Bill: SB0701, the End-of-Life Option Act
Name: Peg Sandeen, PhD, MSW
Organization: Death with Dignity National Center
Position: SUPPORT

My name is Peg Sandeen. I am testifying in support of Senate Bill 701, the End-of-Life Option Act. I am the executive director of the Death with Dignity National Center and a social worker with a PhD in Social Research. I have more than 20 years of experience working directly with people who are terminally ill, including individuals who have opted to hasten their death using medication prescribed under death with dignity legislation. In addition, I am an academic, an adjunct instructor of Social Work at Columbia University School of Social Work. I am not speaking on behalf of Columbia, but I note my role as an academic because I will be talking about several academic studies that demonstrate the soundness of death with dignity as a viable and well-researched public policy which is safe and effective.

I represent Death with Dignity and over 4,000 Marylanders, a number of whom are here today, who support the right of all individuals with a terminal illness to die on their own terms. Some of those supporters are dying themselves. People like Christine Hodgdon, a 39-year-old woman with metastatic breast cancer and a steadfast advocate for death with dignity. Like so many Marylanders who are moved personally by this issue, she submitted written testimony, and I hope you will take a moment to read her story.

Christine is but one of the strong majority of Marylanders who support this law. Recently, we commissioned a poll from Gonzales Research [1], a local polling firm, and the results show two-thirds of Marylanders support the End-of-Life Option Act. In fact, solid majorities of Maryland residents in all regions of the state, across the political spectrum, and from all demographic groups support this legislation.

Gonzales Research queried likely voters and 60 percent of respondents in Western Maryland supported the law. Similarly, 65 percent of respondents in the Baltimore suburbs supported the law as did 67 percent of those from the Eastern Shore. In the Washington Metro area, a full 71 percent of respondents stated their support for medical aid in dying.

In my career working with people who are terminally ill and dying, I have come to believe that one of the most difficult things for a terminally ill individual is the silence arising out of society’s unwillingness to face death directly. Public conversations, of which testimony to a legislative body is a perfect example, provide an avenue for private conversations about dying to occur among family members. At least one family in the state of Maryland tonight will have a difficult conversation about dying and last wishes and advance directives because they heard about this hearing today.

The proposed law you are considering today is, at its core, a medical standard of care designed to provide physicians and pharmacists with best practice guidelines for situations in which a terminally ill and competent patient requests the right to control the timing and manner of his/her death. Senate Bill 701 is modeled on legislation that has been enacted in nine jurisdictions, including your Washington, D.C. and New Jersey neighbors.

Beyond providing physicians with best practice guidelines, the End-of-Life Option Act puts decisions about easing suffering in the hands of terminally ill patients, allowing them to engage their family members, their physicians, clergy members and anyone else they choose, if they so choose. It sets aside outdated and archaic government bans on a medical practice that is currently legal for 70 million Americans, a practice that is validated, researched, effective, and full of safeguards to protect vulnerable populations.

The multiple safeguards in Senate Bill 701 include:

- A diagnosis of a terminal illness with a prognosis of six months or less to live, verified by a second opinion.
  A mandatory counseling referral if either the attending or consulting physician believes the patient may not have capacity to make this health care decision.
- Oral and written request. The written request must be witnessed by at least two people, one of whom must be someone who is not a relative or an heir set to receive an inheritance from the individual. The physicians involved cannot be witnesses.
- Information must be provided to the patient on all forms of palliative care, hospice care, and other end-of-life options.
- The patient may opt out at any time and for any reason.
- The patient must self-administer the medication.
- Any health care professional or healthcare institution may choose not to participate.

To emphasize: No physician, pharmacist, nurse, or any type of care facility may be forced to participate. Whether by conscience, religious belief or moral objection, every person potentially involved in this process may refuse to participate.

The policy you are considering has been subject to independent research protocols by individuals from a myriad of academic disciplines. These researchers have examined the safeguards and demonstrated there have not been any instances of abuse or coercion of patients in the more than two decades since the law took effect. These findings over and over refute the arguments by opponents of death with dignity.

Oregon has successfully implemented a death with dignity law for over 20 years. What do we know about the Oregon experience offering death with dignity with these same safeguards you are considering?

The law is rarely used. Statistics collected by the Oregon Health Authority [2] demonstrate only 1,459 individuals have ended their lives using the death with dignity law in 21 years. Every year, about one third of the individuals who go through the process to become qualified patients do not ingest the medication, but rather, go on to die from their underlying condition. Death with dignity for them is all about peace of mind. The median age of participants is 74; 90 percent are enrolled in hospice; over 87 percent of them die at home; over 99 percent of them have insurance, either private or government sponsored. Overwhelmingly, these patients have cancer. Oregon's law has worked exactly as intended: to give dying and suffering patients more options at the end of life.

Opponents of this legislation allege a lot of things this bill does and does not do. For more than two decades now, we have heard these same slippery slope arguments: statements that this law will target individuals who are poor or who are living with disabilities or the elderly; statements suggesting that those without medical care or access to healthcare resources will be forced to end their lives using medical aid in dying because it is cheaper than treating cancer. These slippery slope arguments are just not true. Independent researchers have concluded that the results are quite the opposite.

In 2007, Battin et al. [4] explored data out of Oregon to determine if there was a disproportionate impact of 10 groups of potentially vulnerable patients. The data led the researchers to conclude

> "…people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges…there is no current factual support for so-called slippery-slope concerns about the risks of legalisation of assisted dying—concerns that death in this way would be practised more frequently on persons in vulnerable groups."

To reiterate, there is no current factual support for the slippery slope argument that vulnerable individuals are at risk for being coerced into using the law.

Death with dignity also complements hospice and palliative care services. In a comprehensive study conducted with family members of 86 Oregonians who were participating in death with dignity, researchers [5] concluded:

> "…another concern regarding the legalization of PAD [physician aid in dying] is that PAD would become a substitute for quality end of life care…Insofar as family rating of the quality of a loved one's death is an indicator of end of life care, this

> study adds to the evidence that the choice to pursue PAD does not appear to be due to, or a reflection of, poorer end of life care."

Opponents of death with dignity spill 100 pills on a table, claiming that individuals using death with dignity must ingest all of them and asserting that the practice in Oregon was undignified. While visually startling, it is an outright untruth. No patient in any jurisdiction has been forced to ingest 100 pill capsules. It does not and cannot work that way.

