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INTRODUCTION TO CONFERENCE TRANSCRIPT

Leigh B. Bienen, Kristi Kirschner, and Peter David Blanck†

This 1997 conference, titled Socially-Assisted Dying: Media, Money & Meaning, brought together rehabilitation and medical specialists, representatives of the disability community, lawyers, ethicists, and others to discuss Vacco v. Quill¹ and Washington v. Glucksberg,² the two physician-assisted suicide cases that, at the time, were pending before the United States Supreme Court. The conference provided a forum for discussing the social, medical, and legal implications of socially-assisted dying, with particular emphasis on the disability context.

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 “socially-assisted dying.” 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, and others. The endpoints of the continuum reflect different views and values about life and death.

Active euthanasia, or the administration of lethal treatments, lies at one end of the continuum. Total and pure palliative care lies at the other end of the continuum.³ Yet, as a treatment regime, palliation has a dual nature in that treating symptoms such as pain may sometimes unintentionally hasten death.⁴ Physician-assisted suicide, situated somewhere in the middle of the continuum, authorizes physicians to write prescriptions for lethal doses of medication that patients can then voluntarily ingest. Related practices by physicians and others of withdrawing and withhold-

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¹ The Supreme Court released its opinion after the conference. See Vacco v. Quill, 117 S. Ct. 2293 (1997).
³ Palliation involves the use of medications to treat symptoms.
Persons with disabilities who are ill and facing end-of-life situations must contend with myths and misconceptions about the relative value of their lives. 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." Debate continues within the disability community and among physicians who care for the disabled.

The amici briefs filed in Quill and Glucksberg reflected a range of views expressed by many respected advocates from the disability community. At this conference, scholars with disabilities who were opposed to physician-assisted suicide legalization contended that societal judgments made about quality of life would encourage society to devalue their lives, which are defined in part by the experience and culture of disability. They further argued that limiting access to physician-assisted suicide to people with terminal or chronic illness is inherently discriminatory. The result leads 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 legalization. This view is grounded in the belief that people with disabilities have been denied the right to make their own choices, and that too often, others have imposed undesired life choices upon them.

The participants in the conference disagreed vigorously on many things, but all concurred that there was little or no data on the number or character of the population that might be affected by a change in the laws governing physician-assisted suicide or euthanasia. The following numbers suggest that courts will not be able to make case-by-case determinations or indulge in long philosophical discussions over autonomy to decide individual cases.


See Conference Transcript, supra note 7 (Session IV, comments of Diane Coleman and audience participants).

See id. (comments of Dr. Gill and Dr. Bowman).
In 1995, there were an estimated 1.4 million elderly residents aged 65 and older living in nursing homes. These nursing home residents were predominantly women (75 percent), white, non-Hispanic, and widowed. About 17 percent were classified as having "mental disorders." More than 60 percent were on Medicare or Medicaid. These figures do not include patients hospitalized or institutionalized who are not over 65, or those who are chronically or severely ill, or incapacitated outside of the institutional setting.

Several important legal developments have taken place since April 1997, when the conference took place. First, the Oregon Death with Dignity Act, which permits physician-assisted suicide under certain defined conditions, survived a serious challenge. It is unlikely that any further legal challenge to its application will be forthcoming. The United States Congress, however, passed a law prohibiting the use of

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10 See Achintya N. Dey, Characteristics of Elderly Nursing Home Residents: Data From the 1995 National Nursing Home Survey, 289 ADVANCE DATA 1, 2 (Center for Disease Control and Prevention/National Center for Health Statistics 1997).
11 See id.
12 See id.
13 See id. at 4.
14 See OR. REV. STAT. § 127.800-.897 (1996 Supp.). Oregon's Death with Dignity Act became law through the legislative initiative process in November, 1994. It passed by 51 percent to 49 percent in 1994, and Oregon became the first state to legalize doctor-assisted suicide. On November 4, 1997, the Oregon voters defeated a legislative referral to repeal the law. In Washington and California, statutes legalizing physician-assisted suicide failed to pass by narrow margins. The proposed laws of both California and Washington would have also permitted active euthanasia. See Eugenie Anne Gifford, Comment, Artes Moriendi: Active Euthanasia and the Art of Dying, 40 U.C.L.A. L. REV. 1545 passim (1993) (discussing California Proposition 161, § 2525.2 and Washington's initiative, Measure 119). Proposals to permit physician-assisted suicide have come to a vote before the state legislature in at least four other states: Iowa, Maine, Michigan, and New Hampshire. In February 1998, the Maine legislature defeated an Oregon type statute:

