

11-1989

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Recommended Citation

D. Don Welch, *Walking in Their Shoes: Paying Respect to Incompetent Patients*, 42 *Vanderbilt Law Review* 1617 (1989)

Available at: <https://scholarship.law.vanderbilt.edu/vlr/vol42/iss6/3>

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ESSAY

Walking in Their Shoes: Paying Respect to Incompetent Patients

*D. Don Welch**

One of the great games that judges play is to act as if their decisions are based on objective standards. For understandable reasons, judges prefer that their decrees be seen as resting on accepted principles of law rather than on a judicial choice between two competing, plausible opinions. One such accepted principle has been that decisions giving consent for medical treatment of incompetent patients should be made to serve the "best interests" of the patients.¹ In recent years, courts increasingly have used a new, seemingly less objective standard called "substituted judgment" to replace the best interests standard in certain situations. Under this new standard, a court substitutes the judgment of a third party for that of the incompetent patient. The third party tries to make the decision the incompetent patient would have made if competent.² The Supreme Court of New Jersey has taken

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1. See *In re Schiller*, 148 N.J. Super. 168, 179, 372 A.2d 360, 366 (Ch. Div. 1977) (stating that "[t]he right of the individual, then, is to have a determination that he or she can make the determination and, if not, to have some competent able person to make it in the best interests of the person").

Another statement of the best interests standard is that it requires "what, from an objective standpoint, appears to promote a patient's good without reference to the patient's actual or supposed preferences." PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE & BIOMEDICAL & BEHAVIORAL RESEARCH, 1 MAKING HEALTH CARE DECISIONS 179 (1982) [hereinafter PRESIDENT'S COMM'N].

2. See *Belchertown v. Saikewicz*, 373 Mass. 728, 752, 370 N.E.2d 417, 431 (1977).

the lead in this emerging trend with the decisions in *In re Conroy*³ and its progeny,⁴ developing an analytical scheme that incorporates both the best interests standard and the substituted judgment standard depending on the facts of particular cases.

The thesis of this Essay is that the limited recognition of the substituted judgment standard should be expanded to the point that best interests considerations are understood to be only an ingredient in substituted judgment decision making. The argument involves two phases. The first phase of the argument is to ask and answer three questions: (1) Why do we value informed consent? (2) What is the meaning of the "incompetence" exception to the requirement of informed consent? (3) What do the answers to these first two questions tell us about the character of third-party consent, when a particular patient has been found to be incompetent? This line of questioning leads to a conclusion that considerations of substituted judgment should be given a clear priority over considerations that traditionally have been labeled the patient's best interests.

The second phase of the argument is to analyze the nature of the best interests standard itself: to examine what best interests means, how it is determined, and how the concept has been used by courts. This analysis demonstrates that rather than being an independent value, however subservient to substituted judgment in our deliberations, best interests ultimately should be understood as only a subpart of substituted judgment concerns. This characterization of best interests criteria lends support to the recommendations flowing from the first phase of the argument.

This Essay specifically focuses on how third-party decisions regarding consent to treatment should be made. Final decisions about treatment will not always be dictated by expressions of consent. Historically other factors have overridden patient preferences: the public welfare when vaccinations have been ordered⁵ and the needs of innocent third

3. *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985).

4. *In re Farrell*, 108 N.J. 335, 529 A.2d 404 (1987); *In re Peter*, 108 N.J. 365, 529 A.2d 419 (1987); *In re Jobes*, 108 N.J. 394, 529 A.2d 434 (1987).

5. The case cited most often which declares that mandatory immunization against dangerous diseases is a constitutionally valid exercise of police power is *Jacobson v. Massachusetts*, 197 U.S. 11 (1905). There, the compelling interest of the state in protecting the public's health outweighed personally preferred medical treatment.

The state also has restricted freedom from compulsory vaccination to protect the individual child, in a *parens patriae* mode, as well as to protect other children in the community. See *Prince v. Massachusetts*, 321 U.S. 158, 166-67 (1944).

For a list of cases that hold much the same, see *Brown v. Stone*, 378 So. 2d 218, 222 (Miss. 1980) (stating that "[a]ccording to the great weight of authority, it is within the police power of the State to require that school children be vaccinated against smallpox"); cf. *Maier v. Besser*, 73 Misc. 2d 241, 341 N.Y.S.2d 411 (Sup. Ct. 1972). This case, however, never reached the highest

parties when medical treatment has been ordered.⁶ Just as the autonomy of competent patients is not the only value to be honored in medical decisions, respect for the wishes of surrogate decision makers should not always control these medical decisions. While third-party consent is not determinative of choices of treatment in every case, it should play a major role, and we should be very clear about what a person is being asked to do in considering whether to grant such consent.

I. THE VALUE OF INFORMED CONSENT

Today the notion of "informed consent" is in vogue. It seems almost silly to spend time identifying the value of informed consent in light of the prominence—the almost sacred status—accorded this concept in recent years. The idea of informed consent, however, does not have a long and honored position in the history of the practice of medicine.⁷ Traditionally the physician has assumed an authoritative role that includes discretion to make decisions on behalf of patients. Hippocrates counseled physicians to hide most things from their patients while caring for them and to distract patients from thinking about their illnesses.⁸ While this view of the physician-patient relationship may seem hopelessly antiquated today, the belief that the doctor should control information about the patient's condition persisted well into modern times. In 1847 the American Medical Association adopted a code of ethics that encouraged doctors to bring hope and comfort to their sick patients and to avoid anything that would discourage or depress them.⁹

Consent became a prominent concern within the medical community as a result of the Nuremberg trial revelations of medical atrocities inflicted by physicians in Nazi Germany.¹⁰ However, change came to the world of medicine not through internal reform but through challenges from the outside. Over seventy years ago, Justice Benjamin Cardozo in

court in New York.

6. Some courts have authorized blood transfusions, over the refusal of a pregnant woman, to save a fetus. *See, e.g., Raleigh Fitkin-Paul Morgan Memorial Hosp. v. Anderson*, 42 N.J. 421, 201 A.2d 537, *cert. denied*, 377 U.S. 985 (1964). The District of Columbia Circuit imposed on a mother treatment required to keep her alive citing, among other reasons, the argument that "[t]he state, as *parens patriae*, will not allow a parent to abandon a child, and so it should not allow this most ultimate of voluntary abandonments." *Application of the President & Directors of Georgetown College, Inc.*, 331 F.2d 1000, 1008 (D.C. Cir.), *cert. denied*, 377 U.S. 978 (1964).

7. For a full history of the doctrine of informed consent, see R. FADEN & T. BEAUCHAMP, *HISTORY AND THEORY OF INFORMED CONSENT* (1986).

8. J. KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 4 (1984) (citing 2 HIPPOCRATES, *DE-CORUM* 297 (W. Jones trans. 1967)).

9. *CODE OF ETHICS OF THE AMERICAN MEDICAL ASSOCIATION* (1847), *reprinted in part in J. KATZ, supra* note 8, at 230-31.

10. *See R. FADEN & T. BEAUCHAMP, supra* note 7, at 151-87.

