

# Neurological Diagnosis Is More Than a State of Mind: Diagnostic Clarity and Impaired Consciousness

**T**HE REVIEW BY KOBYLARZ AND SCHIFF IN THIS issue of *ARCHIVES* points toward a future of greater diagnostic precision for states of impaired consciousness with eventual implications for prognosis and treatment of severe brain injury.<sup>1</sup>

Bringing additional clarity to the diagnostic process would seem to be an unimpeachable good. Knowledge, at least in Baconian science, has always been empowering and value-neutral. Unfortunately, improving our understanding of disorders of consciousness is a contentious area. One need only recall the highly publicized case of Terry Schiavo in Florida in which diagnostic distinctions were intentionally conflated by ideology to promote a political agenda.

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In the Schiavo case, a family was divided against itself over the removal of artificial nutrition and hydration from a 39-year-old woman in the permanent vegetative state following anoxic brain injury in 1990.<sup>2</sup> Her husband sought to remove her feeding tube, citing her prior wishes and the futility of the permanent vegetative state. The Schindlers, Ms Schiavo's parents, objected, asserting that their daughter's wishes were not documented and that she had been misdiagnosed and still might recover. That multiple courts had upheld the authority of Mr Schiavo, the validity of her prior wishes, and the diagnosis of the vegetative state did not matter. The Schindlers brought these legal and clinical questions to the public. The Florida legislature and executive branch intervened to override these judicial rulings.<sup>3-5</sup>

Central to this media campaign was the release of a videotape that showed Ms Schiavo with her eyes open and blinking, with a fixed parietic smile. The public, untrained in clinical assessment, was struck by the irony that one could be unconscious and still seem to be awake. That these findings were emblematic of the wakeful unconsciousness of the vegetative state did not matter. This medical diagnosis was now open to popular debate.

Even though the vegetative state had been described 3 decades earlier as a state of wakeful unconsciousness<sup>6</sup> and brought to the national stage in the Karen Quinlan case, it again was open to discussion.<sup>7</sup> Amidst ideological opposition to the right to die, even Ms Schiavo's diagnosis had become a question of politics and not science. To many advocates of the right-to-life position, her diagnosis had taken on broader meaning as a value judgment. To them, clinical assessment had ceased to be a value-neutral exercise.

While a diverse society can ascribe differing meaning to life in a permanent vegetative state, these valuations should neither undermine an accurate diagnosis nor falsely suggest that the recovery of consciousness from the permanent vegetative state is possible. Such misinformation—often the product of journalistic excess—engenders false expectations by erroneously suggesting that the permanently vegetative are capable of a recovery.

## THE ETHICAL OBLIGATIONS OF NEUROLOGISTS

By linking the permanently vegetative state to the minimally conscious state, opponents of choice at the end of life imply that we are forgoing the possibility of recovery when we let the chronically vegetative patient die. Because there is no recovery of consciousness from the permanent vegetative state, it is important to avoid these dangerous connotations and ensure an accurate clinical diagnosis of a patient's brain state. Neurological diagnosis should not simply be a reflection of the practitioner's state of mind but the product of disciplined clinical assessment that is complemented by newly available imaging studies. As Kobylarz and Schiff note, neuroimaging is beginning to add to the history and to the neurological examination, and will lead to deeper insights into mechanisms of injury and recovery. These refinements in our diagnostic abilities will better distinguish which patients have the potential for additional cognitive recovery from those who will remain permanently vegetative. This prognostic information will help families grapple with decisions to continue or withdraw medical care.

Because neurological assessment has become such a contentious issue, neurologists have an ethical obligation to learn about the emerging typology of impaired consciousness following severe brain injury. Practitioners must be precise in their diagnostic assessments, avoid conflation of brain states, and be careful with their rhetoric. Coma, persistent vegetative states, and permanent vegetative states are not interchangeable terms. As the review points out, each state reflects different temporal periods following severe brain damage. Each has different prognostic implications and meanings that are important to distinguish in the clinical encounter with families.