Some claim a health insurance company denied them treatment, but offered medication to hasten death. It is true that insurance companies both deny treatment and cover the provisions under death with dignity laws, but linking them together to suggest that an insurance company would deny care and instead offer death with dignity, is a falsehood. Not one of these claims has ever come to pass or been independently verified. Not in Oregon. Not in Washington State. Not in Vermont. California, Colorado, Washington, D.C., Hawaii, New Jersey, Maine. Nowhere.

What we do know is that opposition to medical aid in dying comes largely from religious groups that say only God can decide when to end one's life. That is why this law contains clear opt-out provisions for medical professionals and states that only those who meet the strict criteria and safeguards in this law will be able to receive this prescription.

It is no coincidence that the very first state to pass death with dignity—Oregon—was recently identified in an article published in the *New England Journal of Medicine* [6] as a state with significant and positive differences in how people die, as compared with other states in the country. We do better than the rest of the country in such benchmarks as the number of people who die at home (as opposed to the hospital), the number of people using hospice, and the number of people who received intensive care services at the end of life. The passage of our law and subsequent end-of-life policy changes sent a signal nationwide, and in Oregon, that dying patients must be accorded more and better care. Death with dignity is part of that equation.

National research published in the *New England Journal of Medicine* indicates that physicians in every state, including Maryland [3], help patients die using prescription medication. By enacting this law, the Maryland Senate will send a strong message that a compassionate response to suffering is available in the state through medical aid in dying, but physicians must follow the carefully regulated safeguards you are considering today. The state of Maryland will shine a bright light on the process to ensure the protection of vulnerable individuals.

As legislators in this great state, if you want to improve the quality of life for dying individuals in your jurisdiction, there is nothing better that you can do than to enact a death with dignity statute. That's what the data tell us. It will be rarely used, but a great source of comfort. Its safeguards will protect vulnerable individuals from coercion.

Physicians in your state are already providing medications to patients to end their lives, but without state oversight. Medical aid in dying will likely improve the quality of end of life care for the whole population, not just for people who contemplate it or use it.

Like many other individuals with a terminal illness who have shared their stories with you and me, Christine Hodgdon cannot control the trajectory of her disease. But she should have control over the time and manner of her death: the right to die on her own terms, with autonomy and peace of mind.

It is time for dying patients in Maryland to have access to this end-of-life option. I urge you to vote yes on Senate Bill 701.

Peg Sandeen, PhD, MSW
Executive Director
Death with Dignity National Center

References (all items are appended in full text in the order listed)

[1] Gonzales Maryland Poll. Gonzales Research & Media Studies, January 2020.

[2] Oregon Public Health Division. Death with Dignity Act Annual Report, Year 21. Available at https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf Accessed February 27, 2020.

[3] Meier, D. E., Emmons, C. A., Wallenstein, S., Quill, T. Morrison, R. S., & Cassel, C. K. (1998). “A national survey of physician-assisted suicide and euthanasia in the United States.” *New England Journal of Medicine*, 338(17), pp. 1193-1201.

[4] Battin, M. P., van der Heide, A., Ganzini, L, van der Wal, G., & Onwuteaka-Philipsen, B. D. (2007). “Legal physician-assisted dying in Oregon and the Netherlands: Evidence concerning the impact on patients in ‘vulnerable’ groups.” *Journal of Medical Ethics*, 33, pp. 591-597.

[5] Smith, K. A., Goy, E. R., Harvath, T. A., & Ganzine L. (2011). “Quality of death and dying in patients who request physician-assisted death.” *Journal of Palliative Medicine*, 14(4), pp. 1-6.

[6] Tolle, S. W., & Teno, J. M. (2017). “Lessons from Oregon in embracing complexity in end-of-life care.” *New England Journal of Medicine*, 376(11), pp. 1078-1082.

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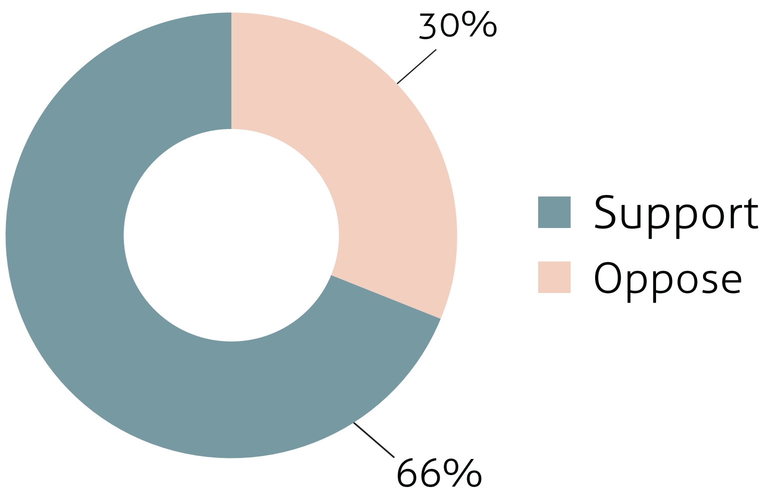
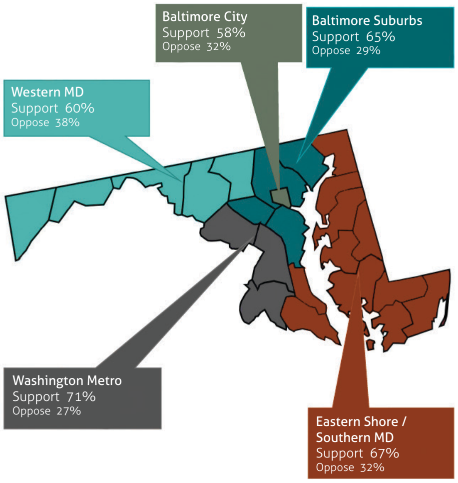
Death with Dignity
NATIONAL CENTER
www.deathwithdignity.org

Polling Shows Strong Support for Death with Dignity in Maryland

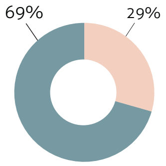
A January 2020 poll conducted by Gonzales Research & Media Services[1] shows 66 percent of Maryland voters favor "legislation that would allow a terminally ill adult patient to obtain a physician's prescription for drugs to end his or her life, voluntarily, and with informed choice."



