

Features

Characteristics and Proportion of Dying Oregonians Who Personally Consider Physician-Assisted Suicide

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Physician-assisted suicide (PAS) became legally available in Oregon in October 1997. The Oregon Death with Dignity Act (ODDA) limits eligibility to adult Oregon residents who are judged by two physicians to have less than six months to live. Patients must be able to make independent decisions and ingest the lethal dose, and there is a 15-day waiting period between request and receipt of a lethal prescription.¹

The Oregon Department of Human Services (DHS) compiles and reports statistics annually about those who receive a lethal prescription.² During the first six years of legal-

ization, 171 persons died after ingesting a lethal prescription according to the requirements of the Act. Compared to the average Oregon decedent, PAS users were younger, better educated, and more likely to be Caucasians or Asians dying of chronic diseases. A majority of the 171 PAS users had health insurance, were enrolled in hospice, and all but one died in community settings. According to physicians' reports, patients most commonly sought PAS because of decreased quality of life, loss of autonomy and control of bodily functions, and feeling they were a burden to family. The DHS data contribute valu-

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able information about the individuals who use PAS, but represent a small proportion of dying patients who consider PAS or take preliminary steps toward it.³

Past studies have examined patients' attitudes and desires for hastened death in states where PAS is not available and have found that patients commonly express wishes to end their lives,⁴ although these desires may change over time.⁵ Pain and depression have been associated with the desire for hastened death⁶ and with consideration of PAS or euthanasia,⁷ but the DHS data do not support the idea that patients with greater pain or symptoms are more likely to actually use PAS in Oregon,⁸ and clinical depression is an exclusion criterion for legal PAS.

We conducted this study to determine the prevalence of PAS support, PAS consideration, and PAS requests in a population of recently deceased Oregonians for whom legal PAS was an option. In addition, we sought to determine which demographic and clinical features predict those most likely to consider PAS, to understand better why some who consider PAS do not follow through with a formal request, and to discover why some who make a formal request do not obtain or use the lethal prescriptions they requested.

METHODS

After securing approval for research involving human subjects at the investigators' university and the state public health department, we selected a systematic monthly random sample of Oregon death certificates for deaths from June 2000 to March 2002. To match the patient population eligible for PAS, we limited decedent eligibility to Oregon residents older than 18 years, who died from natural causes. We also excluded sudden deaths with no prior end-of-life care (for example, myocardial infarction with immediate death), in-hospital deaths, and those who were reported to DHS as PAS deaths. We selected 100 percent of eligible minority deaths occurring statewide during the study time frame ($n = 779$), in order to have a large enough sample

to make comparisons by race and ethnicity. For White decedents, we randomly selected 8 percent ($n = 2,269$) of death certificates from 29,130 that met inclusion criteria. Using case-finding methods previously reported,⁹ we located family caregivers, defined as individuals having a significant relationship to the patient, whether by blood, marriage, or other close affiliation. Telephone interviews were conducted from two to five months (median, 130 days; range, 76 - 160 days) after a family member's death. Eligible respondents were at least 18 years old and had primary or shared responsibility for patient care and/or decision making during the terminal illness.

Study data consisted of information from death certificates and from family informants. Data from death certificates included decedent age, gender, race (classified as one of four mutually exclusive categories: White, Black, Asian-Pacific Islander, or American Indian), ethnicity (Hispanic origin, regardless of race), death information (date, location, and cause of death), and informants' name. Family informant data on PAS were collected as part of a larger 69-item questionnaire focusing on a spectrum of end-of-life care issues.¹⁰ Patients' symptom distress was measured using a validated version of the five-point Global Distress Index of the Memorial Symptom Assessment Scale,¹¹ the Family Memorial Symptom Assessment Scale-Global Distress Index (FMSAS-GDI).¹² The FMSAS-GDI includes the following 11 symptoms: sadness, worry, irritability, nervousness, lack of appetite, lack of energy, drowsiness, constipation, dry mouth, dyspnea, and pain. Six closed-ended items explored decedent opinions of, considerations about, and requests for PAS. Two open-ended narrative items invited respondents to mention "anything else about the topic of physician-assisted suicide" and, when appropriate, to describe the decedent's formal request for PAS.

