CENTER FOR PRACTICAL
BIOETHICS
GUIDANCE AT THE CROSSROADS OF DECISION

Landmark Cases —
a study guide for ethics committees

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PREFACE

Law is not necessarily ethical; ethical reflection need not be confined within the limits of law. Nevertheless, ethics committees, in their self-education, can profit from a consideration of classic cases, eight of which are included in this study guide. Often, the courts are the origin of or substantiate legally particular insights that enter into ethical thinking, e.g., the issue of withdrawing venilator support from a permanently unconscious patient and its reasoning in Quinlan; artificial food and hydration as medical treatment in Cruzan; "limited-objective" and "pure-objective" best interest tests in Conroy, etc. These cases have been subsequently cited in other legal arenas and are often referred to in bioethics literature.

Ethics committees would do well to study the enclosed court judgments and to apply to the legal conclusions those same ethical strategies we use when any case is brought to our attention. What conflict brought the case into the court? In the resolution, was there sufficient justification for the right or value affirmed by the courts? Were those whose rights or values were denied treated with dignity? Is there a clash between a personal and a social ethic underlying the contested issue and is the argument valid for the ethic which was upheld?

In their 1986 *Handbook for Hospital Ethics Committees*, Judith Wilson Ross et al said:

> Although it is not the ethics committee's responsibility to assess legal concerns, committee members should have a general knowledge of the way in which legal requirements impinge upon clinical health care decisions. In addition, they need specific knowledge of the legal reasoning upon which some court decisions are based. (Ross, J. W., Sister Corrine Bailey, Vicki Michel, and Deborah Pugh. 1986. *Handbook for Hospital Ethics Committees* (AHA Publishing.)

This study guide is offered to help to achieve this purpose.

Most summaries are found in Patrick D. Kelly, JD, 1994. *Legal Aspects of Shortening Life by Withholding/Withdrawing Treatment* printed by Midwest Bioethics Center, 1100 Pennsylvania Avenue, Kansas City, Missouri 64105 (816) 221-1100. All articles are reprinted with the permission of the journal in which they appear.

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The case of

KAREN ANN QUINLAN

1976

Matter of Quinlan
Supreme Court of New Jersey 1976, 355 A. 2d 647

Summary (Facts)

Karen Ann Quinlan, a twenty-two-year-old who ingested a harmful mix of drugs and alcohol, suffered two fifteen-minute periods of interrupted breathing which left her in a chronic vegetative state without any cognitive functions.

Evidence in the case included statements the patient made earlier referring to her "distaste for continuance of life by extraordinary medical procedures." These statements were deemed by the court as remote, impersonal and lacking trial "probative weight."

Mr. Cruzan, the patient's father, sought appointment as her guardian along with the authority to terminate "all extraordinary medical procedures." This petition was opposed by the doctors, the hospital,the prosecutor, and the guardian ad litem.

The trial court refused the order to withdraw life-supporting apparatus. The father/guardian appealed.

Holding

The State's interest to maintain life weaken, and a patient's right of privacy grows, as the degree of bodily invasion increases and as prognosis dims.

Notwithstanding an acceleration of death, no criminal homicide results, and no civil liability would follow. However, because of the lapse of intervening time, a more current assessment of the prognosis was needed if the prognosis of the then-attending physician was unchanged (and it being contemplated that the guardian would employ different physicians). The new physician should seek concurrence of the ethics committee, the guardian, and the patient's family.

70 N.J. 10
In the Matter of Karen Quinlan, An Alleged Incompetent. Supreme Court of New Jersey. Argued Jan. 26, 1976. Decided March 31, 1976. (abridged)

Resumé

The father, Mr. Quinlan, sought to be appointed guardian of person and property of his twenty-one-year-old daughter who was in a persistent vegetative state and sought the express power of authorizing the discontinuance of all extraordinary procedures for sustaining his daughter's vital processes. The superior Court. . .denied authorization for termination of the life-supporting apparatus and withheld letters of guardianship over the person of the incompetent. The father appealed and the Attorney General cross-appealed. The Supreme Court, Hughes, C.J., held that a decision by the daughter to permit a noncognitive, vegetative existence to terminate by natural forces was a valuable incident of her right to privacy which could be asserted on her behalf by her guardian; that the state of the pertinent medical standards and practices which guided the attending physicians who held the opinion that removal from the respirator would not conform to medical practices, standards and traditions was not such as would justify the court in deeming itself bound or controlled thereby in responding to case for declaratory relief; and that upon the concurrence of guardian and family, should the attending physicians conclude that there was no reasonable possibility of the daughter's ever emerging from her comatose condition to a cognitive, sapient state and that the life-support apparatus should be discontinued, physicians should consult with hospital ethics comittee and if the committee should agree with the physicians' prognosis, the life-support systems may be withdrawn and said action shall be without any civil or criminal liability, therefore, on the part of any participant, whether guardian, physician, hospital or others.

Modified and remanded .

The opinion of the Court was delivered by HUGHES, C.J.

The Litigation

The central figure in this tragic case is Karen Ann Quinlan, a New Jersey resident. At the age of twenty-two, she lies in a debilitated and allegedly moribund state at Saint Clare's Hospital in Denville, New Jersey. The litigation has to do, in final analysis, with her life—its continuance or cessation—and the responsibilities, rights and duties, with regard to any fateful decision concerning it, of her family, her guardian, her doctors, the hospital, the State through its law enforcement authorities, and finally the courts of justice.

The issues are before this Court following its direct certification of the action under the rule, R.2:12-1, prior to hearing in the Superior Court, Appellate Division, to which the appellant (hereafter "plaintiff") Joseph Quinlan, Karen's father, had appealed the adverse judgment of the Chancery Division.

Due to extensive physical damage fully described in the able opinion of the trial judge, Judge Muir, supporting that judgment, Karen allegedly was incompetent. Joseph Quinlan sought the adjudication of that incompetency. He wished to be appointed guardian of the person and property of his daughter. It was proposed by him that such letters of guardianship, if granted, should contain an express power to him as guardian to authorize the discontinuance of all extraordinary medical procedures now allegedly sustaining Karen's vital processes and hence her life, since these measures, he asserted, present no hope of her eventual recovery. A guardian ad litem was appointed by Judge Muir to represent the interest of the alleged incompetent.

By a supplemental complaint, in view of the extraordinary nature of the relief sought by plaintiff and the involvement therein of their several rights and responsibilities, other parties were added. These included the treating physicians and the hospital, the relief sought being that they be restrained from interfering with the carrying out of any such extraordinary authorization in the event it were to be granted by the court. Joined, as well, was the Prosecutor of Morris County (he being charged with responsibility for enforcement of the criminal law), to enjoin him from interfering with, or projecting a criminal prosecution which otherwise might ensure in the event of cessation of life in Karen resulting from the exercise of such extraordinary authorization were it to be granted to the guardian.

The Attorney General of New Jersey intervened as of right pursuant to R. 4:33-1 on behalf of the State of New Jersey, such intervention being recognized by the court in the pretrial conference order (R. 4:25-1 et seq.) of September 22, 1975. Its basis, of course, was the interest of the State in the preservation of life, which has an undoubted constitutional foundation.

The matter is of transcendent importance involving questions related to the definition and existence of death, the prolongation of life through artificial means developed by medical technology, undreamed of in past generations of the practice of the healing arts; the impact of such durationally indeterminate and artificial life-prolongation on the rights of the incompetent, her family and society in general; the bearing of constitutional right and the scope of judicial responsibility, as to the appropriate response of an equity court of justice to the extraordinary prayer for relief of the plaintiff. Involved as well is the right of the plaintiff, Joseph Quinlan, to guardianship of the person of his daughter.

The Factual Base

An understanding of the issues in their basic perspective suggests a brief review of the factual base developed in the testimony and documented in greater detail in the opinion of the trial judge.

On the night of April 15, 1975, for reasons still unclear, Karen Quinlan ceased breathing for at least two 15-minute periods. She received some ineffectual mouth-to-mouth resuscitation from friends. She was taken by ambulance to Newton Memorial Hospital. There she had a temperature of 100 degrees, her pupils were unreactive and she was unresponsive even to deep pain. The history at the time of her admission to that hospital was essentially incomplete and uninformative.

Three days later, Dr. Morse examined Karen at the request of the Newton admitting physician, Dr. McGee. He found her comatose with evidence of decortication, a condition relating to derangement of the cortex of the brain causing a physical posture in which the upper extremities are flexed and the lower extremities are extended. She required a respirator to assist her breathing. Dr. Morse was unable to obtain an adequate account of the circumstances and events leading up to Karen's admission to the Newton Hospital. Such initial history or etiology is crucial in neurological diagnosis. Relying as he did upon the Newton Memorial records and his own examination, he concluded that prolonged lack of oxygen in the bloodstream, anoxia, was identified with her condition as he saw it upon first observation. When she was later transferred to Saint Clare's Hospital she was still unconscious, still on a respirator and a tracheotomy had been performed. On her arrival Dr. Morse conducted extensive and detailed examinations. An electroencephalogram (EEG) measuring electrical rhythm of the brain was performed and Dr. Morse characterized the result as "abnormal but it showed some activity and was consistent with her clinical state." Other significant neurological tests, including a brain scan, an angiogram, and a lumbar puncture were normal in result. Dr. Morse testified that Karen has been in a state of coma, lack of consciousness, since he began treating her. He explained that there are basically two types of coma: sleep-like unresponsiveness and awake unresponsiveness. Karen was originally in a sleep-like unresponsive condition but soon developed "sleep-wake" cycles, apparently a normal improvement for comatose patients occurring within three to four weeks. In the awake cycle she blinked,, crieed out and did things of that sort but was still totally unaware of anyone or anything around her.

Dr. Morse and other expert physicians who examined her characterized Karen as being in a "chronic persistent vegetative state." Dr. Fred Plum, one of such expert witnesses, defined this as a "subject who remains with the capacity to maintain the vegetative parts of neurological function but who. . . no longer has any cognitive function.

Dr. Morse, as well as the several other medical and neurological experts who testified in this case, believed with certainty that Karen Quinlan is not "brain dead." They identifed the Ad Hoc Committee of Harvard Medical School report as the ordinary medical standard for determining criteria specified in that report and was therefore not "brain dead" within its contemplation.

In this respect it was indicated by Dr. Plum that the brain works in essentially two ways, the vegetative and the sapient. He testified:

> We have an internal vegetative regulation which controls body temperature, which controls breathing, which controls to a considerable degree blood pressure, which controls to some degree heart rate, which controls chewing, swallowing and which controls sleeping and waking. We have a more highly developed brain which is uniquely human which controls our relations to the outside world, our capacity to talk, to see, to feel, to sing, to think. Brain death necessarily must mean the death of both of these funtions of the brain, vegetative and the sapient. Therefore the presence of any function which is regulated or governed or controlled by the deeper parts of the brain which in laymen's terms might be considered purely vegetative would mean that the brain is not biologically dead.

Because Karen's neurological condition affects her respiratory ability (the respiratory system being a brain stem function) she requires a respirator to assist her breathing. From the time of her admission to Saint Clare's Hospital Karen has been assisted by an MA-1 respirator, a sophisticated machine which delivers a given volume of air at a certain rate and periodically provides a "sigh" volume, a relatively large measured volume of air designed to purge the lungs of excretions. Attempts to "wean" her from the respirator were unsuccessful and have been abandoned.

The experts believe that Karen cannot now survive without the assistance of the respirator; that exactly how long she would live without it is unknown; that the strong likelihood is that death would follow soon after its removal, and that removal would also risk further brain damage and would curtail the assistance the respirator presently provides in warding off infection.

It seemed to be the consensus not only of the treating physician but also of the several qualified experts who testified in the case, that removal from the respirator would not conform to medical practices, standards and traditions.

The further medical consensus was that Karen in addition to being comatose is in a chronic and persistent "vegetative" state, having no awareness of anything or anyone around her and existing at a primitive reflex level. Although she does have some brain stem function (ineffective for respiration) and has other reactions one normally associates with being alive, such as moving, reacting to light, sound and noxious stimuli, blinking her eyes, and the like, the quality of her feeling impulses is unknown. She grimaces, makes sterotyped cries and sounds and has chewing motions. Her blood pressure is normal.

Karen remains in the intensive care unit at Saint Clare's Hospital, receiving 24-hour care by a team of four nurses characterized, as was the medical attention, as "excellent." She is nourished by feeding by way of a nasal-gastro tube and is routinely examined for infection, which under these circumstances is a serious life threat. The result is that her condition is considered remarkable under the unhappy circumstances involved.

Karen is described as emaciated, having suffered a weight loss of at least forty pounds, and undergoing a continuing deteriorative process. Her posture is described as fetal-like and grotesque; there is extreme fexion-rigidity of the arms, legs and related muscles and her joints are severely rigid and deformed.

From all of this evidence, and including the whole testimonial record, several basic findings in the physical area are mandated. Severe brain and associated damage, albeit of uncertain etiology, has left Karen in a chronic and persistent vegetative state. No form of treatment which can cure or improve that condition is known or available. As nearly as may be determined, considering the guarded area of remote uncertainties characteristic of most medical science predictions, she can *never* be restored to cognitive or sapient life. Even with regard to the vegetative level and improvement therein (if such it may be called) the prognosis is extremely poor and the extent unknown if it should in fact occur.

She is debilitated and moribund and although fairly stable at the time of argument before us (no new information having been filed in the meanwhile in expansion of the record), no physician risked the opinion that she could live more than a year and indeed she may die much earlier. Excellent medical and nursing care so far has been able to ward off the constant threat of infection, to which she is peculiarly susceptible because of the respirator, the tracheal tube and other incidents of care in her vulnerable condition. Her life accordingly is sustained by the respirator and tubal feeding, and removal from the respirator would cause her death soon, although the time cannot be stated with more precision.

The determination of the fact and time of death in past years of medical science was keyed to the action of the heart and blood circulation, in turn dependent upon pulmonary activity, and hence cessation of these functions spelled out the reality of death.

Developments in medical technology have obfuscated the use of the traditional definition of death. Efforts have been made to define irreversible coma as a new criterion for death, such as by the 1968 report of the Ad Hoc Committee of the Harvard Medical School (the Committee comprising ten physicians, an historian, a lawyer, and a theologian), which asserted that:

> From ancient times down to the recent past it was clear that, when the respiration and heart stopped, the brain would die in a few minutes; so the obvious criterion of no heart beat as synonymous with death was sufficiently accurate. In those times the heart was considered to be the central organ of the body; it is not surprising that its failure marked the onset of death. This is no longer valid when modern resuscitative and supportive measures are used. These improved activities can now restore "life" as judged by the ancient standards of persistent respiration and continuing heart beat. This can be the case even when there is not the remotest possibility of an individual recovering consciousness following massive brain damage. . .

The Ad Hoc standards, carefully delineated, included absence of response to pain or other stimuli, pupilary reflexes, corneal, pharyngeal and other reflexes, blood pressure, spontaneous respiration, as well as "flat" or isoelectric electroencephalograms and the like, with all tests repeated "at least twenty-four hours later with no change." In such circumstances, where all of such criteria have been met as showing "brain death," the Committee recommends with regard to the respirator:

> The patient's condition can be determined only by a physician. When the patient is hopelessly damaged as defined above, the family and all colleagues who have participated in major decisions concerning the patient, and all nurses involved, should be so informed. Death is to be declared and then the respirator turned off. The decision to do this and the responsibilitiy for it are to be taken by the physician-in-charge in consultation with one or more physicians who have been directly involved in the case. It is unsound and undesirable to force the family to make the decision. . . .

But, as indicated, it was the consensus of medical testimony in the instant case that Karen, for all her disability, met none of these criteria, nor indeed any comparable criteria extant in the medical world and representing, as does the Ad Hoc Committee report, according to the testimony in this case, prevailing and accepted medical standards.

We have adverted to the "brain death" concept and Karen's disassociation with any of its criteria, to emphasize the basis of the medical decision made by Dr. Morse. When plaintiff and his family, finally reconciled to the certainty of Karen's impending death, requested the withdrawal of life support mechanisms, he demurred. His refusal was based upon his conception of medical standards, practice and ethics described in the medical testimony, such as in the evidence given by another neurologist, Dr. Sidney Diamond, a witness for the State. Dr. Diamond asserted that no physician would have failed to provide respirator support at the outset and none would interrupt its life-saving course thereafter, except in the case of cerebral death. In the latter case, he thought the respirator would in effect be disconnected from one already dead, entitling the physician under medical standards and, he thought, legal concepts, to terminate the supportive measures. We note Dr. Diamond's distinction of major surgical or transfusion procedures in a terminal case not involving cerebral death, such as here.

> The subject has lost human qualities. It would be incredible, and I think unlikely, that any physician would respond to a sudden hemorrhage, massive hermorrhage or a loss of all her defensive blood cells, by giving her large quantities of blood. I think that . . .major surgical procedures would be out of the question even if they were known to be essential for continued physical existence.

This distinction is adverted to also in the testimony of Dr. Julius Korein, a neurologist called by plaintiff. Dr. Korein described a medical practice concept of "judicious neglect" under which the physician will say:

> Don't treat this patient anymore. . .it does not serve either the patient, the family, or society in any meaningful way to continue treatment with this patient.

Dr. Korein also told of the unwritten and unspoken standard of medical practice implied in the foreboding initials DNR (do not resuscitate), as applied to the extraordinary terminal case:

> Cancer, metastic cancer, involving the lungs, the liver, the brain, multiple involvements, the physician may or may not write: Do not resuscitate. . . .It would be said to the nurse: if this man stops breathing don't resuscitate him. . .No physician that I know personally is going to try to resuscitate a man riddled with cancer and in agony and he stops breathing. They are not going to put him on a respirator. . . .I think that would be the height of misuse of technology.

While the thread of logic in such distinctions may be elusive to the non-medical lay mind, in relation to the supposed imperative to sustain life at all costs, they nevertheless relate to medical decisions, such as the decision of Dr. Morse in the present case. We agree with the trial court that the decision was in accord with Dr. Morse's conception of medical standards and practice.

Guardianship

We turn to that branch of the factual case pertaining to the application for guardianship, as distinguished from the nature of the authorization sought by the applicant. The character and general suitability of Joseph Quinlan as guardian for his daughter, in ordinary circumstances, could not be doubted. The record bespeaks the high degree of familial love which pervaded the home of Joseph Quinlan and reached out fully to embrace Karen, although she was living elsewhere at the time of her collapse. The proofs showed him to be deeply religious, imbued with a morality so sensitve that months of tortured indecision preceded his belated conclusions (despite earlier moral judgments reached by the other family members but unexpressed to him in order not to influence him to see the termination of life-supportive measures sustaining Karen. A communicant of the Roman Catholic Church, as were other family members, he first sought solace in private prayer looking with confidence, as he says, to the Creator, first for the recovery of Karen and then, if that were not possible, for guidance with respect to the awesome decision confronting him.

To confirm the moral rightness of the decision he was about to make he consulted with his parish priest and later with the Catholic chaplain of Saint Clare's Hospital. He would not, he testified, have sought termination if that act were to be morally wrong or in conflict with the tenets of the religion he so profoundly respects. He was disabused of doubt, however, when the position of the Roman Catholic Church was made known to him as it is reflected in the record in this case. While it is not usual for matters of religious dogma or concepts to enter a civil litigation (except as they may bear upon constitutional right, or sometimes, familial matters; cf *In re Adoption of E*, 59 N.J. 36, 279 A 2d 785 (1971)), they were rightly admitted in evidence here. The judge was bound to measure the character and motivations in all respects of Joseph Quinlan as prospective guardian; and insofar as these religious matters bore upon them, they were properly scrutinized and considered by the court.

Thus germane, we note the position of that Church as illuminated by the record before us. We have no reason to believe that it would be at all discordant with the whole of Judeo-Christian tradition, considering its central respect and reverence for the sanctity of human life. It was in this sense of relevance that we admitted as *amicus curiae* the New Jersey Catholic Conference, essentially the spokesman for the various Catholic bishops of New Jersey, organized to give witness to spiritual values in public affairs in the statewide community. The position statement of Bishop Lawrence B. Casey, reproduced in the *amicus* brief, projects these views:

(a) The verification of the fact of death in a particular case cannot be deduced from any religious or moral principle and, under this aspect, does not fall within the competence of the church; that dependence must be had upon traditional and medical standards, and by these standards Karen Ann Quinlan is assumed to be alive.

(b) The request of plaintiff for authority to terminate a medical procedure characterized as "an extraordinary means of treatment" would not involve euthanasia. This upon the reasoning expressed by Pope Pius XII in his "allocutio" (address) to anesthesiologists on November 24, 1957, when he dealt with the question:

> Does the anesthesiologist have the right, or is he bound, in all cases of deep unconsciousness, even in those that are completely hopeless in the opinion of the competent doctor, to use modern artificial respiration apparatus, even against the will of the family?

