ Since “[t]he physicians in no way could claim expertise in knowing the value of their patient’s vegetative life,” their recommendations should not be decisive.²⁹⁶ According to this logic, the patient’s autonomous treatment preferences (as expressed by her conservator) were correctly attributed more weight by the court than the physicians’ “medical integrity.”²⁹⁷

290. PRESIDENT’S COMM’N, *supra* note 288, at 44.

291. See Murphy, *supra* note 288, at 478.

292. *In re Wanglie*, No. PX-91-283 (Minn. Dist. Ct. 1991), reprinted in 7 ISSUES IN L. & MED. 369 (1991).

293. Robert M. Veatch & Carol Mason Spicer, *Medically Futile Care: The Role of the Physician in Setting Limits*, 18 AM. J.L. & MED. 15, 21 (1992) (discussing *Wanglie*, No. PX-91-283) (citations omitted).

294. *Wanglie*, No. PX-91-283.

295. Murphy, *supra* note 288, at 457.

296. Veatch & Spicer, *supra* note 293, at 29; see also Murphy, *supra* note 288, at 463.

297. The *Wanglie* court did not engage in balancing the physicians’ “medical integrity” against the patient’s autonomy since it limited itself to deciding *who* the appropriate decision-maker should

Similarly, in *In re Doe*,²⁹⁸ a case involving a thirteen-year-old girl with a neurological degenerative disorder, massive brain damage, and no reasonable hope of recovery, the physicians and the hospital bioethics committee recommended, over the girl's parents' objections, that all extraordinary life-sustaining measures be discontinued. One of the treating physicians concluded that "[i]t's to the point the patient is being abused through medical technology."²⁹⁹ This physician further testified that he found it "ethically and morally unconscionable" to continue treatment.³⁰⁰ Notwithstanding this testimony, as well as evidence that the lingering death of the patient "was having a disastrous effect on the Hospital personnel and [was] demoralizing to the nursing and house staff,"³⁰¹ the court rejected the hospital's and physicians' request to discontinue life support. Instead, physicians were required to continue therapy that they found inappropriate.³⁰²

Veatch and Spicer distinguish between "physiologically futile care," that is, care that is not technically effective in that it is unlikely to achieve the medical goal (for instance, antibiotics will not cure a virus), and "normatively futile care," that is, care that will not produce a "worthwhile outcome."³⁰³ Veatch and Spicer conclude that the patient herself, and not the physician, is the "appropriate

be, not *what* the decision should be.

298. 418 S.E.2d 3 (Ga. 1992).

299. *Judge Rules Parents May Keep Comatose Child Alive*, CHICAGO TRIB., Oct. 18, 1991, at C4.

300. *Id.*

301. Murphy, *supra* note 288, at 458 (quoting *In re Doe*, No. D-93064, slip op. at 23 (Ga. 1991)).

302. See also *In re Baby K*, 16 F.3d 590, 597 (4th Cir. 1994) (holding that the Emergency Treatment and Active Labor Act (EMTALA), 42 U.S.C. § 1395dd (2000), "does not provide an exception for stabilizing treatment [that] physicians may deem medically or ethically inappropriate," finding that EMTALA preempts the Virginia statute that does provide such an exception, and therefore requiring physicians to treat an anencephalic infant, notwithstanding the physician's argument that it was outside the prevailing standard of medical care to treat aggressively an infant without a complete brain who was doomed to die within a short time); *Gray v. Romeo*, 697 F. Supp. 580, 589, 591 (D.R.I. 1988) ("[C]onsideration of the integrity of medical ethics does not present a compelling justification to refuse Marcia Gray's wishes. Indeed, medical ethics incorporates the principle that the patient, not the health care provider, determines what the course of care should be Accordingly, if Marcia Gray cannot be promptly transferred to a health care facility that will respect her wishes, the Rhode Island Medical Center must accede to her requests."); John J. Paris, *Physicians' Refusal of Requested Treatment: The Case of Baby L.*, 322 NEW ENG. J. MED. 1012 (1990) (describing *In re Baby L*, in which a mother sought continued treatment for her two year old child who suffered from repeated bouts of pneumonia and cardiopulmonary arrests, but who was unresponsive, except to pain. Physicians unanimously agreed that further medical intervention was not in the best interests of the patient. Ultimately, the case was rendered moot when the patient was transferred to a willing physician).

303. Veatch & Spicer, *supra* note 293, at 23.

decision-maker” to evaluate whether a particular outcome is normatively beneficial to the patient.³⁰⁴ While it is generally accepted that physicians have no duty to provide physiologically futile care, there is an ongoing controversy about their obligation to provide patients with requested care that the physician believes to be futile from a normative perspective.³⁰⁵

Wanglie and *Doe*, among other cases in which health care providers were compelled by courts to provide treatment to patients whom the health care providers considered “hopeless,” have caused a backlash within the medical community against the dominance of patient autonomy in medical decision-making. Many physicians and commentators believe that patient autonomy has “gone too far” in demanding that physicians provide care that they consider ineffective or “futile,” arguing that the competing ethical value of “beneficence” requires doctors to “do only what is medically helpful” and that “[i]ndividual autonomy cannot be so inflated in importance as to destroy the principle of beneficence.”³⁰⁶ These commentators assert that the physician has the right to not provide a medical treatment, even if technically effective, if the physician concludes that the treatment will not benefit the patient.³⁰⁷

Discontent within the medical community about this trend has led many states to pass statutes that permit physicians to refuse to provide “medically ineffective” care or care that is “contrary to applicable health-care standards.”³⁰⁸

304. *Id.*

305. See, e.g., James F. Drane & John L. Coulehan, *The Concept of Futility: Patients Do Not Have a Right To Demand Medically Useless Treatment*, HEALTH PROGRESS, Dec. 1993, at 28, 30; Stephen H. Miles, *Informed Demand for “Non-Beneficial” Medical Treatment*, 325 NEW ENG. J. MED. 512 (1991) (arguing that respect for patient autonomy does not obligate physicians to provide treatment “in ways that are fruitless or inappropriate”); Robert M. Sade, *Medical Care as a Right: A Refutation*, 28 NEW ENG. J. MED. 1288 (1971) (contending that viewing medical care as the right of the patient is immoral). But see Allen S. Brett & Laurence B. McCullough, *When Patients Request Specific Interventions: Defining the Limits of the Physician’s Obligation*, 315 NEW ENG. J. MED. 1347, 1349 (1986) (advancing the position that if there is a “theoretical medical basis for a patient’s request for medical treatment, the patient’s unique circumstances and stated reasons for wanting the intervention should guide the final decision-making process”); Robert M. Veatch & Carol Mason Spicer, *Futile Care: Physicians Should Not Be Allowed To Refuse To Treat*, HEALTH PROGRESS, Dec. 28, 1993, at 22, 27 (distinguishing normative from physiological futility and concluding that “the licensed professional who is given a monopoly over the control of life should be expected to promise to use that technology when patients or surrogates ask for it”).

306. Drane & Coulehan, *supra* note 305, at 30.

307. See, e.g., *id.* at 29.

308. ALASKA STAT. § 13.52.060(f) (2005) (“A health care provider . . . may decline to comply with an individual instruction or a health care decision that requires medically ineffective health care or health care contrary to generally accepted health care standards applicable to the provider, institution, or facility. In this subsection, ‘medically ineffective health care’ means health care that

The Society of Critical Care Medicine, the American Thoracic Society, and the American Medical Association have all issued policy statements affirming that physicians have no obligation to provide treatment that in their best judgments would be futile, offer no benefit to the patient, and only prolong the dying process.³⁰⁹ The American Thoracic Society adopted the *Saikewicz* court's reference to the "ethical integrity of the medical profession" when it wrote: "Forcing physicians to provide medical interventions that are clearly futile would undermine the ethical integrity of the medical profession."³¹⁰ Thus, there has been some effort within the medical community to re-assert the authority of physicians to direct patient care even over the patient's objection.³¹¹

Criticizing the focus on patients' rights, Edmund Pellegrino observes: "In

according to reasonable medical judgment cannot cure the patient's illness, cannot diminish its progressive course, and cannot effectively alleviate severe discomfort and distress."); ME. REV. STAT. ANN. tit 18-A, § 5-807 (2005) (stating that a health care provider or institution may refuse to comply with health care instruction for reasons of conscience or if the instruction or decision requires the provision of medically ineffective care or care contrary to applicable health-care standards); MD. CODE ANN., HEALTH-GEN. § 5-611(b)(1) (West 2005) ("[N]othing in this subtitle may be construed to require a physician to prescribe or render medically ineffective treatment."); N.D. CENT. CODE § 23-06.5-09(3) (2005) ("This chapter does not require any physician or health care provider to take any action contrary to reasonable medical standards."); WYO. STAT. ANN. § 35-22-410(v) (2005) (establishing no liability for declining to comply with a health care decision that is "contrary to the conscience or good faith medical judgment of the health care provider, or the written policies of the institution").

309. American Thoracic Soc'y, *Withholding and Withdrawing Life-Sustaining Therapy*, 155 ANNALS OF INTERNAL MED. 478, 481-83 (1991); Task Force on Ethics, Soc'y for Critical Care Med., *Consensus Report on the Ethics of Foregoing Life-Sustaining Treatments in the Critically Ill*, 18 CRITICAL CARE MED. 1435 (1990); Am. Med. Ass'n, E-2.035, Futile Care (Jan. 4, 2005), <http://www.ama-assn.org> (search "E-2.035"; then follow "Professionalism: E-2.035 Futile Care").

310. American Thoracic Soc'y, *supra* note 309, at 477; *see also* Sade, *supra* note 305, at 1290-91 ("Any doctor who . . . is compelled by law to make any decision he would not otherwise have made, is being forced to act against his own mind, which means forced to act against his own life. He is also being forced to violate his most fundamental professional commitment, that of using his own best judgment at all times for the greatest benefit of his patient.").

311. However, it is unclear whether these medical organizations acknowledge the difference between treatment that is technically ineffective and treatment that is unlikely, in the physician's view, to continue or improve the patient's quality of life. For example, the AMA does not appear to advocate leaving to the physician whether a particular treatment will benefit a patient since it defines resuscitative efforts to be "futile" if "they cannot be expected to restore cardiac or respiratory function to the patient or to *achieve the expressed goals of the informed patient*." Murphy, *supra* note 288, at 468 n.122 (emphasis added) (citations omitted). This quote seems to suggest that the determination of whether a treatment will benefit a patient from a normative standpoint should be made by the patient, and not the physician.

the last twenty-five years autonomy has superseded beneficence as the first principle of medical ethics.”³¹² This is the most radical reorientation in the long history of the Hippocratic tradition.³¹³ Pellegrino argues for a balancing of the patient’s right to autonomy with the physician’s right to autonomy.³¹⁴ Others oppose the idea of physicians becoming “vending machines” dispensing treatment as ordered by their patients.³¹⁵ Still others suggest that to demand that a physician provide treatment that is “morally unpalatable . . . [is] likely to have a corrosive effect upon the dedication and zeal with which [a physician] ministers to patients.”³¹⁶ In objecting to a mother’s insistence that her severely handicapped infant be aggressively treated, Gordon B. Avery suggests that, without some authority over their actions, physicians cannot be held responsible for their acts.³¹⁷

This Article does not suggest that health care providers sacrifice their ability to provide professional advice to patients or that beneficence has no role in medical decisions. Rather, it suggests that health care providers’ professional advice must be informed by the professional ethics generally accepted within their respective professional communities and not by their own personal belief systems. Both those who argue in favor of permitting physicians to withhold care that they determine to be medically futile and those that posit that it is patients, not physicians, who should decide whether care is beneficial focus their inquiry on the *benefit to the patient*.³¹⁸ “Personal medical benefit consists of such advantages as restoration of health, cure, pain relief, comfort, alleviation of suffering, and improved well-being or quality of life. The principle of beneficence calls on physicians to help patients achieve those particular goals”³¹⁹ The disagreement among commentators revolves around *who is in*

312. Edmund D. Pellegrino, *The Relationship of Autonomy and Integrity in Medical Ethics*, 24 BULL. PAN AM. HEALTH ORG. 361, 361 (1990).

313. *Id.*

314. Pellegrino, *supra* note 40, at 51-52.

315. Paul A. Gomez, *Promises and Pitfalls: An Analysis of the Shifting Constitutional Interests Involved in the Context of Demanding a Right To Treatment in Health Care*, 64 ALB. L. REV. 361, 391 (2000).

316. J. David Bleich, *The Physician as a Conscientious Objector*, 30 FORDHAM URB. L.J. 245, 245 (2002).

317. Gordon B. Avery, *Physicians’ Refusal of Requested Treatment, Views from the Journal’s Editorial Board*, 10 J. PERINATOLOGY 409 (1990).

318. Although Murphy argues in favor of physicians’ rights to refuse to provide treatment that they believe is medically futile, he confirms that one of the fundamental tenets of the Hippocratic tradition is that “physicians must act solely for the benefit of their patients.” Murphy, *supra* note 288, at 466.

319. Drane & Coulehan, *supra* note 305, at 32.

the best position to make that determination—the patient or the physician.

In contrast, those who favor expanding refusal statutes and the rights of health care professionals to decline to administer care based on their personal beliefs base their reasoning on whether participation in the treatment will harm *the health care professional*; that is, whether such treatment will offend the health care professional's personal sense of morality. For example, Pellegrino proposes a tripartite model of physician autonomy that recognizes the physician's "autonomy as a person which gives moral status to the physician's personal moral values and conscience."³²⁰ While Pellegrino acknowledges that the physician does not have the right to impose her will or conception of the good on the patient, he concludes that even where a physician's adherence to her sense of morality potentially will harm a patient, "the Catholic physician cannot violate her conscience to provide a morally objectionable procedure or treatment."³²¹ This Article challenges this approach, advocating instead an approach in which the patient's interests prevail, even if ministering to these interests compromises the physician's personal beliefs (but not the medical ethics to which she is bound).

Traditional concepts of medical ethics instruct that medical decision-making should be based on four core ethical principles: patient autonomy (patient self-determination), non-maleficence (health care professional should do no harm), beneficence (health care professional should do "good"), and justice (a concept involving the fair distribution of scarce medical resources).³²² Other than the ethical principle of justice, which commentators generally agree should not be considered in individual medical decisions,³²³ these ethical principles focus on the patient's needs. Refusal statutes, conversely, inappropriately permit the health

320. Pellegrino, *supra* note 40, at 51-52. The other components of physician autonomy are "autonomy as a physician, which gives moral status to the physician's knowledge and obligation to use it wisely and well"; and "autonomy as a member of a profession, of a moral community with collective obligations to patients and society." *Id.*

321. Edmund D. Pellegrino, *The Physician's Conscience, Conscience Clauses, and Religious Belief: A Catholic Perspective*, 30 *FORDHAM URB. L.J.* 221, 243 (2002). Pellegrino advises: "Conscientious objection implies the physician's right not to participate in what she thinks morally wrong, even if the patient demands it." *Id.* at 242. To his credit, he suggests that religious physicians who refuse to provide certain types of care should notify their patients in advance of their objections. However, while he acknowledges that such advance notification may not be possible in emergencies or in remote locations, he nevertheless concludes that the religious physician should not provide the objectionable treatment. *Id.* at 243.

322. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 37-40 (4th ed. 1994).

323. See, e.g., PRESIDENT'S COMM'N, *supra* note 288, at 100; Brett & McCullough, *supra* note 305, at 135-51.

care professional to place her personal moral, religious, or political judgment ahead of her patients' health interests.³²⁴

IV. PROPOSED COMPROMISES: BALANCING THE ACCESS RIGHTS OF PATIENTS AGAINST THE PERSONAL BELIEFS OF HEALTH CARE PROFESSIONALS

Unlike professional ethics that are based on a consensus of values generally accepted by the medical professional community, personal morals are usually viewed to derive from religion.³²⁵ The right to religious freedom is firmly entrenched in the United States and has enjoyed protection throughout American history. However, since there is no corresponding right to health care in the United States, it is not surprising that the rights of religious health care professionals have taken priority over the access needs of patients. According to commentator Katherine White, refusal clauses are neither constitutionally mandated by the Free Exercise Clause, nor constitutionally forbidden by the Establishment Clause; as a result, they remain in political play.³²⁶

The First Amendment provides, "Congress shall make no law respecting an establishment of religion, or prohibiting the free exercise thereof"³²⁷ Some religious health care providers argue that requiring them to provide access to health services to which they have religion-based objections burdens their rights to exercise their religion freely.³²⁸ Thus, for example, they argue that their free exercise rights are abridged by state laws requiring religious hospitals to provide their employees with medical insurance that covers contraception or mandating that religious hospitals dispense emergency contraception to rape victims.

At least two commentators have suggested reasons why this argument cannot be supported. In analyzing the somewhat muddled law concerning the Free Exercise Clause, both Brietta Clark and Katherine White conclude that

324. See Adam Sonfield, *Rights vs. Responsibilities: Professional Standards and Provider Refusals*, GUTTMACHER REP., Aug. 2005, at 7, available at <http://www.guttmacher.org/pubs/tgr/08/3/gr080307.pdf>.

325. This is not to say that an atheist cannot have personal morals that are as firmly entrenched as that of religious believers.

326. White, *supra* note 149, at 1729-30.

327. U.S. CONST. amend. I. The First Amendment has been interpreted to apply to the states through the Fourteenth Amendment of the U.S. Constitution. *Cantwell v. Connecticut*, 310 U.S. 296, 303 (1940). The free exercise of religion is also protected by statute, *see, e.g.*, Title VII of the Civil Rights Act of 1964, 42 U.S.C. § 2000e-2(a)(1) (2000), which provides in relevant part that it is an unlawful employment practice to "discharge . . . or otherwise . . . discriminate against any individual with respect to his compensation, terms, conditions or privileges of employment, because of . . . religion."

328. See Clark, *supra* note 10, at 649-65; White, *supra* note 149, at 1728.

under the more recent, less stringent test established by *Employment Division v. Smith*,³²⁹ as well as under the stricter test developed in *Sherbert v. Verner*³³⁰ and required under various state “Religious Freedom Restoration Acts” (RFRAs),³³¹ religious health care providers would be unlikely to prevail. In *Smith*, the appellants were arrested under an Oregon law criminalizing possession of a controlled substance when they were caught using peyote. At least one of the appellants argued that his use of peyote was part of his religious practice and therefore protected by the Free Exercise Clause.³³² In the majority opinion, Justice Scalia distinguished between absolute protection for religious belief and qualified protection for religious conduct,³³³ and concluded that, since the Oregon criminal law was a neutral law of general applicability that did not target religion,³³⁴ its application to the appellant was not prohibited by the Free Exercise Clause.³³⁵ According to the Court, the stricter *Sherbert* test applies only where a law is non-neutral or not of general applicability (for example, an unemployment compensation law that requires consideration of the individual circumstances of the employee in deciding whether she deserves compensation) or where a law implicates other constitutional rights.³³⁶

Like the Court in *Smith*, the Court in *Sherbert* distinguished governmental regulation of religious beliefs, which is impermissible, from governmental regulation of “certain overt acts prompted by religious beliefs or principles . . .” which is permissible where the actions regulated “pose . . . some substantial threat to public safety, peace or order.”³³⁷ However, because it found that the appellant’s conduct in refusing to work on her Sabbath Day due to her Seventh Day Adventist beliefs did not pose such a threat, the Court required the state to

329. 494 U.S. 872 (1990).

330. 374 U.S. 398, 404 (1963).

331. Congress reacted to the *Smith* decision by enacting the Religious Freedom Restoration Act (RFRA) of 1993, Pub. L. No. 103-141, 1993 U.S.C.C.A.N. (107 Stat.) 1488, *invalidated by City of Boerne v. Flores*, 521 U.S. 507 (1997). RFRA re-established the “compelling interest” test even as applied to rules of general applicability, but was found to be unconstitutional as applied to states. *Boerne*, 521 U.S. 507. However, RFRA may be constitutionally applied to the federal government. *See, e.g., Gonzales v. O Centro Espirita Beneficente Uniao Do Vegetal*, 126 S. Ct. 1211 (2006). After *Boerne*, many states enacted their own versions of RFRA. *See, e.g., FLA. STAT. ANN. § 761.03* (West 2005) (re-establishing the “compelling interest” test abrogated in *Smith* for laws in Florida).

332. *Smith*, 494 U.S. at 897.

333. *Id.* at 877-79.

334. *Id.* at 878-82.

335. *Id.* at 890.

336. *Id.* at 881-82.

337. *Sherbert v. Verner*, 374 U.S. 398, 403 (1963).

justify its denial of unemployment compensation to the appellant with a “compelling state interest.”³³⁸ The Court found that the mere possibility that “unscrupulous claimants feigning religious objections to Saturday work might . . . dilute the unemployment compensation fund”³³⁹ was not substantiated in the record and did not constitute such a compelling interest. Furthermore, the Court concluded that even if such a possibility did “threaten to dilute the fund and disrupt the scheduling of work, it would plainly be incumbent upon the appellees to demonstrate that no alternative forms of regulation would combat such abuses without infringing First Amendment rights.”³⁴⁰

Thus, while *Smith* applies a rational basis test to generally-applicable neutral state laws that do not target religion, *Sherbert* and various state RFRA’s apply a compelling interest test to state laws that potentially impair the free exercise of religion. Whether the rational basis test or the compelling interest is applied, Clark and White contend that, because of the strong policy arguments in favor of state laws requiring health care providers to offer reproductive services, states should be able to demonstrate that they have compelling interests that justify their laws.³⁴¹ Clark observes:

Thus, in the religious hospital conflict [i.e. as in *Sherbert*], even if courts do apply . . . [the compelling interest test], an exemption would probably still be denied in light of the countervailing government interests to ensure access to medically necessary care and to help counter gender discrimination in the health care system.³⁴²

Regarding individual health care professionals, the state may also have a compelling interest in assuring that these professionals practice in a competent manner.³⁴³

While the Free Exercise Clause may not protect the rights of religious providers to refuse to provide health services that the government considers necessary to protect public health, the Establishment Clause does not appear to prohibit the adoption of refusal clauses. The Establishment Clause “sets a maximum amount of assistance” that the government may offer religious entities.³⁴⁴ One might also argue that in adopting refusal laws that exempt

338. *Id.*

339. *Id.* at 407.

340. *Id.*

341. Clark, *supra* note 10, at 664; White, *supra* note 149, at 1728.

342. Clark, *supra* note 10, at 664.

343. See, e.g., *Noesen v. Wis. Dep’t of Reg. & Licensing Pharm. Examining Bd.*, No. 05CV212, slip op. at 15-16 (Wis. Cir. Ct. Feb. 3, 2006).

344. White, *supra* note 149, at 1729.

religious providers from, for example, general laws requiring the dispensing of emergency contraception for rape victims, states are unconstitutionally endorsing the practice of religion. However, since most refusal clauses exempt objectors who base their position on either religious *or* moral convictions, it is likely these clauses would survive a challenge based on the Establishment Clause.³⁴⁵ Even if the clauses exempted religious providers only, the trend among courts is to permit broad governmental accommodation of religion³⁴⁶ short of actual endorsement of a particular religion.³⁴⁷

Still, an Establishment Clause challenge might be raised successfully if a refusal clause permits only members of one religious sect to assert their religious-based refusals; conversely, a clause that exempts all religious providers might be viewed as relieving from religious objectors burdens that otherwise would interfere with their free exercise of religion. In *Children's Healthcare Is a Legal Duty, Inc. v. Min de Parle*,³⁴⁸ the Eighth Circuit Court of Appeals held that a provision in the Medicare Act that exempted sanatoria operated by "Religious Non-Medical Health Care Institutions" from various medical standards that were required from other institutions receiving reimbursement under the Act does not violate the Establishment Clause.³⁴⁹ Although a lower court had held that the original version of the provision was unconstitutional because it specifically exempted only sanatoria operated by "Christian Science" practitioners,³⁵⁰ Congress amended the law to refer to religious providers in general, causing the Court of Appeals to conclude that the provision was "by its terms sect-neutral."³⁵¹ Moreover, the court determined that the exemption "possessed a secular legislative purpose because it removes a special burden imposed by the Medicare and Medicaid Acts upon persons who hold religious objections to

345. *Id.*

346. *See, e.g.,* County of Allegheny v. ACLU Greater Pittsburgh Chapter, 492 U.S. 573, 601 n.51 (1989) (noting that government efforts to accommodate religion are permissible under the Establishment Clause when they remove burdens on free exercise of religion).

347. The *Allegheny* court observed: "Whatever else the Establishment Clause may mean (and we have held it to mean no official preference even for religion over nonreligion), it certainly means at the very least that government may not demonstrate a preference for one particular sect or creed . . ." *Allegheny*, 492 U.S. at 605 (citation omitted).

348. 212 F.3d 1084 (8th Cir. 2000).

349. *Id.* at 1100.

350. *Children's Healthcare is a Legal Duty, Inc. v. Vladeck*, 938 F. Supp. 1466, 1478-80 (D. Minn. 1996).

351. *Min de Parle*, 212 F.3d at 1090. As the dissent points out, this is a curious conclusion since the legislative history of the provision demonstrates that the "sole impetus for the present law was the alleged plight of Christian Scientists." *Id.* at 1102.

medical care.”³⁵² Thus, even if a refusal statute limits itself to religious, as opposed to moral, objectors, proponents might successfully argue that that such statutes are merely “relieving a burden” from religious health care providers so that they would be able to freely exercise their religious beliefs.³⁵³

Because refusal clauses seem to lie in a legally gray area, they have been subject to an abundance of political play in the past thirty years. The increasing political influence of religious groups in America during this period has resulted in an increase and broadening of religion-based refusal clauses passed by state legislatures and Congress. Meanwhile, no corresponding lobbying group has been effective in passing legislation to protect patient access to health care.

In fact, with the development of large managed care plans and the increase in the number of hospital mergers, patients’ freedom to choose their health care providers has decreased. Since many managed care plans and merged hospitals involve religiously affiliated institutions, the availability of certain types of medical procedures, especially in the areas of emergency contraception, abortion, sterilization, and assisted reproduction, has decreased.³⁵⁴ Catholic hospitals have been one of the fastest growing segments of health care. Susan Fogel and Lourdes Rivera report that in 1999, Catholic systems reported a 25.1% increase in the number of Catholic-owned acute care hospitals and a 22.8% increase in staffed beds, while the number of non-Catholic hospitals during the same time period decreased.³⁵⁵ Additionally, Fogel and Rivera report that by 2002 seven of the top ten hospitals in the United States were Catholic. Further, they note that by 2004, five of the ten largest health care systems in the United States were Catholic; Catholic institutions controlled the largest single group of non-profit hospitals in the United States; the Ascension Health System was the largest non-profit system with net patient revenues of over \$7.2 billion; and eighteen percent of all hospitals and twenty percent of all hospital beds in the United States were controlled by Catholic systems.³⁵⁶ They also report that there were 171 mergers or acquisitions of secular hospitals by Catholic health systems between 1990 and 2001.³⁵⁷ In addition to the growing influence of religious hospitals as the result of

352. *Id.* at 1093.

353. Notwithstanding the courts’ general sympathy to governmental accommodations of religion, White suggests that where the government provides funding to health care institutions, but allows religious institutions to modify the package of services they provide, an Establishment Clause challenge might be successful. White, *supra* note 149, at 1732.

354. See Fogel & Rivera, *Saving Roe is Not Enough*, *supra* note 38, at 729-32.

355. *Id.*

356. *Id.*

357. *Id.* In addition to formal mergers, many religious hospitals and long-term care facilities develop other types of corporate relationships, including the creation of for-profit subsidiaries, joint ventures, acquisitions or other contractual affiliations with for-profit hospital systems or mergers

mergers, their influence is spreading as the result of what William Bassett calls the “corporate transformation of hospitals and acute care medical facilities under the impetus of managed care imperatives.”³⁵⁸ He points out that patients are often not in the position to choose their health insurers, let alone their own health providers since, increasingly, those choices are being made by their employers or unions³⁵⁹ or, if they are poor, by the government.³⁶⁰

Catholic hospitals are governed by the Ethical and Religious Directives for Health Care Services, promulgated by the United States Conference of Catholic Bishops.³⁶¹ These directives prohibit virtually all reproductive health services, including contraception other than “natural family planning,” most infertility treatments, sterilizations, and abortion.³⁶² There are no exceptions for rape, incest, or to protect the life or health of the pregnant woman.³⁶³ The directives also prohibit harvesting the eggs of cancer victims for later implantation and permit Catholic hospitals to refuse to withdraw artificial nutrition in accordance with a terminally ill patient’s wishes.³⁶⁴ The United States Catholic Conference Board opposes counseling HIV-infected patients regarding the use of condoms to prevent the spread of HIV.³⁶⁵ Some or all of these positions are taken by health facilities owned by other religious denominations, for example, Seventh-Day Adventists, the Southern Baptist, and American Baptist hospitals.³⁶⁶ Thus, many patients may be deprived of medically indicated care simply because the hospital that serves their geographic area is owned by a religious institution.

Patient access to care is particularly affected in rural areas where there may be few providers who offer the care required. For example, in 2000, eighty-seven

involving public and community hospitals. Unless the religious hospital is completely absorbed by a for-profit system, the religious hospitals’ moral directives often apply to these ventures. *See* Bassett, *supra* note 38.

358. Bassett, *supra* note 38 at 457.

359. *Id.*

360. *Id.* at 517-18. The Federal Medicaid statute requires that recipients have access to family planning. However, the Balanced Budget Act, enacted in 1997, permits religious hospitals and Medicaid and Medicare managed care plans to refuse to provide reproductive health services to which they object on moral grounds. If they do so object, the state is charged with providing information to recipients about where such service is available. *Id.*

361. Fogel & Rivera, *Saving Roe is Not Enough*, *supra* note 38, at 732.

362. *Id.*

363. *Id.*

364. *Id.* at 737.

365. Bassett, *supra* note 38, at 511-12. However, while the Board does not promote the use of condoms, it does permit the provision of accurate information about prophylactic devices proposed by some medical experts as ways to reduce the transmission of HIV. *Id.*

366. *Id.* at 504-07.

percent of counties in the United States had no abortion provider. One third of American women lived in these counties, which means that they had to travel to other counties or other states to obtain this constitutionally protected service. Of women obtaining abortions in 2000, twenty-five percent traveled at least fifty miles, and eight percent traveled more than one hundred miles.³⁶⁷ As of February 2006, fourteen out of sixty-seven Pennsylvania counties did not have hospital emergency rooms with policies requiring the dispensing of emergency contraception on-site.³⁶⁸

One of the problems with the various new corporate forms assumed by religious hospitals is that it is often difficult for patients to know in advance which hospitals have policies restricting access to certain procedures. In order to maintain federal funding, many religious hospitals have expanded their boards of directors to add members of the public and have opened their hiring policies beyond members of their particular religious sect.³⁶⁹ With the decline of charitable immunity protections, they have also begun to restructure to protect their assets from suit.³⁷⁰ The result of this “re-incorporation movement,” according to Bassett, is to

separat[e] hospital facilities as independent corporations from their sponsoring religious bodies [to] dampen[] religious symbolism and religious control . . . [and to hide] the religious ministry to the sick behind bland neutral facades. For prospective hospital patients and insurance purchasers today it is not always easy to distinguish a religious hospital from another private, community, or in many cases, commercial health care franchises[sic].³⁷¹

This point was confirmed by a national survey in 2000 that found that almost half of the women questioned believed that if they were admitted to a Catholic hospital, they would be able to get services that were contrary to Catholic teachings.³⁷²

The Hyde-Weldon Amendment, as well as the most recently enacted state refusal statutes, allow health care providers not only to refuse to provide certain types of care, but also to refuse even *to inform* patients of the availability of

367. GUTTMACHER INSTITUTE, STATE CENTER, STATE FACTS ABOUT ABORTION: PENNSYLVANIA 2 (2006), *available at* <http://www.guttmacher.org/pubs/sfaa/pdf/pennsylvania.pdf>

368. ACLU of Penn., PA Hospital List (Feb. 8, 2006), <http://www.aclupa.org/education/clarabellduvalreproductiv/emergencycontraceptionproj/> (follow “Do the hospitals in my county provide EC to rape victims?” hyperlink; then follow “Counties A-E” hyperlink).

369. Bassett, *supra* note 38, at 545.

370. *Id.* at 549.

371. *Id.* at 551-52.

372. Fogel & Rivera, *Saving Roe is Not Enough*, *supra* note 38, at 740.

certain types of care, thus further restricting patients' rights to receive medically indicated care. There has been some movement by states to require managed care organizations and insurance companies to inform their members of any restrictions on the covered services.³⁷³ For example, California enacted the Kuehl-Thomson Health Benefits Act of 1999,³⁷⁴ which requires a paragraph to be inserted in twelve-point boldface type and posted in a prominent location on the websites of health plans, disability plans, and Medi-Cal plans that specifically states which services might not be covered. However, until all states follow California's lead, patients will be disadvantaged by lack of information in their choice of providers. Medicaid recipients outside of California who are mandatorily enrolled in managed care plans that refuse to provide certain services are often not given information about how to obtain the services that their health care provider refuses to provide. Moreover, as Fogel and Rivera point out, even if these patients "have the right to go out-of-plan to obtain these services . . . that assumes that there are out-of-plan geographically-accessible services and that the women know how to access them."³⁷⁵

Several authors have suggested that, in view of these changes in the health care system, the prerogative of religious institutions to adhere to their religious beliefs should no longer be viewed as absolute, but instead should be balanced against the rights of patients to have access to health care.³⁷⁶ Among the so-called compromise tactics suggested to achieve the balance between patients' rights to access and health care professionals' rights to refuse treatment are: (1) full disclosure so that patients know, before they sign up for a managed care plan or enter a hospital, whether the health care provider objects to providing particular types of care;³⁷⁷ (2) open and direct access laws that allow patients whose

373. *Id.* at 741; see also Bassett, *supra* note 38, at 579 (reporting that eleven states require that subscribers be notified of any restrictions on services provided by their plans).

374. CAL. HEALTH & SAFETY CODE § 1363.02 (West 2006); see also, WASH. REV. CODE ANN. § 48.43.065(2)(b) (West 2006) (requiring notification of the service the carrier refuses to cover and written information about where such services may be obtained).

375. Fogel & Rivera, *Saving Roe is Not Enough*, *supra* note 38, at 742.

376. See Bassett, *supra* note 38; Clark, *supra* note 10, at 692.

377. White, *supra* note 149, at 1742-43; see also Patient Self-Determination Act, Pub. L. No. 101-508, § 4206, 104 Stat. 1388-44 (1990) (codified as amended in relevant part at 42 U.S.C. 1395cc(f) (2000)) (requiring hospitals to inform patients at the time of admission of "an individual's rights under State law (whether statutory or as recognized by the courts of the State) to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives" and of "the written policies of the provider or organization respecting the implementation of such rights . . ."); *In re Requena*, 517 A.2d 869, 870 (N.J. Super. Ct. App. Div. 1986) (holding that the family of a patient seeking withdrawal of artificial nutrition should have received advance notification of the nursing home's

managed care providers refuse to provide certain types of care to seek care directly from other providers whose reimbursement will be paid by the managed care plan;³⁷⁸ (3) referrals to other qualified providers;³⁷⁹ (4) merger agreements that provide for care that is objected to by the religious partner to be provided by the secular partner;³⁸⁰ (5) classification of hospitals as either secular and truly sectarian institutions, with laws permitting only the latter to refuse to provide certain services;³⁸¹ (6) harsher standards that allow refusal to treat only on the basis of “true conscientious objection”;³⁸² and (7) suggestions that objectors consider shifting specialties or selecting a different occupation.³⁸³

Each of these proposed compromises raises problems of its own. Full disclosure and open access will only work under limited conditions. The recipient must be sufficiently educated to understand the materials provided by the managed care plan and sufficiently sophisticated to understand the potential ramifications of her choice of health plans on her future health care; there must be alternative health plans available; and they must be convenient. Under-educated (often poor) clients may not comprehend the necessary information. In fact, many educated health care consumers have found themselves bewildered in trying to choose among various health plans, considering the range of services addressed in their brochures. Also, managed care plans have little incentive to provide information about providers outside of their networks, since providing such information reduces a managed care plan’s control over its members’ health care.³⁸⁴ Moreover, it can be difficult for an individual to anticipate at the time she joins a health plan exactly what services she may need in the future. For example, a woman might enroll in a health plan anticipating that she will require prenatal

policy against such withdrawal).

378. White, *supra* note 149, at 1745.

379. Fogel & Rivera, *Saving Roe is Not Enough*, *supra* note 38, at 729; Law, *supra* note 38, at 290.

380. Fogel & Rivera, *Saving Roe is Not Enough*, *supra* note 38, at 747 (suggesting that mergers are one of several “creative solutions to preserve some range of access to otherwise prohibited services,” but noting that “the solutions are limited” and produce results with which “not everyone is always happy”); White, *supra* note 149, at 1736-37.

381. ACLU REPROD. FREEDOM PROJECT, *supra* note 8.

382. Law, *supra* note 38, at 303.

383. Karen E. Adams, *Moral Diversity Among Physicians and Conscientious Refusal of Care in the Provision of Abortion Services*, 58 J. AM. MED. WOMEN’S ASS’N 223 (2003), available at <http://www.jamwa.org/index.cfm?objectid=E5027C02-D567-0B25-5358598D0C27E4AB>; Jeffrey Blustein & Alan R. Fleischman, *The Pro-Life Maternal-Fetal Medicine Physician*, HASTINGS CENTER REP., Jan.-Feb. 1995, at 26; John M. Thorp, Jr. et al., *Integrity, Abortion and the Pro-Life Perinatologist*, HASTINGS CENTER REP., Jan.-Feb. 1995, at 27.

384. White, *supra* note 149, at 1746.

coverage, not realizing at the time that she will want a tubal ligation at the time of her third caesarian section. In addition, poor patients may not have the cars, phones, or child care necessary to search for a willing provider.³⁸⁵

Encouraging referrals to other qualified providers is a helpful alternative only in non-emergency situations and only if other qualified providers are available and convenient. A few statutes, as well as some codes of ethics, require that patients be transferred to other willing providers, at least in the context of end-of-life care.³⁸⁶ However, in addition to the possibility that there may be no willing provider available, especially in rural areas (and even in urban areas when the treatment is a controversial one), this option overlooks some possibilities. As a threshold matter, a patient may be unwilling to accept a new provider.³⁸⁷ Even more notably, a health care professional may decide that her personal beliefs are so inflexible that she cannot condone participating in the requested treatment even if her participation is limited to informing or referring the patient to another provider (as in the *Noesen* case).³⁸⁸ Likewise, Pellegrino states that “[r]espect for the patient’s autonomy does not include referral to a physician who will carry out the procedure if that procedure involves an act the physician deems intrinsically and seriously wrong. For a conscientious physician, this would be an inadmissible degree of formal cooperation.”³⁸⁹ Bassett addresses a number of “creative accommodations” that have been advocated, including referrals, “contracting out” services to another provider, creation of separate facilities, and financing and sharing resources with out-patient clinics.³⁹⁰ However, he also concludes that these options “are not a principled solution”³⁹¹ in that they constitute “moral cooperation” in care that the health care professional finds objectionable.³⁹² Furthermore, he cites examples from Germany where mandated referral by organizations with moral objections “was so profoundly humiliating to women petitioning [for referral] that it set off

385. *Id.* at 1746.

386. *See, e.g.*, N.H. REV. STAT. ANN. § 137-H:6(III) (2005); 20 PA. CONS. STAT. ANN. § 5409 (2005); *see also* Snyder & Leffler, *supra* note 29, at 562 (stating that physicians should consider transferring the care of the patient to a willing provider).

387. *See In re Requena*, 517 A.2d 869 (N.J. Super. Ct. App. Div. 1986).

388. Disciplinary Proceeding Against Neil T. Noesen, 01 P.H.M. 080 (Wis. Pharm. Examining Bd. Feb. 28, 2005) (proposed final decision & order), *aff’d*, *Noesen v. Wis. Dep’t of Reg. & Licensing Pharm. Examining Bd.*, No. 05CV212 (Wis. Cir. Ct. Feb. 3, 2006).

389. Edmund D. Pellegrino, *Commentary: Value Neutrality, Moral Integrity, and the Physician*, 28 J. L. MED & ETHICS 78, 79 (2000).

390. Bassett, *supra* note 38, at 526.

391. *Id.* at 527.

392. *Id.* at 529.

strident opposition in Germany that continues until today.”³⁹³

The fourth proposal, involving merger agreements between religious and non-religious health care institutions, can work only if the religious partner agrees that the secular partner may provide the objectionable services. Like referral, this option constitutes a type of “creative accommodation” that would be considered “moral cooperation.” However, White cites several instances in which these types of arrangements seemed to work. For example, Deaconess Hospital in Montana deeded real estate property to Planned Parenthood prior to merging with a Catholic-affiliated hospital.³⁹⁴ White also discusses arrangements in which Catholic facilities have created independent physician-sponsored clinics to provide reproductive services, either inside Catholic facilities (but with a separate entrance) or at separate nearby facilities.³⁹⁵ Yet, White also notes that as Catholic hospital involvement in mergers has increased, the church hierarchy has become more involved in the negotiations and has sought to enforce the directives more strictly, thus terminating many consolidation negotiations between Catholic and non-Catholic health care entities. In 1996-1997, five of nine consolidation negotiations between Catholics and non-Catholic health care entities were terminated due to Catholic doctrinal issues.³⁹⁶

Another more useful suggestion for addressing the problems proposed by the conflict between health care institutions’ religious tenets and the medical needs of patients has been proposed by the American Civil Liberties Union Reproductive Rights Project. The ACLU suggests that refusal clauses should be analyzed using the following principles: (1) the more the burdens of refusal fall on people who do not share the beliefs that motivate the refusal, the less acceptable any claimed right to refuse; and (2) the more public and secular the setting, the less acceptable an institution’s claimed right to refuse.³⁹⁷

Thus, religiously affiliated hospitals that treat the public would not be permitted to refuse, on the basis of their religious beliefs, to dispense emergency contraception, perform abortions and sterilizations, withdraw life support, etc. On

393. *Id.* at 535.

394. White, *supra* note 149, at 1736.

395. *Id.* at 1736-37.

396. *Id.* at 1738. White notes that “church leaders have sought to enforce the Catholic Ethical and Religious Directives more stringently, preventing Catholic facilities from providing family planning, sterilization, or emergency contraception.” *Id.* Catholic facilities are also discouraged from associating with institutions that provide abortions. U.S. CONFERENCE OF CATHOLIC BISHOPS, ETHICAL AND RELIGIOUS DIRECTIVES FOR CATHOLIC HEALTH CARE SERVICES, FOURTH EDITION, at Directive 45 (4th ed. 2001), available at <http://www.usccb.org/bishops/directives.shtml#partfour> (“Catholic health care institutions need to be concerned about the danger of scandal in any association with abortion providers.”).

397. ACLU REPROD. FREEDOM PROJECT, *supra* note 8, at 6.

the other hand, truly sectarian institutions that open their doors only to people who share their beliefs would be permitted to refuse to provide insurance coverage for contraception to their employees. Yet, this proposal fails to address situations in which a religiously affiliated hospital is the only hospital in the region, where a Medicaid recipient is involuntarily assigned to a religious managed care plan, or where, due to corporate restructuring, the religious nature of the hospital is obscured.

In a similar vein, William Bassett proposes that religious health care institutions should not be permitted to refuse to provide certain types of care unless they make full disclosure to patients and patients are able to choose freely other available providers:

To remain free to curtail otherwise legally-permissible medical procedures the hospitals must accentuate their religious identity in unmistakable terms so that patients know what their choices are, avoid monopolization of general health services in particular communities, and restrain the semblance of competitive commercialization. Patients must know in advance what services are or are not available from contract health care providers and practically and feasibly be able to act on those choices.³⁹⁸

Bassett further suggests that, notwithstanding the line of cases that protect the rights of religious health care institutions to freely exercise their religious beliefs, the state should be permitted to abridge such rights in four cases: (1) when children and handicapped victims require treatment for rape or incest; (2) when adult female victims of sexual crimes require emergency treatment; (3) in the provision of blood transfusions, organ transplants, or medically routinized and standard care procedures, such as dialysis, or to save or prolong the life of mentally incompetent adults entrusted to the care of the hospital; and (4) in providing care to sexually active AIDS patients.³⁹⁹ Since Bassett himself recognizes a generalized inability, due to various social forces, of individuals to choose their health care providers, it is not clear why he would limit the State's ability to override the religious rights of health care institutions only to these limited instances. Following his line of reasoning, whenever individuals' freedom to choose their health care providers is limited, these providers should be required to offer the requested and medically indicated care.

Also problematic is the fact that the solutions proposed by both the ACLU and Bassett pertain to institutional health care providers only. Neither challenges the right of individual health care professionals to assert their religious or moral objections to patient care. In fact, the ACLU lauds the Church Amendment as a

398. Bassett, *supra* note 38, at 565.

399. *Id.* at 572-73.

useful model for protecting the rights of individual health care professionals to refuse to participate in medically indicated treatments based on their personal moral or religious beliefs,⁴⁰⁰ provided that the refusing health care professional furnishes the patient with accurate and complete information, refers the patient to another provider, and provides the “objectionable” medical care in emergency situations.⁴⁰¹ None of the proposed compromises suggest that individuals who choose to become health care professionals, who obtain monopolistic licenses awarded by the state, and who assume a fiduciary duty to “put their patients’ interests first” should be precluded from imposing their personal religious or moral beliefs on their patients.

While accepting the general principle that individual health care professionals have the right to refuse to participate in certain treatments, at least one author has suggested that refusals should not be honored without challenge. Raising the possibility that many refusal clauses may relieve health care professionals from participating in abortions when in reality they hold no strong religious convictions but merely want to avoid a controversial issue, Sylvia Law suggests that the reasons for the health care professional’s refusal should be evaluated.⁴⁰² Like those who conscientiously object to military service, physicians should be excused from participating in abortions only if they have “true conscientious objections.”⁴⁰³ Presumably, this would require health care professionals to “make their case” before some sort of professional or institutional review board.

This idea is explored further in an article by William Nelson and Cedric Dark,⁴⁰⁴ suggesting that “claims of conscience” should be first brought to a health care professional’s immediate supervisor to evaluate such claims for validity. Claims that appear to be valid would then be passed on to an organizational review board composed of members from various ethnic, religious, and academic settings. The mission of this board would be to evaluate the genuineness of the claim based on the following factors: (1) whether the objection fits within “a coherent system of moral, religious, cultural or philosophical beliefs; (2) whether the belief reflects “a consistently and diligently held core value of the petitioner”; (3) whether the belief is such “a key component of the petitioner’s internal

400. ACLU REPROD. FREEDOM PROJECT, *supra* note 8, at 10; *see also* Bassett, *supra* note 38, at 456 (“While the rights of conscience of each and every health care professional must be securely safeguarded at law, institutional ambiguities should be resolved in favor of the individual patient.”).

401. Fogel & Rivera, *Saving Roe is Not Enough*, *supra* note 38, at 729.

402. Law, *supra* note 38, at 303.

403. *Id.*; *see also* Conscientious Objectors, 32 C.F.R. §§ 75.3-5 (2006) (requiring conscientious objectors to demonstrate a “firm, fixed and sincere” belief).

404. William A. Nelson & Cedric K. Dark, *Evaluating Claims of Conscience*, HEALTHCARE EXECUTIVE, Mar.-Apr. 2003, at 54.

framework that violation of that belief would cause significant harm to him or her"; and (4) whether it would be "inconsistent with the petitioner's core values to participate in the procedure or treatment."⁴⁰⁵ If the claim is found to be valid, some sort of reasonable accommodation should be made by the institution that does not create undue hardship for the organization, its employees, or the patient. If the claim is found not to be valid, the petitioner should be reassigned or possibly terminated, in which case the petitioner would retain the right to file an appeal, including possibly an external one.⁴⁰⁶

Whether any health care settings other than those affiliated with universities would have the knowledge, interest, and resources to undertake the establishment of such boards is questionable. Moreover, it is likely that these health care institutional boards, in an attempt to avoid litigation, would find in favor of the health care professionals in the majority of cases that would come before them. Nevertheless, establishing a formal procedure that would require health care professionals to articulate and defend their objections would filter out health care professionals whose objections do not arise from their "core values." Of course, this procedure would apply only to health care professionals working in an institutional setting, and not to health care practitioners in private practice. The only potential existing mechanisms for reviewing the justification for provider refusals among private practitioners are their respective professional boards. However, these boards are often under-staffed, under-funded, and without the requisite expertise; consequently, their willingness and ability to undertake such a task is dubious. Furthermore, this type of examination, at least in public hospitals and state licensing boards, may raise questions under the Free Exercise Clause because it would require a neutral body to inquire into the "centrality" of the refusal to the individual's core beliefs. This mode of inquiry was rejected by the Supreme Court, insofar as it would be exercised by courts since it "would enmesh judges in an impermissible inquiry into the centrality of particular beliefs or practices to a faith."⁴⁰⁷ Most importantly, it is arguable that the depth of a health care professional's personal beliefs is irrelevant in light of her undertaking the responsibility to put the patient's best interest ahead of her own interests.

Finally, several commentators have suggested that if a physician cannot participate in a medical procedure due to her personal moral or religious beliefs, she should consider practicing in an area of medicine in which the patient's access to care would not be compromised.⁴⁰⁸ However, since changing medical

405. *Id.* at 54.

406. *Id.* at 55.

407. *Employment Division v. Smith*, 494 U.S. 872, 876-77 (1990).

408. *See, e.g., Adams, supra* note 383, at 225-26 (maternal-fetal medicine); Blustein & Fleischman, *supra* note 383, at 26 (same); Thorp et al., *supra* note 383, at 28 (same).

technology and changing social mores may implicate a clinician's moral and religious beliefs in ways that cannot be foreseen at the outset of her professional training, this suggestion is impractical. For example, an internist training today might not consider whether she has moral objections to the application of technologies and treatments derived from stem cell research simply because the technology has not yet been developed.

A key assumption in most of these proposals is that individual, as opposed to institutional, health care providers generally have a right, based on their religious beliefs or personal moral codes, to refuse to provide medically indicated health care to their patients. This Article contests this assumption on the grounds that the primary goal of health care professionals should be to promote their patients' health, not to advance their own personal moral judgments.

V. DISTINGUISHING PROFESSIONAL ETHICS AND THE PERSONAL BELIEFS OF HEALTH CARE PROVIDERS

In cases involving reproductive issues, health care professionals have tended to assert religious or moral objections, whereas they have generally asserted professional ethical objections, rather than religious objections, in cases involving end-of-life issues. While courts often have refused to accept health care professionals' personal interpretations of their professional ethical responsibilities, they generally attribute significant weight to *commonly accepted* professional ethics. Thus, in upholding patients' legal rights to refuse medical treatment, courts have relied upon the medical community's generally accepted ethical principle that patients have the right to refuse unwanted medical care. The ethical principle that favors patient autonomy has also manifested itself in many of the cases that address issues of medical futility, "trumping" physicians' objections based on their personal value judgments regarding what constitutes "quality of life."⁴⁰⁹

409. These cases generally involve the provision of care that has the desired physiological effect, but where there is a dispute between caregivers and the patient's surrogate about the net benefit of the treatment to the patient's quality of life. Conversely, several physicians' organizations have issued statements and several states have passed statutes that state that physicians are not required to provide "ineffective" treatment. *See, e.g.*, ALASKA STAT. § 13.52.060(f) (2005); ME. REV. STAT. ANN. tit 18-A, § 5-807 (2005); MD. CODE ANN., HEALTH-GEN. § 5-611(b)(1) (West 2005); N.D. CENT. CODE § 23-06.5-09(3) (2005); WYO. STAT. ANN. § 35-22-410(v) (2005); American Thoracic Soc'y, *Withholding and Withdrawing Life-Sustaining Therapy*, 155 ANNALS OF INTERNAL MED. 478, 481-83 (1991); Task Force on Ethics, Soc'y for Critical Care Med., *Consensus Report on the Ethics of Foregoing Life-Sustaining Treatments in the Critically Ill*, 18 CRITICAL CARE MED. 1435 (1990); Am. Med. Ass'n, E-2.035, *Futile Care* (Jan. 4, 2005), <http://www.ama-assn.org> (search "E-2.035"; then follow "Professionalism: E-2.035 Futile Care").

