Sixth Annual Report on Oregon's Death with Dignity Act

1547



Department of Human Services

Office of Disease Prevention and Epidemiology March 10, 2004



Sixth Annual Report on Oregon's Death with Dignity Act

6

For more information contact:

Darcy Niemeyer Department of Human Services, Health Services Office of Disease Prevention and Epidemiology 800 N.E. Oregon Street, Suite 730 Portland, OR 97232 E-mail: darcy.niemeyer@state.or.us Phone: 503-731-4023 Fax: 503-731-4082 <u>http://www.dhs.state.or.us/publichealth/chs/pas/pas.cfm</u>

> Contributing Editor: Richard Leman, MD Data Analysis: David Hopkins, MS

Acknowledgements

This assessment was conducted as part of the required surveillance and public health practice activities of the Department of Human Services and was supported by Department funds.

Table of Contents

Summary	4
Introduction	6
History	6
Requirements	7
Methods	
The Reporting System	9
Data Analyses	10
Results	11
Patient Characteristics	12
Physician Characteristics	13
Lethal Medication	13
Complications	14
End of Life Concerns	14
Comments	15
References	17
Tables	
Table 1	19
Table 2	21
Table 3	22
Table 4	23

Summary

Physician-assisted suicide (PAS) has been legal in Oregon since November 1997, when Oregon voters approved the Death with Dignity Act (DWDA) for the second time (see <u>History</u>, page 6). The Department of Human Services (DHS) is legally required to collect information regarding compliance with the Act and make the information available on a yearly basis. In this sixth annual report, we characterize the 42 Oregonians who, in 2003, ingested medications prescribed under provisions of the Act, and look at whether the numbers and characteristics of these patients differ from those who used PAS in prior years. Patients choosing PAS were identified through mandated physician and pharmacy reporting. Our information comes from these reports, physician interviews and death certificates. We also compare the demographic characteristics of patients participating during 1998-2003 with other Oregonians who died of the same underlying causes.

In 2003, 42 physicians wrote a total of 67 prescriptions for lethal doses of medication. The number of prescriptions written increased in each of the previous years: 58 prescriptions were written in 2002, 44 in 2001, 39 in 2000, 33 in 1999, and 24 in 1998. Thirty-nine of the 2003 prescription recipients died after ingesting the medication. Of the 28 persons who did not ingest the prescribed medication, 18 died from their illnesses, and 10 were alive on December 31, 2003. In addition, two patients who received prescriptions during 2002 and another who received a prescription in 2001 died in 2003 after ingesting their medication for a total of 42 PAS deaths during 2003.

There were four more patients who used PAS in 2003 than in 2002, and the number of patients ingesting lethal medication has increased over the six years since legalization. In 2003, 42 patients died from PAS, compared to 38 in 2002, 21 in 2001, 27 in 2000, 27 in 1999, and 16 in 1998 [1-5]. The 42 patients who ingested lethal medications in 2003 represent an estimated 14/10,000 total deaths, compared with 12.2 in 2002, 7.0 in 2001, 9.1 in 2000, 9.2 in 1999, and 5.5 in 1998. Compared to all Oregon decedents in 2003, PAS participants were more likely to have malignant neoplasms

(83%), to be younger (median age 73 years), and to have more formal education (48% had at least a baccalaureate degree).

During the past six years, the 171 patients who took lethal medications differed in several ways from the 53,544 Oregonians dying from the same underlying diseases. Rates of participation in PAS decreased with age, but were higher among those who were divorced or never married, those with more years of education, and those with amyotrophic lateral sclerosis, HIV/AIDS, or malignant neoplasms (see <u>Patient</u> <u>Characteristics</u>, page 12).

Physicians indicated that patient requests for lethal medications stemmed from multiple concerns related to autonomy and control at the end of life. The three most commonly mentioned end-of-life concerns during 2003 were: loss of autonomy, a decreasing ability to participate in activities that made life enjoyable, and a loss of dignity (see End of Life Concerns, page 15).

During 2003, 37 patients (88%) used pentobarbital as their lethal medication, four patients (10%) used secobarbital, and one (2%) used secobarbital/amobarbital (Tuinal). (see <u>Lethal Medication</u>, page 14).