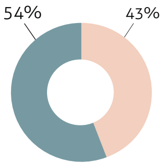


Majorities of Maryland residents in all regions of the state, across the political spectrum, and from all demographic groups support the End-of-Life Option Act.

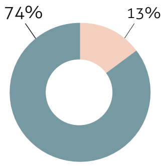
Democrat



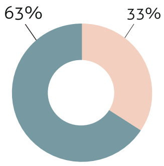
Republican



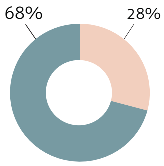
Unaffiliated



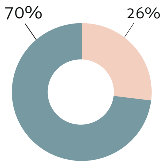
Men



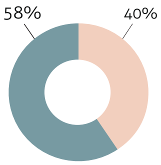
Women



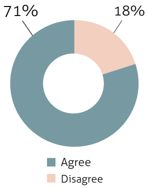
White

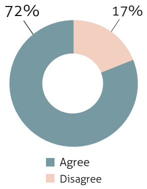


African American



"Adults in the final stages of a terminal disease have a right to stop their suffering if they choose."





"We have the right to make our own medical decisions without government interference."

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[1] *This poll was conducted by Gonzales Research & Media Services from December 23rd through January 4th, 2020. A total of 838 registered voters in Maryland, who indicated that they are likely to vote in the 2020 general election, were queried by live telephone interviews, utilizing both landline (39%) and cell phone (61%) numbers. A cross-section of interviews was conducted throughout the state, reflecting general election voting patterns. The margin of error (MOE), per accepted statistical standards, is a range of plus or minus 3.5 percentage points. If the entire population was surveyed, there is a 95% probability that the true numbers would fall within this range.*

January 2020

Gonzales Maryland Poll

Gonzales Poll

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Background and Methodology

Patrick E. Gonzales graduated magna cum laude from the University of Baltimore with a degree in political science.

His career in the field of public opinion research began in the mid-1980s as an analyst with *Mason-Dixon Opinion Research*. During this time, Mr. Gonzales helped develop, craft and implement election surveys and exit polls for television and radio in the Baltimore-Washington D.C. metro area.

Mr. Gonzales has polled and analyzed well over a thousand elections in Maryland and across the country since that time. Furthermore, he and his associates have conducted numerous market research projects, crafting message development plans and generating strategy blueprints for businesses and organizations throughout the state.

Over his 35 years conducting public opinion polls, Patrick Gonzales has been widely recognized by his peers for his ability to conduct unbiased surveys, and analyze the results in an impartial, evenhanded manner.

Mr. Gonzales frequently appears on radio and television in the Baltimore-D.C. region as a guest commentator.

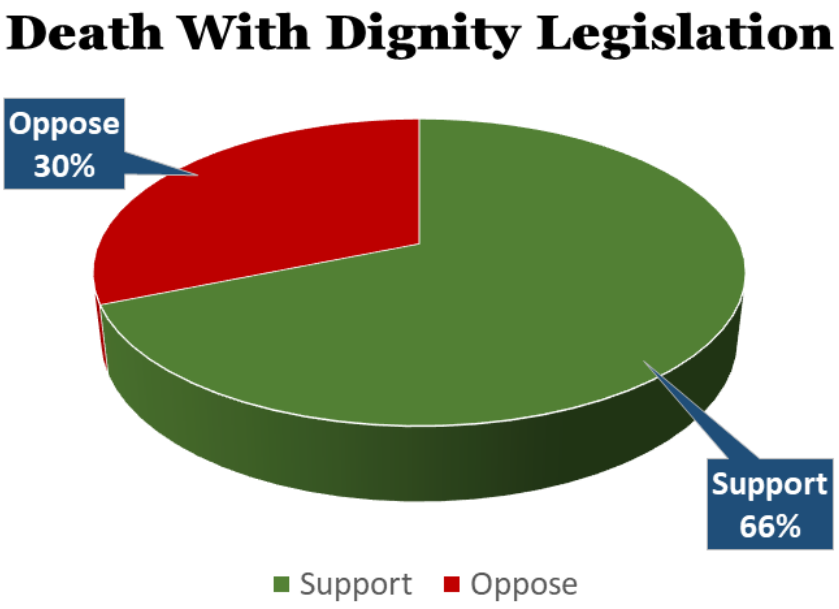
This poll was conducted by ***Gonzales Research & Media Services*** from December 23rd through January 4th, 2020. A total of 838 registered voters in Maryland, who indicated that they are likely to vote in the 2020 general election, were queried by live telephone interviews, utilizing both landline (39%) and cell phone (61%) numbers. A cross-section of interviews was conducted throughout the state, reflecting general election voting patterns.

The margin of error (MOE), per accepted statistical standards, is a range of plus or minus 3.5 percentage points. If the entire population was surveyed, there is a 95% probability that the true numbers would fall within this range.

