Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death with Dignity Act

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Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death with Dignity Act

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Context The Oregon Death with Dignity Act, passed by ballot measure in 1994 and enacted in October 1997, legalized physician-assisted suicide for competent, terminally ill Oregonians, but little is known about the effects of the act on clinical practice or physician perspective.

Objective To examine Oregon physicians' attitudes toward and practices regarding care of dying patients since the passage of the Death with Dignity Act.

Design, Setting, and Participants A self-administered questionnaire was mailed in February 1999 to Oregon physicians eligible to prescribe under the act. Of 3981 eligible physicians, 2641 (66%) returned the questionnaire by August 1999.

Main Outcome Measures Physicians' reports of their efforts to improve care for dying patients since 1994, their attitudes, concerns, and sources of information about participating in the Death with Dignity Act, and their conversations with patients regarding assisted suicide.

Results A total of 791 respondents (30%) reported that they had increased referrals to hospice. Of the 2094 respondents who cared for terminally ill patients, 76% reported that they made efforts to improve their knowledge of the use of pain medications in the terminally ill. Nine hundred forty-nine responding physicians (36%) had been asked by a patient if they were potentially willing to prescribe a lethal medication. Seven percent of all survey participants reported that 1 or more patients became upset after learning the physician's position on assisted suicide, and 2% reported that 1 or more patients left their care after learning the physician's position on assisted suicide. Of the 73 physicians who were willing to write a lethal prescription and who had received a request from a patient, 20 (27%) were not confident they could determine when a patient had less than 6 months to live.

Conclusion Most Oregon physicians who care for terminally ill patients report that since 1994 they have made efforts to improve their ability to care for these patients and many have had conversations with patients about assisted suicide.

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THE OREGON DEATH WITH DIGnity Act was passed by ballot measure in 1994, and enacted in October 1997.[1] This measure legalized physician-assisted suicide by allowing a physician to prescribe a lethal dose of medication for a mentally competent, terminally ill patient for the purpose of self-administration. Experts predicted that legalized assisted suicide would divert attention and resources from efforts to improve care for dying patients.[2-5] Several lines of evidence, however, support the contention that care for terminally ill patients in Oregon has improved since the passage of the Death with Dignity Act. For example, more than one third of Oregonians who die are enrolled in a hospice program and two thirds have completed an advance directive before death.[6,7] Since legalization, death from physician assisted suicide has been rare,[8,9] but little is known about the broader effects of the Death with Dignity Act on clinical practice or the perspectives of Oregon physicians on care of the dying.

In 1999, we surveyed all Oregon physicians who were eligible to prescribe under the Death with Dignity Act. Based on responses of 144 physicians (5% of respondents) who had received a request for physician-assisted suicide, we published information on the characteristics and outcomes of requesting patients and the interventions made by physicians other than assisted suicide.[8] These data indicated that 1 in 10 requests for a lethal prescription resulted in assisted suicide. Physicians reported that as a result of palliative in-

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Table 1. Characteristics of Responding Physicians*

Characteristic	Respondents (N = 2641)
Age, mean (SD), y†	48 (10)
Sex	
Men	2027 (77)
Women	549 (21)
Missing	65 (2)
Importance of religion, mean (SD)‡	6.3 (3.6)
Religious affiliation	
Catholic	386 (15)
Protestant	1028 (39)
Jewish	186 (7)
Muslim	10 (<1)
Other	203 (8)
None	795 (30)
Missing	30 (1)
Practice setting§	
Private or group practice	2062 (78)
Health maintenance organization	262 (10)
Medical school	184 (7)
Veterans Affairs	70 (3)
Other	204 (8)
Primary specialty	
Internal medicine‖	954 (36)
Family practice	669 (25)
General surgery or surgical subspecialty	560 (21)
General practice	79 (3)
Gynecology	240 (9)
Neurology	81 (3)
Radiation oncology	28 (1)
Other	21 (1)
Missing	9 (<1)
Size of population in practice location	
Rural or small town (population <25 000)	592 (22)
Medium-sized city (population 25 000-250 000)	865 (33)
Large city (population >250 000) or suburb	1161 (44)
Missing	23 (1)

