

A Philosophical Analysis of Substitute Decision-Making: The Case of Ms. Nancy Cruzan

by Jacqueline J. Glover

It is difficult to be a moral agent, to make decisions that reflect a solid moral character and advance the moral values we share with others in a community. We must deliberate carefully about the choices we make on our own behalf, recognizing that although we may be the ones primarily affected, others necessarily will be too. How much more difficult are the decisions we make on behalf of others. Yet, such decisions cannot be avoided. As members of a moral community we share a concern for the well-being of others. And more particularly, within specific roles and relationships, such as spouse, parent or professional, we are responsible for the well-being of certain specific others. Although we may be affected by all our choices, we recognize what a grave burden it is to make choices that primarily affect someone else. The tragic story of Ms. Nancy Cruzan, and the court opinions that have been rendered, help highlight the complexities that accompany such substitute decision-making. This essay contains an analysis of the major features of substitute decision-making in an attempt to provide some guidance for making morally sound decisions. Five major questions will be addressed: What justification can be provided for substitute decision-making? Who is an appropriate substitute decision-maker? What are appropriate standards for decision-making? What limits are there to substitute decisions? How do we consider the interests of other parties?

What Justification can be Provided for Substitute Decision-Making?

The majority opinion of the Missouri Supreme Court clearly identified one question as central to the decision in the case of Nancy Cruzan. "May a guardian order that all nutrition and hydration be withheld from an incompetent ward who is in a persistent vegetative state, who is neither dead..., nor terminally ill?"¹ The foundation of their answer is the claim that the

authority for a substitute (third party) choice comes from the state's authority, not from any constitutional right of the ward. The guardian is a delegatee of the state's *parens patriae* power.² If this is the case, and the state has a well-acknowledged interest in preserving life,³ then the guardian, as the state's delegatee, should also primarily advance this interest in preserving life. Therefore, a guardian cannot order the withholding of nutritional support and the subsequent death of an incompetent ward.

The Court is certainly correct in identifying the need to provide a justification for substitute decisions. In order to determine what decisions are acceptable, we must first understand the purpose the substitute decision is meant to fulfill. What is the rationale behind the use of substitute decision-makers?

The framework the Court provides of state delegatee for the preservation of life has a major shortcoming. If it were the function of every substitute decision-maker to decide to preserve life, then there hardly seems a need for a special decision-maker. There is no requirement for independent knowledge, assessment or choice regarding the particularities of the individual and his or her life. The state delegatee framework eliminates the need for a substitute decision-maker more than it provides the rationale for one.

A more appropriate framework for understanding substitute decision-making is the moral framework of shared decision-making in medicine. One of the central values in a moral community, and in medicine particularly, is the well-being of the individual. Yet the notion of well-being or benefit is far from straightforward. It requires two kinds of expertise, the expertise of the health care professional who can say what medicine can do for a patient, and the expertise of the patient who can say what this means for his or her life. We count as beneficial those things which promote our unique goals and values.

Understanding the idea of well-being or benefit requires the expertise of the health care professional who can say what medicine can do for a patient, plus the expertise of the patient who can say what this means for his or her life.

As a general rule in health care, beneficial interventions are those which prolong life or prevent premature death, restore function, improve quality of life, reduce or eliminate pain and/or suffering, or improve knowledge, either the patient's or the professional's. Yet it is often the case that desired goals are in direct competition with each other and that one can be accomplished only at the expense of others, or that some goals are simply preferred above others. A universal ranking of goals is highly unlikely, as individuals will balance personal goals and values differently. The patient's perspective is thus essential in determining how well-being is to be understood.

Another key value in a moral community is that of respect for persons. Each of us is valuable in ourselves, for who we are as unique individuals, and not merely for what role we play in the plans of others. As Immanuel Kant, an eighteenth century philosopher, phrased it, we are valuable as ends, not merely as means.⁴ Each of us has life plans and goals by which we make our daily decisions. When we respect choices, we are allowing persons to function as ends in themselves, as autonomous or self-determining. When we do otherwise, we treat persons as mere objects to be

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manipulated according to our own agendas. Respect means paying close attention to who persons really are for themselves, not just for us. This is a very difficult ideal to meet, but one which requires the moral framework of shared decision-making.

