Oregon's Death with Dignity Act: The Second Year's Experience

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Summary

In November 1997, approval of the Death with Dignity Act made Oregon the only state allowing legal physician-assisted suicide (PAS). With passage of the Act came concerns that participation in the Death with Dignity Act might be forced onto poor, uneducated or uninsured patients, or that patients with inadequate end-of-life care might disproportionately seek to participate. We previously reported that during 1998, the first year of implementation, 23 Oregonians received prescriptions for lethal doses of medication; 15 of them died after ingesting these medications. Their participation was not associated with low educational level, lack of health insurance or poor access to hospice care. Physicians of terminally ill patients using PAS in 1998 reported patient concerns over loss of autonomy and control of bodily functions. Here we report results from 1999, summarizing information from physician reports, physician interviews, and death certificates. We also present information from interviews with families that were conducted to help us better understand patients' reasons for requesting PAS.

Patients participating in PAS were identified through mandatory physician reporting, and additional data were obtained from physician interviews and death certificates. We interviewed families of patients who participated between September 15, 1998 and October 15, 1999.

In 1999, 33 prescriptions were written for lethal doses of medication, and 27 patients participated in legal PAS (26 of the 33 1999 prescription recipients and one 1998 prescription recipient). Of the remaining seven 1999 prescription recipients, five died of their underlying illness and two were still alive at the end of the year. One additional 1998 death, from late in that year, also was included in this report, increasing the number of prescriptions in that year from 23 to 24, and the number of PAS deaths from 15 to 16.

The median age of the 27 patients who took lethal medication in 1999 was 71 years. Sixteen were male, 26 were white and 12 were married. Nine were from the Portland metropolitan area, and 13 were college graduates. The most frequent underlying diseases were end-stage cancer (17 patients), amyotrophic lateral sclerosis (4 patients), and chronic obstructive pulmonary disease (4 patients). All patients had health insurance and 21 were in hospice before death. These 27 patients using PAS in 1999 (9 PAS deaths /10,000 Oregon deaths) were demographically and medically similar to the 16 patients using PAS in 1998 (6 PAS deaths /10,000 Oregon deaths), though more likely married (44% vs. 13 %; $P<0.05$). The 27 1999 participating patients also were demographically comparable to Oregonians dying of similar diseases, though more likely college educated (Relative Risk = 12.1, 95% Confidence Interval [3.8-38.7]).

Multiple concerns motivated patient PAS requests in 1999. The 27 physicians interviewed most frequently cited patient concerns about loss of autonomy (81%) and decreasing ability to participate in activities that make life enjoyable (81%). The 19 family members interviewed most frequently cited patient concerns about losing autonomy (63%), losing control of bodily functions (68%), and physical suffering (for example, pain, difficulty breathing, difficulty swallowing; 53%). Fourteen (74%) family members added that patients wanted to control the manner and time of their deaths.

In the second year of legal PAS in Oregon, the number of patients who died after ingesting lethal medications increased compared to the first year, but remained small relative to the total number of Oregonians who died. Patients were motivated by multiple, interrelated concerns, including concerns about losing autonomy, losing control of bodily functions, decreasing ability to participate and physical suffering, as well as a determination to control the end of their lives.

Introduction

When voters approved the Death with Dignity Act in November 1997, Oregon became the only state allowing legal physician-assisted suicide [1]. The Oregon Death with Dignity Act requires that the Oregon Health Division (OHD) monitor compliance with the law, collect information about the patients and physicians who participate in legal physician-assisted suicide, and publish an annual report. Information about participating patients and physicians helps in evaluating concerns that physician-assisted suicide might be forced onto poor, uneducated or uninsured patients; or that it might be disproportionately sought by patients with inadequate end-of-life care [2,3]

We previously reported that during 1998, the first year of the Act's implementation, 15 Oregonians used physician-assisted suicide [4]. Their participation was not associated with low education level, lack of health insurance or poor access to hospice care. Physician interviews indicated that patients requested lethal medication because of concerns over losing autonomy and control of bodily functions, not worsening pain or financial loss.