ANALYSIS

Quantitative data were analyzed using SPSS 11.0¹³ and EpiInfo 2002.¹⁴ The *chi-square*

(χ^2), χ^2 test for trend, and *t*-test were used to test for statistical significance, and relative risks (RR) with 95 percent confidence intervals (CI) were calculated. Multiple logistic regression analyses were performed to identify independent factors predictive of patients' considerations of PAS. Qualitative data were analyzed using NVivo.¹⁵ A first coder arranged data into logical categories and identified themes using strategies of textual analysis and codebook development.¹⁶ The trustworthiness of the categories, the themes, and coding was verified by having a second coder review all coded text, resolving any discrepancies through dialogue with the first coder.

RESULTS

We located 2,197 family members (72 percent of the total population considered), and 1,927 (88 percent) were confirmed to be study eligible. Of those who were eligible and located, 1,384 (72 percent) agreed to participate. Based on demographic information from death certificates, study decedents whose families participated and those who did not were similar in terms of gender and place of death, but not with respect to race, age, or level of education. Fewer families of Black, Hispanic, or Asian-Pacific Islanders participated than did families of White decedents (χ^2 , $p < .001$ for each pairwise comparison), whereas participation rates were the same for Whites and American Indians. Family members of decedents under age 65 were less likely to participate than families of older decedents (χ^2 , 45 percent versus 51 percent, $p = .03$), as were families of decedents with less than a high school education compared to families of persons with post-baccalaureate degrees (χ^2 , 41 percent versus 52 percent, $p = .005$).

Decedents' characteristics and group comparisons are presented in table 1. A majority of decedents were female (57 percent), elderly (median age, 81 years), and White (82 percent), with less than a high school education (66 percent). Family caregivers were predominantly female (71 percent), middle-aged (median, 59 years), and very involved in the

patient's care and treatment decision making, as either the main person (50 percent), or in conjunction with other family members (45 percent).

Decedents' opinions about PAS were reported by family to be 44 percent in favor, 15 percent neutral, and 41 percent opposed, after excluding from analysis the 362 individuals (26 percent of total) who had not expressed an opinion to family members during the course of their terminal illness (for example, because of dementia). Protestants (RR .5, 95 percent CI: .5 - .6) and Roman Catholics (RR .5, 95 percent CI: .4 - .7) were about half as likely to support PAS, compared to those with no religious affiliation, as were those for whom religion was very important (RR .5, 95 percent CI .4 - .7), compared to those with low religiosity. Decedents who were younger and more highly educated, with incomes above \$30,000 per year, were more likely to be in favor of PAS. White decedents were more likely to be in favor of PAS than Black decedents (see table 1).

According to family caregivers, 236 decedents (17 percent) personally considered PAS as an option during their terminal illnesses. On univariate analysis, the following characteristics were significantly associated with considering PAS: younger age, lower religiosity, high school education, cancer diagnosis, and enrollment in hospice. Rates of PAS consideration in patients with amyotrophic lateral sclerosis (ALS—also known as Lou Gehrig disease) (RR: 2.8, 95 percent CI: .9 - 8.9), while not statistically significant, were also elevated. None of the study's 62 Black decedents were reported to have considered PAS as an option, compared to 20 percent of White decedents (χ^2 , $p < .001$). Those with annual household incomes above \$30,000 were more likely to consider PAS than those with lower incomes (see table 1).

Symptom distress was higher for decedents who considered PAS when examined as an aggregate score on the FMSAS-GDI (*t*-test, mean: 1.25 versus .97, $p < .001$) and as the number of 11 specific symptoms experienced in the last week of life (*t*-test, mean:

Table 1
 Characteristics of the Entire Study Population, Those Who Favor PAS, and Those Who Personally Considered PAS
 (2000 - 2002)