The voice of the individual is crucial. If the individual's voice is silent, someone else must speak for him or her. Substitute decision-makers must speak from a position of intimate knowledge, they must share the individual's life-world. Ideally, the substitute should be part of the individual's biography.

Substitute decision-making thus arises from the dual concern to promote the well-being of individuals and to respect them as persons. The voice of the individual is essential. If the individual's voice is silent, someone else must speak for him or her.

Yet the majority in *Cruzan* raises an important point when it argues that it is literally impossible for someone to make an **autonomous choice on behalf** of someone else. The choice is then no longer self-determined, but rather, other-determined. This argument might be persuasive if autonomy narrowly defined were the only consideration. But respecting choices is part of a much richer concept of respecting persons and their own unique identities. We struggle to respect people and the integrity of their lives, not merely their expressed preferences. We also struggle to promote the well-being of each individual, whether he or she has communicated specific preferences or not.

The Court was perhaps correct in pointing out the inadequacies in the concepts of autonomy, privacy, and liberty as justifications for substitute decisions. When persons are incompetent they are by definition no longer autonomous, or at liberty to deliberate or act in private concerning how best to advance their own values and goals. But this cannot mean that we do not have similar obligations to incompetent and competent patients or that incompetent patients do not retain their claims to our due consideration. What it does suggest

is that substitute decision-making is more adequately grounded in a moral framework of shared decision-making that includes the richer concepts of individual well-being and respect.

Who is an Appropriate Substitute Decision-Maker?

The moral framework of shared decision-making that requires the voice of the individual patient also requires that the substitute voice be as close to the individual as possible. The substitute is literally speaking for the individual and thus must speak from a position of intimate knowledge. Substitute decision-makers must share the life-world of the individual, meaning the experiences and circumstances that are part of the identity of both patient and surrogate and the source of their relationship with each other. The substitute decision-maker must not only comprehend the biography of the individual, but ideally should be a part of it.

Being a substitute decision-maker should follow from an existing relationship that already includes a commitment to the individual's well-being. It is not so much that the substitute decision-maker has a right to make a choice for the individual, but rather that the substitute has a responsibility to join with the health care professional in making a choice. The most appropriate substitute decision-makers are those whose responsibility precedes their role as substitute. Our most obvious decision-makers are those who love us and/or are obligated to care for and about us. Family and friends most closely fit these requirements. The state, in whatever form, seems the least likely candidate and therefore the substitute decision-maker of last resort. The state's responsibility is the most abstract and remote from the intimacy of the daily life of the individual.

Being a substitute should follow from an already existing relationship of care and responsibility for the patient. The State is the least likely candidate and ought to be the decision-maker of last resort.

What are Appropriate Standards for Decision-Making?

In accordance with the moral framework of shared decision-making, the standard for substitute decisions should be the well-being of the patient as understood by the patient. This standard is more difficult to approach as the relationship between incompetent patient and substitute decision-maker becomes more distant. As knowledge about the particular goals and values of the individual patient decreases, reliance on some generalized account of goals and values increases. This shift to "anyone's" goals is apparent in the three standards for decision-making articulated by the New Jersey Supreme Court in the *Conroy* case and reviewed in the Missouri majority opinion.⁵

In *Conroy* the preferred test is called "subjective" and seeks to ascertain whether the patient's own known values would have clearly decided the issue. When this is not possible—where death is impending but not imminent, and absent any clear evidence of the patient's expressed wishes—the State may authorize a guardian to withdraw life-sustaining treatment, but only under either of two "best interests" tests:

- (1) "Limited objective" test: This combines some trustworthy evidence of patient preferences with an analysis of net burdens and benefits. In order to forego life-sustaining treatment, we must be able to judge that the patient would refuse treatment because the burdens of continued life outweigh the benefits of continued life.
- (2) "Pure objective" test: This is reserved for when patient preferences cannot be known. Life-sustaining treatment can be withdrawn when two conditions are satisfied: (i) The burdens of life must clearly and markedly outweigh the benefits; (ii) The effect of administering life-sustaining treatment must be inhumane.

