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MULTICULTURALISM IN MEDICAL DECISIONMAKING: THE NOTION OF INFORMED WAIVER

Elysa Gordon*

Western¹ bioethics and health law bestow paramount importance on the principle of individual autonomy,² which recognizes an individual's right to determine matters of importance to his or her own life. In health care, this means providing information to individuals that enable them to make knowledgeable decisions about their medical treatment and respecting their choices regarding medical care. The value of autonomy in medical decisionmaking underlies the American tort-law doctrine of informed consent.³

As reflected in the informed consent doctrine, the Western notion of autonomy favors the individual over the community, self-reliance over dependence, action over passivity, scientific rationality over spirituality, and forthrightness over harmony.⁴ An une-

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1. This Note defines "Western" as it is set forth in Anglo-Saxon liberal political and moral theory and as embodied in American legal ideology and doctrines. See generally BAILEY KULIN & JEFFREY STEMPL, FOUNDATIONS OF THE LAW 47-72 (1994); J.M. KELLY, A SHORT HISTORY OF WESTERN LEGAL THEORY (1992); SUSAN MOLLER OKIN, WOMEN IN WESTERN POLITICAL THOUGHT (1979); BERTRAND RUSSELL, A HISTORY OF WESTERN PHILOSOPHY (1945); IRA KATZNELSON & MARK KESSELMAN, THE POLITICS OF POWER (1979); WESTERN CIVILIZATION: RECENT INTERPRETATIONS FROM 1715 TO THE PRESENT (C. Stewart Doty ed., 1973). See also JOHN LOCKE, SECOND TREATISE OF GOVERNMENT (C.B. Macpherson ed., 1980); JOHN STUART MILL, ON LIBERTY (E. Rapaport ed., 1978).

2. See *infra* notes 14-17 and 23 and accompanying text discussing the predominance of the principle of autonomy in Western moral and political theory and in the U.S. Constitution.

3. See 1 BARRY R. FURROW ET AL., HEALTH LAW 409 (1995) ("The doctrine of informed consent developed out of strong judicial deference to individual autonomy, reflecting a prevalent belief in American jurisprudence that an individual has a right to be free from nonconsensual interference with his or her person, and a basic moral principle that it is wrong to force another to act against his or her will.").

4. The notions of self-determination, patient participation, and truth-telling are evident in the earliest case law and by scholars on informed consent. See, e.g., *Schloendorff v. Society of N.Y. Hosp.*, 211 N.Y. 125, 129, 105 N.E. 92, 93 (N.Y. 1914) ("Every human being of adult years and sound mind has a right to determine what shall be done with his own body . . ."); Alexander Capron, *Informed Consent in Catastrophic Disease Research and Treatment*, 123 U. PA. L. REV. 340, 365-76 (1974).

quivocal emphasis on Western values in medical decisionmaking, however, erroneously assumes that all people approach health and illness in similar ways. It overlooks that, in some non-Western cultures, individuals expect and desire that others will make decisions about their medical care and that individuals do not want to receive information on which such decisions will ultimately be based.⁵ Persons identifying with non-Western cultures may be more spiritual, more family or community sensitive, or more tolerant of authority and social stratification. They may value decision-making processes that are less confrontational and defer more to physician discretion. Imposing Western beliefs and practices on non-Western patients may create deleterious health consequences for them and risks viewing them as abstractions, stripped of the cultural and social settings in which they live. It ignores the fact

(suggesting that informed consent protects individual autonomy and fosters rational decisionmaking by the patient).

5. For the purposes of this Note, culture is defined as a significant factor guiding the way individuals view, experience and interact with the world. *See, e.g.*, E. LEACH, *SOCIAL ANTHROPOLOGY* 38-9 (1982) (citing noted anthropologist, E.B. Taylor's definition of culture as "that complex whole which includes knowledge, belief, art, morals, law, custom and any other capabilities and habits acquired by man as a member of society."); R.M. KEESING, *CULTURAL ANTHROPOLOGY: A CONTEMPORARY PERSPECTIVE* 518 (1981) (defining culture as "systems of shared ideas, systems of concepts and rules and meanings that underlie and are expressed in the ways that humans live"); RACHEL E. SPECTOR, *CULTURAL DIVERSITY IN HEALTH AND ILLNESS* 68 (4th ed. 1996) ("another way of understanding the concept of culture is to picture it as the luggage that each of us carries around for our lifetime."); CECIL G. HELMAN, *CULTURE, HEALTH AND ILLNESS* 3 (1994) ("culture can be seen as an inherited 'lens', through which the individual perceives and understands the world . . ."). This Note proposes viewing culture, not in a vacuum, but as one important element influencing how individuals may view the world and behave. It recognizes that cultures are heterogeneous and that generalizations about particular cultural groups can lead to stereotyping and misuse. *See id.* at 4-5 (warning against the failure to view culture in its particular context); DON C. LOCKE, *INCREASING MULTICULTURAL UNDERSTANDING* 6-11 (1992) (emphasizing the importance of remembering that there are differences within cultural groups and providing ten elements to understand such differences); STANLEY SUE AND THOM MOORE, *EDS., THE PLURALISTIC SOCIETY* 23-27 (1984) (advocating a culturally pluralistic view that emphasizes an individual's subjective culture influenced by one's objective culture). In addition, culture must be comprehensively defined to include not only ethnicity, but gender, religion, and socioeconomic status. A layering of cultural systems provides a richer understanding of an individual's belief system and guards against stereotyping. *See, e.g.*, HELMAN, *supra*, at 4-5 (proposing that culture must be viewed in its particular context influenced by its particular historical, economic, social, political, and geographical elements and citing important influence of individual factors such as age and gender, educational factors, and socioeconomic factors); Susan M. Wolf, *Shifting Paradigms in Bioethics and Health Law: The Rise of A New Pragmatism*, 20 AM. J. L. & MED. 395, 401 n. 39-43 (1994) (noting the rise of empiricism in bioethics coupled with an attention to the intersection of race, gender, and economic status).

that culture informs the perception of health and illness and prescribes the parameters of medical decisionmaking.⁶ Further, insisting on a singular notion of autonomy, defined by Western values and applied to all individuals, fails to respect individual autonomy in a different and fuller sense by diminishing an individual's right to decide how and by whom decisions of consequence to his or her life are made.⁷

In the United States, the law regarding patient autonomy does little to accommodate a competent patient's desire, for cultural or other reasons, to limit his or her role in medical decisionmaking. This Note argues that the law regarding medical decisionmaking must be reformed to accommodate patients holding non-Western beliefs. It proposes a doctrine of "informed waiver" to serve as a

6. In their 1995 study, Leslie Blackhall et al., assessed the attitudes of two hundred subjects from four ethnic groups and found ethnicity to be a primary factor related to attitudes toward patient autonomy. Blackhall et al., *Ethnicity and Attitudes Toward Patient Autonomy*, 274 JAMA 820, 825 (1995) ("Although the patient autonomy model is founded on the idea of respect for persons, people live, get sick, and die while embedded in the context of family and culture and inevitably exist not simply as individuals but in a web of relationships."). See also Edmund D. Pellegrino, *Patient and Physician Autonomy: Conflicting Rights and Obligations in The Physician-Patient Relationship*, 10 J. CONTEMP. HEALTH & POL'Y 47, 54 (1993) ("Sickness is a test of our values. For each of us, our response to sickness is unique, and thus the way we express our autonomy is also unique."). This Note contends that a consideration of cultural difference, or a multiculturalist approach, does not, however, require resorting to cultural or ethical relativism. Cultural and ethical relativists suggest that morality is relative to the culture and society in which one is raised and lives and that questions of right and wrong are always relative to, and determined, by culture. John D. Arras & Bonnie Steinbock, *Introduction: Moral Reasoning in the Medical Context*, in *ETHICAL ISSUES IN MODERN MEDICINE* 1, 6-7 (John D. Arras & Bonnie Steinbock eds., 4th ed. 1995). As a result, extreme cultural relativists risk justifying brutal and intolerant practices, such as oppression and mutilation in the name of respect for cultural difference. See generally *id.* at 7-8; Allen Buchanan, *Judging the Past: The Case of the Human Radiation Experiments*, 26 HASTINGS CENTER REP. 25, 26 (May-June 1996) ("Cultural ethical relativism, strictly speaking, denies that there are any human rights."); Sandra D. Lane & Robert A. Rubinstein, *Judging the Other: Responding to Traditional Female Genital Surgeries*, 26 HASTINGS CENTER REP. 31, 32 (May-June 1996) (citing human rights scholar Alison Slack who identifies two opposing concerns, the "absolute right of 'cultural self-determination' and the right of the individual not to be subjected to a tradition or practice that might be harmful or fatal."). Multiculturalism, however, encourages critical thinking about the values of different cultures and seeks multiple perspectives on ethical and moral issues within a moral framework that respects human dignity and human rights. See Buchanan, *supra*, at 26 ("Human rights, by definition, are the rights we have simply by virtue of our humanity, regardless of differences in our cultures, and regardless of when or where we live.").

7. See Pellegrino, *supra* note 6, at 48-9 ("To obstruct the capacity for autonomy is to assault an essential part of a person's humanity, because the choices we make are so much an expression of our membership in the human community, of who we are or what we want to be as individual members of that community. Human beings are owed respect for their autonomy because they have an inherent dignity.").

counterweight to the Western biases now present in the informed consent doctrine and to enable health care providers to respect their patients' autonomy in the fullest sense. Part I defines the Western notion of patient autonomy. First, it describes the principle of autonomy rooted in Western traditions of self-governance and personal and political freedom of choice. Second, it discusses the legal vision of autonomy as expressed by American courts in the doctrine of informed consent and the laws on medical decision-making. Part II illustrates that the values reflected in the Western definition of autonomy do not hold true for all patients, and may even prove harmful for some patients' welfare. Part III proposes a framework whereby culture might be incorporated into a definition of autonomy in legal and medical practice. It examines how the law and health care providers might accommodate cultural difference and concludes that a notion of informed waiver is the best compromise for enabling patients to forgo Western-defined approaches to medical decisionmaking.

I. A Western Conception of Autonomy

Culture has long been recognized in the social sciences as a predominant factor influencing perceptions and expressions of health and illness. Western cultural values shaped the notion of patient autonomy in American legal and medical doctrine and practice. One commentator writes, "we learn from our own cultural and ethnic backgrounds how to be healthy, how to recognize illness and how to be ill."⁸ Cultural values may be further refined by the overlapping "culture" of gender, class, religion, and even sexual orientation.⁹ For example, a culture may inculcate more emotional or passive decisionmaking for women¹⁰ and those with diminished

8. SPECTOR, *supra* note 5, at 65. See also HELMAN, *supra* note 5, at 4 (arguing that individuals' beliefs and practices relating to illness and health are a central feature of the culture).

9. See Wolf, *supra* note 5. New works examine this layering in the medical context. See, e.g., IT JUST AIN'T FAIR: THE ETHICS OF HEALTH CARE FOR AFRICAN AMERICANS (Annette Dula & Sara Goering eds. 1994) (race-attentive essays); FEMINIST PERSPECTIVES IN MEDICAL ETHICS (Helen Bequaert Holmes & Laura M. Purdy eds. 1992) (gender-attentive essays). For a well-written analysis of the intersection of race, poverty, and gender, see Dorothy E. Roberts, *The Future of Reproductive Choice for Poor Women and Women of Color*, 12 WOMEN'S RTS. L. REP. 59 (1990). For the role of religion in one's perception of health and illness, see SPECTOR, *supra* note 5, at 135-168.

10. See generally CAROL GILLIGAN, IN A DIFFERENT VOICE (1982) (proposing that women's motives, moral commitments and psychological development are different from men); HELMAN, *supra* note 5, at 146-156, 149 (examining anthropological research on "gender cultures" and the relationship between gender and health)

economic resources.¹¹ Fear of discrimination and actual or perceived powerlessness may promote greater distrust of one's ability to participate equally in medical treatment.¹² Moreover, educational and language barriers may inhibit active participation in medical decisionmaking as well as augment dependence on family and community members.¹³ Members of a particular culture may share all or part of their cultural norms, and may cast off or modify these values when they find themselves in a Western culture. Political, economic, and social forces may alter the way culture is transmitted and maintained among generations. However, many elements of culture are unconsciously and consciously passed from one generation to the next.

A. The Moral Vision of Autonomy — Respect for Persons

In Western moral and political theory, respect for autonomy is a guiding principle and refers to personal self-governance that is free from control or interference by others.¹⁴ Autonomy acknowledges that all human beings have a capacity for moral dignity and that those who possess moral dignity are determiners of their own destinies.¹⁵ The American vision of autonomy, derived from philosoph-

("Whatever the contribution of biology to human behavior, it is clear that culture also contributes a set of guidelines -both explicit and implicit- which are acquired from infancy onwards, and which tell the individual how to perceive, think, feel and act as either a 'male' or a 'female' member of that society.").

11. See, e.g., GEORGE HENDERSON & MARTHA PRIMEAUX, *TRANSCULTURAL HEALTH CARE* 199-201 (1981) (discussing how poverty restricts patients' capacity for self-actualization).

12. For a general discussion of the interrelatedness of power and culture, see ELAINE PINDERHUGHES, *UNDERSTANDING RACE, ETHNICITY, AND POWER* 109-146 (1989).

13. See, e.g., JACOB LINDENTHAL & MADELEYN SCHNEIDER, *HEALTH CONCERNS OF HISPANICS IN NEW YORK CITY* 16-17 (1991) ("Too often, young, inexperienced children who accompanied their parents have been expected to translate and interpret medical symptoms . . .").

14. The Western moral and political theory of individualism, as exemplified by the works of Locke and Mill strongly influenced the Western conception of autonomy. LOCKE, *supra* note 1, at 17 ("The natural liberty of man is to be free from any superior power on earth and not to be under the will or legislative authority of man, but to have only the law of nature for his rule."); MILL, *supra* note 1, at 54 ("Where not the person's own character but the traditions or customs of other people are the rule of conduct, there is wanting one of the principal ingredients of human happiness and quite the chief ingredient of individual and social progress."). For a discussion of American individualism, see Steven Lukes, *The Meaning of Individualism*, in *supra* note 1, at 192-94.

