

OREGON'S DEATH WITH DIGNITY ACT: THE SECOND YEAR

IN 1997, OREGON became the first and only state to legalize physician-assisted suicide (PAS). The first lethal dose of medication was legally prescribed in 1998, and a total of 16 patients used PAS that year.¹ Physician interviews done in 1998 indicated that patients chose to use PAS because of concerns about loss of autonomy and loss of control of bodily functions. However, it was not clear if these first patients would be typical of other patients who might choose this option. In 1999, we looked at whether the numbers and characteristic of patients using legal PAS had changed from 1998.² In addition, we interviewed family members to get another perspective on patients' motivations.

REQUIREMENTS OF THE ACT

The Death with Dignity Act is the citizen's initiative that legalized PAS in Oregon.³ It allows terminally-ill patients to obtain a prescription for lethal medication from an Oregon physician. Euthanasia, in which a physician directly administers a lethal medication, is not permitted.

Patients eligible to use the Act must: (a) be 18 years of age or older; (b) be an Oregon resident; (c) be capable of making and communicating health-care decisions; (d) have a terminal illness with <6 months to live; and (e) voluntarily request a prescription. The patient must make one written and two verbal requests (separated by at least 15 days) of their physician. The prescribing physician and a consultant physician are required to confirm the terminal diagnosis and prognosis, determine that the patient is capable and acting voluntarily, and refer the patient for counseling if either believes that the patient's judgment is impaired by a psychiatric or psychological disorder. The prescribing physician must also inform the patient of feasible alternatives, such as comfort care, hospice care and pain control options.

The law mandates that the Oregon Health Division (OHD) monitor the Act's implementation. To be in legal compliance with the law, physicians are required to report the writing of all prescription for lethal medications to the Health Division.⁴ During the last legislative session, the statute was amended to include a requirement for health-care providers dispensing lethal medications (e.g., pharmacists, dispensing physicians) to also report to the Health Division. See our website (www.ohd.hr.state.or.us/chs/pas/pas.htm) for copies of the reporting forms.

1999 INFORMATION SOURCES

We determined the number of patients legally receiving prescriptions for lethal medication, and the numbers using PAS from the required physician report forms. Death certificates provided data on patient demographics and underlying illness. We interviewed prescribing physicians to learn about the patient's end-of-life care and the circumstances surrounding the death. We also asked physicians about patient concerns that contributed to the patient's request for the lethal medication.

This year we also talked with relatives or close friends of patients who died between September 15, 1998 and October 15, 1999 (we refer to both here as family members). We identified these family members through the patient's health-care providers, whom we asked to identify a relative or friend of the patient who was well acquainted with the patient's health care decisions — including the decision to use PAS.

We asked family and physicians about six possible patient concerns that could have contributed to the patient's request for lethal medication. These included concerns about loss of autonomy, decreasing ability to participate in activities that make life enjoyable, loss of control of bodily functions, being a burden on family and friends, and the financial cost of treating or prolonging illness.

Physicians were asked if patient concern about uncontrollable pain contributed to the request for lethal medication. Because some family members had difficulty distinguishing pain from other physical suffering, family members were asked if the patient's concern about physical suffering contributed to the request. Physical suffering included pain, dyspnea, dysphagia, and the side-effects of medication.

WHAT HAPPENED IN 1999?

Thirty-three prescriptions for lethal medication were written in 1999, compared to 24 in 1998. Of the 22 physicians who wrote these 1999 prescriptions, 14 were in family practice or internal medicine, five were oncologists, and three were in other subspecialties. The 27 patients who died in 1999 after ingesting a lethal dose of medication included 26 of the 1999 prescription recipients and one of the 1998 prescription recipients. The results presented here focus on patients who died after ingesting a lethal dose of medication, referred to as participating patients.