Gonzales January 2020 Poll Results

Death With Dignity Legislation

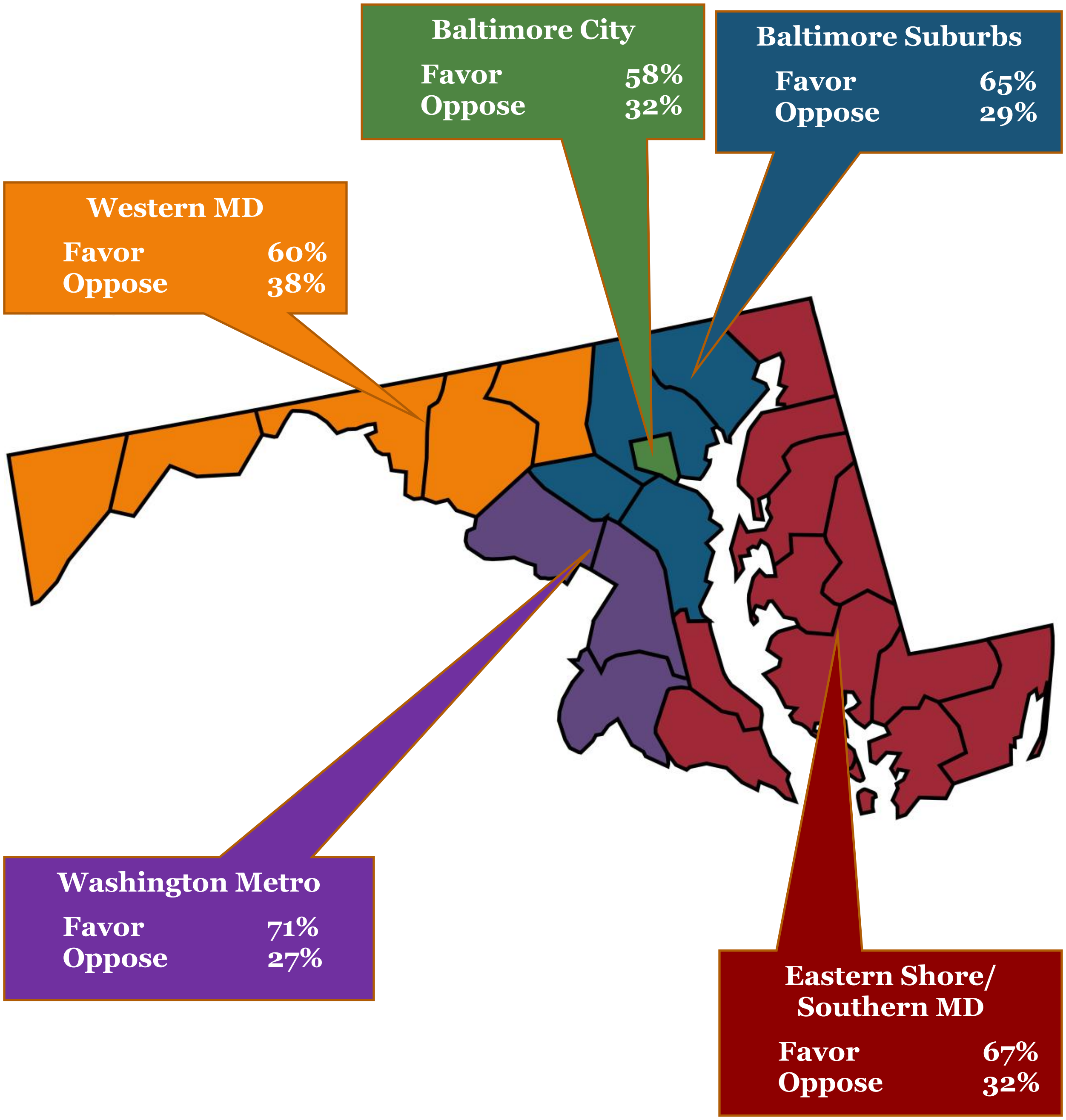
Among Maryland voters, a decisive 66% favor "legislation that would allow a terminally ill adult patient to obtain a physician's prescription for drugs to end his or her life, voluntarily, and with informed choice" (44% "strongly favor" and 22% "somewhat favor"), while 30% oppose such legislation (18% "strongly oppose" and 12% "somewhat oppose"), with 4% providing no response.



The results by party, gender, and race:

Death With Dignity Legislation	**Favor**	**Oppose**
Democrat	69%	29%
Republican	54%	43%
Unaffiliated	74%	13%
Men	63%	33%
Women	68%	28%
White	70%	26%
African-American	58%	40%

Death With Dignity Legislation by Region



Doctors Should Never Help Patient Die or Adults Have Right to Stop Suffering

We asked Marylanders whether, "*Doctors should never take part in any activities that would help a patient die,"* or "*Adults in the final stages of a terminal disease have a right to stop their suffering if they choose"* came closer to their point of view.

Statewide, 71% say that adults in the final stages of a terminal disease have a right to stop their suffering, while 18% say that a doctor should never help a patient die, with 11% offering no opinion.

The results by gender and race:

Doctors Never or Adults' Right	**Doctors Never**	**Adults' Right**
Men	21%	69%
Women	15%	73%
White	14%	74%
African-American	28%	64%

Suicide is Morally Wrong or Right to Make Own Medical Decisions

We also asked whether, "*No matter the circumstances, suicide is morally wrong and the law should not permit it,"* or "*We have a right to make our own medical decisions without interference from the government"* came closer to their viewpoint.

Statewide, 72% say that we have the right to make our own medical decisions without government interference, while 17% say that suicide is morally wrong and the law should never permit it.

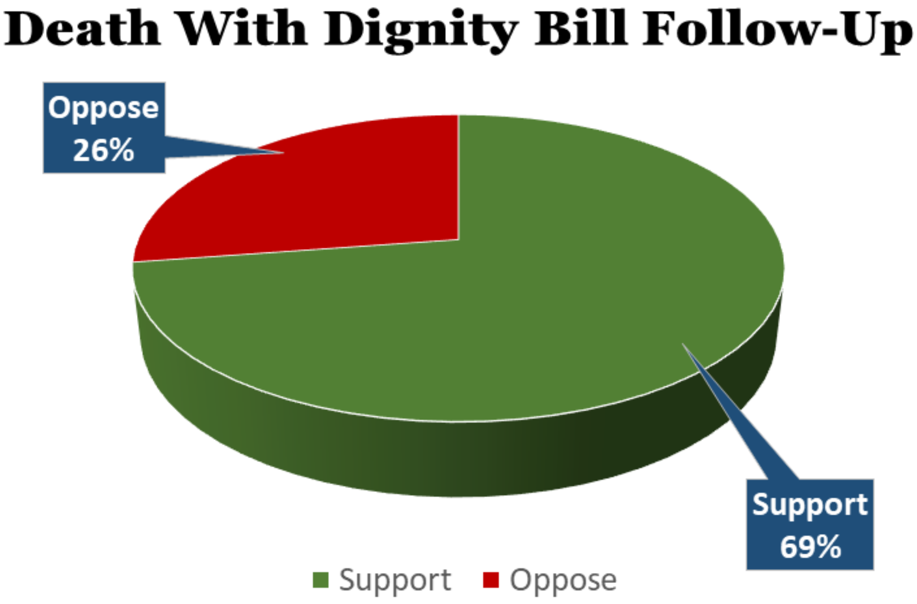
The results by gender and race:

Morally Wrong or Own Decision	**Morally Wrong**	**Own Decision**
Men	18%	70%
Women	16%	74%
White	15%	73%
African-American	21%	70%

Death With Dignity Bill Follow-Up

We ended by asking Maryland voters, "*The Maryland General Assembly is considering a death with dignity bill that would allow a terminally ill adult patient to voluntarily make an informed choice to obtain a physician's prescription for drugs to end his or her life, with the consultation of his/her doctor, family, and faith. Do you favor or oppose this legislation"*

This time, 69% favor a death with dignity bill, (45% "strongly favor" and 24% "somewhat favor"), while 26% oppose it (17% "strongly oppose" and 9% "somewhat oppose"), with 5% providing no response.



