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Medical Law and Ethics in the Post-Autonomy Age[†]

ROGER B. DWORKIN*

Patient autonomy has long been the dominant rhetorical value in American medical law and medical ethics. It has been far less dominant in fact. Now, developments in genetics raise serious questions about the scientific validity of the assumptions on which autonomy-based law and ethics rest, and new attention to the values of civic republicanism, community, and inclusiveness raises questions about the extent to which the dominance of autonomy is desirable. Yet a move away from autonomy is frightening, especially when no one can be sure what will take its place. In this Essay, I shall examine in a preliminary way the extent to which autonomy really dominates our medical law and ethics, the extent to which reformulation seems desirable in light of scientific developments and changing values, and the direction medical law and ethics might safely move in a post-autonomy age.

RHETORIC AND REALITY

Autonomy can mean a number of different things. To the liberal individualist (that is, the typical American), it means the ability and the opportunity to *choose* one's course of action and to *act* to effectuate one's choice. It means freedom from constraint as long as one's behavior does not injure others. It tends not to recognize the extent to which most actions, even the most apparently private ones, have an impact on others,¹ and the more apparently private an activity is, the more liberal individual autonomy insists that it not be regulated.

Concern for patient autonomy in the liberal individualist sense dominates the rhetoric of American medical law and medical ethics. Cardozo's dictum that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body"² is ubiquitous. The entire law of informed consent is premised on the dominance of patient autonomy over competing values, including the value of good medical care.³ Abortion

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1. See generally MARY ANN GLENDON, *RIGHTS TALK* (1991).

2. *Schloendorff v. Society of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914).

3. See, e.g., *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972); *Mohr v. Williams*, 104 N.W. 12 (Minn. 1905).

law,⁴ right-to-die law,⁵ and even some wrongful birth and life opinions⁶ are explained textually as reflecting respect for patient autonomy. Occasionally, the law goes to extraordinary lengths to preserve the apparent dominance of autonomy, for example, by resorting to the fiction of "substituted judgment"⁷ to decide cases of never-competent patients approaching death⁸ and of incompetent potential organ donors,⁹ on the basis of what those persons would have decided for themselves if they had been competent.

Yet, in reality, autonomy does not seem to be as dominant a value as rhetoric would suggest. This is not surprising. Not only does liberal individualist autonomy ignore the needs of others, but also, by putting all of its eggs into the choose-and-act basket, liberal individualism disables itself from dealing effectively with cases involving persons who cannot choose and act effectively. It reduces human beings to their choose-and-act function, thus creating the risk that the law will treat incompetent persons as less than human. Liberal individualism also overemphasizes one aspect of humanness even in competent persons. This poses some danger, especially if science should reveal that our ability to choose is not as great as we think it is.

Of course, the law allows autonomy to be sacrificed when important public needs are at stake. Thus, compulsory vaccination laws are plainly valid.¹⁰ However, their existence does not really challenge autonomy's dominant position. It simply demonstrates that even a dominant value must sometimes be sacrificed for the public good.

Often, however, autonomy yields in the face of less clearly public concerns. The most obvious rejections of autonomy are professional licensure statutes¹¹ and the regulation of drugs and medical devices by Congress and the Food

4. See, e.g., *Webster v. Reproductive Health Servs.*, 492 U.S. 490, 549 (1989) (Blackmun, J., concurring in part and dissenting in part); *Roe v. Wade*, 410 U.S. 113 (1973).

5. See, for example, *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990), and cases discussed therein.

6. E.g., *Procanik v. Cillo*, 478 A.2d 755, 764 (N.J. 1984) (Handler, J., concurring in part and dissenting in part).

7. For an extensive analysis and critique of the concept of substituted judgment, see Louise Harmon, *Falling off the Vine: Legal Fictions and the Doctrine of Substituted Judgment*, 100 YALE L.J. 1 (1990).

8. See, for example, the cases collected *id.* at 46 n.214.

9. *Hart v. Brown*, 289 A.2d 386 (Conn. Super. Ct. 1972). See generally John A. Robertson, *Organ Donations by Incompetents and the Substituted Judgment Doctrine*, 76 COLUM. L. REV. 48 (1976).

10. *Jacobson v. Massachusetts*, 197 U.S. 11 (1905).

