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DEPRESSION IN THE CONTEXT OF DISABILITY AND THE "RIGHT TO DIE"

ABSTRACT. Arguments in favor of legalized assisted suicide often center on issues of personal privacy and freedom of choice over one's body. Many disability advocates assert, however, that autonomy arguments neglect the complex sociopolitical determinants of despair for people with disabilities. Specifically, they argue that social approval of suicide for individuals with irreversible conditions is discriminatory and that relaxing restrictions on assisted suicide would jeopardize, not advance, the freedom of persons with disabilities to direct the lives they choose. This paper examines the idea promoted by some proponents of assisted suicide that it is reasonable to be depressed about one's diminished quality of life in cases of irreversible illness or disability and, therefore, such depression should not call into question the individual's competence to request assistance in dying. The concept of rational depression is defined and examined in the context of: four real-life cases involving individuals with disabilities who requested assistance in dying; a set of criteria commonly applied to decision-making to determine rationality; and research bearing on the emotional status of people with disabilities. It is concluded that although disability is associated with particular socially mediated stressors, there is no theoretical or empirical evidence to indicate that depression and its role in the "right to die" is dynamically different, more natural, or more reasonable for disabled people than for non-disabled people.

KEY WORDS: assisted dying, assisted suicide, competence, depression, disability, medical decision-making, quality of life, rational suicide, right to die

INTRODUCTION

Recently, I was asked to present my disability research before a group of advocates with disabilities. One man listened intently as I told of developing training materials for health professionals focusing on the health issues of persons with disabilities. When I had finished my presentation, he was the first to offer feedback. Because he had cerebral palsy and his speaking style was difficult for new acquaintances to understand, he patiently waited for his personal assistant to translate each phrase. "Tell the health professionals why people with disabilities get depressed and suicidal," he urged. "Tell them about institutions. Let them know the real reasons people with disabilities give up."



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I knew him by reputation. Born in an impoverished rural family, undereducated and institutionalized for much of his life, he had waged a long battle to direct his own life and had become a nationally respected disability rights activist. In his fight to establish accessible public transportation, he had committed civil disobedience by placing his wheelchair and his body in the pathway of public buses. He was equally impassioned in his support of policies that would provide in-home services for persons with disabilities in lieu of forced nursing home placement.

"Are you asking me to make sure health professionals know that oppression leads to depression?" I asked. He nodded vigorously, his eyes expressing relief that I had grasped the social and political weight of his concerns.

The struggle for equal citizenship, for basic self-determination, and even for survival is ongoing for Americans with disabilities. That struggle provides an illuminating context for examining "right to die" issues for people with disabilities. Although arguments to legalize assisted suicide, for example, often center on issues of personal privacy and freedom of choice over one's body, many disability advocates assert that assisted suicide is a political issue as much as a personal one. They believe its legalization would jeopardize, not advance, the freedom of persons with disabilities to direct the lives they choose.¹

As expressed by the man commenting on my research, disability activists who oppose legalization fear that the sources of disabled people's despair are often misattributed to their bodies rather than to their social circumstances.² They denounce society's willingness to facilitate dying in persons with disabilities and other irreversible conditions rather than offering suicide intervention or addressing the remediable social problems underlying the death wish, such as poverty, institutionalization, isolation, and lack of meaningful social roles.

THE PLACE OF DISABILITY AND CHRONIC ILLNESS IN THE RIGHT TO DIE DEBATE

The place of disability in the debate over legalizing assisted dying is not always clear. News stories often discuss legalization as relevant exclusively to individuals in the final stages of terminal illnesses, the so-called "hopeless" cases. Over the past decade, however, the definitional boundaries of "hopelessness" and, correspondingly, the parameters of

candidacy for assistance in dying under proposed statutes have expanded to include persons with incurable chronic illnesses and disabilities. Both the philosophy and practice of assisted suicide reflect this expansion.³ For example, Derek Humphry in his book, *Final Exit*, argues philosophically for the progressive expansion of candidacy for assisted suicide (from terminally ill to disabled individuals):

What can those of us who sympathize with a justified suicide by a handicapped person do to help?...When we have statutes on the books permitting lawful physician aid-in-dying for the terminally ill, I believe that along with this reform there will come a more tolerant attitude to the other exceptional cases.⁴

Similarly, when she was president of the Hemlock Society, Faye Girsh called for more public tolerance of euthanasia in cases of chronic conditions:

A judicial determination should be made when it is necessary to hasten the death of an individual whether it be a demented parent, a suffering, severely disable [sic] spouse or a child...As life expectancy increases, chronic diseases proliferate and medical science can lengthen life almost indefinitely. We must find ways to provide help to people who wish to hasten the dying process.⁵

Palliative care physician Timothy Quill, often described as a moderate and cautious proponent of legalization, has included persons with non-terminal multiple sclerosis as potential recipients of physician assisted suicide.⁶ The frequently cited Harvard Model Act, a model statute for legalized assisted suicide, explicitly includes persons with irreversible but non-terminal conditions.⁷

Moreover, where assisted suicide has been documented as actually taking place, persons with disabilities commonly are recipients. A review of cases linked to Jack Kevorkian, for example, reveals that many involved non-terminal disabilities such as spinal cord quadriplegia, multiple sclerosis, pain disorders, and chronic fatigue syndrome.⁸ In the Netherlands where the courts have permitted physicians to practice assisted suicide and active euthanasia in accordance with guidelines for two decades, persons with non-terminal physical and mental disabilities have been helped to die.⁹

FOUR ILLUSTRATIVE CASES: BOUVIA, BERGSTEDT, RIVLIN, AND McAFEE

The organized disability community opposition to the right to die movement was sparked by four well-publicized cases involving

persons with disabilities who requested assistance to die: Bouvia, Bergstedt, Rivlin, and McAfee. Although technically involving treatment refusal or withdrawal rather than active suicide assistance, these cases usefully illustrate many of the points made by the disability opposition to legalized assisted dying.

Elizabeth Bouvia was born with cerebral palsy and was placed in an institution after her parents divorced.¹⁰ She was bright, attractive, and determined to direct her own life. At age 18, she left the institution to live on her own and went on to graduate from college, planning to become a social worker. She experienced significant barriers along the way, however, including poverty, wrangles with government assistance programs, job discrimination, and personal stresses. Occasionally she fell into depression and even made suicide attempts involving substance abuse but would resurface to resume her life. In her early twenties, however, her difficulties intensified. She fell in love with a prisoner and married him upon his release. In rapid succession, she lost her brother in an accident, dropped out of graduate school, and had a miscarriage. After a period of poverty and homelessness, her marriage foundered. Within weeks of her marital break-up, Bouvia checked herself into a hospital complaining of joint pain and requesting medication. Once admitted, she announced her intention to die by refusing to eat while comforted by narcotics.

When her physicians attempted to provide suicide intervention through psychiatric treatment and tube feedings, Bouvia consulted attorneys and initiated a long precedent-setting court battle for her "right to die." Although she told newspaper reporters that she was tired of "the struggle to live within the system,"¹¹ her attorneys argued that her disability had diminished her quality of life to a level that validated her decision to die. Disability rights activists were incensed to hear Ms. Bouvia described as helpless and hopeless. Many found it hard to believe that a 26-year-old person with a congenital disability could be suddenly hopelessly debilitated when just months earlier, she had been a vibrant young newlywed expecting a child. Several had attended a conference presentation at which Bouvia's attending physician conceded that there was, in fact, no conclusive medical evidence of the joint degeneration she reported having.¹² In view of the facts, the activists charged that it was discriminatory to offer her any less suicide prevention than would be offered to a non-disabled person who had experienced a similar spate of overwhelming life stresses and losses. Although ultimately successful in her quest for court approval of her starvation, Bouvia has not yet

acted on it. Unfortunately, however, she has become bed-bound and dependent on morphine. Now in her forties and living again in her own apartment with assistance, she is viewed by many in the disability community as a victim of both disability prejudice and the ambitions of the right to die campaign.

Kenneth Bergstedt led a house-bound existence after acquiring quadriplegia in childhood.¹³ Following his mother's death, his father became his primary caregiver. By all accounts, the family knew little about resources available to assist people with disabilities to go to school, hold jobs, and live in the community. When his father developed a terminal illness, thirty-one year-old Bergstedt anticipated losing his only source of care. Fearing institutionalization, he petitioned the court to allow his father to disconnect his ventilator. A psychiatrist found him to be depressed but, deeming it a natural consequence of Bergstedt's low quality of life, prescribed no treatment or suicide intervention.¹⁴

When a newspaper article reported his dilemma, disability advocates tried to contact him, but his father told them Bergstedt did not wish to speak to anyone. Subsequent articles in the disability press declared the situation an unnecessary tragedy founded on the family's, professionals', and court's lack of knowledge of options. Bergstedt died when his father sedated him and turned off his ventilator. In reviewing the case months later, the court upheld his right to an assisted death but observed that he should have received better information about his life options before receiving assistance to die.¹⁵

