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The evolution of surrogates' right to terminate life-sustaining treatment

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Depending on one's beliefs and philosophical leanings, removing life-sustaining treatment can be viewed as causing a patient's death or allowing a patient to die. The dramatic and very public debate surrounding the medical decisions made for Terri Schiavo illuminate widespread societal disagreement about the moral consequences of withdrawing support. This divergence stems from the differing attitudes about life and death that inform people's views regarding the kinds of end-of-life decisions that deserve legal protection. American courts have long protected patients' right to consent to care, which necessarily implies a reciprocal right to refuse care [1]. The "right to die," however, is a relatively recent concept made contentious by advances in life-sustaining medical technology.

The movement to challenge the decisions made for Terri Schiavo threatened to destabilize end-of-life law that had developed over the last quarter of the 20th century, principally through the cases of Karen Ann Quinlan and Nancy Cruzan. The New Jersey Supreme Court's opinion, *In re Quinlan*, articulated the interests at stake in a decision to remove life-sustaining care from an incapacitated person, and the United State Supreme Court's opinion in *Cruzan v. Director, Missouri Department of Health* balanced the right to die against the interests of the state. Although the extensive public discussion about Schiavo had little effect on right-to-die jurisprudence, it dramatically illustrated the range of difficulties that can complicate decision making concerning the termination of treatment. These three cases helped to create and to solidify the legal justifications for permitting a surrogate to make treatment decisions that result in the death of an incapacitated person.

The Quinlan Case

On April 15, 1975, 21-year-old Karen Quinlan ceased breathing for at least two 15-minute periods [2]. Three days later, Dr. Morse, the neurologist in charge of her care, diagnosed her as comatose and in a persistent vegetative state. A respirator and nasogastric feeding tube sustained Karen's body.

The Quinlan family was not immediately unanimous in its decision to remove Karen from the respirator after learning that her condition was unlikely to improve. Her mother and siblings believed it was appropriate to cease care, but her father remained hopeful that she would recover—both parents' decisions were shaped by their religious beliefs. Eventually, her father agreed to end treatment, having been

reassured by his priest that doing so was not a sin. Quinlan's friends and family supplied evidence of her wishes, noting that she had spoken on several occasions about not wanting to be kept alive by extraordinary means. Karen's family released the hospital, attending physicians and staff from liability, but Dr. Morse refused to take her off the respirator, believing that doing so was not justified within the tradition of medical ethics. Thus, in this first right-to-die case, the conflict lay between the family's unified desire and the physician's ethical beliefs.

Quinlan's father petitioned the court to appoint him as her guardian, with express power to authorize the discontinuance of all extraordinary medical procedures that sustained her life, because these presented "no hope of her eventual recovery" [3]. He also sought to prevent the physicians, hospital staff and the county prosecutor from interfering with the decision. The New Jersey attorney general intervened to protect the state's interest in preserving life.

The New Jersey Supreme Court, appreciating the gravity of the case, wrote:

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 the 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 [4].

In finding for the Quinlan family, the court identified a right to decline life-saving medical treatment under the general right of privacy developed in *Griswold v. Connecticut* and *Roe v. Wade* [5]. The court held that life support could be removed if the physicians and a hospital ethics committee agreed that Quinlan had no reasonable possibility of returning to a "cognitive, sapient state" [6]. Her right to privacy, according to the court, outweighed the state's interest in preserving her life, and her father, as her surrogate, could exercise that right for her. Quinlan lived for nine years after doctors removed her from the respirator [7].

The Cruzan case goes to the U.S. Supreme Court

Many states followed the *Quinlan* decision, and passed legislation that provided legal immunity to physicians who carried out their patients' written instructions (i.e., advance directives) for end-of-life care should they become incompetent [8]. The court's decision also gave great impetus to the formation of hospital ethics committees [9]. In 1990, the case of Nancy Cruzan provided the Supreme Court of the United States the opportunity to address the issues in *Quinlan* at the national level.

Nancy Cruzan fell into a persistent vegetative state after sustaining injuries in a car accident on January 11, 1983 [10]. Her parents, after learning of the permanence of her condition, asked the hospital to remove the artificial feeding and hydration tube. The hospital refused to do so without court approval. Cruzan's parents won authorization to remove treatment from the Missouri trial court, which found that a person in Cruzan's condition had a state and federal constitutional right to refuse "death prolonging procedures" [11]. The court ascertained her wish to exercise this right based on the testimony of a former roommate, who recounted that Cruzan had said during a somewhat-serious conversation that she would not want to continue hydration and feeding unless she could live "halfway normally." The State of Missouri and Cruzan's court-appointed guardian appealed the decision.

