Oregon Death with Dignity Act

Data summary 2016



Acknowledgments

Report written by: Public Health Division, Center for Health Statistics

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For more information, see:

 $\underline{http://public.health.oregon.gov/ProviderPartnerResources/Evaluationresearch/}$

 $\underline{deathwith dignity act/Pages/index.aspx}$

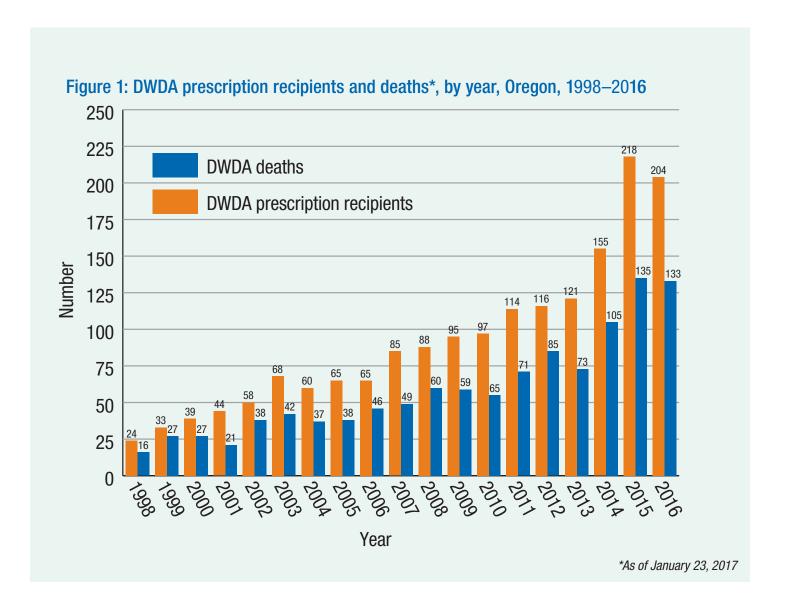
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Executive summary

Oregon's Death with Dignity Act (DWDA) allows terminally-ill adult Oregonians to obtain and use prescriptions from their physicians for self-administered, lethal doses of medications. The Oregon Public Health Division is required by the DWDA to collect compliance information and to issue an annual report. In 2016, 204 people received prescriptions under the DWDA. As of January 23, 2017, 133 people had died in 2016 from ingesting the prescribed medications, including 19 prescription recipients from prior years. Characteristics of DWDA patients were similar to previous years: most patients were aged 65 years or older (80.5%) and had cancer (78.9%). During 2016, no referrals were made to the Oregon Medical Board for failure to comply with DWDA requirements.

Introduction

Oregon's Death with Dignity Act (DWDA), enacted in late 1997, allows terminally-ill adult Oregonians to obtain and use prescriptions from their physicians for self-administered, lethal doses of medications. The Oregon Public Health Division is required by the DWDA to collect compliance information and to issue an annual report. Data presented in this summary, including the number of people for whom DWDA prescriptions were written (DWDA prescription recipients) and the resulting deaths from the ingestion of the medications (DWDA deaths), are based on required reporting forms and death certificates received by the Oregon Public Health Division as of January 23, 2017. More information on the reporting process, required forms, and annual reports is available at: http://www.healthoregon.org/dwd.



Participation summary and trends

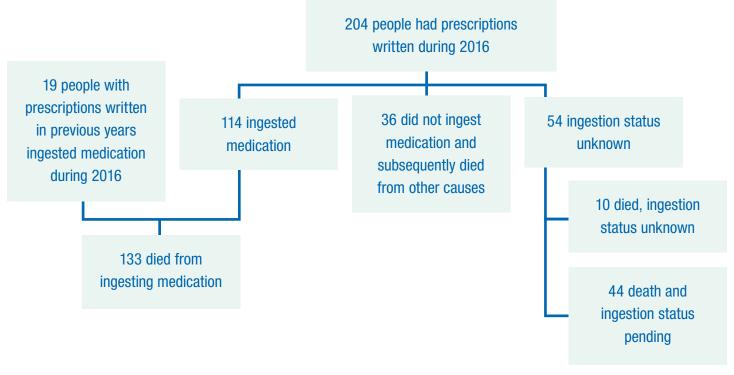
During 2016, 204 people received prescriptions for lethal medications under the provisions of the Oregon DWDA, compared to 218 during 2015 (see Figure 1). As of January 23, 2017, the Oregon Public Health Division had received reports of 133 people who had died during 2016 from ingesting the medications prescribed under DWDA, compared to 135 during 2015.