The remaining two cases are strikingly similar to each other but dramatically different in outcome. In the late 1980s, David Rivlin, a young quadriplegic man in a Michigan nursing home, requested assistance to die through withdrawal of his ventilator. With the Bouvia legal precedent in place, the court recognized his right to refuse "treatment." Media coverage of Rivlin's story focused on his assisted death as an exercise of basic liberties. In fact, Jack Ke-vorkian later cited Rivlin as his inspiration for developing his first suicide mechanism. Ironically, instead of a freedom fighter, a careful reading of the media reports reveals a demoralized young man incarcerated not by quadriplegia but by the lonely and meaningless regimentation of American nursing home existence. Like Bouvia, he had once tried to live in his own home but discovered that Michigan provided less than \$10 per day for adequate assisted living in the community. In contrast, the state funded nursing home placement at \$230 per day.¹⁶

Rivlin died when a hospice physician, with whom he had no prior relationship, volunteered to sedate him and remove his ventilator. In his last media interview, Rivlin emphasized that he did not wish to die but could find no other exit from the restrictions and boredom of the institution. He condemned society's attitudes toward people with disabilities and exhorted the public to help others with disabilities "before it's too late."¹⁷ Tragically, if Rivlin had lived in one of several states that adequately funds in-home personal assistance, he would have had the option to live, as he wished, in his own home while pursuing an education and a job.

Within months of Rivlin's death, another quadriplegic man receiving long term services in an institution petitioned a state court for the right to turn off his ventilator.¹⁸ Like Bouvia, Larry McAfee, a resident of Georgia, said his disability rendered life intolerable. The court affirmed that the diminished quality of his life justified his right to die. Disability rights activists and their allies publicly denounced state policies that supported institutional living while withholding funds for assisted independent living. In contrast to the other three cases described here, however, advocates managed to break through to McAfee and offer emotional support as well as options for living and working that he had not known were possible. Instead of acting on his option to escape disability through dying, McAfee escaped institutional life, found assistance to live in the community, and learned how he could resume his past work as an engineer through computer adaptations. In 1990, he addressed the Georgia state senate, reproaching the state for failing to support citizens with disabilities, inviting the legislators to "imagine a life without control," and urging them to redirect state healthcare funding "to independent living opportunities that can easily be made available..., throughout the United States."¹⁹

Disability activists who oppose legalized assisted suicide diverge sharply from most health professionals, ethicists, legal experts and members of the public in their interpretation of the facts in these cases. Their definition of the problem differs. Even their language differs. When others focus on personal autonomy, the activists talk about social coercion. When others perceive compromised quality of life, the activists perceive inadequate supports for living. Although all observers agree that persons with disabilities who request assistance to die are suffering, they differ importantly in their understanding of the nature and causes of the distress. The role of depression in such requests, particularly its impact on rational decision-making, is particularly controversial.

RATIONAL DEPRESSION OR SOCIAL OPPRESSION?

The concept “rationality” has surfaced repeatedly in discussions of the right-to-die of individuals with health conditions. It is used in several different but related senses. In some contexts, the word “rational” refers to the soundness of the reasoning *process* leading up to the decision to die. For example, James Werth has written extensively about “rational suicide” as a decision arrived at through a rational weighing of circumstances, alternatives, and consequences.²⁰ He recommends assessing the rationality of decisions to die through the application of standard criteria (discussed further in a later section). However, the word “rational” can also be an evaluative descriptor of either the final *choice* itself or of the *individual* who makes the choice. In this sense, the choice to die is deemed rational when it seems understandable or reasonable to others in the surrounding social environment.²¹ The individual who makes rational decisions is considered a competent or rational person. The different meanings of “rational” are intertwined, in that decisions resulting from a rational decision-making process are expected to be rational (reasonable) conclusions. Furthermore, a person who is capable of engaging in rational decision-making is said to be a rational (competent) individual. The entanglement of these meanings (process, decisional outcome, person) is exemplified by Gallagher–Thompson and Osgood’s definition of rational suicide as “a sane, well-thought-out decision by an individual who is mentally competent, and who is capable of reasoning and choosing the best alternative among the many available.”²² It may be difficult to separate such interrelated concepts in real-life determinations of rational judgment. As Robert Burt observes, “The distinction between the rationality of a decision and the rationality of the reasoning process leading to that decision is conceivable in principle but exceedingly difficult to apply in practice.”²³