Professions establish their own acceptable standards of competence, as well as unique professional ethics. General medical malpractice standards require physicians to practice in accordance with “the degree of skill and care ordinarily possessed by a reasonable and prudent physician in the same medical specialty acting under the same or similar circumstances.”⁴¹⁰ Departing from this standard may result in liability or professional disciplinary actions. The standard of care is established through expert testimony on the customary practice within a particular specialty, reference to medical literature, and guidelines established by institutions, accrediting agencies, and professional associations. Thus, a physician or other health care professional who refuses to provide medically indicated treatment to a patient because the health care professional has determined that providing the treatment would violate her religious beliefs is likely to be found to have committed professional malpractice; most refusal statutes, however, wrongly provide immunity for this type of malpractice.⁴¹¹

The prevailing ethical norms of professionals are codified in their codes of professional ethics. These are standards that are collectively defined and accepted.⁴¹² An individual physician, nurse, or pharmacist may have her own personal beliefs and values derived from her religion, culture, family, and community. However, these are personal beliefs, as opposed to professional standards. Clearly, professional ethics have a place in professional decision-making, since they are at the core of every profession. The question is what place, if any, an individual health care provider’s personal moral and religious beliefs should have in medical decision-making.

“Professional integrity” in medicine, according to Miller and Brody, “represents what it means normatively to be a physician; it encompasses the values, norms and virtues that are distinctive and characteristic of physicians.”⁴¹³

410. Levine, *supra* note 288, at 101.

411. See, e.g., 745 ILL. COMP. STAT. ANN. 70/4 (West 2006); MISS. CODE ANN. § 41-107-5(2) (West 2005); MO. ANN. STAT. § 197.032 (West 2005).

412. Various medical professional codes of ethics have carved out exceptions from their general requirements that the primary duty of the professional is to the patient to permit the professional to follow her own personal beliefs, especially regarding reproductive services. For example, the American College of Physicians’ (ACP) *Ethics Manual*, states: “The ethical duty to disclose relevant information about human reproduction to the patient may conflict with the physician’s personal moral standards on abortion, sterilization, contraception, or other reproductive services. A physician who objects to these services is not obligated to recommend, perform, or prescribe them.” Snyder & Leffler, *supra* note 29, at 564. Notably, the *Ethics Manual* does not carve out a similar exception regarding any other types of care. See *id.* Where ethics codes do carve out these exceptions, they fail to reconcile the contradiction inherent in advancing the best interests of the patient and, at the same time, protecting the personal interests of the health care provider.

413. Franklin G. Miller & Howard Brody, *Professional Integrity and Physician-Assisted Death*,

Unlike “personal integrity” which relates to “the full identity of persons which characterizes their lives as a whole,” professional integrity relates to the “moral identity of those who occupy a distinctive social role.”⁴¹⁴ “While there remains some free scope for individuality in the practice of medicine, and a good physician may have a unique personal style, professional identity generally constrains individual expression in a way that personal identity does not.”⁴¹⁵

Thus, an athletic orthopedic surgeon may, due to his personal values, believe that a patient should undergo repair of the tendon in his knee so that the patient can continue skiing, but the patient might decide that the risks of surgery outweigh the value to him of continuing his own athletic pursuits. A reconstructive plastic surgeon may, on the basis of her personal aesthetic values, believe that nasal reconstructive surgery on a woman with an already small nose would not be aesthetically pleasing, but most people would agree that, while the surgeon might discuss with the patient the patient’s reasons for requesting the surgery (as well as the risks of surgery), the surgeon’s aesthetic opinions should not be determinative. A heart surgeon might recommend against bypass surgery in a homosexual patient dying from AIDS because surgery would be too risky and unlikely to extend the patient’s life, but not because she thought that the patient “deserved to die” as a result of his assumptively promiscuous behavior. No one would suggest that the physician’s personal values should prevail over the patient’s wishes in these medical decisions, all of which will affect the patient’s, and not the physician’s, life.

Similarly, a physician’s personal attitudes about medical procedures should not influence his advice to patients who do not share his beliefs. A Jewish physician should not advise non-Jewish parents to circumcise their newborn son unless his advice is based on prevailing medical standards. A nurse who is a Jehovah’s Witness should not advise a hemophiliac not to accept blood transfusions. Physicians, like all other humans, carry their own personal biases and prejudices that affect who their friends are, what clubs they join, and so on. No one expects physicians to carry these prejudices into their medical practices. Yet many refusal clauses allow physicians to refuse to provide certain controversial medical procedures for *any* reason, including personal prejudice. Even those that require some moral or religious justification rarely provide explicit exceptions when the result of the exercise of such moral or religious beliefs is denial of care to an identifiable group or class of people. The physician who refused to provide artificial insemination to a lesbian may be just one

HASTINGS CENTER REP., May-June 1995, at 8, 9.

414. *Id.*

415. *Id.*

example of this type of situation.⁴¹⁶ Another example would be a nurse who refuses to participate in the care of a homosexual with AIDS because her religion instructs her that AIDS is the homosexual's just punishment for immoral behavior.

While Miller and Brody distinguish personal integrity from professional integrity, they argue that a physician should not have to sacrifice her personal integrity in the exercise of her professional integrity. They argue, for example, that a physician who is conscientiously opposed to performing abortions should not be obligated to compromise her personal integrity or her conscience by performing abortions, even if performing abortions would not violate her professional integrity.⁴¹⁷ Similarly, Pellegrino views physicians as forming "consciences in two inseparable dimensions of their lives—the professional and the personal" where "[b]oth professional and personal conscience are owed protection."⁴¹⁸ In defending the rights of religious physicians to exercise their religious objections to participating in certain medical treatments, Pellegrino goes so far as to state that a secular society's demands for "value neutrality" "is a psychological schism that violates the integrity of the person as a unity of body, soul, and psyche,"⁴¹⁹ and that "value neutrality" elevates "secularism to the level of a social orthodoxy."⁴²⁰ He argues that "[p]ersonal and professional ethics are not fully separable from each other"⁴²¹ and that the autonomy of the physician demands that she be allowed to express her beliefs through her actions.⁴²² As far as Catholic physicians are concerned, Pellegrino writes that "to . . . ignore,

416. *N. Coast Women's Care Med. Group, Inc. v. Superior Court*, No. D045438, 2006 WL 618767 (Cal. Ct. App. Mar. 14, 2006) (ordering the superior court to vacate its summary judgment for the plaintiff in a case involving a physician's refusal to inseminate a patient involved in a lesbian relationship, finding that there is an issue of fact as to whether the refusal was based on the patient's status as a lesbian or as an unmarried person). In either case, the physician allegedly based her refusal on her personal prejudices, as opposed to medical or professional ethical considerations.

417. Miller & Brody, *supra* note 413, at 10.

418. Pellegrino, *supra* note 321, at 229; *see also* Pellegrino, *supra* note 40, at 51-53.

419. Pellegrino, *supra* note 321, at 240. The "human potential" movement at the end of the twentieth century promoted the concept that an individual should seek "wholeness" in his life and work. This movement was reflected in discussions within the legal profession along two axes. Those at one pole believed that "the lawyer needs a role-specific ethic which puts the client first, even in relation to the lawyer as a fully connected, rooted person . . ." Stephen L. Pepper, *Autonomy, Community, and Lawyers' Ethics*, 19 CAP. U. L. REV. 939, 960 (1990). The other pole consisted of those who were critical of professional norms that "bleach out" one's religion. *See, e.g.*, Howard Lesnick, *The Religious Lawyer in a Pluralist Society*, 66 FORDHAM L. REV. 1469, 1486 (1997-1998).

420. Pellegrino, *supra* note 321, at 240.

421. Pellegrino, *supra* note 40, at 51.

422. Pellegrino, *supra* note 389.

repress, or act against conscience for any reason is a violation of philosophical as well as theological ethics, an error in moral agency and a sin against God.”⁴²³

If separating the personal from the professional creates a psychically damaging schism in the individual, this would mean that the physician who personally believes that experiencing pain without complaint will hasten a person’s journey to heaven is justified in applying this strongly held belief in his medical practice by withholding pain medication. Or that a physician who believes that abortions are so antithetical to her personal beliefs that she is unwilling to participate in the procedure even to save the life of the pregnant woman nonetheless is fulfilling her professional responsibilities. These are untenable positions.⁴²⁴

Mark Wicclair takes a more thoughtful approach. He argues for a more limited basis upon which physicians would be justified in conscientiously objecting to participating in certain types of medical treatment.⁴²⁵ He asserts that “an appeal to conscience has significant moral weight only if the core ethical values on which it is based correspond to one or more core values in medicine.”⁴²⁶ A physician’s personal beliefs, which arise from her moral framework or religious orientation, have less weight. Wicclair uses the following examples to illustrate his point.⁴²⁷ One physician, Dr. K, disagrees with her patient’s decision to reject aggressive therapy for his life-threatening condition. Her patient, who is suffering from terminal cancer, prefers to become a hospice patient to experience as little pain and loss of dignity as possible. However, Dr. K believes that she would be betraying her calling as a physician if she lets the patient die without further efforts to stop the disease’s progress. Another physician, Dr. L, is opposed to providing pain medication because he believes that pain is a sign of a moral flaw and is therefore deserved. Because of this belief, when his patient requests pain medication, Dr. L responds that he cannot, in good conscience, prescribe any. Wicclair suggests that Dr. K’s conscientious objection has more moral weight than Dr. L’s moral objections because Dr. K’s objections “can be defended by citing certain values within medicine, such as life and health,”⁴²⁸ even though it fails to consider other important goals such as the

423. Pellegrino, *supra* note 321, at 227-28.

424. Nevertheless, Pellegrino argues that even emergency situations “cannot excuse physicians from fidelity to their personal or moral beliefs. Genuine efforts by patients or families to find a physician whose beliefs are congruent with the patient’s must continue; meanwhile, the attending physician must continue to care for the patient in accord with the physician’s deepest held beliefs.” Pellegrino, *supra* note 389, at 80.

425. Mark R. Wicclair, *Conscientious Objection in Medicine*, 14 *BIOETHICS* 205 (2000).

426. *Id.* at 217.

427. *Id.* at 215-21.

428. *Id.* at 216.

amelioration of suffering, patient autonomy, and dignity. In contrast, Dr. L's opposition to pain medication "is based on beliefs and values which are foreign to medicine."⁴²⁹ This approach is consistent with the approach of this Article in positing that health care professionals should be encouraged to apply principles of professional ethics in treating their patients; however, they should be discouraged from injecting their personal moral or religious beliefs into their practice.

Describing medical professionalism "as an activity that involves both the distribution of a commodity and the fair allocation of a social good but that is uniquely defined according to moral relationships,"⁴³⁰ Wynia and colleagues propose a normative guide of medical professionalism that focuses on the cultivation by physicians of a "devotion to health care values by placing the goals of individual and public health ahead of other goals,"⁴³¹ and by placing the health interests of others ahead of their own personal interests to avoid "even the appearance that they are primarily devoted to their own interests rather than to the interests of others."⁴³² This medical professionalism, for example, requires physicians to provide health care during an epidemic when they risk their own health,⁴³³ a value that was sorely tested during the AIDS epidemic of recent decades.⁴³⁴ However, according to Wynia and colleagues, it is not enough to hold these values; physicians must also speak out about these values, demonstrating "the shared standards of the profession, which may sometimes conflict with *personal* beliefs."⁴³⁵ Although these authors were most concerned about the role of medical professionalism within the context of market competition and financial self-interest, their emphasis on returning to core medical values applies equally in the context of physicians who put their own personal moral judgments above their patient's interests. Just as the rise in physicians' incomes in the past forty years has, according to Wynia and colleagues, "fostered the trust-destroying belief, whether true or not, that physicians as a group are greedy and take

429. *Id.* at 217.

430. Matthew K. Wynia et al., *Medical Professionalism in Society*, 341 NEW ENG. J. MED. 1612, 1612 (1999).

431. *Id.* at 1613.

432. *Id.* While the authors focus on financial self-interest, the same point applies to physicians who place their personal morality ahead of their obligations to patients.

433. Snyder & Leffler, *supra* note 29, at 565.

434. See *Glanz v. Vernick*, 750 F. Supp. 39 (D.C. Mass. 1990) (involving an estate that filed a legal suit against a hospital and surgeon alleging that the surgeon had refused to perform surgery on the decedent because of his HIV status); Lindsey Gruson, *AIDS Fear Spawns Ethics Debate as Some Doctors Withhold Care*, N.Y. TIMES, July 11, 1987, at A1.

435. Wynia et al., *supra* note 430, at 1614.

advantage of patients,”⁴³⁶ so the assertion by health care professionals that their personal moral judgments trump patients’ health interests is likely to undermine patient trust.

Health care professionals’ fiduciary duty to their patients has been well established in various contexts. Legal actions against physicians for breaching their fiduciary duty to patients have increased in recent years as patients have suspected that their physicians’ treatment decisions were motivated by financial incentives provided by managed care organizations, rather than by the patients’ health interests.⁴³⁷ The American Medical Association emphasized physicians’ fiduciary duty to their patients when it issued a report on physicians who refer to facilities in which they have a financial interest, noting that “the profession of medicine is unique and that physicians are expected to put their patients’ interests first.”⁴³⁸ In the context of medical malpractice litigation, one court described the physician’s fiduciary duty as follows:

The relation of physician and patient has its foundation on the theory that the former is learned, skilled, and experienced in those subjects about which the latter ordinarily knows little or nothing, but which are of the most vital importance and interest to him, since upon them may depend the health, or even life, of himself or family; therefore the patient must necessarily place great reliance, faith, and confidence in the professional word, advice, and acts of the physician.⁴³⁹

That reliance and faith is undermined when a physician or other health care professional puts her own needs above those of her patient.

The fact that health care professionals control patient access to medical care is also relevant in determining the degree to which their personal beliefs should affect their provision of care. Arguing that the physicians in the *Wanglie* case should not have had the right to withhold life support over the objections of the patient’s husband, Veatch and Spicer contend that the decision to stop mechanical ventilation was based on the physicians’ personal ethical and philosophical standards, rather than medical science. In such cases, the clinicians’ beliefs and values should not prevail over the patient’s conservator’s wishes, especially since the medical profession is a “licensed professional

436. *Id.* at 1613.

437. See *Breach of Fiduciary Duty-New Legal Approach for Plaintiffs*, ONCOLOGY NEWS INT’L, Dec. 1997, at 28, available at <http://clinicalfreedom.org/FIDUC01.HTM>.

438. Council on Ethical & Judicial Affairs, *Conflicts of Interest: Physician Ownership of Medical Facilities*, 267 JAMA 2366, 2366 (1992).

439. *Witherell v. Weimer*, 421 N.E.2d 869, 876 (Ill. 1981) (citation omitted).

monopoly.”⁴⁴⁰ This idea received additional attention in R. Alto Charo’s recent article in the *New England Journal of Medicine*, in which she criticized the growing invocation of refusal statutes by health care professionals to excuse them from participating in abortions, prescribing contraception, and performing other controversial medical treatments.⁴⁴¹ She suggests that it would be easier to permit health care professionals to refuse to participate in certain procedures, based on their consciences

if states did not give these professionals the exclusive right to offer such services. By granting a monopoly, they turn the profession into a kind of public utility, obligated to provide service to all who seek it. Claiming an unfettered right to personal autonomy while holding monopolistic control over a public good constitutes an abuse of the public trust—all the worse if it is not in fact a personal act of conscience but, rather, an attempt at cultural conquest.⁴⁴²

In other words, in view of physicians’ exclusive ability to provide the requested resource, it would be unjust to allow physicians’ personal beliefs to prevail over the patient’s autonomous decision.

VI. PRESUMPTION AGAINST THE RIGHT TO REFUSE

The widely accepted ethical principle that patients are autonomous individuals with the right to make the final decisions concerning their medical care, along with the corresponding principle that appears in all medical professionals’ codes of ethics that the “patient’s interest comes first” leads to the following general rule: patient care decisions should be based on patient autonomy, as mediated by the clinician’s conclusion that the requested therapy (1) is not medically contraindicated (since it is both medically effective and not considered unethical within the profession’s generally accepted concept of ethical practice) and (2) is not illegal. A similar position is taken by Allan Brett and Laurence McCullough in discussing patients who request specific medical interventions.⁴⁴³ They suggest the following rule:

When a patient seeks to exercise a positive right to an intervention, a necessary condition is that there is either an established or a theoretical medical basis for the patient’s request. If that necessary condition has been satisfied, the patient’s unique circumstances and stated reasons for wanting the intervention should

440. Veatch & Spicer, *supra* note 293, at 36; *see also id.* at 26-28.

441. R. Alta Charo, *The Celestial Fire of Conscience—Refusing To Deliver Medical Care*, 352 *NEW ENG. J. MED.* 2471 (2005).

442. *Id.* at 2473.

443. Brett & McCullough, *supra* note 305.

guide the final decision-making process.⁴⁴⁴

A health care professional's personal religious or moral beliefs should not enter into the decision-making process. Under this model, health care professionals would be discouraged from invoking their personal moral, religious, or political beliefs to justify their refusal to participate in abortions, prescribe contraception, or withdraw life support at the request of the patient.

Where there is ongoing disagreement within the medical ethics community about a particular form of treatment, physicians would not be obligated to provide it. For example, health care professionals would not be obligated to participate in physician-assisted suicide, notwithstanding the patient's request, since the requested action is not generally accepted from a medical ethics standpoint⁴⁴⁵ and, moreover, is currently illegal in all states except Oregon.⁴⁴⁶ If the status of this activity changes from both the viewpoint of prevailing medical ethics and the law, the obligations of health care professionals would similarly change.

This does not mean that a health care professional could not object to participating in certain types of treatment on the basis of her *personal* conscience; that is, based on her personal religious, moral, or political beliefs. However, personal conscientious objections should be discouraged. Professional schools and organizations should actively promote the concept that the patient's best interests must prevail over the health care professional's personal beliefs. There should be a presumption against the validity of conscientious objection based on personal, as opposed to professional, values by health care

444. *Id.* at 1349.

445. In *Washington v. Glucksberg*, 521 U.S. 702 (1997), the Court found against several terminally ill patients and their physicians when they challenged as unconstitutional a Washington statute prohibiting assisted suicide. In holding that the statute did not violate the patients' Fourteenth Amendment liberty interests, the Court relied on statements of the American Medical Association and other medical groups that "[p]hysician-assisted suicide is fundamentally incompatible with the physician's role as healer." *Id.* at 731. Balancing this interest in the integrity of the medical profession, along with several other important state interests, against the patient's liberty interest in physician-assisted suicide, the Court upheld the constitutionality of the statute. *Id.* at 735. This is one of the few cases in which a physician's professional integrity, along with other state interests, was found to outweigh patients' liberty interests in making autonomous decisions concerning their health. *Cf.* *Gonzales v. Oregon*, 126 S. Ct. 904 (2006), in which the Court, on other grounds, effectively upheld Oregon's Death with Dignity Act, ORE. REV. STAT. §§ 127.800-897 (2003), by enjoining enforcement of the Federal Controlled Substances Act, 21 U.S.C. §§ 801-971 (2000), against physicians acting pursuant to the Oregon law. Oregon's statute permits physicians to prescribe lethal doses of medications to patients that the patients may self-administer.

446. *Gonzales v. Oregon*, 126 S. Ct. at 911.

professionals, whose first obligation should be to promote patient health, not their own interests, and who, through their state-granted licenses, control patient access to medical care.

CONCLUSION

This Article has reviewed current legislation and judicial opinions concerning the right of health care professionals to refuse to participate in health care treatments to which they object on the basis of their personal moral or religious beliefs. Ultimately, this Article proposes a new model for such “conscientious objections,” one that presumes the general obligation of health care professionals, who hold monopolistic state licenses, to participate in requested medical care that is not contraindicated or illegal, notwithstanding their personal moral objections. This model is based on the premise that it is the patient’s best interest (as determined by the patient, but mediated by the health care professional’s medical judgment), not the health care professional’s personal interests, that should govern the professional relationship. This should be the standard taught in professional schools and promoted by professional associations. “Conscientious objections” should be permissible based on prevailing medical ethics; however, to the extent that they are based on the personal morals of the health care professional, they should be actively discouraged.

NOTE

Executions and Torture: The Consequences of Overriding Professional Ethics

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INTRODUCTION

Physicians often face conflicts between their professional duty of loyalty to patients and their concomitant responsibilities to third parties. These latter responsibilities may be to family members or to other parties interested in a patient's welfare. Or they may take an economic form, as is increasingly reflected by the influence of health plans and other third-party payers in clinical decision-making.¹ A physician may have a responsibility to perform a court's

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1. See Marc Rodwin, *Conflicts in Managed Care*, 332 NEW ENG. J. MED. 640 (1995); see also Marsha R. Gold et al., *A National Survey of the Arrangements Managed-Care Plans Make with Physicians*, 333 NEW ENG. J. MED. 1678 (1995) (describing physicians' financial and other incentives to withhold services from patients). Conflicts between professional duty and financial incentives are not new to the medical profession. They existed well before managed care was introduced in the United States. Indeed the ancient symbol of the physician and healing, the Staff of Asclepius (a simple rod adorned by a single serpent), has long been confused with and mistakenly replaced by the Caduceus of Mercury (Hermes), a winged staff wrapped in a pair of snakes. Hermes was also identified as "the patron god of thieves, merchants, and travelers . . . the god of games, luck, and commerce . . . [and] an ingenious deceiver." See Robert A. Wilcox & Emma M. Whitham, *The Symbol of Modern Medicine: Why One Snake Is More Than Two*, 138 ANNALS INTERNAL MED. 673, 676 (2003).

request for a forensic evaluation or to perform actions on behalf of state institutions like prisons, which require specific duties of physicians that conflict with their traditional commitments. Or the responsibility may be to the military, whose ultimate goal is to protect the security of a population. In each case, a physician's additional or peripheral responsibilities may divide her initial duty to patient care.

Military duties are often particularly difficult to reconcile with other personal, professional, or even legal duties. The history of judicial deference to the military in this country, embedded in the Constitution² and known as the separate community doctrine,³ reflects our willingness to cabin military duties as both separate from other duties and, for the most part, unconditional.⁴ Perhaps it should not be surprising that when a service member believes a given order to be in conflict with his or her own moral value or ethical code, an available justification for otherwise unethical behavior is employed: The imposed military duty constitutes a *separate* responsibility, apart from those normally attaching to an individual in his or her "personal" life.⁵ If duties can be thus

2. U.S. CONST. art. I, § 8, cl. 14.

3. See *Solorio v. United States*, 483 U.S. 435, 448 (1987) (discussing the principle of deference); *Chappell v. Wallace*, 462 U.S. 296, 301 (1983) (stating that "[t]he military constitutes a specialized community governed by a separate discipline from that of the civilian"); *Parker v. Levy*, 417 U.S. 733, 758 (1974) ("[T]he different character of the military community and of the military mission requires a different application of [First Amendment] protections."); *Orloff v. Willoughby*, 345 U.S. 83, 94 (1953) ("The military constitutes a specialized community governed by a separate discipline from that of the civilian."); *Carter v. McClaughry*, 183 U.S. 365, 390 (1902) (members of the military belong to a "separate community recognized by the Constitution"); see also James M. Hirschhorn, *The Separate Community: Military Uniqueness and Servicemen's Constitutional Rights*, 62 N.C. L. REV. 177 (1984). The separate community doctrine is also known as the doctrine of military necessity and the nonreviewability doctrine. See, e.g., Stanley Levine, *The Doctrine of Military Necessity in the Federal Courts*, 89 MIL. L. REV. 3 (1980); Stephen Lewis Rabinowitz, Note, *Goldman v. Secretary of Defense: Restricting the Religious Rights of Military Servicemembers*, 34 AM. U. L. REV. 881, 897 (1985); see generally Comment, *God, the Army, and Judicial Review: The In-service Conscientious Objector*, 56 CAL. L. REV. 379, 379-85, 413-47 (1968).

4. See *Rostker v. Goldberg*, 453 U.S. 57, 64-65 (1981) ("[I]n no other area has the Court accorded Congress greater deference."); see also *Wallace v. Chappell*, 661 F.2d 729, 732 (9th Cir. 1981) ("[T]he Supreme Court has voiced a general objection to judges 'running the army'" (quoting *Orloff v. Willoughby*, 345 U.S. 83, 93-94 (1953))), *rev'd on other grounds*, 462 U.S. 296 (1983); Joseph E. Broadus, *Don't Ask, Don't Tell, Yes: Don't Second-Guess the Military*, 79 A.B.A. J. 54 (Oct. 1993) (noting that military policy has always been upheld in the courts because the special needs of the military require that the courts defer to expert military opinion).

5. This justification reflects what Gerald Postema refers to as a "schizophrenic" view of role morality, by which one "simply dissociates the private personality from the . . . professional

compartmentalized, one may consider himself free from personal responsibility for actions performed while operating in a specific and sanctioned role such as soldier, attorney, or physician. One may only be held professionally responsible and thus judged on the basis of shared professional ethical guidelines. It remains an open question how individuals ought to honor their personal values when professional duties require conflicting action, and much of the literature on role morality has focused on this question.⁶ The implications that follow from sacrificing one's personal moral values for professional obligations can be disturbing, even if they are ultimately justifiable from a utilitarian perspective.

More disturbing, however, should be the apparent ease with which robust professional norms and duties in one profession can be suppressed in favor of those in another. Such has been the case with the medical profession and the military. The strong evidence that doctors ignored, justified, or even helped in the humiliation, degradation, and physical abuse of Iraqi detainees at Abu Ghraib has shocked many in both the medical and non-medical communities.⁷ Mounting evidence suggests that physicians falsified and delayed death certificates, shared detainees' medical information with military interrogators, ignored abuse, and covered up homicides⁸—all activities in contravention of international law and medical ethics.⁹ This Note argues that, while these activities were arguably

personality, regarding them as separate, independent selves.” Gerald Postema, *Self-Image, Integrity, and Professional Responsibility*, in *THE GOOD LAWYER* 286, 292 (David Luban ed., 1983).

6. See, e.g., ARTHUR ISAK APPLBAUM, *ETHICS FOR ADVERSARIES: THE MORALITY OF ROLES IN PUBLIC AND PROFESSIONAL LIFE* (1999); R. S. DOWNIE, *ROLES AND VALUES: AN INTRODUCTION TO SOCIAL ETHICS*, 121-45 (1971); Richard Wasserstrom, *Roles and Morality*, in *THE GOOD LAWYER*, *supra* note 5, at 25-37.

7. See M. Gregg Bloche & Jonathan Marks, *When Doctors Go to War*, 352 *NEW ENG. J. MED.* 3 (2005).

8. *Id.* (reporting that U.S. medical personnel: (1) failed to report evidence of detainee abuse and murder in Iraq and Afghanistan; (2) shared health information, including patient records, with army units that planned interrogation; (3) participated in interrogation that was tantamount to torture; and (4) medics and “others” neglected the clinical needs of some detainees. The Pentagon responded to the accusations of the International Committee of the Red Cross by denying allegations that detainee medical files were used to harm detainees.); see also, Robert Jay Lifton, *Doctors and Torture*, 351 *NEW ENG. J. MED.* 415 (2004); Benjamin Meier, *International Criminal Prosecution of Physicians: A Critique of Professors Annas and Grodin's Proposed International Medical Tribunal*, 30 *AM. J. L. & MED.* 419 (2004).

9. “Doctors shall not countenance, condone, or participate in torture or other forms of degrading procedures . . . in all situations, including armed conflict and civil strife.” *World Medical Association Declaration of Tokyo* (1975), reprinted in *THE BREAKING OF BODIES AND MINDS: TORTURE, PSYCHIATRIC ABUSE, AND THE HEALTH PROFESSIONS*, at 272-73 (Eric Stover & Elena O. Nightingale eds., 1985). Though some of the activity also violated military laws, much of it did not.

outside the realm of military duties, they would not have been committed had medical professional norms been obeyed.

The abuse by non-medical reservists has attracted substantial Congressional and media attention¹⁰ centering on personal culpability and the individual transgressions of a few of those involved. The discussion of abuse by physicians and nurses, however, has been far less widespread. Additionally, the focus of discussion about caregiver abuse is often shifted to institutional problems stemming from the influential power of the military and its virtual non-reviewability.¹¹ After all, if the Supreme Court of the United States defers to the judgment of the armed forces, why shouldn't a uniformed physician do the same?

The query itself reveals the answer in its implied understanding of the physician and her role. The physician in question is a professional who has been enlisted, recruited, hired or seconded like any other professional, to advance the goals of the military. She would seem not to have any discrete medical obligations that might challenge, much less override, those attached to her military duties. Her professional ethics are no more robust, supported, or recognized by the military or government than her personal ethics. Given the current status of medical professional norms and responsibilities in the military, which make them virtually indistinguishable from personal norms and responsibilities, a physician's complicity and involvement in "legal" but medically unethical activity in Iraq and Afghanistan should be no more surprising than the participation of non-medical military personnel who follow orders that later come under judicial review.¹²

Physician collaboration with military intelligence teams and participation in interrogation, for instance, is not illegal. Testimony by Colonel Thomas M. Pappas, chief of military intelligence at Abu Ghraib, revealed physicians' systematic role in developing and executing interrogation strategies for individual detainees *for whose care the same physicians were responsible*. Testimony of Thomas Pappas, Commander, 205th MI Brigade (Feb. 9, 2004), <http://www.aclu.org/torturefoia/released/a46.pdf>.

10. See, e.g., Associated Press, *Soldier Gets Closer to Abuse Retrial*, N.Y. TIMES, May 25, 2005, at A8 (discussing the most recent covered event at the time of this writing, regarding the last of several trials to prosecute army reservists involved in the abuse of Iraqi detainees at Abu Ghraib).

11. Meier, *supra* note 8.

12. Whether the actions of those reservists prosecuted in connection with abuses at Abu Ghraib were the result of explicit or implied orders from military leadership apparently remains an open question. However, reservists involved in misconduct that were formally charged include, but are not limited to, the following: Spc. Charles Graner (sentenced to ten years and demoted to private), Sgt. Javal Davis (sentenced to six months, reduced to private and dishonorably discharged), Spc. Roman Krol (sentenced to ten months and bad conduct discharge), Staff Sgt. Ivan L. "Chip" Frederick, II (sentenced to eight and a half years, reduced to private and dishonorably discharged),

This view of the physician and her professional role as deferential to military norms, be they legal or not, is neither new nor unique. On the contrary, the disempowerment of medicine's professional role is a result of gradual degradation by courts and by physicians themselves¹³ over the past thirty years. It is perhaps surprising that certain institutionalized physician behavior has only recently caused widespread concern.¹⁴ The physician involvement at Abu Ghraib typifies a broader situation in which American physicians increasingly allow other duties or perceived duties to trump their ethical obligations to patients and to the profession. This Note focuses on one recent example of the degradation of a physician's core responsibilities—the forced medication of death row inmates for the purpose of executing them—as an example of factors leading up to the professional transgressions committed by physicians and nurses who otherwise represent the best of the medical profession through their service and sacrifice.

Underlying this analysis are two basic claims. First, the state has an interest in preserving, or at least not threatening,¹⁵ public trust in certain professions that benefit society.¹⁶ And second, medical professionals should be given greater

Spc. Armin J. Cruz, Jr. (sentenced to eight months, reduced to private and given bad conduct discharge), Pvt. Jeremy Sivits (sentenced to one year and bad conduct discharge), Spc. Megan Ambuhl (reduced to private and separated from Army), Spc. Sabrina D. Harman (sentenced to six months and bad conduct discharge), Spc. Megan Ambuhl, (discharged from the Army without serving prison time), Pvt. Lynndie England (sentenced to three years and dishonorable discharge). JoAnn Wypijewski, *Judgment Days: Lessons from the Abu Ghraib Courts-Martial*, HARPER'S MAGAZINE, Feb. 1, 2006, at 39.

13. When physicians engage in behavior that is inconsistent with their professional code, they reify the misguided conception of their role. Physicians who give expert testimony to frivolous tort allegations fuel a dangerous growth in malpractice claims. See, e.g., Kathy George, *Doctor Wants Fellow Doctor Suspended over Malpractice Testimony*, SEATTLE POST-INTELLIGENCER, June 7, 2004, at B1. Similarly, those who engage in unethical behavior—even when it is legal—contribute to the degradation of important professional values.

14. In fact, abuse and misconduct by physicians should be of no less concern than transgressions in other professions. The past seventy-five years have borne witness to numerous atrocities in U.S. clinical and research medicine. A series of American medical abuses followed the Nazi experiments on prisoners during the Third Reich (1933-1945). See Belinda Seto, *History of Medical Ethics and Perspectives on Disparities in Minority Recruitment and Involvement in Health Research*, 322 AM. J. MED. SCI. 246 (2001).

15. The trust of military soldiers in physicians is also important. The role of the soldier requires that soldiers put their lives and safety at risk in all sorts of especially demanding ways. To be potentially subjected to harm by their own physicians may frustrate a soldier's willingness to be potentially subjected to harm in warfare. If physicians are known to cause harm to enemies for the sake of national security, they may be perceived or known to cause harm to their countrymen when called on by the interests of national security.

16. Though not an obvious claim, this Note takes for granted the proposition that public trust in

deference in pursuit of their ethical obligations than other professionals by virtue of the nature of their work and its effects. The work of the physician involves particular vulnerabilities on the part of patients and carries the potential to elicit powerful and conflicting psychological and emotional impulses on the parts of both physicians and patients. Although it would be foolish to suggest that medical professional mores should always override competing values, the integrity of the medical professional role is of greater importance than is immediately apparent. Stronger support of medicine's autonomy is called for, as well as a more formal structure of accountability for those who would violate the profession's core values. A history of medical involvement in immoral activity, state-sanctioned or otherwise, demonstrates that abuse flourishes when physicians become morally detached from the interests of their patients.¹⁷ At the very least, judges and policy makers ought to attend more carefully to this phenomenon in their evaluations of medical ethical norms.

Recent medical jurisprudence has either ignored or denied a connection between patient-centered professional morality and responsible care giving.

the medical profession is worth preserving. Indeed, in some cases, government regulation takes general and specific notice of the importance of the doctor-patient relationship and its impermeability. The Medicare anti-kickback statute (42 U.S.C. § 1320a-7b(b) (2005)) and related regulations, for example, were enacted (and are currently enforced) to preserve the traditional role of the physician "to provide treatments . . . in the best interest of the patient." Office of Inspector General, 59 Fed. Reg. 65,372, 65,376 (Dec. 19, 1994). They may serve the additional function of curtailing inappropriate or over-utilization, but that is a secondary purpose. See, e.g., Thomas N. Bulleit, Jr. & Joan H. Krause, *Kickbacks, Courtesies or Cost-Effectiveness?: Application of the Medicare Antikickback Law to the Marketing and Promotional Practices of Drug and Medical Device Manufacturers*, 54 FOOD & DRUG L.J. 279 (1999). As one commentator notes, "It must . . . be shown that the particular relationship and the particular kind and degree of [public] trust it promotes or engenders is, from the standpoint of morality, worth preserving." Wasserstrom, *supra* note 6, at 35. Two questions arise out of Wasserstrom's analysis. First, should a certain role exist? And second, if a certain role exists, should the occupant of that role do what the role, so constituted, requires? This Note focuses more on the second question than the first, which has been argued convincingly in the affirmative. See generally Ralph Cranshaw et al., *Patient-Physician Covenant*, 273 JAMA 1553 (1995); Ezekial J. Emanuel & Nancy N. Dubler, *Preserving the Physician-Patient Relationship in the Era of Managed Care*, 273 JAMA 323 (1995).

17. See, e.g., Troyen Brennan & Robert Kirschner, *Medical Ethics and Human Rights Violations: The Iraqi Occupation of Kuwait and Its Aftermath*, 117 ANNALS INTERNAL MED. 78 (1992); Vincent Iacopino et al., *Physician Complicity in Misrepresentation and Omission of Evidence of Torture in Postdetention Medical Examinations in Turkey*, 276 JAMA 396 (1996); Matthew Lippman, *The Nazi Doctors Trial and the International Prohibition on Medical Involvement in Torture*, 15 LOY. L.A. INT'L & COMP. L. REV. 395 (1993); Jerome Singh, *American Physicians and Dual Loyalty Obligations in the "War on Terror,"* 4 BMC MED. ETHICS E4 (2003) (describing detainee abuse in apartheid South Africa).

Courts' and legislators' inattention in this area degrades the integrity of a physician's professional role and its subsequent responsibilities. Physicians' obligations to non-therapeutic ends ought to be reconsidered in light of increasing role conflict faced by physicians and decreasing support from courts and legislators.¹⁸ Policies protecting physician autonomy in the ethical pursuit of the medical profession should be supported. And the primary duties of physicians employed by the state, whether in prisons, courts, or the military, should be clarified and protected by law.

Reasoning from a specific case to general policy, this Note discusses the involvement of physicians in the forced medication of a death row inmate against the backdrop of the abuse at Abu Ghraib, as well as the psychological dynamics of medical care, which have been all but disregarded in the discussion of physician responsibility to the aims of criminal justice and the military. This Note begins its analysis by reviewing *Singleton v. Norris*, a case that highlights the extreme conflicts of duty that physicians must face when their first-order duty to patient health is challenged and divided. It then reviews further court precedents on the issues raised by *Singleton* and critique the paradoxical concept of "medical best interest" that courts have imposed upon physicians. Next, it considers the conflict between the demands of common morality and professional ethics. Finally, this Note evaluates these competing claims from a consequentialist perspective and concludes by advocating for judicial recognition of the primacy of physicians' professional duties over competing claims.

I. SINGLETON V. NORRIS: PHYSICIAN-ASSISTED EXECUTION

On a warm summer night in Arkansas in 1979, a young man named Charles Singleton walked into York's Grocery Store in the small town of Hamburg and asked for a pack of cigarettes.¹⁹ When Mary Lou York turned around to hand over the cigarettes, Singleton showed his gun and demanded all the money in the register.²⁰ York refused and fought with Singleton.²¹ Singleton fired the gun and missed, then stabbed Mary Lou York in the neck with a knife.²² Charles

18. The Oklahoma House of Representatives is, at the time of this writing, debating a bill that would prevent medical licensing boards from retaliating against state doctors and nurses who participate in executions in Oklahoma. See H.B. 2660, 50th Leg., 1st Sess. (Okla. 2006). The bill was requested by the State Department of Corrections following the refusal of two anesthesiologists in California to comply with a federal court order to anesthetize a death row inmate before lethal doses of medicine were administered. See *infra* note 60.

19. *Dateline NBC: Crazy Like a Fox?* (NBC television broadcast Apr. 5, 1999).

20. *Id.*

21. *Id.*

22. *Id.*

Singleton was prosecuted for robbery and felony murder. Evidence of his guilt was overwhelming and included blood on his clothes, as well as eye and ear witness accounts of the crime.²³ Singleton was convicted and sentenced to death by electrocution in 1979 by the Circuit Court of Ashley County, Arkansas, for capital murder.²⁴ He then remained on death row for longer than any other prisoner in the state's history.²⁵ He appealed through both the state and federal systems on procedural grounds,²⁶ claiming ineffective assistance of counsel and invalid aggravating factors²⁷ until 1998, after twenty years of appeals, when a new issue arose at the intersection of medical ethics, health policy, and law.

During Charles Singleton's lengthy incarceration, he became psychotic and was diagnosed as likely schizophrenic.²⁸ In 1997, the State medicated him involuntarily because he was found to be a danger to himself and others.²⁹ He was subsequently granted a stay of execution by Arkansas's Supreme Court.³⁰ Assuming, *arguendo* that the medication was in Singleton's medical best interest—as well the state's best interest—at the time it was ordered, that rationale expired when Singleton's stay of execution was dissolved. The Constitution requires that prisoners be mentally competent to be executed.³¹ No state may execute mentally retarded individuals³² or individuals who are insane.³³

23. Singleton v. Norris, 319 F.3d 1018, 1020 (8th Cir. 2003).

24. Singleton v. State, 623 S.W.2d 180, 181 (Ark. 1981).

25. Michael R. Wickline, *Man on Death Row 20 Years Loses Appeal*, ARKANSAS DEMOCRAT-GAZETTE, Jan. 25, 2002, at B3.

26. Singleton v. Arkansas, 459 U.S. 882 (1982); Singleton v. Lockhart, 962 F.2d 1315 (8th Cir. 1992) (habeas corpus proceeding); Singleton v. Lockhart, 871 F.2d 1395 (8th Cir. 1989) (habeas corpus proceeding); Singleton v. Endell, 870 S.W.2d 742 (Ark. 1994); Singleton v. State, 623 S.W.2d 180 (Ark. 1981), *cert. denied*, Singleton v. Arkansas, 456 U.S. 938 (1982).

27. Singleton v. Norris, 319 F.3d at 1021.

28. *Id.* at 1031.

29. *Id.* at 1021. Singleton had been intermittently medicated, sometimes voluntarily, during much of his stay in prison prior to 1997. Psychotropic medication was initially prescribed to alleviate anxiety and depression. Singleton did not present with psychotic symptoms until 1987. *Id.* at 1030.

30. Singleton v. Norris, 964 S.W.2d 366 (Ark. 1998).

31. Ford v. Wainwright, 477 U.S. 399, 410 (1986).

32. Atkins v. Virginia, 536 U.S. 304 (2002). The governing standard for determining whether a prisoner is competent to be executed is that the Eighth Amendment forbids the execution only of those who are unaware of the punishment they are about to suffer and why they are to suffer it. *Ford*, 477 U.S. at 422 (Powell, J., concurring). The prohibition against executing inmates who are mentally retarded, therefore, rests on the presumption that mentally retarded individuals are incompetent to be executed because they are unaware of the punishment and its justification.

33. Singleton v. Norris, 319 F.3d at 1023. The Eighth Amendment precludes psychotic inmates from being executed only if they are unaware of the punishment and its justification. *See supra* note

The general legal standard is that the individual being executed understand the crime committed and the punishment prescribed. Thus, Singleton's physicians were faced with a troubling dilemma. Charles Singleton would remain floridly psychotic if left unmedicated, suffering from hallucinations, delusions, and self-mutilation. But he would also remain alive. If he were medicated, he would be killed. The question before the Eighth Circuit Court of Appeals in *Singleton v. Norris*³⁴ was whether a psychotic prisoner could be medicated without consent, even if his psychosis were the only factor keeping him from being executed by the state. The court ruled that a state does not violate the Eighth Amendment when it executes a prisoner who became incompetent during a long stay on death row, but who subsequently regained competency through forced treatment.³⁵

II. EXECUTION OF INCOMPETENT INDIVIDUALS: "A MISERABLE SPECTACLE"

The notion that it is inappropriate to execute incompetent individuals dates back to late fifteenth-century common law. Sir Edward Coke argued, for example, that "because execution was intended to be an 'example' to the living, the execution of 'a mad man' was such a 'miserable spectacle . . . of extreme inhumanity and cruelty' that it 'can be no example to others.'"³⁶ The Supreme Court recently made the following observation in *Ford v. Wainwright*:

[T]oday, no less than before, we may seriously question the retributive value of executing a person who has no comprehension of why he has been singled out and stripped of his fundamental right to life. . . . Similarly, the natural abhorrence civilized societies feel at killing one who has no capacity to come to grips with his own conscience or deity is still vivid today. And the intuition that such an execution simply offends humanity is evidently shared across this Nation.³⁷

The Court noted the prohibition against killing the insane does not merely "protect the condemned from fear and pain without comfort of understanding" but also "protect[s] the dignity of society itself from the barbarity of exacting mindless vengeance."³⁸

32.

34. Singleton, 319 F.3d at 1023.

35. *Id.* at 1027.

36. State v. Perry, 610 So. 2d 746, 749 (La. 1992) (quoting 3 E. COKE, INSTITUTE 6 (1794)).

37. Ford v. Wainwright, 477 U.S. 399, 409 (1986).

38. *Id.* at 410; see also Paul J. Larkin, Note, *The Eighth Amendment and the Execution of the Presently Incompetent*, 32 STAN. L. REV. 765, 777 n.58 (1980) (suggesting no societal retributive interest in executing persons who have no comprehension of why they have been singled out and stripped of their rights to life).

The *Ford* Court, therefore, deferred to an historical and “natural abhorrence” to such “barbarity,”³⁹ and found that the state interest for retribution did not overcome the rights of the condemned nor the dignity of society. According to the Court, the punishment becomes “mindless” when the person does not know the reason for which the punishment is being meted out. Additionally, the Supreme Court has required competency so that convicted individuals would have the opportunity to appeal.⁴⁰ The procedural safeguards anticipated cannot be actively pursued if the individual is not competent. Some believe that competency is required for individuals to make peace with their God before death, or at least to come to terms with their death. Lastly, others have argued that it is inhumane to kill someone with severe disturbances of the cognitive capacities of consciousness, comprehension, or reasoning, regardless of whether these capacities rise to the level sufficient to participate in their own defense or to seek reconciliation in religion.⁴¹

Clearly, this case presents a number of issues concerning the death penalty. The important question, however, for understanding physician behavior is what are, or what should be, doctors’ duties to their patients, and in what manner the law should respect such duties.⁴² This Note aims to address the issues raised by Singleton’s claim and to specifically discuss the ethical duty of a physician employed and instructed by the government to render care so as to effectively

39. See *Ford*, 477 U.S. at 406-10 (outlining rationales for excluding insane individuals from execution); George W. Barnard & Michael L. Radelet, *Ethics and the Psychiatric Determination of Competency To Be Executed*, 14 BULL. AM. ACAD. PSYCHIATRY & L. 37, 39-42 (1986) (discussing rationales for not executing the insane); Matthew S. Collins, *Involuntarily Medicating Condemned Incompetents for the Purpose of Rendering Them Sane and Thereby Subject to Execution*, 70 WASH. U. L.Q. 1229, 1236-41 (1992) (delineating rationales for justifying the ban on execution as practical, religious and humane); Robert F. Schopp, *Wake Up and Die Right: The Rationale, Standard, and Jurisprudential Significance of the Competency To Face Execution Requirement*, 51 LA. L. REV. 995, 998-1010 (1991); David L. Katz, Note, *Perry v. Louisiana: Medical Ethics on Death Row—Is Judicial Intervention Warranted?*, 4 GEO. J. LEGAL ETHICS 707, 709-10 (1991); see also Editorial, “Mindless Vengeance,” ST. PETERSBURG TIMES, Feb. 25, 2003, at 10A (“The U.S. Supreme Court has said execution of the insane serves no cause of justice, and the public shares that opinion.”).

40. This falls out of the Court’s longstanding pronouncement that “[t]he fundamental requisite of due process of law is the opportunity to be heard.” *Grannis v. Ordean*, 234 U.S. 385, 394 (1914).

41. See Schopp, *supra* note 39, at 1046. But see Kursten B. Hensl, Note, *Restored to Health to Be Put to Death: Reconciling the Legal and Ethical Dilemmas of Medicating To Execute in Singleton v. Norris*, 49 VILL. L. REV. 291, 327-28 (2004) (arguing that state action to restore competency for the purpose of execution amounts to nothing more than mindless vengeance).

42. Most state death penalty statutes currently allow or even require physician participation in executions. See Kenneth Baum, “To Comfort Always”: *Physician Participation in Executions*, 5 N.Y.U. J. LEGIS. & PUB. POL’Y 47, 73 n.81 (2001).

prepare his patient for execution. It will not address the ethics of execution as a criminal penalty in the United States,⁴³ nor will it address the so-called *Lackey* claim made on behalf of individuals like Singleton who have been on death row for an extended period of time.⁴⁴ It will, however, include a brief legal history of the issue with the intention of uncovering and introducing some of the professional ethical conflicts for physicians that contribute to the dilemma presented by the *Singleton* case.

III. LEGAL HISTORY: THE “MEDICALLY APPROPRIATE” REQUIREMENT

The Eighth Amendment bars executions of mentally-ill prisoners.⁴⁵ And although the Supreme Court has decided several cases in which a criminal defendant or a convicted criminal may be medicated against his or her will, it denied certiorari on the *Singleton* case.⁴⁶

The Court has noted that a prisoner has a “significant liberty interest” in avoiding the unwanted administration of an antipsychotic drug.⁴⁷ But there are cases in which the Supreme Court has allowed the state to forcibly medicate an inmate or criminal defendant without consent. In *Washington v. Harper*, the Court held that if an inmate is a threat to himself or others while incarcerated *and* if medication is also in his “medical interest,” then the state may forcibly medicate without consent.⁴⁸ The Court has also noted that a state may be justified

43. Singleton’s defense did not include *a priori* Constitutional objections to the death penalty. *Singleton v. Norris*, 319 F.3d 1018 (8th Cir. 2003).

44. Claims that the Eighth Amendment would be violated by the execution of an inmate after many years on death row are called *Lackey* claims, following *Lackey v. Texas*, 514 U.S. 1045 (1995) (mem.) (Stevens, J., respecting the denial of certiorari). Such claims, while not yet ruled on by the Supreme Court, have gained support in international law and in dissents from the Court’s denial of certiorari by Justice Stevens and Justice Breyer. See Jeremy Root, *Cruel and Unusual Punishment: A Reconsideration of the Lackey Claim*, 27 N.Y.U. REV. L. & SOC. CHANGE 281 (2001-2002); see also *Soering v. United Kingdom*, 161 Eur. Ct. H.R. (ser. A) at 44-45 (1989) (holding that extradition of a German national to Virginia in a capital case would violate the prohibition against “inhumane or degrading treatment or punishment” under the European Convention because of the likely length and extreme nature of confinement while on death row); Richard B. Lillich, *Harmonizing Human Rights Law Nationally and Internationally: The Death Row Phenomenon as a Case Study*, 40 ST. LOUIS U. L.J. 699 (1996) (examining the “death row phenomenon” as an example of the growing internationalization of human rights law, i.e., national courts looking to international norms, and international and regional bodies taking national court decisions into account).

45. *Ford v. Wainwright*, 477 U.S. 399, 410 (1986).

46. *Singleton v. Norris*, 540 U.S. 832 (2003).

47. *Washington v. Harper*, 494 U.S. 210, 221-22 (1990).

