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Feature Article

Socially-assisted Dying and People with Disabilities: Some Emerging Legal, Medical, and Policy Implications^{*}

Peter Blanck,^a Kristi Kirschner,^b and Leigh Bienen^c

I. Introduction

Caroline Thomson experienced years of chronic pain and depression following eye surgery. She wanted to die. John Thomson, described as a "loving husband" and a "devoted father" to their daughter, used the Internet and *Final Exit* to figure out how to help his wife achieve that wish. Caroline used items that John purchased at the grocery store to suffocate herself. The county prosecutor charged John Thomson with felony assisted suicide, based on an Iowa statute that was passed in 1996 in response to the national debate over physician-assisted suicide (PAS).¹³ It applies to anyone who assists in a suicide. Thomson's lawyer says the charge was "wholly inappropriate" under the circumstances.²²

The *Thomson* case highlights the increasingly difficult questions that society faces with respect to what we call "sociallyassisted dying" (SAD). SAD, an issue defined by a multitude of complex social, philosophical, legal, and medical factors, was the subject of a 1997 conference entitled, "Socially-Assisted Dying: Media, Money & Meaning," co-convened by this article's authors. The conference brought together rehabilitation and medical specialists, lawyers, disability community representatives, ethicists, and others to discuss *Vacco v. Quill* and *Washington v. Glucksberg*, two physician-assisted suicide cases that, at the time, were pending before the U.S. Supreme Court.^{25,26} The conference provided a forum for discussing the social, medical, and legal underpinnings of SAD, particularly as it applies in the disability context.

This article reflects on complex societal and personal issues raised by SAD in light of the Supreme Court's recent decisions in *Vacco* and *Washington*. It discusses legal and medical perspectives on SAD and disability issues, and considers public policy implications for various stakeholders and decision-makers.

A. "Socially-assisted Dying"

Euthanasia, physician-assisted suicide, withholding or withdrawing life-sustaining treatment, and palliative care are types of assistance in end-of-life decision-making that may be arranged on a theoretical continuum of SAD. This continuum reflects the extent to which society and its members play a life-ending role for terminally ill persons, persons with severe disabilities, the elderly, or others. The endpoints of the continuum reflect different views and values about life, the dying process, and death.

Active euthanasia, or the administration of lethal treatments, would lie at one end of the SAD continuum. Total and pure palliative care might lie at the other end of the continuum. Palliation involves the use of medications to treat symptoms. Yet as a treatment regiment, palliation has a dual nature in that treating symptoms such as pain may lead to the unintentional hastening of death.¹² Physician-assisted suicide, situated somewhere in the middle of the continuum, authorizes physicians to write prescriptions for lethal doses of medication that patients then may ingest voluntarily. Withdrawing or withholding life-sustaining treatment, practices related to but distinct from PAS, also are in this middle range.

The assisted suicide debate reflected in *Vacco* and *Washing-ton* is about where the lines should be drawn on the SAD continuum so that they are acceptable to the state and consistent with constitutionally protected individual liberty interests. Thus, questions such as the following arise: What types of SAD are objectionable and should be prohibited? Should certain individuals have a constitutional right to PAS? Should we as a society adopt a model, as in the Netherlands, where euthanasia as well as assisted suicide are available to people who are suffering, but may or may not be terminally ill?

*The authors were co-conveners of an interdisciplinary conference at Northwestern University entitled, "Socially-Assisted Dying: Media, Money & Meaning," held on April 10 and 11, 1997. The conference was jointly sponsored by the Rehabilitation Institute of Chicago Program in Disability Ethics, the Northwestern University School of Law, the University of Iowa Law, Health Policy and Disability Center, the Northwestern University Institute of Health Services, Research and Policy Studies, the Northwestern University Medical School Department of Physical Medicine and Rehabilitation, and the Northwestern University Medical School Program in Medical Ethics and Humanities. This project was funded in part by a grant to Dr. Blanck from the National Council on Disability. The transcript of the conference will be published in the Cornell Journal of Law & Ethics this fall.

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B. SAD and Disability

Where and how the lines are drawn on the SAD continuum is particularly crucial for socially vulnerable groups, including persons with disabilities and persons in poverty. Some have argued that historical and cultural attitudes in the provision of health care have reflected a willingness to devalue the lives of persons with disabilities. In this context, persons with disabilities have faced myths and misconceptions about the relative value of their lives.¹⁷ The National Council on Disability has noted that, despite diverse views among individual members, the disability community collectively recognizes "the danger of discrimination to the interests and fair treatment of people with disabilities."¹⁸

The amici briefs filed in *Vacco* and *Washington* reflect a range of views on the PAS debate, expressed by many respected advocates from the disability community. At the conference, scholars with disabilities opposed to PAS legalization contended that societal judgments made about the quality of life of persons with disabilities would encourage society to devalue their lives. The result, the scholars argued, would lead to unwarranted decisions to end the lives of persons who may be disabled.