Moreover, professional assessments of “rationality” may be influenced significantly by the values of the clinician. A patient who requests assisted suicide may be viewed as rational by one professional and not rational by another. For example, a case of legal assisted suicide documented in Oregon involved a cancer patient who was evaluated by two physicians as having impaired judgment because of depression, thereby disqualifying her for physician-assisted suicide. However, with the help of right to die advocates, another physician was found who affirmed her decisional competence and assisted in her death.²⁴ Professionals’ views regarding physical

functioning and its contribution to quality of life may also affect judgments of rationality. Surveys in the Netherlands and in the U.S., for example, indicate that physicians are most likely to view a patient's desire for hastened dying as rational or justified when expressed in the context of severe illness or impaired physical functioning.²⁵

Recent referenda and legal initiatives for decriminalizing assisted suicide generally contain caveats regarding depression as a threat to rational judgment. Some proposals require persons requesting suicide assistance to undergo formal assessment by a mental health professional to rule out psychiatric disorders that might impair rational decision-making, while other proposals leave it up to the discretion of the attending physicians. The concern about depression is supported by research that consistently demonstrates a link between depression and suicidal feelings.²⁶ Some proponents of legalized assisted suicide, however, question the relevance of this link for most persons with incurable illnesses and disabilities who seek assisted death. Like the psychiatrist who evaluated Kenneth Bergstedt, they argue that it is reasonable to be depressed about one's diminished quality of life in cases of irreversible severe illness or disability and that even clinical depression does not necessarily impair the capacity for rational judgment.²⁷ The term "rational depression" will be used in the remainder of this article to signify this idea of reasonable despair. Rational depression in the context of disability, then, refers to depressive symptoms or depressive disorder with two defining characteristics: (1) The disturbance in mood is viewed by many observers as reasonable in that it is engendered by an unrelenting illness or disability that severely impairs one's quality of life, and (2) The disturbance in mood does not significantly compromise mental competence, even when a diagnosis of major depression could be made.

In effect, the argument for rational depression in the context of disability asserts that there is something about the despair of persons with disabilities and incurable illnesses who request assistance in dying that is qualitatively different from suicidal despair in other persons and, therefore, depression related to incurable health conditions calls for less rigorous suicide prevention efforts than depression in otherwise healthy individuals.²⁸ This argument appears to rest on three implicit assumptions: (1) Despair over disability is normal, or at least *more* normal than despair triggered by other stressors; (2) Despair over an irreversible condition is itself irreversible; (3) It is disrespectful or unduly burdensome to initiate suicide prevention measures – such as psychotherapy, dissuasion, hospitalization, or

forms of protective vigilance involving family or peer support – when the wish to die is expressed in relation to a permanent and significant physical impairment.

Those assumptions have triggered the charge from disability activists that assisted suicide is blatantly discriminatory.²⁹ The practice, they point out, is not universally offered to all adult citizens but is offered only to persons who have incurable biological defects. Moreover, the practice calls for a two-tiered response from health professionals: if the individual has an incurable disabling condition, the wish to die can be judged rational and the individual can be helped to die, whereas “healthy” individuals who wish to die are given suicide intervention to save their lives. In Elizabeth Bouvia’s court case, disabled activists denounced suggestions reiterated by attorneys, health experts, and the media that despair is a normal and intractable response to disability and that assisted death is a dignified solution. Furthermore, the activists asserted, such thinking derives from the public’s pervasive devaluation of life with disability and serves to rationalize society’s failure to support disabled people’s efforts to live fully in the community.

The position of the activists who opposed the “right to die” in each of the four disability cases described above can be further summarized as follows: people with disabilities, like everyone else, decide to die when life seems untenable. However, disabilities do not render life untenable; rather, it is society’s treatment of people with disabilities that demoralizes them and spoils their quality of life. Through discriminatory practices, neglect, social segregation, and impoverishment, society exhausts the spirits of people with disabilities and then, labeling their depression “rational,” lobbies for a legal mechanism to discard them.

These conflicting views of what drives persons with disabilities to want to die raise critical questions about the psychology of assisted dying: are persons with disabilities pressured to die? Is their despair rational in the context of their disabilities? Is assisted suicide an appropriate response to that despair? The remainder of this paper will examine these questions, using the four disability cases for illustration.

ARE PERSONS WITH DISABILITIES PRESSURED TO DIE?

