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Nancy Cruzan and the Right to Die

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SOUNDING BOARD

NANCY CRUZAN AND THE RIGHT TO DIE

THE national discussion concerning decision making for incompetent patients began with the 1976 case of Karen Ann Quinlan. Because she had been left in a persistent vegetative state after two periods of anoxia, her parents sought court authorization to remove her from a ventilator. The New Jersey Supreme Court, in a landmark, unanimous decision, authorized the removal on the basis of Quinlan's constitutional right of privacy, which the court concluded would be lost unless her parents were given authority to exercise it on her behalf.[1] In the 15 years since *Quinlan,* courts in almost 20 states have reviewed disputes regarding treatment for incompetent patients. Courts in all these states have recognized the general right of competent people to refuse treatment, and in all but two states have also ultimately found that the U.S. Constitution, state constitution, or common law permits a surrogate to make treatment decisions on behalf of an incompetent person. The exceptions have been New York in the cases of Joseph Storar[2] and Mary O'Connor[3] and Missouri in the case of Nancy Cruzan.[4]

The case of Nancy Cruzan is essentially identical to that of Karen Ann Quinlan, with one exception: Nancy Cruzan, a young woman in a persistent vegetative state as a result of a 1983 automobile accident, requires only tube feeding (rather than a ventilator and tube feeding) to continue to survive. Her parents firmly believe she would not want to have tube feeding continued under such circumstances, in part on the basis of her own statement that she would not want to continue to live if she could not be "at least halfway normal." For this reason, a trial judge authorized her parents to have their daughter's tube feeding discontinued.

The Missouri Supreme Court, in a four-to-three opinion, reversed the decision. It held that Cruzan's right to refuse treatment was personal to her, and no one could exercise it on her behalf.[4] Because the consequence of refusal would be death and because the state had a legitimate interest in preserving life regardless of its quality, the court decided that life-sustaining treatment could be terminated only if it could be shown by "clear and convincing evidence" that Cruzan herself had rejected such treatment. Otherwise, the court reasoned, incompetent patients "with all manner of handicaps might find [their families or] the state seeking to terminate their lives." Nancy Cruzan's parents appealed this decision to the U.S. Supreme Court. This is the first time the Court has heard any case involving the right to refuse life-sustaining treatment.

THE MAJORITY OPINION

Chief Justice William Rehnquist wrote the opinion of the Court,[5] which was split five to four, characterizing the case as one involving the right to die and the right to cause death. Without deciding the issue, he said, "for the purposes of this case" the Court would "assume that the United States Constitution would grant a competent person a constitutionally protected right to refuse lifesaving hydration and nutrition." Such a right was seen as implicit in previous Court decisions, based not on the right of privacy but rather on the liberty interest delineated in the 14th amendment. The core of the case, however, was determining whether the state could restrict the exercise of the right to refuse treatment by surrogate decision makers acting on behalf of previously competent patients. In the Court's words, the question was "whether the U.S. Constitution forbids a state from requiring clear and convincing evidence of a person's expressed decision while competent to have hydration and nutrition withdrawn in such a way as to cause death."[5] The Court concluded that the Constitution did not prohibit this procedural requirement. Four basic reasons were given.

The first reason was that this evidentiary standard promotes the state's legitimate interest "in the protection and preservation of human life." The second reason was that "the choice between life and death is a deeply personal decision. . . ." The third was that abuses can occur in the case of incompetent patients who do not have "loved ones available to serve as surrogate decisionmakers." And the fourth reason was that the state may properly "simply assert an unqualified interest in the preservation of human life. . . ."[5]

There is no mathematical formula for the "clear and convincing" standard of proof, which is somewhere between the usual civil standard of "preponderance of the evidence" and the criminal standard of "beyond a reasonable doubt." Courts have described it in this context as "proof sufficient to persuade the trier of fact that the patient held a firm and settled commitment to the termination of life support under circumstances like those presented"[3] and evidence that is "so clear, weighty and convincing as to enable [the factfinder] to come to a clear conviction, without hesitancy, of the truth of the precise facts in issue."[6] The use of this strict standard of proof was justified primarily by the

argument that it is better to make an error on the side of continuing treatment:

> An erroneous decision not to terminate results in a maintenance of the status quo; the possibility of subsequent developments such as advancements in medical science, the discovery of new evidence regarding the patient's intent, changes in the law, or simply the unexpected death of the patient despite the administration of life-sustaining treatment, at least create the potential that a wrong decision will eventually be corrected or its impact mitigated. An erroneous decision to withdraw life-sustaining treatment, however, is not susceptible of correction.[5]

In conclusion, the Court held that Missouri could require clear and convincing evidence of Cruzan's wishes before permitting surrogates to authorize the termination of treatment. Even though "Nancy Cruzan's mother and father are loving and caring parents," Missouri may "choose to defer" only to Nancy Cruzan's wishes, and ignore both the parents' own wishes and their views about what their daughter would want.

The Dissent

Justice William Brennan wrote a dissent for three of the four dissenting members of the Court shortly before announcing his retirement. Following traditional constitutional jurisprudence, Justice Brennan argued that if a fundamental right of a citizen is at stake, state action restricting it "cannot be upheld unless it is supported by sufficiently important state interests and is closely tailored to effectuate only those interests." He chided the Court for not being more forceful in defining the nature of the liberty interest competent adults have in refusing treatment. Instead of simply assuming the liberty interest to be free of unwanted medical treatment, he clearly characterized it as a "fundamental right," one that "is deeply rooted in this Nation's traditions." To restrict such a right, the state must allege more than a general interest in life, because "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."[5]

Second, even if the preservation of life is a legitimate state interest in this context, Justice Brennan asserted that the Missouri restriction is irrational, since it would probably lead to more deaths than would current medical practice. This is because medical measures to sustain life, once begun, cannot now be terminated without clear and convincing evidence of the patient's wishes as long as continued treatment prolongs life. Trials of therapy are thus effectively discouraged by the Missouri rule, a result that is irrational.

Justice Brennan argued that the only legitimate interest the state can assert in Cruzan's case is an interest in accurately determining her wishes. In his view, the Missouri rules were designed not to determine her wishes, but to frustrate them. By permitting only her own statements as probative of her wishes and by using a "clear and convincing" standard to permit them to be determinative, the state effectively deprived her of all other evidence, including the best judgment of those who knew and loved her, as to what decision she would make (substituted judgment) or what decision would be in her best interests. Instead of furthering the citizen's right to decide, the Missouri rules impose "an obstacle to the exercise of a fundamental right."[5]

Justice Brennan also found the notion of erring on the side of life by preserving the status quo to be untenable. As he noted, the status quo proposition itself begs the question: had artificial respiration and feeding not been undertaken in the first place, the status quo would have been death from the accident. Moreover, the majority improperly implied that continued existence and treatment in a persistent vegetative state is either beneficial or neutral, whereas in fact

> an erroneous decision not to terminate life-support robs a patient of the very qualities protected by the right to avoid unwanted medical treatment . . . [a] degraded existence is perpetuated; his family's suffering is protracted; the memory he leaves behind becomes more and more distorted.[5]

Finally, Justice Brennan argued that the Missouri rules are simply out of touch with reality; people do not write elaborate documents about all the possible ways they might die and the various interventions doctors might have available to prolong their lives. Friends and family members are most likely to know what the patient would want. By ignoring such evidence of a person's wishes, the Missouri procedure "transforms [incompetent] human beings into passive subjects of medical technology."[5]

Discussion

The U.S. Supreme Court did not set standards of medical practice for the country in deciding this case. It simply decided that Missouri could constitutionally adopt a particular evidentiary standard. It is thus correct to say, as does the bioethicists' statement elsewhere in this issue,[7] that this very narrow decision "does not alter the laws, ethical standards, and clinical practices permitting the forgoing of life-sustaining treatment that have evolved in the United States since the *Quinlan* case in 1976."[7] It is also important to emphasize that five members of the Court recognized a constitutional right of competent people to refuse life-sustaining treatment.

