

In this series of essays, *The Road Less Traveled*, noted bioethicists share their stories and the personal experiences that prompted them to pursue the field. These memoirs are less professional chronologies and more descriptions of the seminal touchstone events and turning points that led—often unexpectedly—to their career path.

Constructive Disappointment and Disbelief

Building a Career in Neuroethics

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An Unexpected Journey

Sometimes one's greatest academic disappointments can have unexpected outcomes. This is especially true when one is trying to change career trajectories or do something that others did not take seriously. My path into neuroethics was an unexpected journey catalyzed in part by constructive disappointment and the disbelief of colleagues who thought that the work I was pursuing nearly two decades prior was a fool's errand. After all, could anyone—in his or her right mind—ever conceive of waking up a person unconscious from brain injury and getting him to speak? ¹

Previously, in *Rights Come to Mind*, ² I have written about how my collaboration with the physician-scientist Nicholas Schiff moved me from bioethics into the nascent field of neuroethics. ³ Our collaboration was and continues to be a positive force in my professional life. What I discuss here are two seemingly *negative* experiences that ultimately had a virtuous effect on the progress of my work in neuroethics, insights that are only apparent in retrospect.

What Comes After Death and Dying?

Constructive disappointment is something of an oxymoron, and as such it needs a context within which to be understood. To provide that frame, I need to return to a younger self, an idealist physician in the mid 1990s committed to improving

This article is dedicated to Ralph L. Nachman, M.D., former E. Hugh Luckey Distinguished Professor of Medicine and Chair of the Department of Medicine at the New York Presbyterian Weill Cornell Medical Center, whose career advice got better with time. All trainees and faculty members would be fortunate to benefit from such wisdom and guidance. The author acknowledges the support of the Jerold B. Katz Foundation to the Consortium for the Advanced Study of Brain Injury and Weill Cornell Medical College.

the care of patients at the end of life. As a clinical ethicist at my hospital, and founder of our ethics committee, the bulk of the patients I was seeing were dying. There were decisions to withhold or withdraw life-sustaining therapy when families and physicians disagreed. There were futility disputes when clinicians and families had different takes on what was possible and, sadly, impossible. And of course there were questions about pain management and the use of opioids, something that was liberalizing during that era, even as they are being constrained today because of the public health challenges posed by the opioid epidemic.

In an era when palliative care was not yet a recognized specialty,⁴ much of what I was doing would come to be understood as part of that discipline. Here a clinically focused consultation service was bridging the space between a more theoretical approach to ethical questions and a desire to be pragmatically useful. On the theoretical side, my colleagues and I developed clinical pragmatism as a method of moral problem solving⁵ by applying John Dewey's theory of inquiry to the clinical space.⁶

Throughout this process, I continuously ran into problems at life's end.⁷ Naturally, I grew curious about pain and symptom management and about what clinical ethics might have to add to the emergent specialty of palliative care. I applied to the Soros Open Society Institute Project on Death in America for one of its Faculty Scholar grants in order to foster crosstalk between clinical ethics and palliative care. Remarkably, there was very little conversation between the two fields at the time, to the detriment of patients and engaged scholarship. To foster that dialogue, I initiated an ethics feature in a leading palliative care journal.⁸

I became particularly interested in *how* patients and families made the transition from acute, curative care to palliation. From all that I had seen while conducting ethics consultations in a general hospital, it was quite clear that we, as a species, have a very hard time letting go and accepting death and decline. Denial was the dominant emotion as patients approached death, often bolstered by the technological imperative that so easily hijacked rational analysis, moving patients toward what Joan Didion called "magical thinking."⁹

Denial was a great defense mechanism, but only to a point. At a sociological level, we were denying death. Ernst Becker made this point in *The Denial of Death*,¹⁰ a book I first encountered while in college. Becker won a Pulitzer Prize, and his book made the bestseller's list and was the subject of a cameo in Woody Allen's *Annie Hall*. It also presaged the nation's growing preoccupation with death and dying that would flower in the 1990s with a nascent palliative care movement by the time I was finishing my training.