	Study Sample (N = 1,384)	Decedents in Favor of PAS (n = 453)	Relative Risk (95% CIs)	Personally Considered PAS (n = 236)	Relative Risk (95% CIs)
Gender					
Male, n (%)	590 (43)	204 (35)	1.1 (1.0 -1.3)	112 (19)	1.2 (1.0 -1.5)
Female, n (%)	794 (57)	249 (31)	1.0 --	124 (16)	1.0 --
Race/ethnicity					
White, n (%)	1,132 (82)	397 (35)	1.0 --	201 (18)	1.0 --
Black, n (%)	62 (5)	9 (15)	.4 (.2 - .8)	0	-- --
Hispanic, n (%)	60 (4)	13 (22)	.6 (.4 -1.0)	10 (17)	.9 (.5 -1.7)
Asian-Pacific Islander, n (%)	62 (5)	16 (26)	.7 (.5 -1.1)	15 (24)	1.4 (.9 -2.2)
American Indian, n (%)	67 (5)	18 (27)	.8 (.5 -1.2)	10 (15)	1.0 (.6 -1.8)
Age in years					
Less than 65 (%)	195 (14)	79 (41) *	1.7 (1.4 -2.2)	55 (28) *	3.2 (2.2 -4.6)
65 - 84 (%)	690 (50)	257 (37)	1.6 (1.3 -1.9)	137 (20)	2.3 (1.6 -3.1)
85 and older (%)	499 (36)	117 (23)	1.0 --	44 (9)	1.0
Median (range)	81 (31-104)	78 (37-103)	-- --	76.5 (34 -101)	-- --
Education					
Less than HS, n (%)	917 (66)	263 (29) *	1.0 --	135 (15)	1.0 --
HS graduate/some college, n (%)	255 (18)	99 (39)	1.4 (1.1 -1.6)	63 (25)	1.7 (1.3 -2.2)
College graduate, n (%)	121 (9)	47 (39)	1.4 (1.1 -1.7)	20 (17)	1.1 (.7 -1.7)
Post-baccalaureate, n (%)	91 (7)	44 (48)	1.7 (1.3 -2.1)	18 (20) *	1.3 (.9 -2.1)
Income, US \$/year					
< 30,000, n (%)	925 (72)	272 (29)	1.0 --	141 (15)	1.0 --
30,000 - 60,000, n (%)	249 (20)	111 (45)	1.5 (1.3 -1.8)	61 (24)	1.6 (1.2 -2.1)
> 60,000, n (%)	106 (8)	47 (44) *	1.5 (1.2 -1.9)	23 (22)	1.4 (1.0 -2.1)
Religion					
None, n (%)	205 (15)	110 (54)	1.0 --	50 (24)	1.0 --
Roman Catholic, n (%)	205 (15)	56 (27)	.5 (.4 - .7)	40 (20)	.8 (.6 -1.2)
Protestant, n (%)	875 (64)	253 (29)	.5 (.5 - .6)	127 (15)	.6 (.5- .8)
Other, n (%)	74 (5)	31 (42)	.8 (.6 -1.1)	18 (24)	1.0 (.6 -1.6)
Religiosity					
Not very important, n (%)	645 (48)	291 (45)	1.0 --	142 (22)	1.0 --
Very important, n (%)	699 (52)	155 (22) **	.5 (.4 - .6)	92 (13) **	.6 (.5 - .8)
Cause of Death					
Cancer, n (%)	517 (37)	201 (39)	1.4 (1.2 -1.6)	123 (24)	2.0 (1.6 -2.6)
ALS, n (%)	6 (< 1)	1 (17)	.6 (.1 -3.5)	2 (33)	2.8 (.9 -8.9)
COPD, n (%)	95 (7)	34 (36)	1.3 (.9 -1.7)	21 (22)	1.9 (1.2 -2.9)
All other causes, n (%)	766 (55)	217 (28)	1.0	90 (12)	1.0
Hospice					
Enrolled in hospice, n (%)	901 (65)	309 (34)	1.2 (1.0 -1.4)	173 (19) **	1.5 (1.1 -1.9)
Not enrolled in hospice, n (%)	482 (35)	144 (30)	1.0 --	63 (13)	1.0
Symptom distress (FMSAS-GDI, range 0 - 4)					
Mean score (SD)	1.03 (.90)	1.11 (.78)	-- --	1.25 (.81)	-- --

* Statistically significant, χ^2 test for trend.

** Statistically significant, χ^2 test.

5.76 versus 4.92, $p < .001$). At the item level, two symptoms were strongly associated with PAS consideration: sadness (χ^2 , 52.8 percent versus 41.4 percent, $p = .005$) and pain (χ^2 , 72.4 percent versus 60.9 percent, $p = .004$).

