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Cindy Hylton Rushton

Elizabeth E. Hogue

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**THE ROLE OF FAMILIES AS SURROGATE
DECISIONMAKERS AFTER *CRUZAN V.*
DIRECTOR, MISSOURI
*DEPARTMENT OF HEALTH***

Cindy Hylton Rushton and Elizabeth E. Hogue***

I. INTRODUCTION

Nancy Cruzan was twenty-five years old when she was in an automobile accident. When rescue personnel arrived, her heart was not beating and she was not breathing. Her heartbeat and respiration were restored at the scene of the accident, and Nancy was transported to a local hospital. A neurosurgeon who examined her there hypothesized that she had cerebral contusions compounded by significant lack of oxygen. He estimated that Nancy was deprived of oxygen for between twelve and fourteen minutes.¹

Nancy remained in a coma for three weeks. She then progressed to a semiconscious state where she was able to ingest some nourishment. In order to ensure proper nourishment and hydration, however, physicians attending Nancy asked her husband for permission to insert a gastrostomy feeding tube, allowing them to route nourishment directly into Nancy's stomach. Nancy's husband consented to the procedure, and surgeons then implanted the feeding and hydration tube.²

Further efforts to rehabilitate Nancy failed. She remained in a Missouri state hospital in a persistent vegetative state.³ Generally, individuals in this state exhibit motor reflexes but appear to have no cognitive function.⁴

* Clinical Nurse Specialist in Ethics, The Johns Hopkins Children's Center, Baltimore, Maryland; B.S.N., University of Kentucky; M.S.N., Medical University of South Carolina; Doctoral Candidate, School of Nursing, Catholic University of America.

** B.A., Emory University; J.D., The University of Maryland.

1. *Cruzan v. Harmon*, 760 S.W.2d 408, 411 (Mo. 1988) (en banc), *aff'd sub nom. Cruzan v. Director*, Mo. Dep't of Health, 110 S. Ct. 2841 (1990).

2. *Id.*

3. *Id.*; see also Gladwell, *Woman in Right to Die Case Succumbs: Cruzan Was in Coma for Eight Years; Court Ruling Allowed Tube Removal*, Wash. Post, Dec. 27, 1990, at A3, col. 1. On December 14, 1990, Ms. Cruzan's family received permission from a state court to disconnect the tube supplying her with food and water. On December 26, at 3:00 a.m., she died of dehydration while anti-euthanasia protestors held a vigil outside the hospital.

4. *Cruzan*, 760 S.W.2d at 411.

Specifically,

[v]egetative state describes a body which is functioning entirely in terms of its internal controls. It maintains temperature. It maintains heartbeat and pulmonary ventilation. It maintains digestive activity. It maintains reflex activity of muscles and nerves for low level conditioned responses. But there is no behavioral evidence of either self-awareness or awareness of the surroundings in a learned manner.⁵

After several years, it became clear that Nancy would probably not regain her mental capacity. Nancy's parents asked practitioners treating her to stop nourishment and to remove the gastrostomy tube, but since this action would eventually result in her death, hospital personnel refused to honor their request without court approval.⁶

Mr. and Mrs. Cruzan then sought court approval for their request to remove the tube. The trial court granted the request on the basis that a person in Nancy's condition had a fundamental right under the Missouri State and United States Constitutions to refuse, or direct the withdrawal of, procedures that prolong life. The court determined that Nancy's statements to a housemate prior to her accident—that she would not want “to continue her life unless she could live ‘halfway normally’”—constituted a sufficient expression of Nancy's wishes to support the withdrawal of the tube.⁷

The Supreme Court of Missouri reversed the decision of the trial court. Although agreeing that there was a right to refuse treatment based upon the common law doctrine of informed consent,⁸ the court disagreed that there was a sufficient basis in this case to recognize Nancy's right to refuse treatment. Nancy's statements to her housemate were unreliable, said the court, for the purpose of judicially recognizing her purported wish to withdraw treatment.⁹

The state supreme court further declined to recognize a constitutional right to privacy as a basis for the decision to withdraw Nancy's feeding tube. The court observed that no such right to privacy could be found in the Missouri State Constitution and doubted whether such a right existed under the

5. *In re Jobes*, 3 ISSUES L. & MED. 183, 185 (1987); *In re Jobes*, 108 N.J. 394, 403, 529 A.2d 434, 438 (1982) (family or close friend of patient in irreversible vegetative state may exercise right to refuse life-sustaining treatment).

6. *Cruzan*, 760 S.W.2d at 410.

7. *Id.* at 411.

8. *See* *Schloendorff v. Society of New York Hosp.*, 211 N.Y. 125, 129-30, 105 N.E. 92, 93 (1914) (“Every human being of adult years and sound mind has a right to determine what shall be done with his own body.”).

9. *Cruzan*, 760 S.W.2d at 424. Ms. Cruzan's roommate testified that Ms. Cruzan would not want to continue in a vegetative existence without hope.

United States Constitution.¹⁰

Finally, the Missouri Supreme Court rejected the argument that Nancy's parents were entitled to order the termination of nourishment and hydration for their daughter. It concluded that persons cannot assume that choice for incompetent patients in the absence of the formalities required under Missouri's living will statutes or other clear and convincing evidence of a patient's wish to withdraw medical treatment.¹¹

The United States Supreme Court granted certiorari to consider whether Nancy possessed a right to refuse treatment under the United States Constitution that would require the hospital to withdraw life-sustaining treatment under the circumstances.¹² The Court further addressed the following question: Who has the right to make (or condition) decisions regarding the withdrawal of life-sustaining treatment in behalf of mentally incapacitated patients?¹³

This essay explores the legal and ethical bases for surrogate decisionmaking by family members in these situations. This essay concludes that a model of family-centered care for pediatric patients should be transposed upon decisions to withdraw treatment.¹⁴ If treating professionals believe that families make decisions which are not in the best interests of patients, they are free to challenge those decisions before hospital ethics committees and in the courts. As the states begin to adopt standards in light of *Cruzan*, other models of decisionmaking must be addressed to permit states to consider a family-centered model of decisionmaking in behalf of incompetent patients.

