

Reasoned Compassion in a More Humane Forum: A Proposal to Use ADR to Resolve Medical Treatment Decisions

I. INTRODUCTION

A 1990 Gallup poll¹ asked respondents: "If you, yourself, were on life-support systems and there was no hope of recovering, would you like to remain on the life-support system or would you like treatment withheld so that you could end your life?" Eighty-four percent said they would want treatment withheld. Only nine percent of respondents said they would want to be left on the life-support system. Adults "strongly feel that death is preferable to living in permanent pain, or on life-support systems."² Even though seventy-five percent of Americans support the concept of a living will,³ only about twenty percent have actually written one.⁴ And for those who have executed a living will, there is no automatic guarantee that the courts will honor its provisions.⁵ "[T]he goal of private, personal decision making about the manner and timing of one's death often exists more as a matter of abstract legal principle than as a practical reality."⁶

The issue is even more complex when the life in question is that of an incompetent person, with either an inadequate or nonexistent expression of prior wishes. The resulting conflict between the technological ability to sustain life and the possibility of a valid, but unsubstantiated, desire not to be maintained by extraordinary measures is a matter of increasing deliberation within the hospitals, nursing homes, and

1. MIRROR OF AMERICA: FEAR OF DYING, GALLUP POLL (Gallup Poll News Serv., Jan 6, 1990) [hereinafter GALLUP POLL]. The Gallup Poll has conducted surveys of the American public on issues of life and death since 1947. The results published were based on telephone interviews with a random-selected national sample of 1018 adults, 18 and older, conducted November 15-16, 1990. The Gallup Poll states with 95% confidence that the error attributable to sampling and other random effects could be plus or minus 3 percentage points.

2. *Id.* at 3.

3. "A living will is a document which governs the withholding or withdrawal of life-sustaining treatment from an individual in the event of an incurable or irreversible condition that will cause death within a relatively short time, and when such person is no longer able to make decisions regarding his or her medical treatment. Living wills are permitted by statute in most states." BLACK'S LAW DICTIONARY 1599 (6th ed. 1990).

4. GALLUP POLL, *supra* note 1, at 3.

5. *Court Decisions: Evans v. Bellevue Hospital*, 198 N.Y. L.J. 11 (July, 28, 1987).

6. Linda C. Fentiman, *Privacy and Personhood Revisited: A New Framework for Substitute Decision-Making for the Incompetent, Incurably Ill Adult*, 57 GEO. WASH. L. REV. 801, 805 (1988).

courtrooms of this country.⁷

The decision to withdraw life-support systems in order to allow a critically ill patient to die is a deeply personal one, yet the concern over the implication of such actions necessarily draws outsiders into what is already a painful decision for the patient's family. The legal community theorizes about whether such actions are within the confines of the law; the medical community ponders the ethics of terminating a life; and the religious community debates the implications of a person's afterlife.⁸

Resulting legal-medical-religious colloquies theorize whether mere biological existence should be protected, or whether a finer distinction can be drawn between biological existence and what is uniquely human and therefore of higher value. Attempts to resolve this intensely personal and private dilemma range from the blatantly subjective to the ostensibly objective, with decision making authority generally resting within the medical and legal communities.⁹ All too often, families are relegated to advisor or consultant roles, saddled with the burden of proving with "clear and convincing evidence"¹⁰ a patient's wish for the cessation of medical treatment.¹¹

Today, an individual's ability to direct future medical decisions in the event of her incompetency, and her family's or loved ones' power to make those decisions for her, in the absence of clear and convincing evidence, varies widely from state to state. If a car crashed on the George Washington Bridge, which spans the river separating New Jersey and New York, and a passenger were critically injured and rendered incompetent, her self-determination and her family's or loved ones' authority to control

7. "[T]he radical advances in life sustaining equipment and procedures developed by the medical profession in the last twenty years have taxed the common law process in ways that it has never been tested before." Sol Wachtler, *Life and Death Decisions: The Patient's Choice*, 205 N.Y. L.J. 39 (Jan. 23, 1991).

8. Michele Yuen, Note, *Letting Daddy Die: Adopting New Standards for Surrogate Decisionmaking*, 39 UCLA L. REV. 581, 582 (1992).

9. "In the tradition of individual autonomy, the choice has ostensibly been left to each individual patient but has usually, in fact, been made by doctors applying 'medical standards.' Physicians have assumed the responsibility, leaving patients and their surrogates to go through courts to assert their right to decide." George J. Alexander, *Death by Directive*, 28 SANTA CLARA L. REV. 67, 67 (1988).

10. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 279 (1990).

11. Nancy K. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 390 (1988).

her fate would be affected by which state provided the ambulance.¹² "It seems grossly unfair that a person's rights should grow and shrink according to the fortuity of the state in which she may happen to become ill."¹³

Case law is replete with opinions that describe the struggles of families and friends to compel the court to terminate or not to terminate an incompetent person's life-sustaining medical treatment.¹⁴ This process, which subjects families and loved ones to lengthy and complex judicial procedures, tremendous financial cost, emotional expenditure, and public exposure and scrutiny¹⁵ -- during the most intimate and private of decisions -- must be examined in a new light.

This Comment suggests that courts and legislatures review the standards of proof and the mechanisms for cessation of medical treatment decisions, recognizing that evidential mandates of objectivity and "clear and convincing evidence" often place too great a burden of proof on family members -- arguably the most informed decision makers in these personal and private situations.¹⁶ This Comment also proposes that family members, other close friends, or the designated proxy have a rebuttable presumption in favor of their decisions,¹⁷ with parties

12. Yuen, *supra* note 8, at 617 (citing Gibbs, *Love and Let Die*, TIME, Mar. 19, 1990, at 62, 68).

13. *Id.* at 617.

14. See *Cruzan*, 497 U.S. at 261; *Gray by Gray v. Romero*, 697 F. Supp. 580 (D. R.I. 1988); *In re Lawrence*, 579 N.E. 2d 32 (Ind. 1991); *Guardianship of Doe*, 583 N.E.2d 1263 (Mass. 1992); *In re Busalacchi*, No. 59582, 1991 WL 26851 (Mo. App. Mar. 5, 1991), *reh'g and/or transfer denied*, (Mar. 26, 1991), *cause ordered transferred to Mo. S. Ct.* (Apr. 15, 1991), *appeal dismissed* No. 73677 (Mo. Jan. 26, 1993); *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

15. Mr. and Mrs. William Lawrance, parents of Sue Ann Lawrance, a brain-damaged 42 year-old woman, were thrown into the middle of a "right-to-die" controversy when they requested permission to cease Ms. Lawrance's feedings in 1991. She had been disabled from a brain tumor since 1958, and had been in a persistent vegetative state, with no hope of recovery, since 1987 when she fell out of a wheelchair. A Christian Advocacy group for the disabled intervened and secured a court-appointed guardian for Ms. Lawrance and pursued an appeal. The case was to be heard by the state Supreme Court, but Ms. Lawrance died before the court could rule. Her parents and brother were emotionally drained from the experience of making the decision to request termination, as well as the battle to justify their decision. Despite Ms. Lawrance's death, her family asked the high court to examine the case, saying a court decision could prevent other families from having to fight the same battles they had to face. "I would hope it would allow them some freedom of choice to be able to direct their own care," said Mrs. Lawrance. *Right-to-Die Figure Sue Ann Lawrance*, CHI. TRIB., July 21, 1991, at Zone C, 6. See generally *supra* note 14.

16. Rhoden, *supra* note 11, at 438.

17. *Id.* at 437.

representing medical or state interests bearing the burden of proof that a decision is not in the patient's best interests,¹⁸ or that the family member is operating with a selfish motive.¹⁹ Furthermore, this Comment contends that alternative dispute mechanisms should create the forum for challenging family, close friend, or designated proxy decisions regarding cessation of medical treatment.²⁰ A mediation mechanism, followed by mandatory non-binding arbitration prior to any adjudication would rehumanize these situations and provide ample opportunity to examine and resolve conflicting interests. Lengthy and expensive adversarial courtroom dramas would thus be relegated to only the most difficult cases.

Part II of this Comment distinguishes between competent, incapacitated, and persistent vegetative patients and describes the changing concepts of death that have resulted from advances in medical technology. Part III examines the historical concept of the family and proposes a substantial broadening of this concept to reflect the current reality of the American family unit. Part IV presents the predominant decisional frameworks currently employed in making cessation of treatment decisions. Part IV also discusses the wisdom of continued judicial and medical support of the presumption that life-sustaining treatment is preferable, regardless of an individual's physical condition. Part V highlights several state approaches to the resolution of cessation of treatment decisions, emphasizing the New York approach. Finally, Part VI proposes a mediation-based, family-centered decision making model.

II. CLASSIFICATION OF PERSONS AS INCOMPETENT OR INCAPACITATED AND CHANGING CONCEPTIONS OF DEATH

A. Competency, Incompetency, and Persistent Vegetative States

1. Competency

Originating from two Greek terms meaning "self" and "rule" or "law" autonomy is the "quality or state of being self-governing . . .

18. "The physician should be required to prove the unreasonableness of the family choice." *Id.* at 441.

19. General fears include that the family member is anxious to rid the family of the pain of watching a loved one die, or that a family member is interested in conserving possible financial inheritances by eliminating prolonged medical expenses.

20. See Yuen, *supra* note 8; see also Fentiman, *supra* note 6.

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[possessing] self directing freedom and especially moral independence."²¹ "[I]n moral philosophy personal autonomy has come to refer to . . . personal rule of the self by adequate understanding while remaining free from controlling interferences by others and from personal limitations that prevent choice."²²

An autonomous person is considered to be competent and to the extent allowed by law, in charge of his own destiny. Autonomy regarding medical treatment decisions has been supported by the common law for over a century and was expressed by the United States Supreme Court in *Union Pacific Railway Co. v. Botsford* in 1891.²³

[No] right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint, or interference of others, unless by clear and unquestionable authority of law.²⁴

Justice Cardozo, while sitting on the New York Court of Appeals, further clarified the issue when he wrote: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his consent commits an assault, for which he is liable in damages."²⁵

In sum, whether supported by federal constitutional arguments of due process,²⁶ liberty,²⁷ or the right to privacy;²⁸ state constitutional

21. WEBSTER'S NINTH NEW COLLEGIATE DICTIONARY 118 (1990).

22. James Bopp, Jr. & Daniel Avila, *The Siren's Lure of Invented Consent: A Critique of Autonomy-based Surrogate Decisionmaking for Legally-Incapacitated Older Persons*, 42 HASTINGS L. J. 779, 798 nn.106, 108 (1991) (citing R. FADEN & T. BEAUCHAMP, A HISTORY AND THEORY OF INFORMED CONSENT 8 (1986)).

23. Martha N. Mullins, Note, *The Need for Guidance in Decisionmaking for Terminally Ill Incompetents: Is the Ohio Legislature in a "Persistent Vegetative State?"*, 17 OHIO N. U. L. REV. 827, 829 (1991).