*Values are expressed as number (percentage) unless otherwise indicated.
†For comparison of respondents vs nonrespondents (47 [10] years), $P = .001$.
‡Measured using a Likert scale with scores ranging from 0 (religion not important to me) to 10 (religion is important to me).
§Some physicians chose more than 1 practice setting.
‖For comparison of respondents vs nonrespondents (538 [40%]), $P = .03$. "Other" category excluded from analysis because this was not an option for nonrespondents.

terventions, some patients changed their minds about assisted suicide.

This article is based on information submitted by the Oregon physicians who responded to our survey. We report these physicians' attitudes toward the Death with Dignity Act and caring for dying patients, their efforts to improve their ability to care for dying patients, their attitudes, concerns, and sources of information about writing lethal prescriptions, and their discussions and experiences with patients regarding assisted suicide. We compare the characteristics of physicians who received requests for a lethal prescription with those who did not.

METHODS

This study is based on the results of a mailed, self-administered survey. The methods of this study have been previously described.[8] We purchased a list of all licensed physicians from the Oregon Board of Medical Examiners. For the purposes of this study, we included physicians actively practicing in the fields of internal medicine and its subspecialties, family practice, general practice, gynecology, surgery and its subspecialties, radiation oncology, and neurology. We excluded physicians in training and retired physicians.

The survey instrument was developed after reviewing previous surveys on this issue, having discussions with experts in care of the dying, and soliciting information from Oregon physicians who had received requests for assisted suicide. Survey questions were refined following pretesting with a convenience sample of 20 physicians. All questions had forced-choice answers. The survey included demographic characteristics of the physicians, their attitudes toward caring for dying patients, the degree to which they had sought to improve their knowledge about care of dying patients since 1994, and their perceptions about hospice care in Oregon. Survey questions elicited information about physicians' attitudes toward the Death with Dignity Act, their willingness to prescribe lethal medications consistent with the law, their concerns about participating in the Death with Dignity Act, their sources of information about this law, and their conversations with patients about assisted suicide.

We mailed the survey in February 1999, a reminder postcard 2 weeks later, and a second copy of the survey in March 1999, which was coordinated with a fax or a telephone call. In May 1999, after 47% of the sample had responded, we sent a third copy of the survey with a check for $25 and a letter of endorsement from the Governor of Oregon, John Kitzhaber, MD. Surveys were accepted through August 1999. The survey was anonymous and exempted from the requirement for informed consent by the institutional review board at Oregon Health Sciences University. To allow tracking of the questionnaires, returned envelopes were coded with an identifying number. The survey was separated from the identifying envelope on receipt and recoded to render it anonymous. Surveys that were at least two-thirds complete were scanned into an electronic database.

Data Analyses

Summary statistics included proportions for categorical variables and means with SDs for continuous variables. Associations between categorical variables were assessed with the Pearson χ^2 test. We fit logistic regression models to predict the probability that a physician received a request for a lethal prescription. We used 2 different variable selection schemes: stepwise variable selection and best possible model (as evaluated by the score statistic) among κ variable models with κ starting at 1 and increasing. The latter procedure was used as a check to ensure the stepwise procedure did not miss a better model. Regression analyses were run using SAS Version 7.0 (SAS Institute Inc, Cary, NC) and summary statistics were determined using SPSS Version 9.0 (SPSS Inc, Chicago, Ill).

RESULTS

Of 4544 physicians on the list from the Oregon Board of Medical Examiners, 212 were in training, 343 were retired or not in practice, and 8 were deceased. Of the remaining 3981, 2641 (66%) returned a survey that was at least two-thirds complete. TABLE 1 outlines the characteristics of the respondents. Seventy-seven percent of responding physicians were men, 61% practiced internal medicine or family practice, and 22% practiced in a town with a population of less than 25 000.

