Oregonians’ Reasons for Requesting Physician Aid in Dying

Linda Ganzini, MD, MPH; Elizabeth R. Goy, PhD; Steven K. Dobscha, MD

Background: Oregon is the only US jurisdiction with a legal process, the Oregon Death with Dignity Act, that allows terminally ill patients to obtain physician aid in dying (PAD).

Methods: Fifty-six Oregonians who either requested PAD or contacted a PAD advocacy organization completed a survey indicating the importance of 29 reasons for their interest in PAD on a scale where 1 was not important and 5 was very important; 28% of people referred from the PAD advocacy organization enrolled in the study.

Results: Forty-one patients died by the end of the study; 18 received a prescription for medication under the Oregon Death with Dignity Act, and 9 died by lethal dose of medication. The most important reasons for requesting PAD, all with median scores of 5, were wanting to control the circumstances of death and die at home; loss of independence; and concerns about future pain, poor quality of life, and inability to care for one’s self. All physical symptoms (eg, pain, dyspnea, and fatigue) at the time of the interview were rated as unimportant (median score, 1), but concerns about physical symptoms in the future were rated at a median score of 3 or higher. Lack of social support and depressed mood were rated as unimportant reasons for requesting PAD.

Conclusions: At the time they express initial interest in PAD, Oregonians are motivated by worries about future physical discomfort and losses of autonomy and function. When confronted with a request for PAD, health care providers should first work to bolster the patient’s sense of control and to educate and reassure the patient regarding management of future symptoms.

Arch Intern Med. 2009;169(5):489-492

Author Affiliations: Portland Center for the Study of Chronic, Comorbid Mental and Physical Disorders, Health Services Research and Development Service, Portland Veterans’ Affairs Medical Center, and the Department of Psychiatry, Oregon Health and Science University, Portland.

ONE IN 10 DYING PATIENTS will, at some point, wish to hasten death.1-3 In Oregon, such patients may request physician aid in dying (PAD) as outlined in the Oregon Death with Dignity Act (ODDA), which allows a competent, terminally ill patient to receive a lethal dose of a medication, usually a barbiturate, under some conditions.6 Since enactment of the ODDA in 1997, between 1 and 2 persons out of every 1000 who have died in Oregon have chosen PAD.6 To date, our understanding of the reasons Oregonians pursue PAD is almost entirely derived from proxies, via interviews with and surveys of patients’ family members and health care providers. These proxies ranked depression, poor social support, or uncontrolled physical symptoms as less important reasons for patients’ seeking information about PAD than desire for control over the circumstances of death.7-11 The goal of the present study was to directly survey Oregon patients actively interested in the ODDA regarding their reasons for pursuing PAD.

Methods

Patients were recruited for our study from 2 sources. The first group included patients who contacted Compassion and Choices of Oregon (CCO; an organization that informs individuals about end-of-life choices and offers services to those who choose aid in dying) for information about PAD, which resulted in CCO opening a client file. During the past decade, CCO staff have given information to or attended the deaths of three-quarters of Oregonians who chose legal PAD.12 This organization sent letters of invitation to every person who contacted them and who had made an explicit request for a lethal dose of medication under the Oregon Death with Dignity Act to a physician, hospice employee, nurse, or caregiver; was considered mentally capable; and in whom at least 1 physician predicted death within 6 months. The second group included patients who made an explicit request for PAD as outlined in the ODDA. These patients were referred by ethics consultants and palliative medicine and oncology specialists at 4 large medical centers in northwest Oregon.