Justice Brennan eloquently detailed the shortcomings of the opinion, but Justice Sandra O'Connor also added two important points in her concurring opinion. She indicated first that she agreed with the four dissenters that "artificial feeding cannot readily be distinguished from other forms of medical treatment" and therefore that "an individual's deeply personal decision to reject medical treatment, including the artificial delivery of food and water" is constitutionally protected. State statutes that treat tube feeding differently from other life-sustaining medical interventions may thus be unconstitutional. In addi-

tion, Justice O'Connor gave special emphasis to an issue the Court specifically declined to address — naming a surrogate decision maker. Since she agreed that few people will provide explicit instructions, she suggested that everyone appoint a proxy decision maker, and she noted that the *Cruzan* decision "does not preclude a future determination that the Constitution requires the States to implement the decisions of a duly appointed surrogate." This will undoubtedly give a well-deserved boost to durable powers of attorney, and most physicians will properly prefer a real person with whom they can discuss the patient's options to a written living will that may require interpretation.

Nonetheless, given that every indication is that Nancy Cruzan would have chosen either her mother or father to speak on her behalf, and given Justice O'Connor's belief that such a delegation would be constitutionally protected, it is an empty triumph of procedure over substance to deny Nancy Cruzan's parents the right to speak on their daughter's behalf. In fact, the entire opinion can be read as placing form over substance. The lower court did not know that the proper standard of proof was clear and convincing evidence until the Missouri Supreme Court so ruled in the appeal, and it would almost certainly have found that the evidence presented met the "clear and convincing" standard of proof.

The *Cruzan* decision virtually casts in stone the post-Reagan Court's general view that although citizens have personal constitutional rights, the states can restrict them as long as the restriction furthers a legitimate state interest and is not "irrational." Thus, for example, Nancy Cruzan can be subjected to treatment she never consented to, and according to all who knew her would never consent to, in order to further the state's interest in protecting the lives of incompetent patients who do not have loving families, even though Cruzan admittedly has a loving family. Former constitutional adjudication would have required the Missouri restrictions to be narrowly tailored to meet their objectives if a fundamental right was involved. Rules designed to protect those without loving families could not be used against those with loving families. Nancy Cruzan has been deprived not only of her right to decide, but also of the protective role of her family. It is cold comfort when the Court concludes that no other state need follow Missouri's lead. The truth is, if the state of Missouri can inflict its will on Cruzan and her family, none of us are safe from states that wish to control our health care decisions and our deaths.

The incredible leeway the Court cedes to the states can be seen by contrasting *Cruzan* with another case decided on the same day. On the day the Court decided that Missouri could "legitimately and rationally" assume that all families of incompetent patients are a danger to them, it also decided that Ohio could "legitimately and rationally" assume that all families are loving and supportive and thus require a pregnant teenager to notify her parents before obtaining an abortion, in order to uphold "the dignity of the family."[8]

For physicians, perhaps the chief problem with the majority opinion is its almost complete lack of attention to medical reality. The Court did not consider the professional or personal role of Nancy Cruzan's physicians at all, simply referring to them as "hospital employees" who refused to honor her parents' request without a court order. Because the Court ignored physicians, it never discussed the doctor–patient relationship or whether it matters if the physician had a long-standing relationship with the patient and understood what treatment the patient wanted. Even though the Court ignored physicians, lawyers will not, and physicians across the country are likely to be deluged with conflicting opinions and demands regarding what they should do and what they must do in the wake of the *Cruzan* opinion.

Physicians will need to know at least as much about *Cruzan* as is presented here to respond effectively to the flagrant sorts of "advice" they are likely to receive, such as "you can't do that anymore, because of the *Cruzan* opinion." The reality is that the *Cruzan* opinion does not change the law in any state or in any way alter what physicians could or could not do before the opinion. It simply says that existing law in Missouri requiring clear and convincing evidence of a previously competent patient's wishes is constitutional and need not be changed. It also means that other states are free to adopt a similar evidentiary standard, but no state is required to do so. In fact, if state legislatures or courts want to adopt new evidentiary procedures and standards, they would do well to recognize that most families can and do speak for their loved ones, and put the burden on the state to prove by clear and convincing evidence that the family's wishes are inconsistent with the wishes of the patient before removing decision-making authority from the family.

