

The 10-Year Experience of Oregon's Death with Dignity Act: 1998–2007

Background

On 27 October 1997, Oregon's Death with Dignity Act (DWDA) took effect, allowing physicians to prescribe a lethal dose of medication to be self-administered by terminally ill patients.¹ The law specifically prohibits euthanasia, in which a physician administers a lethal dose of medication to a patient (for example, through an injection). During the first 10 years the law was in effect, it was unique in the United States.

Whether jurisdictions should allow terminally ill patients to ingest lethal doses of medication as an option at the end of life continues to be heatedly debated. In the decade since implementation, the DWDA has been amended by the Oregon legislature, and its legality has been argued before the U.S. Supreme Court,² but the law remains in effect. Similar initiatives have been on the ballots in several states, and in November 2008, Washington State passed similar legislation, which took effect in the spring of 2009. A few countries (for example, the Netherlands, Belgium) have laws allowing physician-assisted suicide (similar to Oregon's law) as well as euthanasia (prohibited in Oregon); others have considered similar legislation (for example, Great Britain, Australia).

As the state agency responsible for monitoring participation in the act, the Oregon Department of Human Services believes that accurate data are important to parties on both sides of the policy debate, while we remain neutral about the law itself. During the past decade, annual reports and published articles have documented the number of participants, their demographic characteristics, and underlying medical conditions.³ While trends in the Dutch experience with physician-assisted suicide and euthanasia have recently been published,⁴ no studies have examined trends in DWDA participation in Oregon, which does not allow euthanasia, and has different cultural norms and medical care system than Europe. Trends in practice since implementation are important for other jurisdictions to take into account when considering legislation similar to Oregon's DWDA.

Methods

Data Collection

To receive a DWDA prescription, a patient must be a terminally ill, adult Oregon resident expected to die within six months, capable of making and communicating healthcare decisions, and able to ingest oral medications. DWDA requires the prescribing and consulting physicians, psychiatrist or psychologist (when applicable), and dispensing pharmacist to report their compliance with the DWDA to the Oregon Department of Human Services once a prescription is written. Data collected from the documents include dates of request, type and dose of medication prescribed, and mental health evaluation referrals (when applicable) (find rules and forms at www.oregon.gov/DHS/ph/pas/index.shtml).

After the patient's death certificate is received through standard procedures, we abstract demographic characteristics and underlying illness. The prescribing physician submits additional information about the deceased patient and the process on a standardized questionnaire. If the prescribing physician was not present during ingestion, we accept information from others who attended the patient's death. Data include end-of-life concerns, the process, and complications.

Analysis

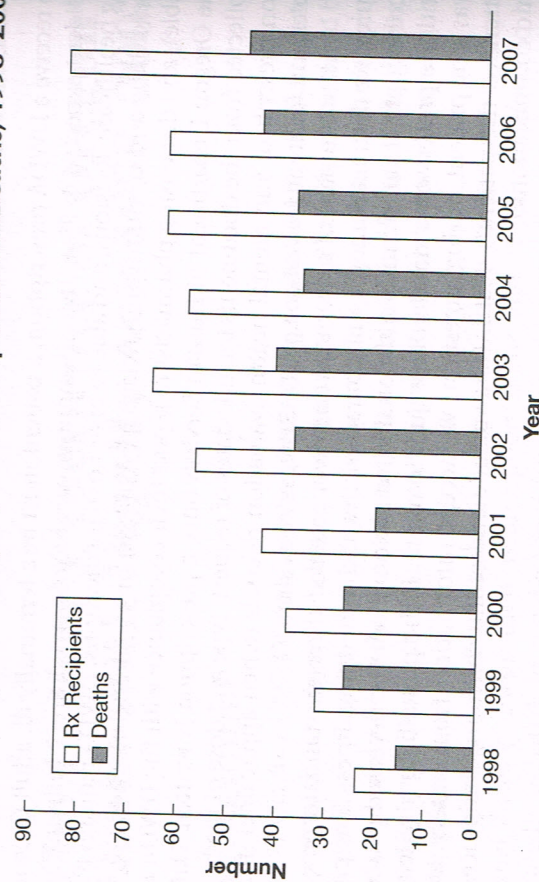
For the purpose of this study, we included all deaths that occurred during the 10 years from 1 January 1998 to 31 December 2007 and resulted from ingesting a legally prescribed lethal dose of medication. Death rates were calculated using as the denominator all Oregon deaths during 1997 through 2006 (the most recent 10 years for which final mortality data were available). Using rate ratios, we compared the characteristics of participating patients to those of other Oregonians who died of the same underlying diseases, based on specific ICD-9 codes listed on death certificates. Although the data are population-based and not a sample, we performed statistical analyses using Mantel-Haenszel *chi*-square test and test for linear trend, and Fisher's exact test, on the assumption that the data are a sample in time.⁵