During 2003, complications were reported for three patients. All involved regurgitation and none involved seizures (see <u>Complications</u>, page 14). One-half of patients became unconscious within four minutes of ingestion of the lethal medication and died within 20 minutes. The range of time from ingestion to death was five minutes to 48 hours. Emergency medical services were called by one patient's family to pronounce death; neither resuscitation nor transport was requested.

Although the number of Oregonians ingesting legally prescribed lethal medications has increased, the overall number of terminally ill patients ingesting lethal medication has remained small, with about 1/7 of one percent of Oregonians dying by physician-assisted suicide.

Introduction

This sixth annual report reviews the monitoring and data collection system that was implemented under Oregon's Death with Dignity Act (DWDA), which legalizes physician-assisted suicide (PAS) for terminally ill Oregon residents. This report summarizes the information collected on patients and physicians who participated in the Act in its sixth year of implementation (January 1, 2003 to December 31, 2003) and examines trends over the six years since legalization. Using physician reports, interviews, and death certificates, we address the following questions: Is the number of residents using legal PAS in Oregon increasing? Do patients who participated in 2003 resemble patients using PAS in previous years and other Oregonians dying from similar diseases? Have any changes occurred in the PAS process during the past six years?

<u>History</u>

The Oregon Death with Dignity Act was a citizen's initiative first passed by Oregon voters in November 1994 with 51% in favor. Implementation was delayed by a legal injunction, but after proceedings that included a petition denied by the United States Supreme Court, the Ninth Circuit Court of Appeals lifted the injunction on October 27, 1997. 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%, retaining the Death with Dignity Act. After voters reaffirmed the DWDA in 1997, Oregon became the only state allowing legal physician-assisted suicide [6].

Although physician-assisted suicide has been legal in Oregon for six years, it remains highly controversial. On November 6, 2001, US Attorney General John Ashcroft issued a new interpretation of the Controlled Substances Act, which would prohibit doctors from prescribing controlled substances for use in physician-assisted suicide. To date, all the medications prescribed under the Act have been barbiturates, which are controlled substances and therefore, would be prohibited by this ruling for use in PAS. In response to a lawsuit filed by the State of Oregon, on November 20, 2001, a US district court issued a temporary restraining order against Ashcroft's ruling pending a new hearing within 5 months. On April 17, 2002, U.S. District Court Judge Robert Jones upheld the Death with Dignity Act. In September 2002, Attorney General Ashcroft filed an appeal, asking the Ninth U.S. Circuit Court of Appeals to overturn the District Court's ruling. At this time, Oregon's law remains in effect.

Requirements

The Death with Dignity Act allows terminally ill Oregon residents to obtain 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" because it is used in 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 PAS, but specifically prohibits euthanasia, where a physician or other person directly administers a medication to end another's life. [6]

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 six 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 oral requests to his or her physician, separated by at least 15 days.
- ☐ The patient must provide a written request to his or her physician, signed in the presence of two witnesses.

- 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, 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 his or her next-of-kin of the prescription request.

To comply with the law, physicians must report to the Department of Human Services (DHS) all prescriptions for lethal medications [7]. 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 cannot 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 [6].

Methods

The Reporting System

DHS is required by the Act to develop and maintain a reporting system for monitoring and collecting information on PAS [6]. To fulfill this mandate, DHS uses a system involving physician and pharmacist compliance reports, death certificate reviews, and follow-up interviews [7].

When a prescription for lethal medication is written, the physician must submit to DHS information that documents compliance with the law. We review all physician reports and contact physicians regarding missing or discrepant data. DHS 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 (e.g., age, place of residence, level of education).

