

Spotlight on Spaulding Science

News from the Schoen Adams Research Institute at Spaulding Rehabilitation



Q&A with Yelena Bodien, PhD

A clinical neuroscientist at Spaulding Rehabilitation for the past 12 years, Dr. Bodien was a Spaulding Brain Injury Research Fellow under the mentorship of Joseph Giacino, PhD, Spaulding's Director of Neurorehabilitation Psychology, and has spent much of her career focusing on disorders of consciousness (DOCs), a condition of prolonged altered consciousness that significantly impairs awareness and arousal. A wide spectrum of clinical syndromes including coma, DOCs are caused by severe damage to the brain from injury or disease. Dr. Bodien is on a mission to better understand the nuances of these disorders to inform treatment decisions using advanced imaging and data-driven science. She also holds an appointment at the MGH Center for Neurotechnology and Neurorecovery, which provides her with a unique perspective on the continuum of recovery. Most recently, Dr. Bodien was first author on a paper that found that a subset of patients with traumatic brain injury (TBI) who were removed from life-sustaining treatment may have recovered given more time.

Q. What attracted you to this field of research?

A. In graduate school, I was studying how disconnection in the brain's circuitry might help us to understand schizophrenia. I went to a professional meeting where Dr. Steven Laureys, one of the biggest names in the field of coma research, presented on a study that looked at patients with severe brain injury who are unresponsive at the bedside—they don't interact, they don't speak, and it looks like they're completely unaware of what's happening around them. But when these patients undergo a functional MRI—which looks not just at the parts of the brain that are damaged structurally but how the brain is responding in real time—and are asked to imagine they are playing tennis or walking around their house, the patterns of activation in the brain for some of these patients look almost identical to what you would see in a healthy, conscious person. I was at a crossroads in my career and that talk inspired me to stay in academia and use the tools I gained in graduate school to really dig deep into what is happening to people who have brain injuries like these. That's what brought me to Spaulding to do my postdoctoral fellowship.

Q. What led to this most recent paper and why is it important?

A. The specific group of people who have the most severe brain injuries and are often slow to recover have really been the inspiration for everything that I do. Recovery from brain injury is very difficult to study because studies are automatically biased by a high proportion of patients who die early. So you frequently feel this tension among medical professionals. On acute side they're saying, 'Well, we have to make the decision early because it gets more complicated later and we don't want to keep people alive if they're only going to survive at level of function that would never have been acceptable to them.' And then on the rehab side, you hear, 'But look at all these stories of people who do recover, these can't all be just miracles because they happen so often.' As somebody who has a background in neuroscience, that tension just became an empirical question: What tools and data do we have at our disposal to be able to test this and be able to understand it from the position of actual data in hand?

Q. Did anything in your findings surprise you?

A. You can have a suspicion about something, but then when you actually see the data behind it, it's a little bit shocking, almost like, this can't possibly be true. We were a bit surprised to see just how good the outcomes could be in people who have these devastating injuries. It's important to clarify that it's not that everybody who had life-sustaining treatment withdrawn would have done well. In fact, what we found is that a substantial number of people would mostly likely have died. So it's not that the clinicians are always wrong, that they're not doing a good job. They're doing the best they can with the information that they have. It's just that there was a proportion of patients that by six months could have been independent and by 12 months could be doing even better—that really was surprising and humbling. So the purpose of this paper hopefully is to underscore that we don't know for sure how people are going to do. Clearly, we are withdrawing life-sustaining treatment on some people who could have recovered, and since we don't know who those people are, maybe we should pause when making that decision.

Q. What are the next steps?

A. Ideally, we need to be able to better predict what the outcome for an individual with a certain behavioral and demographic profile might be. We have already been working on these types of prediction models, but it gets really difficult because every brain injury is completely different, and we don't yet have great ways of grading the severity of an injury or the pathways that may have been damaged. So we're just at a very early place in being able to appropriately classify the brain injury itself. And then there are a lot of non-injury-related, environmental factors that affect somebody's recovery. If somebody has an advocate, who is in that room with them every day, making sure that they're getting the best care possible, I suspect that it helps in the long run, but it's a very hard thing to quantify. Both these considerations make prediction at the individual level really challenging.

Q. What makes you most proud professionally?

A. When this paper came out, it was covered in *The New York Times*, and they left the Comments on so you could see what everybody was saying. While there were some people who feared the implications of this research, the majority were people who said, 'That was me. I was the person for whom they said my family should withdraw treatment. And I'm happy. I participate fully in life. I have a family, I can love, I can feel.' And then I had people emailing me personal correspondences saying how the paper is reflective of their experience and how much they value this kind of work being done. That, to me, has definitely been a major highlight. I was totally taken aback by it and really touched.

Q. What differentiates Spaulding in this field of work?

A. I knew that the one thing that would keep me in academia after graduate school would be to combine my background and imaging with trying to understand what happens to people with these severe brain injuries and disorders of consciousness. There are very few places that do that, and Spaulding is one of them and something that makes it incredibly unique. The relationship between Spaulding and MGH is also something you don't see everywhere—the collaboration and the closeness of people who are working together for a common cause. I think that it benefits the research and the science but the patients and families, most of all. When you have a patient who comes from MGH and they're being seen by somebody who's an expert in disorders of consciousness because they've been trained by Joe Giacino and then they get to Spaulding and they see Joe—that continuity and experience is really rare, and people look to Spaulding as the exemplar of what both clinical care, research, and education in the realm of DOCs should be.

Q. What are your hopes for Spaulding's new Innovative Treatments for Disorders of Consciousness Program funded by philanthropist Scott Sandell?

A. From my perspective, even though it's in very early stages, the really incredible thing that this small pilot grant program has already done is bring together people who are doing DOC research all across the United States and Europe. It has already started new collaborations, spawned new ideas for projects, and enlivened the conversation about what should the future of DOC research be. Even though it has not yet funded a project, I think that just the fact that this grant mechanism exists has already made a difference in bringing more DOC research to Spaulding and bringing together investigators who otherwise would not have an opportunity to collaborate in this area. I mean there are probably clinician researchers at Spaulding and Mass General Brigham who aren't really involved in any of this research who are now going to become DOC investigators, and that's awesome!

Q. If someone gave you \$10 million for your work, what would you do with it?

A. The thing that has really been holding back this research is not having enough data. Our data sets are really lacking in long-term outcomes and the advanced neuro-imaging or behavioral assessments needed to understand the different types of disorders of consciousness and the things that will help us predict outcomes and develop interventions. So my grand plan is to set up a system across all the major academic and community hospitals where every single patient who is in coma when they get to the hospital is enrolled in a program to collect and use their data. This system will follow them for their entire life to see how they recover over the long term and collate all of that data in one centralized location, which can be accessed and expanded to try to answer some of the more complicated sophisticated questions that we have. Philanthropic funding is incredibly important in this area of research because DOCs are something of a niche and don't have a perfect home in the current federal funding model so a donor or foundation really have an opportunity to advance research that might not otherwise happen.

Q. What's the best part of your job?

A. I am motivated by this idea that something that I do today may help somebody else tomorrow. I really believe that what we do here is focused on helping patients and families as soon as possible. We always have an eye towards application in the clinical world, what does this mean for the patient who comes in the door tomorrow, not 10 years from now. And I love that.

