

Comfort Care as Denial of Personhood

BY WILLIAM J. PEACE

It is 2 a.m. I am very sick. I am not sure how long I have been hospitalized. The last two or three days have been a blur, a parade of procedures and people. I do know it is late at night. The hall lights are off, and the nursing staff ebbs and flows at a glacial pace. I have a very high fever, and my body has been vibrating all day. I am sore. To add to my misery, I have been vomiting for several hours. My primary focus is limited to my stomach. I want to stop vomiting. A variety of medications have been prescribed, but none have relieved my symptoms. While I am truly miserable, I know I am medically stable. I am not in the intensive care unit, and this is good. My main worry is MRSA—methicillin-resistant staphylococcus aureus. MRSA represents a very serious risk for a person who has a large open wound and faces an extended hospitalization. Anyone entering my room needs to put on a full hospital gown, for that person's protection and mine.

I have one thing going for me. As a child, I went through the medical mill. I spent years on neurological wards with morbidly sick kids. I learned how to get good medical care and am socially adept, skilled even, in an institutional setting. I may be sick, but I am not rattled.

The last few days have been rough, though. I had a bloody debridement for a severe, large, and grossly infected stage four wound—the first wound I have had since I was paralyzed in 1978. I know the next six months or longer are going to be exceedingly difficult. I will be bedbound for months, dependent upon others for the first time in my adult life. As these thoughts are coursing through my mind, a physician I have never met and the registered nurse on duty appear at my door. As they put on their gowns I am weary but hopeful. Surely there is something that can be done to stop the vomiting. The physician examines me with the nurse's help. Like many other hospitalists that have examined me, he is coldly efficient. At some point, he asks the nurse to get a new medication.

What transpired after the nurse exited the room has haunted me. Paralyzed me with fear. The hospitalist asked me if I understood the gravity of my condition. Yes, I said, I am well aware of the implications. He grimly told me I would be bedbound for at least six months and most likely a year or more. That there was a good chance the wound would never heal. If this happened, I would never sit in my wheelchair. I would never be able to work again. Not close to done, he told me I was looking at a life of complete and utter dependence. My medical expenses would be staggering. Bankruptcy was not just possible but likely. Insurance would stop covering wound care well before I was healed. Most people with the type of wound I had ended up in a nursing home.

This litany of disaster is all too familiar to me and others with a disability. The scenario laid out happens with shocking regularity to paralyzed people. The hospitalist went on to tell me I was on powerful antibiotics that could cause significant organ damage. My kidneys or liver could fail at any time. He wanted me to know that MRSA was a life-threatening infection particularly because my wound was open, deep, and grossly infected. Many paralyzed people die from such a wound.

His next words were unforgettable. The choice to receive antibiotics was my decision and mine alone. He informed me I had the right to forego any medication, including the lifesaving antibiotics. If I chose not to continue with the current therapy, I could be made very

William J. Peace, "Comfort Care as Denial of Personhood," *Hastings Center Report* 42, no. 4 (2012):14-17. DOI: 10.1002/hast.38

comfortable. I would feel no pain or discomfort at all. Although not explicitly stated, the message was loud and clear. I can help you die peacefully. Clearly death was preferable to nursing home care, unemployment, bankruptcy, and a lifetime in bed. I am not sure exactly what I said or how I said it, but I was emphatic—I wanted to continue treatment, including the antibiotics. I wanted to live.

This exchange took place in 2010. I never told my family or friends about what transpired. I never told the surgeon who supervised my care. I never told the wound care nurses who visited my home when I was bedbound for months on end. I have been silent for many reasons, foremost among them fear. My wound and subsequent recovery shattered my confidence. Thanks to the support of my family, I narrowly avoided the outcome that the physician described, but he was correct in much of what he told me. I was bedbound for nearly a year. Insurance covered few of my expenses. I took a financial bath.

But the underlying emotion I felt during my long and arduous recovery was fear. My fear was based on the knowledge that my existence as a person with a disability was not valued. Many people—the physician I met that fateful night included—assume disability is a fate worse than death. Paralysis does not merely prevent someone from walking but robs a person of his or her dignity. In a visceral and potentially lethal way, that night made me realize I was not a human being but rather a tragic figure. Out of the kindness of the physician's heart, I was being given a chance to end my life.

The fear I felt that night and that gnaws at me to this day is not unusual—many paralyzed people I know are fearful, even though very few express it. Many people with a disability would characterize a hospital as a hostile social environment. Hospitals and diagnostic equipment are often grossly inaccessible. Staff members can be rude, condescending, and unwilling to listen or adapt to any person who falls outside the norm. We people with a disability represent extra work for them. We are a burden. We also need expensive, high-tech equipment that the hospital probably does not own. In my case, a Clinitron bed, which provides air fluidized therapy, had to be rented while I was hospitalized. Complicating matters further is the widespread use of hospitalists—generally an internist who works exclusively in the hospital and directs inpatient care. The hospitalist model of care is undoubtedly efficient and saves hospitals billions of dollars a year. However,

there is a jarring disconnect between inpatient and outpatient care, which can represent a serious risk to people with a disability. My experience certainly demonstrates this, as no physician who knew me would have suggested withholding lifesaving treatment.