A comparison of support between the 2 questions by party, gender, and race:

Support Comparison	**Favor Question 1**	**Favor Question 2**
Democrat	69%	71%
Republican	54%	57%
Unaffiliated	74%	82%
Men	63%	68%
Women	68%	70%
White	70%	73%
African-American	58%	61%

Appendix A: Data Tables

QUESTION: Death With Dignity Legislation *The Maryland General Assembly is considering death with dignity legislation that would allow a terminally ill adult patient to obtain a physician's prescription for drugs to end his or her life, voluntarily, and with informed choice.*

Do you favor or oppose this legislation?

DEATH WITH DIGNITY LEGISLATION	Number	Percent
Favor	552	65.9 %
Oppose	253	30.2 %
No answer	33	3.9 %
Total	838	100.0 %

N=838	DEATH WITH DIGNITY LEGISLATION		
	Favor	Oppose	No answer
PARTY			
Democrat	326	136	8
	69.4%	28.9%	1.7%
Republican	127	100	7
	54.3%	42.7%	3.0%
Unaffiliated	99	17	18
	73.9%	12.7%	13.4%

N=838	DEATH WITH DIGNITY LEGISLATION		
	Favor	Oppose	No answer
GENDER			
Male	242	127	13
	63.4%	33.2%	3.4%
Female	310	126	20
	68.0%	27.6%	4.4%

N=838	DEATH WITH DIGNITY LEGISLATION		
	Favor	Oppose	No answer
AGE GROUP			
Under 50	256 69.6%	95 25.8%	17 4.6%
50 or older	296 63.0%	158 33.6%	16 3.4%

N=838	DEATH WITH DIGNITY LEGISLATION		
	Favor	Oppose	No answer
AGE			
18 to 39	137 72.9%	38 20.2%	13 6.9%
40 to 49	119 66.1%	57 31.7%	4 2.2%
50 to 59	122 63.9%	62 32.5%	7 3.7%
60 and older	174 62.4%	96 34.4%	9 3.2%

N=838	DEATH WITH DIGNITY LEGISLATION		
	Favor	Oppose	No answer
RACE			
White	376 69.8%	138 25.6%	25 4.6%
African-American	142 58.4%	96 39.5%	5 2.1%
Other/ Refused	34 60.7%	19 33.9%	3 5.4%

N=838	DEATH WITH DIGNITY LEGISLATION		
	Favor	Oppose	No answer
REGION			
Baltimore Metro	228 63.3%	108 30.0%	24 6.7%
Washington Metro	202 70.9%	77 27.0%	6 2.1%
Rural Maryland	122 63.2%	68 35.2%	3 1.6%

N=838	DEATH WITH DIGNITY LEGISLATION		
	Favor	Oppose	No answer
COUNTY			
Anne Arundel Co.	59 72.8%	17 21.0%	5 6.2%
Baltimore County	70 59.8%	43 36.8%	4 3.4%
Charles County	14 58.3%	10 41.7%	0 0.0%
Harford County	26 65.0%	11 27.5%	3 7.5%
Howard County	31 62.0%	14 28.0%	5 10.0%
Montgomery County	113 79.6%	24 16.9%	5 3.5%
Prince George's Co.	75 63.0%	43 36.1%	1 0.8%
Baltimore City	42 58.3%	23 31.9%	7 9.7%
Eastern Shore	63 67.0%	30 31.9%	1 1.1%
Western Maryland	59 59.6%	38 38.4%	2 2.0%

QUESTION: Death With Dignity Legislation - Intensity *The Maryland General Assembly is considering death with dignity legislation that would allow a terminally ill adult patient to obtain a physician's prescription for drugs to end his or her life, voluntarily, and with informed choice.*

Do you favor or oppose this legislation?

Is that strongly or somewhat favor/oppose?

DEATH WITH DIGNITY LEGISLATION	Number	Percent
Strongly Favor	369	44.0 %
Somewhat Favor	183	21.8 %
Somewhat Oppose	101	12.1 %
Strongly Oppose	152	18.1 %
No answer	33	3.9 %
Total	838	100.0 %

N=838	DEATH WITH DIGNITY LEGISLATION				
	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
PARTY					
Democrat	238 50.6%	88 18.7%	62 13.2%	74 15.7%	8 1.7%
Republican	71 30.3%	56 23.9%	29 12.4%	71 30.3%	7 3.0%
Unaffiliated	60 44.8%	39 29.1%	10 7.5%	7 5.2%	18 13.4%

N=838	DEATH WITH DIGNITY LEGISLATION				
	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
GENDER					
Male	142 37.2%	100 26.2%	58 15.2%	69 18.1%	13 3.4%
Female	227 49.8%	83 18.2%	43 9.4%	83 18.2%	20 4.4%

N=838

DEATH WITH DIGNITY LEGISLATION

	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
AGE GROUP					
Under 50	178 48.4%	78 21.2%	44 12.0%	51 13.9%	17 4.6%
50 or older	191 40.6%	105 22.3%	57 12.1%	101 21.5%	16 3.4%

N=838

DEATH WITH DIGNITY LEGISLATION

	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
AGE					
18 to 39	101 53.7%	36 19.1%	19 10.1%	19 10.1%	13 6.9%
40 to 49	77 42.8%	42 23.3%	25 13.9%	32 17.8%	4 2.2%
50 to 59	80 41.9%	42 22.0%	25 13.1%	37 19.4%	7 3.7%
60 and older	111 39.8%	63 22.6%	32 11.5%	64 22.9%	9 3.2%

