

## PHYSICIAN-ASSISTED DYING AND THE SLIPPERY SLOPE: THE CHALLENGE OF EMPIRICAL EVIDENCE

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Direct physician-assisted dying, typically called physician-assisted suicide by opponents and aid in dying by proponents, is of increasing salience for at least two reasons: legal evolution and changing demographics. As of this writing, physician-assisted dying has been legal in Oregon for a decade. Known as Measure 16 at the ballot box, the Death with Dignity Act (ODDA, or, in Oregon, DWDA) passed in 1994 and came into effect in 1997.<sup>1</sup> Under the Act, it is legal for a physician to provide a lethal drug prescription to a terminally ill Oregon resident who voluntarily requests it, if that resident is a legally competent adult.<sup>2</sup> Under a set of safeguards, the statute allows a person to “end his or her life in a humane and dignified manner.”<sup>3</sup> Voluntary physician-performed euthanasia, wherein the physician administers the lethal drug, is prohibited in Oregon, but it is legal in the Netherlands, Belgium,<sup>4</sup> and, as is expected to become the case shortly, Luxemburg.<sup>5</sup> Non-physician assisted suicide, under specific conditions, is legal in Switzerland, and

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1. OR. REV. STAT. §§ 127.800–127.995 (2007). For a history of the passage of the ODDA, see Kathryn L. Tucker, *In the Laboratory of the States: The Progress of Glucksberg’s Invitation to States to Address End-of-Life Choice*, 106 MICH. L. REV. 1593, 1600–03 (2008). For additional information, see Oregon.gov, Death with Dignity Act, <http://oregon.gov/DHS/ph/pas/index.shtml> (last visited Oct. 21, 2008).

2. OR. REV. STAT. §§ 127.800–127.995 (2005).

3. OR. REV. STAT. §§ 127.805(1) (2005).

4. For an exhaustive account of the law in the Netherlands and Belgium, as well as other European countries, see generally JOHN GRIFFITHS, HELEEN WEYERS, & MAURICE ADAMS, *EUTHANASIA AND LAW IN EUROPE* (2d ed. 2008).

5. The Luxemburg law was given first passage on February 19, 2008. See Julien Ponthus, *Luxembourg Parliament Adopts Euthanasia Law*, REUTERS, Feb. 20, 2008, <http://www.reuters.com/article/worldNews/idUSL2011983320080220>. See also GRIFFITHS, WEYERS, & ADAMS, *supra* note 4.

not illegal in Germany.<sup>6</sup> Over the last several decades, there has been ongoing social and legal ferment in Britain, Australia, France, Spain, Italy, Mexico, China, and many other advanced industrial nations over the medical management of the end of life.<sup>7</sup>

It is in these nations that changing demographics exacerbate the issues. Highly sophisticated health care systems combined with declining birthrates mean that many of the industrialized countries are very rapidly “graying”; there will be more old people than young, and the old will experience more protracted and more highly medicalized deaths. In addition to concerns over the personal and social costs of extended periods of active dying, the perception of enormous health care costs at the end of life is also looming, even if those costs are rarely fully articulated. This further freights the issue.

The central question, thus, becomes whether, and to what degree, active intervention in or facilitation of the dying process is appropriate, both ethically and legally. Should physician-assisted dying be socially accepted, recognized, and legalized?

This article will examine objections to a specific sort of argument in this overall debate, particularly those objections focused on the issue of potential abuse. The article will examine the reactions to a recent, empirically-oriented paper, to be identified as the “target article.” Some of the objections to be considered along the way may seem trivial, and they sometimes represent mere misunderstandings or understandable exaggerations given for the purpose of effect. One, for instance, simply rails against “the vapidness of scientific studies,”<sup>8</sup> as if all empirical research could be jettisoned with a single blow. But some involve much deeper, more serious issues, and it is these objections that I wish to explore.

Many political organizations and religious groups have objected to both social acceptance and legalization of physician-assisted dying,

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6. See GRIFFITHS, WEYERS, & ADAMS, *supra* note 4; see also JOHN F. MONGALE & DAVID C. THOMASMA, *HEALTH CARE ETHICS: CRITICAL ISSUES FOR THE 21ST CENTURY* 315 (2004) (discussing Deutsches Gesellschaft für Humanes Sterben (DGHS) or German Society for Humane Dying).

7. See *Euthanasia: A Continent Divided*, BBC NEWS, Mar. 4, 2008, <http://news.bbc.co.uk/2/hi/europe/7322520.stm> (describing debate in Britain, France, Spain, and Italy); Ponthus, *supra* note 5 (noting debate in Mexico, Australia, and China).

8. Int'l Task Force on Euthanasia and Assisted Suicide, *New Euthanasia/Assisted-Suicide Study Draws International Criticism*, 21 UPDATE No. 3 (2007), available at <http://internationaltaskforce.org/iaa42.htm> (citing Wesley J. Smith, Bioethics.com, *Battin Assisted Suicide Report Demonstrates the Vapidity of “Scientific Studies,”* Sept. 27, 2007, <http://bioethics.com/?p=3383>).

including among the most vocal groups in the United States, the disability-rights organization Not Dead Yet,<sup>9</sup> the Catholic Church,<sup>10</sup> and the International Task Force on Euthanasia and Assisted Suicide, headquartered in Steubenville, Ohio.<sup>11</sup> Further, an ample array of bioethicists, theologians, physicians and hospice physicians, among others, have voiced their objections. All such objectors use both principle-driven and consequence-conscious reasoning.<sup>12</sup> Of course, the organizations and individuals supporting social acceptance and legalization of physician-assisted dying also form an ample array, and they too use principle-driven and consequentialist reasoning.<sup>13</sup> However, it is the purpose of this article to explore a key issue among the objections primarily raised by opponents of physician-assisted dying in responding to a specific kind of reasoning—that having to do with empirical evidence.

#### THE ARGUMENT OVER PHYSICIAN-ASSISTED DYING

First, a bit of background is necessary to understand where the issue of potential abuse in physician-assisted death is located in the overall landscape of discussions concerning end-of-life issues. The following schema in Box 1 summarizes the major positions taken in the dispute over physician-assisted dying.

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9. See, e.g., Not Dead Yet, <http://www.mcil.org/mcil/mcil/ndy.htm> (last visited Oct. 19, 2008) (describing Not Dead Yet as “a national disability rights group which opposes the legalization of assisted suicide and euthanasia, because of the lethal danger to this nation’s largest minority group, people with disabilities.”).

10. See, e.g., CATECHISM OF THE CATHOLIC CHURCH: PART THREE—LIFE IN CHRIST, § 2, ch. 2, art. 5, ¶ 2277, available at [http://www.vatican.va/archive/ccc\\_css/archive/catechism/p3s2c2a5.htm](http://www.vatican.va/archive/ccc_css/archive/catechism/p3s2c2a5.htm).

11. See, e.g., Int’l Task Force on Euthanasia and Assisted Suicide, <http://www.internationaltaskforce.org/> (last visited Oct. 19, 2008) (describing the organization as “[a]ddressing the issues of euthanasia, assisted suicide, advance directives, assisted suicide proposals, ‘right-to-die’ assisted suicide in Oregon, cases, euthanasia practices in the Netherlands, disability rights, pain control and much, much more.”).

12. See, e.g., THE CASE AGAINST ASSISTED SUICIDE: FOR THE RIGHT TO END-OF-LIFE CARE (Kathleen Foley & Herbert Hendin eds., 2002).

13. See, e.g., PHYSICIAN-ASSISTED DYING: THE CASE FOR PALLIATIVE CARE AND PATIENT CHOICE (Timothy E. Quill & Margaret P. Battin eds., 2004).

Box 1: *The Argument Concerning Physician-Assisted Dying*

<i>The argument for physician-assisted dying</i>	<i>The argument against physician-assisted dying</i>
Autonomy	Wrongness of killing
Mercy	Possibility of abuse

The two principal arguments asserted by proponents of assisted dying are phrased in terms of autonomy and mercy.<sup>14</sup> Proponents argue that these ethical principles must govern the very end of life. Under the principle of autonomy or self-determination, people are entitled to be the architects of the very end of their lives; this liberty-right includes dying in a way that is in accord with one's own values and interests—provided, of course, that the harm principle is satisfied and that this does not constitute a serious harm to others.<sup>15</sup> In addition, any indirect expression of preferences that a presently incompetent person had made prior to incapacity are also to be honored under the principle of autonomy—here, advance directives or surrogate decision-makers may be brought into play.<sup>16</sup> Yet the principle of autonomy itself is clear enough: a person is entitled to decide, as far as possible, how the end of his or her life shall go, provided it does not harm others, and provided he or she has the capacity to do so.

The principle of mercy is typically less clearly phrased, but plays an equally important role. It holds that pain and suffering are to be

14. For further elucidation of the discussion in this section, see generally Margaret P. Battin, *Euthanasia*, in *HEALTH CARE ETHICS* 58 (Donald VanDeVeer & Tom Regan eds., 1987) [hereinafter Battin, *Euthanasia*]; Margaret P. Battin, *Euthanasia and Physician-Assisted Suicide*, in *THE OXFORD HANDBOOK OF PRACTICAL ETHICS* 673 (Hugh LaFollette ed., 2003) [hereinafter Battin, *Euthanasia and Physician Assisted Suicide*]; Margaret P. Battin, *Terminal Sedation: Pulling the Sheet Over Our Eyes*, *HASTINGS CTR. REP.*, Sept.–Oct. 2008, at 27–28 [hereinafter Battin, *Terminal Sedation*].

15. E.g., Battin, *Euthanasia*, *supra* note 14, at 67. For a brief definitions of terms, see also Timothy E. Quill & Jane Greenlaw, *Physician Assisted Death*, in *FROM BIRTH TO DEATH AND BENCH TO CLINIC: THE HASTINGS CENTER BIOETHICS BRIEFING BOOK FOR JOURNALISTS, POLICYMAKERS, AND CAMPAIGNS* 137 (2008), available at [www.thehastingscenter.org/Publications/BriefingBook/Detail.aspx?id=2202](http://www.thehastingscenter.org/Publications/BriefingBook/Detail.aspx?id=2202).

16. E.g., Battin, *Euthanasia*, *supra* note 14, at 67–68.

relieved to the extent possible, provided taking such action does not serve some further purpose in the treatment of disease, play a role in religious or other value-commitments of the person, or worsen the state of affairs for an individual.<sup>17</sup>

In my view, these two principles of autonomy and mercy “operate in tandem to underwrite physician-assisted dying: physician assistance in bringing about death is to be provided just when the person voluntarily seeks it and just when it serves to avoid pain and suffering or the prospect of them.”<sup>18</sup> Both of these requirements must be met. Because these principles do not operate independently, it cannot be claimed that permitting physician-assisted dying on the basis of the principle of autonomy would require providing it for lovesick teenagers who want to die but are not terminally ill; likewise, it cannot be claimed that permitting physician-assisted dying on the basis of the principle of mercy would require involuntary euthanasia for someone in pain who nevertheless wants to stay alive. *Both* principles must be in play; but when they are in play, they jointly provide a powerful basis for permitting and respecting physician aid in dying.

Opponents of physician-assisted dying base their objections on two central concerns. One is the principle of the wrongness of killing, variously called the principle of the sanctity of life, of respect for life, of the wrongness of suicide, or of the wrongness of murder.<sup>19</sup> The second objection, the possibility of abuse, is often identified in two ways. First, opponents are concerned with the possibility of undercutting the integrity of the medical profession; second, and closely related, they are concerned with the possibility of the “slippery slope,” the prediction that domestic, institutional, or social pressures will make people victims of assisted dying when that is not their choice.<sup>20</sup>

Both the wrongness-of-killing objection and the possibility-of-abuse objection are fears of those who oppose the legalization of physician aid in dying. However, these objections operate independently, and one could be opposed to euthanasia or assisted suicide on, say, religious grounds concerning the sanctity of life even without fearing the “slippery slope.” Alternatively, one could fear the

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17. See, e.g., Battin, *Euthanasia*, *supra* note 14, at 58–59.

18. Battin, *Terminal Sedation*, *supra* note 14, at 27.

19. See Battin, *Euthanasia and Physician-Assisted Suicide*, *supra* note 14, at 678.

20. See Battin, *Euthanasia and Physician-Assisted Suicide*, *supra* note 14, at 681–82.

corruption of physicians even though one has no principle-based or religious-principle-based objections.

In short, it is autonomy and mercy on the one side, and sanctity of life and/or the possibility of abuse on the other. That is the standoff, argued in a kaleidoscope of ways that vary around these central themes.

These debates have been ongoing over the past several decades among many countries around the globe with advanced industrial economies. These highly developed economies support elaborate health-care systems in which people typically die, at comparatively advanced ages, of degenerative diseases (heart disease, cancer, organ failure) with characteristic downhill slopes.<sup>21</sup> Moral, legal, and religious arguments are all typically addressed under these headings, but it is specifically the empirical arguments about the possibility of abuse that I wish to address in this article.