11. Every state has licensure statutes that limit access to the health professions, thereby excluding practitioners thought to be insufficiently trained or unrespectable. See, e.g., IND. CODE ANN. §§ 25-10-1-1 to 25-10-1-14, 25-13-1-1 to 25-14-3-16, 25-22.5-1-1.1 to 25-24-2-3, 25-27-1-1 to 25-27-1-10, 25-29-1-1 to 25-29-1-9, 25-34.5-1-1 to 25-34.5-3-2 (Burns 1991 & Supp. 1992).

and Drug Administration.¹² Licensure and the control of allegedly beneficial medicines and devices are designed to protect persons from themselves, that is, to paternalistically prevent individuals from autonomously making bad choices. Fraud and profiteering at the expense of the desperate or the ill-advised are not tolerated, and the United States follows an explicit policy of requiring specified levels of certainty about the safety and efficacy of new drugs and devices before it allows them to be made available in interstate commerce.¹³

The law does not honor the freely entered into agreements of doctors and patients. The law of tort, not contract, determines the quality of medical care to which a person is entitled,¹⁴ and a patient may not contract away the right to receive reasonable care.¹⁵ A patient's informed consent to receive medical care does not exempt a health care provider from liability if a consented to risk occurs through negligence, and at least one noted scholar has suggested that informed consent law may be better understood as a way station on the road to strict liability for medical maloccurrences than as a vindication of patient autonomy.¹⁶

Modern law treats informed consent cases as negligence cases, rather than as batteries.¹⁷ That means the patient must show a physical injury in order to win. The loss of dignity, autonomy, free choice, and bodily integrity that is so exalted in the rhetoric of informed consent is worth nothing at judgment time. In order to avoid liability physicians must inform patients either of the risks and benefits that a reasonable physician would disclose,¹⁸ or of all material information, that is, what a reasonable patient, in considering whether to accept the proposed procedure, would need to know to make a reasoned decision.¹⁹ Neither standard has anything to do with patient autonomy. One is directed exclusively to the collective preferences of professionals; the other amalgamates patients into one standard of reasonableness. Honoring autonomy would require the adoption of a subjective standard of disclosure that recognized the patient's right to be unreasonable.

12. 21 U.S.C. §§ 301-337 (1988).

13. See, e.g., *United States v. Rutherford*, 442 U.S. 544 (1979).

14. For a critical analysis of the tort approach, see Richard Epstein, *Medical Malpractice: The Case for Contract*, 1 AM. B. FOUND. RES. J. 87 (1976).

15. *Tunkl v. Regents of Univ. of Cal.*, 383 P.2d 441 (Cal. 1963).

16. Alan Meisel, *The Expansion of Liability for Medical Accidents: From Negligence to Strict Liability by Way of Informed Consent*, 56 NEB. L. REV. 51 (1977).

17. See, e.g., *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972).

18. E.g., *Beattie v. Thomas*, 668 P.2d 268 (Nev. 1983).

19. E.g., *Cobbs*, 502 P.2d at 11.

Similarly, in most jurisdictions the law of causation in informed consent does not serve patient autonomy. Patient testimony is often the only proof available about whether a properly informed patient would have run the risks involved in a procedure. Such testimony, based on bitterness and hindsight, seems unreliable. Nonetheless, at least one state determines causation based on the jury's decision about the credibility of the evidence,²⁰ as it should if patient autonomy is what the case is about. Most states, however, once again objectify the standard and ask what a reasonable patient would have done.²¹ Alternatively, one could create a presumption of causation for the defendant to rebut.²² Neither of these latter two approaches has anything to do with patient autonomy.

At first blush, autonomy may seem to be the primary value underlying the Supreme Court's abortion jurisprudence. However, even a moment's reflection reveals that not to be the case. *Roe v. Wade*²³ may be justly criticized for failing to make its rationale apparent. Nonetheless, the Court plainly rejected autonomy as the basis for the abortion right. The Court specifically rejected the idea that the right of privacy includes a woman's right to do whatever she wants with her own body.²⁴ Moreover, it adopted rules that are entirely inconsistent with a commitment to autonomy. The state is allowed to regulate the woman's decision whether to terminate her pregnancy, not only to protect a viable fetus,²⁵ but also to protect the woman herself. Under *Roe*, abortion may be regulated after the end of the first trimester to the extent necessary to protect maternal health.²⁶ Further, the Court allowed states to prohibit anybody other than doctors from performing abortions even during the first trimester,²⁷ a restriction that can only be understood as reflecting a paternalistic concern for maternal well-being.