24. *Union Pacific Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891).

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

26. "The majority opinion in *Cruzan* left open the question of whether the due process clauses establish a right to refuse lifesaving medical treatment. Chief Justice Rehnquist only assumed that such a right existed for the purpose of deciding the case." JOHN E. NOWAK & RONALD D. ROTUNDA, CONSTITUTIONAL LAW 814 (4th ed. 1991).

27. "Although many state courts have held that a right to refuse treatment is encompassed by a generalized constitutional right of privacy, we have never so held. We believe this issue is more properly analyzed in terms of a Fourteenth Amendment liberty interest." *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 279 n.7 (1990).

guarantees of privacy;²⁹ or common law rights of informed consent,³⁰

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28. Prior to *Cruzan*, numerous state courts [had] reasoned from Supreme Court decisions that the right to privacy is broad enough to grant an individual the right to chart his or her own medical treatment plan. We agree with our sister states. The right to refuse medical treatment is a personal right sufficiently "fundamental" or "implicit in the concept of ordered liberty" to fall within the constitutionally protected zone of privacy contemplated by the Supreme Court.

In re Rasmussen, 741 P.2d 674, 681-82 (Ariz. 1987) *partially overruled by Cruzan v. Director, Mo. Dep't. of Health*; *see, e.g., Bouvia v. Superior Court*, 225 Cal. Rptr. 297 (1986); *Foody v. Manchester Memorial Hosp.*, 482 A.2d 713 (Conn. Supp. 1984); *Severns v. Wilmington Medical Ctr., Inc.*, 421 A.2d 1334 (Del. 1980); *Satz v. Perlmutter*, 362 So.2d 160 (Fla. Dist. Ct. App. 1978), *aff'd* 379 So.2d 359 (Fla. 1980); *Brophy v. New England Sinai Hospital, Inc.*, 497 N.E.2d 626 (Mass. 1986); *In re Spring*, 405 N.E.2d 115 (Mass. 1980); *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417 (Mass. 1977); *In re Quinlan*, 355 A.2d 647 (N.J. 1976), *cert. denied sub nom.*, *Garger v. New Jersey*, 429 U.S. 922 (1976); *In re Farrell*, 514 A.2d 1342 (N.J. Super. Ct. Ch. Div. 1986); *Leach v. Akron General Medical Ctr.*, 426 N.E.2d 809 (Ohio Misc. 1980); *In re of Welfare of Colyer*, 660 P.2d 738 (Wash. 1983).

29. There are at least 10 states that have privacy provisions in their state constitutions, but only a few have used these provisions to decide right-to-die cases. Thomas C. Marks & Rebecca C. Morgan, *The Right of the Dying to Refuse Life Prolonging Medical Procedures: The Evolving Importance of State Constitutions*, 18 OHIO N. U. L. REV. 467, 497 (1992). A Florida Attorney General opinion indicated that § 23, Art. I, State Const. had been construed by *Corbett v. D'Alessandro*, 487 So.2d 368 (2 D.C.A. Fla., 1986) as creating a constitutional right to privacy that included the right to withdraw nutrition and hydration. 90-98 Fla. Op. Att'y Gen. 300 (1990). The state of Arizona was even more explicit:

Unlike the federal constitution, the Arizona Constitution expressly provides for a right to privacy. Article 2 of the Arizona Constitution provides: § 8. Right to privacy Section 8. No person shall be disturbed in his private affairs, or his home invaded, without authority of law. Although Arizona Constitution article 2, § 8 has been invoked most often in a Fourth Amendment context, we see no reason not to interpret "privacy" or "private affairs" as encompassing an individual's right to refuse medical treatment. An individual's right to chart his or her own plan of medical treatment deserves as much, if not more, constitutionally-protected privacy than does an individual's home or automobile.

In re Rasmussen, 741 P.2d at 682.

30. Protection of this common-law right to be free from nonconsensual bodily invasions is at the heart of what is known today as the doctrine of informed consent. Under this doctrine, the patient must have the capacity to reason and make judgments, the decision must be made voluntarily and without coercion, and the patient must have a clear understanding of the risks and benefits of the proposed treatment alternatives or nontreatment, along with a full understanding of the

and self-determination,³¹ a competent person has the power to determine the care of her person, and by carefully utilizing this power, she can guide her treatment even after she becomes incompetent. All too often, however, this power lies unused.

2. *Incompetency and the Persistent Vegetative State*

A person unable to make personal medical treatment decisions is generally considered to be either incompetent or incapacitated. It is important to distinguish individuals once competent from those never competent, because the former presumably had opportunities to communicate in writing, execute relevant legal documents, such as living wills³² or advance directives,³³ or express orally to other people their wishes in the event of incapacitating illness.³⁴ Those individuals who have never been competent can only have their personal 'wishes' subjectively determined for them by family members, medical staff, state human services representatives, or the courts.

This Comment is concerned primarily with the category of

nature of the disease and the prognosis. . . . We hold that the doctrine of informed consent – a doctrine borne of the common-law right to be free from nonconsensual physical invasions – permits an individual to refuse medical treatment.

In re Rasmussen, 741 P.2d at 683.

31. Other courts also have held that the right to refuse medical treatment is both a constitutional right and a common-law right. *See, e.g., Foody*, 482 A.2d at 717-18; *Brophy*, 497 N.E.2d at 633; *Farrell*, 514 A.2d at 1344; *Colyer*, 660 P.2d at 741-43; *cf. In re Rasmussen*, 741 P.2d at 683; *In re Torres*, 357 N.W.2d 332, 339-40 (Minn. 1984) (recognizing constitutional and common-law rights but premising court holding on constitutional and statutory rights); *In re Conroy*, 486 A.2d 1209 (N.J. 1985) (recognizing constitutional right but limiting court holding to application of common-law right); *In re Storar*, 420 N.E.2d 70 (N.Y. 1981) (discussing that whether right to refuse medical treatment is guaranteed by the Constitution is a "disputed question" and premising holding on "common-law principles").

32. For a definition of Living Will, see *supra* note 3.

33. "An advance directive is an 'affirmative directive' to medical personnel or other decision-makers specifying certain wishes of a competent person regarding medical treatment, which that person executes in anticipation of future incompetency." Mullins, *supra* note 23, at 836 n.62 (citing Martyn & Jacobs, *Legislating Advance Directives for the Terminally Ill: The Living Will and Durable Power of Attorney*, 63 NEB. L. REV. 779, 786-87 (1984)).

34. Express documents such as living wills or advance directives that are executed according to a state's statutory requirements are generally accepted by the courts as dispositive evidence of a person's choice. These documents can be challenged, however, by medical, state, or family representatives on the issue of competency at the time of execution.

incompetent patients who are permanently unconscious.³⁵ "Most of what makes someone a distinctive individual is lost when the person is unconscious, especially if he or she will always remain so."³⁵

Permanent unconsciousness is also known as a persistent vegetative state (PVS), the neurological condition that occurs post-coma when the autonomic nervous system continues to function after the cognitive functioning of the mind has ceased.³⁷ A persistent vegetative state is a condition in which the patient:

- (a) shows no evidence of verbal or non-verbal communication;
- (b) demonstrates no purposeful movement or motor ability; (c) is unable to interact purposely with stimulation provided by his environment; (d) is unable to provide for his own basic needs; (e) demonstrates all of the above for longer than three months.³⁸

Recurring characteristics of the PVS patient include a loss of participation, observation, and interaction with their environments, and cessation of all voluntary movement and recognizable communication skills. There is generally no capacity for cognitive or sapient functioning.³⁹

Jane Doe,⁴⁰ a thirty-three year old woman who has been profoundly mentally retarded since infancy,⁴¹ exhibits characteristics typical

35. This category includes formerly competent individuals, however, this Comment concerns only those formerly competent individuals who did not previously express their desires. These individuals and those never competent are often treated similarly with respect to judicial involvement in the resolution of their treatment decisions. Their families also experience similar frustrations in attempting to carry out what they feel is the best choice of treatment or non-treatment.

36. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 123 (1983) [hereinafter DECIDING TO FOREGO].

37. Lawrence K. Altman, *When the Mind Dies But the Brain Lives On*, N.Y. TIMES, Nov. 17, 1987, at C3.

38. *Brophy v. New England Sinai Hosp., Inc.*, 497 N.E. 2d 626, 628, n.4 (Mass. 1986) (citing DECIDING TO FOREGO, *supra* note 36, at 174-175)). These facts are consistent with the definition of persistent vegetative state used by the President's Commission. *Id.*

39. DECIDING TO FOREGO, *supra* note 36, at 174-175.

40. Jane Doe is a pseudonym.

41. Ms. Doe's mother discovered her impairments in early infancy. Brief for Appellee/Guardian of the Ward at 5, *Guardianship of Doe*, 583 N.E.2d 1263 (Mass. 1992) (No. 5637).

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of permanently unconscious patients. She suffers from a genetic disorder⁴² that has progressively destroyed her central nervous system,⁴³ and she also suffers from severe brain atrophy, cortical blindness, and cortical deafness.⁴⁴ Ms. Doe's "limbs are rigidly flexed, her joints contracted, her muscles atrophied and her bones extremely brittle. Ms. Doe breathes through a permanent tracheostomy necessitated by the tendency of her tongue to swell and block her airway."⁴⁵ Ms. Doe is mute. She does not respond to any sounds or to touch. She is unable to see, hear, smell, smile, cry, chew, or swallow.⁴⁶ She displays no voluntary action or behavior.⁴⁷

"The patient in a permanent vegetative coma has no hope of recovery and merely lies, trapped in a technological limbo, awaiting the inevitable. As a matter of established fact, such a patient has no health and, in the true sense, no life for the state to protect."⁴⁸

B. Conceptions of Death

Not long ago the realms of life and death were delineated by a bright line. Now this line is blurred by wondrous advances in medical technology – advances that until recent years were only ideas conceivable by such science-fiction visionaries as Jules Verne and H.G. Wells. Medical technology has effectively created a twilight zone of suspended animation where death commences while life, in some form, continues.⁴⁹

At the turn of the century, no one was confused about a determination of death. If a person's heart stopped beating or her lungs

42. Ms. Doe suffers from Canavan's disease. The "salient clinical features [of Canavan's disease] are onset in early infancy, atonia of the neck muscles, hyperextension of the legs and flexion of [the] arms, blindness, severe mental defects and [megaloccephaly]." *Doe*, 583 N.E. 2d at 1266, nn.6-7. Ms. Doe was diagnosed as suffering from Canavan's Disease in 1988 by laboratory tests that were unavailable before 1986. Victims of this disease rarely live past the age of 10 and usually die from some form of infection. There is no possibility that the disease can be arrested or reversed. Appellee/Guardian's Brief at 8, n.1, *Doe*, 583 N.E.2d 1263 (Mass. 1992) (No. 5637).

43. *Doe*, 583 N.E. 2d at 1266, n.7.

44. Appellee/Guardian's Brief at 9, *Doe*, 583 N.E.2d 1263 (Mass. 1992) (no. 5637).

45. *Doe*, 583 N.E.2d at 1267.