Other respected members of the disability community present at the conference pointed to the right of self-determination as a basis for arguing for PAS legalization. This viewpoint is grounded in the belief that historically, people with disabilities have been denied the right to make their own choices, and too often, others have imposed undesired life choices upon them.

II. Physician-assisted Suicide

A. The Vacco and Washington Decisions

The PAS debate within, as well as outside, the disability community is characterized by a number of issues, including:

- The roles of self-autonomy and privacy in making extremely personal decisions;
- The extent to which the state may intrude on the individual rights of terminally ill individuals, persons with disabilities, or others; and
- The balance between individual rights and state interests in defining social and legal norms about end-of-life decisions.

Notions of individual self-determination and autonomy were cornerstones of the Supreme Court's analysis in *Vacco* and *Washington*.^{25,26} The Court addressed the issue of whether there is a constitutional right to physician-assisted suicide for competent persons with a terminal illness. The Court examined lower appellate court rulings prohibiting state laws that banned PAS for these individuals.

In *Quill v. Vacco*, the Second Circuit recognized that a competent individual with a terminal illness may have a right to PAS under the Equal Protection Clause of the Fourteenth Amendment.²¹ In *Compassion in Dying v. Washington*, the Ninth Circuit found that competent terminally ill patients have a due process liberty interest in choosing PAS.⁷

The Supreme Court approached *Vacco* and *Washington* as companion cases, finding that there was not a fundamental constitutional right to PAS in ending life. The Court concluded that equal protection considerations did not bar states from enacting laws that prohibit PAS.

In its decisions, the Supreme Court was unwilling to dismiss the distinction between withdrawal of life-sustaining treatment and prescribing life-ending medication. In writing for the majority, Chief Justice Rehnquist noted that states may continue to distinguish between refusing treatment and recognizing the right to physician assistance in committing suicide.^{25,26}

Rehnquist wrote: "[T]he distinction between assisting suicide and withdrawing life-sustaining treatment [is] a distinction widely recognized and endorsed in the medical profession and in our legal traditions."^{25,26} The distinction is "certainly rational" and "comport[s] with fundamental legal principles of cause and intent."^{25,26} "When a patient refuses life-sustaining medical treatment," Rehnquist noted, "he dies from an underlying fatal disease or pathology; but if a patient ingests lethal medication prescribed by a physician, he is killed by that medication."^{25,26}

The Court thus held that there was no equal protection violation in the state statute at issue that allowed a doctor to provide palliative care, but that did not allow a doctor to prescribe lifeending medication, even though palliative care sometimes has the "double effect" of causing death. In concurring opinions, however, five of the Justices emphasized that the current decisions did not foreclose further debate about the constitutional limits on the power of the states to punish PAS.

B. After Vacco and Washington

Although the Supreme Court rejected arguments establishing a constitutional right to PAS, the Justices did not attempt, nor explicitly intend, to resolve the issue. Rehnquist emphasized that the holdings permit continuing dialogue between citizens "engaged in an earnest and profound debate about the morality, legality, and practicality of assisted suicide."^{25,26}

Five Justices, including Justices O'Connor and Stevens, intimated that there may be a right to assistance for suicide in future cases. In writing separately in each of the opinions, O'Connor acknowledged that states are currently "undertaking extensive and serious evaluation of physician-assisted suicide and other related issues."^{25,26}

In his concurring opinions, Stevens noted that in upholding the criminal statutes at issue that prohibit assisting suicide, the Court did not rule that future statutory applications necessarily will be invalid. Stevens explained that he would not "foreclose the possibility that an individual plaintiff seeking to hasten her death, or a doctor whose assistance was sought, could prevail in a more particularized challenge."^{25,26} Future cases will determine exactly what such a challenge may require. These challenges will occur on the state level where legislators will be "free to decide whether to allow doctors to help patients die."^{25,26} In speculating on the ramifications of the opinions for stakeholders and state decision makers, Kathryn Tucker, director of Legal Affairs for Compassion in Dying, counsel in both Supreme Court cases, and a speaker at the conference, reflected that "[t]he decisions, while providing no immediate relief to suffering dying patients, signal the possibility of future recognition of a federal constitutional right for competent, dying patients to choose a humane and peaceful death with physician assistance." Tucker views the question answered by the majority as "whether there is a general right to suicide and assistance therein, a question on which the parties had no dispute."