This paternalism continues today, even in the writing of Justice Blackmun, the author and strongest defender of *Roe v. Wade*. *Webster v. Reproductive Services*,²⁸ decided in 1989, made substantial inroads on *Roe v. Wade*. Justice Blackmun's dissenting opinion in *Webster* attempted to provide an autonomy rationale for *Roe*: "It is this general principle, the 'moral fact that a person belongs to himself and not others nor to society as a whole'. . . that

20. *Scott v. Bradford*, 606 P.2d 554 (Okla. 1979).

21. *E.g., Cobbs*, 502 P.2d at 11-12.

22. *See, e.g., Reyes v. Wyeth Lab.*, 498 F.2d 1264 (5th Cir. 1974).

23. 410 U.S. 113 (1973).

24. *Id.* at 153-54.

25. *Id.* at 163-65.

26. *Id.* at 163-64.

27. *Id.* at 165.

28. 492 U.S. 490 (1989).

is found in the Constitution."²⁹ Yet despite this rhetorical commitment to autonomy, Justice Blackmun immediately reaffirmed his support for abortion regulation to protect maternal health after the first trimester.³⁰ The commitment to autonomy in the abortion area is rhetorical, not real.

To some extent, right-to-die law reflects a real concern for individual autonomy, yet here too the law remains unwilling to go where the autonomy principle would push it. Cases about mentally incompetent persons make no sense when considered in autonomy terms. Modern living will and durable power of attorney statutes³¹ offer competent patients an opportunity to make effective advance decisions about whether to reject some or all kinds of life-prolonging medical treatment. The federal Patient Self Determination Act³² reinforces those statutes by requiring hospitals to inform patients on admission of their options under state law. In addition, a number of state courts have held that competent patients have the right to refuse even life-prolonging medical care,³³ and the Supreme Court has recognized that its right to privacy decisions seem to imply the existence of such a right.³⁴ All of these developments support the value of patient autonomy.

Yet even in the right-to-die area, the commitment to autonomy is half-hearted. Some state statutes limit the types of medical treatment a patient may reject. The Indiana Living Wills Act, for example, does not allow a person to refuse appropriate nutrition and hydration.³⁵ More importantly, however, no case or statute supports, and many expressly reject, active behavior to hasten a patient's death.³⁶ A patient may effectively ask not to be resuscitated and perhaps not to be fed, but a request for a lethal injection will not be honored. Refusal to honor such a request is inconsistent with a law based on patient autonomy.

Patient autonomy has even less to do with right-to-die cases about patients who have never been competent and once-competent patients who did not

29. *Id.* at 549 (Blackmun, J., concurring in part and dissenting in part) (quoting *Thornburgh v. American College of Obstetricians and Gynecologists*, 476 U.S. 747, 777 n.5 (1986) (Stevens, J., concurring) (quoting Fried, *Correspondence*, 6 PHIL. & PUB. AFF. 288-89 (1977))).

30. *Id.*

31. The statutes are collected in SOCIETY FOR THE RIGHT TO DIE, REFUSAL OF TREATMENT LEGISLATION (1991).

32. 42 U.S.C.A. § 1395cc(f) (1992).

33. See, for example, the cases collected in *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 269-77 (1990).

34. *Cruzan*, 497 U.S. at 278-79 & n.7.

35. IND. CODE ANN. § 16-8-11-4 (Burns 1990); see Kathleen M. Anderson, Note, *A Medical-Legal Dilemma: When Can "Inappropriate" Nutrition and Hydration Be Removed in Indiana?*, 67 IND. L.J. 479 (1992).

36. *E.g.*, IND. CODE ANN. § 16-8-11-20 (Burns 1990).

express their treatment desires before becoming incompetent. In those cases courts either recognize the impossibility of autonomy-based decision making and authorize medical decisions that are in the patient's best interest,³⁷ or they maintain the fiction of autonomy-centered jurisprudence by engaging in substituted judgment analysis.³⁸ In its less objectionable form substituted judgment attempts to discern from the life and prior statements of a once-competent person what that person's wishes would be and to honor those wishes.³⁹ In its extreme form substituted judgment purports to ask what decision about treatment a never-competent person would make if he were competent for one instant during which he understood everything, including the fact that he would never be competent.⁴⁰ This absurdity has led one expert to liken the test to asking, "[I]f it snowed all summer would it then be winter?"⁴¹

Both the best-interests-of-the-patient approach and the substituted judgment approach result in someone other than the patient (a judge, a guardian, a relative) deciding what to do to or for the patient. Any pretense that the patient's wishes are being followed is a sham.