Fear and devaluation of disability is ingrained in American culture and is reflected in the oppressed status of millions of Americans with

disabilities and disabling chronic illnesses. People with disabilities are one of the most segregated, undereducated, and impoverished minority groups in the country. Over seventy percent of working age disabled adults are unemployed.³⁰ Citizens with disabilities still encounter public buildings, programs, schools, transportation, and services that are open to everyone but them. Moreover, as life spans lengthen and more Americans are requiring monetary and physical assistance to live, the situation is, in some ways, getting worse. Government-funded support programs are being cut. Managed healthcare policies exclude some of the most basic life needs of people with chronic conditions.³¹ The Americans with Disabilities Act (ADA) and other antidiscrimination laws that protect the rights of people with disabilities have been attacked as frivolous in the media and narrowed in scope by the courts.³² Non-disabled Americans admit in surveys that they are fearful of persons with disabilities.³³ According to government funded research, children with disabilities are twice as likely as non-disabled children to be abused.³⁴ Abuse of women with disabilities is more the rule than the exception, a finding that is linked to a high rate of suicide behaviors.³⁵ Parents who have killed their children with disabilities have been excused by sympathetic judges.³⁶

Understandably these facts of disability oppression can take a toll on the morale of persons with disabilities.³⁷ After struggling with employment bias, poverty, blocked access to the community and its resources, unaccommodating and selective health services, lack of accessible and affordable housing, penalizing welfare policies, and lack of accessible transportation, some may experience what is known in the disability community as “disability burn-out.” This term refers to emotional despair engendered by thwarted opportunities and blocked goals. It is aggravated and intensified by years of exposure to disability prejudice and devaluation. In fact, a frequently repeated theme in research interviews with persons with disabilities and illnesses is, “I can live with my physical condition but I’m tired of struggling against the way I’m treated.”³⁸

Many observers with disabilities interpreted the behavior and statements of Bouvia and Rivlin as evidence of disability burn-out. Each was a highly ambitious and bright individual who wanted the essentials of the American dream: a home, family, and career. Unfortunately, each found little social support for those ambitions. After repeated disappointments and losses, both said they found life meaningless and asked to die, and ironically, both received ample

public support for that goal. Disability advocates registered this as a familiar example of society's hypocrisy in championing autonomy. As Dick Sobsey, an international expert on abuse and disability has noted, the "autonomous" decisions of people with disabilities seem to garner support only when they agree with the public's negative view of life with a disability.³⁹

The psychological reality of burn-out is that it tends to discolor one's entire outlook.⁴⁰ Not only does life appear devoid of value but the individual's sense of self may be affected as well. For example, when Bouvia, Rivlin, Bergstedt, and McAfee expressed disappointment or fear regarding their circumstances, they also often expressed devaluation of themselves as people with disabilities. Whereas the public readily accepted the premise that their disabilities caused their depression, many in the disability community interpreted these negative statements about disability as internalized prejudice, drawing a parallel to internalized racism, sexism, and homophobia. Surrounded by invalidation, it is hard not to learn self-blame. Learned rejection of the disabled self, then, may provide an *internal* pressure impelling some individuals toward self-annihilation while social oppression provides a relentless *external* pressure to give up on life.⁴¹

IS THERE A CONCEPTUAL BASIS FOR RATIONAL DEPRESSION?

Many conceptual criteria have been advanced by philosophers and ethicists to gauge the rationality of life and death decision-making. In this section, we will examine their applicability to the notion of rational depression in persons with irreversible conditions who seek assistance to die. The most common criteria for rational decision-making are: (1) mental competence; (2) absence of coercion; (3) persistence of the decision over time; (4) informed consent.⁴²

Mental Competence

To be considered competent to make a rational decision, individuals must be adults capable of considering their course of action with a realistic grasp of their situation, including the consequences of their decision. If a person with a disability who requests assistance to die can fulfill those requirements despite the presence of depression, this lends support to the concept of rational depression.

In all four of the cases reviewed above, psychiatric evaluators found the individuals to be adult, intellectually competent, and oriented to reality. When depression was noted, it was judged inconsequential to rational decision-making capacity.

Most persons in our society who attempt suicide, however, would pass such a test. Although their sense of hopelessness may bias their view of the future, their connection to reality is grossly intact.⁴³ Conversely, the fact that Bouvia and the others could pass a mental status examination was no guarantee that their comprehension of the depth and locus of their problems was unhampered by despair. Bouvia, in fact, had a history of periodic clinical depression and previous suicide attempts. In each case, she had survived and lived to view her circumstances more optimistically. One might question what response was more rational: her despair or her subsequent optimism?