In all cases, the referring agency or health care provider notified requesting patients about the opportunity to take part in the study, and interested patients then contacted the re-
Compassion and Choices of Oregon invited 178 clients to take part in this study. Of these, 12 (7%) were ineligible because they had died, were moribund, lived outside of Oregon, or were not terminally ill, and 47 (28%) contacted the research team expressing interest in participating. The remaining 11 participants were referred from 1 of 4 other medical centers (referring health care providers did not keep track of the number of persons notified about the study). A total of 58 agreed to participate; however, 2 did not complete the section of the study measuring reasons for the request. Study participants were equally divided by sex and were predominantly white, well educated, and lived independently (mean age, 66 years) (Table 1). The most common terminal diagnoses were cancer and amyotrophic lateral sclerosis. Only 1 in 3 participants were enrolled in hospice at the time of the survey, and fewer than half were married. Forty-one participants (73%) died a median of 2 to 3 months after they participated in the study. At death, 18 (44%) had received a prescription for medication under the ODDA, and 9 (22%) died by lethal ingestion.

Study participants confirmed their strong interest in PAD; 55 (98%) strongly supported legalization of PAD, 47 (84%) sought information on obtaining PAD from CCO, and 46 (82%) indicated they explicitly requested PAD. Fifty-four participants (96%) discussed their attitudes about PAD with family and friends, and 47 (86%) indicated that the people closest to them would probably support their choice to pursue PAD. The desire to die in the 2 weeks before the interview was low (mean [SD], 2.1 [3.3]).

The chief reasons participants pursued PAD, all with median scores of 5, were loss of independence, wanting to control the time and manner of death and die at home, and the prospect of worsening pain or quality of life and the inability to care for themselves (Table 2). Other key reasons, with median scores of at least 3.5, were having witnessed intolerable deaths, perception of self as a burden, loss of dignity, and fear of mental confusion in the future. Physical symptoms experienced at the time of initial interest in PAD were much less important: pain, shortness of breath, fatigue, confusion, and loss of bowel and bladder control were all rated a median of 1. In contrast, all physical symptoms that the patient anticipated in the future were rated a median of 3 or higher. Most respondents did not endorse existential reasons, such as feeling ready to die, that life tasks were complete, or that life
was pointless. Social issues were rated overall as not of concern; lack of social support and perception of self as a financial drain were both rated with a median score of 1. Participants did not acknowledge depression as an important reason for pursuing PAD. There were no statistically significant differences in reasons for the request in comparing those who received a lethal prescription and those who did not (data not shown).

Of 56 subjects, 41 (73%) rated a single most important reason for asking for PAD. Eleven requested PAD primarily to feel in control, 5 to avoid dependence on others, 5 because of worries about pain in the future, 4 because of worries about poor quality of life in the future, and 3 because of worries of loss of sense of self. All other most important reasons were chosen 2 times or less.

Our data suggest that when patients first request PAD, they do so not because of physical symptoms or quality of life at the time of the request but in anticipation of future suffering that they perceive as intolerable. Their desire to die is not strong, and they do not believe that their life is poor in quality, meaningless, or worthless. Rather, they appear to be protecting against the risk of future experiences they do not believe they can endure. Although future physical symptoms are important considerations for these individuals, they are more strongly motivated by the prospect of loss of autonomy—loss of control, quality of life, and ability to remain at home, with looming restrictions and dependence on others.

We are aware of only one other study that gathered data directly from persons actively considering or pursuing PAD. Pearlman et al completed longitudinal, qualitative interviews of 12 patients and family members of 23 additional patients from the Pacific Northwest who volunteered to participate in our study may not be representative of other Oregonians at the time they first requested PAD. For example, in our study, 1 in 4 patients to obtain PAD. The ODDA allows a physician to prescribe a lethal dose of medication to be self-administered by a requesting patient whose life expectancy is less than 6 months. A second physician must confirm the limited life expectancy and that the patient is capable of making the request. Between 1997 and 2007, 341 Oregonians died by legal PAD. One requirement of the law is that all prescriptions must be reported to the Oregon Health Division and aggregate data published annually. From this source, we know that, compared with other Oregonians who die, those who choose PAD are somewhat younger, predominantly white, better educated, less likely to be married, and more likely to die of cancer and amyotrophic lateral sclerosis; 86% are enrolled in a Medicare-certified hospice at the time of death.6