*Schloendorff v. Society of New York Hospital*¹¹ set the stage for the development of a modern doctrine of consent when he said that all adults should be able to decide what would be done to their bodies.¹² Cardozo was expounding not a doctrine of knowledgeable self-determination but protection against unauthorized bodily invasion. Cardozo's consent doctrine became the informed consent doctrine in the 1957 case of *Salgo v. Leland Stanford Jr. University Board of Trustees*.¹³

Prior to 1957 legal charges could be brought for unlawful—*i.e.*, unauthorized—touching of one's body, but the concern was with the presence of consent, not the nature or extent of disclosure.¹⁴ While much of the decision in *Salgo* addressed traditional concepts of malpractice and negligence, the court also explicitly laid down a standard for disclosure. In *Salgo* a patient had entered the hospital for diagnostic tests related to circulatory problems. When he became paralyzed from the waist down following one of these tests, he charged, among other things, that his physician had not informed him of the nature of the planned test. Finding in the patient's favor, the court ruled that if physicians do not disclose all of the information to their patients that would be needed in order to make intelligent decisions about proposed medical treatments, they breach their duties to patients and face liability.¹⁵

The doctrine of informed consent injected a significant element of patient participation into medical decision making, a realm long dominated by paternalistic concerns and physician prerogative with regard to patient care. Commentators have formulated various definitions of informed consent. Tom Beauchamp and James Childress have identified the fundamental elements of informed consent as: (1) disclosure of information, (2) comprehension of information, (3) voluntary consent, and (4) competence to consent.¹⁶ Thus, the requirement for informed consent is met when competent patients have received and understood information relevant to their condition and proposed procedures and have freely authorized the implementation of those procedures.¹⁷

11. 211 N.Y. 125, 105 N.E. 92 (1914).

12. *Id.* at 129, 105 N.E. at 93.

13. 154 Cal. App. 2d 560, 317 P.2d 170 (1957).

14. See Tancredi & Weisstub, *Malpractice in American Psychiatry: Toward a Restructuring of the Psychiatrist-Patient Relationship*, in 2 LAW AND MENTAL HEALTH: INTERNATIONAL PERSPECTIVES 83, 103 (D. Weisstub ed. 1986).

15. *Salgo*, 154 Cal. App. 2d at 578, 317 P.2d at 181.

16. T. BEAUCHAMP & J. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 70 (2d ed. 1983). Some commentators have suggested that informed consent be replaced by a lower level of patient involvement, such as patient assent. See generally P. APPELBAUM, C. LIDZ & A. MEISEL, *INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE* (1987).

17. There is the question of whether fully informed consent is ever possible, much less practical. The problem has been articulated by William Curran:

I do not believe that a *fully* informed consent can be obtained from nonscientifically trained

Why is such informed consent important? What basic values, what root concerns, underlie our confidence that informed consent is an important matter? A number of scholars have identified benefits that flow from adherence to the doctrine. Alexander Capron, for example, has described six functions served by informed consent: (1) promotion of individual autonomy, (2) protection of patients and subjects, (3) avoidance of fraud and duress, (4) encouragement of self-scrutiny by medical professionals, (5) promotion of rational decisions, and (6) involvement of the public in promoting autonomy as a general social value and in controlling biomedical research.¹⁸

Scholars have identified other ends as being served by informed consent. Patients are more likely to get appropriate treatment if they are informed and involved.¹⁹ Patient support and cooperation can aid in the success of treatment,²⁰ and in obtaining patient compliance with medical advice.²¹ Studies show that patients involved in treatment are more comfortable, less worried, less withdrawn, and experience shorter hospital stays.²² Granting self-determination to psychiatric patients tempers the intrusion of psychiatry on important social values.²³ Obtaining consent provides protection to medical researchers and care givers from accusations of improper treatment. On a grander scale, requiring truly informed consent may avoid domination by experts and thus foster democracy and freedom.²⁴

Many commentators justify informed consent requirements with these sorts of beneficial consequences in mind, and in doing so impli-

subjects, if by this we mean a complete understanding of the entire project, its objectives, its risks, its benefits, etc. Even the research team may not understand all of these aspects, not only because of self-interest but also because of their own limits of knowledge and experience. Curran, *Ethical Issues in Short Term and Long Term Psychiatric Research*, in *MEDICAL, MORAL AND LEGAL ISSUES IN MENTAL HEALTH CARE* 18, 24 (F. Ayd, Jr. ed. 1974) (emphasis in original).

Studies have shown that strict requirements of patient informed consent are often not met. See, e.g., C. LIDZ, A. MEISEL, E. ZERUBAVEL, M. CARTER, R. SESTAK & L. ROTH, *INFORMED CONSENT: A STUDY OF DECISIONMAKING IN PSYCHIATRY* 136-39 (1984) [hereinafter LIDZ & MEISEL].

18. Capron, *Informed Consent in Catastrophic Disease Research and Treatment*, 123 U. PA. L. REV. 340-76 (1974); see also J. KATZ & A. CAPRON, *CATASTROPHIC DISEASES: WHO DECIDES WHAT?* 82-89 (1975).

19. PRESIDENT'S COMM'N, *supra* note 1, at 42-44.

20. Brodsky, Shaw & McMahon, *Neuropsychiatric Intervention in the Rehabilitation of Head Injured Patients*, 10 *PSYCHIATRIC J.U. OTTAWA* 237 (1985).

21. Francis, Korsch & Morris, *Gaps in Doctor-Patient Communication: Patients' Response to Medical Advice*, 280 *NEW ENG. J. MED.* 535 (1969); Stone, *Patient Compliance and the Role of the Expert*, 35 *J. SOC. ISSUES* 34 (1979).

22. Tobiasen & Hiebert, *Burns and Adjustment to Injury: Do Psychological Coping Strategies Help?* 25 *J. TRAUMA* 1151 (1985).

23. LIDZ & MEISEL, *supra* note 17, at 7. Our society's individualistic strand places value on personal autonomy and independence, resisting efforts to label particular persons as deviant and favoring protection of the weak from those in more powerful positions.

24. See E. FREIDSON, *PROFESSION OF MEDICINE* 335-36 (1970).

cate the basic bioethical principle of beneficence.²⁵ The principle of beneficence is based on the idea that medical treatment should provide some benefit. When this value controls, decisions about treatment are basically teleological in character—that is, we evaluate any potential course of action in terms of the positive consequences that will result.²⁶

Whereas beneficence leads us to think teleologically, in terms of ends and consequences, the bioethical principle of autonomy leads us to think deontologically, in terms of fidelity to first principles and established values. In the informed consent context, autonomy leads us to think specifically in terms of principles and values related to the dignity of persons. Respecting a patient's autonomy does not necessarily entail concern for consequences and thus can be at odds with a physician's vision of medical benefit. When such a conflict arises, an approach to informed consent that begins with patient autonomy places a priority on adherence to that principle over considerations of beneficial results.

While informed consent can be grounded either teleologically or deontologically,²⁷ the principle retains its integrity only when the latter course is taken. All of the benefits that have been identified as following from an insistence on informed consent may be worthwhile. But this kind of calculation does not provide the proper basis for valuing informed consent. We value informed consent not in order to achieve certain other goals, but because of our respect for persons, their bodily autonomy, and their self-determination. We do not view a person's right to control both treatment and research protocols as an instrumental good that serves some of the other benefits listed previously. Rather,

25. See, e.g., Guttmacher, *Whole in Body, Mind, and Spirit: Holistic Health and Limits of Medicine*, in *CONTEMPORARY ISSUES IN BIOETHICS* 55-59 (2d ed. 1982).