His answer made the following points:

1. In ordinary cases the doctor has the right to act in this manner, but is not bound to do so unless this is the only way of fulfilling another certain moral duty.
2. The doctor, however, has no right independent of the patient. He can act only if the patient explicitly or implicitly, directly or indirectly, gives him the permission.
3. The treatment as described in the question constitutes extraordinary means of preserving life and so there is no obligation to use them nor to give the doctor permission to use them.
4. The rights and the duties of the family depend on the presumed will of the unconscious patient if he or she is of legal age, and the family, too, is bound to use only ordinary means.
5. This case is not to be considered euthanasia in any way; that would never be licit. The interruption of attempts at resuscitation, even when it causes the arrest of circulation, is not more than an indirect cause of the cessation of life, and we must apply in this case the principle of double effect.

So it was that the Bishop Casey statement validated the decision of Joseph Quinlan:

> Competent medical testimony has established that Karen Ann Quinlan has no reasonable hope of recovery from her comatose state by the use of any available medical procedures. The continuance of mechanical (cardiorespiratory) supportive measures to sustain continuation of her body functions and her life constitute extraordinary means of treatment. Therefore, the *decision of Joseph. . . Quinlan to request the continuance of this treatment is, according to the teachings of the Catholic Church, a morally correct decision.* (emphasis in original).

And the mind and purpose of the intending guardian were undoubtedly influenced by factors included in the following reference to the interrelationship of the three disciplines of theology, law and medicine as exposed in the Casey statement:

> The right to a natural death is one outstanding area in which the disciplines of theology, medicine and law overlap; or, to put it another way, it is an area in which these three disciplines convene.
>
> Medicine with its combination of advanced technology and professional ethics is both able and inclined to prolong biological life. Law with its felt obligation to protect the life and freedom of the individual seeks to assure each person's right to live out his human life until its natural and inevitable conclusion. Theology with

> its acknowledgment of man's dissatisfaction with biological life as the utimate source of joy. . .defends the sacredness of human life and defends it from all direct attacks.
>
> These disciplines do not conflict with one another, but are necessarily conjoined in the application of their principles in a particular instance such as that of Karen Ann Quinlan. Each must in some way acknowledge the other without denying its own competence. The civil law is not expected to assert a belief in eternal life; nor, on the other hand, is it expected to ignore the right of the individual to profess it, and to form and pursue his conscience in accord with that belief. Medical science is not authorized to directly cause natural death; nor, however, is it expected to prevent it when it is inevitable and all hope of a return to an even partial exercise of human life is irreparably lost. Religion is not expected to define biological death; nor, on its part, is it expected to relinquish its responsibility to assist man in the formation and pursuit of a correct conscience as to the acceptance of natural death when science has confirmed its inevitability beyond any hope other than that of preserving biological life in a merely vegetative state.

And the gap in the law is aptly described in the Bishop Casey statement:

> In the present public discussion of the case of Karen Ann Quinlan it has been brought out that responsible people involved in medical care, patients and families have exercised the freedom to terminate or withhold certain treatments as extraordinary means in cases judged to be terminal, i.e., cases which hold no realistic hope for some recovery, in accord with the expressed or implied intentions of the patients themselves. To whatever extent this has been happening it has been without sanction in civil law. Those involved in such actions, however, have ethical and theological literature to guide them in their judgments and actions. Furthermore, such actions have not in themselves undermined society's reverence for the lives of sick and dying people.
>
> It is both possible and necessary for society to have laws and ethical standards which provide freedom for decisions, in accord with the expressed or implied intentions of the patient, to terminate or withhold extraordinary treatment in cases which are judged to be hopeless by competent medical authorities, without at the same time leaving an opening for euthanasia. Indeed, to accomplish this, it may simply be required that courts and legislative bodies recognize the present standards and practices of many people engagaed in medical care who have been doing what the parents of Karen Ann Quinlan are requesting authorization to have done for this beloved daughter.

Before turning to the legal and constitutional issues involved, we feel it essential to reiterate that the "Catholic view" of religious neutrality in the circumstances of this case is considered by the Court only in the aspect of its impact upon the conscience, motivation and purpose of the intending guardian, Joseph Quinlan, and not as a precedent in terms of the civil law.

If Joseph Quinlan, for instance, were a follower and strongly influenced by the teachings of Buddha, or if, as an agnostic or atheist, his moral judgments were formed without reference to religious feelings, but were nevertheless formed and viable, we would with equal attention and high respect consider these elements, as bearing upon his character, motivations and purposes as relevant to his qualification and suitability as guardian.

If is from this factual base that the Court confronts and responds to three basic issues:

1. Was the trial court correct in denying the specific relief requested by plaintiff, i.e., authorization for termination of the life-supporting apparatus, on the case presented to him? Our determination of that question is in the affirmative.
2. Was the court correct in withholding letters of guardianship from the plaintiff and appointing in his stead a stranger? On that issue our determination is in the negative.
3. Should this Court, in the light of the foregoing conclusions, grant declaratory relief to the plaintiff? On that question our Court's determination is in the affirmative.

This brings us to a consideration of the constitutional and legal issues underlying the foregoing determinations.

Constitutional Legal Issues

The Right of Privacy

It is the issue of the constitutional right of privacy that has given us most concern, in the exceptional circumstances of this case. Here a loving parent, *qua* parent and raising the rights of his incompetent and profoundly damaged daughter, probably irreversibly doomed to no more than a biologically vegetative remnant of life, is before the court. He seeks authorization to abandon specialized technological procedures which can only maintain for a time a body having no potential for resumption or continuance of other than a "vegetative" existence.

We have no doubt, in these unhappy circumstances, that if Karen were herself miraculously lucid for an interval (not altering the existing prognosis of the condition to which she would soon return) and perceptive of her irreversible condition, she could effectively decide upon discontinuance of the life-support apparatus, even if it meant the prospect of natural death. To this extent we may distinguish *Heston, supra*, which concerned a severely injured young woman (Delores Heston), whose life depended on surgery and blood transfusion; and who was in such extreme shock that she was unable to express an informed choice (although the Court apparently considered the case as if the patient's own religious decision to resist transfusion were at stake), but most importantly a patient apparently salvable to long life and vibrant health; a situation not at all like the present case.

We have no hesitancy in deciding, in the instant diametrically opposite case, that no external compelling interest of the State could compel Karen to endure the unendurable, only to vegetate a few measurable months with no realistic possibility of returning to any semblance of cognitive or sapient life. We perceive no thread of logic distinguishing between such a choice on Karen's part and a similar choice which, under the evidence in this case could be made by a competent patient terminally ill, riddled by cancer and suffering great pain; such a patient would not be resuscitated or put on a respirator in the example described by Dr. Korein, and *a fortiori* would not be kept *against his will* on a respirator.

Although the Constitution does not explicitly mention a right of privacy, Supreme Court decisions have recognized that a right of personal privacy exists and that certain areas of privacy are guaranteed under the Constitution. The Court has interdicted judicial intrusion into many aspects of personal decision, sometimes basing this restraint upon the conception of a limitation of judicial interest and responsibility, such as with regard to contraception and its relationship to family life and decision.

The Court in *Griswold* found the unwritten constitutional right of privacy to exist in the penumbra of specific guarantees of the Bill of Rights "formed by emanations from those guarantees that help give them life and substance." Presumably this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances, in much the same way as it is broad enough to encompass a woman's decision to terminate pregnancy under certain conditions. . .

Nor is such right of privacy forgotten in the New Jersey Constitution . . .

The claimed interests of the State in this case are essentially the preservation and sanctity of human life and defense of the right of the physician to administer medical treatment according to his best judgment. In this case the doctors say that removing Karen from the respirator will conflict with their professional judgment. The plaintiff answers that Karen's present treatment serves only a maintenance function; that the respirator cannot cure or improve her condition but at best can only prolong her inevitable slow deterioration and death; and that the interests of the patient, as seen by her surrogate, the guardian, must be evaluated by the court as predominant, even in the fact of an opinion *contra* by the present attending physicians. Plaintiff's distinction is significant. The nature of Karen's care and the realistic chances of her recovery are quite unlike those of the patients discussed in many of the cases where treatments were ordered. In many of those cases the medical procedure required (usually a transfusion) constituted a minimal bodily invasion and the chances of recovery and return to functioning life were very good. We think that the State's interest *contra* weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the State interest. It is for that reason that we believe Karen's choice, if she were competent to make it, would be vindicated by the law. Her prognosis is extremely poor—she will never resume cognitive life. And the bodily invasion is very great—she requires twenty-four hour intensive nursing care, antibiotics, the assistance of a respirator, a catheter and feeding tube.

Our affirmation of Karen's independent right of choice, however, would ordinarily be based upon her competency to assert it. The sad truth, however, is that she is grossly incompetent and we cannot discern her supposed choice based on the testimony of her previous conversations with friends, where such testimony is without sufficient probative weight. Nevertheless we have concluded that Karen's right of privacy may be asserted on her behalf by her guardian under the peculiar circumstances here present.

If a putative decision by Karen to permit this non-cognitive, vegetative existence to terminate by natural forces is regarded as a valuable incident of her right of privacy, as we believe it to be, then it should not be discarded solely on the basis that her condition prevents her conscious exercise of the choice. The only practical way to prevent destruction of the right is to permit the guardian and family of Karen to render their best judgment, subject to the qualifications hereinafter stated, as to whether she would exercise it in these circumstances. If their conclusion is in the affirmative, this decision should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them. It is for this reason that we determine that Karen's right of privacy may be asserted in her behalf, in this respect, by her guardian and family under the particular circumstances presented in this record.

The Medical Factor

Having declared the substantive legal basis upon which plaintiff's rights as representative of Karen must be deemed predicated, we face and respond to the assertion on behalf of defendants that our premise unwarrantably offends prevailing medical standards. We thus turn to consideration of the medical decision supporting the determination made below, conscious of the paucity of pre-existing legislative and judicial guidance as to the rights and liabilites therein involved.

A significant problem in any discussion of sensitive medical-legal issues is the marked, perhaps unconscious, tendency of many to distort what the law is, in pursuit of an exposition of what they would like the law to be. Nowhere is this barrier to the intelligent resolution of legal controversies more obstructive than in the debate over patient rights at the end of life. Judicial refusals to order lifesaving treatment in the face of contrary claims of bodily self-determination or free religious exercise are too often cited in support of a preconceived "right to die," even though the patients, wanting to live, have claimed no such right. Conversely, the assertion of a religious or other objection to lifesaving treatment is at times condemned as attempted suicide, even though suicide means something quite different in the law.

Perhaps the confusion there adverted to stems from mention by some courts of statutory or common law condemnation of suicide as demonstrating the state's interest in the preservation of life. We would see, however, a real distinction between the self-infliction of deadly harm and a self-determination against artificial life support or radical surgery, for instance, in the face of irreversible, painful and certain imminent death. The contrasting situations mentioned are analogous to those continually faced by the medical profession. When does the institution of life-sustaining procedures, ordinarily mandatory, become the subject of medical discretion in the context of administration to persons *in extremis*?

And when does the withdrawal of such procedures, from such persons already supported by them, come within the orbit of medical discretion? When does a determination as to either of the foregoing contingencies court the hazard of civil or criminal liability on the part of the physician or institution involved?

The existence and nature of the medical dilemma need hardly be discussed at length, portrayed as it is in the present case and complicated as it has recently come to be in view of the dramatic advance of medical technology. The dilemma is there, it is real, it is constantly resolved in accepted medical practice without attention in the courts, it pervades the issues in the very case we here examine. The branch of the dilemma involving the doctor's responsibility and the relationship of the court's duty was thus conceived by Judge Muir:

> Doctors. . .to treat a patient, must deal with medical tradition and past case histories. They must be guided by what they do know. The extent of their training, their experience, consultation with other physicians, must guide their decison-making processes in providing care to their patient. The nature, extent and duration of care by societal standards is the responsibility of a physician. The morality and conscience of our society places this responsibility in the hands of the physician. What justification is there to remove it from the control of the medical profession and place it in the hands of the courts?. . . .

Such notions as to the distribution of responsibility, heretofore generally entertained, should however neither impede this Court in deciding matters clearly justifiable nor preclude a re-examination by the Court as to underlying human values and rights. Determinations as to these must, in the ultimate, be responsible not only to the concepts of medicine but also to the common moral judgment of the community at large. In the latter respect the Court has a nondelegable judicial responsibility.

Put in another way, the law, equity and justice must not themselves quail and be helpless in the face of modern technological marvels presenting questions hitherto unthought of. Where a Karen Quinlan, or a parent, or a doctor, or a hospital, or a State seeks the process and response of a court, it must answer with its most informed conception of justice in the previously unexplored circumstances presented to it. That is its obligation and we are here fulfilling it, for the actors and those having an interest in the matter should not go without remedy.

Courts in the exercise of their *parens patriae* responsibility to protect those under disability have sometimes implemented medical decisions and authorized their carrying out under the doctrine of "substituted judgment". . ." For as Judge Muir pointed out:

> As part of the inherent power of equity, a Court of Equity has full and complete jurisdiction over the persons of those who labor under any legal disability. The court's action in such a case is not limited by any narrow bounds, but it is empowered to stretch forth its arm in whatever direction its aid and protection may be needed. While this is indeed a special exercise of equity jurisdiction, it is beyond question that by virtue thereof the Court may pass upon purely personal rights. . .

But insofar as a court, having no inherent medical expertise, is called upon to overrule a professional decision made according to prevailing medical practice and standards, a different question is presented. As mentioned below, a doctor is required "to exercise in the treatment of his patient the degree of care, knowledge and skill ordinarily possessed and exercised in similar situations by the average member of the profession practicing in his field." If he is a specialist he "must employ not merely the skill of a general practitioner, but also that special degree of skill normally possessed by the average physician who devotes special study and attention to the particular organ or disease or injury involved, having regard to the present state of scientific knowledge." This is the duty that establishes his legal obligations to his patients.

The medical obligation is related to standards and practice prevailing in the profession. The physicians in charge of the case, as noted above, declined to withdraw the respirator. That decision was consistent with the proofs below as to the then existing medical standards and practices.

Under the law as it then stood, Judge Muir was correct in declining to authorize withdrawal of the respirator.

However, in relation to the matter of the declaratory relief sought by plaintiff as representative of Karen's interests, we are required to re-evaluate the applicability of the medical standards projected in the court below. The question is whether there is such internal consistency and rationality in the application of such standards as should warrant their constituting an ineluctable bar to the effectuation of substantive relief for plaintiff at the hands of the court. We have concluded not.

In regard to the foregoing it is pertinent that we consider the impact of the standards both of the civil and criminal laws as to medical liability and the new technological means of sustaining life irreversibly damaged.

The modern proliferation of substantial malpractice litigation and the less but even more unnerving possibility of criminal sanctions would seem, for it is beyond human nature to suppose otherwise, to have bearing on the practice and standards as they exist. The brooding presence of such possible liability, it was testified here, had no part in the decision of the treating physicians. As did Judge Muir, we afford this testimony full credence. But we cannot believe that the stated factor has not had a strong influence on the standards, as the literature on the subject plainly reveals. Moreover our attention is drawn not so much to the recognition by Drs. Morse and Javed of the extant practice and standards but to the widening ambiguity of those standards themselves in their application to the medical problems we are discussing.

The agitation of the medical community in the face of modern life prolongation technology and its search for definitive policy are demonstrated in the large volume of relevant professional commentary.

The wide debate thus reflected contrasts with the relative paucity of legislative and judicial guides and standards in the same field. The medical profession has sought to devise guidelines such as the "brain death" concept of the Harvard Ad Hoc Committee mentioned above. But it is perfectly apparent from the testimony we have quoted of Dr. Korein, and indeed so clear as almost to be judicially noticeable, that humane decisions against resuscitative or maintenance therapy are frequently a recognized *de facto* response in the medical world to the irreversible, terminal, pain-ridden patient, especially with familial consent. And these cases, of course, are far short of "brain death."

We glean from the record here that physicians distinguish between curing the ill and comforting and easing the dying; that they refuse to treat the curable as if they were dying or ought to die, and that they have sometimes refused to treat the hopeless and dying as if they were curable. In this sense, as we were reminded by the testimony of Drs. Korein and Diamond, many of them have refused to inflict an undesired prolongation of the process of dying on a patient in irreversible condition when it is clear that such "therapy" offers neither human nor humane benefit. We think these attitudes represent a balanced implementation of a profoundly realistic perspective on the meaning of life and death and that they respect the whole Judeo-Christian tradition of regard for human life. No less would they seem consistent with the moral matrix of medicine, "to heal," very much in the sense of the endless mission of the law, "to do justice."

Yet this balance, we feel, is particularly difficult to perceive and apply in the context of the development by advanced technology of sophisticated and artificial life-sustaining devices. For those possibly curable, such devices are of great value, and, as ordinary medical procedures, are essential. Consequently, as pointed out by Dr. Diamond, they are necessary because of the ethic of medical practice. But in light of the situation in the present case (while the record here is somewhat hazy in distinguishing between "ordinary" and "extraordinary" measures), one would have to think that the use of the same respirator or life support could be considered "ordinary" in the context of the possibly curable patient but "extraordinary" in the context of the forced sustaining by cardiorespiratory processes of an irreversibly doomed patient. And this dilemma is sharpened in the face of the malpractice and criminal action threat which we have mentioned.

We would hesitate, in this imperfect world, to propose to physicians that type of immunity which from the early common law has surrounded judges and grand jurors. . .so that they might without fear of personal retaliation perform their judicial duties with independent objectivity. In Bradley v. Fisher. . .the Supreme Court held:

> It is a general principle of the highest importance to the proper administration of justice that a judicial officer, in exercising the authority vested in him, shall be free to act upon his own convictions, without apprehension of personal consequences to himself.

Lord Coke said of judges that "they are only to make an account to God and the King (the State)."

Nevertheless, there must be a way to free physicians, in the pursuit of their healing vocation, from possible contamination by self-interest or self-protection concerns which would inhibit their independent medical judgments for the well-being of their dying patients. We would hope that this opinion might be serviceable to some degree in ameliorating the professional problems under discussion.

A technique aimed at the underlying difficulty (though in a somewhat broader context) is described by Dr. Karen Teel, a pediatrician and a director of Pediatric Education, who wrote in the *Baylor Law Review* under the title "The Physician's Dilemma: A Doctor's View: What the Law Should Be." Dr. Teel recalls:

> Physicians, by virtue of their responsibility for medical judgments are, partly by choice and partly by default, charged with the responsiblity of making ethical judgments which we are sometimes ill-equipped to make. We are not always morally and legally authorized to make them. The physician is thereby assuming a civil and criminal liability that, as often as not, he does not even realize as a factor in his decision. There is little or no dialogue in this whole process. The physician assumes that his judgment is called for and, in good faith, he acts. Someone must and it has been the physician who has assumed the responsibility and the risk.
>
> I suggest that it would be more appropriate to provide a regular forum for more input and dialogue in individual situations and to allow the responsibility of these judgments to be shared. Many hospitals have established an ethics committee composed of physicians, social workers, attorneys, and theologians. . .which serves to preview the individual circumstances of ethical dilemma and which has provided much in the way of assistance and safeguards for patients and their medical caretakers. Generally, the authority of these committees is primarily restricted to the hospital setting and their official status is more that of an advisory body than of an enforcing body.
>
> The concept of an ethics committee which has this kind of organization and is readily accessible to those persons rendering medical care to patients, would be, I think, the most promising direction for further study at this point. . .[This would allow] some much needed dialogue regarding these issues and [force] the point of exploring all of the options for a particular patient. It diffuses the responsibility for making these judgments. Many physicians, in many circumstances, would welcome this sharing of responsibility. I believe that such an entity could lend itself well to an assumption of a legal status which would allow courses of action not now undertaken because of the concern for liability.

Alleged Criminal Liability

Having concluded that there is a right of privacy that might permit termination of treatment in the circumstances of this case, we turn to consider the relationship of the exercise of that right to the criminal law. We are aware that such termination of treatment would accelerate Karen's death. The County Prosecutor and the Attorney General maintain that there would be criminal liability for such acceleration. Under the statutes of this State, the unlawful killing of another human being is criminal homicide. . . .We conclude that there would be no criminal homicide in the circumstances of this case. We believe, first, that the ensuing death would not be homicide but rather expiration from existing natural causes. Secondly, even if it were to be regarded as homicide, it would not be unlawful.

These conclusions rest upon definitional and constitutional bases. The termination of treatment pursuant to the right of privacy is, within the limitations of this case *ipso facto* lawful. Thus, a death resulting from such an act would not come within the scope of the homicide statutes proscribing only the unlawful killing of another. There is a real and in this case determinative distinction between the unlawful taking of the life of another and the ending of artificial life-support systems as a matter of self-determination.

