

Recognizing Death while Affirming Life: Can End of Life Reform Uphold a Disabled Person's Interest in Continued Life?

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Early in 2005, a real-life drama and two acclaimed films engaged the nation in discussions of issues that had been a staple of the end of life field for over twenty-five years. Terri Schiavo's medical condition resembled that of Nancy Cruzan, whose family had succeeded in convincing the United States Supreme Court to remove her feeding tube. Hollywood's *Million Dollar Baby* and Spain's *The Sea Inside* reminded many of the Broadway play and movie, *Whose Life Is It Anyway*, in which a sculptor, like the boxer and the diver of the contemporary films, chose death over life with disability. The powerful reactions to these motion pictures, the controversy over the Schiavo case, and, in Boston, a public dispute between a leading hospital and a patient's family over the withdrawal of life support, underscore our urgent need to reform how Americans deal with life-prolonging or life-ending decisions.

Sometimes the media, the public, and professionals in end of life treatment and policy frame the debate in terms of "quality of life" versus "sanctity of life," but this casting oversimplifies the story and neglects critiques from people who share many values espoused by the end of life movement but nonetheless oppose some views that pervade the field. A sensitive decision-making process and sound conclusions demand weighing several factors: what gives life meaning and value for a particular individual; what circumstances or setting would permit the ill, disabled, or dying patient to derive comfort and fulfillment in existing relationships, experiences, or activities; whether a presumed decision-maker should ever be replaced by another person in the patient's life; and whether any factors other than patient and family preferences should influence life-ending decisions.

Evolving Views of End of Life and Disability

In the years since the 1976 case of Karen Ann Quinlan, much greater weight has been given, both in law and the culture at large, to informed consent; to the experiences, views, and needs of patients and families in the medical encounter; to respect for patient autonomy and family decision-making; and to the quality, not merely the preservation, of an individual's life. These beliefs have meshed well with the efforts of feminists and other marginalized groups to equalize the power relations between doctor and patient, and they have also supported twenty-first century cultural norms of self-fulfillment, self-determination, and control over one's destiny. These ideals should have promoted an alliance between end of life reform, the emerging scholarship of disability studies, and the movement for disability rights and equality. Unfortunately, many scholars and practicing health care professionals have failed to grasp crucial insights of disability scholars or activists. Despite the common cause of disability scholars and activists with those in the end of life movement around maximizing self-determination and giving more respect and authority to patients in their encounters with medicine, the end of life movement has sharply differed with disability theorists and activists in understanding how illness and impairment affect quality of life.

Thanks to the sustained efforts of scholars, clinicians, and grassroots citizen groups like Compassion in Dying, both clinical practice and case law recognize that ill or dying patients and their intimates often are concerned about their experiences and relationships during whatever time they have left to live, not merely with how long they might be maintained by medications, feeding tubes, and breathing machines. Disability activist and lobbying groups such as Not Dead Yet or Americans Disabled for Attendant Programs Today (ADAPT) also espouse the goals of creating and maintaining opportunities for ill, disabled, or dying people to enjoy fulfilling, meaningful relationships, activities, and experiences for however much time they will live. Compassion in Dying and Not Dead Yet differ in their policy and practice goals for two reasons: they focus on different kinds of paradigm cases, and

they have profoundly different understandings of how illness and disability affect life's meaning and rewards. The typical case for the misnamed "right to die" movement is an elderly man or woman in the final stages of an inevitably terminal illness, who will soon die regardless of how much medical treatment is invested in his or her last days or weeks. The case that fuels the disability rights movement is that of a relatively young person with a disability, who could live for several years with the condition, but who instead asks to die—as in *Million Dollar Baby*, and as in many real-life cases.