15. See Pellegrino, *supra* note 6, at 49 ("[Autonomy] implies an obligation to foster the human capacity for self-determination, to enhance it, and to remove obstacles to its full operation.").

ical notions of individualism, honors a form of self-actualization that is achieved by separating the individual from the community, the secular from the spiritual, and reason from emotion.¹⁶ Several other principles, including confidentiality, privacy, and veracity, may be viewed as derivatives of the principle of autonomy.¹⁷

In the medical context, the concept of patient autonomy responded to the 1960's civil rights movements and a social climate that questioned authority.¹⁸ At the same time, radical advances in life-sustaining and life-creating medical technology fostered a re-examination of the patient's role in determining the course of medical treatment.¹⁹ These unprecedented social and technological developments applied uniquely to Western cultures. Born in the early 1970s, American bioethics was heavily influenced by notions of liberal individualism as expressed by eighteenth and nineteenth century Western philosophers and contemporary public discontent with medical paternalism.²⁰ American bioethicists also equated autonomy with other Western cultural values, such as truth-telling, self-reliance, and patients' active participation in medical decision-making and treatment.²¹ In bioethical theory, personal autonomy

16. The autonomous person, in Western thought, is "consistent, independent, in command, resistant to control by authorities, and the source of his or her own basic values, beliefs, and life plans." TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 68 (3d ed. 1989). See also LOCKE, *supra* note 1, at 35 ("The freedom of man, and liberty of acting according to his own will, is grounded on his having reason."). For a discussion of the predominance of respect for autonomy as a guiding principle in ethical theory, see TOM BEAUCHAMP & LEROY WALTERS, *CONTEMPORARY ISSUES IN BIOETHICS* 26-8 (2d ed. 1982).

17. *Id.* at 28.

18. BEAUCHAMP & CHILDRESS, *supra* note 16, at 67-119.

19. Technological innovation includes cardiopulmonary resuscitation, prenatal diagnosis, in vitro fertilization, and heart transplants. Arras & Steinbock, *supra* note 6, at 3-5. Case law exemplifying re-examination of patients' rights in medical treatment include *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990) (allowing an incompetent patient's family to remove life support where there was clear and convincing evidence of patient's wishes to avoid death-delaying treatment); *In the Matter of Quinlan*, 355 A.2d 647 (1976) (allowing valid surrogates to refuse life-saving measures despite physicians' objections).

20. See Thomas Murray, *Communities Need More Than Autonomy*, HASTINGS CENTER REP. (May-June 1994), at 32 ("In the development of bioethics, autonomy emerged as a powerful protest against evil or thoughtless researchers and paternalistic physicians. It found deep ideological resonance within American popular, legal, and political culture: our celebration of the individual, our anger at infringement of others, our constitutionalized protections of personal liberty, and our faith in markets as fair and efficient methods for distributing social goods from bathtubs - to babies.").

21. See, e.g., Alan Goldman, *The Refutation of Medical Paternalism*, in *ETHICAL ISSUES IN MODERN MEDICINE* 58, 58-66 (John D. Arras & Bonnie Steinbock eds., 4th ed. 1995) (arguing that truth-telling is essential to avoid thwarting the patient's self-determination); Vicki Michel, *Factoring Ethnic and Racial Differences into Bioethics*

emerged as the predominant moral principle guiding medical decisions and treatment.²²

B. The Legal Vision of Autonomy — The Search for Patient Voice

Personal autonomy, as a controlling vision, is firmly established in the law as a fundamental right, evidenced by the constitutional right to bodily integrity, liberty, and self-determination.²³ The doctrine of consent represents the legal embodiment of these rights for patients in the medical context.²⁴ As Justice Cardozo wrote in *Schloendorff v. Society of New York Hospitals*,²⁵ “[e]very human being of adult years and sound mind has a right to determine what

Decisionmaking, 53 GENERATIONS 23 (1994) (“In the last thirty years, we have adopted the view that respect for patient autonomy requires that patients be told everything about their condition and that each patient him- or herself is the only legitimate decisionmaker about treatment or nontreatment.”).

22. BEAUCHAMP & WALTERS, *supra* note 16, at 27. However, the predominance of the principle of autonomy has become a subject of heated debate among bioethicists. See, e.g., Murray, *supra* note 20, at 33 (“autonomy can only be part of the story about how we are to live together, how we are to make families and communities that support the growth of love, enduring loyalties, and compassion.”); Arras & Steinbock, *supra* note 6, at 25-31 (discussing the numerous challenges to liberal individualism and the predominance of autonomy principle by communitarians and feminist ethicists). Some bioethicists have developed models of informed consent and medical decisionmaking that do not assume patients have a private set of values. Charles Lidz et al., *Two Models of Implementing Informed Consent*, 148 ARCHIVES OF INTERNAL MEDICINE 1285 (1988); Ezekiel Emanuel & Linda Emanuel, *Four Models of the Physician-Patient Relationship*, 267 JAMA 2221 (1992). But see James F. Childress & John C. Fletcher, *Respect for Autonomy*, HASTINGS CENTER REP. (May-June 1994), at 34 (“Despite a predictable backlash against the principle of respect for autonomy, it still holds, and should hold, a central place in biomedical ethics in a liberal society in the 1990s.”).

23. See, e.g., U.S. CONST. amend. XIV; *Roe v. Wade*, 410 U.S. 113 (1973) (finding a right to abortion based on a constitutional right to bodily integrity); *Cruzan v. Director, Mo. Dep’t of Health*, 497 U.S. 261 (1990) (finding the right to refuse life-prolonging treatment based on a constitutional right to liberty).

24. The doctrine of informed consent developed from merely a permission to touch to a tool for facilitating medical decisionmaking. See *Mohr v. Williams*, 104 N.W. 12 (Minn. 1905). In *Mohr*, the court found an action for battery in favor of the plaintiff where a physician obtained his patient’s consent to operate on her right ear and during surgery discovered that the left ear actually needed surgery. The physician operated on the left ear and, as a result, the patient claimed further impairment to her left ear. The patient sued the physician for operating on that ear without her consent. The court extended the concept of consent beyond intentional, unauthorized touching to include the right of patients to weigh benefits and risks of medical treatment. The court wrote, “the free citizen’s first and greatest right, which underlies all others [is] . . . the right to himself.” 104 N.W. at 14 (citing *Pratt v. Davis*, 79 N.E. 562 (Ill. 1906)).

25. 105 N.E. 92 (1914).

shall be done with his own body"²⁶ "Informed consent"²⁷ requires health care providers to disclose diagnoses, the nature and purpose of a proposed treatment, and the risks of treatment to the patient.²⁸ In addition, it guides medical decisionmaking by defining the parameters of the patient-physician relationship.²⁹

The law on informed consent represents a struggle to find patients' voice in medical decisionmaking and to level the playing field between patients and their physicians. The voice discovered, however, echoes a notion of autonomy based on Western cultural values. First, informed consent emphasizes the right of the individual to make decisions concerning medical treatment.³⁰ Second, it advocates forthrightness regarding medical prognosis, treatment, and risks. Third, it emphasizes secularism rather than spirituality by utilizing the scientific method. Fourth, it envisions the active participation of the individual patient in medical treatment and decisions about treatment.

The doctrine of informed consent, grounded in tort law³¹ and applying its theories of battery, negligence, and standards of mea-

26. *Id.* at 93.

27. The term "informed consent" was coined in *Salgo v. Leland Stanford Jr. University Board of Trustees*, 317 P.2d 170, 181 (Cal. Ct. App. 1957).

28. 1 FURROW, *supra* note 3, at 415-17. Some jurisdictions may also require physicians to disclose alternative methods of diagnosis or treatment that are generally accepted by the medical community. *See, e.g., Moore v. Baker*, 989 F.2d 1129 (11th Cir. 1993) (requiring disclosure of alternative treatment under Georgia law only where treatment is generally accepted by reasonably prudent physicians); *Gemme v. Goldberg*, 626 A.2d 318 (Conn. Ct. App. 1993) (citing breach of duty by oral surgeon who failed to disclose alternatives to surgery even where alternative was more dangerous). The California Supreme Court held that a physician has a duty to disclose to a patient the risks of a failure to decline a test or procedure viewed as valuable by the physician. *Truman v. Thomas*, 611 P.2d 902 (Cal. 1980). Other cases have considered the duty to disclose prognosis with treatment. *See, e.g., Arato v. Avedon*, 858 P.2d 598 (Cal. 1993) (finding no breach of duty where the physician failed to disclose statistics on life expectancy but stating that a jury may decide what is "material information" to a reasonable patient) (*en banc*).

29. 1 FURROW, *supra* note 3, at 409.

30. It is important to distinguish between the medical and legal notions of informed consent. Beauchamp and Childress describe "two senses" of informed consent. The first sense involves autonomous action and understanding by the patient. The second sense conforms to institutional rules necessary to obtain legally effective informed consent. The latter has more to do with disclosure and the liability of professionals than the autonomous choices of patients. In our litigious society, for many health care institutions and physicians, informed consent may be driven by fears of malpractice, not driven by rights-based ideals. BEAUCHAMP & CHILDRESS, *supra* note 16, at 76-8.

31. W.L. PROSSER, *LAW OF TORTS* § 9 (4th ed. 1971).

suring duty and causation,³² evolved from a right to be free from nonconsensual interference with one's person to a principle of autonomy, liberty, privacy, and the fulfillment of the physician's "duty to warn."³³ Early consent cases premised liability on battery theory,³⁴ requiring that patients demonstrate that they were not informed of the nature of "medical touching."³⁵ Modern law, however, treats informed consent as a negligence action; this is a more nuanced approach that reflects the reality of patient-physician interactions.³⁶

32. A review of the standard of causation in informed consent can be found in 1 FURROW, *supra* note 3, at 433-435. The majority of jurisdictions adopt an objective, reasonable patient test of causality that considers what a reasonable patient would have done if informed. *Id.* at 433. Some jurisdictions have considered a subjective causation test by asking what the particular patient would have done if informed. *See, e.g.,* *Arena v. Gingrich*, 748 P.2d 547 (Or. 1988); *Spencer v. Seikel*, 742 P.2d 1126 (Okla. 1987). In North Carolina, the court in *McPherson v. Ellis*, 287 S.E.2d 892 (N.C. 1982) endorsed a subjective standard, but was later overturned by the state informed consent statute. N.C. GEN. STAT. § 90-21.13(a) (1993) (requiring an objective standard for informed consent). Most recently, the Hawaii Supreme Court in *Bernard v. Char*, 903 P.2d 667 (Haw. 1995) overruled *Leyson v. Steuermann*, 705 P.2d 37 (Haw. Ct. App. 1985) (endorsing a modified objective standard that determines causation from the viewpoint of the particular patient acting rationally and reasonably) and held that causation in an action based on informed consent is to be judged by an objective standard. 903 P.2d at 676.

33. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, MAKING HEALTH CARE DECISIONS: A REPORT ON THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP 18-21 (Oct. 1982).

34. *See Mohr*, 104 N.W. at 12. The question in a battery action is whether the physician informed the patient of the nature of the procedure and whether the patient consented. Proponents of the battery theory argue that its purpose is to protect bodily integrity and thus, it links informed consent to the principle of personal autonomy. *See* RUTH FADEN & TOM BEAUCHAMP, A HISTORY AND THEORY OF INFORMED CONSENT 26-7 (1986). Critics contend that the theory is useful only in situations where a physician intentionally withholds information or acts beyond the scope of a patient's consent. *Id.* at 29-30. In addition, some criticize battery law as providing physicians with only one defense - that they have obtained consent (or presumed consent in the case of emergency care). *See* Jay Katz, *Informed Consent - Must It Remain a Fairy Tale?*, 10 J. CONTEMP. HEALTH L. & POL'Y 69, 78 (1993). Others maintain that battery theory disadvantages the patient because many courts are reluctant to view physicians as acting in bad faith or in an antisocial manner. FADEN & BEAUCHAMP, *supra* at 29-30, 127-8. Currently, Pennsylvania is the only state that characterizes the lack of informed consent as a battery. *Gray v. Grunnagle*, 223 A.2d 663 (Pa. 1966), *on reh'g*, 228 A.2d 735 (Pa. 1967). Most jurisdictions, however, permit a battery approach to informed consent where consent is found to be absent for a particular procedure. 1 FURROW, *supra* note 3, at 410.

35. *Id.* No showing of physical injury is required by battery theory.

36. The negligence theory of liability examines the defendant's unintended harmful act or failure to act. The elements required to establish negligence include a legal duty, a breach of that duty, measurable injury, a direct causal relation between the breach of duty and the injury, and a proximate causal relation between the act or

1. *Toward a Patient-Based Standard of Disclosure*

To decide a negligence action based on the failure to disclose, courts must choose a standard of disclosure. The choice of either a physician or patient-based standard for disclosure directly impacts the extent to which the laws, and thus physicians, acknowledge patients' particular values in medical decisionmaking.³⁷ It determines the connection between the doctrine of informed consent and patient self-determination by influencing the consideration that courts give the patient's voice in medical decisionmaking. It can either frame informed consent as protecting physicians' liability or as protecting patients' medical choices.³⁸

Most jurisdictions follow the patient-based standard,³⁹ considering whether a physician disclosed information that a reasonable patient would consider material to his or her decision whether or not to undergo treatment.⁴⁰ Courts upholding this standard reject the

omission and the injury. As a result, the patient must prove physical injury to win the case. See FAY A. ROZOVSKY, *CONSENT TO TREATMENT: A PRACTICAL GUIDE* § 1.3, at 9 (2d ed. 1990) Advocates of negligence theory applaud its ability to allow physicians to invoke many defenses and its acknowledgment that most physicians act in good faith. 1 FURROW, *supra* note 3, at 412. Opponents, such as Jay Katz, argue that negligence theory reduces the doctrine of informed consent to a "failure to warn law," based more on professional liability and the expectations of the medical profession than on patient decisionmaking and self-determination. Jay Katz, *Informed Consent: A Fairy Tale? Law's Vision*, 39 U. PITT. L. REV. 137, 139 (1977). Other commentators argue that negligence theory and its emphasis on proving physical harm ignores the rights-based aspects of the doctrine of informed consent. See Roger Dworkin, *Medical Law and Ethics in the Post-Autonomy Age*, 68 IND. L. J. 727, 729 (1993) ("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."). Still others suggest that, in the current litigious climate of medical malpractice, cost containment, and health care reform, informed consent has become a defensive risk management weapon. Discussion with Nancy Neveloff Dubler, Esq., Director, Division of Bioethics, Dep't of Epidemiology and Social Science, Montefiore Medical Center, Bronx, N.Y. (April 1996).