Furthermore, the exercise of a constitutional right such as we have here found is protected from criminal prosecution. We do not question the state's undoubted power to punish the taking of human life, but that power does not encompass individuals terminating medical treatment pursuant to their right of privacy. The constitutional protection extends to third parties whose action is necessary to effectuate the exercise of that right where the individuals themselves would not be subject to prosecution or the third parties are charged as accessories to an act which could not be a crime. And under the circumstances of this case, these same principles would apply to and negate a valid prosection for attempted suicide were there still such a crime in this State.

The Guardianship of the Person

The trial judge bifurcated the guardianship, as we have noted, refusing to appoint Joseph Quinlan to be guardian to the person and limiting his guardianship to that of the property of his daughter. Such occasional division of guardianship, as between responsibility for the person and the property of an incompetent person, has roots deep in the common law and was well within the jurisdictional capacity of the trial judge.

The statute creates an initial presumption of entitlement to guardianship in the next of kin, for it provides:

> In any case where a guardian is to be appointed, letters of guardianship shall be granted. . .to the next of kin, or if. . .it is proven to the court that no appointment from among them will be to the best interest of the incompetent or his estate, then to such other proper person as will accept the same. The trial court was apparently convinced of the high character of Joseph Quinlan and his general suitability as guardian under other circumstances, describing him as "very sincere, moral, ethical and religious." The court felt, however, that the obligation to concur in the medical care and treatment of his daughter would be a source of anguish to him and would distort his "decision-making processes." 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 to the next of kin.

Declaratory Relief

We thus arrive at the formulation of the declaratory relief which we have concluded is appropriate to this case. Some time has passed since Karen's physicial and mental condition was described to the

Court. At that time her continuing deterioriation was plainly projected. Since the record has not been expanded we assume that she is now even more fragile and nearer to death than she was then. Since her present treating physicians may give reconsideration to her present posture in the light of this opinion, and since we are transferring to the plaintiff as guardian the choice of the attending physician and therefore other physicians may be in charge of the case who may take a different view from that of the present attending physicians, we herewith declare the following affirmative relief on behalf of the plaintiff. Upon the concurrence of the guardian and family of Karen, should the responsible attending physicians conclude that there is no reasonable possibity of Karen's ever emerging from her present comatose condition to a cognitive, sapient state and that the life-support apparatus now being administered to Karen should be discontinued, they shall consult with the hospital "Ethics Committee" or the body of the institution in which Karen is then hospitalized. If that consultative body agrees that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state, the present life-support system may be withdrawn and said action shall be without any civil or criminal liability therefor on the part of any participant, whether guardian, physician, hospital or others. We herewith specifically so hold.

Conclusion

We therefore remand this record to the trial court to implement (without further testimonial hearing) the following decisions:

1. To discharge, with the thanks of the Court for his service, the present guardian of the person of Karen Quinlan, Thomas R. Curtin, Esquire, a member of the Bar and an officer of the court.

2. To appoint Joseph Quinlan as guardian of the person of Karen Quinlan with full power to make decisions with regard to the identity of her treating physicians.

We repeat for the sake of emphasis and clarity that upon the concurrence of the guardian and family of Karen, should the responsible attending physicians conclude that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state and that the life-support apparatus now being administered to Karen should be discontinued, they shall consult with the hospital "Ethics Committee" or like body of the institution in which Karen is then hospitalized. If that consultative body agrees that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitve, sapient state, the present life support system may be withdrawn and said action shall be without any civil or criminal liability therefor on the part of any participant, whether guardian, physician, hospital or others.

By the above ruling we do not intend to be understood as implying that a proceeding for judicial declaratory relief is necessarily required for the implementation of comparable decisions in the field of medical practice.

Modified and remanded.

For modification and remandment: Chief Justice HUGHES, Justices MOUNTAIN, SULLIVAN, PASHMAN, CLIFFORD and SCHREIBER and Judge Conford—7.

Opposed: None.

QUINLAN: Discussion Questions

Questions for discussion: "70 N.J. 10. In the Matter of Karen Quinlan"

1. Did you notice the early use (in "The Litigation") of "extraordinary" to describe the medical procedures sustaining Karen's "vital processes and hence her life." Distinguish between "ordinary" and "extraordinary" means. What assumption/s lay behind Justice Hughes' use of "vital processes"? Why didn't he simply say, ". . .sustaining Karen's life"?

2. In "The Factual Base," several important insights are made: the types of coma, the definition of "persistent vegetative state," the distinction between p.v.s. and "brain death," levels of brain stem function, the distinction between cardiovascular and brain death, etc. What is the basis for the physicians' unwillingness to remove the respirator from Karen? What ethical implications did such a removal have for them? (Note how the answers to these questions are based on assumptions and definitions that are not shared by the plaintiff.) This case shows how medical ethics differs from bioethics or clinical ethics. Do you see that difference?

3. The dilemma facing the judge (see "Guardianship") was to ascertain if Joseph Quinlan's request to remove ventilator support implied a disrespect for the value of human life. How did Quinlan's religious convictions assist the judge to resolve the dilemma? What role does religion often play in ethical decision-making?

4. The right of privacy ("Constitutional and Legal Issues") forms the basis for Justice Hughes' judgment concerning the legality of withdrawing the ventilator. How does he argue the right of privacy here?

The conflict between the state's interest in preserving life vs. the individual right to privacy finds no absolute right in either arm of the dilemma. Give instances where you believe the state's interest should prevail and where the individual's right should prevail.

What is the significance of the following statement: "We think that the State's interest *contra* weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims." What is implied in this statement that bears on the priority ranking that values assume?

5. The right of physicians to follow prevailing medical standards ("The Medical Factor") necessitates the judge's reflection on "curing," "healing," and "doing justice." He emphasizes that the decision whether or not to remove Karen's ventilator is not solely a medical decision but an ethical one as well, and to that end he makes mention of ethics committees, the first such formal reference made in a legal context. How is such a committee envisioned?

6. If termination of treatment would accelerate death, how can one justify such termination ("Alleged Criminal Liability")? What would be the "cause" of Karen's death?

7. How is guardianship defined ("The Guardianship of the Person")?

8. What conditions were placed on the withdrawing of the ventilator ("Declaratory Relief")?

9. How is the judge's view of ethics committee similar to and different from your own?

Further Readings

Rothman, David J. 1991. *Strangers at the Bedside.* Basic Books: 222-246.

Angell, Marcia. 1994. "After Quinlan: The Dilemma of the Persistent Vegetative State." *NEJM* 330 (May 26, 1994): 1524-5.

Brody, Baruch. 1992. "Special Ethical Issues in the Management of PVS Patients." *Law Medicine and Health Care* 20 (Spring-Summer): 104-115.

Multi-Society Task Force on PVS. 1994. "Medical Aspects of the Persistent Vegetative State." *NEJM* 330 (May 26 and June 2): 1499-1508.

withholding/withdrawing life sustaining treatment

The case of

CLAIRE CONROY

1985

Matter of Conroy
Supreme Court of New Jersey 1985, 486 A. 2nd 1209

Summary

An eighty-four-year-old non-ambulatory nursing home patient was confined to semi-fetal condition with "severe organic brain syndrome." She had necrotic gangrenous leg ulcers and no bowel control. Thepatient was not in a vegetative state. She followed movements with her eyes, showed some head and hand movements and smiled when massaged or when her hair was combed. Her life expectancy could not be predicted but it was thought to be "some months." (The patient died of natural causes while appeal was pending).

The patient's nephew, as her only relative, had been named guardian earlier, and requested removal of the nasogastric tube. The physician declined. The guardian sought a court order authorizing the withdrawal of tube.

The trial court granted the requested order, based on thebelief that the patient was "reduced to a very primitive level." The court stated that it would be wrong to refuse nutrition if the patient could be manually fed.

The intermediate appeals court reversed the decision (though recognized it to be mooted by death):

—limited Quinlan decison to comatose or vegetative patient
—noted cannot base decision on whether "meaningful quality of life"
—opined that nasogastric tube feeding was "not really 'medical treatment'"

Holding

Where death is impending but not yet imminent, and absent clear evidence of expressed patient's 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--upon trustworthy evidence the patient would have refused the treatment, because the "burdens" of continued life (unavoidable and continued severe pain) outweigh the benefits of continued life, or

2. "Pure-objective" test--the presence of burdens (unavoidable and continuing severe pain) which outweigh the benefits of life and a finding that the administration of life-sustaining treatment is "inhumane" (unless there should be trustworthy evidence that the patient earlier expressed a wish to live "in spite of any pain" experience).

Artificial feeding was equated with artificial breathing by respirator, stating each to be "medical procedures."

Requires:

1. Court determination that the general guardian is "suitable" to make the medical decision;

2. State's office of Ombudsman should be notified (which office should treat such notice as a "possible abuse," and effect procedures of the office);

3. Evidence on the patient's medical condition and prognosis should be furnished by the attending physician and nurses, and two physicians (unaffiliated with the attending physician or thE nursing home), and

4. Decision on "best interests" of patient:

   (a) Without court order
   —if other two physicians concur on patient's condition and prognosis, guardian and physician may concur, in withdrawing life-sustaining treatment, if ombudsman also concurs and if spouse,parents, children or other next of kin concur. (They will be without criminal or civil liability if they acted without "bad faith.")

   (b) With court order (not discussed in opinion, but surely follows in such instances where the required concurrences are not present)

Commented on possible inadequacy of inquiry as to patient's earlier statements of treatment preferences.

Commented on inadequacy of collected "information concerning the benefits and burdens" and as to pain suffered under alternate treatment options.

NOT WHEN BURDENS OUTWEIGH BENEFITS

Must Patients Always Be Given Food and Water?

by JOANNE LYNN and JAMES F. CHILDRESS

Many people die from the lack of food or water. For some, this lack is the result of poverty or famine, but for others it is the result of disease or deliberate decision. In the past, malnutrition and dehydration must have accompanied nearly every death that followed an illness of more than a few days. Most dying patients do not eat much on their own, and nothing could be done for them until the first flexible tubing for instilling food or other liquid into the stomach was developed about a hundred years ago. Even then, the procedure was so scarce, so costly in physician and nursing time, and so poorly tolerated that it was used only for patients who clearly could benefit. With the advent of more reliable and efficient procedures in the past few decades, these conditions can be corrected or ameliorated in nearly every patient who would otherwise be malnourished or dehydrated. In fact, intravenous lines and nasogastric tubes have become common images of hospital care.

Providing adequate nutrition and fluids is a high priority for most patients, both because they suffer directly from inadequacies and because these deficiencies hinder their ability to overcome other diseases. But are there some patients who need not receive these treatments? This question has become a prominent public policy issue in a number of recent cases. In May 1981, in Danville, Illinois, the parents and the physician of newborn conjoined twins with shared abdominal organs decided not to feed these children. Feeding and other treatments were given after court intervention, though a grand jury refused to indict the parents.[1] Later that year, two physicians in Los Angeles discontinued intravenous nutrition to a patient who had severe brain damage after an episode involving loss of oxygen following routine surgery. Murder charges were brought, but the hearing judge dismissed the charges at a preliminary hearing. On appeal, the charges were reinstated and remanded for trial.[2]

In April 1982, a Bloomington, Indiana, infant who had tracheoesophageal fistula and Down syndrome was not treated or fed, and he died after two courts ruled that the decision was proper but before all appeals could be heard.[3] When the federal government then moved to ensure that such infants would be fed in the future,[4] the Surgeon General, Dr. C. Everett Koop, initially stated that there is never adequate reason to deny nutrition and fluids to a newborn infant.

While these cases were before the public, the nephew of Claire Conroy, an elderly incompetent woman with several serious medical problems, petitioned a New Jersey court for authority to discontinue her nasogastric tube feedings. Although the intermediate appeals court has reversed the ruling,[5] the trial court held that he had this authority since the evidence indicated that the patient would not have wanted such treatment and that its value to her was doubtful.

In all these dramatic cases and in many more that go unnoticed, the decision is made to deliberately withhold food or fluid known to be necessary for the life of the patient. Such decisions are unsettling. There is now widespread consensus that sometimes a patient is best served by not undertaking or continuing certain treatments that would sustain life, especially if these entail substantial suffering.[6] But food and water are so central to an array of human emotions that it is almost impossible to consider them with the same emotional detachment that one might feel toward a respirator or a dialysis machine.

Nevertheless, the question remains: should it ever be permissible to withhold or withdraw food and nutrition? The answer in any real case should acknowledge the psychological contiguity between feeding and loving and between nutritional satisfaction and emotional satisfaction. Yet this acknowledgment does not resolve the core question.

Some have held that it is intrinsically wrong not to feed another. The philosopher G.E.M. Anscombe contends: "For wilful starvation there can be no excuse. The same can't be said quite without qualification about failing to operate or to adopt some courses of treatment."[7] But the moral issues are more complex than Anscombe's comment suggests. Does correcting nutritional deficiencies always improve patients' well-being? What should be our reflective moral response to withholding or withdrawing nutrition? What moral principles are relevant to our reflections? What medical facts about ways of providing nutrition are relevant? And what policies should be adopted by the society, hospitals, and medical and other health care professionals?

In our effort to find answers to these questions, we will concentrate upon the care of patients who are incompetent to make choices for themselves. Patients who are competent to determine the course of their therapy may refuse any and all interventions proposed by others, as long as their refusals do not seriously harm or impose unfair burdens upon others.[8] A competent patient's decision regarding whether or not to accept the provision of food and water by medical means such as tube feeding or intravenous alimentation is unlikely to raise questions of harm or burden to others.

What then should guide those who must decide about nutrition for a patient who cannot decide? As a start, consider the standard by which other medical decisions are made: one should decide as the incompetent person would have if he or she were competent, when that is possible to determine, and advance that person's interests in a more generalized sense when individual preferences cannot be known.

The Medical Procedures

There is no reason to apply a different standard to feeding and hydration. Surely,

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when one inserts a feeding tube, or creates a gastrostomy opening, or inserts a needle into a vein, one intends to benefit the patient. Ideally, one should provide what the patient believes to be of benefit, but at least the effect should be beneficial in the opinions of surrogates and caregivers.

Thus, the question becomes: is it ever in the patient's interest to become malnourished and dehydrated, rather than to receive treatment? Posing the question so starkly points to our need to know what is entailed in treating these conditions and what benefits the treatments offer.

The medical interventions that provide food and fluids are of two basic types. First, liquids can be delivered by a tube that is inserted into a functioning gastrointestinal tract, most commonly through the nose and esophagus into the stomach or through a surgical incision in the abdominal wall and directly into the stomach. The liquids used can be specially prepared solutions of nutrients or a blenderized version of an ordinary diet. The nasogastric tube is cheap; it may lead to pneumonia and often annoys the patient and family, sometimes even requiring that the patient be restrained to prevent its removal.

Creating a gastrostomy is usually a simple surgical procedure, and, once the wound is healed, care is very simple. Since it is out of sight, it is aesthetically more acceptable and restraints are needed less often. Also, the gastrostomy creates no additional risk of pneumonia. However, while elimination of a nasogastric tube requires only removing the tube, a gastrostomy is fairly permanent, and can be closed only by surgery.

The second type of medical intervention is intravenous feeding and hydration, which also has two major forms. The ordinary hospital or peripheral IV, in which fluid is delivered directly to the bloodstream through a small needle, is useful only for temporary efforts to improve hydration and electrolyte concentrations. One cannot provide a balanced diet through the veins in the limbs: to do that requires a central line, or a special catheter placed into one of the major veins in the chest. The latter procedure is much more risky and vulnerable to infections and technical errors, and it is much more costly than any of the other procedures. Both forms of intravenous nutrition and hydration commonly require restraining the patient, cause minor infections and other ill effects, and are costly, especially since they ordinarily require the patient to be in a hospital.

None of these procedures, then, is ideal; each entails some distress, some medical limitations, and some costs. When may a procedure be foregone that might improve nutrition and hydration for a given patient? Only when the procedure and the resulting improvement in nutrition and hydration do not offer the patient a net benefit over what he or she would otherwise have faced.

Are there such circumstances? We believe that there are; but they are few and limited to the following three kinds of situations: 1. The procedures that would be required are so unlikely to achieve improved nutritional and fluid levels that they could be correctly considered futile; 2. The improvement in nutritional and fluid balance, though achievable, could be of no benefit to the patient; 3. The burdens of receiving the treatment may outweigh the benefit.

When Food and Water May Be Withheld

Futile Treatment. Sometimes even providing "food and water" to a patient becomes a monumental task. Consider a patient with a severe clotting deficiency and a nearly total body burn. Gaining access to the central veins is likely to cause hemorrhage or infection, nasogastric tube placement may be quite painful, and there may be no skin to which to suture the stomach for a gastrostomy tube. Or consider a patient with severe congestive heart failure who develops cancer of the stomach with a fistula that delivers food from the stomach to the colon without passing through the intestine and being absorbed. Feeding the patient may be possible, but little is absorbed. Intravenous feeding cannot be tolerated because the fluid would be too much for the weakened heart. Or consider the infant with infarction of all but a short segment of bowel. Again, the infant can be fed, but little if anything is absorbed. Intravenous methods can be used, but only for a short time (weeks or months) until their complications, including thrombosis, hemorrhage, infections, and malnutrition, cause death.

In these circumstances, the patient is going to die soon, no matter what is done. The ineffective efforts to provide nutrition and hydration may well directly cause suffering that offers no counterbalancing benefit for the patient. Although the procedures might be tried, especially if the competent patient wanted them or the incompetent patient's surrogate had reason to believe that this incompetent patient would have wanted them, they cannot be considered obligatory. To hold that a patient must be subjected to this predictably futile sort of intervention just because protein balance is negative or the blood serum is concentrated is to lose sight of the moral warrant for medical care and to reduce the patient to an array of measurable variables.

No Possibility of Benefit. Some patients can be reliably diagnosed to have permanently lost consciousness. This unusual group of patients includes those with anencephaly, persistent vegetative state, and some preterminal comas. In these cases, it is very difficult to discern how any medical intervention can benefit or harm the patient. These patients cannot and never will be able to experience any of the events occurring in the world or in their bodies. When the diagnosis is exceedingly clear, we sustain their lives vigorously mainly for their loved ones and the community at large.

While these considerations probably indicate that continued artificial feeding is best in most cases, there may be some cases in which the family and the caregivers are convinced that artificial feeding is offensive and unreasonable. In such cases, there seems to be no adequate reason to claim that withholding food and water violates any obligations that these parties or the general society have with regard to permanently unconscious patients. Thus, if the parents of an anencephalic infant or of a patient like Karen Quinlan in a persistent vegetative state feel strongly that no medical procedures should be applied to provide nutrition and hydration, and the caregivers are willing to comply, there should be no barrier in law or public policy to thwart the plan.[9]

Disproportionate Burden. The most difficult cases are those in which normal nutritional status or fluid balance could be restored, but only with a severe burden for the patient. In these cases, the treatment is futile in a broader sense—the patient will not actually benefit from the improved nutrition and hydration. A patient who is competent can decide the relative merits of the treatment being provided, knowing the probable consequences, and weighing the merits of life under various sets of constrained circumstances. But a surrogate decision maker for a patient who is incompetent to decide will have a difficult task. When the situation is irremediably ambiguous, erring on the side of continued life and improved nutrition and hydration seems the less grievous error. But are there situations that would warrant a determination that this patient, whose nutrition and hydration could surely be improved, is not thereby well served?

Though they are rare, we believe there are such cases. The treatments entailed are not benign. Their effects are far short of ideal. Furthermore, many of the patients most likely to have inadequate food and fluid intake are also likely to suffer the most serious side effects of these therapies.

Patients who are allowed to die without artificial hydration and nutrition may well die more comfortably than patients who receive conventional amounts of intravenous hydration.[10] Terminal pulmonary edema, nausea, and mental confusion are more likely when patients have been treated to maintain fluid and nutrition until close to the time of death.

Thus, those patients whose "need" for artificial nutrition and hydration arises only near the time of death may be harmed by its provision. It is not at all clear that they receive any benefit in having a slightly prolonged life, and it does seem reasonable to allow a surrogate to decide that, for this patient at this time, slight prolongation of life is not warranted if it involves measures that will probably increase the patient's suffering as he or she dies.

Even patients who might live much longer might not be well served by artificial means to provide fluid and food. Such patients might include those with fairly severe dementia for whom the restraints required could be a constant source of fear, discomfort, and struggle. For such a patient, sedation to tolerate the feeding mechanisms might preclude any of the pleasant experiences that might otherwise have been available. Thus, a decision not to intervene, except perhaps briefly to ascertain that there are no treatable causes, might allow such a patient to live out a shorter life with fair freedom of movement and freedom from fear, while a decision to maintain artificial nutrition and hydration might consign the patient to end his or her life in unremitting anguish. If this were the case a surrogate decision maker would seem to be well justified in refusing the treatment.