By then, as a society we were beginning to grapple with how we die, motivated by path-breaking books such as Daniel Callahan's *Setting Limits*¹¹ and Sherwin B. Nuland's *How We Die*.¹² Both volumes acknowledged our finitude, and pointed to a better way to make the transition to life's final journey.

As a young physician, I was influenced by both Callahan and Nuland. Callahan was an important mentor while I was working at the Hastings Center as Associate for Medicine. I had the good fortune to review Nuland's book.¹³ In response to my review, Nuland wrote me a lovely note, which initiated a friendship that endured until he died in 2014.¹⁴

Callahan and Nuland's work deeply touched me, straddling both the theory and practice of how we die. As one who aspired to a writing life to accompany my work in the clinic, Callahan and Nuland each modeled how engaged scholarship

and accessible prose could move the dialogue forward and result in meaningful change in practice. They were people to emulate as I embarked upon my career.

I began to write a book about goal setting at life's end, then a rather novel idea, and developed a Goals of Care Assessment Tool (GCAT) to foster the identification of the dying process to help facilitate the transition from cure to care.¹⁵

In my book *A Palliative Ethic of Care*,¹⁶ I used the metaphor of an interstate highway and country road to capture the parallel byways of acute and palliative care. The interstate was highly paced like an intensive care unit, but woe to the driver who didn't get off in time and became stranded without food or fuel between exits. It is sort of like that at the end of life. So many patients die in the intensive care unit (ICU) when there is no benefit to being there. They had missed their exit and were stranded amidst all this technology that would not help them and would only isolate them from their families. My question was: How could I help folks get off in time? I decided that in a dichotomous world that distinguished acute and palliative care, the interstate and the idyllic country road, I would focus on the exit ramp and ways to make this critical transition.

Toward that end, I began to study trajectories of death and dying in the acute care hospital and think of structural changes in the delivery of care that might facilitate these transitions.¹⁷ With the philosopher, Franklin G. Miller, I proposed the establishment of an alternative care unit (ACU) or inpatient hospice that would serve as an alternative to the ICU and would be a way station for dying patients until they could be discharged to home hospice.¹⁸

I hoped to implement this idea and a palliative care service at my hospital, and I went to see my chairman for support. I had written a business plan, had the support of fellow clinicians, and had even begun to negotiate a relationship with an outside agency that had a home hospice service. And on the academic side, I had enjoyed some modest success as a young scholar, writing cited articles and gaining grant support. I thought that the project would receive definite approval, and looked forward to the next chapter in my career.

Except that it did not happen. My chair—an old-school professor of medicine—told me that he was going to give the palliative care service to another department. I was incredibly disappointed. I had had a vision of what the ACU would be like, even imaging how it would be decorated, color scheme and all. But this was all for naught. I had worked for nearly a decade to make this happen and all of a sudden I felt that I had been robbed of both my clinical and academic future. I loved working with dying patients and their families and couldn't imagine doing anything else.

The chair told me that it was a business decision. He had decided that another service that was already partially staffed would be a cheaper alternative to my startup venture that would require new clinician hires. There was a huge cost differential between my service and the alternative: my plans were impossible without philanthropy and startup funds. That was how the chair started to explain his rationale. End of story.

But it wasn't, and here is the epiphany that is only more prescient in retrospect, one that I barely heard at the time I was so upset: My chair told me that others could run a palliative care service. Whereas the ACU was a novel idea, running a palliative care service was no longer at the leading edge of practice or theory. And if I took that on, he said that I would be bogged down by all the clinical responsibilities. Those responsibilities would consume me. These clinical obligations

would squelch my creativity and the work in brain injury that I was just starting to do.

I don't remember his exact words, but to paraphrase, he told me that no one else could do what I wanted to do in brain injury. Although the economics of the palliative care service played a role in his decision, he was the consummate mentor, and made the decision to allow me to pursue something *sui generis* that would be more important to medicine and my career, assuming I could pull it off.