Although mainstream reformers have criticized the way professionals often dealt with patients and their families, the mainstream has too often accepted medicine's view that illness and disability inevitably diminish life's quality. In contrast, disability theorists and activists point to research demonstrating that people with physical, sensory, and cognitive impairments can and do obtain many satisfactions and rewards in their lives. When people with illness and disability report dissatisfaction and unhappiness, they link their distress not to physical pain or to reliance on medications, dialysis, or ventilators, but to those factors that also trouble nondisabled people—problematic relationships, fears about financial security, or difficulties in playing a valued work or other social role. Disability theorists and activists endorse the growth of hospice, palliative care, pain relief, and greater attention to the psychological and social needs of patients and their loved ones; however, they argue that endorsing treatment withdrawal from people simply because their health or their capacities are impaired undermines the goals of human dignity, patient self-respect, and quality of life. Such goals are best achieved by helping people discover that changed health status and even impaired cognition need not rob life of its value. Respect for self-determination and human dignity entails a commitment to fostering the activities, experiences, and relationships that enrich an individual's life by finding techniques and resources to use those capacities that remain. In the case of Elizabeth Bouvia, a woman disabled by cerebral palsy and painful arthritis who sought aid in dying, the California Court of Appeals supported her request to end her life by focusing on her limitations, pointing to her physical immobility and her need for assistance with tasks like eating and toileting. Although the court described her as "alert" and "feisty," it also characterized her as "subject to the ignominy, embarrassment, humiliation and dehumanizing aspects created by her helplessness." The 1996 court decision that supported physician-assisted suicide in *Washington v. Glucksberg* was filled with similar portrayals of life with impairment: it referred to people who are in a "childlike state" of helplessness, as exemplified by physical immobility or by their use of diapers to deal with incontinence.

The disability critics of the California court decision revealed an entirely different side to the Elizabeth Bouvia story. They focused on her remaining capacities and on the social and economic problems that contributed to her isolation and depression. Educational discrimination had prevented her from using her mind; she had been denied the full amount of personal assistance services that would have enabled her to stay in the community; and her depression, which stemmed from serious family problems, would have been immediately treated in a nondisabled person who had attempted suicide.

Many of the disability theorists and activists who protested the court decisions in the Bouvia case—and in the similar Michigan case of David Rivlin, who became quadriplegic and sought death rather than remaining in a nursing home—have very similar physical conditions but entirely different life circumstances. By recruiting paid or volunteer personal assistants, they live in their own homes by themselves or with family and friends. They are in the community, not in institutions. They hold jobs, engage volunteer activities, visit friends, go out to dinner or the movies, and generally participate in ordinary family, civic, and social life. Wheelchairs do not confine; they liberate. Voice synthesizers aid communication for people who can no longer speak. Diapers or catheters are akin to eyeglasses. Using the services and skills of a personal assistant who helps them get into and out of bed, eat their meals, or travel to their next appointment is no more shameful or embarrassing than it is for a nondisabled person to work closely with an administrative assistant or to value the expertise of a mechanic, plumber, or the magician who restores data after a computer crash.

Fortunately, some respected mainstream scholars have acknowledged that societal tolerance of death for people who could live for months or years with disabilities stems from misunderstanding, fear, and prejudice. Excerpts from one clinician-philosopher's recent reflections demonstrate a new receptivity to the disability critique of typical end of life practice and policy.

I am now embarrassed to realize how limited was the basis on which I made my decisions about David Rivlin. . . . [T]here was no medical need for Rivlin to be effectively incarcerated in a nursing home. If Rivlin had been given access to a reasonable amount of community resources, of the sort that other persons with disabilities were making use of at the time, he could have been moved out of the nursing home and probably could have had his own apartment. He could have been much more able to see friends, get outside a bit, and generally have a much more interesting and stimulating life. . . . If we look at a case one way, it seems that the problem is the person's physical disability. If we shift our view, we realize that the problem is not the disability, but rather the refusal of society to make reasonable and not terribly expensive accommodations to it.²

In his 1979 book *Taking Care of Strangers*, Robert Burt exposed the common discomfort of health care professionals in the presence of patients with very significant impairments: "Rules governing doctor-patient relations must rest on the premise that anyone's wish to help a desperately pained, apparently helpless person is intertwined with a wish to hurt that person, to obliterate him from sight." Speaking of a burned and very disfigured patient, Burt contended: "He is a painful, insistent reminder to others of their frailty, an acknowledgement that, in the routine of everyday life, is ordinarily suppressed. Others cannot avoid wishing that he, and his unwanted lesson, would go away. He cannot avoid knowing this of others and wishing it for himself."

