

Oregon's Death With Dignity Act: 20 Years of Experience to Inform the Debate

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Twenty years ago, Oregon voters approved the Death With Dignity Act, making Oregon the first state in the United States to allow physicians to prescribe medications to be self-administered by terminally ill patients to hasten their death. This report summarizes the experience in Oregon, including the numbers and types of participating patients and providers. These data

should inform the ongoing policy debate as additional jurisdictions consider such legislation.

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Twenty years ago, Oregon voters approved the Death With Dignity Act (DWDA) (1), making it the first state in the United States to allow physicians to prescribe medications to be self-administered by terminally ill patients to hasten their death. (Of note, Oregon statute specifically states that these deaths are not “suicides”; therefore, we use the language of the statute—*death with dignity*—rather than *physician-assisted suicide*.) Currently, 5 additional jurisdictions (Washington, Vermont, California, Colorado, and the District of Columbia) have similar laws; 1 (Montana) allows death with dignity by judicial ruling; and 30 more states have considered such legislation, although none has passed.

Although the passage and consideration of these laws indicate that death with dignity is gaining broader use around the country, debate continues over the ethics of such legislation and what it means for the practice of medicine. The questions raised fall into 2 broad categories (2). First, do statutory safeguards protect vulnerable patients? Are participating patients disproportionately poor or uneducated, or do they have financial concerns? Do patients participate because they lack access to health insurance or palliative care? Are they depressed? The second category is more philosophical. Are DWDA laws ethical? Do they interfere with the patient-physician relationship? Do they devalue human life? Although not all of these questions are easily answered with data, parties on both sides of the debate, when formulating opinions and policies, may wish to consider the experience of jurisdictions where death with dignity is legal.

Oregon's DWDA statute requires the Oregon Health Authority (OHA) to collect data on compliance and issue an annual report. Although the OHA takes a neutral position regarding the DWDA legislation, it is committed to presenting data that are useful for informing the debate and public policy decisions. This report summarizes the experience in Oregon, including the numbers and types of participating patients and providers.

METHODS

The Oregon DWDA statute specifies the patient criteria (including adult age, Oregon residency, terminal illness diagnosis, sound mind) and the process for re-

ceiving a prescription (for example, 2 physicians must confirm the diagnosis and prognosis; patients must make 2 oral requests, 15 days apart, and 1 witnessed written request; and patients must be offered hospice). The statute also requires the OHA to develop a reporting system to determine compliance with the statute. Oregon Administrative Rules (3) specify the process for documenting that the qualifications have been met and for reporting to the OHA.

The reporting system includes 3 components: reports submitted by the prescribing and consulting physicians, mental health consultant (if applicable), and dispensing pharmacist documenting compliance with statutory requirements; death certificate abstraction documenting death and demographic characteristics of the patient; and a follow-up questionnaire completed by the attending physician documenting whether the patient ingested the DWDA medications, as well as the DWDA processes, any complications, and the patient's end-of-life concerns. The OHA reports all instances of DWDA noncompliance to the appropriate licensing board.

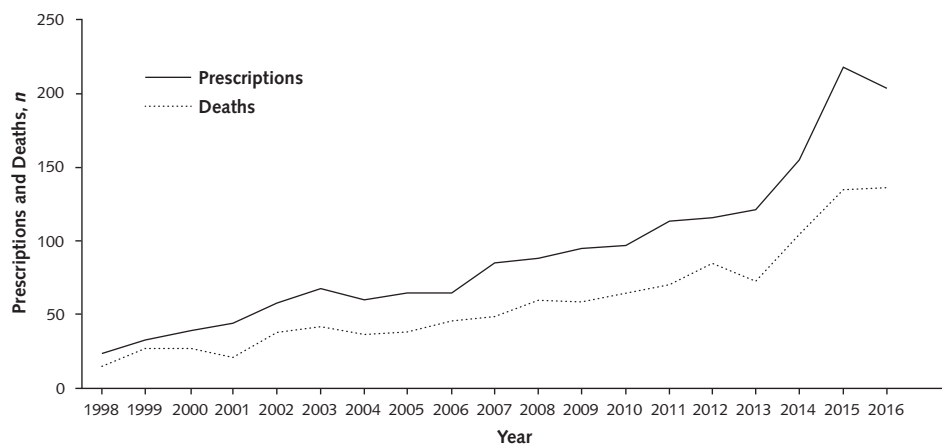
Our annual reports have presented the number of participating patients by demographic and disease characteristics (4). For the current study, we calculated rates for DWDA deaths by using as the numerator all DWDA deaths that occurred from 1998 through June 2017, and as the denominator all Oregon deaths from the same underlying diseases (on the basis of specific codes of the International Classification of Diseases, 10th Revision) that occurred during the same period.

