

Linda Ganzini, "Response to Denny and Emanuel," *The Journal of Clinical Ethics* 17, no. 1 (Spring 2006): 42-5.

## Response to Denny and Emanuel

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This response to Denny and Emanuel focuses on two areas: their critique of the methods used in our study, and their trivialization of the study of PAS.

First, Denny and Emanuel express concern about possible bias in our results. Low rates of participation may bias results, if the study group does not represent the broader population from which the participants were sampled. "Bias" suggests a distortion of the relationship between a risk factor and the outcome, but excluding those thought to be at low risk for an outcome in the prospective study — in this case, those who indicated they would never request PAS — does not result in scientific bias. In prospective studies, researchers frequently and intentionally limit members of the inception cohort to those who are anticipated to be at most risk for an outcome. Prospective studies are very labor intensive and inefficient, and the financial costs of following a large group of subjects who have a low likelihood of the outcomes of interest can be prohibitive. The more valid methodological problem in our study was the rarity of actual PAS requests, which limited our statistical power to detect predictors of this very infrequent outcome.

Yet if our measure failed to predict actual PAS requests, then experts should hesitate to extrapolate from studies about the interest in hastened death to requests for PAS, as the relationship between attitudes and requests for PAS in most other studies remains untested. Taken in total, Oregon data suggest that about 10 percent of terminally ill patients seriously consider PAS.<sup>1</sup> When we set the cut-off point for serious interest in PAS at 5 on our 1 - 10 scale, we obtained a similar proportion. Yet only 1 percent of Oregon decedents have made an actual request for a lethal prescription to a physician, and only 0.1 percent reportedly die by this method. Studies outside Oregon similarly support that about 10 percent of terminally ill patients who were surveyed had some type of interest in PAS or hastened death.<sup>2</sup> But one cannot conclude that because a set of factors such as depression or psychosocial distress are associated with endorsing interest in PAS on a survey, that these factors are necessarily associated with actual requested or completed PAS. Such assumptions often prove to be incorrect, as they fail to recognize a varyingly large gap between attitudes and behaviors. Only prospective and case control studies of patients who have actually made requests for PAS should affect policy, as they are the only studies that are relevant to actual legalization of PAS.

Second, Denny and Emanuel question our ascertainment of the outcome, a request for PAS, and suggest physicians may have forgotten their patients' requests. Our evidence suggests physicians find such requests to be quite memorable.<sup>3</sup> Further, the physicians who cared for patients in our study knew they were in the study, and that they would be eventually asked about their patients' requests, if any.

Denny and Emanuel assert that academic discussion of PAS peaked in 1994, and then declined, reflecting diminished interest. A PubMed search for *physician-assisted suicide* (narrowed to articles relevant to humans, in English) shows that interest, measured by published articles, increased in 1993 to 219, crested in 1997 at 449, and gradually declined through 2005. (Adding *euthanasia* changed the peak to 1993, but this includes a large proportion of studies on passive euthanasia, such as withholding/withdrawing treatment and

advance directives). Most of the articles are ethical and legal analyses or opinion pieces. Another interpretation might be that it is increasingly difficult to write ethical and legal formulations novel enough to be published. The development, funding, execution, analysis, and publication of data-based studies often takes years. They rarely can be produced as quickly as ethical or legal analyses. In the five years from 1995 to 1999, the 101 articles published on PAS were empirical — mostly surveys of the public, patients, families, and clinicians. In the five years from 2000 to 2004, 125 data-based studies were published. Studies such as ours are not "increasingly infrequent," but rather are becoming a larger proportion of publications over time. This represents a natural history of scientific progress, and the evolution of knowledge in medicine.<sup>4</sup>

The comment that PAS, or research on it, may be marginal or fading merits consideration. As media coverage about Terri Schiavo suggests, autonomy and decision making at the end of life capture the imaginations of many Americans, even when their own risk of a similar fate, such as persistent vegetative state, remains low. A 2005 Pew Research Center survey of 1,500 adults reports that Americans remained divided on PAS: 46 percent approved of PAS laws and 45 percent disapproved; 57 percent, who said they gave "great deal of thought" to PAS, approved of legalization, a view not shared by 35 percent, who said they gave "little" or "no thought" to end-of-life issues; 53 percent said that people have the moral right to end their lives if they have a chronic disease, up from 49 percent in 1990.<sup>5</sup> This does not support a statement that there is decreasing support for the issue of PAS based on a realization of its lack of importance.

Only one in 1,000 deaths a year in Oregon are caused by legal PAS, a rate much smaller than predicted when the law was passed. Oregon, with about 1 percent of the U.S. population, is the only state in which PAS is licit. From a public health perspective, PAS does not rank with heart disease, cancer, or stroke as a cause of death; however, it is a more common cause of death than sickle cell anemia, Tay-Sachs disease, tetanus, or rabies. None of these are trivial, and all are disorders that are important enough to warrant current funding from the National Institutes of Health. "Marginal" and "fading" are dismissive terms that communicate that trying to understand why people pursue PAS is not worth our effort.