Inappropriate Moral Constraints

Four considerations are frequently proposed as moral constraints on foregoing medical feeding and hydration. We find none of these to dictate that artificial nutrition and hydration must always be provided.

The Obligation to Provide "Ordinary" Care. Debates about appropriate medical treatment are often couched in terms of "ordinary" and "extraordinary" means of treatment. Historically, this distinction emerged in the Roman Catholic tradition to differentiate optional treatment from treatment that was obligatory for medical professionals to offer and for patients to accept.[11] These terms also appear in many secular contexts, such as court decisions and medical codes. The recent debates about ordinary and extraordinary means of treatment have been interminable and often unfruitful, in part because of a lack of clarity about what the terms mean. Do they represent the premises of an argument or the conclusion, and what features of a situation are relevant to the categorization as "ordinary" or "extraordinary"?[12]

Several criteria have been implicit in debates about ordinary and extraordinary means of treatment; some of them may be relevant to determining whether and which treatments are obligatory and which are optional. Treatments have been distinguished according to their simplicity (simple/complex), their naturalness (natural/artificial), their customariness (usual/unusual), their invasiveness (noninvasive/invasive), their chance of success (reasonable chance/futile), their balance of benefits and burdens (proportionate/disproportionate), and their expense (inexpensive/costly). Each set of paired terms or phrases in the parentheses suggests a continuum: as the treatment moves from the first of the paired terms to the second, it is said to become less obligatory and more optional.

However, when these various criteria, widely used in discussions about medical treatment, are carefully examined, most of them are not morally relevant in distinguishing optional from obligatory medical treatments. For example, if a rare, complex, artificial, and invasive treatment offers a patient a reasonable chance of nearly painless cure, then one would have to offer a substantial justification not to provide that treatment to an incompetent patient.

What matters, then, in determining whether to provide a treatment to an incompetent patient is not a prior determination that this treatment is "ordinary" per se, but rather a determination that this treatment is likely to provide this patient benefits that are sufficient to make it worthwhile to endure the burdens that accompany the treatment. To this end, some of the considerations listed above are relevant: whether a treatment is likely to succeed is an obvious example. But such considerations taken in isolation are not conclusive. Rather, the surrogate decision maker is obliged to assess the desirability to this patient of each of the options presented, including nontreatment. For most people at most times, this assessment would lead to a clear obligation to provide food and fluids.

But sometimes, as we have indicated, providing food and fluids through medical interventions may fail to benefit and may even harm some patients. Then the treatment cannot be said to be obligatory, no matter how usual and simple its provision may be. If "ordinary" and "extraordinary" are used to convey the conclusion about the obligation to treat, providing nutrition and fluids would have become, in these cases, "extraordinary." Since this phrasing is misleading, it is probably better to use "proportionate" and "disproportionate," as the Vatican now suggests,[13] or "obligatory" and "optional."

Obviously, providing nutrition and hydration may sometimes be necessary to keep patients comfortable while they are dying even though it may temporarily prolong their dying. In such cases, food and fluids constitute warranted palliative care. But in other cases, such as a patient in a deep and irreversible coma, nutrition and hydration do not appear to be needed or helpful, except perhaps to comfort the staff and family.[14] And sometimes the interventions needed for nutrition and hydration are so burdensome that they are harmful and best not utilized.

The Obligation to Continue Treatments Once Started. Once having started a mode of treatment, many caregivers find it very difficult to discontinue it. While this strongly felt difference between the ease of withholding a treatment and the difficulty of withdrawing it provides a psychological explanation of certain actions, it does not justify them. It sometimes even leads to a thoroughly irrational decision process. For example, in caring for a dying, comatose patient, many physicians apparently find it harder to stop a functioning peripheral IV than not to restart one that has infiltrated (that is, has broken through the blood vessel and is leaking fluid into surrounding tissue), especially if the only way to reestablish an IV would be to insert a central line into the heart or to do a cutdown (make an incision to gain access to the deep large blood vessels).[15]

What factors might make withdrawing medical treatment morally worse than withholding it? Withdrawing a treatment seems to be an action, which, when it is likely to end in death, initially seems more serious than an omission that ends in death. However, this view is fraught with errors. Withdrawing is not always an act: failing to put the next infusion into a tube could be correctly described as an omission, for example. Even when withdrawing is an act, it may well be morally correct and even morally obligatory. Discontinuing intravenous lines in a patient now permanently unconscious in accord with that patient's well-informed advance directive would certainly be such a case. Futhermore, the caregiver's obligation to serve the patient's interests through both acts and omissions rules out the exculpation that accompanies omissions in the usual course of social life. An omission that is not warranted by the patient's interests is culpable.

Sometimes initiating a treatment creates expectations in the minds of caregivers, patients, and family that the treatment will be continued indefinitely or until the patient is cured. Such expectations may provide a reason to continue the treatment as a way to keep a promise. However, as with all promises, caregivers could be very careful when initiating a treatment to explain the indications for its discontinuation, and they could modify preconceptions with continuing reevaluation and education during treatment. Though all patients are entitled to expect the continuation of care in the patient's best interests, they are not and should not be entitled to the continuation of a particular mode of care.

Accepting the distinction between withholding and withdrawing medical treatment as morally significant also has a very unfortunate implication: caregivers may become unduly reluctant to begin some treatments precisely because they fear that they will be locked into continuing treatments that are no longer of value to the patient. For example, the physician who had been unwilling to stop the respirator while the infant, Andrew Stinson, died over several months is reportedly "less eager to attach babies to respirators now."[16] But if it were easier to ignore malnutrition and dehydration and to withhold treatments for these problems than to discontinue the same treatments when they have become especially burdensome and insufficiently beneficial for this patient, then the incentives would be perverse. Once a treatment has been tried, it is often much clearer whether it is of value to this patient, and the decision to stop it can be made more reliably.

The same considerations should apply to starting as to stopping a treatment, and whatever assessment warrants withholding should also warrant withdrawing.

. . . nutrition and hydration by medical means need not always be provided.

The Obligation to Avoid Being the Unambiguous Cause of Death. Many physicians will agree with all that we have said and still refuse to allow a choice to forego food and fluid because such a course seems to be a "death sentence." In this view death seems to be more certain from malnutrition and dehydration than from foregoing other forms of medical therapy. This implies that it is acceptable to act in ways that are likely to cause death, as in not operating on a gangrenous leg, only if there remains a chance that the patient will survive. This is a comforting formulation for caregivers, to be sure, since they can thereby avoid feeling the full weight of the responsibility for the time and manner of a patient's death. However, it is not a persuasive moral argument.

First, in appropriate cases discontinuing certain medical treatments is generally accepted despite the fact that death is as certain as with nonfeeding. Dialysis in a patient without kidney function or transfusions in a patient with severe aplastic anemia are obvious examples. The dying that awaits such patients often is not greatly different from dying of dehydration and malnutrition.

Second, the certainty of a generally undesirable outcome such as death is always relevant to a decision, but it does not foreclose the possibility that this course is better than others available to this patient.[17] Ambiguity and uncertainty are so common in medical decision making that caregivers are tempted to use them in distancing themselves from direct responsibility. However, caregivers are in fact responsible for the time and manner of death for many patients. Their distaste for this fact should not constrain otherwise morally justified decisions.

The Obligation to Provide Symbolically Significant Treatment. One of the most common arguments for always providing nutrition and hydration is that it symbolizes, expresses, or conveys the essence of care and compassion. Some actions not only aim at goals, they also express values. Such expressive actions should not simply be viewed as means to ends; they should also be viewed in light of what they communicate. From this perspective food and water are not only goods that preserve life and provide comfort; they are also symbols of care and compassion. To withhold or withdraw them—to "starve" a patient—can never express or convey care.

Why is providing food and water a central symbol of care and compassion? Feeding is the first response of the community to the needs of newborns and remains a central mode of nurture and comfort. Eating is associated with social interchange and community, and providing food for someone else is a way to create and maintain bonds of sharing and expressing concern. Furthermore, even the relatively low levels of hunger and thirst that most people have experienced are decidedly uncomfortable, and the common image of severe malnutrition or dehydration is one of unremitting agony. Thus, people are rightly eager to provide food and water. Such provision is essential to minimally tolerable existence and a powerful symbol of our concern for each other.

However, *medical* nutrition and hydration, we have argued, may not always provide net benefits to patients. Medical procedures to provide nutrition and hydration are more similar to other medical procedures than to typical human ways of providing nutrition and hydration, for example, a sip of water. It should be possible to evaluate their benefits and burdens, as we evaluate any other medical procedure. Of course, if family, friends, and caregivers feel that such procedures affirm important values even when they do not benefit the patient, their feelings should not be ignored. We do not contend that there is an obligation to withhold or to withdraw such procedures (unless consideration of the patient's advance directives or current best interest unambiguously dictates that conclusion); we only contend that nutrition and hydration may be foregone in some cases.

The symbolic connection between care and nutrition or hydration adds useful caution to decision making. If decision makers worry over withholding or withdrawing medical nutrition and hydration, they may inquire more seriously into the circumstances that putatively justify their decisions. This is generally salutary for health care decision making. The critical inquiry may well yield the sad but justified conclusion that the patient will be served best by not using medical procedures to provide food and fluids.

A Limited Conclusion

Our conclusion—that patients or their surrogates, in close collaboration with their physicians and other caregivers and with careful assessment of the relevant information, can correctly decide to forego the provision of medical treatments intended to correct malnutrition and dehydration in some circumstances—is quite limited. Concentrating on incompetent patients, we have argued that in most cases such patients will be best served by providing nutrition and fluids. Thus, there should be a presumption in favor of providing nutrition and fluids as part of the broader presumption to provide means that prolong life. But this presumption may be rebutted in particular cases.

We do not have enough information to be able to determine with clarity and conviction whether withholding or withdrawing nutrition and hydration was justified in the cases that have occasioned public concern, though it seems likely that the Danville and Bloomington babies should have been fed and that Claire Conroy should not.

It is never sufficient to rule out "starvation" categorically. The question is whether the obligation to act in the patient's best interests was discharged by withholding or withdrawing particular medical treatments. All we have claimed is that nutrition and hydration by medical means need not always be provided. Sometimes they may not be in accord with the patient's wishes or interests. Medical nutrition and hydration do not appear to be distinguishable in any morally relevant way from other life-sustaining medical treatments that may on occasion be withheld or withdrawn.

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We are grateful to Haavi Morreim and Steven DalleMura for their helpful comments on an earlier version of this paper. We are also grateful for the instruction provided Dr. Lynn by the staff and patients of The Washington Home and its Hospice.

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[9] President's Commission, *Deciding to Forego Life-Sustaining Treatment*, pp. 171-96.

[10] Joyce V. Zerwekh, "The Dehydration Question," *Nursing83* (January 1983), 47-51, with comments by Judith R. Brown and Marion B. Dolan.

[11] James J. McCartney, "The Development of the Doctrine of Ordinary and Extraordinary Means of Preserving Life in Catholic Moral Theology before the Karen Quinlan Case," *Linacre Quarterly* 47 (1980), 215ff.

[12] President's Commission, *Deciding to Forego Life-Sustaining Treatment*, pp. 82-90. For an argument that fluids and electrolytes can be "extraordinary," see Carson Strong, "Can Fluids and Electrolytes be 'Extraordinary' Treatment?" *Journal of Medical Ethics* 7 (1981), 83-85.

[13] The Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, Vatican City, May 5, 1980.

[14] Paul Ramsey contends that "when a man is irreversibly in the process of dying, to feed him and to give him drink, to ease him and keep him comfortable—these are no longer given as means of preserving life. The use of a glucose drip should often be understood in this way. This keeps a patient who cannot swallow from feeling dehydrated and is often the only remaining 'means' by which we can express our present faithfulness to him during his dying." Ramsey, *The Patient as Person* (New Haven: Yale-University Press, 1970), pp. 128-29. But Ramsey's suggestion would not apply to a patient in a deep irreversible coma, and he would be willing to disconnect the IV in the Quinlan case; see Ramsey, *Ethics at the Edges of Life: Medical and Legal Intersections* (New Haven: Yale University Press, 1978), p.275. Bernard Towers describes an appropriate approach to comfort and dignity: "When a patient is conscious to even the smallest degree, and if he appears to be thirsty and to have a swallowing reflex, and if there is no contraindication to oral fluids, his comfort and dignity would surely demand that he be given nourishing liquids, or at least water. If he lapses into coma, good nursing practice has traditionally required sponging out the mouth and moistening the lips. Now, if he lapses into deep coma and is on a dying trajectory, would we then try to 'push' fluids by mouth or nasogastric tube? If we did, dignity would surely suffer. The 'comfort' of the patient would, of course, be unaffected if the coma were deep enough and irreversible." Towers, "Irreversible Coma and Withdrawal of Life Support: Is It Murder If the IV Line is Disconnected?" *Journal of Medical Ethics* 8 (1982), 205.

[15] See Kenneth C. Micetich, Patricia H. Steinecker, and David C. Thomasma, "Are Intravenous Fluids Morally Required for a Dying Patient?" *Archives of Internal Medicine* 143 (May 1983), 975-78.

[16] Robert and Peggy Stinson, *The Long Dying of Baby Andrew* (Boston: Little, Brown and Company, 1983), p. 355.

[17] A recent article discussed a hypothetical case of maintaining a dying, comatose patient on a respirator while withdrawing IV fluids. The authors contend that this approach is not ironic because withdrawal of the respirator "creates the immediate consequence of death for which we must take responsibility. It represents an extreme form of abandonment." Nevertheless, they were willing to stop IV fluids, knowing that death would occur before long. As the article's survey reported, other physicians would have provided nutrition and fluids. See Micetich, Steinecker, and Thomasma, "Are Intravenous Fluids Morally Required for a Dying Patient?"

RICHARD A. McCORMICK

Caring or Starving? The Case of Claire Conroy

The courts have set a trend toward wider discretion in withdrawing or withholding treatment from terminally ill patients. This progression involves some obvious dangers

Claire Conroy was an 84-year-old nursing home resident. She suffered from irreversible physical and mental impairments including arteriosclerotic heart disease, diabetes and hypertension. She could neither speak nor swallow and was fed by a nasogastric tube. Her movements were very limited though she could smile or moan in response to some stimuli. She was restricted to a semifetal position and lacked control of her excretory functions. Thomas C. Whittemore, Miss Conroy's nephew and guardian, requested that the nasogastric tube be removed from his awake but severely demented aunt. The application was opposed by Miss Conroy's guardian "ad litem" (for purposes of litigation).

At trial, two physicians testified that Miss Conroy would die of dehydration in about a week after removal of the nasogastric tube. They also concurred in the opinion that her death would be painful. One physician regarded the nasogastric feeding as optional medical treatment. Miss Conroy's own physician, however, believed that removal of the tube would be unacceptable medical practice. The trial court (Judge Reginald Stanton, Feb. 2, 1983) decided to permit removal of the tube because Miss Conroy's life had become intolerably and permanently burdensome.

This decision was appealed by Miss Conroy's guardian ad litem, but she died while the appeal was pending. However, the appellate division considered the matter too important to be left unresolved. It reversed the trial court's judgment and stated that removal of the nasogastric tube would be tantamount to killing her. A guardian's decision, the court argued, may never be used to withhold nourishment from an incompetent patient. As the court worded it: "The trial judge authorized euthanasia [homicide] . . . . If the trial judge's order had been enforced, Conroy would not have died as the result of an existing medical condition, but rather she would have died, and painfully so, as the result of a new and independent condition: dehydration and starvation. Thus she would have been actively killed by independent means."

Mr. Whittemore took the question to the New Jersey Supreme Court, the same court that had decided the Karen Quinlan case. The court released its decision Jan. 17, 1985. After acknowledging the right of a competent adult to decline medical treatment—a right embraced within the common-law right of self-determination—the court addressed the rights of the incompetent. It noted: "The right of an adult who, like Claire Conroy, was once competent, to determine the course of her medical treatment remains intact even when she is no longer able to assert that right or to appreciate its effectuation."

Clearly a substitute decision-maker or proxy must be called upon to function at this point. May a proxy ever decide that life-sustaining treatment may be withheld or withdrawn from an incompetent but not comatose patient? The court responded in the affirmative and proposed three tests or standards corresponding to three different situations. First, there is the "subjective standard," under which life-sustaining treatment may be withheld or withdrawn "when it is *clear* that the particular patient would have refused the treatment under the circumstances involved" (emphasis added). This clear intent can be concluded from written directives (living will) or oral statements made to family, friends or health providers. It might also derive from a durable power of attorney or appointment of a proxy with authorization to make medical decisions on the patient's behalf.

Second, there is the "limited objective test." Life-sustaining treatment may be withheld or withdrawn from a patient like Claire Conroy when there is trustworthy evidence that the patient would have refused the treatment and the proxy is satisfied that the burdens of the patient's contin-

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ued life with the treatment outweigh the benefits of that life for the patient.

Finally there is the "pure objective test." Under this test the burdens of the patient's life with treatment should clearly and markedly outweigh the benefits the patient derives from life. Furthermore, the unavoidable and severe pain of the patient's life with treatment must be such that continued life-sustaining treatment would be inhumane.

'Judicial disagreements reflect the state of ethical discussion'

In elaborating its decision, which was a reversal of the appellate division's judgment that cessation of artificial feeding was a killing act, the New Jersey Supreme Court made several interesting points. First, it stated that the record in the Conroy case did not satisfy the standards prescribed by the opinion. Second, it rejected several distinctions as analytically unhelpful in this case: the distinction between actively hastening death and passively allowing a person to die; the distinction between withholding and withdrawing; the distinction between ordinary and extraordinary means. For instance, the court viewed the active-passive distinction as "elusive" and "particularly nebulous" where withholding or withdrawing life-sustaining treatment is concerned. It stated: "In a case like that of Claire Conroy, for example, would a physician who discontinued nasogastric feeding be actively causing her death by removing her primary source of nutrients; or would he merely be omitting to continue the artificial form of treatment, thus passively allowing her medical condition, which includes her inability to swallow, to take its natural course?"

Third, the court stated clearly that artificial feeding by nasogastric tube or intravenous infusion is equivalent to artificial breathing by a respirator. In other words, it is a medical procedure and should be provided or withheld according to the criteria applicable to medical procedures.

Finally and very importantly, it stipulated a procedure to be followed in cases like that of Claire Conroy. The person (e.g., family member, guardian, physician) who believes that withholding or withdrawing life-sustaining treatment corresponds to the patient's wishes or would be in her/his best interests must notify an ombudsman. Those with contrary beliefs should do the same. The ombudsman is to treat every such notification of withholding or withdrawing as a possible abuse. Two physicians unaffiliated with the nursing home and with the attending physician must confirm the patient's medical condition and prognosis.

This decision is, in a sense, a linear descendent of a previous case involving withdrawing or feeding. Clarence Herbert underwent surgery for closure of an ileostomy at Kaiser Permanente Hospital, Harbor City, Calif., in 1981. Shortly after successful completion of the surgery, Herbert suffered cardiorespiratory arrest. He was revived and immediately placed on life-support equipment. Within the following three days it was determined that Mr. Herbert was in a deeply comatose state from which he was unlikely to recover. Tests performed by several physicians indicated that he had suffered severe brain damage, leaving him in a vegetative state that was likely to be permanent.

At that time Mr. Herbert's physicians, Dr. Robert Nejdl and Dr. Neil Barber, informed his family of his condition and the extremely poor prognosis. The family then drafted a written request to the hospital personnel stating that they wanted "all machines taken off that are sustaining life." Dr. Nejdl and Dr. Barber complied and removed Mr. Herbert from the respirator. He continued to breathe. After two more days, the two physicians, after consulting with the family (though the record is a bit hazy here), ordered removal of the intravenous line and nasogastric tube that provided hydration and nourishment. Shortly thereafter Mr. Herbert died.

Dr. Nejdl and Dr. Barber were accused of murder by the Los Angeles District Attorney. Los Angeles Municipal Judge Brian Crahan dismissed the case. It was reopened (May 5, 1983) by Superior Court Judge Robert A. Wenke on the grounds that the dismissal was erroneous. The Herbert case received widespread publicity. The implications of Judge Wenke's decision were stated simply by Dr. Barber: "No doctor will take a patient off a respirator now."