48. *Id.* at 227.

in forcibly medicating an insane criminal defendant if it can establish that “it [cannot] obtain an adjudication of [a defendant’s] guilt or innocence by using less intrusive means.”⁴⁹

Non-dangerous criminal defendants may also be forcibly medicated if doing so will render them competent to stand trial *and* if doing so is “sufficiently important to overcome the individual’s protected interest in refusing it.”⁵⁰ In *Sell v. United States*, the Court found that the government had not shown a need for treatment without consent and reversed the Eighth Circuit’s judgment on this issue.⁵¹

The Eighth Circuit is the only federal court that has addressed the issue of whether the state can medicate an inmate for the primary purpose of carrying out his sentence once he has been found guilty.⁵² In a sharply divided six-to-five decision, the Eighth Circuit held in *Singleton* that the Eighth Amendment, forbidding “cruel and unusual punishments,” is not violated by forcibly medicating an insane condemned person so that he becomes sufficiently sane to execute.⁵³ The court held that the state could force a mentally ill criminal defendant to take antipsychotic medication in order to render him sufficiently competent to be executed. To reach this decision, it applied the same test that it used in *Sell*, which went uncontested by the Supreme Court on appeal: The state must: “(1) present an essential state interest that outweighs the individual’s interest in remaining free from medication, (2) prove that there is no less intrusive way of fulfilling its essential interest, and (3) prove by clear and convincing evidence that the medication is medically appropriate.”⁵⁴

A bare majority of the Eighth Circuit found that the government has a compelling interest in carrying out a lawfully imposed criminal sentence. It ruled that the state’s interest in carrying out *Singleton*’s sentence outweighed *Singleton*’s interest in remaining free from medication. Even *Singleton* preferred to be medicated rather than unmedicated, so long as he was not going to be executed as a result. The court also found that no less-intrusive method existed

49. *Riggins v. Nevada*, 504 U.S. 127, 135 (1992).

50. *Sell v. United States*, 539 U.S. 166, 183 (2003).

51. *Id.*

52. In *Perry v. Louisiana*, 498 U.S. 38 (1990) (per curiam), the Supreme Court was presented with the issue of whether the state, in its efforts to cure death row inmates, could force antipsychotic medication on them, but the Court remanded the case to Louisiana and has not resolved the question.

53. *Singleton v. Norris*, 319 F.3d 1018, 1027 (2003) (“A State does not violate the Eighth Amendment . . . when it executes a prisoner who became incompetent during his long stay on death row but who subsequently regained competency through appropriate medical care.”).

54. *Id.* at 1024 (referencing *United States v. Sell*, 282 F.3d 560, 567 (8th Cir. 2002)) (internal quotations omitted).

by which the state could attain its end. Finally, the court found Singleton's medication was medically appropriate and there was no need to factor the issue of execution into the consideration of Singleton's medical interest. Because it was in Singleton's short-term interest to be medicated, it satisfied the third prong of the Eighth Circuit's *Sell* test.

Several problems have been noted in the Eighth Circuit's ruling.⁵⁵ Most troubling to physicians, however, is the problem noted in *State v. Perry*: "[F]orcing a prisoner to take antipsychotic drugs to facilitate his execution does not constitute medical treatment but is antithetical to the basic principles of the healing arts."⁵⁶ The physician who prescribes the drugs arguably violates medical ethical tenets of beneficence and non-maleficence.⁵⁷

The predominant legal question in Singleton's case was whether the forced administration of antipsychotic drugs to render Singleton competent to be executed unconstitutionally deprived him of his "liberty" to reject medical treatment.⁵⁸ But an equally important question, one more reflective of the medical-legal norms surrounding recent scandals in Iraq, Afghanistan, and Guantanamo Bay, is whether the same forced care deprives the medical profession of a right to set appropriate standards for ethical practice.⁵⁹ And if not,

55. See, e.g., Rebecca A. Miller-Rice, *The "Insane" Contradiction of Singleton v. Norris: Forced Medication in a Death Row Inmate's Medical Interest Which Happens to Facilitate His Execution*, 22 U. ARK. LITTLE ROCK L. REV. 659 (2000); Brent W. Stricker, *Seeking an Answer: Questioning the Validity of Forcible Medication To Ensure Mental Competency of Those Condemned to Die*, 32 MCGEORGE L. REV. 317 (2004); Melinda S. Campbell, Comment, *Sell, Singleton, and Forcible Medication—Running Roughshod over Liberty*, 35 U. TOL. L. REV. 691 (2004); Hensl, *supra* note 41.

56. 610 So. 2d 746, 751 (La. 1992).

57. Four central principles (autonomy, beneficence, non-maleficence, and justice) have dominated the public health literature, though the two highlighted (beneficence and non-maleficence) in this discussion have a more robust historical footing in medical ethics. See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* (4th ed. 1994). Moreover, under these circumstances, the physician is re-cast in the role of punisher. The prisoner does not consent to the administration of the drugs, and if the primary reason for their administration is to carry out the condemned prisoner's sentence (rather than, for example, the prisoner's own medical benefit or the safety of fellow prisoners and prison staff), then the administration of the drug arguably becomes *part of* the sentence. It is no doubt a harm (at the very least a dignitary harm) to the patient. And if it is both a harm and part of the prisoner's sentence, it constitutes punishment—punishment to which no court lawfully sentenced the prisoner.

58. U.S. CONST. amend. V. (stating that the government may not "deprive[]" any person of "liberty . . . without due process of law").

59. One report indicates that, of the thirty-six states with death penalty statutes, at least twenty-one require a physician to "pronounce" or "determine" death. AM. COLL. OF PHYSICIANS ET AL., *BREACH OF TRUST: PHYSICIAN PARTICIPATION IN EXECUTIONS IN THE UNITED STATES* 49-72 (1994),

why not? When, if ever, should the law defer to a profession's ethical standards and requirements? In other words, Singleton may not have had a compelling legal or ethical right to avoid execution, but his physician had not only a right, but an obligation to refuse to treat Singleton given the fatal consequences of that treatment and the potential consequences for the profession.⁶⁰ One wonders how the *Singleton* case might have been argued or decided if it had remained before the court during or after the reports of physician involvement at Abu Ghraib had surfaced.

IV. PRECEDENT: THE OFFENSE PRINCIPLE

With more than twenty years of history and appeals, Singleton's case is far more complicated than described thus far. But the central issue of when the state may and should forcibly medicate a person has been difficult for the courts to adjudicate.⁶¹ There is, however, some guiding case law. Several similar issues have come before the courts. In *Washington v. Harper*, which involved the forced medication of a prisoner in a correctional facility, the Supreme Court recognized that an individual has a "significant" constitutionally protected "liberty interest" in "avoiding the unwanted administration of antipsychotic drugs."⁶² However, the Court, apparently guided by principles of harm and

available at http://www.hrw.org/reports/1994/usdp/breach_of_trust.pdf. In twenty-eight states, statutes or regulations require that a physician "shall" or "must" be present at the execution (an additional four states say a physician "may" be present and an additional three states say a physician "shall" or "must" be invited). *Id.* The researchers also found that some state laws, while vague on participation, are often interpreted so that a physician is directly involved in the execution. *Id.*

60. The physicians treating Singleton probably have an exercisable right not to treat him against his wishes, just as physicians are generally protected from professional activity that violates personal, moral, or religious values. *See infra* note 85 (discussing conscience clauses). In February 2006, for instance, two anesthesiologists refused to assist in a California execution after their presence was required by a district court judge. Louis Sahagun & Tim Reiterman, *Execution of Killer-Rapist Is Delayed*, L.A. TIMES, Feb. 21, 2006, at B1. This Note argues that, instead, physicians should have an *obligation* not to forcibly treat patients under these circumstances that, while not absolute, ought to be afforded greater deference by law and policy. It may be further argued that state medical licensing boards and societies should enforce the prohibition against which Singleton's physicians transgressed by rescinding medical licenses from physicians who violate their professional ethics. At least one state legislature (Oklahoma) has anticipated this move by proposing legislation that would protect physicians from the disciplinary actions of licensing boards when physicians participate in executions. *See* H.B. 2660, 50th Leg., 1st Sess. (Okla. 2006).

61. As previously noted, Singleton did not present physicians' professional obligations as a defense on his behalf.

62. 494 U.S. 210, 221-22 (1990).

paternity, concluded that the state law authorizing involuntary treatment amounted to a constitutionally permissible “accommodation between an inmate’s liberty interest in avoiding the forced administration of antipsychotic drugs and the state’s interests in providing appropriate medical treatment to reduce the danger that an inmate suffering from a serious mental disorder represents to himself or others.”⁶³

Singleton’s case differed from Harper’s in that the state’s interest extended beyond protecting Singleton and others from harm since it included a justice interest in carrying out a sentence for punishment. One might easily anticipate an argument on behalf of the state based on the Offense Principle claiming that an offense is committed against Singleton’s victims and their fellow citizens when Singleton escapes his sentence. An argument of this type can be found in another case—*Riggins v. Nevada*.⁶⁴

In *Riggins*, a case involving a defendant unfit to stand trial without treatment by antipsychotic medication, the Court decided that an individual has a constitutionally protected liberty “interest in avoiding involuntary administration of antipsychotic drugs” which only an essential or overriding state interest might overcome.⁶⁵ The Court suggested that forced medication in order to render a defendant competent to stand trial for murder was constitutionally permissible. Citing *Harper*, the Court noted that the state “would have satisfied due process if the prosecution demonstrated . . . that treatment with antipsychotic medication was medically appropriate and, considering less intrusive alternatives, essential for the sake of Riggins’s own safety or the safety of others.”⁶⁶ The Court further noted that the state “might have been able to justify medically appropriate, involuntary treatment with the drug by establishing that it could not obtain an adjudication of Riggins’s guilt or innocence” of the murder charge “by using less intrusive means.”⁶⁷ The question in Singleton’s case, then, may have been whether the execution of an individual is as “essential” or “overriding” a state interest as the adjudication of that individual’s guilt or innocence.

The Supreme Court’s rulings thus far point toward a constitutional permission granted to the government to involuntarily administer antipsychotic drugs to a mentally ill person *if and only if*, among other things, the treatment is

63. *Id.* at 236.

64. *Riggins v. Nevada*, 504 U.S. 127, 135 (1992) (stating that due process would have been satisfied in connection with administration of antipsychotic drugs to defendant during trial if state court had found that treatment was medically appropriate and essential for the sake of the safety of others).

65. *Id.* at 134-35.

66. *Id.* at 135.

67. *Id.*

medically appropriate, which the Court defines as “in the patient’s medical interest.”⁶⁸

V. PRIMARY ETHICAL CHALLENGES

How can any treatment be considered in a patient’s best medical interest when the consequence of that treatment will be certain death for that patient? And what is meant by “the patient’s medical interest”? Should one view the determination of that interest as guided only by the narrow medical evaluation of health before and after treatment? Clearly, the concerns of most physicians will be that while the patient may benefit from treatment in the short term, the secondary result will be death, which is decidedly *not* in the patient’s best medical interest. Physicians are trained to view patients in light of their full medical history and underlying diagnoses as well as the current environment and situation in which they are evaluated. Physicians must include in their evaluations of treatments all likely effects—intended and incidental, immediate and eventual.⁶⁹ The Eighth Circuit disregarded this requirement by dividing Singleton’s medical interests into short- and long-term, and then by considering only the former.

As the four dissenting circuit judges indicated, the majority’s opinion,

leaves those doctors who are treating psychotic, condemned prisoners in an untenable position: treating the prisoner may provide short-term relief but ultimately result in his execution, whereas leaving him untreated will condemn him to a world such as Singleton’s, filled with disturbing delusions and hallucinations [This] ethical dilemma . . . is not simply a policy matter; courts have long recognized the integrity of the medical profession as an appropriate consideration in its decision-making process.⁷⁰

Both the American Medical Association and the American Psychiatric Association have stated that participation in execution by physicians is unethical.⁷¹ Most professional medical organizations share a broad view of what

68. *Id.*

69. Julia C. Spring, *Singleton’s Story: Choosing Between Psychosis and Execution*, 35 HASTINGS CENTER REP. 30 (2005).

70. *Singleton v. Norris*, 319 F.3d 832, 1037 (8th Cir. 2003).

71. “An individual’s opinion on capital punishment is the personal moral decision of the individual. A physician, as a member of a profession dedicated to preserving life when there is hope of doing so, should not be a participant in a legally authorized execution.” A physician may make a determination or certification of death as currently provided by law in any situation. AM. MED. ASS’N, CODE OF ETHICS: ANNOTATED CURRENT OPINIONS § 2.06 (1992) (adopted 1980); AM. PSYCHIATRIC ASS’N, ETHICAL CODE Pmbl. § 1.4 (1992). In 1981, the World Medical Association

is meant by “participation.”⁷² Generally, it is agreed that no physician should pursue a course of treatment that will result in or lead to a patient’s death,⁷³ be that treatment the proximal, secondary, or remote cause.⁷⁴

There may be exceptions to these guidelines, but when they exist they should be asserted explicitly. It is boldly disingenuous to claim that one’s involvement in a patient’s care ceases the moment a physician’s labor is

(WMA) stated that it was unethical for physicians to participate in executions, except to certify death. World Med. Ass’n, *Resolution on Physician Participation in Capital Punishment*, Sept. 1981, available at <http://www.wma.net/e/policy/c1.htm>. Similar pronouncements were made by the American College of Physicians in 1984. Am. Coll. of Physicians Ethics Manual, 101 ANNALS OF INTERNAL MED. 263, 263-74 (1984). The American Public Health Association (APHA) made a similar declaration in 1985. Am. Pub. Health Ass’n, *Participation of Health Professionals in Capital Punishment* (Jan. 1, 2001), <http://www.apha.org/legislative/policy/policysearch/index.cfm?fuseaction=view&id=264>.

72. The AMA’s Council on Ethical and Judicial Affairs has defined physician participation in executions to include three categories of actions: (1) actions that “directly cause the death of the condemned,” such as administering the lethal injection itself; (2) actions that “assist, supervise, or contribute to the ability of another individual to directly cause the death of the condemned,” such as prescribing the necessary drugs; and (3) actions that “could automatically cause an execution to be carried out on a condemned prisoner,” including determinations of death during an execution. Council on Ethical and Judicial Affairs, *Council Report: Physician Participation in Capital Punishment*, 270 JAMA 365 (1993).

73. One may further question what is meant by “treatment,” and, specifically, what constitutes a doctor-patient relationship. What are the duties of a physician to an individual he sees for a forensic evaluation? It would be odd to presume that in the context of forensic evaluation confidentiality would be protected, but informed consent might still be required. In Singleton’s case, there was no doubt among the parties that a doctor-patient relationship existed, though the law avoids defining the specific ways in which the scope of a physician’s duty is narrowed in the prison setting. For a discussion of the history of physician participation in executions, see Baum, *supra* note 42.

74. The courts have employed a “double effect” argument by focusing on whether treating physicians ever intended to medicate Singleton for the purpose of executing him. In one of the district court’s denials of a petition for habeas corpus, the court reasoned that no evidence could be found “that the actions and decisions of the medical personnel involved [in forcibly medicating Singleton] were in any degree motivated by the desire, purpose or intent to make Mr. Singleton competent so that he could be executed.” *Singleton*, 319 F.3d at 1022 (quoting the district court, then reversed by the Eighth Circuit, which granted a stay of execution). This reasoning is as specious as the kind employed as a defense by physicians involved in torture. A physician called upon to evaluate a military prisoner for the purpose of interrogation can easily claim that his intent was unrelated to the interrogation or torture. Similarly, treating prisoners who have been tortured, without reporting the suspected abuse, may be justified because such a responsibility would fall outside the direct scope of the physician’s duties as proposed. These claims must fail if physicians are to be held accountable to any reasonable professional ethical standard.

complete. Other values such as national security or public health and safety may override the physician's duty to care for the patient, but in Singleton's case the legal fiction employed was that physicians were caring only for the patient's immediate medical condition and that their treatment was unrelated to its deferred consequences.

Such a fiction, while implausible, is not unprecedented.⁷⁵ Singleton's involuntary medication was legal under *Washington v. Harper*⁷⁶ during a stay of execution, but became unethical once an execution date was set because treatment was no longer in the patient's best medical interest. This was a novel issue for the courts, as the consequences of treating Singleton with antipsychotic medication affected his medical interests in a way that it did not affect Harper's or Riggins's. While serving a long prison sentence or standing trial *may* not have been in Harper's or Riggins's best medical interest, neither necessarily constituted a specific and certain medical harm. These claims failed in Singleton's defense because they were made on behalf of the inmate-defendant and not the physicians. Limited to a balancing test between the justice of carrying out a lawful sentence and the liberty of an individual not to be forcibly medicated, Singleton's argument ended up begging the question of why he

75. One common approach to the conflict presented by physician participation in executions has been the enactment of state legislation explicitly declaring that such participation does not constitute the practice of medicine. See FLA. STAT. ANN. ch. 922.105(6) (Harrison 2000) ("[F]or purposes of this section, prescription, preparation, compounding, dispensing, and administration of a lethal injection does not constitute the practice of medicine, nursing, or pharmacy."); IDAHO CODE § 19-2716 (Michie 2004) ("[A]ny infliction of the punishment of death by administration of the required lethal substance or substances in the manner required by this section shall not be construed to be the practice of medicine . . ."); 725 ILL. COMP. STAT. ANN. 5/119-5(g) (West 2002) ("Notwithstanding any other provision of law, assistance, participation in, or the performance of ancillary or other functions pursuant to this Section, including but not limited to the administration of the lethal substance or substances required by this Section, shall not be construed to constitute the practice of medicine."); N.J. STAT. ANN. § 2C:49-3(a) (West 2005) ("Any imposition of the punishment of death by administration of the required lethal substances in the manner required by section 2 of this act shall not be construed to be the practice of medicine . . ."); OR. REV. STAT. § 137.473(2) (2003) ("The person who administers the lethal injection under subsection (1) of this section shall not thereby be considered to be engaged in the practice of medicine."); S.D. CODIFIED LAWS § 23A-27A-32 (Michie 1998) ("Any infliction of the punishment of death by administration of the required lethal substance or substances in the manner required by this section may not be construed to be the practice of medicine . . ."); WYO. STAT. ANN. § 7-13-904(a) (Michie 2001) ("Administration of the injection does not constitute the practice of medicine."). Additional measures have recently been taken by at least some legislators, who have introduced legislation that would protect physicians who participate in executions from disciplinary action by state medical licensing boards. See, e.g., H.B. 2660, 50th Leg., 1st Sess. (Okla. 2006).

76. 494 U.S. 210, 221-22 (1990).

should not be treated. It asserted that he should not be treated because doing so would lead to his execution. And it claimed that he should not be executed because execution was only possible after treatment. It is doubtful that the Supreme Court in its discussion of “best medical interests” intended that criminals should be protected by the state from the very actions that the state imposes upon those individuals. *Of course* execution is not in the patient’s medical best interest, but in this case the state does not have that kind of medical interest in mind.

Because Singleton was tried for his crimes, convicted, and sentenced, to claim a right not to be forcibly medicated because it would result in the very punishment to which he had been legally and ethically sentenced seems illogical, unreasonable, and unethical. If one accepts, *arguendo*, the justice of the legal proceedings and their ultimate sentence, one is compelled to evaluate Singleton’s desire not to be treated on the same core grounds as anyone else’s desire not to be treated. One ought not be swayed by the *result* of the decision to forcibly treat only because one believes that result to be unfortunate. Unfortunate though it may be, it has been accepted as just. In other words, Singleton’s autonomy claim against forcible medical treatment is weak because it is predicated on a desire to avoid consequences that he has no right to avoid.

Therefore, the realm of potential ethical challenges posed by the first question, regarding the threat to Singleton’s liberty by forced medication, seems rather limited. In a sense, the competent Singleton has made himself inaccessible and has left in his place an insufficient proxy, the psychotic Singleton. It may be unreasonable to suggest, therefore, that Singleton is being unfairly harmed by medication that will restore his sanity. In this view, it is Singleton who sacrifices his own autonomy and liberty interests when he sacrifices sanity for psychosis. Of course psychosis is not voluntarily acquired, but the decision to *remain* psychotic is voluntary when it is made by a patient with full, if temporary, competence.

More compelling and appropriate to the balancing of competing social values were the interests of the physician and the medical profession. The second legal question, then, was whether the forced care of Singleton deprived the treating physician or physicians of a right to practice medicine within their profession’s ethical framework and guidelines. It is this question that would have been more productive from the perspective of all stakeholders, except the prosecution.

Implicit in this legal question are two ethical questions: Should physicians ever treat a patient when such treatment is not only without the patient’s consent but also not in the patient’s best medical interest? And do the state’s justice interests ultimately trump those of the physicians?

VI. COMMON MORALITY VERSUS PROFESSIONAL ETHIC: "TO DO A GREAT RIGHT, DO A LITTLE WRONG"⁷⁷

The question Singleton's case presents for physicians may be seen as a conflict between a common morality and a professional ethic. Viewed in that light, the moral dilemma resembles that of *Tarasoff v. Regents of University of California*.⁷⁸ In that case, the California Supreme Court held that in certain limited circumstances, when a physician determines or should have determined that her patient presents a serious danger of violence to another, she incurs a duty to use "reasonable care to protect the intended victim."⁷⁹ If she fails to use such care she may be liable for tort damages.⁸⁰

The common morality goal in *Tarasoff* of protecting potential victims from harm was judged by a majority of the presiding court to outweigh the reasonable and valuable professional ethic of confidentiality and undivided commitment to the patient. Should we be guided, then, by the majority in *Tarasoff* when they concluded that the "protective privilege ends where the public peril begins?"⁸¹ Should Singleton's right to liberty end only where public peril begins? More importantly, should the descriptive ethics of a professional code be honored only until such time as it creates or assists some kind of public threat, ranging anywhere from menace to peril?

Even the ethical guidelines of psychiatry, a profession historically supportive

77. Bassanio's bootless plea to Portia in the trial scene. WILLIAM SHAKESPEARE, *MERCHANT OF VENICE* act 4, sc. 1.

78. 551 P.2d 334 (1976).

79. *Id.* at 340. The facts of *Tarasoff* were as follows: Poddar, a University of California graduate student, told his therapist that he intended to kill Tatiana Tarasoff, a young woman whom he had previously dated. The therapist consulted with his supervisor and then contacted the campus police who questioned Poddar and released him once he promised to stay away from Ms. Tarasoff. Two months later, Poddar went to Ms. Tarasoff's home and killed her. Subsequently, her parents filed suit on a variety of tort theories, including the failure of Poddar's therapists to warn Ms. Tarasoff's parents that Poddar was a "grave danger" to their daughter. *Id.* at 339-41.

80. *See id.* at 342. In its second decision in the case, the California Supreme Court found that a "duty to protect," rather than a "duty to warn," exists:

when a therapist determines, or pursuant to the standards of his profession should determine, that his patient presents a serious danger of violence to another, he incurs an obligation to use reasonable care to protect the intended victim against such danger. The discharge of this duty may require the therapist to take one or more of various steps, depending upon the nature of the case. Thus it may call for him to warn the intended victim or others likely to apprise the victim of the danger, to notify the police, or to take whatever other steps are reasonably necessary under the circumstances.

Id. at 340.

81. *Tarasoff*, 551 P.2d at 347.

of strong professional autonomy, ultimately yield to a common morality represented by law. The *Ethical Guidelines for the Practice of Forensic Psychiatry* of the American Academy of Psychiatry and Law (AAPL), for instance, clearly state that “substituted consent” may be obtained “in accordance with the laws of the jurisdiction,”⁸² suggesting that the profession’s ethical guidelines readily yield to the law of the land, whatever it may be. According to AAPL, it would seem that if the courts decide that forcible medication of a psychotic person is legal, then the physician is ethically free and perhaps obligated to act in accordance with that decision, regardless of whether it is in the medical interest of that patient. This represents the unjustified resignation of professional morality to legislative fiat without any regard or concern for potential harm. In fact, by excusing actions when they are sanctioned by law, the AAPL has willingly aligned itself with any practice a legislature may approve. The potential for unwitting collusion is great. The obvious point is that “[t]he law is not the repository of our moral standards and values, even when the law is directly concerned with moral problems. . . . [F]rom the fact that something is legally acceptable, it does not follow that it is morally acceptable.”⁸³

Physicians have historically taken their moral guidance from the maxim *primum non nocere*, meaning “Above all, do no harm.” As W. D. Ross suggests, a *prima facie* obligation must be fulfilled unless it conflicts on a particular occasion with an equal or stronger obligation.⁸⁴ The physician has no obligation to punish. His obligation is to provide care. It should be his first, if not only, obligation.⁸⁵ When a physician enters a treatment relationship with a patient, his

82. Am. Acad. of Psychiatry & the Law, *Ethical Guidelines for the Practice of Forensic Psychiatry* (1989), <http://www.forensic-psych.com/articles/artEthics.html>.

83. *Id.*

84. W. D. ROSS, *THE RIGHT AND THE GOOD* 30-32 (1930).

85. Of course physicians are also citizens whose professional obligation is one of many. A physician may feel compelled by certain moral and religious obligations, in which case she may be able to legally avail herself of conscience clause protection. *See* Church Amendment, 42 U.S.C. § 300a-7 (West 2002); IND. CODE § 16-34-1-4 (Michie 2002); KY. REV. STAT. ANN. §311.800 (Lexis 2001); VA. CODE ANN. § 18.2-75 (Lexis 2002). *See also* J. Andrew West, *Defining the Limits of Conscientious Objection in Health Care*, NEWSL. ON PHIL. & L. (Am. Phil. Ass’n, Newark, De.), Fall 2005, at 25. But in balancing her obligations to patient and her conflicting moral and religious obligations, a physician ought to be required to refer patients in need to other physicians. While a physician may feel precluded from rendering certain types of care, and may even feel compelled to counsel a patient against what she believes to be immoral actions, she ought to assist her patient in finding appropriate care, so long as it is within the boundaries of standard practice among her colleagues. A physician who objects to abortion on moral or religious grounds ought nonetheless to assist her patient in finding a capable physician elsewhere. To do otherwise would be to take advantage of a patient’s dependency. Some physicians may feel compelled by other duties to

role is clear. He *must* treat the patient.⁸⁶ Any obligation the physician may have to contribute to a wider social justice does not, *a priori*, outweigh the obligation to provide care to the patient. If such a competing value were accepted, such as a duty to create greater societal justice, it might be considered unethical for physicians to treat and care for murderers, rapists, and enemies of the state.

Some suggest, however, that the physician can step in and out of her role without difficulty.⁸⁷ This position is extremely problematic. Physicians may refuse to enter a doctor-patient relationship, and such is the case of physicians who take advantage of conscience clauses, which excuse them from the legal

counsel patients against what they believe to be immoral actions (e.g., abortion, risky sexual behavior, unnecessary or cosmetic medical procedures, refusing to donate blood, bone marrow, or organs to a family member in need), but their influence should extend no further than that counsel. The enormous influence physicians have over their patients by virtue of the entrenched and implicit norms of the doctor-patient relationship warrants caution. A physician's influence may be used appropriately in communicating medical advice—as that is the task for which the physician is trained and qualified, and (more importantly) for which the patient seeks a physician out. Offering moral guidance is a primary duty of a clergyperson, not a physician. Again, this is in part because of a clergyperson's experience and training in both ethical decision-making and counseling congregants on moral issues, but more importantly, the clergyperson's influence in that area (ethics, religion, and morality) is implicitly recognized when his or her counsel is sought by a congregant or parishioner.

86. The sufficient elements for a treatment relationship are unclear. Viewed in the context of professional responsibility, one may find a treatment relationship when a medical professional brings his or her medical skills and talents to bear. A physician is not compelled to do so—doctors are free to contract at will. Nor are they compelled to act, always, as physicians. A witness to a crime, for instance, who happens to be a physician, is under no obligation other than those that would attach to non-physicians. But if they bring medical skills, which they are licensed by the state to use, to a task, they should be responsible to at least the core values of the profession. Health organizations as well as professional medical organizations generally interpret treatment and physician responsibility for care broadly. In the case of domestic violence, for instance, the physician's duty is often read to include preserving health not just in the narrow context of the patient's clinical presentation, but in his or her activity beyond the observation room. See, e.g., Council on Ethical and Judicial Affairs, *Physicians and Domestic Violence, Ethical Considerations*, 267 JAMA 3190 (1992).

87. See Paul Appelbaum, *The Parable of the Forensic Psychiatrist: Ethics and the Problem of Doing Harm*, 13 INT'L J.L. & PSYCHIATRY 249, 252 (1990) (using the example of a forensic psychiatrist called upon by the prosecution in a criminal proceeding to present evidence concerning an individual's defense of not guilty by reason of insanity). Appelbaum argues that the doctor is not involved in a healing capacity while offering testimony and therefore has no *professional* duty to preserve the health of a sometime patient. But see, e.g., M. Gregg Bloche, *Clinical Loyalties and the Social Purposes of Medicine*, 281 JAMA 268 (1999); Edmund D. Pellegrino, *Societal Duty and Moral Complicity: The Physician's Dilemma of Divided Loyalty*, 16 INT'L J.L. & PSYCHIATRY 371 (1993).

responsibility to treat under circumstances that violate their religious or moral beliefs.⁸⁸ If, however, a physician does treat an individual with medical care, a doctor-patient relationship necessarily exists.⁸⁹ If the rules and role definitions surrounding the doctor-patient relationship are meant to protect both individuals from potential consequences of the treatment relationship, then what other than treatment would be sufficient criterion for the relationship to exist?⁹⁰

VII. THE CONSEQUENTIALIST APPROACH

Consequences of forced medication include the preservation of effective justice. In the case of Singleton, a guilty man will be punished, his victims will be avenged, and the circle of justice will be complete. On the other hand, forced medication weakens the integrity of physicians' autonomy and professional ethics. Doctors will participate in the execution of their patients against their patients' wishes and without legal recognition of their professional values. Is this, then, truly the best utilitarian outcome?

The deterrent function of criminal justice relies on the perception that sentences are carried out. Perceived weaknesses in the system may weaken its effectiveness. The relevant adverse consequences of this particular action are, however, extremely limited. It is not the criminal justice system, *en toto*, that is being obstructed or impeded. Rather it is the prescribed justice in a particular case in which a certain punishment—the most severe the system allows—is undeliverable. Further, Charles Singleton never attempted to fully escape punishment.⁹¹ He was incarcerated without parole. He was suffering. While he

88. See *supra* note 85.

89. Physicians are often called upon by courts to treat individuals, in which case a doctor-patient relationship does exist and all values that normally attach to the relationship (e.g., confidentiality) should be respected. See, e.g., *Pettus v. Cole*, 57 Cal. Rptr. 2d 46 (Ct. App. 1996) (finding a physician's duty of confidentiality to be inviolable beyond description of "functional limitations" in response to an employee's request for disability leave).

90. The research context, as well as that of forensic evaluations, provides difficult and useful cases. In both, though a doctor-patient relationship is understood *not* to exist, it is helpful to consider which responsibilities remain (e.g., informed consent, do no harm), and which do not (e.g., confidentiality). The military context provides a third and more difficult example. In this case, as with many prompted by the military, extraordinary deference has historically been granted. Once an individual's body is not her own (which must be the case either when an individual voluntarily joins the military or when she is drafted), individual autonomy has been so seriously compromised that patient autonomy can no longer be plausibly respected. Following the same reasoning, a physician's autonomy may be no more robust than a patient's, if they are both soldiers of the state. It may, then, only be professional autonomy, granted by states through the licensing of medical practice, that preserves important social and ethical obligations in the military context.

91. Singleton's Eighth Circuit appeal was not a challenge to the validity of his conviction or

continued to live, he did so in a psychotic state. With regard to the potential weakening of deterrent values, the number of cases involving a death row inmate who is insane and has refused to be treated medically for his mental illness is likely to be insignificant. The integrity of the justice system was not, therefore, practically threatened in this case.

The ruling in *Singleton* more substantially affected the integrity of the medical code. First, *Singleton*'s treating physicians were instructed to act in a professional capacity that was not in their patient's medical best interest. They arguably violated the most sacred provision of their professional code. More important, however, is the potential effect of this ruling on the medical community. A precedent was set establishing the state's right to order a physician to treat a patient not only against the patient's expressed wishes, but also against the physician's best medical judgment, her professional code of ethics, and her prima facie responsibility to do no harm. The consequences of such a precedent are broad. They can be read into the debate over physician-assisted suicide,⁹² the duties of military physicians, forensic evaluation, and palliative care.

This narrow interpretation of a patient's medical best interest favored by the Eighth Circuit renders the value of professional medical duties meaningless. If a physician's duty extends no further than the immediate effect of treatment rendered, without regard to any consequences, then the physician "involvement" in interrogation and abuse at Abu Ghraib, Guantanamo, and in Afghanistan was not illegal. So long as a patient leaves a physician's presence unharmed, it would seem that no misfortune that befalls him outside the doctor's office should be of any concern to the physician. The argument is based on a "see no evil, hear no evil" logic of ethics. To restrict professional duties and obligations to the intent of the practitioner is to all but eliminate the concept of professional role morality. The effect of such a restriction can only be the reduction of professional responsibility to the scope of individual personal responsibility. Insofar as no individual ought to intentionally cause harm to another, the role morality of physicians ought to establish a higher standard of care, one which ought to be supported in law. Once physicians are permitted to deliver care that does not

sentence, but only the manner in which it was to be carried out. *See Singleton v. Norris*, 319 F.3d 1018 (8th Cir. 2003).

92. In its recent decision overruling Attorney General John Ashcroft's challenge to Oregon's Death With Dignity Act, the Supreme Court did not reach the issue of whether allowing physician participation in suicide would invite consequences to medical practice against the public interest. *Gonzales v. Oregon*, 126 S. Ct. 904 (2006). However, the American Medical Association (AMA) supported the Attorney General's position with just such an argument. *Id.* at 932 (citing Attorney General). The AMA held a similar position in an earlier case. Indeed, in *Washington v. Glucksberg*, 521 U.S. 702, 731 (1997), the AMA determined that "[p]hysician-assisted suicide is fundamentally incompatible with the physician's role as healer."

preserve life and health, by order of the state, by request from patients, or by their own will, the nature of the profession and of the work of a physician changes. Courts have often favored this line of reasoning, but only when it serves other public policies, like those disfavoring physician-assisted suicide⁹³ or those aimed at pro-competition business models in health industries.⁹⁴

Even if the *Singleton* Court conceded that given these particular circumstances forced treatment is ethical, treatment still should not have been permitted. The moral acceptance of an act does not sufficiently justify the act.⁹⁵ Though justice may be best served by restoring Singleton to sanity—even if for the sole purpose of executing him—the decision so adversely affects the integrity of medical practice that the otherwise moral act should be avoided. Just as active euthanasia may be morally justified when patients experience extreme, uncontrollable, and unrelenting pain, it may be ethically appropriate to nonetheless restrict physician-assisted suicide because of the difficulties involved in controlling abuses of the practice.

Of greater concern, however, will be the further complication of the already burdensome psychological task of the physician, addressed in Part IX, and the consequences of that complication. The strongest utilitarian argument against allowing physicians to ignore medical ethical norms is based on a psychological understanding of the inherent aggression in medical practice, which will be explored below. This Note argues that there exists a consequent need to rein in that aggression, which may be otherwise unleashed through practices like those that *Singleton* approved. By demanding, requesting, or even allowing physicians to participate in activity that is known to end a patient's life, even if indirectly, courts and legislators are interfering with a delicate but important balance between harmful and helpful behavior that healers have maintained for many years.

93. See, e.g., *Vacco v. Quill*, 521 U.S. 793 (1997); *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 278-80 (1990); *Id.* at 287-88 (O'Connor, J., concurring); George Annas, *The Bell Tolls for a Constitutional Right to Physician-Assisted Suicide*, 337 NEW ENG. J. MED. 1098 (1997). Palliative care, in these cases and their precedent, stands in for euthanasia, all seemingly in deference to the physician's code. This is not so in *Singleton*'s case.

94. See, e.g., 42 U.S.C. § 1320a-7b(b) (1994) (prohibiting improper payments in connection with the delivery of items or services covered by a number of federal health care programs). Additionally, courts have often recognized legal duties outside of the doctor-patient relationship that attach by virtue of a particular relationship. See, e.g., *Craig v. State*, 155 A.2d 684 (Md. 1959) (parents to child); *Territory v. Manton*, 19 P. 387 (Mont. 1888) (husband to wife).

95. In other words, rule utilitarianism is to be favored in this case over act utilitarianism.

VIII. *PRIMUM NON NOCERE*

The prohibition against physicians' participation in death has ancient roots. The Hippocratic Oath disavows this participation,⁹⁶ which has been interpreted by many to be a prohibition against physician-assisted suicide, euthanasia, and involvement in executions.⁹⁷ The National Catholic Bioethics Center has rewritten the passage as follows: "I will neither prescribe nor administer a lethal dose of medicine . . . nor counsel any such thing nor perform act or omission with direct intent deliberately to end a human life."⁹⁸ Though arguably valuable to contemporary medical ethics, this interpretation of the original prohibition is dubious. Ancient Greece practiced capital punishment. And although there is no record of whether physicians participated in executions, the rule does not seem to have been relevant to the prohibition against giving "deadly drugs." Rather, it most likely addressed fears that physicians would collaborate with murder by poisoning.⁹⁹ Appeals, therefore, to ancient values to support a contemporary prohibition against physician involvement in executions are ultimately unconvincing. Furthermore, the Supreme Court has clearly indicated that it shows little deference to the Hippocratic Oath in guiding its constitutional interpretation.¹⁰⁰

More convincing are appeals to another ancient value, one that has been historically misattributed, though not misinterpreted. The paramount principle in Western medical ethics is, and has been, "Do No Harm."¹⁰¹ But where did this principle come from and what does it mean? The idea is often incorrectly attributed to the Hippocratic Oath, but neither the Oath nor any Greek medical treatise contains any such phrase. The closest idea appears in *Epidemic I*: "Practice two things in your dealings with disease: either help or do not harm the patient."¹⁰² It is unclear how or when "First, do no harm" came to be attributed to

96. LUDWIG EDELSTEIN, *THE HIPPOCRATIC OATH* 3 (1943) ("I will not give a drug that is deadly to anyone . . . nor will I suggest the way to such a counsel.").

97. See Lisa R. Hasday, *The Hippocratic Oath as Literary Text: A Dialogue Between Law and Medicine*, 2 YALE J. HEALTH POL'Y L. & ETHICS 299 (2002); see also *Krischer v. McIver*, 697 So. 2d 97 (Fla. 1997) (discussing Florida's interests outweighing patients' desires for physician-assisted suicide).

98. See Restatement of the Oath of Hippocrates, http://www.catholicculture.org/docs/doc_view.cfm?recnum=749 (last visited Apr. 7, 2006).

99. ALASDAIR MACINTYRE, *WHOSE JUSTICE? WHICH RATIONALITY?* 42-68 (1988); STEVEN MILES, *THE HIPPOCRATIC OATH AND MEDICAL ETHICS* 73 (2004).

100. See, e.g., *Compassion in Dying v. Washington*, 79 F.3d 790, 829 (9th Cir. 1996).

101. See BEAUCHAMP & CHILDRESS, *supra* note 57.

102. MILES, *supra* note 99, at 143; see also *id.* at 143 n.23 ("The commonly cited Jones translation follows Littré and goes: 'As to diseases, make a habit of two things—to help, or at least

Hippocratic medicine or how it became *the* paramount principle.¹⁰³ Its history, however, reveals the medical norms our current jurisprudence threatens to degrade. Steven Miles traces the idea to 416 B.C.E., about the time the Hippocratic Oath was written, at which time Nicias, an Athenian general and politician, spoke against what he accurately judged would be a disastrous military expedition to Sicily. He called upon the chair of the Athenian Council to “be the physician of your misguided city . . . the virtue of men in office is briefly this, to do their country as much good as they can, or in any case no harm that they can avoid.”¹⁰⁴

The analogy is striking. To compare a physician to a military leader illuminates the inherently aggressive nature of medical practice and the need to temper aggressive impulses with virtuous principles. It is remarkable to think that the most well known tenet of medical ethics originated from a restraint directed against explicitly hostile activity and not simply well intentioned risk as it has come to be used. As Steven Miles notes,

First do no harm . . . is of overrated utility.

All therapies entail risk. A physician could not perform any surgery or administer any drug (even one dose of penicillin that could cause a lethal allergic reaction) if he or she was obliged to avoid the chance of harm. The pursuit of therapy—any therapy—represents a decision that the probability and magnitude of benefits outweigh the chance and severity of harms. This clinical calculation accepts risks rather than avoiding them.¹⁰⁵

Yet it is worth recognizing the original meaning of the principle, especially when one frames the guidelines within a psychoanalysis of the practice of medicine.

IX. MANAGING CONFLICT AND AGGRESSION: A PSYCHODYNAMIC ACCOUNT

Why should a prohibition against aggression by a physician be so entrenched in the history of modern medicine? Regardless of its history, non-maleficence has persisted as a guiding principle of clinical medicine longer than any other¹⁰⁶ and often undergirds denunciations of physician involvement in human rights

do no harm’ (Hippocrates [1923a]).”). Jonsen notes that the Greek text does not contain the words “at least.” Albert R. Jonsen, *Do No Harm*, 88 ANNALS INTERNAL MED. 827, 828 (1978).

103. BEAUCHAMP & CHILDRESS, *supra* note 57, at 144.

104. *Id.* (citing THUCYDIDES, THE LANDMARK THUCYDIDES: A COMPREHENSIVE GUIDE TO THE PELOPONNESIAN WAR 6.14 (R.B. Strassler ed., 1996)).

105. *Id.* at 144.

106. For an exhaustive account of the four principles (autonomy, beneficence, non-maleficence, and justice) approach to medical ethics, see RAANAN GILLON, PRINCIPLES OF HEALTH CARE ETHICS pt. 1 (1994).

abuses¹⁰⁷ and capital punishment.¹⁰⁸ But why should this one value be so important as to outweigh all others that may inform a physician's decision-making? The answer reveals a potent conflict in the physician's work that the courts have generally not understood or perhaps not valued.

This conflict is what Robert Burt calls the ubiquitous feature of medical practice:¹⁰⁹ Helping patients frequently involves inflicting bodily harm, such as cutting them open, penetrating them with painful needles, catheters, or diagnostic scopes, or invading them with near-poisonous chemicals or radiation.

To carry out these various iatrogenic invasions, physicians must overcome deep-seated inhibitions inculcated in everyone from early childhood. One of the implicit agenda items in initial medical training is to encourage and assist fledgling physicians to transcend their inhibitions (as in their dealings with cadavers, their so-called 'first patients,' in Gross Anatomy Laboratories). Many techniques are offered for this purpose, most notably, the fervent belief that patients are helped to restored health and prolonged life by all medical practice, no matter how horrific particular medical interventions might appear to patients or to physicians.¹¹⁰

In almost every profession, there is a cardinal prohibition. While many professional transgressions may be tempting, and some more devastating than others, there is often one transgression that each profession tends to regard as most important.¹¹¹ In most cases, the prohibition is against some transgression that, while devastating to the profession, is simultaneously seductive and not easily avoided by the professional. For the legal field, perhaps the prohibition against lying is paramount because of the ease and appeal to do so in an adversarial setting. While stealing a client's assets may have equal or even worse practical consequences, the temptation to steal is no greater for a lawyer because of his role. It may, however, be of greater temptation for an accountant because of her role. For the clergy and for therapists, perhaps abuse of power in the relationship between clergyman and congregant or therapist and client is the ultimate transgression because of its adverse effects and also because of the strong pull toward such a transgression that must be consciously avoided. It is the nature of the role in these cases that provides the special opportunity for

107. See, e.g., BRITISH MED. ASS'N, *MEDICINE BETRAYED: THE PARTICIPATION OF DOCTORS IN HUMAN RIGHTS ABUSES* (1992).

108. See AM. MED. ASS'N, *supra* note 71.

109. ROBERT A. BURT, *DEATH IS THAT MAN TAKING NAMES* 87-105 (2002).

110. Robert A. Burt, *The Medical Futility Debate: Patient Choice, Physician Obligation, and End-Of-Life Care*, 5 J. PALLIATIVE MED. 249, 252-53 (2002).

111. See, e.g., *CONFLICT OF INTEREST IN THE PROFESSIONS* (Michael Davis & Andrew Stark eds., 2001).

particular maleficence. For physicians, there is a special opportunity for, and a strong—if largely unconscious—pull toward, aggression.¹¹²

Much has been written about physicians and psychological conflict, particularly around feelings of aggression.¹¹³ Frederick Hafferty's close observation of medical students and physicians is one of the most notable contributions to this discussion.¹¹⁴ In one series of interviews, Hafferty asked medical students near the conclusion of their first year laboratory experience whether they would donate their own bodies to medical schools for educational purposes. What is most interesting about the answers he recorded is the kind of language used by students: "One cannot help but be struck by the symbols of violence and destruction. Answers rarely contained such scientifically neutral terms as dissection, probe, and pick. In their place emerged more physical, graphic terms: slash, rip, pull apart, hack."¹¹⁵

This language of aggression was only present at the end of a lengthy interview and only when students were asked to put themselves in the place of the cadavers with which they had been working. Only then could these students acknowledge the inherently violent nature of medicine.¹¹⁶ The transgression of deep taboos about respect for bodily integrity has always accompanied the duty of the physician, and yet is rarely, if ever, discussed or acknowledged.¹¹⁷ In fact, from surgery to psychiatry, the practice of medicine is invasive, aggressive, and likely accounts for the often detached, or asocial, behavior that traditionally characterizes practitioners.¹¹⁸ Perhaps this is one explanation for some physicians' tendency to depersonalize their encounters with patients. The stereotype of the arrogant surgeon, who has no interaction with his patient and views the body on the table not as a person but as an object, is likely rooted in this psychological conflict. And it is an implicit and historical recognition of this unconscious conflict that underlies the profession's undeterred commitment to principles of beneficence and non-maleficence.

In 1964, Anna Freud addressed medical students at Western Reserve Medical School on the subject of what may dispose or predispose children to a later career in medicine. Drawing from her vast experience with children, she

112. See ROBERT A. BURT, *TAKING CARE OF STRANGERS: THE RULE OF LAW IN DOCTOR-PATIENT RELATIONS* (1979); FREDERICK HAFFERTY, *INTO THE VALLEY: DEATH AND THE SOCIALIZATION OF MEDICAL STUDENTS* (1991).

113. See *id.*; see also BURT, *supra* note 109; JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (Johns Hopkins University Press 2002).

114. HAFFERTY, *supra* note 112.

115. *Id.* at 123.

116. BURT, *supra* note 109, at 92.

117. HAFFERTY, *supra* note 112.

118. *Id.*

discussed the role of aggressive wishes and impulses in medical practice:

[T]he child's wish to help and to cure is . . . very close to the wish to hurt and to maim. The younger the child, the stronger his wish to hurt. The older and more socially adapted he becomes, the more this aggressive wish can be submerged under a strong urge to help.¹¹⁹

Some unconscious "work" is required for the physician to suppress the overwhelming feelings of guilt that would otherwise be associated with aggressive wishes sublimated through medical practice. In other words, for a surgeon to cut into the flesh of a fellow human being, he must depersonalize the object and rest assured that his actions are curative, and will not harm. A physician's ability to do his work, therefore, is crucially based on the knowledge that that work, however antagonistic it may feel or appear, is for the patient's benefit and health. To challenge that premise of medical professionalism is to introduce justification for harmful acts done by physicians consciously or unconsciously. More immediately, it is to threaten the public trust in medical practice.

X. THE SOCIAL PSYCHOLOGY PERSPECTIVE

For years, evidence from social psychology has demonstrated that minimal but incremental degradation of social and professional norms can lead to extreme and otherwise unexpected abuse.¹²⁰ The famous experiments conducted by Stanley Milgram revealed the elements sufficient to turn "normal" people into executioners. In the early 1960s Milgram designed a series of experiments at Yale University to test subjects' obedience to authority.¹²¹ Three of the most

119. Anna Freud, *The Doctor-Patient Relationship*, in EXPERIMENTATION WITH HUMAN BEINGS 642, 643 (Jay Katz ed., 1972).

120. See, e.g., ROBERT B. CIALDINI, *INFLUENCE: THE PSYCHOLOGY OF PERSUASION* 208 (rev. ed. 2003); STANLEY MILGRAM, *OBEDIENCE TO AUTHORITY* (1983); PHILIP G. ZIMBARDO ET AL., *THE PSYCHOLOGY OF ATTITUDE CHANGE AND SOCIAL INFLUENCE* (1991).

121. MILGRAM, *supra* note 120, at 13. Subjects were instructed by a confederate—a "legitimate" authority figure—to give electric shocks to a "victim" whom they could not see. The confederate ordered the subject to give increasingly larger, potentially fatal, shocks to the "victim." Though many of the subjects had reservations, they nevertheless followed orders and administered the shock. *Id.* at 42. The victim acted as though he had been shocked, sometimes crying out in pain and begging for the subject to stop, though in actuality, and unbeknownst to the subject, the victim had not been shocked. *Id.* at 22-23. Sixty-five percent of the "teachers" obeyed orders to punish the learner to the very end of the 450-volt scale. *Id.* at 35. The last two voltage levels were marked "XXX" and were administered after the "learner" had screamed out in protest, complained of a heart condition, and eventually gone silent. *Id.* at 28. In advance of the study, 39 psychiatrists were

important elements of these experiments were: (1) the minimal initial compromises made by subjects to their own sense of responsibility; (2) vague rules and boundaries; and (3) the re-labeling of roles. In the Milgram experiment, individuals were asked to minimally harm others who they were led to believe were fellow subjects, but were actually confederates in the experiment. Their instructions and obligations were vague¹²² and the person asked to administer lethal shocks was re-labeled as the helping “teacher.” Milgram’s experiment powerfully demonstrates the ease with which personal duties toward others can be abandoned in exchange for the identification with an “official” (especially institutional) aggressor.¹²³

Phillip Zimbardo’s famous Stanford Prison Experiment further demonstrates the power of roles and individual transformation in obedience to prescribed role obligations.¹²⁴ One guard wrote in his diary before the experiment, “[a]s I am a pacifist and nonaggressive individual, I cannot see a time when I might maltreat other living things.”¹²⁵ By day five of the experiment, this same student wrote the following in his diary:

This new prisoner, 416, refuses to eat. That is a violation of Rule Two: “Prisoners must eat at mealtimes,” and we are not going to have any of that kind of shit . . . Obviously we have a troublemaker on our hands.

asked how many subjects might administer all 450 volts. *Id.* at 27-30. The estimate was one in one thousand. *Id.* at 31. In the first experiment, none of the 40 subjects stopped before reaching 300 volts. *Id.* at 35. The studies were conducted at Yale University and in Branford and New Haven, Connecticut. They focused on the conflict between obedience to authority and personal conscience. *Id.* at 2-3. Milgram examined justifications for acts of genocide offered by those accused at the World War II, Nuremberg War Criminal trials. *Id.* at 1-2.

122. In the Milgram study, the rules of “the experiment” were clear, but not of the real subjects’ obligations to either the false experiment or the real study. *See supra* note 121.

123. For a general discussions of the psychodynamic phenomenon described by Freud as “identification with the aggressor,” see 2 ANNA FREUD, *THE WRITINGS OF ANNA FREUD: THE EGO AND THE MECHANISMS OF DEFENSE* 109-21 (4th ed. 1973).

124. Craig Haney & Philip Zimbardo, *The Socialization into Criminality: On Becoming a Prisoner and a Guard*, in *LAW, JUSTICE, AND THE INDIVIDUAL IN SOCIETY: PSYCHOLOGICAL AND LEGAL ISSUES* 198 (Tapp & Levine eds., 1977). In the summer of 1971, Philip Zimbardo of Stanford University led an incredible experiment using the psychology building on campus as a makeshift prison. He and two graduate assistants assembled a group of college-aged volunteers, sorted them for emotional stability, and randomly assigned them to positions of either guard or prisoner. Within a few days, those cast as guards assumed the roles of guards and the prisoners started to display the attributes of “first-timers” at real prisons. Within six days, the experiment had to be terminated because the situation became “too real” and too intense, with several prisoners having to be dismissed because of psychological trauma.