The same thing is true in cases about whether to use a child or other incompetent person as an organ donor. Courts apply either a best interest or substituted judgment approach to decide whether the incompetent person would be better off if the donee (a sibling) survived, or whether the incompetent person would choose to save his sibling if he were competent.⁴² Maybe a mentally incompetent four-year-old is better off with a sibling and one kidney than with two kidneys, but any pretense that the four-year-old chose to trade a kidney for a sibling is pretense indeed. Courts authorize transplants from incompetent persons to competent ones because *the courts* think that is the best thing to do, not because of the autonomous choices of incompetent persons.

New drug regulation, injury compensation law, informed consent cases, abortion decisions, right-to-die law, and organ transplantation decisions all demonstrate that American medical law, even as it has developed in the heyday of liberal individualism, is not nearly as autonomy-centered as it claims to be. If that is true, what can we expect as liberalism loses its lustre and science challenges its foundations?

37. See *In re Conroy*, 486 A.2d 1209, 1231-32 (N.J. 1985).

38. See generally Harmon, *supra* note 7, at 40-46.

39. *In re Westchester County Medical Ctr.*, 531 N.E.2d 607, 613-15 (N.Y. 1988); *In re Storar*, 420 N.E.2d 64, 72 (N.Y. 1981).

40. *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 431 (Mass. 1977).

41. *In re Storar*, 420 N.E.2d at 72-73 (quoting expert testimony presented at hearing).

42. See cases collected in Harmon, *supra* note 7, at 32-36.

COMPETING VIEWS OF AUTONOMY

The liberal individualist model of autonomy is so obviously unsuited to the resolution of difficult problems of medical law and ethics and so clearly distanced from the real—as opposed to the rhetorical—law, that one is tempted to consider the possibility that a somewhat different view of autonomy may be more useful. Yet a more refined sense of autonomy seems no more in keeping with reality than liberal individualism and ultimately offers no more desirable guide to solving hard problems.

Unlike liberal individualism, a second possible meaning of autonomy is rooted not so much in choice as in being let alone. It is a physical concept rather than an intellectual one. If you touch me or eavesdrop on me, you have injured my autonomy by invading my space. If you actually do something to change my body, you have injured my autonomy by changing the very constitution of what I am. This view might be called physical essentialist autonomy.

The most moving and troubling legal expression of this view that I have seen is in California Chief Justice Bird's dissent in a sterilization case, *In re Valerie N.*⁴³ A California statute prohibited the sterilization of mentally incompetent persons.⁴⁴ Valerie N. was mentally retarded and incompetent. Her parents challenged the statute in an effort to have Valerie sterilized. The majority of the California Supreme Court struck down the statute. It thought that what was at stake in the case was Valerie's interest in living the fullest and most rewarding life of which she was capable, her right to personal growth and development, to develop to her maximum economic, intellectual, and social level.⁴⁵ In order to protect those interests, the majority focused on Valerie's right to *choose* not to bear children and to *implement* that choice.⁴⁶ In other words it adopted a liberal individualist view. Unfortunately, however, the liberal individualist approach to autonomy cannot work when the individual involved lacks the capacity to make choices. Recognizing Valerie's disability, the court defined the question before it as whether Valerie had a right to have decisions made for her.⁴⁷ It concluded that she did and that no state interest outweighed the right.⁴⁸ Therefore, the statute, which deprived

43. 707 P.2d 760 (Cal. 1985).

44. CAL. PROB. CODE § 2356(d) (West 1979).

45. *In re Valerie N.*, 707 P.2d at 771-73.

46. *Id.* at 771-72.

47. *Id.* at 771.

48. *Id.* at 773-75.

Valerie of the right to have someone decide to have her sterilized, was unconstitutional.

Chief Justice Bird disagreed. She began from the realistic premise that choice was impossible for Valerie.⁴⁹ Moreover, she argued, choice is not the question; the relevant right is Valerie's right to procreate.⁵⁰ The value to be protected is not Valerie's opportunity to develop, but rather her "primal"⁵¹ right not to be sterilized, a right rooted in *bodily* autonomy,⁵² a right which Chief Justice Bird said was constitutional in the deepest sense.⁵³ That is, it is part of what constitutes the human being, Valerie. Since Chief Justice Bird found no state interest strong enough to outweigh Valerie's right to procreate, the statute that protected the right was constitutional, and the majority's approach was unsound.