Physicians who returned their survey after the third request (with accompanying $25.00 incentive) were more likely to "neither support nor oppose" the Death with Dignity Act and less likely to "support" the act ($P=.003$); and more likely to indicate they were "unwilling" to write a lethal prescription compared with respondents "willing" to write a lethal prescription ($P=.003$). Otherwise, these 2 groups did not differ on specialty, population of practice, or number of terminally ill patients cared for in the previous year (data not shown).

Oregon Physicians' Attitudes Toward and Efforts to Improve Care of Dying Patients

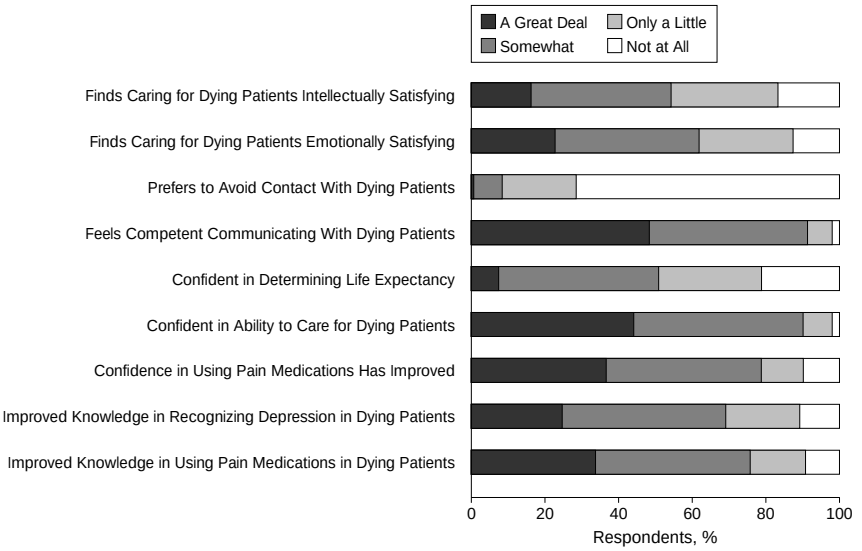
In the previous year, 4 of 5 respondents had cared for at least 1 terminally ill patient, more than one third had cared for 6 or more terminally ill patients, and 8% had cared for 21 or more terminally ill patients (TABLE 2). Thirty-five percent of physicians (74/213) who cared for 21 or more terminally ill patients per year practiced in the specialties of oncology, radiation oncology, pulmonology, or geriatrics. Twenty-seven percent of all respondents had referred 6 or more patients to hospice in the previous 12 months. Thirty percent of respondents reported that they had increased the number of patients they referred to hospice since 1994, while only 72 (3%) had made fewer hospice referrals. Thirty-three percent of responding physicians perceived that the availability of hospice for their patients had increased since 1994, while less than 1% claimed that hospice was less available.

A high proportion of physicians reported they had made efforts to improve their knowledge of palliative care since 1994 (FIGURE 1). Among the 2094 physicians who cared for at least 1 terminally ill patient in the previous year, 76% reported that they had made efforts to improve their knowledge of the use of pain medications in the terminally ill "somewhat" or "a great deal," 69% reported that they sought to improve their recognition of psychiatric

Table 2. Views of Oregon Physicians on Hospice Care and the Oregon Death with Dignity Act