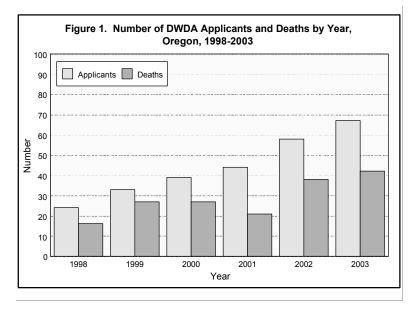
In addition, using our authority to conduct special studies of morbidity and mortality [8], DHS has conducted telephone interviews with prescribing physicians after receipt of the patients' death certificates. Each physician was asked to confirm whether the patient took the lethal medications. If the patient had taken the medications, we asked physicians for information that was not available from physician reports or death certificates--including insurance status and enrollment in hospice. 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, being a burden, loss of control of bodily functions, uncontrollable pain, and loss of dignity. We collected information on the time to unconsciousness and death, and asked about any adverse reactions. Because physicians are not legally required to be present when a patient ingests the medication, not all have information about what happened when the patient ingested the medication. If the prescribing physician was not present, we accepted information they had based on discussions with family members, friends or other health professionals who attended the patients' deaths. We do not interview or collect any information from patients prior to their death. Reporting forms and the physician guestionnaire are available at http://www.dhs.state.or.us/publichealth/chs/pas/pasforms.cfm

Data Analyses

We classified patients by year of participation based on when they ingested the legally-prescribed lethal medication. Using demographic information from 1997-2002 Oregon death certificates (the most recent years for which complete data are available), we compared patients who used legal PAS with other Oregonians who died from the same diseases. Demographic- and disease-specific PAS rates were computed using the number of deaths from the same causes as the denominator. The overall PAS rates by year were computed using the total number of resident deaths. Annual rates were calculated using numerator and denominator data from the same year, except for 2003 where the number of resident deaths from 2002 was used as the denominator.

Results

Both the number of prescriptions written and the number of Oregonians using PAS have increased over the six years that PAS has been legal in Oregon. In 2003, 42 physicians wrote 67 prescriptions for lethal doses of medication. The number of prescriptions written has increased over the six years since legalization: 58 prescriptions were written in 2002, 44 in 2001, 39 in 2000, 33 in 1999 and 24 in 1998. Thirty-nine of the 2003 prescription recipients died after ingesting the medication. Of the 28 recipients who did not ingest the prescribed medication in 2003, 18 died from their illnesses, and 10 were alive on December 31, 2003. In addition, two patients who received prescriptions during 2002 and another who received a prescription in 2001 died in 2003, after ingesting their medication, giving a total of 42 PAS deaths during 2003 (*Figure 1*). Thirty different physicians wrote the 42 prescriptions for lethal medication.



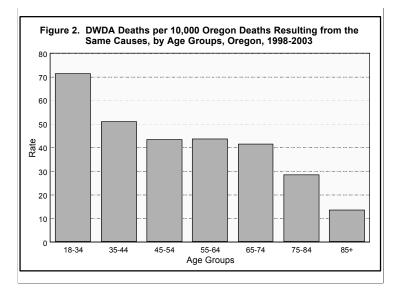
The number of patients ingesting lethal medication has increased over the six years since legalization. The 42 PAS deaths in 2003 compare to 38 in 2002, 21 in 2001, 27 in 2000, 27 in 1999, and 16 in 1998. The 42 patients who ingested lethal medications in 2003 represent an estimated 14/10,000 total deaths compared with 12.2 in 2002, 7.0 in 2001, 9.1 in 2000, 9.2 in 1999, and 5.5 in 1998.

The percentage of patients referred to a specialist for psychological evaluation has declined, falling from 31 percent in 1998 to five percent in 2003.

Patient Characteristics

Oregonians using PAS during 2003 differed from those of previous years in several ways. They were more apt to be older (their median age was 73 compared to 69 for those using PAS in preceding years); they were more apt to have at least a baccalaureate degree (48% did so compared to 38% of their predecessors); and a greater proportion of patients resided in Multnomah, Clackamas, and Washington counties (45% vs. 37%). However, these figures are based on relatively few events and do not represent statistically significant differences (Table 1).

Although year-to-year variations occur, certain demographic patterns have become evident over the past six years. Males and females were equally likely to take advantage of the DWDA, but terminally ill younger persons were significantly more likely to turn to PAS than their older counterparts; 18- to 34-year-olds were 5.3 times more likely to use PAS than were those 85 or older (Table 2 and *Figure 2*). Asian Oregonians were about three times as likely to use PAS as were white Oregonians. Divorced and never-married persons were about two times more likely to use PAS than married and widowed residents. A higher level of education was strongly associated with the use of PAS; Oregonians with a baccalaureate degree or higher were 7.6 times more likely to use PAS than those without a high school diploma. By region, residents living east of the Cascade Range were less than half as likely to use PAS as those living in western Oregon.