The Supreme Court of Missouri reversed the lower court decision, holding that the common law right to refuse treatment was outweighed in this case by the state's interest in preserving life. The Court declined to follow *Quinlan*, and did not recognize a right to privacy that encompassed a right to refuse all medical treatment. Additionally, Missouri law required "clear and convincing evidence" of an incompetent person's wishes before allowing a surrogate to decide to withdraw treatment; the Court held that the evidence was unreliable and insufficient to establish that Cruzan would have refused the treatment. The Court demanded that "[a] decision to refuse treatment, when that decision will bring about death, should be as informed as a decision to accept treatment" [12]. Under this standard, casual remarks were not considered adequate evidence even if they accurately reflected Cruzan's desires.

The U.S. Supreme Court, which had turned down an appeal to *Quinlan*, agreed to hear the Cruzan case. The federal government chose to enter the fray alongside Missouri. Solicitor General Kenneth Starr represented the United States, arguing to the Court that the nation had an interest in preserving life and that, under a traditional reading of the Constitution, a right to refuse treatment could be derived from a general right to privacy [13].

In a 5-4 decision, the Supreme Court affirmed the judgment of the Missouri Supreme Court, holding that Missouri's evidentiary standards were not unconstitutional. In doing so, the Court construed the right to refuse treatment as a due process liberty interest, not as a privacy right which was the *Quinlan* Court's approach. By declaring that the right to refuse treatment was an "interest" rather than a "right," the Court said that the state's interest in preserving life outweighed Cruzan's liberty interest. The majority opinion described Missouri's clear and convincing standard as "a safeguard" of the best interests of the patient, rather than a frustration of Cruzan's and her family's will.

Justice Brennan disagreed strongly in his dissenting opinion. The decision, according to Brennan, ignored the consensus reached by Cruzan's family, her independent and neutral court-appointed guardian and a lower court judge about what Cruzan would have wanted and what would have been in her best interests. Brennan also disagreed

with the majority decision that letting the state exercise its interest in preserving life would protect patients' interests better than letting families decide what was in the patient's best interest.

The Supreme Court decision was not the final judgment on Cruzan's treatment—it only ruled that the Missouri's standards were not unconstitutional. The outcry following the decision prompted several more of Cruzan's friends to come forward to testify to her wishes, and, in December of 1990, a Missouri probate judge found that this added testimony created clear and convincing evidence of Cruzan's desire to refuse futile life-sustaining care. Cruzan died 12 days after her feeding tube was removed, but the three-year fight had taken an irreversible toll on her family [14].

Cruzan had a significant impact on end-of-life decision making across the country. Many states passed legislation related to health care decisions for the incapacitated [15]. With the establishment of these laws, the continuing development of hospital ethics councils and an increase in the number of advance directives in response to media coverage of the Cruzan case, it seemed that the court's role in reviewing life-sustaining treatment decisions had been minimized.

Enter Schiavo

Whereas *Quinlan* and *Cruzan* contributed to evolving legal standards for the termination of treatment for the incapacitated, the litigation surrounding Terri Schiavo engaged settled law. Rather than arising out of a disagreement between the family and an ethically concerned physician, or the family and a cautious hospital and state, the Schiavo dispute stemmed from a feud between family members.

On February 25, 1990, Terri Schiavo suffered cardiac arrest due to a potassium imbalance [16]. As a result of oxygen deprivation, she endured significant brain damage and fell into a persistent vegetative state. After eight years of "pursuing the best medical care for his wife," Michael Schiavo petitioned a Florida court to authorize the removal of her feeding tube [17]. Her parents disagreed with his decision, claiming that Terri would have wanted to remain in that condition, and they sought to obtain guardianship of their daughter.

What ensued was a legal struggle, that, at best, was perpetuated by Terri's parents' refusal to accept her medical condition. Some would argue that it was also driven by election-year politics and sensationalism [18]. Media commentators, Florida Governor Jeb Bush, U.S. Congressmen and even a television psychic questioned the overwhelming medical consensus that Terri was in a persistent vegetative state [19, 20]. Despite these external pressures, Terri's husband, her doctors and the medical community prevailed, using the procedures put in place in response to *Quinlan* and *Cruzan*. Schiavo died on March 31, 2005, after being in a persistent vegetative state for 15 years.