Results

During the years 1998 through 2007, physicians wrote 546 prescriptions, and 341 Oregonians died from ingesting a legally prescribed lethal dose of medication under the Death with Dignity Act. During this same time period, a total of 296,558 residents died of all causes (the total includes DWDA deaths), corresponding to an overall rate of 11.3 DWDA deaths per 10,000 total deaths. The numbers of DWDA patients and rates of participation increased from 16 patients (corresponding to 5.3 per 10,000 deaths) in 1998 to 49 patients (corresponding to 15.6 per 10,000 deaths) in 2007 (see figure 1).

Figure 1

Numbers of Death with Dignity Act Prescriptions and Deaths, 1998–2007



Patient Characteristics

The characteristics of participating patients are summarized in table 1. While most deaths (77 percent) occurred in those 55 to 84 years of age, rates (comparing DWDA patients to those who died of the same underlying diseases) were highest among those 18 to 34 years of age (65.0 per 10,000 deaths) and lowest in those ≥ 85 years (15.2). Most patients (97.4 percent) were White. Education level was associated with participation: those with post-baccalaureate education were 9.5 times more likely to use the DWDA than those lacking a high school education. Rates of participation for people living in rural Oregon east of the Cascade Mountains were lower than for those living in the Portland metropolitan area (rate ratio, or RR = 0.4; 95 percent confidence interval, or CI = 0.3, 0.6).

Patients with cancer accounted for 82.1 percent of the cases (see table 1). Rate ratios were elevated for all types of cancer (RR = 10.5; 95 percent; CI = 4.3, 25.3); with rates for ovarian cancer (82.7 per 10,000 deaths) and pancreatic cancer (76.6) being more than twice that for lung cancer (31.6). Although the absolute numbers of patients are small, the rate for those with amyotrophic lateral sclerosis (ALS) was 67 times higher, and the rate for patients with HIV/AIDS was 57 times higher than that for patients with heart disease.

Death with Dignity Act Process

Trends in the DWDA process are presented in table 2. As reported by physicians, the two most common factors that contributed to patients requesting prescriptions—a loss of autonomy and a decreasing ability to engage in enjoyable

Table 1

Characteristics of 341 DWDA Patients Who Died during 1998–2007 after Ingesting a Lethal Dose of Medication, Compared with 98,942 Oregonians Who Died from the Same Underlying Diseases¹

Characteristics	DWDA Patients 1998–2007 (N = 341) ²	Oregon Deaths, Same Diseases (N = 98,942) ³	Deaths per 10,000 Oregon Deaths	Rate Ratio (95% CI) ⁴
Sex				
Male (%)	183	49,886	36.7	1.1 (0.9–1.4)
Female (%)	158	49,056	32.2	1.0 —
Age				
18–34 (%)	4	615	65.0	4.3 (1.5–12.1)
35–44 (%)	10	1,899	52.7	3.5 (1.7–7.0)
45–54 (%)	31	6,467	47.9	3.2 (1.9–5.2)
55–64 (%)	73	13,298	54.9	3.6 (2.4–5.5)
65–74 (%)	93	23,492	39.6	2.6 (1.7–3.9)
75–84 (%)	98	32,102	30.5	2.0 (1.4–3.0)
85+ (%)	32	21,069	15.2	1.0 —
Median years (range)	69 (25.0–96.0)	76 (18.0–112.0)	—	—
Race				
White (%)	332	95,047	34.9	1.0 —
Asian (%)	6	1,099	54.6	1.6 (0.7–3.5)
Native American (%)	1	702	14.2	0.4 (0.1–2.9)
Hispanic (%)	2	954	21.0	0.6 (0.2–2.4)
African-American (%)	0	1,070	0.0	—
Other (%)	0	43	0.0	—
Unknown	0	27	—	—
Marital status				
Married (%)	154	47,312	32.5	1.0 —
Widowed (%)	73	32,173	22.7	0.7 (0.5–0.9)
Divorced (%)	86	14,817	58.0	1.8 (1.4–2.3)
Never married (%)	28	4,381	63.9	2.0 (1.3–2.9)
Unknown	0	259	—	—
Education				
Less than high school (%)	27	22,170	12.2	1.0 —
High school graduate (%)	95	42,134	22.5	1.9 (1.2–2.8)
Some college (%)	79	18,578	42.5	3.5 (2.3–5.4)
Baccalaureate (%)	71	8,663	82.0	6.7 (4.3–10.5)
Post-baccalaureate (%)	69	5,967	115.6	9.5 (6.1–14.8)
Unknown	0	1,430	—	—
Residence				
Metro counties (%)	140	34,880	40.1	1.0 —
Coastal counties (%)	25	7,833	31.9	0.8 (0.5–1.2)
Other western counties (%)	151	41,150	36.7	0.9 (0.7–1.2)
East of the Cascades (%)	25	15,079	16.6	0.4 (0.3–0.6)

