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Medical Law and Ethics in the Post-Autonomy Age

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Medical Law and Ethics in the Post-Autonomy Age

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 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

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) (en banc); *Mohr v. Williams*, 104 N.W. 12 (Minn. 1905).

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, e.g., *Cruzan v. Director, Mo. Dept. of*

Health, 110 S.Ct. 2841 (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, e.g., cases collected at *id.*, 46 n.214.

⁹ *Hart v. Brown*, 289 A.2d 386 (Conn. Super.

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 and Drug Administration.¹² Licensure and the control of allegedly beneficial medicines and devices are designed to protect persons from themselves, 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

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).

¹² 21 U.S.C. §§ 301-337 (1988).

Dworkin named Poynter Scholar

Professor Roger Dworkin has been named Nelson Poynter Scholar and Director of Medical Studies in the university's Poynter Center for the Study of Ethics and American Institutions. He is the first person to be honored as a Poynter Scholar.

As director of medical studies, Dworkin is in charge of the center's medically related programs. These include, for example, an interdisciplinary medical studies group, an undergraduate course on health and human values, and several extensive educational programs for physicians. He is also involved in consultation about center policies and public representation of the center.

Through his work with the Poynter Center, Dworkin has developed a number of programs



designed to take the law to non-legal audiences. He is bringing insights from his work at the Poynter Center to undergraduates in a course called Health and Human Values, which he co-teaches with Carol Parker, director of the law school's legal writing program. And with Dr. James Rogge, he is putting together a series of presentations on medical ethics for hospital trustees.

"If you believe, as I do," says Dworkin, "that difficult medical decision making is more likely to be well done by an educated

citizenry than by courts or physicians acting alone, then trustees are a natural group of citizens who have demonstrated already that they're interested and concerned, but who are not likely to know very much about issues in medical ethics. In addition, David Smith, director of the Poynter Center, is currently doing a book on the ethical obligations of trusteeship,

certainty about the safety and efficacy of new drugs and devices before it allows them to be made available in interstate commerce.¹³

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"¹⁴ and suggests that it "is turning American political discourse into a parody of itself."¹⁵ Our focus on the individual and his rights increases conflict and impedes the

search for common ground.¹⁶ It ignores responsibility, without which rights become license,¹⁷ and it ignores our interdependence.¹⁸ By making the autonomous actor and "lone rights-bearer"¹⁹ 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."²⁰

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

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

¹⁴ *Id.* at 171.

¹⁵ *Id.*

¹⁶ *Id.* at 14, 154; see also Carl E. Schneider, *Rights Discourse and Neonatal Euthanasia*, 76

Cal. L. Rev. 151, 172 (1988).

¹⁷ Glendon, *supra* note 1, at 14, 45.

¹⁸ *Id.*, at 43-46.

¹⁹ *Id.*, at 47 *passim*.

²⁰ *Id.* at 74.

which makes a focus on trustees especially timely."

In honor of the Poynter Center's 20th anniversary, Dworkin has also been putting together a joint Poynter Center-School of Law conference on "Emerging Paradigms in Bioethics." The conference will test the continuing utility of a principle-based method of medical decision making focused on patient autonomy.

"The focus on autonomy has increasingly come into question from different strains of scholarship," says Dworkin. "Increasingly in the philosophical literature there's criticism of this model, and all the inclusionary approaches to scholarship, such as communitarianism and feminism, question an ethic that is so strongly autonomy-based. I have never felt that a focus on patient autonomy in medical ethics was a satisfactory way to proceed. I also question an ethic that is principle-based."

The conference brings together law professors, philosophers, and faculty in public health to debate other approaches to medical decision making. Each will present an original paper, to be published in the *Indiana Law Journal*. Commentators from departments throughout the university, including Fred

Cate and Susan Williams from the law school, will discuss the papers.

Dworkin has also spent his time at the Poynter Center continuing work on a book, *Limits: The Role of Law in Biomedical Decision Making*.

"The title is meant to be a play on words, suggesting that the law is a limit on developments in biology and medicine," says Dworkin. "But what the book is really concerned with is the limits of the law's ability to limit developments in biology and medicine. I explore existing American legal institutions to find out which ones seem most likely to be able to deal best with which kinds of biomedical development and find out which kind of biomedical developments don't seem well suited to any of our institutions."