N=838

DEATH WITH DIGNITY LEGISLATION

	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
RACE					
White	273 50.6%	103 19.1%	45 8.3%	93 17.3%	25 4.6%
African-American	75 30.9%	67 27.6%	49 20.2%	47 19.3%	5 2.1%
Other/ Refused	21 37.5%	13 23.2%	7 12.5%	12 21.4%	3 5.4%

N=838	DEATH WITH DIGNITY LEGISLATION				
	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
REGION					
Baltimore Metro	150	78	45	63	24
	41.7%	21.7%	12.5%	17.5%	6.7%
Washington Metro	133	69	31	46	6
	46.7%	24.2%	10.9%	16.1%	2.1%
Rural Maryland	86	36	25	43	3
	44.6%	18.7%	13.0%	22.3%	1.6%

N=838	DEATH WITH DIGNITY LEGISLATION				
	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
COUNTY					
Anne Arundel Co.	42	17	7	10	5
	51.9%	21.0%	8.6%	12.3%	6.2%
Baltimore County	42	28	21	22	4
	35.9%	23.9%	17.9%	18.8%	3.4%
Charles County	6	8	3	7	0
	25.0%	33.3%	12.5%	29.2%	0.0%
Harford County	18	8	3	8	3
	45.0%	20.0%	7.5%	20.0%	7.5%
Howard County	23	8	6	8	5
	46.0%	16.0%	12.0%	16.0%	10.0%
Montgomery County	79	34	10	14	5
	55.6%	23.9%	7.0%	9.9%	3.5%
Prince George's Co.	48	27	18	25	1
	40.3%	22.7%	15.1%	21.0%	0.8%
Baltimore City	25	17	8	15	7
	34.7%	23.6%	11.1%	20.8%	9.7%
Eastern Shore	48	15	12	18	1
	51.1%	16.0%	12.8%	19.1%	1.1%
Western Maryland	38	21	13	25	2
	38.4%	21.2%	13.1%	25.3%	2.0%

QUESTION: Doctors Never or Stop Suffering *Which of the following statements comes closer to your view?* (ORDER ROTATED)

- *Doctors should never take part in any activities that would help a patient die.*

  OR

- *Adults in the final stages of a terminal disease have a right to stop their suffering if they choose.*

DOCTORS NEVER or STOP SUFFERING	Number	Percent
Doctors Never	148	17.7 %
Stop Suffering	596	71.1 %
No answer	94	11.2 %
Total	838	100.0 %

N=838	DOCTORS NEVER or STOP SUFFERING		
	Doctors Never	Stop Suffering	No answer
PARTY			
Democrat	89 18.9%	340 72.3%	41 8.7%
Republican	52 22.2%	152 65.0%	30 12.8%
Unaffiliated	7 5.2%	104 77.6%	23 17.2%

N=838	DOCTORS NEVER or STOP SUFFERING		
	Doctors Never	Stop Suffering	No answer
GENDER			
Male	81 21.2%	263 68.8%	38 9.9%
Female	67 14.7%	333 73.0%	56 12.3%

N=838	DOCTORS NEVER or STOP SUFFERING		
	Doctors Never	Stop Suffering	No answer
AGE GROUP			
Under 50	47 12.8%	271 73.6%	50 13.6%
50 or older	101 21.5%	325 69.1%	44 9.4%

N=838	DOCTORS NEVER or STOP SUFFERING		
	Doctors Never	Stop Suffering	No answer
AGE			
18 to 39	20 10.6%	145 77.1%	23 12.2%
40 to 49	27 15.0%	126 70.0%	27 15.0%
50 to 59	41 21.5%	137 71.7%	13 6.8%
60 and older	60 21.5%	188 67.4%	31 11.1%

N=838	DOCTORS NEVER or STOP SUFFERING		
	Doctors Never	Stop Suffering	No answer
RACE			
White	73 13.5%	401 74.4%	65 12.1%
African-American	68 28.0%	156 64.2%	19 7.8%
Other/ Refused	7 12.5%	39 69.6%	10 17.9%

N=838	DOCTORS NEVER or STOP SUFFERING		
	Doctors Never	Stop Suffering	No answer
REGION			
Baltimore Metro	56 15.6%	266 73.9%	38 10.6%
Washington Metro	58 20.4%	202 70.9%	25 8.8%
Rural Maryland	34 17.6%	128 66.3%	31 16.1%

N=838	DOCTORS NEVER or STOP SUFFERING		
	Doctors Never	Stop Suffering	No answer
COUNTY			
Anne Arundel Co.	8 9.9%	69 85.2%	4 4.9%
Baltimore County	23 19.7%	78 66.7%	16 13.7%
Charles County	10 41.7%	13 54.2%	1 4.2%
Harford County	3 7.5%	31 77.5%	6 15.0%
Howard County	8 16.0%	38 76.0%	4 8.0%
Montgomery County	16 11.3%	112 78.9%	12 8.5%
Prince George's Co.	32 26.9%	75 63.0%	12 10.1%
Baltimore City	14 19.4%	50 69.4%	8 11.1%
Eastern Shore	16 17.0%	68 72.3%	10 10.6%
Western Maryland	18 18.2%	60 60.6%	23 23.2%

QUESTION: Morally Wrong or Make Own Decisions *Which of the following statements comes closer to your view?* (ORDER ROTATED)

- *No matter the circumstances, suicide is morally wrong and the law should not permit it.*

  OR

- *We have a right to make our own medical decisions without interference from the government.*

MORALLY WRONG or MAKE OWN DECISION	Number	Percent
Morally Wrong	141	16.8 %
Make Own Decision	604	72.1 %
No answer	93	11.1 %
Total	838	100.0 %

N=838	MORALLY WRONG or MAKE OWN DECISION		
	Morally Wrong	Make Own Decision	No answer
PARTY			
Democrat	81 17.2%	347 73.8%	42 8.9%
Republican	46 19.7%	163 69.7%	25 10.7%
Unaffiliated	14 10.4%	94 70.1%	26 19.4%

N=838	MORALLY WRONG or MAKE OWN DECISION		
	Morally Wrong	Make Own Decision	No answer
GENDER			
Male	67 17.5%	268 70.2%	47 12.3%
Female	74 16.2%	336 73.7%	46 10.1%