26. Beneficence can be further divided into individual beneficence and general beneficence—a distinction that is particularly important in research contexts. Individual beneficence focuses on the benefit received by the person who is the subject of a particular procedure. General beneficence, on the other hand, is concerned with the benefit that could accrue to a broader spectrum of society, perhaps humankind as a whole. In each case, the moral calculus is one of pursuing a course of action that will lead to medical benefit.

27. E.g., LIDZ & MEISEL, *supra* note 17. These authors recognize that the doctrine can be deontologically based (an inherent good flowing from the natural obligation of one human being to another) or teleologically based (providing substantive benefit to those involved or other persons in the society). *Id.* at 4. They state, however, that they see the consequentialist position as being more relevant, *id.*, and couch their discussion of the role of the patient in medical decision making as a way of getting information needed to make the most beneficial decision:

The physician's role in medical decisionmaking is primarily cognitive, medical, and technical. The patient's role is primarily affective, personal, and subjective. Informed consent views medical decisionmaking as a mix of technical and personal considerations; decisions about medical care are not to be made exclusively by physicians, because only the patient has access to the personal information, which is highly relevant to the making of the decision.

Id. at 11. One thesis of this Essay is that this reliance on a consequentialist basis for informed consent is misplaced.

respect for persons is an intrinsic good. Through informed consent we recognize and give force to our respect for an individual's autonomy. In other words, we require informed consent not because we hope to maximize benefit, but because we believe each person should be treated as an autonomous human being.²⁸

By requiring informed consent in treatment and research settings, our society has established the priority of individual autonomy over calculations of benefit.²⁹ In the landmark case of *Natanson v. Kline*³⁰ the court embraced this ordering of concerns. The court stated that Anglo-American law is premised upon the principle of self-determination. All individuals of sound mind are viewed as masters of their own bodies with the freedom to refuse lifesaving or other medical treatments.³¹ The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research concluded that patient self-determination should receive priority over the value of life.³² In addition, it found that patient self-determination was the "bedrock" of the Commission's reflections on informed consent and the patient-practitioner relationship.³³

28. A distinction should be made between insisting that informed consent be grounded in deontological considerations and insisting that all specific decisions regarding informed consent in concrete situations be made through deontological reasoning. The author has argued that neither the teleological nor the deontological model provides an adequate framework for moral decision making. See Welch, *The Moral Dimension of Law*, in *LAW AND MORALITY* 8-12 (D. Welch ed. 1987).

This type of distinction may help make sense of what could be seen to be incompatible statements in R. FADEN & T. BEAUCHAMP, *supra* note 7. On the one hand, they state that respect for autonomy is a prima facie principle "equally weighted" with other moral principles (*e.g.*, beneficence, justice) "in abstraction from particular circumstances." *Id.* at 18. On the other hand, they assert that autonomy is "the single most important moral value for informed consent." *Id.*

It is not inconsistent to hold that autonomy is the primary value which grounds and gives meaning to informed consent and, at the same time, to argue that medical problems cannot be resolved with a preemptive weight given to concerns for autonomy and informed consent. Indeed, acceptance of the recognized exceptions to informed consent rests upon this distinction.

29. This clear separation of the autonomy based deontological grounding from the benefit oriented teleological argument is, unfortunately, not always observed. For example, one study used an ends oriented statement to make the deontological argument: "[T]he requirement of informed consent is justifiable to the extent that it is reasonably calculated to promote the autonomy of individuals. A further deontological justification for informed consent arises from the fact that it also promotes another important and widely held value, rationality." LIDZ & MEISEL, *supra* note 17, at 328.

These observers recognize, however, that the beneficial consequences flowing from enforcement of informed consent could probably not justify the required expenditure of time, resources, and good will required to meet this standard and thus conclude: "Yet we believe, on deontological grounds, that informed consent must not be abandoned." *Id.* at 330 (emphasis in original).

30. 186 Kan. 393, 350 P.2d 1093 (1960).

31. *Id.* at 406-07, 350 P.2d at 1104.

32. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE & BIOMEDICAL & BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 26-27, 44 (1983).

33. PRESIDENT'S COMM'N, *supra* note 1, at 50-51.

Numerous examples exist, however, of a willingness to "trade off" the concern for autonomy for projected benefits. Fay Rozovsky, in a study of statutory standards regarding consent, suggested that patients' rights to autonomy and privacy should prevail unless state interests compel a different decision or unless the best interests of patients would be better served by overriding patient autonomy and privacy.³⁴ James F. Drane has described the doctrine of informed consent as balancing the values of beneficence and autonomy.³⁵ In an appropriate ordering of norms, however, autonomy is not a benefit to be balanced with other benefits in the context of informed consent.

Patient autonomy, as given meaning through informed consent, takes precedence over benefits from medical treatments and, in certain contexts, the courts have readily and clearly expressed this priority.³⁶ We have little difficulty in accepting the priority of patient choice for competent patients. Ill or injured persons who seek medical assistance are asking medical providers "to put themselves—their knowledge, time, energies, and experience—responsively at their disposal."³⁷ The key to effective care is responsiveness, not only to the results of diagnostic tests but to the patients seeking help. Incompetent patients are no less deserving of responsive care from others than are competent patients. Our reasoning should be just as clear when considering the plight of incompetent patients, else we compound their plight by refusing to

34. F. ROZOVSKY, CONSENT TO TREATMENT: A PRACTICAL GUIDE 371 (1984).

35. See Drane, *The Many Faces of Competency*, 15 HASTINGS CENTER REP., Apr. 1985, at 17. Drane's argument illustrates the importance of clear thinking on the rationale underlying the doctrine of informed consent. His conceptualization of informed consent yields a conclusion that is wholly contrary to the thesis of this Essay: "Incompetence both creates a new obligation to identify a surrogate and provides a basis for the physician to set aside the informed consent requirement in favor of what he or she thinks is best for the patient." *Id.*

The problem with this propensity on the part of some observers to override respect for autonomy through a calculation of what is in the patient's best interests will become more evident as we look at the way we handle consent questions for patients who have been judged to be incompetent to make their own decisions. As is argued below, a finding of incompetence should not entail an automatic resort to a best interests calculation.

36. See, e.g., *Montgomery v. Board of Retirement of Kern County Employees' Retirement Ass'n*, 33 Cal. App. 3d 447, 109 Cal. Rptr. 181 (1973) (finding that the courts do not have the power to protect the state's interests in preserving life by forcing a competent adult to accept unwanted treatment); *Satz v. Perlmutter*, 379 So. 2d 359 (Fla. 1980) (upholding a decision to remove life-sustaining mechanical respirator on right to privacy grounds); *Mercy Hosp., Inc. v. Jackson*, 62 Md. App. 409, 489 A.2d 1130 (1985) (upholding a refusal to appoint a guardian when a competent patient refused transfusion on religious grounds), *vacated*, 306 Md. 556, 510 A.2d 562 (1986); *Lane v. Candura*, 6 Mass. App. Ct. 377, 376 N.E.2d 1232 (1978) (finding that the right to privacy includes the right to make a medically irrational choice); *In re Brown*, 478 So. 2d 1033 (Miss. 1985) (holding that the state's interest in having the patient testify at the trial was not sufficiently compelling to override religious rights to refuse transfusion); *In re Quackenbush*, 156 N.J. Super. 282, 383 A.2d 785 (Prob. Div. 1978) (holding that the patient's right to privacy overrides the state's interests in preservation of life in case of extensive invasive medical treatment).