This report reviews the monitoring and data collection system that was implemented under the law, and summarizes the information collected on patients and physicians who participated in the Act in the second year of the Act's implementation (January 1, 1999 to December 31, 1999). We compare patients who participated in 1999 to those who participated in 1998 and to other Oregonians who died of similar diseases. To better understand why some patients choose physician-assisted suicide, we also present information from interviews with family members of patients who participated in the Death with Dignity Act.

The Oregon Death with Dignity Act

The Oregon Death with Dignity Act was a citizen's initiative first passed by Oregon voters in November 1994 by a margin of 51% in favor and 49% opposed. Implementation of the Act was delayed by a legal injunction. After legal proceedings, including a petition that was denied by the United States Supreme Court, the Ninth Circuit Court of Appeals lifted the injunction on October 27, 1997 and physician-assisted suicide became a legal option for terminally ill Oregonians. In November 1997, a measure asking Oregon voters to repeal the Death with Dignity Act was placed on the general election ballot (Measure 51, authorized by Oregon House Bill 2954). Voters rejected this measure by a margin of 60% to 40%, thereby retaining the Death with Dignity Act.

The Death with Dignity Act allows terminally ill Oregon residents to get and use prescriptions from their physicians for self-administered, lethal medications. Under the Act, ending one's life in accordance with the law does not constitute suicide. However, we use the term "physician-assisted suicide" in this report because this is the term used by the medical literature to describe ending life through the voluntary self-administration of lethal medications

prescribed by a physician for that purpose. The Death with Dignity Act legalizes physician-assisted suicide, but specifically prohibits euthanasia, where a physician or other person directly administers a medication to end another's life. [1,5]

To request a prescription for lethal medications, the Death with Dignity Act requires that a patient must be:

- An adult (18 years of age or older)
- A resident of Oregon
- Capable (defined as able to make and communicate health care decisions)
- Diagnosed with a terminal illness that will lead to death within 6 months

Patients meeting these requirements are eligible to request a prescription for lethal medication from a licensed Oregon physician. To receive a prescription for lethal medication, the following steps must be fulfilled:

- The patient must make two verbal requests to their physician, separated by at least 15 days
- The patient must provide a written, witnessed request to their physician
- The prescribing physician and a consulting physician must confirm the diagnosis and prognosis.
- The prescribing physician and a consulting physician must determine whether the patient is capable.
- If either physician believes the patient's judgment is impaired by a psychiatric or psychological disorder, such as depression, the patient must be referred for a psychological examination.
- The prescribing physician must inform the patient of feasible alternatives to assisted suicide including comfort care, hospice care, and pain control.
- The prescribing physician must request, but may not require, the patient to notify their next-of-kin of the prescription request.

To comply with the law, physicians must report to the OHD all prescriptions for lethal medications [5,6]. Reporting is not required if patients begin the request process but never receive a prescription. In the summer of 1999, the Oregon legislature added a requirement that pharmacists must be informed of the prescribed medication’s ultimate use. Physicians and patients who adhere to the requirements of the Act are protected from criminal prosecution, and the choice of legal physician-assisted suicide can not affect the status of a patient's health or life insurance policies. Physicians and health care systems are under no obligation to participate in the Death with Dignity Act [1,5].

The Reporting System

The Death with Dignity Act requires the OHD to develop a reporting system to monitor and collect information on physician-assisted suicide [1]. To fulfill this mandate, the OHD uses a system involving physician prescription reports and death certificate reviews.

When a prescription for lethal medication is written, the physician must submit to the OHD information that documents compliance with the law (see previous section). We review all physician reports and contact physicians regarding missing or discrepant data. OHD Vital Records files are searched periodically for death certificates that correspond to physician reports. These death certificates allow us to confirm patients' deaths, and provide patient demographic data (for example, age, place of residence, level of education). [4]