II. THE SUPREME COURT RULING

In addressing decisions made in behalf of incompetent individuals, the Court, in a 5-4 decision, initially recognized that the choice between life and death is a deeply personal decision of obvious finality. Each state, said the Court, has the right to safeguard the personal element of this choice through the imposition of strenuous evidentiary requirements. The due process

10. *Cruzan*, 760 S.W.2d at 417.

11. *Id.* at 425.

12. *Cruzan v. Director, Mo. Dep't of Health*, 110 S. Ct. 2841 (1990).

13. *Id.* at 2852.

14. For cases recognizing parental authority to refuse treatment in the child's behalf because of incompetence or youth, see generally *In re Barry*, 445 So. 2d 365 (Fla. Dist. Ct. App. 1984) (interest of a ten-month old terminally ill child lacking cognitive brain function outweighed those of the state); *In re L.H.R.*, 253 Ga. 439, 321 S.E.2d 716 (1984) (parent or legal guardian of terminally ill infant may exercise the infant's right to terminate treatment); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976) (father appointed guardian of his daughter and allowed to withdraw life support).

clause of the United States Constitution protects an interest in life, as well as an individual's right to refuse medical treatment.¹⁵

The Court further recognized that, unlike Nancy, not all incompetent patients will have loved ones available who are willing to make difficult treatment decisions. The Court also acknowledged that there are unfortunate cases in which family members act based upon their own best interests to the exclusion of the best interests of the patient. As a result, states are entitled to guard against potential abuse in these situations through the imposition of a heightened evidentiary burden to determine the patient's intent.¹⁶

Based upon these considerations, the Court rejected arguments that close family members must be permitted to substitute their judgment for that of an incompetent patient in the absence of substantial proof that the family's decision reflected one that the patient would make for herself. The Court expressed absolute confidence in Nancy's mother and father as loving and caring parents; actually, if Missouri were required by the United States Constitution to recognize a familial right of "substituted judgment," the Cruzans would be qualified decisionmakers.¹⁷ The Court, however, held that the due process clause requires only that the State recognize the patient's judgment. While close family members may have worthy and noble feelings for the patient, these feelings may not be entirely disinterested if the family does not want to witness the continuation of a life considered hopeless, futile, or degrading.¹⁸

The Court added that there are no automatic assurances that the views of close family members will necessarily be similar to those of the patient. All of the identified reasons for permitting Missouri to require clear and convincing evidence of a patient's wishes led the Court to conclude that the states may choose to defer only to a patient's wishes and to deny recognition of familial wishes. As a result, Nancy's parents, although previously recognized by the Court as loving and caring, were unable to exercise their judgment in behalf of their daughter.¹⁹

The Court's conclusion may best be described as a categorical rejection of any rights of family members to make decisions in behalf of their loved ones; as a result, the balance of power between families and the state is no longer in equilibrium. Instead, the decision disenfranchises family members from

15. *Cruzan*, 110 S. Ct. at 2853.

16. *Id.*

17. For scholarly discussion of the concept of "substituted judgment," see Liacos, *Is "Substituted Judgment" a Valid Legal Concept?*, 5 *ISSUES L. & MED.* 215 (1989); Robertson, *Is "Substituted Judgment" a Valid Legal Concept?*, 5 *ISSUES L. & MED.* 197 (1989).

18. *Cruzan*, 110 S. Ct. at 2856.

19. *Id.*

the decisionmaking process and reduces their involvement to that of bystanders. The only remaining role for family members is to ensure that the previously expressed wishes of a patient are carried out in the event of that patient's incompetence.

This result is unsettling because it demonstrates a schizophrenic regard for families. On the one hand, society espouses and affirms the central importance of family as an institution within our society. Yet when difficult questions must be resolved, family members, as appropriate decisionmakers, are discounted. For example, in the *Cruzan* case, Nancy's husband was permitted to consent to the surgical insertion of the gastrostomy tube, but was prohibited from removing it when, in his (and Nancy's parents') opinion, the tube no longer promoted the quality of life Nancy would have wanted. It appears that a system upheld by *Cruzan* may undermine our basic values regarding maintenance and support of family integrity. This bureaucratic, exclusionary, and individualistic ethic is both isolating and destructive to the institution of family in our society.

Charles Shannon observed that the moral imperative to maintain the family extends beyond social and historical issues:

We are not in a position to replace the family with something else which will be worse. Those moral surgeons who would cut the family from the body of human social institutions simply misconceive its role in our species' biological and cultural life. The mediations provided by the family are not just interchangeable loose parts of our human repertoire, they are things that constitute our humanity itself.²⁰

Despite recognition of the so-called "breakdown in the family structure" of American society, family members remain best able to make decisions in behalf of their loved ones. In cases where families are divided, or unable to make sound decisions in the view of the attending physicians, their decision-making authority may be challenged, or abrogated altogether.

As with children, there are limits to a family's decisionmaking authority. According to the President's Commission for the Study of Ethical Issues in Medicine and Biomedical and Behavioral Research:

The presumption that a family spokesperson is the appropriate surrogate may be challenged for a variety of reasons: decisional incapacity of family members, unresolvable disagreement among competent adult members of the family about the correct decision, evidence of physical or psychological abuse or neglect of the pa-

20. C. SHANNON, *THE POLITICS OF THE FAMILY: FROM HOMO SAPIEN TO HOMO ECONOMICUS* 7 (1989).

tient by the family, an indication that the family's interests conflict substantially with the patient's, or evidence that the family intends to disregard the patient's stable values, preferences, or specific earlier instructions about treatment.²¹

The Commission further recommended that, in spite of the possibility that all family members may be disqualified as surrogate authorities, consultation with family members was appropriate during the decisionmaking process.²²

III. THE MEANING OF FAMILY

The term "family" encompasses a tremendous range of characteristics, behaviors, and experiences. As in other western societies, a homogeneous conception of the family has become obscured in America. Traditional definitions premised upon kinship and marriage have become obsolete as non-traditional living arrangements and relationships have emerged.²³ No longer does "family" necessarily represent the nuclear family, comprised of a mother, father, and children. Our understanding of family composition has been broadened to accommodate prevailing societal trends such as single parenthood, culturally blended marriages, communal living arrangements, and extra-marital cohabitation.²⁴ Societal disintegration and the destructive forces of poverty, illiteracy, substance abuse, and violence contribute to the difficulties in developing a common understanding of the term.