#### THE 800-POUND GORILLA: THE ISSUE OF ABUSE

In this ongoing debate about physician-assisted dying, the 800-pound gorilla has been concern about the potential for abuse: the possibility that social acceptance and/or legalization of physician-assisted dying will lead to generalized, widespread abuse. Exactly *what* is feared varies from one party to another, but what is most frequently articulated is the fear of pressures particular to people in vulnerable groups.

Medical organizations, task forces, and courts in several countries where the issue is under debate have issued warnings about potential abuse. Box 2 presents a collection of such warnings, citing the many different groups identified as potentially vulnerable: the poor, the elderly, members of a minority group, people without access to good medical care (presumably, the uninsured), people with disabilities, the incompetent, those with chronic (rather than terminal) illnesses, young children, and people with dementia.

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21. Joanne Lynn, *Living Long in Fragile Health: The New Demographics Shape End of Life Care*, HASTINGS CTR. REP., Nov.–Dec. 2005 (supp.), at S14–S18.

Box 2: *Concerns about Vulnerable Patients in Health Policy: Statements on Physician-Assisted Dying*<sup>22</sup>

“ . . . no matter how carefully any guidelines are framed, assisted suicide and euthanasia will be practiced through the prism of social inequality and bias that characterizes the delivery of services in all segments of our society, including health care. The practices will pose the greatest risks to those who are poor, elderly, members of a minority group, or without access to good medical care.”

New York State Task Force on Life and the Law, 1994<sup>23</sup>

“ . . . the State has an interest in protecting vulnerable groups—including the poor, the elderly, and disabled persons—from abuse, neglect, and mistakes. The Court of Appeals [Ninth Circuit] dismissed the State’s concern that disadvantaged persons might be pressured into physician-assisted suicide as ludicrous on its face. . . . We have recognized, however, the real risk of subtle coercion and undue influence in end of life situations.”

U.S. Supreme Court, joint opinion in  
Washington v. Glucksberg and Vacco v. Quill, 1997<sup>24</sup>

“Euthanasia and assisted suicide are opposed by almost every national medical association and prohibited by the law codes of almost all countries. . . . If euthanasia or assisted suicide or both are permitted for competent, suffering, terminally ill patients, there may be legal challenges . . . to extend these practices to others who are not competent, suffering or terminally ill. Such extension is the “slippery slope” that many fear.”

Canadian Medical Association, 1998<sup>25</sup>

22. Adapted by permission from BMJ Publishing Group Limited. Margaret P. Battin et al., *Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in “Vulnerable” Groups*, 33 J. MED. ETHICS 591, 592 bx.1 (2007) [hereinafter *Target Article*].

23. THE NEW YORK STATE TASK FORCE ON LIFE & THE LAW, WHEN DEATH IS SOUGHT: ASSISTED SUICIDE AND EUTHANASIA IN THE MEDICAL CONTEXT xiii (1994), available at <http://www.health.state.ny.us/nysdoh/consumer/patient/preface.htm>.

24. *Washington v. Glucksberg*, 521 U.S. 702, 731–32 (1997); see also *Vacco v. Quill*, 521 U.S. 793 (1997).

25. Canadian Med. Ass’n, Policy Statement, Euthanasia and Assisted Suicide (1998), [http://www.cma.ca/index.cfm/ci\\_id/3214/la\\_id/1.htm](http://www.cma.ca/index.cfm/ci_id/3214/la_id/1.htm).

“Both society in general and the medical profession in particular have important duties to safeguard the value of human life. This duty applies especially to the most vulnerable members of society—the sick, the elderly, the poor, ethnic minorities, and other vulnerable persons. In the long run, such persons might come to be further discounted by society, or even to view themselves as unproductive and burdensome, and on that basis, “appropriate” candidates for assistance with suicide.”

“. . . the ramifications [of legalization] are too disturbing for the . . . value our society places on life, especially on the lives of disabled, incompetent, and vulnerable persons.”

American College of Physicians—American Society of Internal Medicine (ACP-ASIM), 2001<sup>26</sup>

“. . . the College concluded that making physician-assisted suicide legal raised serious ethical, clinical, and social concerns and that the practice might undermine patient trust and distract from reform in end of life care. The College was also concerned with the risks that legalization posed to vulnerable populations, including poor persons, patients with dementia, disabled persons, those from minority groups that have experienced discrimination, those confronting costly chronic illnesses, or very young children.”

American College of Physicians, 2005<sup>27</sup>

“. . . allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks . . .”

“Euthanasia could also readily be extended to incompetent patients and other vulnerable populations . . .”

The American Medical Association, 1996,<sup>28</sup> 2005<sup>29</sup>

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26. Lois Snyder & Daniel P. Sulmasy, Ethics & Human Rights Comm., Am. Coll. of Physicians—Am. Soc’y of Internal Med., *Physician-Assisted Suicide*, 135 ANNALS OF INTERNAL MED. 209, 212–13, 214 (2001), available at <http://www.annals.org/cgi/reprint/135/3/209.pdf>.

27. Lois Snyder & Cathy Leffler, Ethics & Human Rights Comm., Am. Coll. of Physicians, *Ethics Manual*, 142 ANNALS OF INTERNAL MED. 560, 570 (2005), available at <http://www.annals.org/cgi/reprint/142/7/560.pdf>.



“In the BMA’s view, legalizing euthanasia or physician-assisted suicide would have a profound and detrimental effect on the doctor-patient relationship. It would be unacceptable to put vulnerable people in the position of feeling they had to consider precipitating the end of their lives . . . The BMA acknowledges that there are some patients for whom palliative care will not meet their needs and wishes, but considers that the risks of significant harm to a large number of people are too great to accommodate the needs of very few.”

British Medical Association, 2003<sup>30</sup>

Are these fears well founded? For a decade, there was little or no way to answer this question because there had been no empirical study produced that was expressly directed towards the issue of abuse of people in vulnerable groups—though the primary data was there for anyone who might have wished to look at it.

#### AN EMPIRICAL STUDY CONCERNING THE ISSUE OF ABUSE

This changed in October 2007, when a group of researchers, myself included, published an article that directly addressed the issue of the abuse of vulnerable people in physician-assisted dying.<sup>31</sup> The article, “Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in ‘Vulnerable’ Groups,” was authored by five individuals: four epidemiologist and/or physician authors (Linda Ganzini MD in Oregon and Agnes van der Heide, MD, PhD, Gerrit van der Wal, MD, PhD, and Bregje Onwuteaka-Philipsen, PhD, in the Netherlands), and myself, someone whose background in philosophy encourages asking questions no one else had thought to pose. The article was published in a British journal of bioethics, *The Journal of Medical Ethics*, with a companion editorial by Timothy Quill, MD in the *British Medical*

28. Am. Med. Ass’n, Ethical Statement E-2.211, Physician-Assisted Suicide (1996) (reaffirmed Aug. 22, 2005), available at <http://ama-assn.org/ama1/pub/upload/mm/31/policye-2-211.pdf>.

29. Am. Med. Ass’n, Ethical Statement E-2.21, Euthanasia (1996) (reaffirmed Aug. 22, 2005), available at <http://ama-assn.org/ama1/pub/upload/mm/31/policye-2-21.pdf>.

30. British Med. Ass’n, End of Life Issues—Patient (Assisted Dying) Bill, June 2003.

31. *Target Article*, *supra* note 22. Some of the material in that brief article, including that adapted in Box 2, the complete results and findings, and some of the discussion, is introduced in the present work and used by permission of the BMJ Publishing Group Limited.

*Journal*.<sup>32</sup> Because this article has been a principal target of much of the criticism to be explored in my discussion here and because it is, as far as I know, the first empirical attempt to address the issue of abuse of groups identified as vulnerable, I take it as a focus for my discussion here. I hasten to stress that this discussion reflects my views alone, not necessarily those of all five authors of the target article.

The target article uses data from both Oregon and the Netherlands—the two jurisdictions where physician assistance in dying is legal and where data is available over an extended period of time—to consider whether there is evidence of disparate impact on people in vulnerable groups in either of these jurisdictions. Sources for the Oregon data included the “nine annual reports issued by the Department of Human Services [which] cover the period since the Oregon Death with Dignity Act (ODDA) took effect in 1997,”<sup>33</sup> plus three surveys of Oregon physicians and hospice professionals.<sup>34</sup> The Oregon data used in the target study are from the Oregon Department of Human Services 2006 report (which includes cumulative data).<sup>35</sup> Since the target study was published, the Oregon data has been updated with another year’s report, but there are no significant changes from the patterns reported in the 2006 report. From the Netherlands, the target article used primary data from the “four nationwide studies (the first of which is known as the Rummelink report) commissioned by the Dutch government . . . [concerning] end-of-life decision making in the years 1990, 1995, 2001, and 2005,”<sup>36</sup> as

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32. Timothy E. Quill, *Physician Assisted Death in Vulnerable Populations*, 335 BRIT. MED. J. 625 (2007).

33. *Target Article*, *supra* note 22, at 592 (citing OR. DEP’T OF HUMAN SERV., OFFICE OF DISEASE PREVENTION & EPIDEMIOLOGY, NINTH ANNUAL REPORT ON OREGON’S DEATH WITH DIGNITY ACT (2007), available at <http://oregon.gov/DHS/ph/pas/docs/year9.pdf> [hereinafter NINTH ANNUAL REPORT ON ODDA] (includes references to all previous annual and cumulative reports)).

34. *Id.* (citing Linda Ganzini et al., *Physicians’ Experiences with the Oregon Death with Dignity Act*, 342 NEW ENG. J. MED. 557 (2000), available at <http://content.nejm.org/cgi/reprint/342/8/557.pdf>; Linda Ganzini et al., *Experiences of Oregon Nurses and Social Workers with Hospice Patients Who Requested Assistance with Suicide*, 347 NEW ENG. J. MED. 582 (2002), available at <http://content.nejm.org/cgi/content/full/347/8/582>; Susan W. Tolle et al., *Characteristics and Proportion of Dying Oregonians Who Personally Consider Physician-Assisted Suicide*, 15 J. CLINICAL ETHICS 111 (2004), available at [http://www.compassionandchoices.org/documents/susan\\_tolle.pdf](http://www.compassionandchoices.org/documents/susan_tolle.pdf)).

35. *Id.* (referring to NINTH ANNUAL REPORT ON ODDA (includes references to all previous annual and cumulative reports)).

36. *Id.* (citing Paul J. van der Maas et al., *Euthanasia and Other Medical Decisions*

well as several smaller, focused Dutch studies.<sup>37</sup> “[T]he Dutch data are from the 2005 nationwide study unless otherwise mentioned.”<sup>38</sup> In effect, the target study covers all the primary data available in Oregon over a nearly ten-year period and in the Netherlands over a period of slightly more than twenty years.

Because the target article is brief and succinct, this present article will reiterate some of the background, sketch the target article’s methodology, and quote the full results. The focus of the present article is on the objections that have been raised to the target article, which was the first attempt to assemble comprehensive *empirical* data about the issue of abuse of the vulnerable. Such objections are of particular importance not only because they reveal many of the misunderstandings of this debate, but also because they point the way for future research.

#### OBJECTIONS TO THE EMPIRICAL STUDY OF ABUSE IN VULNERABLE GROUPS

Objections following the publication of the target article and coordinated editorial have been of three general kinds: to the Oregon Death with Dignity Act and its reporting system; to the Netherlands’

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*Concerning the End of Life*, 22 HEALTH POL’Y 1 (1992) (the full English version of the first nationwide “Rommelink Report”), summarized in 338 THE LANCET 669 (1991); Paul J. van der Maas et al., *Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990–1995*, 335 NEW ENG. J. MED. 1699 (1996), available at <http://content.nejm.org/cgi/content/abstract/335/22/1699> (this second nationwide study is a five-year replication study); Bregje D. Onwuteaka-Philipsen et al., *Euthanasia and Other End-of-Life Decisions in the Netherlands in 1990, 1995, and 2001*, 362 THE LANCET 395 (2003) (the third in this series of nationwide studies); Agnes van der Heide et al., *End-of-Life Practices in the Netherlands Under the Euthanasia Act*, 356 NEW ENG. J. MED. 1957 (2007), available at <http://content.nejm.org/cgi/reprint/356/19/1957.pdf> (the fourth nationwide study)).

37. *Id.* at 594, 596 (citing Marijke C. Jansen-van der Weide et al., *Granted, Undecided, Withdrawn, and Refused Requests for Euthanasia and Physician-Assisted Suicide*, 165 ARCHIVES OF INTERNAL MED. 1698 (2005), available at <http://archinte.ama-assn.org/cgi/reprint/165/15/1698>; Patrick J.E. Bindels et al., *Euthanasia and Physician-Assisted Suicide in Homosexual Men with AIDS*, 347 THE LANCET 499 (1996); G. van der Wal et al., *Medische besluitvorming aan het einde van het leven. De praktijk en de toetsingsprocedure euthanasie [Medical Decision-Making at the End of Life. Practice and Notification Procedure for Euthanasia]*, UTRECHT: DE TIJDSTROOM (2003) (Neth.); Marije L. van der Lee et al., *Euthanasia and Depression: A Prospective Cohort Study Among Terminally Ill Cancer Patients*, 23 J. CLINICAL ONCOLOGY 6607 (2005), available at <http://www.jcojournal.org/cgi/reprint/23/27/6607>; Mette L. Rurup et al., *Physicians’ Experiences with Demented Patients with Advance Euthanasia Directives in the Netherlands*, 53 J. AM. GERIATRICS SOC’Y 1138 (2005)).