The lack of physical access and negative attitudes is a deadly mix that few acknowledge, much less discuss. To be sure, exceptions exist. Last year, James D. McGaughey, executive director of Connecticut's Office of Protection and Advocacy for Persons with Disabilities, wrote in an affidavit in the assisted suicide case *Blick v. Division of Criminal Justice*:

During my service at the Office of Protection and Advocacy for Persons with Disabilities, the agency has represented individuals with significant disabilities who faced the prospect of, or actually experienced discriminatory denial of beneficial, life-sustaining medical treatment. In most such cases physicians or others involved in treatment decisions did not understand or appreciate the prospects of people with disabilities to live good quality lives, and their decisions and recommendations sometimes reflected confusion concerning the distinction between terminal illness and disability. In a number of those cases, despite the fact that the individuals with disabilities were not dying,

decisions had been made to institute Do Not Resuscitate orders, to withhold or withdraw nutrition and hydration, to withhold or withdraw medication or to not pursue various beneficial medical procedures. In my experience, people with significant disabilities are at risk of having presumptions about the quality of their lives influence the way medical providers, including physicians, respond to them.

Disability memoirs often contain stories that recount blatant discrimination by physicians and other health care workers. Few, however, are willing to write about being offered a way to die. I suspect this is because the experience is deeply unsettling, if not horrifying. It is the ultimate insult. A highly educated person who should be free of bias and bigotry deems your very existence, your life, unworthy of living. Jackie Leach Scully has called this nonverbalized bias "disablism." She writes, "People who are nonconsciously or unconsciously disablism do not recognize themselves as in any way discriminatory; their disablism is often unintentional, and persists through unexamined, lingering cultural stereotypes

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about disabled lives.” People with a disability cannot escape such stereotyping within the power structure of the American health care system. Examples of bias abound. For instance, in the searing memoir *Too Late to Die Young*, Harriet McBryde Johnson recounts how medical personnel would not listen to her after she was hospitalized for a fall out of her wheelchair. She explained that she was sensitive to pain medication, but her explanation was completely ignored. Medical personnel then oversedated her to the point that she was no longer lucid, and her personal care attendant was forced to intervene. Upon learning that she was a well-respected lawyer with her own practice, though, the same people suddenly treated her like a professional peer. The contrast in care was stark. The bias McBryde Johnson wrote about is commonplace. It is one reason why I never meet a physician without having a proper introduction. The introduction is not about my health care, but rather to establish my credibility as a human being.

Other people with a disability have been offered the same permanent solution to their perceived suffering that I was. The first chapter of Kenny Fries’s thought-provoking book, *The History of My Shoes and the Evolution of Darwin’s Theory*, is about a medical review required by Social Security. In this routine visit, a physician Fries never met is taken aback by his condition. The physician mutters to himself, amazed and disconcerted. When he is leaving, he “pauses at the door, then he turns back to me and says: ‘I shouldn’t say this to you, but if you ever need medication, you let me know.’” Could the physician simply have been offering to prescribe medication for pain relief? When Fries arrived home later in the day, the meaning of the physician’s words struck home. “I knew what he was offering, the help he couldn’t ever voice out loud. The medication was not for pain but in case I decide that the pain is too much and I do not want to survive. Survival of the fittest . . . His reaction was based on his misunderstanding of what it means to survive in an often inhospitable world.”

Misunderstanding! This misunderstanding infuriates me and is a threat to my life. Why is it we rally around people with a disability who want to die? Society embraces their dignity and autonomy. They are applauded. These people have character! These people are brave! This is an old story, a deeply ingrained stereotype that is not questioned. We admire people with a disability who want to die, and we shake our collective heads in confusion at those who want to live. This mentality plays itself out in popular culture. Hollywood

produces films such as *Million Dollar Baby* that receive accolades (in fact, *Million Dollar Baby* won 2004’s Academy Award for best picture, among other awards). I was stunned not by the film but the audience reaction. When I saw it in the theater, the audience cheered when Maggie—quadriplegic, afflicted with bedsores, and having lost a limb to infection (the latter being an exceedingly rare complication among paralyzed people)—was killed.