Since the law was passed in 1997, a total of 1,749 people have had prescriptions written under the DWDA, and 1,127 patients have died from ingesting the medications. During 2016, the rate of DWDA deaths was 37.2 per 10,000 total deaths.¹

A summary of DWDA prescriptions written and medications ingested is shown in Figure 2. Of the 204 patients for whom prescriptions were written during 2016, 114 (55.9%) ingested the medication and died without regaining consciousness while 36 (17.6%) did not take the medications and subsequently died of other causes.

Ingestion status is unknown for 54 patients prescribed DWDA medications in 2016. Ten of these patients died, but follow up information is not available. For the remaining 44 patients, both death and ingestion status are pending (Figure 2).

Figure 2: Summary of DWDA prescriptions written and medications ingested in 2016, as of January 23, 2017



¹ Rate per 10,000 deaths calculated using the total number of Oregon resident deaths in 2015 (35,709), the most recent year for which final death data are available.

Patient characteristics

Of the 133 DWDA deaths during 2016, most patients (80.5%) were aged 65 years or older. The median age at death was 73 years. As in previous years, decedents were commonly white (96.2%) and well-educated (50.0% had a least a baccalaureate degree).

Patients' underlying illnesses were similar to those of previous years. Most patients had cancer (78.9%), followed by amyotrophic lateral sclerosis (ALS) (6.8%). Of note, 6.8% of patients had heart disease as their underlying illness, an increase from 2.0% during prior years.

Most (88.6%) patients died at home, and most (88.7%) were enrolled in hospice care. Excluding unknown cases, most (99.2%) had some form of health care insurance, although the percent of patients who had private insurance (29.7%) was lower in 2016 than in previous years (57.1%). The number of patients who had Medicare or Medicaid insurance was higher than in previous years (69.5% compared to 41.5%).

Similar to previous years, the three most frequently mentioned end-of-life concerns were loss of autonomy (89.5%), decreasing ability to participate in activities that made life enjoyable (89.5%), and loss of dignity (65.4%).

DWDA processs

A total of 102 physicians wrote 204 prescriptions during 2016 (1-25 prescriptions per physician). During 2016, no referrals were made to the Oregon Medical Board for failure to comply with DWDA requirements. During 2016, five patients were referred for psychological/psychiatric evaluation.

A procedure revision was made in 2010 to standardize reporting on the follow-up questionnaire. The new procedure accepts information about the time of death and circumstances surrounding death only when the physician or another health care provider was present at the time of death. For 27 patients, either the prescribing physician or another healthcare provider was present at the time of death. Prescribing physicians were present at time of death for 13 patients (10.1%); 14 additional cases had other health care providers present (e.g. hospice nurse). Data on time from ingestion to death are available for only 25 DWDA deaths during 2016. Among those 25 patients, time from ingestion until death ranged from seven minutes to nine hours. For the remaining two patients, the length of time between ingestion and death was unknown.

Table 1. Characteristics and end-of-life care of 1,127 DWDA patients who have died from ingesting a lethal dose of medication as of January 23, 2016, by year, Oregon, 1998–2016

Characteristics		2016	1998–2015 (N=994) N (%) ¹		Total (N=1,127) N (%) ¹	
		=133)				
Sex	N (%)¹					
Male (%)	72	(54.1)	510	(51.3)	582	(51.6)
Female (%)	61	(45.9)	484	(48.7)	545	(48.4)
Age						
18-34 (%)	1	(0.8)	8	(0.8)	9	(0.8)
35-44 (%)	1	(0.8)	23	(2.3)	24	(2.1)
45-54 (%)	6	(4.5)	64	(6.4)	70	(6.2)
55-64 (%)	18	(13.5)	206	(20.7)	224	(19.9)
65-74 (%)	52	(39.1)	289	(29.1)	341	(30.3)
75-84 (%)	31	(23.3)	259	(26.1)	290	(25.7)
85+ (%)	24	(18.0)	145	(14.6)	169	(15.0)
Median years (range)	73	(32-97)	71	(25-102)	71	(25–102)
Race						
White (%)	127	(96.2)	956	(96.6)	1,083	(96.5)
African American (%)	0	(0.0)	1	(0.1)	1	(0.1)
American Indian (%)	0	(0.0)	2	(0.2)	2	(0.2)
Asian (%)	2	(1.5)	13	(1.3)	15	(1.3)
Pacific Islander (%)	0	(0.0)	1	(0.1)	1	(0.1)
Other (%)	0	(0.0)	3	(0.3)	3	(0.3)
Two or more races (%)	1	(0.8)	4	(0.4)	5	(0.4)
Hispanic (%)	2	(1.5)	10	(1.0)	12	(1.1)
Unknown	1		4		5	
Marital status						
Married (including Registered Domestic Partner) (%)	62	(47.0)	449	(45.4)	511	(45.5)
Widowed (%)		(19.7)		(23.4)		(23.0)
Never married (%)	8	(6.1)		(7.9)		(7.7)
Divorced (%)	36	(27.3)	231	(23.3)	267	(23.8)
Unknown	1		4		5	, ,
Education						
Less than high school (%)	5	(3.8)	58	(5.9)	63	(5.6)
High school graduate (%)	23	(17.4)	218	(22.1)	241	(21.5)
Some college (%)	38	(28.8)	261	(26.4)	299	(26.7)
Baccalaureate or higher (%)	66	(50.0)	450	, ,	516	(46.1)
Unknown	1	. ,	7	. ,	8	. ,