37. R. ZANER, ETHICS AND THE CLINICAL ENCOUNTER 54 (1988).

respect what we know about them as unique individuals. Such a refusal would mean that their incompetence not only entails the loss of ability to exercise autonomous judgment but also a loss of dignity, as they are reduced to someone else's version of a reasonable person.

II. THE INCOMPETENCE EXCEPTION TO INFORMED CONSENT

If we view informed consent as a reflection of our respect for individual autonomy and not as a means of achieving some other good end, what does this view say about our second question? What is the meaning of the incompetence exception to the requirement of informed consent?³⁸

A full discussion of the meaning of competence and appropriate tests for its determination is not possible here. However, there are a few general implications of the concern for autonomy in competence considerations that should be mentioned. Competence is the measure of whether persons possess the capability for autonomous action. Incompetence means that persons are not able to exercise self-determination in a meaningful way. When persons are not able to understand their own situations, when they are unable to comprehend the likely results of alternative procedures, then those persons are not autonomous in the context of the particular purpose and setting at hand. Self-determination is not possible, and informed consent in its ordinary meaning cannot be a reality.

Persons are judged to be incompetent legally when they are found to be incapable of making personal decisions regarding their care and welfare. This judgment may be made because of age (in the case of children) or condition (mental illness, retardation, senility, or a comatose state). Incompetence is not always an either/or proposition. Often phy-

38. There are other recognized exceptions to the requirement of informed consent: medical emergency, danger to others, patient waiver, and therapeutic privilege. While this Essay focuses on the incompetent patient, this analysis is not irrelevant to formulating a conceptual basis for other exceptions. It could be argued that the only exceptions to the requirement of informed consent that should be allowed are those that can be supported by concerns for respect for persons, not by considerations of medical benefit. Thus, for example, the medical emergency exception could be justified as allowing temporary measures that maintain or restore to the individuals the opportunity to exercise their own judgment. Exceptions to informed consent requirements when others are endangered give evidence of respect for those other persons. The patient waiver is a clear example of allowing persons self-determination about being informed—the right to be informed is not an obligation to be informed.

The therapeutic privilege exception has been the most troubling of the exceptions to informed consent. This exception allows a physician to withhold information when, in the judgment of the doctor, that information would have a negative impact on the patient's health, not in cases in which the physician believes that the information would lead the patient to refuse desirable treatment. In these cases, the exception is clearly based on medical paternalism and on a concern for medical benefit.

sicians deal with gradations along a continuum, and certification of a patient as incompetent requires drawing a line through an unbroken string of progressions. Patients may be competent for one purpose but not for another; a particular patient may be competent one day and incompetent the next. Such cases present a danger of measuring competence by the degree to which a patient agrees with a physician's decisions. The following story reflects this problem:

In Melbourne, Australia, John McEwan, a 27-year-old quadriplegic on a respirator, was certified insane by hospital officials when he expressed a wish to die and went on a hunger strike. McEwan's treatment continued on the basis of the certification. When he changed his mind, he was certified as sane. The hospital also denied the validity of a . . . [Do Not Resuscitate] order McEwan signed, saying he was too depressed to be responsible for this document. McEwan was eventually released from the hospital, and died ten weeks later.³⁹

A Massachusetts appellate court commented upon a similar confusion of competence and agreement in reviewing a probate court's judgment of the competence of a woman refusing amputation of her gangrenous leg.⁴⁰ The probate court judge had ruled that the patient was legally incompetent because she had not made a rational choice after careful consideration of the medical alternatives. The appellate court, however, noted that (1) her competence was not questioned until she withdrew her consent to the treatment preferred by the attending physicians,⁴¹ and (2) the fact that her decision is unfortunate, or seen to be medically irrational, does not justify a conclusion that her capacity to make the decision is impaired to the point of legal incompetence.⁴²

A very real difficulty often exists, however, in deciding whether competence can be determined apart from judging particular decisions. On the one hand, we want to avoid the danger of judging as incompetent those with whom we disagree. This goal can be accomplished by separating respect for persons from respect for their decisions.⁴³ In this vein, our respect for a person's autonomy is not predicated on a case by case examination of each decision. We do not determine whether each decision appears to meet our expectations of what a deliberate, informed, consistent choice would be.

On the other hand, an analysis of a patient's decision has a role in

39. *The Latest Word*, 16 HASTINGS CENTER REP., Aug. 1986, at 52 (citation omitted).

40. *See Lane v. Candura*, 6 Mass. App. Ct. 377, 376 N.E.2d 1232 (1978).

41. *Id.* at 383, 376 N.E.2d at 1235.

42. *Id.* at 383, 376 N.E.2d at 1235-36.

43. An example of the kind of approach that should be avoided is found in the language of a Colorado Supreme Court decision in which the court implied that statutory and common-law protection of the right to withhold consent exists unless it is clear that the patient "lacked the capacity to participate in such decisions or that his refusal to submit to treatment with prolixin was itself irrational or unreasonable." *Goedecke v. Department of Insts.*, 198 Colo. 407, 411, 603 P.2d 123, 125 (1979) (emphasis added).

determining competence. It is difficult to know how to judge a person's competence apart from looking at that person's decisions. We have a clearer notion of what an autonomous decision is than we do of what an autonomous person is. Further, a focus on particular decisions is certainly more in keeping with the nature of our desire to require informed consent, which in turn is concerned with specific people making specific decisions. An autonomous person can fail to act autonomously in certain situations, such as when that person is overwhelmed by information, lacks necessary facts, or is manipulated by clever presentations of information.⁴⁴

One test physicians use to assess competence is to ask whether a patient makes a choice similar to that which a reasonable person would make; another is to ask whether the choice is based on rational reasons. Each of these tests is biased toward the patient who chooses to accept the treatment advice of physicians.⁴⁵ Such a bias is particularly pronounced in psychiatric settings in which resistance to following drug therapy instructions is often viewed as "a form of symptomatic behavior, involving hostility, acting out, and paranoid delusions."⁴⁶ "Whatever mental illness is, the belief that patients are mentally ill affects both the staff's and the patients' perceptions of [the] patients' abilities to participate in decisionmaking, regardless of the legal presumption of competency."⁴⁷ Such a slant in perceptions of competence is not relegated to psychiatric settings: "A particular medical setting establishes certain expectations about what a reasonable person would do, and these expectations play an important role in competency determinations."⁴⁸ Deviation from established expectations can lead to a judgment that a patient's decision making ability, and competence, is impaired because the patient harbors prejudices about health care.

The finding of incompetence should precede any calculation of medical benefits. It is a very troubling fact, if it is true, that decisions as to patient competence often involve a tradeoff between respect for autonomy and beneficence.⁴⁹ When we think about treatment of incompetent patients without their consent, we should not think in terms of medical necessity overriding the value of informed consent. Instead, we should only think in terms of acting in circumstances in which informed

44. R. FADEN & T. BEAUCHAMP, *supra* note 7, at 237.

45. BROWN, *Psychiatric Treatment Refusal, Patient Competence, and Informed Consent*, 8 INT'L J.L. & PSYCHIATRY 83, 90 (1986).

46. *Id.* at 85.