37. 1 FURROW, *supra* note 3, at 410.

38. For an analysis of informed consent as upholding patient choice and a proposal for reframing the doctrine as a constitutional right to patient choice in medical decisionmaking, see Marjorie Maguire Shultz, *From Informed Consent to Patient Choice: A New Protected Interest*, 95 YALE L. J. 219 (1985).

39. 1 FURROW, *supra* note 3, at 414-15 n.8 (citing cases adopting objective standard).

40. *Id.* at 414. Proponents of the reasonable person standard argue that patient autonomy interests require an emphasis on the patient rather than the medical profession. BEAUCHAMP & CHILDRESS, *supra* note 16, at 88. Critics argue that the objective, reasonable person standard "amalgamates patients into one standard of reasonableness." Dworkin, *supra* note 36, at 729. See also BEAUCHAMP & CHILDRESS, *supra*, at 89 ("this reasonable person standard is still plagued by conceptual, moral, and practical difficulties."). The reasonable person standard in tort law may be contrasted with that in criminal law. Criminal law endows a reasonable man standard

approach that requires patients to prove that a reasonable physician in the same or similar medical community would disclose the information. Throughout medical history and practice, physicians, and some lawmakers, believed physicians alone, given their specialized training and expertise, should make treatment decisions for their patients.⁴¹ Indeed, a physician-based negligence standard holds that the duty to disclose and the scope of disclosure is determined by the customs of the professional (medical) community.⁴² The determination of pertinent information for disclosure is viewed as a medical question rather than a question of patient choice. Although approximately twenty-five states, either by case law⁴³ or statute,⁴⁴ adopt the physician-based standard, courts often experience difficulty applying it because of physicians' reluctance to testify against one another and the questionable existence of a community standard in contemporary medical practice.⁴⁵

The case law on informed consent illustrates a trend toward an objective, patient-based standard of disclosure. In 1957, the California Supreme Court held in *Salgo v. Leland Stanford Jr. Univer-*

with certain of the defendant's physical characteristics in the case of manslaughter, for example, but disallows peculiar emotional characteristics. The Model Penal Code, however, allows some subjectivity; defined as the viewpoint of a person in the actor's situation under the circumstances as he believed them to be. The Code allows consideration of some of the actor's mental or emotional characteristics. MODEL PENAL CODE § 210.3(1)(B) (1962). Some areas of criminal procedure, such as the laws of entrapment, preemptory challenge and public welfare offense, have employed a subjective person standard.

41. See Katz, *supra* note 34, at 73 ("The idea that patients were also 'autonomous' human beings, entitled to being partners in decisionmaking, was, until recently, rarely given recognition in the lexicon of medical ethics.").

42. 1 FURROW, *supra* note 3, at 413.

43. *Id.* at 413 n.6 (citing state cases adopting the physician-based standard).

44. *Id.* at 413 n.7 (citing state statutes adopting physician-based standard).

45. Critics of the physician-based standard ask whether a community standard exists in modern medical practice, whether physicians can truly know what information serves the best interest of their patients, and note the potential for abuse in allowing those judged by a law to set its parameters. See, e.g., BEAUCHAMP & CHILDRESS, *supra* note 16, at 87-88. The authors also question whether physicians have sufficient expertise to determine what information is in their patients' best interest. *Id.* at 88. ("Medical custom often expresses the presumptions, values, and goals of a medical orientation, but information provided to patients and subjects needs to be freed from the entrenched values and goals of medical professionals."); Dworkin, *supra* note 36, at 729 (arguing that the professional standard "is directed exclusively to the collective preferences of professionals"). Proponents argue that the professional standard upholds physicians' professional duty to seek their patients' best interests, recognizes physicians' limited time to discuss all possible risks with their patients, and acknowledges physicians' ability to evaluate the impact that risks may have on particular patients. 1 FURROW, *supra* note 3, at 413.

sity Board of Trustees⁴⁶ that physicians had a duty to disclose the risks and alternatives of treatment. This decision simultaneously affirmed patients' right to self-determination in the medical context and physicians' important role in facilitating medical decisions.⁴⁷ Twelve years later, in the landmark case *Canterbury v. Spence*,⁴⁸ the D.C. circuit emphasized patient self-determination and held that a "patient's right of self-decision shapes the boundaries of the duty to reveal."⁴⁹ *Canterbury* paved the way for a recognition of patients' rights in medical decisionmaking and a richer doctrine of informed consent.⁵⁰ Thereafter, courts began to question the efficacy of the professional practice standard and to insist on more meaningful informed consent in medical treatment. Most significantly, *Canterbury* established a patient-oriented disclosure standard by making the reasonable patient, in what the physician knows or should know to be in the patient's position,⁵¹ the measure of the scope of disclosure.⁵² The court rejected prior courts' reliance on the professional practice standard; instead, the court determined that "it is the prerogative of the patient, not the physician, to determine for himself the direction in which his interests lie."⁵³ The court argued that physicians should communicate to the patient "the inherent and potential hazards of the proposed treatment, the alternatives to that treatment, if any, and the results

46. 317 P.2d 170 (Cal. 1957). *Salgo* involved a medical malpractice action where a patient sued his physicians for negligent performance and for failing to warn him of the risk of paralysis. The court held that the physician violated his duty to the patient by withholding facts "necessary to form the basis of an intelligent consent by the patient to the proposed treatment." *Id.* at 181.

47. Some commentators identify *Salgo* as representing the judicial ambivalence that has remained at the heart of the doctrine of informed consent, whether informed consent is "about the extent to which individual and societal well-being is better served by encouraging patients' self-determination or supporting physicians' paternalism." FADEN & BEAUCHAMP, *supra* note 34, at 126-27 (quoting Jay Katz). See also JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 61 (1984) ("Going in two opposite directions - discretion and full disclosure - his [Justice Bray's] answer went nowhere.").

48. 464 F.2d 772 (D.C. Cir.), *cert. denied*, 409 U.S. 1064 (1972). That same year, California and Rhode Island shifted from a physician-based standard to a reasonable, objective patient-based standard. See *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972); *Wilkinson v. Vesey*, 295 A.2d 676 (R.I. 1972).

49. 464 F.2d at 786.

50. *Id.* at 781-82.

51. *Id.* at 791.

52. *Id.* 783-84.

53. *Id.* at 781. It adopted *Schloendorff's* language regarding the patient's right "to determine what shall be done with his own body" and decided that patients' best interests are served when they are informed of information material to their medical decision. *Id.* at 780 (quoting *Schloendorff*, 211 N.Y. at 129, 105 N.E. at 93).

likely if the patient remains untreated.”⁵⁴ The decision criticized the physician-based standard, arguing that it required physicians to guess what information their patients would deem material. Nonetheless, the *Canterbury* court chose an objective, rather than a subjective, patient-based standard, reacting to fears of patients’ hindsight declarations of what they would have decided had the physician disclosed the risks.⁵⁵

The 1990 decision in *Moore v. Regents of University of California*,⁵⁶ clarified the scope of informed consent by requiring physicians to provide clear and precise information regarding their personal interests in the patient that are unrelated to medical treatment options, but which might affect patients’ medical judgment.⁵⁷ The *Moore* court based its decision on three principles: the patient’s right to autonomy, the doctrine of informed consent, and the physician’s duty to disclose all information that is material to the patient’s interest.⁵⁸ *Moore* marked the first time a court extended the physician’s duty to disclose to include informing patients about factors beyond the medical procedure at hand. As a result, it lends support to a proposition that patients may desire an array of information when considering medical treatment.⁵⁹

54. *Canterbury*, 464 F.2d at 787-88.

55. In *Cobbs v. Grant*, the California Supreme Court wrote, “[W]e doubt that justice will be served by placing the physician in jeopardy of the patient’s bitterness and disillusionment. Thus an objective test is preferable: i.e., what would a prudent person in the patient’s position have decided if adequately informed of all significant perils.” 502 P.2d at 11-12. Commentators note the irony of choosing an objective standard for a doctrine developed to promote individual decisionmaking. See, e.g., 1 FURROW, *supra* note 3, at 414; Ben A. Rich, *Postmodern Medicine: Deconstructing The Hippocratic Oath*, 65 U. COLO. L. REV. 77, 98 (1993) (“There is, of course, an exquisite irony in the fact that informed consent, a medico-legal doctrine intended to recognize and facilitate patient autonomy through full disclosure of all pertinent information, should be measured by either an objective or professional standard.”).

56. 793 P.2d 479 (Cal. 1990), *cert. denied*, 499 U.S. 936 (1991).

57. Examples of unrelated interests include the physician’s potential role as researcher, investor or profiteer. In *Moore*, the economic interests in question were profits produced from the nonconsensual patenting of a cell line derived from the patient’s excised spleen and other bodily fluids. The court held that “the existence of a motivation for a medical procedure unrelated to the patient’s health is a potential conflict of interest and a fact material to the patient’s decision.” *Id.* at 486.

58. *Id.* at 485.

59. Perhaps a more accurate interpretation of the *Moore* decision focuses on the majority’s vision of informed consent as a tool to monitor the medical marketplace and the commercial relationships that may arise between physicians and their patients. Discussion with Nancy Neveloff Dubler, Esq., Director, Division of Bioethics, Dep’t of Epidemiology and Social Science, Montefiore Medical Center, Bronx, N.Y. (March 1996).

Most recently, in *Arato v. Avedon*,⁶⁰ the California Supreme Court affirmed that the lack of informed consent can constitute a negligence cause of action and upheld the reasonable patient standard of disclosure. The court, however, explicitly acknowledged that patients' need for medical information may vary and that physicians should not be required to disclose particular species of information regardless of the circumstances.⁶¹ In addition, the court noted that some patients may not benefit from full disclosure of information by stating that "each patient presents a separate problem, that the patient's mental and emotional condition is important and in certain cases may be crucial"⁶² Given the California court's influence on the evolution of the doctrine of informed consent,⁶³ the *Arato* decision is likely to affect the doctrine in other jurisdictions. The court found that physicians had not breached their duty to obtain informed consent by failing to disclose statistical information about mortality rates from radiation and chemotherapy treatment.⁶⁴ It held that a physician should disclose "all material information . . . which the physician knows or should know would be regarded as significant by a reasonable person in the patient's position"⁶⁵ In the end, the court entrusted the

60. 858 P.2d 598 (Cal. 1993).

61. *Id.* at 606 ("the contexts and clinical settings in which physician and patient interact and exchange information material to therapeutic decisions are so multifarious, the informational needs and degree of dependency of individual patients so various, and the professional relationship itself such an intimate and irreducibly judgment-laden one").

62. *Id.* (quoting *Salgo*, 317 P.2d at 181).

63. See *Moore*, 793 P.2d 479 (Cal. 1990); *Truman*, 611 P.2d 902 (Cal. 1980); *Cobbs*, 502 P.2d 1 (Cal. 1972). The lower court decision in *Salgo*, 317 P.2d 170 (Cal. Ct. App. 1957), was also influential and significant.

64. In *Arato*, the plaintiff consented to and underwent radiation and chemotherapy treatment for approximately one year for pancreatic malignancy. During his initial visit with the oncologists, he completed a new patient questionnaire which asked whether he desired "to be told the truth about [his] condition" or whether he wished the physician to "bear the burden for him." 858 P.2d at 600. The plaintiff indicated that he wished to be told the truth. The oncologists discussed the associated risks of the treatment, disclosed that most victims die from pancreatic cancer, and that despite the proposed treatment, the patient was at serious risk of an incurable reoccurrence. *Id.* at 601. The plaintiff died after one year of treatment. His family alleged that by failing to disclose statistics about his life expectancy, his physicians failed to obtain his informed consent. *Id.* at 602. The family argued that these figures were "material" to the patient's decision to choose treatment. *Id.* They stated that had he been aware of the bleak data, he would have foregone treatment and spent his remaining time with his family and business affairs. *Id.* Instead, the patient chose the treatment and died without settling his personal matters which allegedly caused the failure of his contracting business and substantial tax losses.

65. *Id.* at 607.

jury and the physician, rather than the particular patient, with the responsibility for deciding what constitutes material information. Justice Armand Arabian, author of the *Arato* opinion, exemplified the court's ambivalence regarding the standard for disclosure by later writing that the level of disclosure should be "relegate[d] to the venerable American jury, which presumably is also composed of typical patients" and that "any practical guidance must come from the medical profession."⁶⁶ Despite its affirmation of the objective, and to some extent, the physician-based standard, *Arato* supports the notion that some patients may wish not to receive information about likely consequences of medical treatment, and leaves the door open for courts to consider quality of life issues in the context of assessing appropriate informed consent standards.

2. *Respecting Patients' Values in Medical Decisionmaking*

The modern shift toward a reasonable patient standard of disclosure reflects the courts' growing respect for patient rights and voice in medical decisionmaking. In contrast to a subjective standard that requires physicians to disclose information relevant to a particular patient and that judges whether a particular patient would have reached the same, specific decision, the reasonable patient standard advocates a monolithic⁶⁷ and noncontextual⁶⁸ vision of in-

66. Hon. Armand Arabian, *Informed Consent: From The Ambivalence of Arato to the Thunder of Thor*, 10 ISSUES L. & MED. 261 (1994) (analyzing *Arato* opinion and the proper level of disclosure). Professor Judith Daar argues that *Arato* promotes a physician-patient relationship whereby the physician views the patient as patient, and no more. Judith Daar, *Informed Consent: Defining Limits Through Therapeutic Parameters*, 16 WHITTIER L. REV. 187, 195 (1995) ("The physician need not be concerned about the patient as investor, business manager, a father or a spouse."). Another commentator, Alexander Morgan Capron observes that the *Arato* opinion "directs physicians to focus on patients' bodies rather than their lives." Alexander Morgan Capron, *Duty, Truth, and Whole Human Beings*, HASTINGS CENTER REP., 13 (July-Aug. 1993). He further suggests that *Arato* leaves the door open for future courts to consider the whole patient - not just the patient's decisionmaking needs. *Id.* at 14.