Toward a Nascent Neuroethics

At that time I was dabbling in a nascent field that would become neuroethics. Initially I was motivated by the deep brain stimulation project envisioned by Schiff and the ethical hurdles that would need to be overcome to turn a hypothesis into an ethically workable protocol. I had already laid out a preliminary framework for the work in 2000,¹⁹ and was beginning to write more seriously about this topic, albeit without any funding. In a sense, I was self-funding the effort, convinced that the investment would bear intellectual fruit. And as I was becoming more engaged by the challenges of neuroethics and disorders of consciousness, most notably the newly described minimally conscious state,²⁰ my heart was more with the challenges posed by brain research and less and less with the problems of palliative care. I had just written a summative volume on palliative care and ethics and was looking for something new and exciting that would pose novel theoretical questions as I moved into midcareer.

My very wise chair knew this and he saved me from becoming entrenched when I needed to take a risk and move forward. Of course the research could falter or fail, but he sensed my excitement about the brain injury work. His decision gave me a little push that was incredibly painful at the time but was in retrospect the most helpful professional nudge I think I ever received. My gratitude for this momentary disappointment is beyond words.

But the episode still leaves an important question in its wake: Was it a waste of time and effort to devote myself so fully to an area of practice and research for over a decade only to move in another direction?

My late father always told me that nothing you learn is ever wasted, and as usual he was absolutely right.²¹ As the chair of my hospital ethics committee and director of our ethics consultation service, I continue to deal with the ethical and normative challenges posed by end-of-life care. So at least for my "day job," my work in palliative care ethics remained relevant.

A fundamental advantage of coming to neuroethics from clinical ethics was that I was grounded in the real need of patients and families.²² This made me a critic of what I will call the *speculative school of neuroethics*, which trades in what-ifs hypotheticals that might occur, and not the lived experience of the clinic.²³ When some write about the risks of neural privacy or about "reading minds" even as we can not tell families with some degree of certainty whether their loved one will awake from the vegetative state, something is amiss. This line of inquiry, to my mind, distracts us from the quotidian challenges posed by neuropsychiatric research and practice. This line of critique of speculative neuroethics comes directly out of my work conducting ethics consultations. This emphasis on clinical engagement has defined my work. And for me as a scholar, it has also been invaluable, giving me a perspective that has allowed me to draw connections between neuroethics and

the more traditional medical ethics that spawned it, and between palliative care and neuroethics. Early on, following on my work in palliative care, I became worried about the palliative care needs of minimally conscious patients who were often misdiagnosed as vegetative,²⁴ and thereby erroneously thought to be unconscious and insensate. They had the ability to perceive and experience pain because they had intact neural networks that were not present in patients who were vegetative.²⁵

This combination presented the horrific scenario of patients who could feel pain but could not tell us of their distress. Given this, even as I was starting to think of the needs of patients with disorders of consciousness, I was arguing for a neuropalliative ethic of care.²⁶ Even as I moved into neuroethics, I had not strayed from my roots in clinical ethics and palliative care. My past experience allowed for their novel application to another vulnerable population in need. Instead of leaving palliative care, I was actually extending the reach of palliative medicine to patients with disorders of consciousness. Recently, this topic has moved into the mainstream and been included as chapters in definitive texts on palliative medicine.^{27,28}

At a more theoretical level, my prior engagement with clinical ethics and palliative care prepared me to appreciate how the history of the establishment of a right to die led paradoxically to the pervasive nihilism that still haunts patients with disorders of consciousness. I was able to do this by drawing a link between the evolution of a right to die and the perceived futility and disproportionality of intervening in the severely injured brain.

Having worked in clinical ethics and advancing a right to die, I was familiar with the advancement of patient rights at the end of life from *Quinlan*, *Cruzan* and *Schiavo*, all of which involved patients in the vegetative state. This sequence of landmark legal cases, which I had studied as an advocate for the right to die, began to conflict with making an argument for a right to care for patients who appeared vegetative but were in fact minimally conscious.