46. Appellee/Guardian's Brief at 9, *Doe*, 583 N.E.2d 1263 (Mass. 1992) (no. 5367).

47. *Doe*, 583 N.E. 2d at 1267.

48. *In re Eichner*, 73 A.D. 2d 431, 465 (N.Y. 1980).

49. *In re Rasmussen*, 741 P.2d 674, 674 (Ariz. 1987).

stopped inflating, the body's last bit of air soon escaped in a final sigh -- the body got cold -- the limbs got stiff -- the person was dead.⁵⁰ Only recently has modern technology repelled some of death's traditional indicators. "One can see the effect of new medications and processes in the changes in patterns of death. Contrasting the present with the turn of the century, one notes that communicable diseases have greatly declined as a cause of death while degenerative diseases have become more prominent."⁵¹ The dying are older, more often hospitalized, and more likely to suffer for an extended period from the cause of their death than was previously true.⁵² Gone are the days when we pass away gently into the "night," surrounded by friends and loved ones, comforted in our homes. In 1949, half of all deaths occurred in hospitals, and that percentage has increased about ten percent per decade.⁵³

Due to advances in medical care, it is possible in some circumstances to sustain the body's biological functions for extended periods of time while the patient has no sense of pain or pleasure, fear or joy, love or hate, understanding or appreciation, taste or touch or smell or any other aspect of life's experience, with no realistic possibility of sentient life.⁵⁴

Definitions of death are changing. Where once "cessation of circulatory and respiratory functions"⁵⁵ would suffice, definitions increasingly include reference to functions of the brain or brain stem.⁵⁶ Studies reveal a wide range of attitudes about death, from wanting to hold onto life irrespective of pain and discomfort to wanting death to come quickly once an incurable illness is diagnosed.⁵⁷ "As more individuals assert their right to refuse medical treatment, more frequently do the disciplines of medicine, law, philosophy, technology, and religion collide. This interdisciplinary interplay raises many questions to which no single

50. Death is defined as "the cessation of life; permanent cessations of all vital functions and signs." BLACK'S LAW DICTIONARY 400 (6th ed. 1990).

51. Alexander, *supra* note 9, at 68.

52. *Id.* at 5, 17, 18 (citing DECIDING TO FOREGO, *supra* note 36).

53. *Id.*

54. *Id.*

55. "An individual that has sustained either (1) irreversible cessation of circulatory and respiratory function, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead." BLACK'S LAW DICTIONARY 400 (6th ed. 1990).

56. *Id.*

57. Alexander, *supra* note 9, at 70 (citing DECIDING TO FOREGO, *supra* note 36, at 21-22).

person or profession has all the answers."⁵⁸

III. THE FAMILY UNIT AND ITS SUPERIORITY AS DECISION MAKER

The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the choice of the patient, or his family or legal representative if the patient is incompetent to act in his own behalf, should prevail.⁵⁹

The meaning of the term "family" depends on the field of law in which the word is used, the purpose of its use, and the facts and circumstances of each case.⁶⁰ Its most common meaning refers generally to a group of related persons, especially parents and their children, and immediate kindred.⁶¹ The term "family" connotes "some relationship, blood or otherwise."⁶²

The Supreme Court in *Parham v. J.R.*⁶³ reasoned that the legal concept of family begins with the presumption that "natural bonds of affection lead parents to act in the best interests of their children."⁶⁴ Common law proffers authority for parents to act on behalf of their children and authority for spouses, in certain, cases to act on behalf of their marital partners.⁶⁵ Bonds of affection, intimacy, and trust, however, develop between individuals beyond these narrow categories.

The American family unit of the late twentieth century is greater than the sum of traditional family members. Adults form lifelong friendships stronger than those with siblings; same-sex couples live together as life-partners; heterosexual couples choose to commit yet never marry; extended "families" develop as intergenerational units among related and unrelated individuals; people share living space for economic

58. *In re Rasmussen*, 741 P. 2d 674, 679 (Ariz. 1987).

59. *Id.* at 684.

60. *LeRoux v. Edmundson*, 148 N.W.2d 812, 814 (Minn. 1967), *cited in* BLACK'S, *supra* note 3, at 604.

61. *People v. Hasse*, 291 N.Y.S.2d 53, 55 (1968).

62. *Collins v. Northwest Casualty Co.*, 39 P.2d 986, 989 (Wash. 1935).

63. 442 U.S. 584 (1979).

64. *Id.* at 600.

65. A "spouse, individually and without intervention of the court, without the appointment of a guardian, has such authority [to discontinue life-sustaining treatment] under common law, if necessary." *Guardianship of McInnis*, 584 N.E.2d 1389, 1390 (Ohio 1991).

reasons and confide their innermost thoughts and desires. These and other relationships mandate that "family" should reflect and respect emotional connections, not simply, or solely, kinship or marital union. Some state legislation⁶⁶ and judicial opinions⁶⁷ are beginning to give credence to the importance of relationships beyond the outdated concept of the traditional family. More legal recognition is necessary to bring the courts, hospitals, and state legislators into harmony with today's interpersonal reality.⁶⁸ The term "family" is used throughout this Comment to refer to all individuals who have developed significant relationships with each other. The individual with whom the patient has formed emotional bonds will "treat the patient as a person, rather than a symbol of a cause."⁶⁹

"The most obvious decision makers are those who love us . . . or are obligated to care for and about us . . . family and friends most closely fit these requirements."⁷⁰ Opponents of this position, fearful of the slippery slope of passive euthanasia,⁷¹ contend that family members might have self-serving interests, such as reducing emotional and financial turmoil, that might encourage premature cessation of medical treatment for their loved ones. The possibility exists that a family's claim of a patient's prior wish to "die with dignity" is actually a ploy to hasten the patient's death because of avarice, dislike, or an attempt to put an end to the drain on the family's resources.⁷² However, in the words of Chief Justice Burger, "the statist notion that governmental power should supersede parental authority in all cases because some parents abuse and neglect children is repugnant to American tradition."⁷³ The vast majority of families make medical treatment decisions in their loved ones' best interests; yet their actions are often delayed, restricted, and scrutinized by governmental mechanisms designed to frustrate the few who would abuse

66. N. Y. PUB. HEALTH LAW § 2965 (McKinney 1993), recognizes "a close friend" as a potential decision maker for cardio-pulmonary treatment decisions.

67. *In re Kowalski*, 478 N.W.2d 790 (Minn. 1992) (granting lesbian partner guardianship of physically and mentally handicapped partner after eight years of legal action). Sharon Kowalski had been injured in an automobile accident in 1982. *Id.*

68. Statistics reveal that nearly half of marriages end in divorce. In addition to the many possible constructions of the family outlined above, some divorced persons establish new family units with "her and his children" in one household, yet may never remarry.

69. *In re Jobs*, 529 A.2d 434, 445 (N.J. 1987).

70. Bopp and Avila, *supra* note 22, at 789 n.56 (citing Glover, *A Philosophical Analysis of Substitute Decision-Making: The Case of Ms. Nancy Cruzan*, 5 MIDWEST MED. ETHICS 10 (1989)).

71. *Id.* at 813, nn.190-91.

72. *In re Colyer*, 660 P.2d 738, 747 (Wash. 1983).

73. *Parham v. J.R.*, 442 U.S. 584 (1979).

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such power. Unfortunately, it is the patient and her family on whom the burden of delay must fall.

No potential actor in this drama is free of unconscious or potentially self-serving motives; yet the family is the entity most often criticized. "The physician's aggressive treatment may reflect his own fear of death and dying, his concern with demonstrating professional competence, or his desire to generate a large fee."⁷⁴ Another physician arguing against treatment may reflect his or her personal views about the physician's role in easing suffering or comforting the dying, or reflect the reality of needing another hospital bed for a more hopeful prognosis.⁷⁵

Of judges, medical personnel, and families, the latter category is the most closely associated with the patient and the most familiar with her life, preferences, and fears. Family members and close friends are better able to compare the patient's current degree of participation in life to the former (if different) degree of participation. Families therefore are the best choice for making unwelcome and excruciatingly painful decisions regarding cessation of medical treatment. The problem, however, is that "courts require a higher quantum of justification than is typically available,"⁷⁶ and those most likely to know what the patient would have wanted often base this on intuitive, nonverbal knowledge, which is difficult to prove in a court of law.⁷⁷ These decisions can never realistically be made by a purely logical, analytical test,⁷⁸ despite the court's attempts to impose an analytical framework. "Complete objectivity . . . is neither possible nor desirable, and its absence should not be seen as a problem."⁷⁹

IV. DECISIONAL FRAMEWORKS FOR REQUESTS TO END MEDICAL TREATMENT

The current legal-medical decision making system is founded upon a general tendency to accept the medical presumption for treatment, forcing families to use legal measures to overcome this presumption.⁸⁰

74. Fentiman, *supra* note 6, at 811.

75. *Id.*

76. Rhoden, *supra* note 11, at 390.

77. *Id.* at 391.

78. *Id.* at 439.

79. *Id.* at 440.

80. *Id.* at 379 (citing *In re Conroy* 486 A.2d 1209, 1233 (N.J. 1983)).

Courts have acquiesced to the medical preference for obsessive, aggressive⁸¹ treatment for many terminally ill and persistent vegetative patients, even though "physicians' reactions to terminal or chronic illness reflect a complex interaction of ethical values, medical socialization, the impact of medical technology, the fear of legal liability, and the relative power and authority of physicians and hospitals vis-a-vis patients."⁸²

There appears to be no empirical data proving the inherent superiority of juridical or medical decision making over family members in medical treatment decisions for incompetent persons. Several state constitutions, as noted before,⁸³ have explicitly guaranteed an individual's right to privacy with regard to medical decision making. Case law, however, still contains far too many examples of judicial rationalizing⁸⁴ and state posturing in the name of *parens patriae*.⁸⁵ The presumption against the family and in favor of court-controlled decision making subjugated to the state's interests continues.⁸⁶ The following Section describes the existing range of decision making procedures and indicates how a particular state's constitution can impact the process.⁸⁷

81. Rhoden, *supra* note 11, at 421.

82. *Id.* at 420.

83. For a discussion of state guarantees of privacy, see *supra* note 29.

84. We do not view the judicial resolution of this most difficult and awesome question — whether potentially life-prolonging treatment should be withheld from a person incapable of making his own decision — as constituting a "gratuitous encroachment" on the domain of medical expertise. Rather, such questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this ideal is our responsibility and that of the lower court, and is not to be entrusted to any other group purporting to represent the "morality and conscience of our society," no matter how highly motivated or impressively constituted.

Superintendent of Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 435 (Mass. 1977).

It is important to note that there is no acknowledgment of family interests or participation in the decision making process.

85. The literal meaning of this term is "parent of the country," and refers to the traditional role of the state as sovereign and guardian of persons under legal disability, such as juveniles or the insane. BLACK'S LAW DICTIONARY 1114 (6th ed. 1990).