The matter eventually reached the Court of Appeal. On Oct. 12, 1983, Judge Lynn Compton exonerated Dr. Nejdl and Dr. Barber of any unlawful conduct. In the course of this opinion, the court made several interesting and important points. First, Judge Compton noted that even though life-support devices are self-propelled, still each drop of I.V. fluid is "comparable to a manually administered injection or item of medication." Hence disconnecting such devices is "comparable to withholding the manually administered injection." Second, the court viewed intravenous nourishment and fluid as "being the same as the use of the respirator." Third, medical nutrition and hydration resemble medical procedures rather than typical ways of providing nutrition and hydration. Hence they are to be evaluated in terms of their burdens and benefits. Finally, since the court viewed the physicians' actions as omissions rather than affirmative actions, the resolution of the case depends on whether there was a duty to continue to provide life-sustaining treatment. The court asserted that there is no such duty once the treatment is useless. And it was useless in Herbert's case because it merely sustained biological life with no realistic hope of a return to a cognitive, sapient state. Thus, continued use of life sustainers was "disproportionate."

These two cases have a key difference. Clarence Herbert was judged to be in a permanent vegetative state. Claire Conroy was not. She was incompetent but not comatose. Of those in a permanent vegetative state, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research wrote in *Decisions to Forgo Life-Sustaining Treatment*, 1983, 190: "Most patients with permanent unconsciousness cannot be sustained for long without an array of increasingly artificial feeding interventions—nasogastric tubes, gastrostomy tubes, or intravenous nutrition. Since permanently unconscious patients will never be aware of nutrition, the only benefit to the patient of providing such increasingly burdensome interventions is sustaining the body to allow for a remote possibility of recovery. The sensitivities of the family and of care-giving professionals ought to determine whether such interventions are made."

A footnote to this last sentence notes that it can be anticipated that courts will grant requests to withhold or withdraw further treatment, including I.V. drips, from such patients. And that is just what the court did in the Herbert case. But the New Jersey Supreme Court also did the same thing in principle in the Conroy case, and for some of the same reasons. That is, both courts regard feeding by I.V. lines and nasogastric tubes as basically medical procedures to be judged by a burdens-benefits calculus. Furthermore, both courts (to a lesser degree the New Jersey Supreme Court) allow "quality-of-life" components to function in determining the best interests of the patient.

There is another feature of these decisions that could easily be missed. Both represent reversals of lower courts that held that withholding or withdrawing nutrition-hydration from comatose and/or incompetent patients would constitute murder. I think it fair to say that these judicial disagreements reflect the state of ethical discussion that preceded them and still surrounds them.

One of the first shots in this discussion was fired by hospice nurse Joyce V. Zerwekh. She argued in Nursing, January 1983, that it is not always more merciful to administer I.V. fluids to a dying patient. There are both beneficial and detrimental effects associated with dehydration and the judgment must be individualized.

Since the Zerwekh study, the literature has piled up impressively. For instance, Kenneth Micetich, M.D., Patricia Steinecker, M.D., and ethicist David Thomasma (all of Stritch School of Medicine, Loyola University, Chicago) concurred that I.V. fluids may not be morally required under a threefold condition: 1) The patient must be dying. "Death will be imminent (within two weeks) no matter what intervention we may take." 2) The patient must be comatose. Comatose patients would experience no pain, thirst, etc. 3) The family must request that no further medical procedures be done in the face of impending death (Archives of Internal Medicine, 1983).

James Childress of the University of Virginia and Joanne Lynn, M.D., of George Washington University carried the matter a step further. They argued that there are cases, even though relatively few, when it is in the best interests of patients to be malnourished and dehydrated. They listed three situations: 1) The procedures that would be required could be considered futile. 2) The improvement in nutritional and fluid balance, though achievable, could be of no benefit to the patient (e.g., persistent vegetative state). 3) There are cases where the burdens to be borne in receiving the treatment may outweigh the benefit. Terminal pulmonary edema, nausea and mental confusion may be more likely in some patients as a result of artificial hydration and nutrition (Hastings Center Report, October 1983).

'The notion of "dying patient" is ambiguous'

Even more recently a group of distinguished clinicians advocated the withholding of parenteral fluids and nutritional support from severely and irrevocably demented patients and, occasionally, from elderly patients with permanent mild impairment of competence, a group characterized as "pleasantly senile" (New England Journal of Medicine, 1984).

Such voices have not gone unchallenged. Daniel Callahan (Hastings Center) agrees that it is morally licit to discontinue feeding in the circumstances noted by Lynn and Childress. Yet he is profoundly uneasy with that conclusion. The feeding of the hungry, whether they be poor or physically unable to feed themselves, is "the most fundamental of all human relationships" (Hastings Center Report, October 1983). It is, he argues, extremely dangerous to tamper with so central a moral emotion. There remains a deep-seated revulsion at stopping feeding even under legitimate circumstances. As I read him, Mr. Callahan would respect that revulsion and continue feeding as "a tolerable price to pay to preserve—with ample margin to spare—one of the few moral emotions that could just as easily be called a necessary social instinct."

Gilbert Meilaender of Oberlin College carries this a step further. He argues that the withdrawal of nourishment from permanently unconscious patients involves us in "aiming at their deaths." This we should never do. Nor does their permanent comatose state mean that it is useless to feed them. In these cases, feeding remains care for the embodied person, and it is dualistic to think otherwise. Nor is the care "in any strict sense medical treatment." It treats no particular disease; rather "it gives what all need to live" (Hastings Center Report, December 1984).

A physician (Mark Siegler) and an attorney (Alan J. Weisbard) are deeply troubled by the emerging literature justifying withholding or withdrawing of hydration and nutritional support (Archives of Internal Medicine, January 1985). They reject the idea that anyone (physicians, families, courts) can properly make such judgments for the incompetent. Therefore, they want to reverse the stream of this literature and offer several arguments to bolster this reversal. First, patients will be protected against diagnostic errors, inadequate treatment and unscrupulous (e.g., for financial reasons) care. Second, physicians will not be compelled to make ad hoc, quality-of-life judgments. Third, the medical profession will be protected against the gradual dilution of its dedication to the welfare of patients. Finally, society will benefit by rejecting this practice because it bears the seeds of unacceptable consequences (e.g., devaluation of the unproductive).

'May the quality of life preserved be a proper dimension of the calculus?'

This is a sampling of the literature that preceded and still surrounds the Claire Conroy decision. Where does it leave us? With several key issues and a final caution:

1. *The notion of a dying patient:* Who would be said to be a dying patient? If a patient needs dialysis to survive, is that patient a dying or nondying patient? If one needs a respirator to survive and will die without it, is that person dying or not? If one needs a nasogastric tube or a gastrostomy for food intake, is that person dying or not? I am suggesting that the notion of "the dying patient" is ambiguous and sometimes related to the technology available. However, the category is often presented as if it were utterly clear. This is a key issue; for if a patient is said to be nondying, but dies as a result of nutrient-withdrawal, then that withdrawal appears to be positively causal, and the withdrawer a killer.

2. *The nature of artificial hydration-nutrition:* Is this most properly characterized as a medical procedure, as both the appeals court of California and the New Jersey Supreme Court, as well as much of the literature, contend? Or does it more closely resemble providing a person with a bowl of soup? Does the simple fact that artificial feeding "gives what all need to live" (Meilaender) imply that how it is given makes no difference in its description? Most of us would not know how to go about providing nutrition and hydration by nasogastric tube and I.V. lines. These procedures require skilled medical training. Does that not constitute them strictly medical procedures? This is an issue because normal feeding has profound symbolic importance in human relationships and societal structure. It is one thing to starve the hungry. We should be appalled at the idea. It is quite another to withhold or withdraw a medical procedure. That we do routinely, and justifiably.

Whether artificial nutrition and hydration are medical procedures or not is often confused by the introduction of terms such as hunger and thirst. People can be denied artificial nutrition and hydration without experiencing hunger and thirst. Conversely, they can feel hunger and thirst without being malnourished or dehydrated. The usage "feed the hungry and thirsty" in this context tends to predispose us to regard artificial nutrition and hydration as something other than medical procedures.

3. *The intention of death:* When we withdraw nutrition and hydration from a permanently comatose patient, must we be said to be "aiming at death" (Meilaender)? The answer to this question will depend very closely on how we answer the first two. For example, if permanently comatose patients or profoundly incompetent ones are said to be dying patients (because their condition prevents normal ingestion of food, e.g., swallowing) and if artificial feeding by nasogastric tube is to be regarded as a medical procedure, then withdrawal of nutrients represents only omission of a medical procedure for a dying patient. This need not involve "aiming at death"; otherwise any such omission (e.g., of a respirator) would in principle involve this reprehensible intent.

On the other hand, if the patient is viewed as nondying, and artificial provision of nutrients is not a medical procedure but rather an instance of "normal, ordinary care," then omission of such nutrients could be more suspect.

Let me put it this way. Those who contend that withdrawing hydration and nutrition involves us in "aiming a death" or being involved in "the direct causal responsibility for death" (Siegler, Weisbard) must be consistent an apply their analysis to the competent patient. Is a competent patient who refuses a nasogastric tube or a gastrostomy guilty of suicide ("aiming at his own death")? Most o us would and should answer: "It all depends." If the patient can be tided over a transitory illness and returned t normal life, the treatment would surely be obligatory an refusal of it, other things being equal, would be suicidal. I however, this is not the case and the artificial feeding i foreseeably permanent, the treatment would be morall optional. Being such, it would not necessarily involve death-aim. It need involve only a thoroughly Christia assertion that there are values greater in life than living, th we all retain the right to decide how we shall live while dyin

4. *The burden-benefit calculus:* Where medical procedures are in question, it is generally admitted that the cr terion to be used is a burdens-benefits estimate. This wa the criterion proposed by the Sacred Congregation for t Doctrine of Faith in its Declaration on Euthanasia (May 1980) and by the President's commission. The questio posed is: Will the burden of the treatment outweigh t benefits to the patient? The general answer: If the trea ment is useless or futile, or if it imposes burdens that ou weigh the benefits, it may be omitted.

However, an ambiguity remains. What is to count as burden, and correlatively as a benefit? If a patient's life can be prolonged, but only in a comatose state, is that a benefit to the patient? Or if treatment will preserve life, but only a pain-racked, incompetent life, is that a benefit?

The issue here is this: In weighing the burdens-benefits of a treatment, is it the burden of the treatment only (e.g., its pain, expense etc.) that is legitimately considered, or may we include in the assessment the burden of continued existence itself? In other words, may the quality of life preserved be a proper dimension of the calculus?

The President's commission answered this last question in the affirmative when it defined the patient's best interest broadly to "take into account such factors as the relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of the life sustained." Both the Herbert court and the Conroy court did the same. For instance, the Conroy court (New Jersey Supreme Court) acknowledged that "although we are condoning a restricted evaluation of the nature of a patient's life in terms of pain, suffering and possible enjoyment under the limited-objective and pure objective tests, we expressly decline to authorize decision-making based on assessments of the personal worth or social utility of another's life, or the value of that life to others."

Some continue to attempt to finesse this extremely difficult and delicate issue by conceptualizing decisions in terms of "ordinary" and "extraordinary" means. But it will not work. Such terms only disguise the quality-of-life component unavoidably present in some of these decisions. For this reason nearly every recent commentator would agree with the President's commission when it stated: "The claim, then, that the treatment is extraordinary is more of an expression of the conclusion than a justification for it."

My own opinion on these issues is that the permanently comatose and *some* noncomatose but elderly incompetent patients may be classified broadly as dying; that feeding by I.V. lines and nasogastric tubes is a medical procedure; that its discontinuance need not involve aiming at the death of such patients; and that the burden-benefit calculus may include, indeed often unavoidably includes, a quality-of-life ingredient, providing we draw the line at the right place.

And that brings us to the caution. The Claire Conroy case and the decision of the New Jersey Supreme Court may appear to be isolated instances. That is not the case. There are many thousands of nursing home residents like Claire Conroy. They are a terribly vulnerable population. They are elderly and often suffer from crippling disabilities. They often are without surviving relatives. Physicians play a more limited role in nursing homes than in hospitals, and patient advocacy is correspondingly less intense. Furthermore, as the New Jersey Supreme Court notes, nursing homes are often afflicted with industry-wide problems that make them a very troubled and troublesome component of the health care system. And all of this at the very time when there are economic and social pressures on health care delivery. Together these factors may make it extremely difficult to keep patients' best interests at the heart of these decisions. In other words, the potential for abuse is enormous.

This suggests the wisdom of Daniel Callahan's statement at a spring conference on these problems in 1984: "The time to curtail abuses in the future is to begin now in trying to go through those steps that will draw lines very carefully." We have moved from Quinlan (persistent vegetative state—removal of respirator) to Herbert (persistent vegetative state—removal of respirator, nasogastric tube and I.V. lines) to Conroy (incompetent but noncomatose—removal of nasogastric tube). The progression is obvious, and obviously dangerous, unless we draw clear lines based on clear criteria. If we do not, we will not long be confined within the limits set forth in cases like Conroy.

Technology can help us or hurt us, individually and societally, and in ways that are awesome in their implications. The recent technological revolution in methods of hydration and nutritional maintenance is a case in point. That is why the ultimate caution was well stated by the New Jersey Supreme Court: When evidence of a person's wishes is equivocal, or the best interests determination doubtful, "it is best to err, if at all, in favor of preserving life." ■

CONROY: Discussion Questions

1. How does one make an argument for withholding/withdrawing life sustaining treatment for a patient, once competent but now incompetent?

2. Most states were making advance directives several years before advance directives became part of health care delivery. How was the argument made about honoring the wishes of a patient, once competent but now incompetent?

How would the argument be made if Claire Conroy had never been competent?

3. The artificial nature of medical food and hydration was made in the Cruzan case five years later. Justice Sandra Day O'Connor wrote that artificial food/hydration is medical treatment and thus lies under the same rules: if the withdrawal of medical treatment can be justified, so, too, can withdrawing artificial food and hydration. The analogy was made here with the respirator. Explain.

4. Intention plays a pivotal role in ethics. Give an argument that withdrawing artificial food/hydration need not be intending death (or "aiming at death" as Meilaender says).

5. The burden/benefit calculus is a unique feature of utilitarian ethical theory. In that theory, only consequences are morally relevant. How would you state the argument in the Conroy case from a burden/benefit perspective? What problems could someone have with the argument so stated?

6. In the Lynn/Childress article, the authors propose a three-fold quide for withholding/withdrawing food and hydration. What are they? Are they adequate?

7. McCormick indicates that the New Jersey Supreme Court proposed three standards that could be employed regarding proxy consent to withholding/withdrawing food and nutrition: the "subjective standard," the "limited objective test" and the "pure objective test." Under what conditions would each be used?

8. How do the Conroy and Herbert (McCormick article) cases differ?

Further Readings

Annas, George J. 1985. "From Quinlan to Conroy." *Hastings Center Report* 15 (April): 24-26.

McMahan, Jeff. 1993. "Killing, Letting Die, and Withdrawing Aid." *Ethics* (January): 251-279.

Steinbrook, Robert and Bernard Lo. 1988. "Artificial Feeding—Solid Ground, Not a Slippery Slope." *NEJM* 318 (February 4): 286-290.

withholding/withdrawing life sustaining treatment

The case of

NANCY CRUZAN

1990

U.S.-Supreme Court Cruzan vs. Director Missouri Department of Health, 1990
407 U.S. 261, 110 S. Ct. 2841, 111 L. Ed.2d 224

Summary

A thirty-year-old accident victim suffered lack of oxygen to her brain for six to twenty minutes. She was in a persistently comatose and vegetative state, sustained by a gastronomy feeding tube, although her respiration and circulation were normal. She was oblivious to her surroundings except for reflexive grimace-like responses to sound or pain. The patient was in a state of progressive spastic quadriplegia with irreversibly contracted extremities. The opinion of medical professionals was that she could live thirty-years. She now lies in a Missouri state hospital at the state's expense.

Before the injury, Nancy Cruzan had been a "vivacious, active, outgoing, and independent person." She had expressed in a "very serious" conversation with a friend the feeling that she would not wish to continue living if she couldn't be half-way normal, and "do things for yourself." Many other statements to family members suggested that "she would not want to continue her present existence without hope as it is." She remarked upon the stillborn death of a niece as perhaps "part of a greater plan" so as not to have to face a "possible life of mere existence." Commenting on the death of a grandmother after a long illness, she said it was better for her grandmother "not to be kind of brought back and forth" by treatment.

Her parents, acting as guardians, requested discontinuation of the feeding tube. Officials of the state hospital declined, absent a court order. The parents initiated suit, seeking declamatory judgment sanctioning discontinuation of the feeding tube.

After the hearing, the trial court entered finding that Ms. Cruzan "would not wish to continue with nutrition and hydration." It concluded that no state interest outweighed her "right to liberty," and that denial of her wish constituted unequal protection of the law.

Missouri Supreme Court [760 S.W.2d 408] reversed the trial court (by a 4-3 decision), stating trial court had "erroneously declared the law" [not particularized].

The court concluded that the feeding tube was "not heroically invasive," was not a "painful invasion," and was not "oppressively burdensome."

Futhermore, it ruled that "the state's interest in the preservation of life," stated to be "particularly valid" where a ward was not terminally ill, was "unqualified" and outweighed her constitutional right of "privacy" or her common law right to refuse treatment.

The court questioned, without deciding, whether a guardian's authority extends to allow an exercise, derivatively, of the ward's constitutional rights, or may be limited by statutory grant and limited against an election of non-treatment.

Holding by U.S. Supreme Court

Noting that a patient's right to refuse treatment is a "logical corollary" of the common law doctrine of informed consent, stated that "it may be inferred" from prior decisions that a competent person has a "constitutionally protected *liberty* interest" in refusing treatment (emphasis added).

With respect to the right of an incapacitated patient to have a decision for non-treatment be made by a surrogate, it was noted that the state court had implicitly acknowledged the right and imposed a "procedural safeguard" to assure that the decision "conforms as best it may" to the wishes expressed by the patient. Then the Supreme Court cast the issue for decision as whether the State's imposition of the burden of "clear and convincing evidence," as asserting "'a societal judgment about how the risk of error should be distributed between the litigants,'" was constitutionally permissible, held it to be permissible, and held that the state Supreme Court finding that the burden had not been satisified was not constitutionally erroneous.

Rejected an appellant proposition that the "substituted judgment" of "close family members" should control in an instance of absence of clear and convincing evidence of the patient's wishes.

Principal Dissenting Opinion Contentions

Charged that the majority opinion (in finding a lack of clear and convincing evidence as to the patient's treatment choices) "failed to consider" significant hearing testimony of expressed desires of the patient.

Criticized the proposition [of the majority opinion] that the State's interest in guarding against "potential abuses" of unfortunate situations in which family members may act at variance to protection of the patient should allow such state interest to override the patient's interests, arguing that such potential abuses can be avoided in the course of court procedures involving service of a neutral guardian ad litem and "searching inquiry" of a trial judge, as had occurred in the case.

The *Cruzan* Decision

(Following MO Supreme Court Decision)

by Richard A. McCormick, S.J.

The Missouri Supreme Court decision on Nancy Cruzan is, in my judgment, so bad that it may prove to be pedagogically useful. It is muddled, confused and/or downright wrong on virtually every key issue.

Imagine the following scenario. There are four one-thousand-bed long term care facilities strategically placed near population centers in Missouri. Each bed contains a patient in a persistent vegetative state (PVS). Each is sustained by a gastrostomy feeding tube at state expense for an average of 20–25 years, many of them outliving their families and dear friends.

Is this an impossibly fanciful caricature? Not at all, if the pivotal tenets of *Cruzan (760 S.W.2d 408)* are valid and allowed to stand. Yet our sense of the "fitting," indeed our common sense, is powerfully assaulted by this scenario. I mentioned "pivotal tenets." Note the following: (1) The Court explicitly adverted to the fact that it was deciding the case "not only for Nancy, but for many, many others." It was establishing precedent for Missouri. (2) It disallowed any quality of life considerations in adjudicating such cases. "The state's interest is not in quality of life" (422), but in life itself. "Life is precious and worthy of preservation without regard to its quality." (419) (3) This interest "is an unqualified interest in life." (420, 422) (4) Even merely vegetative life (PVS) is a benefit to the patient and must be preserved by artificial nutrition-hydration. (5) The Court seems to believe that withdrawal of Nancy's gastrostomy tube would be tantamount to killing her. It refers to a "decision to cause death." (422) This matter, however, remains unclear in the dicta of the decision.

In the remainder of this commentary, I want to raise six substantive issues and conclude by pointing out what I believe to be the philosophical root of the Court's misguided judgment.

Substantive Issues

1. The State's Interest. As noted, the *Cruzan* Court sees the state's interest in life itself, not its quality, and this interest is "unqualified." The Court nowhere defines quality of life. It should have looked at the literature. It would have discovered two senses of that term and tempered its rationale accordingly. The first refers to the value of a life to society in terms of functional contributions, social usefulness, etc.—and, therefore, to the valuation of that life by a society using such a criterion. That quality of life in this sense—an arbitrarily defined level of functioning—has no legitimate place in cases like that of Cruzan is obvious.

