



In the Blink of the Mind's Eye

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In the Blink of the Mind's Eye

BY JOSEPH J. FINS AND NICHOLAS D. SCHIFF

Imagine rushing to the hospital because your loved one has had a serious brain injury or cardiac arrest. The doctors tell you that the patient is unconscious and will not recover. Still reeling from the sudden news, you are asked about any end-of-life care preferences and whether you will agree to a do-not-resuscitate order.

You and your loved one had some conversations about death and dying and signed advance directives after the Schiavo affair, but in retrospect, it all seems incredibly superficial and provides little guidance. It is such a lonely moment—asked such things by doctors you don't know or trust. The one person who could guide you is lying in the bed before you on a breathing machine. If only you could ask . . . Now imagine rolling your loved one down to the hospital's

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MRI machine and asking him if he wants to live or die by reading his responses on the scanner.

This is still the stuff of science fiction, but researchers from the Universities of Cambridge and Liege just reported in the *New England Journal of Medicine* how functional magnetic resonance imaging, or fMRI, might someday be used as a communication tool for patients with disordered conscious, in the vegetative and minimally conscious states. They studied fMRI brain activations seen when patients were asked to imagine tasks like hitting a tennis ball or seeing the rooms in their home. Patients were asked to use one of these responses for yes and the other for no. The images demonstrated an especially profound discordance between what was seen on clinical exam and what was indicated by neuroimaging for one patient, previously deemed vegetative, who could communicate.

This technology does more than open up the possibility of communicating with people thought to be unconscious and unreachable. It also suggests that neuroimaging must eventually be integrated into the clinical assessment of many patients who are vegetative or minimally conscious. This is a dramatic finding and a potential game-changer for clinical practice.

But it is not so simple. Only five of fifty-four patients studied demonstrated the ability to follow researchers' commands, and all of these had traumatic brain injury. And, paradoxically, some patients with higher levels of cognitive function—similar to the locked-in patient Jean Claude Bauby, who authored *The Diving Bell and the Butterfly* by blinking his left eye—might not be able to communicate using this fMRI paradigm. Scientifically, it is important that we further understand the variance in measured responses. Only then will this technology become a reliable resource to assess the presence or absence of consciousness and one's ability to communicate.

But, for the few patients for whom it might work, can a signal on an MRI scan help guide decisions about end-of-life care? Might these responses reach the clinical standard of decision-making capacity or legal competence? Can patients show enough understanding for the rest of us to appreciate that their choices reflect authentic patient self-determination? Certainly, this is not yet the case, nor will it be anytime soon. As a proxy for "discussion" with the patient, this mind-brain interface may be inferential and misconstrued. After all, even when we are simply talking with each other, miscommunication can occur.

The pitfalls of reading too much into this technology become apparent if we recall the 2001 Wendland case from California. Robert Wendland recovered to a minimally conscious state several months after a motor vehicle accident. His wife, Rose, consented to routine medical care, including the replacement of several dislodged feeding tubes, until physicians sought her authorization for a fourth insertion. She refused after consultation with her children and Robert's brother, all of whom felt that Mr. Wendland would not have wanted the intervention. Mr. Wendland's doctors agreed,

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as did all members of the hospital's twenty-member ethics committee. Mr. Wendland's parents, however, objected and sought a restraining order. In response, Rose Wendland petitioned the court to be named Robert's conservator—a request the court granted. Eventually, the case ended up in the California Supreme Court, which heard arguments despite Mr. Wendland's death from pneumonia, citing the ongoing legal relevance of the question.

The Supreme Court held that Rose Wendland did not present the necessary clear and convincing evidence of her husband's prior wishes. Two conversations in which Mr. Wendland had "allegedly expressed a desire not to live like a 'vegetable'" were deemed not to meet the clear and convincing evidence standard because one took place when Mr. Wendland "was recovering from a night's bout of drinking." The other occurred after Mr. Wendland lost his father-in-law, with whom he had been close. The Supreme Court agreed with the judgment of the trial court, which wrote that:

neither of these conversations reflect an exact "on all-fours" description of conservatee's present medical condition. More explicit direction than just "I don't want to live like a vegetable" is required to justify a surrogate decision-maker terminating the life . . . of someone who is not in a PVS [persistent vegetative state].