A family is "a collection of individuals who share love, common grief, dwellings, interests, parentage, concerns, and aspirations."²⁵ Ordinarily, family is defined by kinship or blood relationships; however, an individual's "family" may be composed of a close friend or distant relative. This broad use of the term recognizes that those who are most knowledgeable, and have the most concern for the individual, may not be relatives by blood or marriage.²⁶ For the purposes of this discussion, the family is

that entity which consists of at least two human beings, one of whom is an adult, who are in relationship one to another in the sense that they coexist during at least some portion of time, communicate, recognize members, meet some of the emotional needs of

21. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL ISSUES IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT 128 (1983) [hereinafter PRESIDENT'S COMM'N].

22. *Id.* at 128-29.

23. See generally Hacker, *Farewell to the Family?*, 29 N.Y. REV. BOOKS 37-42 (1982), reprinted in J. AREEN, CASES AND MATERIALS ON FAMILY LAW 79-88 (1985).

24. See Lewis, *The Family—How Relevant?*, in THE FAMILY: SETTING PRIORITIES 19 (T. Brazelton & V. Vaughn eds. 1979).

25. *Id.*

26. PRESIDENT'S COMM'N, *supra* note 21, at 127.

members, and experience their identities as both individuals and as a group.²⁷

IV. A MORAL FRAMEWORK FOR FAMILY DECISIONMAKING

A morally defensible framework for competent adults is based upon a framework of shared decisionmaking.²⁸ This framework gives priority both to promoting a patient's well-being and respecting the patient's right to self-determination. Choices among treatment options should promote the well-being of the individual according to his or her unique goals, values, and preferences. Decisions are shared between the patient and the professionals who render health care.²⁹ These professionals offer expert knowledge, recommendations, and advice about medically accepted and available options, and the patient interprets those choices in light of her life goals and values.³⁰ To comprehend the values that influence choices of action, the context of an individual's life, including her familial, cultural, religious, and spiritual affiliations and preferences, must be appreciated.³¹

When a patient lacks the capacity to make choices, someone else must represent her particular values and preferences. Generally, family members act as surrogates unless the individual or the court has previously designated someone else.³² The surrogate endeavors to make choices based upon the patient's previously expressed directives or knowledge of her unique preferences and values. If these criteria are unavailable, the decision is made as a reasonable person in the patient's circumstances.³³ The surrogate acts in the patient's behalf to interpret the treatment options that will advance the patient's interests, goals, and preferences. Likewise, a framework based upon collaboration and shared decisions can also be extended to surrogates who make decisions in behalf of their loved ones.³⁴

27. G. White, A Philosophical Analysis of the Normative Status of the Family 12 (1986) (unpublished manuscript).

28. See generally HASTINGS CENTER, GUIDELINES ON THE TERMINATION OF LIFE-SUSTAINING TREATMENT AND THE CARE OF THE DYING (1988) [hereinafter HASTINGS CENTER].

29. See generally PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL ISSUES IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, MAKING HEALTH CARE DECISIONS: A REPORT ON THE ETHICAL AND LEGAL IMPLICATIONS OF INFORMED CONSENT IN THE PATIENT-PRACTITIONER RELATIONSHIP (1982).

30. See *id.* at 43-44.

31. Grodin & Burton, *Context and Process in Medical Ethics: The Contribution of Family-Systems Theory*, 6 FAM. SYS. MED. 421, 435 (1988).

32. See HASTINGS CENTER, *supra* note 28, at 24; PRESIDENT'S COMM'N, *supra* note 21, at 127-28.

33. HASTINGS CENTER, *supra* note 28, at 28.

34. PRESIDENT'S COMM'N, *supra* note 21, at 132.

When surrogate decisions are necessary, various concerns about family member discretion arise when the patient is no longer legally competent. One concern questions the ability of a surrogate to interpret the interests of another.³⁵ A central problem associated with surrogate decisionmaking is the inherent difficulty in judging (and acting upon) beneficial and burdensome events experienced by others.³⁶ The legitimacy of judging the quality of another's life may also be questioned since an individual attaches unique meaning to her own life. Moreover, "society has a significant interest in protecting and promoting the high value of human life."³⁷ If an individual documents her preferences and values regarding life and death, however, those preferences should be honored.³⁸

As a practical matter, the majority of individuals have neither formalized their values regarding life and death nor identified a guardian to act in their behalf if incompetent to do so.³⁹ In light of the available options, it is prudent and proper to presume that family members are capable of assuming the role of surrogate. As Professor Rhoden suggests, the judicial standards previously used for determining an incompetent patient's wishes have failed to yield less subjective decisions when family members are disqualified.⁴⁰ A family's strong bonds of affection and commitment, its history of shared experiences over an extended period of time, its willingness to assume responsibility, and its assessment of the individual's life in question yield the greatest concern for the well-being of their relative.

Aside from functional characteristics such as procreation, economic cooperation, and socialization of children, the family serves as a kinship organization. As a natural group, a family is emotionally and functionally interconnected. Under optimal conditions a family: provides support, love, encouragement, protection, and concern for its members; fosters individuation of its members; attempts to help its members to actualize their potential; and encourages its members to lead fulfilling lives while cultivating a sense of belonging.⁴¹

Kinship often transcends other relationships. Traditionally, the family has provided a sanctuary for intimacy in an otherwise impersonal and func-

35. Rhoden, *Litigating Life and Death*, 102 HARV. L. REV. 375, 378 (1988).

36. *In re Peter*, 108 N.J. 365, 376, 529 A.2d 419, 425 (1987).