N=838	MORALLY WRONG or MAKE OWN DECISION		
	Morally Wrong	Make Own Decision	No answer
AGE GROUP			
Under 50	49 13.3%	271 73.6%	48 13.0%
50 or older	92 19.6%	333 70.9%	45 9.6%

N=838	MORALLY WRONG or MAKE OWN DECISION		
	Morally Wrong	Make Own Decision	No answer
AGE			
18 to 39	22 11.7%	134 71.3%	32 17.0%
40 to 49	27 15.0%	137 76.1%	16 8.9%
50 to 59	39 20.4%	141 73.8%	11 5.8%
60 and older	53 19.0%	192 68.8%	34 12.2%

N=838	MORALLY WRONG or MAKE OWN DECISION		
	Morally Wrong	Make Own Decision	No answer
RACE			
White	81 15.0%	393 72.9%	65 12.1%
African-American	51 21.0%	171 70.4%	21 8.6%
Other/ Refused	9 16.1%	40 71.4%	7 12.5%

N=838	MORALLY WRONG or MAKE OWN DECISION		
	Morally Wrong	Make Own Decision	No answer
REGION			
Baltimore Metro	50 13.9%	263 73.1%	47 13.1%
Washington Metro	56 19.6%	215 75.4%	14 4.9%
Rural Maryland	35 18.1%	126 65.3%	32 16.6%

N=838	MORALLY WRONG or MAKE OWN DECISION		
	Morally Wrong	Make Own Decision	No answer
COUNTY			
Anne Arundel Co.	6 7.4%	66 81.5%	9 11.1%
Baltimore County	23 19.7%	81 69.2%	13 11.1%
Charles County	7 29.2%	14 58.3%	3 12.5%
Harford County	2 5.0%	29 72.5%	9 22.5%
Howard County	5 10.0%	37 74.0%	8 16.0%
Montgomery County	23 16.2%	115 81.0%	3 2.1%
Prince George's Co.	26 21.8%	86 72.3%	7 5.9%
Baltimore City	14 19.4%	50 69.4%	8 11.1%
Eastern Shore	16 17.0%	65 69.1%	13 13.8%
Western Maryland	19 19.2%	61 61.6%	19 20.4%

QUESTION: Death With Dignity Follow-Up *The Maryland General Assembly is considering a death with dignity bill that would allow a terminally ill adult patient to voluntarily make an informed choice to obtain a physician's prescription for drugs to end his or her life, with the consultation of his/her doctor, family, and faith.*

Do you favor or oppose this legislation?

DEATH WITH DIGNITY LEGISLATION FOLLOW-UP	Number	Percent
Favor	579	69.1 %
Oppose	220	26.3 %
No answer	39	4.7 %
Total	838	100.0 %

N=838	DEATH WITH DIGNITY LEGISLATION FOLLOW-UP		
	Favor	Oppose	No answer
PARTY			
Democrat	335 71.3%	120 25.5%	15 3.2%
Republican	134 57.3%	88 37.6%	12 5.1%
Unaffiliated	110 82.1%	12 9.0%	12 9.0%

N=838	DEATH WITH DIGNITY LEGISLATION FOLLOW-UP		
	Favor	Oppose	No answer
GENDER			
Male	258 67.5%	104 27.2%	20 5.2%
Female	321 70.4%	116 25.4%	19 4.2%

N=838

	DEATH WITH DIGNITY LEGISLATION FOLLOW-UP		
	Favor	Oppose	No answer
AGE GROUP			
Under 50	272 73.9%	79 21.5%	17 4.6%
50 or older	307 65.3%	141 30.0%	22 4.7%

N=838

	DEATH WITH DIGNITY LEGISLATION FOLLOW-UP		
	Favor	Oppose	No answer
AGE			
18 to 39	151 80.3%	28 14.9%	9 4.8%
40 to 49	121 67.2%	51 28.3%	8 4.4%
50 to 59	132 69.1%	53 27.7%	6 3.1%
60 and older	175 62.7%	88 31.5%	16 5.7%

N=838

	DEATH WITH DIGNITY LEGISLATION FOLLOW-UP		
	Favor	Oppose	No answer
RACE			
White	393 72.9%	120 22.3%	26 4.8%
African-American	147 60.5%	85 35.0%	11 4.5%
Other/ Refused	39 69.6%	15 26.8%	2 3.6%

N=838	DEATH WITH DIGNITY LEGISLATION FOLLOW-UP		
	Favor	Oppose	No answer
REGION			
Baltimore Metro	244 67.8%	96 26.7%	20 5.6%
Washington Metro	205 71.9%	65 22.8%	15 5.3%
Rural Maryland	130 67.4%	59 30.6%	4 2.1%

N=838	DEATH WITH DIGNITY LEGISLATION FOLLOW-UP		
	Favor	Oppose	No answer
COUNTY			
Anne Arundel Co.	61 75.3%	15 18.5%	5 6.2%
Baltimore County	75 64.1%	38 32.5%	4 3.4%
Charles County	13 54.2%	9 37.5%	2 8.3%
Harford County	26 65.0%	11 27.5%	3 7.5%
Howard County	34 68.0%	10 20.0%	6 12.0%
Montgomery County	114 80.3%	19 13.4%	9 6.3%
Prince George's Co.	78 65.5%	37 31.1%	4 3.4%
Baltimore City	48 66.7%	22 30.6%	2 2.8%
Eastern Shore	66 70.2%	26 27.7%	2 2.1%
Western Maryland	64 64.6%	33 33.3%	2 2.0%

QUESTION: Death With Dignity Follow-Up - Intensity *The Maryland General Assembly is considering a death with dignity bill that would allow a terminally ill adult patient to voluntarily make an informed choice to obtain a physician's prescription for drugs to end his or her life, with the consultation of his/her doctor, family, and faith.*

Do you favor or oppose this legislation?

Is that strongly or somewhat favor/oppose?

