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Joseph J. Fins
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Introduction

I

By now the scene is familiar and the story predictable. An expectant family is in my office at Weill Cornell Medical College sharing the story about how a son or daughter, husband or wife, mother or father sustained a brain injury. They have come to Cornell to participate in scientific studies designed to understand how the brain recovers from disorders of consciousness, serious conditions like the vegetative and minimally conscious states. Their goals are modest. They want to know if their loved one is aware and if they will get better, be able to understand, speak, and love again.

When they arrive, most are worn out. They are like refugees, having been cast aside by an indifferent health care system that provided brilliant emergent care only to abandon them thereafter. Irrespective of differences in race, ethnicity, class, or state of origin, a stereotypic pattern of neglect emerges.

Although each case is unique, the overall story becomes rather predictable. Families face a pervasive nihilism with practitioners assuming a static notion of brain injury. Despite stunning scientific evidence to the contrary, the prevailing view in the clinic is that all brain injuries are immutable. From this perspective, it is preordained that the injured brain cannot recover and that the humane course is to pursue palliative care, to let nature take its course.

At the bedside, this translates into early – some might say premature – decisions to withhold or withdraw life-sustaining therapies, writing do-not-resuscitate orders or removing of ventilators, even before patients have had a chance to declare themselves. More worrisome have been reports of families urged to turn their loved ones into organ donors before their prognosis is clear.

Most families do choose a palliative course, knowing that even under the most optimistic of scenarios their loved ones will need ongoing medical care and years of rehabilitation. Theirs is a reasonable choice, and perhaps a logical one, appreciating the considerable challenges, when early optimism and the promise of recovery do not get translated into desired outcomes. For these families, death is preferable to survival and what some would describe as an even worse outcome, a diminished or extinguished ability to interact with others.

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But the families we interviewed are put together differently. Although the advent of palliative care has its origins in patients' rights, the families we spoke to did not view such recommendations as enfranchising. To them, the palliative care option, often promoted forcefully, is a choice that they cannot sanction. Instead, the recommendation was often seen as overly prescriptive and an affront to their exercise of choice. These families can't seem to let go. It is not about religiosity but a different kind of devotion, a depth of obligation to their family member and a sense that the world would be intolerably incomplete without their loved one.

From afar, their choices may seem selfish, compelling others to endure a life that no one would choose for themselves. But that's the point. These families *didn't* choose the outcomes with which they must now contend. Like all families suddenly summoned to an emergency room or the waiting room outside an operative suite, they hoped and prayed that their family member would survive only to have their appeals answered – in part. But unlike the more fortunate, they have learned a cruel lesson. They have come to appreciate that choice in those circumstances is a charade.

Families might think they are directing care when they authorize a treatment or sign a consent, but outcomes are determined by the nature of the injury, when and where the injury occurred, the skill of the surgeon, and just plain luck.

No, the families we interviewed did not wish lives of cognitive and physical impairment for their loved ones, but once it became apparent that would be the outcome, they felt compelled to sustain the life that their loved one's had been dealt. That too was a choice out of their hands and really the only thing to do. Unless their loved one was in intractable pain, they were not going to acquiesce to those who urged that care be withheld or withdrawn. They would continue to care and to hope.

Given their desire for ongoing treatment, families find their goals completely out of sync with the chronic care system to which patients will be discharged. If patients survive their acute injuries, and their families withstand pressures to remove life support contrary to their wishes, a pattern of neglect emerges. Patients are often discharged prematurely while still unstable and then they find themselves in facilities that are unequipped to provide necessary care. Once in chronic care, families must wage war with bureaucrats and utilization reviewers to qualify for ongoing rehabilitation. Many simply struggle to obtain a credible diagnosis, importantly trying to determine if their loved one is conscious.

This book seeks to give voice to their struggles and to explain why the scientific study of brain injury, whose mysteries constitute a holy grail of science, has had so little impact on the lived experiences of patients who have a tenuous grip on consciousness. Brilliant science and rather indifferent care. It is a paradox worthy of a book, and one ripe for denial.

And therein lies the challenge of writing such a volume. This is difficult terrain: healthy people, generally in their prime, struck down by an injury that will threaten their lives and forever alter them and their relationships. The prospect of a brain injury is a scenario our conscious selves would prefer not to imagine. It is a problem space that can be disavowed when considered in the aggregate, a distant probability that can be avoided. It is much harder to ignore when it becomes personal.