Logistic regression was used to identify variables independently associated with PAS consideration. Decedent's age (OR: .76, 95 percent CI: .7 - .9), religiosity (OR: .69, 95 percent CI: .6 - .8) and symptom distress (OR: 1.5, 95 percent CI: 1.2 - 1.8) were the only significant independent predictors in the model. Neither cancer diagnosis nor hospice enrollment was independently significant in the model.

Of the 236 decedents who considered PAS, 198 respondents gave answers to the open-ended question: "Is there anything else you wanted to mention about PAS?" By far, the most commonly mentioned themes were opinions or concerns about pain ($n = 32$), suffering ($n = 25$), and the right of individuals to make a choice ($n = 31$) based on their personal preferences ($n = 23$). The most commonly mentioned experiences were those that involved a "bad death" ($n = 31$) or barriers to PAS ($n = 27$). Some respondents listed more than one opinion or experience.

Twenty-five patients (2 percent) formally requested a lethal prescription from a physician in accordance with the ODDA. The formal requesters were more likely to have cancer than those who considered but did not request PAS (χ^2 , 76 percent versus 24 percent, $p = .011$). Only one person (< 0.1 percent) completed the required waiting period and obtained a lethal prescription, but did not use it. When asked to "tell more about the formal request," respondents spontaneously identified physician factors ($n = 17$) and waiting until the decedent was too close to death ($n = 5$) as the reason that no prescription was received. The physician factors were refusal of the request ($n = 11$) or provision of information that dissuaded the decedent from pursuing a prescription ($n = 5$: that PAS was illegal, or unnecessary, or impossible, or that it was too early to consider PAS). No unreported cases of PAS were identified through this epi-

demologic study of community-based deaths in Oregon.

CONCLUSIONS

Since the ODDA became legal in the fall of 1997, approximately one in 1,000 terminally ill Oregonians has received and used a lethal prescription. This study confirmed that, regardless of legalization, many more people consider PAS than follow through with it. Rates of PAS consideration for study patients in Oregon were about the same as for those dying in states where PAS is illegal.¹⁷ Family interviews indicate that dying patients were about nine times more likely to personally consider PAS than to make a formal request to start the process, and nearly 200 times more likely to consider it than to follow through with obtaining a lethal prescription. However, our sample did not include any patients who died under the ODDA by taking a lethal prescription—approximately one out of 1,000 Oregon deaths. Had we included these decedents, we would have concluded that dying Oregonians were approximately 100 times more likely to consider PAS than to follow through with obtaining a lethal prescription.

Terminally ill patients who personally considered PAS were different from the majority who did not consider it an option for themselves. Consistent with previous studies about support for and consideration of PAS or euthanasia, dying Oregonians who were Black, older, and more religious were less likely to personally consider using legal PAS to end their lives.¹⁸

Patients' diagnoses also differed between the two groups. The rates of PAS consideration for cancer patients in this study were higher than for patients with other diagnoses, and rates for ALS patients were also elevated. Persons with cancer comprise the largest group of PAS users, but patients with ALS have the highest rates of PAS consideration and usage in Oregon¹⁹ and of euthanasia in the Netherlands.²⁰ Patients with cancer or ALS may be disproportionately represented because both diseases tend to have long death trajectories

and minimal cognitive impact, allowing patients the time and ability to fully consider and complete the formal request process.

The role of pain and psychological symptoms on PAS consideration is controversial. Pain has been associated with a desire for hastened death,²¹ but most researchers emphasize the greater contribution of depression and/or hopelessness.²² We found that greater overall symptom distress independently predicted personal consideration of PAS. Those who considered PAS also were reported to experience a higher number of symptoms, with pain and sadness most strongly associated with PAS consideration. Pain has not been commonly reported in those who move beyond consideration to ultimately take a lethal prescription under the ODDA.²³ Physician reports about the 171 Oregonians who used PAS cited concerns about autonomy far more frequently than pain as motivation for the patient's decision, indicating that those who follow through with PAS may have different motives from those who merely consider PAS.²⁴