While the door may be "half open" for future rulings in PAS cases, it also may be half closed. The Court examined the limits of legitimate state interests in banning assisted suicide. It cast suicide as a public health problem exacerbated by untreated depression. Relying on empirical study, the Court noted that many patients who contemplate PAS withdraw the request when treated for depression. A recent study of attitudes toward PAS gathered from oncologists, oncology patients, and the public, found that "patients who had seriously considered and prepared for euthanasia or physician-assisted suicide were significantly more likely to be depressed."⁸

In its decisions, the Court explained that states continue to have a legitimate interest in protecting vulnerable groups, including people with disabilities. The Court recognized the risk of social, economic, and medical coercion for certain individuals and their families who are making end-of-life decisions.

Yet the opinions are cautionary, suggesting a shared unwillingness to allow legislators the opportunity to proceed down the "slippery slope" from legalization of PAS toward the legalization of passive and active euthanasia. As echoed by members of the disability community at the conference, this "slippery slope," according to Rehnquist, "likely, [would be] in effect, a much broader license, which could prove extremely difficult to police and contain."²⁵

III. Perspectives from the Medical Community

In the medical community, the PAS debate extends beyond the question of whether a competent terminally ill patient has a legal right to die. For decades, members of the hospice movement have been drawing attention to the way society cares for dying patients.¹⁸

Conference participants suggested that the PAS debate sends a clear message to the medical community that it must meet the end of life needs of all individuals—those with and without disabilities. Teaching efforts and research initiatives are informing physicians about the complex issues. A current multi-center study known as SUPPORT—Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment—funded in part by the Robert Wood Johnson Foundation, is assessing physicians' effectiveness in communicating with seriously ill patients about end-of-life care preferences. In addition, the U.S. Department of Health's Health Care Financing Administration recently granted the hospice and palliative care movement a billing authorization for reimbursement for services.

A. Physicians' Attitudes and Knowledge About PAS

Recent attitudinal surveys in Oregon, Michigan, and Washington reflect mixed views by physicians on PAS. A majority of physicians polled (40 percent-60 percent) are in favor of pursuing PAS legalization in some form.^{1,2,15} But almost one-third (29 percent) of the respondents in Oregon thought that legalization of PAS could result in lethal overdoses given to patients without their request.

An overwhelming proportion (93 percent) believed that patients would be motivated to request PAS because of concern about being a burden to others or because of financial pressures (83 percent). Approximately half were not confident that they could predict when patients were truly terminally ill, defined as having fewer than six months to live. About one-third of its physicians were not confident they could recognize depression in patients requesting PAS. Half were not sure what medications they would prescribe in any event.

In the Michigan survey, physicians who were more experienced in caring for terminally ill patients were less likely to support legalization of PAS (or voluntary euthanasia). Less experienced physicians were more likely to support legalization. The Washington State survey indicated that patient requests for PAS appeared to be more motivated by nonphysical concerns (such as the fears of losing control, being a burden, dependency, and loss of dignity) than by physical concerns (such as severe pain).

Semantic and conceptual confusion also clouds the PAS debate. "Terminal," "intractable suffering," and "depression" are terms that medical practitioners increasingly have difficulty applying in clinical contexts. Frequent references to the case of Elizabeth Bouvia illustrate that to physicians, the moral acceptability of patients deciding to end their lives is marked by uncertain boundaries.⁶ Bouvia lived with cerebral palsy and endured chronic pain—conditions that are neither terminal nor hopeless. The conclusion that she was "dying and beyond hope" is an example of conceptual confusion.

Discussions of various end-of-life clinical practices provide other examples of confusion. An article in *People* recently argued for PAS.¹⁹ The interviewer asked Dr. Timothy Quill to describe a situation in which helping a patient to end a terminal illness is appropriate. Quill identified a patient with advanced AIDS who is deteriorating and will need a ventilator to extend his life. But the patient decides he is ready to die and does not want to go on the ventilator. Twelve hours later, he dies. Yet, what Quill described were the conditions for withholding lifesustaining treatment at the request of a competent patient, a practice that is legal.²⁴

B. Defining SAD and PAS

Like medical practitioners, many participants at the 1997 SAD conference were uncertain about the definition of PAS. At the conference, participants were surveyed about SAD and PAS issues. Approximately two-thirds of the 200 respondents identified themselves as health care professionals, while the remaining one-third included lawyers, religious leaders, and disability

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advocates. We found that approximately 80 percent of the respondents *incorrectly* identified active euthanasia as an example of PAS. Only 53 percent correctly identified a scenario describing PAS. Furthermore, 50 percent of the respondents incorrectly identified the currently legal practice of withdrawing dialysis at the request of a competent patient as PAS.