While Dworkin foresees an audience of legal and medical policy-makers, he hopes that the book will also reach other interested people. His undergraduates will have the first opportunity to determine whether he has succeeded in his desire to make difficult material accessible: They are reading chapters of the book for class this spring.

(The accompanying text is excerpted from Professor Dworkin's full article in the *Indiana Law Journal*.)

***We should combine respectful paternalism
with respect for all
affected members of society.***

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."²¹

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

²¹ Id. at 45-46.

²² See, e.g., *Little v. Little*, 576 S.W.2d 493 (Tex. Civ. App. 1979).

²³ See, e.g., *In re A.C.*, 573 A.2d 1235 (D.C. App. 1990).

²⁴ 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).

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?²² 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 a percent chance of saving her fetus?²³

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 negligence²⁴ 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 $PS(M) > PS(N_1 + N_2 + \dots N_i)$.

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 re-emphasizing 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 counselors are con

sulted 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 free will-determinism and nature-nurture debates. 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 geno-

type 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-a-vis the non-predisposed; the existence of identifiable predisposed persons could heighten demands to ban smoking and clean up workplaces 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?

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, the individual's ability to

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

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 his choice was the product of free will 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 taxpayers, persons down the block, etc., 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:

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 offspring,²⁵ 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.²⁶

Terminally ill patients who are

²⁵ 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.

²⁶ 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, all might lead one to question the wisdom of retaining a tort of failure to obtain informed consent.

²⁷ 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.

Experience is the best teacher

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. Society cannot be allowed to solve its health care cost crisis by running roughshod over its sickest members.²⁷

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 the 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.

Jack Kimberling, JD'50, has always been a friend of both IU and the law school, serving on the school's Board of Visitors as well as on the Board of Directors of the IU Foundation. This semester, Kimberling is down in the trenches, sharing his substantial and extensive trial experience with law students through teaching two trial process courses at the school.

Kimberling's interest in teaching others how to litigate is long-standing. He developed an in-house training program for young associates at Dewey Ballantine Bushby Palmer & Wood, where he is a partner. He has taught trial advocacy classes at the University of Southern California and Loyola-Los Angeles.

"In the early '70s," he says, "I chaired a committee of the American College of Trial Lawyers that was concerned with how law students learned trial advocacy. We surveyed all the accredited schools and discovered that even that long ago, 80 percent of them offered a course on trial practice. But the schools had problems with both staffing and materials. Because they couldn't get regular assistance from practitioners, they were forced to draft faculty with little trial experience. Even when the schools could get help from lawyers, they often faced the problem of good lawyers who were not good teachers."

Kimberling developed strong views about the kinds of contributions practicing attorneys can make to students in a clinical course.

"I told my students early on that I would not be regaling them with stories from practice, unless the anecdote illustrated a mistake I had made from which I thought they

could benefit. And I encouraged them to let me know if I lapsed—by coming into class early and writing WAR STORIES in two-foot high letters on the board, if necessary."

The committee's report led the National Institute of Trial Advocacy to develop trial materials that allow students to practice their trial skills through simulations. At IU, the trial courtroom is equipped with remote videotaping equipment, as are interview rooms, so students alternate between live and videotaped presentations. Kimberling individually critiques all of the student videotapes and performances, and the students critique each other (often offering the toughest evaluations).

"So far, the students have all taken depositions, done a *voir dire* and picked a jury, and done an opening statement. As the semester continues, they will handle problem and expert witnesses, direct and cross examination, and closing arguments. At the end of the semester, each team will participate in an entire trial."

In addition, Kimberling has invited U.S. District Judge John Tinder to do one session on criminal trials.

"About half of the students in my classes have already committed to litigation, and there are several who are quite talented. At first, the students seemed a little intimidated, but no longer. I had one who argued with me last week, and I was glad to see it."

Kimberling says he is enjoying the contact with students.

"I find it interesting and enriching. Being at the school brings back good feelings and happy memories. Teaching here would be rewarding for that reason alone."