The first difficulty is in determining whether there is sufficient evidence of patient preference to abide by some kind of subjective standard. This difficulty is obvious in the Missouri case where the Supreme Court disagreed with the trial court's evaluation of the evidence of Ms. Cruzan's preferences as clear and convincing. The clearest evidence of patient preference would be some type of advance directive such

as a living will or a durable power of attorney. Such directives are rare, however. And even here it is questionable whether one can sufficiently anticipate the relevant circumstances in order to make an "informed consent" that is only hypothetical. Some type of interpretation is always required. Most frequently, we rely upon the information and interpretation provided by close friends and family.

Yet difficulties also arise in determining what kinds of information are sufficient. When the subjective standard is very narrowly interpreted, then family information is limited to the communication of comments the individual made concerning possible treatment decisions. This appears to be the standard employed by the majority, which disregards information the Cruzan family has about Nancy based on their long-term intimacy and shared biography.

Difficulties also arise when there is little or no familiarity with the goals and values of the incompetent individual. If one accepts only a subjective standard, it will be of little or no use in these circumstances. Yet it seems outside the framework of shared decision-making to make a best-interests calculation based on some general rather than specific assessment of well-being.

The majority opinion clearly points out these gaps between the incompetent individual's values and the understanding that someone else has about them. Their point is well-taken that a substitute decision will always only approximate the choice of another. And in the instances where the substitute decision-maker is a stranger, the approximation is only an abstraction based on what anyone would likely prefer.

The framework of shared decision-making clearly justifies the role of family and friends as substitute decision-makers who help promote the well-being of those for whom they care based on very particular notions of benefit. This is true even if the framework does not, in fact, apply to situations where substitute decision-makers are strangers to their incompetent wards. Rather than denying the role of families and turning all substitutes decision-makers into strangers, as would happen if the state made all decisions, the more reasonable approach would be to generalize the moral framework of shared decision-making and require even strangers to assume the attitude of family or friend. It would be a fiction, but a more productive fic-

tion, than pretending the state is in a better position than a family or friend to assess the well-being of a loved one.

What Limits are there to Substitute Decisions?

When we claim the legitimacy of substitute decisions, does this mean we do so without any limits, and that whatever a substitute decision-maker says is to be regarded as in the patient's best interests? Such "unbridled" authority was clearly troubling to the majority in the Supreme Court ruling.⁶ A policy that relied solely on substitute decisions would overlook the reality of conflict of interest and of disagreement among care-givers.

Rather than denying the legitimacy of substitute decisions, such difficulties call for additional guidelines. Each substitute decision-maker is obligated to promote the well-being of the patient from the patient's own perspective insofar as this is possible. Others, especially health care professionals, are involved in assessing whether this responsibility is being discharged in good faith. Where there is disagreement among family and/or friends, or between substitute decision-makers and health care professionals, a third party perspective should be sought.

Substitute decisions that involve significant compromise to patient well-being as commonly understood require careful scrutiny as to the patient's wishes or the degree of compromise.

Additionally, substitute decisions are limited in two general ways.⁷ First, substitute decisions are subject to the same limits placed on decisions by competent patients, such as public health concerns (e.g. not refusing mandatory vaccination) or constraints posed by the criminal law (e.g. not requesting intentional maiming). Furthermore, because of the inescapable uncertainty involved in substitute decisions, those decisions that involve a significant compromise to patient well-being as commonly understood require careful scrutiny as to the patient's wishes or the degree of compromise. For example, a competent individual may be permitted to refuse a life-saving blood transfusion, but a substitute decision-maker might not be allowed to make that decision on the individual's behalf. This is not to argue that

such decisions can **never** be made, but only that when decisions involve a variation from a commonly shared notion of well-being, such decisions require close scrutiny and may be vetoed on the basis of lack of evidence of preference or lack of justification for the alternative assessment of well-being.