38. *Id.* at 592 (referring to van der Heide et al., *supra* note 36).

practices and reporting patterns, as well as to the four nationwide studies that provide information about those practices and reporting patterns; and to the specific empirical study reported in the target article itself. This article will focus particularly on the third category, since objections to the target article itself typically also include objections to the Oregon and Netherlands laws, reporting systems, or practices. In addition, this article will focus on objections to the target article because empirical research on the issue of abuse of vulnerable people is of central importance in the argument about physician-assisted dying. Finally, as one of the authors of the target article, I also have a personal interest in exploring such objections.

Objections to social acceptance or legalization of physician-assisted dying for fear of the possibility of abuse should be taken very, very seriously. The target article asked:

Would accepting or legalising physician-assisted dying at a patient's explicit request weigh more heavily on patients in vulnerable groups—the elderly, women, the uninsured, the poor, racial or ethnic minorities, people with disabilities, people with sometimes stigmatised illnesses like AIDS, and others? Would vulnerable patients be especially heavily targeted? Would these patients be pressured, manipulated, or forced to request or accept physician-assisted dying by overburdened family members, callous physicians, or institutions or insurers concerned about their own profits? This slippery slope argument assumes that abusive pressures would operate on all seriously or terminally ill patients but would selectively disfavour patients whose capacities for decision making are impaired, who are subject to social prejudice or who may have been socially conditioned to think of themselves as less deserving of care. These pressures would result, it is assumed, in heightened risk for physician-assisted dying among vulnerable persons compared with background populations.<sup>39</sup>

If it is true that patterns of abuse particularly affecting people in vulnerable groups are evident, proponents of physician-assisted dying (myself included) will have to rethink their support for such practices. As the target article insists, the objections that have been raised include:

[C]oncerns both for those who oppose physician-assisted dying on moral grounds and for those who support it but are uneasy about

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39. Reproduced with permission from BMJ Publishing Group Limited. Margaret P. Battin et al., *Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in "Vulnerable" Groups*, 33 J. MED. ETHICS 591, 591 (2007).

the possible social consequences of legalisation. They are also concerns for proponents of legalisation who assume that the risks for vulnerable patients are heightened if these practices remain underground, as well as for those who favour legalisation but fear that vulnerable patients will be denied a privilege reserved for better-situated patients and that healthcare inequities already affecting vulnerable persons will be exacerbated. In short, slippery-slope concerns about vulnerable patients confront both those who do and those who do not find physician-assisted dying objectionable on moral grounds.<sup>40</sup>

In short, we need to look at issues of abuse closely and in a non-ideological way. We must seek to prevent abuse if it is occurring, or is likely to occur. Conversely, we must also refrain from blocking a practice that is legal, does not result in abuse, and is desired by some patients. The underlying reason for looking at these objections thus becomes the dual objective of preventing abuse while also recognizing the liberty of an individual to act on his or her own values where no abuse is present. To simply assert that abuse could occur is not an adequate argument, though it has been the mainstay of almost all secular opposition. It is time to evaluate such claims more thoroughly.

Although most opposition to physician-assisted dying is phrased in terms of the mere possibility for abuse, this is not to say that the issue has not been examined further. Actually, there have been many other works addressing the issue of abuse in the context of physician-assisted dying. A recent example is a book titled *Understanding Assisted Suicide: Nine Issues to Consider*, authored by John B. Mitchell.<sup>41</sup> Mitchell explores whether “permitting physician-assisted suicide would/would not result in a ‘slippery slope’ ending in involuntary termination of our most vulnerable and powerless citizens.”<sup>42</sup> While the work is alert to some of the empirical evidence available, it does not attempt to assess that information in a systematic way. Similarly, many other critiques—both positive but especially those that are negative—point to some of the empirical data from

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40. Reproduced with permission from BMJ Publishing Group Limited. Margaret P. Battin et al., *Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in “Vulnerable” Groups*, 33 J. MED. ETHICS 591, 591 (2007).

41. See generally JOHN B. MITCHELL, *UNDERSTANDING ASSISTED SUICIDE: NINE ISSUES TO CONSIDER* (2007).

42. *Id.* at 57–104.

Oregon and the Netherlands, but often in a selective manner and without a rigorous assessment of such data.<sup>43</sup>

The target article constituted an effort to provide an empirical evaluation of abuse based on a thorough analysis of all available data. As a sequel, the present article examines several responses to the target article<sup>44</sup> and its effort to assemble *empirical* evidence concerning the possibility of abuse.

#### WHAT THE TARGET STUDY SHOWS: NO EVIDENCE OF ABUSE OF PEOPLE IN VULNERABLE GROUPS

What follows are the results, drawn directly from the target article; they provide an overview of all the then-available empirical data in Oregon and the Netherlands. The data are drawn from multiple sources, address differing questions, and are of varying strengths; the results are presented in descending order from those based on the most robust data to those based on data which is partial, inferential, or in other ways less secure. The results are presented verbatim and in detail because the data is complex and considerable misunderstanding has arisen from inaccurate assessment. Since the target study was published, the Oregon data has been updated with another year's report, but there are no significant changes from the patterns reported here.

#### Box 3: *Results from the Target Study*<sup>45</sup>

##### **IS THERE EVIDENCE OF HEIGHTENED RISK TO PEOPLE IN VULNERABLE GROUPS?**

###### **Findings based on robust data**

###### The elderly: no evidence of heightened risk

In Oregon, 10% of patients who died by PAS [physician-assisted suicide] were 85 or older, whereas 21% of all Oregon deaths were among persons in

43. See, e.g., THE CASE AGAINST ASSISTED SUICIDE, *supra* note 12; PHYSICIAN-ASSISTED DYING, *supra* note 13.

44. Responses to the target article included letters, blog entries, articles concerning both the target article itself and the coordinated editorial in the *British Medical Journal*, as well as various other writings on the possibility of abuse.

45. Adapted by permission from BMJ Publishing Group Limited. Margaret P. Battin et al., *Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in "Vulnerable" Groups*, 33 J. MED. ETHICS 591, 594-96 (2007).

this age category. Persons aged 18–64 years were over 3 times more likely than those over age 85 years to receive assisted dying. In the Netherlands, rates of assisted dying were lowest in the people over 80 (0.8% in 2005), next lowest in the age range 65–74 years (2.1%) and higher below age 65 (3.5%). People over 80 formed 30% of the group of patients whose requests were refused and 13% of those whose requests were granted and carried out.<sup>46</sup>

Women: no evidence of heightened risk

In Oregon, 46% of individuals receiving assisted dying were women and women were not more likely than men to use assisted suicide. In the Netherlands, despite some fluctuation in different years of the nationwide studies, the rates tend to be slightly higher in men.

Uninsured people: no evidence of heightened risk

Three Oregon patients (1%) did not have documented health insurance, and in four cases, insurance status was unknown. In contrast, 16.9% of non-elderly adults in Oregon were uninsured<sup>47</sup> (persons 65 and older are insured by Medicare). In the Netherlands, virtually all patients are covered by mandated nationwide health insurance.

People with AIDS: heightened risk found

In nine years in Oregon, a total of six persons with AIDS died under the ODDA; although the numbers are small (2% of the total of 292 ODDA deaths), persons with AIDS were 30 times more likely to use assisted dying than those who died of chronic respiratory disorders in the interview portions of the nationwide studies in the Netherlands, very few patients with AIDS had received a physician's assistance in dying. However, in an Amsterdam cohort of 131 homosexual men with AIDS diagnosed between 1985 and 1992 who had died before 1 January 1995, 22% died by euthanasia or PAS.<sup>48</sup>

**Findings based on partly direct, partly inferential data**

People with low educational status: no evidence of heightened risk

In Oregon, the likelihood of dying by PAS was correlated with higher educational attainment. Terminally ill college graduates in Oregon were 7.6 times more likely to die with physician assistance than those without a high

46. Jansen-van der Weide et al., *supra* note 37.

47. Kaiser Family Foundation, State Health Facts Online, <http://www.statehealthfacts.org/profileind.jsp?ind=126&cat=3&rgn=39> (last visited Oct. 24, 2008).

48. Bindels et al., *supra* note 37.

school diploma. While no direct quantified data are available in the Netherlands about the educational status of patients receiving assisted dying, information in the 1990 study about professional status, associated with educational status, showed no special relationships to patterns of euthanasia or PAS.

The poor: no evidence of heightened risk

The Oregon data do not include direct measures of income, employment or assets, but death under the ODDA was associated with having health insurance and with high educational status, both indirect indicators of affluence. In the Netherlands, data inferred from the postal codes of the location in which the person was living before death showed that the overall rates of assisted dying were somewhat higher for people of higher socioeconomic status.<sup>49</sup>

Racial and ethnic minorities: no evidence of heightened risk

In Oregon, 97% of the 292 patients who had a physician's assistance in suicide were white; six of the non-white patients were persons of Asian descent, one was Hispanic and one was Native American. Although 2.6% of Oregonians are African-American, no African-American has received physician-assisted dying under the Act. Dutch mortality statistics do not include information about race or ethnicity; however, even the most vocal opponents of assisted dying in the Netherlands do not claim that it is imposed more frequently on stigmatised racial or ethnic minorities.

Persons with nonterminal physical disabilities or chronic nonterminal illnesses: no evidence of heightened risk

In one sense, virtually all patients who are seriously or terminally ill are to some extent physically disabled and chronically ill. Patients who are dying lose functional capacities and may be bedridden toward the end; in this sense, most patients who received assistance in dying in either Oregon or the Netherlands were chronically ill and (recently) disabled. Cancer, the diagnosis in about 80% of all cases of assisted dying in both Oregon and the Netherlands, is often identified as a chronic illness; so is amyotrophic lateral sclerosis (ALS), also a frequent diagnosis. Concerns about persons in vulnerable categories have focused, however, on pre-existing physical disabilities and chronic non-terminal illnesses.

Although the data from Oregon do not indicate whether a person had a disability before becoming terminally ill (defined as having 6 months or less

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49. van der Wal et al., *supra* note 37.



to live), no one received physician-assistance in dying who was not determined by two physicians to be terminally ill—that is, no one received such assistance for disability alone. That some patients received lethal prescriptions that they did not ingest and lived longer than 6 months may represent limitations in prognostication, although clinicians caring for terminally ill cancer patients are likely to overestimate rather than underestimate survival.<sup>50</sup> In the Netherlands, assisted dying for disability alone would not be illegal in principle; a terminal diagnosis is not required by the Dutch guidelines, and a person who faces unbearable suffering, in his or her own view, and who has been offered all forms of treatment but has no hope of improvement may request assistance in dying. Estimates made by physicians of the amount of life forgone can be used to make an approximation of disability or chronic illness status: about 0.2% of patients receiving euthanasia or assistance in suicide were estimated to have forgone more than 6 months of life, or less than 10 of the approximately 2400 cases in 2005. Dutch general practitioners infrequently grant and frequently refuse assistance in dying to patients whose diagnosis is “old age/general deterioration” or “other” (this includes the category of patients with no terminal illness and no ALS or multiple sclerosis).<sup>51</sup> There is thus no evidence that physician-assisted dying poses heightened risk to people with disabilities who are not also seriously ill.

Minors and mature minors: no evidence of heightened risk

The Oregon ODDA requires that a patient be an adult (18 years of age or older) before assisted dying is granted; no cases of physician-assisted death were reported among minors. In the Netherlands, mature and relatively mature minors are understood to have some decision-making capacity and are not excluded under the Dutch guidelines, but because they are below the age of majority must be regarded as “vulnerable.” Since death rates among minors in the Netherlands (0.4% of all deaths) were the lowest in any age group, it is difficult to reach statistically firm conclusions. In 2001, less than 1% of all deaths of persons aged 1–17 years were the result of euthanasia: no cases of PAS were found in this age group.

The Netherlands has recently developed a protocol for euthanasia in newborns with very serious deficits who have a hopeless prognosis and experience what parents and medical experts deem to be unbearable suffering; the decision is to be made in collaboration with the parents and

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50. Paul Glare et al., *A Systematic Review of Physicians' Survival Predictions in Terminally Ill Cancer Patients*, 327 BRIT. MED. J. 195 (2003), available at <http://www.bmj.com/cgi/reprint/327/7408/195.pdf>; NICHOLAS A. CHRISTAKIS, *DEATH FORETOLD* (1999).