Characteristics	No. (%) of Respondents (N = 2641)
Terminally ill patients cared for in previous 12 mo	
0	530 (20)
1-5	1144 (43)
6-20	739 (28)
≥21	213 (8)
Missing	15 (1)
Patients referred to hospice in previous 12 mo	
0	730 (28)
1-5	1193 (45)
6-20	619 (23)
≥21	88 (3)
Missing	11 (<1)
Hospice referrals in 1998 compared with 1994	
Much higher	114 (4)
Somewhat higher	677 (26)
No change	1649 (62)
Somewhat lower	37 (1)
Much lower	35 (1)
Missing	129 (5)
Change in availability of hospice service for patients between 1994 and 1998	
Much more available	230 (9)
Somewhat more available	634 (24)
No change	1655 (63)
Somewhat less available	16 (1)
Much less available	3 (<1)
Missing	103 (4)
Writing a lethal prescription is immoral or unethical	
Agree	784 (30)
Neither agree nor disagree	291 (11)
Disagree	1550 (59)
Missing	16 (1)
Attitudes toward Death with Dignity Act or legalization of physician-assisted suicide	
Strongly support	576 (22)
Support	773 (29)
Neither support nor oppose	449 (17)
Oppose	408 (15)
Strongly oppose	424 (16)
Missing	11 (<1)
Change in position on Death with Dignity Act since 1994	
More supportive	346 (13)
No change	2108 (80)
More opposed	174 (7)
Missing	13 (<1)
Willingness to prescribe a lethal medication consistent with the Death with Dignity Act	
Willing	886 (34)
Uncertain	524 (20)
Unwilling	1217 (46)
Missing	14 (1)
Change in willingness to prescribe consistent with the Death with Dignity Act since 1994	
More willing	373 (14)
No change	2044 (77)
Less willing	201 (8)
Missing	23 (1)

Figure 1. Attitudes and Confidence in Care of Dying Patients



Responses of 2094 Oregon physicians who cared for at least 1 terminally ill patient in previous year.

disorders, such as depression, and 79% reported that their confidence in the prescribing of pain medications had improved.

Physicians who had cared for 1 or more dying patients in the previous year were asked about their attitudes toward care of dying patients (Figure 1). In general, these physicians were confident in the care of dying patients, felt competent in communicating with dying patients, and reported that they rarely avoided dying patients. However, 38% reported they found caring for dying patients "not at all" or "only a little" emotionally satisfying, and 46% reported that this type of work was "not at all" or "only a little" intellectually satisfying.

Oregon Physicians' Views on the Oregon Death with Dignity Act

Thirty percent of all physician respondents agreed with a statement that writing a lethal prescription for a patient under the Death with Dignity Act was immoral and/or unethical, 59% disagreed, and 11% neither disagreed nor agreed (Table 2). A total of 1349 respondents (51%) supported the Death with Dignity Act, 832 (32%) opposed it, and 449 (17%) neither supported nor opposed the law. Four out of 5 claimed they had not changed their views on the law since it passed in 1994. For those who did change their view, almost twice as many reported that they had become more supportive (13%) than more opposed (7%). Fourteen percent of physicians reported that they had become more willing to prescribe a lethal medication since 1994, but 8% were less willing. Overall, one third of respondents were willing to write a lethal prescription under the law, 20% were uncertain, and 46% were unwilling. Fifty-three percent of respondents would consider obtaining a physician's assistance to end their own lives if terminally ill, including 88% of those who were willing to prescribe a lethal medication for a patient.

Effect of the Oregon Death with Dignity Act on Physicians' Clinical Practice

Ninety-one percent of respondents were "somewhat" or "a great deal" comfortable discussing their opinion of the Death with Dignity Act with a patient who would ask. Only 18% of physicians agreed with the statement that "since the Death with Dignity Act was enacted, some patients expect me to be available to provide a lethal prescription." One or more patients had asked 949 respondents (36%) if they would potentially be willing to prescribe a lethal medication (TABLE 3), including 54% of physicians (513/952) who had cared for 6 or more terminally ill patients in the previous year.

Overall, 21% of physicians reported that at least 1 patient was more positive or comfortable about the physician's care after knowing the physician's position on the Death with Dignity Act. Twenty-eight percent of physicians who were opposed to the law reported that at least 1 patient in their care was more positive knowing the physician's position on the Death with Dignity Act, compared with 21% of physicians who supported the law and 10% who neither supported nor opposed the law ($P<.001$). Since the Death with Dignity Act was enacted, at least 1 patient in 7% of physicians' practices became upset or concerned because of the physician's position on physician-assisted suicide; 2% of physicians reported that a patient left their care after knowing the physician's position (Table 3). More than twice as many physicians who opposed the Death with Dignity Act reported that a patient was concerned or upset or left the physician's practice because of the physician's view on assisted suicide, compared with physicians who supported the Death with Dignity Act. Six percent of physicians had initiated a discussion about physician-assisted suicide with a terminally ill patient, including 10% of physicians who opposed the law and 6% of physicians who supported the law.

