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Politicians cause trouble when they play physician

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(864) 298-4100 (800) 800-5116 By Joseph J. Fins, M.D.

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Just four weeks ago, prominent physician-legislators in Congress debated Terri Schiavo's fate. Hours later they passed a special bill requiring review of her case in federal court. Broadcast live by C-Span, many Americans were given a lesson in neurology by physicians who were neither qualified nor well suited to that task. None of these doctors were neurologists and none had actually examined her.

Confusing their role as the people's representatives and doctors, proponents of the bill asserted that Ms. Schiavo was not in the persistent or permanent vegetative state. They made their "diagnosis" based upon highly edited video snippets, which seemed to indicate that Ms. Schiavo was responding to her mother and intentionally looking towards her.

Although the video was heart-wrenching, the unfortunate reality of that tape was that it was emblematic of the vegetative state, a paradoxical state of "wakeful unresponsiveness" in which the eyes are open but there is no evidence of consciousness. Ms. Schiavo's eye movements were reflexive and automatic, and random — like blinking. They did not convey awareness but were a sign that she was in a vegetative state.

This is what the courts determined based on the expert testimony of doctors who actually examined her. It was also what the thoughtful and careful Guardian Ad Litem Jay Wolfson found following his appointment by Florida Gov. Jeb Bush to

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More details

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neutrally determine the facts in Ms. Schiavo's case back in December 2003.

When Congress debated the issue a month ago, her diagnosis was not in doubt. The courts had found clear and convincing evidence that she was in the vegetative state. Nonetheless, partisan doctor-legislators exchanged science for ideology, ignored the clinical facts and asserted that she was not vegetative at all. One even noted that she was not vegetative according to his definition of that state.

For the record, there are scientific criteria for diagnosing complex brain states, just as there are for the diagnosis of a heart attack or cancer. These are not diagnostic categories that each doctor can make up for himself in order to satisfy a particular point of view. There are criteria that have been established by expert panels based on scientific evidence.

It is the role of physicians and legislators to educate the public and not to misrepresent the facts. Making these complex clinical and legal judgments one of popular referendum or ad hoc partisan legislation sets a dangerous precedent. It distorts the integrity of the diagnostic process and the credibility of all doctors. I wonder whether families will believe me the next time I have to tell them that their loved one is in a vegetative state.

More critically, such partisan politics erodes the rule of law and threatens our freedom to direct care at the end of life, one invoked by the majority of patients and their families. For Terri Schiavo, it meant being subjected to treatments the courts have ruled she did not want. One of the most troubling legacies of the Schiavo case is that it has added to the confusion in the public mind about disorders of consciousness following severe brain injury. Some of that confusion has been intentional and politically motivated. By suggesting consciousness where there is none, ideological opponents of choice sought to cast doubt on the ethical propriety of removing life-sustaining therapy.

While we should respect differences of opinion about the meaning of a life in a permanent vegetative state, these valuations should neither undermine an accurate diagnosis nor falsely suggest that the recovery of consciousness is possible. Ethical judgments must begin with the clinical facts. Misinformation makes informed consent or refusal of treatment impossible and will only compound the grief of families touched by severe brain injury.

As we consider the displacement of medical expertise by congressional vote, we would be well advised to recall that society depends upon medicine and the law to maintain order. Some 75 years ago, the late Supreme Court Justice Benjamin Cardozo reminded us that the two learned professions — medicine and the law — were "united in common quest, the quest for the rule of order, the rule of health and disease, to which for individuals as a society we give the name of law."

We can only hope that America will recall the enduring wisdom of Justice Cardozo as we reflect upon Terri Schiavo's legacy and the deep divisions in our national psyche that her death exposed and which now must be healed. It will be a complicated bereavement for us all.



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