37. PRESIDENT'S COMM'N, *supra* note 21, at 184.

38. *See generally* *Cruzan v. Director, Mo. Dep't of Health*, 110 S. Ct. 2841 (1990); *In re Farrell*, 108 N.J. 335, 529 A.2d 404 (1987); *In re Eichner*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 64 (1981).

39. *See Cruzan*, 110 S. Ct. at 2857 n.1 (O'Connor, J., concurring).

40. Rhoden, *supra* note 35, at 437.

41. Lewis, *supra* note 24, at 20-22.

tionalized world.⁴² These intimate relationships transcend impersonal associations with others and lead to more meaningful relationships based upon personal commitments to one another. Personal commitments to others are composed of these intimate relationships and are central to defining oneself "even when the concerns of the relationship are independent of, or hostile to, the values of the culture and the welfare of others."⁴³

Family members often experience a "privileged emotional climate" worthy of protection from intrusion by outsiders.⁴⁴ As the nuclear family developed, a shield of privacy was erected to protect the family from outside intrusion. Like other intimate relationships, social intrusion into family relationships has traditionally been limited, or at least regulated, by giving priority to standards of privacy and personal autonomy.⁴⁵ By doing so, intimate personal relationships may flourish in a protective environment. As a result, a sense of solidarity emerges that separates the interests of individual family members from those of the surrounding community.⁴⁶ Strict standards should therefore govern warranted intrusions into family relationships.

Families also serve as a normative system that consists of formal (and informal) rules and regulations which govern the conduct of major aspects of life. This complex system of norms is organized for the preservation of basic familial and societal values.⁴⁷ The emergence of a consistent system of shared values begins in early childhood and continues throughout one's life, and the family of origin plays an important role in shaping this view of the world.⁴⁸ Therefore, family members have a unique perspective on the life experiences and values of a relative, based upon a shared value structure and common experiences.

For example, a family may place high priority on achievement and cognitive ability. Throughout childhood, activities that promote academic

42. May, *The Metaphysical Plight of the Family*, 2 HASTINGS CENTER STUD. 19, 19 (May 1974).

43. Schoeman, *Rights of Children, Rights of Parents, and the Moral Basis of the Family*, 91 ETHICS 6, 14 (1980).

44. E. SHORTER, *THE MAKING OF THE MODERN FAMILY* 205 (1975).

45. Laws infringing on a person's right to privacy are subject to strict scrutiny and will be upheld only upon a demonstration that the law is necessary to serve a compelling state interest. See *Roe v. Wade*, 410 U.S. 113 (1973) (invalidating state law barring woman's choice of abortion); *Eisenstadt v. Baird*, 405 U.S. 438 (1972) (extended right of access to contraceptives to unmarried persons); *Griswold v. Connecticut*, 381 U.S. 479 (1965) (invalidating state criminal law barring married couples from using contraceptives); cf. Kramer, *The Birth of Privacy Law: A Century Since Warren and Brandeis*, 39 CATH. U.L. REV. 703 (1990) (discussing the genesis of the "right to be let alone" and describing its incorporation into contemporary American jurisprudence).

46. Schoeman, *supra* note 43, at 15.

47. See generally E. GROVES, *THE FAMILY AND ITS RELATIONSHIPS* (1932).

48. *Id.*

achievement are consistently rewarded, while irresponsible behavior and poor grades are consistently reprimanded. Through family discussions and interactions, individual contributions to society are evaluated by their potential to advance the quality (or state) of knowledge in a particular field. If an individual from this particular family were asked for her definition of a meaningful life, her response would predictably mirror the manifested values of her family. In addition, a family's experience in making decisions and managing stress plays an intimate role in how health care decisions are considered and made.

The family also serves as an instrument or agent of the larger society to reinforce and sanction the behaviors of its members and to assure that the broad goals of society are upheld. The internal control and authority structure of the family provides the system by which rules and obligations are enforced and rewarded. Hence, shared values, beliefs, meanings, and patterns of interaction develop within, and are expressed by, the family, reflecting their uniqueness and consistency with larger social structures. For instance, a family that values achievement and cognitive ability would likely view a life in a persistent vegetative state as a life not worth living. Their viewpoint would reflect not only the unique view of their family; it would reflect a common societal sentiment that a life devoid of pleasure and meaningful interaction is not in the best interests of the individual.

One reason for disqualifying family members as surrogate decisionmakers is their questionable emotional stability. Many have suggested that the crises surrounding illness and injury generate such tremendous stress that family members are incapable of making rational judgments. Traditionally, the emotions have been viewed as disruptive forces that obscure rational judgment and compel us to behave in "regrettable, or at least irrational, ways."⁴⁹ Moreover, the traditional Kantian view of moral judgment, predicated on rationality, impartiality, and universality, instructs us to divorce our moral judgments from the distractions of emotion.⁵⁰

Certainly, family members experience a great deal of emotional upheaval during crises. Instead of viewing the emotional state as a liability, however, some authors have suggested that emotions serve an important role in decisionmaking.⁵¹ In recent literature, emotions play not only a motivational role, as some traditionalists acknowledge; they also perform an epistemologi-

49. Calhoun & Solomon, *Introduction to WHAT IS AN EMOTION?: CLASSICAL READINGS IN PHILOSOPHICAL PSYCHOLOGY* 8 (C. Calhoun & R. Solomon eds. 1984).