The type of terminal illness is a strong predictor of the likelihood of a patient using PAS (Table 3). The rates of DWDA deaths to non-PAS deaths resulting from the same causes were high for three conditions: amyotrophic lateral sclerosis (ALS) (249.0 per 10,000), HIV/AIDS (171.4), and malignant neoplasms (37.6). Among the causes associated with at least three deaths, the lowest rate (9.7) was for patients with chronic lower respiratory diseases (CLRD), such as emphysema. Persons with ALS (Lou Gehrig's disease) were more than 25 times as likely to use PAS as were those with CLRD.

During 2003, most patients died at home, but two died at assisted living residences while another died in a physician's office. All individuals had some form of health insurance (Table 4). As in previous years, most (93%) of the patients who used PAS in 2003 were enrolled in hospice care. The median length of the patient-physician relationship was ten weeks.

Physician Characteristics

The prescribing physicians of patients who used PAS during 2003 had been in practice a median of 21.5 years (range 3-35). Their medical specialties included: internal medicine (12%), oncology (38%), family medicine (45%), and other (5%).

Prescribing physicians were present while 12 (29%) of the 42 patients ingested the lethal medications. Among the remaining 30 patients, 67% ingested the medication in the presence of another health-care provider/volunteer.

During 2003, one case involving possible non-compliance with DWDA provisions regarding witnessing of signatures was reported to the Oregon Board of Medical Examiners.

Lethal Medication

During 1998-2002, secobarbital was the lethal medication prescribed for 85 of the 129 patients (66%). During 2003, 37 patients (88%) used pentobarbital, four patients used secobarbital, and one used secobarbital/amobarbital. Since the DWDA was implemented, 52% of the PAS patients used secobarbital, 46% used pentobarbital, and 2% used other medications (mostly secobarbital/amobarbital).

<u>Complications</u>

During 2003, physicians reported that three patients experienced complications: a small emesis was reported for one patient who died 20 minutes after ingestion of the lethal medication. Another patient consumed about 60% of the prescribed pentobarbital, regurgitated about one-third of the medication consumed to that point, and then drank one-half of the remaining medication, dying 20 minutes later. A third patient drank one-half of the prescribed medication and about 30 seconds later regurgitated one-third of what had been consumed, retaining only about 3 grams of the barbiturate. This patient lived for 48 hours after having ingested only about one-third of the intended dose.

One physician reported that a patient fell asleep before ingesting the entire dose of medication. The patient died 40 minutes after ingestion.

None of the patients regained consciousness after ingesting the lethal medication.

Emergency medical services were contacted by a family in one case to pronounce death but not to intervene or transport the patient.

End of Life Concerns

Physicians were asked if, based on discussions with patients, any of seven endof-life concerns might have contributed to the patients' requests for lethal medication (Table 4). In nearly all cases, physicians reported multiple concerns contributing to the request. During 2003, one patient (2%) was reported to have one end-of-life concern, 13 (31%) had two concerns, 15 (36%) had three concerns, nine (21%) had four concerns, and four (10%) had five concerns. The most frequently reported concerns included losing autonomy (93%), a decreasing ability to participate in activities that make life enjoyable (93%), and loss of dignity (82%). (The frequency of the latter concern was assessed for the first time in 2003.)

Comments

During the six years since legalization, the number of prescriptions written for physician-assisted suicide and the number of terminally ill patients taking lethal medication has increased. However, the number has remained small compared to the total number of deaths in Oregon, with about 1/7 of one percent of Oregonians dying by PAS. This proportion is consistent with numbers from a survey of Oregon physicians [9]. Overall, smaller numbers of patients appear to use PAS in Oregon compared to the Netherlands [10]. However, as detailed in previous reports [1-5], our numbers are based on a reporting system for terminally ill patients who legally receive prescriptions for lethal medications, and do not include patients and physicians who may act outside the provisions of the DWDA.

