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“Physician-Assisted Suicide among Oregon Cancer Patients”: A Fading Issue

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Articles like Ganzini and colleagues’ “Physician-Assisted Suicide Among Oregon Cancer Patients” are increasingly infrequent. Public and academic discussion of physician-assisted suicide (PAS) and voluntary euthanasia reached a dramatic highpoint in 1994 with the passage of Oregon’s Death with Dignity Act.¹ Since the Supreme Court’s 1997 ruling that there is neither a constitutional right nor constitutional prohibition to PAS, however, interest in the subject has declined significantly. Physicians and lawmakers alike have gradually come to the realization that the furor over PAS affects only a very small minority of U.S. patients. The percentage of terminally ill patients who are mentally competent and would actually take advantage of legalized PAS leaves only a very few individuals directly impacted by PAS legislation — a population much smaller than perhaps is suggested by the attention focused on the topic. Ganzini and colleagues’ findings illustrate some of the factors that make the legal status of PAS a relatively marginal issue for the American public in its efforts to improve patients’ experiences at the end of life.

PROBLEMS OF METHODOLOGY

Before considering the implications of Ganzini and colleagues’ findings, we must consider whether the data are reliable and generalizable. Overall, several aspects of the study cast doubt on the soundness of the final conclusions. First, the sample population from which the researchers glean most of their results is biased by a number of factors. A significant part of this bias cannot be attributed to any fault of the researchers: a large number of physicians declined to refer their patients to the study, often without explanation, and more than 30 percent of eligible participants declined to enroll. However, additional bias occurred when 80 subjects who indicated initially that they were uncertain or uninterested in requesting PAS were never re-evaluated. As the authors’ and others’ previous findings indicate, patients’ interest in PAS can vary significantly over time, increasing as well as decreasing.² Thus, those patients with no initial inclination towards PAS might have subsequently expressed interest. Excluding these subjects — more than 60 percent of those enrolled — from further data collection not only reduced the sample size unnecessarily, but distorted the final results by eliminating patients whose PAS interest may have developed over time, rather than presenting at the first assessment.

Another problematic aspect of the study design concerns whether the assessment questionnaires accurately gauged PAS interest and its correlates. The decision to classify any interest greater than 4 on a 10-

point scale as "serious interest" in PAS, for example, may confound data interpretation. It seems quite possible that a patient's choice of a number in the middle of the scale, such as 5, could indicate "mild" rather than "serious" interest. Accordingly, there seems to be significant potential for a disconnect between patients' expressed level of PAS interest and researchers' interpretation of this self-report. The decision to ask doctors, rather than subjects, about the occurrence of physician-patient PAS discussions may also confuse the authors' interpretation of the factors associated with PAS interest. As all the other possible correlates of PAS interest were self-reported by the patients, gathering this one piece of information from an external source — especially a physician who treats many terminally ill patients and may have a faulty recollection — may undermine the final data analyses. The assessments' questionable sensitivity and specificity seems best evidenced by the fact that one of the two patients who explicitly requested PAS failed to indicate any PAS interest whatsoever on the questionnaire, while other subjects expressing "serious" levels of interest never even brought up the subject with their physicians. These methodology concerns indicate that the results should be interpreted very cautiously.

LONGITUDINAL INTEREST IN PAS

The most critical finding in Ganzini and colleagues' work is that terminally ill patients' interest in PAS fluctuates significantly over time. No individual subject had the same self-reported level of interest for more than two evaluations in a row (unless that level is zero), nor consistently expressed a high level of interest in obtaining a lethal prescription. Additionally, the data displayed in figure 1 are from the subgroup of participants who are probably most interested in PAS; 40 percent of patients who were assessed multiple times expressed zero interest on all assessments subsequent to the initial evaluation and were not included in this graph. These longitudinal data indicate that an individual patient's self-reported PAS interest is typically highly unstable, moving up and down over the course of a few months.

DEPRESSION, PAIN, DIGNITY, AND INTEREST IN PAS

There is a widely held public perception that uncontrollable pain plays a pivotal role in a terminally ill patient's desire for PAS, and is the primary justification for legalizing the prescription of lethal medications.³ Contrary to this belief, however, almost all previous studies on attitudes toward PAS have found that depression and other indicators of psychological distress are more strongly correlated with elevated interest and desire for PAS among terminally ill patients, eclipsing pain level or even the wish for a dignified death, another rationale often championed by PAS advocates.⁴

Ganzini and colleagues confirm these findings, concluding that feelings of depression, hopelessness, being a burden to one's friends and family, and dissatisfaction with medical care all played a statistically significant role in heightened interest in PAS among patients. It is important that the two patients in the study who made explicit requests for PAS both showed signs of clinical depression. In contrast, neither man felt that he was in unbearable pain. Although some proponents argue that the legal status of PAS allows those with unbearable suffering to end their lives with dignity, empirical studies like those of Ganzini and colleagues consistently show that depression and general psychological distress play a more significant role in increasing patients' interest in PAS.⁵

IMPORTANCE FOR PHYSICIANS AND POLICY MAKERS

The themes reiterated by Ganzini and colleagues have important indications for future action, both at the local level of health professionals as well as the state and national levels of government. The most significant implication of this study for physicians dealing with terminally ill patients is that an individual patient's interest in PAS often fluctuates considerably and rapidly. Those patients who are initially interested in PAS

may decide against it in the coming weeks or months, just as patients who are opposed may eventually gain interest. Rather than taking quick action or assuming that a patient who indicates interest in PAS will soon move to make an explicit request, physicians should understand that such interest is particularly volatile over time, and make a concerted effort to understand the motives behind a particular patient's interest.