Characteristics of Physicians Who Received Requests for Assisted Suicide

Since November 1997, 144 physicians (5%) had received an explicit request for a lethal prescription as set forth in the Death with Dignity Act.[8] Logistic regression analyses were performed to model characteristics predictive of physicians

who received a request (TABLE 4). Variables considered in the model included physician sex, specialty, population of practice, number of terminally ill patients cared for in previous year, willingness to prescribe a lethal prescription, attitudes toward care of dying patients, confidence in the use of pain medications, and degrees of improvement in knowledge of pain or psychiatric medications in terminally ill patients since 1994. The 2 variable selection schemes yielded the same "best" model. Each ordinal increase in number of terminally ill patients cared for in the previous year resulted in an increased likelihood of receiving a request for a lethal prescription such that physicians who cared for 21 or more terminally ill patients per year were 29 times more likely to receive a request than physicians who cared for no terminally ill patients in the previous year. Other significant predictors included willingness to write a prescription, finding care of the dying patient intellectually satisfying, and having sought to improve knowledge of pain medications since 1994.

Table 3. Oregon Physicians' Conversations With Patients About Assisted Suicide

	Overall (N = 2641)	Physicians' Attitude Toward the Death with Dignity Act, No. (%)			*P* Value
		Support	Neither Support nor Oppose	Oppose	
Since November 1997, physician asked by patient if potentially willing to prescribe lethal medication					
No patients	1684 (64)	855 (64)	316 (71)	505 (61)	.01
1-2 patients	621 (24)	317 (24)	78 (17)	224 (27)	
≥3 patients	328 (12)	173 (13)	54 (12)	100 (12)	
Missing	8 (<1)				
Physician reported patient concerned or upset about physician's position on assisted suicide					
No patients	2444 (93)	1279 (96)	419 (94)	735 (89)	<.001
≥1 patient	180 (7)	60 (4)	28 (6)	92 (11)	
Missing	17 (1)				
Physician reported patient left care because of physician's position on assisted suicide					
No patients	2566 (97)	1320 (99)	439 (98)	796 (96)	.007
≥1 patient	58 (2)	19 (1)	7 (2)	32 (4)	
Missing	17 (1)				
Physician reported patient felt more positive about care after knowing physician's position					
No patients	2057 (78)	1058 (79)	398 (89)	592 (72)	<.001
1-2 patients	290 (11)	167 (13)	29 (6)	93 (11)	
≥3 patients	268 (10)	111 (8)	20 (4)	137 (17)	
Missing	26 (1)				
Physician initiated discussion of assisted suicide with terminally ill patient since November 1997					
No	2465 (93)	1268 (94)	440 (98)	747 (90)	<.001
Yes	166 (6)	76 (6)	9 (2)	81 (10)	
Missing	10 (<1)				

Sources of Information and Physician Concerns About the Death with Dignity Act

Among the 1841 physicians who were not morally opposed to writing a lethal prescription, 58% were at least "a little" concerned about being labeled a "Kevorkian" if they wrote a lethal prescription, 82% were concerned that writing a lethal prescription might violate federal Drug Enforcement Agency law, and 65% were concerned that their hospital might sanction them (FIGURE 2). The Death with Dignity Act allows hospital systems to forbid writing prescriptions under the act on their premises or by physicians they directly employ. Eighteen percent of respondents practiced in a hospital system that has a policy forbidding prescription of lethal medications in accordance with the Death with Dignity Act.