(Continued)

Table 1 (Continued)

Characteristics	DWDA Patients 1998-2007 (N = 341) ²	Oregon Deaths, Same Diseases (N = 98,942) ³	DWDA Deaths per 10,000 Oregon Deaths	Rate Ratio (95% CI) ⁴
Underlying illnesses				
Neoplasms (%)	280	(82.1)	66,255	(67.0)
Lung and bronchus (%)	65	(19.1)	20,557	(20.8)
Pancreas (%)	30	(8.8)	3,914	(4.0)
Breast (%)	30	(8.8)	5,134	(5.2)
Colon (%)	23	(6.7)	5,315	(5.4)
Prostate (%)	20	(5.9)	4,365	(4.4)
Ovary (%)	17	(5.0)	2,055	(2.1)
Lymphoid/ hematopoietic (%)	10	(2.9)	5,728	(5.8)
Skin (%)	10	(2.9)	1,380	(1.4)
Brain (%)	8	(2.3)	1,751	(1.8)
Esophagus (%)	7	(2.1)	1,819	(1.8)
Oral Cavity (%)	6	(1.8)	521	(0.5)
Bladder & Ureter (%)	6	(1.8)	1,878	(1.9)
Liver (%)	6	(1.8)	1,470	(1.5)
Kidney (%)	5	(1.5)	1,471	(1.5)
Other (%)	37	(10.9)	8,897	(9.0)
Amyotrophic lateral sclerosis (%)	26	(7.6)	962	(1.0)
Chronic respiratory disease (%)	15	(4.4)	17,721	(17.9)
HIV/AIDS (%)	7	(2.1)	304	(0.3)
Heart disease (%)	5	(1.5)	12,375	(12.5)
Illnesses listed below ⁵ (%)	8	(2.3)	1,325	(1.3)
			60.4	14.9 (4.9-45.6)

Notes

1. The same underlying disease is defined by specific ICD-9 code.

2. Unknowns were excluded when calculating percentages.

3. Ibid.

4. Confidence interval.

5. Includes alcoholic hepatic failure, corticobasal degeneration, diabetes mellitus with renal complications, hepatitis C, organ-limited amyloidosis, scleroderma, and Shy-Drager syndrome.

activities—increased over the 10-year period. In addition, reports of concerns about inadequate pain control (including fear of future pain) increased from 12.5 percent in 1998 to 32.7 percent in 2007 ($p < 0.02$), and reports about being a burden on family members or caregivers increased from 12.5 percent in 1998 to 44.9 percent in 2007 ($p = 0.01$).

The proportion of patients referred for a formal mental health evaluation declined, from 43.5 percent in 1999 to 0.0 percent in 2007 ($p < 0.001$); since 2003, the proportion has been 5.4 percent or less. Evaluations were more

