

Special Article

EXPERIENCES OF OREGON NURSES AND SOCIAL WORKERS WITH HOSPICE PATIENTS WHO REQUESTED ASSISTANCE WITH SUICIDE

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**ABSTRACT**

**Background** Oregon's 1997 Death with Dignity Act legalizes physician-assisted suicide. To date, information about patients who have requested this option has come from surveys of physicians. Although 78 percent of the 91 Oregonians who have died by assisted suicide were enrolled in hospice programs, there is little information about the experiences of hospice practitioners with these patients.

**Methods** In 2001, we mailed a questionnaire to all hospice nurses and social workers in Oregon.

**Results** Of 545 eligible hospice nurses and social workers, 397 (73 percent) returned the survey, including 71 percent of nurses and 78 percent of social workers. Since November 1997, 179 of the respondents (45 percent) had cared for a patient who requested assistance with suicide. Hospice nurses reported on 82 patients who had received prescriptions for lethal medication. Ninety-eight percent of the nurses had discussed the request with a coworker, and 77 percent of the requests had been presented at a hospice interdisciplinary conference on patient care. A very important reason for the request was to control the circumstances of death. The least important reasons included depression, lack of social support, and fear of being a financial drain on family members. Although the patients were concerned about burdening others, only 11 percent of hospice nurses rated their family caregivers as more burdened than family caregivers for other hospice patients.

**Conclusions** Since assisted suicide was legalized in Oregon, many hospice nurses and social workers have provided care for a patient who requested assistance with suicide. They rated desire for control as a very important reason for these requests. (N Engl J Med 2002;347:582-8.)

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**T**HE Death with Dignity Act legalizes physician-assisted suicide for terminally ill persons in Oregon who request it. Since the law was enacted in 1997, most information about patients who receive prescriptions for lethal medications has come from interviews with and surveys of physicians.<sup>1-6</sup> These data have highlighted the importance of a desire to maintain independence and con-

trol, an inability to engage in pleasurable activities, a poor quality of life, and readiness to die as reasons that patients request assistance with suicide. The concern that such requests would be made by patients who were depressed or motivated by financial considerations, who lacked social support, or who were receiving inadequate palliative care has not been substantiated to date. These findings have been criticized, however, on the basis that reporting physicians are potentially biased and subject to an inherent conflict of interest and that they may have failed to recognize depression or explore existential and social issues sufficiently.<sup>7-9</sup>

Although physician-assisted suicide has been viewed as an alternative to hospice care,<sup>10,11</sup> 78 percent of the 91 persons in Oregon who died by assisted suicide between 1998 and 2001 were enrolled in hospice programs.<sup>6</sup> On the basis of interviews with family members, the Oregon Health Division reported that the median period of enrollment in a hospice program for 19 patients who died by assisted suicide in 1999 was seven weeks.<sup>2</sup> Hospice nurses and social workers may be able to provide important information about such persons, because they visit patients and family caregivers frequently in the last weeks of life, have expertise in providing care at the end of life, and can compare hospice patients who request a prescription for a lethal medication with other hospice patients. We conducted a survey of hospice nurses and social workers in Oregon in order to determine their experiences with and views on patients who received prescriptions for lethal medications under the Oregon law.

**METHODS**

**Study Design**

We mailed a questionnaire to nurses and social workers who care for patients enrolled in hospice programs in Oregon. All 50 Medi-

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care-certified hospice programs in Oregon, as well as 1 program each in Washington and Idaho that provide care for Oregon residents, participated in the study. Oregon's one inpatient hospice program and one prison hospice program were excluded. Each hospice was asked to submit the names of all employees who were nurses or social workers. Fifty hospices submitted the names of all eligible employees (a total of 533). Two hospices submitted 21 names and informed us that they would deliver surveys to the other 19 eligible employees, who wished to remain anonymous.

The questionnaire was based on a previous questionnaire sent to physicians in Oregon<sup>1</sup> and was initially tested with six hospice nurses and social workers. As a result of this test, some questions were clarified and others deleted, including certain questions about demographic characteristics of hospice patients, since the initial respondents were reluctant to report information that might reveal the identity of a patient.