For this report, we also included telephone interviews with all prescribing physicians after receipt of their patients' death certificate. Each physician was asked to confirm whether the patient took the lethal medications. We also collected data not available from physician reports or death certificates – including insurance status, end-of-life care, and medical and functional status at the time of death. We asked why the patient requested a prescription, specifically exploring concerns about the financial impact of the illness, loss of autonomy, decreasing ability to participate in activities that make life enjoyable, loss of control of bodily functions, and uncontrollable pain. If the patient took the lethal medication, we collected information on the time to unconsciousness and death, and asked about any unexpected adverse reactions. Many terminally ill patients have more than one physician providing care at the end of life: to maintain consistency in data collection, we only interviewed prescribing physicians. Information about prescribing physician – such as age, sex, number of years in practice, and medical specialty – were collected during the interviews. We do not interview or collect any information from patients prior to their death. Reporting forms and the physician questionnaire are available at www.ohd.hr.state.or.us/cdpe/chs/pas/pas.htm. [4]

Data Collection and Analysis

Using physician reports, death certificates, and prescribing physician interviews from the reporting system described, we collected information on all patients who received a prescription for lethal medications and died in 1998 and 1999. Prescription recipients died either by ingesting their lethal medications or from their underlying illnesses. Because of possible differences between patients who used the lethal medication and patients who received lethal medications but never used them, we looked at these two groups separately. Our report focuses on patients who chose physician-assisted suicide and died after taking their lethal medications.

Comparison to 1998 participants and all Oregonian who died of similar diseases

The comparisons presented here include all patients who died in 1999 (January 1, 1999 through December 31, 1999) after ingesting a lethal dose of medication prescribed under the Death with Dignity Act. These patients were compared with those who died in 1998 after ingesting a lethal dose of medication (for 1998 patients, see the first year report at http://www.ohd.hr.state.or.us/cdpe/chs/pas/ar-index.htm.). We also compared patients who chose physician-assisted suicide in 1999 with all Oregonians who died from similar underlying diseases in 1998 (the most recent year that finalized Oregon mortality data were available). The proportion of deaths resulting from legal physician-assisted suicide were calculated for 1998 and estimated for 1999 using total and disease-specific 1998 deaths in the denominator.

Interviews with Family Members

We interviewed close relatives or friends (subsequently referred to as "family") of patients who participated between September 15, 1998 and October 15, 1999. We selected this period to minimize recall inaccuracies, conducting interviews within approximately one year of death, and to allow families a mourning period for deaths occurring in late 1999. Physicians, or other providers involved in the patient's terminal health care, identified the most appropriate family member to interview (one per patient). Each family member knew of the patient's request for and use of lethal medication, and was involved in the patient's health-care decisions. Patients were excluded if no family familiar with their illness and death could be identified, or if the family member declined the interview. Oral informed consent was obtained from all family members interviewed.

Most questions on the family interview were analogous to those asked of participating physicians, including questions probing specific concerns that may have contributed to the patients request for lethal medication. Additional questions were asked regarding physical suffering, finances, and hospice care. Some family members had difficulty separating pain from other aspects of physical suffering (for example, difficulty breathing, difficulty swallowing, and medication side effects); so, we did not distinguish pain from physical suffering in assessing family responses. Consequently, physician responses about pain are not directly comparable to family responses about physical suffering.

Statistical Methods

Proportions were compared using Pearson's chi-square test and Fisher's exact test. Continuous variables were compared using Wilcoxon Rank Sum test. Unadjusted relative risks with 95% confidence intervals (CIs) were calculated when comparing participating patients to the 1998 death cohort. Physician and family responses were compared using a corrected McNemar's chi-square test for paired proportions. Two-tailed P values ≤ 0.05 were considered statistically significant. Statistical calculations were performed using SAS [8].

Results

The results from our report are presented in two formats. In addition to this electronic report, the results are presented in a manuscript published in the New England Journal of Medicine (Title: "Legalized physician-assisted suicide in Oregon – The second year") on February 24, 2000 [9].

Year 2 Patients and Physicians Participating in the Death with Dignity Act

In 1999, 33 prescriptions for lethal doses of medication were written, compared to 24 prescriptions written in 1998. Ten (30%) of the 33 prescriptions were written in the last two months of the year. Five 1999 prescription recipients died from their underlying disease; two were alive at the end of the year. In total, 27 patients died after ingesting the medication in 1999: 26 of the 1999 prescription recipients and one of the 1998 prescription recipients. The one other 1998 prescription recipient alive on December 31, 1998 died in 1999 from their underlying disease. (In our 1998 report we included 23 prescription recipients and 15 physician-assisted suicide deaths. A 24th 1998 prescription recipient participated late in that year and was not reported until 1999. This individual ingested the medication, bringing the total number of physician assisted suicide deaths in 1998 to 16.)