Over the last six years the rate of PAS among patients with ALS in Oregon has been substantially higher than among patients with other illnesses. This finding is consistent with other studies. In the Netherlands, where both PAS and euthanasia are openly practiced, one in five ALS patients died as a result of PAS or euthanasia [11]. A study of Oregon and Washington ALS patients found that one-third of these patients discussed wanting PAS in the last month of life [12]. It is not known with certainty why ALS patients would be more likely to choose PAS than would other terminally ill patients. Oregon HIV/AIDS patients are also disproportionately likely to use PAS, a finding consistent with studies elsewhere [13].

Physicians have consistently reported that concerns about loss of autonomy and decreased ability to participate in activities that make life enjoyable are important motivating factors in patient requests for lethal medication across all six years. Interviews with family members during 1999 corroborated physician reports [2]. These findings were supported by a recent study of hospice nurses and social workers caring for PAS patients in Oregon [14].

The availability of PAS may have led to efforts to improve end-of-life care through other modalities. While it may be common for patients with a terminal illness to consider PAS, a request for PAS can be an opportunity for a medical provider to explore with patients their fears and wishes around end-of-life care, and to make patients aware

of other options. Often once the provider has addressed a patient's concerns, he or she may choose not to pursue PAS [15]. The availability of PAS as an option in Oregon also may have spurred Oregon doctors to address other end-of life care options more effectively. In one study, Oregon physicians reported that, since the passage of the Death with Dignity Act in 1994, they had made efforts to improve their knowledge of the use of pain medications in the terminally ill, to improve their recognition of psychiatric disorders such as depression, and to refer patients more frequently to hospice [16].

References

1. Chin G, Hedberg K, Higginson G, Fleming D. Legalized physician-assisted suicide in Oregon—The first year's experience. N Engl J Med, 1999;340:577-83.

2. Sullivan AD, Hedberg K, Fleming D. Legalized physician-assisted suicide in Oregon—The second year. N Engl J Med, 2000;342:598-604.

3. Sullivan AD, Hedberg K, Hopkins D. Legalized physician-assisted suicide in Oregon, 1998-2000. N Engl J Med, 2001;344:605-7.

4. Hedberg K, Hopkins D, Southwick K. Legalized physician-assisted suicide in Oregon, 2001. N Engl J Med, 2002;346:450-2.

5. Hedberg K, Hopkins D, Kohn M. Five years of legal physician-assisted suicide in Oregon. N Engl J Med, 2003;348:961-4.

6. Oregon Revised Statute 127.800-127.995. Available at http://www.dhs.state.or.us/publichealth/chs/pas/ors.cfm

7. Oregon Administrative Rules 333-009-000 to 333-009-0030. Available at http://www.dhs.state.or.us/publichealth/chs/pas/oars.cfm

8. Oregon Revised Statute 432.060. http://www.leg.state.or.us/ors/432.html

9. Ganzini L, Nelson HD, Schmidt TA, et al. Physicians' experiences with the Oregon Death with Dignity Act. N Engl J Med, 2000;342:557-63.

10. Willems DL, Daniels ER, van der Wal G, et al. Attitudes and practices concerning the end of life: A comparison between physicians from the United States and from The Netherlands. Arch Intern Med, 2000;160:63-8.

11. Vledink JH, Wokke JHJ, Van Der Wal G, et al. Euthanasia and physician-assisted suicide among patients with amyotrophic lateral sclerosis in the Netherlands. N Engl J Med, 2002;346:1638-44.

12. Ganzini L, Silveira MJ, Johnston WS. Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington. J Pain Symptom Manage, 2002;3:312-7.

13. Bosshard G, Ulrich E, Bar W. 748 Cases of suicide assisted by a Swiss right-to-die organization. Swiss Med Wkly, 2003;133:310-317.

14. Ganzini L, Harvath TA, Jackson A, et al. Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. N Engl J Med, 2002;347:582-8.

15. Bascom PB, Tolle SW. Responding to requests for physician-assisted suicide: "these are uncharted waters for both of us…". JAMA, 2002;288:91-8.

16. Ganzini L, Nelson HD, Lee MA, et al. Oregon physicians' attitudes about and experiences with end-of-life care since the passage of the Oregon Death with Dignity Act. JAMA 2001;285:2363-9.