The questionnaire included demographic information about the respondent and his or her views about the Oregon Death with Dignity Act. Each respondent provided information only about the most recent patient who had made an explicit request for a lethal prescription since November 1997 and who had subsequently died. Respondents rated the importance of 21 possible reasons why the patient had made the request, on a scale ranging from 1 (not at all important) to 5 (very important). They marked a separate box if they did not know whether the reason was important or had not discussed it with the patient or a family member. Respondents were asked to compare the characteristics of the patient who had requested assistance with suicide and his or her family caregivers with the characteristics of other hospice patients and their family caregivers on a scale ranging from 1 (much less than other hospice patients or family members) to 5 (much more than other hospice patients or family members). On a 10-point scale, respondents rated the patient's overall peacefulness (with 0 denoting very much at peace and 9 not at all at peace), suffering (with 0 denoting none and 9 severe, unremitting suffering), and pain (with 0 denoting none and 9 severe, unremitting pain) in the two weeks before death and the quality of the process of dying (with 0 denoting very bad and 9 very good).

The questionnaires were mailed between July and September 2001, followed by a reminder postcard, a second copy of the questionnaire, and a personalized reminder letter. We sent anonymous employees two sets of questionnaires through their hospice directors. The first questionnaire that was mailed included a check for \$10 or, in the case of anonymous employees, an offer of \$10. Surveys were accepted until January 31, 2002. To allow for tracking of the questionnaires, return envelopes were coded with an identifying number. The survey was separated from the envelope on receipt and recoded with a new number, rendering it anonymous. Because the survey was anonymous, the institutional review board at the Portland Veterans Affairs Medical Center waived the requirement for obtaining informed consent.

In some cases, a nurse and a social worker probably cared for the same patient; therefore, the survey results are reported separately for the two groups of respondents. Because nurses give continuous care and have more contact with patients and their families than do social workers, they were the primary informants for the purpose of this study.

**Statistical Analysis**

Summary statistics are presented as frequencies and proportions for categorical variables. Respondents' ratings of the importance of the reasons for requesting assistance with suicide are presented as medians with interquartile ranges. The ratings provided by social workers and nurses were compared with the use of the Mann-Whitney U test.<sup>12</sup> Other continuous, normally distributed variables were compared with Student's t-test and are reported as means ±SD. All P values are based on two-sided tests.

**RESULTS**

Twenty-eight hospice employees on the original list of 573 staff members were excluded because they no longer worked at the hospice program or did not care for patients in Oregon. Of 545 potential respondents, 397 (73 percent) returned the survey: 306 of 429 nurses (71 percent) and 91 of 116 social workers (78 percent). The response rate per hospice program ranged from 25 to 100 percent.

A total of 179 respondents (45 percent) reported that since November 1997, they had cared for one or more patients who had explicitly requested a prescription for lethal medication from a physician under the Death with Dignity Act; 172 respondents (122 nurses and 50 social workers) provided information about the patient (or the most recent patient, if there was more than one). These respondents had provided hospice care for a mean of 7.6 years (Table 1). Twenty-six percent opposed the Death with Dignity Act, 59 percent

**TABLE 1. CHARACTERISTICS OF HOSPICE NURSES AND SOCIAL WORKERS WHO CARED FOR A PATIENT WHO REQUESTED ASSISTANCE WITH SUICIDE.\***

CHARACTERISTIC	NURSES (N=122)	SOCIAL WORKERS (N=50)†	P VALUE
Age — yr	47.9±9.6	50.1±8.4	
Length of hospice employment — yr	7.6±5.3	7.6±5.2	
Sex — no. (%)			0.002
Women	115 (94)	39 (78)	
Men	7 (6)	11 (22)	
Type and size of area served by hospice — no. (%)			
Rural area or small town, <25,000 residents	45 (37)	13 (26)	
Medium-sized city, 25,000–250,000 residents	46 (38)	21 (42)	
Large city, >250,000 residents	29 (24)	13 (26)	
Missing data	2 (2)	3 (6)	
Attitude toward the Death with Dignity Act — no. (%)			0.05
Strongly support	29 (24)	18 (36)	
Support	40 (33)	15 (30)	
Neither support nor oppose	14 (11)	10 (20)	
Oppose	18 (15)	3 (6)	
Strongly oppose	21 (17)	3 (6)	
Missing data	0	1 (2)	
Attitude toward requests for assistance with suicide — no. (%)‡			
Actively oppose in most or all cases	1 (1)	0	
Neither support nor oppose	69 (57)	23 (46)	
Actively support in some or all cases	51 (42)	26 (52)	
Missing data	1 (1)	1 (2)	

\*Plus-minus values are means ±SD.