The median age of the 27 patients participating in 1999 was 71 years. They were similar to the 16 patients participating in 1998 with respect to demographic characteristics, underlying illness, hospice use, and health insurance coverage (Table 1), although a higher proportion of patients participating in 1999 were married (44% versus 13%, P = 0.05). Sixty-three percent of 1999 patients had end-stage cancer – most commonly lung cancer – and 78% were in hospice before death (Table 1).

In 1999, the median time between first requesting physician-assisted suicide and ingesting the lethal medication was 83 days, longer than the 22 days observed in 1998 (P = 0.006; Table 2). One patient used the prescription more than 6 months after it was written (247 days). Twenty-six participating patients were prescribed $\geq$9 grams secobarbitol, usually in conjunction with antiemetics; one patient was prescribed 6 grams of phenobarbitol. The median time between ingestion and unconsciousness was 10 minutes (range: 1 to 30 minutes); and between ingestion and death, 30 minutes (range: 4 minutes to 26 hours). Twenty-four patients died within four hours, and three after 11 hours. Two of the latter three ingested the entire dose, and one ingested two-thirds of the dose before becoming unconscious after 13 minutes and dying 26 hours later.

In 1999, 22 physicians legally prescribed the 33 lethal doses of medication. Six of them also prescribed in 1998. Fourteen of the 22 physicians were in family practice or internal medicine, five were oncologists, and three were in other subspecialties. Their median age was 52 years (range 30 to 78 years) and the median number of years they had been in practice was 20 years (range 1 to 48 years). According to physician reports, eight (31%) participating patients received a prescription from the first physician they asked (data unavailable for one patient: Table 2). Of

the remaining 18 participating patients, 10 (56%) asked one other physician and eight (45%) asked two to three physicians.

Comparison with the 1998 Oregon Death Certificate Cohort

During 1998, a total of 29,281 Oregonians died; 6,994 died of cancer and 76 died of amyotrophic lateral sclerosis (ALS). Using these 1998 values for comparison, patients who ingested lethal medications in 1999 represented an estimated 9/10,000 total Oregon deaths and 39/10,000 Oregon cancer deaths. Patients participating in 1998 represented 6/10,000 total and 20/10,000 cancer deaths. The four participating 1999 patients with ALS represented approximately 5% of ALS deaths (no 1998 participants had ALS). Participating 1999 patients resembled a cohort of 6,901 Oregonians who died from similar underlying illnesses with respect to age, race, and residence (Table 3). However, as education increased so did likelihood of participation (Chi-square test for linear trend, $P<0.001$), and college graduates were more likely to participate than people without a high school education (Relative Risk = 12.1; 95% Confidence Interval [3.8-38.7]; $P<0.001$).

Concerns contributing to requests for lethal medication

Physician Interviews

Based on 1999 physician interviews, multiple end-of-life concerns contributed to patient prescription requests. Eighteen (68%) of 27 patients discussed three or more concerns with their physicians: 13 of these patients included among these concerns loss of autonomy, decreasing ability to participate in activities that make life enjoyable, and loss of control of bodily functions. In 1998, only seven (44%) of 16 physicians included three or more reasons for patient prescription requests. The most frequently cited patient concerns in both years were loss of autonomy (1999, 81%; 1998, 75%; Table 2) and decreasing ability to participate in activities that make life enjoyable (1999, 81%; 1998, 69%; Table 2). In 1999, seven (26%) of 27 patients expressed concern about worsening pain as their illness progressed, compared with two (13%) of 16 in 1998, though this difference was not statistically significant ($P = 0.30$). The financial implications of treating or prolonging the illness were not reported to be a concern for any patient.

