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Editorial

The Right to Die: Some Personal Reflections on the Terri Schiavo Case and the Role of Hydration and Nutrition in Hopelessly Ill Patients

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Terri Schiavo, 41, died March 31, 2005 at the Pinellas Park hospice where she lay for years while her husband and her parents fought in the nation's most divisive—and most heavily litigated—right-to-die dispute .Although tragic, the plight of Terri Schiavo provides a valuable case study. The conflicts surrounding her situation offer important lessons in medicine, law and ethics.[1] The following is a summary of Ms Sciavo's case and my personal thoughts about it:

On February 25, 1990, 26-year-old Terri Schiavo suffered a sudden cardiac arrest, the cause of which was not determined. She thereafter lapsed into a persistent vegetative state (PVS). She remained in a vegetative state for fifteen years. She died of dehydration on March 31 2005, nearly two weeks after her feeding tube was removed in accordance with a court order.

Her husband, Michael Schiavo, had long sought to have the feeding tube taken out, arguing that she would not have wanted to be maintained in a vegetative state, but her parents fought to keep her alive. Members of the United States Congress, the Florida Legislature and Florida Governor Jeb Bush intervened to keep Ms Schiavo's feeding tube in place.

After many rulings and appeals, in November 2002, a judge again ordered Ms. Schiavo's feeding tube removed. The Schindlers, Ms. Schiavo's parents, appealed again.

With appeals running out, the Schindlers in September 2003 asked a federal court to intervene. Governor Jeb Bush filed a brief in the case supporting the Schindlers.

On October 10, 2003, the federal court judge ruled that the federal court has no jurisdiction in the Florida case. On October 15, 2003, doctors removed the feeding tube.

On October 21, 2003, Governor Bush successfully pushed for an emergency act of the Florida Legislature to restore the feeding tube. The law became known as "Terri's Law." A lawsuit challenging its constitutionality was immediately filed.

On September 23, 2004, the Florida Supreme Court struck down Terri's Law.

On January 24, 2005, the U.S. Supreme Court refused to hear arguments for Terri's Law.

On February 23, 2005, the Schindlers in another hearing asked for more time to file appeals. The appeals would address whether new therapies would help their daughter and whether their daughter's religious beliefs prohibited withholding nutrition.

On March 18, 2005, the feeding tube was removed and thirteen days later, on March 31 2005, Terri Schiavo died.

Before reviewing the ethical questions raised by this landmark case, a brief review of her medical illness is

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in order. There was general agreement that Ms. Schiavo was in a persistent vegetative state or PVS. PVS is a condition of patients with severe brain damage in whom coma has progressed to a state of wakefulness without detectable awareness.[2] There is still controversy in both the medical and legal fields as to whether this condition is irreversible. Ms Schiavo had all the features of prolonged PVS.

The syndrome was first described in 1940 by Ernst Kretschmer, after whom it also has been called Kretschmer syndrome.[3]

The term PVS was coined in 1972 by Scottish neurosurgeon Bryan Jennett and American neurologist Fred Plum to describe a syndrome that seemed to have been made possible by medicine's increased capacities to keep patients' bodies alive.[2]

Many patients emerge from a vegetative state within a few weeks, but those who do not recover within 30 days are said to be in a persistent vegetative state. The chances of recovery depend on the extent of injury to the brain and the patient's age, with younger patients having a better chance of recovery than older patients. Generally adults have a 50 percent chance and children a 60 percent chance of recovering consciousness from a PVS within the first 6 months. After a year, the chances that a PVS patient will regain consciousness are very low and most patients who do recover consciousness experience significant disability. The longer a patient is in a PVS, the more severe the resulting disabilities will be. Rehabilitation can contribute to recovery, but many patients never progress to the point of being able to take care of themselves. Few people have been reported to recover from PVS. Some authorities hold that PVS is, in fact, irreversible, and that the reportedly recovered patients were not suffering from true PVS. In the United States, it is estimated that there may be as many as 15,000 patients who are in a persistent vegetative state.[4-5]

Nonetheless, some dispute still remains over the reliability of PVS diagnosis, particularly when a limited number of physicians (or physicians without experience in the area of PVS) make the diagnosis. One study of 40 patients diagnosed with PVS in the United Kingdom determined that 43% were misdiagnosed.[6] This highlights the need for very vigorous diagnostic criteria to be used in making a PVS diagnosis. For example, not every comatose patient is in PVS. Specific tests under the supervision of qualified professionals are needed in order to make a diagnosis of PVS.

PVS has been at the center of much controversy in recent years. Most of this controversy comes from the difficulty in defining and understanding this condition, and this has led to discussion over how people in this state are to be treated. The greatest public controversy stems around the euthanasation of patients with this condition. The case of Terri Schiavo, who remained in this state for approximately 15 years, shined a spotlight on this topic.

Legal Definition

As opposed to brain death, PVS is not recognized as death in any known legal system. This legal grey area has led to several court cases involving people in a PVS, between those who believe that they should be allowed to die and those who are equally determined that, if recovery is possible, care should continue. The media circus case of Terri Schiavo in the United States is an example of PVS, having been so diagnosed by multiple court-appointed physicians. A dispute of this diagnosis was a major issue in a lengthy and unsuccessful court challenge.
The Schiavo case was governed by Florida Law, under which the legal definition of "PVS" is:

> "Persistent vegetative state" means a permanent and irreversible condition of unconsciousness in which there is (a) the absence of voluntary action or cognitive behavior of any kind and (b) an inability to communicate or interact purposefully with the environment.