While family-physician communication is instrumental in preventing conflicts in end-of-life care, *Schiavo* demonstrates that some disputes arise outside of the

medical setting. With recognition of a right to refuse treatment—and clinical and legal mechanisms protecting incapacitated persons—the roles of physicians and courts in these situations are settled for now.

Notes and references

1. *Pratt v Davis*, 79 NE 562, 564 (Ill. 1906); *Schloendorff v Society of New York Hospitals*, 105 NE 92, 93 (NY 1914).
2. *In re Quinlan*, 348 A2d 801, 806 (NJ Super. Ct. Ch. Div. 1975).
3. *In re Quinlan*, 355 A2d 647, 651 (NJ 1976).
4. *In re Quinlan*, 355 A2d 647, 652 (NJ 1976).
5. *In re Quinlan*, 355 A2d 647, 663 (NJ 1976), citing *Griswold v Connecticut*, 381 US 479 (1965); *Roe v Wade*, 410 US 113 (1973).
6. *In re Quinlan*, 355 A2d 647, 671 (NJ 1976).
7. Stryker J. Right to die; life after Quinlan. *New York Times*. March 31, 1996: Section 4:5.
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9. Fletcher JC. The bioethics movement and hospital ethics committees. *MD Law Rev*. 1991;50:869.
10. *Cruzan v Director, Missouri Dept. of Health*, 497 US 261, 266 (1990).
11. *Cruzan v Director, Missouri Dept. of Health*, 497 US 261, 268 (1990), quoting App. To Pet. For Cert. A99.
12. *Cruzan v Harmon*, 760 SW2d 408, 424 (Mo 1988).
13. Brief for the United States as Amicus Curiae Supporting Respondents, *Cruzan v Director, Missouri Dept. of Health*, 497 US 261 (1990) (No. 88-1503), 1989 WL 1115266.
14. Colby WH. From Quinlan to Cruzan to Schiavo: What have we learned? *Loyola Univ Chicago Law J*. 2006;37:286. In response to the ruling, an anti-abortion group called Operation Rescue attempted to break into the hospital and re-insert her feeding tube. Thirty-two police officers were posted to protect the family and the hospital. The founder of this organization would later become a spokesperson for Terri Schiavo’s parents and made several guest appearances on Fox News. See also Goodnough A. Victory in Florida feeding case emboldens the religious right. *New York Times*. October 24, 2003:A1.
15. For example, in 1990, the number of states with statutes addressing health care powers of attorney approximately doubled to 30, and by 1991 41 states had laws on living wills. Also, in 1991 the New York Society for the Right to Die reported “more than half a million people requested the society’s living-will forms since Cruzan gained the spotlight.” See DeBenedictis DJ. Cruzan’s death doesn’t still debate: Euthanasia opponents prevented from appealing decision allowing tube removal. *ABA J*. 1991;77:26.
16. *In re Guardianship of Schiavo*, No. 90-2908GD-003, 2000 WL 34546715 1 (Fla Cir CT 2000).
17. *In re Guardianship of Schiavo*, No. 90-2908GD-003, 2000 WL 34546715 2 (Fla Cir CT 2000).

18. Terri Schiavo's parents challenged the diagnosis of PVS, although the court found their expert witness lacking in credibility. *In re Guardianship of Schiavo*, No. 90-2908GD-003, 2000 WL 34546715 4 (Fla Cir CT 2000). Her parents also filed a motion claiming that Terri tried to say that she wanted to live in March 2005. While she was still living, a CT scan showed that a significant portion of her cerebral cortex had been replaced with cerebrospinal fluid, which was confirmed by an autopsy. See Associated Press. *Terri Schiavo Timeline, June 15, 2005*. Available at: http://www.cbsnews.com/elements/2005/03/21/in_depth_health/timeline681968.shtml. Accessed August 7, 2006.
19. Babington C. Viewing videotape, Frist disputes Fla. doctors' diagnosis of Schiavo. *Washington Post*. March 19, 2005:A15. Available at: <http://www.washingtonpost.com/wp-dyn/articles/A48119-2005Mar18.html>. Accessed August 7, 2006.
20. JC. *Fox's psychic friend: Crossing Over's John Edward claimed Terri Schiavo is "definitely clear on what's happening to her now."* Available at: <http://mediamatters.org/items/200503250006>. Accessed August 7, 2006.

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