50. L. BLUM, *FRIENDSHIP, ALTRUISM AND MORALITY* 2 (1980).

51. See, e.g., Callahan, *The Role of Emotion in Ethical Decision-Making*, 18 *HASTINGS CENTER REP.* 9, 9 (June/July 1988) ("The ideal goal is to come to an ethical decision through a personal equilibrium in which emotion and reason are both activated and in accord.").

cal (or informing) role in moral judgment. From this perspective, emotions are viewed as an outlet for revealing the morally salient features of a situation; they are a reflection of what is important.⁵² Emotions serve both to raise the consciousness and motivate action. When emotions are activated by some stimulus, such as the catastrophic cerebral injury of a loved one, a cascade of responses are activated to serve as beacons for individual action. Emotions encourage action. Hence, emotional involvement may promote perseverance in the resolution of difficult ethical dilemmas.⁵³

Because of their emotional investment and energized emotional state, family members are uniquely qualified to act as surrogates for their relatives. Health care providers or agents of the court cannot generate an emotional investment in the individual which is commensurate with that of the family. They lack the benefit of shared experiences over time and may therefore draw only upon their professional relationship with the individual when determining a patient's best interest. They may also have other competing interests. Consequently, a court's reliance on objective standards and generalized principles, which are used in a dispassionate and disinterested manner, may prohibit an accurate and complete appreciation of the context of the decision and the relevant life goals, values, and preferences of the incompetent individual.

If the emotions of family members are viewed as informative, rather than obfuscating, they provide an important dimension for assessment and action. The emotions serve as a barometer for both recognizing regions of the situation that are morally significant and identifying an occasion for moral action. A moral framework that (i) attends to the particularities and context of a specific situation, (ii) incorporates the values and expectations involved in familial roles and relationships, and (iii) cultivates moral sensitivity to emotions will yield a more satisfactory resolution to the quandary of continued treatment.⁵⁴

Another concern with family-centered decisionmaking involves the assumption that a family will advance its interests over those of the individual. As John Hardwig has argued, a family has legitimate interests when a relative's life has a direct impact on the lives of others.⁵⁵ Familial duties and participation in family activities are the direct responsibility of all members

52. See generally C. TAYLOR, *HUMAN AGENCY AND LANGUAGE: PHILOSOPHICAL PAPERS* (1985).

53. Callahan, *supra* note 51, at 10.

54. See generally J. CHILDRESS, *WHO SHOULD DECIDE?: PATERNALISM IN HEALTH CARE* 55 (1982) (chapter entitled *Respect for Persons*).

55. Hardwig, *What about the Family?*, 20 *HASTINGS CENTER REP.* 5, 5 (Mar./Apr. 1990).

of a society. Although there is little formal punishment for unfulfilled family obligations, there are pervasive and consistent socially mediated pressures, and direct and indirect rewards and sanctions, all of which motivate individuals to conform to familial and societal norms.⁵⁶ The essence of family membership requires moral decisionmaking based upon utilitarianism.⁵⁷ Therefore, family members necessarily have interconnected interests that may not be separated.

When an individual is permanently unconscious and incapable of self-expression, some have argued that her interests are limited to the prolongation of biological life.⁵⁸ Since these individuals cannot be burdened in the usual sense, and the reasons for continued treatment may be absent, an assessment of the burdens of continued existence must be enlarged reasonably to consider the burdens on those most affected by their care—the family.⁵⁹

This assessment should not deliberately disregard the autonomy of the individual. Rather, an enlarged conception of respect for the person, which encompasses respect for the family, is necessary to appreciate that person fully. To treat the patient respectfully is to acknowledge and value her existence outside the medical context without resort solely to the advancement and preservation of professional or state interests.⁶⁰ The patient's interests are necessarily embedded in the interests of her family members, to whom her life is valuable. To respect the individual fully is to acknowledge the importance of her world and the relationships that are central to it.

Unilateral decisionmaking based solely upon "medical indications" or state statutes denies the fullness of an individual's life and the value of the relationships which have sustained it over a lifetime. As Professor Annas has claimed, unilateral decisionmaking denies a person like Nancy Cruzan the right to have her family speak for her and to exercise its natural, protective role.⁶¹ Thus, "she is deprived of her only voice and is effectively made a nonperson."⁶² Unfortunately, individuals constructing health policy, and those involved in individual health care decisions, often mistrust the motives of a family because of a limited number of personal experiences. Those neg-

56. W.J. GOODE, *THE FAMILY* 6 (1964).

57. Hardwig, *supra* note 55, at 6.

58. J. GLOVER, *CAUSING DEATH AND SAVING LIVES* 39-59 (1977); McCormick, *To Save or Let Die: The Dilemma of Modern Medicine*, 229 J. A.M.A. 172, 175 (1974).

59. PRESIDENT'S COMM'N, *supra* note 21, at 185.

60. These arguments may also be applied to the care of children. See Rushton & Glover, *Involving Parents in Decisions to Forego Life-Sustaining Treatment for Critically Ill Infants and Children*, 1 A.A.C.N. CLINICAL ISSUES IN CRITICAL CARE NURSING 206 (1990).

61. Annas, *Nancy Cruzan in China*, 20 HASTINGS CENTER REP. 39, 39-40 (Sept./Oct. 1990).

62. *Id.* (endnote omitted).

ative experiences color future familial interactions and are translated into a defensive and distrusting, rather than a supportive and faithful, approach to decisionmaking, which ultimately devalues the family as a decisionmaker.

V. LEGAL BASIS OF FAMILY DECISIONMAKING IN DECLINING TREATMENT

The legal basis for a family-centered model of decisionmaking may be derived from judicial decisions regarding (i) withdrawal of life-sustaining treatment and (ii) "no code" or "do not resuscitate orders."

States (other than Missouri) may reject the clear and convincing evidentiary standard of *Cruzan* when assessing the patient's interests by following *In re Nancy Ellen Jobes*.⁶³ In that case, the Supreme Court of New Jersey recognized the primacy of family member decisions in behalf of incompetent loved ones.