47. LIDZ & MEISEL, *supra* note 17, at 326.

48. Drane, *supra* note 35, at 18.

49. R. FADEN & T. BEAUCHAMP, *supra* note 7, at 291. Faden and Beauchamp assert that such tradeoffs are usually made in determinations of the competence of patients and subjects. *Id.*

consent is not possible.

When we allow an incompetence exception to informed consent, we are not balancing the value of autonomy with the value of beneficence. Rather, we are admitting that our normal way of showing respect for that person is not appropriate and that another vehicle must be found. That vehicle is third-party consent.

In this regard, I take exception to the way in which Tom Beauchamp and Ruth Faden legitimize third-party consent:

[I]f a person is *nonautonomous* and situated in a context in which consent is required, it is a prima facie moral principle (*not* derived from the principle of respect for autonomy, but rather from beneficence) that some mechanism for the authorization of procedures or decisions other than obtaining the person's consent should be instituted.⁵⁰

This difference over the philosophical grounding for third-party consent has important implications for the choice of standards to be used in making these decisions about treatment, as will be seen below.⁵¹

III. GROUNDS FOR TREATMENT OF INCOMPETENT PATIENTS

While much of the discussion about medical care for the incompetent has focused on the right to refuse treatment, that discussion begins with the premise that incompetence does not compromise a patient's right to treatment. The impossibility of securing a patient's consent in the moment of decision should not become a barrier to the patient's receiving appropriate medical care.⁵²

Because of the variety of circumstances in which this issue has arisen, a patchwork of judicial precedents on the right of an incompetent to refuse treatment has resulted. The right has been noted in common law⁵³ and in constitutional law.⁵⁴ While courts most easily deal with cases in which a person expressed a desire, when competent, to invoke the right to refuse treatment, the recognition of that right has not been limited to that fact situation. Courts have also recognized the "right to refuse treatment and allow life to terminate through natural forces" for incompetent patients who have not expressed clearly their wish for that choice.⁵⁵ The issue, then, is not whether incompetent pa-

50. *Id.* at 288 (emphasis in original).

51. *See infra* Part III.

52. *See, e.g., In re Quinlan*, 70 N.J. 10, 41, 355 A.2d 647, 664, *cert. denied*, 429 U.S. 922 (1976).

53. *E.g., Eichner v. Dillon*, 73 A.D.2d 431, 426 N.Y.S.2d 517 (1980) (right to privacy), *modified sub nom. In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266, *cert. denied*, 454 U.S. 858 (1981).

54. *E.g., Foody v. Manchester Memorial Hosp.*, 40 Conn. Supp. 127, 482 A.2d 713 (Super. Ct. 1984); *Quinlan*, 70 N.J. at 38-42, 355 A.2d at 662-64.

55. *In re Beth Israel Medical Center*, 136 Misc. 2d 931, 937, 519 N.Y.S.2d 511, 515 (Sup. Ct.

tients have a right to receive or reject medical treatment, but how and by whom decisions about such treatment should be made.

A. The Appropriateness of Substituted Judgment

If it is determined that a patient is not competent to consent to certain procedures, and if we then turn to a third party to give consent, what are we asking that third party to do? What is the nature of the decision to be made? While there are many variations on this theme, third parties have been asked to render their judgment in accord with the two different guidelines: the incompetent person's best interests and substituted judgment.

The best interests standard fits well with the concern for beneficence. Under this approach, decisions are made for the incompetent person which promote that person's best interests. Courts and others who adhere to this guideline often use a fairly narrow, explicitly medical view of what the person's best interests are. Providers choose or avoid procedures with an eye toward the consequences that will result and the benefit of those consequences.

Substituted judgment is an effort to make the decision the person would have made if competent. As we have seen time and time again, subjects and patients do not always make the decisions that others feel are in their best interests. The substituted judgment standard requires the third party giving consent to sort through the incompetent person's particular preferences. The factors to be weighed always will include medical benefit, but they also may include such matters as a person's aversion to or preference for risk, the way particular alternatives affect the person's lifestyle, the person's religious beliefs, the impact on family, and other considerations that are highly particular to an individual.

The substituted judgment standard should be chosen over the best interests standard when a third party attempts to make a treatment decision for another. The primary value to be protected is individual autonomy, not well being. Informed consent is a measure of our respect for that person's values, beliefs, and preferences, and third-party consent should be viewed as an extension of that respect.

While a great deal has been written on the best interests and substituted judgment standards in recent years, considerable imprecision and confusion still exist. As evidence I offer the fact that such leading authorities as Paul Appelbaum, Charles Lidz, and Alan Meisel could write the following:

All surrogate decision makers are, in a general way, under a duty to act in the best interests of incompetent patients. The difficulty with the best interests standard is

not in the statement of it but in giving content to it. The substituted judgment approach is, in fact, one way of doing so. That is, a surrogate who makes a decision for an incompetent patient on the basis of that patient's instructions—written or oral, express or implied—is seeking to implement the patient's best interests *as that patient would have defined them*. Thus, the substituted judgment approach is merely one way in which the best interests standard is given content.⁵⁶

This statement is exactly wrong. Substituted judgment is not a way of giving content to the best interests standard. Rather, best interests is one item that should be taken into account when making a substituted judgment. The inverted relationship in which these authors place the two concepts reflects their failure to acknowledge the priority that autonomy should have over beneficence in their development of a theory of informed consent. Autonomy may not always trump beneficence in final decisions about treatment, but we should never lose sight of the fact that informed consent—and by extension, third-party consent—is a process in the service of respect for persons.

One approach to third-party consent incorporates both best interests and substituted judgment. For example:

The court should take the next occasion to carefully define a substituted judgment and best interest rule that supports good faith decisions by families and physicians to implement the wishes of incompetent patients if known, or to make treatment decisions consistent with the patient's best interests if the patient's wishes are not known.⁵⁷

However, the real world seldom presents us with such alternative choices. The Supreme Court of New Jersey, faced with the application of a guardian to remove a nasogastric feeding tube from an incompetent nursing home patient, moved from the two categories of best interests and substituted judgment to three tests: subjective,⁵⁸ limited objective,⁵⁹ and pure objective.⁶⁰ This modification represents a recognition of the difficulties posed by a bifurcation of patients' conditions, but simply increasing the number of categories from two to three does not

56. P. APPELBAUM, C. LIDZ & A. MEISEL, *INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE* 99 (1987) (emphasis in original).

57. Annas, *Precatory Prediction and Mindless Mimicry: The Case of Mary O'Connor*, 18 *HASTINGS CENTER REP.*, Dec. 1988, at 31, 33.

58. *In re Conroy*, 98 N.J. 321, 361-64, 486 A.2d 1209, 1229-31 (1985) (stating that a subjective test allows surrogate decision makers to make the decision they believe the patient would have made when there have been clear expressions by the patient, when competent, of desires about life-sustaining treatment).

59. *Id.* at 365, 486 A.2d at 1232 (finding that life-sustaining treatment can be withheld or withdrawn when there is trustworthy evidence that the patient would have refused treatment and the burdens of continued life outweigh the benefits of that life for the patient).

60. *Id.* at 366, 486 A.2d at 1232 (holding that life-sustaining treatment can be withheld or withdrawn if the net burdens of the patient's life with treatment clearly and markedly outweigh the benefits of life and when administering life-sustaining treatment would be inhumane because of recurring, unavoidable, and severe pain).

offer a workable solution to the problem.