This legal definition is found in State Law 765.101(12).

There were two key questions in this case:
1) Was Schiavo's condition hopeless?
2) Would she have wanted her feeding tube removed?

While we need to be aware of the difficulties in prognosticating PVS patients, in the case of Ms. Schiavo

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there was general agreement, from a medical point of view, that she was in an irreversible stage of PVS and was consequently hopelessly ill with no chance of recovery.

Secondly, there is no strong evidence that she would have wanted her feeding tube removed because there was no documented living will by Ms. Schiavo.

Islamic View

I have previously published on the topic of brain death and suggested that when brain death is present, life support can be removed.[7,8] Ms. Schiavo did not meet the criteria of brain death.

So what is permissible in cases like Terri Schiavo, where the patient is not brain dead but have virtually no hope of recovery? In the position paper published by the ethics committee of Islamic Medical Association of North America (IMANA), this issue was discussed and I reproduce the statement:

> IMANA believes that when death becomes inevitable, as determined by physicians taking care of terminally ill patients, the patient should be allowed to die without unnecessary procedures. While the patient is still alive, all ongoing medical treatments can be continued. IMANA does not believe in prolonging misery on mechanical life support in a vegetative state. All of the procedures of mechanical life support are temporary measures. When a team of physicians, including critical care specialists, have determined, no further or new attempt should be made to sustain artificial support. Even in this state, the patient should be treated with full respect, comfort measures and pain control. No attempt should be made to withhold nutrition and hydration. In such cases, if and when the feeding tube has been withdrawn it may not be reinserted. The patient should be allowed to die peacefully and comfortably. No attempt should be made to enhance the dying process in patients on life support. Suicide and Euthanasia are prohibited in Islam (Qur'ān 17:33). Muslim physicians are instructed to uphold the sanctity of human life. IMANA is absolutely opposed to Euthanasia and assisted suicide in terminally ill patients by healthcare providers or patient's relatives.[9]

Ms. Terri Schiavo, in my opinion, should have been allowed a dignified death. She was starved to death after thirteen days of withholding food and water. While I may not have put in a feeding tube, I would have allowed provision of water with ice chips, sips of water and liquid diet as tolerated.

Cost to Society

During the very public debate regarding Ms. Schiavo's care, very little mention was made of the financial cost of over a decade long care in an institution. I often wondered why the family was unable/unwilling to take care of Ms. Schiavo at home. If that option had been pushed, I have a feeling that Ms. Schiavo would not have lingered on for over a decade hovering between life and death. Many of our ethical issues in medical care are directly a price we pay for advanced technology. A patient like Ms. Schiavo in many parts of the world would have succumbed to complications such as pneumonia and sepsis and would have died a natural death. While the exact cost of care for Terri Schiavo is not known, my best estimate is that for the fifteen plus years of total care the cost must have been well over a million dollars. No one seemed to address whether this expense was justified. Eventually this cost is borne by the tax payers.

Another key issue in this discussion is the role of feeding and nutrition in hopelessly ill patients. Is tube feeding a medical treatment? What is the intention behind the withdrawal of food and fluids?

The following arguments have been advanced that tube-feeding is a medical treatment and can therefore be stopped without breaching the duty of care:

a) It is a medical response to pathology, namely the patient's inability to swallow or to swallow safely.
b) It uses artificial means.

The following counter arguments have been proposed that food and fluids are part of the basic nursing care all patients deserve:

a) Tubes can be passed and operated by people other than doctors (e.g. nurses and family care givers).
b) The concept of 'artifice' is potentially mislead-

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ing. We bottle feed-babies and use knives and forks ourselves.

Euthanasia has been defined as 'the intentional killing by act or omission of a person whose life is felt not to be worth living'. Intention is a critical religious, ethical and legal concept. So, was the Terri Schiavo case one of 'Let poor Terri die' or was it a case of 'Let us kill poor Terri'?

Similarly, should Terri Schiavo have been given antibiotics for life-threatening infections during the course of her long illness? If not, what is the difference between withholding antibiotics and withdrawing tube-delivered food and fluids?

From my point of view, a patient who develops pneumonia, for which treatment is not provided, dies (foreseeably, but not certainly) of pneumonia and PVS. If a patient simply has tube-delivered food and fluids withdrawn, the patient dies (foreseeably and certainly) of dehydration/starvation and PVS. There is an ethically significant difference.

Conclusion

Persistent vegetative state is a condition that will continue to be at the center of controversy until there is greater understanding of the condition and more accurate definitions and methods for diagnosis. At this point, the only known hope for recovery is the chance, spontaneous natural recovery of the patient. As with all medical conditions, there will be continued interaction between government, business, academia, medical practitioners, and the public to formulate the discourse and develop the treatments surrounding PVS. Advances in medical technology have far outpaced laws that regulate its use. Congress should play a constitutional role by listening to religious leaders and ethicists as well as doctors and scientists and write laws that address both moral and medical concerns.

IMANA recommends all Muslims to have a "living will", "advance directive" and a case manager to help physicians know their wishes when they are unable to give directions (i.e. in a coma).[9] Ms. Schiavo's case went through an extensive legal battle primarily because of the absence of any written directive from her.

As a postscript, Ms. Schiavo's body at autopsy weighed 112 pounds and had a height of 62 inches. Her brain showed marked global anoxic-ischemic encephalopathy resulting in massive cerebral atrophy. Her brain was half the expected weight. There was hypoxic damage and neuronal loss in her occipital lobes, which indicates cortical blindness. No areas of recent or remote traumatic injury were found.[10]

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