86. Countervailing state interests are generally founded upon four concerns: 1) the preservation of life, 2) the prevention of suicide, 3) the protection of the interests of innocent third parties, and 4) maintaining the ethical integrity of the medical profession. Deel v. Syracuse Veterans Admin. Medical Ctr., 729 F. Supp. 231, 233-34 (N.D.N.Y. 1990); see *Saikewicz*, 370 N.E.2d at 435.

87. Marks & Morgan, *supra* note 29, at 497.

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A. *Substitute Judgment Standard*

Courts called on to decide cases involving the request to terminate life-sustaining medical treatment for an incompetent or incapacitated patient generally employ a substitute judgment analysis or a best interests analysis. The substitute judgment analysis is one in which:

[T]he judge, after hearing, must try to identify the choice which would be made by the incompetent, taking into account the present and future incompetency of the individual as one of the factors which would necessarily enter into the decision-making process of the competent person.⁸⁸

As established in *In Re Quinlan*,⁸⁹ and further refined in *Superintendent of Belchertown State School v. Saikewicz*,⁹⁰ the substituted judgment decision is a subjective process that rests on two assumptions: (1) the incompetent person shares the same rights as a competent person; and (2) a surrogate may exercise these rights based on a personal judgment of what the patient would have chosen if competent.⁹¹ The substituted judgment doctrine is most useful when prior evidence aids the court in assessing the patient's wishes. Substituted judgment becomes less reliable when there is not a strong indication of a patient's prior wishes⁹² or when the patient was never competent and never able to partake of or interact with the surrounding social environment. In such cases, the decision maker must impose a best interests standard or quality of life standard on the patient.

88. *In re Doe*, 583 N.E.2d 1263, 1267 (Mass. 1992) (quoting *Saikewicz*, 370 N.E.2d at 431).

89. *In re Quinlan*, 355 A.2d 647 (N.J. 1976) (diverging from *In re Conroy*, 486 A.2d 1209 (1985). The father of a previously competent young woman requested permission to disconnect her from her respirator. *Id.*

90. 370 N.E.2d 417, 428-31 (Mass. 1977). The guardian ad litem of profoundly retarded man requested refusal of life-saving medical treatment that would disorient the patient and cause him considerable pain. *Id.*

91. Kevin Quinn, *Substituted Judgment: The Best Interests of Incompetent Patients: The capacity for Interpersonal Relationships as a Standard for Decisionmaking*, 76 CAL. L. REV. 897, 911 n.70 (1988).

92. *Id.* at 912.

B. *Best Interests Standard*

The best interests test generally is employed by the court when the patient has never expressed, or had the capacity to express, any preference related to the cessation of medical treatment. As opposed to the substitute judgment analysis, which attempts to exercise any past stated preferences of the patient, the best interests analysis looks at objective, relevant facts apart from the patient's preferences, including but not limited to "the patient's age, level of consciousness, condition, and isolation, together with the restrictions on his or her physical freedom."⁹³

In *In re Conroy*,⁹⁴ the court rearticulated the substitute judgment standards of *Quinlan* and *Saikewicz*, but further established two versions of the best interests test for use when there is no clear and convincing proof of a patient's attitude about termination of treatment.⁹⁵ The limited-objective test requires some trustworthy evidence that the patient would have refused treatment.⁹⁶ The pure-objective test is to be utilized when there is no trustworthy evidence, and (1) the burdens of initiating or continuing life-sustaining treatment "clearly and markedly" outweighed the benefits, and (2) the "recurring, unavoidable and severe pain of the patient's life" would be such that the effect of administering life-sustaining treatment would be inhumane.⁹⁷ The imposition of these tests by the New Jersey Supreme Court diluted the sympathetic approach for the family as established in *Quinlan* by making it more difficult for a family member to prove the patient's wishes. Furthermore, the court's emphasis on pain as the determining factor is largely irrelevant for two reasons: Some medical experts believe that persistently vegetative patients do not experience pain at a perceptible level of consciousness, and modern medication can now reduce or eliminate pain for conscious patients and would certainly be as effective for unconscious ones as well.

93. Stewart G. Pollack, *Life and Death Decisions: Who Makes Them and by What Standards?*, 41 RUTGERS. L. REV. 505, 520 (1990).

94. *In re Conroy*, 486 A.2d 1209 (N.J. 1985). The nephew of an incompetent, institutionalized, elderly woman sought removal of a nasogastric tube inserted by a physician. Mrs. Conroy's nephew believed that his aunt would not have wanted to be subjected to the treatment and artificially prolonged. The trial court granted permission for removal of the tube and the guardian ad litem appealed. Even though Mrs. Conroy died while the appeal was pending, the appellate court reversed, holding that withdrawal of the tube would be tantamount to killing her. The Conroy case outlined requirements for deciding to terminate or withhold medical treatment for incompetent patients and is considered the benchmark in this area of the law. *Id.*

95. *Id.*

96. *Id.*

97. *Id.*

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The judge is trained in the law, yet is personally unfamiliar with the details and realities of an incompetent's life. Surely the family in its broadest sense is a better decision maker. Yet the state's interest in sustaining life, established and justified through the *parens patriae* doctrine and reinforced through continuing court involvement in many states, tremendously affects the ability of families or persons close to the incompetent patient to make life-ending treatment decisions.

In contrast with such examples of judicial resolution, some states have concluded that family members or previously selected surrogates are better determinants than a judge or representative of the state.⁹⁸ In accord with the President's Commission report, these states are concluding that "decision making about life-sustaining care is rarely improved by resort to courts."⁹⁹

V. STATE MECHANISMS FOR DETERMINATION OF CESSATION OF MEDICAL TREATMENT DECISIONS

A. Massachusetts

The Supreme Judicial Court of Massachusetts uses a substitute judgment analysis to determine cessation of medical treatment decisions¹⁰⁰ and continues to rest decisional power firmly and totally within the court system.¹⁰¹ Recognizing that the use of substitute judgment for never-competent persons is a "legal fiction,"¹⁰² the court in *Doe* nevertheless followed its own lead in *Saikewicz*, and emphasized the court's reliance on objective criteria as a means of bringing "the substituted judgment into step with the values and desires of the affected individual."¹⁰³

98. Pollack, *supra* note 93, at 538; *see also In re Lawrence*, 579 N.E.2d 32, 36 (Ind. 1991) (holding in relevant part: ". . . that Sue Ann's parents had authority under the Health Care Consent Act 'to consent, as surrogate decisionmakers, to the withdrawal of artificially delivered nutrition and hydration from their daughter . . . who would otherwise remain indefinitely in a persistent vegetative state. . . .'"); *In re Quinlan*, 355 A.2d 647, 664 (N.J. 1976) (authorizing Karen Quinlan's father to direct the removal of life-support systems).

99. DECIDING TO FOREGO, *supra* note 36, at 247.

100. *See, e.g., Guardianship of Doe*, 583 N.E.2d 1263 (Mass. 1992).

101. Refer to the quote from *Saikewicz*, *supra* note 84.

102. Substituted judgment for a never-competent person "is the legal mechanism by which society (at least in Massachusetts) attempts to vindicate liberty interests, albeit through a legal fiction." *Doe*, 583 N.E.2d at 1268.

103. *Id.* (quoting *Superintendent of Belchertown Sch. v. Saikewicz*, 370 N.E.2d 417, 430-31 (Mass. 1977)).

Massachusetts judges must evaluate five factors before substituting their judgment for that of an incompetent patient's: the patient's expressed preferences, the patient's religious convictions and any relationship to refusal of treatment, impact on the patient's family, possibility of adverse side effects, and future prognosis with and without treatment.¹⁰⁴ The lower court in *Doe* determined, and the Massachusetts Supreme Judicial Court affirmed, that judges could make their decisions based on "a 'preponderance of the evidence with an extra measure of evidentiary protection' [by reason of] specific findings of fact after a 'careful review of the evidence.'"¹⁰⁵ The higher court emphasized the seriousness of these decisions and the ultimate power of the judge to make them by "forcefully impress[ing] on judges . . . [that] they are required to set forth their findings in 'meticulous detail' [rather] than . . . [by] merely label[ing] their findings as meeting a particular standard."¹⁰⁶

Massachusetts therefore stops short of applying more stringent "beyond a reasonable doubt" or "clear and convincing evidence" standards.¹⁰⁷ However, the court's emphasis on exacting and meticulous fact-finding tends to weigh the balance in favor of medical interests rather than family interests, primarily because, as previously noted, the family may not be in possession of uncontrovertible facts supporting a patient's purported wish not to be artificially maintained.

B. New York

The State of New York has a recognized hierarchy of persons eligible to make decisions regarding "Do Not Resuscitate" orders for incompetent persons and a procedure for reviewing those decisions. The statute is limited to only the cessation of, or refraining from initiating, cardio-pulmonary resuscitation,¹⁰⁸ recognizes a competent person's right to issue an order not to resuscitate and will not review or override that person's decision if witnessed and subsequently recorded in the patient's medical chart.¹⁰⁹ The statute further recognizes the authority of a designated health care agent to act on the patient's behalf.¹¹⁰ If a health care agent has not been designated, the state will select a health care proxy

104. *Id.*

105. *Id.* at 1271.

106. *Id.*

107. *Guardianship of Doe*, 583 N.E.2d 1263, 1271 (Mass. 1992).

108. N.Y. PUB. HEALTH LAW § 2968 (McKinney 1993).

109. *Id.* § 2964.

110. *Id.* § 2965.

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who is able, willing, and competent to act as surrogate for the patient from a priority listing of people. The list includes: (1) a committee of the person or a guardian (although section 2965 does not require the appointment of a committee of the person or a guardian), (2) a spouse, (3) a son or daughter eighteen years of age or older, (4) a parent, (5) a brother or sister eighteen years of age or older, or (6) a close friend. The selected surrogate "shall make a decision regarding cardio-pulmonary resuscitation on the basis of the adult patient's wishes, including a consideration of the patient's religious and moral beliefs, or, if the patient's wishes are not known and cannot be ascertained, on the basis of the patient's best interests."¹¹¹

The surrogate may decide against resuscitation only after the attending physician and an independent physician concur that (1) the patient has a terminal condition, (2) the patient is permanently unconscious, (3) resuscitation would be futile, or (4) resuscitation would impose an extraordinary burden on the patient when balanced against probable outcomes.¹¹²

The surrogate is presumptively granted decision making power to withdraw or withhold resuscitation and is therefore not required to go to court or provide extensive "evidence" before making this decision.¹¹³ The attending physician or any other physician may at any time, however, cancel the surrogate's order upon a determination that the patient no longer suffers from any one of the four conditions specified in Section 2965(3)(c)(i-iv) (listed in the preceding paragraph).

The New York statute mandates that each hospital establish a dispute mediation system,¹¹⁴ whether through a newly constituted body or through an existing hospital committee. The dispute mediation system

111. *Id.* § 2965 (3)(a).

112. *Id.* § 2965 (3)(e).