The 27 participating patients from 1999 represented an estimated 9 PAS deaths per 10,000 total Oregon deaths; the 16 participating patients from 1998 represented 6 PAS deaths per 10,000 total Oregon deaths. The median age of the 1999 participating patients was 71 years. All but one were white, and 59% were male. Almost two thirds of the patients had cancer. All had health insurance; 18 of the 27 patients had private insurance. Most patients were enrolled in hospice. Overall, these patients were similar to the patients who participated in 1998 with respect to demographics and end-of-life care, except that 1999 patients were significantly more likely to be married than 1998 patients (44% vs. 13%, respectively).

The patients who used PAS were demographically comparable to other Oregonians who died of similar underlying diseases, with the exception of educa-

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tion. Compared to Oregonians who died from similar diseases, college-educated patients were 12 times more likely to use PAS compared to patients without a college education.

END-OF-LIFE CONCERNS

Information on patient end-of-life concerns was available from the physicians for all 27 patients. Often more than one concern was at the root of the patient's request. The most frequently reported concerns were about losing autonomy and a decreasing ability to participate in activities that make life enjoyable. Physicians for 13 patients cited both of these concerns accompanied by concern about losing control of bodily functions. While the number of patients concerned about uncontrollable pain increased from 2 in 1998 to 7 in 1999, this difference was not statistically significant.

Of the 24 patients who died between September 15, 1998 and October 15, 1999, family members of 19 (79%) were interviewed. Like physicians, interviews with family members indicated that more than one concern often contributed to the patient's request for medication. The most frequently reported concerns were those about losing autonomy and control of bodily functions. All eight patients concerned about being a burden on family and friends were also concerned about these two issues. The one patient who was concerned about the financial implications of the illness was also concerned with all issues except physical suffering. For other patients, physical suffering was noted by family members as an important factor contributing to loss of autonomy and a decreasing ability to take part in activities that make life enjoyable. One family member did not think that any of the

specific end-of-life concerns we asked about contributed to the patient's request for lethal medication.

Most concerns reported by families and physicians were very similar. Although not directly comparable, 53% of family members mentioned the broader concern about physical suffering, in contrast to 32% of physicians who mentioned the more narrowly-defined concern about pain.

In addition to the specific concerns we explored, most family members volunteered reasons they felt the patient chose to use PAS. Fourteen (74%) of the 19 family members interviewed emphasized the patients' determination to control their death if their illness made living unbearable. Most also discussed the patient's desire to avoid a prolonged death where he/she lost control of mind and body, with four family members specifically noting the patient's fear of ending life comatose on a respirator, despite having advance medical directives.

WHAT ABOUT COMPLICATIONS?

During our interviews with physicians, we asked whether they were present at the time the patient took the lethal medication or at the time of death, about the timing of events, complications such as vomiting or seizures, and whether or not 911 had been called to request emergency medical assistance. Physicians were present when 16 (59%) of the 27 patients took the medications, and when 13 (48%) of the patients died. The median time after swallowing the medications until unconsciousness was 10 minutes (range 1-30 minutes). The median time from ingestion until death was 30 minutes (range 4 minutes-26 hours); however,

three patients lived for 11 or more hours after ingestion. None of the physicians reported that patients experienced vomiting and/or seizures.

None of the physicians or families we spoke to reported that 911 had been called. Subsequent to filing our official report, we have heard of instances in which 911 was called. For example, in one case, the patient needed assistance unrelated to and prior to taking the lethal medication. In another case, the EMTs were called to certify that the patient had died. While none of these instances reflect problems with the medications per se, they do suggest that it may be advisable to have a trained medical professional present at the time the patient is taking the medication.

SUMMARY

While the number of physician-assisted suicides in Oregon in 1999 increased from 1998, these numbers remained small relative to the overall number of Oregon deaths. The decision to choose PAS appears to be influenced by a complex set of patient end-of-life concerns. Information from both families and physicians indicates that patients who choose this option are greatly concerned about losing control of their lives due to their terminal illness, and that they are determined to control the timing and manner of their death when they feel their lives have become unbearable.

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3. Death with Dignity Act; ORS 127.800-127.995.
4. OAR 333-009-0010 through 333-009-0030.