But there is another sense to the term, one that apparently escaped the Court's notice. It refers to the biological condition of the individual and its relationship to the pursuit of life's goods and goals. Quality of life in this second sense is critical to good decision making. This was acknowledged by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research when it defined the patient's best interest broadly to "take into account such factors as the relief of suffering, the preservation or restoration of functioning and the quality as well as the extent of the life sustained." The Baby Doe rules imply a quality-of-life dimension when they exempt from aggressive life-sustaining treatment babies who will be permanently unconscious. Both the *Herbert* and the *Conroy* courts did the same. For instance, the *Conroy* court (New Jersey Supreme Court) acknowledged that "although we are condoning a restricted evaluation of the nature of a patient's life in terms of pain, suffering and possible enjoyment under the limited-objective and pure objective tests, we expressly decline to authorize decision making based on assessments of the personal worth or social utility of another's life, or the value of that life to others."

The *Cruzan* Court rejects any—even restricted—quality of life ingredient as pertaining to the state's interest. In doing so it achieves two remarkable results. First, it puts itself at odds with most persons whose best interests it proposes to protect. Human persons have an enormous stake in the quality of their lives—how they live, how they die, and how they live while dying. That is the assumption that undergirds living wills and durable power of attorney arrangements for medical decisions. For instance, I myself, along with countless others I am sure, have specified in my living will that, if I am in a PVS, I do not want artificially administered nutrition and hydration. I judge this to pertain to my personal well-being. Yet the logic of the *Cruzan* Court would sweep this directive aside. Its interest is in life, not its quality, and this interest is "unqualified." I take that to mean that personal preferences—and the moral and religious soil that nourishes them—are not in any way a state interest. If "unqualified" does not mean this, what does it mean?

> Human persons have an enormous stake in the quality of their lives—how they live, how they die, and how they live while dying.

Weigh carefully these words of the Court: "Given the fact that Nancy is alive and that the burdens of her treatment are not excessive for her, we do not believe her right to refuse treatment, whether that right proceeds from a constitutional right of privacy or a common law right to refuse treatment, outweighs the immense, clear fact of life in which the state maintains a vital interest." (424) Those words are absolute. They state quite astonishingly: given life (even PVS life) and the absence of burden in maintaining it, the state's "vital interest" overwhelms and negates any other consideration or putative right. One has to wonder why the Court even bothered to discuss the adequacy or inadequacy of information about Nancy's preferences and intent.

The second result of the Court's blanket refusal to consider any quality of life ingredient in these cases is that it

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reduces overall personal well-being and best interests to its biological component. That is vitalism, a point I shall return to below. The Court states (427) that it chooses "to err on the side of life." Actually it is erring on the side not of life, but of biologism. When we conflate the complex notion of personal "best interests" into sheer medical effectiveness, we equate the **personally** beneficial with the **medically** effective and thereby give powerful analytic support to the noxious idea that whatever can be done **ought** to be done.

2. The Guardian's Authority. When an individual is presently incompetent (and has not reliably expressed her preferences previously) or has always been incompetent, decisions about that person's care must fall to others. The analytic basis for this proxy responsibility has varied from court to court depending on the circumstances (e.g., right of privacy in *Quinlan*, common law right of self-determination in *Fox*, best interests in *Storar*, etc.). In other words, if no third party could make decisions about termination of treatment, either the patient's right of privacy, or right of self-determination or best interests would be frustrated.

The *Cruzan* Court rejects the right of privacy as a basis for withdrawing Nancy's gastrostomy tube. Such a right cannot be exercised by third parties. It also denies that the "common law right to refuse treatment—founded in personal autonomy—is exercisable by a third party absent formalities." Why? Because "a guardian's power to exercise third party choice arises from the state's authority, not the constitutional rights of the ward. The guardian is the delegatee of the state's *parens patriae* power." (425) And, of course, the state has this "unqualified" interest in life, even PVS life.

It is the source of the guardian's power that interests me here. The *Cruzan* Court says it is delegated by the state. That confuses **origin** with **recognition**—at least for previously competent patients—a confusion traceable to the Court's utterly legalistic approach to these matters. The logical upshot of this confusion: it becomes impossible to get patients off useless or even burdensome treatment (for if this state's interest in life is "unqualified," what matters the burden?). What the Court has done is to place all third party decision making responsibilities under the notion of guardianship.

I want to argue that the common law notion of self-determination, which is valid for the competent patient, must lead spontaneously to a notion of **family** self-determination for the incompetent one, if best interests and ultimately human dignity are to be served. In other words, the state does not exactly **originate** third party power as it does in some instances of guardianship; it merely **recognizes** (or notarizes) it, at least for cases like the *Cruzan* case.

There are two good reasons for arguing this: First, the family is normally in the best position to judge the real interests of the incompetent patient. The family knows those treatments that might be particularly disturbing and those that the patient may have accepted without distress in the past.

> **The family knows those treatments that might be particularly disturbing and those that the patient may have accepted without distress in the past. The family is a basic moral community affirmed to have not only rights, but also responsibilities in determining how best to serve the interests of its incompetent members.**

Second, and more importantly, our society places great value on the family. The family is a basic moral community affirmed to have not only rights, but also responsibilities in determining how best to serve the interests of its incompetent members. For this reason the principle of self-determination can best be understood to extend beyond the individual to encompass the notion of familial self-determination. This familial autonomy or self-determination is a value highly treasured. While it perhaps should not take precedence over individual autonomy in cases where patients are or were competent, it certainly justifies a prominent role for family members in helping to assess what is in the best interests of the incompetent one. Family members are given enormous responsibility for moral nurture, theological and secular education, and decisions about the best interests of their incompetent members throughout the lifetime of the family unit. It should be no different in the case when the incompetent family member is seriously or terminally ill. Occasionally this may lead a family to decide that the incompetent one's interests can best be served by declining a medical intervention.

To me this means that "familyness" and the kinship bonds we call family are the basic source or foundation of a proxy's power, not the state's grant. Of course, the principle of familial self-determination cannot ride unchecked. Society's responsibility to assure that the interests of its incompetent members are served will place some limits on familial self-determination. However, the state should intervene only when the familial judgment so exceeds the limits of reason that the compromise with what is objectively in the incompetent one's best interest cannot be tolerated.

This is the thrust of much of what Charles B. Blackmar says in his dissent. In his words: "I believe that decisions about Nancy's future should be made by those near and dear to her..." Exactly. This is, as a matter of fact, done all the time, and it is done by people who would be shocked to learn that they may do so because they have been empowered by the state. As Blackmar stated: "Decisions of this kind are made daily by the patient or relatives..." (428) That fact should have alerted the *Cruzan* Court that its understanding of the source of third party responsibility was incomplete.

3. The Notion of a Dying Patient. The Court repeats several times that Nancy is not dying or "terminally ill." I suggest that the notion of a "dying patient" or "terminally ill" one is ambiguous. Who is said to be terminally ill is often a function of available technology. A person with end-stage renal disease is a dying patient—if no dialysis is available. A patient without spontaneous respiration is a terminal patient—if no respirator is at hand. A person who cannot take food and water in normal ways is a dying patient—unless we intervene technologically with an N.G. tube or gastrostomy tube.

"Terminally ill" is, therefore, capable of two readings. First, it can refer to an incurable condition that will lead to death in a short time whether interventions are used or not. I will call this the **narrow** sense. Missouri adopted it in its living will statute when it specified "terminal condition" as "a death will occur within a short time *regardless of the application of medical procedures.*" (emphasis added) The second sense is **broader**. The Uniform Rights of the Terminally Ill Act (URITA) defined "terminal condition" as follows: "an incurable or irreversible condition that, *without the administration of life-sustaining treat-*

ment, **will**, in the opinion of the attending physician, result in death within a relatively short time." (emphasis added) In the first sense Nancy Cruzan is not terminal. In the second sense she is.

This is a crucial issue for two reasons. First, if Nancy is said to be nondying, that assertion strengthens the state's interest in her fate in the face of a decision that could leave her dead. Second (and this buttresses the first point), if she is nondying but dies as a result of nutrient withdrawal, that makes such withdrawal look positively causative, a killing act. This seems to be the approach of the *Cruzan* Court. For it refers to "a decision to **cause** death" (422) and "seeks to **cause** the death of an incompetent"(425).

That language assumes the answer to a serious philosophical issue—the difference between an **occasion** and a true **cause**. Take an analogy. Suppose hurricane winds bend and break a sapling tree. We prop it up, hoping to revive it, but see that it will never return to full budding form, even though it will stand and possibly produce a few anemic leaves. So we remove the prop and the tree dies. What killed the tree? Was it not the hurricane winds? Analogously, if we remove nutritional props from Nancy, was it not the original anoxic trauma that **caused** her death, that killed her?

This matter is only muddied by the usage "starve." I have heard physicians adamantly assert that the term is an exclusively medical term. I question that. While the term can be parsed in terms of medical effects and phenomena, it is a value term. "To starve another" means to withhold food and water from one **to whom it ought to be given**. That leaves totally untouched the question of "to whom it ought to be given" and the criteria for this determination. To jump ahead a bit, "ought to be given" assumes that the person will derive genuine benefit from feeding. More of this below.

4. <u>The Nature of Artificial Nutrition-Hydration</u>. The *Cruzan* Court, in contrast to virtually every other authoritative source, regards this issue as irrelevant. "The issue is not whether the continued feeding and hydration of Nancy is medical treatment; it is whether feeding and providing liquid to Nancy is a burden *to her*." (423) I believe the Court is straightforwardly wrong here. Regardless of their ultimate conclusion on the matter, all authorities (moral theologians, philosophers, courts, professional medical societies) have seen this as a key issue. For if artificial nutrition-hydration is not medical care or treatment, but simply identical with the normal provision of food and water, it pertains to those procedures we refer to as "ordinary care." In other words, we do not judge its withholding or withdrawal as we would, for instance, a respirator or other medical treatments.

As I read the literature, most—not all—commentators view artificial nutrition-hydration as medical treatment. This is true of the *Barber, Conroy, Jobes, Brophy* courts. It is true of the President's Commission, the American Medical Association and the American Academy of Neurology. It is true of many philosophers and theologians.

The *Cruzan* Court regards the whole discussion as a "semantic dilemma" and is determined to avoid it. Even here it fails, and in two ways.

First, it does indeed take a position—the position that artificial nutrition-hydration is not medical treatment. It states: "Common sense tells us that food and water do not treat an illness, they maintain a life." In short, it is not medical treatment because it does not treat a disease. This is similar to the argument of some philosophers that artificial nutrition-hydration is not medical treatment because it merely provides "what all need to live."

This is analytically incomplete, and, I believe, ultimately wrong. It assumes that **how** nutrients are supplied and **why** their artificial provision is necessary is irrelevant to the idea of treatment. Is it not the case that the inability to eat is caused by Nancy's cerebral anoxia and the subsequent ongoing cerebral cortical atrophy? Is not such atrophy and dysfunction a disease? When we use medical technology to bypass the inability to eat normally, in a broad sense we **treat** that disease even though we do not cure it. We should not, I think, equate all treatment with cure; otherwise many medical modalities that we commonly regard as treatment would not merit the name (prostheses, bypass surgery, analgesics for pain, some infertility interventions, etc.).

The second move by the *Cruzan* Court is to assert that the "medical argument" (artificial nutrition-hydration = medical treatment) is dangerous. "It seems to say that treatment which does not cure can be withdrawn." That is a thudding *non sequitur*. It need say or imply nothing of the kind. All it need say is that any treatment may be withheld or withdrawn when it is, in human estimate, nonbeneficial to the patient. There are many treatments that cannot cure but ought to be used and not withdrawn, e.g., analgesics for pain in terminal illness as noted above.

5. <u>The Burdens-Benefit Calculus</u>. Everyone—from the Congregation for the Doctrine of the Faith (*Declaration on Euthanasia*, 1980) to the President's Commission—agrees that the criterion for treatment decisions is the burdens-benefit calculus. Briefly, if a proposed treatment will offer no benefit, or the benefit will be outweighed by the burdens, the treatment is morally optional.

The *Cruzan* Court focuses only on the burden of the treatment. In doing so it supposes that preservation of life in a PVS is a benefit to the patient. Indeed, it says so explicitly. This point constitutes my most crucial disagreement with the decision. Furthermore, it is the point that sharply divides opinion on this and similar cases.

For instance, Judge David Kopelman (trial court of the *Brophy* case) asserted: "The proper focus should be on the quality of treatment furnished to Brophy, and not on the quality of Brophy's life." He went on to state that Brophy "does derive a benefit in that his life is sustained." He further stated that artificial nutrition-hydration "is useful in that it preserves his life and prevents his death."

Similarly, a group of philosophers and theologians signed a statement on artificial feeding of PVS patients. At one point it reads as follows:

> "In our judgment, feeding such patients and providing them with fluids by means of tubes is not useless in the strict sense because it does bring to these patients a great benefit, namely, the preservation of their lives."[1]

Robert Barry, O.P., is in this same corner. Of Clarence Herbert he states: "Provision of food and fluids would have been of nutritional value to him because they would have sustained his life."[2] At another place he states (of Herbert) that food and fluids "could have achieved their fundamental purpose which was to sustain his bodily functions and support its natural defenses against diseases."[3] Any quality of life approach is too susceptible to biases and prejudices and "there is no rational way in which the 'quality of life' of individuals could be justly and certainly assessed."

Of a sharply different view is Daniel Callahan. Speaking of the "irreversibly comatose, utterly vegetative," he says that food and water can be stopped. Why? "Neither provides any genuine benefit; there is no meaningful life of any kind—it is a mere body only, not an embodied person."[4]

John Paris, S.J., agrees. "Those who argue that quality of life cannot be a consideration in the treatment decisions for such (persistent vegetative) patients are placing the maintenance of mere biological existence above all other considerations."[5] Dennis Brodeur is of the same view. Artificial nutrition-hydration that "simply puts off death by maintaining physical existence with no hope of recovery...is useless and therefore not ethically obligatory."[6] Similarly the American Academy of Neurology stated: "Once this PVS diagnosis has been clearly established, medical treatment in general, including artificial feeding, provides no benefit to those patients."[7]

> The Catholic tradition never counted mere vegetative life a patient-benefit. The *Cruzan* court does.

I agree with the Callahan-Paris-Brodeur approach. When the American Medical Association adopted a similar position, the then archbishop of New Orleans (Philip Hannan) stated: "The Church strongly condemns this position."[8] With all due respect, I believe that is just plain wrong. In my view, those who take such a position have departed from the substance of the Catholic tradition on this matter. That tradition never counted mere vegetative life a patient-benefit. The *Cruzan* Court does.

6. The Major Concern of the *Cruzan* Court. In any number of places the Court leads us to believe that withdrawing artificial nutrition-hydration from Nancy will expose others with a reduced quality of life to similar withdrawals. In other words, allowing any quality of life consideration here would open the door to abuses of the weak.

This is certainly a legitimate concern and I do not wish to minimize it. But the proper response is not the safeside victimization of Nancy Cruzan and her family. It lies rather in hard and fast exception-stoppers. Concretely, third party decisions to withdraw nutrition-hydration should be rigidly controlled by two conditions: irreversible PVS and the dying condition. (It is here that the notion of "the dying patient" becomes urgently relevant—and possibly divisive.)

The Philosophical Roots of the *Cruzan* Court

At the outset I stated that I believe the Court to be "muddled, confused and/or downright wrong on virtually every key issue." I have tried to list some of these issues. But perhaps more important is the underlying philosophy that has guided the Court's deliberations.

That philosophy is what I call "legal positivism." The Court has decided the *Cruzan* case only on the narrow basis of constitutional or legal precedent. Finding analytical soft spots in the dicta of previous courts, it has ignored the wisdom and plain common sense struggling for expression in those decisions.

I can put this another way by saying that the *Cruzan* Court gave no weight to moral tradition. It faced profound human problems with only legal tools and categories. Equivalently this means that it was attempting to decide human problems without benefit of the values that inform the human. This is like facing medical dilemmas with only medical tools and expertise, as if medical good is simply identified with personal good. The case of Nancy Cruzan goes far deeper than the reach of constitutional and legal precedent. If we deny that, we freeze the ability of courts to face new and profoundly human problems. We paralyze their ability to be wise.

[1] William May, *et. al.*, "Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons," *Issues in Law and Medicine* 3 (Winter, 1987), pp. 203–217, at 209.

[2] Robert Barry, O.P., "The Ethics of Providing Life-Sustaining Nutrition and Fluids to Incompetent Patients," *Journal of Family and Culture* 1 (n. 2, 1985), pp. 23–37, at 32.

[3] *Loc. cit.*, pp. 32–33.

[4] Daniel Callahan, "Feeding the Dying Elderly," *Generations* (Winter, 1985), p. 17.

[5] John J. Paris, S.J., "Critical Life Issues," *Health Progress* 66 (December, 1985), p. 23.

[6] Dennis Brodeur, "Feeding Policy Protects Patients' Rights, Decisions," *Health Progress* 66 (June, 1985), pp. 38–43.

[7] Summarized in the *Newsletter of the Society for the Right to Die* (Summer, 1988).

[8] Cited in *National Catholic Register*, April 6, 1986.

The *Cruzan* Decision: A Moral Commentary

by Gilbert Meilaender

In this commentary I focus on issues important for moral analysis. I attempt no discussion of the merits or demerits of the Missouri Supreme Court's decision as a piece of legal reasoning, a matter on which I have little competence. It should be clearly said, however, that the *Cruzan* decision is an excellent example of moral analysis. It directs attention to crucial issues, turns away from flaws in decisions of courts in some other jurisdictions, and renders a verdict that should be applauded and (one hopes) imitated.

In arguing for this point of view, I may come under the indictment of Judge Blackmar who, in his dissenting opinion, writes that he is not "impressed with the crypto-philosophers cited in the principal opinion, who declaim about the sanctity of any life without regard to its quality. They dwell in ivory towers." It is difficult, however, to take seriously as moral analysis the separate dissenting opinions of Judges Blackmar and Welliver. (The dissenting opinion of Judge Higgins is more carefully crafted.) In any case, to consider how we ought to think about sanctity or quality of life is precisely not to dwell in an ivory tower; it is to ponder the difficult problems of how to care for the many different human beings for whom we have some responsibility and with whom we are united in a bond of citizenship.

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The Missouri Court directs our attention to considerations which are crucial and often confused in discussions of cases like that of Nancy Cruzan. Much of the moral argument surrounding cases like this one imports language that was being used several decades ago to wage a different battle. Twenty years ago the central struggle was this: to stop useless and/or burdensome treatments for irretrievably dying patients. That is, to let them die. Some opposed such "letting die," thinking it equivalent to killing. They failed, I believe, to distinguish adequately between the aim of an act and its foreseen result. To aim at caring for a dying patient by withdrawing death-prolonging treatments may result in a somewhat earlier death, but the aim is not to kill. The aim is to let die. Others opposed such "letting die" on different grounds, arguing that if we were (on humanitarian grounds) prepared to let such patients die, we should be willing to end their suffering still sooner by deliberately aiming to hasten their death. They failed, I think, to distinguish adequately between the aim and the motive of an act—supposing that aiming to kill a fellow human being became permissible if our motives were praiseworthy.

The Cruzan decision is an excellent example of moral analysis. It directs attention to crucial issues, turns away from flaws in decisions by other courts, and renders a verdict that should be applauded and imitated.

Paul Ramsey characterized these two viewpoints as "opposite extremes" that turned out to be strangely alike. The one never found reason to acknowledge inevitable death and permit it to come. The other never found reason to permit death to come without taking the next step and hastening its arrival. Neither could just "let die" the irretrievably dying patient.[1]

In that context the language of "letting die" was very important and powerfully applicable. We were arguing about patients who really were dying patients—about whether we should let them die, should fight against that death as long as we were able, or should hasten the coming of that inevitable death. In that context to argue for "letting die" staked out an important position in the dispute; one which sought to continue to care for dying patients while giving up futile attempts to cure, but one which refused ever to abandon care for still-living human beings. Chapter three of Ramsey's *Patient as Person* remains the classic expression of such a viewpoint and will continue to repay careful study. I return to it below.

The context has now changed, and it is to the great credit of the Missouri Court to have recognized this. We are no longer arguing about irretrievably dying patients, yet the language of the argument often sounds as if we were. The Court is very clear and to the point: "[T]his is not a case in which we are asked to let someone die. Nancy is not dead. Nor is she terminally ill." She isn't dying and, hence, no treatment can be said to be prolonging her dying. If there were such a death-prolonging treatment, we could simply withdraw it and let death take her. But no such treatment is ready at hand for us to withdraw. We cannot simply let her die, because she is not a dying patient. If we want her to go away, we will have to aim at her death (not just let it come as the result of an action aimed at caring for her). This too the Court sees and says. We can add the next sentence to those quoted above. "[T]his is not a case in which we are asked to let someone die. Nancy is not dead. Nor is she terminally ill. This is a case in which we are asked to allow the medical profession to make Nancy die by starvation and dehydration."