In a *Nature Reviews Neuroscience* article, I made this connection, which seems rather obvious in retrospect, but which tied the sociology of the right to die and the neglect of this population together.²⁹ By articulating a right to die for patients in the vegetative state, we had overgeneralized the argument at the expense of those with severe brain injury who appeared vegetative but were not, and those who were in the *persistent* vegetative state and still capable of regaining a liminal state of consciousness. And in the process, I was initiating a new discourse in medical ethics about disorders of consciousness, writing what I believe was the first article on this broader theme in the *Hastings Center Report* in 2005, called "Rethinking Disorders of Consciousness."³⁰

But I was making a contrarian argument, running counter to one of the sacrosanct catechisms of American bioethics. Those who had been entrenched in the rights language of a right to die began to attack me, perhaps thinking that if I began to question the conceptual origins of the right to die, we would unravel the hard won right to die. I of course did not want to do this, but then again, I did not want to be intellectually dishonest and simplify the clinical details of patients in a liminal state of consciousness to make the ethics *easier*. If we believed in informed consent and informed refusal, then we had to ensure that families were informed about what we now knew about disorders of consciousness. It was not as clear-cut as was once thought.

We had learned that some people who appeared vegetative actually harbored covert consciousness. I was simply pointing out nosological issues related to how we categorize patients with disorders of consciousness: that not all patients thought to be vegetative were in fact vegetative. Some were minimally conscious, and this was a difference that should make a difference in how these individuals were treated. To my mind, the distinction had enormous ethical implications that could not be sacrificed to an ideological stance about a right to die. There was a countervailing need to appreciate a right to care for this population.

The challenge was that now we had two seemingly opposing ideas to contend with, ones that straddled the political spectrum as well: preserve the right to die and affirm the right to care for those who might be helped and who might have desired it as expressed in their prior wishes.³¹ This became all the more important as ideology crept into the debate amidst the controversy over Terri Schiavo. In an article that I wrote with my late teacher Fred Plum, I argued that diagnosis should not be based on ideology and should be *more than a state of mind*, the title of an article that we coauthored.³²

Why Would You Want To Do That?

Arguing for the integrity of the diagnostic process was central to our work, because any therapeutic intervention to improve the lot of patients with disorders of consciousness would hinge on properly distinguishing vegetative from minimally conscious patients. In our work using deep brain stimulation, we wanted, simply put, to activate intact neural networks that were underactivated. In patients who were vegetative, these networks were not present; therefore, it was critical that we had diagnostic clarity as we embarked on therapeutic engagement with the injured brain.

At one level this was a neurological question, and one that we were getting better at making use of multimodal assessments, using neuropsychological testing and emerging methods in neuroimaging that could identify patients who had covert consciousness. This was, and continues to be, an area of active research, and one in which progress is being made.³³ I remain optimistic about our scientific prospects.

A more challenging barrier is attitudinal, and involves how bioethicists willingly conflate categories, glossing over distinctions that matter. As I have asserted, part of this is ideological, and Kuhnian:³⁴ the generation that worked so hard to establish a right to die does not want to contribute to its demise by acknowledging additional complexity in our diagnostic schema. Another is a failure to expend the effort to learn about the scientific and clinical basis of these emerging categories and engage in proportionate inductive reasoning, leaving preconceptions and ideology behind.

These errors of omission can have consequences for patients and the future of this work. They can also have consequences for careers, especially in one's formative years when reputations have yet to be made and the accoutrements of academic life—funding and tenure—have yet to be secured.

I vividly remember talking to a senior bioethicist, who was the president of a leading bioethics center, about my work.³⁵ As we returned from a meeting and were driving up Park Avenue in a taxi, I tried to explain our project exploring the use of deep brain stimulation in the minimally conscious state. His response has

stayed with me a decade later, “why would you want to do that?” I don’t know why he asked that and can only speculate here that it was reflective of a generational nihilism toward severe brain injury forged by the central place that cases such as *Quinlan* had in the establishment of a right to die.

But what is of concern in an autobiographical reflection, is how I felt when my career goals were summarily dismissed by a leader in my field. In retrospect, I realize how ill prepared I was for the challenge a decade ago from this senior scholar. It could have easily derailed me and it did give me pause. What exactly was I doing with my career? Why had I abandoned a rather favorable career trajectory in ethics and palliative care to pursue a field that still did not have a name?

I had the rather odd sense of *deja vu* recently when Art Caplan, another leader in our field, gave a talk at the November 2017 meeting of the International Neuroethics Society entitled, “Neuromodulation of the Dead, PVS and Minimally Conscious State.” One could give a lecture simply deconstructing the title but time does not permit that.