There are several limitations in our study. Our results focus on patients at the time they are first requesting PAD, yet 5 in 6 requests are ultimately not honored by physicians.11 Furthermore, among those who are successful in obtaining a prescription, some may wait until they are more ill and symptomatic to take it. For example, 20 of 56 of our study participants (36%) were enrolled in hospice. Similarly, physicians reported that 32% of 141 Oregon patients were enrolled in hospice at the time of the first PAD request.11 In contrast, 86% of Oregonians who die by lethal ingestion are ultimately enrolled in hospice.6 Although experienced physical symptoms were not a motivator for initially pursuing a lethal dose of medication, they may be cogent in the choice to ultimately die by a lethal prescription.

A second limitation is that only 47 of 166 clients (28%) invited by CCO to participate enrolled in the study; those who volunteered to participate in our study may not be representative of other Oregonians at the time they first request PAD. For example, in our study, 1 in 4 patients had limited self care or complete disability. In contrast, Oregon physicians reported that 59% of patients were con-

<table>
<thead>
<tr>
<th>Reason</th>
<th>Median Score (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wanting to control circumstances of death</td>
<td>5 (4-5)</td>
</tr>
<tr>
<td>Future poor quality of life</td>
<td>5 (4-5)</td>
</tr>
<tr>
<td>Future pain</td>
<td>5 (4-5)</td>
</tr>
<tr>
<td>Future inability to care for self</td>
<td>5 (3-5)</td>
</tr>
<tr>
<td>Loss of independence</td>
<td>5 (2-5)</td>
</tr>
<tr>
<td>Wanting to die at home</td>
<td>5 (1.25-5)</td>
</tr>
<tr>
<td>Perception of self as burden</td>
<td>4 (2-5)</td>
</tr>
<tr>
<td>Loss of dignity</td>
<td>4 (1-5)</td>
</tr>
<tr>
<td>Witnessed bad death(s)</td>
<td>4 (1-5)</td>
</tr>
<tr>
<td>Future mental confusion</td>
<td>3.5 (1-5)</td>
</tr>
<tr>
<td>Not wanting others to care for me</td>
<td>3 (1.25-5)</td>
</tr>
<tr>
<td>Worry about loss of sense of self</td>
<td>3 (1-5)</td>
</tr>
<tr>
<td>Future dyspnea</td>
<td>3 (1-5)</td>
</tr>
<tr>
<td>Ready to die</td>
<td>3 (1-5)</td>
</tr>
<tr>
<td>Future fatigue</td>
<td>3 (1-5)</td>
</tr>
<tr>
<td>Future loss of bowel/bladder control</td>
<td>3 (1-5)</td>
</tr>
<tr>
<td>Unable to pursue pleasurable activities</td>
<td>1 (1-4)</td>
</tr>
<tr>
<td>Life is pointless</td>
<td>1 (1-4)</td>
</tr>
<tr>
<td>Life tasks are complete</td>
<td>1 (1-4)</td>
</tr>
<tr>
<td>Perceive self as financial drain</td>
<td>1 (1-3.75)</td>
</tr>
<tr>
<td>Poor quality of life</td>
<td>1 (1-3)</td>
</tr>
<tr>
<td>Current pain</td>
<td>1 (1-2.75)</td>
</tr>
<tr>
<td>Unable to care for self now</td>
<td>1 (1-2)</td>
</tr>
<tr>
<td>Current dyspnea</td>
<td>1 (1-2)</td>
</tr>
<tr>
<td>Lack of support</td>
<td>1 (1-1)</td>
</tr>
<tr>
<td>Depressed mood</td>
<td>1 (1-1)</td>
</tr>
<tr>
<td>Current mental confusion</td>
<td>1 (1-1)</td>
</tr>
<tr>
<td>Current loss of bowel/bladder control</td>
<td>1 (1-1)</td>
</tr>
</tbody>
</table>