So this book is a story about an individual, Margaret Worthen. Maggie was a senior at Smith College when she sustained a brain injury in 2006. Her story, as told by her mother Nancy, is one that can neither be denied nor forgotten. Like all the many narratives that comprise this book, Maggie's story, as Nancy reminds us, is about "… *a real person and … what happened to her.*"

Maggie's young life, full of promise, was interrupted and nearly severed, only to resume at the edge of known neuroscience. And here she is joined by nearly forty others whose families agreed to be interviewed. Their family narratives, comprising nearly ninety hours of interviews and 2,750 pages of transcripts, fill out a broader canvas that depicts a landscape of clinical neglect now challenged by scientific discovery.

That pioneering work, not yet influencing clinical practice, but increasingly gaining attention in the media and the wider scientific community, is also the subject of this book, which will consider its emergence and ultimate relevance to clinical practice. Although the history of medicine is lamentably marginalized, the intellectual history of disorders of consciousness is a tale that must be told, lest we misunderstand how so much scientific promise has been discounted in the clinic.

To tell this story, I return to Maggie's and draw upon the confluence of the scientific and historical: the progression a patient makes from acute injury to recovery tracks precisely with the historical advent of each of these brain states. So as Maggie makes the progression from coma into the vegetative state (VS) and on to the minimally conscious state (MCS), we will consider how these states were first described and how modern science is refining what we think we know.

Although the structure of the book follows the arc of Maggie's life after her injury, we will digress from her story to share other narratives as rich and textured as hers. Each is worthy of their own book, but in this effort they are cast in a supporting role. They are here to provide an additional detail or share a variation on a theme. In some cases these digressions can encompass a chapter or two, as in the case of pivotal cases or my discussion of the first effort to use deep brain stimulation (DBS) in the MCS. I hope that the reader finds these excursions useful and that they help to place Maggie's experience within the context of a broader canvass. By doing so, her tale becomes less an anecdotal account of one patient and more the representative trajectory of many other patients and families.

Maggie's medical history continues with a discussion of the origins of the vegetative state. Here I draw upon historic accounts of my late teacher, and later colleague, Dr. Fred Plum, co-originator of the persistent vegetative state (PVS) and the court-appointed neurologist in the Quinlan right-to-die case in 1976. Plum's seminal work, with the Scottish neurosurgeon Bryan Jennett on the vegetative state, first published in *The Lancet* in 1972, will be complemented by recounting the remarkable story of Terry Wallis and how the MCS emerged as a diagnostic category thirty years later.

Along the way, I will consider the role that neuroimaging has had on our growing understanding of the injured brain, most notably the disturbing, yet fascinating, finding that neuroimaging can reveal a discordance between what is observed on clinical examination with what is inferred from brain scans. Such discrepancies, when a scan seemingly refutes a diagnosis of unconsciousness, portend a reconfiguration of diagnostic categories and ethical norms for patient care.

My consideration of the neuroscience of disorders of consciousness will coalesce around my Cornell colleague, neurologist and neuroscientist Dr. Nicholas Schiff. Schiff has studied the capability of minimally conscious patients to process language and led the first studies using DBS in the MCS. That work culminated in a landmark 2007 *Nature* publication.

I was privileged to serve as a co-investigator on the DBS in MCS study, designing the ethical framework enabling that effort to continue. That study, its origins, ethical justification, and surgery, is told through first-person accounts from many of the investigators, and most notably, the subject's mother, Corinth Pecco. Up until now, Ms. Pecco had preferred to remain anonymous. This is the first and only account of her recollections of and response to the historic surgery performed on her son Greg.

DBS, along with new drug therapies and the use of neuroimaging, are discussed collectively as constituting a new era of neuroprosthetic communication through which patients will be enabled to communicate with the assistance of device, drug, or machine. This potential, and the science that is revealing the potential of the seemingly silent brain to speak when given help, is a story that is just being written. These developments will have profound implications for how we think about the utility (versus the futility) of intervening in the injured brain and consequently how we structure and finance ongoing rehabilitation and chronic care for patients, many of whom now only know neglect.