Ten-Year Trends in the Practice of the Oregon Death with Dignity Act, 1998-2007

Characteristic	Total	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	p value ¹
Number of deaths	341	16	27	27	21	38	42	37	38	46	49	—
End-of-life concerns (n)	337	16	27	27	17	38	42	37	38	46	49	—
Steady loss of autonomy (%)	89.0	75.0	77.8	92.6	94.1	84.2	92.9	86.5	78.9	95.7	100	0.007
Less able to engage in enjoyable activities (%)	86.6	68.8	81.5	77.8	76.5	NA	92.9	89.5	89.5	95.7	85.7	0.007
Loss of dignity (%)	81.6	NA	NA	NA	NA	NA	78.6	78.4	89.5	76.1	85.7	0.5
Losing control of bodily functions (%)	58.2	56.3	59.3	77.8	52.9	47.4	57.1	64.9	44.7	58.7	63.3	0.8
Burden on family, friends/caregivers (%)	39.2	12.5	25.9	63.0	23.5	36.8	38.1	37.8	42.1	43.5	44.9	0.01
Inadequate pain control or concern about it (%)	27.3	12.5	25.9	29.6	5.9	26.3	21.4	21.6	23.7	47.8	32.7	0.02
Financial implications of treatment (%)	2.7	0.0	0.0	3.7	5.9	2.6	2.4	5.4	2.6	0.0	4.1	0.1
Psychiatrist consulted (n)	335	16	23	25	21	38	42	37	38	46	49	—
Yes (%)	10.7	31.3	43.5	20.0	14.3	13.2	4.8	5.4	5.3	4.3	0.0	< 0.001
Receiving hospice care at time of death (n)	339	15	27	26	21	38	42	37	38	46	19	—
Yes (%)	85.8	73.3	77.8	88.5	76.2	92.1	92.9	89.2	92.1	76.1	87.8	0.4
Terminal diagnosis to prescription written (n)	244	6	9	11	16	24	37	33	26	41	41	—
≤ 10 weeks (%)	52.0	33.3	44.4	54.5	37.5	41.7	54.1	48.5	53.8	65.9	53.7	0.07
Prescription written to ingestion (n)	341	16	27	27	21	38	42	37	38	46	49	—
≤ 2 weeks (%)	61.9	81.3	55.6	81.5	52.4	60.5	71.4	73.0	60.5	47.8	51.0	0.02
Prescribing M.D. present at ingestion (n)	341	16	27	27	21	38	42	37	38	46	49	—
Yes (%)	32.8	50.0	59.3	51.9	42.9	34.2	28.6	16.2	21.1	32.6	22.4	< 0.001

Note

1. Chi-square test for trend.

likely among patients older than 75 years (14.3 percent) than those aged less than 65 years (4.3 percent; p for trend = 0.01). Hospice coverage remained high throughout the study period, and was 87.8 percent in 2007.

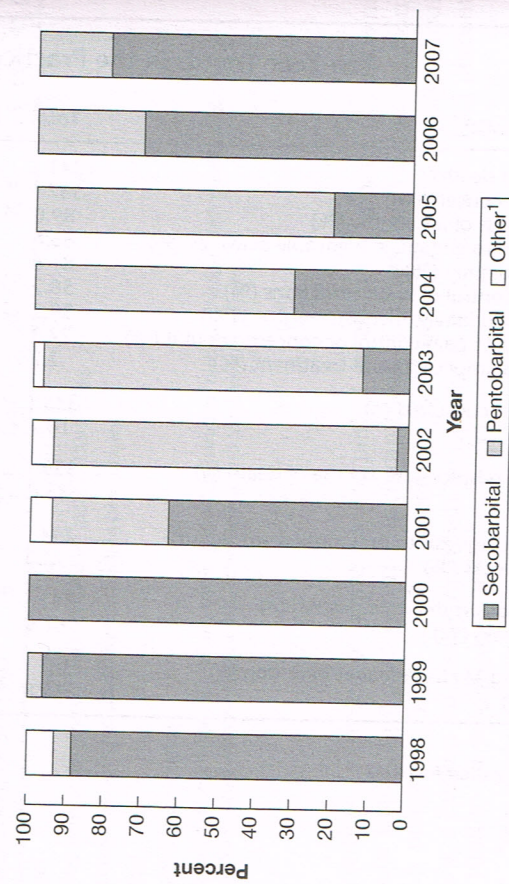
The interval between a terminal diagnosis and receiving a prescription shortened, although it was not statistically significant ($p = 0.07$), while the interval between receiving a prescription and ingesting medication lengthened ($p = 0.02$). Of 546 patients who received a prescription, 17 (5.0 percent) lived more than six months after receiving it. Of these, 11 (64 percent) lived six to 12 months, and six lived 12 to 23 months. While 106 participants (32 percent) had been patients of the prescribing physician for one year or more, 170 patients (51 percent) had known the prescribing physician for three months or less (median length of physician-patient relationship = 11 weeks). The percentage of prescribing physicians who were present at ingestion of the medication decreased from 59.3 percent in 1999 to 22.4 percent in 2007 ($p < 0.001$). The majority of patients (319; 93.5 percent) ingested their medications at home; this did not change over the study period.