Family Interviews

Of the 24 participating patients who died after ingesting a lethal dose of medication between September 15, 1998 and October 15, 1999, family members of 19 (79%) were interviewed: eight spouses, two siblings, seven children, one parent and one close friend. Eighteen interviews included discussions beyond what was explored in the structured instrument. Two patients had been married for over 45 years to the spouses who were present at their deaths. Family interviews were not done for five patients because the contact was overwrought ($n = 1$) or had no

current telephone number (n = 2); or the provider could not identify an appropriate contact (n = 2).

Similar to physicians, family members often cited multiple concerns contributing to the patient's decision to request the prescription (Table 4). Twelve (63%) of the 19 family members noted at least three concerns. Overall, the most frequently cited reasons identified for patient participation were concern about loss of control of bodily functions (68%), loss of autonomy (63%), and physical suffering (53%). Nine family members (47%) included concern about decreasing ability to participate in activities that make life enjoyable. Ten family members (53%) included patient concern about both loss of control of bodily functions and loss of autonomy. All of eight family members (47%) who believed the patient was concerned about being a burden also reported that the patient was concerned about loss of autonomy and/or loss of control of bodily functions. (Two family members did not know if concern about becoming a burden on family and friends was an issue for the patient.) Four of 10 patients who were concerned about physical suffering were not reported by family to be suffering when use of the lethal medication was first discussed. The one patient who expressed concern to a family member about the financial impact of the illness was concerned about all issues except physical suffering. This patient was privately insured and spent only a "little bit" of money on health-related expenses. One spouse did not believe that any of the concerns we explored in the structured interview contributed to the patient's request.

Overall, physician responses for these 19 patients were similar to those of family (P = 0.15 to 0.34) for all concerns except physical suffering. Physicians cited concern about loss of autonomy (83%) and decreasing ability to participate (78%) more often than families (63% and 47%, respectively). Concern about loss of control of bodily functions was mentioned by 61% of physicians. Physicians reported patient concerns about pain (32%) less frequently than families reported the more broad concerns about physical suffering.

During the interviews, families raised additional patient concerns not explicitly addressed in the structured interview. Fourteen of 19 family members volunteered that the patients were determined to control the circumstances of their death. Eleven of these 14 and three other family members mentioned the patient's wish to avoid a prolonged death, with four specifically noting the patient's fear of ending life comatose on a respirator despite having advanced medical directives. Many family members noted improved pain management after patients initiated hospice. In addition, six family members mentioned how difficult it was fulfill the requirements of the Act.

Discussion

In 1999, the second year of legal physician-assisted suicide in Oregon, the number of patients choosing this option increased compared to 1998, but remained small compared to the overall

number of deaths in Oregon. Although concern about possible abuses persists [10-12], information on participating patients indicates that poverty, lack of education or insurance, or poor end-of-life care are not important factors influencing patient decisions to use the Death with Dignity Act. Physician and family interviews suggest that the concerns contributing to patient requests for prescriptions relate to losing autonomy, losing control of bodily functions, decreasing ability to participate in activities that make life enjoyable, physical suffering, and a determination to control the timing and manner of death.

Compared with Oregonians dying from similar diseases, participating patients were better educated but otherwise alike with respect to age, race, and other demographic factors. The relative under-representation of married persons in 1998 [4] was not seen in 1999. Although most patients spent out-of-pocket money on medical expenses (for example, on prescription drugs) all participants were insured for most other major medical expenses, often through a combination of Medicare and private supplemental policies.

The family members we interviewed reported that the majority of participating patients did not have difficulty identifying a physician willing to write the prescription for lethal medication. However, half of these patients asked more than one physician, indicating that not all Oregon physicians are willing to participate in physician-assisted suicide. This finding is consistent with reports on the attitudes of Oregon physicians and medical students toward physician-assisted suicide [13,14]. Some physicians who refused to prescribe lethal medication acted as consulting physicians.

As best we could determine, all participating physicians complied with the provisions of the Act. Although the Health Division is not a regulatory agency for physicians, it does report to Oregon's Board of Medical Examiners any cases of non-compliance. Under reporting and non-compliance is thus difficult to assess because of possible repercussions for noncompliant physicians reporting to the division. In an independent anonymous survey, Oregon physicians reported writing 29 legal prescriptions for lethal doses of medication from December 1997 through August 1999 [15]. All but one physician had reported to the Health Division by the time they completed the survey (the status of one report was undetermined).