II

The potential is astounding, but so too are the barriers, notwithstanding progress made in the past decade. These threats transcend the real challenges posed by neuroscience. They speak to the place of science in society and the forces that can promote or retard the translation of new insights into clinical practice. One key barrier is health care financing and how we pay for rehabilitation. The paradox is striking: the promise of neuroscience and the challenge of reimbursement schema that truncates the potential for recovery.

Brains recover by biological standards, not reimbursement criteria. To impose the latter on the former is to fail to take account of time frames needed for recovery by the injured brain, which as a nonlinear system resists simple predictive models. Yet that is precisely what *medical necessity* presupposes. It dictates the length of rehabilitation, access to brain-injury treatment programs, and other benefits. A reimbursement construct, written into federal law, medical necessity is seen by families as scripting dire outcomes. It is an affront to patients and families because it denies care notwithstanding our evolving understanding of biomarkers of the recovering brain.

Although medical necessity is currently the object of a class action lawsuit that might temper its effects, how these reforms – if they come to pass – will affect patients with severe brain injury remains unclear. As we shall see, this population of patients is a deeply marginalized class who conceivably may not benefit from revisions to medical necessity provisions.

And whatever happens to medical necessity, it will take place against the larger backdrop of what might come to pass under the Affordable Care Act, President Obama's health care plan, which laudably seeks to broaden access and provide efficient and evidence-based care. But what of access for those whose injuries are so biologically complex so as to defy simple notions of efficiency? Put another way, if we do not yet understand how brains recover from the MCS, and the time it might take, how could anyone say progress is delayed? Or that a patient is an inefficient outlier whose benefits should be curtailed?

And as the family narratives amply show, this is what happens. Rehabilitation is curtailed and stopped. Patients not "showing progress" are discharged from rehabilitation programs to nursing homes where they linger without rehabilitation or diagnostic oversight. The impact of a medical necessity determination is high, potentially depriving a patient of the opportunity to recover or, as critically, be placed in a medical context in which an emerging recovery might be identified.

This is not a trivial problem. Recent data reveals that the diagnostic error rate of patients with traumatic brain injury in nursing homes diagnosed as vegetative may in fact be as high as 40 percent, with those patients actually being in the MCS. This is troubling data and a significant error rate with profound implications. It means that a large number of patients are taken to be permanently unconscious when in fact they may be conscious, albeit in the MCS. Although there is a risk to the following speculation, I am haunted

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by it: imagine lying in a nursing home bed, cognitively impaired and wondering why the staff and even your family are treating you as if you are not there. What could possibly be the reason? Don't they care? Don't they know I am here?

These are questions we can only imagine being asked. That is, until we can probe the brains of patients whose partial or absent motor output suggests a lack of consciousness but whose neuroimages show activations potentially consistent with the ability to sustain thought, language, and emotion. So, absent proper support for rehabilitation and diagnostic assessment, the conscious can easily be mistaken for the unconscious.

As a first step toward reform, I suggest that we reconsider the place of *medical necessity*, a reimbursement category used to assess progress in conditions whose pace of recovery is well understood. In such conditions, physicians and policy makers can predict additional recovery based on the achievement of certain milestones and make fiscal (and ethical) judgments about the utility of additional therapies or rehabilitation. Because that is still not possible with patients in the MCS, we will need to develop new constructs that incorporate elements of the patient's history, clinical exam, and imaging and EEG studies to better predict outcomes. These constructs will need to broaden the definitions of progress currently embedded in medical necessity, which require the demonstration of *physical* improvement versus better indicators of brain-based changes that might portend additional recovery.

In tandem with these efforts, families should have a better opportunity to appeal discharge decisions and determinations about a patient's rehabilitative status and have access to expert, if not simply better, assessment to remediate the unacceptably poor state of evaluation to which this population is subjected. This will require cross-training of internists and geriatricians who primarily staff chronic care facilities. These physicians are not typically trained to provide neurological or physiatry assessments, and they will need to learn more about the assessment and management of patients with disorders of consciousness, if more expert evaluators are not available.

But it will take more than cross-trained physicians to better assess and rehabilitate these patients. In addition to the reform of professional education, I would also suggest that we reframe our conception of rehabilitation and view this process through the prism of an educational reform. I make this argument because, as we will see, there is early scientific evidence that the brain recovers from severe injury utilizing processes, like axonal regeneration, seen in normal development. Although this remains speculative, it appears that the brain makes reparative connections much the way it originally made connections in the naturally maturing and developing brain. It

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seems that developmental processes, honed over millennia of evolution, are being recast to serve a regenerative function.