Medications Prescribed

During the 10 years, secobarbital and pentobarbital were the primary medications prescribed, but the proportions varied by year (figure 2). Overall, 10 grams of pentobarbital most often led to death within one hour (91.6 percent of patients) compared to other barbiturate and dose combinations (table 3). Of the 316 patients with known time until death, 61 (19.3 percent) lived longer than

Figure 2

Types of Medication Ingested by Oregon Death with Dignity Act Decedents, 1998–2007



Note

1. Includes secobarbital and pentobarbital prescribed in combination, or with morphine.

Table 3

Interval between Ingestion and Unconsciousness/Death by Medication Type and Dose¹

	Total ²	Secobarbital, 9 g.	Secobarbital, 10 g.	Pentobarbital, 9 g.	Pentobarbital, 10g
	n	%	n	%	n
Total	341	100	113	33.3	58
Unconsciousness	273	88.9	78	83.0	52
0–10 minutes	34	11.1	19	17.0	4
11 + minutes	34	—	19	—	2
Unknown	34	—	19	—	2
Death ³	255	80.7	72	73.5	45
0–60 minutes	39	12.3	17	17.3	8
>6 hours	22	7.0	9	9.2	3
Unknown	25	—	15	—	2

Notes

1. Other combinations of medications and doses were taken by $n = 11$.

2. Ibid.

3. In addition, one patient ingested 10 grams of secobarbital, remained unconscious for 65 hours, awakened, and died from his illness two weeks later. He is not included in this report.

one hour after ingestion; 22 (7.0 percent) lived longer than six hours. In addition, in 2005 one person ingested 10 grams of secobarbital, remained unconscious for two and one-half days before re-awakening, and died two weeks later from his underlying illness. Patients who ingested a partial dose before becoming unconscious (5.8 percent of patients) were more likely to live longer than six hours compared to those who ingested the entire dose (22.2 percent versus 6.2 percent $p = 0.03$). Patients who experienced partial emesis (5.7 percent) were more likely to live longer than six hours than those who did not (21.1 percent versus 6.1 percent; $p = 0.04$).

Physicians' Characteristics

From 2001 through 2007, 109 different physicians wrote one or more DWDA prescriptions for medications that were ingested by their patients. (Physician identifier codes are not available for 1998 through 2000.) Of these physicians, 72 (66.1 percent) wrote one prescription; 17 (15.6 percent) wrote two; while three physicians (2.0 percent) wrote more than 10. These three physicians wrote 62 (22.8 percent) of 271 prescriptions written during 2001 through 2007. Medical specialties of the 109 physicians included family practice (41.3 percent), internal medicine (27.5 percent), and oncology (20.2 percent). Most physicians (57.8 percent) had been in practice for 20 or more years.

From 1998 through 2007, the Oregon Department of Human Services filed 18 reports with the Oregon Medical Board for physicians failing to adhere to the requirements of the DWDA, most commonly for improper completion of the patient's written request (for example, the patient and witnesses did not sign at the same time). Other reasons included failure to file required documentation in a timely manner (one report was filed more than a year after the patient's death), incomplete documentation, and failure to wait 48 hours after the written request before writing the prescription. The Oregon Medical Board's investigations did not find that any physicians had violated good faith compliance with the act.

Discussion

Oregon's DWDA law remains controversial 10 years after its implementation. Proponents and opponents disagree even on what terminology should be used; because of the connotations of the language, proponents prefer the terms "physician aid in dying," "hastened death," and "death with dignity," and opponents prefer the term "physician-assisted suicide." The terms "suicide" and "dignity" have political implications, in that they can influence acceptance or rejection of proposed legislation similar to Oregon's DWDA. We continue to struggle to find a term to describe what is permitted under Oregon's law that is widely understandable and maintains our neutrality.

While the number and rate of patients who participate in DWDA increased in the decade that the law has been in effect, the number of participants remains small compared to the number of all deaths in Oregon, corresponding to 0.1 percent. Jurisdictions that allow euthanasia have higher rates

than Oregon does: from 1990 through 2005, the rate of euthanasia in the Netherlands fluctuated between 1.7 percent and 2.4 percent, and physician-assisted suicide fluctuated from 0.1 percent to 0.2 percent of all deaths.⁶ This likely reflects different cultural norms and end-of-life medical care practices in the Netherlands and Oregon.