Responses from both physician and family interviews indicate that patient's decisions to request PAS were motivated by multiple interrelated concerns. Physical suffering was discussed by several families as a cause of loss of autonomy, inability to participate in activities that made life enjoyable, or a "non-existent" quality of life. For example, "She would have stuck it out through the pain if she thought she'd get better…[but she believed that] when quality of life has no meaning, it's no use hanging around." For another participant, a feeling of being trapped because of ALS contributed to concern about loss of autonomy. Family members frequently commented on loss of control of bodily functions when discussing loss of autonomy. Those reporting patient concern about being a burden on friends and family also reported concern about loss of autonomy and control of bodily functions. Reasons for requesting a prescription were sometimes so interrelated they were difficult to categorize. According to one family member

being asked to distinguish reasons for the patient's decision, "It was everything; it was nothing; [he was suffering terribly]."

Difficulty categorizing and differences in interpreting the nature of the concerns made physician and family member responses hard to compare quantitatively. Nonetheless, family interviews corroborate physician reports from both years [4] that patients are greatly concerned about issues of autonomy and control. In addition, responses of both physicians and family consistently pointed to patient concerns about quality of life and the wish to have a means of controlling the end of life should it become unbearable. As one family member said, "She always thought that if something was terminal, she would [want to] control the end…It was not the dying that she dreaded, it was getting to that death."

Initially, we also wanted to compare responses of family members we interviewed to family members of other Oregonians who died of similar causes but did not use the Death with Dignity Act. We identified patients by randomly selecting death certificates. We then contacted the physicians on the death certificates to see if the patients would have been eligible to use PAS (if they had chosen to) and to identify an appropriate family member to interview. One in four physicians contacted did not identify a family member; one in three patients were not eligible or had no family who knew about their illness and death. Of 12 eligible patients initially identified, three family members were too overwrought to be interviewed, two who had consented to be interviewed stopped the interview because of overwhelming emotion, and four had had limited discussion with patients on the end-of-life issues we raised. We stopped these interviews because of difficulties in identifying patients and family members, and in conducting the interviews.

When family members of the patients who used PAS discussed patient's concerns about physical suffering, they included concerns about difficulty breathing and difficulty swallowing, as well as pain. Some patients were concerned that to adequately control pain, the side effects of the medication would render quality of life meaningless. A previous study found that physical factors, especially difficulty breathing, became important predictors of decreasing will to live as death drew near [16]. However, it is important to note that among patients here, concern about physical suffering was not always equivalent to experiencing it. End-of-life care was available to participating patients, and three quarters of them were in hospice before dying. Family members noted improved pain management for the patients after entering hospice. Physician reports did note a slight increase in the number of patients concerned about pain, but this is consistent with hospital-based reports from Oregon wherein an overall increase in pain has been reported among terminally ill patients [17].

Oregonians choosing physician-assisted suicide appeared to want control over how they died. One woman had purchased poison over a decade before her participation, when her cancer was first diagnosed, so that she would never be without the means of controlling the end of her life should it become unbearable. Like many others who participated, she was described as "determined" to have this control. Another woman was described as a "gutsy woman" who was "…determined in her lifetime, and determined about [physician-assisted suicide]." Family

members expressed profound grief at losing a loved one. However, mixed with this grief was great respect for the patient's determination and choice to use physician-assisted suicide. As one husband said about his wife of almost 50 years, "She was my only girl; I didn't want to lose her…but she wanted to do this."

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Table 1: Characteristics of 43 patients who died after ingesting a lethal dose of medication – Oregon, 1998 and 1999.