The bill, rejected by the House 99 to 42, aroused passionate arguments on both sides of the issue, with lawmakers recalling relatives and friends who had suffered painful deaths and others invoking religious objections against the legislation. The bill was similar to an Oregon law: ... . Last Year, South Dakota and Virginia enacted laws that prevent authorities from holding physicians liable for prescribing or administering medication to relieve pain even if the dosage hastens death.


15 The Oregon statute was immediately challenged in federal district court and found to be in violation of the Equal Protection Clause. The court issued an injunction. See Lee v. Oregon, 891 F. Supp. 1429 (D. Or. 1995). A federal appeals court overturned the decision on the grounds that the challengers lacked standing because the law had not yet gone into effect. See Lee v. Oregon, 107 F.3d 1382 (9th Cir. 1997). The United States denied certiorari. See Lee v. Harcheloroad, 118 S. Ct. 328 (1997). Denying certiorari in October of 1997 was not a judgment on the merits. Refusing to hear the challenge to the state initiative was, however, consistent with the court's view, expressed in June 1997, that the state legislatures would be granted deference on this issue.
federal funds for physician-assisted suicide.\textsuperscript{16} It remains to be seen how that statute will affect the practice of medicine or law in Oregon and other states that follow the Oregon model.

Who is eligible for physician assisted suicide under the Oregon statute? What are the consent provisions? The statutory language governing which patients are eligible for physician-assisted suicide reads as follows:

An adult who is capable, is a resident of Oregon, and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his or her life in a humane and dignified manner in accordance with [this Act].\textsuperscript{17}

The statute defines capable as "not incapable."\textsuperscript{18} The statute further indicates:

"Incapable" means that in the opinion of a court or in the opinion of the patient's attending physician or consulting physician, a patient lacks the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available.\textsuperscript{19}

Additionally, the statute describes the form for socially-assisted dying requests and discusses the qualifications for consulting physicians and witnesses. The reference to a court deciding whether a patient is "incapable," however, is the relevant point. Issues of consent and capacity are now central. In theory, a court is to oversee these decisions, and there will be regulations spelling out how these terms, consent and capacity, will be operationalized.

The Supreme Court has dealt with similar issues in the capital punishment context. For example, in \textit{Ford v. Wainwright},\textsuperscript{20} the Court examined the issue of competency to be executed. In \textit{Ford}, the prisoner developed symptoms of psychosis after eight years on death row.\textsuperscript{21} It

\textsuperscript{17} OR. REV. STAT. § 127.805.s2.01 (1995).
\textsuperscript{18} OR. REV. STAT. § 127.800.s1.01(6) (1995).
\textsuperscript{19} \textit{Id.}
\textsuperscript{20} 477 U.S. 399 (1986).
\textsuperscript{21} \textit{Id.} at 402-04.
was not the prospect of sentencing the prisoner to death, however, that bothered the Court. Instead, the Court examined the procedures used to determine a prisoner’s competency.\textsuperscript{22} Similarly, if provisions in the Oregon Death with Dignity Act come before the Supreme Court, it will probably be the procedures, and not the substance, that will be at issue.

What constitutes evidence of competence or capacity? Is it speech or communication? Is it recognition of reality? If a patient is incompetent, presumably she does not know that she is incompetent or that she is consenting to death. If competency is determined by adherence to regulations, presumptions, bureaucratic decision-making, or committees, then courts will not reverse the decisions. The legal issues will be how elaborate or comprehensive the regulations are, and whether or not decision-makers follow the required procedures.\textsuperscript{23} Or, the courts may not be involved in the decision at all (for better or for worse).

The hospitals, bureaucratic decision-makers, and doctors may well prefer to have the decision about death transferred to a hospital board or another group of decision-makers. Doctors and medical staff will not be enthusiastic about deferring to courts on such decisions. The delays introduced by appellate review also support leaving decision-making within the institutions. It remains to be seen what role lawyers will have in the system. For example, how will lawyers challenge a functioning bureaucracy, with its own institutional imperatives, that is not required to make its decisions public?