Juxtaposing the majority's liberal individualist autonomy with Chief Justice Bird's physical essentialist autonomy highlights the need for an alternative approach. The majority makes the mistake of treating a person as if she is nothing more than a choice maker and actor. As noted previously, extreme cases, like those involving incompetent persons, make plain the insufficiency of that approach. However, the approach is also inadequate for competent persons. Choice making is a characteristic of healthy persons, but it is not their only characteristic. We must be cautious not to factually overrate even healthy persons' abilities to choose and not to ethically overvalue that capacity. Overvaluation risks dehumanizing incompetent persons and creating an ethical vacuum if and when we learn that healthy persons' abilities to choose are more constrained than we like to think.

Yet Chief Justice Bird's approach is also unsatisfying. Her physical essentialist view turns Valerie into a breeding machine and ignores the negative impact on Valerie's life of that approach. Is Valerie to be left free to procreate no matter how traumatic the experience is for her, or is she to be institutionalized for her own protection? If the latter, she will retain the constitutive, primal ability to procreate, but will never be able to exercise that ability. What good does it do to protect Valerie's right to procreate if she never gets the chance to procreate and also loses her opportunity to develop to her maximum potential?

Liberal individualist autonomy and physical essentialist autonomy thus seem to impale us on the horns of a dilemma. A third approach to autonomy would

49. *Id.* at 781 (Bird, C.J., dissenting).

50. *Id.* at 784-85.

51. *Id.* at 785.

52. *Id.*

53. *Id.* at 786.

treat the individual as dominant, but attempt to avoid the failings of both liberal individualism and physical essentialism. This approach would be rooted in respect for the individual as a complete being. It would deviate from common linguistic meanings of the word "autonomy" by focusing neither on the freedom to choose and act nor on the freedom from physical intrusion. It would simply be an approach that put the interests of the person most affected by an action or proposed action first. It would be a highly realistic approach because it would examine what really happens to a person. Thus, it could avoid resort to rhetorical fictions (like liberal individualism) and sacrifice of a person's well-being to someone else's principles (like physical essentialism). Such an approach might be called respectful paternalism. It would be paternalistic because it would involve someone making decisions for somebody else, presumably in that person's best interest. It would be respectful because it would consider the real impact of an action on the person affected, thus avoiding the imposition of one's principles on another to her detriment, and because it would consider the preferences and choices of the affected person, to the extent they can be ascertained, as part of the decision-making process.

In Valerie N.'s case this approach would begin by rejecting any interests of Valerie's parents, siblings, or future children, any interests of doctors, and any interests of society as relevant to the decision. It would examine the facts about Valerie, including facts about whatever capacity to understand and express a preference Valerie has; it would examine the facts about sterilization and other options; and it would examine the facts about what the real world outcome of a decision to sterilize or not to sterilize would be. This approach would avoid fiction and would protect Valerie from abusive sterilization for someone else's benefit. It would also allow Valerie to be sterilized if that would really be the best thing for her.

This weak version of autonomy seems an improvement over either of the other two approaches. Yet it is not without its shortcomings. By focusing solely on the individual, respectful paternalism, like all forms of autonomy, ignores both reality and important personal and social interests. All autonomy-centered approaches ignore the fact that nobody is autonomous. Everybody lives in groups—families, workplaces, clubs, labor unions, towns, states, countries—and almost everything that affects one person affects others as well.

Insights offered by feminist,⁵⁴ republican,⁵⁵ and communitarian⁵⁶ scholars have demonstrated the impoverishment of an exclusively individual rights based approach to social issues, and developments in genetics cast doubt on the factual underpinnings of such an approach.