What reason could there be to make this our aim? The answer is fairly obvious. Although Nancy Cruzan is neither dead nor dying, her life is the sort no one would choose if given more normal possibilities. Although not dying, she is severely disabled. To see this, however, is to see the true nature of a choice to withdraw nutrition. In doing so we aim at no death-prolonging treatment; rather, we aim at a life thought to be of little or no worth. We judge that life not from the perspective of the one actually living it (a perspective about which we must confess radical ignorance), nor, certainly, from God's perspective, but from our own. We compare it to the sort of life we live (and Nancy Cruzan once lived) and judge it by that standard as a *lebensunwerten Leben*, a life not worth living. Understandably. But it should be clear that in so doing we are not simply rejecting a treatment as useless or inadequate—but a life as unworthy. That judgment of comparative worth the Court clearly discerns and rejects. We can add one more sentence to those quoted above. "[T]his is not a case in which we are asked to let someone die. Nancy is not dead. Nor is she terminally ill. This is a case in which we are asked to allow the medical profession to make Nancy die by starvation and dehydration. The debate here is thus not between life and death; it is between quality of life and death." In these sentences the Court recognizes how drastically the terms of debate have shifted within our country in the last two decades and how inadequate is the language of "letting die" for a case like that of Nancy Cruzan. On these matters crucial for moral analysis this opinion is more clear-headed than many of the decisions from "courts of some... sister states" which the Missouri Court recognizes but does not follow.

The Court makes one further distinction of importance at this point in the argument. Having stated that a decision to withdraw nutrition from Ms. Cruzan cannot be described as "letting die" but must be described as intentional killing, the Court makes clear that it speaks here the language of aim, not of motive. "To be sure, no one carries a malevolent motive to this litigation. Only the coldest heart could fail to feel the anguish of these parents who have suffered terribly these many years." The moral life would be far more straightforward than it is if well-motivated people never did what was wrong and those with evil motives never did right. But such is not the case. And the Court quite rightly distinguishes between the motives that led the Cruzans to court and a proper description of the deed they sought permission to enact.

If I am correct in suggesting that the terms of debate have shifted greatly and that the language of "letting die" no longer really fits the circumstances of a patient like Nancy Cruzan, why is this language still used? On this point also the Court's opinion is clarifying and helpful. It notes a "change of focus"—away from language that focused on treatments (as ordinary or extraordinary) and toward language that focuses on "the patient's medical prognosis and the individual patient's assessment of the quality of her life in the face of that prognosis." The ordinary/extraordinary language, though often confusing to some people, at least directed our attention to certain objective reasons for refusing treatment. An "extraordinary" treatment was either useless or excessively burdensome and could therefore rightly be refused. In refusing treatment on such grounds, a patient might, in effect, be choosing a shorter life, but still choosing life. From among the available life-choices that patient would be choosing a certain life—shorter, but free of certain burdensome or useless treatments.

But the "change of focus" discerned by the Court directs our attention away from such relatively objective grounds for choice. Instead, courts begin to focus simply on the right of individual choice. From that perspective, any treatment, even one that is clearly lifesaving and is not experienced as burdensome, may be refused. Once treatment refusal is grounded simply in autonomous patient choice, there is little ground left for denying patients the right to choose, not just among alternative life-choices, but death itself. Thus the Court says: "Once prognosis becomes irrelevant, and the patient's choice always more important than the state's interest [in preserving life], this standard leads to the judicial approval of suicide." If the only thing that counts is autonomous choice, patients may do more than choose one sort of life by choosing against certain treatments. They may turn against more than a particular treatment: they may turn against life.

In the case of competent patients this may, of course, be difficult to determine legally. There is a clear conceptual distinction between choosing not to live and choosing to live in a certain way (free of the burdens of particular treatments). But even were we to agree that it is morally wrong to choose against life, it would be very difficult for any court of law to determine that in my choices I was rejecting not just the burdens of continued treatment but continued life. (And it would certainly be difficult had I been well instructed by a good lawyer sensitive to the distinction.) Thus, in the case of competent patients, courts will very often need simply to permit competent patients to choose. (This does not mean, naturally, that legislatures could not determine that some choices were not open to competent patients—as some "living will" legislation specifies that nutrition and hydration are not forms of treatment that can be discontinued at patient discretion.)

It may, however, be quite appropriate to treat some incompetent patients differently. Other courts have tended to assume that, since competent patients have a right to refuse treatment, we must find someone to assert that right on behalf of incompetent patients. The Missouri Court wisely sees how problematic is that move. Feeding Nancy Cruzan does not seem to be useless, since it sustains her life (and does not just prolong a dying process). Feeding Nancy Cruzan does not seem to be burdensome, since, as far as we know, she cannot experience this treatment as burdensome. Therefore, a decision to withdraw nutrition and hydration is difficult to construe as a choice against either useless or burdensome treatment. It seems like a choice aimed not at her treatment but at her life. It is the only way to get her to die. Should not the Missouri Supreme Court think that at this point the state's interest in prevention of homicide becomes substantial? It should, and it did.

A decision to withdraw nutrition and hydration from Nancy seems like a choice aimed not at her treatment but at her life. It is the only way to get her to die.

The Court suggests that, at least for incompetent patients, we keep the language of medical prognosis central, that we ground treatment refusals for them in more than a choice asserted on their behalf. This leads us, finally, to consider the possible grounds for such a refusal. Is the provision of nutrition and hydration to Nancy Cruzan either useless or excessively burdensome? I suspect that most of our unexamined assumptions lie here, and that this is the most perplexing element in arguments about cases like this one. We can begin by considering the usefulness of feeding her. She is not a terminally ill patient and will not necessarily die soon if given nourishment and proper care. It is hard, therefore, to avoid saying that if we stop feeding her it is because we think her life is a useless one to live—not because the treatment is itself useless. The treatment seems useless because the life seems not worth sustaining. Is that not essentially what we tend to think?

This much is certainly true: Given alternatives, none of us would choose for ourselves the life Nancy Cruzan now lives. Judging from our perspective as competent adults, her life may seem comparatively worthless. But if we adopt that perspective in making such judgments, there are many lives that seem comparatively worthless. Our nursing homes are quite literally full of people whose lives we would not choose for ourselves. It is, therefore, not empty or irrelevant rhetoric when the Court writes: "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. This latter concern is especially important when considering a person who has lost the ability to direct her medical treatment." Nancy Cruzan is still living, still one of us. As such, she has a claim upon our continued care. She is, to be sure, severely disabled and—so far as we can tell—unlikely ever to recover from her disability. But this means only that we can probably never cure her. It does not release us from the obligation to provide her what care we can. The Court is quite right to worry about an argument which "seems to say that treatment which does not cure can be withdrawn" on that ground alone.

The argument that does need serious consideration here is one Paul Ramsey put forward in *The Patient as Person*—and later recanted. The argument does not perfectly fit the Cruzan case, since Ramsey meant to be talking only about dying patients, but it fits well enough. Ramsey argued that our actions toward the sick and dying ought to be governed by a categorical imperative: "Never abandon care." But he went on to explore two possible "qualifications" of this imperative, the first of which is especially relevant here. That first qualification was: "Never abandon care...except when [the patient is] irretrievably inaccessible to human care."[2] If there should be a patient who was really beyond our care, who could no longer receive that care, then, Ramsey wondered, could we really be obligated to give what could not be received? He wrote:

> The proposed justifiable exception depends on the patient's physiological condition which may have placed him utterly beyond reach. If he feels no suffering, he would feel no hunger if nourishment is withheld. He may be alone, but he can feel no presence...The sort of situation that may be covered and resolved by the present proposal in ethical analysis, if it is valid, are the cases of patients in deep and irreversible coma who can be and are maintained alive for many, many years...Acts of charity or moving with grace among the dying that now communicate no presence or comfort to them are no longer required. If it is the case that

> a wife is tragically mistaken when she takes twitches of the eyes to be a sort of language from her husband irreversibly comatose for seven years, or when she takes such reflex actions as the response of the lips to a feeding cup to be evidence of reciprocation and some minimal personal relatedness, then her care is now worthless. Indeed it is no longer care for him. It is no contradiction to withhold what is not capable of being given and received?[2]

If there is to be moral justification for withdrawing the feeding tube from a patient like Nancy Cruzan, this would be far better than the sorts of arguments the Missouri Court rightly rejects. For this argument is not grounded in a judgment that such a life is not worth living. It is grounded only in the judgment that there can be no obligation to give what cannot be received. And Ramsey quite clearly realized that under such circumstances, if such a justification were found acceptable, there would be little reason to bring about death only by withdrawing nutrition. In such cases "it is entirely indifferent to the patient whether his dying is accomplished by an intravenous bubble of air or by the withdrawal of useless ordinary natural remedies such as nourishment."[3] In either case we would not just be allowing the patient to die. We would be aiming at that death—and the justification, if there could be one, would be the sort sketched here.

This possible qualification of the duty never to abandon care Ramsey largely withdrew in his later work, *Ethics at the Edges of Life*. His reason was, simply, doubt whether we should ever say with confidence that a still living human being had passed beyond the reach of our care. "The serious objection to searching for such exceptions is that—even within the stringent limits of indications of a patient's impenetrable solitude silencing any need on our parts to feel an obligation to continue to extend care—one still might do the deadly deed to someone still in a penultimate stage, to someone who while beyond showing response to us may still be within reach of violation at our hands, and so not altogether in God's keeping."[4]

If it is hard to make the case that feeding Nancy Cruzan is useless (without judging her life—and not just her treatment—to be useless), we might yet consider the possibility that such treatment should be rejected on grounds not of uselessness but of excessive burden. At first blush this will seem a rather difficult argument to make. As the Court notes: "If the testimony at trial that Nancy would experience no pain 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." If she is said not to possess our ordinary capacity for experience, she cannot be held to experience feeding as a burden.

But perhaps this does not quite get at what one might have in mind in describing such feeding as a burden to her. Thus, for example, the brief submitted by the plaintiffs-respondents, considering (and rejecting) some medical testimony which had suggested that Ms. Cruzan might have "some limited perception of her environment," had argued: "But even if the testimony was believable, it would not detract from Nancy's right to be free from unwanted, invasive, medical treatment. Indeed, it would make her dilemma all the more horrible and compel withdrawal of this treatment if she somehow had some limited perception of her condition..." Judge Blackmar, in his dissent, put what I take to be the same opinion slightly more graphically: "If she has any awareness of her surroundings, her life must be a living hell."

We should be clear that the Court quite rightly rejected the argument presented by the plaintiffs-respondents; for they had argued both that Ms. Cruzan was incapable of experiencing anything and that her treatment was burdensome to her. But if one supposes that we should never say with certainty that such a patient is beyond experiencing the care we give, we must take seriously the objection that this care would be experienced as terribly burdensome. I am not certain I am prepared to believe this. Judge Blackmar wrote that, on such a supposition, her life must be a living hell. But "hellish" is the one thing it would not be. For what is terrible about hell is the ultimate isolation to which it sentences one. To be in hell is to be utterly enclosed within the self—caring for no one and being cared for by no one. If Ms. Cruzan is not incapable of experiencing our care, it would be hellish to know that others were discussing how to get her to die. It would not, however, be hellish to know that others were—despite their frustration, anxiety, and sense of hopelessness—struggling to care for her as best they could.

Nancy Cruzan is not dying and therefore cannot simply be "allowed to die." A feeding tube is not prolonging her dying but sustaining her life. She is not a "vegetable," but a severely disabled human being. If we judge her life worthless, we may have difficulty refraining from making the same judgment about other human beings not in PVS. All this the Court has seen clearly and interjected into public discussion.

All this, of course, is speculation about what we cannot know. What we do know the Court has plainly stated: Nancy Cruzan is not dying and cannot therefore simply be "allowed to die." A feeding tube is not prolonging her dying but sustaining her life. She is not a "vegetable," but a severely disabled human being. If, adopting our perspective as competent adults, we judge her life worthless, we may have difficulty refraining from making the same judgment about other human beings not in persistent vegetative states. All this the Court has seen clearly and interjected into public discussion. One can only wish that the Missouri Court had been given an opportunity to speak sooner. But even now we should be grateful that it has done so.

Notes

[1] Paul Ramsey, *The Patient as Person* (New Haven: Yale University Press, 1970), pp. 144ff.

[2] *Ibid.*, pp. 161f.

[3] *Ibid.*, p. 161.

[4] Paul Ramsey, *Ethics at the Edges of Life* (New Haven: Yale University Press, 1978), p. 224.

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The *Cruzan* Decision: 9.5 Theses for Discussion

(Following US Supreme Court Decision)

by Gilbert Meilaender

In its long-awaited decision in the case of Nancy Cruzan, the United States Supreme Court upheld the decision of the Missouri Supreme Court. Although that is the decision for which I had hoped and which I think correct, I am not greatly encouraged by the rationale provided in the opinion issued by the Court's majority and am even less encouraged by Justice O'Connor's concurring opinion and the dissenting opinions authored by Justices Brennan and Stevens. The theses below seek to explore some of the reason for this judgment.

(1) If we concentrate on moral rather than legal issues, it is hard to find important differences between the majority opinion authored by Chief Justice Rehnquist and the dissenting opinion authored by Justice Brennan. The majority opinion assumes "for purposes of this case" what Justice Brennan certainly asserts: that a competent person has "a constitutionally protected right to refuse lifesaving hydration and nutrition." In the case of an incompetent person, the Court majority holds that any of the states is entitled to require rigorous proof that this person, when still competent, authorized removal of a feeding tube in the event of his or her future incompetence. The majority does not demand that the states require as rigorous a demonstration of clear and convincing evidence as Missouri had; it simply views such a requirement as constitutionally permitted.

Justice Brennan's dissent, although it regards the "right to be free of unwanted medical intervention" as a fundamental constitutional right, does not describe that right as absolute. Justice Brennan grants that this right may be limited by countervailing state interests, but holds that the kind of evidence Missouri required is so strict that it will result in failure to honor what were genuinely the desires of many now incompetent persons.

> An act that causes death and an act that results in death are—for all of us who still think there is a distinction between killing and allowing to die—quite different morally.

Justice Brennan is less inclined than the Court majority to defer to Missouri's judgment about the kind of evidence needed to establish a person's desire to refuse treatment. He is more inclined than the Court majority to find that Missouri's rigorous evidentiary requirement would not achieve its supposed purpose: assuring that the wishes of the now incompetent person are accurately determined and enacted. This relative willingness or unwillingness to defer to the judgment of a state legislature is no doubt important in a variety of ways, but it does not point to any very important difference in understanding the moral issues at stake in *Cruzan*.

(2) Between the majority opinion and the Brennan dissent there may, however, be the following difference, which would be important for moral reflection and judgment. Although the facts of the Cruzan case lead all of us to concentrate on patients who were once competent but are no longer, there are also patients who have never been competent (e.g., infants, the profoundly retarded). Only Justice Scalia in his concurring opinion seems to realize this. But the majority opinion, without precisely noting the significance of this fact, seems to make room for its possible implications. The majority opinion, considering the claim that incompetent persons have the same right to refuse treatment as the competent, notes the difficulty with such a claim: "[A]n incompetent person is not able to make an informed and voluntary choice to exercise a hypothetical right to refuse treatment or any other right. Such a 'right' must be exercised for her, if at all, by some sort of surrogate." In the circumstances of the Cruzan case, the Court majority then simply notes that the state of Missouri is entitled to require clear and convincing evidence that a surrogate decision maker is really choosing what Ms. Cruzan herself, when competent, desired.

If, however, we think of cases unlike Cruzan—involving persons who have never been competent—it is clear that no surrogate can know what that person would have desired. The concept has no application in such cases. In such instances some have turned to "substituted judgment," but the Court majority seems (rightly, I think) to doubt the coherence of such a move. The Court may therefore be suggesting that we can quite properly have stricter rules governing treatment refusals for incompetent than competent patients. The issue of artificial feeding is a good one to consider here, since (as I will argue again below) withdrawal of a feeding tube often can only be construed as aiming at the patient's death. The majority opinion may be pointing us toward a compromise in public pol-

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icy that would go something like this: Even if we permit competent patients the liberty to make choices that seem to aim at their death (and, hence, are suicidal), we might well surround the lives of incompetent persons with greater protection against choices that, in effect, aim to end their lives—against, that is, injustice. Even while holding that it is never morally right to choose to die or to aim at another's death, we could grant competent adults the liberty to make such a morally wrong choice while protecting the incompetent against the infliction of such injustice. Such a vision may be buried within the majority opinion. But in my view only Justice Scalia really discerns the possibility of such a compromise, and he is quite right to ask why such a possible public policy should be a matter for constitutional adjudication rather than public argument and debate.

(3) Between Justice O'Connor's concurring opinion and Justice Brennan's dissent there is relatively little to choose. Her view differs from Brennan's only in her somewhat greater willingness to defer to a state legislature when it attempts to establish procedures to ensure that the wishes of incompetent persons are truly ascertained and honored. She goes out of her way, however, to emphasize the right of competent adults to refuse any care provided by medical personnel, including feeding. Moreover, she adds the conjecture—not really required by this case—that *if* a now incompetent patient previously executed an advance directive refusing treatment of any sort (including feeding), the Constitution might well *require* the states to implement and enforce the wishes expressed in that directive. And in her eagerness to endorse various forms of surrogate decision making she is likely to blur the distinctions needed for the sort of compromise position outlined in (2) above.

(4) If the majority opinion, the O'Connor concurring opinion, and the Brennan dissent shape the contours of future thinking, we may safely predict the following: The trend toward an absolutist understanding of patient autonomy, which so dominated medical ethics from the mid-1970s to the mid-80s, will win the day legally. From all sides we will be encouraged and enjoined to execute advance directives; that is, to attempt to outline our treatment desires and extend our autonomy even into any period of our future incompetence. Whether this view is grounded constitutionally in a supposed right to privacy or in a liberty interest to refuse unwanted treatment will not be terribly important. Commentators of all stripes discussing a wide variety of social ills will continue to be disturbed by the fragmentation of our society, but—in our characteristically schizophrenic way—we will continue to bemoan that fragmentation while enshrining it in our understanding of the principles that should govern treatment refusals.

We must distinguish between those whose aim is to reject burdensome and invasive treatment and those whose aim is to stop nourishing a person without cognitive capacity in order to bring about that person's death.

(5) We seem destined to continue to describe the facts of the Cruzan case in ways that are mistaken and misleading. The majority opinion is not without fault on this score. (Its sins are, however, not even in the same league with those of Justice Stevens, to which I will turn later.) Discussing the request by Nancy Cruzan's parents to stop nutrition and hydration, the majority opinion states: "All agree that such a removal would cause her death." Later, however, a decision to withdraw Ms. Cruzan's feeding tube is characterized as a decision which "all agree will result in her death." Granting the difficulties in law of articulating and applying a concept of proximate cause, an act that *causes* death and an act that *results* in death are—for all of us who still think there is some point to the distinction between killing and allowing to die—quite different morally. Confusion increases when only a few sentences later the majority opinion describes withdrawal of the feeding tube as "a decision to terminate a person's life." Justice Brennan is guilty of the same confusion when he characterizes a decision to withdraw Ms. Cruzan's feeding tube both as a "right to avoid unwanted medical care" and as a right "to choose to die with dignity."

(6) How we describe a decision to stop feeding someone like Nancy Cruzan is crucial. Her case is persistently described as one dealing with removal of a feeding tube; that is, removing intrusive, unwanted medical care. That description is inaccurate. Ms. Cruzan's parents did not seek removal of the tube, they wanted it in place for administering medications and fluids that would reduce seizures while she died. What they wanted stopped was not the intrusion of the tube but its use to nourish and sustain her life. What they wished to decline was not medical intrusion but nourishment. To see this is to begin to appreciate the force of a sentence from Justice Scalia's concurring opinion: "Suppose that Nancy Cruzan were in precisely the condition she is in today, except that she could be fed and digest food and water *without* artificial assistance." Indeed! We would then distinguish very quickly between those whose aim was to reject burdensome and invasive treatment and those whose aim was to stop nourishing a person without cognitive capacity in order to bring about that person's death.

If Justice O'Connor's view about the enforceability of advance directives wins the day, we will have developed a constitutional right to assisted suicide.