	2016		1998–2015		Total		
Characteristics	(N=133)		(N=	(N=994)		(N=1,127)	
Residence							
Metro counties (Clackamas, Multnomah, Washington) (%)	54	(40.9)	427	(43.3)	481	(43.0)	
Coastal counties (%)	10	(7.6)	70	(7.1)	80	(7.1)	
Other western counties (%)	57	(43.2)	413	(41.8)	470	(42.0)	
East of the Cascades (%)	11	(8.3)	77	(7.8)	88	(7.9)	
Unknown	1		7		8		
End of life care							
Hospice							
Enrolled (%)	118	(88.7)	868	(90.4)	986	(90.2)	
Not enrolled (%)	15	(11.3)	92	(9.6)	107	(9.8)	
Unknown	0	,	34		34	, ,	
Insurance							
Private (%)	35	(29.7)	534	(57.1)	569	(54.0)	
Medicare, Medicaid or other governmental (%)	82	(69.5)	388	(41.5)	470	(44.6)	
None (%)	1	(0.8)	13	(1.4)	14	(1.3)	
Unknown	15	,	59		74		
Underlying illness							
Malignant neoplasms (%)	105	(78.9)	767	(77.2)	872	(77.4)	
Lung and bronchus (%)	16	(12.0)	177	(17.8)	193	(17.1)	
Breast (%)	12	(9.0)	74	(7.4)	86	(7.6)	
Colon (%)	12	(9.0)	61	(6.1)	73	(6.5)	
Pancreas (%)	9	(6.8)	64	(6.4)	73	(6.5)	
Prostate (%)	6	(4.5)	41	(4.1)	47	(4.2)	
Ovary (%)	3	(2.3)	37	(3.7)	40	(3.5)	
Other (%)	47	(35.3)	313	(31.5)	360	(31.9)	
Amyotrophic lateral sclerosis (%)	9	(6.8)	80	, ,	89	(7.9)	
Chronic lower respiratory disease (%)	2	(1.5)	44	(4.4)	46	(4.1)	
Heart disease (%)	9	(6.8)	26	(2.6)	35	(3.1)	
HIV/AIDS (%)	0	(0.0)	10	(1.0)	10	(0.9)	
Other illnesses (%) ²	8	(6.0)	67	(6.7)	75	(6.7)	
DWDA process							
Referred for psychiatric evaluation (%)	5	(3.8)	52	(5.3)	57	(5.1)	
Patient informed family of decision (%) ³	119	(89.5)		(93.6)	977	, ,	
Patient died at				,		, ,	
Home (patient, family or friend) (%)	117	(88.6)	931	(94.0)	1,048	(93.4)	
Long term care, assisted living or foster care facility (%)	9	(6.8)	46	(4.6)	55	(4.9)	
Hospital (%)	3	(2.3)	1	(0.1)	4	(0.4)	
Other (%)	3	(2.3)	12	(1.2)	15	(1.3)	
Unknown	1	(=)	4	(·· -)	5	()	