In addition to illuminating the instability of PAS interest, Ganzini and colleagues' data regarding the significant role that depression and poor mental health play in PAS interest re-emphasize to physicians the importance of mental health assessments and treatment for terminally ill patients. Physicians should maintain a low threshold for signs of depression in such patients and should be sure to request psychological assessment and counseling for the terminally ill. This applies equally to terminally ill patients who make no PAS requests; as Ganzini and colleagues and others' data indicate, approximately one in five terminally ill patients suffers from major depressive disorder, including those uninterested in obtaining a lethal prescription.

The authors' one suggestion for physicians — that they initiate more conversations with their patients about PAS — seems misguided. They interpret their finding that only half of patients expressing PAS interest actually discuss the option with physicians to signify poor communication between doctors and their patients. Rather than indicating a lack of communication, however, this finding seems more likely to reflect patients' feelings that such a conversation implies a much more serious level of intent than expressing interest on an anonymous questionnaire. Furthermore, such physician-initiated discussion might be potentially harmful to patients' decision making. In their conclusions, the authors dismiss the widespread apprehension among physicians that bringing up the subject of PAS may be understood by the patient as an endorsement. In support of this dismissal, the authors cite both psychology literature and their own data, claiming psychiatric patients are not more likely to have suicidal thoughts after being asked about suicidal intentions, and pointing to their eight subjects who were assessed multiple times, but never expressed any PAS interest subsequent to the initial evaluation. These arguments alone, however, are insufficient to discount the concerns of a perceived endorsement of PAS by a physician.

First, the psychiatry literature may not be an appropriate comparison: while a psychiatrist will never advocate suicide as an option for a mentally ill patient, a physician might legally approve PAS for a terminally ill patient. Second, the eight subjects mentioned by the authors already had an interest in PAS, by their own report. To counter worries of perceived endorsement, it would be important to know whether patients who communicated no initial interest in PAS came to express interest after repeated evaluation. Unfortunately, in this study design, these individuals were not followed-up after the first assessment. Thus, without further data, the authors' dismissal of the concern that patients will read endorsement into a physician's initiations of PAS discussion seems premature and unsupported by empirical data.

For legislators and policy makers, the implications of Ganzini and colleagues' findings are twofold. First, the percentage of terminally ill individuals who would actually take advantage of the PAS option is markedly small, estimated at significantly less than 1 percent of the general patient population.⁶ The legal status of PAS simply does not impact the lives of the great majority of Americans, hospital patients, or even terminally ill patients as a genuine personal option. Policy makers should accordingly be in no rush to legalize PAS or euthanasia before sufficient research can examine the full range of implications of such legislation, as the few lives directly impacted by the legal status of PAS are more than counterbalanced by the potential dangers and pitfalls of legalization. Second, with the legislation that already exists, policy makers should be sure to institute and enforce mandatory waiting periods in recognition of the fluctuation of PAS interest among terminally ill patients. In light of Ganzini and colleagues' evidence that patients' interest in PAS is unstable over short periods of time, mandatory waiting periods will help to assure that patients are consistent in their desire for PAS, rather than making an explicit request during an upswing of their oscillating interest that will soon diminish.

CONCLUSION

Ganzini and colleagues' findings reiterate the instability of PAS interest among terminally ill patients, as well as the significant role played by depression and psychological distress in elevated PAS interest levels. Physicians should accordingly be cautious in taking initial interest in PAS seriously among the terminally ill as an indication of stable preference. The trends reemphasized in this study – instability of interest, disinclination to act on interest, and the strong role of poor mental health in interest – indicate the exceedingly small population of individuals that the legal status of PAS directly affects, a conclusion with important implications for policy makers faced with questions of legalizing PAS. Rather than debating over PAS questions that affect only a minute fraction of patients, doctors and policy makers should focus on the broader-impact issue of enriching end-of-life care for the 2.4 million Americans who die each year by improving pain management, mental health treatment, and options for hospice and palliative care.⁷

DISCLAIMER

The opinions expressed are the authors' own. They do not reflect any position or policy of the National Institutes of Health, the Public Health Services, or the Department of Health and Human Services.

NOTES

1. D. Shalowitz and E.J. Emanuel, "Euthanasia, Physician-Assisted Suicide: Implications for Physicians," *The Journal of Clinical Ethics* 15, no. 3 (2004): 232-6.

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; L. Ganzini et al., "Physicians' Experiences with the Oregon Death with Dignity Act," *New England Journal of Medicine* 342, no. 8 (2000): 557-63.

3. Shalowitz and Emanuel, "Euthanasia, Physician-Assisted Suicide," see note 1 above; C.H. Baron et al., "A Model State Act to Authorize and Regulate Physician-Assisted Suicide," *Harvard Journal on Legislation* 33 (1996): 1-34.

4. Death With Dignity National Center, *Death with Dignity*, 2006, <http://www.deathwithdignity.org/>, accessed 10 January 2006.

5. L. Ganzini et al., "Interest in Physician-Assisted Suicide," in this issue of *JCE*; A. Bottomley, "Depression in Cancer Patients: A Literature Review," *European Journal of Cancer Care* 7 (1998): 181-91.

6. A.L. Back et al., "Physician-Assisted Suicide and Euthanasia in Washington State: Patient Requests and Physician-Responses," *Journal of the American Medical Association* 275, no. 12 (1996): 919-25; E. J. Emanuel, "What Is the Great Benefit of Legalizing Physician-Assisted Suicide?" *Ethics* 109 (1999): 629-42.

7. Shalowitz and Emanuel, "Euthanasia, Physician-Assisted Suicide," see note 1 above.