RESULTS

From 1998 through June 2017, 1857 Oregonians received DWDA prescriptions, and 1179 (64%) died from ingesting the prescribed medications. During this period, 614 972 Oregonians aged 18 years and older died of all causes, for an overall DWDA rate of 19 per 10 000 total deaths; 215 983 Oregonians aged 18 years and older died of the same underlying diseases,

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Figure. DWDA prescriptions and deaths, 1998 to 2016.

DWDA = Death With Dignity Act.

for a DWDA rate of 54.6 per 10 000 deaths from these underlying diseases.

From 1998 through 2013, DWDA deaths increased an average of 14% annually; from 2013 through 2015, DWDA deaths increased by 36% annually, but they leveled off in 2016 (Figure). Prescriptions for DWDA medications followed a similar pattern. During this period, Oregon's population increased 2.5 times, from 1.6 million in 1998 to 4.1 million in 2016. Among patients who received a DWDA prescription, the percentage who died after ingesting the medications remained relatively stable.

Patient Characteristics

Overall, the median age of DWDA patients was 72 years (range, 25 to 102 years), 52% were men, 96% identified as white, and 72% had some college or higher education (Table). The median age of death was 76 years for the population of Oregonians who died of the same underlying diseases. Rates of DWDA participation were highest in patients aged 55 to 64 years and decreased in patients aged 75 years and older. Rates increased with higher educational attainment: DWDA participation was more than 10 times greater in patients with postbaccalaureate education (191 per 10 000 deaths) than in those who did not graduate from high school (16 per 10 000 deaths). During the first decade after the DWDA was enacted (1998 to 2007), 9% of patients were aged 85 years and older; during the second decade (2008 to 2017), the proportion increased to 18%. In addition, 26% of patients had some college or higher education during the first decade (1998 to 2007), increasing to 76% during the second decade (2008 to 2017).

Underlying Diseases

Most DWDA patients had cancer (77%), followed by amyotrophic lateral sclerosis (ALS; 8%), chronic respiratory disease (5%), and heart disease (2%). Among the population of Oregonians who died of the same underlying diseases, rates of participation were highest

among patients with ALS, HIV/AIDS, or cancer. During the second decade (2008 to 2017), only 3 DWDA patients had HIV/AIDS as their underlying disease.

End-of-Life Concerns

Regardless of underlying illness, most patients (as reported by their physicians) cited a loss of autonomy (91%) or a decreasing ability to participate in activities that make life enjoyable (89%) as reasons for seeking death with dignity. Concerns about pain were reported by 26% and finances by 4%. Specific end-of-life concerns varied by underlying illness. Cancer patients reported greater concern about inadequate pain management (30%) than other patients (12%), and patients with ALS reported greater concern about loss of control of bodily functions (60%) than other patients (45%). Reported concerns remained similar between decades.

DWDA Process

Most patients participating in DWDA were enrolled in hospice (88%). During the first decade (1998 to 2007), 11% of patients had a formal psychiatric evaluation, but only 3% had one during the second decade (2008 to 2017). Health care providers were present at the time of death for 42% of patients: 80% during the first decade (1998 to 2007) and 30% during the second (2008 to 2017). Overall, 5% of patients lived more than 6 months after their prescription was written. Seven patients (0.6%) regained consciousness after ingesting the DWDA medications; 6 of them died of their underlying illness (1 patient is still alive).