THE INADEQUACY OF AUTONOMY

The American style of discussing rights is so deviant from that of other western democracies that Professor Mary Ann Glendon refers to it as a "dialect"⁵⁷ and suggests that it "is turning American political discourse into a parody of itself."⁵⁸ Our focus on the individual and his rights increases conflict and impedes the search for common ground.⁵⁹ It ignores responsibility, without which rights become license,⁶⁰ and it ignores our interdependence.⁶¹ By making the autonomous actor and "lone rights-bearer"⁶² our model for social thought, we inadvertently disparage and injure those who do not fit the model, "the very young, the severely ill or disabled, the frail elderly, as well as those who care for them"⁶³

Glendon recalls the standard argument against mandatory seatbelt or motorcycle helmet laws: "It's my body and I have the right to do as I please with it," and remarks,

This way of thinking and speaking ignores the fact that it is a rare driver, passenger, or biker who does not have a child, or a spouse, or a parent. It glosses over the likelihood that if the rights-bearer comes to grief, the cost of his medical treatment, or rehabilitation, or long-term care will be spread among many others. The independent individualist, helmetless and free on the open road, becomes the most dependent of individuals in the spinal injury ward.⁶⁴

The same point can be made in every area of bioethics: Pregnant women have fetuses, mates, and parents. Mentally incompetent women like Valerie

54. *E.g.*, Leslie Bender, *A Lawyer's Primer on Feminist Theory and Tort*, 38 J. LEGAL ED. 3 (1988).

55. *E.g.*, MICHAEL J. SANDEL, *LIBERALISM AND THE LIMITS OF JUSTICE* (1982).

56. *E.g.*, GLENDON, *supra* note 1.

57. *Id.* at 171.

58. *Id.*

59. *Id.* at 14, 154; *see also* Carl E. Schneider, *Rights Discourse and Neonatal Euthanasia*, 76 CAL. L. REV. 151, 172 (1988).

60. GLENDON, *supra* note 1, at 14, 45.

61. *Id.* at 43-46.

62. *Id.* at 47 *passim*.

63. *Id.* at 74.

64. *Id.* at 45-46.

N. have parents or guardians and may have children. Persons with genetic diseases have relatives at different degrees of risk. Persons with healthy organs may have siblings with unhealthy ones. Potential surrogate mothers may have husbands, preexisting children, the new child, men with whom they have contracted and those men's wives, all of whom are affected by the surrogate mother's behavior. Dying persons have families with both emotional and financial needs.

Autonomy-based systems undervalue those other persons' needs. They assume that it is possible to ascertain who is most affected by an action or condition and then allow that person's interests to trump all others. The factual assumption is true sometimes, but only sometimes. Who is most affected by a decision about whether to use a kidney from an incompetent "donor" to save a dying competent sibling with end stage renal disease?⁶⁵ Who is most affected by a decision whether to perform a Caesarian section delivery that may shorten the life of a terminally ill, episodically competent pregnant woman by a few days in order to run an *X* percent chance of saving her fetus?⁶⁶

Even when the factual assumption is correct, the decision to let the most affected person's interests dominate is problematic. If, as will almost always be the case, the most affected person is involved with others, surely taking some account of the other persons' interests seems appropriate. A full social impact calculus would consider the number of persons affected, the nature and extent of the effects on them, the certainty of the effects on them, and alternative ways to modify those effects, as well as the interests of the person most affected. In some cases the sum of the effects on others may outweigh the impact on the person most affected.

One could adapt Learned Hand's famous formula for determining negligence⁶⁷ to express the point: If *P* is the probability of an effect, *S* is its severity (considering all types of negative effects—pain, loss of money, emotional distress, etc.), *N* is each collateral person affected, and *M* is the person most affected, then the interests of the person most affected should prevail only if

$$PS(M) > PS(N_1 + N_2 + \dots N_i).$$

65. See, e.g., *Little v. Little*, 576 S.W.2d 493 (Tex. Civ. App. 1979).

66. See, e.g., *In re A.C.*, 573 A.2d 1235 (D.C. App. 1990).

67. A person's behavior is negligent if the burden of taking adequate precautions is less than the product of the probability of injury and the severity of the injury if it occurs, that is, if $B < PL$. *United States v. Carroll Towing Co.*, 159 F.2d 169, 173 (2d Cir. 1947).

The interests of the person most affected should prevail only if the probability and severity of the effect on him is greater than the probability and severity of the effect on everybody else.

The danger in this approach is that the judge or other person performing the calculus may undervalue the effect on M and overvalue the effects on the various Ns, especially if the Ns are healthy and competent and M is not. A system that rejects an exclusive focus on the person most affected must include a method to prevent itself from becoming a way to legitimate imposition on underdogs.