It remains good medical practice to discuss future care with patients and to document their wishes. It is also good practice to encourage patients to execute both a living will (to spell out in as much detail as possible how they would like to be treated if they become incompetent) and a durable power of attorney (formally designating someone to make health care decisions for them if they are unable to make them for themselves).[7,9] These discussions and documents will help, but they will obviously not solve real treatment problems for real patients. That will require the compassion — and often the courage — to act in a manner consistent with the patient's wishes, and if these are not known, consistent with the best interests of the patient and good medical practice. Outside Missouri and New York, there is no legal obligation to provide incompetent patients with medical care that is either unwanted or not medically indicated.

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THE NEW TECHNOLOGY ASSESSMENT

TECHNOLOGY assessment is not a new phenomenon in medicine. The most able and conscientious physicians have always sought to understand the effects of the interventions they apply.[1] With the development of clinical research, attempts to establish safety and efficacy became more systematic and scientific, culminating in the crown jewel of traditional technology assessment, the randomized clinical trial.

The determination of safety and efficacy remains an essential element of technology assessments, but in recent years such assessments have broadened in scope. They now encompass the measurement of effectiveness, considerations of quality of life and patients' preferences,[2,3] and especially the evaluation of costs and benefits.[4] Although such assessments were published as early as the mid-1970s,[5,6] widespread interest in the new type of technology assessment has flourished only recently, stimulated by concern about the quality, effectiveness, and escalating cost of health care.[7,8] When Congress passed and the President signed the Omnibus Budget Reconciliation Act of 1989, the prospect of more influential, better-funded technology assessments was created; the act called for almost $600 million to be spent over the next five years to support research on the outcomes, effectiveness, and appropriateness of medical care. Private foundations also believe that technology assessment can make important contributions to American health care, and they have allocated tens of millions of dollars to this activity.

Admiration for the new technology assessment is not universal. Many practicing physicians believe it will further erode their ability to practice as they deem best; similarly, medical researchers, pharmaceutical manufacturers, and producers of medical devices fear that it will inhibit the development and diffusion of new forms of technology. These fears may be justified, but the new technology assessment is here to stay and will probably have a large effect on medical practice. It is therefore imperative for physicians and the producers of health care technology — along with others who aspire to find the best uses for health dollars — to try to understand and improve it. To do so, it is necessary to know how the new technology assessment differs from the old type, what is special about it in medicine, what features make an assessment credible, and when one should be performed. Most important, we must recognize what an assessment can and cannot do.

WHAT IS NEW ABOUT THE NEW TECHNOLOGY ASSESSMENT?

The most striking differences between the new and the old forms of technology assessment arise from a broadening of perspective. The old form emphasized the biomedical perspective — that is, the safety and efficacy of an intervention. The new technology assessment, with its broader perspective, is usually conducted by different researchers who apply different methods and seek different data. Because it evaluates a wider spectrum of consequences of health interventions, the new technology assessment is more challenging, more complex, more controversial, and potentially more useful than the old one.

The distinguishing features of the new technology assessment can be discerned in its approach to specific forms of technology. Consider, for instance, a new test for cystic fibrosis[9] that detects a mutation in the recently identified gene associated with the disease.[10] This test is particularly suited to analysis with the new technology assessment because technical performance is only one of its important characteristics. It is necessary, but not sufficient, to confirm that the test detects the mutation. There are additional questions. How sensitive and specific is the test in various populations? What will families do after they learn that a fetus has tested positive for cystic fibrosis? How do the costs of screening for cystic fibrosis compare with the benefits? What are the ethical implications of using the new test to screen the general population, when even small false positive rates will lead to the abortion of many normal fetuses? Like its predecessor, the new technology assessment explores biomedical characteristics, but it also grapples with broader issues such as these.

As the perspective of technology assessment has changed, so has the identity of the assessors. Initially, assessments were carried out by the scientists and physicians who developed a form of technology or used it in caring for their patients. As formal trials of interventions became more common, biostatisticians and other specialists in the design and performance of clinical trials came to have important roles. With its increased emphasis on costs, quality of life, and patient satisfaction, the new technology assessment continues to draw on the traditional areas of expertise, but the skills of collaborating researchers trained in such disciplines as economics, epidemiology, operations research, and psychometry have been added. These researchers use a wide variety of sources and methods to carry out their evaluations.

There is also a difference in the audience for technology assessment — that is, its consumers. Formerly,