51. Jansen-van der Weide et al., *supra* note 37, at 1700 tbl.1.

requires their full approval. This is known as the Groningen protocol.<sup>52</sup> Such cases are infrequent—22 cases have been reported to district attorneys in the Netherlands during the past 7 years, and there are an estimated 10 to 20 cases annually among the somewhat over 1000 children born in the Netherlands who die during the first year of life, about 1% of newborn deaths.

#### **Findings based on inferential or partly contested data**

##### Patients with psychiatric illness, including depression and Alzheimer Disease: no evidence of heightened risk

Approximately 20% of requests for physician assistance in dying came from depressed patients, but none progressed to PAS.<sup>53</sup> None of the 292 patients who died under the ODDA were determined to have a mental illness influencing their decision, though there have been three disputed cases among the 9-year total of 456 who received prescriptions.<sup>54</sup> Because not all patients who requested assistance were specifically evaluated by mental health professionals and because many cases of depression are missed in primary care, it is possible that some depressed patients received lethal prescriptions; it is also possible that a patient without a mental disorder at the time of receiving the prescription became depressed by the time they ingested it. There is, however, no direct evidence that depressed patients are at higher risk for receiving assistance in dying under the ODDA.

In the Netherlands, about two-thirds of explicit requests for assistance in dying are not granted. In 31% of all requests not granted in the 1995 study, the physician gave the presence of psychiatric illness as at least one reason for not complying. Physicians in the interview portion of the 1995 Dutch nationwide study mentioned depression as the predominant symptom in patients who died by PAS or euthanasia in 3% of all cases, compared with “loss of dignity” in 60%, pain as an associated complaint in 45% and debility in 43%. In one study, cancer patients with depressed mood were

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52. Eduard Verhagen & Pieter J.J. Sauer, *The Groningen Protocol—Euthanasia in Severely Ill Newborns*, 352 NEW ENG. J. MED. 959, 959 (2005), available at <http://content.nejm.org/cgi/reprint/352/10/959.pdf> (Despite the title of that article, the practice is more frequently called “termination of life” rather than “euthanasia” when referring to newborns.).

53. Ganzini et al., *Physicians’ Experiences with the Oregon Death with Dignity Act*, *supra* note 34.

54. N. Gregory Hamilton & Catherine A. Hamilton, *Competing Paradigms of Response to Assisted Suicide Requests in Oregon*, 162 AM. J. PSYCHIATRY 1060 (2005), available at <http://ajp.psychiatryonline.org/cgi/reprint/162/6/1060>; Linda Ganzini, Letter to the Editor, *Physician-Assisted Suicide*, 163 AM. J. PSYCHIATRY 1109 (2006) available at <http://ajp.psychiatryonline.org/cgi/reprint/163/6/1109-a>.

four times more likely to request euthanasia, but how often the request was granted is unknown.<sup>55</sup>

In 1994, the Dutch supreme court ruled in the *Chabot* case, in which a psychiatrist assisted with suicide for a woman with intractable depression but without concomitant physical illness, that “intolerable suffering” might consist in mental suffering alone without somatic origins and not involving the terminal phase of a disease, though the Court commented that such cases would be rare and that they require heightened scrutiny.<sup>56</sup> The 2001 Dutch interview study estimated that about 3% of all requests for euthanasia or PAS that physicians had received the previous year were from patients with predominantly psychiatric or psychological illnesses, but none were granted. In the Dutch 1995 nationwide substudy on end-of-life decision making in psychiatric practice, there appeared to be about 2 to 5 physician-assisted deaths on request per year, mostly but not always in patients with a concurrent serious physical illness, often in the terminal phase. Explicit requests for a physician’s assistance in dying are not uncommon in psychiatric practice in the Netherlands, and a majority of Dutch psychiatrists consider assisted suicide for psychiatric patients acceptable in certain circumstances. However, this rather liberal attitude appears to be associated with quite reluctant practice: despite the fact that Dutch law would permit it, it occurs only very rarely.

Since 2002, the Netherlands has also recognized as legal advance euthanasia directives of patients with dementia, including Alzheimer Disease. Although approximately 2200 demented patients with advance directives requesting euthanasia after the onset of dementia die annually having being treated by a physician who knows about this directive—indeed, in 76% of such cases, compliance with the directive was discussed—euthanasia is seldom performed.<sup>57</sup>

Let us proceed, then, to the objections to these findings.

*Objection No. 1: Data Are Unverifiable*

Concerns have been raised that the data from Oregon and the Netherlands is soft and hence not adequately informative. This objection (like almost all others considered here) must be understood, in part, as an objection to both the Oregon and the Dutch reporting and data-gathering systems as well as to the target article itself.

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55. van der Lee et al., *supra* note 37.

56. JOHN GRIFFITHS, EUTHANASIA AND LAW IN THE NETHERLANDS 329–40 (1998).

57. Rurup et al., *supra* note 37.

However, this objection, that the data are unverifiable, in some ways appears to involve misunderstandings of one or both elements. While the claim does have some merit, it is grossly over-interpreted.

Stephen Drake, for example, claims that the data are unverifiable in that it is not possible to verify information from anonymous self-reports by physicians.<sup>58</sup> Indeed, it would not be possible to verify information from anonymous self-reports if anonymous reports were the only information collected and if the source could not be identified. In both Oregon and the Netherlands, however, physician self-reports are not anonymous. The government entity to which the report is submitted knows the identity of the reporting physician, although that identity is not made public.<sup>59</sup> In both Oregon and the Netherlands, the reports are augmented with other information. For example, in both jurisdictions, physicians' reports are supplemented with death certificates.<sup>60</sup> In Oregon, telephone interviews are conducted with reporting physicians.<sup>61</sup> The three-part nationwide studies from the Netherlands also include extensive physician interviews, which are drawn from a broad sample of virtually all physicians and conducted independently of what physicians actually report.<sup>62</sup> Regardless of procedures for verifying data, the Oregon Department of Human Services (ODHS) does acknowledge that it has no way of knowing if its data is accurate or complete.<sup>63</sup> However,

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58. Stephen Drake, *Latest Pro-Euthanasia Research Redefines "Slippery Slope" and Uses "Soft" Data*, 79 NEWSL. EUTHANASIA PREVENTION COAL., Oct. 2007, at 3, available at <http://www.euthanasiaprevention.on.ca/Newsletters/newsletter79.pdf>.

59. OR. DEP'T OF HUMAN SERV., OFFICE OF DISEASE PREVENTION & EPIDEMIOLOGY, EIGHTH ANNUAL REPORT ON OREGON'S DEATH WITH DIGNITY ACT 1, 9, 12-13 (2006), available at <http://oregon.gov/DHS/ph/pas/docs/year8.pdf> [hereinafter EIGHTH ANNUAL REPORT ON ODDA]; see also all four nationwide studies from the Netherlands cited *supra* note 36.

60. According to Oregon's year eight report, "Patients choosing PAS [physician-assisted suicide] were identified through mandated physician and pharmacy reporting. Our information comes from these reports, physician interviews and death certificates." EIGHTH ANNUAL REPORT ON ODDA, *supra* note 59, at 4. For the Netherlands, see all four nationwide studies cited *supra* note 36.

61. "In addition, using our authority to conduct special studies of morbidity and mortality, DHS conducts telephone interviews with prescribing physicians after receipt of the patients' death certificates." EIGHTH ANNUAL REPORT ON ODDA, *supra* note 59, at 9.

62. See all four nationwide studies from the Netherlands cited *supra* note 36.

63. *E.g.*, Oregon's year eight report says that "as detailed in previous reports, our numbers are based on a reporting system for terminally ill patients who legally receive prescriptions for lethal medications, and do not include patients and physicians who may act outside the provisions of the DWDA [ODDA]." EIGHTH ANNUAL REPORT ON ODDA, *supra* note 59, at 15.

that is not to say the ODHS knows nothing about the nature of the reports received from physicians.

*Objection No. 2: Data Does Not Cover All Cases*

It is also often claimed that the data in both Oregon and the Netherlands miss those cases of physician-assisted dying that went unreported by the physicians who performed them. Among the critics of the target article, Eleanor Grogan, for example, uses the claim that 19.8% of cases in the Netherlands go unreported to conclude on behalf of the Association of Palliative Medicine Ethics Committee that “[the Association] remain[s] concerned that ‘vulnerable’ groups may be receiving assisted dying in the Netherlands.”<sup>64</sup>

Regarding Oregon, this objection centers around the assertion that the ODHS publicizes physician-reported data for cases in which a legal prescription is provided and the patient ingests the drug but that this data does not include those cases in which a prescription is provided but not utilized.<sup>65</sup> The objection also rests on the assertion that the ODHS does not actively search for cases beyond those in which a prescription is provided and ingested.<sup>66</sup> Regarding the Netherlands, this objection focuses on the assertion that, beyond the data already contained in the nationwide studies, many physicians acknowledge that they do not report some cases of assisted suicide or euthanasia at all.<sup>67</sup> These claims contribute to the overall objection that the target article is empirically unsound. In other words, it is argued that although the target article claims to be a study of the practice of assisted dying in two jurisdictions, the target article does not cover all of the cases in either Oregon or the Netherlands.<sup>68</sup> In both Oregon and the Netherlands, this objection typically further assumes that the cases that *are not* included are likely to be more problematic from a moral point of view than those that *are* included.

The objection appears to have particular weight in the case of the Netherlands, where it has been acknowledged that not all cases of physician-assisted dying are reported. In the mid-1980’s, when the

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64. Eleanor Grogan et al., *Are Vulnerable Groups No More Likely to Receive Physician-Assisted Dying?*, J. MED. ETHICS, Nov. 8, 2007, <http://jme.bmj.com/cgi/eletters/33/10/591>.

65. See, e.g., Herbert Hendin & Kathleen Foley, *Physician-Assisted Suicide in Oregon: A Medical Perspective*, 106 MICH. L. REV. 1613, 1636–37 (2008).

66. *Id.*

67. E.g., Grogan et al., *supra* note 64.

68. *Id.*

practice was not yet fully legal but was tolerated under specific guidelines, reporting levels were extremely low; in fact, in the first nationwide study, published in 1990, just 18% of physicians reported cases of physician-assisted dying to the Ministry of Justice, as was required under the guidelines.<sup>69</sup> During the following years, the rate of reporting climbed: 41% in 1995, 54% in 2001, and 80% in 2005.<sup>70</sup> Even so, it is still the case that a sizeable number of cases go unreported.

However, the four Dutch nationwide studies, which use cross-sectional analyses of interview, death-certificate, and questionnaire data, cover all deaths in the years 1990, 1995, 2001, and 2005 that involve medical decision-making. These include deaths associated with withholding or withdrawing treatment, the use of opiates in the treatment of pain, terminal sedation, physician-assisted suicide or euthanasia, and the category known as LAWER or “life-ending acts without explicit request.”<sup>71</sup> A death that does not involve medical decision-making, for example, would be death due to immediately fatal trauma, a fairly small proportion of total deaths. Because the nationwide Dutch data cover not only reported cases but also extralegal, unreported cases of euthanasia, physician-assisted suicide, and LAWER identified by means of three different measures, it is simply inaccurate to state that the only information about assisted deaths in the Netherlands is gleaned from anonymous, voluntary reports by physicians.

Nor is such a statement true in Oregon. The ODHS’s published data includes only the cases legally reported under the ODDA, but its information is not confined to the data that physicians volunteer.<sup>72</sup> The ODHS also collects information by means of telephone interviews with physicians, correlating physician reports with death certificates, and examining mandatory reports from pharmacists.<sup>73</sup> As mentioned above, the data included in the target article also covers three additional surveys conducted in Oregon; these failed to uncover any extralegal or unreported cases.<sup>74</sup> Although it is clearly the case

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69. van der Maas et al., *Euthanasia and Other Medical Decisions Concerning the End of Life*, *supra* note 36.

70. See the second, third, and fourth nationwide studies from the Netherlands cited *supra* note 36.

71. See all four nationwide studies from the Netherlands cited *supra* note 36.

72. EIGHTH ANNUAL REPORT ON ODDA, *supra* note 59, at 9.

73. *Id.*

74. *Target Article*, *supra* note 22, at 592.

that the body of information about assisted dying in the Netherlands is more extensive than that in Oregon,<sup>75</sup> it does not follow that the information on Oregon is therefore comprised of “unverifiable” anonymous physician self-reports.