†Two counselors whose professional training was unknown are included in this group.

‡Data are for responses to the question, "If a hospice client for whom you cared and who met the requirements of the Oregon Death with Dignity Act requested a lethal prescription from a physician, how would you respond?"

supported it, and 14 percent neither opposed nor supported it. Only one respondent would have actively opposed a patient's choice of assisted suicide in most or all cases. Thirty-eight social workers reported on 38 patients, and 82 nurses reported on 82 patients who had actually received prescriptions for lethal medications. The nurses reported that 55 of the 82 patients who had received prescriptions died by assisted suicide and 17 died from other causes; in the case of 10 patients, the nurse was uncertain whether the lethal medication had been taken.

Eighty of the 82 hospice nurses (98 percent) reported that they had discussed the patient's request for a prescription with one or more coworkers: those attending a hospice interdisciplinary conference on patient care in 63 cases (77 percent), a hospice social worker in 60 cases (73 percent), and the patient's physician in 45 cases (55 percent). Fifty nurses (61 percent) reported that the patient had been evaluated by a clinical social worker, and 40 (49 percent) reported that the patient had been evaluated by a psychologist, psychiatrist, or mental health nurse practitioner.

#### Patients Who Received Prescriptions for Lethal Medications

The mean ( $\pm$ SD) age of the 82 patients who received prescriptions for lethal medications was  $63.6 \pm 11.5$  years; 41 were men, and 41 were women. In 68 of the patients (83 percent) the terminal disease was cancer, in 10 (12 percent) it was cardiopulmonary disease, and in 7 (9 percent) it was a neurologic disease; some nurses reported more than one terminal disease. Thirty-five patients (43 percent) resided in a rural area or a town with a population of less than 25,000, 28 (34 percent) in a town with a population of 25,000 to 250,000, and 19 (23 percent) in a city with a population of more than 250,000.

According to the hospice nurses, the most important reasons for requesting assistance with suicide, among patients who received prescriptions for lethal medications, were a desire to control the circumstances of death, a desire to die at home, the belief that continuing to live was pointless, and being ready to die (Table 2). Depression and other psychiatric disorders, lack of social support, and concern about being a financial drain were, according to nurses, relatively unimportant. Seventy-seven percent of the nurses reported that patients who received prescriptions for lethal medications were more fearful of loss of control over the circumstances of death than were other hospice patients, whereas 8 percent reported that such patients were less fearful than other hospice patients. Sixty-two percent of the nurses said that patients who received prescriptions for lethal medications were more likely to be concerned about loss of independence than were other hospice patients, whereas 9 percent said

**TABLE 2.** IMPORTANCE OF REASONS FOR REQUESTING A PRESCRIPTION FOR A LETHAL MEDICATION, AMONG PATIENTS WHO RECEIVED PRESCRIPTIONS.\*