The majority in *Cruzan* thought the decision to withdraw artificial hydration and nutrition crossed this threshold of a commonly shared notion of well-being. In addition to its claim that evidence of Nancy's preferences was not sufficient, the majority gives two reasons why the guardians' decision should not be upheld. First, the decision involved termination of nutritional support. Second, it involved a patient who is not terminally ill and who is persistently vegetative and cannot be "oppressively" burdened.

Although the Court apparently viewed the equating of nutritional support with medical treatment as a "semantic dilemma,"⁸ it seems clear from the tone of the opinion that the majority regards the distinction as profound. They begin their analysis with the powerful statement, "This is a case in which we are asked to allow the medical profession to make Nancy die by starvation and dehydration."⁹ "And common sense tells us that food and water do not treat an illness, they maintain a life."¹⁰

One cannot adequately analyze the case of Ms. Nancy Cruzan without discussing the essential question of the moral significance of providing nutritional support. Those who argue that it is different from medical treatment and must always be provided point to its direct association with life or death, and its importance as a powerful symbol of human community. From the suckling infant to the funeral wake, humans connect and reconnect with each other through the sharing of food and drink.

One cannot adequately analyze *Cruzan* without discussing the question of the moral significance of providing nutritional support.

Those who argue that artificial hydration and nutrition are medical treatments that can be foregone, according to the standards that govern such decisions, do so on the basis that they

have inherent risks and possible side effects and are instituted by skilled health care providers to compensate for impaired physical functioning.

Both observations are correct, and sometimes the view we hold depends on the descriptive language we choose. When we talk about providing food and water we capture in our language the richness of the human bond that is an essential part of shared meals. When we talk about hyperalimentation or total parenteral nutrition, the emphasis shifts away from the human enjoyment of a shared meal to a medical event in response to a physiological dysfunction. This is not to suggest that one language is more correct than another or that one should adopt the language that is most appropriate to one's views. What the variation in language suggests, and what we must pay close attention to, is that the meaning of the provision of nutritional support varies according to the context, and that the meaning outside medical contexts may not be immediately transferable to within medical contexts.

For the Cruzan family, the gastrostomy tube does not symbolize nurture for Nancy, but is instead the barrier to the death which they believe she would prefer. For the Cruzans and others like them, withdrawal of food is the appropriate act of caring.

Those who argue that nutritional support must always be provided because of its powerful symbolism tend to minimize the fact that symbols of caring and nurturing will depend upon the context. For the Cruzan family, the gastrostomy tube does not represent the nurturing of their daughter, but is instead the barrier to the death which they believe she would prefer. For the Cruzans and others like them, the withdrawal of nutritional support is the appropriate act of caring.

It is, indeed, essential to maintain community attitudes of caring that are represented in actions that advance our shared values. Actions that also symbolize a broader context of caring help to sustain and renew values for future generations. The strong presumption in favor of providing nutritional support can be justified on these grounds. However, such a presumption cannot legitimately be

expanded to an imperative always to provide nutritional support. In some circumstances, nutritional support is actually viewed as harmful. It is hard to imagine how an act viewed as harmful can be regarded at the same time as a symbol of caring.

Those who argue that nutritional support must always be provided cannot accept the notion that it might be harmful in certain circumstances. Such an acknowledgment would seem to undermine the provision of nutritional support as an act of caring. What must be claimed, therefore, is that the provision of nutritional support is **always** beneficial. Yet there are clearly circumstances where the side effects of nutritional support are burdensome to the patient, as for example in the increased secretions that result in the uncomfortable suctioning of a dying cancer patient.¹¹ What must be argued, then, and what the majority opinion does argue, is that Ms. Cruzan is in a state where she cannot be harmed by the provision of nutritional support, but rather will be benefited. To say Ms. Cruzan is not benefited would be to argue that her life is not worth living.