*Objection No. 3: “Excessive Secrecy:” Data Inadequate or Missing*

A more substantial concern, recently voiced by Herbert Hendin and Kathleen Foley in the *Michigan Law Review*,<sup>76</sup> objects to the data provided by the ODHS on the grounds that (1) the Department does not collect adequate information about the patient, and (2) that the Department collects information only from the physician who actually wrote the prescription for the life-ending drug, rather than from all of the physicians who saw the patient.<sup>77</sup> Hendin and Foley describe the ODHS’s website statement that there is no evidence of abuse as “overreaching in the conclusions they draw from the limited information they have.”<sup>78</sup> The ODHS, they say, “does not collect the information it would need to effectively monitor the law . . . [and fails to serve] as the protector of the welfare of terminally ill patients.”<sup>79</sup> They also note that Oregon destroys individual information about patients who die under the ODDA, and does not make their identities public.<sup>80</sup>

Hendin and Foley call these policies, designed as they are to protect patient-doctor confidentiality, matters of “excessive secrecy.”<sup>81</sup> As Marilyn Golden, a policy analyst with the anti-assisted suicide and anti-euthanasia Disability Rights Education and Defense Fund in Berkeley, California stated, “This makes it impossible for any outside researcher to avail themselves of the data. . . . The truth is, we really don’t know what’s happening in Oregon.”<sup>82</sup> The International Task Force on Euthanasia and Assisted Suicide portrayed with

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75. The study in the Netherlands covers twenty years of information, whereas the Oregon study covers ten years of information. *See*, the four nationwide Dutch studies *supra* note 36; and the Oregon reports, *supra* notes 33, 34.

76. Hendin & Foley, *supra* note 65, at 1613.

77. *Id.* at 1614.

78. *Id.* at 1636–37.

79. *Id.* at 1613.

80. *Id.* at 1614.

81. *Id.* at 1627.

82. Claudia Rowe, *Family Fights for Assisted-Suicide Vote*, SEATTLE POST-INTELLIGENCER, July 3, 2008, available at [http://seattlepi.nwsourc.com/local/369419\\_suicide03.html](http://seattlepi.nwsourc.com/local/369419_suicide03.html).

derision a decade-old remark attributed to Barbara Coombs Lee, president of Compassion and Choices, an organization which supports the right of terminally ill, mentally competent patients to choose aid in dying,<sup>83</sup> that the “people of Oregon do not deserve to know the details of the individual fatal diseases and death.”<sup>84</sup> The Task Force also alleged that doctors were told to lie on death certificates.<sup>85</sup>

As we have seen, this objection focuses primarily on Oregon. It is true that under the ODDA, the cause of death in an assisted-dying case is to be attributed to the underlying illness, since the statute expressly asserts that assistance under the ODDA “shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law.”<sup>86</sup> It is also true that the Oregon data made public is skeletal, in the sense that it is confined to incidence data, demographic data, underlying illness, end-of-life care and concerns data, complications and timing data, and data about the process of dying after the lethal medication has been ingested.<sup>87</sup> The information is also limited to the comparative data for the years during which the ODDA has been in force.<sup>88</sup> The data contains no patient or physician identifiers.

Despite these limitations, however, this data is adequate for many purposes. For example, the data is sufficient to demonstrate the very low rate of utilization of the ODDA, which is about 0.15% of the total annual mortality.<sup>89</sup> In other words, for every thousand people who have died in Oregon since the ODDA has become available, only one or two die with the assistance of a physician. This data is entirely

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83. See, e.g., Compassion & Choices, <http://www.compassionandchoices.org> (last visited Oct. 24, 2008).

Compassion & Choices is a nonprofit organization working to improve care and expand choice at the end of life. As a national organization with over 60 local groups, affiliates and chapters, and 30,000 members, we help patients and their loved ones face the end of life with calming facts and choices of action during a difficult time. We also aggressively pursue legal reform to promote pain care, put teeth in advance directives and legalize physician aid in dying.

*Id.*

84. Int'l Task Force on Euthanasia and Assisted Suicide, *10 Years Under Oregon's Assisted-Suicide Law*, 22 UPDATE No. 2 (2008), available at <http://www.internationaltaskforce.org/iua44.htm>.

85. *Id.*

86. OR. REV. STAT. § 127.880 (1995).

87. See generally OREGON DEATH WITH DIGNITY ACT ANNUAL REPORTS, available at <http://oregon.gov/DHS/ph/pas/ar-index.shtml>.

88. *Id.*

89. *Target Article*, *supra* note 22, at 593 bx.2.



adequate to rebut histrionic claims that the ODDA saw “record highs”<sup>90</sup> in the most recent year. Even at its highest point in 2007, there were only 49 ODDA deaths altogether, or 15.6 ODDA deaths for every 10,000 deaths.<sup>91</sup> That is just one or two out of every thousand deaths—not out of every thousand people, but out of every thousand people who die in that year, a very small fraction of the total population. The data also provides information about (1) whether the patients in question were members of any of the groups identified as vulnerable, (2) what counties they resided in, (3) whether the physician was present when the medication was ingested, and (4) whether emergency medical services were called.<sup>92</sup>

How should Oregon respond to this attack on the availability of ODDA data? Publicizing patient identifiers would, of course, provide more access to family members who could then be interviewed. Such disclosure might also underwrite the inspection of homes in the interests of protecting patients, much like that done by agencies that monitor child and elder abuse. It would make searching public and commercial databases possible for matters like marriage licenses, weapons permits, criminal records, or shopping behavior. Perhaps the inquisitive might learn something about the reasons for which the patient in question elected to utilize the ODDA. But the invasion of privacy would be immense, as the drafters of the ODDA clearly recognized, and would subject family members and others to the intense and sometimes highly politicized pressures of advocacy groups. Would demonstrators picket outside the home of a recent decedent, if his or her identity were revealed? Would they harass other family members or associates of a decedent who might also be terminally ill? Bottom dredging for lurid detail has already occurred with the few patients whose identities have become known (Kate Cheney for example).<sup>93</sup> All the privacy protections afforded to patients by HIPAA in ordinary medical circumstances would vanish if identities of patients were revealed.

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90. Int’l Task Force on Euthanasia and Assisted Suicide, *10 Years Under Oregon’s Assisted-Suicide Law*, *supra* note 84.

91. OR. DEP’T OF HUMAN SERV., OFFICE OF DISEASE PREVENTION & EPIDEMIOLOGY, TENTH ANNUAL REPORT ON OREGON’S DEATH WITH DIGNITY ACT (2008), *available at* <http://oregon.gov/DHS/ph/pas/docs/year10.pdf> [hereinafter TENTH ANNUAL REPORT ON ODDA].

92. *Id.*

93. *See infra* notes 138–141 and accompanying text.

As displayed in Box 4, Oregon's current ODDA data release policy clearly privileges patient confidentiality.

Box 4: *Oregon State Public Health Division Data Release Policy*<sup>94</sup>

#### **Release of Information Regarding the Death with Dignity Act**

The Death with Dignity Act requires that the Oregon Department of Human Services collect information pertaining to compliance (ORS 127.865 (2)) and to make available to the public an annual statistical report (ORS 127.865 (3)).

- The Department of Human Services's role is limited to collecting information so that we can monitor compliance and provide a report regarding the effects of this legislation.

- Confidentiality is critical and the Act specifically states that information collected is not a public record and is not available for inspection by the public (ORS 127.865 (2)). The protection of confidentiality conferred by the Death with Dignity Act precludes the Department of Human Services from releasing information that identifies patients or participants, to the public, media, researchers, students, advocates, or other interested parties.

- The Department of Human Services will NOT confirm on a case-by-case basis whether an individual has used, or a provider has been involved with, Death with Dignity. We will not release a report when the first case occurs and we will not respond to questions regarding number of cases within a specific time period.

- Within the principles of confidentiality, the Department of Human Services will publish an annual report which will include information on how many prescriptions are written, and how many people actually take the prescribed medication. The specificity of any data released will depend upon whether we can ensure that confidentiality will not be breached.

94. Or. Dep't of Human Serv., Oregon State Public Health Division Data Release Policy, <http://oregon.gov/DHS/ph/pas/policy.shtml> (last visited Oct. 20, 2008).

To reiterate, the Department of Human Services's role in reporting on the Death with Dignity Act is similar to other public health data we collect. The data are population-based and our charge is to maintain surveillance of the overall effect of the Act. The data are to be presented in an annual report, but the information collected is required to be confidential. Therefore, case-by-case information will not be provided, and specificity of data released will depend on having adequate numbers to ensure that confidentiality will be maintained.

Thus, Hendin and Foley's objection alleging excessive secrecy cloaks a controversial assumption that the ODHS does not collect the information necessary to effectively monitor the ODDA and thus fails to serve as the protector of the welfare of terminally ill patients. Yet, protecting confidentiality is also protecting the welfare of terminally ill patients. The ODHS is not a police organization. The kind of continuous and intrusive surveillance that Hendin and Foley appear to have in mind as necessary to protect the welfare of terminally ill patients is by no means part of the ODHS's charge. Rather, the charge of the Department, as the policy puts it, is "population-based," statistical in character, concerned with monitoring patterns of utilization of the ODDA, but not intended to ferret out abuse.<sup>95</sup> Hendin and Foley insist that "[e]nsuring adequate care for patients is the aim of monitoring,"<sup>96</sup> and in a general sense, they are correct; but this is not to warrant intrusive surveillance in every area of medical practice. The ODHS does investigate cases in which the physician's report appears to have deficiencies or does not correlate with the death certificate or other information, and further, the ODHS does report cases involving inadequate reporting or unexpected side effects to the Board of Medical Examiners or the Board of Pharmacy respectively.<sup>97</sup> But this reporting, in turn, does not make the Department responsible for the day-to-day operations of the law.

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95. EIGHTH ANNUAL REPORT ON ODDA, *supra* note 59.

96. Hendin & Foley, *supra* note 65, at 1627.

97. EIGHTH ANNUAL REPORT ON ODDA, *supra* note 59, at 13.

During 2005, four cases were referred to the Oregon Board of Medical Examiners, one involving witnessing of signatures and three others for failure to file required documentation in a timely manner. One case, in which a patient awakened after ingesting the prescribed medication, was referred to the Board of Pharmacy.

*Id.*

*Objection No. 4: Flaws in Study Design or Scope*

A rather varied set of objections points to what are seen as flaws in design or scope of the target article. Some of these are objections to features of the Oregon or Dutch studies, some to features of the target study, and some to both. Either way, these objections typically address the way the empirical claims are derived or interpreted.

Consider one such example. Desmond O'Neill, Director of the Centre for Ageing, Neuroscience and the Humanities at the Adelaide & Meath Hospital in Dublin, objects to the structure of the target study in that it identifies the category of "elderly" as people over 85 and does not include the 65–84 age range.<sup>98</sup> This is a misreading of the data. The target article includes all age categories in its analysis. What the data actually shows is that incidence rates for physician-assisted dying in the 65–84 age range in Oregon are lower than those for younger people ages 45–64, but that the rate for the age group 85+ is lower still.<sup>99</sup> Similarly, in the Netherlands, rates of assisted dying are lowest in the age range over 80 (0.8% in 2005), next lowest in the age range 65–74 (2.1%), and higher below age 65 (3.5%).<sup>100</sup> Thus the category known in gerontology as the "young old" receive assisted dying more frequently than the "old old," but both the young old and the old old receive assistance less frequently than those who are not old at all.

Nevertheless, O'Neill's concern raises an interesting point. While it is tempting to think of people over 70 as "old," in jurisdictions like the Netherlands and Oregon, which have very long lifespans (approximately 78 in Oregon, and almost 80 in the Netherlands),<sup>101</sup> to die at 70 (the average age in both the Netherlands and Oregon for assisted dying) is to die at a comparatively "young"

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98. Desmond O'Neill, Rapid Response to Timothy Quill Editorial, *Concerns Not Dispelled*, BRIT. MED. J., Oct. 3, 2007, <http://www.bmj.com/cgi/eletters/335/7621/625#177583>.

99. *Target Article*, *supra* note 22, at 595 tbl.1.

100. *See supra* note 46 and accompanying text.

101. The 2008 estimated average life expectancy at birth in the Netherlands is 79.25 years for both sexes, 76.66 years for men, and 81.98 years for women. Cent. Intelligence Agency, *Netherlands*, in THE WORLD FACTBOOK, <https://www.cia.gov/library/publications/the-world-factbook/geos/nl.htm> (last visited Oct. 24, 2008). For Oregon, average life expectancy is 77.9 years for both sexes, 75.5 years for men and 80.0 years for women. U.S. CENSUS BUREAU, POPULATION DIV., AVERAGE LIFE EXPECTANCY AT BIRTH BY STATE FOR 2000 AND RATIO OF ESTIMATES AND PROJECTIONS OF DEATHS: 2001 TO 2003, [www.census.gov/population/projections/MethTab2.xls](http://www.census.gov/population/projections/MethTab2.xls) (last visited Oct. 24, 2008).

age. Thus, those who die at “elderly” ages, defined as older than the average life expectancy, are clearly at lower risk.