Characteristics	2003 (N = 42)*	1998-2002 (N= 129)*	Total (N = 171)*
	((
Sex			
Male (%)	19 (45)	71 (55)	90 (53)
Female (%)	23 (55)	58 (45)	81 (47)
Age			
18-34 (%)	0 (0)	2 (2)	2 (1)
35-44 (%)	2 (5)	3 (2)	5 (3)
45-54 (%)	4 (10)	10 (8)	14 (8)
55-64 (%)	8 (19)	21 (16)	29 (17)
65-74 (%)	9 (21)	46 (36)	55 (32)
75-84 (%)	14 (33)	37 (29)	51 (30)
85+ (%)	5 (12)	10 (8)	15 (9)
Median years (Range)	73 (40-93)	69 (25-94)	70 (25-94)
Race			
White (%)	41 (98)	125 (97)	166 (97)
Asian (%)	1 (2)	4 (3)	5 (3)
Other (%)	0	0	0
Marital status			
Married (%)	15 (36)	60 (47)	75 (44)
Widowed (%)	12 (29)	29 (23)	41 (24)
Divorced (%)	10 (24)	32 (25)	42 (25)
Never married (%)	5 (12)	8 (6)	13 (8)
Education			
Less than high school (%)	2 (5)	14 (11)	16 (9)
HS graduate (%)	8 (19)	43 (33)	51 (30)
Some college (%)	12 (29)	23 (18)	35 (21)
Baccalaureate or higher (%)	20 (48)	49 (38)	69 (40)
Residence			
Metro counties (%)**	19 (45)	48 (37)	67 (39)
Coastal counties (%)***	3 (7)	11 (9)	14 (8)
Other W. counties (%)	19 (45)	60 (47)	79 (46)
E. of the Cascades (%)	1 (2)	10 (8)	11 (6)
Underlying illness			
Malignant neoplasms (%)	35 (83)	100 (78)	135 (79)
Lung and bronchus (%)	9 (21)	24 (19)	33 (19)
Breast (%)	6 (14)	10 (8)	16 (9)
Pancreas (%)	4 (10)	12 (9)	16 (9)
Colon (%)	3 (7)	7 (5)	10 (6)
Other (%)	13 (31)	47 (36)	60 (35)

Table 1. Demographic characteristics of 171 DWDA patients who died after ingesting a lethal dose of medication, by year, Oregon, 1998-2003.

Oregon's Death with Dignity Act

Characteristics (Cont'd)	2003 (N=42)*	1998-2002 (N=129)*	Total (N=171)*
Underlying Illness (Cont'd)			
Amyotrophic lateral sclerosis (%)	3 (7)	10 (8)	13 (8)
Chronic lower respiratory dis. (%)	1 (2)	8 (6)	9 (5)
HIV/AIDS (%)	2 (5)	1 (1)	3 (2)
Illnesses listed below (%) [#]	1 (1)	10 (8)	11 (6)

* Unknowns are excluded when calculating percentages.

** Clackamas, Multnomah, and Washington counties.

*** Excluding Douglas and Lane counties.

Includes aortic stenosis, congestive heart failure, diabetes mellitus with renal complications, gastrointestinal stromal tumor, myelodysplastic syndrome, pulmonary disease with fibrosis, scleroderma, and Shy-Drager syndrome.

Table 2. Demographic characteristics of 171 patients who died during 1998-2003 after ingesting alethal dose of medication compared with 53,544 Oregonians dying from the same underlying diseases.