A similar blurring of boundaries occurred in the ruling of the Second Circuit's decision in *Quill*. The Second Circuit Court equated withdrawing a ventilator from a terminally ill patient with the writing of a prescription for a lethal dose of medication.²¹ Yet the predominant legal, ethical, and medical stance for the last 20-plus years has been that withdrawing and withhold-ing life-sustaining treatment at the request of a competent patient is *not* suicide. Rather, it is a legal practice allowing the course of the disease to proceed without unwanted medical intervention.

The medical profession is re-focusing attention on the care and needs of dying patients as a result of the PAS debate. Current research continues to indicate that the issues surrounding PAS are more complex than previously thought.¹¹ Confusion and clinical ambiguity around concepts such as "terminal," "hopeless," "intractable suffering," "depression," and the practical and moral distinctions between various end-of-life clinical practices, warrant caution before proceeding with any sweeping public policy on PAS.

C. People with Disabilities and SAD

A lack of knowledge in the medical community about issues within the heterogeneous disability community may be traced to inadequate theoretical and practical training in the area.¹² Philosophical perspectives on disability generally are not included in medical or law school curricula. Studies show that health professionals often take a dimmer view of life with disabilities than do the persons who actually live with those disabilities.^{9,10} Other studies have shown that members of the medical profession are not uniformly accurate at predicting patients' preferences in endof-life care.^{1,9,10, 23}

One group of physicians was asked to predict what their patients would want regarding end-of-life care (for example, CPR, ventilator for an indefinite period of time, medical nutrition and hydration for an indefinite period of time, and hospitalization in the event of pneumonia).²³ There was no relationship between the physicians' predictions and the responses of patients. Physicians seemed to make predictions for their patients based on their own personal preferences for end-of-life care. Thus, even when physicians attempt to be empathic, their perspectives appear to be influenced by their conscious and unconscious personal values and expectations.²³

In its position paper on assisted suicide, the National Council on Disability argued against making biased quality of life judgments about people living with disabilities. The Council noted that "[o]ne of the hallmarks of societal attitudes toward disabilities has been a tendency of people without disabilities to overestimate the negative aspects and underestimate the positive features of the lives of those who have disabilities."¹⁸ Negative attitudes toward people with disabilities have caused the disThe following scenario illustrates how attitudes may influence clinical outcomes. A 29-year-old woman with cerebral palsy and chronic pain is admitted to a hospital. Her doctors wanted to insert a feeding tube because of life-threatening weight loss. There is some debate about whether her poor oral intake was, in fact, an act of suicide (despite the known fact that she previously had attempted to starve herself). She refused the feeding tube, recognizing that she likely would die if the malnutrition proceeds. What should her doctors do?

Outcome 1: Overwhelmed with pity for the woman, and feeling that they would want someone to help them die if they were in her dependent state, they comply with her request as a rational response to her circumstances.

Outcome 2: The doctors recognize that the woman has cerebral palsy, a congenital, nonprogressive disability and has adjusted well to her disability. The doctors identify factors that might explain her depression, including that she recently lost a brother to a drowning accident, had a miscarriage, suffered the break-up of her marriage, had to leave graduate school, and lost her support to live in the community. The doctors arrange for mental health services to meet her needs, and assist her in returning to community, vocational and social activities. They attempt to restore her ability to be "self-determining," which was compromised more by her mental state and psychosocial circumstances than by her disability.

This is the story of Elizabeth Bouvia.⁶ Many in the judicial and medical ethics communities responded to her refusal of a feeding tube by following *Outcome 1*. As a result, *Outcome 1's* practice of complying with the disabled patient's request to withdraw life-sustaining treatment, without further inquiry, has become routine. (See transcript of Conference to be published in the *Cornell Journal of Law & Ethics* this fall.)