The majority opinion thus places a second limitation on the substitute decision-maker, claiming that quality of life decisions are always inappropriate. The Court argues that nutritional support is beneficial to Ms. Cruzan because she is not terminally ill and the provision of nutritional support is not unduly burdensome and will sustain her life. For a substitute to decide to end her life under these circumstances would be to cross the threshold of a common understanding of well-being and claim that life itself is not a benefit.

It is questionable, however, whether sustaining life in a persistent vegetative state is commonly understood to be an unqualified benefit, as the majority opinion would argue. The Court stresses, "The state's concern with the sanctity of life rests on the principle that life is precious and worthy of preservation without regard to its quality."¹²

But why are quality of life judgments inappropriate? One might argue that while it may be acceptable for competent individuals to make such judgments, it is allowable for incompetent patients only when there is sufficient evidence of preference. The majority opinion argues there is not enough evidence of Ms. Cruzan's assessment of quality of life to justify withdrawal of nutritional support. This was not, however, the view of the trial court.

One might also argue that in the absence of clear patient preference, it is impossible for anyone else to determine whether a life is of low quality. Yet if this were the case, it would be difficult to make sense of the majority opinion's own acknowledgment that "The quality of her life is severely diminished to be sure."¹³

There are other precedents to suggest that permanent unconsciousness is commonly understood to be a life of such reduced quality that life-sustaining treatment may be foregone. In addition to publications and court cases that the majority opinion itself quotes, the most recent Baby Doe regulations that are intended to reflect a concern for the sanctity of life also regard irreversible coma as a condition that does not require life-sustaining treatment.¹⁴ Required, however, are all "appropriate nutrition, hydration, and medication which in the treating physician's reasonable medical judgment will be most likely to be effective in ameliorating or correcting (the patient's) condition."¹⁵ Many would argue that nutrition and hydration are not appropriate and therefore can be foregone.

Those who would allow the withdrawal of nutritional support do so on the basis that the individual has no opportunity for any human interaction and cannot experience either benefit or harm. As the majority opinion states, "If the testimony at trial that Nancy would experience no pain even if she were allowed to die by starvation and dehydration is to be believed, it is difficult to argue with any conviction that feeding by a tube already in place constitutes a painful invasion for her."¹⁶ Because Nancy has no opportunity to experience either pain or satisfaction, how can any action either harm or benefit her? Perhaps, then, the interests of other parties such as families could take precedence.¹⁷

However, the majority opinion strives to make the even stronger claim that it is **irrelevant** whether we can or cannot make quality of life judgments. The majority's point is that we **should** not make such decisions. However, their defense of this claim rests on a questionable balancing of the interests of third parties.

How Do We Consider the Interests of Other Parties?

The majority opinion acknowledges that the only benefit to be offered to Ms. Cruzan is the extension of her life. There is no possibility for

life. There is no possibility for experience of any sort. The majority also acknowledges that the circumstances of Ms. Cruzan's condition constitute a grave burden upon her family. They write, "Only the coldest heart could fail to feel the anguish of these parents who have suffered terribly these many years. They have exhausted any well-spring of hope which might have earlier accompanied their now interminable bedside vigil. And we understand, for these loving parents have seen only defeat through the memories they hold of a vibrant woman for whom the future held but promise."¹⁸

But in the face of their compassion the majority maintains that the interest in preserving Ms. Cruzan's life outweighs the interests of some third parties, including her family or those who might possibly benefit from the use of funds presently used to maintain Ms. Cruzan. Yet at the same time the majority bases its argument that interests in preserving life are always overriding, on the claim that certain others besides the patient may be adversely affected. They write, "The State's interest is in the preservation of life, not only Nancy's life, but also the lives of persons similarly situated yet without the support of a loving family. This interest outweighs any rights invoked on Nancy's behalf to terminate treatment in the face of the uncertainty of Nancy's wishes and her own right to life."¹⁹ And in their summary statement they write, "we choose to err on the side of life, respecting the rights of incompetent persons who may wish to live despite a severely diminished quality of life."²⁰