		2016	1998-2015 (N=994)		Total (N=1,127)	
Characteristics	(N=133)					
Lethal medication						
Secobarbital (%)	86	(64.7)	582	(58.6)	668	(59.3)
Pentobarbital (%)	0	(0.0)	386	(38.8)	386	(34.3)
Phenobarbital (%)	39	(29.3)	17	(1.7)	56	(5.0)
Other (combination of above and/or morphine) (%)	8	(6.0)	9	(0.9)	17	(1.5)
End of life concerns ⁴	(N=133)		(N=994)		(N=991)	
Losing autonomy (%)	119	(89.5)	906	(91.6)	1,025	(91.4)
Less able to engage in activities making life enjoyable (%)	119	(89.5)	888	(89.7)	1,007	(89.7)
Loss of dignity (%) ⁵	87	(65.4)	680	(78.8)	767	(77.0)
Losing control of bodily functions (%)	49	(36.8)	475	(48.1)	524	(46.8)
Burden on family, friends/caregivers (%)	65	(48.9)	408	(41.3)	473	(42.2)
Inadequate pain control or concern about it (%)	47	(35.3)	249	(25.2)	296	(26.4)
Financial implications of treatment (%)	7	(5.3)	31	(3.1)	38	(3.4)
Health-care provider present (collected since 2001)	(N=133)		(N=924)		(N=1,057)	
When medication was ingested ⁶						
Prescribing physician	14		149		163	
Other provider, prescribing physician not present	14		256		270	
No provider	5		86		91	
Unknown	100		433		533	
At time of death						
Prescribing physician (%)	13	(10.1)	136	(15.0)	149	(14.4)
Other provider, prescribing physician not present (%)	14	(10.9)	281	(31.0)	295	(28.5)
No provider (%)	102	(79.1)	489	(54.0)	591	(57.1)
Unknown	4		18		22	
Complications ⁶	(N=133)		(N=994)		(N=1,127)	
Difficulty ingesting/regurgitated	3		27		30	
None	24		530		554	
Unknown	106		437		543	
Other outcomes						
Regained consciousness after ingesting DWDA medications ⁷	0		6		6	

	2016	1998–2015	Total (N=1,127)				
Characteristics	(N=133)	(N=994)					
Timing of DWDA event							
Duration (weeks) of patient-physician relationship							
Median	18	12	13				
Range	1–1,484	0-1,905	0-1,905				
Number of patients with information available	132	992	1,124				
Number of patients with information unknown	1	2	3				
Duration (days) between first request and death							
Median	56	46	48				
Range	15-539	14-1,009	14–1,009				
Number of patients with information available	133	994	1,127				
Number of patients with information unknown	0	0	0				
Minutes between ingestion and unconsciousness	inutes between ingestion and unconsciousness						
Median	4	5	5				
Range	1–60	1–38	1–60				
Number of patients with information available	24	532	556				
Number of patients with information unknown	109	462	571				
Minutes between ingestion and death							
Median	27	25	25				
Range	7min-9hrs	1min-104hrs	1min-104hrs				
Number of patients with information available	25	537	562				
Number of patients with information unknown	108	457	565				

- 1 Unknowns are excluded when calculating percentages.
- 2 Includes deaths due to benign and uncertain neoplasms, other respiratory diseases, diseases of the nervous system (including multiple sclerosis, Parkinson's disease and Huntington's disease), musculoskeletal and connective tissue diseases, viral hepatitis, diabetes mellitus, cerebrovascular disease, and alcoholic liver disease.
- 3 First recorded beginning in 2001. Since then, 52 patients (4.9%) have chosen not to inform their families, and 21 patients (2.0%) have had no family to inform. There was one unknown case in 2002, two in 2005, one in 2009, and three in 2013.
- 4 Affirmative answers only ("Don't know" included in negative answers). Categories are not mutually exclusive. Data unavailable for four patients in 2001.
- 5 First asked in 2003. Data available for 133 patients in 2016, 863 patients between 1998–2015, and 996 patients for all years.
- 6 A procedure revision was made mid-year in 2010 to standardize reporting on the follow-up questionnaire. The new procedure accepts information about time of death and circumstances surrounding death only when the physician or another health care provider is present at the time of death. This resulted in a larger number of unknowns beginning in 2010.
- 7 There have been a total of six patients who regained consciousness after ingesting prescribed lethal medications.

 These patients are not included in the total number of DWDA deaths. These deaths occurred in 2005 (1 death), 2010 (2 deaths), 2011 (2 deaths) and 2012 (1 death). Please refer to the appropriate years' annual reports on our website (http://www.healthoregon.org/dwd) for more detail on these deaths.



For more information: http://www.healthoregon.org/dwd Contact: DWDA.info@state.or.us

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