Table 2. Reasons for Wanting Physician Aid in Dying

Abbreviation: IQR, interquartile range (25th percentile to 75th percentile). Participants marked the importance of their reasons for requesting physician aid in dying on a scale from 1 to 5. 1 was “reason not at all important in decision to request a lethal prescription” and 5 was “reason is very important in decision to request a lethal prescription.” Marks not on an integer were estimated to the quarter interval.
fined to bed or a chair for more than half their waking hours when first requesting PAD. The very reasons that individuals may not have been able to participate in our study—lack of energy, poor motivation, disabling physical symptoms, or functional impairment—may have contributed to interest in hastened death. Despite the potential for selection bias, there is substantial agreement between the results of the present study and Oregon physicians’ and hospice workers’ previous reports of patients in Oregon who choose PAD.

The results of the present study may provide helpful approaches for patients who request PAD. Patients who actively pursue PAD appear, at least initially, to be motivated by worries about future physical discomfort and impending losses in autonomy and function. Having witnessed intolerable deaths, these patients need to have their sense of control supported. Health care providers should focus on reassuring patients that all efforts will be made to ensure that they will be able to die where they wish and that pain and other symptoms will be controlled.

If opposition to legalization of PAD is based on moral and religious beliefs about the value of life and ethical concerns about physicians’ actions, then patients’ reasons for hastening death may be irrelevant. However, for many policy makers and health care providers, judgment of Oregon’s law is conditional and based on PAD being used as an option of last resort. Lethal prescriptions should not substitute for competent end-of-life care. Our data support the assertion that initial pursuit of PAD does not appear to stem from lack of access to symptom management. Alternatively, for some, support of PAD legalization was based on the specter of patients with grave suffering from symptoms that could not be controlled even with good care. This support may wane faced with evidence that experienced physical symptoms are not paramount reasons for requesting PAD. However, as noted by Cassell, it is not the absolute level of pain, but the meaning of the pain, the prospect of its worsening, and its effect on one’s sense of self that are the true components of suffering. Whether or not PAD can be justified, our findings clarify the source of these patients’ suffering, which may lead to more compassionate care.

Accepted for Publication: August 4, 2008.

Correspondence: Linda Ganzini, MD, MPH, Research Service (Mail Code R&D 66), Portland Veterans’ Affairs Medical Center, PO Box 1034, Portland, OR 97239 (Linda.Ganzini@va.gov).

Author Contributions: Drs Ganzini, Goy, and Dobscha had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: Ganzini, Goy, and Dobscha. Acquisition of data: Ganzini and Goy. Analysis and interpretation of data: Ganzini, Goy, and Dobscha. Drafting of the manuscript: Ganzini. Critical revision of the manuscript for important intellectual content: Ganzini, Goy, and Dobscha. Obtained funding: Ganzini, Goy, and Dobscha. Administrative, technical, and material support: Ganzini and Goy. Financial Disclosure: None reported.

Funding/Support: This study was supported by a grant from the Northwest Health Foundation and Career Development Awards from the Department of Veterans Affairs Health Services Research and Development Service (Drs Goy and Dobscha).

Role of the Sponsor: The funding source had no role in any aspect of the study.

Disclaimer: The views expressed herein are those of the authors and do not necessarily represent the views of the Department of Veterans Affairs.

REFERENCES


Correction

Error in Text. In the Original Investigation titled “Oregonians’ Reasons for Requesting Physician Aid in Dying” by Ganzini et al, published in the March 9 issue of the Archives (2009;169[5]:489-492), an error occurred in the text on page 490. In the first paragraph of the “Results” section, the last sentence should have appeared as follows: “At death, 18 (44%) had received a prescription for medication under the ODDA, and 9 (22%) died by lethal ingestion.” Online versions of this article on the Archives of Internal Medicine Web site were corrected on March 9, 2009.