*Objection No. 5: Euthanasia Widespread*

The objection that euthanasia is far more widespread than usually acknowledged is an expansion of the more limited Objection No. 2, considered above (that the empirical studies assessed in the target article do not cover all cases). In particular, this broader objection points to the notorious “thousand cases” of euthanasia in the Netherlands where there was no current, explicit consent, the so-called LAWER cases (to be discussed below), and claims that the official reports miss such cases. This is, as we have seen, simply not true; the Dutch reports cover all deaths involving medical decision-making, including physician-performed euthanasia, physician-assisted suicide, and LAWER.<sup>102</sup>

Daniel Callahan, for example, who was then president of the Hastings Center,<sup>103</sup> defends the publication (with “considerable trepidation”<sup>104</sup>) in the 1989 *Hastings Center Report* of an article written by Dutch cardiologist, Richard Fenigsen.<sup>105</sup> Dr. Fenigsen alleged in his article that “that there were far more instances of euthanasia than reported, that regulations promulgated by Dutch courts to control the practice were widely ignored, and that euthanasia without informed consent of patients (called “nonvoluntary euthanasia”) was common.”<sup>106</sup> Dr. Callahan cites a few “memorable” lines from those letters written in response to Dr. Fenigsen’s article:

One of them was the claim that the Dutch meaning of euthanasia was that of “a deliberate life-ending action . . . [as the result of] an enduring [patient] request. ‘Euthanasia,’ therefore, is by necessity, *voluntary*.”<sup>107</sup> Another letter asserted that “it is impossible for people who do not want euthanasia to be forced or maneuvered

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102. See *supra* notes 69–70 and accompanying text. LAWER stands for “life-ending acts without current explicit request.”

103. The Hastings Center, <http://www.thehastingscenter.org/> (describing the organization as “a nonpartisan research institution dedicated to bioethics and the public interest since 1969.”).

104. Daniel Callahan, *Organized Obfuscation: Advocacy for Physician-Assisted Suicide*, 38 HASTINGS CTR. REP., Sept.–Oct. 2008, at 30, 31 (2008).

105. Richard Fenigsen, *A Case Against Dutch Euthanasia*, 19 HASTINGS CTR. REP., Jan.–Feb. 1989 (supp.), at 22.

106. Callahan, *supra* note 104, at 31.

107. *Id.* (citing *Mercy, Murder, and Morality*, Letters, 19 HASTINGS CTR. REP., Nov.–Dec. 1989, at 47, 47) (emphasis in original)).

into it because that would violate the definition of euthanasia.”<sup>108</sup> The notion that one could not be forced into something because it would violate a definition is surely imaginative (and philosophers of language should take note). The letters evaded the question of whether nonvoluntary euthanasia (now turned into an oxymoron) actually took place.<sup>109</sup>

Here, conceptual misunderstandings already make analysis of the empirical claims difficult. The Dutch did *define* euthanasia as voluntary, and chose not to include cases that did not involve current, voluntary consent within the category of “euthanasia.”<sup>110</sup> Nevertheless, that does not mean the Dutch were doing sleight-of-hand. Rather, they had another category, LAWER or “life-ending acts without current explicit request,” to describe the notorious “1000 cases.”<sup>111</sup> The most reliable account of such cases makes it clear that they did not involve putting to death people who did not want to be put to death, as is often assumed by opponents. Rather, this was a procedure allowing an easier death for people who had made an antecedent informal request for euthanasia before they became incompetent, or who were no longer capable of expressing their wishes but were perceived to be suffering severely.<sup>112</sup> These LAWER cases reflect physicians’ perceptions of the moral urgency of ending someone’s agony when he or she has become incompetent and is no longer able to express a request.<sup>113</sup>

The Dutch have been perfectly upfront about the thousand cases (now down to about 550 a year), and recognize that euthanasia and LAWER are different things. “Euthanasia” is understood as a good death at the patient’s current, explicit request; LAWER is a mercy death for someone dying in severe suffering.<sup>114</sup> The Dutch do not

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108. *Id.* (citing *Mercy, Murder, and Morality*, Letters, 19 HASTINGS CTR. REP., Nov.–Dec. 1989, at 47, 48).

109. *Id.*

110. That’s because unlike their neighbors the Germans, the Dutch understand the term “euthanasia” in the Greek sense, *eu-thanasia*, “good death.” Ktriaki Mystakidou et al., *The Evolution of Euthanasia and Its Perceptions in Greek Culture and Civilization*, 48 PERSPECTIVES IN BIOLOGY & MED. 95, 95 (2005).

111. See van der Maas et al., *Euthanasia and Other Medical Decisions Concerning the End of Life*, *supra* note 36.

112. Loes Pijnenborg et al., *Life Terminating Acts Without Explicit Request of Patient*, 341 THE LANCET 1196, 1197 (1993) (59% of physicians had some information about their patients wishes).

113. *Id.* at 1196–99.

114. RAPHAEL COHEN-ALMAGOR, EUTHANASIA IN THE NETHERLANDS: THE POLICY AND PRACTICE OF MERCY KILLINGS 148 (2004).

pretend that everything is perfectly fine, but they also recognize that anti-euthanasia advocacy images that portray these cases as outright murder—conjuring up scenarios where awake, alert, terrified patients are cowering in their beds as the doctor approaches with the lethal injection—are unconscionably distorted.<sup>115</sup>

Another version of this type of “scope” objection claims that many of the cases in other categories of Dutch medical decision-making examined under the nationwide studies are really euthanasia, not simply the overuse of opiates for pain relief under the principle of double effect. The allegation is that those doctors really did *intend* the deaths of those patients. But, as Timothy Quill has adroitly pointed out, clinical intentions are ambiguous,<sup>116</sup> and it is not really possible to separate out what the doctor foresees and what the doctor intends. When prescribing very heavy doses of morphine or when using practices like terminal sedation, the doctor not only foresees that death will occur, but also intends that that patient die well. The doctor, in essence, is aiding in the death of the patient.

Of course, it is possible that sedation is wholly palliative in character and not simultaneously used to facilitate a specific kind of death. This would be particularly true if nutrition and hydration were continued, as opposed to the more usual practice of withholding.<sup>117</sup> However, because nutrition and hydration are commonly withheld, such cases are presumably comparatively rare.

My guess is that if we were to apply Dr. Fenigsen’s criteria in the United States, where such a vast proportion of deaths are “negotiated” but not identified as physician-caused, and where we engage in frequent charades over double effect, we would see a picture very much like the one conjured up by opponents in the Netherlands. Curiously, it is in the Netherlands that the ambiguity of clinical intentions in the use of terminal sedation is less problematic, morally speaking. That is because the Dutch authorities place a limit on how far in advance of the expected death terminal sedation without

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115. John Bookser Feister, “*Thou Shall Not Kill:*” *The Church Against Assisted Suicide*, ST. ANTHONY MESSENGER MAG. ONLINE, June 1997, <http://www.americancatholic.org/Messenger/Jun1997/feature1.asp> (discussing the ad techniques used in the political campaigns surrounding the ballot measures in 1994 in Oregon and elsewhere).

116. Timothy E. Quill, *The Ambiguity of Clinical Intentions*, 329 NEW ENG. J. MED. 1039–40 (1993).

117. Interview with Jay A. Jacobson MD, Infectious Disease Specialist, LDS Hospital, Division of Medical Ethics, in Salt Lake City, Utah (July 2008).

nutrition or hydration may be utilized—no more than two weeks.<sup>118</sup> The rationale for this limit is that it is not medically sound to sedate someone in this way for longer than two weeks (this applies only to continuous deep sedation), since “If the patient’s life expectancy exceeds one to two weeks, continuous deep sedation would affect the time of death, which would be hastened by dehydration”<sup>119</sup>—that is, continuous deep sedation without nutrition or hydration would kill the patient. If the guideline’s two-week limit is followed, sedation is normal medical practice and therefore does not have to be reported. Euthanasia and assisted suicide, in contrast, are never normal medical practice and are always required to be reported. Thus, the two-week limit on terminal sedation, in effect, ensures doctors do not use terminal sedation as a form of silent euthanasia in a way that eludes the reporting requirement.<sup>120</sup>

The Dutch nationwide studies identify the number of cases of euthanasia and physician-assisted suicide in the range of 2,000–3,000 annually.<sup>121</sup> The Fenigsen view, in dramatic contrast, estimates the number at approximately 25,000.<sup>122</sup> The vast difference in these

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118. Comm. on Nat’l Guidelines for Palliative Sedation, Royal Dutch Med. Ass’n (KNMG), Guidelines for Palliative Sedation 3–4 (2005) (English summary), available at [http://knmg.artsennet.nl/uri/?uri=AMGATE\\_6059\\_100\\_TICH\\_R193567276369746](http://knmg.artsennet.nl/uri/?uri=AMGATE_6059_100_TICH_R193567276369746)

119. *Id.* at 4.

120. Interview with Mette L. Rurup, Post Doctoral Researcher, EMGO Institute, Department of Public and Occupational Health, VU University Medical Center, in Amsterdam (Aug. 2008).

121. van der Heide, et al., *supra* note 36, at 1961 (According to the 2005 nationwide report of 9965 deaths studied 1.7% were cases of euthanasia, 0.1% were cases of assisted suicide and 0.4% were LAWER cases.).

122. Richard Fenigsen, *supra* note 105, at 22–30. The report, commonly known as the Rummelink Report, of the Dutch governmentally appointed Committee to Investigate the Medical Practice Concerning Euthanasia gives the raw data on actions by physicians to end the lives of patients. Using the numbers reported in the nationwide study, the definition of euthanasia employed results in different conclusions about the number of euthanasia cases each year. The committee, which defines euthanasia to include only active termination of life upon request, found that 2,300 cases of euthanasia (0.8% of all annual deaths) occur each year in the Netherlands. By contrast, Dr. Fenigsen derives 25,306 cases of euthanasia (19.4% of the total annual deaths) from the same data by using the definition of euthanasia of Joseph Fletcher, which defines euthanasia in four forms: (1) voluntary and direct, (2) voluntary but indirect, (3) direct but involuntary, and (4) both indirect and involuntary. Included in Dr. Fenigsen’s calculations were 8,100 patients who died from an overdose of morphine given with, he asserts, the intent to terminate life (which number the commission listed under pain relief, not euthanasia; see the nationwide studies, *supra* note 36). Of these 8,100 patients, according to Dr. Fenigsen, 4,941 (61%) were given lethal doses of morphine with the intent of terminating life without the patient’s consent. See Richard Fenigsen, *The Report of the Dutch Governmental Committee on Euthanasia*, 7 ISSUES L. & MED. 339, 340–41 (1991–1992), available at [http://findarticles.com/p/articles/mi\\_m6875/is\\_n3\\_7/ai\\_n25021304/print](http://findarticles.com/p/articles/mi_m6875/is_n3_7/ai_n25021304/print).



numbers is the result of a difference so intrinsic as to what counts as assisted dying, that it challenges the feasibility of rigorous research at all. Further, it questions the possibility of settling on the scope of the phenomenon being studied, even at the broadest level.

*Objection No. 6: Data Cannot Get at Cases of Depression*

The assertion that the background data in Oregon and the Netherlands, and hence the target article, cannot reach cases of depression is one of the more prevalent objections to the empirical work so far. For example, Alex Schadenberg argues, indeed correctly, that the Oregon data does not make it possible to analyze the decision-making processes of patients.<sup>123</sup> Madelyn Hicks laments the absence of a standardized depression-screening tool.<sup>124</sup> Linda Ganzini, one of the authors of the target article, is quoted by the International Task Force on Euthanasia and Assisted Suicide as saying that it is “risky how low the rate of mental health evaluation is.”<sup>125</sup> The International Task Force also complains that patients are never interviewed prior to their deaths.<sup>126</sup>

Overall, it is fair to say that parties both favoring physician-assisted dying and those in opposition agree that the rates of euthanasia and assisted suicide ought to be minimized in mental disorders.<sup>127</sup> It is probably also fair to say that all parties acknowledge that depression may be a partial factor in some cases. Lastly, all parties must acknowledge that depression is a frequent factor in *requests* for assisted dying. As estimated in Oregon, about 20% of requests for physician-assisted death under the ODDA are from people who are depressed, though none of these cases

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123. Alex Schadenberg, *Assisted Suicide in Oregon: Lessons Learned and Unanswered Questions*, May 20, 2004, <http://www.lifenews.com/bio276.html>.

124. Madelyn H. Hicks, Rapid Response to Timothy Quill Editorial, *Mentally Ill Given Short Shrift*, BRIT. MED. J., Oct. 10, 2007, <http://www.bmj.com/cgi/eletters/335/7621/625#177848>.

125. Int'l Task Force on Euthanasia and Assisted Suicide, *10 Years Under Oregon's Assisted-Suicide Law*, *supra* note 84 (citing Tim Christie, *Assisted-Suicide Law Passes 10-Year Mark*, THE REGISTER-GUARD, March 19, 2008, at C15).