Leaving aside the question of what it would have taken for the majority to regard the evidence of Ms. Cruzan's preferences as clear and convincing, there remains an interesting inconsistency in how we ought to regard the interests of other parties. It seems ironic that the interests of those most intimately associated with Ms. Cruzan are counted less than the interests of a population of unknown others who might be at risk from inadequate substitute decisions. As Judge Higgins writes in his dissenting opinion, "the majority elects to ignore the facts and law of this case and 'choose(s) to err' on the side of life of incompetent persons who may wish to live, a case not before the Court at this time."²¹

As outlined in this essay, the appropriate role of the family as substitute decision-maker can be justified on the basis of a moral framework of

shared decision-making that seeks to respect patients and to promote their well-being. The majority opinion effectively removes families from this important responsibility in its effort to protect family-less patients from bad substitute decisions. A far more appropriate approach would be to acknowledge the framework of shared decision-making and the necessary role of the family, plus other parties in case of conflict of interest or disagreement, and seek other means like guardianship reform to safeguard the interests of others. The unjustified interference of the state between families and their loved ones seems a very high price to pay for the protection of other parties who might be more effectively protected by other means.

¹ *Cruzan*, by *Cruzan v. Harmon*, 760 S.W. 2d 408, at 410.

² *Cruzan*, at 425.

³ The state's interest in preserving life, as well as preventing suicide, protecting innocent third parties, and safeguarding the integrity of the medical profession, appears in at least fourteen recent court cases and is cited in *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977).

⁴ Immanuel Kant, *Grounding for the Metaphysics of Morals* (1785), trans. James W. Ellington (Indianapolis: Hackett Publishing Co., 1981), p. 36.

⁵ *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985).

⁶ *Cruzan*, at 416.

⁷ President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment*. (Washington, D.C.: U.S. Government Printing Office, 1983), p. 133.

⁸ *Cruzan*, at 423.

⁹ *Cruzan*, at 412.

¹⁰ *Cruzan*, at 423.

¹¹ Phyllis Schmitz and Merry O'Brien, "Observations on Nutrition and Hydration in Dying Cancer Patients," in Joanne Lynn (ed.), *By No Extraordinary Means* (Bloomington, Indiana: Indiana University Press, 1986), pp. 29-38.

¹² *Cruzan*, at 419.

¹³ *Cruzan*, at 424.

¹⁴ See President's Commission, note 8 supra; Current Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association, 1986; and Child Abuse and Neglect Prevention and Treatment Program: Final Rule, *Federal Register* 50: 14878-14901 (1985).

¹⁵ Id.

¹⁶ *Cruzan*, at 423.

¹⁷ See President's Commission, note 8 supra, pp. 181-186.

¹⁸ *Cruzan*, at 412.

¹⁹ *Cruzan*, at 426.

²⁰ *Cruzan*, at 427.

²¹ *Cruzan*, at 441.

The Cruzan Decision: A Confusion of Confusions

by John M. Swomley

The *Cruzan* case is the story of a young woman, Nancy Beth Cruzan, who was apparently killed in an auto accident January 22, 1983. She was resuscitated after about 15 minutes of respiratory and cardiac arrest. The absence of oxygen (anoxia) during this period led to permanent brain damage. She never regained consciousness. After six weeks of rehabilitative measures at a medical center in Joplin, Missouri, she was discharged as "essentially unimproved and unre-

sponsive to rehabilitation." All the physicians who have participated in her case, including three neurologists and a neurosurgeon, agree there is no hope of recovery.

Nancy's parents, who serve as co-guardians, sought permission in the Circuit Court of Jasper County to discontinue further use of a gastrostomy

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