There are many ways to judge the importance of studying PAS, and the most important benefits are not related to political advocacy for or against the issue: it may improve patient care. Information from PAS studies may help refine conceptual models of suicide, which most would agree is a public health problem, especially among medically ill elderly. Open study of PAS is facilitated in Oregon because it is legal, which allows the collection of information to guide clinical practice. Findings may help clinicians who struggle with PAS requests in other states, where PAS is illegal, and secret — clinicians are understandably reticent to discuss cases with peers. If one in 10 terminally ill patients, at some point, wish to hasten death, then, nationally, thousands of patients are affected each year. Clinicians err in avoiding discussion of such difficult issues. As underscored by Fallowfield and coauthors in their studies of cancer patients, silence can result in heightened fear and anxiety, not in increased calm and equanimity.<sup>6</sup> Because interest in PAS is a proxy for potentially remediable suffering, research is crucial and systematic and thorough exploration by physicians in clinical settings is mandatory.

The dominant characteristics of those who request PAS are a desire to be in control of one's life, to minimize dependence on others, and to maintain self-sufficiency.<sup>7</sup> Conceptual models developed to explain why people request PAS cannot ignore this data. Currently, palliative care focuses on symptom management, spirituality, and family needs, not on how to leave this world in the "driver's seat." Highlighting a group of people with these values underscores the need for diversification of treatment in palliative care and development of individualized approaches reflecting the values of this minority. Even with the best care at the end of life, not all suffering can be assuaged, and some patients may be comforted to learn they have some choices.

Study of legal PAS can be considered a cautionary tale. During the peak of speculation about Oregon's law in the mid-1990s, experts predicted that legalized PAS would undermine palliative care; lead to legalization of other types of euthanasia; prey on the poor, the underprivileged, women, and on minorities; and lead to PAS clinics in Oregon for individuals from other states.<sup>8</sup> None of this has happened. Studies on PAS cannot overcome moral objections to it, but can serve as humbling reminders that our expertise alone cannot guarantee accurate prediction.

## DISCLAIMER

The views expressed are the author's and do not represent the views of the Department of Veterans Affairs or the U.S. government.

## NOTES

1. L. Ganzini et al., "Physicians' Experiences with the Oregon Death with Dignity Act," *New England Journal of Medicine* 342 (2000): 557-63; Oregon Department of Human Services, <http://www.ohd.hr.st.or.us/chs> (2003); S.W. Tolle et al., "Characteristics and Proportion of Dying Oregonians who Personally Consider Physician-Assisted Suicide," *The Journal of Clinical Ethics* 15 (2004) 111-8.

2. E.J. Emanuel, D.L. Fairclough, and L.L. Emanuel, "Attitudes and Desires Related to Euthanasia and Physician-Assisted Suicide Among Terminally Ill Patients and Their Caregivers," *Journal of the American Medical Association* 284 (2000): 2460-8; K.G. Wilson et al., "Attitudes of Terminally Ill Patients Toward Euthanasia and Physician-Assisted Suicide," *Archives of Internal Medicine* 160 (2000): 2454-60; H.M. Chochinov et al., "Desire for Death in the Terminally Ill," *American Journal of Psychiatry* 152 (1995): 1185-91.

3. S.K. Dobscha et al., "Oregon Physicians' Responses to Requests for Assisted Suicide: A Qualitative Study," *Journal of Palliative Medicine* 7 (2004): 450-61.

4. Results from the term "physician-assisted suicide" x survey, with the following limitations: relevant to humans, in English, with an abstract — then individually examined for data.

5. <http://people-press.org/reports>, 2006.

6. L.J. Fallowfield, V.A. Jenkins, and H.A. Beveridge, "Truth May Hurt but Deceit Hurts More: Communication in Palliative Care," *Palliative Medicine* 16 (2002): 297-303.

7. B. Carlson et al., "Oregon Hospice Chaplains' Experiences with Patients Requesting Physician-Assisted Suicide," *Journal of Palliative Medicine* 8 (2005): 1160-6; L. Ganzini et al., "Oregon Physicians' Perceptions of Patients who Request Assisted Suicide and Their Families," *Journal of Palliative Medicine* 6 (2003): 381-90; L. Ganzini et al., "Experiences of Oregon Nurses and Social Workers with Hospice Patients who Requested Assistance with Suicide," *New England Journal of Medicine* 347 (2002): 582-8; Ganzini et al., see note 1 above.

8. K. Faber-Langendoen, "Death by Request: Assisted Suicide and the Oncologist," *Cancer* 82 (1998): 35-41; J.L. Bernat, "The Problem of Physician-Assisted Suicide," *Seminars in Neurology* 17 (1997): 271-9; E.J. Emanuel and E. Daniels, "Oregon's Physician-Assisted Suicide Law: Provisions and Problems," *Archives of Internal Medicine* 156 (1996): 825-9; P.A. Singer and M. Siegler, "Euthanasia: A Critique," in *New England Journal of Medicine* 322 (1990): 1881-3; E.D. Pellegrino, "Ethics," *Journal of the American Medical Association* 273 (1995): 1674-6; R.D. Truog and C.B. Berde, "Pain, Euthanasia, and Anesthesiologists," *Anesthesiology* 78 (1993) 353-60.