Modern genetics compounds the difficulties by simultaneously reemphasizing the poverty of autonomy-based approaches and highlighting the risks in surrendering the focus on individuals. Genetic medicine illustrates convincingly the shortsightedness of the individually focused approach, and genetic research throws the possibility of liberal individualist autonomy into doubt.

Genetic medical practice challenges the conventional notion of the individually based doctor-patient relationship. Genetic medicine only makes sense if it is understood as a family-centered, rather than an individually focused form of medical practice. Typically, physicians and other genetic counsellors are consulted by couples who want to learn their risk of having a child with a genetic disease, by couples and their already affected children, or by persons who seek information about their own health based on the condition of their relatives. Each of these situations requires learning about one person to help another. Each may present the diagnostician with information about persons whom he has never seen and may raise serious questions about his obligations. To what individual does the doctor owe a duty when tests of husband, wife, and child reveal that the husband is not the child's father? What are the doctor's duties when diagnosis of a person present in the doctor's office necessarily informs him that relatives of that person are at risk for developing avoidable colon cancer or having a child with hemophilia? In a profession whose *raison d'être* is doing family studies to reveal family information, these questions cannot be answered by thoughtless recitation of tired slogans about the doctor owing an exclusive obligation to his patient. Indeed, often it is not even clear who the patient is.

Modern genetic research compounds the inadequacy of the individual autonomy model by rekindling the debates between free will and determinism and between nature and nurture. As scientists map the human genome, they increasingly discover not only the genes for well-known genetic diseases, but also uncover the genetic roots of a wide variety of diseases and behaviors that are often not thought of as genetic. What does it mean to talk of an autonomous individual if the individual's genotype predisposes him to alcoholism, schizophrenia, crime, cancer, or heart disease? To the extent that most

American law and ethics are based on assumptions about personal moral accountability, modern genetics throws those legal and ethical positions into question.

However, to say that modern genetics throws legal and ethical positions into question is not to say that it answers the question. A predisposition to cancer is not cancer. A person with a predisposition to lung cancer who later contracts the disease could be viewed as a blameless victim to be compensated by insurance or whatever social mechanism exists to pay for catastrophic diseases. Alternatively, he could be viewed as having heightened individual responsibility—to learn of his disposition and avoid risky behavior like smoking or working around known carcinogens—and be denied relief if he “allows” himself to contract cancer. Alternatively again, he could be viewed as deserving of some social measures to equalize his position vis-à-vis the nonpredisposed; the existence of identifiable predisposed persons could heighten demands to ban smoking and clean up work places and could impose the costs of lung cancer on those who activate others’ predispositions.

Recognizing that there are limits to what individuals can do or control is not a concession to total determinism. The danger of modern genetics, like the danger of the old eugenics, is that society will mistakenly believe it proves more than it does and use it as an excuse to injure further those who are already disadvantaged. Thus, again, the challenge is to incorporate new understandings in a way that moves away from the excesses of individual autonomy and its frequent inability to help solve problems, without legitimating imposition on underdogs. How is that to be done?

RESPECT FOR ALL INDIVIDUALS

I suggest that a useful way to begin would be (1) to refocus our rhetoric and our rules away from concern for individual *choice* and toward *respect* for individuals, while (2) recognizing that individuals live in groups whose individual members deserve respect too. In other words, we should combine what I have called respectful paternalism with respect for all affected members of society. Respect for individuals requires valuing their apparently freely made choices, even if we do not always follow them. Respect for individual affected members of society recognizes the reality of the social condition but reduces risks of imposition by insisting on finding real impacts on real persons before those interests may be weighed against others. Respect for all individuals rejects as unacceptably dangerous a focus on the alleged interests of society as a whole.

Under this approach, it would be unnecessary to ask who is most affected by a proposed action. The full interests of whoever is being acted upon, as

well as other affected persons, are all relevant. If one person is most affected, the degree of impact on him will necessarily be reflected in the social calculus, which takes the total impact on each affected person into account.