113. New York law defines a surrogate as "the person selected to make a decision regarding resuscitation on behalf of another person." N.Y. PUB. HEALTH LAW § 2961(17) (McKinney 1993). Allowing a surrogate to make a life or death decision for an incompetent appears to be contrary to the prior common law in New York. See *In re Storar*, 420 N.E.2d 64 (N.Y. 1981), cert. denied sub nom. *Storar v. Storar* 454 U.S. 858 (1981); see also *New York v. Eulo*, 472 N.E.2d 286, 296 (N.Y. 1984) ("In the absence of such evidence of personal intent [there, due to the patient's incompetence] a third party has no recognized right to decide that the patient's quality of life has declined to a point where treatment should be withheld and the patient should be allowed to die."); *In re Kerr*, 517 N.Y.S.2d 346, 348 (N.Y. Sup. Ct. 1986) ("When a person is not competent to make such a life or death decision, the court must intervene in favor of life prolonging treatment, despite the feelings and desires of those closest to the patient."); Susan M. Golden, *Do Not Resuscitate Orders: A Matter of Life and Death in New York*, 4 J. CONTEMP. HEALTH L. & POL'Y 449 (1988).

114. N.Y. PUB. HEALTH LAW § 2970 (1)(a) (McKinney 1993).

is mandated to mediate all disputes, including those regarding the determination of the patient's capacity, among all potential parties.¹¹⁵ During the mediation process, Do Not Resuscitate orders are revoked and cannot be reissued unless the dispute has been resolved or seventy-two hours have passed without resolution. All participants involved in the mediation are entitled to seek judicial review.¹¹⁶

If any party initiates a special proceeding challenging a decision regarding the issuance of an order not to resuscitate, that party must show, by clear and convincing evidence, that the decision is contrary to the patient's wishes or best interests.¹¹⁷ A patient's refusal to consent to a Do Not Resuscitate order is not subject to judicial review.¹¹⁸ In sum, the New York mechanism provides an early presumption in favor of the family or selected surrogate, but somewhat dismantles that presumption by making it easy for physicians to intercede and restrict enactment of those decisions.

C. New Jersey

The 1976 New Jersey case of Karen Ann Quinlan¹¹⁹ is still a significant decision, representing a genuine sensitivity to,¹²⁰ and recognition of, the importance of the family as the ultimate decision maker in cessation of medical treatment situations. Karen Quinlan was a previously healthy, young woman who, after losing consciousness, remained in a persistent vegetative state. After the physician denied her father's request to disconnect her from a respirator, her father sought a judgment of incompetency, which would give him, as guardian, the right to order the discontinuance of extraordinary medical procedures. When Mr. Quinlan's resulting lawsuit was rejected by the lower court, the New Jersey Supreme Court granted an immediate appeal.¹²¹

The state supreme court focused on Karen's prognosis. Determining that it was unlikely that Karen would ever return to a cognitive and sapient life,¹²² the state supreme court rejected the lower court's contention that Mr. Quinlan's guardianship would cause him

115. *Id.* § 2972 (1-4).

116. *Id.* § 2972 (3).

117. *Id.* § 2973 (1).

118. *Id.*

119. *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

120. Rhoden, *supra* note 11, at 383.

121. *Id.*

122. *Quinlan*, 355 A.2d at 669.

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anguish and would distort his decision making processes.¹²³ The court stated:

We disagree, for we sense from the whole record before us that while Mr. Quinlan feels a natural grief, and understandably sorrows because of the tragedy which has befallen his daughter, his strength of purpose and character far outweighs these sentiments and qualifies him eminently for guardianship of the person as well as the property of his daughter. Hence we discern no valid reason to overrule the statutory intendment of preference of the next of kin.¹²⁴

The court's assessment of the issues in *Quinlan* is representative of the way courts should treat these cases,¹²⁵ and could have paved the way much earlier to more caring and humane resolutions of these complex issues. However, *Quinlan* deviated from *Conroy*,¹²⁶ which slightly shifted the focus to the *proof* of the patient's best interests, rather than the right of the family to determine the choice of treatment if the patient can never recover.¹²⁷ In the years following *Quinlan*,¹²⁸ courts generally acknowledged the state's interests but found that the "interest [in preserving life] weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims."¹²⁹ This analysis was applied in almost every right-to-die ruling after that case.¹³⁰ However, the Supreme Court in *Cruzan*¹³¹ clearly reestablished the predominant power of the state's interests over the individual's.

D. Missouri

The State of Missouri controls decisions concerning the cessation of medical treatment through its judicial process and its extremely difficult test for proving that cessation of treatment is the patient's preference. Missouri uses a clear and convincing standard with the burden of proof on

123. *Id.* at 670.

124. *Id.*

125. Rhoden, *supra* note 11, at 383.

126. *In re Conroy*, 486 A.2d 1209 (1985).

127. *Id.*

128. *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

129. *Id.* at 678.

130. Bopp & Avila, *supra* note 22, at 794.

131. *Cruzan v. Director, Mo. Dept. of Health*, 497 U.S. 261 (1990).

the party (family) requesting treatment discontinuance.¹³² The United States Supreme Court's plurality opinion in *Cruzan*¹³³ held that Missouri's use of the clear and convincing standard for determination of Nancy's prior wishes did not violate her rights under the United States Constitution. "The case of Nancy Cruzan illustrates how government can protect even minimal life to the detriment of one's right to refuse to continue such an existence."¹³⁴

Missouri's *parens patriae* doctrine protects life of all definitions. Nancy Cruzan's parents, family, and friends were stymied for more than eight years in their efforts to allow her to die. After the Supreme Court's 1990 opinion, however, the case was reconsidered by the State of Missouri when "new evidence" was presented pursuant to Nancy's previously stated wishes. At that time, perhaps content with the strong grant of power afforded by the nation's highest Court, the State of Missouri decided that the evidence did meet its "clear and convincing" standard, and Nancy's artificial life-support mechanisms were allowed to be removed. She died eight days later.

More recently, the State of Missouri acquiesced in another long battle over a family's request to terminate treatment. Since November of 1987, Christine Busalacchi had been a resident at the same state-run hospital as Nancy Cruzan, and her father had attempted similar legal action to allow her to die. His earlier efforts were denied, and in 1990, he was even forbidden to remove her from the state nursing facility or from the state itself. However, early in 1993, Missouri's Attorney General requested a dismissal of the case before the state supreme court, in effect leaving Mr. Busalacchi free to decide his daughter's fate.¹³⁵ He transferred her to another hospital, where she died after her feeding tube was removed.¹³⁶ It is uncertain whether this indicates a softening of Missouri's intractable standard of proof.¹³⁷

132. *Id.*; *In re Busalacchi*, No. 59582, 1991 WL 26851 (Mo. App. Mar. 5, 1991), *reh'g and/or transfer denied*, (Mar. 26, 1991), *cause ordered transferred to Mo. S. Ct.* (Apr. 15, 1991), *appeal dismissed* No. 73677 (Mo. Jan. 26, 1993).

133. *Cruzan*, 447 U.S. at 261.

134. Marks & Morgan, *supra* note 29, at 467.

135. THE COLUMBUS DISPATCH, *Comatose Woman Dies After Support Removed*, March 8, 1993, at 3A.

136. *Id.*

137. It should be noted that in other situations Missouri is also reluctant to relinquish control over the right to forego life-sustaining treatment. Generally, state statutes that deal with life-prolonging measures are limited by either "imposing a variety of conditions precedent" or by "limiting the procedures encompassed by the statute." Marks & Morgan, *supra* note 29, at 470. Missouri has a very restrictive statute. *Id.* In considering the Missouri Living Will Act, Judge Welliver noted in dissent in *Cruzan v. Harmon*:

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VI. MEDIATION-BASED FAMILY-CENTERED DECISION MAKING

For every horror story like the Cruzan's or Busalacchi's, there are now more and more courts in other states more sympathetic and respectful of the family.

[This] judicial reaction to the death-and-dying issue reflects basic beliefs about the roles of the family, the medical profession, and the courts in our society. By delegating decision-making to the family, courts have affirmed their belief that the family, more than anyone else, is familiar with the patient's preferences and is best situated to make medical decisions for an incompetent patient. Because courts are returning decision-making to the incompetent patient's family, hospitals and other health care facilities should consider making available the services of a bioethicist or of an institutional ethics committee. Recourse to such committees is consistent with judicial deregulation of these deeply personal decisions and with the attempt to devise appropriate and responsive procedures.¹³⁸

The above comment, by an associate justice on the New Jersey Supreme Court, suggests what this Author hopes is a perspective shared by an increasing number of courts. Informal discussions with hospital physicians indicate that many life and death decisions already occur at the patient's bedside, away from the courtroom.¹³⁹ These decisions need to

Yes, we Missourians can sign an instrument directing the withholding or withdrawal of death-prolonging procedures, but, after the Missouri amendments, "death prolonging procedure" does not include: (1) "[T]he administration of medication," (2) "the performance of medical procedure deemed necessary to provide comfort, care as to alleviate pain" (3) "the performance of any procedure to provide nutrition" or (4) "the performance of any procedure to provide . . . hydration." If we cannot authorize withdrawing or withholding "medication," "nutrition" or "hydration," then what can we authorize to be withheld in Missouri? The Missouri Living Will Act is a fraud on Missourians who believe we have been given a right to execute a living will, and to die naturally, respectably, and in peace.

Cruzan v. Harmon, 760 S.W.2d 408, 441 (Mo. 1988).

138. Pollack, *supra* note 93, at 538.

139. Informal conversation with Dr. Taniguchi, Children's Hospital, Columbus, Ohio.

be made in an atmosphere of support and compassion. Family members may never have encountered an issue of such enormity, finality, and emotional import. Without a supportive environment for decision making, opportunities for confusion, miscommunication, and conflict are rife -- between family members, and between the family and the hospital staff.

An early warning mechanism for anticipating difficulties and identifying potential conflict among decision makers could eliminate many small conflicts before they escalate. A procedure for enhancing communication among the parties, and for providing informal mediation when disagreement or confusion is first suspected, may facilitate resolution and minimize the family's emotional cost. Mandatory referral to formal mediation for unresolvable conflicts, followed by mandatory but non-binding adjudication, all within the hospital, would provide procedural due process for all parties, yet keep the conflict in an environment best suited for its resolution. Only when all of the above measures have been exhausted should access to the courts by opposing parties be permitted.

Many courts have acknowledged the inappropriateness of the civil court system for resolution of these moral and ethical issues. The nature of the judicial system is adverse to humane treatment of these issues:¹⁴⁰ It is lengthy, adversarial, and expensive. More importantly, it does not provide opportunities for opposing parties to attempt resolution or

140.

The *Brophy* case . . . illustrate[s] some of the difficulties that can arise when courts are asked to settle disputes about life-sustaining treatments. To begin with, the legal process may be protracted. Even with an expedited appeals process, the final decision in the *Brophy* case was handed down 19 months after Patricia Brophy's original petition.