The dual-option approach dictates that one criterion be used for one type of patient and a different criterion for a second type of patient. Patients who clearly fall into the substituted judgment category are ones who gave clear, comprehensive (preferably written) statements of their treatment preferences for a specific set of diagnostic, prognostic, and life style circumstances prior to encountering such circumstances. In addition, they reaffirmed those preferences when the particular situation developed. Further, patients falling into the substituted judgment category made both statements of preference while fully informed, with no hint of duress, at a time when they were indisputably competent. On the other hand, patients who clearly fall into the best interests category are unable to give any indication of their wishes at the time and have given no prior indication of beliefs, values, or preferences through direct statements or life style choices.

Obviously, most patients present themselves somewhere between these two extremes. As a result, placing a patient into one category or the other, or even within one of the three *Conroy* categories, is often an arbitrary decision, difficult to justify when the consequence is so fundamental to the right to affect one's own medical treatment.

Most often those we label as incompetent come to us with histories within which we can recognize meaningful value clusters. Exceptional cases exist involving infants or persons who have had such severe mental deficiencies throughout their lives that nothing can be identified that approaches the valuing of a centered self.⁶¹ In those rare cases in which we have no clues to patient preference, substituted judgment may look like an objective process. With no evidence to the contrary we assume this patient would want what a normal, rational person would want. As we shall see below, however, such a process has only the appearance of objectivity.⁶² Aside from such special cases, decisions should take into account any evidence available concerning the beliefs, values, and priorities of the unique individual.

Those who work with handicapped persons sometimes refer to those of us without serious handicaps as the "temporarily able bodied." In the same sense, people we consider competent are temporarily competent. We have all been children and thus legally incompetent. Many of us will be considered incompetent for certain purposes near the end of life. Between these phases is a host of physical, mental, and social factors that may render each of us incompetent at one time or another.

61. Children constitute another unique class of individuals in that they have never been legally competent to make decisions about medical treatment.

62. See *infra* text accompanying notes 75-96.

In that vast majority of cases which involve persons with some history of competence, when consent is required of a third party, the third party should try to extend that person's right to self-determination through the time of incompetence.

If we view third-party decisions in the context of acting out of respect for the incompetent patient, the narrowness of any objective best interests test becomes clear. Justice Stanton, in *In re Visbeck*,⁶³ offered a criticism of the *Conroy* "objective" tests⁶⁴ that illustrates the problem. Justice Stanton states, very straightforwardly, "I must say that I think that rule [objective test] is wrong because it manifests a much too limited view of what is at stake in these cases."⁶⁵ Stanton urges that such quality of life considerations as losing mental capacity, being totally dependent on others, and being deprived of all privacy be considered.⁶⁶ Using these quality of life standards clearly involves a substituted judgment: Responsible people who believe these factors should be considered "are looking at the matter from the viewpoint of the patient herself. They are thinking about whether the patient's life has meaning for the patient herself, whether it has become impossibly burdensome to the patient herself."⁶⁷

The *Conroy* court required the pain standard because it was looking for some way to make these decisions that could be based on objective data. In its desire to limit the grounds for decision making to something that can be measured, such as physical pain, the *Conroy* court reduced a human being to a biological response system. An appropriate response to the predicament of sick and damaged human beings does not simply measure the severity of pain, but understands suffering in a more comprehensive way and looks to the desires of the patient to find the best way to cope with such suffering. For the incompetent patient, indications of those desires can include prior expressions of preference, even advance written directives. The patterns of patients' lives provide additional information about their values, goals, beliefs, and lifestyle preferences. These decisions should not be thought of as falling in line with some objective, reasonable standard. Instead, we should recognize that subjective factors will influence each decision made by a third party for an incompetent patient.⁶⁸

63. 210 N.J. Super. 527, 510 A.2d 125 (1986).

64. See *supra* notes 58-60 and accompanying text.

65. *Visbeck*, 210 N.J. Super. at 539, 510 A.2d at 131.

66. *Id.*

67. *Id.* at 540, 510 A.2d at 132.

68. As Richard Zaner has observed: "Every case uniquely evokes prominent modalities of feeling. Emotion, passion, striving, wanting . . . all are in many modalities invariably found as texturing every case of distress or damage." Zaner, *Is "Ethicist" Anything to Call a Philosopher?*, 7 HUM. STUD. 71, 83 (1984) (emphasis in original). All too often feelings in a medical context "are

Attempts to ground third-party consent decisions in a substituted judgment model are not without their critics. The New Jersey court in *Conroy*, for example, concluded that "in the absence of adequate proof of the patient's wishes, it is naive to pretend that the right to self-determination serves as the basis for substituted decision-making."⁶⁹ Robert Destro picks up on this theme, expressing his concern that once privacy and self-determination rationales are used to permit third parties to exercise the rights of the mentally disabled, the decisions are reduced to a functional analysis, creating "an open invitation to the making of legal policy which is based on precisely the 'irrational prejudice against the mentally retarded'" which the Supreme Court condemned in the *Cleburne Living Center* case.⁷⁰

Other commentators have noted problems with substituted judgment decisions because the decisions require the decision makers to construct a patient's self without any meaningful background information. These commentators argue that such a construct conceals the "vacuum of subjective intentionality."⁷¹ Ultimately, they assert, substituted judgment simply objectifies the standard of the patient which is reconstructed by the values of the decision makers.⁷²

The response to such charges is fairly straightforward. Substituted judgment does not involve making decisions without background information. To the extent the standard is used to hide a vacuum of intentionality, it is used wrongly. The purpose of the construct is to avoid an objectified standard, to reject the too easy reliance on the values of surrogate decision makers.

The strength of the substituted judgment standard lies precisely in the help it gives us in avoiding the dangers identified by the *Conroy* court and others. The point is, of course, that some third party must make these decisions, lest the incompetent be denied any right to treatment, and the questions are which party and on what grounds.

One clue about making substituted judgments lies in what Richard Zaner calls affiliative feeling. He explains that effective clinical thinking requires that the clinician appreciate the patient's experiences and feel-

apparently deliberately ignored as extraneous to the problems of medical management." *Id.* at 86.

69. *Conroy*, 98 N.J. at 364, 486 A.2d. at 1231.

70. Destro, *Quality-of-Life Ethics and Constitutional Jurisprudence: The Demise of Natural Rights and Equal Protection for the Disabled and Incompetent*, 2 J. CONTEMP. HEALTH L. & POL'Y 71, 115 (1986) (quoting *City of Cleburne v. Cleburne Living Center, Inc.*, 473 U.S. 432, 450 (1985)).

71. Tancredi & Weisstub, *supra* note 14, at 107.

72. *Id.* In the same vein, Walter Weber has urged that the substituted judgment standard be rejected as a "dangerous sham." Weber, *Substituted Judgment Doctrine: A Critical Analysis*, 1 ISSUES L. & MED. 131, 153 (1985).

ings, and understand their significance to the patient.⁷³ Zaner's point is that the patient's subjective life is not inaccessible to others. While he is not directing his comments to incompetent patients, and is urging clinicians actively to elicit patient responses repeatedly until the clinician actually almost feels the patient's pain or symptoms,⁷⁴ the same concern should apply to incompetent patients. The mode of discovery may be more varied and imaginative with those who are unable clearly to voice their needs and wishes, but the goal is the same: do not take patients for granted. Do not assume any patient fits into a standard mold. Strive to understand each patient's individuality, to empathize with the patient's suffering and distress, and then to act on that understanding.