Even the most elaborate regulations written, however, cannot protect anyone if they are ignored, unknown, or not understood. Mentally retarded defendants, for example, have been sentenced to death, had their convictions upheld, and been executed, without having any mitigating evidence of their impairment presented to the jury or court by their inept or inattentive attorneys.\textsuperscript{24}

Many residents of institutions have suffered from strokes or from diseases such as Alzheimer’s which make their mental capacity indeterminate in the most profound sense.\textsuperscript{25} What is the status of a “competency” which comes and goes, depending on the time of day or other

\textsuperscript{22} See id. at 416-17.
\textsuperscript{23} Kathryn Tucker’s conference presentation describes a situation in which the Washington state procedures for the termination of life support, which were on their face adequate, were totally ignored. See Conference Transcript, supra note 7 (Session IV).
\textsuperscript{25} While it is difficult to measure the number of people in nursing home who suffer from dementia, from a variety of causes, it has been estimated to be in the range of 50 to 60 percent. See Pearl S. German et al., The Role of Mental Morbidity in the Nursing Home Experience, 32 Gerontologist 152, 156, 158 (1992).
random factors? The courts are theoretically available to protect and ensure basic constitutional rights for patients and doctors, and for persons who are not patients. Few cases, however, will actually reach the courts. Even if these cases do reach the courts, appeals take years and the circumstances may change before final resolution by the courts.

In most cases, institutional administrators will be deciding who is capable of consenting to assisted suicide and under what circumstances. Dead women and men tell no tales, and who is to say, when someone is dead, that they would not have been dead in six months anyway. At least in large hospitals with federal and state funding, there will be seminars on physician-assisted suicide regulations and staff will be urged to carefully adhere to the regulations.

One large, unaddressed question is the role of surrogate decision-makers. The power of attorney for health care, which is routinely assigned by thousands of people when they make their wills or in anticipation of travel, surgery or a serious illness, fully delegates to a surrogate decision-maker the legal authority over the autonomy of the assignor. Thus, the person holding the power of attorney for health care decisions stands in the shoes of the patient. This means the person with the power of attorney can decide anything the patient could decide if she were able.

Once an individual has the power of attorney for health care decisions, can she authorize physician-assisted suicide in the same manner as the patient herself? Absent a specific statute precluding surrogate decision-makers from making such decisions, the presumption is that existing legal structures remain in place. Therefore, surrogate decision-makers can make decisions regarding the termination and the refusal of life-prolonging treatment as long as they follow regulations.

After the conference, the United States Supreme Court addressed physician-assisted suicide and determined that courts must respect and defer to state legislatures. Notions of individual self-determination and autonomy were cornerstones of the Supreme Court’s analysis in Quill and Glucksberg, where it examined lower appellate court rulings that prohibited state laws banning physician-assisted suicide for competent persons with terminal illnesses.

In Quill v. Vacco, the Second Circuit Court of Appeals recognized that a competent individual with a terminal illness may have a right to physician-assisted suicide under the Equal Protection Clause of the Fourteenth Amendment. In Compassion in Dying v. Washington, the Ninth Circuit Court of Appeals found that competent terminally ill patients

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have a due process liberty interest in choosing physician-assisted suicide.\textsuperscript{27}

The Supreme Court approached \textit{Quill} and \textit{Glucksberg} as companion cases, finding that there was not a fundamental constitutional right to physician-assisted suicide in ending life.\textsuperscript{28} The Court also concluded that equal protection considerations did not bar states from enacting laws that prohibit physician-assisted suicide.\textsuperscript{29}

In its decisions, the Supreme Court maintained the distinction between withdrawal of life-sustaining treatment and prescribing life-ending medication.\textsuperscript{30} 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: "[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... it is certainly rational... [and it] comports with fundamental legal principles of causation and intent."\textsuperscript{31} Rehnquist also noted, "When a patient refuses life-sustaining medical treatment, 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."\textsuperscript{32}