Many factors contribute to the substantial difference in the number of patients who personally consider PAS and the number who make a formal request for it.²⁵ Patients' desire for PAS has been reported to fluctuate over time.²⁶ Concerns about suffering²⁷ or a lack of understanding about end-of-life care options²⁸ may be the catalyst for considering PAS, with the desire for PAS diminishing as these issues are resolved. For others, access and eligibility are issues. Surveys of Oregon primary care physicians indicate that less than one-half would be personally willing to participate in PAS.²⁹ DHS data describing those who ultimately died by lethal prescription indicate that 69 percent changed doctors to find a physician willing to participate in the ODDA.³⁰

Oregon physicians indicate that about one in 10 patients who make a request for PAS receive, and ultimately take, a lethal prescription.³¹ Families in this study reported a lower rate, as only one of 25 patients who made a formal request received a lethal prescription. These discrepancies in rates of report may

reflect differences in definition of what constitutes a request.

Even with a physician's cooperation, obtaining a lethal prescription via the ODDA can be a complex and lengthy process, requiring motivation and the ability to advocate for oneself within the health care system. Physicians who have received PAS requests consistently describe those patients as independent, with extremely strong and forceful personalities.³² The profile of those who have used PAS in Oregon is similar to that of our study subjects who personally considered PAS, consisting disproportionately of younger, higher-income Whites or Asians. These data challenge the assumption that dying patients using PAS would be more likely to be disenfranchised.³³ In fact, while our data indicate that those with only a high school education were as likely to personally consider PAS, Oregon DHS data indicate that persons with post-baccalaureate degrees were significantly more likely to follow through and take a lethal prescription.³⁴ This further suggests that access to lethal prescriptions may be greater for those with the educational and/or interpersonal resources to navigate the bureaucratic request process.

Strengths of this study include the large sample and the high participation rate of family caregivers, given the sensitivity of the topic. However, several limitations of the study argue for caution in generalizing findings. First, the study is limited to the only state in the country in which PAS is a legal option. Second, although almost 72 percent of those who were located and confirmed eligible completed the interview, the response rate is only 53 percent when considering refusals and those who could not be located,³⁵ and the sample could not include non-English-speaking caregivers or those without telephones. Third, the views of caregivers cannot be assumed to be entirely concurrent with patients' views, and lay people are not always well informed about the specifics of various medical conditions or eligibility criteria for PAS under Oregon law.³⁶ Finally, it is likely that some patients would not reveal their PAS consider-

ations to family members, which could underrepresent the proportion of patients who personally considered PAS.

Almost half of dying Oregonians, for whom legal PAS was an option, were in favor of PAS, and nearly one-fifth personally considered it during their terminal illnesses. Those who considered but did not use PAS were remarkably similar to the 171 Oregonians who used PAS in the six years since legalization. Barriers cited by families of the 2 percent of dying patients who made a formal request for PAS, but did not receive a prescription, included physicians' reluctance or refusal and waiting too long to start the process. The complexity of the process and the need to negotiate barriers erected by medical professionals may partially explain why those with the highest levels of education are the most likely to take a lethal prescription, whereas those with only a high school education are as likely to consider it, but are much less likely to actually receive or take a lethal prescription. This study adds to previous data showing that while dying patients often consider a hastened death, requests for PAS remain rare, despite legalization.

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Clarifying Distinctions between Contemplating and Completing Physician-Assisted Suicide

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The Oregon Death with Dignity Act (ODDA) was passed by popular vote in 1994 and was implemented in 1997. It allows a competent, terminally ill patient to request a medication to be self-administered for the purpose of hastening death. A set of safeguards include a 15-day waiting period during which the patient must make three separate requests for the medication; evaluation of the patient's prognosis and decision-making capacity by a second physician; mental health evaluation if there is concern regarding a mental disorder influencing the decision; and notification of alternatives, including hospice and comfort care.¹ Over the past 15 years several other states, including Washington, California, Maine, Michigan, and Hawaii, have considered, both by ballot measure and through legislative efforts, legalization of some form of physician-assisted death, but all have rejected it. Oregon remains alone among states in the United States as a laboratory allowing exami-

nation of implementation of such a law. Internationally, the Netherlands and Belgium have legalized euthanasia and, in the Dutch case, also physician-assisted suicide (PAS).

To date, studies in Oregon have focused on understanding (1) healthcare professionals' views on assisted suicide, and, since implementation, their actions around patients who request PAS; (2) the characteristics of patients who actually request PAS, as perceived by healthcare professionals; and (3) the views of some groups of patients such as those with amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig disease) or cancer, and general medical outpatients, who imagine the conditions under which they might request PAS.² The study by Tolle and her coauthors fills an important gap in this research by examining the differences between considering PAS and requesting and receiving a medication to hasten death.