In practice, one's overall capacity for rational decision-making is not the sole criterion used to evaluate the ability of persons to make life and death decisions. Some experts point out that decisional capacity is not an all-or-none phenomenon and that an individual may be competent in some mental functions but not others⁴⁴ or competent to make some kinds of decisions but not others.⁴⁵ Crisis counselors advise persons who have suffered an acute loss, such as the death of a spouse or child, not to make major decisions until they have recovered from the initial stages of grief. Human rights organizations argue that death row prisoners should not be allowed to relinquish their lives if they decide to forego the appeals process. Ethicists oppose proposals that would allow impoverished persons to sell their own organs for transplantation. Such bans acknowledge the reality that the judgment of rational adults can be impaired by such factors as emotional loss, the pressures of incarceration, and economic hardship. Furthermore, the bans suggest that it is proper to intercede in such circumstances to protect rational adults from pressured decision-making. Emotional loss, the pressures of institutional confinement, and economic hardship are significant factors in the lives of many persons with disabilities. Bouvia had experienced a string of crushing personal losses, Rivlin and McAfee expressed feelings of virtual imprisonment in institutions, Bergstedt feared forced placement in an institution, and at least three of these individuals had experienced life-altering poverty. It is unlikely that non-disabled persons in analogous circumstances of duress would be supported if they decided life was untenable.

Absence of Coercion

Like the evaluation of competence, the evaluation of coercion has been oversimplified by many who rush to judgments of rationality. Too often, it is considered sufficient to ensure that the decision-maker is not explicitly pressured by family, health professionals, or other interested parties. Usually neglected are the less tangible but nonetheless powerful pressures of blocked options and pervasive social devaluation. Throughout most of their lives, the choices persons with disabilities make to live and work as they wish are socially nullified. Yet when they ask to die, they are supported as autonomous decision-makers by proponents of assisted dying.

Furthermore, what many proponents fail to acknowledge is that demoralized persons are particularly vulnerable to negative persuasion.⁴⁶ It does not require a brutally insensitive health professional or a group of scheming relatives to convince some persons with disabilities that they should die. Only a small word or gesture from the most loving family member or dedicated professional can confirm the individual's fear that she/he is a burden who would be better off dead.⁴⁷ Many persons with disabilities live a coerced existence every day. Some may be closer to the edge than anyone realizes until some event pushes them over the threshold into suicidal despair.

Persistence Over Time

Adaptation to life with a disability is not an all-or-none linear process. More commonly, triumphs as well as difficulties ebb and flow. Resolutions give way to be replaced by better resolutions as persons heal, learn, and grow. Emotional well-being may vary with fluctuations in social support, changes in functioning, and life stresses. Because disability is one of the most feared of all human conditions, it makes sense that the adjustment process for some is complex and protracted. Furthermore, because the social oppression of persons with disabilities is a daily reality, it is common for crises to occur, linger, resolve, and recur.⁴⁸

In light of these facts, it is misleading to rely on the persistence of the wish to die as an indicator of rationality. I know many experienced persons with disabilities who can recall feeling suicidal for weeks and months in the course of their adjustment because of physical, psychological, or social pain. Some were plagued by these impulses for years before they abated. They now express appreciation for family members and health professionals who opposed their

requests to die – requests that, in hindsight, seem to them irrational. Not surprisingly, many of these “veterans” of disability are vocal opponents of legalized assisted suicide.

Informed Consent

If disability were a valued status, perhaps information regarding strategies and options for living well with a disability would abound. As it stands, ignorance abounds. One of the most common laments of persons with disabilities and their families is, “We don’t know where to get information.”⁴⁹

Although it may seem logical to seek advice from physicians and other health professionals, research indicates that unless they specialize in rehabilitation, health professionals generally lack practical information about assisted living, rehabilitation technology, community resources and other options for living fully with disabilities.⁵⁰ Moreover, studies suggest that such professionals consistently underestimate the potential and quality of life of people with disabilities.⁵¹ This is a critical problem for several reasons. First, health professionals are likely to be the first informants for families trying to make sense of new disabilities. Second, because health professionals are generally viewed as authorities, their opinions carry particular weight when patients and families must make treatment decisions. Third, professionals’ assessment of a disabled person’s potential can be critical in convincing a third party payor to invest in services that will affect the individual’s quality of life. Last, physicians and other health professionals play gatekeeping roles in assisted dying. Like the mental health consultants in the Bouvia and Bergstedt cases, they may endorse assisted death as appropriate, rather than recommend intervention, because they have limited knowledge about options for living with a disability.

