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Physician Paternalism and Severe Disability: Strengthening Autonomy through Therapeutic Engagement

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Dr. Gill's rehab inpatient, Joel, is a decorated former Navy Seal. By age 35, he had served around the globe for a decade. His military career ended two years later, when he suffered a spinal cord injury from two gunshot wounds to his neck. The injuries left him an incomplete quadriplegic—Joel can eat and swallow and move his arms somewhat, but he cannot use his hands; he has nerve pain and spasticity in his extremities. Three months ago, following his initial surgery and monthlong hospitalization, Joel was sent to Dr. Gill's unit.

During these months, Dr. Gill has kept a close watch on Joel's depression and adaptation to his medical condition. In general, Joel's depression is in line with what any formerly able-bodied—indeed athletic—person would experience in a like situation. Joel has rejected antidepressant medication, however, and has been determined competent to do so. He is not married and did not have a romantic relationship at the time of his injury. On the occasions when some of his friends from the Seals or from college have visited, Dr. Gill has watched Joel enjoy their company and even laugh.

Nevertheless, Joel has said and shown that he does not want to live in his current condition. Lamenting that he is unable to take his own life, he ribbed Dr. Gill, "And I'm sure you're not gonna help me, doc, are you? Even if I did keep your country safe and all that other hero stuff. Right?" Joel has had hospital staff pull up information about spinal cord injuries on the computer that he keeps in his room and has decided that his physical condition is not going to improve. Dr. Gill and the team have shown Joel an Internet support group for people with spinal cord injuries and have told him that, like many of those in the support group, Joel could be discharged from the unit to a handicap-adapted home and could live independently with round-the-clock caregivers to feed him and tend to his other activities of daily living. But Joel does not want to put any friend or family member into that role, so active discharge planning is on hold.

Now Joel has developed acute renal failure from antibiotics he was taking for infected pressure sores. Dr. Gill tells Joel that he must undergo temporary hemodialysis and that he (Dr. Gill) expects that Joel's kidney function will return to normal.

In response, Joel says, "This is the gift I've been waiting for. This kidney failure will kill me, right, doc? I'm going to refuse the hemo-whatever, so send the shrinks in to interview me again. I'm as sane as you are, and I don't want to live like this."

Commentary

Joel's story sounds familiar, doesn't it?

Physically fit, vibrant person in his prime becomes injured in an instant with [insert spinal cord injury, multiple trauma, burns]. Person survives the initial trauma but has extensive physical disability. Person questions whether life is worth living and refuses life-sustaining treatment (or requests some other form of assistance in dying).

This narrative arc keeps us in its grip. It repeatedly scores hits at the box office: *Whose Life Is It Anyway?* (1978 stage play, 1981 movie) and *Million Dollar Baby* (the Academy Award winner in 2005). These stories raise profound questions: what gives life meaning and quality? Who decides? What role should medical professionals play? Is a request for medical assistance in dying a form of assisted suicide?

The case of [Dax Cowart](#) established this paradigm more than 40 years ago [1, 2]. Dax was a returning Vietnam fighter pilot who sustained burns over 68 percent of his body surface area in a freak gas explosion that killed his father. For decades, he waged a public battle against the medical profession for continuing to treat him for ten months following his accident despite his explicit refusal. His case settled what has become the overarching consensus: the competent patient has the right to refuse medical treatment, even life-sustaining treatment. But the devil is in the details.

Was Dax competent (or more specifically, did he have "decision-making capacity," or DMC [3]) immediately after the explosion? At that point, Dax told the farmer who came upon him to get him a gun because he was already a "dead man" [1, 2]. Did he have decision-making capacity in the ER? How about when he was in the ICU, heavily sedated, intubated, and critically ill after innumerable debridements and surgeries? Many clinicians and clinical ethicists would have serious reservations about Dax's ability to make a truly informed decision at this point in the ICU because complex medical and emotional factors (such as his severe pain, the use of narcotics, emotional shock at comprehending the extent of his injuries, and grief over the death of his father) would most likely impede his cognitive and emotional processing.

But at some point Dax did regain capacity. When? Hard to tell exactly. Reasonable people will disagree about the moment in time because there is no bright line. Decisional capacity is not an all-or-none phenomenon [4]. It's a matter of degree. It is also highly likely, indeed commonplace, that people can satisfy the criteria for decisional capacity but be unable to accurately forecast how they will adjust when faced with loss and

adversity. Psychiatrist-ethicist Jodi Halpern, MD, PhD, elegantly deconstructs errors in what is known as “affective forecasting” and why they challenge patients and clinicians who are making serious health decisions in situations such as Dax’s and Joel’s [5]. She describes three mechanisms that seem to underlie forecasting errors: (1) focalism, in which one tends to emphasize factors that will change (or have changed) over those that will remain the same; (2) immune neglect, in which the person fails to take into account that defense mechanisms (such as denial, use of humor) will aid in adapting and coping to lessen unhappiness; and (3) inability to predict genuine adaptation or to recognize that what is valued will likely shift in response to the circumstances and that lost sources of meaning will likely be replaced with new sources.

These psychological mechanisms are *why* we continue to struggle with these cases. It’s no surprise that the recent story of Tim Bowers, the 32-year-old, newly married and expectant father, re-energized and re-engaged the questions teed up by Dax’s case [6]. Tim sustained a cervical spinal cord injury ([SCI]) after falling from a tree while hunting. Within hours of admission,

his family told him they’d asked the doctors to bring him out of a drug-induced coma. They had terrible news—and a horrific question to ask. He had fallen 16 feet as he was climbing to his tree stand, and he had shattered his spine. He likely would spend the rest of his life connected to a breathing machine, unable to walk and never able to hold the baby that Abbey was carrying in her womb. Would he rather be disconnected from the respirator? Tim Bowers, just 32 years old, decided it was his time [6].