67. The American law of informed consent generally assumes that all patients share a desire for the same amount and type of information from their physicians and that medical decisions are made in similar medical settings. Exceptions to these presumptions in the case law include courts' consideration of exceptions to the requirement of disclosure, including emergencies, patient waivers, and therapeutic privilege. See 1 FURROW, *supra* note 3, at 435-39.

68. Peter H. Schuck, *Rethinking Informed Consent*, 103 YALE L. J. 899, 906 (1994) ("Contextualization would advance the aim of cost-effectiveness and would also be desirable in its own right . . . by tailoring the law's requirements more carefully to the different settings in which risks arise and are discussed, assessed, and acted upon."). Schuck argues for a movement away from a unitary informed doctrine toward one "with different requirements for different treatments and choice contexts." *Id.* at 954.

formed consent.⁶⁹ It defines "reasonable person" as a person holding Western values and favoring Western approaches to medical decisionmaking. Although courts have not adopted the pure subjective standard,⁷⁰ recent case law and statutes acknowledge that different patients may approach medical decisionmaking in different ways. In addition to the *Moore* and *Arato* courts' reflection on the values held by particular patients, some courts hold that a patient may testify as to what she or he would have done if fully informed.⁷¹ In *Fain v. Smith*,⁷² the Alabama Supreme Court adopted a modified objective standard that considered the needs of "a reasonable person with all the characteristics of plaintiff, including idiosyncrasies and religious beliefs."⁷³

Recent cases concerning the right to die and the right to refuse or demand medical treatment also exemplify courts' increasing willingness to respect patients' right to make decisions consistent with their own values. In *Cruzan v. Director, Mo. Dep't of Health*,⁷⁴ the Supreme Court allowed an incompetent patient's family to remove life support where there was clear and convincing evidence regarding the patient's wishes regarding death-delaying treatment. The decision expanded the notion of informed consent to include the right not to consent, or to refuse treatment.⁷⁵

69. Some commentators also suggest that the objective standard fails to honor the underlying values of informed consent by limiting individual self-determination. See, e.g., BEAUCHAMP & CHILDRESS, *supra* note 16, at 90-1 ("Despite many problems that plague the subjective standard of law, it is a preferable moral standard of disclosure from the standpoint of the principle of respect for autonomy, because it acknowledges the independent informational needs and desires of persons in the process of making difficult decisions."); Dworkin, *supra* note 36, at 729 ("Honoring autonomy would require the adoption of a subjective standard of disclosure that recognized the patient's right to be unreasonable.").

70. Due to fears that the patient, with hindsight, will decide that the information not disclosed was material to his or her decision and that she or he would have declined treatment. See *Canterbury v. Spence*, 464 F.2d 772, 790-91 (D.C. Cir.) ("It places the physician in jeopardy of the patient's hindsight and bitterness."), *cert. denied*, 409 U.S. 1064 (1972).

71. 1 FURROW, *supra* note 3, at 415. See e.g., *Bourgeois v. McDonald*, 622 So.2d 684 (La. Ct. App.) (allowing patient testimony as an inextricable part of informed consent issues), *writ denied*, 629 So.2d 1177 (La. 1993). Although a subjective standard for disclosure has not been adopted by any state, some jurisdictions have adopted a subjective causation standard. Other jurisdictions have offered "subjective" variations on objective measure of proximate cause. Recently, however, a Hawaii Supreme court overruled a "modified objective standard" in favor of an objective reasonable patient test. See *Bernard v. Char*, 903 P.2d 667 (Haw. 1995).

72. 479 So.2d 1150 (Ala. 1985).

73. *Id.* at 1155.

74. 497 U.S. 261 (1990).

75. *Id.* at 270.

Cruzan also solidified the holding in *Matter of Quinlan*⁷⁶ which extended self-determination to include allowing valid surrogates to refuse life-saving measures.⁷⁷ In subsequent cases, courts have permitted patient representatives to facilitate incompetent patients' desire for death-delaying treatment that physicians deemed futile and inappropriate.⁷⁸ Courts have even begun to consider patients' decisions to hasten death where the medical condition is terminal.⁷⁹ These decisions not only affirm the value of patient voice in medical decisionmaking, but they support decisionmaking approaches that include family and community members.

Congress expressly legislated patients' right to express their individualized values in medical decisionmaking. In 1990, the Patient Self-Determination Act⁸⁰ (the "PSDA") became law as part of the federal Omnibus Budget Reconciliation Act of 1990.⁸¹ Congress enacted the PSDA in response to the right to die movement,⁸² allowing patients to exercise their desire not to receive life-prolonging or futile treatment. The Act reinforced Do Not Resuscitate statutes by requiring health care providers to provide patients with information about advanced directives, hospital protocols, and state law regarding the right to refuse treatment.⁸³ The law re-

76. 355 A.2d 647 (N.J.) (allowing a patient to discontinue death-delaying medical treatment based on the patient's right to privacy and self-determination), *cert. denied sub nom Garger v. New Jersey*, 429 U.S. 922 (1976).

77. *Cruzan*, 497 U.S. at 284.

78. See, e.g., *In re Baby K*, 16 F.3d 590 (4th Cir.), *cert. denied*, 115 S. Ct. 91 (1994) (requiring a hospital to provide life-sustaining treatment to anencephalic infant at parents' request); *In re Wanglie*, No. PX-91-283 (Hennepin County, Minn., P. Ct. June 28, 1991), *reprinted in* 7 ISSUES L. & MED. 369 (1991) (allowing incompetent patient's representative, her husband, to demand futile death-delaying treatment for patient). *Cruzan*, however, clearly requires that surrogates demonstrate "clear and convincing evidence" of the patient's wishes to refuse treatment. *Cruzan*, 497 U.S. at 284.

79. See *Compassion in Dying v. State of Washington*, 79 F.3d 790 (9th Cir. 1996) (declaring that Washington's ban on physician-assisted suicide is unconstitutional because it violated due process clause as applied to terminally ill patients who wished to hasten their own deaths), *petition for cert. filed*, 65 U.S.L.W. 3085 (U.S. July 3, 1996) (No. 96-110); *Quill v. Vacco*, 80 F.3d 716 (2d Cir. 1996), *petition for cert. filed*, 64 U.S.L.W. 3795 (U.S. May 16, 1996) (No. 95-1858) (finding no fundamental right to assisted suicide but holding that laws prohibiting assisted suicide violated Equal Protection Clause).

80. 42 U.S.C. § 1395cc(f) (1994).

81. Pub. L. No. 101-508, §§4206, 4751, 104 Stat. 1388 (1990).

82. For discussion of the right-to-die movement, see HARRY R. GLICK, *THE RIGHT TO DIE, POLICY INNOVATION AND ITS CONSEQUENCES* 53-132 (1992). For a discussion of DNR/advanced directives, see BARRY R. FURROW ET. AL., *BIOETHICS: HEALTH CARE LAW AND ETHICS* 216-18, 263-79 (1991).

83. 2 FURROW, *supra* note 3, at 443. Compliance is required by all health care institutions and long-term care facilities participating in Medicare and Medicaid pro-

quires that those covered by the Act provide every patient with written information describing his or her rights under state law to make decisions concerning medical care, including the right to accept or refuse medical treatment and the right to devise advanced directives.⁸⁴ In addition, covered providers must provide written documentation delineating the provider's specific policies regarding these rights.⁸⁵ As a result, all American health care institutions must have formal policies that consider patients' involvement and rights in medical decisionmaking.⁸⁶ Moreover, the PSDA necessitates provider-patient communication about particular patients' wishes on life-sustaining treatment by requiring that physicians document whether that patient has signed any advanced directive.⁸⁷

3. *The Exceptions to Informed Consent*

The law also recognizes several exceptions to informed consent. As acknowledged in *Canterbury*⁸⁸ and *Cobbs v. Grant*⁸⁹ and later affirmed in *Arato*,⁹⁰ patients may neither benefit from nor desire to receive certain medical information. The right to forgo Western-defined approaches to medical decisionmaking is found in three exceptions to the doctrine of informed consent: emergency, therapeutic privilege, and waiver. In the emergency case, where the patient is unconscious and prompt treatment is required, courts agree that physicians can dispense with informed consent as long as the physician acts according to customary "emergency practice."⁹¹ Some courts hold that consent is implied in emergency situations.⁹²

grams. The Secretary of Health and Human Services is required to cut all Medicaid and Medicare funding to non-compliant institutions. 42 U.S.C. § 1395cc(b) (1994). The statute applies to patients upon admission to hospitals and nursing facilities, prior to receipt of care by home health care agencies and hospice programs and at the time of membership in a health maintenance organization. 42 U.S.C. §§ 1395cc(f)(1)(A), 1396a(w)(1)(A) (1994).

84. 42 U.S.C. § 1395cc (f) (1994).

85. 42 U.S.C. §§ 1395cc(f)(1)(A), 1396a(w)(1)(A) (1994).

86. See generally Richard A. Shugrue, *The Patient Self-Determination Act*, 26 CREIGHTON L. REV. 751 (1993) (examples of policies developed by providers).

87. In recent years, many commentators have critiqued the effectiveness of the Patient Self-Determination Act on promoting patient autonomy and completion of patient advanced directives. See, e.g., Mathy Mezey, *Making the PSDA Work For the Elderly*, 18 GENERATIONS 13 (1994). The limitations of the PSDA and advanced directives are discussed in Part III of this Note.

88. 464 F.2d at 786-89.

89. 502 P.2d 1, 1 (Cal. 1972).

90. 858 P.2d at 609. See generally 1 FURROW, *supra* note 3, at 436-37.

91. 1 FURROW, *supra* note 3, at 435.

92. *Id.*

The exception of therapeutic privilege allows physicians to withhold information from a patient when disclosure may cause the patient emotional or physical harm.⁹³ Although courts rarely invoke the privilege to dismiss a case, many state statutes incorporate the privilege to protect patients from themselves.⁹⁴ *Canterbury* upheld a "therapeutic exception" that enabled physicians to validly override the disclosure requirement where such disclosure posed a threat to the patient's "well-being" or in the case of an emergency.⁹⁵ Paradoxically, this exception undermined the patient-based standard by allowing physicians to employ their professional discretion to withhold information from their patients. It suggested, however, the court's understanding that patients may have varied needs for medical information and supported a movement toward a more comprehensive informed consent.⁹⁶

93. *Canterbury*, 464 F.2d at 789. In addition, the *Salgo* court established the defense of "therapeutic privilege," whereby full disclosure may be tempered by physician discretion. 317 P.2d at 181. The court's discussion did not, however, provide physicians with guidelines regarding physician discretion nor did it detail its legal basis for the doctrine of informed consent. It also failed to explicitly ground informed consent in battery or negligence theory.

94. See, e.g., ALASKA STAT. § 09-55.556 (b)(4) (1994); DEL. CODE ANN. tit. 18, § 6852 (b)(3) (1989); N.Y. PUB. HEALTH LAW § 2805 (d)(4) (McKinney 1993); OR. REV. STAT. § 677.097 (2) (1989); TEX. REV. ANN. CIV. STAT. art. 71, § 6.07 (a)(2) (West Supp. 1990); VT. STAT. ANN. tit. 12, § 1909(d) (Supp. 1995).

95. *Canterbury*, 464 F.2d at 788-89 (citing other defenses to allegations of failure to disclose such as patient's prior knowledge of the information not disclosed and the immateriality of nondisclosed information).

96. Following *Canterbury*, 464 F.2d 772 (D.C. Cir. 1972), *Cobbs v. Grant*, 502 P.2d 1 (Cal. 1972) and *Wilkinson v. Vesey*, 295 A.2d 676 (R.I. 1972) affirmed an objective, patient-based standard for disclosure and causation. *Cobbs* also affirmed the defenses for non-disclosure including emergency, incompetence, therapeutic privilege, patient waiver, or dangers remote and commonly known to be remote. 502 P.2d at 10. Similarly, *Wilkinson* recognized the defenses of emergency and therapeutic privilege. 295 A.2d at 686, 689. In a more recent case, *Wheeldon v. Madison*, 374 N.W.2d 367 (S.D. 1985), the South Dakota Supreme Court proposed that the physician-based standard could conflict with patient needs. ("We agree that the right to know - to be informed - is a fundamental right personal to the patient and should not be subject to restriction by medical practices that may be at odds with the patient's informational needs."). *Id.* at 374. In *Truman v. Thomas*, 611 P.2d 902 (Cal. 1980), the California Supreme Court relied on *Canterbury* and expanded the duty of physician disclosure to include the material risks of not consenting to recommended treatment. The case involved an action brought by the children of a woman who died from cervical cancer. They alleged that the physician failed to disclose the risks of not allowing a Pap Smear test, which the patient repeatedly refused. The physician, and the court minority, argued that the duty to disclose applies only to treatments to which patients consent. One commentator writes that this right to an informed refusal requires a physician to take time to maximize the patient's choices. 1 FURROW, *supra* note 3, at 425. Most recently, courts have considered the relevance of nonmedical interests for informed consent. See *Moore v. Regents of the University of California*, 793 P.2d 479 (Cal.

The third exception of patient waiver allows patients to forgo their right to receive medical information. Waiver provisions have been adopted either by statute⁹⁷ or by judicial ruling.⁹⁸ The U.S. Supreme Court defines waiver as the voluntary and intentional relinquishment of a known right.⁹⁹ A definition of waiver in the context of informed consent may be analogized to other areas of law where waiver of individual rights has been an issue.¹⁰⁰ In medicine, the notion of waiver acknowledges that some patients prefer to trust their physicians' professional judgment and that others may lack confidence in the ability to analyze risk information.¹⁰¹ The law allows patients to waive their right to give an informed consent, as long as it is made with full information and without coercion¹⁰² and, in the case of research and experimental treatment, where there exists "no more than a minimal risk to the patients."¹⁰³

1990), *cert. denied*, 499 U.S. 936 (1991) (imposing an obligation on physicians to disclose their research and economic interests); *Arato v. Avedon*, 858 P.2d 598 (Cal. 1993) (considering and rejecting obligating physicians to disclose statistical mortality rates of particular procedure).