Also, adversarial courtroom proceedings often are not the best way to establish medical facts and judgments accurately. An important issue in the *Brophy* case was whether patients in persistent vegetative states suffer from hunger or thirst if tube feedings are withheld. Because doctors testified on both sides of this question, the issue became controversial. There is consensus in the medical literature, however, that patients in persistent vegetative states do not feel pain. . . . When such errors of fact go uncorrected throughout the appeals process, the resulting court decisions will be based on incorrect medical judgments and may cause confusion and cynicism.

Robert Steinbrook & Bernard Lo, *Artificial Feeding - Solid Ground, Not a Slippery Slope*, 318 NEW. ENG. J. MED., 286-90 (1988).

compromise.¹⁴¹

How do we create alternative mechanisms? Will mediation within the hospital inordinately burden the system? Who should supervise and evaluate? What would encourage participation?

This Section proposes an alternative dispute resolution (ADR) system for hospital implementation that would address treatment decisions more effectively and humanely, and could also be used for other conflicts within the hospital environment. The system would be created by modifying the existing institutional ethics committee. By revising the structure and identifying new purposes for ethics committees, emphasis, support, and recognition can be on the family -- where it belongs. An ADR system may also help the doctor do his or her job with less fear of litigation or need for defensive medical actions, because the family would be the ultimate decision maker.¹⁴²

A. *The Hospital Ethics Committee - Original Creation and Purpose*

The Congressional Office of Technology Assessment has defined an ethics committee as a "[c]onsultative committee in a hospital or other institution whose role is to analyze ethical dilemmas and to advise and educate health care providers, patients, and families regarding difficult treatment decisions."¹⁴³ Other definitions have emphasized the multidisciplinary¹⁴⁴ or interdisciplinary nature of the committee structure and the tendency for committees to "deal with issues regarding the withholding or withdrawal of life sustaining treatment from patients who

141. "There is nearly universal agreement, especially among judges, that these issues should not come to court unless there is a clear question of law, or if all alternative means for resolving the dispute have been tried and failed." Joan McIver Bison & Mary Beth West, *Hospital Ethics Committees: Mediation and Case Review*, FORUM, Summer/Fall 1991, at 23.

142. "Until the present liability system is repaired, we have no chance of eliminating defensive medicine practices and of returning standards of care to what patients need to have done; not what professionals feel they must do in order to protect themselves." Orrin G. Hatch, *Reforms Needed to Increase Access to Health Care*, FORUM, Summer/Fall 1991, at 7 (estimating that \$.25 of every health care dollar is spent on defensive medicine).

143. Susan M. Wolf, *Ethics Committees and Due Process: Nesting Rights in a Community of Caring*, 50 MD. L. REV. 798, 801 n.18 (1991) (citing OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, LIFE-SUSTAINING TECHNOLOGIES AND THE ELDERLY 444 (1987)).

144. Wolf, *supra* note 143, at 801 n.18 (citing R. Cranford & A. Doudera, INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE DECISION MAKING 5 (1984)).

lack decision making capacities."¹⁴⁵

The hospital ethics committee is a relatively recent phenomenon, developing over the last decade in response to increased concern over life-sustaining treatment decisions.¹⁴⁶ More than one writer has traced the origin of the ethics committee concept to a 1975 law review article by a Texas physician,¹⁴⁷ the suggestions of which were subsequently incorporated by nursing home administrators¹⁴⁸ into the ethics committee for Karen Ann Quinlan.¹⁴⁹

The New Jersey Supreme Court in *Quinlan*¹⁵⁰ recommended that the committee "validate requests by clinicians, families, or surrogates to remove life-sustaining equipment if the committee, like the court, concluded that 'there is no reasonable possibility of [the patient ever regaining] a cognitive, sapient state.'"¹⁵¹ This early clinical role of the ethics committee was expanded in 1982 by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.¹⁵² "[T]he Commission proposed that the ethics committee might prove a more useful mechanism to resolve questions of clinical ethics than the courts."¹⁵³ *In re Torres*,¹⁵⁴ a 1983 Minnesota case, was the first case¹⁵⁵ to consider the recommendations of three independent biomedical ethics committees in reaching a decision regarding a comatose patient with irreversible brain damage. Based on the advice of two of these committees, the court ruled that the respirator could be disconnected

145. Diane E. Hoffmann, *Regulating Ethics Committee in Health Care Institutions - Is It Time?*, 50 MD. L. REV. 746 (1991) [hereinafter Hoffmann, *Regulating Ethics*] (citing Cranford & Doudera, *supra* note 144, at 6-7).

146. John C. Fletcher, *The Bioethics Movement and Hospital Ethics Committees*, 50 MD. L. REV. 859, 869 (1991).

147. Karen Teel, *The Physician's Dilemma: A Doctor's View: What the Law Should Be*, 27 BAYLOR L. REV. 6 (1975).

148. B. HOSFORD, MAKING YOUR MEDICAL DECISIONS: YOUR RIGHTS AND HARSH DECISIONS TODAY 126 (1982).

149. *In re Quinlan*, 355 A.2d 647 (N.J. 1976), *cert. denied*, 429 U.S. 922 (1976).

150. *Id.* at 671.

151. *Id.*, cited in Gail J. Povar, *Evaluating Ethics Committees: What Do We Mean by Success?*, 50 MO. L. REV. 904, 904 n.1 (1991).

152. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, MAKING HEALTH CARE DECISIONS 187-188 (1982) [hereinafter MAKING HEALTH CARE DECISIONS].

153. Povar, *supra* note 151, at 904-05.

154. 357 N.W. 2d 332 (Minn. 1984).

155. Paula C. Hollinger, *Hospital Ethics Committees and the Law*, 50 MD. L. REV. 742, 743 (1991).

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if the patient's legal guardian so requested.¹⁵⁶ A major increase in the mid-1980s of "infant care review committees" concerned with life-saving intervention for handicapped infants brought the "ethics committee movement into the institutional mainstream."¹⁵⁷ Whereas less than one percent of hospitals had ethics committees in 1982,¹⁵⁸ by 1985, more than sixty percent of American hospitals and almost ten percent of nursing homes had ethics committees.¹⁵⁹

There appear to be no reliable data on the effectiveness of ethics committees.¹⁶⁰ Committees vary widely in membership, procedures, perceived roles, and responsibilities.¹⁶¹ Criticisms of ethics committees generally concern a lack of focus or conflicting purpose. "Some so-called ethics committees have as goals confirming prognoses, providing emotional support for care givers, or reducing legal liability for physicians or hospitals."¹⁶²

Although the stated purpose of ethics committees since their inception has been to protect the patient, concerns have arisen that the committees may have conflicting goals of protecting the patient, protecting the health care providers, and protecting the health care institution. Such a lack of priorities or focus makes

156. *Id.* at 743 (citing *In re Torres*, 357 N.W. 2d 332, 341 (Minn. 1984)).

157. *Id.*

158. DECIDING TO FOREGO, *supra* note 36, at 446.

159. AM. HOSP. ASSOC. NEWS, Dec. 5, 1988, at 1, col. 1, *cited in* Hoffmann, *Regulating Ethics*, *supra* note 145, at 746-47.

160. In a multi-state survey of hospital ethics committees, 91% of non-federal hospitals in Maryland reported having an ethics committee, but 15% were inactive, meaning they never met or had infrequently met. The District of Columbia reported 78% of hospitals with ethics committees. Virginia reported only 25% of ethics committees within hospitals, with 33% of those inactive. Hoffmann, *Regulating Ethics*, *supra* note 145, at 756-58, (citing Diane E. Hoffmann, *Does Legislating Hospital Ethics Committees Make a Difference?: A Study of Hospital Ethics Committees in Maryland, the District of Columbia, and Virginia* (1991) (to be published in a forthcoming issue of *Law, Medicine & Health Care*) (unpublished manuscript on file with the MARYLAND LAW REVIEW) [hereinafter Hoffmann, *Study*]).

161. One committee's view: "We have never formally stated in writing the exact purpose or purposes of our committee but have decided to proceed in an informal manner. . . . We felt that to formalize our objectives might be counterproductive to the work of our committee." Bernard Lo, *Behind Closed Doors: Promises and Pitfalls of Ethics Committees*, 317 NEW ENG. J. MED. 46, 47 (1987).

162. *Id.* at 47. One hospital administrator suggested using the ethics committee as a "public relations tool" for unpopular decisions. *Id.* at 47 (citing J.W. Summers, *Closing Unprofitable Services: Ethical Issues and Management Responses*, 30 HOSP. HEALTH SERV. ADM. 8 (1985)).

patients particularly vulnerable.¹⁶³

Other critics attack their lack of accountability, absence of rationale for their recommendations, and lack of broad-based representation.¹⁶⁴

A 1990 American Hospital Association Management Advisory suggested certain activities as "particularly suitable" for ethics committees: (1) directing educational programs on ethics, (2) creating a forum for discussion of ethical issues, (3) case consultation and providing resources to people involved in decision making, (4) conducting retrospective review of bioethical decisions, (5) developing institutional policies regarding bioethical issues, and (6) networking with other committees for educational purposes.¹⁶⁵

Of the activities listed above, case consultation has proven to be one of the "more contentious roles assumed by institutional ethics committees."¹⁶⁶ Committee opinions are often promoted as merely advisory,¹⁶⁷ but their institutional and psychological force often creates a mandatory impression on those requesting guidance.¹⁶⁸ Even the President's Commission Report in 1983 reported that although only eighteen percent of ethics committees perceived their purpose as making final treatment decisions, thirty-one percent characterized final decision making as one of their actual functions.¹⁶⁹

Committees have also been criticized as being anti-patient, with a predominately professional medical membership.¹⁷⁰ The procedures of many committees limit or prevent patients or family members from attending sessions.¹⁷¹ Recent literature suggests that many committees

163. Hoffmann, *Regulating Ethics*, *supra* note 145, at 767 (citation omitted).

164. *Id.*

165. AMERICAN HOSPITAL ASSOCIATION, MANAGEMENT ADVISORY: ETHICS COMMITTEES (1990), *cited in* Povar, *supra* note 151, at 905-06; *see also* Fletcher, *supra* note 146, at 876 (noting that ethics committee has four major functions: provide a forum, educate, consult, and develop policies).

166. Povar, *supra* note 151, at 912.

167. Wolf, *supra* note 143, at 809 (criticizing the "myth that committees are purely advisory").

168. Karen Ritchie, *When It's Not Really Optional*, 1988 HASTINGS CENTER REP. 25, *cited in* Wolf, *supra* note 143, at 809, n.43.

169. DECIDING TO FOREGO, *supra* note 36, at 451 (table F3).

170. Povar, *supra* note 151, at 912.

171. A 1982 survey indicated that only 25% of committees that reviewed cases permitted patients to bring cases to the committee, with only 19% allowing patients to attend meetings. Forty-four percent of the committees allowed family members to attend meetings. Lo, *supra* note 161, at 47 (citing S. J. Youngner et al., *A National Survey of Hospital Ethics Committees*, 11 CRITICAL CARE MED. 902 (1983)).