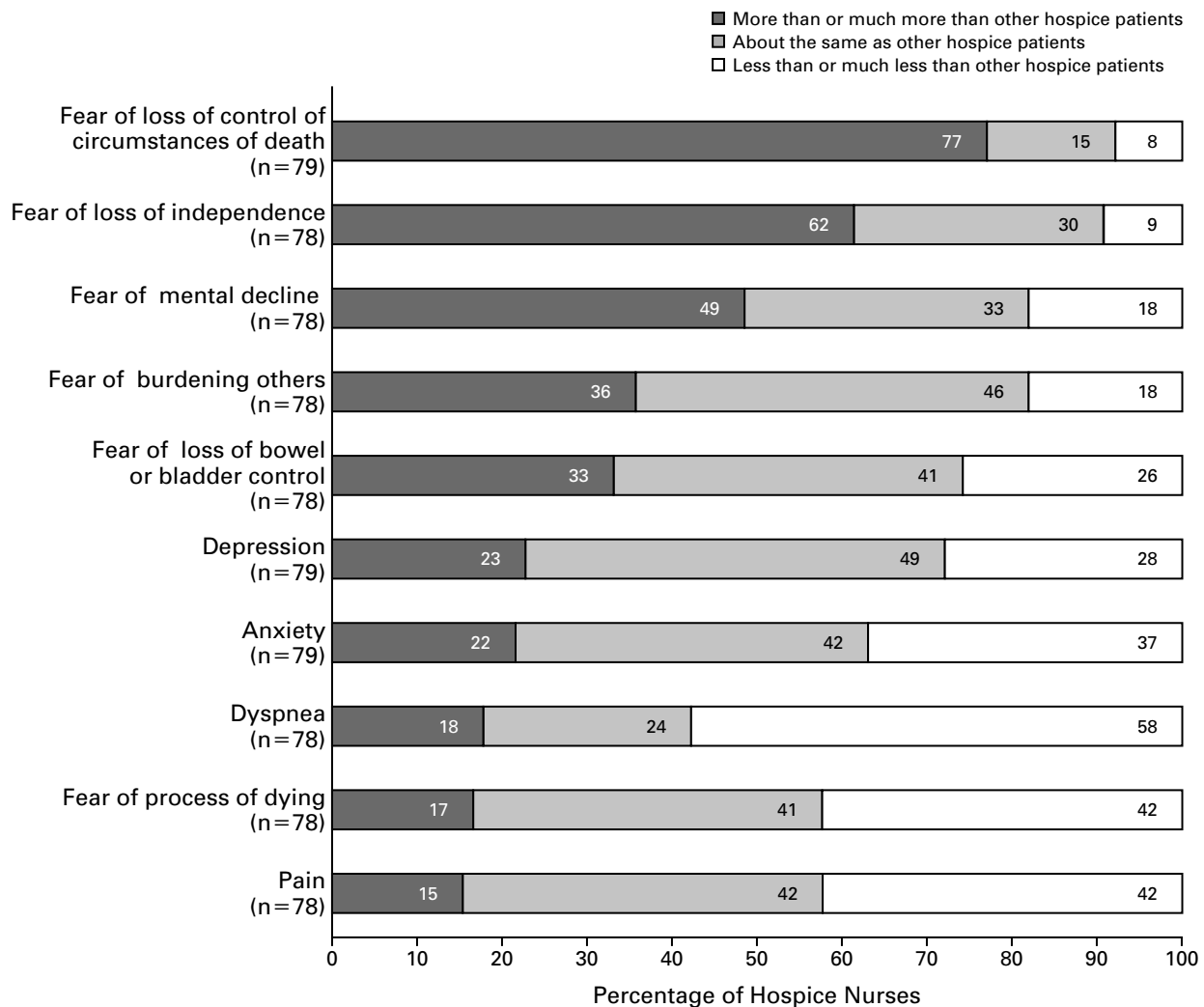
PATIENT'S REASON	RESPONSE OF HOSPICE NURSE (N=82)	
	NO. OF RESPONSES†	SCORE
		median (interquartile range)
Desire to control circumstances of death	77	5.0 (5.0–5.0)
Readiness for death	73	5.0 (4.0–5.0)
Desire to die at home	69	5.0 (3.0–5.0)
Continued existence viewed as pointless	66	5.0 (3.0–5.0)
Loss of independence or fear of losing independence	75	4.0 (4.0–5.0)
Poor quality of life or fear of poor quality	75	4.0 (4.0–5.0)
Loss of dignity or fear of losing dignity	73	4.0 (3.75–5.0)
Pain or fear of worsening pain	75	4.0 (3.0–5.0)
Inability to care for self or fear of inability to do so	70	4.0 (3.0–5.0)
Perception of self as a burden to others or fear of becoming a burden	71	4.0 (3.0–5.0)
Inability to engage in pleasurable activities	67	4.0 (3.0–5.0)
Life tasks complete	63	3.0 (2.0–5.0)
Fatigue or fear of worsening fatigue	67	3.0 (2.0–5.0)
Dyspnea or fear of worsening dyspnea	69	3.0 (1.0–5.0)
Loss of or fear of losing bowel or bladder function	65	3.0 (1.0–4.5)
Confusion or fear of confusion	67	3.0 (1.0–4.0)
Experience of witnessing bad deaths	44	2.0 (1.0–3.75)
Perception of self as financial drain on others or fear of becoming financial drain	60	2.0 (1.0–3.0)
Depression or other psychiatric disorder	59	2.0 (1.0–3.0)
Nausea or fear of worsening nausea	67	2.0 (1.0–3.0)
Lack of social support	65	1.0 (1.0–2.0)

\* Respondents were asked to report only reasons that were given in actual conversations with the patient or family. Reasons were scored on a 5-point scale for their importance in the decision to request a prescription for a lethal medication, with 1 denoting not at all important, and 5 very important.