Suffice it to say that no one is contemplating neuromodulation of the dead, brain dead or otherwise. The implication of such a phrase suggests a rejection of brain death or the embrace of un-nuanced vitalism. For the record, Schiff and I recently wrote an essay asserting the relevance of brain death and contextualizing this diagnosis within the broader frame of disorders of consciousness.³⁶ Second, the scholarly community that writes about disorders of consciousness abjures the use of “PVS” as an abbreviation because it risks a conflation of the persistent and permanent vegetative state. Furthermore, the literature on neuromodulation has been focused on patients in the minimally conscious state, not vegetative patients. I suspect that a recent article in *Current Biology* from scientists in France using vagal nerve stimulation of a patient in the vegetative state prompted this topical inclusion.^{37,38}

Although Caplan had nice things to say about my book, *Rights Come to Mind*, which he had recently reviewed for the Dana Foundation noting “it is a wonderful book; perhaps the best book ever to emerge from the young field of neuroethics,”³⁹ his talk was a conflation of diagnostic categories, differences that make both a scientific and normative difference. My response was that this conflation sought to undermine the legitimate justice claims and rights^{40,41,42,43,44} of patients who were conscious by linking them rhetorically with those who were not. The structure of his argument reminded me of the earlier conversation in the cab ride on Park Avenue.

Despite a decade’s worth of progress in the diagnosis and treatment of these patients,^{45,46} it seemed that skepticism still remained within mainstream bioethics. Brain states that were biologically distinct were still conflated to satisfy preconceptions. It was frustrating, but now not entirely unexpected. But unlike during the cab ride up Park Avenue, this time I did not wither in the face of skepticism or outright opposition to my work. Indeed, I relished the chance to offer a rebuttal.

So as Caplan was finishing, I jumped to the microphone to be first in line for questions so that I could challenge his argument. I was eager to critique his science, his nosology, and his normative stance. But as fate would have it, the moderator did not allow any questions. She said we had to move on because the session had run over. Perhaps that was the case, but I suspect that she knew what was coming and did not want to upend a plenary talk with an academic quarrel. I was disappointed, but now feel grateful that I was spared an unplanned public confrontation.

And here are two lessons for young scholars. First, novel arguments breed disbelief and skepticism. Second, as the late American Senator Daniel Patrick Moynihan once said,^{47,48} “No argument gets settled in one generation.” Taken together, this means that academe resists new ideas, and that it will take time to prevail, if in fact one’s ideas have any merit at all. So strength and persistence are necessary to simply carry on, much less prevail.

One way to persevere is to work collaboratively and in an interdisciplinary manner. If you are part of a team, the possibility for progress expands, and there is diversification of risk. And when others advance in their areas of expertise, your own work can move forward informed by a colleague’s progress. My collaboration with Schiff has been mutually beneficial. By articulating the ethical arguments for proceeding with the research we have done, neuroscience has advanced. And these advances have in turn prompted the need for new ethical analysis and reflection. It has truly been what C.P. Snow might have termed a two culture collaboration^{49,50} and one that has created its own synthesis between the sciences and the humanities.⁵¹ In writing about Snow’s legacy, I believe that he anticipated bioethics as a bridging, or intermediate culture, between the sciences and the humanities.⁵² Our collective work in neuroethics falls squarely in this interdisciplinary tradition, which I believe has tremendous importance to both the integrity of the sciences and the instrumentality of the humanities.^{53,54}

A Finale

Recently I was asked to write another autobiographical piece⁵⁵ and noted that the genre is rather self-indulgent. Now I wonder if I have moved into the season for reflection, an academic finale when reminiscences become a lame substitute for new ideas, an homage to fading creativity. I hope not, and more importantly hope that others don’t see it that way.

My intent here was not to revel in sentimentality but rather to share my past in order to inform the trajectories of other scholars who will confront political challenges and skeptics. These barriers are inevitable, and can either derail or inform. The examples I share, which were quite deflating in the moment, turned out to be revelatory and catalytic. I hope those of you who have read thus far find solace here when you are confronted by disappointment and skepticism. More often than not, these are more preludes than a finale.

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