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do not provide patients access to the committee's services at all.¹⁷² Other literature indicates that many physicians and other health care personnel are often unaware of the committee's existence, let alone its purpose.¹⁷³

Two distinct models of ethics committee function have developed over the years, with widely different purposes and impacts.¹⁷⁴ The consultation model of an ethics committee focuses on the needs of caregivers with no procedural protection to the patient.¹⁷⁵ The adjudicatory model focuses on patients' rights and protections when the committee is giving advice or rendering treatment decisions. The danger is the fluid transition between the two models.¹⁷⁶

That poses real dangers, especially for patients and their families, who may not be included at all in the committee's process. This dangerous double identity reflects the fact that we are still in the midst of a struggle between traditional physician paternalism and a newer effort to recognize patient's rights. . . .¹⁷⁷ The physician is likely to concentrate on medical effectiveness, while the patient is likely to concentrate on whether the prospective benefits of treatment outweigh the physical, psychological, and other burdens to her.¹⁷⁸

It is essential to recognize the adjudicatory function of ethics committees and to provide mechanisms to ensure due process for patients and families. "All indications are that most [ethics committees] fail even to give the patient notice and an opportunity to be heard, much less other tools a patient might need to participate effectively in the ethics committee's proceedings."¹⁷⁹ The danger is that because the "advice" of ethics committees carries "decisive weight" for the many disputes that never find their way into court "the committee will serve as the forum of

172. Povar, *supra* note 151, at 913 (citing Roy B. Nash et al., *The Hospital Ethics Committee: Who Knows It Exists and How to Access It*, 9 H.E.F.C. 9-11 (1989)).

173. Thirty-nine percent of physicians and health care workers were unaware of their hospital's ethics committee, even though it had been in existence at least two years and conducted at least five consults within the last year. Hoffmann, *Regulating Ethics*, *supra* note 145, at 760, n.90 (citing Hoffmann, *Study*, *supra* note 160).

174. Wolf, *supra* note 143, at 804-05.

175. *Id.*

176. *Id.*

177. *Id.* at 805.

178. *Id.* at 813.

179. Wolf, *supra* note 143, at 802.

last resort. ¹⁸⁰

Ethics committees thus have always been a battleground on which traditional physician paternalism and control have gone head to head with the newer commitment to patient's rights. To this day the battle remains unresolved. That is the root of ethics committees' double identity. They spring from modern medical ethics and its commitment to patient's rights, but have been thoroughly dominated and shaped by physicians. Thus it is no surprise that the very ambivalence that many (if not most) physicians feel toward ceding decisional authority to patients is played out in the ethics committee. This is all the more predictable because the very cases that come to the ethics committee are the hard cases, the ones in which there is some dispute between the doctor and patient or patient's surrogate.¹⁸¹

Despite the criticisms, this Comment contends that ethics committees can become a fairer pro-patient force in the medical arena, especially with regard to life-sustaining treatment decisions. Ethics committees currently exist in a majority of hospitals and a sizeable minority of nursing homes. They have operated within the health care system long enough to gain some measure of acceptability, if only among facility administrators and committee participants. They already make decisions and have an impact on patients and their families. However, many ethics committees "fail or flounder" for lack of institutional support, recognition, or underuse.¹⁸² "The time has come for ethics programs to be part of the culture of health care and to gain enough independence and community support to be viewed as credible institutions. In the 1990s, ethics programs must become accepted actors in the health care arena and the communities they serve."¹⁸³

180. *Id.*

181. *Id.* at 827.

182. Fletcher, *supra* note 146, at 875.

183. *Id.*

B. A New Design and Purpose for Ethics Committees

The focus, organization, and procedures of existing ethics committees must be examined to assure recognition of the special needs of the patient and the patient's family when considering termination of treatment decisions. In a sense, the committee must perform a patient's advisory and advocacy function, to counter the imbalance of power afforded doctors and hospitals.¹⁸⁴

The ethics committee has considerable procedural power due to its ability to control the procedures for decision making. Hospital staff committee members collectively also carry associational power. When all of these sources of power are contrasted with the relatively few sources of power that patients and family have, the imbalance is striking.¹⁸⁵

In addition to focusing on the patient, specific dispute resolution procedures must be instituted "before there is a real need, so they can become known; gain credibility and acceptance, and be viewed as a valid and effective forum for resolving disputes. . . . [T]hey must [also] be perceived as fair and equitable."¹⁸⁶ Ury, Brett, and Goldberg propose a dispute resolution model "that would direct disputes along a low-cost path to resolution."¹⁸⁷ The model would put the focus on the party's interests, build in "loopbacks" to negotiation, provide low-cost rights and power backups, provide consultation before mediation and feedback after, arrange procedures in a low cost to high cost sequence, and provide

184. The composition of ethics committees may not reassure patients that their wishes and interests are represented. Typically, most members of ethics committees are physicians, who may assess the importance of medical problems or the risks and benefits of treatment differently from patients. Patients or surrogates who disagree with the committee's recommendations may say that the composition of the committee was biased against them.

Lo, *supra* note 161, at 46-50.

185. Joan M. Gibson & Mary Beth West, *Hospital Ethics Committees: Mediation and Case Review*, NIDR FORUM, Summer/Fall 1991, at 22.

186. Michael E. Carbine, *Adapting Dispute Resolution Techniques to the Health Care Field*, NIDR FORUM, Summer/Fall 1991, at 16 (citing Robert Stein, a Washington-based attorney specializing in Dispute Resolution).

187. William L. Ury et al., *Designing an Effective Dispute Resolution System*, 4 NEGOTIATION J. 413, 414 (1988).

necessary motivation, skills, and resources.¹⁸⁸

Disputes over patient care are not always the result of conflicts over ethical principles or obligations.¹⁸⁹ These conflicts "may also result from misunderstandings, stress, or lack of attention to the details of care. Despite stalemates over conflicting ethical principles or duties, agreements on particular recommendations for patient care may be possible."¹⁹⁰ Ethics committees are well-positioned to improve patient and family experiences when faced with treatment decisions. If the committee is visible and easily accessible, and resources exist to correct the patient-family-physician imbalance, this Author believes that most disputes concerning cessation of medical treatment for incompetent patients could be resolved within the hospital structure. As Thomas Metzloff both suggested and predicted: Dispute resolution in the health care system could be a "gatekeeper" for the court system.¹⁹¹ Dispute resolution "procedures could be used to handle certain kinds of cases before they enter the judicial system, even before attorneys are involved. . . . [H]ealth care providers could offer a statutory dispute resolution option as the first recourse before going to court."¹⁹²

Metzloff, Clark Havinghurst,¹⁹³ and Michael Carbine contend that dispute resolution is best used to resolve fact-based health care issues.¹⁹⁴ This Comment, however, proposes that mediation and other ADR techniques provide humane mechanisms for resolving difficult ethical and emotional issues as well. Adversarial adjudication generates hostility, inaccuracy, and emotional devastation. The adversarial system creates winners and losers, but there are no winners when a family faces a dying loved one. A hospital ethics committee can provide a range of informal to more formal procedures to guide a treatment dispute towards resolution.

But certain questions about the DR process must be settled before such options are offered. For example, how would the option be offered? . . . Is it voluntary or mandated? Would it

188. *Id.*

189. Lo, *supra* note 161, at 48.

190. *Id.*

191. Carbine, *supra* note 186, at 16 (quoting Thomas Metzloff, Director of the Private Adjudication Center's Medical Malpractice Research Project).

192. *Id.*

193. Clark Havinghurst, of Duke University Law School, was quoted in Michael Carbine's article as saying that "arbitration and other DR techniques are most likely to be useful in health care disputes that primarily involve matters of fact." *Id.* at 17.

194. These included issues such as Medicare payment denials, medical staff disputes, nursing home grievances, and licensing and quality assurance activities. *Id.*

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entail binding or non-binding decisions? Does it provide an opportunity for the aggrieved individual, whether provider or consumer, to opt out of the alternative process without penalty? Who represents the [patient] or provider? Who makes the decisions?¹⁹⁵

1. Structure

The hospital ethics committee should have three goals: (1) to provide patient and family with additional medical information and advice, (2) to provide physician peer review, and (3) to operate as a provider of alternative dispute resolution mechanisms to resolve treatment decision disputes. Initially, the committee would provide medical information and advice on factual matters concerning the patient's condition and prognosis. At any point, a party should be able to request, and attend, a committee review of the medical treatment and prognosis by the attending physician. Requests for counseling, mediation, and arbitration may be initiated by a patient, family member, or health professional, but must stay within the hospital environment and exhaust all available mechanisms before gaining access to the courts.

In a family-based decision making model, a broader definition of family would incorporate non-traditional families and would provide a method for determining if other persons are more qualified than a blood relative to decide for a patient. There should be a broad rebuttable presumption that the family (or chosen decision maker) represents the patient's best interests. Parties disputing the family's (or chosen decision maker's) determination should bear the burden of proving the decision is contrary to the patient's best interest. Examples of this would include patients estranged from their parents or families and patients with unmarried or same-sex partners. The burden of proof for challenging the decision maker should fall on the person attempting to replace the family as decision maker. The goal in any dispute would be to have each side hear the other's concerns and come to a solution or consensus.

195. Carbine, *supra* note 186, at 16.

2. *Initial Contact and Informal Mediation*

When a seriously-ill patient first enters the hospital, a hospital-provided counselor¹⁹⁶ (for example, a social worker or pastoral counselor trained in mediation) should approach the family to offer the hospital's general reassurance and support.¹⁹⁷ The counselor could make sure that the family unit is aware of the ethics committee's counseling, advice, and mediation services. The counselor could provide printed material, provide a telephone number for twenty-four hour access to advice and information, and informally let the family know that their emotional needs and the patient's physical and emotional needs are respected by the hospital staff. The written material and reference number would be particularly effective because during initial admission most patients and family members are too emotionally preoccupied to absorb much information.

The counselor should keep informed about the condition of a terminally ill or incompetent patient and should approach the family whenever a treatment decision is imminent. Also, if the attending physician or another health professional recognizes that conflict exists among family members, the counselor should be notified. If a conflict is identified early, informal mediation could be offered literally at the patient's bedside or outside the hospital room. A waiting room or cafeteria or other non-threatening location would give the counselor-mediator an opportunity to attempt informal resolution.¹⁹⁸

A mediator may be able to move the negotiations beyond name-calling by encouraging the disputants to vent their emotions and acknowledge the other's perspective. A mediator can help parties move past a deadlock over positions by getting them to identify their underlying interests and develop creative solutions that satisfy those interests. Where each side is reluctant to

196. The counselor can be a staff member or independent counselor from outside the hospital, but the counselor reports to, and is monitored by, the ethics committee at large, or designated hospital administrator.