† For each reason, some respondents reported that they did not know whether it was important or had not discussed it with the patient or family, or they did not answer the question.

that such patients were less concerned about loss of independence than were other hospice patients (Fig. 1).

Hospice social workers reported that the desire to control the circumstances of death, the wish to die at home, loss of independence or fear of such loss, and loss of dignity or fear of such loss were the most important reasons for requesting prescriptions for lethal medications; the median score for all these reasons was 5 on the 1-to-5 scale. They ranked lack of social support and depression as the least important reasons; the median score for both was 1. Social workers rated fear of loss of dignity as more important (median score, 5; interquartile range, 4 to 5;  $P=0.05$ ) than



**Figure 1.** Characteristics of Patients Who Received Prescriptions for Lethal Medications, as Compared with Other Hospice Patients, According to Hospice Nurses.

A total of 82 nurses reported on patients who received prescriptions. For each characteristic, the number of nurses who responded is shown in parentheses. Because of rounding, percentages may not total 100.

did nurses and the belief that continuing to live was pointless as less important (median score, 4; interquartile range, 3 to 5;  $P=0.05$ ) than did nurses.

As assessed by the hospice nurses, the mean score for overall pain in the last two weeks of life was  $3.1 \pm 2.3$ . Many of the nurses reported that pain or fear of pain was an important reason for the request for assistance with suicide. Only 15 percent of the nurses, however, reported that the patient had more pain, on average, than other hospice patients, whereas 42 percent reported that the patient had less pain, on average, than other hospice patients (Fig. 1). Other physical symptoms, such as fatigue and dyspnea, were reported to be only moderately important rea-

sons for the request, and 58 percent of the nurses reported that the patients who received prescriptions for lethal medications had less dyspnea than other hospice patients (Fig. 1).

**Patients Who Requested but Did Not Receive Prescriptions**

Hospice nurses reported that 39 patients had requested but not received a prescription for lethal medication; in 1 case, the nurse did not know whether the patient had received a prescription. Thirteen patients did not receive a prescription because they could not find a physician willing to provide it, 13 because of a change of mind, 12 because they died before they

could meet the requirements of the law, 7 because they chose to hasten death by voluntarily discontinuing food and fluids, and 4 because they did not meet the law's criteria. Some nurses reported more than one reason.

As compared with the patients who received prescriptions for lethal medications (Table 2), those who requested but did not receive a prescription were considered to be more depressed (27 patients; median score, 2.0; interquartile range, 1.0 to 4.0;  $P=0.04$ ) and to place less value on dying at home (29 patients; median score, 4.0; interquartile range, 2.5 to 5.0;  $P=0.007$ ). Nurses rated the quality of dying as better for patients who received a prescription (mean score,  $6.8\pm 2.7$ ) than for those who requested but did not receive one ( $5.5\pm 3.0$ ,  $P=0.02$ ); however, there was no significant difference between these two groups with respect to scores for overall suffering, pain, or peacefulness in the two weeks before death (data not shown).

#### Views of Families

Eighty-five percent of hospice nurses reported that all close family members of patients who received a prescription for a lethal medication knew about it, and 90 percent said that all or most of the family members accepted the patient's decision to pursue assisted suicide (Table 3). Seventy-seven percent of nurses and social workers reported that they had discussed the patient's request for a prescription with the family. Although many patients were reportedly concerned about burdening family members, only 11 percent of hospice nurses reported that the family members of patients who received prescriptions for lethal medications were more burdened by caregiving than the family members of other hospice patients, and only 3 percent reported that the family members of patients who received prescriptions were more financially burdened (Fig. 2). Eighty-four percent of the nurses rated the caregivers of patients who received prescriptions as finding at least as much meaning in caring for the patient as the caregivers of other hospice patients. Overall, families of patients who received prescriptions for lethal medications were more accepting of and prepared for the patient's death, although they were somewhat more likely to be distressed than were the family members of other hospice patients.