Toward Further Change

These insights should prompt clinicians and policymakers to question how truly autonomous is anyone's wish to die when living with changed, feared, and uncertain physical impairments that lead to anguish and to interpersonal struggles with the very professionals, family members, and friends who are assumed to be supports in a time of trouble. The spirit of such observations illustrates the danger of relying on a simple notion of patient autonomy when deciding to withdraw life-sustaining treatment.

Consider this case from the end of life literature, reported by M. Edwards and Susan Tolle: Their patient—conscious, alert, with mobility impairments that had lasted for forty years—had recently developed breathing problems that necessitated use of a ventilator, which rendered him unable to speak. Finding this increased disability intolerable, he sought death, and family, professionals, and the hospital ethics committee concurred with his autonomous wish. Edwards and Tolle proposed a seven-step procedure to assure themselves that such an aided death is acceptable. Absent from their analysis is any exposure to or contact with people who have more than two weeks of experience living as ventilator users. The case description provides no information on how effectively this patient was communicating (whether by writing, pointing to letters and words, or using a communication technology). It contains no information about whether this man's decision was affected by concerns over how his relationships with family and friends might be changed by his different means of communication. Presumably these clinicians knew that nonvocal but conscious and responsive individuals have been able to interact in family and work settings. One wonders why these clinicians did not urge such means upon this patient before acceding to his pleas for death rather than life without speech. He may have been psychologically abandoned by his family and clinicians when he most needed their energy, resourcefulness, and imagination to help him devise a new way to express himself.

The most recent report on the workings of Oregon's law on physician-assisted suicide offers yet another illustration of social rather than medical issues at work in requests for assisted dying. The most frequently cited reasons for seeking to die stemmed from loss of enjoyable activities, loss of autonomy, and loss of dignity. Yet these were mentally alert individuals who should have been aided by professionals and their own social networks to discern that autonomy and dignity can reside in self-expression, in determining what activities to pursue, and in obtaining the assistance to undertake them. This reframing of autonomy and dignity is urgently necessary as a way to restore self-respect and pride to people who feel shame at needing physical or emotional help from those around them. Have they lost their own ability to provide love, support, friendship, and guidance to their families and friends, and if so, what professional psychological help might let them regain those capacities? Or have they lost their connections to the social world, and so been denied a way to give and to receive help and support?

For people living with disabilities, the data on Oregon's assisted suicides provokes concern. One can respect individual choice but worry that the Oregon data, like the case involving ventilator withdrawal, graphically support Burt's reflections on the ambivalence of health care professionals and families toward people with significant disability. When these data reveal that fear of burdening others is of much greater concern to patients who seek suicide than concerns about finances or physical pain, then how can professionals and families know that the supposedly autonomous wish to end life is not a response to a patient's deep fear that she has become disliked, distasteful to, and resented by the very people from whom she seeks expertise, physical help, and emotional support? And when we learn that divorced and never-married individuals are twice as likely as married or widowed people to use physician-assisted suicide, we must ponder whether a single dying person feels especially alone and abandoned. It is probably the rare friend who has the time, energy, or willingness to make a sustained, reliable, and deep commitment to live through another's illness and death. Once the severely disabled, ill, or dying person is seen as "other"—as different, not quite in the human and moral community, even past friendship and familial bonds—social bonds can diminish. To anyone with the capacity to perceive the difference between warmth, toleration, and coldness in how he or she is treated by others, the thought of days, months, or years of life subject to resentful, dutyfilled physical ministrations may be a fate worse than death, akin to imprisonment and solitary confinement. What needs to change is not the patient's physical or cognitive situation, but the emotional and interpersonal environment; that environment can change only when professionals lead the way to supporting the capacities and thereby affirming the humanity of severely ill and imminently dying people.