97. *See, e.g.*, ALASKA STAT. § 09-55.556 (b)(2) (Supp. 1994); ARK. CODE ANN. § 16-114-206 (b)(2)(c) (Michie 1987); DEL. CODE ANN. tit. 18, § 6852 (b)(2) (Supp. 1994); N.H. REV. STAT. ANN. § 507-C(2)(II)(b)(3) (1983); UTAH CODE ANN. § 78-14-5(2)(c) (Supp. 1995); VT. STAT. ANN. tit. 12, § 1909(c)(2) (Supp. 1995).

98. *Arato*, 858 P.2d at 609 (acknowledging that a "patient may validly waive the right to be informed"); *Holt v. Nelson*, 523 P.2d 211, 219 (Wash. Ct. App. 1974) ("A physician need not disclose the hazards of treatment when the patient has requested she not be told about the dangers . . ."); *Cobbs v. Grant*, 502 P.2d 1, 12 (Cal. 1972) ("[A] medical doctor need not make disclosure of risks when the patient requests that he not be so informed."); *Canterbury v. Spence*, 464 F.2d 772, 786 (D.C. Cir. 1972) (determining that physicians should not be held liable for failure to disclose resulting from a patient's specific request not to be informed).

99. *Miranda v. Arizona*, 384 U.S. 436, 475-76 (1966); *Johnson v. Zerbst*, 304 U.S. 458, 464 (1938).

100. *See* Alan Meisel, *The "Exceptions" to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking*, 1979 WIS. L. REV. 413.

101. *See id.* at 459; Joseph Goldstein, *For Harold Laswell: Some Reflections on Human Dignity, Entrapment, Informed Consent, and the Plea Bargain*, 84 YALE L.J. 683, 694 (1975).

102. 1 FURROW, *supra* note 3, at 437.

103. This refers to the Department of Health and Human Services (DHHS) standards for permitting a waiver of informed consent in research. *See* 45 C.F.R. § 46.116 (d)(1) (1995). The Federal Drug Administration standards are more detailed, containing four criteria that are necessary to invoke an exception to informed consent. 21 C.F.R. § 50.23 (a)(1)-(4) (1996).

II. Culture and the Limits of the Western Definition of Autonomy

Case One

M.Y., a fifty-nine year old Korean woman, was admitted to the hospital for exploratory surgery following an exam by her doctor indicating a growth on M.Y.'s neck. M.Y. did not question her general physician, her primary provider since she immigrated to the United States ten years ago, about her condition or the procedure. Once admitted, M.Y.'s two grown sons, her daughter, and her brother-in-law visited daily. Each time the surgeon entered the room to discuss the surgery with M.Y., her family ushered him quickly from the room and questioned him about the procedure and its risks. When the surgeon stated that he could not disclose this information without M.Y.'s permission or presence, the family asked him to shield M.Y. from any "bad news" and for him to tell M.Y. that she would soon be discharged. When the surgeon finally approached M.Y. alone, after visiting hours, she reluctantly made eye contact and requested that he discuss her case with her primary physician and family. She refused to sign the informed consent documents without the presence of her sons and brother-in-law.¹⁰⁴

Case Two

E.R., a thirty-four year old Puerto Rican man living with AIDS arrived for his clinic appointment accompanied by his sixty-five year old mother and twenty year old sister. He informed the clinic staff that he had not renewed his medications, because his mother and sister believed they were harmful. E.R. and his mother announced that they had consulted a well-respected community healer. The clinic staff explained the life-threatening risks of refusing the prescribed medication and expressed their doubts about the healer's credentials and expertise. E.R. and his family adamantly refused the staff's recommended treatment and continued to follow the healer's instructions for care. In addition, E.R. requested that his physicians confer with the healer in determining his medical treatment. He informed the clinic social worker and physician that he would abide by the healer's assessment of the physicians' recommendations. The clinic physician threatened to request a psy-

104. Based on interview with Dr. Michael Lee, Yale University, New Haven, Conn., January 1996.

chological consultation to determine E.R.'s competency for medical decisionmaking.¹⁰⁵

The preceding case examples illustrate the tensions that arise when physicians attempt to "fit" patients into a noncontextual model of medical care and decisionmaking and care. The cases also demonstrate how well-meaning efforts to enforce the doctrine of informed consent risk depriving patients of their autonomy by denying his or her particular cultural values. M.Y. may be precluded from choosing to have her family closely involved in her medical care and E.R. may be prevented from refusing unwanted medical treatment. In the case of M.Y., the physician denied the patient the right to waive her right to decide and hear information. In the case of E.R., the clinic staff denied the patient the right to delegate decisionmaking authority to a culturally-respected practitioner or to waive his right to decide. In both cases, the health care providers risk jeopardizing their relationships with their patients. In the end, the Western ideal of informed consent neither promotes self-determination nor promotes the patient-physician relationship.

M.Y. and E.R.'s stories are not uncommon scenarios in the medical clinic or in the private physician's office. Studies demonstrate that ethnicity is a significant factor related to attitudes toward medical decisionmaking.¹⁰⁶ Most importantly, American health care providers practice, and American patients reside, in a nation rich in cultural diversity. More than nine million legal immigrants are expected to enter the United States during this decade.¹⁰⁷ This marks the largest wave of immigration since the first decade of the twentieth century.¹⁰⁸ Between 1990 and 1995, more than four million immigrants entered American society.¹⁰⁹ A large percentage of these individuals come from developing countries and the non-Western world. Instead of assimilating into a great "melting pot,"

105. Based on the author's experience as a therapist in an outpatient AIDS clinic at Bronx Municipal Hospital, Bronx, N.Y., during June 1991-May 1993.

106. Blackhall, *supra* note 6 (assessing attitudes toward disclosure and prognosis of two hundred subjects from four ethnic groups); Joseph Caresse & Lorna Rhodes, *Western Bioethics on the Navajo Reservation*, 274 JAMA 826 (1995) (assessing the tensions between the belief system in traditional Navajo culture and the requirements of the informed consent law by interviewing thirty-four Navajo patients and health care providers on a Navajo Indian reservation in northeast Arizona).

107. Mary Sit, *Coming To America as Asians and Latinos Lead The Latest Wave*, THE BOSTON GLOBE, June 25, 1995, at A2.

108. *Id.*

109. Peter Francese, *America at Mid-Decade*, 17 AMERICAN DEMOGRAPHICS 23 (February 1, 1995).

many sub-cultures seek and celebrate their ethnic heritage. Not all people living in the United States share Western values,¹¹⁰ as expressed in American laws, concerning medical decisionmaking. This section analyzes the tensions raised by the case examples and illustrates that the elements of Western-defined autonomy - individualism, activism, rationalism, and veracity - sometimes conflict with beliefs traditionally found in African, Asian, Hispanic, and Native American cultures.¹¹¹

A. Active Participation in Medical Care

Western culture's bias toward individualism implies a preference for active participation in medical decisionmaking. The Western patient may favor controlling all or most aspects of his or her medical care, aggressively pursuing or challenging their health care providers, and actively treating illness or delaying death. Non-Western cultures, however, may feel more comfortable deferring to a physician's authority, favor less assertive interactions with their physicians, and accept illness and death as an inevitable part of life.

Japanese physicians are traditionally paternalistic and authoritative toward patients and their families, reflecting social values that emphasize law, order, and authority.¹¹² Doctors expect patients and their families to behave in a modest, non-assertive manner.¹¹³ The Japanese norm of *enryo* governs much of the behavior in interpersonal relationships.¹¹⁴ *Enryo* consists of a collection of behavior that calls for restraint, reserve, and lack of assertiveness in social interactions. This norm reflects a more general Asian cultural characteristic of inconspicuousness as a means of insuring

110. Robin M. Williams, a noted sociologist, identified fifteen cultural themes that generally reflect the Anglo-Saxon influence on American culture including efficiency, practicality, equality, individual freedom, secular rationality, and independence. ROBIN M. WILLIAMS, *AMERICAN SOCIETY: A SOCIOLOGICAL INTERPRETATION* 452-502 (3d ed. 1970).

111. See *supra* note 5 (recognizing dangers of generalizing about cultures).

112. See Rihito Kimura, *Conflict and Harmony in Japanese Medicine: A Challenge to Traditional Culture in Neonatal Care*, in *TRANSCULTURAL DIMENSIONS IN MEDICAL ETHICS* 145, 151 (Edmund Pellegrino et al. eds., 1992). See also Hiroyuki Hattori et al., *The Patient's Right to Information in Japan - Legal Rules and Doctors' Opinions*, 32 *SOC. SCI. MED.* 1007, 1007 (1991) ("In Japan, however, the concept of informed consent has not yet been generally accepted by the medical profession. The right of the patient to take part in the decision-making process to a large extent remains ignored.") .

113. This is particularly true with professionals such as physicians, government officials, and employers. Kimura, *supra* note 112, at 146.

114. HENDERSON & PRIMEAUX, *supra* note 11, at 264.

harmonious relations and respect for those in authority.¹¹⁵ Traditional Chinese and Taiwanese patients may also demonstrate an unquestioning respect for and deference to authority.¹¹⁶

B. Individualism and Self-Reliance

The Western, and particularly the American, vision of patient autonomy favors individualism.¹¹⁷ Individualism conceives of persons as independent, self-reliant and self-respecting.¹¹⁸ It protects the rights of the individual over the group.¹¹⁹ For many cultures, however, the perception of self and the individual is defined by relationships with others.¹²⁰ Patient autonomy is perceived and achieved by family or community consensus and centralized decisionmaking.¹²¹ Many cultures value the harmonious functioning of the family more than individual decisionmaking.¹²² Some cultures are more comfortable with deferring to the authority of their physicians. Others may value self-reliance, but equate the concept of "self" with that of "community."¹²³

Although Asian cultures¹²⁴ are highly diverse, they generally follow a family-centered model of medical decisionmaking, defer to medical authority, and value harmony. In Japan, the group is generally viewed as more important than the individual and is intimately involved with an individual's sense of self.¹²⁵ For traditional

115. Inconspicuousness is defined as the avoidance of attracting special attention to oneself. *Id.* at 273.

116. *Id.* at 75.

117. See *supra* notes 3-4 (discussing individualistic strains in the Western notion of autonomy).

118. See WILLIAMS, *supra* note 110, at 495.

119. See, e.g., Arras & Steinbock, *supra* note 6, at 26 (individual as the unique focal point of moral concern); Mark Salgo, *Two Cheers For Community*, HASTINGS CENTER REP. 33, 33 (May-June 1994) (noting the individualistic instinct of liberalism).

120. See Blackhall, *supra* note 6, at 824 (finding that Korean-American and Mexican-American patients favor family decisionmaking models).

121. The Blackhall study defined this model as "the sole responsibility of the family to hear bad news about the patient's diagnosis and prognosis and to make the difficult decisions about life support." *Id.* at 824.

122. See, e.g., HENDERSON & PRIMEAUX, *supra* note 11, at 264-65 (describing the emphasis on harmony and avoidance of conflict by Asian cultures).

123. Robert F. Murray, Jr., *Minority Perspectives on Biomedical Ethics*, in TRANS-CULTURAL DIMENSIONS IN MEDICAL ETHICS 35, 40 (Edmund Pellegrino et al. eds., 1992).

124. Members of the Asian American community have their origins in China, Hawaii, the Philippines, Korea, and Japan. SPECTOR, *supra* note 5, at 178.

125. HELMAN, *supra* note 5, at 17 (citing T. Tamura and A. Lau, *Connectedness Versus Separateness: Application of Family Therapy to Chinese Families*, 31 FAM. PROC. 319, 319-40 (1992)).

Chinese, Filipinos, and Japanese, medical decisions include not only the patient's interest, but also the interest of his or her whole family.¹²⁶ Some Chinese patients may refuse medical information and request that the physician confer only with the patient's spouse or children.¹²⁷ Many Chinese also place high value on the individual in relationship to others and to the environment.¹²⁸ Chinese Marxists define the essence of a human being as the "sum of social relations."¹²⁹ Confucianists¹³⁰ and traditional Chinese view the universe as an indivisible entity where each person is linked to one another in harmonious balance.¹³¹ Japanese Buddhist principles in bioethical decisionmaking focus on *kyokan* (feeling of togetherness) and *ningen* (human person in relational context).¹³² In addition, respect for, and deference to, physicians by Japanese is strong, and patients often trust their physicians with total and final decisionmaking authority.¹³³ Koreans may view the Western model of patient autonomy not as empowering, but as "isolating and burdensome to patients who are too sick and ignorant about their condition to be able to make meaningful choices."¹³⁴ As a result, these patients preferred a more family-centered model of decisionmaking.¹³⁵

In one study, Mexican-Americans also favored family-centered decisionmaking and were less likely to believe that the patient should be truthfully informed about diagnosis and prognosis.¹³⁶ Mexican culture emphasizes the needs of the collective: *La familia*.¹³⁷ As a result, many traditional Mexicans view illness as a

126. Ren-Zong Qui, *Medical Ethics and Chinese Culture*, in *TRANSCULTURAL DIMENSIONS IN MEDICAL ETHICS* 155, 167 (Edmund Pellegrino et al. eds., 1992). See also Doris Wilkinson, *Family Ethnicity in America*, in *FAMILY ETHNICITY* 15, 39 (Harriette Pipes McAdoo ed., 1993).

127. Qui, *supra* note 126, at 167.

128. One commentator goes so far as to suggest that "rights-oriented individualism is essentially alien to the Chinese." *Id.* at 172.

129. *Id.* at 171. At the same time, the Chinese are "spiritually individualistic in the sense that they always pay a considerable amount of attention to self-development and self-perfection." *Id.*

130. Confucianists believe that what distinguishes humans from animals is their humanness (*ren*) or capacity for loving others. *Id.* at 172.

131. SPECTOR, *supra* note 5, at 243.

132. Kimura, *supra* note 112, at 151.

133. See Hattori, *supra* note 112, at 1007.

134. Blackhall, *supra* note 6, at 824.

135. *Id.*

136. *Id.* at 823-24.