#### DISCUSSION

Although assisted suicide has been legal in Oregon since 1997, it has occurred only rarely, accounting for 6 to 9 of 10,000 deaths per year.<sup>6</sup> However, 45 percent of the hospice nurses and social workers in Oregon who responded to our survey had cared for at least one patient who had explicitly requested a prescription for lethal medication from a physician under the law,

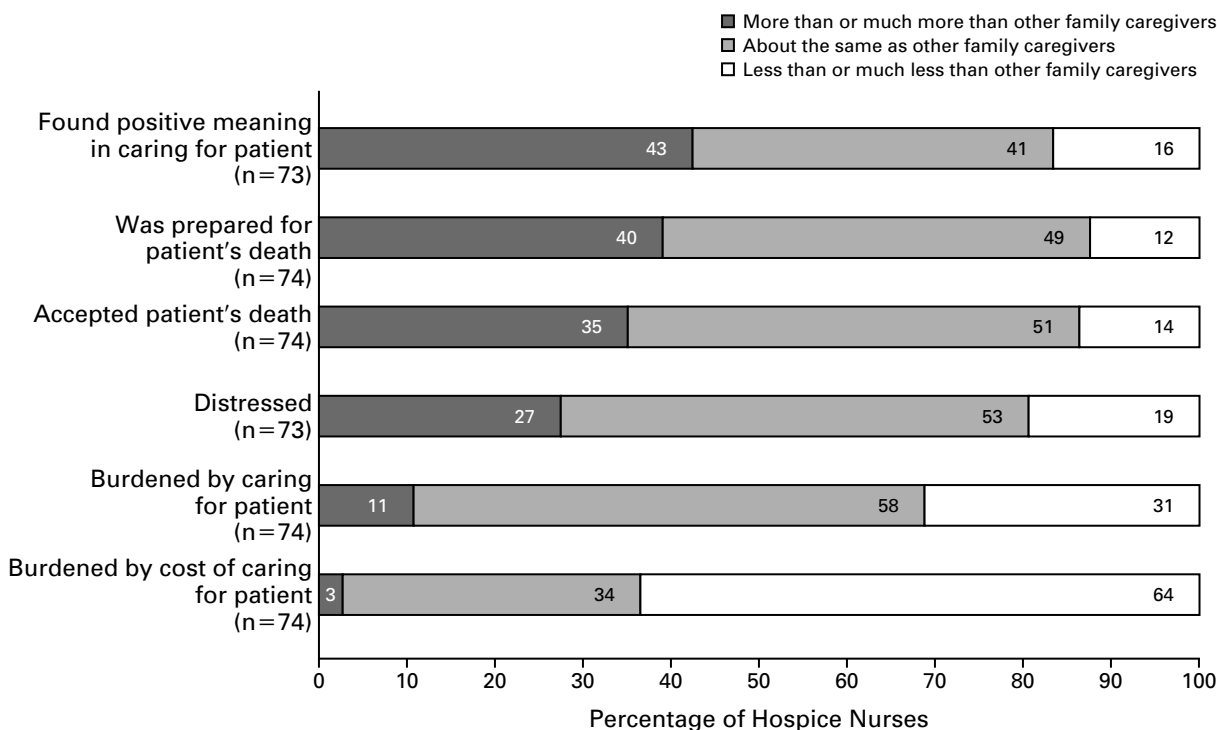
**TABLE 3.** ATTITUDES OF FAMILIES OF PATIENTS WHO RECEIVED PRESCRIPTIONS FOR LETHAL MEDICATIONS.

QUESTION AND RESPONSE	NURSES (N=82)	SOCIAL WORKERS (N=38)
	no. (%)	
Were family members aware of the patient's request?		
All knew	70 (85)	28 (74)
One or two knew	11 (13)	6 (16)
None knew	0	0
No family to notify	1 (1)	2 (5)
Missing data	0	2 (5)
Did the hospice practitioner discuss the request with the family?		
Yes	63 (77)	29 (76)
No	19 (23)	7 (18)
Missing data	0	2 (5)
Did family members accept the patient's decision?		
All accepted it	36 (44)	14 (37)
Most accepted it	38 (46)	17 (45)
Many opposed it	3 (4)	1 (3)
All opposed it	1 (1)	1 (3)
Unsure or missing data	4 (5)	5 (13)
Was the patient's decision influenced by the family?		
Not at all	55 (67)	25 (66)
Somewhat	22 (27)	8 (21)
A great deal	3 (4)	1 (3)
Missing data	2 (2)	4 (11)

and 30 percent had cared for a patient who had received a prescription. According to the respondents, the desire to control the circumstances of death was a very important reason for these requests.