Characteristics	PAS patients 1998-2003 (N = 171)*	Oregon deaths, same diseases (N =53,544)*	DWDA deaths per 10,000 Oregon deaths	Rate ratio (95% CI**)
Sex				
Male (%)	90 (53)	26,972 (50)	33.4	1.1 (0.8-1.5)
Female (%)	81 (47)	26,572 (50)	30.5	1.0
Age				
18-34 (%)	2 (1)	281 (1)	71.2	5.3 (1.2-22.9)#
35-44 (%)	5 (3)	985 (2)	50.8	3.8 (1.4-10.3)
45-54 (%)	14 (8)	3,235 (6)	43.3	3.2 (1.6-6.6)
55-64 (%)	29 (17)	6,674 (13)	43.5	3.2 (1.7-6.0)
65-74 (%)	55 (32)	13,309 (25)	41.3	3.1 (1.7-5.4)
75-84 (%)	51 (30)	17,969 (34)	28.4	2.1 (1.2-3.7)
85+ (%)	15 (9)	11,091 (21)	13.5	1.0
Median years	70	76		
Race				
White (%)	166 (97)	52,100 (97)	31.9	1.0
Asian (%)	5 (3)	535 (1)	93.5	2.9 (1.2-7.1)+
Other (%)	0	898 (2)	0	0
Unknown	0	11		
Marital status				
Married (%)	75 (44)	26,003 (49)	28.8	1.0
Widowed (%)	41 (24)	17,742 (33)	23.1	0.8 (0.6-1.2)
Divorced (%)	42 (25)	7,530 (14)	55.8	1.9 (1.3-2.8)+
Never married (%)	13 (8)	2,168 (4)	60.0	2.1 (1.2-3.7)+
Unknown	0	101		
Education				
Less than high school (%)	16 (9)	12,954 (25)	12.4	1.0
HS graduate (%)	51 (30)	22,855 (43)	22.3	1.8 (1.0-3.2)
Some college (%)	35 (21)	9,598 (18)	36.5	3.0 (1.6-5.3)
Baccalaureate or higher (%)	69 (40)	7,392 (14)	93.3	7.6 (4.4-13.0)#
Unknown	0	745		
Residence				
Metro counties (%)	67 (39)	19,333 (36)	34.7	1.0
Coastal counties (%)	14 (8)	4,374 (8)	32.0	0.9 (0.5-1.6)
Other W. counties (%)	79 (46)	22,259 (42)	35.5	1.0 (0.7-1.4)
E. of the Cascades (%)	11 (6)	7,578 (14)	14.5	0.4 (0.2-0.8)+

* Unknowns are excluded when calculating percentages.

** Confidence interval.

The ratio is statistically significant according to the chi-square test for trend.

+ The ratio is statistically significant according to the chi-square test.

Underlying illnesses	PAS patients 1998-2003 (N = 171)	Oregon deaths, same diseases (N =53,544)	DWDA deaths per 10,000 Oregon deaths	Rate ratio (95% CI*)
Malignant neoplasms (%)	135 (79)	35,906 (67)	37.6	3.9 (2.0-7.6)+
Lung and bronchus (%)	33 (19)	12,037 (23)	27.4	2.8 (1.4-5.9)+
Breast (%)	16 (9)	3,037 (6)	52.7	5.4 (2.4-12.3)+
Pancreas (%)	16 (9)	2,190 (4)	73.1	7.5 (3.3-17.1)+
Colon (%)	10 (6)	3,171 (6)	31.5	3.3 (1.3-8.0)+
Prostate (%)	9 (5)	2,670 (5)	33.7	3.5 (1.4-8.8)+
Ovary (%)	9 (5)	1,178 (2)	76.4	7.9 (3.1-19.9)+
Skin (%)	6 (4)	522 (1)	114.9	11.9 (4.2-33.2)+
Other (%)	36 (21)	11,101 (21)	32.4	3.4 (1.6-7.0)+
Amyotrophic lateral sclerosis (%)	13 (8)	522 (1)	249.0	25.7 (11.1-59.9)+
Chronic lower respiratory dis. (%)	9 (5)	9,300 (17)	9.7	1.0
HIV/AIDS (%)	3 (2)	175 (<1)	171.4	17.7 (4.8-64.9)+
Illnesses listed below (%)**	11 (6)	7,641 (14)	14.4	1.5 (0.6-3.6)

Table 3. Underlying illnesses of 171 patients who died during 1998-2003 after ingesting a lethal dose of medication compared with 53,544 Oregonians dying from the same underlying diseases.

* Confidence interval.

** Includes aortic stenosis, congestive heart failure, diabetes mellitus with renal complications,

gastrointestinal stromal tumor, myelodysplastic syndrome, pulmonary disease with fibrosis, scleroderma, and Shy-Drager syndrome.