In determining an individual's interests, his ability to choose and the negative impact of taking that away from him are relevant. If the person has never been able to choose because of incompetence, nothing is accomplished by pretending he is capable of choice. Therefore, depriving him of choice is no burden and should be ethically and legally irrelevant. If a person is competent or has previously expressed a choice while competent, respect for individuals requires valuing that choice and recognizing that overriding it demeans the individual. Even if the individual's choice was genetically or otherwise predetermined, that choice must be valued if the individual believed he had a choice and feels, or would have felt, injured if his choice is not followed. To put it differently, the choices of competent persons are worth points in the legal and ethical calculus. However, choices do not end the inquiry. They may be illusory; the person may no longer be aware of them; and other people count too. Therefore, the way to make a decision is to consider what is best for everyone concerned, while specifically assigning a value to choices in order to avoid running roughshod over affected persons. Everyone concerned means each person concerned. In a sense everyone is affected by everything, but some persons, like taxpayers and persons down the block, have interests so small as to be *de minimis*. The social collectivity's interests must not be considered. If they are, respect will give way to tyranny, and the poor, the unpopular, the different will never win.

Perhaps the approach suggested here can be made clearer by applying it to a few examples.

Under the respect-for-all-affected-individuals approach, Valerie N. should be sterilized. She could never make choices; therefore, no consideration of her choices is relevant. Sterilization affords her maximum respect. It maximizes her chance to achieve her potential, and it protects her from being imposed upon. It also makes life better for her parents, who as human beings, deserve to be considered.

On the other hand, suppose the question is whether to sterilize Mary X, who is mildly mentally retarded and a carrier of the gene for hemophilia. The goal is to prevent her from transmitting hemophilia. Mary does not want to be sterilized. Respect for her requires us to value her choice even though it is not enough to end the inquiry because her ability to choose is questionable and because other persons are affected. Decision making requires inquiry into the pleasure Mary will receive from the opportunity to bear a child and be a mother as well as the pain and sense of loss she will undergo both if sterilized and if not sterilized. Will Mary lose her liberty to live in an unrestricted

environment if she is not sterilized? Everything relevant to maximizing Mary's welfare must be considered. In addition, the well-being of her potential offspring⁶⁸ and the burden on Mary's parents of refusing to sterilize her are relevant. The well-being of the state or society is not, because evaluating the costs and benefits to society of increasing by even one the population of persons with hemophilia would always lead to sterilization. It would sacrifice the individual and demean an entire class of persons who are different from the majority. That is simply an ethic of might makes right and is unacceptable. Respectfully considering the interests of all relevant individuals, but not the state, would almost surely lead to refusing to sterilize Mary, although facts could be imagined that would lead to the other result.

Respect for all affected individuals would require that before consenting to treatment patients be given the amount of information that a person who cared about their well-being (including their psychological and dignitary well-being) would give them—not the amount a hypothetical reasonable doctor would provide or a reasonable patient would want. Conversation with close family members of the patient and some attention to their desires would be relevant as well. Failure to provide adequate information under such a vague standard should be viewed as an ethical lapse. Whether it makes sense also to treat it as a tort is beyond the scope of this Essay.⁶⁹

Terminally ill patients who are incompetent and have expressed no choices about withholding or withdrawing medical care deserve respect. They retain an interest in dignity and in avoiding unnecessary suffering. However, their loved ones' interests are also strong and should be accorded great weight. Suffering from watching a close relative die a prolonged death is real. On the other hand, the anguish of believing one was premature in letting the loved one die is real as well. Respect for relatives requires that they be accorded significant discretion in deciding whether to allow the patient to die. The doctor's sense that he is wasting his time in a futile exercise is probably worth something, especially if the patient is past suffering and the family is split. An identified salvable patient's need for the dying person's hospital bed is also relevant. A generalized concern about not wasting resources is not.

68. Daughters will not have hemophilia. Sons may, but the alternative for them is not to be born. The feasibility of sex selection through selective abortion also may affect the calculus.

69. Of course, ethical obligations do not always become legal obligations. The difficulty of complying with vague standards that are fact sensitive, questions about the efficacy of communications, the problems of developing rules to control conduct after the fact through common-law adjudication, and doubt about whether there is any loss that the community should bear through shifting might all lead one to question the wisdom of retaining a tort of failure to obtain informed consent.

Society cannot be allowed to solve its health care cost crisis by running roughshod over its sickest members.⁷⁰

Medical law and ethics based on individual autonomy are rooted in fiction and ignore important values. The salutary role of the autonomy focus is that it avoids state imposition and abuse of the weak. As the illustrations here suggest, an approach rooted in respect for all individuals would avoid fiction and increase the chance of sound results by considering all relevant persons and values in each case, while keeping the door to state imposition and abuse of the powerless tightly closed.

70. This does not mean there can be no health care rationing. It means it must only be done in advance of a particular need in a system in which all potentially needy claimants can be accorded respect.