It is disturbing to think that a person with a disability who requests assistance in dying may be viewed as fully informed about options and, therefore, rational in her/his deliberations, simply because she/he has consulted health professionals. Experienced persons with disabilities report that most of their problems are socially mediated, not medical.⁵² Like Larry McAfee, they learn critical information from peers with disabilities and non-medical advocates that was not available from their health professionals. Unfortunately, it may take years for a newly disabled person to connect with advocates. By then, burn-out and despair may have become well established and, in Rivlin’s words, “it’s too late.”

This examination of four criteria for rational decision-making suggests that they are flawed as indicators of rationality in persons with disabilities. The experience of disability is too complex and socially mediated to be reducible to these abstract tests. When existing theoretical guidelines fail, it can be helpful to review extant empirical data. The next step in determining the validity of rational depression in the context of chronic illness and disability is to review research bearing on disability and quality of life.

IS THERE EMPIRICAL SUBSTANTIATION OF RATIONAL DEPRESSION ASSOCIATED WITH DISABILITY?

Research on quality of life and life satisfaction of persons with disabilities is clear and consistent across studies regarding several important points:⁵³ (a) There is no consistent association between severity of impairment and ultimate emotional adjustment or perceived quality of life.⁵⁴ If anything, there is evidence that persons with the most limiting disabilities (e.g., quadriplegics and ventilator users) value life more than persons with lesser impairments;⁵⁵ (b) It is common for people to say their lives are better after becoming disabled than they were before disability;⁵⁶ (c) Approximately half of all people with disabilities say they do not wish to be “cured”;⁵⁷ (d) Generally, persons slowly change their priorities about what is most important in life after acquiring disabilities;⁵⁸ (e) Depression and suicidal behaviors in persons with disabilities are generally related to social factors, such as social isolation and lack of a meaningful role, not to objective measures of impairment.⁵⁹

There is no empirical support, therefore, for the notion that depression is a normal or rational correlate of impaired functioning, once the initial adjustment period has passed. Since there is no evidence directly linking degree of impairment to life (dis)satisfaction, and since the overwhelming majority of people learn, with support, to value life despite extensive permanent impairments, there is no basis for assuming that the desire to die is qualitatively different for persons with and without disabilities. According to the research literature, suicide is triggered by a sense of hopelessness related to psychiatric disorders, emotional vulnerability, and/or demoralizing psychosocial stresses.⁶⁰ There is no evidence of a unique death-seeking dynamic associated with disability that displaces the usual suicide dynamic in some persons and is somehow more rational than “ordinary” suicide.⁶¹

Although the basic dynamics of suicide appear similar for people with and without disabilities, there are hazards for despair that are characteristic of the disability experience in our culture. Most of them have already been mentioned as facets of the social oppression endured by people with disabilities. They include isolation, abuse, poverty, blocked access to the structures and resources of the community, forced institutionalization, loss of social roles, education and work discrimination, suppression of sexual expression, lack of relationships or social support, denial of self-determination, and immersion in messages of invalidation. Not one of these is inherent in disability itself. They derive from cultural values that disparage human limitation, difference, vulnerability, and interdependence. Two studies of reported legal assisted suicides in Oregon underscore the centrality of feared dependency in assisted suicide.⁶² Although proponents in that state had argued that legalized assisted suicide was necessary for cases of intractable pain and suffering, pain was not an issue for the overwhelming majority of the 42 people who reportedly died by assisted suicide in the first two years of legalization. Feared loss of autonomy and loss of control of bodily functions – that is, fear of the disabling aspects of terminal illness – were the foremost concerns. Also mentioned were the inability to participate in activities that make life enjoyable and the fear of being a burden on others.⁶³ Although these concerns may have been precipitated by incurable illness, they are not necessarily impervious to social and psychological interventions that could address fears of dependency and explore meaningful options for activities and roles. Unfortunately, the research reports provide little information about the kinds of psychosocial interventions that were or were not employed in these cases.

CONCLUSION

Acquiring a disability seems so catastrophic to Americans that much of the public and many health professionals believe that disability should be separated out and handled differently from other human conditions in matters of life and death. Proponents of assisted suicide for people with incurable illnesses and disabilities generally exempt this class of individuals from the routine protections extended to citizens in despair. To support the exemption, they submit the idea that the hopelessness impelling some persons with disabilities toward

death is a more rational brand of hopelessness than that experienced by non-disabled persons seeking death. Most would never suggest that suicide intervention should be suspended for “healthy” people, regardless of the severity or irreversibility of their loss.⁶⁴ In effect, they seem to be saying that it is right to feel hopeless if you have a severe disability. However, they have yet to back this claim with empirical evidence. In fact, in a rigorous review of 350 articles and reports bearing on the desire for hastened death in people with illnesses and chronic conditions, Mishara concluded: “...we have no empirical evidence indicating if the desire for a premature death by euthanasia is any different, any less linked to mental disorders, or any more rational than the desire to commit suicide.”⁶⁵