Characteristics	1999 (N = 27)		1998 (N = 16) [a]		Total (N = 43)	
Age – Median, years (range)	71	(31-87)	70	(25-94)	70	(25-94)
Race – White (%)	26	(96)	16	(100)	42	(98)
Sex - Male (%)	16	(59)	8	(50)	24	(56)
Marital status						
Married (%) *	12	(44)	2	(13)	14	(33)
Widowed (%)	6	(22)	5	(31)	11	(26)
Divorced (%)	8	(30)	5	(31)	13	(30)
Never married (%)	1	(4)	4	(25)	5	(13)
Education						
Less than high school graduate	2	(7)	3	(19)	5	(12)
High school grad./some college(%)	12	(44)	9	(56)	21	(49)
College graduate (%)	13	(48)	4	(25)	17	(40)
Residence						
Portland metropolitan area (%)	10	(37)	7	(44)	17	(40)
Other Oregon	17	(63)	9	(56)	26	(60)
Underlying Disease						
Cancer (%)	17	(63)	14	(88)	31	(72)
Lung	5	(18)	5	(31)		
Colon	3	(11)	0	-		
Ovarian	0	-	3	(19)		
Other cancer	9	(33)	6	(38)		
Other diseases (%)	10	(37)	2	(12)	12	(28)
Acquired Immune Deficiency Syndrome	1	(4)	0	-		
Amyotrophic Lateral Sclerosis	4	(15)	0	-		
Congestive Heart Failure	0	-	1	(6)		
Chronic Obstructive Pulmonary Disease	4	(15)	1	(6)		
Multi-system organ failure	1	(4)	0	-		
Hospice [b]						
When sought prescription (%)	12	(44)	10	(67)	22	(52)
Immediately prior to death (%)	21	(78)	11	(73)	32	(76)
Advance medical directives [c] (%)	25	(96)	14	(93)	39	(95)
Insurance [d]						
Private (%)	18	(69)	9	(56)	27	(64)
Medicare only (%)	4	(15)	4	(25)	8	(19)
Oregon Medicaid (%)	4	(15)	2	(13)	6	(14)
none (%)	0	-	1	(6)	1	(2)
Mobility before death [b]						
good (%)	7	(26)	4	(27)	11	(26)
poor (%)	10	(37)	7	(47)	17	(40)
none (%)	10	(37)	4	(27)	14	(33)

[a] The sixteenth 1998 patient was not included in 1998 report [4] as the death was not reported until late in 1998.

* Significantly more participants were married than not married (including widowed, divorced and never married) in 1999 compared to 1998, P=0.03

[b] For 1998, n = 15; for total, n = 42 (1 respondent did not know)

[c] For 1999, n = 26; for 1998, n = 15; for total, n = 41 (2 respondents did not know)

[d] Insurance coverage for the patient's terminal illness. For 1999, n = 26, for total, n = 42 (1 respondent did not know)

Table 2: Death with Dignity Act utilization characteristics for 43 patients who died after ingesting a lethal dose of medication – Oregon, 1998 and 1999.

Characteristics	1999 (N = 27)	1998 (N = 16) [a]	Total (N = 43)
First physician approached wrote prescription [b] (%)	8 (31)	8 (53)	16 (39)
Referred for psychiatric evaluation (%)	10 (37)	5 (31)	15 (35)
Prescribed ≥ 9 grams secobarbitol (%)	26 (96)	14 (88)	40 (93)
Died at home (%)	25 (93)	13 (81)	38 (88)
Physician present when patient ingested medication (%)	16 (59)	8 (50)	24 (56)
Physician present when patient died (%)	13 (48)	6 (38)	19 (44)
Vomited or had seizures after ingesting medication [b] (%)	0 -	0 -	0 -
Emergency medical services called after ingestion (%)	0 -	0 -	0 -
End-of-life concerns expressed to physician			
Financial implications of treatment	0 -	0 -	0 -
Burden on friends and family (%)	7 (26)	2 (13)	9 (21)
Losing autonomy [c] (%)	21 (81)	12 (75)	33 (79)
Decreasing ability to participate in activities that make life enjoyable (%)	22 (81)	11 (69)	33 (77)
Losing control of bodily functions (%)	16 (59)	9 (56)	25 (58)
Worsening pain (%)	7 (26)	2 (13)	9 (21)
Timing of events			
Duration (weeks) of patient-physician relationship			
Median	22	11	22
Range	2-817	2-540	2-817
Days between first and second oral requests			
Median	21	19	20
Range	14-96	14-68	14-96
Days between first oral request and death			
Median *	83	22	45
Range	15-289	15-75	15-289
Days between prescription receipt and death			
Median	7	2	3
Range	0-247	0-22	0-247
Minutes between ingestion and unconsciousness [d]			
Median	10	5	5
Range	1-30	3-20	1-30
Minutes between ingestion and death [e]			
Median	30	22	30
Range	4-1560	10-690	4-1560

[a] The sixteenth patient in the first year was not included in the first annual report due to the late date of that death in that year.