But most critical to the relevance of a potential interrogation by neuroimaging is what the Supreme Court made of a 1997 videotaped interview assessing Mr. Wendland's preferences. Using a rather low-tech yes/no board, Mr. Wendland's physician asked the following questions:

- Q: Do you have pain?
A: Yes.
Q: Do your legs hurt?
A: No.
Q: Do your buttocks hurt?
A: No.
Q: Do you want us to leave you alone?
A: Yes.
Q: Do you want more therapy?
A: No.
Q: Do you want to get into the chair?
A: Yes.
Q: Do you want to get back in bed?

- A: No.
Q: Do you want to die?
No answer.
Q: Are you angry?
A: Yes.
Q: At somebody?
A: No.

The court placed special emphasis on this exchange and the notable lack of an answer to the question of whether Mr. Wendland wanted to die. While acknowledging that "experts dispute the consistency and accuracy of Robert's responses to questions," the court wrote that "it is difficult to ignore the

fact that he declined to answer the question, 'Do you want to die?' while giving facially plausible 'yes' or 'no' answers to a variety of other questions about his wishes."

Although the Supreme Court was careful to circumscribe the applicability of its decision to the narrow class of patients represented by Mr. Wendland—those who are conscious (albeit minimally so) and without formal advance care planning—the emphasis it placed on the video is worrisome, especially in light of the advent of technologically seductive neuroimaging, of which the *New England Journal of Medicine* paper is a harbinger.

There is a risk in reading too much into these one-sided interviews. Like the responses obtained from Mr. Wendland, those received from the one patient who seemed able to communicate in the *New England Journal of Medicine* study depended entirely upon what questions were asked. The patient could neither initiate responses nor formulate questions. His responses were binary in nature and indicated only yes or no.

Whether the yes/no box is a primitive one or a sophisticated fMRI, the response seems unlikely to meet the "clear and convincing" evidentiary standard. In the Wendland case, it seems to us that the court allowed his lack of response to cast too much doubt. What did it really mean? Did he understand the question? Was he fatigued? Did his attentiveness lapse? Given all these possibilities, should we add his lack of response to the list of uncertainties undermining his articulated prior wishes and the clear and convincing standard? Conversely, relying excessively on a bright flare associated with yes or no on an fMRI would imply too much certainty when there should be doubt. Such deference would constitute a procedural error when seeking a patient's current

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wishes. Suppose the patient really wanted to say, "Maybe . . . who wants to know?"

In both cases, the patient's inability to initiate questions, or to give nuanced responses, or to show understanding commensurate with the gravity of the decision—in line with what James Drane eloquently described as a sliding scale of competence—calls his decision-making capacity into question. With these limitations, we would grade such responses at the level of assent or dissent, at best, and assert that they cannot indicate informed consent or refusal.

Despite these cautions, this breakthrough in neuroimaging may lead to future opportunities to ask patients with disorders of consciousness about their preferences. Until then, it will certainly help identify conscious individuals misdiagnosed as vegetative who are in fact able to follow commands or to communicate with varying degrees of accuracy. These devastating medical errors must be avoided. But despite neuroimaging's investigative promise, like most technologies, we also need to determine when it need not be used. Not all patients will need a scanner for clinical assessment. And when these technologies are employed, their use should be guided by the patient's history, the nature of the injury, the clinical

exam, and knowledge of the underlying neurobiology of the patient's condition. Only an integrated approach can meaningfully add to patient assessment and avoid technologically driven category errors.

Whatever its promise, neuroimaging should never become a routine arbiter of whether life-sustaining therapy should be withdrawn. It is our strongly held view that if a patient articulated a preference or completed an advance directive before losing decision-making capacity, the prior wishes should guide care. We may be tempted to use the scanner to adjudicate family disputes like those in the Schiavo or Wendland cases, but the likelihood is that the answers we seek will be vague, misleading, or simply unobtainable, despite all the technology. These ambiguous outcomes should not have the potential to undermine authentic premorbid choices.

If this technology someday matures as a means to fully assess decision-making capacity, it would remove the choice from a surrogate and restore it to the patient. That requires a huge technical leap, however. In the meantime, it would be tragic and ironic if a technology that gives voice to some patients thought to lack one inadvertently undermined the autonomous wishes of others.

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