Outcome 2 too rarely occurs in the medical sphere. Frequently, this outcome is driven by the families of the disabled patients or other disability advocates whose perspectives often are dismissed as intrusive. In an article addressing the impact of assisted suicide on people with disabilities, EEOC Commissioner Paul Steven Miller eloquently expressed the failures of a health system that overlooks *Outcome 2*: "Without being offered a choice of independent living alternatives and counseling, with special emphasis on psychological issues facing persons with disabilities, the right to assisted suicide is no right at all; it is the inevitable manifestation of society's prejudice."¹⁷

At the conference, physicians voiced concern that health care providers may not be sensitive to the perspectives of disabled patients who often are vulnerable due to their compromised ability to advocate for themselves. In addition, conference participants suggested the need for further discussion on therapeutic and administrative safeguards to protect the rights of disabled patients. However, no matter how carefully constructed, these safeguards will not protect these patients if society continues to view health care as a privilege, disability as a tragedy, and allows the allocation of health care resources to be dictated by demands of the market.

IV. Conclusion

The debate over PAS will continue in state legislatures, state regulatory agencies, and state funding agencies.²⁰ Those involved in the debate will include doctors and administrators at state and private institutions and hospitals, members of the disability community and their families, lawyers, insurance professionals, ethicists, and others. Hospitals will need to reassess their internal review policies in light of the Supreme Court's unwillingness to invalidate existing criminal statutes. Ultimately, the PAS debate will need to be guided by an understanding of the lives of persons throughout society who face end-of-life decisions.

Despite the decisions in *Vacco* and *Washington*, state legislatures still will have the authority to criminalize assisted suicide by doctors and others, to enact statutes regulating PAS, or to abstain from the issue and apply existing criminal statutes to assisted-suicide situations. State laws supporting the criminalization of assisted suicide create opportunities for prosecutorial discretion. Although county prosecutors have the authority to decide whether to prosecute physicians or others for assisting in suicides, they must rely on doctors, family members, nurses, or other observers for information that would indicate a statutory violation.

One distinction that may emerge in the debate surrounding *Vacco* and *Washington* is whether PAS should be considered as part of a "medical treatment continuum," or as part of a continuum based on criminal law notions of suicide and homicide. At least in *Vacco*, the Supreme Court implied that an appropriate analogy was to traditions based in the homicide statutes. While suicide is not defined identically in every state, it is usually classified as a "crime against the person" under homicide provisions of state criminal codes. In this context, the analysis has focused on the intent to cause death, the reasons for the suicide, determination about whether mental illness is present, the act causing death, and the time between the act and death.

Conceptualizing assisted suicide as a type of killing also leads to practical and philosophical comparisons to issues surrounding capital punishment. In *Vacco* and *Washington*, Stevens noted the parallel between the circumstances involving assisted suicide and capital punishment. Stevens opined that our society already deems some lives as less worthy than others; if we are going to give our worst criminals an easy and predictable death by "lethal injection," why shouldn't we do the same for our loved ones? Why not for those whom society no longer wishes to care or support in institutional settings? What about the elderly, those who are infirm, the less than "perfect?"

A host of other issues will arise if assisted suicide is classified as either a type of suicide or homicide. However, viewing assisted suicide as a public health issue may provide insight into preventive measures that may lower risk factors and improve the lives of members of the disability community.

In addition, the Americans with Disabilities Act of 1990 (ADA) will increasingly factor into the SAD debate.^{3,4,5} The ADA

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is a comprehensive civil rights law that addresses discrimination against millions of Americans in the areas of employment, state and local governmental services, public accommodations, and health insurance. The legislative findings accompanying the ADA conclude that, subjected to "a history of purposeful unequal treatment and relegated to a position of political powerlessness in our society," persons with disabilities are perhaps the major consumers of a health care system that historically has failed to meet their needs.³

Persons with disabilities involved in the PAS dialogue have invoked the ADA on both sides of the debate. Proponents in favor of legalization have emphasized that self-determination is central to the goals of the ADA.²⁴ They argue that PAS should be legalized to avoid the overprotective rules and policies that Congress targeted in enacting the ADA.

Opponents of legalizing PAS argue that inadequate health care, health insurance coverage, and the lack of economic power of many people with disabilities will extend to a lack of a voice in life-ending decision-making.¹² Thus, if terminally ill patients are not receiving adequate palliative or mental health care, opponents argue that they are not receiving equal access to health care as mandated by the ADA.

Participants at the conference agreed that study is lacking on a broad range of factors, such as advances in medical technology and changes in societal norms. Future debate on SAD issues likely will involve more complex issues than those that faced by the parties in *Vacco* and *Washington*, and those faced by John and Caroline Thomson of Iowa.

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