+ The ratio is statistically significant according to the chi-square test.

Table 4. Death with Dignity Act participant end of life care and DWDA utilization. Based on physician interviews for 171 patients who died after ingesting a lethal dose of medication - Oregon, 1998-2003.

Characteristics	2003 (N=42)*	1998-2002 (N=129)*	Total (N=171)*
End of Life Care			
Hospice			
Enrolled (%)	39 (93)	106 (83)	145 (86)
Declined by patient (%)	3 (7)	21 (17)	24 (14)
Unknown	-	2	2
Insurance			
Private (%)	22 (52)	80 (63)	102 (61)
Medicare or Medicaid (%)	20 (48)	44 (35)	64 (38)
None (%)	_	2(2)	2(1)
Unknown	-	3	3
End of Life Concerns [⁺]			
Losing autonomy (%)	39 (93)	106 (85)	145 (87)
Less able to engage in activities making life enjoyable (%)	39 (93)	99 (79)	138 (83)
Loss of dignity (%) ⁺⁺	31 (82)	_	31 (82)
Losing control of bodily functions (%)	24 (57)	73 (58)	97 (58)
Burden on family, friends/caregivers (%)	16 (38)	44 (35)	60 (36)
Inadequate pain control (%)**	9 (21)	28 (22)	37 (22)
Financial implications of treatment (%)	1 (2)	3 (2)	4 (2)
PAS Process			
Referred for psychiatric evaluation (%)	2 (5)	28 (23)	30 (18)
Patient died at			
Home (patient, family or friend) (%)	39 (93)	121 (94)	160 (94)
Long term care, assisted living or foster care facility (%)	2 (5)	6 (5)	8 (5)
Hospital (%)	0	1 (1)	1 (1)
Other (%)	1 (2)	1 (1)	2 (1)
Lethal Medication			
Secobarbital (%)	4 (10)	85 (66)	89 (52)
Pentobarbital (%)	37 (88)	41 (32)	78 (46)
Secobarbital/amobarbital (%)	1 (2)	2 (2)	3 (2)
Other (%)	0	1 (1)	1 (1)
Health-care provider present when medication ingested [#]			
Prescribing physician (%)	12 (29)	22 (39)	34 (34)
Other provider, prescribing physician not present (%)	20 (48)	29 (51)	49 (49)
No provider (%)	10 (24)	6 (11)	16 (16)
Unknown	0	2	2
Regurgitation/seizures after medication ingested	- /-·		_ /
Regurgitated (%)	3 (7)	4 (3)	7 (4)
Seizures (%)	0	0	0
Neither (%)	39 (93)	121 (97)	160 (96)
Unknown	0	4	4

	2003	1998-2002	Total
Characteristics (cont'd)	(N=42)*	(N=129)*	(N=171)*
Emergency Medical Services			
Called for intervention after lethal medication ingested (%)***	0	0	0
Not called after lethal medication ingested (%)	42 (100)	126 (100)	168 (100)
Unknown	0	3	3
Timing of PAS Event			
Duration (weeks) of patient-physician relationship			
Median	10	13	13
Range	0-405	0-851	0-851
Duration (days) between 1 st request and death			
Median	36	43	39
Range	16-737	15-466	15-737
Minutes between ingestion and unconsciousness			
Median	4	5	5
Range	1-20	1-38	1-38
Unknown	2	18	20
Minutes between ingestion and death			
Median	20	30	25
Range (minutes - hours)	5m-48h	4m-37h	4m-48h
Unknown	1	12	13

* Unknowns are excluded when calculating percentages unless otherwise noted.

** Patients discussing concern about inadequate pain control with their physicians were not necessarily experiencing pain.

*** Excludes calls to pronounce death.

The data shown are for 2001-2003. Information about the presence of a health care provider/volunteer, in absence of the prescribing physician, was first collected in 2001. Attendance by the prescribing physician has been recorded since 1998. During 1998-2002 the prescribing physician was present when 47% of the patients ingested the lethal medication.

+ Affirmative answers only ("Don't know" included in negative answers). Available for 17patients in 2001.

++ First asked in 2003.