The demographic characteristics and medical diagnoses of patients remained stable over the 10 years. Participation rates remained highest among persons younger than 85 years, who were White or Asian, had more formal education, and had a diagnosis of cancer. When the DWDA was first enacted in Oregon, considerable debate focused on whether or not vulnerable populations, such as persons of color or patients who were poor or uneducated would be coerced into participating in the DWDA. The Oregon data demonstrate that this has not materialized, a finding similar to that in the Netherlands.⁷

The reported primary concerns of patients that led to a request for medication have also remained stable. The two most common concerns of patients that were reported by physicians during the first years—a loss of autonomy and a decreasing ability to engage in enjoyable activities—continued to be the most common in the tenth year. These findings are consistent with those of other studies based on interviews with patients and family members that examine Oregon patients' motivations for using the DWDA, which include wanting control over the circumstances surrounding death and concerns about loss of function, dignity, and independence.⁸

Several worrisome trends, however, have emerged over the decade. The increase in reported concern about inadequate (current or future) pain control is noteworthy, as is the concern about being a burden on caregivers. The DWDA specifically requires the prescribing physician to review alternatives to DWDA, including comfort care, hospice care, and pain control. During the 10-year study period, enrollment in hospice among patients remained consistently high, with 73 percent to 93 percent of patients receiving hospice care at the time of death (mean = 86 percent). Nonetheless, patients' reported concerns about inadequate pain control underscore the need for physicians to address the pain of terminally ill patients, which is supported by a recent requirement for physicians to take training in pain control for licensure in Oregon. The increase in reported concerns about inadequate pain control in DWDA patients merits further study, as does the concern about being a burden.

Another worrisome trend is a decline in requests for formal psychiatric evaluation: evaluations decreased from approximately one-third of the patients in the first two years after implementation of the act, to none in 2007. Psycho-social evaluation is part of hospice intake, and physicians may not have thought a more formal evaluation was necessary. Nonetheless, a recent study of terminally ill patients in Oregon who requested a prescription under the act found that three of 18 patients who received prescriptions met clinical criteria for depression.⁹ Although the act expressly requires evaluation by a licensed psychiatrist or psychologist if a condition causing impaired judgment is suspected, the decline in formal evaluations raises concerns that depression

remains undiagnosed in some patients who request and receive a prescription under the DWDA.

Changes in the DWDA medication prescribed over time appear to have been driven not by evidence of efficacy or risk of complications, but by availability and cost. In May 2001, Eli Lilly Company reported that it stopped producing secobarbital due to lack of raw materials, leading to a decline in its use. Physicians then began prescribing oral ingestion of the available liquid (injectable) form of pentobarbital, which costs approximately \$1,500 for 10 grams, compared to approximately \$100 for 10 grams of oral secobarbital.¹⁰ In September 2003, Ranbaxy Pharmaceuticals began producing secobarbital, coinciding with an increase in its use. While both medications led to unconsciousness within 10 minutes for most patients (89 percent), the time until death was less consistent; these findings are similar to the Dutch experience, where 12 percent of patients had prolonged time until death and 2 percent awakened.¹¹

Most participating physicians wrote one or two prescriptions from 2001 through 2007 (years for which data are available); however, three physicians wrote more than 10 prescriptions each, and wrote nearly one-fourth of all of the prescriptions written. Previous studies indicate that as many as half of Oregon physicians may not be willing to write a prescription under the DWDA.¹² Thus, patients may be referred to physicians within larger health systems who have more experience with DWDA, or physicians who are known to be advocates of the act. This may account for why half of patients knew the prescribing physician for three months or less.

Issues not addressed in Oregon's law have been a source of controversy since DWDA implementation. The act outlines requirements prior to a prescription being written, but not procedures after the medication is dispensed. For example, it does not require a prescribing physician to follow a patient, nor to reassess a patient for decline in cognitive function that might develop and lead to impaired judgment. Several studies have found that a patient's interest in acquiring a DWDA prescription fluctuates over time.¹³ Thus, it may be prudent for prescribing physicians to have an ongoing dialog with patients to assure that end-of-life concerns are met. The act also does not require a physician to be present when a patient ingests the prescribed medication. In addition, while the act assigns to the Oregon Department of Human Services responsibility for monitoring participation in the DWDA, it does not assign enforcement authority nor does it provide resources to support regulatory activities, which has left us open to charges of bias.¹⁴

Data regarding Oregon's experience with DWDA in the past decade are important for the ongoing policy debate. While our experience might not be directly applicable to other jurisdictions with different population characteristics (Oregon's residents are mostly White) and end-of-life care practices (Oregon has high levels of hospice coverage and advanced care planning),¹⁵ Oregon's experience provides an important perspective as a jurisdiction that allows self-ingestion of lethal doses of medication, but not euthanasia. This option continues to be used by only a small number of terminally ill Oregonians.

Notes

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