Who merely contemplates PAS, and who pursues it to the point of obtaining a lethal prescription? How do people progress from one level of intention to another? The importance of distinguishing these groups has not always been appreciated, even by leading researchers in the field. Outside of Oregon, researchers have surveyed patients who have

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advanced disease regarding their interest in PAS or hastened death.³ The results of these studies are consistent with the findings of Tolle and her coauthors, in that religious factors, race, and age are associated with potential interest in PAS. However, studies examining patients who actually pursue hastened death are rare. We therefore have little direct knowledge of the characteristics and desires of the group we most wish to understand. Tolle points out that only one in 100 patients who consider PAS die after ingesting a lethal prescription. As such, risk factors for considering PAS might not be the same risk factors for actually obtaining a lethal prescription. For example, in the study by Tolle and colleagues, both groups are more likely to be White, younger, and have cancer. According to families, however, patients who had low educational levels were more likely to personally consider PAS, whereas patients with higher levels of education were more likely to obtain a lethal prescription.

When it is in the course of their illnesses that patients contemplate PAS may be relevant in distinguishing between patient subgroups. For example, we know from previous studies that some patients contemplate suicide shortly after diagnosis.⁴ Many patients who completed PAS expressed an interest in it early in the course of their illness.⁵ This interest tends to reflect strong desires for autonomy and control, and is not associated with the level of symptom distress.⁶ In contrast, Tolle and colleagues found an association between symptom distress during the last week of life and consideration of PAS. This would suggest that some patients may consider PAS when symptom control falters or as they become more uncomfortable with approaching death. Most of these patients do not live through the 15-day waiting period or they lose the capacity to make the decision to proceed with PAS.

Why do such a small number of patients who consider PAS actually pursue it? The attrition likely reflects finding alternatives to PAS, barriers to obtaining a prescription (including physicians' responses), and patients'

characteristics. Physicians reported that 46 percent of the patients who requested PAS changed their minds following a substantive intervention by a physician, such as symptom management, treatment of depression, or referral to hospice.⁷ Qualitative interviews with physicians support that referral to hospice is especially successful among patients who are transitioning from curative to comfort treatments, who do not fully understand their options, or who have not yet experienced the benefits of hospice.⁸ On the other hand, patients who are already in hospice when they make a request for PAS are more likely to persist, having found that the full course of palliative care does not meet their needs for control and independence.⁹

Tolle and colleagues report that families believe physicians can present insuperable barriers to receiving a prescription. This may result in the patient and family feeling ignored or dismissed.¹⁰ Patients take risks in bringing the issue up with their physician and may misinterpret their physician's discomfort or the reasons for their physician's refusal. Indeed, interviews with physicians suggest that many practitioners struggle between discomfort in collaborating with a patient who wishes to hasten death and their obligation to not abandon the patient. At times physicians will care for patients whose opinions and actions they do not approve of; physicians may even find patients' opinions and actions repulsive. Although physicians are not required to facilitate suicidal acts that they consider unethical, they are expected to still give good care to self-destructive patients. Oregon physicians who declined requests for PAS for moral reasons reported to us that they were willing to assist in finding a prescribing physician and to find acceptable alternatives for patients. The physicians focused on giving good care and offered what they could to patients and their families short of PAS.¹¹

Our clinical experience in Oregon suggests that it may be easier for tough, independent, and self-sufficient people to start the conversation about dying by asking about PAS. Pa-

tients may thus bring up PAS as a means to communicate their fears and anxieties about dying, or their need to discuss the value and meaning of remaining life. Yet this is also the group of patients who may be most likely to complete PAS and for whom the prospect of *more care*, rather than *care that they control*, may be threatening. One of the objections to PAS is that, by agreeing to provide the means to death, physicians may communicate to a patient that his or her life is not worth living. Clinically we have seen this untoward effect with patients who wish to hasten death by stopping life-sustaining treatments. On the other hand, one of us, while acting as a psychiatric consultant, observed the painful experience of two patients whom she disqualified for the option of ODDA. These disqualifications resulted in extraordinary pain and anger for both of the patients and their families, which interfered with much-needed opportunities to resolve other emotional issues. In both cases, the interpretation by the patients was not, "My life is valued," but, "I am powerless."