The Court 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 life-ending medication.\textsuperscript{33} This was found even though palliative care sometimes has the "double effect" of causing death.\textsuperscript{34} Although the Supreme Court rejected arguments establishing a constitutional right to physician-assisted suicide, the Justices did not attempt, nor explicitly intend, to resolve the issue. Chief Justice Rehnquist emphasized that the holdings permit continuing dialogue between citizens "engaged in an earnest and profound debate about the morality, legality, and practicality of physician-assisted suicide."\textsuperscript{35} Additionally, five of the concurring Justices indicated that the decisions did not foreclose further debate about the limits the Constitution places

\textsuperscript{29} See Vacco v. Quill, 117 S. Ct. 2293, 2296 (1997).
\textsuperscript{30} See id. at 2298, 2298 n.6.
\textsuperscript{31} Id. at 2298 (citations omitted).
\textsuperscript{32} Id.
\textsuperscript{33} See id. at 2302.
\textsuperscript{35} \textit{Glucksberg}, 117 S. Ct. at 2275.
upon the power of the states to regulate, criminalize or prohibit physician-assisted suicide.36

These five concurring Justices, including Justices O'Connor and Stevens, intimated that there may be a right to assistance for suicide in future cases. Writing separately, Justice O'Connor acknowledged that states are "presently undertaking extensive and serious evaluation of physician-assisted suicide and other related issues."37 Justice Stevens noted that the results in Quill and Glucksberg did not mean that future statutory applications would necessarily be invalid.38 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."39 Future cases will determine exactly what such a challenge may require. These cases will occur, however, in the states, where legislators will be "free to decide whether to allow doctors to help patients die."40

Speculating about the ramifications of Quill and Glucksberg 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 for future recognition of a federal constitutional right for competent, dying patients to choose a humane and peaceful death with physician assistance."41 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."42

While the door may be "half open" for future rulings in physician-assisted suicide cases, it may also 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 studies, the Court noted that many patients who contemplated physician-assisted suicide withdrew their requests when treated for depression.43 A recent study of attitudes toward physician-assisted suicide gathered from oncologists, oncology patients, and the

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36 See id. at 2290 (Souter, J., concurring); id. at 2303 (O'Connor, J., concurring); id. at 2304 (Stevens, J., concurring); id. at 2310 (Ginsburg, J., concurring for substantially the same reasons as Justice O'Connor); id. at 2310-11 (Breyer, J., concurring).
37 Id. at 2303 (O'Connor, J., concurring).
38 See id. at 2304 (Stevens, J., concurring).
39 Id. at 2309.
40 Judy Peres, Assisted-Suicide Bans Upheld: Justices Say There's No Constitutional Right to Aided Death, but Leave Door Open for States, Cm. Txl., June 27, 1997, at 1.
41 Telephone Interview by Peter Blanck with Kathryn Tucker, Counsel, Compassion in Dying (July 1997).
42 Id.
43 See Glucksberg, 117 S. Ct. at 2273.
public found that “patients who had seriously considered and prepared for euthanasia or physician-assisted suicide were significantly more likely to be depressed.”

In its decision, 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 cautionary opinions also suggested a shared unwillingness to allow legislators the opportunity to proceed down the “slippery slope” from legalization of physician-assisted suicide toward the legalization of passive and active euthanasia. As echoed by members of the disability community at our conference, this “slippery slope,” according to Chief Justice Rehnquist, would “likely, in effect, be a much broader license, which could prove extremely difficult to police and contain.”

Recent attitudinal surveys in Oregon, Michigan, and Washington reflect mixed views by physicians on physician-assisted suicide. A majority of physicians polled (40-60%) are in favor of legalization in some form. Almost one-third (29%) of the respondents in Oregon, however, thought that legalization of physician-assisted suicide could result in lethal overdoses given to patients without their request. An overwhelming proportion (93%) believed that patients would be motivated to request physician-assisted suicide because of concern about being a burden to others or because of financial pressures (83%). Half were not confident that they could predict when patients were truly terminally ill, defined as having less than 6 months to live. About one-third of its physicians were not confident they could recognize depression in patients requesting physician-assisted suicide. Half were not sure what medications they would prescribe in any event.