B. *The Fallacy of Best Interests*

The best interests criterion requires that the surrogate decision maker use an objective assessment of what will benefit the incompetent patient.⁷⁵ Such an objective best interests standard does not exist. It is an illusion, fostered by courts and medical providers. It is not surprising that courts and physicians would seek to rely on such a standard, in the same way that it is not surprising that judges are drawn to other formalistic modes of reasoning. A judicial decision that rests on an impartial application of an objective value premise appears to carry more authority than a decision in which the judge openly admits to choosing one opinion over another. In any dispute in which a judge chooses a "best interests" option over others, however, the judge is accepting one opinion about the most appropriate care for a patient over a differing opinion.

The best interests standard may be appropriate in the context of property dispositions because the decision concerns items which are measured by monetary value.⁷⁶ Indeed, the best interests standard originated in the context of resolving family disputes, controlling incompetent persons' property, and authorizing gifts from the estates of incompetent persons.⁷⁷ In the context of medical treatment decisions, however, the best interests of the patient is "an evasive and almost en-

73. R. ZANER, *supra* note 37, at 318.

74. *Id.* at 316.

75. PRESIDENT'S COMM'N, *supra* note 1, at 179-81.

76. Marzen, *Medical Decision Making for the Incompetent Person: A Comprehensive Approach*, 1 ISSUES L. & MED. 293, 308 (1986).

77. PRESIDENT'S COMM'N, *supra* note 1, at 177. The substituted judgment standard originated in this same context but, as is argued above, this standard is much more adaptable to the patient care setting.

tirely vacuous expression.”⁷⁸

An analysis of the language judges have used in such cases is instructive. Consider the reasoning of the *Beth Israel*⁷⁹ court in discussing how to decide whether treatment should be withheld from an incompetent patient: “Clearly, some objective standards must be employed. Otherwise, these matters will turn merely on the subjective attitudes or personal beliefs of those making the decision. The danger in that is obvious.”⁸⁰ The court refers to *Conroy* and *Rivers v. Katz* for specific guidance about how such decisions should be made. The court also looks to the New York Mental Hygiene Law section 80⁸¹ for a definition of “best interests”:

“[P]romoting personal well-being by the assessment of the risks, benefits and alternatives to the patient of a proposed major medical treatment taking into account factors including the relief of suffering, the preservation or restoration of functioning, improvement in the quality of the patient’s life with and without the proposed major medical treatment and consistency with personal beliefs and values known to be held by the patient.”⁸²

However, the court then says no procedure should be withheld if doing so would conflict with the patient’s prior wishes, or would be inconsistent with the patient’s “character or beliefs.”⁸³ Further, the *Beth Israel* court stated, “Lastly, the focus must always be on attempting to ascertain what is or would be the particular patient’s choice in the matter. . . .”⁸⁴

The list of items suggested for consideration in contemplating what the particular patient’s choice would be includes such matters as the patient’s views on life-prolonging measures, the quality of the patient’s life, the patient’s religious or ethical views, and the views of those close to the patient.⁸⁵ The *Beth Israel* court states that an objective best interests standard must be used, but the content given to that standard—the patient’s values, beliefs, character, and views on life-prolonging measures, in short, a focus on what would be the particular patient’s choice—speaks to an effort to make the decision the patient would have made, if competent. This approach, as the reader readily will recognize, is a substituted judgment analysis, not a best interests

78. Marzen, *supra* note 76, at 309.

79. *In re Beth Israel Medical Center*, 136 Misc. 2d 931, 519 N.Y.S.2d 511 (Sup. Ct. 1987).

80. *Id.* at 938, 519 N.Y.S.2d at 516.

81. *Id.* at 938, 519 N.Y.S.2d at 516 (citing *Rivers v. Katz*, 67 N.Y.2d 485, 495 N.E.2d 337, 504 N.Y.S.2d 74 (1986); *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985); N.Y. MENTAL HYG. LAW § 80 (McKinney 1988)).

82. *Id.* at 938-39, 519 N.Y.S.2d at 516 (quoting N.Y. MENTAL HYG. LAW § 80.03(d) (McKinney 1988)).

83. *Id.* at 939, 519 N.Y.S.2d at 517.

84. *Id.* at 940, 519 N.Y.S.2d at 517.

85. *See id.*

analysis.

The certitude that accompanies judicial handling of a best interests approach is probably rooted in the manner in which health care professionals and commentators have approached the subject. Thomas J. O'Donnell has written about the ethical concepts of consent, for example, but sees this approach as a problem only for researchers: "It is because procedures in the therapeutic context look solely to the good of the individual patient that legitimate limitations of informed consent (in the sense of the fully informed consent of the actual patient) present no great problem."⁸⁶ The implication of this approach is clear: as long as doctors are doing what they think is best for patients, they do not have to pay attention to the patients' desires.

The way best interests is used often implies that some objective, factual determination by a third party of a person's best interests is possible. Such a determination often entails a narrow medical view of a person's interests.

[P]hysicians are taught to search for the best treatment for a given problem and to recommend that treatment to patients exhibiting that problem—indeed, to attempt to convince the patients to accept the treatment if the patients exhibit any resistance to the recommendation. And, for a physician, the "best" treatment is almost always defined in technical medical terms—that treatment most likely to alleviate a patient's illness—rather than in terms of a patient's personal preferences. . . .⁸⁷

The language of "medical necessity" is sometimes used to mask the value judgments being made. The hospital administration in *In re Estate of Dorone*⁸⁸ petitioned for authority to administer blood during an operation, "if in the opinion of the surgeon it were to become *medically necessary* to do so."⁸⁹ The court appointed the hospital administration as temporary guardian to consent "if necessary,"⁹⁰ ruling that "nothing less than a fully conscious contemporaneous decision *by the patient* will be sufficient to override evidence of medical necessity."⁹¹ The question is, of course, necessary for what? The answer is necessary to save a life. The value choice being made is that living should take priority over adherence to religious beliefs—a priority routinely rejected by many Jehovah's Witnesses. This particular case is complicated by the emergency nature of the situation, at least when the first authorization was sought. A second "emergency" authorization was sought two days later when a blood clot developed, illustrating the often voiced concern that

86. O'Donnell, *Ethical Concepts of Consent*, in *MEDICAL, MORAL AND LEGAL ISSUES IN MENTAL HEALTH CARE*, *supra* note 17, at 1.

87. LIDZ & MEISEL, *supra* note 17, at 322.

88. 517 Pa. 3, 534 A.2d 452 (1987).

89. *Id.* at 7, 534 A.2d at 454 (emphasis added).

90. *Id.*

91. *Id.* at 9, 534 A.2d at 455 (emphasis in original).

physicians wait until emergencies develop in order to legitimize their taking actions that are contrary to their patients' wishes.⁹²

Decisions about medical treatment are inherently subjective and cannot be separated from the values and preferences of the decision maker. If the values and preferences being used are not those of the patient, the decisions will be colored by the personal eccentricities of the decision maker. Howard Brody has observed that neonatologists, in making arguments about what treatments were appropriate for newborns, based their arguments on personal opinions. Consequently, Brody found the phrase "the infant's best interests" useless in this context.⁹³ Best interests simply cannot function as an objective criterion to yield certain answers to these complex problems.