An additional, intriguing finding by Tolle and colleagues was that among the 1,384 family members interviewed, there were no reports of assisted suicide outside the law. Although it is unclear how well the interviews would have detected additional illegal assisted suicide or how willing family members who had assisted in a suicide would have been to participate in the study, it is worth noting that this would represent a rate of assisted suicide lower than found in previous studies done in other states. Emanuel and coauthors estimate a rate of PAS and euthanasia in other states in the United States as approximately one in 250,¹² as compared to Oregon's yearly rate of one in 1,000 PAS deaths under the ODDA.¹³ If the rate in Oregon is similar to other states in the United States, approximately three in 1,000 cases of PAS or euthanasia in Oregon outside the law each year should be found.

This raises the interesting question of whether legalization of assisted suicide can

drive the rate of PAS down. How might legalization have this paradoxical effect? First, when physicians understand the law and the safeguards, they may become less willing to act outside such a safe harbor; they report a magnified sense of scrutiny that inhibits participation even within the law.¹⁴ Second, the law's safeguards may be such substantial hurdles that patients simply don't make it over them. Family members reported that starting the process too late was an impediment to receiving PAS. Third, the now-ingrained response among Oregon physicians of referring a patient to hospice when the patient requests PAS may actually ameliorate the need for euthanasia and assisted suicide. Finally, Quill points out that one advantage of legalized PAS is that it invites patients to share their concerns and fears—giving the physician the opportunity to intervene.¹⁵ Whatever the reason, these data do not support a slippery slope of increasing death-hastening acts—within or outside the law.

Although Tolle and colleagues' study provides important information about patients who contemplate PAS in Oregon, we are still left with little direct information from those who seriously pursue it; there are currently no studies of patients actually in the process of considering PAS or who have chosen PAS. We also need a better understanding of these patients' and families' views of their physicians' efforts. Finally, if some patients and families are considering PAS only in the final weeks of life because of poor symptom control, fear, or anxiety, then there is opportunity for intervention; we need to understand this group better, and develop and employ more appropriate clinical strategies.

NOTES

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3. W. Breitbart et al., "Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients with Cancer," *Journal of the American Medical Association* 284 (2000): 2907-11; W. Breitbart, B.D. Rosenfeld, and S.D. Passik, "Interest in Physician-Assisted Suicide Among Ambulatory HIV-Infected Patients," *American Journal of Psychiatry* 153 (1996): 238-42; H.M. Chochinov et al., "Desire for Death in the Terminally Ill," *American Journal of Psychiatry* 152 (1995): 1185-

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4. L. Ganzini et al., "Oregon Physicians' Perceptions of Patients Who Request Assisted Suicide and Their Families," *Journal of Palliative Medicine* 6 (2003): 381-90.

5. Ibid.

6. S.K. Dobscha et al., "Oregon Physicians' Responses to Requests for Assisted Suicide: A Qualitative Study," *Journal of Palliative Medicine* 7 (2004): 450-60.

7. Ganzini et al., "Physicians' Experiences with the Oregon Death with Dignity Act," see note 2 above.

8. See note 6 above.

9. Ganzini et al., "Physicians' Experiences with the Oregon Death with Dignity Act," see note 2 above.

10. P.B. Bascom and S.W. Tolle, "Responding to Requests for Physician-Assisted Suicide: 'These are Uncharted Waters for Both of Us . . .,'" *Journal of the American Medical Association* 288 (2002): 91-98.

11. See note 6 above.

12. Emanuel et al., "Attitudes and Desires Related to Euthanasia," see note 3 above.

13. Oregon Department of Human Services, <http://www.ohd.hr.st.or.us/chs>, 2003.

14. See note 6 above.

15. T. Quill and M.P. Battin, "Excellent Palliative Care as the Standard, and Physician-Assisted Death as a Last Resort," in *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice at the End of Life*, ed. T. Quill and M.P. Battin (Johns Hopkins University Press, in press); T. Quill, *Caring for Patients at the End of Life: Facing an Uncertain Future Together* (Oxford: Oxford University Press, 2001).