Nancy Jobes was pregnant with her first child when she was injured in an automobile accident on March 21, 1980. After her admission to Riverside Hospital for treatment of the injuries sustained, doctors discovered that her fetus had died. During surgery to remove the fetus, Mrs. Jobes suffered a loss of oxygen and blood to the brain. This caused irreversible damage to the portion of her brain controlling thought and movement. Mrs. Jobes never regained consciousness.⁶⁴

In July 1980 Mrs. Jobes was transferred to the Lincoln Park Nursing Home. Her condition remained unchanged. She was incontinent and required a catheter for continuous bladder irrigation. Mrs. Jobes received routine enemas for bowel evacuation and suffered from chronic urinary tract infections. Antibiotics and antiseizure medications were regularly administered as well. Because Mrs. Jobes was unable to take sustenance orally she received nutrition and hydration through a jejunostomy tube (j-tube) inserted directly into her small intestine.⁶⁵

After Mrs. Jobes had remained in a persistent vegetative state for five years, her husband petitioned the Chancery Division for a court order that would permit the removal of the feeding tube. The nursing home had re-

63. 108 N.J. 394, 529 A.2d 434 (1987).

64. *Jobes*, 108 N.J. at 401, 529 A.2d at 437. For a concise analysis of this decision, see *In re Jobes*, 3 ISSUES L. & MED. 183 (1987).

65. *Jobes*, 108 N.J. at 402, 529 A.2d at 438. See generally Comment, *Artificial Nutrition and the Terminally Ill: How Should Washington Decide?*, 61 WASH. L. REV. 419 (1986). The jejunostomy tube introduces liquified food into the small intestine. Complications often result, including wound opening, herniation, peritonitis, nerve damage, and hemorrhage. *Id.* at 425-26 nn.49-50.

fused this request on moral grounds.⁶⁶

After a seven-day trial, the court found that there was clear and convincing evidence that Mrs. Jobs was in a persistent vegetative state and would want the j-tube removed. Removal of the tube was authorized; however, the court held that the nursing home would not have to participate and could transfer Mrs. Jobs to another facility.⁶⁷

The nursing home and Mr. Jobs appealed; the New Jersey Supreme Court granted direct certification. The court held that families or close friends of an irreversibly vegetative patient may exercise judgment and refuse life-sustaining medical treatment in the patient's behalf. The court stated that a guardian must be appointed only if no close relatives are available and the patient has not left clear and convincing evidence that they wish for another to make medical decisions in their behalf.⁶⁸

Applying this rule to the case, the court observed that the family of Mrs. Jobs was a close and loving one. The court therefore assumed that the family would be the most qualified surrogate because of its intimate knowledge of the patient's philosophy of life. The court defined close family members to include spouses, parents, siblings, or adult children. A court may also look to aunts, uncles, cousins, or others if they function as the patient's nuclear family. In the absence of these persons, a court may appoint a guardian to make decisions in the patient's behalf.⁶⁹

The court acknowledged that some situations may arise where family members will not act to protect a patient's best interests. However, these cases are exceptional. In this situation, the burden is placed upon health care professionals to initiate guardianship proceedings.⁷⁰

The court also recognized situations where health care professionals fail to determine whether a family is acting in the patient's best interests. However, practitioners will not be subject to either criminal or civil liability if these determinations are made in good faith.⁷¹

Thus, *Jobs* provides a strong basis for a state to reject the standards upheld in *Cruzan* in favor of a decisionmaking process that relies on the family—unless health care professionals prove that the family lacks appropriate judgment or ability to make decisions in behalf of the patient.

66. *Jobs*, 108 N.J. at 410, 529 A.2d at 442.

67. *Id.* at 401, 529 A.2d at 437.

68. *Id.* at 420, 529 A.2d at 447. See generally Moore, *Two Steps Forward, One Step Back: An Analysis of New Jersey's Latest Right-to-Die Decisions*, 19 RUTGERS L.J. 955 (1988) (analyzing *Jobs* and its two companion cases).

69. *Jobs*, 108 N.J. at 420, 529 A.2d at 447.

70. *Id.*

71. *Id.*

In addition to cases like *Jobes*, decisions concerning “no code” or “do not resuscitate” orders may also provide a strong foundation for family-centered decisionmaking. An example is *In re Shirley Dinnerstein*.⁷²

The patient in that case was a sixty-seven year old woman suffering from Alzheimer’s disease. Destroying the brain, the condition is progressive and unremitting; it results in loss of memory, personality disorganization, loss of intellectual function, and, eventually, the loss of all motor function. The disease typically leads to a vegetative or comatose condition, followed by death. To date, there is no known cure for the disease and no available treatment which can slow or arrest its course.⁷³

Shirley Dinnerstein was diagnosed with Alzheimer’s disease in July 1975. She entered a nursing home in November 1975, where her complete disorientation, frequent psychotic outbursts, and deteriorating ability to control elementary bodily functions made her dependent upon intensive nursing care.⁷⁴

In February 1978 the patient suffered a massive stroke, leaving her completely paralyzed on her left side. By the time the case was decided, she was in a persistent vegetative state and fed through a nasogastric tube. Her condition was hopeless because she would never recover; yet, no one could predict with certainty when she would die.⁷⁵ Under these circumstances, her attending physician recommended that, when and if cardiac arrest occurred, resuscitation efforts should not be undertaken.

Resuscitation efforts typically involve the use of cardiac massage or chest compression and delivery of oxygen and mechanical ventilation through an endotracheal tube into the lungs. Various plastic tubes are usually inserted intravenously to supply medications (or stimulants) directly to the heart. These medications may also be supplied by direct injection into the heart with a long needle. A defibrillator may be used, applying electric shock to the heart to induce contractions. A pacemaker, in the form of an electrical conducting wire, may also be fed through a large blood vessel directly to the heart’s surface to stimulate contractions and to regulate heartbeat. These procedures, to be effective, must be initiated without delay because cerebral anoxia will normally produce irreversible brain damage within three to five minutes, and total brain death within fifteen minutes. Many of the procedures described above may be characterized as highly intrusive and, in some cases, violent. The defibrillator, for example, causes violent and painful

72. 6 Mass. App. Ct. 466, 380 N.E.2d 134 (1978).

73. *Dinnerstein*, 6 Mass. App. Ct. at 467, 380 N.E.2d at 135.