125. *Id.* at 207.

If that's the way he wants it, that's the way he gets it. We throw him into the Hole ordering him to hold greasy sausages in each hand. After an hour, he still refuses . . . I decide to force feed him, but he won't eat. I let the food slide down his face. I don't believe it is me doing it. I just hate him more for not eating.¹²⁶

Although the Stanford Prison Experiment is most often cited as an example of how role definitions can be used to incite individuals to perform harmful behavior they would otherwise eschew, it may serve as an example of the equally powerful potential of role definition to prevent harm. Whereas a pacifist cast into the role of a guard may be incited to do harm, a physician that self-identifies as such and honors his first-order medical duties may be protected from competing impulses or external incentives to do harm. Milgram's and Zimbardo's studies, despite ethical flaws that are striking in retrospect, helped explain the observation that good men do bad things and brought the interaction of situational variables into the foreground of criminal behavior. The studies also show how strong role identification can either support or counteract these situational factors.¹²⁷

XI. THIRD-PARTY INFLUENCES AND INFLUENCE ON THIRD PARTIES

While interested third parties may create a certain pressure that threatens medical professionals' loyal observance of medical ethics and values, these same third parties often rely on the medical profession's fidelity to its code of practice. Non-medical professionals expect and perhaps appreciate the staunch allegiance to medical codes and values traditional Western medicine demands. As Richard Wasserstrom observes,

The existence of a system of role-defined behavior can . . . create expectations relevant to the behavior of others not directly affected by the existence of the role. These other persons also will come to expect that the role-defined behavior will continue, and this may give them license to act on these

126. *Id.* at 209.

127. One need only look to the psychological evaluations of the Nazis to remember the ease with which monstrous actions can be disassociated from personal morality, if protected by a defined role. *See, e.g.,* THE NUREMBERG INTERVIEWS (Leon Goldensohn & Robert Gellately eds., 2004); Hannah Arendt, *Thinking and Moral Considerations: A Lecture*, 38 SOC. RES. 417 (1971) (describing, for example, the ease and disunity of personality with which Adolph Eichmann carried out his political and military obligations as he saw them). *But see* Postema, *supra* note 5 (discussing the Socratic observation of humanity's inherent need for unity of self and the consequent pain that comes from psychological disunity caused by moral conflict).

expectations rather than from a more universal moral perspective.¹²⁸

Wasserstrom's analysis was directed at attorneys but is equally applicable to the recent events at Abu Ghraib, where it may be argued that physician involvement in detainee interrogation led to torture that might otherwise not have taken place. As Bloche and Marks note, interrogators knew that physicians were observing interrogation of detainees.¹²⁹ Applying Wasserstrom's intuition to this situation, one can easily imagine interrogators' reliance on the medical role as a "check" on their behavior. Non-interference by physicians could easily be read as permission—not just by the individual physicians, but by the medical profession and its ethics.

XII. OBJECTIONS

The call for greater deference to the integrity of medical norms and guidelines is largely based on the physician's right to honor her role obligation of non-maleficence. However, the physician's *prima facie* obligation to "do no harm" may be interpreted as an instruction not to always avoid harming any patient, but to strive in one's work to always balance harm against benefit. Clearly, the physician who breaks his patient's ribs to administer CPR is weighing harm against benefit in a way that is unquestionably ethical and appropriate. As Jay Katz wrote in a discussion of the inadequacy of professional codes of medical ethics, many of the ethical dilemmas encountered by physicians have "been all too uncritically assumed [to] be resolved by fidelity to such undefined principles as *primum non nocere*"¹³⁰ The objection, then, would be that the act of medicating Charles Singleton was not, in fact, in contradiction to the physician's duty. It could be argued that the physician is not "doing harm" by treating the patient because the benefits to society of that action far outweigh the costs to the individual. One may further argue that by refusing to medicate Singleton, the physician has indeed "done harm" to Singleton's victims, to society, and to the criminal justice system.

The problem with such an argument, however, is that while the idea of non-maleficence may include a balancing of harm and benefit to any one particular patient, it is quite a different matter to suggest that harms against that same patient should be weighed against benefits to someone or something other than that patient. In rare cases care may be ethically withheld from, or harm even inflicted on, a patient for the benefit of others. We may consider it ethical to sacrifice one for the good of the many, or we may have no choice but to do so—

128. Wasserstrom, *supra* note 6, at 32.

129. Bloche & Marks, *supra* note 7.

130. JAY KATZ, EXPERIMENTATION WITH HUMAN BEINGS 7 (Jay Katz ed., 1972).

as in any number of classic ethical dilemmas in which an individual endangers the public health, harms another party, or makes use of scarce resources for which he cannot pay. But we should not allow *physicians* to make these decisions. Nor should we allow physicians to take part in care that is the result of others' decision-making when that care violates the professional medical code.

Another objection is based on an argument for role differentiation, which asserts that some subjects of a physician's clinical work like soldiers, prisoners, defendants in court proceedings, or detainees should not be considered patients. It may be argued, for instance, that in certain clinical contexts no doctor-patient relationship exists, even when a physician is providing care and treatment to an individual.¹³¹ If no such relationship exists, then the potential for harm to individuals is not the physician's responsibility.¹³² This is a dangerous line of reasoning and brings to mind Edmund Burke's well known caution that good people doing nothing is all that evil requires to succeed. Physicians who determined detainees' "fitness" for torture under authoritarian regimes in the 1970s and 1980s maintained that their work served state campaigns against subversion and thus should not be judged by the ethics of patient-physician relations.¹³³ The alternative view is that when a physician brings medical skills and training to a situation, he ought to be bound by medical ethics.

131. See, e.g., *Eid v. Duke*, 816 A.2d 844 (Md. 2003) (noting that generally, no doctor-patient relationship exists between an insured and a doctor who examines him for the insurance company or an employee and the doctor who examines him for the employer); *Hoover v. Williamson*, 203 A.2d 861 (Md. 1964) (same); *New York Cent. R.R. Co. v. Wiler*, 177 N.E. 205 (Ohio 1931) (same); see also Michael L. Perlin, *Power Imbalances in Therapeutic and Forensic Relationships*, 9 BEHAV. SCI. & L. 111, 115-21 (1991) (explaining why, in the context of forensic evaluations in which no doctor-patient relationship is believed to exist, the dual loyalties of forensic evaluators can lead them to misuse their power); Andrew Skolnick, *Health Professionals Oppose Rules Mandating Participation in Executions*, 269 JAMA 721, 722 (1993) (noting physicians' arguments that no doctor-patient relationship exists between a condemned death row inmate and the physician who participates in the execution). But see, e.g., *Betesh v. United States*, 400 F.Supp. 238, 245 (D. D.C. 1974) (under Maryland common law, physicians who examine employees owe a "duty of good medical care with respect to all aspects of the examination, even if no doctor-patient relationship exists between them.").

132. Various arguments along these lines have appeared in varying contexts, some notorious in the recent history of medicine. See, e.g., ROBERT PROCTOR, *RACIAL HYGIENE* (1988); see also CHRISTIAN PROSS & ALY GÖTZ, *THE VALUE OF THE HUMAN BEING: MEDICINE IN GERMANY 1918-1945* (1991).

133. M. Gregg Bloche, *Psychiatry, Capital Punishment, and the Purposes of Medicine*, 16 INT'L J.L. & PSYCHIATRY 301 (1993).

XIII. THE IMPORTANCE OF ROLE IN VARYING CONTEXTS

Few if any would argue with the view that physicians should not be involved in torture or human rights abuses and should be compelled to report such activities when they occur. But the idea that physicians should not use their skills and training to support legitimate social purposes such as public safety, justice, or the appropriate rationing of limited resources is not as compelling. The profession's social responsibility has led many physicians to participate in a myriad of endeavors, some of which did not benefit their (non-)patients. Examples are physicians' work in the military (where doctors treat wounded patient-soldiers for return to combat), in forensics (where doctors' medical evaluations often lead to adverse consequences for their patient-evaluees), and in research (where doctors' experimental "treatments" can have adverse consequences with little or no benefit to the individual patient-subject). In some cases, the competing values weighed by the physician are between the individual health and welfare of the patient and the relative health of the community. Vaccination, for instance, which may pose a minimal risk to the individual, is justified by the long-term collective benefit of high immunization rates preventing epidemics.¹³⁴ But in other cases, a physician's undivided commitment to patient well-being, either at the level of the individual or the population, is challenged by decidedly non-medically therapeutic duties, as in the *Singleton* case.

The problem exists not when an individual chooses one set of obligations over another, but when the individual ignores the sacrifice of one over the other. When personal or professional behavior potentially criticizable on moral grounds is blocked from such criticism by an appeal to the existence of the actor's role which is claimed to make the moral difference, the integrity of other roles is not compromised, it is obliterated. And in eliminating the competing role(s), the actor eliminates those values that might otherwise be morally relevant, if not decisive, reasons for acting or not acting.

XIV. IMPLEMENTATION: "WHAT MEN DAILY DO"¹³⁵

Hard cases make bad law. And hard-line rules make bad ethics. It is

134. *Jacobson v. Massachusetts*, 197 U.S. 11 (1905) (upholding the constitutionality of a legislature choosing between medical arguments on behalf of individuals and medical arguments on behalf of the public population). See also Kathleen R. Stratton et al., *Adverse Events Associated with Childhood Vaccines Other than Pertussis and Rubella: Summary of a Report from the Institute of Medicine*, 271 JAMA 1602 (1994).

135. "Oh, what men dare do! What men may do! What men daily do, not knowing what they do." WILLIAM SHAKESPEARE, *MUCH ADO ABOUT NOTHING* act 4, sc. 1.

unfortunate that advocates for increased legal deference to physicians' professional responsibility and ethical norms often give short shrift to implementation concerns—specifically how, and how well, a policy protecting physicians' right to pursue life and health to the exclusion of other social values will be implemented. Given the unique nature of Singleton's case, presuming that a very small number of death row inmates are or will be psychotic and refuse treatment for their mental illness,¹³⁶ one can imagine little difficulty in implementing a policy safeguarding physicians' duty to pursue health and life, even at the expense of other social or ethical values. However, other possible applications of such a bright line rule elevating physicians' responsibilities to do no harm and to pursue health above all other responsibilities are troubling. In the case of end-of-life care, for instance, a system of shared decision-making is preferable. If a competent patient wishes to refuse treatment, even if it will certainly hasten death, that wish should be honored.¹³⁷ While such a policy may involve physicians in allowing patients to effectively commit suicide, it is informed by a greater concern about implementation. Ideally, one might encourage physicians to argue for life and pursue treatment even in the most dire of patients' circumstances. But a default rule that allows, or even requires, the substituted judgment of a physician for a patient poses intolerable risks, not only because of the insult to patient autonomy, but also because of the potential for abuse by physicians. Just as physicians may be drawn by unconscious aggressive impulses to hasten death, they may also overcompensate when guarding against these impulses by pursuing life when it should not be artificially maintained.

136. While it is estimated that approximately two-fifths of all males and two-thirds of all females in prison have pronounced psychiatric or behavioral problems, psychosis is rare in the prison population. See Rod Morgan, *Imprisonment: Current Concerns and a Brief History Since 1945*, in THE OXFORD HANDBOOK OF CRIMINOLOGY 1137, 1162 (Mike Maguire et al. eds., 2d ed. 1997). Over the past thirty years, the number of people with mental illness and other mental disabilities on death row has steadily increased. Nat'l Coal. to Abolish the Death Penalty, Fact Sheet: Mental Competency and the Death Penalty, http://www.ncadp.org/fact_sheet6.html (last visited Mar. 22, 2006). Although precise statistics are not available, it is estimated that 5-10% of people on death row have a serious mental illness. ACLU, Mental Illness and the Death Penalty (Jan. 31, 2005), <http://www.aclu.org/capital/mentalillness/10617pub20050131.html>; see also Traolach Brughs et al., *Psychosis in the Community and in Prisons: A Report from the British National Survey of Psychiatric Morbidity*, 162 AM. J. PSYCHIATRY 776 (2005) (finding a weighted prevalence of probable functional psychosis of 4.5 per 1000 in the non-prison population and a weighted prevalence of 52 per 1000 in the British prison population).

137. The case of Dax Cowart, now famous in the bioethics literature, is an example of an unfortunate situation in which a patient's right to refuse life sustaining treatment ought to be protected (though not exclusively, and not without much conversation and counseling) even if treating physicians are required to forego their pursuit of health and life. See DAX'S CASE: ESSAYS IN MEDICAL ETHICS AND HUMAN MEANING (Lonnie D. Kliever ed., 1989).

The case of Donald Cowart is an illustrative counterpoint to the Singleton case. In the summer of 1973, Donald "Dax" Cowart was critically injured in an explosion in which his father lost his life. Cowart was left blind and with third-degree burns over more than sixty-five percent of his body. Despite his repeated protests, Cowart was forced to undergo excruciating medical treatments and surgeries for more than a year. He left treatment with severe disfigurement, the loss of his fingers, partial hearing loss, and blindness. He went on to marry and to become a successful attorney and remains steadfast in his position that treatment should have been stopped when he, a competent adult, ordered that he be allowed to leave the hospital and return home to die from his injuries. He was repeatedly declared to be competent by a psychiatrist during this period.¹³⁸

In Cowart's case, the value of patient autonomy may have ultimately outweighed a physician's responsibility to avoid participation in patients' death.¹³⁹ This view is a concession to the theoretical goal that physicians *never* forego their pursuit of health and wellness, even in the face of patient protest. Again, the theoretical compromise is driven by practical concerns about institutional incapacity to care appropriately for patients forced to undergo treatment and the potential for abuse, especially when patients *cannot* be saved or cured. For most, *Cowart* presents a clear case in which the costs of requiring policy to defer to physicians' credo outweigh the potential benefits. The costs include patients' suffering and loss of liberty and physicians' involvement in hastening certain death, while the potential benefits are possible recovery and restoration to health for the patient and protecting the integrity of the medical code. *Singleton* seems an equally clear case in which the known benefits of keeping physicians far from the possibility of doing harm outweigh the costs of postponing execution of a prisoner and maintaining a prisoner in a state of psychosis.

Between the *Cowart* and *Singleton* cases lies another set of cases for which implementation concerns are less clear: physician-assisted suicide. The cost of forcing those in pain and near the end of their lives to suffer needlessly or to commit suicide by other more desperate means must be weighed against the countervailing potential cost of physician abuse under a policy allowing physician participation in suicide. This conflict strikes at the center of an internal role conflict for physicians. Some who support physician-assisted suicide see the potential for a new ethic of caring, one encompassing assisted death as part of the professional role. But those well-meaning physicians who would euthanize their

138. *Id.*

139. This is indeed the predominant view in the medical ethics literature. *But see* ROBERT A. BURT, *TAKING CARE OF STRANGERS: THE RULE OF LAW IN DOCTOR-PATIENT RELATIONS* 1-21 (1979).

patients with compassion are also often stressed, fatigued, and bewildered by the new responsibility.¹⁴⁰ In other words, the anxiety felt even by those who support physician-assisted suicide may reveal important dynamics of the physician-patient relationships that are protective of both individuals' health and welfare and ought to be preserved.

Another implementation concern cuts the other way. An argument favoring individual moral reasoning when confronted with conflicting roles neglects the likelihood that external factors will almost always determine the outcome. Yeats writes about the dangers of making a thing "subject to reason."¹⁴¹ Gerald Postema takes Yeats's observation to be a condemnation of moral philosophers' inclination to "play" with professional ethics without full knowledge of the concrete details.¹⁴² The physicians at Abu Ghraib were under attack daily by enemies with whom the detainees were formerly allied. Their safety was ensured by the same men and women who committed abuses and sought their aid. In these circumstances, the reasonable consideration of conflicting moral values is an unreasonable expectation. Two conclusions can follow: Either no role requirement will be observed in such situations or only the strongest will.

If courts and legislators fail to recognize—or worse, disregard—the importance of strong professional moral guidelines, the degradation of medical norms will continue even in the least stressful of environments and certainly in situations like those surrounding physicians at Abu Ghraib. Institutional endorsement and support for non-negotiable duties (such as "do no harm") are required precisely for situations in which case-by-case evaluations are frustrated by situational bias.

CONCLUSION: THE PROTECTION OF ROLE

The problem of role conflict is a familiar one in moral theory. This Note does not attempt to resolve it. It is intended, however, to highlight the tensions inherent in the inevitable conflict among medicine's various commitments. Clinical fidelity to the individual patient should be a standard of medical responsibility that is extremely difficult to violate. For some years, the public conception, self-conception, and morale of the medical profession have been

140. Roger S. Magnusson, "Underground Euthanasia" and the Harm Minimization Debate, 32 J.L. MED. & ETHICS 486, 487 (2004). Magnusson's observations about physicians' reactions to assisted-suicide reveal the particular conflicts outlined above.

141. "Once one makes a thing subject to reason, as distinguished from impulse, one plays with it, even if it is a very serious thing. I am more ashamed because of things I have played with in life than of any other thing." Postema, *supra* note 5, at 286.

142. *Id.*

declining.¹⁴³ The productive transition from physician paternalism to patient autonomy has had the unfortunate consequence of dispiriting practitioners and rendering them less able to keep faith with patients.¹⁴⁴ Whether this transition has prompted courts and policy makers to abandon their faith in physicians, or vice-versa, is unclear.

The current trend in medical legislation and jurisprudence is dangerous. It signals an environment in which doing harm is laudable and doing good amounts to “dangerous folly.”¹⁴⁵ *Singleton v. Norris* reflects the current disregard for physician’s role integrity, and the abuses at Abu Ghraib reflect the serious consequences of further neglect. It remains, therefore, the responsibility of medical ethicists and professional organizations to convince and remind courts that there is more at stake in the protection of the physician’s prescribed role than mere professional exclusion, political autonomy, or social equity. What is at stake is, quite literally, a matter of life and death.

143. M. Gregg Bloche, *Cutting Waste and Keeping Faith*, 128 ANNALS INTERNAL MED. 688 (1998).

144. Bloche *supra* note 87.

145. “I am in this earthly world; where to do harm / Is often laudable, to do good sometime / Accounted dangerous folly.” WILLIAM SHAKESPEARE, *MACBETH* act 2, sc. 2.

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SYMPOSIUM

Foreword

A World Less Silent: Celebrating Jay Katz's Contributions to Law, Medicine, and Ethics

David C. Tolley, M.A.*

On October 15, 2004, more than one hundred and twenty people convened at the Yale Law School for what has come to be known as “Jay Katz Day.” Many of them former students of Dr. Katz’s, they came from as far as Geneva and California, and from as near as their offices down the halls of the law school. It was a day of celebration and reflection on what Harold Koh, Dean of the Yale Law School, called “the healing wisdom of Jay Katz.”¹ It was also a day of great anticipation.

I had the privilege of serving as the primary coordinator for this conference, and I was in dialogue with Dr. Katz from the beginning—“What are you planning?” he often wanted to know. “Who will be there? What are the topics?” For many weeks through the spring and summer of 2004, Dr. Katz and I spoke often about how much he was looking forward to this great event. Besides the many scholars we invited, I sent more than one hundred invitations to friends and family of the Katz’s.

However, two weeks prior to the symposium, Dr. Katz fell ill with a serious respiratory infection. He spent the better part of those two weeks in a Boston hospital. Knowing that he had been discharged from the hospital on the afternoon

* Teaching fellow, Yale University; Adjunct Faculty, Fairfield University and Sacred Heart University. This symposium was convened and sponsored by the Yale Institution for Social and Policy Studies and its Interdisciplinary Center for Bioethics, as well as the Yale Law School.

1. Harold Hongju Koh, *Introductory Remarks—The Healing Wisdom of Jay Katz*, 6 YALE J. HEALTH POL’Y L. & ETHICS 397 (2006).

of the October 14th—the day before the conference was to begin—we all hoped that he would be able to attend, but we were unsure. I met a friend of the Katz's, a gentleman who had been taking care of their New Haven home while Dr. Katz and his wife were in Boston, at 7:30 a.m. on Wall Street behind the law school. He and I carried Dr. Katz's recliner into the conference hall in hopes that he would be able to be with us.

Immediately to the right as people filed into the conference hall to begin the day, his recliner sat poised and ready—we, and his chair, were ready for him. Mid-morning, during Robert Burt's keynote presentation, Dr. Katz arrived; he too was ready for us. It was a spectacular moment.

As Professor Burt paused to acknowledge Dr. Katz's arrival, the room rose to its feet in joy and relief. Characteristically humble, Dr. Katz waved and blew a respectful kiss to the room, sat down in his recliner and nodded at Professor Burt to proceed please. There Dr. Katz sat for the rest of the day—smiling, nodding, and waving politely, as person after person offered their reflections on what he has meant, and what he will continue mean, for scholarship and practice in law, medicine, and ethics.

In the first paper of this symposium, *The Uses of Psychoanalysis in Law: The Force of Jay Katz's Example*,² Robert Burt reflects upon how Dr. Katz has turned our attention to the life of the unconscious in order to help us all turn a more honest eye toward ourselves. Professor Burt compares Dr. Katz's work with that of Joseph Goldstein, and Burt recounts how Dr. Katz as scholar and teacher illuminated systemic patterns of repression and denial that play out to the detriment of legal and medical practice. Professor Burt calls our attention to ways we can think about structuring policies and practices so that we pay attention to the often mischievous unconscious, so that the unconscious does not operate mischievously in secret.

Professors Elyn Saks and Charles Bosk offer responses to Burt's work.³ Professor Saks focuses upon how certain fundamental precepts of psychoanalysis can shape medical practice for the better, and Professor Bosk reflects upon how the sociological milieu of contemporary bioethics is more complex than we usually realize, and he suggests ways that Dr. Katz's work can contribute to more honest, effective research in the sociology of medicine.

Alex Capron takes a sobering look at the state of the ethics of research with human subjects and the long distance we still have to go in order to deal

2. Robert Burt, *The Uses of Psychoanalysis in Law: The Force of Jay Katz's Example*, 6 YALE J. HEALTH POL'Y L. & ETHICS 401 (2006).

3. Elyn Saks, *Response—Our Debt to Jay Katz*, 6 YALE J. HEALTH POL'Y L. & ETHICS 415 (2006); Charles Bosk, *Response—A More Skeptical Bioethics*, 6 YALE J. HEALTH POL'Y L. & ETHICS 425 (2006).

adequately with the moral dilemma at the heart of research with human subjects: “We are asking you to do this not for yourself but for others, even though we know that the role human subject research entails real and sometimes unforeseen risks including death.”⁴ Professor Capron highlights the problems entailed in heralding often complex, jargon-laden informed consent forms as benchmarks of ethical research. He also pays particular attention to the problematic nature of many physicians’ dual roles as caregiver and researcher. His call is for a willingness to acknowledge these problems that often linger in the shadows, unexposed to the light, and find ways of moving towards constructive resolutions.

Professors Ruth Faden and Larry Palmer respond to this second paper.⁵ Professor Faden elaborates on two issues Capron raises: how moral dilemmas are sometimes ignored in research and how informed consent can sometimes promise more than it can actually deliver. And Professor Palmer takes Capron’s paper as a springboard into a discussion of Dr. Katz’s work as it relates to broader issues in bioethics like race, genomics, and what he calls “community engagement.”

In the third major paper of this volume, Ellen Wright Clayton pays particular attention to the physician-patient relationship.⁶ She highlights places where silence still persists in medical relations to the detriment of medical care. What Professor Clayton terms “barriers to conversation” occupy the bulk of her reflections. She cites an exaggerated fear of diseases like cancer, an over-confidence in what genetic testing really tells us, and a lack of awareness regarding potential treatment options as examples of conversation barriers. But the most significant reason for the persistent silence between doctor and patient, Clayton acknowledges, is that the kind of communication and deep identification Dr. Katz calls for is both time consuming and exhausting—both emotionally and professionally. In short, what Dr. Katz encourages medical professionals to do “makes them squirm.” However, Professor Clayton, as both physician-scholar and physician-caregiver, admonishes medical professionals to heed Dr. Katz’s hard advice nonetheless.

Professors Alan Meisel and Susan Wolf respond to Clayton’s paper.⁷

4. Alexander M. Capron, *Experimentation with Human Beings: Light or Only Shadows*, 6 YALE J. HEALTH POL’Y L. & ETHICS 431, 431 (2006).

5. Ruth Faden, *Response—Reflections on Jay Katz’s Legacy*, 6 YALE J. HEALTH POL’Y L. & ETHICS 451 (2006); Larry Palmer, *Jay Katz: From Harms to Risks*, 6 YALE J. HEALTH POL’Y L. & ETHICS 455 (2006).

6. Ellen Wright Clayton, *The Web of Relations: Thinking About Physicians and Patients*, 6 YALE J. HEALTH POL’Y L. & ETHICS 465 (2006).

7. Alan Meisel, *Response—From Tragedy to Catastrophe: Lawyers and the Bureaucratization of Informed Consent*, 6 YALE J. HEALTH POL’Y L. & ETHICS 479 (2006); Susan Wolf, *Response—Doctor and Patient: An Unfinished Revolution*, 6 YALE J. HEALTH POL’Y L. & ETHICS 485 (2006).

Professor Meisel reflects upon the bureaucratization of informed consent by lawyers and how this affects the physician-patient relationship, and Professor Wolf focuses upon Dr. Katz as a revolutionary for thinking about the physician-patient relationship; she ends her remarks with a substantive and inspirational rallying cry.

The collection of papers in this symposium all come from influential scholars. The constructive work they offer here is important. But the work in this collection is also personal, as the occasionally informal style reveals. Most of the authors are former students of Dr. Katz's whose remarks are enriched by their ability to place the person Jay Katz alongside the scholar Jay Katz. What one realizes is that Dr. Katz's contributions to law, medicine, and ethics, which are undeniably profound, are especially profound because of the person Jay Katz is. It is my strong impression that Dr. Katz has always self-consciously attached the personal to the professional—a self-consciousness that is important but sorely lacking in the fields of law, medicine, and ethics generally speaking. In this light, Dr. Katz serves as an exemplar of the person-scholar that many of us who participated in "A World Less Silent: Celebrating Jay Katz's Contributions to Law, Medicine, and Ethics," hope we can become in the years ahead.

One message that resounded throughout "Jay Katz Day" is that Dr. Katz's scholarship has much to offer for the future of scholarship in bioethics. You will see at numerous points how various writers remark that Dr. Katz's wisdom—his "healing wisdom"—offered insights thirty years ago that are every bit as important now as they were then. In a time of heightened anxiety over health care issues and a legally contentious clinical and research environment, a world less silent would go a long way towards improving relations between patients, practitioners, and payers.

Introductory Remarks

The Healing Wisdom of Jay Katz

Harold Hongju Koh, M.A., J.D.*

I have known Jay Katz for over forty years, and I have been his colleague for nearly twenty. It is my great joy to welcome you all here and especially to thank Bob Levine and Alex Capron, Bo Burt, David Tolley, and Carol Pollard for putting this program together.

You all know Jay Katz's story. He was born in Germany and emigrated to the United States at the age of eighteen. He earned his doctorate at Harvard Medical School, which he followed with a medical internship at Mount Sinai. Next is the part of his resume that has always been the most exciting and mysterious to me: his service as Captain Katz of the United States Air Force. (Imagine what that must have been like!) He first came to Yale as an assistant medical resident more than fifty years ago, and then to the Yale Law School as Assistant Professor of Psychology of Law in 1958. In time, Jay became Professor of Law, Science, and Medicine; the John Garver Professor of Law and Psychoanalysis; and the inaugural Elizabeth K. Dollard Professor of Law, Medicine, and Psychiatry. He has received numerous honorary degrees and delivered many named lectures. His greatest works, of course, are his books: *The Family and the Law*,¹ with our beloved colleague, Joe Goldstein; *Psychoanalysis, Psychiatry, and Law*,² with Joe Goldstein and Alan Dershowitz; *Experimentation with Human Beings*,³ with Alex Capron and Eleanor Swift Glass; and his landmark work, *The Silent World of Doctor and Patient*.⁴ Reading the

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1. JOSEPH GOLDSTEIN & JAY KATZ, *THE FAMILY AND THE LAW: PROBLEMS FOR DECISION IN THE FAMILY LAW PROCESS* (1965).

2. JAY KATZ ET AL., *PSYCHOANALYSIS, PSYCHIATRY AND LAW* (1967).

3. JAY KATZ ET AL., *EXPERIMENTATION WITH HUMAN BEINGS: THE AUTHORITY OF THE INVESTIGATOR, SUBJECT, PROFESSIONS, AND STATE IN THE HUMAN EXPERIMENTATION PROCESS* (1972).

4. JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (Johns Hopkins Univ. Press 2002) (1984).

introduction to that book, one can see that Jay's special skill lies in his ability to be both an outsider and an insider in the worlds of law and medicine. Upon reflection, the concept of "outsider-insider" is a description not just of Jay as a person, but also of the role that he defined for a doctor vis-à-vis his patient. On the one hand, Jay said, the doctor must be united with his patient in the act of healing and analysis; on the other, he must be sufficiently removed from his patient to retain his own objectivity.

Let me mention three recollections of Jay that, to me, exemplify his role as an "outsider-insider." The first time I met Jay, I was in junior high school here in New Haven with his children, Sally, Danny, and Amy. I met Jay when my parents and I visited their home. After greeting my parents, Jay reached out to me, smiling, his face absolutely aglow. I remember looking at him and thinking, "This man looks like a leprechaun—a German-Jewish leprechaun!" He was an immigrant. I was from a family of immigrants. He was the quintessential outsider-insider, welcoming another outsider into the fold. I remember his words most clearly. He said, "Harold, I want you to know that you are most welcome here."

My second memory is from the mid-1980s, when I first came to teach at Yale Law School. Jay was the most generous colleague that one could imagine. Only a year after I had arrived, our friend, the brilliant Professor Bob Cover, suddenly died of a heart attack in the early summer. School was not in session. We were all separated at the time, and we were all shattered. We were called together by then-Dean Guido Calabresi to Mory's, where we shared a sad, quiet meal together. As we sat together, Guido called upon Jay to say something. Jay stood and mused for a few minutes about what Bob had meant to our community. He spoke about what it meant that Bob had died, about what it meant for all of us to hear about his loss in this way, and about what it meant for all of us to think about his mortality—and our own. Then he sat silently, and we sat silently. I realized for the first time how comfortable Jay felt with silence. I felt a weight lifting from my own heart. I understood that, whatever was to happen, we were part of this community together. I felt for the first time Jay's unique healing touch.

My third recollection is of a time when Jay came to see me early in my tenure as a professor. I was about to start working very closely with someone Jay knew well, and he asked me if we could talk. He told me that this mutual friend wanted me to know something very personal—that person's sexual orientation. This person felt that if we were going to be working very closely together, I would soon learn this person's sexual orientation. Rather than coming out to me directly, the person wanted someone else to explain it to me and to assess my reaction. This person trusted one person to be the messenger and mediator, and that person was Jay Katz.

Two things stood out about the conversation. The first was that as soon as he had delivered his message, Jay sat back in his chair. He seemed totally relaxed, open to whatever I was going to say. He seemed completely responsive. Having told me this intimate information, he was ready to counsel me on how to receive it. I was deeply moved by the gesture. I was equally moved that the messenger was Jay. Second, I remember what he said as he got up to leave. Jay lit a cigarette (which was allowed in those days), and he said to me, "I know you will understand, Harold. I know you will empathize. I know you will be generous."

So these are the three lingering and powerful images that I have of Jay Katz: the welcoming leprechaun, the healer of communal sorrow, the messenger of intimacy. As we start this symposium to celebrate Jay's genuinely remarkable career, I hope we can all remember that, whatever we have done, we have known that Jay would understand, that Jay would empathize, and that Jay would be generous.

Jay has taught us that much goes on in the silent world of doctor and patient. In that world, there is humanity, grief, humiliation, anger and confusion. But what Jay has introduced into that silent world is compassion. What he has introduced is understanding. What he has introduced, most of all, into the silence is wisdom, and in that wisdom, healing.

I welcome you to this celebration of the healing wisdom of Jay Katz.

The Uses of Psychoanalysis in Law: The Force of Jay Katz's Example

Robert A. Burt, M.A., J.D.*

Jay Katz has been one of the most profound and enduring influences on my life as a legal scholar. His influence began at the very moment I entered the Yale Law School as a student in 1962. My understanding of the uses of psychoanalysis in legal analysis begins with the memory of my first encounter with him. I believe that my personal experience mirrors more generally how Jay came to influence all of his students—those lucky enough to sit in his classes as well as those who have only encountered him through his writings.

Here then is my memory of my first classroom session with Jay Katz. I had just arrived at Yale Law School in 1962 after two years at Oxford studying law. Yale treated my Oxford degree as the equivalent of the first year course of study; so I began in effect as a transfer student with second-year status. (If you'll excuse the pun, it was transference all the way down from that moment onward.) This transfer status meant that I was immediately eligible for taking some upper-class courses and I enrolled in Family Law—taught by Professors Joe Goldstein and Jay Katz—and this was the first class I attended on my first day at Yale.

Before class, we were told to read the New York state statute governing divorce and then the complaint and counter-complaint filed by a couple, identified by pseudonym as Sadie and Perry Lesser.¹ In their cross-filings, Sadie and Perry alleged that each inflicted indignities on the other, described in considerable detail, drawn from some twenty years of marriage. With this advance reading, I came to class with thirty or so fellow students.

Jay and Joe sat side by side at the front of the room, and Joe began with a classically open-ended question. "What's going on here?" he asked—and then he and Jay sat silently waiting for some response. I was puzzled—not just by the question, which seemed extraordinarily odd to me based on my previous Oxford law classes, but even more by the prolonged silence from the teachers that followed that odd question. (The silence, I would bet, lasted no more than fifteen seconds, but in the garrulous world of lawyering to which I'd already been

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1. JOSEPH GOLDSTEIN & JAY KATZ, *THE FAMILY AND THE LAW* 19 (1965).

initiated, this fifteen seconds of silence seemed like a very long time indeed.) Then one student raised his hand and spoke, and then another and another. The students were drawn repeatedly to the technical details in the statute—the differences between “divorce” and “separation from bed and board,” for example, and the way the parties’ pleadings related to those different standards. Joe and Jay listened respectfully and occasionally commented directly on one or another of the students’ responses. But after all of the upraised student hands had been recognized, Joe said “What else?” and silence again ensued. Then a few more hands up, a few more comments from the teachers and then again, “Anything else?” and then silence once more.

I sat silent throughout all this, impressed at my fellow students’ technical command and self-confidence and unclear about what was expected in an American law classroom (though I soon thereafter learned that this was a very unusual American law classroom, even at Yale). Then Jay spoke. He may have been entirely silent up to this moment, but in any event had not said much, content to leave the prior interactions more to Joe. And Jay spoke, of course, in his accented English which seemed to me at that moment like the very embodiment of Sigmund Freud himself. Jay said, “Here’s one possibility about what’s going on. These two people are at war. They are fighting one another for their self-respect, even for their lives. This is a life-and-death struggle between Sadie and Perry Lesser.”

At those words I remember feeling an enormous release of tension, a sense of recognizing something in myself and in the world that I had only vaguely glimpsed before, an opening of feelings that I had not known were in me. This may sound melodramatic, but for me this was high drama of an intensely personal kind. I had come to that classroom with two years’ previous experience of law training and at least ten years’ prior conviction that I wanted to be a lawyer. But my initial exposure to law training at Oxford had only left me with an unsatisfied question and a foreboding. Why, I had asked myself at the end of this previous two years, did I want to become a lawyer? The law as I had seen it seemed to be a set of intricate finger-exercises; I had learned that I could do the exercises reasonably well, play the game according to the rules at hand. But for what? Why was I there, what did I want from this profession? Suddenly, unexpectedly, in Jay and Joe’s classroom, I had an answer. Or maybe not an answer, but at least the beginnings of an answer—coupled with a conviction that I was in the right place. I was where I wanted to be. I was where I needed to be. I was in a Yale Law School classroom with Joe Goldstein and Jay Katz.

Then Joe amplified Jay’s observation about the war between the Lessers. “Our task in this course,” he said, “is to evaluate the weapons that the law gives to Sadie and Perry to wage this warfare that started outside of the courtroom, and to ask whether the availability of these legal weapons makes matters better or

worse for these two people, for their children, and for society.” I was dazzled, captivated, and enchanted. And I remain so today.

Jay and Joe ultimately took different paths in pursuing these questions—not so noticeably in the many classes that I took with them from 1962 through 1964, but much more in their later writings. In the course of this paper, I will explore some of those differences because they illuminate various possibilities for the uses of psychoanalysis in legal thinking. The lesson that both Jay and Joe taught—the premise that they shared—was that the law properly understood must encompass the entire dimension of the human condition. The law may aspire to rational control in human affairs. And in this pursuit of rational control, the law may aspire to complete transparency among legal actors in acknowledging the relationship between the law’s means and its ultimate goal of rational control. But psychoanalysis teaches that this aspiration to rationality and transparency encounters many stubborn, and even intractable, obstacles because of how pervasive non-rational thinking is in human psychological functioning. And psychoanalysis teaches that the aspiration to rationality and transparency will fail, will even become a perversely self-defeating caricature of itself, unless legal actors persistently give explicit and respectful attention to the non-rational dimensions of their enterprise.

Jay and Joe shared these two premises and imparted them to their students. Their respectful and fearless attention to the non-rational dimensions, buried beneath the confident, imperialist claims of legal rationality, was the shock and the thrill of recognition that I experienced in my first encounter with Joe and Jay and Sadie and Perry Lesser.

From these shared premises drawn from psychoanalysis, two diverging strands emerge—two strands not only exemplified in the different paths that Joe and Jay took in their own work but also in the history of psychoanalytic thinking generally. As in most things psychoanalytic, these two strands can be traced back to the mind of the movement’s founder. At the risk of oversimplification, one could draw a distinction between the early and the late Freud. Freud’s initial ambition was to deploy the insights and methodology of psychoanalysis to tame the irrational—as his famous aphorism put it, “where id was, there ego shall be”²—whereas the later Freud is more skeptical about the attainability of this goal, as in his late essay *Analysis Terminable and Interminable*,³ or in his book,

2. SIGMUND FREUD, *New Introductory Lectures on Psychoanalysis* (1930), reprinted in 22 THE STANDARD EDITION OF THE COMPLETE PSYCHOLOGICAL WORKS OF SIGMUND FREUD 80 (James Strachey ed. & trans., 1964).

3. SIGMUND FREUD, *Analysis Terminable and Interminable* (1937), reprinted in 23 THE STANDARD EDITION OF THE COMPLETE PSYCHOLOGICAL WORKS OF SIGMUND FREUD 209 (James Strachey ed. & trans., 1964).

Civilization and Its Discontents.⁴ This distinction between early and late Freud may be somewhat overdrawn; but as a heuristic, it is helpful for identifying divergent uses for psychoanalysis in law and, in particular, for placing Joe and Jay along this spectrum in Freud's thinking.

As I see it, the dominant ambition of Joe's approach to psychoanalysis in law, as his intellectual career unfolded, was to identify principles for resolving legal disputes that took explicit account of the non-rational and did not simply impose a rational facade on unruly psychological forces. The paradigmatic expression of this approach was in Joe's work on disputes about the welfare of children, with the collaboration of Anna Freud and Albert Solnit (and in later works also with Sonya Goldstein).⁵ With his collaborators, Joe used psychoanalytic premises to demonstrate that children's thinking was organized very differently from conventional adult conceptions of rationality. At a minimum, this demonstration required that children, especially very young children, be understood as deeply embedded in non-rational thinking which only gradually gives way to self-consciously transparent rational thinking; and we must further understand that this is an extended process that requires supportive attention to children's developmentally distinctive non-rationality in order to succeed.

But Joe had a further ambition—and this, I believe, was his distinctive contribution in his collaborative works—which was to identify rules that were themselves respectful of children's developmentally distinct non-rationalities, rules that could be applied by legal decision-makers in resolving a wide range of child welfare disputes. Thus from the premise that every child needs a continuous relationship with an adult caretaker, Joe drew rules to preserve continuity by protecting actual ongoing custodial relationships with children against challenges from biological parents, notwithstanding the fact that the custodians had no biological link with the child. Joe argued that these custodians were the children's sole "psychological parents," and, in psychoanalytic terms, this meant that they were the children's true parents.⁶ In divorce disputes between two

4. SIGMUND FREUD, *Civilization and Its Discontents* (1930), reprinted in 21 THE STANDARD EDITION OF THE COMPLETE PSYCHOLOGICAL WORKS OF SIGMUND FREUD 59 (James Strachey ed. & trans., 1964).

5. JOSEPH GOLDSTEIN, ANNA FREUD & ALBERT SOLNIT, BEFORE THE BEST INTERESTS OF THE CHILD (1979) [hereinafter GOLDSTEIN ET AL., BEFORE THE BEST INTEREST OF THE CHILD]; JOSEPH GOLDSTEIN, ANNA FREUD & ALBERT SOLNIT, BEYOND THE BEST INTERESTS OF THE CHILD (1973) [hereinafter GOLDSTEIN ET AL., BEYOND THE BEST INTEREST OF THE CHILD]; JOSEPH GOLDSTEIN, ALBERT SOLNIT, SONYA GOLDSTEIN, & ANNA FREUD, THE BEST INTERESTS OF THE CHILD: THE LEAST DETRIMENTAL ALTERNATIVE (1986) [hereinafter GOLDSTEIN ET AL., THE BEST INTERESTS OF THE CHILD].

6. See GOLDSTEIN ET AL., BEFORE THE BEST INTERESTS OF THE CHILD, *supra* note 5, at 39-57

biological parents, Joe applied the continuity principle to require that the day-to-day custodian of the child be given full, legally unchallengeable authority to control all aspects of the child's upbringing—choice of schools, of religious affiliation and even of visitation arrangements with the non-custodial parents.⁷ These examples illustrate Joe's general mission—to use psychoanalytic premises to resolve legal disputes.

Jay had a very different agenda. His central concern was not to resolve disputes but to create them. Jay's mission was to provoke conflict where one or even all parties to a relationship had not previously acknowledged or even understood that they were fighting about anything. The paradigmatic context for Jay's provocative endeavor was the relationship between physician and patient. In the traditional understanding of this relationship—from Hippocrates' time onward, as Jay demonstrated in his historical scholarship⁸—there was no acknowledged conflict between physician and patient. The very definition of the relationship required that the physician was in charge and the patient was compliant; they were "of one mind," and the physician was that mind, while the patient literally had no mind of his own.⁹

This traditional conception violated norms of self-determination rooted in the ideology of post-Enlightenment Western individualism and Jay invoked these norms to buttress his case against the traditional conception of the doctor-patient relation. But the heart of his case did not rest on these norms. Jay's signal contribution was in his use of psychoanalytic premises to demonstrate that the traditional conception was not accurate, but rather was a crude simplification, even a falsification, that served to suppress awareness of the conflicts that physicians and patients regularly experienced with one another. Even more profoundly, Jay argued that this traditional conception of inherent unity of purpose between physicians and patients served to mask the conflicts that each felt within themselves.

The core of these conflicts concerned the issue of rational control. For the patient, the cherished ideal of rational self-control is threatened by the illness that drives him to seek the physician's assistance. This psychological vulnerability was the basis for the traditional medical stance that patients were inherently incapable of exercising autonomous choice about their treatment regimes. But Jay showed how physicians' cherished ideal of rational self-control is equally

(discussing familial bonds between children and longtime caretakers who are not their parents).

7. See GOLDSTEIN ET AL., BEYOND THE BEST INTERESTS OF THE CHILD, *supra* note 5, at 31-40.

8. See JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT 30-47 (Johns Hopkins Univ. Press 2002) (1984) [hereinafter KATZ, SILENT WORLD] (tracing the "history of silence" between doctor and patient).

9. See *id.* at xl-xlvi.

undermined by the multiple uncertainties that are an inescapable part of medical practice. The basic goal of scientific medicine during the past 150 years has been to expand the scope of rational mastery over illness and an impressive range of medical interventions has been devised for this purpose. But Jay maintained that the vast array of these interventions in itself creates an unsettling problem for every individual physician who is obliged to “keep up with the field”—to match his or her personal capacity to control a patient’s illness with the complex, ever-burgeoning tools for such control provided by medical science. And even for the most up-to-date physician, uncertainty remains inescapable in dealings with every specific patient due to the inherent biological variability of each patient and because so much remains unknown about disease processes generally.

In the face of these vulnerabilities, patients and physicians both cherish the fantasy that illness will be magically cured. As Jay put it in his influential book, *The Silent World of Doctor and Patient*, “Deep in patients’ unconscious, physicians are viewed as miracle workers, patterned after the fantasized all-caring parents of infancy.”¹⁰ Physicians, on their side of this unconscious transaction, want to be “miracle workers,” to assure both their patients and themselves that the “fantasized all-caring parents of infancy” are still available when needed, whether by their patients or by themselves. Jay’s goal was not to destroy this shared fantasy; psychoanalytic premises instruct us that he could not do so even if he wanted to. But these premises also tell us that fantasies can have both “adaptive” and “maladaptive” consequences and, as the good psychoanalyst that he is, Jay’s goal has been to identify the fantasies that were giving shape to perceptions of real-world interactions and to sort out the ways in which those fantasies were helpful or obstructive to the underlying goals of the participants in these interactions.

To return to the contrast between Jay and Joe: Joe’s goal was to take the law’s promise to protect the best interest of the child and—as he phrased it—to “pour[] content into . . . the law’s standard” through the use of psychoanalytic premises.¹¹ Joe began, then, with a legal standard which was patently indeterminate—it was acknowledged by virtually everyone to be subject to rudderless judicial application—and his ambition was, through psychoanalytic insight, to make this standard clearly determinate.

Jay worked in exactly the opposite direction. Jay began with the law’s standard of “informed consent,” which was widely understood as clearly determinate; physicians are obliged to do only what patients request and, toward that clear-cut end, to inform patients about all available options. Jay embraced this standard for normative reasons quite aside from psychoanalytic premises.

10. *Id.* at 192.

11. Joseph Goldstein, *Psychoanalysis and Jurisprudence*, 77 YALE L.J. 1053, 1074 (1968).

But his basic goal was to unmask the indeterminacy—the multiple, interlocking unconscious fantasies within and between patients and physicians—that was concealed by the misleadingly simple formula of “informed consent.” It is in this sense that Joe used psychoanalysis to resolve conflict where all of the legal actors had previously acknowledged the existence of conflict, while Jay used psychoanalysis to create an awareness of conflict where all of the actors had previously been locked in a mutually reinforcing fantasy that no conflict existed.

Both of these contrasting uses of psychoanalysis fit within the premises of the field. Freud’s original aspiration for psychoanalysis as a scientific medical enterprise is especially congenial to Joe’s ambition for identifying dispositive standards within the discipline to guide conduct—criteria, one might say, of “normal and healthy” versus “abnormal and pathological” behavior. Jay’s goal of introducing complexity and indeterminacy is more congenial to the way that psychoanalysis has evolved in its clinical expression as a therapeutic modality. Jay’s approach also reflects later doubts about the determinate character of the psychoanalytic enterprise that were expressed by Freud, as well as many contemporary psychoanalytic theorists.¹²

Jay’s path of using psychoanalytic premises to identify and amplify conflicts where none had previously been acknowledged is the path that I have tried to follow in my own thinking and legal writing. There is a cost to this approach: The conventional idea of law demands the resolution of disputes whereas Jay’s approach leans much more toward the provocation and prolongation of disputes than to their resolution. Though this inclination cuts against the grain of conventional legal thinking, I believe there is a deep, socially helpful truth that can emerge from this unconventional perspective.

Let me illustrate this truth by examining two specific applications of the contrasting perspectives that Joe and Jay present. First, let us briefly consider Joe’s approach to the child custody dispute in *Painter v. Bannister*,¹³ a decision of the Iowa Supreme Court that attained considerable notoriety as a “culture clash” in the mid-1960s. The object of this clash was Mark Painter, a seven-year-old whose mother and younger sister had died two years earlier in an automobile accident and whose father, Harold, had immediately afterward sent Mark to live with his maternal grandparents on their Iowa farm. After re-marrying, Mark’s father sought to regain custody but Mark’s grandparents, the Bannisters, resisted. The Iowa court awarded permanent custody to the grandparents, characterizing their home as a “stable, dependable, conventional, middle-class middlewest

12. See, e.g., HANS LOEWALD, *Psychoanalysis as an Art and the Fantasy Character of the Psychoanalytic Situation*, in PAPERS ON PSYCHOANALYSIS 352 (1980).

13. 140 N.W.2d 152 (Iowa 1966).

background”¹⁴ whereas Harold Painter’s home would be “unstable, unconventional, arty, Bohemian and probably intellectually stimulating.”¹⁵ Joe approved of the Iowa court’s disposition but not of its articulated rationale for rejecting the “arty . . . and probably intellectually stimulating” father.¹⁶

I cannot help but imagine some small smile playing across Joe’s face as he spoke against the virtually unanimous condemnation among “liberal intellectuals” of this corn-fed Iowa ruling. But Joe had a supervening principle drawn from the psychoanalytic premises underlying the “continuity” standard; Mark should stay with his grandparents because the psychologist’s examination conducted in the case demonstrated that the Bannisters had become Mark’s “psychological parents” during the two years he had lived with them.

Joe’s resolution is not vulnerable to the same charge of cultural bias as the Iowa Court’s decision. But I believe he was misled by his underlying conception of the role for psychoanalysis in addressing legal conflict. Put in conventional terms, there was a clear-cut and acknowledged dispute between Harold Painter and the Bannisters—each wanted custody of Mark and each party was willing only to envision some limited visitation arrangement for the other. Conventionally understood, the court’s role was to resolve the dispute in favor of one claimant or the other. There is a powerful practical imperative behind this understanding of the judicial role. A dispute raged between the two parties and each believed that only one of them could prevail. But this practical imperative says nothing about the true “best interests” of the disputed child. Joe’s invocation of the psychoanalytically based continuity principle does purport to speak to Mark’s best interest. But I believe that on the particular facts of Mark’s case this is erroneous and that this specific error illuminates the larger mistake that pervades Joe’s goal of using psychoanalysis for definitive dispute resolution.

In my view, thinking about Mark Painter’s best interests must begin by acknowledging the tragic losses that he had endured. Mark’s psychological need for continuity of caretaking had not been displaced by the sudden deaths of his mother and younger sister. This need was almost certainly intensified—and from this perspective—almost certainly further undermined, by his father’s decision to send him from their family home in Alaska a half-continent away to Iowa and to grandparents whom he had hardly known. Perhaps Harold Painter was so shattered by the death of his wife and daughter that he felt he had nothing to offer Mark in responding to their common loss, but the further disruption of losing contact with his father virtually at the same time when he lost his mother and sister must have taken some added toll on Mark.

14. *Id.* at 154.

15. *Id.* at 156.

16. *Id.*

When Mark's father suddenly re-appeared and sought to resume his custodial role but was rebuffed by Mark's grandparents, there were two different ways of framing the custodial question. One way was, what choice between these two contending parties would best serve Mark's current needs—who should prevail between them? An alternative way of framing the question was, how can these contending parties be led to understand that Mark's needs may best be served (and perhaps can only be served) if his father and grandparents can find some way to transcend their hostility and work together, wholeheartedly, so that Mark might have a continuous, strong relationship with both of them?