Participating Physicians

Since 2000 (when coding of prescribers began), 374 physicians have written prescriptions under the DWDA. Of these, 230 (62%) wrote 1 prescription and 110 (29%) wrote 2 to 5, 24 (6%) wrote 6 to 19, and 10 (3%) wrote more than 20 prescriptions (most prescriptions written by 1 physician, 85; second most, 33). Annually, the number of physicians who wrote a prescrip-

Table. Characteristics of DWDA Patients Who Died From Ingesting a Lethal Dose of Medication Compared With Oregonians Who Died of Similar Diseases, 1998-2017*

Characteristic	DWDA Patients, n (%) (n = 1179)†	Deaths in Oregon From Similar Diseases, n (n = 215 983)	Rate of DWDA Deaths per 10 000 Oregon Adult Deaths From Similar Diseases‡
Sex			
Male	612 (51.9)	109 315	56.0
Female	567 (48.1)	106 668	53.2
Age			
18-34 y	9 (0.8)	1226	NA
35-44 y	25 (2.1)	3443	72.6
45-54 y	72 (6.1)	12 461	57.8
55-64 y	230 (19.5)	30 741	74.8
65-74 y	354 (30.0)	50 930	69.5
75-84 y	308 (26.1)	64 816	47.5
≥85 y	181 (15.4)	52 366	34.6
Median (range), y	72 (25-102)	76 (18-109)	-
Race/ethnicity			
White	1132 (96.0)	200 632	56.4
African American	1 (0.1)	2459	NA
Native American	3 (0.3)	1553	NA
Asian	17 (1.4)	2929	58.0
Other/multiple	9 (0.8)	634	NA
Hispanic	12 (1.0)	3352	35.8
Unknown	5 (0.4)	4424	NA
Highest education level			
Less than high school	66 (5.6)	41 238	16.0
High school diploma	253 (21.5)	88 901	28.5
Some college	310 (26.3)	47 257	65.6
Bachelor's degree	283 (24.0)	22 058	128.3
Postgraduate degree	259 (22.0)	13 569	190.9
Unknown	8 (0.7)	2960	NA
Underlying illness			
Cancer	909 (77.1)	138 843	65.5
Amyotrophic lateral sclerosis	94 (8.0)	2140	439.3
Chronic respiratory disease	58 (4.9)	40 360	14.4
Heart disease	22 (1.9)	27 900	7.9
HIV/AIDS	10 (0.8)	707	141.4
Other	86 (7.3)	6033	NA
End-of-life concerns			
Loss of autonomy	1070 (90.8)	-	-
Unable to participate	1054 (89.4)	-	-
Loss of dignity	802 (68.0)	-	-
Loss of bodily control	546 (46.3)	-	-
Burden to family	503 (42.7)	-	-
Pain	308 (26.1)	-	-
Financial cost	41 (3.5)	-	-
DWDA process§			
Enrolled in hospice	976 (87.9)	-	-
Provider present at death	457 (42.0)	-	-
Referred for psychiatric evaluation	59 (5.0)	-	-
Lived >6 mo after prescription	53 (4.5)	-	-
Failed attempts	7 (0.6)	-	-

DWDA = Death With Dignity Act; NA = not available/applicable when the numerator is <10.

* Includes deaths through 30 June 2017. Percentages may not sum to 100 due to rounding.

† Unless otherwise indicated.

‡ Calculated only for numerators ≥10.

§ Percentages exclude patients with unknown values.

|| Six of these 7 patients ended up dying of their underlying illness so are not included in the overall 1179 (1 patient is still alive).

tion increased from 22 (0.2% of licensed Oregon physicians) in 2000 to 102 (0.6%) in 2016. The median duration of the patient-physician relationship was 13 weeks (range, 1 to 1905 weeks).