74. *Id.*

75. *Id.* at 467-68, 380 N.E.2d at 135.

muscle contractions.⁷⁶

The patient's immediate family, consisting of a son and daughter, agreed with the doctor's recommendation to withhold resuscitation in the event of cardiac or respiratory arrest. They joined with their mother's physician in petitioning the court for a "no code order."⁷⁷

The Massachusetts Appeals Court decided that withholding life-sustaining treatment in the form of resuscitation, to ease the imminent passing of a terminally ill patient, was permissible in light of both the patient's history and condition and the wishes of her family.⁷⁸

Jobs and *Dinnerstein* are examples of medico-legal decisions that offer an analytical framework for family-centered decisionmaking. While states remain free to reject family members as decisionmakers in accordance with the *Cruzan* case, there is a sound legal basis for family-centered decisions involving incompetent patients.

VI. A FAMILY-CENTERED MODEL FOR SURROGATE DECISIONMAKING

The concept of family-centered care provides the basis for delivering health care services to children.⁷⁹ This approach is based upon respect for the family as the constant in the child's life; it recognizes the unique strengths of each family in caring for their child, and it supports collaboration at all levels of decisionmaking. In addition, it advocates optimal com-

76. *Id.* at 468-69, 380 N.E.2d at 135-36. Early defibrillation is now accepted both nationally and internationally as the simplest, safest, and most accurate treatment for cardiac arrest. The widespread implementation of automated external defibrillators has increased the survival rate from sudden cardiac arrest. Bocka, *Automatic External Defibrillators*, 18 ANNALS EMERG. MED. 1264 (1989); Cummins, *From Concept to Standard-of-Care? Review of the Clinical Experience with Automated External Defibrillators*, 18 ANNALS EMERG. MED. 1269 (1989).

77. Also referred to as an ONTR (order not to resuscitate) or a DNR (do not resuscitate), a "no code" order, when "entered in a patient's medical record[,] instructs the nursing staff, as part of the attending physician's ongoing instructions to the nursing staff for the care of the patient, not to summon the code team in the event of cardiac or respiratory arrest." *Dinnerstein*, 6 Mass. App. Ct. at 469 n.3, 380 N.E.2d at 136 n.3 (citing Rablein, Gillerman & Rice, *Orders Not to Resuscitate*, 295 NEW ENG. J. MED. 364 (1976)); see also Legislative Comment, *Do Not Resuscitate Orders: A Matter of Life and Death in New York*, 4 J. CONTEMP. HEALTH L. & POL'Y 449 (1988) (analyzing the New York DNR law as it pertains to an adult with capacity, an adult without capacity, and a minor).

78. *Dinnerstein*, 6 Mass. App. Ct. at 474-75, 380 N.E.2d at 138-39. Although cardiopulmonary resuscitation (CPR) is meant to prevent unexpected death, CPR is not appropriate in the care of a terminally ill patient because it may violate "an individual's right to die with dignity." *Standards for Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care*, 227 J. A.M.A. 837, 864 (1974).

79. See T. SHELTON, E. JEPFSON & B. JOHNSON, *FAMILY-CENTERED CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS* 7 (2d ed. 1987).

munication among health care providers and family members.⁸⁰ These concepts are generally applicable to family decisionmaking, particularly when an individual becomes incapable of self-expression.

A model for surrogate decisionmaking that recognizes the central role of the family is necessary to protect and interpret the interests of its members. This model maintains family integrity while creating a balanced partnership between families and health care professionals. A family-centered health care system can become a reality through the establishment of structures that facilitate optimal partnerships between the individual, the family, health care professionals, and society.⁸¹ States should adopt family-centered policies to address surrogate treatment decisions.

VII. RECOMMENDATIONS TO THE STATES

States should begin with a framework that affirms the primacy of the family as the surrogate decisionmaker. Absent disqualifying motivations, a family's decision to discontinue treatment should be honored.⁸²

In cases involving surrogate decisionmakers, the decisionmaker's actions should be guided by her unique interpretation of the patient's best interest. This interpretation should be based upon historical evidence, shared experiences, and common values. A family must also consider its own interests in relation to (i) their moral obligations as family members⁸³ and (ii) the boundaries of the moral obligation to preserve life at all costs.⁸⁴ Generally, as long as the decisions of the family fall within the range of morally acceptable action, the decisions should be honored.

The presumption favoring familial decisionmaking for the terminally ill is not absolute. States must establish procedural safeguards both to ensure adequate evaluation of the evidence concerning the patient's wishes and identify appropriate surrogates.⁸⁵ Generally, physicians and state authorities

80. *Id.*; see also SURGEON GENERAL'S REPORT: CHILDREN WITH SPECIAL HEALTH CARE NEEDS CAMPAIGN '87: COMMITMENT TO FAMILY CENTERED COORDINATED CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS (1987).

81. See generally Gibbs, *Love and Let Die*, TIME, Mar. 19, 1990, at 64 ("[I]n a poll conducted last month for TIME/CNN, 80% of those surveyed said decisions about ending the lives of terminally ill patients who cannot decide for themselves should be made by their families and doctors, rather than lawmakers.").

82. Rhoden, *supra* note 35, at 437 n.273 ("According to a poll conducted for the President's Commission, 57% of persons would want a family member to make medical decisions for them if they were incapacitated.").

83. Hardwig, *supra* note 55, at 6.

84. See generally *On Withdrawing Artificial Nutrition and Hydration*, ORIGINS, June 7, 1990, at 53; NCCB Committee for Pro-Life Activities, *Guidelines for Legislation in Life-Sustaining Treatment*, ORIGINS, Jan. 24, 1985, at 526.

85. Rhoden, *supra* note 35, at 439-40.

must bear the burden of proof when questioning the motives and competencies of familial decisionmakers.⁸⁶

Instead of categorically discounting families, states must address the special cases that challenge this basic premise. For instance, individuals who are "unbefriended" and lack ties of kinship or affiliation with others will require alternative surrogates to the family-centered approach. Although consensus for the proper solution to these problems is lacking, institutions and states must develop and test (rather than avoid) the various models of surrogate appointment. Some suggestions include surrogate committees, court-appointed guardians, state ombudsmen, or public fiduciaries.⁸⁷

However, not all family members are willing to assume the role of surrogate when decisions to forego treatment are involved. When a family cannot (or is unwilling to) accept the surrogacy role, or when there are serious questions surrounding the propriety of family decisions, an unencumbered and timely process to identify an appropriate surrogate must be instituted. Clarification of the circumstances that necessitate judicial intervention is essential. For example, a requirement for review by ethics committees prior to judicial review should be firmly established.

