SELECTED SUMMARY

The Terry Schiavo case : possible implications for India

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Annas GJ. "Culture of Life" politics at the bedside: the case of Terri Schiavo. *N Engl J Med* 2005; 352: 1710-1715.

I was in India during the final phase of the Terri Schiavo case and was surprised at the media attention the case received. The news media failed to address the relevance to India as much as to US. In the three months since her death, much has been written about the issues.

"Culture of life"

American physicians, bioethicists and lawyers thought that the law concerning termination of life-support was well settled after the Cruzan judgement in 1990. The religious right, pro-life groups have characterised the liberal movements (pro-abortion, the right to terminate life-support, physician-assisted suicide, etc.) as a "culture of death". Only God can take away life. It follows then that, for the first time in its history, the US Congress on Sunday, March 20, 2005, passed emergency legislation aimed at prolonging the life of Terri Schiavo.

The case of Karen Quinlan

The legal history of the law regarding termination of life support begins in 1976 when Karen Quinlan's parents asked a judge to discontinue the use of a ventilator in their daughter, who was in a persistent vegetative state. Ms Quinlan's physicians, afraid of a murder charge, had refused the parent's request. The New Jersey Supreme Court ruled that competent persons have a right to refuse life-sustaining treatment and that this right is not lost when a person becomes incompetent. After a hospital ethics committee confirms that there is "no reasonable possibility of a patient returning to a cognitive, sapient state", life-sustaining treatment can be stopped.

This encouraged all states to enact "living will" legislation to provide legal immunity to physicians honouring patients' written "advance directives" specifying how they would want to be treated if they ever became incompetent; and it encouraged hospitals to establish ethics committees that could attempt to resolve disputes without going to court.

The case of Nancy Cruzan

The New Jersey Supreme Court ruling applied only to New Jersey. In deciding the Nancy Cruzan case in 1990, the US Supreme Court ruling became applicable throughout the country. Nancy Cruzan was a young woman in a persistent vegetative state who required tube feedings to sustain life. The Missouri Supreme Court had ruled that the tube feeding could be discontinued on the basis of Nancy's right of self-determination, but that only Nancy herself should be able to make this decision. Since she could not do so, tube feeding could be stopped only if those speaking for her, including her parents, could produce substantial evidence that she would refuse tube feeding if she could speak for herself.

The US Supreme Court, in a five-to-four decision, agreed, saying that the state of Missouri had the authority to adopt this high standard of evidence because of the irreversibility of the outcome.

Supreme Court Justice Sandra Day O'Connor recognised that young people do not generally put explicit treatment instructions in writing. She suggested that had Cruzan simply said something like "If I'm not able to make medical treatment decisions myself, I want my mother to make them," such a statement should be a constitutionally protected delegation of the authority to decide on her treatment.

The Cruzan case encouraged people to assign a power of attorney designating someone (a health care proxy) to make decisions for them if they became incapacitated. In the absence of a health care proxy, most states grant decision-making authority to a close relative, usually the spouse.

The Schiavo case in the courts

Terri Schiavo had a cardiac arrest in 1990 when she was 27 years old. She lived in a persistent vegetative state, nourished and hydrated through tubes. There was no living will nor had she designated a health care proxy. In 1998, Michael Schiavo, her husband, petitioned a state court to discontinue tube feedings. Her natal family wanted to continue life support. A judge accepted the medical diagnosis of persistent vegetative state and concurred with the husband that, if she could make her own decision, she would choose to discontinue life-prolonging procedures.

Ms Schiavo's parents were permitted to challenge the court findings on the basis of a claim of a new treatment they believed might restore cognitive function. Five physicians were asked to examine Ms Schiavo — two chosen by the husband, two by the parents, and one by the court. On the basis of the majority's opinion, the trial judge ruled that Terri Schiavo was in a persistent vegetative state. The appeals court affirmed the decision. The Supreme Court of Florida refused to hear an appeal.

The parents, with the support of conservative religious organisations, approached the state legislature. The legislature

passed "Terri's Law," granting Governor Bush the authority to order the feeding tube reinserted, and he did so.

The constitutionality of this law was immediately challenged. The Florida Supreme Court ruled that the law was unconstitutional because it violated the separation of powers that no branch of government may encroach on the constitutional powers of another, and no branch may delegate to another its constitutionally assigned power.

In January 2005, the US Supreme Court refused to hear an appeal by Governor Bush. Thereafter, the trial court judge ordered that the feeding tube be removed at 1 pm, Friday, March 18, 2005.

US Congress at the bedside

Under pressure from religious conservatives, the US Congress convened in an emergency session and passed a bill, "For the relief of the parents of Theresa Marie Schiavo" on March 21. The new law provided that "the US District Court for the Middle District of Florida shall have jurisdiction" to hear a suit "for the alleged violation of any right of Theresa Marie Schiavo under the Constitution or laws of the United States relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life." The law gave the parents a legal standing to file a suit and instructed the federal court to ignore all previous legal proceedings.

The following day, the US District Court Judge issued a careful opinion denying the request of the parents for a temporary restraining order concluding that the parents had failed to demonstrate "a substantial likelihood of success on the merits" of the case. The decision was upheld on appeal.

The case of Terri Schiavo resulted in no changes in the law, nor were any good arguments made that legal changes were necessary.

Comments

End-of-life decisions in India are compromised by a lack of a legal framework, social customs and complex family structure and interactions.

Increasingly, patients in India are dying in hospitals. Doctors in India's ICUs, when dealing with patients on ventilators with a terminal incurable disease, are compelled to continue futile treatment as there is no legal framework to discontinue life support (1). Families of such patients are left to cope with both the emotional trauma of loss as well as financial stress of heavy medical bills.

Even with a legal framework in place, effective implementation of advance directives and health care proxy need open discussion of end-of-life care within the family. This is not a subject most people want to talk about. In its absence, there is greater chance of disagreement in extended families. In absence of a health care proxy, by social custom, a senior male member of the family acts as decision maker. Can he really reflect the interests and wishes of the patient?

In the US, while the Terri Schiavo case may not have established any new legal precedents, the case has raised the issue once again and many institutions, states, and people are paying more attention to this area. As Quill (2) says, "the ... case...raises ... questions about how to define family and how to proceed if members of the immediate family are not in agreement." How can one expect a judge to determine which person in the family has the right to make decisions on behalf of the patient? (3)

de Boufort (4), in describing end-of-life decision making in the Netherlands, states that Dutch society with a "...reputation as iconoclasts with respect to end-of-life decision making" has dealt with similar cases without the extreme politicisation seen in the Schiavo case. However, as Quill (2) and Bloche (5) point out, even in the US, it is very rare for a court to get involved in end-of-life care.

So what do we learn from the sad case of Terry Schivao?

For all the reasons Pandya (1) enumerates, India must enact laws to make the living will a valid legal document. It is important for everyone to designate a health care proxy. We must openly discuss our choices for end-of-life care with our loved ones. When called upon to act as proxies, we must remember that it is the patient's likely choice that we have to express, not our own wishes (2).

References

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4. de Beaufort I. Patients in a persistent vegetative state – a Dutch perspective. *N Engl J Med* 2005; 352: 2373-2375.
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