Neurologists also have a responsibility to engage in careful diagnostic assessment and to keep abreast of developments that can help distinguish the permanently unconscious from those who may retain some degree of awareness and become capable of meaningful interaction and communication. An important distinction to be

made clinically is that between the vegetative and minimally conscious states.<sup>8</sup> Without careful assessment these brain states can be confused and conflated; there can be errors of commission from misdiagnosis or omission when patients progress into a minimally conscious state without anyone noticing. And as the Schiavo case shows, all of this occurs against a broader cultural context.

### CULTURAL REFLECTIONS AND NEUROLOGICAL DIAGNOSIS

The great Spanish filmmaker Pedro Almodovar has given voice to that broader cultural context in his Academy Award-winning film *Talk to Her*. It is a film worthy of study because it reflects many of the cultural myths that continue to influence the diagnosis and assessment of patients with catastrophic brain injury.

The film depicts a ballerina and a bullfighter with severe brain injuries. These 2 women are in a long-term care facility and both are thought to be in a vegetative state. The bullfighter dies. The ballerina survives and regains consciousness. Her recovery is hailed as an inexplicable miracle. Though her emergence into consciousness is a work of fiction, Almodovar's plot captures popular conceptions surrounding severe brain injury. He also scripts a recovery for one of his characters that is reflective of our most advanced understanding of mechanisms of recovery following severe brain injury. At the risk of confusing art with reality, Almodovar's ballerina moved from the persistent vegetative state following traumatic brain injury into the minimally conscious state. And from that tenuous grasp on consciousness she emerged to a fuller recovery.

Almodovar's film is also about isolation: social isolation and the cognitive isolation that can follow brain injury. Although the Spanish title of the film, *Habla con Ella* or *Talk with Her*, captures the importance of relationships, the English has been badly translated as *Talk to Her*. This subtle switch of preposition is critical when we make judgments about the sort of cognitive life that is worth fostering. *With* suggests reciprocity of communication. We talk with our friends, not to our friends. We have relationships with others, not to others. That single preposition signifies that the ballerina remains part of a broader human community; one marked by communication and connectedness.

It was this loss of connectedness or "cognitive sapient state" that prompted the New Jersey Supreme Court to authorize the removal of Karen Ann Quinlan's ventilator.<sup>9</sup> That courageous decision rewrote legal precedent and launched the right-to-die movement in the United States. It enfranchised each of us to make choices about how we hope to live and die.

### THE RIGHT TO DIE AND THE RIGHT TO CARE

Today as we grapple with the mysteries of consciousness lost and regained, we need to recall the origins of the right-to-die movement without being dominated by its early history. While the right-to-die struggle began with the vegetative state, it does not end there.

In the decades since the Quinlan case, the right to die has expanded beyond those with catastrophic brain injury. An irretrievable loss of consciousness is no longer the

predicate for the refusal of life-sustaining interventions. Societal consensus, upheld by decisions in our highest courts, have allowed quality-of-life judgments by patients and their surrogates.<sup>10</sup> Each of us can make choices about the kind of life that we would find tolerable and worth living.

Because of this evolution, we are not opening Pandora's box by using neuroimaging to peer into the workings of the severely injured brain. When we acknowledge the cognitive potential of the minimally conscious we are neither compelling patients to live that kind of life nor suggesting that the chronically vegetative will soon awake. We simply are being intellectually honest about mechanisms of recovery.

This recognition of regained consciousness will compel us to accept our responsibilities to those who may yet be part of our community, though they have long remained out of our collective gaze.<sup>11</sup> An unknown number of patients who may be in the minimally conscious state likely reside in our nation's nursing homes. But as Jennett and colleagues<sup>12</sup> have observed from autopsy studies, there is likely a heterogeneity of underlying anatomical substrates even for patients with severe disability following traumatic brain injury. We need to identify patients with some potential for recovery while they are still alive and provide them with emerging rehabilitation strategies and therapies. We need to acknowledge their glimpses of consciousness and validate the observations of family members that are now too easily dismissed. And as we bring hope to some, we need to offer closure to others who still harbor false hopes about miraculous recoveries from permanent "coma." New knowledge about the injured brain should neither preclude choice nor abridge the right to die. Instead, it should foster more informed choices by differentiating those who might be helped from others beyond the reach of any intervention known to science.

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