137. Wilkinson, *supra* note 126, at 34-35 (citing numerous studies holding the paramount importance of family interactions among Mexican-Americans).

"family affair."¹³⁸ The centrality of family in daily living and decisionmaking is also found among Puerto Ricans and Mexican-Americans.¹³⁹

A long history of slavery and racism has led American Blacks¹⁴⁰ to forge connections to their African cultural traditions, which emphasize family and community relations.¹⁴¹ Native Americans¹⁴² emphasis on family includes residential proximity, mutual aid, and involvement in daily life activities.¹⁴³ Like many Indians, the Indians of the Southwest are family and tribal oriented, rather than individualistic.¹⁴⁴ A sense of trust and connection to the tribe often connects a Native American's medical decision to tribal values and relationships.¹⁴⁵

138. *La familia* is a broad concept that may include single households, combinations, and/or all extended relatives. Wilkinson, *supra* note 126, at 37. It may include not only blood relatives, but also special friends. *Id.* at 160. See also VERN L. BULLOUGH & BONNIE BULLOUGH, HEALTH CARE FOR THE OTHER AMERICANS 79-80 (1982) (discussing Mexican culture and hospitalization); LINDENTHAL & SCHNEIDER, *supra* note 13, at 10 (describing Mexican culture's notion of *La familia*).

139. See BULLOUGH & BULLOUGH, *supra* note 138, at 81 (noting the extended family pattern in both Mexico and Puerto Rico); Wilkinson, *supra* note 126, at 37; Catherine Street Chilman, *Hispanic Families in the United States*, in FAMILY ETHNICITY 141, 150-55 (Harriette Pipes McAdoo ed., 1993).

140. Black Americans may have origins in Africa, the West Indian islands, the Dominican Republic, Haiti, and Jamaica. SPECTOR, *supra* note 5, at 191.

141. In her article examining coping strategies of African-Americans, Alfrieda Daly notes the importance of family and the notion of community as extended family in providing care for individuals in need. Alfrieda Daly et al., *Effective Coping Strategies of African Americans*, 40 SOCIAL WORK 240 (1992). She cites numerous scholars who evaluate the impact of slavery and racism on African-American family systems and affirm the persistence of family and community networks in African-American culture. *Id.* at 241-42. See also LOCKE, *supra* note 5, at 24-25 (noting scholars who suggest that the family is one of the strongest and most important traditions in the African-American community). In his essay on African-American perspectives on biomedical ethics, Robert F. Murray examines the differences between African-American and Euro-American ethos. He suggests that African-Americans value the principle of self-determination and inclusive and communalistic approaches to decisionmaking. Murray, *supra* note 123, at 37-39. Murray argues that the African-American patient's concept of him or herself as an individual is closely linked to the African-American community. *Id.* at 40.

142. There are approximately two hundred Indian tribes in the United States. Native Americans live predominantly in the western states. Alaska, Arizona, California, New Mexico, and Oklahoma have the greatest numbers of Native Americans. However, successful tribes have reclaimed their lands in Connecticut and Maine. SPECTOR, *supra* note 5, at 216.

143. Wilkinson, *supra* note 126, at 32-33.

144. BULLOUGH & BULLOUGH, *supra* note 138, at 110.

145. See, e.g., Caresse & Rhodes, *supra* note 106.

C. Secularism and Scientific Rationality

Western culture favors secular, rather than spiritual or emotional, approaches to decisionmaking. It values the sciences and the application of reason as a means of mastering the environment.¹⁴⁶ Scientific rationality, the belief that all assumptions must be capable of being objectively measured and observed, tends to disregard emotional and social influences.¹⁴⁷ Non-Western cultures may view illness as resulting from social¹⁴⁸ or supernatural causes¹⁴⁹ and may advocate holistic solutions that consider all aspects of the patient's life.¹⁵⁰ Indeed, the folk sector in non-Western communities is large.¹⁵¹ Moreover, conceptions of life, death, and suffering influence how an individual deals with illness. The

146. This norm is grounded in the works of eighteenth century philosophers such as Hobbes and Mill. Arras & Steinbock, *supra* note 6, at 25. It also informs the basic premises of the medical perspective of health and illness including scientific rationality, the emphasis on objective, numerical measurement, mind-body dualism, and the emphasis on the individual patient, rather than on the family or community. HELMAN, *supra* note 5, at 101. See also WILLIAMS, *supra* note 110, at 488 ("Very broadly, emphasis upon science in America has reflected the values of the rationalistic-individualistic tradition.").

147. HELMAN, *supra* note 5, at 101-107 (describing Western medicine's perspective of disease in terms of Western dependence on scientific rationality).

148. Examples of commonly believed social causes of illness among some cultures are witchcraft, sorcery, or the "evil eye." *Id.* at 69. Navajo Indians believe that witchcraft exists and that witches can bring sickness to those that displease them. SPECTOR, *supra* note 5, at 218. The Islamic tradition believes in the power of the evil eye. BULLOUGH & BULLOUGH, *supra* note 138, at 124.

149. Examples of supernatural causes of illness are religion, spirits, and fate. HELMAN, *supra* note 5, at 69. For example, the Hopi Indians associate illness with evil spirits. SPECTOR, *supra* note 5, at 218. Many Black Americans belong to the Pentecostal faith and other religious faiths that reflect a reliance on the healing powers of religion. *Id.* at 195.

150. Holistic medicine considers the patient's relations with others, the natural environment, supernatural forces, and emotional symptoms. HELMAN, *supra* note 5, at 69. In African-American cultures, emotional expression may be strongly encouraged and often serves as a tool for decisionmaking. Murray, *supra* note 123, at 40.

151. The folk sector includes individuals who socialize in either secular or spiritual healing, or a combination of both. HELMAN, *supra* note 5, at 67. Although Native American culture is extremely diverse and each tribal group has its own religion, folklore, disease treatment and decisionmaking methods, most Native Americans believe that health reflects life in harmony with nature and that opposing energies of the body can be controlled by spiritual means. SPECTOR, *supra* note 5, at 217. Native Americans may seek help from a shaman. HENDERSON & PRIMEAUX, *supra* note 11, at 136. Mexican and Puerto Ricans often seek treatment from folk practitioners. LINDENTHAL & SCHNEIDER, *supra* note 13, at 15-16. One type of Hispanic folk practitioner is the curandero/a. See SPECTOR, *supra*, at 283-87; BULLOUGH & BULLOUGH, *supra* note 138, at 82-84. See also HELMAN, *supra*, at 68-72 (describing folk healers in different non-Western cultures); BULLOUGH & BULLOUGH, *supra* note 138, at 130 (citing the Amish as a religious cultural group with a strong tradition of folk medicine).

idea that one can control pain or suffering is more compatible with Western values of independence, active decisionmaking, and scientific thinking than many non-Western beliefs that nature should take its course or that suffering is a form of punishment imposed by another. Chinese spirituality may promote a more passive approach to medical treatment evidenced by less emphasis on treatment and life-prolonging measures. One Chinese writer sums up the Chinese attitude toward life, illness, and death as follows: "[t]reasure human life but do not attach to it."¹⁵² Indians relate life, suffering, and death to a higher source of good. They view pain as a normal part of life and death as a natural event in every person's life. When an Indian person is ill or dying, the main question asked is whether their life was morally and spiritually meaningful.¹⁵³ Both Roman Catholic theology and folk medicine influence Latin American beliefs about health and illness. Mexicans, for example, view health as a gift from God and illness as a consequence of immoral behavior.¹⁵⁴ Many African-Americans retain traditional African beliefs in alternative medicine, including magic and religion.¹⁵⁵

D. Fortrightness

Western culture's vision of patients' self-determination and active participation in medical treatment favors patient-physician communication and physician disclosure of medical information.¹⁵⁶

152. Qui, *supra* note 126, at 170.

153. Mary F. Kodiath & Alex Kodiath, *A Comparative Study of Patients Who Experience Chronic Malignant Pain in India and the United States*, 18 *CANCER NURSING* 189, 195-96 (1995). In their comparative study of Indian and American cancer patients' experience of pain, Mary and Alex Kodiath discovered that differences in beliefs about life and death caused Indians to experience pain and then request medical assistance whereas Americans immediately requested medical assistance. *Id.* at 192.

154. Antonia M. Villarruel & Bernard Ortiz de Montellano, *Culture and Pain: A Mesoamerican Perspective*, 15 *ADVANCED NURSING SCI.* 21, 29 (1992) (studying beliefs related to the experience of pain in ancient Mesoamerica to establish a clear link between cultural meanings and the expression of pain by contemporary Mexican-Americans).

155. In sub-Saharan Africa, it is estimated that nearly eighty percent of black Africans employ alternative medicine either as the only form of health care available or in combination with Western medicine. B.O. Osuntokun, *Biomedical Ethics in the Developing World: Conflicts and Resolutions*, in *TRANSCULTURAL DIMENSIONS IN MEDICAL ETHICS* 105, 132-33 (Edmund Pellegrino et al. eds., 1992).

156. This value may be most clearly exemplified in the law of informed consent and the 1990 Patient Self-Determination Act. See also George J. Annas & Frances H. Miller, *The Empire of Death: How Culture and Economics Affect Informed Consent in the U.S., the U.K., and Japan*, 20 *AM. J.L. & MED.* 357, 361-62 (1994) (citing LYNN PAYER, *MEDICINE AND CULTURE* 127 (1988) (linking the aggressive American ap-

Non-Western cultures may prefer controlling the expression of feelings, withholding negative medical information to protect sick patients from anguish and sadness, and avoiding direct confrontation. Asian culture highly values harmony and avoidance of conflict.¹⁵⁷ Many Japanese de-emphasize truth-telling and full disclosure to patients for fear of causing unnecessary grief or disrespect.¹⁵⁸ Native American culture represents the most poignant example of how a non-Western culture's beliefs may conflict with Western notions of autonomy. In traditional Navajo culture, for example, speech is a religious act that has the power to either heal or harm.¹⁵⁹ A recent study of informed consent at a Navajo reservation medical clinic illustrated this belief and demonstrated that laws requiring forthrightness about negative medical information and risks of treatment were culturally troubling for Navajo physicians and patients.¹⁶⁰

III. Including Cultural Difference in Practice

The Western conceptions of patient autonomy, as embodied in the law of informed consent, do not apply universally.¹⁶¹ As a re-

proach toward medicine to the frontier spirit and to Americans' desire to problem-solve)).

157. HENDERSON & PRIMEAUX, *supra* note 11, at 264-65.

158. See ANNAS & MILLER, *supra* note 156, at 374-75.

159. Anthropologist Gary Witherspoon writes that, according to Navajo belief, speech and thought are religious acts that have the power to either heal or harm. GARY WITHERSPOON, LANGUAGE AND ART IN THE NAVAJO UNIVERSE 28-29 (1977). See also Carrese & Rhodes, *supra* note 106, at 826, 828 (stating that Navajos view reality as a "mirror of language" and encourage thinking and talking "in the Beauty way" (hÓzhÓ), emphasizing positive, and avoiding negative, thought and speech). For a detailed discussion of hÓzhÓ, see WITHERSPOON, *supra*, at 18, 23-26.

160. In their study, Carrese and Rhodes found that discussing negative information, in compliance with the Patient Self-Determination Act, conflicted with the concept of hÓzhÓ and that such conversations were interpreted as potentially harmful by Navajo patients and informants. The Navajo study participants also expressed a discomfort with advance care planning discussions. Nineteen of the twenty-two informants stated or implied that advance care planning was a dangerous violation of traditional Navajo values. Ten informants refused to even discuss the issues at all because they felt it was too dangerous. Carrese & Rhodes, *supra* note 106, at 828.

161. Empirical studies also demonstrate that a theory of patient autonomy "which premises that all people desire the same things and attempt to get them in similar ways" does not pan out in clinical practice. Carl E. Schneider, *Bioethics With a Human Face*, 69 IND. L.J. 1075, 1076 (1994). Schneider's article implies that this empirical work underscores the role of cultural factors in patients' lives and urges bioethicists and lawyers to "think more deeply, rigorously, and richly about the problems of bioethics in general and about its autonomy paradigm in particular." *Id.* at 1077. Similarly, Professor Susan Wolf argues that the field of bioethics, and to a lesser extent, health law, is experiencing a shift from universalized and philosophical abstractions toward context and "empirical realities." She credits this rise in empiri-

sult, American courts' emphasis on the value of patient autonomy often fails to address the experiences of individual patients in the medical clinic. More significantly, by narrowly defining the scope of autonomy in terms of Western values, and by monolithically applying a Westernized notion of informed consent, health law and bioethics deprive non-Western cultures of their right to self-definition, and tend to devalue the notion of autonomy. It is possible to advocate simultaneously for respecting cultural difference and to recognize that there exist universal moral values. One such universal value is individuals' right to self-determination. The point of self-determination in the medical context is that the patient has a right to make a voluntary choice about medical decisionmaking and treatment. It is not that every patient must inculcate the Western notion and expression of autonomy.

As established in Part I, the law generally recognizes patients' rights to control their own health care. The informed consent doctrine evolved from a right to be free from nonconsensual interference with one's person¹⁶² to a principle of patient autonomy.¹⁶³ A patient-based, rather than physician-based standard for disclosure, is approaching a majority position among jurisdictions.¹⁶⁴ Congress requires physicians to facilitate some level of dialogue about patient values through the Patient Self-Determination Act. Moreover, physicians' fiduciary obligation, requiring that they act exclu-

cism with the development of empirical studies, beginning in the 1980s, on a range of bioethical topics. These studies produced significant data demonstrating that the predominant models of bioethical theory conflicted with the physician-patient experience in the medical clinic. Wolf, *supra* note 5, at 403. See also Martha Minow, *Who's The Patient?*, 53 MD. L. REV. 1173, 1177-78 (1994) ("[C]ross-cultural comparisons of medical practices indicate the great significance of family in many cultures and recommend degrees of involvement and deference to family members in patient decisions that might be deemed violations of patient autonomy in other contexts.").

162. See *Mohr v. Williams*, 104 N.W. 12 (Minn. 1905). The battery standard used in *Mohr* was overruled by *Thor v. Super. Ct.*, 855 P.2d 375 (Cal. 1993).