(7) This suggests a difficulty with the possible public policy compromise outlined in (2) above. Those desiring to refuse nourishment in order to die, or those for whom such a desire, convincingly documented, is asserted by a duly appointed surrogate, do not wish to die without assistance. They want a considerable amount of help from medical personnel, although this help is no longer characterized as intrusive. What they want may properly be described as assistance with suicide. That may pose, and we should hope it poses, grave difficulties for many caregivers. And it may also permeate our caregiving institutions with a kind of profound symbolic dissonance. If Justice O'Connor's view—that wishes expressed in clear advance directives have a constitutional right to be enforced—wins the day, we will have developed a constitutional right to assisted suicide. The sense that all of us are aggrieved when one of our fellow citizens takes his life (a sense

enshrined in the common law tradition which Justice Scalia admirably unpacks) will finally give way to the belief that we are isolated, autonomous individuals. The majority opinion seems to recognize that such questions may be involved, though it does not coherently address them. Noting that "the majority of States in this country have laws imposing criminal penalties on one who assists another to commit suicide," the Court majority writes: "We do not think a State is required to remain neutral in the face of an informed and voluntary decision by a physically able adult to starve to death." But that claim, potentially so far-reaching in its implications for artificial feeding cases, is never precisely related to the Cruzan case in the majority opinion. Once, however, we see that assisted suicide is under debate here we might well think Justice Scalia correct when he says that such an issue ought to be a matter for public debate rather than constitutional determination.

It needs to be said clearly that withdrawing a feeding tube—at least in cases like that of Nancy Cruzan—is properly construed as an act that aims at her death.

(8) In the face of the terminological confusions that abound in the majority opinion and in Justice Brennan's dissent, it needs to be said again that withdrawing a feeding tube—at least in cases like that of Nancy Cruzan—is properly construed as an act that aims at her death. The care she is receiving, even if we call it medical treatment, is not experienced by her as burdensome; hence, withdrawing the feeding tube is not simply rejecting the burdens of treatment. Nor is the care useless, since it preserves her life. Of course, the life she lives is not one that would be the first choice of any of us. But our responsibility is to benefit the life she has, not to determine whether her life has any benefit or worth. Moreover, as I noted in (6) above, when we stop feeding we do not necessarily cease all medically intrusive intervention. We stop feeding not to free her from a burden but to see to it that she dies. Up to the present time we have been unable to face this truth—hence, the terminological confusions. Perhaps a frank acknowledgment that we were indeed recommending assisted suicide would be more honest.

I am aware, of course, that my characterization of withdrawing a feeding tube as aiming at her death will continue to be disputed. For example, Richard McCormick, S.J., has suggested that we consider the following analogy: "Suppose hurricane winds bend and break a sapling tree. We prop it up, hoping to revive it, but see that it will never return to full budding form, even though it will stand and possibly produce a few anemic leaves. So we remove the prop and the tree dies. What killed the tree? Was it not the hurricane winds? Analogously, if we remove nutritional props from Nancy, was it not the original anoxic trauma that caused her death, that killed her?" The short answer to this no doubt rhetorical question is "no." Moreover, as the language of assisted suicide comes increasingly to the fore, it will become apparent to all that the answer is "no." McCormick's claim that we are simply "letting die" those in Ms. Cruzan's circumstances when we stop nourishment will prove to have been a stopgap measure—language needed to tide us over while we worked up the gumption to face a more adequate description of the act. A human being who does not or cannot achieve "full budding form," who puts forth only "a few anemic leaves," but who can continue indefinitely to live this less-than-fully-flourishing life with some assistance (propping) from us, is not a dying human being. She may be ill or seriously disabled, but she is not dying. And, therefore, she cannot be "allowed to die," though she can be killed.

As infants, all of us were in need of a good deal of propping—including, significantly, feeding. Some of us have flourished and, we like to imagine, now get along without propping. Others of us are more anemic and still need a great deal of propping. If we need it, others should try to give it. If others need it, we should try to give it. The fact that one of us is very anemic and in need of endless propping means simply that others must benefit that weak life as best they can and refrain from judging it as a life of no benefit to the one who lives it.

(9) The viewpoint outlined in (8) above may be grounded in religious belief, but it needs no such ground. Its warrant may be simply a firm commitment to treat human beings equally, making no comparative judgments about the worth of others' lives. Justice Stevens in particular seems to worry that "faith," "some theological abstraction," "theology" or "speculative philosophy" may without any constitutional warrant be inserted into these deliberations. He need not fear. In fact, something almost the opposite is true.

The position held by the dissenters in the Cruzan case would be safe only in a community with certain widely shared religious beliefs. We can see how this may be if we recall an argument made by Albert Camus about capital punishment. He suggested that the justice or injustice of the death penalty depends on the ultimate frame of reference within which it is used and understood. Capital punishment could be justified only where there was a socially shared religious belief that the final verdict on any person's life was not given in this world. In such a religious society, to condemn a fellow human being to death would not involve divine pretension. Those who issued and executed the verdict would know that, however necessary it seemed to be, it could still be overturned by the only perfectly competent judge, God himself. But what of a society lacking such shared beliefs? In it, Camus thought, execution must mean elimination from the only community that indisputably existed; and, hence, execution would be a godlike activity. Only in a society that believed in the Eternal could it be right to exercise an ultimate mastery over this finite life.

Our responsibility is to benefit the life Nancy has, not to determine whether her life has any benefit or worth.

Similarly, it would be one thing to judge Nancy Cruzan's life no longer worth our care, to aim at her death, if we shared the belief that in so doing we were handing her over to One who might discern in her worth beyond our ability to discover. It is quite another when our decision eliminates her from the only community we are agreed in valuing. The worth of her life, however disabled she may be, lies simply in the fact that she shares with us the human community. As far as we as a publicly constituted people are concerned, she is either valued and treated equally within this community or she is deemed less than our equal.

(9.5) About all these matters Justice Stevens is very confused. I offer here only half a thesis for reasons of charity. He argues against equating Nancy Cruzan's life with "the biological persistence of her bodily functions." Is she no longer a living human being? Well, not exactly. "Nancy Cruzan is obviously 'alive' in a physiological sense. But for patients like Nancy Cruzan, who have no consciousness and no chance of recovery, there is a serious question as to whether the mere persistence of their bodies is 'life' as that word is commonly understood, or as it is used in both the Constitution and the Declaration of Independence." Yet, Justice Stevens does not recommend burying her while her heart still beats. It is clear that in wanting to let her die he is, in fact, turning against not her treatment but that physiological life (biological persistence) she still has.

Justice Stevens is concerned that Ms. Cruzan's rights to life and liberty are in conflict. By holding that her "life expired when her biological existence ceased serving any of her own interests," he no longer needs to worry about her right to life—since she is dead. Yet, of course, he must presuppose some kind of ongoing existence if he is to be concerned for her interest in liberty, in freedom from unwanted medical treatment. He goes so far as to suggest different definitions of life and death for different people. Some of us might argue that our life ends when our continued biological existence no longer serves any of our other interests; others of us might define life "to encompass every form of biological persistence by a human being." Evidently we get to choose whether we are still alive, still a member of a community and entitled to its care, and we get to make different choices and "die" at different points along some spectrum of possibilities. Here is a recipe for chaos. More important, such confused and confusing views will make it only more difficult than it has already become to believe that we share a common life and have a stake in the lives of each other.

> We stop feeding not to free Nancy from a burden but to see to it that she dies. Until the present time we have been unable to face this truth.

Clear and Convincing Evidence: The Case of Nancy Cruzan

by Richard A. McCormick, S.J.

My initial reaction to the Supreme Court decision in the case of Nancy Cruzan was quite critical. Why? Four reasons especially. First, I judged that one of its primary repercussions would be to remove families from participating in decisions concerned with the best interests of their dear ones. I view such distancing as highly undesirable. There should be in morality and public policy a presumption that family members are best positioned to determine what an incompetent family member would choose or what is in the incompetent's best interest. A presumption yields, of course, to contrary evidence. But to disallow Lester and Joyce Cruzan's testimony to qualify as a source of clear and convincing evidence struck me as a presumption in the opposite direction, and therefore divisive of families.

My second reason for a critical response was that the Supreme Court, very much as Missouri had done, left totally unprotected those who have been incompetent from birth and babies. Missouri's Supreme Court had asserted that its interest in the preservation of life was "strong enough to foreclose any decision to refuse treatment for an incompetent person unless that person had previously evidenced, in clear and convincing terms, such a decision for herself." (Justice Stevens in his dissent.) Absent that previous evidence, the interest in preservation of life prevails. This means that the always incompetent (e.g., Joseph Saikewicz, John Storar) must be kept alive no matter what. When the Supreme Court says that such an evidentiary requirement (clear and convincing, from the patient herself) is not unconstitutional, it means that it does not violate the liberty interest of the incompetent contained in the due process provisions of the 14th Amendment. But that seems to imply that the always incompetent have no such liberty interest. Strictly speaking, I suppose, they do not. That is, those who were never really free hardly have liberty interests. But at the root of the liberty interest is the dignity interest. And they certainly have that.

My third reason for an initial negative response was the lack of a sustained and enlightening analysis of the state's interest in the preservation of life. Justice Stevens adverted to this in his dissent. Indeed, by failing to make this analysis, the Supreme Court seemed to equate the preservation of life with the preservation of the biological persistence of Nancy's bodily functions.

> There should be in morality and in public policy a presumption that family members are best positioned to determine what an incompetent family member would choose or what is in the incompetent's best interest.

Finally, if evidence must be clear and convincing from the patient herself, it struck me that the *Cruzan* decision would foster a general reluctance to start life-preserving interventions if it is to be so difficult to stop them when they are no longer beneficial to the patient.

My second reaction was much less critical. Once again, for several reasons. First, it is clear that the decision was crafted along the most narrow grounds. It stated only that Missouri's heightened evidentiary requirement was not unconstitutional. It did not say it was necessary or wise or the only available approach. In other words, the Constitution permits, but does not require, a heavy burden of proof. I believe it was to be expected that the Court's ruling would be strictly constructionist. That did not help the

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Cruzans very much; but it leaves a lot of room for future development, what Justice O'Connor refers to as "the more challenging task of crafting appropriate procedures for safeguarding incompetents' liberty interests."

Second, the Court explicitly acknowledged for competent persons the existence of a constitutionally protected (14th Amendment) liberty interest in refusing unwanted medical treatment. Indeed, it agrees that such a liberty interest perdures into incompetency when it, along with Missouri, supports a surrogate's decision to reject treatment as long as there is clear and convincing evidence of the patient's wishes.

Central to both the constitutional and moral issues is a balancing of interests, specifically those of Nancy and those of the state.

Third, there are indications in the dicta that the Court would find lesser evidentiary demands and other arrangements constitutionally acceptable. For instance, writing about surrogate decision makers and the duty of a state to accept such decisions, Justice O'Connor states: "In my view, such a duty may well be constitutionally required to protect the patient's liberty interest in refusing medical treatment."

Finally, I am relieved that the Court did not anchor the right to refuse treatment in the right to privacy. Indeed it explicitly rejects such a basis when it notes (footnote 7) that "we believe this issue is more properly analyzed in terms of a Fourteenth Amendment liberty interest."

At this juncture it is appropriate to make two points. First, I am not a constitutional lawyer or historian. Therefore, I read the constitutional aspects of this decision as an amateur. Second, however, it is remarkable how indistinguishable is so-called constitutional reasoning from straight-out moral reasoning. Because of this considerable overlap I am emboldened to continue the discussion and raise some philosophical issues that seem to me to be incomplete.

The Supreme Court has clearly acknowledged a liberty interest in refusing unwanted medical treatment. It has also acknowledged relevant state interests. It describes the constitutional problem as follows (citing *Youngberg v. Romeo*): "Whether respondent's constitutional rights have been violated must be determined by balancing his liberty interests against the relevant state interest." This is the structure not only of the constitutional issue, but also the structure of the moral issue. Central to both the constitutional and moral issue is a <u>balancing</u> of interests, specifically those of Nancy and those of the state. Before a balancing of interests can be successfully accomplished, an accurate statement of those interests must be made. It is here that I find the Court's analysis quite vulnerable.

Let me begin with the state's interest. As the Court notes, "Missouri relies on its interest in the protection and preservation of human life, and there can be no gainsaying this interest."

Realizing that this is a very general statement, the Court tries to particularize it by noting that the state's interest is really in safeguarding "the personal element of this choice [between life and death] by heightened evidentiary requirements." These "heightened evidentiary requirements" refer, of course, to the patients' own earlier statements made while competent. One can bicker all day whether clear and convincing personal statements are the best way to protect the "personal element." Obviously, Justice O'Connor thinks other ways would be constitutionally acceptable. She notes that the *Cruzan* decision does not "prevent States from developing other approaches for protecting an incompetent individual's liberty interest in refusing medical treatment."

But this is not my concern. It is rather "the personal element of this choice" as the state's interest to be protected. What does this phrase mean? The Court notes that "the choice between life and death is a deeply personal decision of obvious and overwhelming finality" and it wants to protect this personal dimension. True enough, but perhaps not enough of the truth. Decisions that can lead to life or death are indeed <u>ordinarily</u> "of obvious and overwhelming finality." The Court includes the removal of Nancy's gastrostomy tube in this category. But Nancy's situation is not ordinary. She is in a persistent vegetative state. Release from this state is hardly a matter of "overwhelming finality." What is or was of overwhelming finality, I would argue, was the original cerebral insult that left Nancy in this condition. Let me put this in another way. The Court professes an interest in "the personal element of this choice." It was precisely this "element" that led it to support the constitutionality of Missouri's heightened evidentiary requirements. At this point, however, I want to question the significance of this "personal element" <u>in these circumstances.</u> Once a person is in a persistent vegetative state, there would seem to be no "personal element of this choice" remaining to protect. What I am suggesting is that the analytic soft spot in the Court's approach is the equation of a decision about the persistently vegetative Nancy Cruzan with an "ordinary" decision between life and death.

The urgent question is the evaluation of life in a persistent vegetative state. Is such a life a value to the one in such a condition? Is its preservation a benefit to the patient and therefore a state interest?

The point I am making can be urged from several different perspectives. For instance, in allowing Missouri's heightened evidentiary requirements, the Court asserts that "we think a State may properly decline to make judgments about the 'quality' of life that a particular individual may enjoy, and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual." In short, no "quality-of-life" judgments. Paradoxically, in refusing to allow <u>any</u> quality-of-life dimension, the Supreme Court (with Missouri) is actually making precisely such a judgment. It is saying that preserving a life even <u>in that condition</u> represents a value to the person and a state interest.

But does it really? I believe Justice Brennan is much closer to the truth when he argues that "no state interest could outweigh the rights of an individual in Nancy Cruzan's position." Brennan immediately continues: "The only state interest asserted here is a general interest in the preservation of life. But the state has no legitimate general interest in someone's life, completely abstracted from the interest of the person living that life, that could outweigh the person's choice to avoid medical treatment." Justice Stevens is getting at the same idea when he asserts that Missouri's policy "is an effort to define life, rather than to protect it." He continues: "Missouri insists, without regard to Nancy Cruzan's own interests, upon equating her life with the biological persistence of her bodily functions." He sees this as aberrant. So do I. And it is at the very heart of every key notion in this discussion (state's interest, patient benefit).

The urgent question is the evaluation of life in a persistent vegetative state. Is such a life a value to the one in such a condition? Is its preservation a benefit to the patient and therefore a state interest? Avoiding this question is obviously the more comfortable path. But it cannot be avoided, it can only be delayed. Missouri gave its answer when it referred to "the immense, clear fact of life in which the state maintains a vital interest." Obviously, then, the "immense clear fact of life" is identified with <u>any</u> life regardless of condition.

> For several years I have asked audience after audience if they would want artificial nutrition and hydration were they irreversibly unconscious. With virtual unanimity the answer has been no.

Some philosophers also take this point of view. Writing about artificial nutrition and hydration for permanently vegetative patients, William May and others stated: "In our judgment, feeding such patients and providing them with fluids by means of tubes is <u>not</u> useless in the strict sense because it does bring to these patients a great benefit, namely, the preservation of their lives." (*Issues in Law and Medicine*, vol. 3, no. 3, 1987.) This "great benefit" and Missouri's "immense, clear fact of life" strike me as examples of biologism or vitalism. By these terms I refer to a positive evaluation of circulation and ventilation regardless of what personal goals it enables for the individual.

We are understandably afraid of allowing a quality-of-life ingredient a role in decision making for the incompetent. It is dangerous. But I agree with Bernard D. Davis, professor emeritus at Harvard Medical School, that "irreversible coma is so clearly definable, as a special class, that it could be given special treatment without starting on a slippery legal slope." (*Wall Street Journal*, July 31, 1990.) What is that special treatment? A reversal of the presumption currently honored. At present, absent any prior expression of preference, we must presume an interest of the patient, or the state, in continuing life support. Davis proposes that in this extreme case (persistent vegetative state) evidence of a prior request should no longer be required. With appropriate safeguards we should presume a preference for termination of treatment.

What is the basis for this shift of presumptions? Davis refers to a "meaningful estimate...of public attitudes" and suspects that a survey of such attitudes would find a large majority opposed to continuing life-preservation for persistently vegetative patients. I do not have to suspect this. I am convinced of it. For several years I have asked audience after audience if they would want artificial nutrition and hydration were they irreversibly unconscious. With virtual unanimity the answer has been no. These people were saying that they did not regard <u>continuing in that condition</u> a benefit to them. For if they regarded this as a benefit, especially a "great benefit," they would be inconsistent in rejecting it if the treatment were otherwise not burdensome. If the vast majority of people do not regard existence in a persistent vegetative state as a genuine benefit, why should the state assert such continuance as an interest? In Justice Stevens' words, "life, particularly human life, is not commonly thought of as a merely physiological condition or function." For that reason Stevens concluded "there is no reasonable ground for believing that Nancy Beth Cruzan has any <u>personal</u> interest in the perpetuation of what the State has decided is her life."

The Supreme Court has judged that Missouri's heightened evidentiary requirements are not unconstitutional, that they are not an infringement of Nancy's liberty interest. Implied in such a view, I believe, is a further judgment that continuance in a persistent vegetative state is a patient benefit and therefore a state interest. I cannot accept that. So, while the *Cruzan* opinion has in my view analytic soft spots, it does leave the door wide open for further development. In that there is hope.

CRUZAN: Discussion Questions

Questions following the Missouri Supreme Court decision

1. The Missouri Supreme Court felt there were two separate interests in life that were at stake here, viz., the interest in sustaining the life of the individual patient and the interest in the sanctity of life itself. What arguments can be brought to bear to show the priority of one interest over another?

2. Did the court view Nancy's condition terminal or non-terminal? What difference did it make in the outcome of the state court's decision? Is there a moral difference between life-sustaining and death-prolonging treatment? How is "terminal" defined?

3. Dr. Meilander suggests that at issue is the determination of "a life not worth living," rather than the determination of a treatment as useless or inadequate. Can you give the arguments for/against his position? In your opinion which is the stronger argument? Why?

4. What is the role of the surrogate in cases where the patient once had decisional capacity and in cases where the patient never had decisional capacity? Why is there a difference here? How can you argue that Nancy's parents ought/ought not be her surrogates?

5. How would you identify the philosophical foundation for the Missouri Supreme Court's decision? Do you agree with McCormick that it is "legal positivism"? Could it be any other position?

Questions following the U.S. Supreme Court decision

1. What is the most convincing argument you can make that the preservation of human life is not simply the preservation of vegetative life? Where is the weakest point in your argument?

2. Why does the Court state that to base its majority judgment in a "liberty interest" is a stronger argument than to base it in "the right to privacy"?

3. Again, there is a "balancing" of liberty interests against the state's interest in preserving life. Like much ethical argument that attempts to balance one good over another, the U.S. court placed personal liberty over the state's interest. Do you think the argument is strong? Where is its weakest point?

4. Is it ethically significant that Nancy's food and hydration was administered through a gastrostomy tube and that Karen Quinlan's air was administered through a ventilator? What reasons do you have to support your answer?

5. Why is the definition of death ethically significant? All states recognize the heart/lung definition of death (when the heart stops beating and the lungs stop breathing) and most states recognize brain death (a flat EEG signifying no activity of brain or brain stem). Brain death is a product of this century. Why did it come into being? What ethical significance holds here?

6. Efforts are being made to extend "brain death" to include the irreversible loss of higher brain activities (consciousness) as one finds in patients in a permanent vegetative state. Argue this issue pro and con.

Further Readings

Midwest Medical Ethics. 1989. 5:1 and 2 (Winter-Spring). The entire issue is devoted to the Missouri Supreme Court ruling.

See also:

Susan M. Wolf. 1990. "Nancy Beth Cruzan: In No Voice At All." *Hastings Center Report* 20: 38-40 and James Bopp, Jr. 1990. "Choosing Death for Nancy Cruzan." *Hastings Center Report* 20: 42-47.

Midwest Medical Ethics. 1990. 6:4 (Fal). The entire issue is devoted to the U.S. Supreme Court ruling. (*Midwest Medical Ethics* is the precursor of *Bioethics Forum*, published by Midwest Bioethics Center, 1100 Pennsylvania Avenue, Kansas City, MO 64105)