I believe this second way of framing the question is preferable based on the psychoanalytic premise of preserving continuity that Joe himself invoked. Mark had already suffered a terrible loss of continuous caretaking. A decision definitively choosing between two of Mark's surviving, psychologically important caretakers would almost certainly be understood by him as another blow, another loss of a continuous relationship. It may be that these two rival contenders for a continuous relationship with Mark were so deeply estranged that they never could be brought to realize Mark's need for both of them to work together. It may be that a judge would be forced, simply as a practical matter, to choose between them, even though the act of choosing itself would be psychologically damaging to Mark. But it would be deceptive, and misleading to the disputing parties themselves, for the legal system to claim that this choice is anything but a disservice to Mark's best interest or, in Joe's preferred formulation, that the choice could yield a "least detrimental alternative."¹⁷ No good—and not even a diminished detriment—can come from this choice for Mark. If the warring members of his extended family truly understood that Mark could only benefit if they could transcend their battle over him, they would realize that a forced choice between them can only cause him harm.

This is the clear, single-minded message that the legal system should present to these warring parties. The system should not pretend for a moment that Mark's interests will be served if a judge makes the choice that the warring parties are demanding. And no experts, whether speaking from a specifically psychoanalytic or from any other professional psychological perspective, should lend the prestige of their authority to this pretense, even if the warring parties or the legal system itself tries to enlist them in this misleading endeavor.

There is a proper role for psychological experts in this dispute. It is to advise the warring parties about Mark's urgent need for them to resolve their conflict, to engage the parties in extended, sympathetic discussions about the bases for their conflict, and to explore possibilities for transcendence through empathic understanding of themselves and their erstwhile adversaries. This is the role

17. See GOLDSTEIN ET AL., THE BEST INTERESTS OF THE CHILD, *supra* note 5.

conception that lies beneath Jay's use of psychoanalytic premises in his approach to legal institutions.

Jay made this clear in his account of the function of the "informed consent" norm in doctor-patient relations. In Jay's account, the informed consent requirement is not a rule that simply shifts the traditional conception that doctors make unilateral decisions that bind patients to a new conception wherein patients make unilateral decisions that bind their doctors. That is, Jay did not see the "informed consent" requirement as a rule for resolving disputes in the way that Joe intended his "psychological parent" rule. For Jay, the "informed consent" requirement can only properly be understood, as he put it in *The Silent World*, as an "obligation for conversation."¹⁸ The goal of this conversation is not for one participant to rule the other, but for doctor and patient to converse honestly and trustingly with one another in order to reach agreement about the best course for treatment.

Jay's vision of both the possibilities for and the obstacles to this conversation—and the ultimate consequences of failure to reach agreement—are elegantly set out in his account of the justification for overriding the norm of "informed consent" through time-limited civil commitment of people with mental illness. Jay's account, *The Right to Treatment—An Enchanting Legal Fiction*, published in 1969, sets out the essential psychological premises which lay beneath all of his work on the role of informed consent in doctor-patient relations.¹⁹ This might appear paradoxical, since Jay's 1969 article deals with mentally ill people who, by strict legal definition, are incapable of giving or withholding informed consent and this incapacity is the essential justification for forcing treatment on them. But Jay's psychological premises erode strict categorical distinctions between mental capacity and incapacity. The way in which Jay dealt with the role of patient consent in civil commitment proceedings ultimately is the same way he addressed informed consent in all treatment relations, even when "mental illness" or "incapacity," strictly speaking, does not seem to be at issue.

I want to quote an extended passage from Jay's 1969 article. In this passage, and in the article generally, Jay purports only to speak about people with mental illnesses. But as I quote this passage, I urge you to listen for resonances with his account of the psychological vulnerabilities of all people facing serious illness, whether physical or mental. Here is what Jay said:

18. KATZ, *SILENT WORLD*, *supra* note 8, at 130.

19. Jay Katz, *The Right to Treatment—An Enchanting Legal Fiction?*, 36 U. CHI. L. REV. 755 (1969).

Most persons whom society involuntarily commits are consciously and unconsciously so convinced that no one cares, indeed they look at offers of help with such suspicion, that a sustained period of exposure to an unaccustomed world of trust, respect, and care is required in order to attempt to modify these beliefs. It is possible, without precisely knowing when it is and when it is not, to change defiant, ignorant, and fearful attitudes about treatment through patient and persistent efforts in an institutional setting. Behind the conscious refusal of treatment, other unconscious wishes also operate—to be protected, to be cared for, to be sustained, to be helped. What weight should be given to these wishes when they are almost drowned out by words which damn their own self and the world?²⁰

If there are, as I believe there to be, significant psychological similarities between the people whom Jay thus describes as appropriate candidates for civil commitment and many people who refuse to accept treatment regimes offered by physicians for physical and mental illnesses, do these similarities mean that physicians generally are justified in overriding patients' refusals? Jay refused to accept this corollary. But his refusal is not based on any categorical distinction between mentally "abnormal" and mentally "normal" refusals of treatment. Jay ultimately refused to accept coerced treatment for mentally "abnormal" people on the same ground that he refused to accept it for mentally "normal" people. For civil commitment, Jay endorsed what he called "a middle ground, which seeks to take into account the complexities of conscious and unconscious dynamics and at the same time attempts to keep such judgments from running wild."²¹

Jay's "middle ground" was to permit some coerced interaction with a physician, but coercion limited to a definite and relatively short time period. During this time-limited forced relationship, Jay said, the psychiatrist's interventions would necessarily

be restricted to an exploration of resistances to treatment and thus would extend only to an opportunity to learn to appreciate the value of treatment and those who offer it.

... [But t]he imposition of time limits will suggest to both patient and therapist that the day will arrive when both will have either to bow to the strength of unconscious forces that prevent therapy or to respect the conscious and unconscious convictions that deny its necessity. . . . The participants will know that the task before them is to reach consensus or to respectfully differ on

20. *Id.* at 771 (footnote omitted).

21. *Id.*

the need for treatment.²²

If, according to Jay's prescription, consensus is not reached and "respectful" difference on the need for treatment persists, then treatment cannot go forward. In this way, but in this way alone, the individual's autonomous right to refuse treatment comes into the foreground.

I believe that this depiction of the permissible role for coercion in doctor-patient relations when the possibility of mental illness is at issue precisely parallels Jay's account of the role of informed consent in the doctor-patient relationship generally. Unlike the conventional lawyer's account which begins with the premise—one might say, with an almost irrebuttable presumption—of individual autonomy, Jay's psychoanalytic perspective instructs that the capacities for individual autonomy and for rational self-control are inevitably at issue in the opening phase of the doctor-patient relationship. The goal for this opening phase is for both parties, the doctor and the potential patient, to explore this capacity. This exploration, moreover, must acknowledge and explore the doubts not only for the potential patient, whose capacity for rational self-control may be clouded by the impact of illness, but also for the doctor whose passion for rationalist scientific control of disease may be frustrated by the challenge of the potential patient's condition.

It is psychologically misleading to characterize this opening phase of the doctor-patient relationship as a free interchange between autonomous, rationally self-controlling individuals. The threat that both parties inevitably feel about their capacity to maintain rational self-control dictates that the relationship itself will feel mutually coercive in crucially important respects. This mutual coercion is not wrong or normatively inappropriate on either the patient or the doctor side of the transaction; it is psychologically inevitable and wrongful only if unacknowledged. Through the "obligation of conversation" that Jay prescribed, these mutually coercive elements should be brought into explicit, acknowledged visibility. As Jay observed, for interactions between psychiatrists and potential patients, as well as for the opening phases of all interactions between doctors and potential patients, "the task before them is to reach consensus or to respectfully differ on the need for treatment."²³

If disagreement persists, then disengagement must follow. But this consequence is not necessarily a victory for individual autonomy as psychologically understood. As Jay observed in his 1969 article, the conventional, relentlessly rationalist, legal account of individual autonomy

asserts that no matter what the balance of instinctual and ego forces or of

22. *Id.* at 773-74.

23. *Id.* at 774.

libidinal and destructive superego forces or of inner and outer world distortions, persons should be left to pursue their own fate if they so “state.” Such a proposition can be as destructive of human life as its opposite of over-readiness to hospitalize. . . . Such an approach is as insensitive as the abuse of power that leads to indefinite incarceration without treatment and with treatments that are of no value or ineffective or even harmful.²⁴

Jay’s goal throughout his work was not to reject the law’s rationalist account of individual autonomy but to identify the shortcomings of that account as measured by a psychoanalytically informed perspective on human psychological functioning and to show ways that this humane psychological vision can be brought into harmony with the law’s rationalism. This approach does not yield rules for settling legal disputes. Such dispositive rules, as with the conventional account of the patient’s right to self-determination, can too readily serve as barriers to self-exploration by patients and physicians—in effect, as conversation stoppers. Jay’s goal has always been to provoke conversation and to use psychoanalytic premises to identify the proper subject-matter for these conversational disputes.

In my own work on issues of biomedical ethics specifically²⁵ and constitutional adjudication more generally²⁶—even from my first encounter with him when I was a law student in 1962—I have been guided by Jay’s example. I thank him for that.

24. *Id.* at 770-71.

25. *See, e.g.*, ROBERT A. BURT, *DEATH IS THAT MAN TAKING NAMES: INTERSECTIONS OF AMERICAN MEDICINE, LAW, AND CULTURE* (2002); ROBERT A. BURT, *TAKING CARE OF STRANGERS: THE RULE OF LAW IN DOCTOR-PATIENT RELATIONS* (1978).

26. *See, e.g.*, ROBERT A. BURT, *THE CONSTITUTION IN CONFLICT* (1992).

Response

Our Debt to Jay Katz

Elyn Saks, M.Litt., J.D.*

Professor Jay Katz is a giant in the field of law and medicine. His particular interest in law and psychoanalysis drew many students to his classes and his office for stimulating conversation. As a person with a longstanding interest in psychoanalysis and law (indeed, I am in training now to become a “research psychoanalyst”), I turned to Jay Katz as someone to learn from and emulate. How might we best bring to bear the insights from a deep inquiry into human nature on our understanding of the law? Law requires a theory of the person, and psychoanalysis provides one of the richest that exists. Still, combining psychoanalysis with the law raises many challenges. Working at the interface of these two disciplines, Professor Katz has been a model for others interested in this endeavor. It is a deep honor to be asked to reflect on and celebrate the work of Jay Katz in this symposium.

In this brief response, I focus on three things. First, I address the interesting distinction between the work of Professors Katz and Goldstein that Robert Burt has so carefully laid out. Second, I discuss how I see psychoanalysis informing Katz’s work. Third, I discuss how his work has led other investigators, including me, to pursue a research agenda that probably could not even have been formulated without his influence.

I. RECONCILING GOLDSTEIN AND KATZ

Let us turn first to Burt’s paper.¹ The distinction that Burt draws between the work of Goldstein and that of Katz is extremely rich and well-taken. Burt suggests that Goldstein uses psychoanalytic principles to pour content and

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1. Robert Burt, *The Uses of Psychoanalysis in Law: The Force of Jay Katz’s Example*, 6 YALE J. HEALTH POL’Y L. & ETHICS 401 (2006).

meaning into indeterminate legal standards, to make them determinate so as to resolve legal disputes. To take Robert Burt's example, Goldstein suggests that the child's best interests in a custody dispute are to be placed with the person who is the child's "psychological parent." By contrast, Katz uses the insights of psychoanalysis to *create* disputes in order to complicate situations where there is seemingly the absence of any dispute. Consider, for example, the myth that doctors' and patients' interests are the same, thus obviating the need for rigorous informed consent.

Burt's distinction captures, and is meant to capture, something aspirational for Goldstein and Katz, even if their aspirations are not always fulfilled in practice. The psychoanalytic principles which Goldstein invokes may, when applied, be no less indeterminate than the general rules they are meant to explicate. For instance, the concept of a "psychological parent" can be extremely hard to apply. How many years do we look back? What if both parents are psychological parents? What if the psychological parent also poses some kind of harm to the child? What if one parent takes care of the daily needs of the child, but is emotionally cold and detached, while the other parent has poor skills in providing daily care, but is warm and connected to the child? One could propose a bright-line rule, for example, that the parent who has spent the most hours with the child in the last two years is deemed to be the "psychological parent." But, while such rules may be relatively easy to apply and certainly bind the decision-maker, they also risk getting things badly wrong.

In contrast, Katz introduces complexity at one stage of the process, but may then invoke determinate principles at another (e.g., that the patient must be willing to converse at the risk of an intervention being imposed on him or her). Conversation may be open-ended, but ultimately, if the parties cannot agree, there must be a decision and hence a rule. Yet if people know this decision rule in advance, the party whom it benefits may have less incentive to talk; conversation may be stopped in its tracks. If the outcome will (eventually) be in my favor, what incentive do I have to keep the conversation going?

What the above suggests is that if we take a temporal perspective, both Katz's and Goldstein's approaches may find their natural homes. We do not have to choose between the two, for they each are appropriate at different points in the course of a conversation. Goldstein looks at the point at which it is obvious that conversation alone cannot resolve the dispute, when the resources of conversation have been exhausted and a decision has to be made. And Katz looks at an earlier point where careful and honest searching may lead, so to speak, to a negotiated truce.

In the end, as much as Goldstein would like to resolve disputes with clear rules and little room to fudge, he cannot avoid the parties negotiating at times when the rules are unclear; and as much as Katz would like conversations to

continue and ultimately yield an agreement, he cannot avoid ending conversation at times by imposing some definitive resolution between the parties.

Finally, the differences between Katz and Goldstein may also have more to do with their normative preferences regarding the exercise of discretion by authorities than with their beliefs concerning psychoanalysis. Goldstein is worried about abuses of power and therefore attempts to articulate determinate rules, based on determinate psychoanalytic positions, which constrain authority. Although Katz is also mindful of abuses of power, he is more hopeful about the power of conversation to lead to optimal solutions.² Goldstein fears discretion and Katz embraces it. Ultimately, a decision to take either of these positions may turn on one's tolerance for ambiguity. But how much tolerance is optimal in this context, and for legal actors in particular, is an open question.

II. THE SILENT WORLD OF PSYCHOANALYSIS

Katz's work is thoroughly influenced by psychoanalytic ideas. A central theme throughout his work is that unconscious and irrational influences on decision-making are pervasive. This of course is Freud's central insight.³ Also important are Katz's psychoanalytic ideas about how those unconscious and irrational processes affect the doctor-patient relationship in particular. For example, the patient may unconsciously and irrationally endow the doctor with omnipotent powers to cure him, and the doctor may have unconscious fantasies about being an all-powerful rescuer or savior. These fantasies emerge most pointedly in the course of a psychoanalytic treatment, and, as an analyst, Katz will have experienced them at close hand. A third and extremely important insight in his work is that we must apply these principles not only to patients, but also to doctors. Psychoanalysts are trained to be mindful of their own fantasies

2. Thus, in an especially hopeful passage, Katz writes:

If doctors could learn, and in turn teach their patients, that it is possible to sit down and reason together about the most important personal anxieties and fears that illness and its treatment engenders, then they could also point the way to living life not by submission but by mutual respect, with careful attentiveness to one's own and the other's rationalities and irrationalities. Living the life of medicine in such new and unaccustomed ways could extend the dominion of reason and thus make doctors true healers to mankind.

JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 226 (Johns Hopkins Univ. Press 2002) (1984) [hereinafter KATZ, *SILENT WORLD*].

3. See, e.g., SIGMUND FREUD, *The Interpretation of Dreams* (1900), reprinted in 4, 5 *THE STANDARD EDITION OF THE COMPLETE PSYCHOLOGICAL WORKS OF SIGMUND FREUD* 1 (James Strachey ed. & trans., 1964) [hereinafter, FREUD, *Interpretation of Dreams*]; SIGMUND FREUD, *The Psychopathology of Everyday Life* (1911), reprinted in 6 *THE STANDARD EDITION OF THE COMPLETE PSYCHOLOGICAL WORKS OF SIGMUND FREUD* 1 (James Strachey ed. & trans., 1964).

and fears as they treat patients. They must maintain their vigilance lest they fall into unwitting “enactments” with their patients.

All of the above leads Katz to propose a new understanding of psychological autonomy that takes into account the influence of the unconscious and the irrational. He is not satisfied with abstract principles, such as Kant’s, that lack a foundation in both the rational *and* the irrational aspects of human nature.⁴

Finally, Katz proposes a means of accommodating the decision-making frailties he describes: a searching conversation about the patient’s—and the doctor’s—thoughts and fantasies. Psychoanalysis is the “talking cure,”⁵ and that, in part, is what Katz wants for all physician-patient interactions. He is, of course, mindful that doctors cannot be expected to conduct a mini-analysis when they are informing patients. Yet for the analyst, as for Katz, insight is key: The truth shall set one free.

One striking thing about Katz’s approach is its origins in a discipline that, until relatively recently, involved the most “silent” doctor of all—the analyst. Classical analysts are meant to be anonymous to their patients, sparing in what they will say, and neutral as to the values of their patients. Analyst neutrality is an important part of Katz’s perspective. But the traditional anonymity and abstinence—which may lead to virtual silence—seem to conflict with Katz’s prescription for conversation. The good analyst will be conversing with herself, so to speak, in order to be mindful of her participation in the phenomena emerging in the consulting room. But she will not reveal her thoughts and fantasies to the patient.

Even among classical analysts, of course, the “blank screen” is currently understood as somewhat mythic.⁶ And there are also other psychoanalytic schools that bring the doctor’s relationship with the patient into sharper focus as the agent of change.⁷ There are also raging debates about how “self-disclosing”

4. See, e.g., KATZ, SILENT WORLD, *supra* note 2, at 108.

5. See SIGMUND FREUD, *Five Lectures on Psycho-Analysis* (1910), reprinted in 11 THE STANDARD EDITION OF THE COMPLETE PSYCHOLOGICAL WORKS OF SIGMUND FREUD 1, 21 (James Strachey ed. & trans., 1964).

6. See, e.g., James L. Fosshage, *Toward Reconceptualizing Transference: Theoretical and Clinical Considerations*, 75 INT’L J. PSYCHOANALYSIS 265 (1994); Jay R. Greenberg, *Prescription or Description: The Therapeutic Action of Psychoanalysis*, 17 CONTEMP. PSYCHOANALYSIS 239 (1981); Irwin Z. Hoffman, *The Patient as Interpreter of the Analyst’s Experience*, 19 CONTEMP. PSYCHOANALYSIS 389 (1983).

7. See, e.g., JOSEPH M. NATTERSON & RAYMOND J. FRIEDMAN, A PRIMER OF CLINICAL INTERSUBJECTIVITY (1995); ROBERT D. STOLOROW ET AL., PSYCHOANALYTIC TREATMENT: AN INTERSUBJECTIVE APPROACH (1987); Howard B. Levine & Raymond J. Friedman, *Intersubjectivity and Interaction in the Analytic Relationship*, 69 PSYCHOANALYTIC Q. 63 (2000); Thomas H. Ogden, *The Analytic Third: Implications for Psychoanalytic Theory and Technique*, 73 PSYCHOANALYTIC

analysts should be.⁸ It would be interesting to explore whether Katz's ideas would lead him to recommend a different relationship between analysts and patients than classical analysts have prescribed. It would also be interesting to see whether he would think disclosure is desirable in order to respect patients, even when this is not optimal therapeutically (and, to make things harder, when what is optimal therapeutically will have the effect of increasing the patient's overall autonomy).

III. OUR CONTINUING DEBT

This leads me to discuss three directions that Katz's works suggest we take, and that I and others have begun to pursue. The first is to study informed consent in Katz's very domain—that of psychoanalysis. What are psychoanalysts' practices regarding informed consent, and what should those practices be? Should analysts simply assume consent if the patient keeps coming back? Or should analysts inform patients at the beginning of treatment about the nature, risks and benefits of, and alternatives to, the treatment? Are there other or different elements of informed consent, in this context, and if so, what are they?

Perhaps most intriguing is the question whether informed consent is even possible in the psychoanalytic context. Perhaps the patient can understand, for example, transference and regression⁹ only after they have already occurred, at which point it might be too late to act on that understanding since the patient can no longer easily extricate himself from the relationship with the analyst. Another important issue is whether informed consent in the psychoanalytic process is likely to be therapeutic or counter-therapeutic. Analysts' norms concerning abstinence, for example, might be such that the informed consent process would be in tension with these norms and might therefore be counter-therapeutic.

I intend to do legal, theoretical, and empirical research on this question.¹⁰ It

Q. 167 (2004); Robert D. Stolorow & George E. Atwood, *Deconstructing the Myth of the Neutral Analyst: An Alternative from Intersubjective Systems Theory*, 66 PSYCHOANALYTIC Q. 431 (1997); Robert D. Stolorow, *From Isolated Minds to Experiential Worlds: An Intersubjective Space Odyssey*, 54 AMER. J. PSYCHOTHERAPY 149 (2000).

8. See, e.g., NATTERSON & FRIENDMAN, *supra* note 7.

9. "Transference" refers to the "displacement of patterns of feelings, thoughts, and behavior, originally experienced in relation to significant figures during childhood, onto a person involved in a current interpersonal relationship." PSYCHOANALYTIC TERMS AND CONCEPTS 196-97 (Burness E. Moore & Bernard D. Fine eds., 1990). "Regression" means a "return to a more developmentally immature level of mental functioning." *Id.* at 164-65.

10. My project on informed consent is supported by grants from the International Psychoanalytic Association's Research Advisory Board and the American Psychoanalytic Foundation. See Elyn Saks, *Informed Consent and the Therapeutic Alliance* (Feb. 12, 2006)

will be interesting to see what analysts do, what their reasons are, and whether obtaining patients' informed consent has been helpful or harmful. Looking at the informed consent question directly in the psychoanalytic process should lead to insights that will be helpful in other medical contexts. Indeed, Katz has already shown that bringing psychoanalytic ideas to bear on understanding informed consent in the general medical context is a fruitful approach.¹¹ At a minimum, one would expect analysts to be more sensitive than others to unconscious and irrational forces at work in the informed consent process.

The second direction in which Katz's work leads us concerns our stance toward the seriously mentally ill. Katz writes mostly about non-psychiatrically ill patients (the exception is his *Enchanting Legal Fiction* article¹²). His emphasis on the pervasive influence of the irrational and the unconscious has the effect of breaching a perhaps idealized and distinct boundary between the mentally ill and the mentally healthy. Psychoanalysis teaches that we all have many unconscious and irrational fantasies. Psychiatric patients and other patients (indeed, people generally) are on a continuum. Two paths are then possible: to restrict the freedom of some apparently rational people or to protect the choices of some apparently irrational people.

In my own work on abrogating patient choice¹³ I draw on three broad principles, all rooted in Katz's work: protecting the right to be unconventional (our "autonomy interest"); protecting those incapable of caring for themselves (our "paternalism interest"); and not discriminating on the basis of irrational beliefs that are pervasive among the non-ill and ill alike (our "nondiscrimination interest"). Katz has given special emphasis to the idea that all of us are pervasively irrational.¹⁴

Another principle that comes from Katz's work is to identify culprits that may compromise patients in the doctor/patient relationship, e.g., fantasies about doctor omnipotence. With these pitfalls in mind one can design instruments to assess people's capacity in different contexts. Katz's ideas have certainly

(unpublished manuscript, on file with the author). The empirical part of the project has just begun, four hundred surveys having been recently sent to analysts around the country.

11. This is the central endeavor of KATZ, SILENT WORLD, *supra* note 2.

12. Jay Katz, *The Right to Treatment—An Enchanting Legal Fiction?*, 36 U. CHI. L. REV. 755 (1969) [hereinafter Katz, *Enchanting*].

13. See, e.g., ELYN R. SAKS, REFUSING CARE: FORCED TREATMENT AND THE RIGHTS OF THE MENTALLY ILL (2002); ELYN R. SAKS, *Competency To Decide on Treatment and Research: The MacArthur Capacity Instruments*, in 2 COMMISSIONED PAPERS BY THE NATIONAL BIOETHICS ADVISORY COMMISSION: RESEARCH INVOLVING PERSONS WITH MENTAL DISORDERS THAT MAY AFFECT DECISION-MAKING CAPACITY 59 (1999); Elyn R. Saks, *Competency To Refuse Treatment*, 69 N.C. L. REV. 945 (1991).

14. KATZ, SILENT WORLD, *supra* note 2, at 118-19.

influenced my colleagues and me in formulating the “California Scale of Appreciation” (CSA), an instrument we have designed to measure one aspect of capacity to consent to research.¹⁵

The CSA measures deficiencies in a subject’s understanding of the factors bearing on a decision to participate in research. An example of a “deficiency” in this regard is a subject’s belief that the researcher is omnipotent—an item coming directly from Katz’s work. Another example would be a subject’s belief that withdrawing from the study would cause some catastrophic event to occur. Katz’s underscoring of the pervasive influence of the irrational has also led us to require a gross departure from the norm in how one fails to appreciate the issues in order to be classified as incompetent; to do otherwise would be to risk discriminating against the mentally ill. To that end, we make use of the idea of a “patently false belief” in judging patients’ appreciation.

One interesting problem arises, though, when one accepts Katz’s account of our compromised decisional abilities: Why *should* we distinguish between the mentally ill and the mentally healthy in a case in which their decisions are motivated by the same fantasy?¹⁶ For example, if a psychotic patient says his reason for agreeing to undergo surgery is that his doctor is God and therefore no harm will befall him, we would say he was incompetent to decide. But what about the non-ill patient who has the same *unconscious* fantasy that leads him to the same decision? What difference does it make whether the fantasy is conscious?

In his *Enchanting Fiction* paper, Katz speaks of the primary process overrunning secondary process ways of thinking in this situation.¹⁷ Although descriptively true, this does not address why consent is invalid, as a normative matter, when this “overrunning” occurs (and not when it does not). Put differently, why does the invasion of the primary process matter if both patients

15. Elyn R. Saks et al., *The California Scale of Appreciation: A New Instrument To Measure the Appreciation Component of Capacity To Consent to Research*, 10 AM. J. GERIATRIC PSYCHIATRY 166 (2002).

16. Elyn R. Saks, *Mental Health Law: Three Scholarly Traditions*, 74 S. CAL. L. REV. 295 (2000).

17. See Katz, *Enchanting*, *supra* note 12, at 769-70. For the distinction between “primary process” and “secondary process” see FREUD, *Interpretation of Dreams*, *supra* note 3, at ch. 7. According to Moore and Fine, the concept of primary process, on a descriptive level, “embraces such characteristics of unconscious mentation as the disregard of logical connections, the coexistence of contradictions, the absence of a temporal dimension and of negatives, and the use of indirect representation and concretization (imagery).” Secondary process thinking is “[g]overned by the reality principle: it accounts for reality-attuned, logical thought, exemplified by delayed, modulated drive gratification through problem-solving (the internal activity of trial and error).” PSYCHOANALYTIC TERMS AND CONCEPTS, *supra* note 9, at 148.

have the same belief and that belief is the real reason they are making their decision? Why should we care whether the primary process thinking has become conscious?

One response to the notion that unconscious and conscious fantasies should be equally regarded is that unconscious fantasies are not accessible. But psychoanalysts make judgments all the time (fairly reliable judgments, one hopes) about fantasies the patients themselves may be unaware of. The ability to do so is the whole premise of psychoanalysis. Indeed, many patients do not acknowledge these fantasies even after they are brought to their attention, and yet the analyst may be quite certain that they exist and are exerting force toward certain action.

In addition to the “access” issue, more general proof issues may exist. The best way to *establish* that the psychoanalyst got it right is if the patient acknowledges that she did. But this is not the only way. In the end, notwithstanding the issue of practicality, the question of unconscious fantasies underlying choice is one of immense theoretical interest.

This puzzle aside, Katz’s work normalizing the pathological and pathologizing the normal is extremely important as we think about how to treat those with serious mental illness. A few points seem to follow from his humane, yet sophisticated, approach. Even severely mentally ill people have pockets of health that can and should be tended. Like healthy people, they deserve respect and respectful conversation. Indeed, psychiatric patients desire to be treated with dignity just as do the mentally healthy. Moreover, given their patent vulnerabilities, these patients perhaps should receive more, rather than less, respectful conversation. As Katz rightly points out, many seriously ill psychiatric patients have the unconscious fantasy that they are not deserving of respect.¹⁸ How much more important, then, to give it to them. The conversation should help empower even psychotic patients to mobilize what strengths they have to make competent decisions.

In fact, empirical research shows that patients with schizophrenia are capable of normal decision-making.¹⁹ For instance, on the California Scale of Appreciation, only between approximately eight and thirteen percent of older outpatients with psychosis were incompetent.²⁰ This percent of the patients held patently false beliefs—again, the barometer of unacceptable beliefs—bearing on their condition and the research they were participating in. This result should

18. See Katz, *Enchanting*, *supra* note 12, at 768, 771.

19. Laura B. Dunn et al., *Assessing Decisional Capacity for Clinical Research or Treatment: A Review of Instruments*, AM. J. PSYCHIATRY (forthcoming 2006) (manuscript at 32-41, on file with author).

20. *Id.* at 170.

perhaps not be surprising given Katz's work. The mentally ill and mentally healthy may be much closer to each other than we might have expected or would wish to believe.

The third and final direction that Katz's work suggests is toward new efforts to enable seriously ill psychiatric patients to make competent choices even when they initially appear incompetent. For example, my colleagues at University of California, San Diego School of Medicine and I are designing and studying "enhanced consent" protocols which allow schizophrenic patients to attain as much understanding as normal controls in a brief period of time.²¹ Our notion is that the problem may not be in the patients' capacities but rather in the investigators' way of presenting the material. That is, the problem lies with the means of informing for consent and not with the patients' ability to be informed. Katz's prescription of searching for ways of communicating and obtaining consent has fueled much of this research.

In closing, I would like to say one thing about the idea of "conversation." Some people might say that this idea represents a desire and goal of very verbal people. In the same way, some people might say that psychoanalytic conversations are only attractive to and effective with "sophisticated" people. But I think this criticism misses the point of Katz's call for conversation. This call is about respecting people, wherever they are, and helping them, in their own language, to understand and explore what is happening to them, and some of their deeper feelings about what is happening to them. You do not have to be a college graduate to appreciate the enormous benefits of conversation. Everyone, at some level, wants and can be benefited by such conversation.

Jay Katz has begun a deep and rich—as well as important—conversation with the discipline of psychoanalysis which shows no sign of ending. Our debt to him is enormous.

21. Laura B. Dunn et al., *Improving Understanding of Research Consent in Middle-Aged and Elderly Patients with Psychotic Disorders*, 10 AM. J. GERIATRIC PSYCHIATRY 142 (2002); Laura B. Dunn & Dilip V. Jeste, *Enhancing Informed Consent for Research and Treatment*, 24 NEUROPSYCHOPHARMACOLOGY 595 (2001). In addition, my colleagues and I are engaged in a NIMH-funded empirical study of an enhanced consent procedure using DVDs.

Response

A More Skeptical Bioethics

Charles Bosk, M.A., Ph.D.*

When I first read Professor Burt's paper, *The Uses of Psychoanalysis in Illuminating Biomedical Ethics*,¹ I was overcome by feelings of regret and self-pity occasioned by not having ever had as part of my graduate coursework the intellectually provocative experience that the paper describes so well. But after working through these feelings, I began to be able to identify the qualities that make Jay Katz's work so rich and, by contrast, the features that make more pedestrian efforts in bioethics so irritating.² Professor Burt describes two basic methodological lessons he discovered while sitting in Jay Katz's class and reading his writings. From these, I draw one substantive principle.

The first methodological lesson Burt describes is to look for the tensions underneath the smooth surface of social relations, to look for conflicts where social arrangements are organized in ways that deny their existence. The second lesson he describes is to never trust policies, regulatory regimes, or social processes that celebrate the rational self-control that they provide decision-makers. The substantive lesson I draw from this is that we should know better than to trust those social fictions we create in an effort to convince ourselves that we are the kind of decision-makers rational choice theories assume that we are. Uncertainty and indeterminacy cannot be eliminated from social life by grants of autonomy that deliver something much less in practice than what they promise in theory. There are some enduring, existential difficulties built into group life that no organizational policies or bureaucratic procedures can erase.

Now some might say that these are difficult lessons. I would agree, but add that it is the hardness of these lessons, their unblinking look at the human

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1. Robert Burt, *The Uses of Psychoanalysis in Law: The Force of Jay Katz's Example*, 6 YALE J. HEALTH POL'Y L. & ETHICS 401 (2006).

2. The work of Jay Katz on informed consent, JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (Johns Hopkins Univ. Press 2002) (1984), is the touchstone for this commentary. But the same points could just as easily have been made focusing on Jay Katz's work on human experimentation or reproductive rights.

condition, especially the vulnerabilities and anxieties of both the ill and their care-takers, that make Jay Katz's work so worth reading and re-reading. Jay Katz never pretends that one can achieve informed consent in a single encounter. The achievement of what we once ponderously called "fully informed voluntary consent" is more an aspirational goal than it is an easily measured, concrete outcome. Vulnerable and anxious patients can understand something one moment and forget it the next. Nor are physicians neutral channels through which information passes without distortion. Far from disinterested parties, physicians often convey, albeit unintentionally, an unreasonable optimism, if only to quiet underlying feelings of inadequacy created by a social role that places them both in charge and powerless in the face of incurable illnesses. False hope prevents the motivation of physicians from flagging. At the same time, desperate patients and their families hang on to the thin reed of the statistically improbable medical remedy, which inhibits them from either giving voice to vague anxieties or framing specific questions. On the shop floor of the modern hospital "consent" has become an intransitive verb. The question that one commonly hears there—"Has the patient been consented yet?"—is evidence of how hard it is to absorb the lessons Jay Katz has tried to teach. The usage also signals that we ought to continue trying to teach the deeper lessons contained in his teachings and writings.

Because I have limited space, I am going to ask the reader's indulgence as I make several sweeping—but not, I believe, inaccurate—generalizations. One reason that medical residents think nothing of asking each other, "Has the patient been consented yet?" is that the understanding of the ethical problems in American bioethics encourages such usage. American bioethics shares with American culture an ethos of meliorism, a "can-do" optimism.³ American culture, and American bioethics as a concrete manifestation of that culture, often seem to be guided by the implausible notion that all problems are soluble if we use scientific methods to analyze social difficulties. Such analyses will then lead us to adopt better procedures, to formulate better rules, and to provide better training, all of which lead to improved outcomes.

What is striking in the theories that I was taught oh-so-long-ago as a graduate student was just how naïve they appeared to be about human nature.⁴

3. See, e.g., PHILIP RIEFF, *FREUD: THE MIND OF THE MORALIST* 392 (1961). For a presentation and critique of the views of the American Progressive Movement see *THE PROGRESSIVE MOVEMENT: 1900-1915* (Richard Hoftsadter ed., 1965). A trenchant critique of the "helping professions" is contained in C. Wright Mills, *Professional Ideology of Social Pathologists*, 49 *AMER. J. SOC.* 165 (1943). For a discussion of how melioristic optimism has impacted medical care, see SHELIA ROTHMAN & DAVID J. ROTHMAN, *THE PURSUIT OF PERFECTION: THE PROMISE AND PERILS OF MEDICAL ENHANCEMENT* (2003).

4. A great deal of American Social Theory sits uneasily between attempts to develop a

For progressive social theorists in the first third of the twentieth century, when groups conflict, better communication solves all difficulties. There is no recognition that the resolution of some conflicts requires structural change, a redistribution of resources, rather than simply more complete sympathy, empathy, and understanding among contending parties.⁵ Lacking a dynamic theory of the unconscious, American social theorists had no convincing way to explain the intrapsychic, structural, or cultural forces that might, operating below the surface, block amity and cooperation.⁶

This spirit of American meliorism has crept into bioethics by a reliance on bureaucratic fixes that move decision-making authority from physician to institutional ethics committee and a reliance on procedures that are “legitimized” by the proper signatures on official documents. What we have failed to do is to pay equal attention to the forces that may inhibit the new policies and procedures from achieving the intended goals. For example, as production pressures on physicians mount, as more tasks have to be accomplished and more information fitted into the typical doctor-patient encounter, as supervisory authorities monitor more closely the time physicians spend with patients—so that unproductive physician outliers are more easily sanctioned—informed consent has become a casualty to the pressure to control costs and to increase productivity.⁷ Not only

“scientific” approach to society, pragmatic philosophy, and the political movement that we identify as “progressivism.” The sociologist/philosophers that I am drawing on most heavily for these discussion are CHARLES HORTON COOLEY, *HUMAN NATURE AND THE SOCIAL ORDER* (1902) and GEORGE H. MEAD, *MIND, SELF AND SOCIETY: FROM THE STANDPOINT OF A SOCIAL BEHAVIORIST* (Charles W. Morris ed., 1934). For two interesting discussion of how Mead’s philosophy “geared into the world”—to borrow a term from the phenomenologist Alfred Schutz—and guided his involvement in urban reform politics in Chicago, see Dmitri N. Shalin, *G.H. Mead, Socialism, and the Progressive Agenda*, 93 *AMER. J. SOC.* 913 (1988).

5. For an example of how much American Social Theory in the Progressive age rested on communication as a solution to the social problems that trailed in the wake of mass immigration, urbanization, and industrialization, see the “Society” section of Mead’s *Mind, Self and Society*, and pay particular attention to how many times Mead invokes communication as necessary for human progress. MEAD, *supra* note 4, at 227-336. For a good analysis of how fundamental the idea of communication is to American civil religion, see ROBERT N. BELLAH, *BEYOND BELIEF: ESSAYS ON RELIGION IN A POST-TRADITIONAL WORLD* 168-89 (1970).

6. The absence of a dynamic theory of the unconscious means that failures of memory, various misspeakings and mis-hearings—that is, shared misunderstandings—and all the other accidents and misfirings of social life not only lack meaning but, more importantly, cannot be imbued with meaning at the level of in our individual or collective lives.

7. See David Mechanic et al., *Are Patients’ Office Visits with Physicians Getting Shorter?*, 344 *NEW ENG. J. MED.* 198 (2001) for an interesting discussion of how, although the actual amount of time of an average encounter has marginally increased, both patients and physicians report feeling more rushed during the typical visit. For a discussion of the impact of this sense of being

are our policy solutions often unmindful of the structural and psychic barriers that stand in the way of their implementation; our ways of talking about the success and their failure of those solutions are often equally thin.

This thin conceptualization of the dilemmas of the human condition embedded in medical care that leads to policies that are both simplistic and unrealistically optimistic is not true of Jay Katz's work. However, the policy solutions and value commitments found in his work are not markedly different than those offered by mainstream American bioethicists. He too would like to see patients exercise more decision-making authority. His value commitments are no less egalitarian or democratic than the more optimistic cast of much of American bioethics. What makes Jay's work both so inspiring to me, and such a model of "the reality principle" is that Jay recognizes that there are some problems that can be confronted but not definitively resolved, and that such recognition is the first step towards developing honest ways of dealing with them.

As a graduate student I was taught that the notion that some problems recurred in the human condition was the gloomy response of Weber, Durkheim, and Freud to modernity.⁸ Tragic Europeans were compared to sunny Americans. Though my teachers were careful to emphasize that sunny and tragic were merely descriptive, not evaluative, terms, we all realized that these adjectives carried career implications. Thus, many of us were confronted with a very difficult choice as we went about our work. One alternative was to embrace a sunny but impoverished understanding of human behavior that promised to improve some perceived social problem. The rationale for such cheery self-delusion went no deeper than the realization that those who fund social research prefer promises that their investments will yield returns. The second alternative was to adopt a more sober but also more powerful perspective that recognizes the irremediable difficulties built into social life, acknowledges that defending against some dangers in social life creates new vulnerabilities, and takes the law of unintended consequences seriously. The second alternative required some courage. Sponsors of funded research prefer results to a more profound understanding of problems that will recur in one form or another no matter how social life is organized. Journal editors prefer positive results to a demonstration that the more some

rushed on trust within the doctor-patient relationship, see David Mechanic, *The Functions and Limitations of Trust in the Provision of Medical Care*, 23 J. HEALTH POL. POL'Y & L. 661 (1998); and David Mechanic & Marsha Rosenthal, *Responses of HMO Medical Directors to Trust Building in Managed Care*, 77 MILBANK Q. 283 (1999).

8. See generally EMILE DURKHEIM, *THE ELEMENTARY FORMS OF RELIGIOUS LIFE* (Karen E. Fields trans., The Free Press 1995) (1912); MAX WEBER, *THE PROTESTANT ETHIC AND THE SPIRIT OF CAPITALISM* (Talcott Parsons trans., Routledge 1992) (1930); SIGMUND FREUD, *Civilization and Its Discontents* (1930), reprinted in 21 THE STANDARD EDITION OF THE COMPLETE PSYCHOLOGICAL WORKS OF SIGMUND FREUD 59 (James Strachey ed. & trans., 1964).

things change the more they stay the same.

Jay Katz's work stands as a model of how we can be honest, realistic advocates for positions at the same time that we acknowledge the inherent limits not only of those positions but of our own inherent human limitations. Nothing is to be gained from pretending the existential dilemmas involved in becoming ill, trying to heal, or acting as a caregiver are anything other than difficult work that require much more than we are able to give. Rather than simply mourn our failures to achieve the rational utopias that our policies seem to promise, we need to learn from the failures, and since our failures are multiple, there will always be much to consider. Determining what constitutes sensible action in trying times and under trying conditions is difficult. So long as we only blink, but do not shut our eyes in the face of these difficulties, there is much that we can learn.

Experimentation with Human Beings: Light or Only Shadows?

Alexander M. Capron, LL.B.*

We have failed Jay Katz. Like the man looking under the lamp-post for his keys—not because that was where he was standing when he dropped them but because the light is better there—we have labored too long in the light and poked too infrequently into the shadows where the often painful truth is to be found. We have treated as exact the imprecise process of balancing research risks and benefits. We have exalted autonomy and made a sacrament of consent forms—even those that run to hellish lengths, littered with jargon—and forgotten the myriad constraints on subjects' choices. We have realized that, however well-intentioned researchers may be, their individual judgment of when and how to conduct research is usually very partial, in both senses of that word. Yet, from that realization we have moved to the contradictory conclusion that by instituting prior review by Institutional Review Boards (IRBs), we have solved the ethical problems involved in deciding when and how to conduct research.

Above all, we have developed elaborate rules and processes to normalize human experimentation, to treat it as an ordinary activity. We have thus avoided looking clearly at the moral dilemma that lies at the heart of every research encounter: "We are asking you to do this not for yourself but for others, even though we know that the role of human subject entails real and sometimes unforeseen risks including death." Such a statement is significant not because—or not solely because—it clearly describes the potential harm. I agree with Jay that this is not the critical issue,¹ though it is hardly one that we can ignore, in

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1. Jay Katz has acknowledged the point often made by investigators that subjects may be at no greater risk than patients in ordinary treatment, but he suggested that it may be beside the point: "I want to distract attention from the prevalent and extensive debate on the permissible limits of physical harm to subjects and, instead, draw attention to the neglected and scant debate on the justifications for encroachments on subjects' rights to decisional authority in the conduct of research." Jay Katz, *Human Experimentation and Human Rights*, 38 ST. LOUIS U. L.J. 7, 10 (1993) (citations omitted).

light both of the historical abuses of research subjects² and also of what has occurred much more recently at such renowned medical institutions as the University of Pennsylvania³ and Johns Hopkins.⁴ Rather, its central significance lies in its frank description of the aims of research and, hence, of the potential divergence of interest between the prospective subject and the person offering to enroll him or her in the research project.

I think Jay rightly expected that this sort of frank conversation was achievable when he began developing the modern scholarly analysis of research with human beings some forty years ago. Of course, he can take pleasure in seeing the things that have been accomplished because of the light he shed on ethical problems in the conduct of research. Doubtless, many harms have been prevented by the creation of the process of prior review of research projects and, on a more optimistic note, by investigators' "self-scrutiny" as they prepare to explain (or, one might say, defend) their protocol to a research ethics committee or to engage in a dialogue with prospective subjects whose informed consent they hope to obtain.⁵ The process may be imperfect, but compared to what took place

2. Such infamous research abuses as the Nazi concentration camp experiments and the Japanese Unit 731 during World War II and the U.S. government's Tuskegee syphilis study, conducted between 1932 and 1972, are chronicled, along with more recent cases, in JONATHAN D. MORENO, *UNDUE RISK: SECRET STATE EXPERIMENTS ON HUMANS* (2000).

3. In September 1999, Jesse Gelsinger, an eighteen-year-old young man with a mild form of an inherited immune deficiency who had volunteered for a study aimed at eventually curing his type of illness, died in a gene transfer experiment at the University of Pennsylvania's Institute of Human Gene Therapy. The FDA not only shut down the trial in which Gelsinger had participated and all gene transfer trials at that university but also suspended work at other leading medical institutions, as heightened scrutiny revealed at least six other unreported deaths attributable to genetic transfer research. Larry Thompson, *Human Gene Therapy: Harsh Lessons, High Hopes*, *FDA CONSUMER*, Sept.–Oct. 2000, at 19, 20–24, available at http://www.fda.gov/fdac/features/2000/500_gene.html.

4. On May 4, 2001, Ellen Roche, a healthy twenty-four-year-old woman who had volunteered for a study of asthma at Johns Hopkins Medical School where she worked as a lab technician, inhaled hexamethonium through a nebulizer (which was intended to challenge her airway). Shortly thereafter, she developed dyspnea and was hospitalized. Less than a month later, on June 2, 2001, she died of respiratory and renal failure. On July 19, 2001, the Office for Human Research Protections of the U.S. Department of Health and Human Services temporarily suspended all federally funded research at Johns Hopkins Medical Institutions. Mimi Zucker, *Johns Hopkins Cited After Research Death*, *RESPIRATORY REVIEWS*, Sept. 2001, at 1.

5. See Paul Freund, *Legal Frameworks for Human Experimentation*, 98 *DÆDALUS* 315, 323 (1969) ("To analyze an experiment in terms of risks and benefits . . . by way of presentation for consent is a salutary procedure for self-scrutiny by the investigator—like the preparation of a registration statement by a corporation issuing securities."), cited in JAY KATZ & ALEXANDER MORGAN CAPRON, *CATASTROPHIC DISEASES: WHO DECIDES WHAT?* 88 (1975).

in the 1950s and 1960s, the required oversight has effected the abandonment or salutary modification of many projects that should not have been undertaken. And as poor as many consent documents may still be, they would probably be worse were it not for the attention of review committees and commentators.

Moreover, the processes and rules that originated in the United States have now spread around the world,⁶ albeit not quite as quickly as the practice of Western research institutions and pharmaceutical companies performing clinical trials in the countries of the South over the past decade. But that rising tide—or, more accurately, tidal wave—is not necessarily a bad thing. To narrow the “10/90 gap”—the fact that less than ten percent of global health investment is dedicated to problems that account for ninety percent of global disease⁷—investigators must discover and test preventive and curative interventions for the diseases that place a crushing burden on developing societies and that send a terribly high proportion of people in those societies to early graves. Yet the value of this research to more people in more parts of the world only makes it all the more important to be clear about what is at stake. We need to take another look at the heart of the matter before we simply export to Cambodia, Cameroon, and Costa Rica the rules and procedures developed over the past thirty years in the North. To begin to take that deeper look, I suggest we return to the point where Jay began his examination of human experimentation forty years ago.

I. THE BEGINNING

Jay has recounted how, around 1960, he first encountered the Nuremberg

6. Council Directive 2001/20, Directive on the Approximation of the Laws, Regulations and Administrative Provisions of the Member States Relating to the Implementation of Good Clinical Practice in the Context of Clinical Trials on Medicinal Products for Human Use, 2001 O.J. (L 121) 34 (EC), *available at* <http://europa.eu.int/eur-lex/lex/JOYear.do?year=2001> (follow “May” hyperlink; then follow “L121” hyperlink; then follow “34” hyperlink); CANADIAN INSTS. OF HEALTH RESEARCH ET AL., TRI-COUNCIL POLICY STATEMENT: ETHICAL CONDUCT FOR RESEARCH INVOLVING HUMANS (1998) (amended 2000, 2002, and 2005), *available at* <http://www.pre.ethics.gc.ca/english/policystatement/policystatement.cfm>; COUNCIL OF EUR., ADDITIONAL PROTOCOL TO THE CONVENTION ON HUMAN RIGHTS AND BIOMEDICINE CONCERNING BIOMEDICAL RESEARCH (2004); COUNCIL FOR INT’L ORGS. OF MED. SCIS., INTERNATIONAL ETHICAL GUIDELINES FOR BIOMEDICAL RESEARCH INVOLVING HUMAN SUBJECTS (2002); EUROPEAN AGENCY FOR THE EVALUATION OF MEDICINAL PRODUCTS, ICH TOPIC E 6: GUIDELINE FOR GOOD CLINICAL PRACTICE (2002), *available at* <http://www.emea.eu.int/pdfs/human/ich/013595en.pdf>; INT’L CONFERENCE ON HARMONISATION OF TECHNICAL REQUIREMENTS FOR REGISTRATION OF PHARMS. FOR HUMAN USE, ICH HARMONISED TRIPARTITE GUIDELINE: GUIDELINE FOR GOOD CLINICAL PRACTICE E6(R1) (1996), *available at* <http://www.ich.org/LOB/media/MEDIA482.pdf>.

7. GLOBAL FORUM FOR HEALTH RESEARCH, THE 10/90 REPORT ON HEALTH RESEARCH 2003-2004, at 35 (2004).

proceedings against the Nazi physicians in the criminal law casebook that was then being prepared by colleagues on the faculty of Yale Law School, which he had recently joined.⁸ What transpired in Nazi Germany has shaped Jay's life not only as a person but as a scholar,⁹ and it is not surprising that as he thought about the sickening "medical experiments" conducted in the concentration camps he determined to pursue the subject directly through a seminar on human experimentation, which led to the production of his seminal casebook.¹⁰ It was in connection with that book that I first encountered the subject of research with human subjects in 1970. After Abe Fortas (for whom I was supposed to clerk) resigned from the Supreme Court, Jay correctly surmised that I might be interested in returning to New Haven from Washington, D.C., for family reasons. Jay asked me to join him to finish the casebook and to collaborate on another project on "catastrophic diseases" (the issues raised by heart and kidney transplantation and haemodialysis).

The first thing I did was read through the existing materials in preparation for both teaching the seminar with Jay and editing and restructuring the book, which we saw as our major project for that year (though it took a little longer). As readers of the casebook know, it does not begin with the so-called "Doctors' Trial" before the tribunal at Nuremberg but with two more contemporary American case studies. The materials are organized according to a sequence—policy formulation, administration, and review of consequences—that owed much to the social scientists on the Yale Law School faculty.¹¹ Yet there was no question that the story of the Nazi doctors was central both to the book and to Jay's examination of the whole subject.

I found myself very comfortable with Jay's orientation to the subject, his aspiration to shine a bright, clear light on the burgeoning phenomenon of human

8. RICHARD C. DONNELLY ET AL., CRIMINAL LAW (1962).

9. Jay Katz, Human Sacrifice and Human Experimentation: Reflections at Nuremberg, Address at the Conference Commemorating the Fiftieth Anniversary of the Nazi Doctors' Trial at Nuremberg Convened by International Physicians for the Prevention of Nuclear War and Physicians for Social Responsibility (Oct. 27, 1996) (transcript available at <http://www.law.yale.edu/outside/html/Publications/pub-katz.htm>).