126. *Id.*

127. JOHN GRIFFITHS ET AL., EUTHANASIA AND LAW IN THE NETHERLANDS 329–40 (1998) (The Dutch do not agree that physician assisted suicide in mental disorders should be ruled out altogether. Psychological suffering can be intolerable just as physical suffering can, the courts ruled in *Chabot*, but performing euthanasia in such cases requires a heightened level of scrutiny.).

progressed to assistance in dying.<sup>128</sup> Also, as estimated in the nationwide studies in the Netherlands, about two-thirds of overall requests are turned down or not honored, not infrequently because of depression.<sup>129</sup>

The claim that people who are depressed *make requests* for assistance is not, however, to be confused with the claim that people who are depressed *receive* assistance. Both jurisdictions rely on the professional competencies of physicians to screen for depression. Proponents of physician-assisted dying tend to assume this safeguard is adequate, pointing to the fact that, as we have seen, in the Netherlands about two-thirds of requests are not acted upon, and a large majority of these refusals result from instances where the physician determines that depression played a role in the request.<sup>130</sup> Similarly, Oregon built in a statutory safeguard for physician-assisted death requests due to depression, by requiring that the attending physician assess the patient's mental capability and also obtain a second physician opinion.<sup>131</sup> Opponents, on the other hand, tend to assume that reliance on the professional competencies of physicians in screening for depression is not adequate.

A recent study in Oregon, using standard measures of depression and hopelessness, found that “[a]mong patients who requested a physician’s aid in dying, one in four had clinical depression. However, more than three quarters of people who actually received prescriptions for lethal drugs did not have a depressive disorder.”<sup>132</sup> The authors of the study concluded that although most terminally ill Oregonians who receive aid in dying do not have a depressive disorder, the current practice of the ODDA “may fail to protect some patients whose choices are influenced by depression from receiving a prescription for a lethal drug.”<sup>133</sup>

Is this reliance on physician competencies to screen for depression adequate? It is frequently asserted that many physicians

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128. *Target Article*, *supra* note 22, at 596 (citing Ganzini et al., *Physicians’ Experiences With the Oregon Death with Dignity Act*, *supra* note 34, at 557–63).

129. *Id.*

130. Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 2002, ch.2 § 2(a)–(f) (requirements of due care).

131. OR. REV. STAT. § 127.815(1)(a), (b) (2007).

132. Linda Ganzini, Elizabeth R. Goy, & Steven K. Dobscha, *Prevalence of Depression and Anxiety in Patients Requesting Physicians’ Aid in Dying: Cross Sectional Survey*, 337 BRIT. MED. J., Oct. 8, 2008, at a1682, available at [http://www.bmj.com/cgi/content/full/337/oct07\\_2/a1682](http://www.bmj.com/cgi/content/full/337/oct07_2/a1682).

133. *Id.* (abstract).

are poorly trained in recognizing depression.<sup>134</sup> This is surely true, but often misinterpreted. On the one hand, there is the risk that a physician will fail to recognize depression when it is occurring. Alternatively, there is also the possibility of a physician over-interpreting as depression the kind of sadness that may well occur when a person faces the end of life, conflating sadness with the kind of decision-impairing depression that would interfere with a well-thought-out choice about how to die. These considerations raise several distinct problems. First, there is the issue of whether physician diagnoses of depression are accurate, particularly in sorting out the varieties of “depression” associated with the end of life.<sup>135</sup> Second, there is the issue of which direction a failure to diagnose depression might lead. Third, this also raises questions about what form any oversight of depression assessments might take. The Dutch researcher Mette Rurup is finding in interview studies now in progress that even where requests for physician assistance are not at issue, people’s expressions of a wish to die are underlain by extraordinarily varied reasons.<sup>136</sup>

Schadenberg implies that in order to prevent physician-assisted dying among those suffering from depression, outside observers would need to be present to interview patients.<sup>137</sup> However, this would hardly solve the problem. As is the case in other issues discussed within this article, it is necessary to arrive at some prior understanding about what counts as “depression”—clinical depression? sadness? something else? The next step would then be to determine what forms of depression do or do not disqualify a person from obtaining physician-assisted dying. Currently, it is clear that certain types of mental issues identified as depression already block the majority of patient access.

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134. See, e.g., Hendin & Foley, *supra* note 65, at 1615–17.

135. Very common in these arguments is a conflation of several senses of depression: the transitory, pathological but treatable sense of depression as a mental illness, and the ubiquitous sadness experienced by terminally ill people who are about to lose their lives.

136. See Mette L. Rurup & Bregje D. Onwuteaka-Philipsen, EMGO Institute, Research Project, *Older People with the Wish to Die*, [http://www.emgo.nl/research\\_prog/care/research\\_projects\\_74.asp](http://www.emgo.nl/research_prog/care/research_projects_74.asp) (last visited Oct. 25, 2008) (describing the ongoing research project). See also TENTH ANNUAL REPORT ON ODDA, *supra* note 91 (“As in previous years, the most frequently mentioned end-of-life concerns were: loss of autonomy (100%), decreasing ability to participate in activities that made life enjoyable (86%), and loss of dignity (86%). During 2007, more participants were concerned about inadequate pain control (33%) than in previous years (26%).”).

137. Schadenberg, *supra* note 123.

The case of Kate Cheney, an 85-year-old widow terminally ill with stomach cancer who requested an assisted death, is often put forth as a cautionary tale in discussions of depression.<sup>138</sup> Many exaggerated claims have circulated about this case, particularly that her daughter was pressuring her into deciding to die.<sup>139</sup> Yet the facts are that the initial reviewing psychiatrist found that Kate had mild, potentially reversible cognitive deficits and agreed that a second mental health professional should be consulted;<sup>140</sup> thus, one clinician who saw her asserted that she did not meet the requirements of the law. Kate then saw two additional mental health experts, both of whom found her decision-making capacity to be fully intact and that she was eligible to choose to make use of the ODDA.<sup>141</sup>

How are such disagreements to be evaluated? Are the criteria in play different from one physician to another, and is the finding of the one physician accurate and the findings of the others inaccurate? Or is it the other way around? Alternatively, is the disagreement because Kate's impairment was temporary, perhaps because the different clinicians were seeing her in different conditions? Other such disagreements might well occur, but it is not obvious that what we always need is more information about the patient. After all, when two or more different clinicians give different findings, there will always be a disagreement to be explained—though in some cases, perhaps like that of Kate, explanation may involve a change in the patient's condition. Sometimes, however, what we need is not more information about the patient, but more about the physicians in question. What criteria are they using? How did they conduct their examination of Kate? And what political or ideological motives, conscious or subconscious, might be at play?

On a final note under this objection, to claim that we cannot get at the true incidence of depression does not undercut the comparatively modest claim made in the target article: namely, that there is no evidence that physician-assisted dying in Oregon or the Netherlands is practiced more frequently on people made vulnerable by mental illness, including depression.

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138. Hendin & Foley, *supra* note 65, at 1626–27.

139. Ganzini, Letter to the Editor, *supra* note 54.

140. *Id.*

141. *Id.*

*Objection No. 7: Misconstrual of “Vulnerable” Patients*

This objection takes a variety of forms: that not just those in “vulnerable” groups are to be considered vulnerable, but “all people facing such serious concerns and conditions are vulnerable” (Grogan);<sup>142</sup> that people “are made vulnerable by their situation” (Thorns);<sup>143</sup> and that “vulnerability applies to the majority of the population at any one time” (O’Neill).<sup>144</sup>

The claim that the notion of vulnerability is inappropriately applied, to a certain extent, rings true. However, any one of these three positions would so stretch the notion of vulnerability that it would apply to all patients, or indeed to most people. If such were the case, this would undercut the basis for particular vigilance concerning people in the very groups originally identified as vulnerable: the poor, the elderly, women, etc. Although it is appropriate to be consider these groups with particular vigilance, as the target article asserted,

to observe that patients are members of potentially vulnerable groups is to assert neither that each such person or the group as a whole is actually vulnerable nor that people who are seriously or terminally ill but not considering physician-assisted dying are not vulnerable. But it is to recognize a special and appropriate concern about persons and groups seen as vulnerable because of impairment, disadvantage or stigmatisation.<sup>145</sup>

The interesting issue is whether there should be heightened scrutiny of requests for physician-assisted dying when such requests come from people in “vulnerable” groups. There is considerable reason to think this should be so. For example, consider the concern expressed by *Not Dead Yet* about the treatment of persons with disabilities:

Since 1983, many people with disabilities have opposed “right-to-die” proponents who have advocated that people with severe disabilities should receive suicide assistance, not suicide prevention. Our opposition was ignored, and many people with disabilities have already died as a result.

No proposed law authorizing physician-assisted suicide applies to all citizens equally, but singles out individuals based on their

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142. Grogan et al., *supra* note 64.

143. Andrew Thorns, Rapid Response to Timothy Quill Editorial, *There is More to Vulnerability*, BRIT. MED. J., Oct. 1, 2007, <http://www.bmj.com/cgi/eletters/335/7621/625#177412>.

144. O’Neill, *supra* note 98.

145. *Target Article*, *supra* note 22, at 591.

health status in violation of the Americans with Disabilities Act. Current trends in managed care and health care rationing have already reduced and threaten to further diminish the availability of health care and related services needed by people with disabilities.<sup>146</sup>

Similarly, Schadenberg argues that within our society exists a significant level of social bias that connects certain types of disabilities and physical conditions to intolerable suffering.<sup>147</sup>

These authors are surely correct about the levels of social bias in our society toward people with disabilities. However, while these concerns are of paramount importance, they may be used to reach an unjust conclusion if they result in a requirement of heightened scrutiny for access to assistance in dying for people in certain groups, effectively preventing a disabled individual from making an end-of-life decision that an able-bodied person would be permitted to make. In any event, these concerns underscore the difficulties of defining terminal illness in the first place. For many people with long-term chronic disabilities, life expectancy is not shortened, but for some, the line between living with a disability and living with terminal illness is less clear.

#### *Objection No. 8: Author Bias*

Among the objections to empirical research on the practice of physician-assisted dying in Oregon and the Netherlands in general and to the target article in particular are those alleging that such research and/or its authors are biased. Accusations of bias are found in many writings on end-of-life issues (by both sides in the argument), and it is no doubt true that the various authors on all sides of this issue each have an antecedent point of view. As for the target article, for example, Schadenberg calls it “propaganda.”<sup>148</sup> “Dr. Peter Saunders, head of the British group Care Not Killing, warned that the study was a ploy to get support for legalized euthanasia in the U.K.”<sup>149</sup> Patrick Goodenough calls the target article’s first author, myself, an “assisted

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146. Not Dead Yet, *supra* note 9.

147. Alex Schadenberg, *Recent Study: Propaganda or Research?*, 79 NEWSL. EUTHANASIA PREVENTION COAL., Oct. 2007, at 3, available at <http://www.euthanasia-prevention.on.ca/Newsletters/newsletter79.pdf>.

148. *Id.*

149. Int’l Task Force on Euthanasia and Assisted Suicide, *New Euthanasia/Assisted-Suicide Study Draws International Criticism*, *supra* note 8 (citing CHRISTIAN TODAY, Sept. 28, 2007).

suicide advocate” and says that my views on physician-assisted suicide are well known.<sup>150</sup> Goodenough also claims that Wesley Smith says that I am an “ardent euthanasia and assisted suicide legalization activist—[who] supports PAS for categories of people way beyond the terminally ill.”<sup>151</sup> Stephen Drake alleges that I use “research for political purposes.”<sup>152</sup> The International Task Force on Euthanasia and Assisted Suicide says that I call suicide advocacy “humanitarian,” but at the same time acknowledges that vulnerable people are the most likely to be affected.<sup>153</sup> The director of the International Task Force, Rita Marker, also quotes me as saying that PAS may be warranted for financially-strapped elderly,<sup>154</sup> and that I “speak[] about the benefits of suicide.”<sup>155</sup>

Of course, in order to call an article “propaganda,” the allegation must either involve a charge about the intentions of the authors or the character of the paper, or both. It is of course no secret that some “science” is highly ideological in character. The question is how to demonstrate this. After all, the *critique* of a specific piece of science may be equally ideological in character.

Then there is critique of specific authors. With respect to the target article, as shown above, most of the critique has been leveled against the first author, myself. It is true that I have long supported, and written in favor of, both social acceptance and legalization of physician assistance in dying. To advocate acceptance and legalization of physician assistance in dying, however, is not to advocate such assistance for any specific individual or group of individuals, or that such assistance be imposed on anyone. And such advocacy is certainly not to try to advertise the “benefits” of suicide in the twisted sense used by Rita Marker.<sup>156</sup> Fortunately, one of the most vigorous opponents, Wesley Smith, corrects one of the more frequently repeated *ad hominem* objections: he replies correctly to

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150. Patrick Goodenough, *Study Defending Assisted Suicide Written by Assisted Suicide Advocate*, 79 NEWSL. EUTHANASIA PREVENTION COAL., Oct. 2007, at 2, available at <http://www.euthanasiaprevention.on.ca/Newsletters/newsletter79.pdf>.

151. *Id.*

152. Int'l Task Force on Euthanasia and Assisted Suicide, *New Euthanasia/Assisted-Suicide Study Draws International Criticism*, *supra* note 8 (citing a Not Dead Yet News & Commentary Blog, Oct. 1, 2007).

