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We can rewrite script for some brain injuries

Minimally conscious patients seem vegetative, but with help, they could recover and communicate

By Joseph J. Fins

Imagine being in a nursing home months after a brain injury. Gravely injured, your life was saved by heroic medical care. Discharged from the hospital, you were in a vegetative state, in which your eyes were unseeing and unknowing: a state of wakeful unresponsiveness. But over the ensuing months your brain has begun to heal.

Your family sometimes thinks they see you stir and respond. But when the doctor stops by, you lie inertly in bed, unresponsive and silent. He chalks up your family's observations to wishful thinking, denial or outright delusion. But the doctor's wrong. You are there.

If this sounds like a science fiction film with people trapped inside their heads, think again. This scenario is all too real. Recent studies suggest that over 40 percent of patients in chronic care thought to be vegetative after traumatic brain injury are in the minimally conscious state.

Vegetative and minimally conscious patients can look the same. But they are different. Unlike the vegetative state, MCS patients are aware of themselves, others and their environment. Simply put, they are conscious, even if no one notices.

But how could they be so routinely misdiagnosed? Some reasons are innocent enough. MCS as a diagnostic category only dates to 2002. So it's a question about the dissemination of new medical knowledge and what doctors know. But its more complicated. MCS patients may be conscious, but their behaviors can suggest otherwise. They don't consistently show evidence of awareness. Only skilled and persistent evaluation can prove that they are "there," inside their heads.

A more troubling explanation is that society has written them off, a consequence of how the right-to-die movement in the United States was birthed. Think of Quinlan, Cruzan and Schiavo, and you will appreciate that the legal "right to die" was established because of the futility of the vegetative state. Problematically, this nihilism got over-generalized to patients thought vegetative but who were actually minimally conscious.

But now we can make this critical distinction, thanks to better bedside diagnostic tests and brain scans, which can sometimes demonstrate brain flares in seemingly quiet brains.

So, have we rewritten the script of the horror film that we imagined?

Sadly, no.

I have just written a book chronicling the lives and struggles of these patients and families. After brilliant life-saving care, many are often subjected to premature palliative care and decisions to withhold or withdraw care before their prognosis is clear. On discharge they end up in what is euphemistically called "custodial care," segregated from the rest of us. There they linger in isolation, improperly diagnosed and alone.

Those lucky enough to get rehabilitation get less than what they need or deserve. Families are stretched by expenses and abandoned by a health care system that arbitrarily limits care.

The neglect of these patients is especially heart-wrenching because there is another — more optimistic — possibility. Neuroscience is on the cusp of success. For the first time in history, new drugs, devices and neuroimaging tools can help some patients recover, and even communicate.

In a pilot study of the first use of deep brain stimulation in MCS, in which I participated, an individual who could neither eat by mouth nor communicate regained these capabilities with a brain pacemaker. When paced, he could say six- or seven-word sentences, say the first 16 words of the Pledge of Allegiance and tell his mother he loved her.

The restoration of functional communication through a neuroprosthetic device placed him back into the nexus of his family. With it he overcame the exile of his injury and a disinterested health-care system.

To be sure, our success was experimental, a first step. But this scientific proof of principle, and the work of others, suggests that we can rewrite the script for some patients. And it demands we try.

Decades ago these patients would have died. Now medicine helps them survive. The question is, will we build upon this success and more fully restore the lives we have saved? This is more than an insurance question or a scientific one. It is a fundamental question of human rights. We must recognize the dignity and worth of conscious individuals, our fellow citizens, who have too long been sequestered and beyond our gaze.

Fins is author of "Rights Come to Mind: Brain Injury, Ethics and the Struggle for Consciousness," published by Cambridge University Press. He teaches at Weill Cornell Medical College and Yale Law School and co-directs the Consortium for the Advanced Study of Brain Injury at Weill Cornell and Rockefeller University.