10. JAY KATZ ET AL., EXPERIMENTATION WITH HUMAN BEINGS: THE AUTHORITY OF THE INVESTIGATOR, SUBJECT, PROFESSIONS, AND STATE IN THE HUMAN EXPERIMENTATION PROCESS (1972).

11. Jay was particularly influenced by the policy-oriented jurisprudence of Harold Lasswell (who famously described politics as "who says what, in which channel, to whom, and with what effect") and Myers McDougal. See, e.g., HAROLD D. LASSWELL & MYERS S. MCDUGAL, JURISPRUDENCE FOR A FREE SOCIETY: STUDIES IN LAW, SCIENCE AND POLICY (1992); Harold D. Lasswell & Myers S. McDougal, *Jurisprudence in Policy-Oriented Perspective*, 19 U. FLA. L. REV. 486 (1967).

subjects research so as to impede any repetition of the atrocities perpetrated by the Nazi doctors and others in the name of medical science. I had not expected to be teaching and conducting research at a law school, but rather to be pursuing civil rights work of the sort I had undertaken—sometimes as a defendant—in Mississippi while in law school and before (which had, indeed, led me to law school in the first place). The things that motivated me—justice and fair treatment, equality and non-discrimination, autonomy—transferred easily from a civil rights context to the subject of human experimentation; indeed, with the revelations about the Tuskegee study,¹² the fields of civil rights and human subjects research clearly converged.

Yet I soon came to see that Jay's concern for subjects' rights was only one facet of what he thought was important here. The other aspect—and its neglect—is the heart of what this paper discusses. I begin by stating my thesis, and then I go back and connect it to the larger subject of the ethics of research with human beings, by starting again with Nuremberg. Thinking as I have these past months about that period more than thirty years ago when Jay and I were working elbow-to-elbow each day, I have come to the conclusion that part of Jay's message became obscured precisely because he was surrounded by lawyers. We lawyers (and later some of the philosophers who have labored in the vineyards of bioethics and have bottled some of its most notable vintages) have provided a *vocabulary of rights* (and reciprocal duties)—the right of privacy (and the duty of confidentiality), the right of bodily integrity (and the duty to do no harm), and, above all, the right of self-determination (and the duty to obtain informed consent).

Starting with the Doctors' Trial as Jay did, it is easy to look at research through the lens of human rights, since the transcript of that case—like other accounts of what transpired in the camps as well as in experiments both before and after the Nazi era—makes clear the horrible things that can happen when research is carried out with no attention to subjects' rights. Yet the very resonance of the rights language has obscured the other part of Jay's analysis, the one which, in my view, is actually closer to his central scholarly preoccupation, namely, to supply a *vocabulary of relationships* to fill the gaps, the moral silences, at the heart of human experimentation. It is that vocabulary—a language not solely of duties but of hopes and fears, of uncertainties and magical

12. See, e.g., PUB. HEALTH SERV., U.S. DEP'T OF HEALTH, EDUC. & WELFARE, FINAL REPORT OF THE TUSKEGEE SYPHILIS STUDY AD HOC ADVISORY PANEL (1973), available at <http://biotech.law.lsu.edu/cphl/history/reports/tuskegee/tuskegee.htm> [hereinafter TUSKEGEE ADVISORY PANEL REPORT]; Jay Katz, *Reservations About the Panel Report on Charge 1*, in TUSKEGEE ADVISORY PANEL REPORT, *supra*, at 14; J.H. JONES, BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENTS (1993).

thinking—that ties Jay’s work on experimentation to his central focus on the physician-patient relationship.

II. BACK TO THE BEGINNING, ONCE AGAIN

The enormity of the Nazi doctors’ abuse of the concentration camp inmates in their so-called research program is so great that I feel a risk in using it as a starting point; yet, it is the beginning of the story. The risk is that any discussion that tries to draw lessons from it for today impliedly aligns the Nazi crimes with contemporary research practices. This presents a two-fold problem, seeming at once to diminish the suffering and deaths of thousands of people at Buchenwald, Dachau, Natzweiler, and Ravensbrück, and to saddle current investigators with the callous disregard of life exhibited by Karl Brandt and his co-defendants. By noting the risks inherent in this comparison, I hope we will be able to avoid or diminish them in what follows.

Given the importance of the Doctors’ Trial to Jay’s thinking, we need to examine carefully the lessons of Nuremberg. Looking to the eponymous code that for most bioethicists is “Nuremberg,” the lessons appear to be that investigators must not use human beings for research without their free and informed consent, that those human subjects must remain free to withdraw from research despite that consent, and that the risks must be minimal and always proportionate to scientific ends that are themselves reasonably attainable.¹³ This is indeed what has guided, and continues to guide, the development of subsequent declarations, guidelines and regulations. It is not a bad lesson, but it is incomplete in at least two respects.

First, this interpretation treats Nuremberg like a moment in time, the final frame in a film. We need to wind the film back. To understand the meaning of Nuremberg, we must apprehend how those physicians came to be standing in the dock before that tribunal. This is not a tale solely about a group of sadistic monsters but also one about science gone wrong. The Nazi experiments were not simply a perversion of medical science; they were also an extension of that science. Long before the Nazis came to power, the arrogance of modern science led some physicians in the Nineteenth Century intentionally to infect healthy, but obviously uninformed and powerless, men, women, and even children with venereal diseases and to administer noxious and sometimes permanently harmful substances to them.¹⁴ The prevailing attitude toward research subjects was merely an extension of the way that hospital patients were treated as “material” for

13. 2 TRIALS OF WAR CRIMINALS BEFORE THE NUREMBERG MILITARY TRIBUNALS UNDER CONTROL COUNCIL LAW NO. 10, at 181-83 (1946-1949).

14. See KATZ ET AL., *supra* note 10, at 284-92.

medical education.¹⁵ By the time of the Second World War, the ideology among some scientists (and not only in Germany)—to perfect mankind by weeding out weak or deviant specimens, and to provide knowledge that would be of benefit to the public and especially of use to the state—had overwhelmed physicians' assumed fidelity to the welfare of their patients. Looking back at the history of scientists' abuse of both patients and healthy subjects—which aroused concern and criticism from some quarters but seldom if ever serious discipline—it is possible to see how the lawyer for Siegfried Ruff could argue with a straight face to the Nuremberg tribunal that there was no reason for his client to have regarded mistreatment of subjects as criminal because there were no "written legal norms."¹⁶

By thinking of Nuremberg principally in terms of rules for ethical conduct in research and therefore pursuing ever greater refinements of those rules, we risk forgetting that there are goals that can seem worthwhile, even noble, yet whose pursuit puts in jeopardy the very society that science is supposed to enrich and advance. Today, with the biotechnological imperative stronger than ever, Jay's understanding of Nuremberg would lead us to pause and reconsider, very seriously, Hans Jonas's conclusion that "progress is an optional goal, not an unconditional commitment."¹⁷

15. See SUSAN E. LEDERER, *SUBJECTED TO SCIENCE: HUMAN EXPERIMENTATION IN AMERICA BEFORE THE SECOND WORLD WAR* 9 (1995).

16. See KATZ ET AL., *supra* note 10, at 300-01. This was, of course, an overstatement, as first the Prussian government in 1900 and then the Weimar government in 1931 had actually adopted rules on research that forbade experiments without free and informed consent. The obvious fact that the defendants did not feel themselves bound by any legal norms might be ascribed to the 1931 rules being mere guidelines without legal force, as some authorities contend. See Norman Howard-Jones, *Human Experimentation in Historical and Ethical Perspectives*, 16 SOC. SCI. & MED. 1429, 1436 (1982). Others, however, maintain that the rules were German law with binding effect until the Third Reich's fall in 1945. Hans-Martin Sass, *Reichsrundschreiben 1931: Pre-Nuremberg German Regulation Concerning New Therapy and Human Experimentation*, 8 J. MED. & PHIL. 99, 100 (1983). Sadly, however, Ruff's basic point—that many pre-World War II researchers who had done horrible things had still reaped honors, not opprobrium—was essentially correct.

17. Hans Jonas, *Philosophical Reflections on Experimenting with Human Subjects*, 98 DÆDALUS 219 (1969). While the well-known admonition summarizes the point, the full passage is worth considering:

Let us not forget that progress is an optional goal, not an unconditional commitment, and that its tempo in particular, compulsive as it may become, has nothing sacred about it. Let us also remember that a slower progress in the conquest of disease would not threaten society, grievous as it is to those who have to deplore that their particular disease be not yet conquered, but that society would indeed be threatened by the erosion of those moral values whose loss, possibly caused by too ruthless a pursuit of scientific progress, would make its most dazzling triumphs not worth having.

This leads me to the second reason why Nuremberg should not be reduced to the specific rules of the Code. To understand its lesson, we must understand what the judges saw as the central wrong in the defendants' conduct. One interpretation focuses on the fact that the victims were largely members of persecuted minorities. The Nazi campaign of "racial hygiene," actively championed by physicians, began with stigmatized groups—first, the mentally handicapped (the useless "fressers") and then Jews, gypsies, and other captive populations, who were themselves described as a disease weakening the health of the German people.¹⁸ In his opening statement to the panel of American judges at the Doctors' Trial, Telford Taylor drew attention to the minority status of the victims,¹⁹ and the theme he sounded there was echoed in the work of the new United Nations and especially in its human rights documents, which take human equality and non-discrimination as core principles.²⁰

Is this, then, the lesson of Nuremberg, that we need to protect vulnerable groups from harm in research? There is much that supports such a view—not only the story of research before (and, regrettably, after) World War II, which all too frequently made inmates of mental institutions and orphanages, patients in the public wards of hospitals, and racial minorities the objects (one cannot even say "subjects") of study,²¹ but also the experiments carried out by the Japanese military during the War in Unit 731, whose barbarities lack the infamy that attaches to the Nazi experiments only because the United States refrained from prosecuting after the war in order to conceal data about the chemical and biological agents tested by the Japanese on civilian populations and captured soldiers.²²

Id. at 245.

18. See ANDREW GOLISZEK, *IN THE NAME OF SCIENCE: A HISTORY OF SECRET PROGRAMS, MEDICAL RESEARCH, AND HUMAN EXPERIMENTATION* 87-99 (2003).

19. 1 TRIALS OF WAR CRIMINALS BEFORE THE NUREMBERG MILITARY TRIBUNALS UNDER CONTROL COUNCIL LAW NO. 10, at 27 (1946-1949).

20. Article 5 of the Universal Declaration of Human Rights, adopted by the United Nations General Assembly in the wake of the judgment in the Doctors' Trial, states that "[n]o one shall be subjected . . . to cruel, inhuman or degrading treatment or punishment." Universal Declaration of Human Rights, G.A. Res. 217A (III), art. 5, U.N. Doc. A/810 (Dec. 10, 1948). In 1966, Article 7 of the International Covenant on Civil and Political Rights explicated that this means that "no one shall be subjected without his free consent to medical or scientific experimentation." International Covenant on Civil and Political Rights, G.A. Res. 2200 (XXI), U.N. Doc. A/6316 (Dec. 16, 1966).

21. See KATZ ET AL., *supra* note 10, at 284-92, 306-21; TUSKEGEE ADVISORY PANEL REPORT, *supra* note 10; Gretchen Reynolds, *The Stuttering Doctor's 'Monster Study'*, N.Y. TIMES MAG., Mar. 16, 2003, at 36.

22. SHELDON H. HARRIS, *FACTORIES OF DEATH: JAPANESE BIOLOGICAL WARFARE, 1932-1945, AND THE AMERICAN COVER-UP* (2002); PETER WILLIAMS & DAVID WALLACE, *UNIT 731: THE*

While the Nuremberg judges could have focused on the persecution of vulnerable minorities and the consequent need to develop rules to protect them, this was not the direction they took. Why not? Much of the actual judgment can be traced to material provided by the American expert medical witnesses, A.C. Ivy and Leo Alexander.²³ Perhaps they thought it best to rehabilitate the damaged reputation of modern scientific medicine (of which pre-War Germany had boasted many of the most renowned exemplars) by affirming the ancient standards of the profession, and suggesting that the problem was simply that, under the influence of a malign regime, the defendants had departed from the Hippocratic injunction, "above all, do no harm."²⁴ Perhaps too, as Daniel Wikler has argued, Dr. Alexander did not want to be seen as an American Jew pleading for a special standard to protect a minority group, so he emphasized the general nature of the wrong (while having, of course, to be less than candid about the actual practices prevailing in the United States at the time).²⁵ For whatever reasons, the judgment was framed as a matter of universal application.

The question, then, is whether that distorts the reality of research with human subjects. When Nuremberg teaches that the well-being of individual subjects is in inherent tension with the good of the group, and hence that researchers must be constrained by limits (to obtain informed consent, to avoid coercion, to use human subjects only for good reason, to limit risks), is that a false lesson? Professor Wikler seems to think so, and concludes that the Nuremberg judgment is essentially a human rights document (that is, one aimed at protecting persons who are vulnerable to harm or neglect) and that the crimes of the Nazi physicians came from violating the principle that every person is of equal value and has the same rights.²⁶ There is much evidence on his side, because the catalogue of unethical research is replete with examples of subjects from especially vulnerable groups, even in the post-1946 United States: debilitated elderly patients at the Jewish Chronic Disease Hospital,²⁷ mentally handicapped children at the Willowbrook State School,²⁸ inmates (including children) in state facilities and prisons in the Cold War radiation experiments,²⁹

JAPANESE ARMY'S SECRET OF SECRETS (1989).

23. Michael A. Grodin, *Historical Origins of the Nuremberg Code*, in *THE NAZI DOCTORS AND THE NUREMBERG CODE* 121, 132-37 (George J. Annas & Michael A. Grodin eds., 1992).

24. LUDWIG EDELSTEIN, *THE HIPPOCRATIC OATH* 3 (1943).

25. Daniel Wikler, Harvard Sch. of Public Health, *The Ethics of Research with Human Subjects: History and Its Lessons for the Present*, Address at the National Continuing Medical Education Program in Anhui, China (Aug. 23, 2004).

26. *Id.*

27. See KATZ ET AL., *supra* note 10, at 9-65.

28. See *id.* at 1007-10.

29. See ADVISORY COMM. ON HUMAN RADIATION EXPERIMENTS, *THE HUMAN RADIATION*

to name but a few infamous examples.

This “equal treatment” lesson is worth remembering, but so is the “group versus individual” lesson, as Nuremberg has an element of both. These lessons can be complementary, even in the case of patients serving as research subjects, for whom I have long maintained greater protections are needed.³⁰ The circumstances need not be as extreme or the subjects as utterly defenseless as they were in the Nazi era for research to pose what Jay called the “age-old question: When may a society, actively or by acquiescence, expose some of its members to harm in order to seek benefits for them, for others, or for society as a whole?”³¹ Why have we so routinely failed to confront that question in the thirty-odd years since it was posed in the experimentation casebook? Fundamentally, I think, the reason is that an honest exploration of this question and its implications would simply be too painful, not only for investigators but for the rest of us as well. Jay understood this well, though perhaps he did not foresee that this same disinclination would pose an impediment to the field of bioethics being able to grasp and appreciate his vision of research with human beings as an enterprise that must confront certain inherent tensions that arise from us *all*—not just certain, powerless minorities—being vulnerable to intentional and unintentional harm.

III. IGNORANCE, DISPLACEMENT, DENIAL

Our persistent refusal to confront this unsettling truth produces a number of other symptoms that have the effect of reinforcing the avoidance of the inherent dilemma. Jay long ago demonstrated that another reason for failing to address the issue of conflicting interests is that physicians are so little educated about the need to talk with their patients generally that the notion of a candid dialogue in the context of an experimental intervention simply never occurs to them.³² We are doing a little better in medical schools these days, but for many student-physicians (as for their mentors as well), “informed consent” is still not a professionally generated custom, nor a welcome stimulus for dialogue with their patients. Instead, it remains a legally generated chore, simply one more procedure to be done to a patient, with an eye on malpractice law or the standards of the Joint Commission on Accreditation of Healthcare Organizations.³³ So, too,

EXPERIMENTS 210-12, 263-83 (1996).

30. Alexander M. Capron, *The Law of Genetic Therapy*, in *THE NEW GENETICS AND THE FUTURE OF MAN* 133, 149 (Michael P. Hamilton ed., 1972).

31. KATZ ET AL., *supra* note 10, at 1.

32. Jay Katz, *The Education of the Physician-Investigator*, 98 DÆDALUS 480 (1969).

33. See, e.g., JOINT COMM'N ON ACCREDITATION OF HEALTHCARE ORGS., 2006-2007 STANDARDS FOR BEHAVIORAL HEALTH CARE (2006); JOINT COMM'N ON ACCREDITATION OF

investigators who attend the few hours of specialized education now required for anyone applying for federal research funds are more likely to be taught the regulatory formalities of prior review and the locally preferred version of an acceptable informed consent form than to be tutored in how to have an honest conversation with prospective subjects.

Thus, not surprisingly, whenever these obligations are not imposed, they are seldom spontaneously respected. Let me give you just one recent example. Last year, three Manhattan physicians reported that they had developed an alternative to old-fashioned tonsillectomy in which the tonsils are shaved down but not removed, which allows their patients, including those under three years of age and those who had been suffering from severe sleep apnea, to go home within hours of general anesthesia.³⁴ This practice may have been better for the children (and their parents), or it may not have, but it was indisputably a sharp break from the strong recommendation of the American Academy of Pediatrics. In other words, the physicians had tested an *experimental* protocol on 226 children, including 38 who were under the age of three. Had they informed the parents and asked whether they were willing to enroll their child in a study? No. In fact, they had not even submitted their plans to an IRB for review, since no federal research support or investigational drug was involved.

Even when investigators do acknowledge an obligation to obtain subjects' informed consent, their aversion to confronting what is really at issue can produce some very striking displacement. A decade ago, Jay critiqued a UCLA study in which schizophrenic patients who had recovered from their psychotic disorders were withdrawn from medication in order to learn more about the prodromal signs and symptoms of relapse.³⁵ Jay recognized the potentially important contribution such a study could make but was highly critical of the way the investigators tried to defend it in terms of benefits to the subjects. The investigators' behavior led to an inexcusable blurring of the line between the goal of the treatment the patients had been receiving—to improve their health—and the goal of the study—to produce scientific knowledge. Though it did not convey the real likelihood of a relapse or the harm this might pose to subjects, the consent form ironically went into exquisite detail about the trivial risks of a needle prick to obtain blood samples, which could have lulled subjects into thinking "that the investigators would disclose any other risks in similar detail and with similar candor."³⁶ Having read hundreds of consent forms over the years, I am convinced that investigators often unconsciously displace their

HEALTHCARE ORGS., 2006 HOSPITAL ACCREDITATION STANDARDS (2006); JOINT COMM'N ON ACCREDITATION OF HEALTHCARE ORGS., 2005-2006 STANDARDS FOR LONG TERM CARE (2005).

34. Roni Rabin, *The Consent Gap*, *NEWSDAY*, Aug. 26, 2003, at A31.

35. Katz, *supra* note 1, at 41-51.

36. *Id.* at 47.

anxiety over the truly worrisome points by paying attention to minor risks about which they can offer more reassurance. Unfortunately, this practice implicitly makes the process of prior IRB review and subject consent seem like much ado about nothing.

After ignorance and displacement, the third problem is denial. When investigators think of this topic at all, they are likely to feel defensive: "Why are we subject to such scrutiny in the first place? Our activity is an honourable, even a noble one; compared to ordinary practice, we are not only more competent (and hence less likely to harm), but our whole approach is more scientific. Better the controlled risk of a clinical trial than the uncharted risks from the routine (and often misguided) administration of a standard intervention whose relative merits have never been adequately tested." As a factual matter, this view is probably correct, but as an ethical matter, it misses the mark. The defensiveness of physician-investigators arises from a sense that our insistence on prior review and an informed consent dialogue impugns their motives. That is not the case (though one can see why they might think so, given the laxity of attention to such matters in ordinary care). Rather, our message to physician-investigators is (or should be) that their enterprise is, in principle, laudable, but that all those who work on it, including the subjects (or, as the current lingo has it, the "research participants"), must be aware both of the nature of the enterprise and of everyone's role in it—including the investigator's.

The suggestion that individual researchers might be tempted to defend the value of their activities against what they see as criticism is supported by an analysis of the Declaration of Helsinki, first adopted by the World Medical Association (WMA) in 1964, which is a well-known expression of the medical profession's collective response to the dilemmas posed by human research.³⁷ The Declaration can be fruitfully analyzed as a defense of a morally worthy activity against the criticism that it amounts to exploitation of some for the benefit of all. The Declaration, like the Code, is open to several reasonable interpretations, but the perspectives tend to be of the glass is half empty or half full variety. The glass is half full view is that the WMA articulated high ethical aspirations for physicians; today, many strong advocates for patient welfare regard the Declaration (which has been strengthened in several respects over the years) as a bulwark against the pressures to cut back on what is owed to subjects, particularly in developing countries.³⁸ Looking at the Declaration in this fashion, one can see why the WMA in recent years has been tied up in knots over

37. World Med. Ass'n, *Declaration of Helsinki* (1964) (last amended 2000), available at <http://www.wma.net/e/policy/b3.htm>.

38. RUTH MACKLIN, *DOUBLE STANDARDS IN MEDICAL RESEARCH IN DEVELOPING COUNTRIES* (2004).

whether, and if so how, to officially amend its code to refine the way its rules apply in certain circumstances and to allow for exceptions. My own sense is that the WMA would do better to state its aspirations more clearly and to leave the task of drafting detailed guidance, with suitable caveats, to others.

The glass is half empty view is that, rather than a true embrace of research ethics, the Helsinki Declaration was the medical establishment's attempt to distance itself from the Nuremberg Code.³⁹ Unhappy with a statement formulated by lawyers in the context of a criminal trial of monsters with whom upstanding physicians felt no kinship,⁴⁰ the WMA promulgated its own statement of duties, the thrust of which is to preserve the autonomy not of research subjects but of physicians, especially in the context of "research combined with professional care," to which the original 1964 version devoted most of its attention.⁴¹ Just as investigators chafe at requirements that implicitly criticize what they see as an activity of high moral worth (establishing safe and more effective care for patients), so practicing physicians want it recognized that their patients are inherently protected by their Hippocratic tradition.

IV. THE THERAPEUTIC ILLUSION

This is, of course, the nub of the difficulty identified by Jay—that physicians' failures to confront the fact that their dual roles in biomedical research are a problem rather than a solution leads them to disregard the need to discuss this duality frankly with their patients. Recently in *The Lancet*, David Horrobin described how his perception of clinical trials was radically altered when, after forty years as a biomedical and clinical researcher, he was diagnosed with advanced mantle cell lymphoma.⁴² Living in the "parallel universe" of cancer patients searching for information about possible treatments (including experimental ones), Horrobin came to some very caustic conclusions about the unethical nature of many oncology trials, which equally "apply to any other rapidly lethal disease."⁴³ For example, he criticized the effect of commercialism, saying that promising agents that lack patent protection are not pursued and that, in conducting trials, pharmaceutical companies use "overpowered" designs to make it "more difficult for rivals to recruit" from the limited pool of patients with

39. Alexander M. Capron, *Human Experimentation*, in MEDICAL ETHICS 135, 155 (Robert M. Veatch ed., 2d ed. 1997).

40. Sharon Perley et al., *The Nuremberg Code: An International Overview*, in THE NAZI DOCTORS AND THE NUREMBERG CODE, *supra* note 23, at 149, 157.

41. World Med. Ass'n, *supra* note 37.

42. David F. Horrobin, *Are Large Clinical Trials in Rapidly Lethal Diseases Usually Unethical?*, 361 THE LANCET 695 (2003).

43. *Id.* at 695.

the condition in question.⁴⁴ The heart of Horrobin's criticism, however, concerns the way patients are misled into becoming subjects. In particular, he claims that "although the risk of harm is usually well described in patient information leaflets, almost nothing adequate is ever said about the assumed effect size and the real chance of benefit."⁴⁵ Not only are subjects not warned about this low expectation of benefit, but large, multi-center trials, which are now the norm, are so cumbersome that "most patients entering most oncology trials will be dead before the results are known."⁴⁶

Once death becomes certain, many patients do have an interest in helping scientists to advance knowledge, but while they are still searching for a way to save their lives, the notion that patients are motivated by altruism is "a figment of ethicist's and statistician's imagination," in Horrobin's experience.⁴⁷ Thus, when patients who are still trying to find an effective cure are enrolled in large trials (which are large precisely because the predicted effects are small), their hopes—and their trust in the medical profession—are abused. Put another way, rather than dispelling patients' therapeutic illusions, physicians in these circumstances may be exploiting those illusions to enroll them as subjects in trials where the likelihood of a therapeutic response may well be much smaller than that of adverse events, which are "usually much more predictable and reliable in their occurrence."⁴⁸

Dr. Horrobin's scathing critique underlines the need to attend seriously to the precepts of research ethics rather than merely to recite their familiar injunctions. For example, an assurance that refusing to take part in a research project will not entail any adverse consequences is a standard part of informed consent documents. The statement aims to insulate potential subjects' decisions about participating in research from any sense that the person (or institution) on whom they are dependent for care will punish them for declining to enroll. Such a statement may make sense when the intervention in question is a discrete addition to what would otherwise occur (e.g., any intervention with normal volunteers or any extra test or procedure for patient-subjects). But the utility of such a statement is much more questionable when the research intervention *is* the

44. *Id.* at 696.

45. *Id.*

46. *Id.*

47. *Id.*

48. *Id.* Physicians are sometimes critical of patients' unrealistic hopes (and magical thinking) that lead them to pursue what the medical establishment regards as "quack remedies" and to ignore the suggestions of their physicians. Yet Dr. Horrobin points to the reciprocal phenomenon: By participating in clinical trials of interventions that are unlikely to produce a significant benefit for them, patients miss the chance to try other "potential treatments, many of which are not toxic" and "neither fringe nor irrational," but are merely unattractive to commercial sponsors.

prospective “treatment,” and not some addition thereto. In that case, refusing to be a research subject typically means that the patient cannot obtain the intervention.⁴⁹ Consequently, because of the therapeutic illusion, the patient may perceive the statement that refusal would not entail any adverse consequences as either naïve or disingenuous.

To forestall this result—and to increase the likelihood that patients’ decisions will embody the sort of free choice that IRBs expect the “no adverse consequences” language to provide—investigators need to engage in much franker conversations with their potential subjects. Particularly in cases where the stakes are the highest—that is, when subjects have lethal diseases for which few if any effective therapies are available—it is essential that investigators make clear to each patient whether the research intervention holds any real chance of benefiting him or her. In the many instances when Horrobin’s skepticism about the likelihood of such benefits is justified, investigators will need to address the patient’s (probable) therapeutic misconception by making clear that the justification for asking the patient to enroll in the trial is to gain knowledge rather than to benefit him or her. For this to happen, IRBs will have to insist that the consent process involves an honest conversation, not merely a rote recitation of a very hollow reassurance. Even more important is that physician-investigators will need careful and supportive education in how to deal with the feelings—their own as well as patients’—that may be stimulated by an honest admission of the utilitarian (as opposed to beneficent) premise that inheres in the design of most clinical studies. To this end, a vocabulary of relationships—of common fear and uncertainty, of shared and diverging aims and hopes, and of mutual dependence and unequal power—must be explored, cultivated, and employed. It will not be enough to ask whether one has the right to do something; one must also ask why it would be the right thing for this person to do under these circumstances.

V. LIGHT AHEAD, OR JUST MORE SHADOWS?

The title of this paper asks whether we can see any light or only shadows in the field of research with human beings. This is, as my children would be quick to tell me, a trick question, for there can never be shadows without light. Perhaps we dwell in apparent darkness because one source of great intellectual and moral

49. The exception would be if a physician were willing and able to offer the experimental intervention under one of the “compassionate use” exceptions to the FDA rules for an Investigational New Drug (IND) (i.e., one which is licensed for clinical testing); exceptions can occur on a single patient basis or as part of an Expanded Access Program, which is usually for drugs in the late stages of development, where clinical trials have shown apparent effectiveness. Besides agreement from the physician, the patient would need approval from the drug sponsor and the FDA to receive an IND on a “compassionate” basis outside the clinical trial.

illumination—namely, Jay’s insights into the problems created by the silence at the heart of this relationship—has not been brought from the wings to center-stage, where we would see the light as well as the shadows it creates. The blame for this lies with those of us who have been, in one way or another, Jay’s students and have failed adequately to assume his mantle. I want to conclude, therefore, by considering what we can do to help ensure that Jay’s light shines as and where it should.

Having devoted much of this paper to the forces that have kept the light off-stage, I am under no illusion that what needs to be done can be easily accomplished, much less that these ideas are self-executing. My central thesis here has been that the failure of the system to address the true dilemma at the heart of human experimentation undermines the ethical legitimacy of the whole enterprise. There are mechanisms, such as the Secretary’s Advisory Committee on Human Subjects Research, through which these issues could be fruitfully addressed. Likewise, professional organizations of bioethicists and of IRB members could be encouraged to take this issue on; this was the heart of the keynote address that I delivered to the Public Responsibility in Medicine and Research annual conference in the winter of 2003.⁵⁰

Inevitably, some researchers will decry this effort and describe it as one more unnecessary burden that will slow down research. There may be room here to answer this complaint with Hans Jonas’s response,⁵¹ but we should also point out that bringing these issues out in public, especially in bodies that have the authority to address them, may well result in removing unnecessary requirements. As Jay wrote in his reservations to the report of the Advisory Commission on Human Radiation Experiments, a national board on human subjects research could “delineate exceptions to the informed consent requirements when competing principles require it.”⁵² Some epidemiologists, for example, complain that requiring individual consent for including information in disease registries not only adds to the difficulty and expense of collecting such data but may so bias the data as to defeat their scientific utility.⁵³ Yet we permit all sorts of similar activities, such as routine surveillance, to be carried out under

50. Alexander M. Capron, Research with Human Beings: More Issues than Ever!, Keynote Address at Public Responsibility in Medicine and Research’s 2003 Annual IRB Conference (December 7, 2003) (transcript available at <http://www.primr.org/education/publications.html>).

51. See *supra* text accompanying note 17.

52. Jay Katz, *Statement by Committee Member Jay Katz*, in ADVISORY COMM. ON HUMAN RADIATION EXPERIMENTS, THE HUMAN RADIATION EXPERIMENTS 543, 548 (1996).

53. Julie R. Ingelfinger & Jeffrey M. Drazen, *Registry Research and Medical Privacy*, 350 NEW ENG. J. MED. 1452 (2004) (recommending an NIH Certificate of Confidentiality and the combination of IRB review and two tiers of separate coding between data source and registry as a substitute for individual informed consent).

the public health authority without individual consent. In such cases, permission for scientists to act comes from our democratically elected representatives. Of course, we must be alert to failures in oversight or inadequate controls, but, in theory, the collective balancing of risks and benefits through an open, public, and, one trusts, accountable process is sometimes an adequate substitute for individual balancing.

Sometimes, indeed, it is *only* through a collective act that the welfare of individuals can be protected. Just recently, the Cambodian government cancelled a randomized controlled trial that was also being carried out in several African countries; in this trial, HIV-negative sex workers would have received either the AIDS drug tenofovir or a placebo for a year, to see whether the drug was effective in preventing them from becoming infected.⁵⁴ At issue in the case was not only the question of benefit but the conflict inherent in research with vaccines or other preventive measures: The research can only succeed if a statistically significant number of subjects are exposed to the risk of harm despite the best efforts of researchers to educate the subjects about behavioral changes that will reduce the risk. In Cambodia, activists claimed that by failing to involve the organization that represents sex workers in planning the trial, the American sponsors had not designed educational interventions that would be effective and that they were not going to provide adequate treatment of those who seroconverted (either because they were on the placebo or because tenofovir failed to protect them). The researchers admitted that they had not communicated their plans adequately but insisted that they had adequately engaged the relevant communities.⁵⁵

Part of this dilemma relates to the controversial issue of post-trial benefits. Who owes what to whom and when? In the Cambodian case, should the trial sponsors have been responsible for providing lifelong HIV treatment for subjects who developed a condition that they probably would have gotten anyway in the absence of the trial? But the case is also an object lesson in the importance of taking seriously those collective interests of subjects that it is unrealistic to expect individual subjects to be able to protect in the context of a one-on-one relationship with a physician-investigator who is trying to recruit the patient into a trial.

Finally, we need to address the conflicts in the system that go beyond the dual role of physicians as investigators. For a start, this means taking seriously the inherent conflicts for IRBs, searching for better ways to insulate their members and staff from institutional pressures and, when that cannot be effected,

54. Kimberly Page-Shafer et al., *HIV Prevention Research in a Resource-Limited Setting: The Experience of Planning a Trial in Cambodia*, 366 THE LANCET 1499, 1499 (2005).

55. *Id.* at 1499-1502.

creating alternative, more independent review mechanisms. Were IRBs' decisions more open to scrutiny, not only would they be improved, but the boards could also participate in a process of mutual learning through the development of something akin to a common law of research ethics.⁵⁶ Taking that idea a step further, the Tuskegee Syphilis Study Ad Hoc Advisory Panel proposed that Congress establish a national board that could review and interpret the federal research regulations.⁵⁷

In such an effort, it seems to me essential to go beyond the Office for Human Research Protection and other signatories to the Common Rule⁵⁸ to include the FDA, both to ensure consistency among regulatory bodies and because so many of the situations in which powerful forces discourage opening up the researcher-subject relationship are in studies under the FDA's jurisdiction. Indeed, recent developments in the administration of clinical trials have made the risk of silence even greater. Faced with the need for speed, efficiency, and lower costs, pharmaceutical companies are hiring contract research organizations, which often rely on private physicians rather than university medical centers for Phase III testing.⁵⁹ Pointing to the added costs for drug companies when deadlines are missed in the approval process, McKinsey & Company recently urged clinical trial managers to "think like marketers" in dealing with physician-investigators, in order to overcome the failure to recruit enough patients in time, which "accounts for 85 to 95 percent of all days lost during clinical trials."⁶⁰ The specific advice was to set a target for the number of patients needed in a trial, and to treat that target as a "sales challenge" by using marketing techniques "to get enough patients to buy the 'product'—in this case, participation in the trial."⁶¹

Not surprisingly, the McKinsey authors see physicians as "salespeople" and remind the pharmaceutical companies that they need to "identify and manage the top performers systematically" by developing "deeper relationships with physicians who consistently deliver high number of patients."⁶² Nowhere in this advice do these consultants suggest that it might be necessary for physicians to inform patients that they have been "offered incentives—not only payment for their own time and other expenses but also free equipment, all-expense-paid trips

56. See, e.g., KATZ & CAPRON, *supra* note 5, at 127-29.

57. TUSKEGEE ADVISORY PANEL REPORT, *supra* note 12, at 23-24.

58. Basic HHS Policy for Protection of Human Research Subjects, 45 C.F.R. § 46.101-.124 (2005).

59. Kurt Eichenwald & Gina Kolata, *Drug Trials Hide Conflicts For Doctors*, N.Y. TIMES, May 16, 1999, at A1.

60. Janice Cruz Rowe et al., *A Cure for Clinical Trials*, 2002 MCKINSEY Q. 134, 135, available at <http://www.mckinseyquarterly.com> (search for "Cure for Clinical Trials").

61. *Id.* at 137.

62. *Id.* at 138.

to conferences, and invitations to speak at prestigious events.”⁶³ In fact, disclosure of such information would be essential to protecting patient-subjects’ role as informed decision-makers; what patient wouldn’t want to know that the physician he or she trusts actually has a “deep relationship” with the company whose drug is being tested? Moreover, it would also be indispensable to the oversight process more generally. Since the consultants advise their pharmaceutical clients to “track the percentage of patients who . . . complete the trial, for this information permits those companies to develop accurate databases of physicians who have good access to patients, the necessary infrastructure, and the commitment to ensure that enough patients go on to the finish line,”⁶⁴ financial incentives may just as easily compromise the care with which physician-investigators apply inclusion and exclusion criteria, monitor and report clinical data, and continue or discontinue patient-subjects’ participation in a trial as they influence their recruitment practices.

This is not a pretty picture, but following Jay’s example we should not turn away; rather, we must confront it. And we should be under no illusion that this is an aberration; it is simply a franker description of the phenomenon that affects not only pharmaceutical trials but a much wider range of research with human beings. Perhaps the very starkness of this most recent slide away from professionalism—with physicians becoming self-interested marketers—will prompt the leadership of the profession to act. Let us then be clear that what is needed is not a return to the world of silence, the world where conflicts went unacknowledged and illusions were exploited rather than confronted. Rather, what is needed is to lift up the light that Jay has given us and to look clearly at what has been too long obscured in the shadows.

63. *Id.* at 137.

64. *Id.* at 138.

Response

Reflections on Jay Katz's Legacy

Ruth Faden, Ph.D., M.P.H.*

Like all the contributors to this issue, I am indebted to Jay Katz. When I was a graduate student at Berkeley, 3000 miles away from Yale Law School, I wrote Jay Katz a letter (we corresponded through letters in those pre-e-mail days). I had decided to write my dissertation on informed consent, and Jay's casebook, *Experimentation with Human Beings*,¹ had become my bible. It was then, and arguably remains today, the most thorough and diverse collection of materials on research ethics and law ever assembled between two covers. Amazingly, Jay not only responded to my letter, he also invited me to come to Yale for a chat. And I went. We talked for many hours. Jay then graciously and patiently read drafts of every chapter of my dissertation. Jay could not possibly have known how instrumental that conversation in New Haven was to my intellectual life, nor could he have known how much his comments on my drafts meant to me as I was working on my dissertation. A decade later, when Tom Beauchamp and I were writing our book on informed consent,² Jay's voice was constantly in mind and his work was my inspiration. In *Experimentation with Human Beings*,³ and later in *The Silent World of Doctor and Patient*,⁴ Jay evidenced that human psychology and human relationships are essential to understanding informed consent. Jay created the intellectual space in which I, as a student of human attitudes and behavior, could become a scholar of informed consent.

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1. JAY KATZ ET AL., *EXPERIMENTATION WITH HUMAN BEINGS: THE AUTHORITY OF THE INVESTIGATOR, SUBJECT, PROFESSIONS, AND STATE IN THE HUMAN EXPERIMENTATION PROCESS* (1972).

2. RUTH R. FADEN & TOM L. BEAUCHAMP, *A HISTORY AND THEORY OF INFORMED CONSENT* (1986).

3. KATZ ET AL., *supra* note 1.

4. JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (Johns Hopkins Univ. Press 2002) (1984).

Not surprisingly, Jay's voice is also very present in Alex Capron's paper.⁵ And perhaps for that reason, there is little in Capron's paper with which I disagree. In this response, I elaborate on several themes in his paper that I find resonant precisely because they capture well some of Jay Katz's most insightful and complex contributions.

Capron is right to say that those of us who have followed Jay in exploring the moral dimensions of human experimentation have failed him. In numerous respects, scholars of biomedical ethics have accommodated the practice of human experimentation. We are comfortable with its place in science, and we do not question its place at the bedside. We have adopted the sanitized language of medical science in which "human experiments" have become "clinical trials" and "research studies," and, as Capron notes, the human beings on whom we experiment have become "research participants," rather than "human subjects."⁶ These shifts in our language have served to soften the moral edginess of human experimentation, to make it more acceptable, more routine.

I am not suggesting that accommodating medical research is, on balance, necessarily wrong. Although Capron is right to remind us of Hans Jonas's conclusion that "progress is an optional goal,"⁷ there can be little doubt that accommodating medical research within the framework of protections that has emerged over the past forty years has allowed substantial advancement in human welfare with far less abuse of the rights and interests of human beings than might otherwise have been expected.

However, I do submit that these accommodations have made it harder to see certain moral challenges for what they are. The current discussion of financial conflicts of interest in medical research, for example, touches only superficially on what is at the core of the matter. Physicians who conduct research on human beings, or who collaborate with such research, have always been deeply and inescapably conflicted. Fundamental conflicts were present long before financial considerations began to emerge as a concern. As early as 1953, when the post-war boom in medical science was just getting underway, Otto Guttentag recognized that the moral values and obligations of the scientist are profoundly different from, and can easily conflict with, the moral values and obligations of the practicing physician. Guttentag argued for a clear separation between what he called the "physician-experimenter" and the "physician-friend" in order to prevent the experimental exploitation of the sick that this conflict could

5. Alexander M. Capron, *Experimentation with Human Beings: Light or Only Shadows*, 6 YALE J. HEALTH POL'Y L. & ETHICS 431 (2006).

6. *Id.* at 442.

7. *Id.* at 437 (citing Hans Jonas, *Philosophical Reflections on Experimenting with Human Subjects*, 98 DÆDALUS 219, 245 (1969)).

otherwise produce.⁸ Guttentag who, like Jay, talked about *physicians making their patients subjects of experiments*, recognized the moral challenge in its rawest form. By contrast, most physicians and bioethics scholars, both then and now, talk about *physicians enrolling their patients in clinical trials*, a linguistic accommodation that enables us to look right past the moral conundrum at the heart of clinical research with human beings.

I can testify from first-hand experience that Jay does not believe in making accommodations. His principal concern has always been the dignity and rights of the people on whom experiments are conducted. When we were serving together on President Clinton's Advisory Committee on Human Radiation Experiments (ACHRE), Jay always moved our discussions to what I believe he views as the first and fundamental principle of ethical human experimentation: Did the subjects provide valid informed consent? It did not matter if the experiment posed no or little risk. As Capron notes, Jay's foremost commitment is to the authority of human beings to decide for themselves whether to volunteer to be subjects of medical experimentation.⁹

At the same time, Capron is also right to point out that consent is a facile and ultimately inadequate answer to the core dilemma in human experimentation: When is it justifiable to expose some human beings to harm so that all people may benefit?¹⁰ What is especially remarkable about Jay Katz is that, while he is a staunch defender of the essential moral importance of informed consent to ethical human experimentation, he is also an acute analyst of how human relationships and psychology make the prerequisites of valid consent—such as honesty, communication, and understanding—difficult. In *The Silent World of Doctor and Patient*, Jay powerfully describes how the human dynamics of illness, dependence, and desperation complicate, sometimes beyond recognition, any conversation about choice and consent.¹¹

As Capron argues, in our obsession with the rules and forms of consent we have failed to attend to the important implications for the ethics of human experimentation of Jay's critical insights into the power of magical thinking, displacement, and denial.¹² Despite decades of critical commentary, research ethics review committees continue to engage in an often fruitless obsession with the wording of consent forms while neglecting critical concerns about the extent to which people understand what is perhaps the most important moral fact of

8. Otto E. Guttentag, *The Problem of Experimentation with Human Beings: The Physician's Point of View*, 117 *SCIENCE* 207 (1953).

9. Capron, *supra* note 5, at 431 n.1.

10. *Id.* at 440.

11. KATZ, *supra* note 4, at 130-64.

12. Capron, *supra* note 5.

all—that they are agreeing to be subjects in an experiment. As Jay points out, people who are sick have a powerful need to believe in miracles, a need that the doctors who care for them often feel compelled to encourage, both because hope can be therapeutic and because it can be so difficult for a healer to admit the limits of her capacity to help. Yet once again, despite the voluminous literature prompted by Jay's insights, review committees rarely challenge physician-scientists about the extent to which their patient-subjects have an accurate understanding of whether, or to what extent, participating in research will make them better.

Capron also invites us to consider Jay's work in the context of the lessons of Nuremberg. Capron rightly cautions that Nuremberg should not be reduced to the specific rules of the Code but must be understood more deeply as expressing the boundaries of what is morally permissible in human experimentation.¹³ Jay, who frequently has reminded me of the Code's first principle, which begins "[t]he voluntary consent of the human subject is absolutely essential,"¹⁴ certainly does not reduce the lessons of Nuremberg to legalistic rules. An unforgettable moment from our time on ACHRE exemplifies Jay's profound grasp of what lies beneath and beyond the rules. We were hearing testimony about radiation experiments that had been conducted on boys at a state institution in Massachusetts to which they had been committed.¹⁵ There was discussion about parental consent, and it was suggested that, since the science required a setting in which the children's diets could be controlled, boys in the residential setting of a state home were ideal for this research. Jay then asked, simply, had the investigators considered selecting as subjects children at Choate or Exeter? The room fell silent. Even if the risks had been minimal and the parental consent valid and meaningful, Jay was quick to see the fundamental immorality of the research.

In the field of biomedical ethics, Jay is rightly revered for his extraordinary insights about consent and communication, relationships and silences. But as this powerful anecdote suggests, for me, the real brilliance of Jay Katz lies in his uncanny capacity to discern when the conduct of physicians and scientists crosses a critical moral divide, and why.

13. *Id.* at 433-39.

14. 2 TRIALS OF WAR CRIMINALS BEFORE THE NUREMBERG MILITARY TRIBUNALS UNDER CONTROL COUNCIL LAW NO. 10, at 181 (1948-1949).

15. ADVISORY COMM. ON HUMAN RADIATION EXPERIMENTS, THE HUMAN RADIATION EXPERIMENTS 196-226 (1995).

Response

Jay Katz: From Harms to Risks

Larry I. Palmer, LL.B*

Jay Katz's towering presence in the scholarship on human experimentation has been a source of personal and professional inspiration. As I noted over thirty years ago in my review essay about his classic work, *Experimentation with Human Beings*,¹ Jay's scholarship asks tough and penetrating questions about a truth we modern professionals hold to be sacred.² We have always assumed that growth in scientific knowledge and social progress are linked. Yet as Alex Capron discusses in his paper,³ scientific knowledge has sometimes been produced by means we would *not* consider socially progressive. Jay's analysis of the history of experimentation with human beings before, during, and after the Nazi era dispels the comforting notion that the Nazi investigators were individuals working outside the moral ethos of modern medicine and science (i.e., that they were merely racists and sadists). Instead, Jay reveals that they were physician-investigators searching aggressively (albeit blindly) for even better ways of making science socially useful and relevant.⁴

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1. JAY KATZ ET AL., *EXPERIMENTATION WITH HUMAN BEINGS: THE AUTHORITY OF THE INVESTIGATOR, SUBJECT, PROFESSIONS, AND STATE IN THE HUMAN EXPERIMENTATION PROCESS* (1972).

2. Larry I. Palmer, Commentary, *The High Priests Questioned or at Least Cross-Examined*, 5 RUTGERS-CAM. L.J. 237 (1973-1974).

3. Alex Capron, *Experimentation with Human Beings: Light or Only Shadows?*, 6 YALE J. HEALTH POL'Y L. & ETHICS 431 (2006).

4. See, e.g., Jay Katz, *The Consent Principle of the Nuremberg Code: Its Significance Then and Now*, in *THE NAZI DOCTORS AND THE NUREMBERG CODE: HUMAN RIGHTS IN HUMAN EXPERIMENTATION* 227 (George J. Annas & Michael A. Grodin eds., 1992) (observing that the Nuremberg Code's relentless and uncompromising commitment to the psychological integrity of research subjects has not been matched either prior to its promulgation or since); Jay Katz, *The Nuremberg Code and the Nuremberg Trial: A Reappraisal*, 276 JAMA 1662, 1663 (1996) (noting that, in the history of medical science, harms, including death, have always been associated with

In this response, I illustrate Jay's broad influence on the entire field of bioethics by beginning with a personal tribute that honors Jay as a scholar and teacher. As one of his former students, I can attest that his method of combining scholarship and teaching deserves the label "inspirational." Second, I discuss how my own scholarship and teaching have been shaped by Jay's courageous insistence that to protect human subjects we must develop new types of institutional arrangements.⁵ Jay used his position on bioethics commissions (starting with the panel to review the Tuskegee Study of Untreated Syphilis in the Negro Male)⁶ and his writings to advocate for institutional change of the manner in which we regulate research. Finally, I argue that Jay Katz's scholarship and career provide a warning to those of us who call ourselves "bioethicists" in what I have called the "human genome era."⁷ Bioethics is now in some senses a new "profession," with all of the accompanying risks and benefits of that societal recognition. We may need to return to Jay's work to uncover the reflective skills for analyzing our own role in promoting, or perhaps impeding, "social progress."

I. JAY'S INFLUENCE: A PERSONAL REFLECTION

I was one of approximately thirty students in Jay's Family Law class in the spring of 1968. At a certain point in the course, Jay invited Anna Freud to participate in our class for several weeks. On those occasions, the classroom was also packed with a large number of law school faculty members, including Joe Goldstein.

medical research, but death had not been part of the research design before the Nazi doctors); Jay Katz, *The Regulation of Human Experimentation in the United States—A Personal Odyssey*, 9 IRB: REV. OF HUM. SUBJECTS RES. 1, 2 (1987) [hereinafter Katz, *Regulation*] (arguing that Nazi studies had antecedents and recounting some earlier examples of investigators discounting the dignity of human beings); Jay Katz, Human Sacrifice and Human Experimentation: Reflections at Nuremberg, Address at the Conference Commemorating the Fiftieth Anniversary of the Nazi Doctors' Trial at Nuremberg Convened by International Physicians for the Prevention of Nuclear War and Physicians for Social Responsibility (Oct. 27, 1996) (transcript available at <http://www.law.yale.edu/outside/html/Publications/pub-katz.htm>) (reviewing other examples of research involving human subjects where human dignity was not maintained and observing that in medicine's quest to become a respected science, "doctors lost sight of the fact that it is one thing to experiment with atoms and molecules and quite another to do so with human beings").

5. Larry I. Palmer, *Paying for Suffering: The Problem of Human Experimentation*, 56 MD. L. REV. 604 (1997).

6. See PUB. HEALTH SERV., U.S. DEP'T OF HEALTH, EDUC. & WELFARE, FINAL REPORT OF THE TUSKEGEE SYPHILIS STUDY AD HOC ADVISORY PANEL (1973) [hereinafter TUSKEGEE ADVISORY PANEL REPORT], available at <http://biotech.law.lsu.edu/cphl/history/reports/tuskegee/tuskegee.htm>.

7. Larry I. Palmer, *Disease Management and Liability in the Human Genome Era*, 47 VILL. L. REV. 1 (2002).

The presence of Joe Goldstein and others signaled to me that our discourse with Anna Freud was part of a much wider conversation about the relationship between psychoanalysis and law, a topic Robert Burt elegantly addresses in his paper for this symposium.⁸ More important, it signaled to me Jay's generosity and openness to ideas and colleagues. In the classroom discussion of *Painter v. Bannister*,⁹ Anna Freud outlined her rationale for defending the court's disposition of the child custody dispute in favor of the grandparents, i.e., the "psychological parent," over the child's biological father. As it turned out, what was going on during Anna Freud's visits to our class was the outlining of themes that she, Joe Goldstein, and Albert Solnit subsequently pursued in their *Beyond the Best Interests of the Child*.¹⁰ Experiencing something rare and wonderful during that course stimulated me to work with my own students in such a way that the larger context of my scholarship could in turn inspire each student to find his or her light.¹¹ Thus, my first tribute to Jay is a personal note of gratitude: He has the ability to inspire those of us exposed to his light to take risks when we speak as citizens and as scholars.¹²

II. JAY'S INFLUENCE: TEACHING ETHICS

When Alex Capron was editor of a special edition of the American Society of Law, Medicine and Ethics' journal honoring Jay's work, he asked me to contribute a piece, and I chose to write about how Jay's approach to human research could be a model for revitalizing interdisciplinary teaching.¹³ At the time I was co-teaching a seminar for undergraduates on "Institutions and Social Responsibility"¹⁴ in Cornell University's Biology and Society Program that used some materials from Jay's casebook on human experimentation.¹⁵ In the course

8. Robert Burt, *The Uses of Psychoanalysis in Law: The Force of Jay Katz's Example*, 6 YALE J. HEALTH POL'Y L. & ETHICS 401 (2006).