DISCUSSION

During the past 20 years, participation in DWDA has increased among terminally ill Oregonians but remains low compared with all Oregon deaths. Partici-

pants were largely white or Asian, had at least some college education, and had cancer or ALS.

Oregon's experience indicates that concerns about whether DWDA patients are uneducated or have financial concerns have not been borne out by the data. Most participants had at least some college education, and 22% had postbaccalaureate education. Financial concerns were infrequently reported as a motivation to request death with dignity. Thus, although DWDA participation has grown in all demographic groups, it seems to have increased most among patients with higher education. This may reflect better knowledge about options at the end of life, which other researchers have found to be associated with white race and higher education (5).

Processes outlined in DWDA statutes are meant to safeguard patients from abuse. Most patients were enrolled in hospice, which may indicate that attention is being paid to ensuring that patients have access to quality end-of-life care. Nonetheless, approximately one quarter of DWDA patients reported concerns about pain as a motivating factor. Some potentially concerning changes have occurred since Oregon's DWDA was enacted. Fewer patients in the second than the first decade of the DWDA received a psychological consultation. This decrease is troubling, because other researchers have found that a substantial proportion of patients requesting death with dignity have clinical depression (6). Fewer patients in the second than the first decade of the DWDA had a health care professional present when they ingested the medications. Over 20 years, 7 patients regained consciousness after ingestion. Patients and families might benefit from the support of health care professionals being present throughout the process.

Although Oregon's DWDA outlines the patient qualifications and processes for a prescription to be written, the law itself does not address what happens from the time the prescription is written until the patient's death. It does not include requirements for who is to be present when medication is ingested, which medications should be prescribed, how to dispose of dispensed DWDA medications not ingested, or how to determine whether a patient is "mentally capable" and whether this should be reassessed when the patient decides to take the medications. Moreover, it does not require the prescribing physician to continue to follow the patient until he or she dies; thus, no safeguards are in place for a patient who loses cognitive function after the prescription is written.

The primary concerns presented in the American College of Physicians position paper on the ethics and legalization of physician-assisted suicide (7) relate to philosophical arguments concerning the nature of the patient-physician relationship, trust in the relationship, and the societal role of physicians. Although these issues cannot be addressed directly by data, the Oregon experience may provide insight. Most DWDA patients report "existential" concerns, such as loss of autonomy and inability to enjoy activities that make their lives meaningful, as primary reasons for their request. These

reports are consistent with patient interviews that found that the primary reasons for requesting death with dignity were concerns about quality of life and loss of independence, as well as the desire to control the timing and location of death (8). That approximately one third of patients who receive prescriptions never take the medications supports the premise that patients want choices. The DWDA statute specifies that no health care provider should be compelled to participate against his or her wishes, and only a few Oregon physicians have written prescriptions for DWDA medications, similar to what has been seen in other jurisdictions (9). After 20 years, most Oregon physicians have not participated in the DWDA, and of those who have, most have written only a few prescriptions.

It is important to consider death with dignity within the spectrum of end-of-life options, including cessation of eating and drinking, withdrawal of life support, the "halo" effect from opioid medications, and terminal sedation to relieve pain. A recent study from the Netherlands found that physician-assisted suicide comprised 0.1% of end-of-life practices from 1990 to 2015, and this percentage did not change over time (10). Data collection for the DWDA is mandated by the statute, but no structured data reporting exists for other end-of-life options. Although gathering more information from DWDA patients might be helpful for informing the debate, it would have to be balanced with respect for their privacy at the end of life. Collecting data on all aspects of end-of-life care, including how patients, their families, and physicians are choosing which options to pursue, would provide an important context for the DWDA debate (11).

Since 1997, the number of patients and physicians participating in the DWDA has increased but remains low, with fewer than 0.2% of Oregonian decedents and 0.6% of Oregon physicians participating. The goals of all parties should be to ensure that terminally ill patients have their concerns addressed and that they have access to excellent end-of-life care, regardless of their beliefs about the ethics of death with dignity or whether it should be a legal option.

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