Real-life cases abound. Jack Kevorkian eluded being convicted even though he killed people who were disabled and not terminally ill. In 1990, a Georgia court ruled that thirty-four-year-old Larry MacAfee, a quadriplegic who was not terminally ill, had the right to disconnect himself from his respirator and die. The court declared that MacAfee’s desire to die outweighed the state’s interest in preservation of life and in preventing suicide, thereby upholding his right to assistance in dying. Just the year before, another man, David Rivlin, also sought court intervention in his wish to die. Unlike MacAfee, who changed his mind after receiving support from the disability community, Rivlin utilized court-sanctioned, physician-assisted suicide. In 2010, Dan Crews expressed a desire to die because he feared life in a nursing home, and he asked to be disconnected from his respirator. In 2011, Christine Symanski, a quadriplegic, starved herself to death. I could cite many other examples, but the common theme remains the same—people with a disability who publicly express a desire to die rather than live become media darlings. They get complete and total support in their quest.

Ironically, who is discriminated against? Those people with a disability who choose to live. We face a great challenge in that society refuses to provide the necessary social supports that would empower us to live rich, full, and productive lives. This makes no sense to me. It is also downright dangerous in a medical system that is privatized and supposedly “patient-centered”—buzzwords I often heard in the hospital. It made me wonder, how do physicians perceive “patient-centered” care? Is it possible that patient-centered health care would allow, justify, and encourage paralyzed people to die? Is patient-centered care a euphemism that makes people in the health care system feel better? When hospitalized, not once did I feel well cared for. All I felt was fear, for when it comes to disability, fear is a major variable. I fear the total institutions Erving Goffman wrote about—places where a group of people are cut off from the wider community for extended periods of

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time, and every aspect of their lives is controlled by administrators (nursing homes, prisons, hospitals, rehabilitation centers). I do not fear further disability, pain, or even death itself. I fear strangers—the highly educated men and women who populate institutions nationwide.

What I experienced in the hospital was a microcosm of a much larger social problem. Simply put, my disabled body is not normal. We are well equipped to deal with normal bodies. Efficient protocols exist within institutions, and the presence of a disabled body creates havoc. Before I utter one word or am examined by a physician, it is obvious that my presence is a problem. Sitting in my wheelchair, I am a living symbol of all that can go wrong with a body and of the limits of medical science to correct it.

In the estimation of many within the field of disability studies, the idea of normal or the mainstream is itself destructive. The poet Stephen Kuusisto has written that “the mainstream is one of the great, tragic ideas of our time. There is no mainstream. No one is physically solid, reliable, capable as a solo act, protected against catastrophe; there is only the stream in which each one of us must work to find solace in meaning.” This leads me to ask, Who decides what is normal or mainstream? Certainly not people with a disability. When I see a disabled body, I see potential, adaptation, and the very best that humanity has to offer. As one who has not been seen as normal for over thirty years, I know that the power to define what is normal rests with “the normate,” to use Rose Marie Garland-Thomsen’s awkward phrase. The normates define and control what it means to be different. They dictate not only what is healthy but also how ill health is treated.

This is where disability studies has much to offer. In fact, the mere presence of people with disabilities is valuable. Our bodies have been medicalized. Why is the disabled body so objectionable? What are the practical and theoretical implications of the rejection of the disabled body? If those working within the health care industry were smart, they would listen to what people with disabilities have to say.

Reflections from a Troubled Stream: *Giubilini and Minerva on “After-Birth Abortion”*

BY MICHAEL HAUSKELLER

But when a creature pretending to reason, could be capable of such Enormities, he dreaded lest the Corruption of that Faculty might be worse than Brutality itself. He seemed therefore confident, that instead of Reason, we were only possessed of some Quality fitted to increase our natural Vices; as the Reflection from a troubled Stream returns the Image of an ill-shapen Body, not only larger, but more distorted.

—Jonathan Swift, *Gulliver’s Travels*

When Jonathan Swift published “A Modest Proposal for Preventing the Children of Poor People of Being a Burden on their Country or Parents, and for Making Them Beneficial to the Publick” in 1729, many early readers were shocked and repulsed by the author’s seemingly sincere suggestion to conquer poverty in Ireland by allowing and encouraging the Irish poor to sell their infant children as delicacies to rich English land owners. The author’s elaborate demonstration that such a practice, if widely accepted, would benefit everyone and harm no one, did not make the whole proposal appear any less monstrous. Most people felt—as they would still today—that it simply didn’t matter how *rational* it may be, treating babies as gastronomic resources, destined to be killed and served at the tables of the rich, is about as immoral as it can get. Swift knew this, too, of course, and his “Modest Proposal” was in fact a satire intended to draw attention to the unashamed exploitation of the Irish poor and to the essential heartlessness of a particular kind of economic

Michael Hauskeller, “Reflections from a Troubled Stream: Giubilini and Minerva on ‘After-Birth Abortion,’” *Hastings Center Report* 42, no. 4 (2012): 17–20. DOI: 10.1002/hast.53