163. See *Schloendorff v. Soc'y of N.Y. Hosp.*, 211 N.Y. 125, 105 N.E. 92 (1914).

164. See 1 FURROW, *supra* note 3, at 414. Some commentators interpret *Arato* as reaffirming the reasonable patient standard in California, supporting therapeutic discretion privilege, and ignoring the reality that some patients may want to avoid information. See, e.g., *id.* at 427 (interpreting *Arato* as troubling because the court bent over backwards to defer to medical practice and discretion). Others, however, argue that *Arato* opened the door to greater physician obligations. Alexander Morgan Capron goes so far as to suggest that *Arato* revealed that "the heart of the . . . [patient's] claim goes beyond decisionmaking about chemotherapy and radiation to the relevance of life expectancy information to Mr. Arato's general existence." See, e.g., Capron, *supra* note 66, at 13-14. He argues that a notion of informed consent based on patients' rights to make decisions about their bodies is narrow, that informed consent doctrine must require physicians to communicate and learn about their patients as people, not merely as decisionmakers. *Id.*

sively in patients' best interests, necessitates communication between physicians and patients.¹⁶⁵ These communications enable physicians to better understand their patients' concerns, and as a result, assist them in evaluating their patients' best interest. Some courts require physicians to provide additional information in order to maximize patients' medical choices,¹⁶⁶ and to disclose patients' nonmedical interests such as physicians' research and economic interests.¹⁶⁷ In addition, laws relating to surrogate decisionmaking for incompetent patients provide a model for including individuals other than the patient in the decisionmaking process.¹⁶⁸ Current law, however, does not explicitly recognize alternative decisionmaking approaches for competent patients. At the heart of the law guiding surrogate decisionmaking¹⁶⁹ and patients' right to forego life sustaining medical treatment¹⁷⁰ remains the notion that decisionmaking belongs only to the informed patient.¹⁷¹ A doctrine of informed consent based on the broad principle of au-

165. This fiduciary duty includes an obligation to act exclusively in the patient's best interests. Schuck, *supra* note 68, at 921 ("This duty underscores the purpose of informed consent proper, which is not simply to provide information to empower the patient to protect her own interests, but also, and perhaps more important, to further the physician's responsibility to place the patient's interest above her own. Only through dialogue with the patient can a physician come to understand the contours of the patient's interests and thus, be in a position to help advance them.").

166. *Truman v. Thomas*, 611 P.2d 902, 906 (Cal. 1980) ("If the physician knows or should know of a patient's concerns or lack of familiarity with medical procedures, this may expand the scope of required disclosure.").

167. See, e.g., *Moore v. Regents of the Univ. of Cal.*, 793 P.2d 479, 485 (Cal. 1990).

168. For a detailed discussion of the principles applied to proxy decisionmakers, see 2 FURROW, *supra* note 3, at 349-52, 369. See also Colleen M. O'Connor, *Statutory Surrogate Consent Provisions: An Overview and Analysis*, 20 MENTAL & PHYSICAL DISABILITY L. REP. 128 (1996) (examining existing statutory surrogate provisions in the U.S.).

169. *Id.*

170. See *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 269 & 277 (1990) (finding that a competent adult has the right to choose to forgo life sustaining treatment); *In re Westchester County Med. Ctr.*, 72 N.Y.2d 517, 531 N.E.2d 607, 534 N.Y.S.2d 886 (1988) (acknowledging a narrow right to refuse medical treatment); *In re Conroy*, 486 A.2d 1209, 1223 (N.J. 1985) ("[T]he right to decline medical treatment is, in any event, embraced within the common law right to self-determination."); *Bouvia v. Super. Ct.*, 225 Cal. Rptr. 297 (Cal. Ct. App. 1986) (applying principles of informed consent to the right to forgo life sustaining treatment such as feeding and hydration).

171. *Bouvia*, 225 Cal. Rptr. at 343 (citing American Hospital Association statement supporting the notion that "the controlling decision belongs to a competent, informed patient.").

tonomy requires explicit provisions that respect patients as choice-making individuals and that honors patients' ultimate choices.¹⁷²

This section explores the ways to include patients' voices and particular values in medical decisionmaking and proposes how the law might recognize alternative decisionmaking approaches for competent patients. First, it examines the applicability of the federal Patient Self-Determination Act (the "PSDA") and advanced directives. Second, it considers the potential for health care providers to foster cultural sensitivity in medical decisionmaking. Third, it concludes that courts must assume a leadership role in promoting cultural accommodation in medical care by articulating the concept of informed waiver that allows patients to opt out of Western notions of informed consent.

A. The PSDA and Advanced Directives

The PSDA¹⁷³ and the case law affirming patients' rights to make medical choices in accordance with their values represent how existing law might accommodate cultural difference. The PSDA requires all Medicare and Medicaid health care providers to inform patients of their right to make health-care decisions, to execute advanced directives, and to otherwise control their health care under their respective state law.¹⁷⁴ It supports cultural sensitivity by requiring providers to specify explicitly, in their written policies, the patient's right to make and express medical decisions consistent with his or her values.¹⁷⁵ In addition to the PSDA, living wills and health care proxies document patients' values regarding death-delaying treatment and encourages patients to communicate these wishes to their physicians and loved ones. Developing a similar forum for initiating and recording dialogue with competent patients about the type of relationship they want to have with their providers and about their preferred means of medical decisionmaking upholds the notion of patient autonomy embodied in advanced directives. It also provides evidence of patients' choices and physicians' compliance with those choices. Some legal and medical commentators argue that compensation rates minimize the

172. KATZ, *supra* note 34, at 86 (writing that an adherence to the principle of autonomy "is based on the assumption that many patients are capable of comprehending what they need to know in order to decide what is best for themselves and that, therefore, they must be treated as adults possessed of the capacity for self-determination.").

173. 42 U.S.C. § 1395cc(f) (1994).

174. 42 U.S.C. § 1395cc(f), 1396a (w) (1994).

175. 2 FURROW, *supra* note 3, at 442.

time providers can devote to a dialogue with patients¹⁷⁶ and that contemporary health care delivery systems assign enrolled patients to a series of professionals that the patient does not know and who do not intimately know the patient.¹⁷⁷ For these reasons, physicians should attach directives regarding medical decisionmaking values to the patient's chart. This practice enables all the patients' providers, with minimal effort, to know their patients' values regarding medical care.¹⁷⁸ Moreover, physicians and patients should routinely reevaluate the status of patient directives to insure that the document reflects the patient's current values.

Although many commentators herald advanced directives as "magic bullets"¹⁷⁹ that ensure respect for a patient's values after he or she becomes incapacitated, advanced directives pose problems for accommodating a competent patient's desire to limit or delegate his or her role in medical decisionmaking. First, the idea that a competent person should delegate his or her right to be informed or decide about his or her care is not expressly stated in statutory language and case law. Indeed, the fact that physicians are uncertain about how to relate to and include health care proxies for incompetent patients¹⁸⁰ suggests that they might experience even greater discomfort deferring to a competent patient's proxy. Second, the style and substance of the PSDA and advanced directives conflict with some cultures' unwillingness to talk about and plan for adverse medical conditions. Third, despite public and professional education, few patients actually execute advanced directives.¹⁸¹ As a result, advanced directives may not provide the best approach to including cultural values in medical decisionmaking.

176. See Cathy J. Jones, *Autonomy and Informed Consent in Medical Decisionmaking: Toward a New Self-Fulfilling Prophecy*, 47 WASH. & LEE L. REV. 379, 407 (1990); Schuck, *supra* note 68, at 922.

177. See Schuck, *supra* note 68, at 926.

178. Peter Schuck suggests that physicians and patients contract about the patient's preferred level of informed consent. A patient's directive about her values relevant to her medical care may be viewed as an individual "contract" between the patient and provider in ways similar to current advanced directives. *Id.* at 956-57.

179. Nancy Neveloff Dubler, *The Doctor-Proxy Relationship: The Neglected Connection*, 5 KENNEDY INST. OF ETHICS J., 289, 289 (1995).

180. *Id.*

181. According to recent data, only ten to twenty-five percent of older adults completed advanced directives. *Id.* at 291. See also Carl Schneider, *Bioethics With A Human Face*, 69 IND. L. J. 1075, 1080 (1994) (examining empirical evidence that suggests that individuals do not wish to make medical decisions and that bioethicists must re-examine the autonomy paradigm).

B. Health Care Providers and Bioethicists

The traditional culture of medicine has been described as "antiparticipatory, heroic, interventionist, and paternalistic."¹⁸² Physicians historically placed greater emphasis on longevity, rather than quality, of life for their patients.¹⁸³ With these factors in mind, it is not surprising that medical education and practice have traditionally not encouraged physicians to investigate and understand patients' cultural values. The Hippocratic Oath¹⁸⁴ mandating that physicians above all, do no harm, and the renewed emphasis on family practice,¹⁸⁵ however, encourage providers to sensitively and comprehensively treat their patients.¹⁸⁶ These themes represent an invitation for physicians to increase their awareness of cultural difference in medical practice.

In addition, several bioethicists have re-examined the meaning and scope of patient autonomy.¹⁸⁷ They suggest that individuals

182. Patricia Peppin, *Power and Disadvantage in Medical Relationships*, 3 TEX. J. WOMEN & L. 221, 224 (1994). Jay Katz explored the relationship between physicians and patients and concludes that physicians never placed a premium on communicating with their patients, rather, the historical relationship is one of silent authority. He wrote, "disclosure and consent, except in the most rudimentary fashion, are obligations alien to medical thinking and practice." KATZ, *supra* note 47, at 1.

183. KATZ, *supra* note 34, at 71.

184. Ludwig Edelstein, *Ancient Medicine: Selected Papers of Ludwig Edelstein*, in ETHICAL ISSUES IN MODERN MEDICINE 54, 54 (John D. Arras & Bonnie Steinbock eds., 1995) (reprinting the Hippocratic Oath).

185. In his best-selling book, Dr. Nuland offers the image of the family doctor as a form of medical practice that historically encouraged physicians to comprehensively treat patients. SHERWIN B. NULAND, *HOW WE DIE* 266 (1994).

186. Some commentators argue that the Hippocratic maxim to benefit patients is ambiguous in cross cultural contexts because notions of benefit and harm have culturally specific meanings. John Carrese, *Commentary*, HASTINGS CENTER REP. 16 (July-Aug. 1993).

187. Professor Edmund Pellegrino reconceives autonomy from a negative concept, arising from a moral claim against intrusion of human rights, to a positive one. He argues that the negative aspect of autonomy, prevalent in Western moral and political philosophy, distorts the idea of patient autonomy by equating it with "total independence from the physician or others in making treatment decisions." Pellegrino, *supra* note 6, at 50. His positive model of autonomy implies an obligation to "foster the human capacity for self-determination, to enhance it, and to remove obstacles to its full operation." *Id.* at 49. He also argues that the moral principle of beneficence, requiring one to prevent, remove, and to not inflict harm, is essential to the actualization of autonomy. *Id.* at 51. Jay Katz places an even greater value on autonomy and self-determination than Professor Pellegrino, but agrees that a singular application of the principle is self-defeating. He writes that "abstract principles tend to express generalizations about conduct that are ill-suited for application to actual cases in which human psychological capacities to exercise rights must be considered." KATZ, *supra* note 47, at 107. He proposes the concept of a "psychological autonomy" that requires "self-reflection and conversation with others" to better understand the mechanics of an individual's decisionmaking process. *Id.* at 111.

express their autonomy in unique ways that vary with their prior values and cultural, personal and social relationships, and that it is beneficent and just to empower patients to express these values in their decisions about medical treatment. They lend support for inclusion of cultural difference in the legal and medical contexts. Other ethicists adopt a communitarian approach that questions "both the rationalism of liberalism's approach to method and their claim to value neutrality."¹⁸⁸ Communitarians reject the predominance of individual rights in favor of shared values and goals of a community.¹⁸⁹ Perhaps the strongest support for including cultural difference is found in feminist and critical race ethics and theories.¹⁹⁰ These approaches criticize the traditional autonomy model of the genderless, raceless, and classless patient.¹⁹¹

In theory, bioethicists and health care providers can respect cultural difference by initiating and endorsing guidelines and incentives that encourage physicians to approach patients about their cultural values.¹⁹² They might advocate on behalf of their patients, galvanizing their professional associations and institutions to develop practice guidelines that explicitly recognize patients' cultural values in medical care and decisionmaking. They might advise medical schools to place greater emphasis on communication skills and cultural awareness.¹⁹³ In turn, medical schools, residency pro-

188. Arras & Steinbock, *supra* note 6, at 26.

189. *Id.* at 27. See also articles in *Individualism and Community: The Contested Terrain of Autonomy*, HASTINGS CENTER REP. 32-35 (May-June 1994) (containing three articles debating the predominance of the principle of autonomy in light of the conflict between autonomy and community).

190. See generally Arras & Steinbock, *supra* note 6, at 28-30; Wolf, *supra* note 5, at 397-98 n.9, 401 nn.39-41 (citing principles posed by feminist and race attentive literature).

191. See generally FEMINIST LEGAL THEORY: FOUNDATIONS (D. Kelly Weisberg ed., 1993); Richard Delgado & Jean Stefancic, *Critical Race Theory: An Annotated Bibliography*, 79 VA. L. REV. 461 (1993).

192. Jay Katz proposes that "meaningful change can come about only through medical education and the education of patients." KATZ, *supra* note 47, at 228-29. He suggests an interactive model for informed consent that emphasizes dialogue between physician and patient. *Id.* at 229.