Strategies to support and enhance the capabilities of the family as decisionmaker must be developed. Consumers must be educated about living wills and durable powers of attorney for health care issues. Health care professionals and families must be encouraged to assist patients to "*authentically* exercise their freedom of self-determination."⁸⁸ According to Sally Gadow, individuals should therefore be assisted "to discern and clarify their values in the situation, and on the basis of that self-examination, to reach decisions which express their reaffirmed, perhaps recreated, complex of values."⁸⁹

A greater articulation (and reexamination) of health care decisionmaking is necessary in the moral analysis of decisions to forego treatment. Health care providers, families, and society must collaborate to define the range of morally acceptable choices in each individual situation. In doing so, societal and community standards and values should be examined. No longer, as Nancy Rhoden suggests, should the technological imperative and the preser-

86. *Id.* at 441 ("[C]ourts should put the burden of proof on the physician to show that the family's decision is unreasonable.").

87. HASTINGS CENTER, *supra* note 28, at 24-25.

88. Gadow, *Existential Advocacy: Philosophical Foundation of Nursing*, in *NURSING: IMAGES AND IDEALS: OPENING DIALOGUE WITH THE HUMANITIES* 85 (S. Spicker & S. Gadow eds. 1980) (emphasis in original).

89. *Id.*

vation of life at all costs be sustained.⁹⁰ Thus, health care consumers must take responsibility for communicating with health care providers and policy makers to articulate relevant values and treatment parameters. Additionally, health care consumers must begin to appreciate the limits of technology in order to avoid inappropriate demands for futile therapies.⁹¹

Living will legislation and procedures identify specific interventions that should be eliminated when suffering or cognitive impairment precludes cognitive awareness and the exercise of choice.⁹² When defining their preferences, competent individuals must be assisted within a framework that pursues a life worth living, not a life annexed by technology. Throughout this process, however, health care consumers must recognize that sharing decisionmaking authority does not mean that they can insist upon any desired treatment. Rather, choices are made from among the medically acceptable (and available) options which can reasonably be expected to promote the patient's well-being.⁹³

A framework based upon an individual's values would neither require individuals to imagine all patient outcomes nor anticipate every contingency. This is unrealistic and unnecessarily restrictive. For example, the vitalist may convey a deeply held value for life in any form, regardless of cognitive functioning. For this individual, prolongation of biological life at all costs may be her ultimate goal.

To others, however, a life devoid of pleasure, reason, and cognition may be more burdensome than the expectation of death. For instance, if an individual states that they "do not want to be kept alive on a respirator," these preferences could be illuminated by discerning (i) her perception of what life on a respirator would be like and (ii) the particularities of why that life would not be worth living. In this case, the individual may ultimately value cognitive ability, the capacity to experience pain or pleasure, and meaningful interaction with others. Moreover, decisionmakers should give import to the patient's self-care capabilities, such as feeding independently, and the pa-

90. Rhoden, *supra* note 35, at 379.

91. Lamm, *High-Tech Health Care and Society's Ability to Pay*, HEALTHCARE FIN. MGMT., Sept. 1990, at 21. "There is an almost unlimited number of things that we can do to people at the margin. Health Economist Victor Fuchs calls it 'the flat of the curve medicine.'" *Id.* at 24; see also P. MENZEL, MEDICAL COSTS, MORAL CHOICES 3 (1983).

92. See generally AMERICAN SOCIETY OF LAW AND MEDICINE, LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS (A. Doudera & J. Peters eds. 1982); SOCIETY FOR THE RIGHT TO DIE, HANDBOOK OF LIVING WILL LAWS (1987); P. WILLIAMS, THE LIVING WILL SOURCE BOOK (1986).

93. PRESIDENT'S COMM'N, *supra* note 21, at 43-44. The Commission recommended "that patient and provider collaborate in a continuing process intended to make decisions that will advance the patient's interests both in health . . . and in self-determination." *Id.* at 43.

tient's ability to control independent physiology, such as breathing without a respirator. When the individual's values are expressed in this way, caregivers could more accurately assess whether the interventions proposed will advance or violate an individual's preferences.

A family should be afforded the opportunity to communicate meaningfully with policy makers and health care professionals. For example, the establishment of advisory committees and institutional ethics committees with members who do not provide health care would enhance the present understanding of the familial perspective. Mechanisms facilitating an ongoing dialogue with administrators and policy makers are essential to ensure that institutional policies and legislative initiatives are consistent with community values. In addition, any developed standards must not unfairly (or unlawfully) discriminate against the poor and socially disadvantaged segments of society.

Moreover, the health care community must abrogate the various barriers to optimal decisionmaking in the clinical setting, e.g., environmental barriers, inadequate communication, asymmetric information, lack of support systems, and paternalistic professional attitudes. A greater commitment to documentation of patient preferences and values must also occur at every level of the health care system. Research initiatives that explore the values, beliefs, and perceptions of family members in the experience of surrogate decisionmaking would provide policy makers and health care professionals with substantive fodder for internal policies and therapeutic interventions. Finally, development of tools to assess the values, motives, and competency of family members as decisionmakers is necessary.

VIII. CONCLUSION

The health care community must affirm the commitment to the family as the appropriate surrogate decisionmaker. In doing so, medical professionals will recognize the interconnected relationships between the biological, psychological, social, and moral dimensions of our lives, as expressed through the family. Although the authority of the family is not absolute, it is incumbent upon health care professionals and legislators to devise policies which do not unfairly disenfranchise the family by artificially placing it in an adversarial position with one of its members.