He died about 5 hours after the ventilator was withdrawn, a day after sustaining his injury. The question remains for many: was this an act of autonomy, based upon Mr. Bowers’s full informed consent? Or was it “uninformed consent to die,” as argued by Paul Tobin, president and CEO of the United Spinal Association [7]?

Halpern argues that it is extraordinarily difficult to make clear, unequivocal decisions in the face of complex unexpected tragedies [5]. One cannot simply “know” what he or she would want ahead of time and put it in writing because so much relevant information is simply not available beforehand. Indeed, studies show that many people will change their minds about what is tolerable when their conditions change, as Christopher Reeve eloquently describes in his autobiography about life after SCI, *Still Me* [8]. People like Tim Bowers—intubated, sedated, and in an ICU—simply cannot fully comprehend all the necessary relevant information at once, after a single presentation [9]. Furthermore, these decisions are also not made in a vacuum. They are highly interactional. Outcomes can be influenced by how the information is framed and by the perspectives and beliefs of others [10].

So now we are faced with Joel—a decorated Navy Seal, four months after a gunshot wound to the spine, in an inpatient rehab unit with incomplete quadriplegia. He has lived with the knowledge of his SCI for four months. He has moved from acute care to a rehabilitation unit. He can communicate freely, without the impediment of an endotracheal tube. He is also portrayed as stoic, probably depressed, but refusing antidepressant treatment. He questions whether he wants to live with SCI, but initially there is no life-sustaining treatment for him to refuse or remove. But that changes when Joel develops temporary renal failure. Now he needs short-term dialysis. Joel sees a way to facilitate his death: refuse dialysis. So here's the question Dr. Gill has to answer: does Joel have adequate decision-making capacity to refuse dialysis? And, if so, what then?

The short answer is probably *yes*. Unless his depression is severe, Joel probably meets the basic criteria for establishing DMC: he understands his condition, his choices, and the likely consequences of refusing dialysis. But that doesn't mean he is fully competent. There are [reasons](#) the conclusion he has drawn should be challenged. Does he fully appreciate what life with SCI might be like outside of a hospital? I'm not sure. We are told that "Dr. Gill and the team have shown Joel an Internet support group for people with spinal cord injuries" and told him that he "could be discharged from the unit to a handicap-adapted home and could live independently with round-the-clock caregivers to feed him and tend to his other activities of daily living." Joel, however, "does not want to put any friend or family member into that role." Let's look critically at the questions these statements raise and the physician's role.

1. Does Joel understand that a paid personal assistant (PA) is different from a family caregiver? In general, I recommend that patients hire a PA rather than rely on friends or family members when possible. The relationship between the person with the disability and the PA is then a respectful employer-employee one; the patient gets to hire and fire and direct his care. This arrangement also reduces family members' stress, resentment, and role confusion (between, e.g., marriage partner and caregiver roles).
2. Has Joel been on any outings to a restaurant, movie, or sporting event yet?
3. Has he actually met and talked to others living with SCI? Although he is four months into living with SCI, there is still much he doesn't know.

I have come to believe that my most important job as a rehab doctor is not to order consults, tests, medicines, equipment, or therapy. My most important job is to help my patients (and their families) imagine possible narratives for the next chapter of life. That requires curiosity and mental freedom. Patients who are depressed, grieving, or angry may be limited in their ability to imagine possible futures. They need our help to do so.

Thus, my primary goal with Joel would be to encourage him to give himself more time to explore what life is like for others with similar disabilities and life circumstances. He is

really just beginning to learn that he can be self-determining even if he's not physically independent. He needs to see for himself that he can go to school, a faith community, or out to a movie and dinner; re-enter the work force; play adapted sports; and participate in the arts. He needs to learn that he can still fall in love or be a parent—whether he can play ball with his future child or not. He would learn some of this from me and some of it from his nurses and therapists, but much of it he would learn from the real experts—people who live with disabilities themselves. He will need a village to help him at first. Eventually he will be part of that village helping others.

I would remind Joel that a disability such as SCI is a major disruption to one's life narrative, but so are other events such as bankruptcy, unemployment, and the death of a parent, child, or spouse. I would ask him to describe for me what feels intolerable in the here and now. What does he imagine would be intolerable when he thinks about his future? I would explain to him that many people with disabilities initially question whether life will be "worth living," but most do, with time, find that it is [11]. I would explore with him times when he has had to reinvent aspects of himself in the past. We would talk about his demonstrated ability to be resilient. I would want him to know that I believe he can have a life worth living and will be there for the duration to help him.

But, in the end, I would also tell Joel that I [respect his agency](#). I would encourage him to imagine what he thinks would happen if he refuses dialysis. What other decisions would he need to be prepared to make? Would he continue to go to therapy, eat and drink, take his medications? Will he want to go on trips outside of the hospital? See any friends or family? And what if his kidneys recover and he survives without dialysis? How would he feel? My hope would be to keep the lines of communication open, to explore any inconsistencies or feelings of ambivalence Joel may have, and to offer him opportunities to reconsider his decision. And, of course, I would offer him opportunities to talk to mental health professionals, spiritual advisers, and, most importantly, people with SCI who have been where he is now.

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