Among the 886 physicians who were willing to prescribe, 23% had received information from a guidebook produced by the Oregon Health Sciences University Center on Ethics in Health Care entitled *The Oregon Death with Dignity Act: A Guidebook for Health Care Providers*, 21% had received information on the Death with Dignity Act from other physicians, 11% had received information from the Oregon Medical Association, 9% from a group that advocates for persons who elect assisted suicide, and 8% from experts or resource persons in their health care system. Fifty-five percent of all physicians who were willing to prescribe, including 15% (11/73) of willing physicians who had actually received a request, had not sought information about the law from any source. Twenty-seven percent of all willing physicians, including 16% (12/73) of willing physicians who had received a request, were "not at all" or "only a little" confident about finding reliable information about what to prescribe for a lethal medication. Thirty-eight percent of willing physicians, including 27% (20/73) of willing physicians who had received a request, were "not at all" or "only a little" confident about their ability to determine when a patient has less than 6 months to live.

COMMENT

The passage of the Death with Dignity Act divided Oregon's medical community; however, both proponents and opponents of this law did agree that it un-

derscored the need to improve care of the dying in Oregon. Many physicians who responded to the survey reported they had made efforts to improve their ability to care for terminally ill patients, were more likely to refer these patients to hospice, and believed that hospice is more accessible since passage of the Death with Dignity Act. In 1994, 22% of all deaths in Oregon occurred in persons enrolled in hospice; by 1999, the proportion had increased to 35%. Despite the respondents' perception that hospice had become more available since 1995, the geographic range and capacity of community hospice increased only minimally between 1995 and 1999 (Ann Jackson, MBA, written communication, October 1, 2000). This suggests that physicians became more aware of already available services.

In 1999, assisted suicide was the cause of death in 9/10 000 of Oregon deaths, and between 1997 and 1999, 5% of Oregon physicians received an explicit request for a prescription for a lethal medication.[8,9] A much larger proportion of physicians discussed assisted suicide or the Death with Dignity Act with patients. Physicians perceived that more patients found these conversations helpful than upsetting, whether the physicians supported or opposed assisted suicide. In some cases, however, these conversations resulted in a rupture of the relationship, and these ruptures were more likely if the physician opposed assisted suicide. Oregon patients who feel strongly about the right to pursue assisted suicide may prefer to find a physician whose values match theirs early in the course of treatment to avoid having to do so at a later stage of illness. On the other hand, such disruptions may be unnecessary if the physician conveys empathy, respect, and understanding, and clarifies his/her willingness to refer the patient to another physician in a manner that does not communicate abandonment, should the desire for a lethal prescription persist despite palliative care.

In general, patient queries and concerns about assisted suicide as well as explicit requests for lethal medications were especially common for physicians who cared for many terminally ill patients—each ordinal increase in the number of terminally ill patients cared for increased odds of receiving an explicit request for assistance in suicide between 2 and 7 times. Some commentators have expressed concern, and some studies have supported that requests for assisted suicide may occur in the context of poor care, including physician's negative attitudes about care of the dying, or lack of physician knowledge about alternatives to assisted suicide.[10-19] Although our data cannot address all of these concerns, we did find that Oregon physicians who received requests rated themselves more intellectually satisfied by care of dying patients and more likely to have attempted to improve their knowledge of prescribing pain medication for the terminally ill than Oregon physicians who did not receive requests.

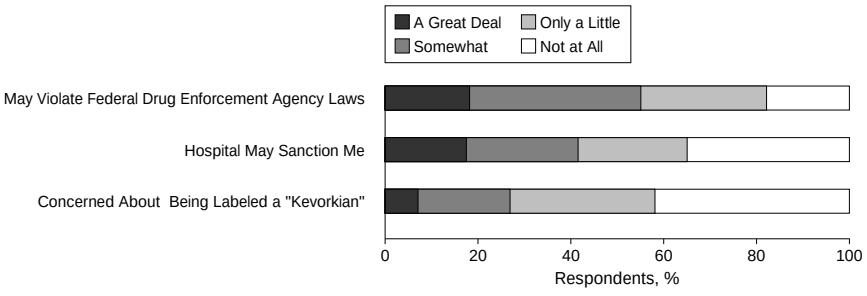
Other survey findings, however, are of concern. Among physicians who were willing to prescribe and who had received a request for a lethal prescription, 1 in 7 had not obtained information about the Death with Dignity Act from any 1 of several credible sources, 1 in 6 were not confident about finding reliable lethal prescribing information, and 1 in 4 were not confident in determining 6-month life expectancy. Patients who make requests of these physicians may receive a lethal prescription without the comprehensive evaluation currently recommended.[20] We previously demonstrated that palliative interventions were significantly associated with changes of mind about assisted suicide among dying patients in Oregon.[8] These findings underscore that Oregon's extensive efforts at palliative care education must continue if patients are to obtain assisted suicide as only an option of last resort. It also reinforces the need for the second physician consultant (as required in the act) to have expertise in end-of-life care and the act.[1]