9. 140 N.W.2d 152 (Iowa 1966).

10. JOSEPH GOLDSTEIN ET AL., *BEYOND THE BEST INTERESTS OF THE CHILD* (2d ed. 1979); see also JOSEPH GOLDSTEIN ET AL., *IN THE BEST INTERESTS OF THE CHILD* (1986).

11. Larry I. Palmer, *Research with Human Subjects as a Paradigm in Teaching*, 16 L. MED. & HEALTH CARE 183 (1988).

12. Joe Goldstein's warning to psychoanalysts to distinguish between their roles as scientists and their roles as mere citizens should be heeded by bioethicists today, who regularly are called upon to provide normative answers to whether a particular line of research—for instance, stem cell research on cloned embryos—should proceed. See Joseph Goldstein, *Psychoanalysis and Jurisprudence*, 77 YALE L.J. 1053, 1059-60 (1968).

13. Palmer, *supra* note 11.

14. *Id.* at 183.

15. KATZ ET AL., *supra* note 1, at 9-65.

of writing my article during the summer of 1989, I took a morning away from my duties as a vice president at Cornell to go to the library. There I encountered David Feldshuh, the author of the play, *Miss Evers' Boys*,¹⁶ a fictionalized account of the Tuskegee Study.

As we stood in the library lobby conversing, David, a physician by training with a Ph.D. in theater arts, asked me: "Do you know anything about the Tuskegee Syphilis Study?" Inspired, perhaps, by the generosity toward the perspectives of other scholars I remembered from Jay's class, I tried to hear the anxiety or the silence behind David's question and recognized the invitation to conversation. I told him about the paper I was writing, about Jay's role on the Tuskegee Syphilis Study panel, and about how I had followed the developments regarding the Tuskegee Study since 1972.¹⁷ That conversation led David to ask me to read a draft of what would become *Miss Evers' Boys* before he took the play to the Sundance Festival. David was not concerned, as some critics were, with the politics of race and gender that might overshadow his attempts, as a white, male, Jewish physician-playwright, to portray the fictitious heroine of his play—an African-American public health nurse. Rather, he was concerned with his portrayal of the African-American physician. The implication—albeit a fictitious one—that Dr. Brodus, a black physician, was somehow involved in a study condemned as unethical and racist would raise some special issues.¹⁸ The litigation on behalf of the survivors of the Tuskegee Study against the United States Government and the State of Alabama had alleged that the men were placed in the study without their consent solely because they were African-Americans.¹⁹

That conversation sparked several collaborations, including presentations of excerpts from the play before various audiences followed by interdisciplinary panel discussions about the issues of race, gender, and research raised by *Miss Evers' Boys*. The moving response of a large Cornell alumni audience to one of our panels convinced me to bring *Miss Evers' Boys* to Cornell as a way of engaging the entire campus in a conversation about research ethics, race, and gender. The 1991 theater production of *Miss Evers' Boys* at Cornell was a focal point of freshman orientation and became part of the eventual production of the prize-winning educational video, *Susceptible to Kindness: 'Miss Evers' Boys' and the Tuskegee Syphilis Study*.²⁰

16. DAVID FELDSHUH, *MISS EVERS' BOYS* (1995).

17. Palmer, *supra* note 2, at 245.

18. Palmer, *supra* note 5, at 614-16.

19. *Id.* at 609.

20. Videotape: *Susceptible to Kindness: 'Miss Evers' Boys' and the Tuskegee Syphilis Study* (Cornell Univ. 1994).

In writing the study guide to accompany the video, I was inspired again by Jay's approach to teaching and scholarship, in which framing the question is the key to analysis. Recall that each part of Jay's casebook starts with a narrative introduction that ends with four to six overarching questions.²¹ These questions help both the teacher and the student organize the process of reflection and engaging discussion provoked by the 200 to 300 pages that follow each introduction. I thought our forty-two minute video, which included vignettes from the play, comments by "experts," interviews with survivors from the Tuskegee Study, and documentary material about the conditions in rural Alabama, needed a set of questions that would help teacher-leaders guide a reflective discussion of the issues raised by the various vignettes from the play.²² I organized the study guide around a major question for each of the six vignettes from the play. For instance, given Jay's analysis of the role of the Hippocratic Oath in the success or failure of physician-scientists in securing consent,²³ I encouraged discussion leaders to ask, in relation to the nurse-scientist, Miss Evers, "[i]n a religiously diverse society, before whom should modern professionals take their oath?"²⁴ While that question related to the first of the six vignettes, the same question is discussed by the expert commentators on the video. Furthermore, in designing the questions, I had to keep in mind that the leaders and students considering my questions would come from a variety of disciplines.

Building from this interdisciplinary and collaborative work on the Tuskegee project, I began to develop a research agenda around two issues that are pervasive in research on human subjects. First, in my own writing about the issues of race and genetics, I have been inspired by Jay to develop a framework that will help us question some common assumptions about how to deal with increasingly diverse research subjects. Second, I have been drawn to consider what it means to be a "professional" in the field of bioethics.

III. PROFESSIONALISM, RACE, AND HUMAN SUBJECTS RESEARCH

The Institute of Medicine and others have called for greater training in "cultural competency"²⁵ on the part of health professionals in response to

21. KATZ, *supra* note 1, at 7, 8.

22. See Larry I. Palmer, *Writing Law*, in *WRITING AND REVISING THE DISCIPLINES* 113, 121-23 (Jonathan Monroe ed., 2002).

23. JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 93-94 (Johns Hopkins Univ. Press 2002) (1984).

24. LARRY I. PALMER, *SUSCEPTIBLE TO KINDNESS: MISS EVERS' BOYS AND THE TUSKEGEE SYPHILIS STUDY: STUDY GUIDE FOR DISCUSSION LEADERS* 9, 11 (1994).

25. INST. OF MED., *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN*

granting agencies' insistence that racial and ethnic minorities have "an equal opportunity" to participate in clinical trials. My concern is that we assume too easily that minority medical students, minority physicians, or minority outreach workers will not experience a cultural divide in seeking to recruit minority research subjects. Discussions of this topic often ignore the possibility that minority professionals may, in some cases, be committed primarily to the modern biomedical definition of "professional," thereby sharing with their non-minority colleagues tendencies toward silence in terms of sharing risks.²⁶ To put it another way, why should we believe that minority physicians will not concentrate as much as their majority counterparts on minimizing physical harm during interventions, while largely ignoring risks to the subject's sense of human dignity? Why do we assume that minority professionals will necessarily show greater respect for the authority of subjects to say "no" to participation in research?²⁷

When I listen to current discussions about the need to recruit minority members as organ donors, donors of tissue samples for genetic tests, or participants in clinical trials for diseases that disproportionately affect African-Americans such as sickle-cell anemia, I often think back to the conflicted role of Dr. Brodus in *Miss Evers' Boys*. Dr. Brodus is the same race as the men involved in the Tuskegee study, but he is culturally different from them. He does not, for instance, understand much about the form of folk dance in which one of the men is deeply involved.²⁸ He, like the white doctor in the play, Dr. Douglas, needs the black public health nurse, Miss Evers, to translate his medical terminology.²⁹ Dr. Brodus questions Dr. Douglas's decision to start the study of untreated syphilis in the Negro male, but eventually acquiesces when Dr. Douglas suggests that a scientific study might prove that both races are biologically the same.³⁰ Dr. Brodus's fictionalized struggle illustrates that employing racially diverse medical professionals is not a quick fix for the problems raised by the vulnerability of minority subjects. What we need, rather, is for bioethicists of all racial and ethnic backgrounds to find a forum for having open discussions about racial and ethnic differences in the genomic era.³¹ Issues of race and ethnic status cannot be resolved by a procedural approach built on avoiding physical harms. Thinking about race in the post-Tuskegee world, where *de jure* segregation no longer

HEALTHCARE 199-214 (2002) (encouraging medical educators to increase physician skills in cultural competence as a means of eliminating health disparities).

26. KATZ, *supra* note 23, at 1-29.

27. See Palmer, *supra* note 5, at 611-13.

28. FELDSHUH, *supra* note 16, at 72-73.

29. *Id.* at 72, 75-77.

30. *Id.* at 39-44.

31. Ari Patrinos, 'Race' and the Human Genome, 36 NATURE GENETICS S1 (2004).

exists, requires us to embrace Jay's call for more attention to risks to human dignity in human research.

IV. BIOETHICS AS A PROFESSION

The second challenge we must face is that of the professionalization of bioethics itself.³² When Jay, the insider and the outsider, worked with Alex Capron and Eleanor Glass on their classic book on human experimentation,³³ they challenged scientists of all kinds, including social scientists, to examine the ethics of their work. Since the outset of the Human Genome Project, the ethical, legal, and social implications (ELSI) of genetic developments have become part of the federal research agenda. But the allocation of three to five percent of genetic research funds to ELSI work³⁴ may be both a curse and a blessing.

We, the bioethicists, now have a potential source of funding that equips us to convince university administrators to build centers for bioethics within universities. This institutionalization within the federal research funding structure may be seen as a positive sign that we can carry on the process of providing the critical analysis of research development. On the other hand, given the failures that Alex Capron outlines in his paper,³⁵ we ought to pay attention to the possible downsides of our marriage to federal funding. Given this dilemma, how do we avoid becoming captive to the ethos that scientific knowledge automatically leads to social progress? How many of us will have the courage that Jay demonstrated to dissent?³⁶ Will we be able to challenge federal funding officials when the funding of our centers or programs is partially dependent upon our maintaining a certain kind of favorable visibility among program officers?

I am not suggesting that any of these dangers has been realized in any particular ELSI project of which I am aware. I am, however, suggesting that it is our responsibility to start asking questions about our own role in relationship to the funding for our work, and to develop a research agenda that reflectively assesses and challenges our own relatively new profession. We should not make

32. In *Grimes v. Kennedy Krieger*, 782 A.2d 807 (Md. 2001), the court relied upon bioethics literature to hold that researchers could be civilly liable for an impaired informed consent process where parents were asked to consent, on behalf of their children, to participation in a lead-abatement study involving low-income housing. See Larry I. Palmer, *Genetic Health and Eugenics Precedents: A Voice of Caution*, 30 FLA. ST. U. L. REV. 237, 244-53 (2001).

33. KATZ ET AL., *supra* note 1.

34. Human Genome Program, U.S. Dep't of Energy Office of Sci., Human Genome Project Information: Ethical, Legal, and Social Issues, http://www.ornl.gov/sci/techresources/Human_Genome/elsi/elsi.shtml (last visited Apr. 11, 2006).

35. Capron, *supra* note 3.

36. Katz, *Regulation*, *supra* note 4.

the fatal error of presuming that our own good intentions and so-called “expertise” in bioethics provide sufficient insurance against our participating in or enabling affronts to human dignity within the research process.

Let me use an illustration from my own recent work as the principal investigator on a grant for teaching cultural competency in medical schools. My proposal involved a disease-based model for training in cultural competency and built on some work dealing with sickle cell anemia already being done at my current institution.³⁷ When I was filling out the human subjects protection section of the grant proposal, I was tempted to state that there were minimal risks to the students and faculty involved in my “teaching experiment” because the *physical* risks were minimal. I was further tempted to admit only a risk of loss of confidentiality during the evaluation required by the request for proposals. Perhaps it was working on this paper that pushed me to venture beyond such boilerplate statements. Instead, I felt compelled to outline for the peer-review group the true risks to human dignity I could foresee even at this research design stage of the study. I proposed including in the consent form, in addition to the standard language about possible physical harms, some language about the risks of stigma and dignitary harms to both individuals and communities that might result from participation in a project that attempts to deal with race.

For example, in the context of a training program meant to increase the “cultural competency” of future physicians, it is possible that some of the materials used, such as the educational video on the Tuskegee Syphilis Study, could provoke teachers and leaders to make statements that would make some individuals feel stereotyped and disrespected. This risk applies to both minority and non-minority students. Being labeled a “racist” has professional implications for a future physician of any race or ethnicity. On the other hand, a racial or ethnic minority student’s learning might be hindered by provocative and insensitive statements by white students about supposed customs of Jews, Muslims, African immigrants, “Hispanics,” or African-Americans. These risks are real and worthy of mention in the context of a training project because training *is* human experimentation. We should be aware of the dignitary risks involved in education, in attempting to shape people’s minds as educators in a value-laden field such as ethics. Jay’s approach to research with human subjects, as I observed above, provides an excellent framework for analyzing the nature of teaching and education. If knowledge changes people, then those of us involved

37. Kathy Keadle, *Bridging the Gap*, MEDICINE (Univ. of Louisville, Louisville, KY), Fall/Winter 2002, at 8, available at <http://www.louisville.edu/hsc/medmag/fw02/sickle.html>; Tiffani Humphrey et al., The Medical Student Sickle Cell Project: Innovation, Outreach, Opportunities, Oral Presentation at the 32nd Annual Convention of the Sickle Cell Disease Association of America, Inc. (Sept. 30, 2004) (on file with author).

in the transmission of knowledge to others are constantly involved in human experimentation.

V. LESSONS FOR THE GENOMIC ERA

I have shown how Katz's analysis of human experimentation has influenced my own thinking with respect to issues of race, ethics, and education. I would like to close with some thoughts about how his insights should influence *all* of our thinking in the near future. Specifically, I want to caution that Katz's fundamental insight—that we must always consider carefully the potential implications of our work for the dignity of human persons—will be crucial as we enter the genomic era. Genomic science has conclusively shown that we are biologically one race.³⁸ With such worldwide scientific consensus and the growth of the research enterprise, we should be careful not to overlook the persistent and growing risks associated with social, ethnic, and religious differences. Put another way, as scholars and citizens, we are at risk of failing to respect “the dignity of difference.”³⁹ Jonathan Sacks, a theologian, philosopher, and rabbi, insightfully describes the challenge of thinking about ethical discourse in a pluralistic society: “Plato’s assertion of the universality of truth is valid when applied to science and a description of what is. It is invalid when applied to ethics, spirituality, and our sense of what ought to be.”⁴⁰

Jay challenges us—particularly those of us trained as lawyers—to move beyond law’s traditional focus on physical harms to subjects, to consider how risk-taking on the part of both subjects and investigators enhances or diminishes human dignity.⁴¹ I would propose that in dealing with the issue of race in the genomic era, we must combine Jay’s quest for *individual* human dignity within the research process with a new *systemic or institutionalist* perspective towards the dignity of racial, ethnic, and religious differences. Those of us mentored by Jay, as a teacher, scholar, and friend, are aware that the challenge to be faced involves not only protecting individuals, but also respecting—without stigmatizing—groups and developing analyses of the research process that facilitate that respect.

Genomics, informational technology, and a global economy have dramatically changed our human environment since the publication of Jay’s pioneering book on human experimentation. Alex Capron’s work at the World

38. Patrinos, *supra* note 31, at S1.

39. JONATHAN SACKS, *THE DIGNITY OF DIFFERENCE: HOW TO AVOID THE CLASH OF CIVILIZATIONS* (2d ed. 2003).

40. *Id.* at 54.

41. Jay Katz, *Statement of Committee Member Jay Katz, in* ADVISORY COMM. ON HUMAN RADIATION EXPERIMENTS, *THE HUMAN RADIATION EXPERIMENTS* 543 (1996).

Health Organization demonstrates that the scope of our concern as bioethicists has expanded to encompass the globe and its varied peoples. What has not changed—and, in my view, should not—is our continuous effort to emulate the respect for every human being Jay modeled in his teaching, scholarship, and everyday encounters.

The Web of Relations: Thinking About Physicians and Patients

Ellen Wright Clayton, M.D, J.D.*

Like the other contributors to this symposium, I owe a profound debt to Jay Katz for his intellectual rigor, his gentle but firm Socratic pedagogy, and his unparalleled generosity of time and friendship. I first met Jay during my last year of law school when, at the urging of friends, I enrolled in his seminar on informed consent. By that time, he had collected most of the materials on which he based his important book. Not surprisingly, a single semester could not contain all of that material, so many of us continued on into the second semester. During that time I learned a number of things, but largely in the abstract mode that often characterizes the law school classroom. Fortunately, I had the opportunity after my first year in medical school to work on Jay's book, *The Silent World of Doctor and Patient*.¹ I am not sure that I contributed much. I have always viewed that summer as Jay's effort to create a tutorial designed to make sure I "got it." Even so, it required actually taking care of patients for the last twenty years to bring some of his lessons home.

Over the years, I have come to see the physician-patient relationship not simply as a dyad of autonomous individuals, but as one part, albeit an important and complex part, of a web of dynamic interactions that influence both parties. This perspective has important implications. The work of Barabási² and others³ has shown that networks are fluid, self-creating, and always changing. At the same time, networks tend to respond poorly or unexpectedly to deliberate

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1. JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (Johns Hopkins Univ. Press 2002) (1984).

2. See generally ALBERT-LASZLÓ BARABÁSI, *LINKED: HOW EVERYTHING IS CONNECTED TO EVERYTHING ELSE AND WHAT IT MEANS FOR BUSINESS, SCIENCE, AND EVERYDAY LIFE* (2003).

3. See, e.g., SERGEI N. DOROGOVTSSEV & JOSÉ F. F. MENDES, *EVOLUTION OF NETWORKS: FROM BIOLOGICAL NETS TO THE INTERNET AND WWW* (2003); Stephen H. Strogatz, *Exploring Complex Networks*, 410 NATURE 268, 268-76 (2001).

attempts to induce change. Pressure at one point can lead to a countervailing response at another. This understanding provides additional insights into people's actions and suggests both reasons for resistance as well as the possibility of support from unanticipated sources.

In rereading Jay's book, I was struck by its prescience and by some of the questions and dilemmas that remain unresolved or have emerged in new forms. One of the most powerful stories for me in his book is that of Iphigenia Jones, the twenty-one-year-old woman who, shortly before her wedding, discovered that she had developed breast cancer. At the suggestion of her surgeon, she initially agreed to have a mastectomy because he firmly believed it was the best alternative. He later decided to tell her about other options because of "his misgivings about having to perform such a mutilating procedure on a person that young and attractive."⁴ After much thought, she chose lumpectomy and radiation (an approach now referred to as "breast conserving therapy" or BCT), later expressing in a public forum "her great joy over now being able to begin life with her beloved physically unscarred."⁵ The original surgeon apparently was comfortable with her decision, but the physicians who listened to her story almost unanimously agreed that it had been crazy or inappropriate to let her choose her therapy.

Twenty years later, this story elicits an array of issues and questions, some old and some new. I, for one, feel more than a twinge of irritation every time I read that the surgeon had second thoughts about his decision (only) because she was young and pretty. It was a wonderful thing that he decided to offer her more options, but other women should have had those choices as well. The discriminatory attitudes and stereotypes that pervade society, in this case with respect to gender, not surprisingly affect the physician-patient relationship as well as the delivery of health care more generally. These effects are now the subjects of intense scrutiny, and evidence is mounting that differences in health are attributable in part to provider attitudes about what sorts of intervention are appropriate for different people.⁶ The government has set aggressive goals for decreasing disparities in health outcomes, but they will be difficult to achieve without addressing discriminatory provider attitudes.

Happily, the notion of shared decision-making has made sufficient inroads

4. KATZ, *supra* note 1, at 90-91.

5. *Id.* at 91.

6. For example, white men are more often offered cardiac catheterization and thrombolysis in the event of a heart attack than are minorities or women. *See generally* COMM. ON UNDERSTANDING & ELIMINATING RACIAL & ETHNIC DISPARITIES IN HEALTH CARE BD. OF HEALTH SCI. POLICY, INST. OF MED., *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE* (Brian D. Smedley, et al. eds., 2003).

today that it would be uncommon to find a chorus of physicians who would publicly admit that it was crazy to let Iphigenia make her own choice. Many doctors probably believe that her surgeon should have made the decision or at least made her go along with his recommendation, but most would hesitate to admit to such a blatant disregard of patients' wishes. Nonetheless, a study reported in the *Journal of the American Medical Association*⁷ in 2004 reveals some of the problems that still remain. Following up on studies demonstrating that women who had BCT had equivalent survival rates and greater quality of life and satisfaction with the procedure than those who received more aggressive surgery, the authors developed a "decision board" with information about the various options to improve patient communication. The board included explanations of treatment choices, side effects, implications for the breast, and implications for long-term survival, which were then read together by the patient and the surgeon. The researchers recruited community surgeons from Ontario, Canada, to compare consultations using a decision board with those using surgeons' normal procedures for disclosure. The authors reported that the women whose surgeons used the decision board knew more about their treatment options, were more satisfied with their decision-making, and were more likely to choose BCT. Put another way, usual practice still is not good enough to empower women to make decisions that fit their lives. These findings are all the more striking because the surgeons who agreed to participate in this trial were probably more likely than most physicians to believe in the importance of exploring options. It is difficult to imagine, for example, that a physician who believed that mastectomy was the only appropriate intervention would have agreed to take part in this research.

Iphigenia's case might proceed differently today. Many women diagnosed with breast cancer at the age of twenty-one are offered genetic counseling. Particularly if other members of her family had also been affected, she might be offered genetic testing. Happily, in the absence of a positive family history, her risk of having a germline mutation that would have predisposed her to develop cancer would be less than fifteen percent despite her youth.⁸ But if she decided to proceed with testing that uncovered a harmful mutation, her decision about surgery could well have been different. Several investigators have shown that women with breast cancer who are found to have these mutations before the time

7. Timothy Whelan et al., *Effect of a Decision Aid on Knowledge and Treatment Decision Making for Breast Cancer Surgery: A Randomized Trial*, 292 JAMA 435 (2004).

8. See Kathleen E. Malone et al., *BRCA1 Mutations and Breast Cancer in the General Population: Analyses in Women Before Age 35 Years and in Women Before Age 45 Years with First-Degree Family History*, 279 JAMA 922 (1998); Beth Newman et al., *Frequency of Breast Cancer Attributable to BRCA1 in a Population-Based Series of American Women*, 279 JAMA 915 (1998).

of surgery are more likely to choose bilateral mastectomy.⁹ Some of their choices may reflect the growing consensus that more aggressive surgery decreases the risk of recurrence in mutation carriers. Others may be driven by the fear of cancer that grips our society or other psychological and social factors. Although genetic variants are rarely determinative, messages about the inexorability of disease if one has mutations can be particularly strong. At a meeting several years ago, for example, an eminent geneticist said that if he were a woman who had a mutation in BRCA1, he would immediately get a bilateral mastectomy and oophorectomy¹⁰ no matter what his age or cancer status. These are strong words. One interesting effect of considering genetic testing is that Iphigenia almost surely would have had much more conversation with her providers than usually occurs between physician and patient because of the norms of non-directiveness and attention to personal values that are almost uniquely espoused in the setting of genetic counseling and cancer genetics.

In his book, Jay elegantly described the intrapsychic forces that lead patients to have magical expectations, such as their desires to be taken care of in ways that they wish or believe they had been as children and their tendency to see physicians as more powerful than they actually are.¹¹ He also pointed out the chronic tendency of medicine to promise more than it can possibly deliver, an issue to which I shall return later. But the last variant of Iphigenia's story illustrates another important factor, namely the ways in which social understandings of disease affect the ability of physicians and patients to communicate effectively. Here is one place where seeing medicine as situated in a complex social web is particularly important. When I was a child, people did not talk about cancer. It was seen as embarrassing or too scary. Today, many people tell the world that they have or have had cancer, often using this fact as a rallying cry. One needs only look around to see yellow "LIVESTRONG" wrist bands and the rainbow of ribbons or think of the leaders of the National Breast Cancer Coalition who proudly proclaimed their efficacy in obtaining funding for research. But the fear of cancer is still larger than life. Physicians know that people dramatically overestimate their likelihood of developing or dying of cancer, especially in comparison with other causes.¹² This may lead people to

9. See Caryn Lerman et al., *BRCA1 Testing in Families with Hereditary Breast-Ovarian Cancer: A Prospective Study of Patient Decision Making and Outcomes*, 275 JAMA 1885 (1996); Mark D. Schwartz et al., *Impact of BRCA1/BRCA2 Counseling and Testing on Newly Diagnosed Breast Cancer Patients*, 22 J. CLINICAL ONCOLOGY 1823 (2004); Jeffrey Weitzel et al., *Effect of Genetic Cancer Risk Assessment on Surgical Decisions at Breast Cancer Diagnosis*, 138 ARCHIVES SURGERY 1323 (2003).

10. Oophorectomy is the surgical removal of the ovaries.

11. See KATZ, *supra* note 1, at 104-29.

12. Women's Fear of Heart Disease Has Almost Doubled in Three Years, but Breast Cancer

make decisions that on their face seem irrational given the statistics, perhaps to the dismay of clinicians.

The public also tends to see genetic variation as more determinative of health and personal characteristics than it really is. Some of this perception may be attributable to public culture, to movies like *Gattaca*, to numerous novels, or to cartoons that show “genes” for willingness to pay \$3.75 for a cup of coffee at Starbucks. Much of the responsibility, however, resides with the scientific community itself, when investigators tout the importance of their new findings. They often carelessly refer to the “gene for” *X* disease or fail to acknowledge other factors that contribute to the appearance of illness. Conversation may be impeded by the unwarranted sense of the inexorability of biology that both clinicians and patients sometimes have.

Jay pointed out in his book that patients often have different views about the causes and therapies for diseases than their physicians. He cited, for example, Solzhenitsyn’s story in *Cancer Ward* about Kostoglotov, who wished to treat his malignancy with “a mandrake root from Issyk Kul” instead of the recommended therapy.¹³ The prevalence and impact of these different understandings is now much clearer. The National Center for Complementary and Alternative Medicine (CAM) reported this year that of more than thirty thousand people interviewed in the United States, “36% of adults are using some form of CAM. When megavitamin therapy and prayer specifically for health reasons are included in the definition of CAM, that number rises to 62%.”¹⁴ Although the majority of people said that they used CAM in addition to conventional medicine, thereby creating the potential for adverse interactions, physicians often do not ask about these interventions, and patients may not reveal them even if asked. Kostoglotov chose not to disclose his plans to his oncologist, knowing that she would not agree and might even force him to accept further radiation.

And these are not the most dramatic conflicts that can occur in a country as culturally diverse as ours. In her heart-rending book, *The Spirit Catches You and You Fall Down*,¹⁵ Anne Fadiman recounts the tale of a young Hmong girl with an intractable seizure disorder. Her physicians fought to control her seizures and were frequently frustrated that she was not receiving her medications at home.

Remains Most Feared Disease, http://www.nhlbi.nih.gov/health/hearttruth/press/fear_doubled.htm (last visited Jan. 19, 2006) (explaining that heart disease and lung cancer cause more deaths than breast cancer).

13. KATZ, *supra* note 1, at xlii.

14. NAT’L CTR. FOR COMPLEMENTARY & ALTERNATIVE MED., NAT’L INSTS. OF HEALTH, THE USE OF COMPLEMENTARY AND ALTERNATIVE MEDICINE IN THE UNITED STATES 2 (2004), *available at* <http://nccam.nih.gov/news/camsurvey1014.pdf>.

15. ANNE FADIMAN, *THE SPIRIT CATCHES YOU AND YOU FALL DOWN: A HMONG CHILD, HER AMERICAN DOCTORS, AND THE COLLISION OF TWO CULTURES* (1998).

They later discovered that her parents had a hard time understanding the instructions and in any event believed that seizures were not a disorder but rather were caused by a wandering soul or evil spirits, problems which could only be addressed by animal sacrifices or special ceremonies.

Although Fadiman's book is a particularly stark demonstration that allopathic medicine has its own culture or worldview, similar although usually less daunting cultural barriers to conversation occur all the time, whether clinicians recognize it or not.¹⁶ Some of these clashes have been documented eloquently either by patients and their families or by those who speak on their behalf in such works as *The Long Dying of Baby Andrew*,¹⁷ recounting the prolonged course of a premature baby in a neonatal intensive care unit, and *People Like That Are the Only People Here*,¹⁸ Lorrie Moore's semi-autobiographical story about having a young child with cancer. In both cases, the parent-narrators experienced the health care system as deeply alienating; they were not comfortable with the course of care and felt judged as a result. Medical schools are struggling to find ways to give students and clinicians the tools to surmount these barriers.¹⁹

Clinicians, of course, are not patients' sole sources of information about health and health care. When I see an eighteen-month-old brought in for in-toeing, it is generally not the parent who is primarily concerned. Usually there is a grandmother who, remembering practice in the past, thinks that the child needs orthopedic shoes or even Denis Browne splints. In the intervening years, we have learned that in-toeing is almost always a normal developmental process and that the prior practices are actually harmful. Most children outgrow in-toeing, and most of those who don't, like Michael Jordan, tend to do fine. Yet other "knowledges" like those of the grandmother in this case are ubiquitous in pediatrics. You have to know them in order to address them, but how you act on this knowledge varies. Sometimes it is a matter of advising the parent what to tell the grandmother, and sometimes the best thing to do is to fold your cards.

The health care system itself poses formidable barriers to conversation. Many scholars have written about the role of informed consent in an era of managed care.²⁰ One basic question is if plans will pay only for certain

16. Janelle S. Taylor, *Confronting "Culture" in Medicines' "Culture of No Culture"*, 78 ACAD. MED. 555 (2003).

17. ROBERT STINSON & PEGGY STINSON, *THE LONG DYING OF BABY ANDREW* (1983).

18. LORRIE MOORE, *BIRDS OF AMERICA* (1998).

19. See, e.g., Renee C. Fox, *Cultural Competence and the Culture of Medicine*, 353 NEW ENGL. J. MED. 1316 (2005); Elizabeth K. Kachur & Lisa Altshuler, *Cultural Competence Is Everyone's Responsibility!*, 26 MED. TCHR. 101 (2004).

20. See, e.g., Mark A. Hall, *A Theory of Economic Informed Consent*, 31 GEORGIA L. REV. 511 (1997); Joan H. Krause, *Reconceptualizing Informed Consent in an Era of Health Care Cost*

interventions and if patients tend to use only those therapies for which third party payment is available given the high cost of medical care, what if anything needs to be disclosed about non-covered options? Some argue that disclosing the rationing or allocation strategy at the time of entry into the plan is sufficient, while others urge that the increasing importance of economic incentives and limits of coverage increase the urgency of disclosure at the time when decisions are being made about intervention. No consensus has emerged, and in any event, the pressure on physicians to see more patients, many of whom have multiple medical problems, means that there is often little time to talk.²¹

Twenty years ago, Jay urged that we ought to be able to have more useful dialogue because so much more was known about the etiology of disease and how to treat it. Still more information is available today, but new knowledge does not necessarily promote shared decision-making. Much remains unknown. Indeed, the watchword of today's science is complexity: the recognition that it is never possible to specify all the factors that influence an individual clinical case. As has always been true, clinicians have a hard time keeping up with what actually is known, and as a result, frequently cause injuries that could otherwise have been avoided. In part to help physicians with this flood of information, organizations are now creating tools such as clinical practice guidelines, typically based on rigorous review of the medical literature and expert opinion. These tools, however, rarely give much weight to the importance of patients' wishes and values, usually focusing instead on such readily quantifiable outcomes as longevity, disease-free survival, and the incidence of adverse side effects. Efforts are being made to incorporate measures of patients' opinions into assessments of care,²² but in a time when these instruments increasingly are being used as metrics to assess clinicians' actions, the failure to attend sufficiently to patients' values looms large. Returning to Iphigenia, suppose she had a germline mutation in BRCA1, and the evidence showed that bilateral mastectomy would optimize her chance of disease-free survival. Could there come a time when the medical community would consider her surgeon to be practicing substandard medicine and the hospital and third party payer would penalize him were he to perform a lumpectomy with subsequent radiation? How might this affect their conversation?

Containment, 85 IOWA L. REV. 261 (1999); Susan M. Wolf, *Toward a Systemic Theory of Informed Consent in Managed Care*, 35 HOUST. L. REV. 1631 (1999).

21. The average outpatient visit lasts fifteen to twenty minutes, with longer duration being associated with more testing and admission to the hospital. David Blumenthal et al., *The Duration of Ambulatory Visits to Physicians*, 48 J. FAM. PRAC. 264 (1999); David Mechanic et al., *Are Patients' Office Visits with Physicians Getting Shorter?*, 344 NEW ENGL. J. MED. 198 (2001).

22. Mark Sullivan, *The New Subjective Medicine: Taking the Patient's Point of View on Health Care and Health*, 56 SOC. SCI. MED. 1595 (2003).

The constraints on physicians posed by managed care and evidence-based medicine are simply more recent manifestations of the conflicts of interest that pervade the practice of medicine, which Jay so perceptively but too gently described in his book. Physicians for millennia have promised to be devoted solely to the interest of each particular patient. A few years ago, the institution in which I practice required its practitioners to affirm that we would place our patients' interests above our own. Hundreds of us signed our names on wall coverings, which were then hung in a main hallway to demonstrate our commitment. This, however, is a promise that cannot be kept. Practitioners have always had to balance the demands of any particular patient against the needs of other patients, their families, their communities, and themselves. Clinicians have always been influenced by the broader society for both good and ill, the latter as evidenced by the impact of discriminatory attitudes. Even the issues of cost and effects of reimbursement, so prominent in today's debates about health care, have always been problems. Unless these competing claims and forces are acknowledged, it is not possible to decide how they are to be balanced so that the physician can realistically inform the patient about what care the doctor can and cannot provide.

Here is where, for me, Jay's most important contribution appears. It is easy for physicians to say that patients have all kinds of magical, irrational, contradictory, and counterfactual beliefs and expectations. After all, we say patients are ignorant of medicine and their diseases cause them to regress. It is quite another to admit that physicians are not always rational either. They, too, are influenced by intrapsychic phenomena, such as transference and countertransference. Jay illustrated these influences beautifully in his recounting of the interactions between Dr. Christian Barnard and Philip Blaiberg, in which Barnard asked Blaiberg to undergo the second heart transplant ever attempted in order to help *Barnard* get his confidence back after the death of Louis Washkansky, the first transplant recipient.²³ Happily, Blaiberg did well after his transplant, but it was clear that Barnard was driven to some extent by his own needs. Dr. Barnard is not unique in this regard. Most clinicians have complex reasons for going into medicine. We receive all sorts of gains from our practice, both economic and personal, some of which can affect the ways in which we see or treat our patients.

Physicians have a remarkable ability to deny the forces that influence them. To pick one of my pet peeves, large pharmaceutical companies now spend more than \$12 billion per year on drug detailing, that is, efforts to educate providers about new products. It should be no surprise that this detailing influences

23. KATZ, *supra* note 1, at 130-33.

prescribing.²⁴ Companies do not thrive if they waste money on that grand a scale. Physicians, however, persist in believing that they are unaffected by these practices.²⁵ Although medical associations have issued guidelines that limit detailing and gift giving,²⁶ many physicians see these activities as at worst modestly problematic.²⁷ It is difficult to change behavior if the actors deny its causes.

Medicine also poses numerous stresses, and physicians do not deal with all of these tensions equally well. Physicians often react badly to uncertainty, as Jay documented in his extended colloquy about the history of breast cancer treatment with its heated battles over the appropriate type of surgery.²⁸ He pointed out that clinicians typically are trained to act as if the appropriate interventions are clear. There are two points in that sentence. One is the emphasis on action; it is hard to sit and watch. And acting is more comfortable if one is confident about what one is going to do. But despite the enormous advances in science, uncertainty has not gone away. The topics have changed, the number of questions has grown, and yet the pressure to act and act quickly has increased.

Physicians hate it when their patients do not do well. It can be hard to go talk with someone whose health is declining. As Jay demonstrated in the story of his mother's abandonment by her physician²⁹ and as all clinicians know, the doctor's first response to bad news is typically one of avoidance. This reaction is even stronger when the patient's worsening course is the result of a mistake. While this is hardly surprising, failing to talk with patients makes them very angry. In research we conducted at Vanderbilt University more than a decade ago, parents whose children had suffered perinatal injuries often said that they sued because they believed that information was being withheld or that they simply wanted to find out what had happened. With regard to the physician-patient relationship, the respondents reported that "physicians would not listen (13% of sample), would not talk openly (32%), attempted to mislead them (48%), or did not warn about long-term neurodevelopmental problems (70%)."³⁰ For purposes of

24. Ashley Wazana, *Physicians and the Pharmaceutical Industry: Is a Gift Ever Just a Gift?*, 283 JAMA 373 (2000).

25. Kerry J. Breen, *The Medical Profession and the Pharmaceutical Industry: When Will We Open Our Eyes?*, 180 MED. J. AUSTL. 409 (2004).

26. Am. Med. Ass'n, *Ethical Opinions and Guidelines on Gifts* (2004), <http://www.ama-assn.org/ama/pub/category/4001.html> (last visited August 30, 2004).

27. Allan S. Brett et al., *Are Gifts from Pharmaceutical Companies Ethically Problematic? A Survey of Physicians*, 163 ARCHIVES INTERNAL MED. 2213 (2003).

28. KATZ, *supra* note 1, at 175-84.

29. *Id.* at 223-24.

30. Gerald B. Hickson et al., *Factors That Prompted Families to File Medical Malpractice Claims Following Perinatal Injuries*, 267 JAMA 1359 (1992).

understanding why people sue, claimants' perceptions are all that matter. As Marshall McLuhan might say in this setting, "perception is reality." But in all likelihood, these complaints contained more than a grain of truth.

The first step to addressing the barriers to communication that physicians face is to recognize their presence. As Jay so clearly instructed, this can only be achieved by self-reflection. Even then, a person's ability to know what motivates her will always be incomplete. There are clues, though, to when the doctor should try harder. The most powerful clue is a desire to avoid conversation, a feeling that often indicates that more dialogue is needed.

But here is where the rub really comes. For most physicians, and I include myself here, the kind of respectful, self-aware attention to the needs and interests of patients that Jay called for is simply not possible much of the time. The easy excuses are that the medical system is not set up to accommodate prolonged mutual exploration of options and that the costs in terms of lost revenues would be exorbitant. Jay explicitly declined to consider the issue of costs at any length,³¹ but he did point out the costs of not talking can be high as well.

The more difficult problem is that most of us simply do not have adequate communication skills or the thoroughgoing respect for others that Jay would have us demonstrate. These are goals to which we should aspire, but I would suggest, perhaps heretically, that this is a promise that cannot be fulfilled. We humans generally lack the capacity to achieve that level of awareness of self and other even in our closest relationships, to say nothing of across the gulf between physician and patient. In this regard, Jay's vision of informed consent raises some of the same magical expectations of care that he so clearly identified and urged us to challenge.

There also are competing interests that legitimately interfere with the ability to meet the needs of individual patients. Other patients have needs as well, for both attention and resources. Allocation is necessary in medicine as in all other aspects of life, but the fear of the "r" word—rationing—has made it difficult to engage in reasoned analysis. In addition, Jay acknowledged that physicians' personal needs can conflict with and, on occasion, even justify overriding the wishes of patients.³² Attempting to address the psychosocial aspects of medicine can be exhausting and is certainly among the most challenging parts of practice. I have found that I can attend effectively on the inpatient service of the hospital for only a few weeks at a time. The time commitment of being on call is difficult, but it pales in comparison to trying to meet the emotional, educational, and medical needs of patients, their families, residents, and students. These efforts take a toll on family, friends, and other obligations. Every day is a lesson in humility,

31. KATZ, *supra* note 1, at 227-28.

32. *Id.* at 162-63.

especially if one thinks about the goals that Jay set for us.

The most thoughtful physicians I know squirm when they read Jay's work. The more thoughtful they are, the more they squirm. If you think about it, the job of attending to the emotional aspects of clinical care is impossible. We are parts of a complex network, and our ability to act is both constrained and enabled by forces in and outside of ourselves. Autonomy is relative, not absolute. Jay described numerous problems and vast silences. More have emerged since he wrote *The Silent World*, only some of which I have addressed in this paper. And while the law has at least brought attention to the issue of informed consent and scared physicians half to death, it actually has done little to protect patients' interests in shared decision-making. The courts do not award compensation for dignitary injuries alone, which are the primary result of silence. State legislatures, in general, have been even less protective of patients' interests, enacting explicit but limited criteria for what needs to be disclosed. And lawyers have created a sea of consent forms that sinking patients rarely read. As Jay clearly pointed out, courts speak of "reasonable physicians" and "reasonable patients" when the real world issues are always about individuals who exhibit both reason and unreason and who fail to communicate.

But in closing, I would like to point to more positive aspects of the physician-patient relationship, which can promote at least some aspects of the care to which Jay aspires. In this regard, the web in which we live and work can support our interactions with patients. Here, I will speak primarily from my own experience as an academic general pediatrician. It is really wonderful when your patients get better, especially when something you did helped the process. (One of the reasons I like pediatrics is that kids have an amazing ability to get better no matter what you do.) And getting to talk with children and parents can be a real joy. Somewhere I heard that children do better in school if their physicians ask them about how they are doing and find something to praise. I do not know if this works or not, but it sure is fun, and it gives parents a chance to brag about their kids and kids a chance to be acknowledged by another adult in front of their parents. I encourage all the residents and students I work with to do this as well. As the possibility of conversation increases with a child's age, it is gratifying to help adolescents deal with injury, illness, and normal development. This is a setting where it can be emotionally fulfilling to talk with a teenager!

Many of the greatest rewards come from talking with parents. Often, the issues seem minor from a medical perspective, but for the parents, they can be emotionally draining. A while ago, I saw a young girl with a unilateral tender breast mass. Puberty now occurs earlier in childhood and usually begins with breast development, which is often asymmetric. Most mothers do not remember every aspect of their own bodily transformation. A brief conversation revealed that this mother was worried that her daughter had breast cancer. The child was

not yet a reader, so I said simply, "It is extremely unlikely that your child has C-A-N-C-E-R." You can imagine the relief that came over the mother's face. We then went on to talk about what was probably happening and to develop a plan for follow up.

The practice of pediatrics is about empowering children and their families. Most of the time, sick children are not in the hospital. They may come to the pediatrician to find out what is wrong, but what happens next requires collaboration between parent and physician. The doctor can prescribe an antibiotic for a bacterial infection, but she will not be the one to give it. The parent may not be able to afford the medicine, may not have the time to go get it or give it (it is hard to administer medications four times a day when you work outside the home and your child goes to school), may doubt the efficacy of that particular drug (Joey did not get better on amoxicillin last time), or may be pursuing alternative interventions at the same time. All these factors have to be negotiated. Older children are part of the mix as well. The young teen with asthma needs to take his medications and to let his parents know when he develops breathing problems so that they can seek care in a timely fashion. This can be a challenge given the psychological issues that often attend adolescence. Collaboration is important even when children are in the hospital. Parents can provide critical emotional support for their child. They can help mediate the interactions between their child and the host of providers they encounter. And sometimes, parents discover mistakes, either after or preferably before they occur.

Why do we do all this talking and negotiating? The reasons are complex and vary in their nature. Some are deontological, some are utilitarian, and some are personally reinforcing for the physician. Talking is the right thing to do. Medical care implicates values and concerns that can only be elicited through conversation. Collaboration leads to better outcomes. Parents and children are calmer and more adherent to the course of action ultimately agreed upon. Communication can be gratifying all by itself. It makes me feel good when I connect with a parent or a child.

What it comes down to is this. Despite the advances in technology, medicine is still intensely personal. Computer interviewing is making inroads, but human beings are still better at getting the history of what patients are experiencing, which remains a key to diagnosis. Even though patients and their families now have unparalleled access to information through the Web and other places, they frequently prefer to receive counseling from a clinician.³³ Respectful shared

33. Michael J. Green et al., *Effect of a Computer-Based Decision Aid on Knowledge, Perceptions, and Intentions About Genetic Testing for Breast Cancer Susceptibility: A Randomized Controlled Trial*, 292 JAMA 442 (2004).

decision-making is difficult, and truthfully, impossible much of the time. The networks in which physicians and patients live both impede and promote needed conversation. Jay's great gift to us is that he identified some of the barriers and potholes so we can try to do better.

Response

From Tragedy to Catastrophe: Lawyers and the Bureaucratization of Informed Consent

Alan Meisel, J.D.*

I have not seen Jay in more than ten years—when he accepted an invitation to speak in Pittsburgh. I also have not thought about informed consent much in the last ten or fifteen years, with the exception of a single moment of weakness when I succumbed to a colleague's entreaties to co-author a paper on the subject a few years ago. My ambivalence about informed consent has nothing—and everything—to do with Jay. My reluctance to continue to engage the subject resulted from my belief that everything important to say about informed consent had already been said, endless times, and by people far wiser than I, most notably Jay Katz. And, so I thought, not only had everything been said, so little had been achieved—at least judging from my own experiences with doctors, both as a patient and as a teacher, and the reports of friends and family members. Having read Ellen Wright Clayton's paper, *The Web of Relations: Thinking About Physicians and Patients*,¹ I can see that I was wrong. Not everything had been said.

For me to talk about informed consent is therefore a labor of love. A labor of love out of respect for a doctor—in the original meaning of the word: teacher—who kindled a flame in me possibly before he had even heard of informed consent himself.

Long ago and in another century when I was a sophomore or junior at Yale, Branford College, of which I was a resident, sponsored an evening lecture. Whatever its title was, it was enticing enough to assure my attendance, where I heard a speaker talk about something, to use the parlance of the time, that really turned me on.

A few years later, when beginning my second year of law school within the

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1. Ellen Wright Clayton, *The Web of Relations: Thinking About Physicians and Patients*, 6 YALE J. HEALTH POL'Y L. & ETHICS 465 (2006).

walls of Yale, and needing another course to register for, I ran across one called "Experimentation with Human Beings." The professor's name immediately rang a responsive chord; it was that gentleman whose talk I had enjoyed a few years earlier at Branford. I registered for that seminar. And that's why I'm here today, rather than working on Wall Street. The year was 1970, thirteen years after the first case to use the term "informed consent," the *Salgo* case,² but still a couple of years before *Canterbury v. Spence*,³ *Cobbs v. Grant*,⁴ and the tidal wave of informed consent litigation that they spawned.

In *Silent World*, Jay recognizes the distinction between the *idea* of informed consent and the *legal doctrine* of informed consent.⁵ This paper discusses another chapter in the tale of informed consent. Jay wrote so eloquently about what happened to the idea of informed consent when it fell into the hands of lawmakers. This response discusses what happened to the legal doctrine of informed consent when it fell into the hands of lawyers and health care managers.

In her paper, Ellen Wright Clayton observed that "[h]appily, the notion of shared decision-making has made sufficient inroads today that it would be uncommon to find a chorus of physicians who would publicly admit that it was crazy to let Iphigenia make her own choice."⁶ Shared decision-making is certainly more common than it was two decades ago, but like Clayton, I seriously doubt that it is anything like the universally operative paradigm. I would venture to guess that, in fact, it is still a fairly rare bird. Rather, what commonly passes for informed consent today is often a withered and bureaucratized version of shared decision-making. What passes for informed consent today is too often the same as it was twenty, thirty, or forty years ago—namely: "sign here." Except, rather than signing the single piece of paper of a generation or two ago, patients are now asked to sign a novel-, or at least a novella-, length document.

We moved from the lofty idea of informed consent circa 1960, to the informed consent form, in a quarter century, give or take a few years—a cautionary tale if there ever was one. In fact, as early as 1966, early enough to be included in Jay's *Experimentation with Human Beings*, a physician gave us a humorous example of what was to come:

Consent Form for *Hernia* Patients:

2. *Salgo v. Leland Stanford Jr. Univ. Bd. of Trs.*, 317 P.2d 170 (Cal. Ct. App. 1957).

3. *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972).

4. *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972).

5. JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 48-84 (Johns Hopkins Univ. Press 2002) (1984) [Hereinafter KATZ, *SILENT WORLD*].

6. Ellen Wright Clayton, *The Web of Relations: Thinking About Physicians and Patients*, 6 YALE J. HEALTH POL'Y L. & ETHICS 465, 466-67 (2006).

...

Operative procedure is as follows: The doctor first cuts through the skin by a four-inch gash in the lower abdomen. He then slashes through the other things—fascia (a tough layer over the muscles) and layers of muscle—until he sees the cord (tube that brings the sperm from testicle to outside) with all its arteries and veins. The doctor then tears the hernia (thin sac of bowels and things) from the cord and ties off the sac with a string. He then pushes the testicle back into the scrotum and sews everything together, trying not to sew up the big arteries and veins that nourish the leg.⁷

He then set out fifteen possible complications, including such things as: “[l]arge artery may be cut and I may bleed to death . . . [,] tube from testicle may be cut. I will then be sterile on that side . . . [, and] I may be run over going to the hospital.” Following that list, there are signature lines for the patient, the patient’s lawyer, the lawyers for the hospital, the doctor, the anesthesiologist, and to underscore the absurdity, a signature line for the patient’s mother-in-law.⁸

In *Silent World*, Jay was concerned about the gulf between the idea of informed consent and the manner in which courts had translated this idea into legal rules—rules that go far in undermining the idea itself. If the manner in which the law undermines the idea of informed consent through such aspects of the legal doctrine as the standard of disclosure, the materialized risk requirement, and the therapeutic privilege, to name just a few, is a tragedy, what has been done in the name of operationalizing informed consent by lawyers and health care managers is a catastrophe. The courts (and later the legislatures) may have eviscerated the idea of informed consent, but they left it to the health care managers—and the lawyers who counsel them—to bury the eviscerated remains.

Consider as an example the question that has been asked countless times by every attending to every resident: “Did you get the patient consented?” I don’t know what is more dispiriting: the language which treats the patient as an object rather than a subject and transforms what should be a process into an event (and butchers the English language all at the same time); or the fact that it is the house staff who play the major role in this process, or event, or whatever one calls it—rather than the senior attending physician who should be doing it and modeling it for the house staff.

Informed consent in practice today is certainly different from the simple, paternalistic days of yore that Jay decried in *Silent World*. I hope and believe that, on balance, more of today’s physicians make a genuine effort to provide

7. Preston J. Burnham, *Medical Experimentation on Humans*, 152 SCIENCE 448 (1966), reprinted in JAY KATZ, *EXPERIMENTATION WITH HUMAN BEINGS* 659 (1972).

8. *Id.*

patients with information about their options. But different is not necessarily better. The aim of informed consent, as it has been translated into action in the clinical setting today, is just an updated and more sophisticated version of its precursor in the traditional doctor-patient relationship: to make the patient reliant on the doctor; to assure that the doctor's wishes will prevail, and that the patient will not independently develop wishes or that any such wishes will not become manifest.

In the good old paternalistic days, this goal was achieved in significant part by nondisclosure and possibly by a reassuring statement from the doctor such as, "Let me worry about that." Today, the form has changed—indeed, it has changed 180 degrees—but the message is the same. Today, the byword is disclosure—but the doctor's purpose is often the same. Thus, the emphasis is on "getting the patient consented"—i.e., getting a signed consent form for the intern to bring back to the resident like a set of antlers from a safari. Often, informed consent takes the form of a medical *Miranda* warning in which risk disclosure substitutes for conversation. That way, if something goes wrong, it is the patient's responsibility and not the doctor's. This converts an affirmative duty of doctors into a defense of assumption of risk against patients.