Once we have understood the disability community's concerns about cases involving alert people with physical, but not cognitive and affective disabilities, we can better understand the reaction to the unfortunate case of Terri Schiavo. By the time her husband sought to withdraw her feeding tube, all the medical experts were certain that she had not even minimal cognitive capacity or consciousness. Schiavo's supporters in the disability community were almost certainly mistaken about her potential for interaction or responsiveness, and they may have done damage to their efforts to join with others seeking to reform treatment of disabled or dying people. Yet the apprehension in the disability community, apprehension about societal indifference and neglect, is more understandable after reviewing a few of the many instances in which law, medicine, bioethics, and government programs failed to help traumatically disabled patients discover the financial, technological, social, and psychological resources that could sustain them and provide the opportunity for rewarding life. When people with relatively intact cognitive and emotional capacities are neglected, neglect is even more likely for those with greatly diminished cognitive and emotional function.

Although the intense court reviews of Schiavo's situation consistently confirmed her PVS diagnosis, professional literature contains scattered information on patients who were misdiagnosed as being in that state and were consequently denied rehabilitation and treatment from which they might have benefited. Some misdiagnosed patients have limited ability to respond meaningfully to others;

this diagnostic error cost such patients between one and four years of interaction with people and the world around them. It is rare for courts or scholars to champion continued treatment for cognitively impaired people who might still enjoy some level of life satisfaction and human interaction.³

The disability equality perspective on end of life and treatment withdrawal cases described here should demonstrate that the alliance of disability studies and disability rights with the evangelical religious groups is more apparent than real. Disability critics of much health care practice share more with end of life reformers who seek to promote an emphasis on respect for the dignity and capacities of people facing illness, disability, and death. Like these reformers, they seek the means for maintaining dignity and capacity; the aptly named Not Dead Yet strives to convince people with disabilities, their families, and their health care providers that people can still find satisfaction and quality in their lives. The president of Not Dead Yet clearly articulated the ways in which disability opposition to life-ending decisions is truly a quest for quality, rather than sanctity, of life:

The far right wants to kill us slowly and painfully by cutting the things we need to live, health care, public housing and transportation, etc. The far left wants to kill us quickly and call it compassion, while also saving money for others perhaps deemed more worthy.

[W]e also have an attitude about disability that diverges from the mainstream. . . . Frankly, I think that's why we were deliberately excluded from the last decade of policy making conducted off the public radar screen, why the right-wing-left-wing script was so important . . . no matter how untrue and exclusionary.⁴

These comments lead to a case with disturbing implications for mainstream discussions of patient autonomy, family decision-making, and professional obligation. Barbara Howe, a seventy-nine-year-old woman with amyotrophic lateral sclerosis, using a ventilator, was being treated at Boston's Massachusetts General Hospital. Howe's daughters and grandchildren visited her consistently. Howe had indicated that she wished to stay alive as long as she could appreciate family visits and had named one of her daughters to serve as health care proxy. In March of 2005 she was thought to be conscious and alert but was unable to speak or to show responses through any facial or bodily movements. Yet the hospital sought to remove Howe's daughter as her health care proxy and to discontinue ventilator support. After legal wrangling, a reportedly reluctant daughter agreed that ventilatory support could be withdrawn on June 30 (Ms. Howe died while still on ventilatory support before that date).

Although the details of Howe's case are not yet and may never become public record, the published reports give considerable basis for concern. If case law and mainstream end of life practice are to continue their adherence to patient autonomy, health care proxy decision-making, and rights to receive as well as rights to forego life-sustaining treatment, they should question the basis on which the hospital staff sought to end treatment in the face of expressed wishes of patient and family to continue that treatment. On what basis did staff feel that the treatment was inhumane since the patient had requested that she be kept alive regardless of pain if she was appreciating her family's visits? Did the hospital staff have reason to believe that it knew the patient better than did her family because the staff was with her for many more hours every day? Was the staff experiencing the kind of pain and ambivalence Burt describes in the presence of a conscious yet unexpressive woman with complete physical paralysis? Did the hospital, like the hospital in the 1991 case of Helga Wanglie, believe that continuing to provide expensive treatment no longer served either the patient or the public good? Was stewardship of resources an unstated but serious concern, and should it become a legitimate public concern? If end of life practice and law answer yes, as they well may need to do, the field will have to rethink its almost unquestioned championing of patient autonomy and family decision-making if those autonomous or proxy decisions are to maintain, rather than to forego, expensive life-sustaining treatment.