Table 4. Predictors of Oregon Physicians Receiving an Explicit Request for Assisted Suicide Since Enactment of the Death with Dignity Act

	Adjusted Odds Ratio (95% Confidence Interval)*
Number of terminally ill patients physician cared for in previous years	
None	1.0
1-5	6.7 (1.6-27.9)
6-20	13.5 (3.3-56.4)
≥21	28.7 (6.7-122.6)
Physician finds caring for dying patients intellectually satisfying	
Not at all or only a little	1.0
Somewhat	1.8 (1.2-2.8)
A great deal	3.7 (2.3-6.0)
Physician sought to improve knowledge of pain medication in terminally ill	
Not at all or only a little	1.0
At least somewhat	1.7 (1.0-3.0)
Physician willingness to prescribe a lethal medication	
Unwilling or uncertain	1.0
Willing	2.1 (1.5-3.0)

*See the "Results" section for a list of adjusted variables.

Figure 2. Concerns About Prescribing Lethal Medications



Responses of 1841 Oregon physicians who are not morally opposed to physician-assisted suicide.

There are several limitations in our study. We did not measure actual physician skill in pain and symptom control. One study of oncologists revealed that the physicians' self-assessment of their palliative care skills appeared to exceed their practice as assessed by treatment scenarios (Ezekiel J. Emanuel, MD, PhD, written communication, October 17, 2000). Of concern, one study[21] documents an increase in families' perceptions of pain among Oregon patients who died in acute care hospitals between 1997 and 1998. Respondents were slightly older and less likely to specialize in internal medicine than nonrespondents. Finally, it cannot be concluded that attempts by Oregon physicians to improve their ability to care for terminally ill patients is solely attributable to passage of the Death with Dignity Act. Nationally, there have been extensive efforts to improve physicians' competence in caring for dying patients. Whether the efforts of Oregon physicians differ from the efforts of physicians in other states is unknown, as no comparison is available. Our results are more important in countering concerns that legalized assisted suicide would undermine attempts to enhance care for the dying.

Assisted suicide is legal only in the Netherlands and Oregon. Studies from Oregon offer a rare opportunity to examine changes in end-of-life care in the context of legalized assisted suicide. Overall, our findings reinforce that Oregon physicians have made care of the dying a focus for their own professional education since 1994 and are more likely to refer patients to hospice. Many physicians who care for terminally ill patients have had conversations with patients about this issue. Rarely are these conversations upsetting for the patient. A large proportion of physicians, despite not being morally opposed to assisted suicide, have practical concerns about participating in the Death with Dignity Act and only a minority are willing to provide a lethal prescription to a qualified patient. Some physicians who are willing to assist in legalized suicide may lack knowledge necessary to evaluate patients' eligibility. On the other hand, requests are more likely to come to physicians who report that they care for many terminally ill patients, find their care intellectually satisfying, and have attempted to improve their knowledge of pain medications.

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Analysis and interpretation of data: Ganzini, Nelson, Lee, Kraemer, Schmidt.
Drafting of the manuscript: Ganzini.
Critical revision of the manuscript for important intellectual content: Ganzini, Nelson, Lee, Kraemer, Schmidt, Delorit.
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