By contrast, informed consent can be viewed as a medical cafeteria, in which the options are laid out in front of the patient and the patient directed to choose. What is missing from this picture is a lack of advice by the doctor, an abdication of moral responsibility just as surely as failing to disclose would be. Alternatively, informed consent can become an exercise in "information dumping." Overload the patient with information, thereby complying with the letter of the law but undermining the idea of informed consent. And putting it in writing reduces the chance of discussion even more. Finally, the *idea* of informed consent—as well as the more modest goals of the law—can readily be subverted by providing information but providing it at a level of complexity aimed at undermining understanding rather than enhancing it.

Twenty years ago, Jay set forth a vision of a better world and of a better doctor-patient relationship. He pointed out to us—among other things—the tragedy of what the law had done to a noble idea. Today, twenty years later, in some respects things have gotten worse.

What or who is responsible for this? Doctors are the usual whipping-boys, being frequently criticized, as I have done, for their wooden approach to providing information to patients. In fairness, most times they are just following lawyers' orders, either their own lawyers or hospital or nursing home lawyers—to get it in writing and to give it in writing, too. The lawyer's standard advice—"Document it; if it's not in writing, it didn't happen"—sometimes comes directly from a lawyer; other times it is filtered through institutional health care managers.

Not only, as Ellen Wright Clayton observed, does medicine have *its* own culture or world view which creates barriers to conversation,⁹ so too does the culture of lawyers. Part of this culture—especially when giving advice to clients about matters to be carried out repeatedly, over indefinite periods of time, and by many people—tends towards the bureaucratic. So if the handiwork of judges and legislators is not enough to undermine the idea of informed consent, the handiwork of lawyers and their clients—health care managers through whose hands lawyers’ advice passes—administers the coup de grace. The awkwardly and hopefully named “informed consent form” epitomizes this. As lawyers became increasingly aware of the necessity for doctors not only to obtain consent from patients but first to provide them with information that can be used in making a decision whether to consent or not, lawyers rightly advised their clients—both individual health care professionals and health care institutions—to disclose this kind of information. But instead of focusing on the goals that the requirement of obtaining informed consent sought to promote—patient self-determination, informed decision-making, and protection from harm chief among them¹⁰—lawyers instead focused on *documenting* whether information had been disclosed, even if in fact it had not been. Thus the centerpiece of informed consent became the consent form rather than the process of disclosure—and the opportunity it provided for discussion between physician and patient.

The challenge for us—twenty years after the publication of *Silent World*, almost fifty years since the phrase informed consent was first uttered in a judicial opinion—is how to reclaim Jay’s vision and make it a reality. I am afraid that we as doctors, as lawyers, and as health care managers still have much for which to strive in order to achieve that vision.

Those of us in legal education—especially those of us who were inspired by Jay—have a special responsibility to him and to his intellectual legacy, not to mention to patients and even to doctors. Our responsibility is to educate the next generation of lawyers to practice law—especially to counsel clients—with as much wisdom as Jay urged physicians to use to counsel patients. Perhaps then, the next generation of lawyers can begin to contribute to a genuine collaboration between doctors and patients. I can think of no more fitting a way to honor Jay from all of us—his daughters and sons in law.

9. Clayton, *supra* note 1.

10. See JAY KATZ, *SILENT WORLD*, *supra* note 5.

Response

Doctor and Patient: An Unfinished Revolution

Susan M. Wolf, J.D.*

The second half of the twentieth century saw an attempt to revolutionize the doctor-patient relationship. Jay Katz's work has been pivotal.¹ Professor Katz himself has dubbed his proposal to upend millennia of Hippocratic silence and paternalism "radical."² Radical it is, trading physician silence for openness even about the physician's uncertainty, substituting joint decision-making by doctor and patient for physician solo decision-making, and in cases of conflict recognizing the patient's dominion over her own body.

Just how radical this proposal is has become even more apparent since Katz published *The Silent World of Doctor and Patient*³ in 1984.

First, a raft of empirical research has documented continued physician

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1. JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* (Johns Hopkins Univ. Press 2002) (1984) [hereinafter KATZ, *THE SILENT WORLD*]; Jay Katz, *Disclosure and Consent: In Search of Their Roots*, in *GENETICS AND THE LAW II*, at 121 (Aubrey Milunsky & George J. Annas eds., 1980); Jay Katz, *Informed Consent: Legal and Ethical Aspects*, in 2 *ENCYCLOPEDIA OF BIOETHICS* 770 (Warren T. Reich ed., 1978); Jay Katz, *Informed Consent—A Fairy Tale? Law's Vision*, 39 U. PITT. L. REV. 137 (1977); Jay Katz, *Informed Consent: Must It Remain a Fairy Tale?*, 10 J. CONTEMP. HEALTH L. & POL'Y 69 (1993) [hereinafter Katz, *Informed Consent: Must It Remain a Fairy Tale?*]; Jay Katz, *Limping Is No Sin: Reflections on Making Health Care Decisions*, 6 CARDOZO L. REV. 243 (1984); Jay Katz, *Physician-Patient Encounters "On a Darkling Plain"*, 9 W. NEW ENG. L. REV. 207 (1987); Jay Katz, *Why Doctors Don't Disclose Uncertainty*, HASTINGS CENTER REP., Feb. 1984, at 35.

2. Katz, *Informed Consent: Must It Remain a Fairy Tale?*, *supra* note 1, at 84.

3. KATZ, *THE SILENT WORLD*, *supra* note 1.

reluctance to talk to patients about treatment options.⁴ Data further show physician failure to follow patient preferences, even when explicitly articulated orally or in writing.⁵ The definitive study remains the Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatments (SUPPORT) by Joanne Lynn, Joan Teno, and colleagues.⁶ The SUPPORT research shows that

4. Alfred F. Connors et al. (The SUPPORT principal investigators), *A Controlled Trial To Improve Care for Seriously Ill Hospitalized Patients*, 274 JAMA 1591, 1595 (1995) (finding that even the SUPPORT intervention did not increase the proportion of patients or surrogates who succeeded in having a discussion with their doctor about end-of-life treatment choices); Jan C. Hofmann et al., *Patient Preferences for Communication with Physicians About End-of-Life Decisions*, 127 ANNALS INTERNAL MED. 1 (1997) ("Physicians . . . are frequently unaware of patient preferences for end-of-life care; this suggests that communication about these issues may be inadequate."); Harlan M. Krumholz et al., *Resuscitation Preferences Among Patients with Severe Congestive Heart Failure*, 98 CIRCULATION 648, 653 (1998) ("Despite the fact that these patients were very ill and their physicians expected many of them to die within the next 2 months, we found that only about one quarter of the patients and physicians reported that they had discussed resuscitation issues.").

5. Connors et al., *supra* note 4, at 1596 ("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."); Marion Danis et al., *A Prospective Study of Advance Directives for Life-Sustaining Care*, 324 NEW ENG. J. MED. 882 (1991) (finding that advance directives may be ignored or overridden in the clinic); Paul Haidet et al., *Outcomes, Preferences for Resuscitation, and Physician-Patient Communication Among Patients with Metastatic Colorectal Cancer*, 105 AM. J. MED. 222, 227 (1998) ("Where a conversation between physician and patient was reported, physician understanding of patients' preferences was not better than in those instances when such a conversation had not occurred."); Joan M. Teno et al., *Do Advance Directives Provide Instructions That Direct Care?*, 45 J. AM. GERIATRICS SOC'Y 508 (1997) [hereinafter, Teno et al., *Do Advance Directives Provide Instructions That Direct Care?*] (suggesting that advance directives do not help communication and do not guide medical decision-making); Joan M. Teno et al., *Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients?*, 5 J. CLINICAL ETHICS 23 (1994) [hereinafter Teno et al., *Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients?*] (finding that advance directives did not affect decision-making on resuscitation for seriously ill patients).

6. The SUPPORT team has published a number of studies. See, e.g., Connors et al., *supra* note 4 (suggesting that enhancing communication between doctors and patients may not be enough to change end-of-life practices); Kenneth E. Covinsky et al., *Communication and Decision-Making in Seriously Ill Patients: Findings of the SUPPORT Project*, 48 J. AM. GERIATRICS SOC'Y S187-93 (2000) (reviewing the published articles from SUPPORT and concluding that there is poor communication between patients, physicians, and surrogates but that deficiencies in communication are not likely to be corrected by a simple intervention); Hofmann et al., *supra* note 4 (showing that most patients do not discuss end-of-life options with physicians even though they may want to do so); Russell S. Phillips et al., *Findings from SUPPORT and HELP: An Introduction*, 48 J. AM.

even when patients express their preferences about big-ticket items such as life-sustaining treatment, and even when the patient is assigned a nurse-advocate to champion those preferences, it does not work.⁷ Physicians continue marching down the treatment path they choose.

Moreover, there is reason to fear that the gulf between doctor and patient and the barriers to change are even worse when the physician is white and the patient is a person of color.⁸ Study after study shows physicians offering fewer treatment

GERIATRICS SOC'Y S1 (2000) (demonstrating that physicians often do not know patients' preferences); Teno et al., *Do Advance Directives Provide Instructions That Direct Care?*, *supra* note 5 (explaining that advance directives do not help communication); Teno et al., *Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients?*, *supra* note 5 (stating that advance directives did not affect decision-making); see also Dale G. Larson & Daniel R. Tobin, *End-of-Life Conversations: Evolving Practice and Theory*, 284 JAMA 1573 (2000).

7. See Connors et al., *supra* note 4, at 1595–98.

8. See, e.g., COMM. ON UNDERSTANDING & ELIMINATING RACIAL & ETHNIC DISPARITIES IN HEALTH CARE, INST. OF MED., *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE* 1 (2003) [hereinafter INST. OF MED.]; MOREHOUSE MED. TREATMENT & EFFECTIVENESS CTR., MOREHOUSE SCH. OF MEDICINE, *A SYNTHESIS OF THE LITERATURE: RACIAL AND ETHNIC DIFFERENCES IN ACCESS TO MEDICAL CARE* (1999), available at <http://www.kff.org/minorityhealth/upload/A-Synthesis-of-the-Literature-Racial-Ethnic-Differences-in-Access-to-Medical-Care-Report-2.pdf>; Lisa A. Cooper et al., *Patient-Centered Communication, Ratings of Care, and Concordance of Patient and Physician Race*, 139 ANNALS INTERNAL MED. 907 (2003) (finding that race-concordant visits are longer and characterized by more patient-positive affect compared with race-discordant visits); Lisa Cooper-Patrick et al., *Race, Gender, and Partnership in the Patient-Physician Relationship*, 282 JAMA 583 (1999) (finding that African Americans rate their interactions with white physicians as less participatory); Warren J. Ferguson & Lucy M. Candib, *Culture, Language, and the Doctor-Patient Relationship*, 34 FAM. MED. 353, 359 (2002) (“Minority patients, especially those not proficient in English, are less likely to engender empathic responses from physicians, less likely to establish rapport with physicians, less likely to receive sufficient information, and less likely to be encouraged to participate in medical decision making.”); Hofmann et al., *supra* note 4, at 9 (“[J]ust as nonwhites receive less intensive use of resources . . . they may also be less likely to have their needs met for discussions about care preferences at the end of life.”); Nancy L. Keating et al., *Patient Characteristics and Experiences Associated with Trust in Specialist Physicians*, 164 ARCHIVES INTERNAL MED. 1015, 1017 (2004) (finding that black patients were 18% less likely to develop a completely trusting relationship with their specialist than white patients); Thomas A. LaVeist & Tamyra Carol, *Race of Physician and Satisfaction with Care Among African-American Patients*, 94 J. NAT'L MED. ASS'N 937 (2002) (“[P]atients who were race concordant reported higher levels of satisfaction with care compared with African American patients that were not race concordant. . . .”); Thomas A. LaVeist & Amani Nuru-Jeter, *Is Doctor-Patient Race Concordance Associated with Greater Satisfaction with Care?*, 43 J. HEALTH & SOC. BEHAV. 296, 303 (2002) (finding that patients are more satisfied with physicians of their own race than with a physician of a different race); David R. Levy, *White*

options, performing fewer treatment interventions, and listening less. The results are poorer health outcomes, psychological and physical harm, and dignitary insult.

Meanwhile, old-style Hippocratic practice remains remarkably entrenched in many quarters. Witness an article published by the *New York Times* science section in 2004. A physician offered a case report entitled *Give Up? No Way. On a Matter of Life or Death, a Patient Is Overruled*.⁹ The article recounted a physician's decision to order an assault on a competent patient, who had persistently stated over the course of several days that he did not want to be intubated. This patient had earlier suffered a heart attack followed by cardiac catheterization. When aggressive use of blood thinners filled the patient's lungs with blood and compromised his breathing, the physician authoring this case report decided to override the patient's express rejection of intubation. "As an experienced doctor, wasn't I in a better position to make Mr. Smith's decision than Mr. Smith?"¹⁰ This is classic Hippocratic paternalism, favoring the physician's assessment of what will serve the patient's well-being over the patient's choice. As the medical team forcibly intubated the patient and then put in a central line, Mr. Smith predictably became violent. What followed was a "rocky hospital course" requiring two weeks on the ventilator.¹¹ For that entire time, the physician who ordered the intubation avoided the patient's bedside. It was only after the tube was finally removed that the physician summoned the courage to go see the patient. Remarkably, the physician admits that, "[w]hen I went to see him, I realized I had never really looked at him as a person."¹²

Resistance to overturning Hippocratic paternalism is not limited to physicians. Judges have fallen prey as well. Katz famously diagnosed judicial ambivalence and resistance in the case law on informed consent.¹³ As he

Doctors and Black Patients: Influence of Race on the Doctor-Patient Relationship, 75 PEDIATRICS 639 (1985) (describing racial difference that may affect the doctor-patient relationship and the impact racism may have on black patients); see also Earl Ford et al., *Coronary Arteriography and Coronary Bypass Surgery Among Whites and Other Racial Groups Relative to the Hospital-Based Incidence Rates for Coronary Artery Disease: Findings from NHDS*, 79 AM. J. PUB. HEALTH 437 (1989) (finding that black men are only half as likely to undergo angiography and one third as likely to undergo bypass surgery as white men); Charles Maynard et al., *Blacks in the Coronary Artery Surgery Study (CASS): Race and Clinical Decision Making*, 76 AM. J. PUB. HEALTH 1446 (1986) (finding that surgery is recommended for whites more often than blacks).

9. Sandeep Jauhar, *Give Up? No Way. On a Matter of Life or Death, a Patient Is Overruled*, N.Y. TIMES, Oct. 5, 2004, at F5.

10. *Id.*

11. *Id.*

12. *Id.*

13. KATZ, *THE SILENT WORLD*, *supra* note 1, at 48–84.

recounts, Justice Cardozo's breakthrough announcement in 1914 that "every human being of adult years and sound mind has a right to determine what shall be done with his own body"¹⁴ was followed by decades of physician and judicial silence. It was mid-century before judges returned to the question of the patient's right to decide and thus entitlement to information material to the decision.¹⁵ Even then, it was slow going. Not until the 1972 decision in *Canterbury v. Spence* did a court robustly articulate the physician duty of informed consent,¹⁶ and that decision, too, shows great ambivalence over tampering with physician custom and discretion.¹⁷ Post-*Canterbury* many state legislatures rushed to protect physicians from what changes the courts managed to demand.¹⁸

Judicial ambivalence continues to this day. Witness *Arato v. Avedon*, decided twenty-one years after *Canterbury*.¹⁹ Mr. Arato was a forty-two-year-old husband and father diagnosed with pancreatic cancer. Despite seventy visits to the oncologist, he was never told the dismal survival statistics associated with his cancer. Nor was he told when the physicians offered him a rigorous chemotherapy and radiation regimen that had "shown promising response rates" in experimental trials that this regimen would at best extend his life a few months.²⁰ After Mr. Arato's death his wife and children sued, arguing that his physicians had failed to disclose information material to his treatment decision, with the result that his consent was not informed. The upshot, they claimed, was that he undertook treatment he would otherwise have declined and, harboring false hope, never settled his business affairs. Consequently, at his death his business failed, to his family's detriment.

The issue on appeal was the adequacy of the trial court's jury instructions, which spoke only generally of physician duties to provide material information and gave no guidance on whether mortality statistics were material. What most clearly reveals the court's continuing ambivalence toward disrupting physician custom by requiring disclosure, however, is the court's treatment of the physicians' defense.

Dr. Avedon, the chief oncologist, defended withholding mortality rates, even

14. *Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

15. *Salgo v. Leland Stanford Jr. Univ. Bd. of Trs.*, 317 P.2d 170 (Cal. Dist. Ct. App. 1957); see also KATZ, *THE SILENT WORLD*, *supra* note 1, at 60–65.

16. *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972).

17. KATZ, *THE SILENT WORLD*, *supra* note 1, at 71–80 (commenting on *Canterbury*'s ambivalent approach to the therapeutic exception, among other issues).

18. See 1 BARRY R. FURROW ET AL., *HEALTH LAW* 413 & n.7 (1995) (noting that over twenty-five states adopted a standard for disclosure based on physician custom despite *Canterbury*'s rejection of that standard); KATZ, *THE SILENT WORLD*, *supra* note 1, at 81–82.

19. 858 P.2d 598 (Cal. 1993).

20. *Id.* at 600.

though Mr. Arato had indicated on an office intake questionnaire that he wanted to be told “the truth.”²¹ The physician argued that he did not want to deprive his cancer patients of a hope of cure, no matter how misplaced that hope might be. He did not want to give his patients “a cold shower.”²² Further, the physician claimed that statistical life expectancy data described the experience of aggregates. He claimed that those group statistics had little predictive value for the individual patient. Dr. Avedon argued that discovering Mr. Arato’s cancer early, in the course of an unrelated surgery, plus the location of the tumor on the distal portion of the pancreas, suggested a better prognosis than the statistics indicated.²³

The physician failed to address the fact that statistics are always about aggregates and serve only as a starting point for discussion. The physician has to help the patient interpret the persuasiveness of the statistics (depending on how recent the studies are, sample size, whether multiple studies have produced numbers that agree, and other factors). Then the doctor has to address whether the patient’s case suggests better or worse odds than the aggregates studied. Statistics are the crucial starting point for this conversation, not the end point.

The court nonetheless bought the physician’s defense hook, line, and sinker. Without questioning already settled law that the physician had to disclose all material information to obtain effective consent, the court proclaimed its commitment to avoiding the “extremes of ‘patient sovereignty’ and ‘medical paternalism.’”²⁴ Yet the court then embraced every paternalistic argument offered by the defense. “Statistical morbidity values derived from the experience of population groups are inherently unreliable.”²⁵ They “offer little assurance regarding the fate of the individual patient.”²⁶ Treating these statistics as “conclusive” suggests “medical abdication of the patient’s well-being.”²⁷

As always, the court’s language is revealing. It suggests that the physician should convey what is reliable and assuring, not something as probabilistic and unsettling as survival statistics. Further, the physician should serve the patient’s well-being as the physician conceives it, not a particular patient’s express wish for the truth.

This is a throwback to old-style, paternalistic practice. It ignores the fact that part of a doctor’s job is giving bad news. Surely, that is part of an oncologist’s

21. *Id.*

22. *Id.* at 601.

23. *Id.*

24. *Id.* at 606.

25. *Arato v. Avedon*, 858 P.2d 598, 607 (Cal. 1993).

26. *Id.*

27. *Id.*

job, especially if he is then seeking informed consent to burdensome treatment, as in this case. Physicians need training and may need help to do this well, but retreating from the challenge is lapsing back into the Hippocratic silence that Katz decries. There is no doubt that sustaining a patient's hope and ability to function in the face of bad news is a challenge, but a vast literature now speaks to the skill of doctors and other health professionals in doing just that.²⁸ Further, many studies have documented the public's wish for honest information, even if the news is dire.²⁹ Without that information, it is hard to see how terminal patients could make medical decisions, cope, make peace with family and friends, and settle their affairs. Indeed, this is precisely what Mr. Arato's family complained of in their suit, namely that withholding the facts about how bad his prognosis was deprived Mr. Arato of the chance to do those things.

28. See, e.g., J.T. Ptacek & Tara L. Eberhardt, *Breaking Bad News: A Review of the Literature*, 276 JAMA 496 (1996); Michael W. Rabow & Stephen J. McPhee, *Beyond Breaking Bad News: How To Help Patients Who Suffer*, 171 W.J. MED. 260 (1999); Ronald P. Strauss et al., *Physicians and the Communication of "Bad News": Parent Experiences of Being Informed of Their Child's Cleft Lip and/or Palate*, 96 PEDIATRICS 82 (1995). A substantial literature offers improved methods of disclosing bad news to patients. See, e.g., Walter F. Baile et al., *SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer*, 5 ONCOLOGIST 302 (2000); Afaf Girgis & Rob W. Sanson-Fisher, *Breaking Bad News 1: Current Best Advice for Clinicians*, 24 J. BEHAV. MED. 53 (1998) [hereinafter Girgis & Sanson-Fisher, *Current Best Advice*]; Afaf Girgis & Rob W. Sanson-Fisher, *Breaking Bad News: Consensus Guidelines for Medical Practitioners*, 13 J. CLINICAL ONCOLOGY 2449 (1995).

29. See, e.g., V. Jenkins et al., *Information Needs of Patients with Cancer: Results from a Large Study in UK Cancer Centres*, 84 BRIT. J. CANCER 48, 49 (2001) (reporting that 87% of 2331 patients surveyed said that they would prefer "to have as much information as possible, both good and bad"); H. Miyata et al., *Disclosure Preferences Regarding Cancer Diagnosis and Prognosis: To Tell or Not To Tell?*, 31 J. MED. ETHICS 447, 449 (2005) (finding that 86.1% of cancer patients surveyed in Japan indicated they desired full disclosure); Martin H.N. Tattersall et al., *The Take-Home Message: Patients Prefer Consultation Audiotapes to Summary Letters*, 12 J. CLINICAL ONCOLOGY 1305, 1307 (reporting that 171 of 182 cancer patients enrolled in the study "wanted all information, good or bad"); see also L.J. Fallowfield, *Truth May Hurt But Deceit Hurts More: Communication in Palliative Care*, 16 PALLIATIVE MED. 297, 302 (2002) ("There is little or no convincing evidence supporting the contention that terminally ill patients who have not been told the truth of their situation die happily in blissful ignorance."); Girgis & Sanson-Fisher, *Current Best Advice*, *supra* note 28, at 53 (discussing the increase over the last forty years in the number of patients who want to know about their diagnosis). For a highly influential study of patients' preferences see generally Louis Harris et al., *Views of Informed Consent and Decisionmaking: Parallel Surveys of Physicians and the Public*, in 2 PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMEDICAL & BEHAVIORAL RESEARCH, MAKING HEALTH CARE DECISIONS: THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP 17 (1982).

Moreover, communicating the facts of Mr. Arato's prognosis virtually required that his doctors articulate the survival statistics for Mr. Arato's type of cancer and the expected impact of the chemotherapy/radiation regimen offered. The fact that less than five percent of patients with pancreatic cancer survived at least two years and that the regimen would at best give him only a few extra months was material.

On the physician's side of the table, no oncologist would seriously consider treating cancer patients without careful attention to survival statistics. Such statistics are basic to oncology decisions.³⁰ All of medicine is moving toward evidence-based practice and increased attention to data in an effort to improve care.³¹ Rejecting the statistics also means rejecting the trend toward evidence-based medicine, a trend overwhelmingly seen as essential to eliminating inappropriate variation in practice patterns and to improving care. To be sure, statistics are based on the experience of population groups, but that is precisely what makes those statistics reliable. One cannot practice competent oncology without understanding the empirical literature and interpreting the statistics. Determining the implications of those statistics for an individual case is a further interpretive act. The physician must compare the characteristics of the sample population with those of the patient. The aggregate statistics are where the physician begins. To suggest that physicians should avoid this process and regard the statistics as "inherently unreliable" is to argue for malpractice.

Perhaps, though, Dr. Avedon was not arguing that statistics were irrelevant to his practice, but that sharing statistics with his patient would have been a mistake because the patient would not have had the ability to understand the numbers. Even this narrower version of the argument is hard to defend, though. Patients are given statistical information all the time, be it about their chances to conceive a child, their genetics, or the chances a drug will have side effects.³²

30. See, e.g., Aman Buzdar & Cynthia Macahilig, *How Rapidly Do Oncologists Respond to Clinical Trial Data?*, 10 *ONCOLOGIST* 15, 15–16 (2005); Monika K. Krzyzanowska et al., *Factors Associated with Failure To Publish Large Randomized Trials Presented at an Oncology Meeting*, 290 *JAMA* 495, 495 (2003) ("Large randomized controlled trials are the criterion standard upon which most treatment decisions are made . . .").

31. See, e.g., Leah L. Albers, "Evidence" and Midwifery Practice, 46 *J. MIDWIFERY & WOMEN'S HEALTH* 130 (2001) (midwifery); Mohit Bhandari et al., *From Eminence-Based Practice to Evidence-Based Practice: A Paradigm Shift*, *MINN. MED.*, Apr. 2004, at 51 (orthopedics); Donna Hallas & Bernadette Mazurek Melnyk, *Evidence-Based Practice: The Paradigm Shift*, *J. PEDIATRIC HEALTH CARE*, Jan.-Feb. 2003, at 46 (pediatrics); David L. Sackett & William M.C. Rosenburg, *The Need for Evidence-Based Medicine*, 88 *J. ROYAL SOC'Y MED.* 620 (1995) (general medicine); Annette Sterr, *Training-Based Interventions in Motor Rehabilitation After Stroke: Theoretical and Clinical Considerations*, 15 *BEHAV. NEUROLOGY* 55 (2004) (neurology).

32. See, e.g., Andria Dyck et al., *Pharmacists' Discussions of Medication Side Effects: A*

Certainly, patients may need help to interpret the statistics properly. Genetic counselors, for example, train to do exactly that. Oncologists, too, need to know how to communicate such information. For lack of the statistical data, how can a patient know whether generalities such as “the prognosis is poor” mean that 40%, 20%, or 5% of people with the same kind of cancer survive two years? And knowing which number applies may be highly material to the patient’s treatment decision.³³

Thus, we see in *Arato* judicial as well as physician resistance to Katz’s revolution. Faced with a rising and salutary empiricism, with statistical analyses and meta-analyses,³⁴ the court and physicians seek refuge in silence. Katz teaches

Descriptive Study, 56 PATIENT EDUC. & COUNSELING 21, 22 (2005) (noting that empirical evidence shows that patients prefer numerical (e.g., 0.1%, 1 out of 1000) rather than verbal (e.g., rare, infrequent) frequency descriptors in learning of risks associated with medications); Mercy Y. Laurino et al., *Genetic Evaluation and Counseling of Couples with Recurrent Miscarriage: Recommendations of the National Society of Genetic Counselors*, 14 J. GENETIC COUNSELING 165, 178 (2005); Practice Comm., Am. Soc’y Reprod. Med., *Elements To Be Considered in Obtaining Informed Consent for ART*, 82 FERTILITY & STERILITY S202, S202 (2004) (recommending information to be disclosed to patients before utilizing assisted reproductive technologies); Practice Comm., Am. Soc’y Reprod. Med., *Information on Commonly Asked Questions About Genetic Evaluation and Counseling for Infertile Couples*, 82 FERTILITY & STERILITY S97, S100 (2004) (providing statistical data about genetic diseases that ought to be shared with patients in preconception counseling).

33. In fact, a considerable literature exists on how to properly convey statistical data to patients and how to frame those statistics. See, e.g., Sidney T. Bogurdus, Jr. et al., *Perils, Pitfalls, and Possibilities in Talking About Medical Risk*, 281 JAMA 1037 (1999); Dyck et al., *supra* note 32, at 22; Ronald M. Epstein et al., *Communicating Evidence for Participatory Decision Making*, 291 JAMA 2359 (2004); Hitinder Singh Gurm & David G. Litaker, *Framing Procedural Risks to Patients: Is 99% Safe the Same as a Risk of 1 in 100?*, 75 ACAD. MED. 840 (2000); see also, e.g., Amos Tversky & Daniel Kahneman, *The Framing of Decisions and the Psychology of Choice*, 211 SCIENCE 453 (1981) (arguing that changes in how information is presented to a decision-maker can significantly alter the decision made). For example, empirical evidence shows that patients are more willing to undergo a particular procedure if told that 99% of previous patients did not have any complications than if told that complications are seen in 1 out of 100 people who underwent the procedure. Gurm & Litaker, *supra*, at 841. Thus, the pertinent question for physicians is not whether to give patients statistical information, but how.

34. See generally Ethan M. Balk et al., *Correlation of Quality Measures with Estimates of Treatment Effect in Meta-analyses of Randomized Controlled Trials*, 287 JAMA 2973 (2002) (stating that a pre-planned meta-analysis of individual trials with deliberately introduced variables may maximize the effectiveness of results from randomized trials); Jesse A. Berlin & Graham A. Colditz, *The Role of Meta-analysis in the Regulatory Process for Foods, Drugs, and Devices*, 281 JAMA 830 (1999) (analyzing the effectiveness of meta-analyses to test the reliability of randomized trials).

us this is more than lagging behind, more than an anachronism. It is resistance, anxiety, and reaction. Sadly, this response is not confined to those facing the rough and tumble of the real world. We see it penetrating the academy as well.

Carl Schneider's book, *The Practice of Autonomy*,³⁵ is an example. He takes issue with Katz and others, accusing them of a hyper-rationalistic commitment to patient autonomy.³⁶ Schneider claims that this argument for autonomy is at odds with what many patients want: the doctor making treatment decisions.

Schneider's accusation of hyper-rationality is especially peculiar applied to Katz's work. Given Katz's psychoanalytic perspective, it is no surprise to see his insights built on acknowledging and accepting the *non*-rational. Indeed, Katz is a master at describing the child-like regression and surrender that illness invites. Thus, it is puzzling to see Schneider claim that "Katz reproves patients who shirk decisions."³⁷ In fact, Katz finds the child-like desire to flee from making decisions and to surrender to the doctor part of being a patient: "Since illness is a situation of neediness and fear, it stimulates wishes to surrender to authority and fantasies about omnipotent caretakers to whom one must yield."³⁸

Schneider's book turns on a chapter in which he reviews empirical studies of what information patients want and what decisional role.³⁹ He points to a number of studies in which patients say they want the doctor to decide. However, the studies he cites cover a wide range of decisional circumstances. They range from studies asking whether the respondent would like her physician to pick which drug she is prescribed for hypertension to studies asking whether the respondent would want the physician to decide if she received life-sustaining treatment. Yet people may well feel that it is fine for the doctor to make the former choice but unacceptable for the doctor to make the latter. Once the decision has been made to take some kind of medication for hypertension, choosing which drug may seem to be a relatively inconsequential and delegable decision. It may even seem a rather technical decision involving drug comparisons the doctor knows best. On the other hand, deciding whether to forgo life-sustaining treatment has life-or-death consequences and clearly implicates the patient's subjective values—would she rather suffer the burden of artificial ventilation to try to live longer, or has she had enough? Thus, lumping together these decisional scenarios confuses the picture.

Further, Schneider mixes tiny studies that would not be included in any

35. CARL E. SCHNEIDER, *THE PRACTICE OF AUTONOMY: PATIENTS, DOCTORS, AND MEDICAL DECISIONS* (1998).

36. *Id.* at 11–17, 30–31, 35.

37. *Id.* at 12.

38. KATZ, *THE SILENT WORLD*, *supra* note 1, at 211–12.

39. SCHNEIDER, *supra* note 35, at 35–46.

rigorous meta-analysis with more powerful studies that may actually mean something. Missing is a real meta-analysis that would allow Schneider to aggregate and interpret studies. Only that would allow him to come up with a persuasive picture of what the studies show about preferences for information and decisional roles.

The deeper problem, however, is that Schneider misses Katz's point. Sure, a lot of patients show up in a doctor's office (or, to follow the methodology of many of these surveys, imagine showing up) and say they want the doctor to take care of them, for the doctor to decide. That does not answer the question, though, of what information the patient wants and what decisional role. Instead, it sets up the question. It is precisely at this starting point that Katz calls for conversation, candor, and connection. Indeed, the physician may have to educate the patient about her entitlement to information and decisional authority. The real question is what does the patient want then, informed of her options and authority. Schneider is giving up on patients too soon, before they even reliably know that they can function as adults in the doctor-patient relationship without risking abandonment by or anger from their physician.

What do we make of all this resistance, then, from the clinic, the courts, and the academy? Professor Katz has heard it all before—the revolution is doomed. Commentators have complained that Katz's vision asks too much of the physician, that it is unrealistic. They argue that there is not enough time for doctor and patient to explore values and options as Katz envisions.⁴⁰ They note that the physician and patient in this county often meet as strangers from different worlds, not one.⁴¹ They object that the physician increasingly serves her organization, not the patient, anyway.⁴²

40. See SCHNEIDER, *supra* note 35, at 145–46; see also Adrian Edwards & Glyn Elwyn, *Involving Patients in Decision Making and Communicating Risk*, 10 J. EVALUATION CLINICAL PRAC. 431, 434 (2004) (finding that while many doctors want to involve patients in decision-making, the doctors surveyed agreed that lack of time remained an obstacle).

41. See E. HAAVI MORREIM, *BALANCING ACT: THE NEW MEDICAL ETHICS OF MEDICINE'S NEW ECONOMICS* 149–50 (1991) (explaining that patients and physicians do not conceive of risks in the same way); SCHNEIDER, *supra* note 35, at 146–47; see also Renee R. Anspach, *Prognostic Conflict in Life-and-Death Decisions: The Organization as an Ecology of Knowledge*, 28 J. HEALTH & SOC. BEHAV. 215, 230 (1987) (“As [patients] become increasingly reliant upon physicians to interpret an increasingly esoteric knowledge, they run the risk of becoming peripheral to life-and-death decisions and a truly informed consent becomes difficult to attain.”).

42. See MORREIM, *supra* note 41, at 100 (arguing that physicians should not “commandeer others’ money and property just because a given patient has need of it”); SCHNEIDER, *supra* note 35, at 186–206; see also MARC A. RODWIN, *MEDICINE, MONEY, AND MORALS: PHYSICIANS’ CONFLICTS OF INTERESTS* 162 (1993) (finding that when HMOs pay physicians to limit the use of resources, doctors are more likely to limit medical care to increase their income); Anspach, *supra* note 41, at

It would be easy to be discouraged. The time pressures, care between strangers, and pressures on physicians to serve the organization rather than patient are real. Yet in the face of all of that, what is remarkable is how far the revolution has actually come.

Yes, SUPPORT shows physician resistance to doing as patients wish at the end of life. But this is against the background of profound change in how we look at such decisions. The last few decades have seen tremendous agreement that decision-making should be a shared process but that patient preferences should rule.⁴³ And that agreement prevails even when the predicted consequence of honoring the patient's wish is her death.⁴⁴

Yes, physician failure to listen and establish a positive therapeutic relationship is worse when the patient is a person of color, a woman, or both. But there is tremendous agreement throughout the medical profession—from the clinic to the Institute of Medicine—that this problem is serious and must be addressed.⁴⁵ And there are promising ideas for enlisting whole communities as well as individual doctors and patients to address it.⁴⁶

229 (suggesting that physicians are structurally and organizationally disengaged from their patients); Margaret Urban Walker, *Keeping Moral Space Open*, HASTINGS CENTER REP. Mar.-Apr. 1993, at 33 (discussing the role of the clinical ethicist in protecting the patient from medical bureaucracy).

43. See TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 77–80 (5th ed. 2001); Eric J. Cassell, *Consent or Obedience? Power and Authority in Medicine*, 352 NEW ENG. J. MED. 328, 329 (2005).

44. See, e.g., ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* §§ 2.01–2.05 (3d ed. 2005) (discussing *In re Quinlan*, 355 A.2d 647 (N.J. 1976), *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990), and their progeny); Lewis M. Cohen, *Practical Considerations in Dialysis Withdrawal: "To Have That Option Is a Blessing"*, 289 JAMA 2113, 2114 (2003).

45. See, e.g., INST. OF MED., *supra* note 8, at 160–179, 552–93; ALEXANDRA DUNDAS TODD, *INTIMATE ADVERSARIES: CULTURAL CONFLICT BETWEEN DOCTORS AND WOMEN PATIENTS* 77 (1989) (observing that “the darker a woman’s skin and/or the lower her place on the economic scale, the poorer the care and efforts at explanation she received”); Anita L. Stewart et al., *Interpersonal Processes of Care in Diverse Populations*, 77 MILBANK Q. 305 (1999) (analyzing how the social-psychological aspects of the patient-physician relationship affect the quality of care in diverse populations); see also sources cited *supra* note 8 (describing further research showing worse therapeutic relationships between doctors and minorities and women).

46. See, e.g., INST. OF MED., *supra* note 8, at 580 (outlining strategies for improving communication skills of physicians); Timothy S. Carey et al., *Developing Effective Interuniversity Partnerships and Community-Based Research to Address Health Disparities*, 80 ACAD. MED. 1039 (2005) (suggesting that universities work with communities to promote racial understanding in research medicine); see also, e.g., Janice C. Blanchard, *Racial and Ethnic Disparities in Health: An Emergency Medicine Perspective*, 10 ACAD. EMERGENCY MED. 1289, 1291 (2003) (providing

Yes, the court in *Arato* falls apart like a terrified patient faced with the dire statistics, the death sentence of pancreatic cancer. But at least the judges hold true to *Cobbs*,⁴⁷ their own precedent, maintaining that the physician should disclose everything material. And though the court suggests that it cannot face these statistics and refuses to mandate a charge requiring the jury to face them either, the court allows the jury to consider whether the statistics were material, and if so, find the physician liable for failure to inform the patient adequately.

Yes, Schneider is among those arguing that we have gone too far in pursuing patient autonomy, that many patients do not want to decide for themselves. But even Schneider reads the empirical studies to say that patients do want the relevant information.⁴⁸ And beyond that, he sees a “telling pattern[]” in the studies suggesting that change is coming in what decisional role patients prefer.⁴⁹ The data show that younger patients are more likely than older ones to prefer participation in medical decisions or to prefer actually making those decisions themselves.⁵⁰

suggestions for improving patient-physician relationships); Elizabeth Harrison & Suzanne M. Falco, *Health Disparity and the Nurse Advocate*, 28 ADVANCES NURSING SCI. 252, 262–63 (2005) (explaining that nursing interventions at the community level may assist in the identification of values to improve the patient-physician relationship); cf. Neal Dickert & Jeremy Sugarman, *Ethical Goals of Community Consultation in Research*, 95 AM. J. PUB. HEALTH 1123 (2005) (discussing how to involve communities in health research); Alice K. Page, *Ethical Issues in International Biomedical Research: An Overview*, 37 J. HEALTH L. 629, 645–47 (2004) (“By ensuring that the role of the community goes beyond the simple participation of its individual members as research subjects, community consultation is designed to respect the culture, values, and dignity of the community and to obtain full understanding and acceptance of the research project.”).

47. *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972).

48. SCHNEIDER, *supra* note 35, at 36.

49. *Id.* at 41.

50. For example, a study of more than 2750 people in 2002 found that patients below age forty-five desired more participation in medical decision-making than patients above forty-five. Wendy Levinson et al., *Not All Patients Want To Participate in Decision Making*, 20 J. GEN. INTERNAL MED. 531, 533 (2005). Schneider recognizes this pattern but says “it is unclear whether this [empirical evidence] represents a change in the direction of social attitudes or a stable difference between the young and the old.” SCHNEIDER, *supra* note 35, at 33. The authors of the 2002 study struggled with this same question. See Levinson et al., *supra*, at 534. They speculated, however, that as the current, information-seeking generation ages, future studies may find the older population favoring more participation in medical decisions. See *id.* The empirical evidence may support a combination of both hypotheses: Severe illness in later life may incline older individuals to defer to a physician’s best judgment, but a generation accustomed to making decisions about their health care is unlikely to surrender that autonomy readily as they age. In any case, numerous studies show that younger patients want more participation in health care decisions than older patients. See, e.g., Mark A. Davis et al., *Impact of Patient Acuity on Preference for Information and*

Would this gut-wrenching struggle, this ferocious ambivalence, surprise Dr. Katz? I think not. Any less resistance would suggest we had missed the mark, that we were failing to seek fundamental change. After all, this is a revolution. Profound resistance comes with the territory.

So where does this unfinished revolution go from here? Alexander Capron urges in his forward to the new edition of *Silent World* that we look to the next generation of physicians to realize Jay's vision.⁵¹ Capron suggest that nothing short of generational change will bring the needed transformation. But I think he underestimates the challenge. It will take more.

We have to await not just the next generation of physicians, but the next generation of patients. We have to look to our children, raised with a different set of expectations about their body, their decisions, their illness, and their death. The doctor-patient relationship is a two-way street.

There is reason to be optimistic about change among both patients and doctors. The data showing younger patients preferring a more active decisional role in their care jibe with changes we see around us, changes in families, in schools, on television, and on the Internet. We see greater candor with children and adolescents about their bodies and medical care. We see older children better able than many of their parents to navigate the Web and find out about illness, disability, medical options, and peer experiences. We see efforts to encourage children to see their bodies as their own, and refuse unwanted contact.⁵²

Among physicians, we see greater efforts in medical school and beyond to

Autonomy in Decision Making, 6 ACAD. EMERGENCY MED. 781, 784 (1999) (finding age a significant factor in the desire of emergency department patients to participate in medical decision-making); Glenn Salkeld et al., *A Matter of Trust: Patient's Views on Decision-Making in Colorectal Cancer*, 7 HEALTH EXPECTATIONS 104, 112 (2004) (finding similar results in an Australian cancer study); Suzanne C. Thompson et al., *Preferences for Involvement in Medical Decision-Making: Situational and Demographic Influences*, 22 PATIENT EDUC. & COUNSELING 133, 137–38 (1993) (finding that younger adults wanted more involvement, regardless of the severity of the medical condition).

51. Alexander Morgan Capron, *Foreword* to KATZ, *THE SILENT WORLD*, *supra* note 1, at xxxii.

52. Evidence of the efforts to encourage children and adolescents to make their own decisions about their bodies includes Jennifer M. Cohn et al., *Adolescent Decisional Autonomy Regarding Participation in an Emergency Department Youth Violence Interview*, 5 AM. J. BIOETHICS 70, 70–74 (2005); Kimberly M. Mutcherson, *Whose Body Is It Anyway?: An Updated Model of Healthcare Decision-Making Rights for Adolescents*, 14 CORNELL J.L. & PUB. POL'Y 251 (2005); and John S. Santelli et al., *Guidelines for Adolescent Health Research: A Position Paper of the Society for Adolescent Medicine*, 33 J. ADOLESCENT HEALTH 396 (2003). *See also* Ingrid Runeson et al., *Professionals' Perceptions of Children's Participation in Decision Making in Healthcare*, 10 J. CLINICAL NURSING 70, 77 (2001) (studying how medical professionals perceive children's expressions of autonomy).

teach them to talk with patients and to listen. Explicit training in medical ethics or bioethics has penetrated the medical school curriculum and become part of residency. Physicians in practice are less and less surprised to see patients arrive for an office visit having researched their illness and toting Internet print-outs.⁵³

Of course, generational change in doctors and patients may not be enough. *Arato* reveals persisting physician paternalism as well as judicial sympathy for that approach. We may need to await the next generation of judges and legislators as well.

Yet change is afoot. Katz analyzes the fitful start to this revolution. Over forty years elapsed between Justice Cardozo's 1914 announcement of a patient's "right to determine what shall be done with his own body"⁵⁴ and judicial development of the requirement of informed consent, starting in 1957. Has the revolution progressed in the nearly fifty years since then?

I am arguing that it has. Let me illustrate with the personal.

It is 1958, one year after the doctrine of informed consent fitfully erupted in *Salgo*,⁵⁵ as Katz chronicles. I am five years old, dressed in my best smock dress, told we are going to visit my grandparents. Instead, we pull up to a huge grey building I have never seen. My parents take me inside. I am panicking. They place me on a bare examining table in a cavernous room, empty save for a man and a canister. The stranger forces a mask on my face. My parents wrestle me onto my back. I am being murdered. I fight for my life. I lose consciousness. The total silence, the terror, the utter conviction I was being killed haunt me still. It is surely part of why I do this work.

Flash forward, through a series of informed consent cases, including *Natanson*,⁵⁶ *Canterbury*,⁵⁷ *Cobbs*,⁵⁸ and *Arato*.⁵⁹ I am a mother of twins, now five

53. See, e.g., Jeffrey P. Lake, *Internet Use by Colorectal Surgery Patients: A Surgeon's Tool for Education and Marketing*, 70 AM. SURGEON 553, 556 (2004) (45.1% of 298 surveys returned in a 2004 study indicated that patients used the Internet to research their condition prior to their first visit to the clinic); Sanjay K. Pandey et al., *Women's Health and the Internet: Understanding Emerging Trends and Implications*, 56 SOC. SCI. & MED. 179, 181–82 (2003) (analyzing the increase in women's use of the Internet to find health information); Matthew R.G. Taylor et al., *Use of the Internet by Patients and Their Families To Obtain Genetics-Related Information*, 76 MAYO CLINIC PROC. 772 (2001) (finding in a 2001 study that 47% of 155 respondents referred to a genetics clinic from their general practitioner acknowledged using the Internet to research their genetic condition before their clinic visit).

54. *Schloendorff v. Soc'y N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

55. *Salgo v. Leland Stanford Jr. Univ. Bd. of Trs.*, 317 P.2d 170 (Cal. Ct. App. 1957).

56. *Natanson v. Klein*, 350 P.2d 1093 (Kan. 1960).

57. *Canterbury v. Spence*, 464 F.2d 772 (D.C. Cir. 1972).

58. *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972).

59. *Arato v. Avedon*, 858 P.2d 598 (Cal. 1993).

years old themselves. Both have needed surgery. In each case, we tell our sons everything, as best we can. We play with dolls and doctor kits, go to see the hospital ahead of time, and read books together. Why? Not just because my husband and I are good guys, but because the doctors, and nurses, and social workers told us to do so. After almost fifty years, something has changed, some combination of medical personnel, practice, and institution. Perhaps even parenting has changed.

And who do these children become? Who is this next generation of patients, growing up mid-revolution?

Not long ago one of my sons was ill. He needed blood to be drawn from a vein at the hospital lab. He refused. He would not get in the car. As his anxiety mounted, he defended himself. He struck karate poses and waved a plastic sword at us. At the height of this he screamed, "It's *my* body!"

That stopped me in my tracks. My son was right. He was not making the choice we wanted, but he was right. My husband, exasperated, hissed at me, "You taught him that." And so I had. But not just me—we had both taught him that, as had his teachers, and his books. It is your body. Say no.

Now, I can imagine emergencies in which we might have to wrestle my child to the ground to get urgent medical care. But, in truth, this was not one of those times. Nothing irrevocable would happen if we failed to reach the lab that day. So we did not go. Instead, we went to see the pediatrician in his office the following day. And what finally persuaded my son to go the lab was nothing we did. It was conversation with his doctor. Our son sat on the examining table eye-to-eye with his pediatrician. Even at five years old, he listened to his doctor explaining why he needed blood drawn and what his choices were. My son decided: "OK. Let's go to the hospital, Mom." That is how powerful doctor-patient dialogue can be.

Fifty years ago, would the child's cry that "it's my body" have been met with respect or with muscle? Would the physician have stood in dialogue with his young patient? Would the child have tasted control, conversation, and choice? Would he have glimpsed something like rights?⁶⁰

I doubt it. There are deep changes afoot. Jay Katz's vision calls for no less—profound changes, not just in doctoring, but in caring for our children, our families, ourselves. It is a revolution. Unfinished, yes, but in motion.

60. See generally NANCY E. WALKER ET AL., CHILDREN'S RIGHTS IN THE UNITED STATES: IN SEARCH OF A NATIONAL POLICY 144 (1999) (discussing the role of parents in making medical decisions for children); Martha Minow, *What Ever Happened to Children's Rights?*, 80 MINN. L. REV. 267, 268–80 (1995) (outlining the development of children's rights from the 1960s to the 1990s).

Closing Remarks

Jay Katz: From Adjunct to Core

Guido Calabresi, M.A., LL.B.*

What is left to say after this wonderful Symposium? A lot, actually. Taking the titles of the keynote presentations and extrapolating from them reveals what I mean.

The title of Robert Burt's presentation was "The Uses of Psychoanalysis in the Law: Illuminating Biomedical Ethics."¹ Extrapolate this to: "Illuminating Medical Ethics." Jay has done this magnificently, not only through his knowledge of psychoanalysis, but through his extraordinary life experiences, some of which—like those of being a refugee, an immigrant, and an outsider—I share in part, but many of which are unique to him. Jay has also illuminated medical ethics through his exceptional understanding of law—in *its* fullest meaning, and of medicine, in *its* fullest meaning.

Alex Capron's presentation was entitled "Experimentation with Human Beings: Light or Only Shadows?"² Let us call it: "Human Beings: Light or Only Shadows?" What are we? Are we capable of being both immensely good and appallingly bad? What can we achieve that will survive us? Few can speak to such things intelligibly. Fewer still can do so with any depth. Jay has done so deeply, feelingly, and with both nuance and strength. We have all been enlightened, even when he looked into the shadows.

The third presentation, by Ellyn Wright Clayton, was entitled "The

* Judge, United States Court of Appeals for the Second Circuit; Sterling Professor Emeritus of Law and Professorial Lecturer in Law, Yale Law School. This text is a lightly edited transcript of remarks delivered at a symposium honoring Jay Katz on October 15, 2004. See David Tolley, *Foreword—A World Less Silent: Celebrating Jay Katz's Contributions to Law, Medicine and Ethics*, 6 YALE J. HEALTH POL'Y L. & ETHICS 393 (2006).

1. This presentation is published under a slightly modified title. See Robert A. Burt, *The Uses of Psychoanalysis in the Law: The Force of Jay Katz's Example*, 6 YALE J. HEALTH POL'Y L. & ETHICS 401 (2006).

2. Alex M. Capron, *Experimentation with Human Beings: Light or Only Shadows?*, 6 YALE J. HEALTH POL'Y L. & ETHICS 431 (2006).

Physician-Patient Relationship.”³ Take from this: “Relationship.” And this is my theme. Jay came to the Yale Law School as an adjunct—that is, connected to the law school, but, in a literal sense, also peripheral. He was the same in the medical school—again, connected, but peripheral. I knew him way back then. I knew those who, with the best of intentions (perhaps), meant to keep him peripheral, to keep his “relationship” that of adjunct. And I watched with delight, amazement, affection, and admiration, as this “Master of Relationship” became ever more central, fundamental, and ultimately the absolute core of our enterprise. Was it the result of his soaring scholarship, or was his soaring scholarship the result of his having become truly and completely interdisciplinary—at the center of law and medicine no less than of psychoanalysis? Who can say? Maybe it was both. But his capacity for “relationship,” in the very best sense of that word, was certainly a crucial part of that achievement from which we, and the whole world of scholarship and of humane dealings, have benefited. Who can believe that Jay was ever “adjunct”? For there is no one who—in his relationship with students and colleagues, and with legal and medical scholarship—is more at the heart of what we are about, and whose achievements we are more proud to claim for *our* school.

Let us take another cut at excerpting the words in the all of the titles: “Jay Katz: Illuminating Ethical Human Relationships.” Jay, we are in your debt; we will remain so as long as we walk this earth, and those who follow will continue to benefit from what you have done, long after we all are gone!

Thank you, dear teacher and friend.

3. This presentation is published under a slightly modified title. See Ellyn Wright Clayton, *The Web of Relations: Thinking About Physicians and Patients*, 6 YALE J. HEALTH POL’Y L. & ETHICS 465 (2006).