197. Peter Szanton suggested that self-supporting mediation programs needed to develop procedures (pipelines) that would "direct disputes away from the adversarial paths they normally follow toward new paths that direct them to dispute resolution screening, and then on to mediation, arbitration or another dispute resolution process." David O'Connor, *The Design of Self-Supporting Dispute Resolution Programs*, 8 NEGOTIATION J. 85, 85 (1992).

198. This process would be similar to that offered in small claims courtrooms in Columbus, Ohio. Mediation is offered to disputants just before their cases are heard by the magistrate. If they attempt mediation and are not successful, the parties go on to court, but often informal mediation leads to resolution.

propose a compromise out of fear of appearing weak, the mediator can make such a proposal. Mediators are thus well placed to shift the focus from rights or power to interests. Mediation can serve as a safety net to keep a dispute from escalating to a rights procedure, such as litigation. . . .¹⁹⁹

Interceding early gives the mediator-counselor the opportunity to eliminate potential problems resulting from communication deficiencies or misunderstandings based on incorrect or out-of-date information. If each party hears the other's views and all parties disconnect their egos from the actual disagreement, it may be possible to reach a solution.

3. Formal Mediation

Thus far, the ethics committee has been involved only in a supervisory capacity, by reviewing the activities and weekly (or bi-weekly) reports of the mediator-counselor. If bedside counseling and informal mediation are not successful, the counselor-mediator would notify the disputants that their disagreement would be heard by the formal in-hospital mediation program.²⁰⁰ At this point, a different mediator should be used to reinforce additional formality.²⁰¹ The strength of mediation is its "capacity to help deal with the problems created by dispute selection and elaboration and therefore . . . its capacity to deescalate the conflict."²⁰²

Among the tools of successful mediators are procedures for correcting the defects just mentioned: shuttling between parties

199. Ury et al., *supra* note 187, at 413, 420 (1988). Counselors should receive mediation and negotiation training, and ideally, all medical and nursing programs should include some form of alternative dispute resolution training for emerging doctors, nurses, and other health care professionals.

200. One hospital in Texas provides several levels of mediation. A designer has trained large numbers of supervisors so that there is always some supervisor close to the disputants who can mediate. Key individuals in personnel, pastoral care, and social services have also been identified as expert providers of formal mediation services. In addition, the design has agreed to provide professional mediators who can be called on for assistance in particularly difficult disputes.

Id. at 420.

201. The hospital could possibly have a small contingent of counselor-mediators — perhaps as few as two to four — that could serve to formally mediate disputes handled previously by the other counselor-mediators.

202. Craig A. McEwen & Thomas W. Milburn, *Explaining a Paradox of Mediation*, 9 NEGOTIATION J. 23, 30 (1993).

who cannot or will not meet, interpreting statements made by parties who do not understand each other, encouraging trust or suggesting agreements that do not require trust, allowing a proud party to concede to the mediator instead of the other party, reminding the parties about the costs of struggle or adjudication, and casting doubt on the likelihood that the other party can be pushed into further concession or that a judge will rule in one's favor.²⁰³

At this mediation session, both parties would be encouraged to provide evidence supporting their positions. They would be advised that if a resolution or compromise or joint agreement is not reached,²⁰⁴ the issue would be taken before the ethics committee's adjudicatory board (Board).²⁰⁵

203. *Id.* (citing P.J. Carnevale & D.G. Pruitt, *Negotiation and Mediation*, 43 ANNUAL REVIEW OF PSYCHOLOGY, 531-82 (1992)).

204. The session should be limited to two hours, with each party able to ask for a brief recess to talk to other family members or relieve the tension.

205. "Primary sentiment for expanding the role of hospital ethics committees and allowing them to substitute for judicial decisionmaking stems from a handful of judicial decisions." *Quinlan*, 355 A.2d at 669.

[W]ith the exception of the Mass. Sup. Judicial Court's *Saikewicz* opinion, which appropriated to the courts the role of making all life and death decisions for incompetents, nearly every court confronted with such a decision has pleaded for legislative guidance, not judicial resolution, of these medical dilemmas.

The courts realize that frequently judicial involvement is nothing more than a facade designed to gain approval and immunity for the family-physician decision. When asked to make actual treatment decisions the courts are acutely aware of their limitations and lack of clinical experience.

John J. Paris & Frank E. Reardon, *Ethics Committees in Critical Care*, 2 CRITICAL CARE CLINICS 111, 113 (1986); *see also In re Terry*, 573 A.2d 1235, 1251-53 (D.C. Cir. 1990).

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4. *Ethics Committee Adjudication*²⁰⁶

The Board would do a periodic review and update of patient and counselor interaction, and would sit as a quasi-judicial body²⁰⁷ if earlier forms of dispute resolution had not solved the problem. A recommended composition of the Board would include a doctor, a nurse,²⁰⁸ an attorney or retired judge,²⁰⁹ a representative of the family's religious background, or an ecumenical pastor, and a social worker or psychologist.

Board decisions would be advisory, but intended to represent the likely outcome if either party were to take the issue to court. All costs of counseling, mediation, and board adjudication would be free, provided as part of the hospital's total commitment to caring. If a party wanted legal representation during the board hearing, that party would bear the cost. Costs of outside legal action would also be borne by each party, with the understanding that hospital representation or participation would not be gratis because of the availability of numerous internal dispute resolution mechanisms within the hospital environment.

The intrusion of this model on the overall operation of the hospital would be minimal. Interaction of the counselor-mediator with affected families would be subtle, informal, and private. Additional burdens on an ethics committee would also be minimal if the committee were functioning in more than name only. If the hospital itself were disputing a patient's or family's treatment preference, then, following informal mediation between the family and hospital representatives, the dispute would be referred to another hospital's ethics committee for mediation or board adjudication.

206. In 1983, the President's Commission stated the belief that ethics committees could be "more rapid and sensitive than judicial review," but also suggested that further study was needed to ascertain the balance of advantages versus disadvantages. *DECIDING TO FOREGO*, *supra* note 36, at 168-69.

207. Ethics committees as decision making bodies may have some advantages over both family and the courts. They are better able to interpret medical facts and opinions, can include community members to represent decisionmaking values known to be shared by the patient, and their broad membership presents diverse views for consideration. Hoffmann, *Regulating Ethics*, *supra* note 145, at 784-85.

208. The doctor would address medical prognosis issues, and the nurse treatment and quality of care issues. Many ethics committees currently exclude the participation of nursing or other health care professionals other than physicians, but a nurse's presence is advisable, because "[n]urses have close contact with patients and families and may take the role of patient advocates. They may raise previously overlooked issues, contribute new information, or express the questions and viewpoints of patients and families." Lo, *supra* note 161, at 47.

209. The attorney, retired judge, or private law judge would address legal issues and also contribute to a balance of power away from the medical perspective.

5. Analysis

This Comment recommends legislative action to mandate hospital ethics committees and describe their responsibilities. Although one commentator believes that legislation requiring the establishment of ethics committees is not yet warranted,²¹⁰ this Author contends that ethics committees are essential to complete patient care. It may not be necessary to strictly regulate committee structure or composition, because hospitals and communities vary, but the existence and purpose of committees can and should be mandated. The best way to assure compliance would be to connect failure to comply with restrictions in federal funding. Maryland was the first state to enact legislation requiring the creation of "patient care advisory committees,"²¹¹ and it appears to be close to recognizing such committees as decision makers in cases involving persistent vegetative patients.²¹²

VII. CONCLUSION

Disputes and conflicts will always be inherent in decision making for terminally ill and incompetent patients on life-support systems. Safeguards already exist or can be crafted to protect the patient from improperly made decisions. However, it is essential to create a presumption in favor of the family rather than the medical or legal communities and to provide a dispute resolution process within the hospital to protect both patient and familial autonomy during difficult decisions. With continuing advances in medical technology and resulting longer life expectancies, the circumstances that render the decisions necessary occur more and more frequently.²¹³ There were only 600,000 persons eighty-five years old and older in the United States in 1950; by the year 2030,

210. Hoffmann, *Regulating Ethics*, *supra* note 145, at 751.

211. Hollinger, *supra* note 155, at 742.

212. The Maryland Health Law section of the Maryland State Bar proposed that families, after consultation with ethics committees, be permitted to remove life-sustaining treatment from relatives in a persistent vegetative state. Under the current state law, families of these patients must petition for a court order to remove treatment. Hoffmann, *Regulating Ethics*, *supra* note 145, at 750, 755.

213. In 1986, one expert estimated that there were at least five to ten thousand patients suspended in persistent vegetative states in the United States. Rhoden, *supra* note 11, at 424 (citing R. Cranford, *Patients With Permanent Loss of Consciousness*, in *BY NO EXTRAORDINARY MEANS: THE CHOICE TO FORGO LIFE-SUSTAINING FOOD AND WATER* 186, 189 (J. Lynn ed. 1986)).

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there will be an estimated eight million.²¹⁴ Without more caring forums, and a presumption that the family is the most knowledgeable decision maker, many more individuals will linger indefinitely²¹⁵ while the courts continue to resist the greater concern and better substituted judgment of families.²¹⁶

Lynne Sims-Taylor

214. JOAN KRAUSKOPF ET AL., *ELDERLAW: ADVOCACY FOR THE AGING* § 1.7 (from reproduction from the Draft) (West 1993).

215. It was estimated that with continued artificial nutrition and hydration Nancy Cruzan could have "lived" another 15 to 30 years.

216. It is not only the unspoken wishes of the incompetent in a persistent vegetative state that are at stake. Although most states today acknowledge the right of a competent person to refuse medical treatment, the families of these individuals often face a tremendous ordeal. In 1990, a man was refused his request to be removed from a respirator, despite his "Do Not Resuscitate Order," affidavit, conscious declaration, agreement of his wife and eldest son and one of his doctors. The hospital was afraid of legal liabilities and aware of the "governmental duty to protect life." *Deel v. Syracuse Veterans Admin. Medical Ctr.*, 729 F. Supp. 231, 233 (N.D.N.Y. 1990).

In 1988, a forty-six year-old woman was irreversibly incompetent following a massive cerebral hemorrhage, despite a series of invasive medical procedures initiated to save her life (brain surgery, craniotomy, gastrostomy, endotracheal tube, brain shunt). The hospital adamantly refused to honor the family's request to discontinue life-saving treatment. It ultimately took her family more than nineteen months to get the court to force compliance to an action they were positive was what their wife, mother, and daughter would have wanted. *Gray by Gray v. Romero*, 697 F. Supp. 580 (D.R.I. 1988).

In 1984, despite a conscious man's opposition to using a mechanical respirator, his doctors insisted that it remain connected as he would die otherwise; ethical concerns barred their acceding to his contrary wishes. *Bartling v. Super Ct.*, 209 Cal. Rptr. 220, 225 (1984). The hospital put his hands in restraints to prevent him from removing the respirator; he made a deposition stating he wanted it removed, but the trial court denied. He appealed, but died prior to the appellate hearing - still connected to the respirator. The court of appeals eventually reversed the trial court's opinion, but long after, Mr. Bartling suffered an ignoble death. *Id.*