The stories of Helga Wanglie and Barbara Howe clearly reveal the need for end of life reform to re-examine the possibility of setting limits to its own commitments to patient autonomy or family

decision-making in the face of public resource constraints. This issue could lead to even more division between the mainstream end of life field and the disability theorists and activists who seek both a shift in an understanding of “quality of life” and a distribution of resources to individuals who need physical, medical, and social support to maintain a life with dignity and meaning.

Next Steps

This largely absent disability perspective could profitably enliven the world of end of life reform. The post-Schiavo reaction, with its renewed calls for advance directives for all Medicare patients, should encourage bioethicists to redesign the current forms, which ask people only about which interventions they do and do not want. Instead, the forms should describe the various medical scenarios that might occur in certain situations and encourage people to consider what they would or would not want done in each instance. Which physical and cognitive capacities can they imagine losing and still find life rewarding? What activities do they envision as essential for life satisfaction? These educational documents should help people imagine not only what physical changes may occur, but also what social, technological, and financial resources they might require to maintain themselves after the onset of serious illness and disability. Recognizing how difficult it is for anyone to project herself into a radically different situation, the end of life field has moved away from advance directives and instead endorsed family decision-making and health care proxies. Indeed, many families will accurately gauge their loved one’s desires, whether for continuing or ending life-sustaining treatment; nonetheless, widespread discomfort in the face of physical and cognitive changes in a spouse, parent, sibling, or friend suggest that even intimates may fail to appreciate the rewards and satisfactions remaining in their loved one’s life. I would therefore suggest that revamped advance directives and drastically revised educational materials continue to be indispensable in helping us out of the end of life care morass.

End of life reform and society generally have never successfully confronted the rationing question; neither has the disability rights movement or the field of disability studies. Groups like Not Dead Yet bring an invaluable perspective on disability to end of life conversation, and they need to be sought out as we search for progress in reforming end of life practice. Activists from Not Dead Yet and ADAPT, as well as disability scholars from philosophy, psychology, health economics, and other disciplines, need to participate regularly in the mainstream conversation; they need to help determine criteria for allocating national resources among all the many health, disability rights, environmental, and social justice problems we face. They also need to be recruited for hospital and hospice ethics committees, and they need to train physicians, nurses, and social workers in new ways of understanding life with disability. The events of this year demonstrate how desperately the disability perspective needs to become part of the conversation rather than being excluded from it.

At the end of life, facing decline and death, these “disability issues” are issues for everyone—learning how to affirm and celebrate what gives life meaning and simultaneously acknowledge loss of capacity and eventually loss of life itself.

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¹ Adrienne Asch, “Recognizing Death while Affirming Life: Can End of Life Reform Uphold a Disabled Person’s Interest in Continued Life?” *Improving End of Life Care: Why Has It Been So Difficult?* Hastings Center Report Special Report 35, no. 6 (2005): S31-S36.

² H. Brody, “Bioethicist’s Apology,” *Health*, October 6, 2004: 6.

³ Exceptions are R.S. Dresser and J.A. Robertson, "Quality of Life and Non-Treatment Decisions for Incompetent Patients," *Law, Medicine and Health Care* 17 (1989): 234-44, and *In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64, 438 N.Y.S.2d 266 (1981).

⁴ D. Coleman, testimony before the Subcommittee on Criminal Justice, Drug Policy and Human Resources of the Committee on Government Reform of the U.S. House of Representatives, *Oversight Hearing on Federal Health Programs and Those Who Cannot Care for Themselves: What Are Their Rights, and Our Responsibilities?* April 19, 2005.