All treatment decisions, whether made by a patient or a physician, are "tainted by idiosyncrasy."⁹⁴ Weighing the risks and benefits inherent in a decision to undergo or to refuse treatment is a value laden process. In the case of physicians, such factors as the physicians' educational background and the psychological and emotional effects of their personal experiences may influence the balance.⁹⁵ Ignoring the subjective elements that shape every physician's judgment is to imbue medical practice with a scientific aura that is foreign to the physicians who insist the medicine they practice is an art.

The objective view of medical decisions is undermined by studies that show wide variations in practice among similar cultures, or even within the same country.⁹⁶ Medical practices are strongly influenced by cultural values, by norms of local practice, and apparently by such factors as patients' marital status and possession of private medical insurance. What is medically indicated or medically required is not an issue of factual determination by uninvolved medical personnel. Best interests is a matter of one person's opinion about what is best. And if treatment decisions are going to be based on someone's value influenced opinion, should it not be the patient's opinion? That is what substituted judgment is all about.

When a substitute decision maker must be used, as in the case of incompetent patients, every effort must be made to apply the patient's values and concerns. A broader, holistic view of an individual's interests—physical, psychological, social, financial, and spiritual—subsumes

92. See *id.* at 7-8, 534 A.2d at 454-55.

93. See Brody, *In the Best Interests of . . .*, 18 HASTINGS CENTER REP., Dec. 1988, at 37, 38.

94. Clayton, *From Rogers to Rivers: The Rights of the Mentally Ill to Refuse Medication*, 13 AM. J.L. & MED. 7, 19 (1987).

95. *Id.*

96. See, e.g., L. PAYER, *MEDICINE AND CULTURE: VARIETIES OF TREATMENT IN THE UNITED STATES, ENGLAND, WEST GERMANY, AND FRANCE* (1988).

a scientific, medically indicated view of best interests into a substituted judgment perspective. Only an effort to stand in that patient's shoes will begin to reveal the totality of the patient's interests.

IV. INFORMED CONSENT AS INDIVIDUALIZED TREATMENT

The model of informed consent that emerges from this discussion is very "this patient" oriented. While the emphasis of this Essay has been on the implications of such an approach for standards of third-party consent for incompetent patients, this approach also implies certain criteria for evaluating the adequacy of disclosure⁹⁷ and the validity and voluntariness of a patient's consent. This model of informed consent cannot be imposed into the physician-patient relationship by courts or critics. Its promise can be realized only as those involved on both sides of conversations about treatment incorporate this view of the roles of physicians and patients into the clinical setting. Taking this approach seriously may well call for a recasting of the relationship between doctor and patient.⁹⁸

Underlying this approach is an image of a covenant between doctor and patient. This covenant model contrasts with the traditional medical model. The medical model can increase the distance between doctor and patient, emphasizing the superior position of the healer, while the covenant model can close that gap, building a sense of community between the two. The first concern of the medical model is that persons be healed, while the covenant model is first concerned that persons be treated with respect. The medical model views informed consent as a

97. Judicial opinions about the standard by which to judge the adequacy of disclosure have moved from the "reasonable medical practitioner" model, *e.g.*, *Natanson v. Kline*, 186 Kan. 393, 409, 350 P.2d 1093, 1106 (1960), to the "reasonable" person as patient standard, *e.g.*, *Canterhury v. Spence*, 464 F.2d 772, 791 (D.C. Cir.), *cert. denied*, 409 U.S. 1064 (1972); *Cobbs v. Grant*, 8 Cal. 3d 229, 245, 502 P.2d 1, 11-12, 104 Cal. Rptr. 505, 515-16 (1972). Some courts have focused more recently on the particular patient receiving the information. *See McPherson v. Ellis*, 305 N.C. 266, 287 S.E.2d 892 (1982); *Scott v. Bradford*, 606 P.2d 554 (Okla. 1979).

98. As one commentator has stated:

A superficial regard for consent would tend to argue that patient self-determination is important, and that the consent mechanism is simply another instrument by which a patient's rights or individual liberties are enhanced. But to interpret consent in this way is to succumb to a legalistic view of the transaction and reduce the process to a piece of paper which the patient signs. Valid consent, on the other hand, is more appropriately conceived as the *intention* of doctor and patient to be to each other persons, to establish a consensual therapeutic relationship, to form a healing alliance. The consent document, together with all that it reflects, is symbolic of this intention.

H. SMITH & L. CHURCHILL, *PROFESSIONAL ETHICS AND PRIMARY CARE MEDICINE* 63 (1986) (emphasis in original). Smith and Churchill point out that such a therapeutic alliance entails *mutual* respect: "[D]octors are not free to define the good for patients without their participation, but neither are patients free to impose upon physicians notions of the good which are foreign to the physician's personal values and professional standards." *Id.* at 58.

step that must be taken in order to produce the most beneficial result. The covenant model views informed consent as a step that must be taken because we respect the autonomy of each person.

The medical model understands that patient autonomy is a value to be protected but is more willing to balance that value with the medical good that can be achieved. A medical model posits third parties making decisions for incompetent patients in the patients' best interests. Doctors are expected to provide adequate information for these decisions, based on some notion of customary professional standards or a notion of the rational patient.

The covenant model views patient autonomy as claiming priority over calculations of medical benefit. Consent is informed only when the adequate information is provided so that the particular decision maker can make an appropriate decision. Third-party decision makers should focus on the personality of the particular incompetent patient rather than on statements of what is medically indicated.

Even if incompetent, a person still has beliefs, values, and preferences. The patient is a person with rituals of meaning, symbols of interpretation, and some developed sense of self. Even for persons incompetent to exercise autonomous judgment, these personal attributes remain important. The whole purpose behind obtaining consent from someone else on behalf of an incompetent person, the very reason we do not simply give the researcher or the physician unfettered discretion to do what is best, is to attempt to make the elements that comprise a unique personality—the patient's desires, needs, priorities, and beliefs—as close to controlling in the decision as they would be if that person were competent.

To return to our three questions: First, we value informed consent because of our respect for persons and personal autonomy, our belief that each person should be allowed to determine what happens to his or her body. Second, in this context, the incompetence exception to a requirement of informed consent means that a particular individual is not capable of exercising that kind of autonomous judgment in a specific setting. Third, when consent is sought from a third party, that person is responsible to act consistently with the beliefs and values of the incompetent person. Substituted judgment is the guideline that best recognizes this fundamental grounding of informed consent and that affords the best opportunity for preserving the integrity of individuals when they are not competent to make certain decisions for themselves.

I conclude this Essay with one final comment. Just as Justice Cardozo's opinion in *Schloendorff* gave voice to an uneasiness about a model of the physician-patient relationship that did not protect pa-

tients from unauthorized bodily invasion,⁹⁹ the Nuremberg Trials brought us face to face with the fundamental flaws of a system in which the medical attendant dictates what will be done to the patient.¹⁰⁰ Power has been reallocated. It is no longer acceptable to conceive of a patient as being in the hands of a physician who is responsible for acting in a way that will produce the greatest benefit. The model of a covenant, with physician and patient exercising their independent judgment and mutually agreeing upon a course of action, is more in keeping with our conviction that patients, too, are to be respected as persons. Indeed, the physician is authorized to act by the patient. A medical school may give persons certain knowledge and skills and degrees, but those persons are not physicians until someone called a patient grants them that role.

99. *See supra* notes 11-13 and accompanying text.

100. *See supra* note 10 and accompanying text.