Support of assisted dying for people with non-terminal conditions coincides with a broader societal debate regarding the burdensomeness of some lives. Courts are considering whether states can deny life-sustaining health services to medicaid recipients, articles appear in respected ethics journals asking “Is there a duty to die.”⁶⁶ and Princeton’s Peter Singer disputes the personhood of children and adults with significant cognitive disabilities.⁶⁷ In a sample of U.S. oncologists who have participated in euthanasia or assisted suicide, 75% reported that one of the dominant motivating factors was “emotional burden on the patient’s family.”⁶⁸ The study’s authors further report: “In three cases (7.9%), concerns about financial burdens played a key role in motivating euthanasia or PAS. In one case (2.6%), the family wanted to ‘get it over with.’”⁶⁹ As this paper is being written, a British quadriplegic woman referred to as Miss B has just won court approval of her ventilator disconnection. Notably, Miss B explicitly cited her economic circumstances as contributing to her wish to die, indicating that she did not have access to the resources available to others, such as quadriplegic actor Christopher Reeve.⁷⁰ Unlike Mr. Reeve, who has written eloquently about transcending his own past urges to die,⁷¹ Miss B is now dead.⁷² While assisted suicide proponents discuss “justified suicide by a handicapped person,”⁷³ our society becomes increasingly open in questioning the support of incurably ill and disabled people.

The message that people with chronic illnesses and disabilities are burdens conveys a sense of stigma that may more powerfully erode a person’s will to live than does any physical condition. Unfortunately, when persons with grave illnesses or permanent disabilities become depressed and suicidal, they are much less likely to receive basic

psychological services⁷⁴ – including suicide intervention and treatment for depression – than the average American because:

- (a) Mental health services are frequently inaccessible to them, both physically and financially;
- (b) Health professionals often misunderstand the social and psychological stresses of living with permanent conditions, due to their inadequate training regarding these experiences;
- (c) Others view despair in disabled or chronically ill people as “natural” or attributable to their irreparable physical status and therefore not requiring treatment.

However, psychotherapists and suicidologists who work with persons with chronic conditions have discovered that this population generally benefits from treatment for depression.⁷⁵ In other words, incurable physical conditions do not imply incurable emotional distress. Interventions offered to this population can include psychotherapeutic and pharmacological treatment for depression, increased support from family and friends, assistance in exploring activities and roles that maintain quality of life without requiring physical vigor, and peer support to combat feelings of isolation and social invalidation. That such intervention may be withheld in the name of mercy is misguided and unacceptable. Although economic and time constraints may be a barrier, compassionate care of ill and disabled persons must include efforts to alter demoralizing life circumstances. For example, dignified in-home personal assistance services can alleviate the individual’s fear of burdening family caregivers and the fear of ending up in a nursing home.

This examination of issues underlying assisted dying for persons with disabilities and chronic illnesses, augmented by the stories of Bouvia, Bergstedt, Rivlin and McAfee, yields three challenges to notions of rational depression and disability:

- (1) Making rational decisions about the value of one’s life may be difficult for individuals who have internalized years of irrational public devaluation. As is true for other “at risk” minority groups – e.g., gay teen-agers and young African American men – their immersion in prejudice may result in internal pressures that drive people with disabilities toward self-annihilation.
- (2) Barriers to living meaningfully as one wishes represent an external pressure toward self-annihilation. If the individual is denied recourse to a thwarted existence or is not informed about all of

her/his options, the right to assisted death becomes a forced solution that is neither “rational” nor a genuine “right.” It is, instead, a desperate attempt to escape oppression.⁷⁶

- (3) Until the lives of people with disabilities and chronic illnesses are valued equally to the lives of non-disabled people, and until health professionals learn more about disability to temper their biases, legalized assisted dying will continue to endanger this segment of the population. Dim assessments of life with disability influence judgments about offering life-sustaining interventions.⁷⁷ Currently, there is no way to insure that observers who assess the rationality of a disabled individual’s desire to die are sufficiently knowledgeable about disability, and sufficiently unimpaired by conditioned prejudice regarding disability, to act in support of that individual’s genuine self-determination rather than in response to their own unconscious bias against life with a disability.

NOTES

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