Patients who received prescriptions for lethal medications were concerned about burdening their families. Their families, however, were considered less likely to be burdened by caretaking, including the cost of care, and were more likely to find positive meaning in providing care than were the families of other hospice patients. Among these patients, the fear of being a burden may have reflected their own reaction to the thought of being dependent during the dying process rather than communication with their families.

Outside of Oregon, one of the most consistent findings in studies of seriously or terminally ill patients is that depression increases the likelihood of a preference for hastening death.<sup>13-18</sup> According to a survey of physicians in Oregon, 20 percent of patients who requested a prescription for lethal medication were depressed, though no depressed patients received prescriptions.<sup>1</sup> Hospice social workers have expertise in evaluating mood disorders in terminally ill patients. In our study, hospice social workers rated depression as one of the least important of all 21 possible reasons for requesting assistance with suicide among pa-



**Figure 2.** Characteristics of Family Caregivers of Patients Who Received Prescriptions for Lethal Medications, as Compared with Family Caregivers of Other Hospice Patients, According to Hospice Nurses.

A total of 82 nurses reported on patients who received prescriptions. For each characteristic, the number of nurses who responded is shown in parentheses. Because of rounding, percentages may not total 100.

tients who received prescriptions for lethal medications. The view that continued existence would be pointless, an inability to engage in pleasurable activities, and a poor quality of life were rated as important reasons for requesting assistance with suicide and may be manifestations of occult depression. Additional studies of persons in Oregon who request assistance with suicide are needed to validate the importance of all these reasons.

The Death with Dignity Act has provisions to ensure that patients who choose assisted suicide are terminally ill, have adequate decision-making capacity, are not influenced by depression or acting impulsively, and have been offered alternatives.<sup>19</sup> Our results suggest that enrollment in a hospice program may offer additional protection. Most requests for assistance with suicide that are made by patients enrolled in hospice programs are discussed with coworkers, often at interdisciplinary conferences. Many such patients are evaluated by clinical social workers with expertise in end-of-life care. In Oregon, enrollment in a hospice program does not appear to be a barrier to receiving a prescription for a lethal medication, and even hospice nurses and social workers who oppose the legal-

ization of assisted suicide rarely oppose a patient's choice on this issue.

Our study has several limitations. Twenty percent of all persons who die by assisted suicide in Oregon are offered hospice care but refuse it.<sup>6</sup> Our findings may not apply to such persons. The views of the hospice employees who did not respond to our survey (27 percent of those contacted) are not represented. Although we asked respondents to base information about the patient's reasons for requesting assistance with suicide on actual conversations with the patient or family, the degree to which their responses accurately represent their patients' views is unknown. In addition, our survey was not preceded by qualitative interviews and may therefore not encompass all important aspects of hospice employees' views and experiences with respect to patients who request assistance with suicide.

According to the Oregon Health Division, between 1998 and 2001, 71 persons enrolled in hospice programs died by assisted suicide.<sup>6</sup> The hospice nurses whom we surveyed provided information about 55 patients who died by assisted suicide in the same period. In most hospice programs, one nurse assumes

the primary caretaking role for a patient from enrollment until death, but it is possible that in some cases two nurses in our survey reported on the same patient. In addition, each respondent was asked to provide information on only one patient who had requested assistance with suicide, and some patients may have been missed.

In summary, hospice nurses and social workers in Oregon corroborated the views of physicians that patients request assistance with suicide because they want to control the circumstances of death and maintain their independence and because they view their quality of life as poor and are ready to die. Even though not all hospice nurses and social workers support the Death with Dignity Act, they are all willing to care for patients who make this choice. The high quality of care at the end of life provided by hospice programs may explain, in part, the very low rate of assisted suicide among patients in Oregon who are enrolled in such programs.

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The views expressed in this article are those of the authors and do not necessarily represent the views of the Department of Veterans Affairs, Oregon Health and Science University, the Oregon Hospice Association, or the Greenwall Foundation.

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