If the brain regenerates by recapitulating a process normally reserved for development, might it not make good sense to recast therapeutic efforts geared toward the injured brain like a kind of reeducation, in which the object is not the developing youth, but the developmental processes that may undergird recovery? That means that rehabilitation centers will need to transform into schools. They will need to meet patients along their new developmental continuum and help them achieve their maximal potential.

Practically, this would require a theoretical reconsideration of the methods and the quantity of rehabilitative efforts. It would seem prudent to have rehabilitation experts work collaboratively with early age educators who shepherd early learners in motor tasks, the acquisition of language and linguistic skills, and behavioral norms for communal living.

Reframing rehabilitation as education would also necessitate us asking how much intervention is appropriate. Educators speak of more, not less early childhood education and the critical importance of pre-K education on the developing brain's long-term prospects. And preschools incrementally increase the amount of time their little learners go to school, starting slow but eventually extending the school day until they approximate older children.

Given the constraints of fatigue and injury, should not the same strategy be invoked for patients undergoing recovery or, might we say, the redevelopmental process from brain injury? The amount of rehabilitation given to brain-injured patients is paltry if compared to educational interventions. As educational experts speak of extending the school day and the school year, rehabilitation specialists might consider increasing the amount and frequency of their ministrations.

Of course, rehabilitation efforts will be severely limited if next-generation assistive devices are not available to patients, as therapist-teachers instruct their patient-students in how to use these prosthetic tools in the service of their reeducation and recovery. But absent support for the development of neuroprosthetics, patients identified as conscious will remain forever unable to translate their thoughts into words. They will remain condemned to a life of isolation and cognitive imprisonment that might find some degree of liberation through the machinations of modern neuroscience.

So it is essential that the National Institutes of Health (NIH) and the private sector work together to develop these tools for this population. Their development will redound to benefit others less severely afflicted. They will serve a dual purpose as probative devices of discovery helping to elucidate the circuitry that underlines brain injury and neurological and psychiatric

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disorders, like Parkinson's disease and depression, which are now understood as diseases that result from disordered brain wiring.

Therefore, any agenda for reform must contend with barriers to the development of these devices. A central challenge is one of classification when it comes to funding streams. For better or worse, tools like DBS and neuroimaging can both serve as platforms for therapeutic/restorative and diagnostic/investigative purposes. Because of their current and potential diagnostic or therapeutic capabilities, they are cast as clinical whose primary support is not the basic science purview of the NIH, but the commercial realm of the private sector. Truth be told, these prostheses can operate at both the basic science and therapeutic levels. But this dual purpose leaves them stuck in a funding gulf, starving from levels of funding and investigative freedom only available from the NIH or prone to the market pressures of industry, which seeks more immediate product development.

We are at a pivotal time in the development of the neurosciences and the confluence of technologies from engineering, imaging, and informatics that make accelerated and substantive process possible in ways not previously envisioned. It is a golden moment that could represent a renaissance in the neurosciences all in the service of patients whose very existence has been demonstrated by this same technology. Without neuroimaging we would not now be contending with the ethical challenge of what we owe those who are behaviorally inactive but demonstrate awareness on brain scans. Here, technology has revealed the discordance between brain and body and the dependency of these patients upon others for access to communication and community. We need to see such developments as an ethical obligation that confers responsibilities on society. A failure to restore functional communication is much more than a denied entitlement or a failed investment in a scientific curiosity. It is the perpetuation of the segregation that has placed conscious individuals outside the medical mainstream and sequestered them in chronic care far from the neuroscience that might make their integration back into civil society possible.

A failure to attend to the present needs of these patients, and to support the forward-looking science that will serve them decades hence, will silence the untapped capability of these conscious individuals to engage with others. It will deprive those who are conscious, but unable to speak, the solidarity of human community, something only made possible by the restoration of functional communication.