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45 See Glucksberg, 117 S. Ct. at 2273.
46 See id. at 2273.
47 Id. at 2274.
49 See Lee, supra note 48, at 311.
50 See id.
51 See id. at 312.
52 See id. at 312-13.
53 See id. at 313.
Like medical practitioners, participants at the conference were uncertain about the definition of physician-assisted suicide. At the conference, we distributed surveys with nine clinical scenarios representing examples of palliative care, withdrawing and withholding life sustaining treatment, physician-assisted suicide, and active voluntary and involuntary euthanasia. Forty percent of the 200 respondents identified themselves as health care professionals, with the remaining 60 percent including lawyers, religious leaders, disability advocates allied health professional and others. About 80% of the respondents incorrectly identified active euthanasia as an example of physician-assisted suicide. Only 53% correctly identified a scenario describing physician-assisted suicide. Moreover, some respondents were incorrect in identifying the currently legal practice of withdrawing dialysis at the request of a competent patient as physician-assisted suicide.\(^5^4\)

A similar blurring of boundaries occurred in the Second Circuit’s decision in *Quill*. The Second Circuit equated withdrawing a ventilator from a terminally ill patient with writing a prescription for a lethal dose of medication.\(^5^5\) Yet the predominant legal, ethical, and medical position for over twenty years has been that withdrawing and withholding life-sustaining treatment at the request of a competent patient is *not* suicide. Rather, this is a legal practice allowing the course of the disease to proceed without unwanted medical intervention.

At the conference, many physicians sensitive to disability issues emphasized that it was wrong to assume that health care providers are equipped to deal with disability issues or to recognize their inability to do so in certain circumstances. Newly disabled patients or disabled patients who are depressed are vulnerable because their ability to advocate for themselves, seek out resources, and educate their health care providers may be compromised.

Many medical community members are beginning to address the “slippery slope” concerns that the physician-assisted suicide debate raises for persons with disabilities by devising therapeutic and administrative safeguards. No matter how carefully constructed, however, “safeguards” and “safety nets” will not protect patients devalued by a system and a society that views health care as a privilege, disability as a tragedy, and leaves the allocation of health care resources to the demands of the market.

\(^5^4\) More specific information regarding the survey’s participants and their answers will be released this year. See Kristi Kirschner et al. (manuscript in progress) (on file with authors).

The debate over physician-assisted suicide will continue in state legislatures, state regulatory agencies, and state funding agencies. 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, ethicists, and many others. Hospitals will need to reassess their internal review policies in light of the Supreme Court's unwillingness to invalidate existing criminal statutes. Lawyers will need to reevaluate their duties to clients, both individual and institutional. Ultimately, the physician-assisted suicide debate needs to be guided by an understanding of the lives of persons throughout society who face end-of-life decisions.

After Quill and Glucksberg, as before, state legislatures have the authority to criminalize assisting suicide by doctors and others, enact statutes regulating physician-assisted suicide, or abstain from the issue and apply existing criminal statutes to assisted suicide situations. Viewing assisted suicide as a public health issue provokes examination of the preventive measures that have been taken to lower risk factors and improve life potentials for groups at risk, particularly for all members of the disability community.

The Americans with Disabilities Act of 1990 (ADA) will increasingly factor into the socially-assisted dying debate. The ADA 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. Persons with disabilities involved in the physician-assisted suicide dialogue at the conference 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. Therefore, physician-assisted suicide should be legalized to avoid the overprotective rules and policies that Congress targeted in enacting the ADA. Opponents of legalizing physician-assisted suicide argue that inadequate health care and health insurance coverage, and the lack of economic power of many people with disabilities will extend to the lack of a voice in life-ending decision-making. Thus, if terminally ill patients are not receiving adequate

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56 The discussion will also continue in academic journals. See, e.g., Yale Kamisar, Pope and John Lecture, 88 J. CRIM. L. & CRIMINOLOGY (forthcoming 1998).


58 Participants in the conference commented that disabled persons received different care and medical advice, based upon the view of their condition by medical professionals. See
palliative or mental health care, opponents argue that they are not receiv-
ing equal access to health care as mandated by the ADA.

Participants in the Socially-Assisted Dying Conference agreed that reliable data are lacking on a broad range of factors in this debate. A strong and comprehensive factual basis is needed to support a reasonable policy position on either side. The next generation of decisions to be made may not be less but more complex than those that faced the plaintiff in *Quill* and *Glucksberg*.

Conference Transcript, *supra* note 7 (remarks of Carol Gill, Marca Bristo and Audience Participants in Session V).