[b] For 1999, n = 26; for 1998, n = 15; for total, n = 42 (1 respondent did not know)

[c] For 1999, n = 26; for total, n = 42 (1 respondent did not know)

* Significantly greater in year 2 (1999) than year 1 (1998), P=0.006

[d] For 1999, n = 24; for 1998, n = 12; for total, n = 36 (7 respondents did not know)

[e] For 1999, n = 25; for 1998, n = 15; for total, n = 40 (3 respondents did not know)

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Table 3: Characteristics of patients participating in 1999 and Oregon residents who died from similar disease in 1998.

Demographic Characteristic	Participating 1999 patients (N=27)	Oregon deaths, similar diseases (N=6901)	Estimated proportion of participating 1999 patients (per 10,000)	Estimated Risk Ratio (95% CI [a])
Mean age, years (SD)	68 (14)	73 (14)	–	–
Race				
White	26	6686	39	1.0 [b]
Non-white	1	198	50	0.7 (0.1-5.6)
Sex				
Female	11	3481	32	1.0 [b]
Male	16	3420	47	1.5 (0.7-3.2)
Residence				
Other Oregon	17	4405	38	1.0 [b]
Portland metropolitan	10	2496	40	1.0 (0.4-2.3)
Education [c]				
Did not graduate high school	2	1701	12	1.0 [b]
High school graduate & some college	12	4121	29	2.3 (0.5-9.8)
At least college graduate	13	899	143	12.1 (3.8-38.7)
Marital Status at Death				
Married	12	3386	35	1.0 [b]
Widowed	6	2231	27	0.8 (0.3-2.0)
Divorced	8	976	81	2.3 (1.0-5.5)
Never married	1	290	34	1.0 (0.1-7.5)

[a] CI denotes confidence intervals

[b] Reference category

[c] $P<0.001$ for Chi-square test for trend

Table 4: Patient characteristics and concerns reported by family members of 19 patients who died after ingesting a lethal dose of medication between September 15, 1998 and October 15, 1999.

Characteristics	**Family reporting (N=19)**
Had difficulty identifying a physician to write prescription [a] (%)	4 (24)
Enrolled in hospice (%)	17 (89)
Number of weeks patient was in hospice before death [b]	
Median	7
Range	2-25
Physical suffering present day before death (%)	13 (68)
Medication controlled physical suffering on day before death [c]	
Completely (%)	5 (33)
Somewhat (%)	7 (47)
Not at all (%)	3 (20)
Insurance [d]	
Private (%)	15 (79)
Medicare only (%)	1 (5)
Oregon Medicaid (%)	3 (16)
Spent money on illness-related expenses (%)	16 (84)
End-of-life concerns expressed to family [e]	
Financial implications of treatment (%)	1 (5)
Burden on friends and family [a] (%)	8 (47)
Losing autonomy (%)	12 (63)
Decreasing ability to participate in activities that make life enjoyable (%)	9 (47)
Losing control of bodily functions (%)	13 (68)
Physical suffering [f] (%)	10 (53)

[a] n = 17 (Two family members did not know)
[b] n = 16 (Three family members did not know)
[c] Includes two patients with surgical intervention for pain; n=15 (Four family members could not evaluate the level of pain control).
[d] Insurance coverage for the patient's terminal illness.
[e] Includes responses coded as, "Yes, likely" and "Yes, definitely"
[f] Includes pain, difficulty breathing, difficulty swallowing, side-effects of pain medication. Not comparable to the more narrowly defined concern about pain cited by physicians.