153. *Id.*

154. *Id.*

155. RITA MARKER, DEADLY COMPASSION: THE DEATH OF ANN HUMPHRY AND THE TRUTH ABOUT EUTHANASIA 148–52 (1993).

156. *Id.*

repeated claims that I “failed to disclose” that I am a member of the Advisory Board of the pro-legalization Death With Dignity National Center by pointing out that journals require disclosure of *financial* conflicts of interest.<sup>157</sup> Well, I have no such conflicts.

More importantly, those pursuing this line of *ad hominem* objections fail to recognize that the target article has five authors, not just one.<sup>158</sup> Three are well-known epidemiological researchers in the Netherlands with varying views about the ethical issues in assisted dying, but who do not take public stands on them; one is a distinguished physician in Oregon, associated with the Oregon Health and Science University. Whatever “biases” one author might have had in seeking to examine empirical data about the issue of abuse has been rigorously—I repeat, rigorously—deleted by the others, all of them empiricists by training.

Even more importantly, this line of *ad hominem* argument seems to assume that people who hold individual views about a particular social issue are thereby disqualified from engaging in objective research on it. It is a safe guess that with a highly controversial social issue like physician-assisted dying, most people who are at all familiar with the issue have a view about it (whether for or against, or sometimes moving back and forth as they reflect on the issue). If the *ad hominem* argument were right in holding that people with antecedent views about an issue cannot be objective, then virtually no one, on either side, would be able to conduct such research. What is far more desirable, as I have argued elsewhere, is the practice of “oppositional collaboration,” where researchers on opposite sides of an issue collaborate in assembling their data: they visit the same locations at the same times; read the same articles and pore through the same books; design protocols together, and interview the same people at the same times, always in the room together so that each hears what the other one hears.<sup>159</sup>

Perhaps the most important error in allegations of bias, though, lies in the assumption that an examination of abuse of people in vulnerable groups would be of interest primarily to pro-legalization

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157. James Coyne, *Lessons in Conflict of Interest: The Construction of the Martyrdom of David Healy and the Dilemma of Bioethics*, 5 AM. J. BIOETHICS 3 (2005).

158. *Target Article*, *supra* note 22.

159. Margaret P. Battin, *Empirical Research in Bioethics: The Method of “Oppositional Collaboration,”* in ENDING LIFE: ETHICS AND THE WAY WE DIE 316–20 (2005).



parties. To repeat what the target article points out, because this point is so important:

These are concerns both for those who oppose physician-assisted dying on moral grounds and for those who support it but are uneasy about the possible social consequences of legalisation. They are also concerns for proponents of legalisation who assume that the risks for vulnerable patients are heightened if these practices remain underground, as well as for those who favour legalisation but fear that vulnerable patients will be denied a privilege reserved for better-situated patients and that healthcare inequities already affecting vulnerable persons will be exacerbated. In short, slippery slope concerns about vulnerable patients confront both those who do and those who do not find physician-assisted dying objectionable on moral grounds.<sup>160</sup>

In my own view, a study like the target article serves as a potential mind-changer: if one has been supportive of legal aid-in-dying but discovers that in jurisdictions where it actually is legal that it is associated with extensive abuse, one ought to change one's mind.

#### WHAT THESE CRITIQUES DO NOT SHOW

In short, these critiques do not succeed in undercutting the conclusion of the study in question: that there is no evidence of heightened risk of physician-assisted dying to vulnerable patients in either legal or extralegal practice groups, with the one exception of persons with AIDS. However, that there is no current factual support for "slippery slope" concerns does not show that there is no room for future research. Here is the fuller conclusion, again from the target paper, reproduced in Box 5.

Box 5: *The Comprehensive Picture in Oregon and the Netherlands*<sup>161</sup>

The data from Oregon and the Netherlands are the most informative sources concerning legal physician-assisted dying, though they are not comparable

160. Reproduced with permission from BMJ Publishing Group Limited. Margaret P. Battin et al., *Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in "Vulnerable" Groups*, 33 J. MED. ETHICS 591, 591 (2007).

161. Reproduced with permission from BMJ Publishing Group Limited. Margaret P. Battin et al., *Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in "Vulnerable" Groups*, 33 J. MED. ETHICS 591, 596-97 (2007).

in a number of respects: they cover different time periods, were obtained by different methods, and are of different strengths. Neither the Oregon nor the Dutch studies were corrected throughout for considerations of whether diagnoses that may make physician-assisted dying attractive are equally distributed in vulnerable and non-vulnerable groups. Clearly, more work needs to be done.

Where they do overlap, however, the studies are largely consistent. Where the data are robust, the picture in Oregon and the Netherlands is similar: in both jurisdictions, a smaller percentage of older people received assistance in dying than of younger patients; gender ratios were slightly higher for males over time; and assistance was not more common among the uninsured. Socioeconomic data of intermediate strength, usually inferred from other, more robust data, also suggest similar pictures in the two jurisdictions: recipients of assistance in dying were likely to be of equal or higher educational status and were less likely than the background population to be poor. Data that are robust in one jurisdiction but partly inferential and hence less secure in the other did not reveal cases in either data set of assisted dying associated with physical disability alone without concomitant serious or terminal illness. The rates of physician-assisted dying among mature minors, which is legal in the Netherlands, were too low to be statistically valid. Although the rates of request for physician-assisted dying may have been higher among patients with depression, it appears that most such requests do not culminate in euthanasia, even though such cases may be legal in the Netherlands if given heightened scrutiny; studies of patients in the process of making requests are needed to clarify the risk conferred by depression. Even where the data involve very few cases or are absent in one or the other jurisdiction, the picture appears to match: neither in Oregon nor in the Netherlands was there any report of assisted dying disproportionately practised among racial minorities. Thus, there is no evidence of heightened risk of physician-assisted dying to vulnerable patients in either legal or extralegal practice groups, with the sole exception of people with AIDS.

Thus, we found no evidence to justify the grave and important concern often expressed about the potential for abuse—namely, the fear that legalised physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups. The evidence available cannot provide conclusive proof about the impact on vulnerable patients, and full examination of practice in Oregon would require studies of the complexity, duration, and comprehensiveness of the four nationwide Dutch studies. Nevertheless, the joint picture yielded by the available data in the two jurisdictions shows that people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges. This conclusion

does not directly speak to the moral issues in physician-assisted dying; it does not argue whether physician-assisted dying would be more or less appropriate for people in some groups; and it does not show that people in vulnerable groups could not be disproportionately affected in the future or in other jurisdictions. It also does not show whether low rates of physician-assisted dying among vulnerable persons reflect a protective effect of safeguards or, rather, are evidence of unequal access to assistance. But it does show that there is no current factual support for so-called slippery slope concerns that death in this way would be practiced more frequently on persons in vulnerable groups.

#### THE REAL QUESTION

More important to the question explored here, however, is what the reaction ought to be when, as is the case with the target article, a rigorous empirical study finds no evidence of abuse. The present article has explored many of the reactions that have appeared in newsletters, blogs, and elsewhere following the publication of the target article, ranging from fault-finding with the data it assembles to accusations of bias.

To be sure, much of this discussion comes from circles and organizations antecedently opposed to acceptance or legalization of physician-assisted dying. Such opposition is, of course, to be respected. But what is more difficult to respect is the way in which those conclusions are drawn.

As I argued at the outset, opposition to physician-assisted dying is generally based on two central concerns: (1) the principle of the sanctity of life, variously called the wrongness of killing, the wrongness of suicide, or the wrongness of murder; and (2) the possibility of abuse, often identified in the dual ways of undercutting the integrity of the medical profession and the possibility of the slippery slope.

The target study has found that there is no evidence supporting slippery slope fears. Why then the continuing opposition? Most of the opponents discussed in the present article argue less on principle-based or religious-principle-based grounds, but instead base their concerns primarily on slippery slope fears: this is true of all the task forces, courts, and medical organizations cited in Box 2, above, as well as of groups like Not Dead Yet. However, it is not these opposition groups that are calling for collection of data concerning aid in dying among people with disabilities. As Kathryn Tucker and the late Paul Spiers pointed out, it is the pro-legalization group

Compassion and Choices that has called for the ODHS to collect data about disabilities that are independent of or that preexist a terminal illness. The anti-legalization groups have not done so, suggesting, perhaps, that they fear their concern will turn out to have no basis in fact.<sup>162</sup>

What, then, might be a plausible response to the target article's finding that, with the exception of people with AIDS, there is no evidence of heightened risk for any of the ten groups identified as "vulnerable"? Wouldn't the most plausible response from those writing on behalf of people in vulnerable groups be: *Whew! We were so worried that our people would be abused, but now we see there is no evidence for such a claim. We are now ready to entertain the idea that—barring further evidence to the contrary—social acceptance and legalization should be supported. Indeed, we need to work to see that they are not shortchanged in access to physician-assisted dying, if that is what they clearly, genuinely, indeed autonomously want.*

#### THE POSITIVE CONTRIBUTION: TOWARD AN AGENDA FOR FURTHER RESEARCH

The objective of the target article was extremely limited: to explore whether there is current evidence of abuse—understood as reflected in higher rates of utilization of physician-assisted death—in specific groups identified as "vulnerable." The target article recognized that, even with regard to the data at hand, more work clearly needs to be done. However, there can be an additional positive contribution as well: the target article and the critiques explored here can jointly provide a beginning for an agenda for further research, both closing the gaps in the data currently available and posing new research questions.

Two issues are particularly important. First, studies of the complexity, duration, and comprehensiveness of the nationwide Dutch studies would be required to fully examine ODDA practice in Oregon. Particularly important to the way in which the Dutch studies were conducted was the assurance of protection from legal action that was guaranteed by the Ministry of Justice for information disclosed in the studies: physicians were free to report what they actually did

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162. Kathryn Tucker & Paul Spiers, *The Sky is Not Falling: Disability and Patient Directed Aid in Dying*, in *END OF LIFE ISSUES AND PERSONS WITH DISABILITIES* 135–43 (Timothy H. Lillie & James L. Werth eds., 2007).

without fear of prosecution.<sup>163</sup> This is what made it possible to obtain information about cases which had not been reported as required under the guidelines, and to determine their characteristics. There were no differences between reported and unreported cases in the Netherlands except that the unreported cases did not involve consultation and, obviously, were not reported. With respect to every other characteristic studied they were the same. Similar assurances would be necessary in Oregon for an adequate study; otherwise fully candid information could not be obtained.

Second, studies of the decision-making processes of dying patients who requested assistance in dying would also be appropriate, *if* it is possible to conduct them without intrusion and, *if* similar studies are conducted for other end-of-life decision-making by patients. These studies would be particularly informative if they could be targeted not just at broad decision-making processes of dying patients (e.g., “is this person methodical and deliberative, or is this person characteristically impulsive and changeable?”), but more directly focused on dying patients’ decision-making processes as they make their choices about how to die. In the target article, the findings are based on the numbers of deaths in each group identified as vulnerable, not, as the International Task Force on Euthanasia and Assisted Suicide correctly pointed out, on whether those individual patients had actually experienced pressure to end their lives. The evidence available gives no reason to think either that these people have been selectively pressured, or at the very least, that if they were pressured, they were unable to resist the pressure. After all, their rates of assistance in dying are lower than those for people not in vulnerable groups.

But this does not fully answer the question about pressures on people who are making end-of-life decisions. A possible area for further research would be to try to examine pressures within domestic, clinical, and organizational settings—after all, pressures could come from overwrought or greedy family members, impatient or overworked physicians, or cost-conscious insurers or health-care systems. However, such research would be informative only if it examined patients in other medical situations as well: facing surgery or chemotherapy; seeking pain-relieving drugs; and considering whether to terminate respiratory support or quit dialysis in long-term

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163. See the accounts of methodology in van der Maas et al., *Euthanasia and Other Medical Decisions Concerning the End of Life*, *supra* note 36.

chronic conditions, for example. Such research would have to avoid the naïve assumption that only patients at the end of life are pressured, as sensitive exploration will no doubt reveal that many other patients are pressured as well. What the results from the target article encourage us to consider, however, is whether legalization under the sorts of safeguards that are part of both Oregon and Dutch law would provide protection against just such pressures, protection that is not provided when a patient's dying is "negotiated" in less conspicuous ways.

Dan Callahan, the distinguished co-founder of The Hastings Center, once remarked that he thought he could call around for fifteen or twenty minutes and find a willing physician.<sup>164</sup> No doubt he could, but that is surely because he is a famous, persuasive, articulate, well-connected person; imagine how difficult it would be to find a sympathetic doctor, at least in the U.S., if he were poor, in a racial minority, uninsured, of low socioeconomic status, or in any of the categories of vulnerable people. The really interesting thing about the target article is that in both Oregon and the Netherlands, it is people of comparative privilege—younger, richer, non-disabled, non-minority, etc.—who appear to be those who get what they want. This is the aspect that now needs exploration, and indeed, it needs to be *cooperative* exploration between opponents and proponents with the common, non-ideological intent of developing a still broader picture of decision-making at the end of life.

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164. Personal communication from Daniel Callahan, The Hastings Center (August 2008).