193. Many medical schools offer "Introduction to Clinical Medicine" (ICM) as a requirement of first and second year medical students. The course curriculum includes interviewing techniques and the impact of race, gender, and poverty on health. Interview with Steven M. Wexler, M.D., emergency medicine resident at Bronx Municipal Hospital Center and Lara Gordon, first-year medical student at SUNY Brooklyn Medical College in New York, N.Y. (Dec. 10, 1995). Bioethicists Robert D. Orr and Patricia A. Marshall outlined guidelines for bridging the cultural communication gap and for cross-cultural ethics consultations. Their suggestions for health care providers include making use of non-family translators, establishing liaisons with community organizations, developing a resource list of hospital employees by ethnic origin to

grams, and bioethical consultants can assist providers in devising dialogues, questionnaires, and role-plays to ascertain patients' cultural values and preferences regarding medical decisionmaking. For example, when initiating a relationship with a patient, health care providers might ask: "How do you feel most comfortable making your medical decisions?"; "Can you describe your beliefs about your family or community members' involvement in making decisions regarding your care?"; or "Can you describe how your cultural or personal values might influence your medical decision-making?" One commentator suggests the concept of a values history,¹⁹⁴ presented as either a written questionnaire provided to the patient for completion and returned to the physician or a discussion between the patient and physician, which is then recorded into the patient's permanent medical record. Merely asking such questions implies a certain level of respect for patient values and non-medical well-being. In addition, open-ended questions avoid accidental disclosure of information perceived as intrusive or harmful by some patients. Several bioethicists have written extensively on reconceiving informed consent to include family and shared decisionmaking.¹⁹⁵ Finally, providers might more fully integrate social workers, nurses, psychiatrists, psychologists, and patient advocates as meaningful members of the health care team. These disciplines have historically considered the impact of individuals' cultural identity in their theory and practice,¹⁹⁶ and patients may perceive these professionals as more closely aligned with their interests than physicians or bioethicists and may be more respon-

serve as cultural "informants," and directly questioning patients about who they consider to be the appropriate decisionmaker and their views on involving spiritual and religious advisors. Orr et al., *Cross-cultural Considerations in Clinical Ethics Consultations*, 4 ARCH. FAM. MED. 159, 164 (1995).

194. See Ben A. Rich, *The Values History: A New Standard of Care*, 40 EMORY L. J. 1109, 1141-52 (1991). Professor Rich proposes that the standard use of a values history "naturally facilitates the recognition and exercise of patient autonomy." *Id.* at 1142. He also notes several studies reporting favorably on the use of values history instruments. *Id.* at 1143 n.130. See also 2 FURROW, *supra* note 3, at 371-72 (describing the values history as a more comprehensive advanced care document that is likely to be well-respected by most courts as a source of relevant information about the patients likely decision).

195. See, e.g., Mark G. Kuczewski, *Reconceiving the Family: The Process of Consent in Medical Decisionmaking*, 26 HASTINGS CENTER REP. 30 (March-April 1996); Minow, *supra* note 161.

196. See Schuck, *supra* note 68, at 938 (suggesting the use of specially trained paraprofessionals to communicate with patients in ways physicians find difficult); Jones, *supra* note 176, at 426 (proposing involvement of patient advocates); Steven R. Smith, *Mental Health Malpractice in the 1990s*, 28 Hous. L. REV. 209, 258 n.302 (1991) (suggesting role of patient advocate initiating and evaluating informed consent).

sive to questions concerning their medical decisionmaking preferences and concerns. Physicians' concerns about their lack of time to efficiently engage clients in such conversations are addressed by delegating the task among interdisciplinary team members.

In contemporary medicine, characterized by the consolidation of health care practices and industries in the race to compete in the new era of managed care, health care providers possess a diminished ability to influence health management. The goals of managed care, emphasizing cost-cutting, limitation of choice and specialized care, rationing, and restrictions of physician autonomy, significantly hinders physicians' power to guide medical decision-making policy and hampers an interdisciplinary care team approach. In addition, today's physicians face pressure to see as many patients as possible in the least amount of time.¹⁹⁷ Requiring that physicians investigate and consider patients' individualized cultural values ignores the reality of contemporary medical practice where providers have limited, and uncompensated, time for patient-physician dialogue.¹⁹⁸ Inclusion of cultural difference requires providing patients with opportunities to communicate their subjective values,¹⁹⁹ giving providers incentives to promote these opportunities,²⁰⁰ and developing cost-effective ways of eliciting and documenting patients' values. Although managed care companies might be a vehicle for initiating culturally sensitive policies if the practice proved competitively favorable to enlist particular client populations, placing the burden of cultural inclusion on the medical community or market forces will probably not bring cultural sensitivity to the clinic.

197. See Schuck, *supra* note 68, at 939-41 (offering a cost analysis of adherence to a comprehensive informed consent doctrine).

198. *Id.* at 921-22 ("The physician incurs a cost for the time that she spends engaging in a meaningful dialogue with the patient about risks . . . The fact that physicians ordinarily are compensated by procedure rather than by time . . . also gives physicians an incentive to minimize the time they spend on the procedure, including the time they spend obtaining a patient's consent.").

199. As Professor Daar observes, "whatever a doctor reveals, the patient will absorb and process according to his or her own values . . . a doctor simply cannot know whether proffered (or retained) information is material only to a patient's treatment choices." Daar, *supra* note 66, at 196.

200. See Jones, *supra* note 176, at 426, 430 n.124 (proposing compensating physicians for dialogue with patients and citing statistics demonstrating that patients may be willing to pay more money for physicians' time). See also Schuck, *supra* note 68, at 920-21, 938-41 (proposing increased cost-effectiveness of informed consent where informed consent is obtained in a more contextual manner and if physicians and patients could customize their own informed consent models through contract).

C. The Notion of Informed Waiver

The law clearly recognizes a patient's right not to receive information.²⁰¹ The right of patient waiver accommodates cultural difference where patients prefer not to hear risks of treatment. The impact of waiver is that the patient remains the ultimate decisionmaker about the process of medical decisionmaking. As a result, the notion of waiver upholds the values of self-determination promoted by the doctrine of informed consent.²⁰²

Alan Meisel identified two separate waiver issues: waiver of information and waiver of decision.²⁰³ A patient may waive his or her right to know information relevant to medical care and a patient may waive the right to make a medical decision individually or to make any decision at all. Patients favoring family and community-centered models of decisionmaking might waive their participation in the decisionmaking process and delegate the right to disclosure and decisionmaking authority to their families and friends. Patients more comfortable with physician authority might employ the waiver to defer medical treatment decisions to their physician. Practically, physicians could record waivers in a patient's chart similar to the procedure for advanced directives. Unlike advanced directives, however, the waiver would be effective immediately and direct a physician's relationship with a competent patient.

In order for a patient to waive his or her right to informed consent, the patient must know that he or she has that right.²⁰⁴ The patient must know that the physician has a duty to disclose information relevant to medical treatment, that the law provides a right to make a decision about that treatment, and that the physician can not provide treatment without the patient's consent. Most significantly, the patient must know of his or her right to waive. Just as the law requires physicians and health care institutions to inform the patient of his or her legal right to informed consent to treatment, the law must obligate physicians and their employers to inform patients of the right to waive informed consent.

201. In the informed consent context, see *Arato v. Avedon*, 858 P.2d 598, 609 (Cal. 1993); *Cobbs v. Grant*, 502 P.2d 1, 12 (Cal. 1972) ("[A] medical doctor need not make disclosure of risks where the patient requests that he not be so informed.").

202. See Meisel, *supra* note 100, at 459 ("A properly obtained waiver is completely in keeping with the values sought to be promoted by informed consent.").

203. *Id.* at 453 n.133.

204. *Id.* at 454.

Some commentators argue that imposing an obligation on physicians to explain the legal right not to have information or to not decide about treatment undermines the effect of informed consent laws.²⁰⁵ They suggest that a patient might infer that he or she should not want the information or that the physician seeks a way around providing the information when, as a matter of law, the patient is entitled to disclosure.²⁰⁶ Some suggest that patients should be forced to discuss risks for their own therapeutic benefit.²⁰⁷ Some fear abuse of patient waivers by health care providers and are reluctant to grant physicians such authority and discretion.²⁰⁸ As a result, these commentators suggest procedures to protect patient interests that require institutional review committees to review all requests for waiver.²⁰⁹ Others propose a conditional obligation, imposing a duty on physicians to inform patients about the right to waive only where the patient expresses a desire to relinquish his or her right to informed consent.²¹⁰ Physicians and risk managers might argue that informing patients of the right not to decide or not to receive information is not clearly enough supported by existing law, and that it contradicts the explicit mandate of informed consent. They might also criticize the wisdom of legally permitting a competent patient to delegate decisionmaking authority when physicians still have difficulties interfacing with proxies for incompetent patients.²¹¹

205. *Id.* at 456 (analogizing "beginning Miranda warnings by informing the suspect that although he has certain rights, he does not have to accept them, thereby undercutting the effect of the warning.").

206. *Id.*

207. Mark Strasser, *Mill and the Right to Remain Uninformed*, 11 J. MED. & PHILOSOPHY 265 (1986).

208. BEAUCHAMP AND CHILDRESS, *supra* note 16, at 106.

209. *Id.*

210. Alan Meisel argues that physicians should not have an absolute obligation to inform patients of the right to waive, but that a constitutional obligation should arise where the patient expressly attempts to waive the right to either information or decisionmaking. He proposes that statements such as "please don't tell me" or "you decide" should "activate the doctor's duty to tell the patient that he has a right to the information and a right to decide, but also has a right to not hear and not to decide - that is, a right to waive." Meisel, *supra* note 100, at 456-57. See also ROBERT M. VEATCH, *A THEORY OF MEDICAL ETHICS*, 105-106 (1981) (recognizing the problems with waivers and suggesting ways to respond to insure that the patient is voluntarily making a decision not to make an informed decision). However, Veatch suggests that there should be limited circumstances where information waivers are justified. *Id.* at 105-106 (citing examples of justified waiver where information giving would violate a patient's religious or moral beliefs as in the case of a Jehovah Witness).

211. Dubler, *supra* note 176.

Defining the right to waive as a separate principle, rather than merely an exception to the doctrine of informed consent, permits a broader legal vision of patient autonomy. Unlike the case of therapeutic privilege, the patient, not the physician, determines that disclosure or individual decisionmaking will be harmful. An explicit right to waive informed consent creates a legal foundation for patients and physicians to choose alternative approaches to care with greater comfort and becomes a vehicle for competent patients to delegate decisionmaking and avoid hearing unwanted information.²¹²

Legal precedent and the litigious nature of contemporary medical practice, however, requires framing the right to waive informed consent as a notion of "informed" waiver. Informed waiver would obligate physicians to inform patients of the right to waive and the risks of forgoing knowledge of medical risks. It is similar to the doctrine of informed consent in that it requires both the physician's disclosure of information and the patient's understanding of the information. Some might argue that forcing patients into any style of decisionmaking insists on Western values, emphasizing forthrightness and individualism.²¹³ The very act of asking patients to individually decide whether they wish to delegate medical decisions to a family member, for example, risks insensitivity to those cultural norms favoring family and communal involvement. Some might contend that there exists a fine line between the amount of disclosure necessary for informed waiver and that required for informed consent. Others might suggest that the notion of waiver, even informed waiver, erodes the ability for sound decisionmaking.

Although informing patients of the risks of waiver invokes Western-defined concepts, it represents a good compromise for including multiculturalism in medical decisionmaking. It is difficult to erase the impact of the patient rights movement and American values from American law and equally unrealistic to expect that physicians and their employers will embrace patients' ability to bypass informed consent without protections against professional liability. Perhaps, then, a law of informed waiver requires support by written contract, documenting the physician's duty to inform patients of the right to waive informed consent and the patient's intentional and voluntary decision to invoke that right. An informed waiver contract might mirror the forms physicians use when obtaining informed consent. Courts might use informed waiver documents to

212. See Michel, *supra* note 21, at 25.

213. *Id.* at 26.

guard against patients' hindsight change of position and to infer individual patients' values regarding medical decisionmaking.

How might patients and health care providers employ a law of informed waiver to accommodate cultural values in medical decisionmaking? In practice, depending on constraints of time, the physician might use the disclosure of the right to waive and the presentation of an informed waiver contract as an opportunity to engage the patient about his or her preferred approach to decisionmaking. Patients can invoke the right to waive to prevent disclosure of unwanted information, delegate the right to decide about treatment, or to neither be informed nor to decide. Facilitating patients' ability to make such decisions does not undermine sound decisionmaking. Rather, it provides a good approach to fostering self-definition and respecting human dignity.²¹⁴

In the case examples provided in Part II, M.Y.'s physician might inform M.Y. of her right to waive the right to decide unilaterally and to hear information about the risks of medical procedures. M.Y. could then choose, and possibly contract, with her physician, to delegate the right to informed consent to a family member. A law of informed waiver would allow M.Y.'s physician to respect her choice of an alternative decisionmaking approach consistent with her cultural values. As a result, M.Y. retains her right to autonomy in the broadest sense. In the case of E.R., a law of informed waiver might enable the clinic staff to accept more comfortably E.R.'s choice of alternative treatment by decreasing the risk of professional liability. E.R. might waive his right to know the particular risks of refusing the staff's recommended treatment if such disclosure interfered with his choice to seek alternative care. He might also waive his right to decide about his medical treatment and, instead, defer this right to his community healer. At minimum, a law of informed waiver, paired with the doctrine of informed consent, might encourage the clinic staff to initiate dialogue with E.R. about his cultural values and medical decisionmaking.

IV. Conclusion

The Western notion of autonomy, as reflected in the doctrine of informed consent, assumes that individuals want to make decisions about their medical care by themselves. Although the principle of autonomy, as a broad principle of the right to free choice and human dignity, is revered by many non-Western societies, each in-

214. Meisel, *supra* note 100, at 459.

dividual defines autonomy according to his or her personal and cultural values. Indeed, the very meaning of health and healing is related to cultural values and these values often determine an individual's approach to medical decisionmaking. A monolithic model of informed consent falls short as a notion of choice and self-determination. Accordingly, this Note argues for a transcultural definition of patient autonomy that, in practice, empowers patients to express themselves in ways germane to their worldview. It proposes doing so through a doctrine of "informed waiver" that enables competent patients to forego their right to receive medical information and permits such patients to delegate medical decisionmaking to others. Judges and legislators have struggled to define the doctrine of informed consent in a manner that reflects the voice of the patient in medical decisionmaking. The proposed doctrine of informed waiver provides a means for patients who reject Western-defined approaches to medical decisionmaking to realize their autonomy in the fullest sense. If lawmakers fail to reform the law regarding medical decisionmaking, if they neglect to consider the impact of multiculturalism, the notion of autonomy will remain a legal fiction for a significant and growing number of American residents.