Some might cast the provision of medical care toward such goals as a discretionary benefit or an entitlement that can be funded or not, depending upon the prevailing political and fiscal winds. But I see such care – and the scientific advances that will make it possible – efforts geared toward the restoration of functional communication, as an intervention that is far

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more fundamental. I view it as reconstituting a basic human right, in which the restoration of voice is now made possible by neuroprosthetics. And through the restoration of functional communication, patients segregated from their families and from society can be more maximally integrated into the community.

This possibility has now been demonstrated – at least at the level of a proof of principle – through DBS and functional neuroimaging. And though the techniques remain preliminary, almost crude, they foreshadow a certain future in which restorative neuroprosthetic technologies will have the power of giving voice to those silenced by severe brain injury. Realizing this scientific potential and affirming the civil rights of those who will benefit from these innovations is the normative objective of this book.

Make no mistake. This challenge is not simply invoking an appeal to legislation like the Americans with Disabilities Act (ADA) to these individuals. Although the ADA's intent to maximally integrate people with disabilities into community, a goal achieved in part by the restoration of functional communication, is laudable, invoking the enforcement power of the ADA will not be possible without a change in societal attitudes.

It would be far easier if the ADA could address the needs of these patients and remediate their marginalization. But it has not, as yet. Patients with disorders of consciousness linger on the fringes of society. Sadly, before society views these patients as properly covered by disability rights legislation, they first need to been seen as a class that might benefit from such protections.

But to date, these patients have been seen as invariably hopeless or worse, outside the human scope of such legislation as the status quo attests. They remain sociologically – if not legally – outside the regulatory protection of the ADA. The neglect and disregard continues, making the sad point that before this population is deemed worthy of disability rights, society needs to acknowledge even more fundamental rights of citizenship.

This is not the first time in the long march of civil rights that individuals were seen as somehow exempted from the rights enjoyed by a dominant class. It is a recurring theme. From Seneca Falls to Stonewall and Selma, our nation's history has borne witness to marginalized groups that had to appeal for rights enjoyed in full by other citizens. And so it is with those with severe brain injury.

But unlike predecessor groups that have achieved some measure of success, it is still early in the struggle for those with severe brain injury. Perhaps the argument is premature. The science that will restore voice is still new and the technical challenges profound. But I have little doubt that the science will outpace society's ability to fully vest those with severe brain injury with the rights enjoyed by other citizens.

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If we take the American civil rights movement as the prototype, we recall that norms, values, and laws can evolve. It was only a little more than half a century ago when our African American brethren were still segregated and excluded from the rights and privileges, even as other Americans enjoyed the fruits of citizenship, the right to vote, access to schools and public accommodations. As the neglect of those with severe brain injury is tolerated, so too have been the practices of discrimination and segregation directed to black America. Those exclusionary practices were accepted and considered normative, until social norms and conventions evolved – and continue to evolve – beyond the tragic legacy of slavery and entrenched discrimination.

The analogy to the American civil rights movement is particularly instructive because it demonstrates how conventional thinking can evolve over time, revealing logical and ethical inconsistencies that make long-accepted practices untenable. When segregation was finally viewed as contrary to American norms and values in *Brown v. Board* in 1954, the Supreme Court recognized the illogic inherent in its 1896 *Plessy v. Ferguson* "separate but equal" decision, appreciating that equality was completely and fully incompatible with segregation.

With all due respect to the heroic legacy of the civil rights movement, a similar transformation needs to occur with respect to patients with severe brain injury. They need to be seen as individuals deserving of the same civil protections owed the rest of us, notwithstanding significant disabilities that paradoxically have placed them beyond society's protective gaze. Their basic rights of citizenry need to be secured so that they can enjoy the benefits of existing protections like the ADA and the inevitable fruits of a generative period of neuroscience.

III

These are serious arguments and that brings me to its messenger. To focus our gaze on the plight of these patients, the story has to be grounded and made personal. It has to have a basis in lived experience and accurately reflect the sociology of severe brain injury in America. To do this one needs testimony and first-person accounts. For this reason this first attempt at an ethnography of this population owes a tremendous debt to my interlocutors and respondents. Their stories lend authenticity to this volume and constitute a data source of tremendous value, and I am deeply indebted to the families who entrusted their stories with me. I hope that I have shared them with the authenticity and deep respect they deserve.

As the custodian of these narratives, I have edited the narratives for ease of reading seeking to be ever-faithful to what was communicated and context. In the cases of Angilee Wallis and Corinth Pecco, excess redaction