DEATH WITH DIGNITY LEGISLATION FOLLOW-UP	Number	Percent
Strongly Favor	375	44.7 %
Somewhat Favor	204	24.3 %
Somewhat Oppose	80	9.5 %
Strongly Oppose	140	16.7 %
No answer	39	4.7 %
Total	838	100.0 %

N=838	DEATH WITH DIGNITY LEGISLATION FOLLOW-UP				
	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
PARTY					
Democrat	226 48.1%	109 23.2%	51 10.9%	69 14.7%	15 3.2%
Republican	85 36.3%	49 20.9%	24 10.3%	64 27.4%	12 5.1%
Unaffiliated	64 47.8%	46 34.3%	5 3.7%	7 5.2%	12 9.0%

N=838	DEATH WITH DIGNITY LEGISLATION FOLLOW-UP				
	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
GENDER					
Male	159 41.6%	99 25.9%	40 10.5%	64 16.8%	20 5.2%
Female	216 47.4%	105 23.0%	40 8.8%	76 16.7%	19 4.2%

N=838

DEATH WITH DIGNITY LEGISLATION FOLLOW-UP

	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
AGE GROUP					
Under 50	176 47.8%	96 26.1%	36 9.8%	43 11.7%	17 4.6%
50 or older	199 42.3%	108 23.0%	44 9.4%	97 20.6%	22 4.7%

N=838

DEATH WITH DIGNITY LEGISLATION FOLLOW-UP

	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
AGE					
18 to 39	98 52.1%	53 28.2%	14 7.4%	14 7.4%	9 4.8%
40 to 49	78 43.3%	43 23.9%	22 12.2%	29 16.1%	8 4.4%
50 to 59	85 44.5%	47 24.6%	18 9.4%	35 18.3%	6 3.1%
60 and older	114 40.9%	61 21.9%	26 9.3%	62 22.2%	16 5.7%

N=838

DEATH WITH DIGNITY LEGISLATION FOLLOW-UP

	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
RACE					
White	272 50.5%	121 22.4%	42 7.8%	78 14.5%	26 4.8%
African-American	82 33.7%	65 26.7%	32 13.2%	53 21.8%	11 4.5%
Other/ Refused	21 37.5%	18 32.1%	6 10.7%	9 16.1%	2 3.6%

N=838

	DEATH WITH DIGNITY LEGISLATION FOLLOW-UP				
	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
REGION					
Baltimore Metro	155 43.1%	89 24.7%	31 8.6%	65 18.1%	20 5.6%
Washington Metro	127 44.6%	66 23.2%	30 10.5%	47 16.5%	15 5.3%
Rural Maryland	93 48.2%	49 25.4%	19 9.8%	28 14.5%	4 2.1%

N=838

	DEATH WITH DIGNITY LEGISLATION FOLLOW-UP				
	Strongly Favor	Somewhat Favor	Somewhat Oppose	Strongly Oppose	No answer
COUNTY					
Anne Arundel Co.	45 55.6%	16 19.8%	3 3.7%	12 14.8%	5 6.2%
Baltimore County	46 39.3%	29 24.8%	16 13.7%	22 18.8%	4 3.4%
Charles County	5 20.8%	8 33.3%	3 12.5%	6 25.0%	2 8.3%
Harford County	17 42.5%	9 22.5%	3 7.5%	8 20.0%	3 7.5%
Howard County	21 42.0%	13 26.0%	3 6.0%	7 14.0%	6 12.0%
Montgomery County	78 54.9%	36 25.4%	13 9.2%	6 4.2%	9 6.3%
Prince George's Co.	54 45.4%	24 20.2%	12 10.1%	25 21.0%	4 3.4%
Baltimore City	26 36.1%	22 30.6%	6 8.3%	16 22.2%	2 2.8%
Eastern Shore	49 52.1%	17 18.1%	9 9.6%	17 18.1%	2 2.1%
Western Maryland	34 34.3%	30 30.3%	12 12.1%	21 21.2%	2 2.0%

Appendix B: Maryland Poll Sample Demographics

PARTY	Number	Percent
Democrat	470	56.1 %
Republican	234	27.9 %
Unaffiliated	134	16.0 %
Total	838	100.0 %

AGE	Number	Percent
18 to 39	188	22.4 %
40 to 49	180	21.5 %
50 to 59	191	22.8 %
60 and older	279	33.3 %
Total	838	100.0 %

AGE GROUP	Number	Percent
Under 50	368	43.9 %
50 or older	470	56.1 %
Total	838	100.0 %

RACE	Number	Percent
White	539	64.3 %
African-American	243	29.0 %
Hispanic	56	6.7 %
Total	838	100.0 %

GENDER	Number	Percent
Male	382	45.6 %
Female	456	54.4 %
Total	838	100.0 %

REGION	Number	Percent
Baltimore Metro	360	43.0 %
Washington Metro	285	34.0 %
Rural Maryland	193	23.0 %
Total	838	100.0 %

Region Classifications

Baltimore Metro	Number	Percent
Baltimore City	72	20.0 %
Anne Arundel County	81	22.5 %
Baltimore County	117	32.5 %
Harford County	40	11.1 %
Howard County	50	13.9 %
Total	360	100.0 %

Washington Metro	Number	Percent
Montgomery County	142	49.8 %
Prince George's County	119	41.8 %
Charles County	24	8.4 %
Total	285	100.0 %

Rural Maryland	Number	Percent
Eastern Shore/Southern Maryland	94	48.7 %
Western Maryland	99	51.3 %
Total	193	100.0 %

2018

Oregon Death with Dignity Act

2018 Data Summary

Oregon Health Authority
PUBLIC HEALTH DIVISION

Acknowledgments

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

Date: February 15, 2019

Revised April 25, 2019: The percents shown for end of life concerns were recalculated on April 25, 2019. See Table 1, footnote 7 for details.

For more information, see: www.healthoregon.org/dwd

Contact: DWDA.INFO@state.or.us

Executive summary

The Oregon Death with Dignity Act (DWDA) allows terminally ill Oregonians who meet specific qualifications to end their lives through the voluntary self-administration of a lethal dose of medications, expressly prescribed by a physician for that purpose. The Act requires the Oregon Health Authority to collect information about the patients and physicians who participate in the Act and to publish an annual statistical report. In 2018, 249 people received prescriptions under the DWDA. As of January 22, 2019, 168 people had died in 2018 from ingesting the prescribed medications, including 11 who had received the prescriptions in previous years. Characteristics of DWDA patients were similar to those in previous years: most patients were aged 65 years or older (79.2%), and most had cancer (62.5%). During 2018, two physicians were referred to the Oregon Medical Board for failure to comply with DWDA requirements.

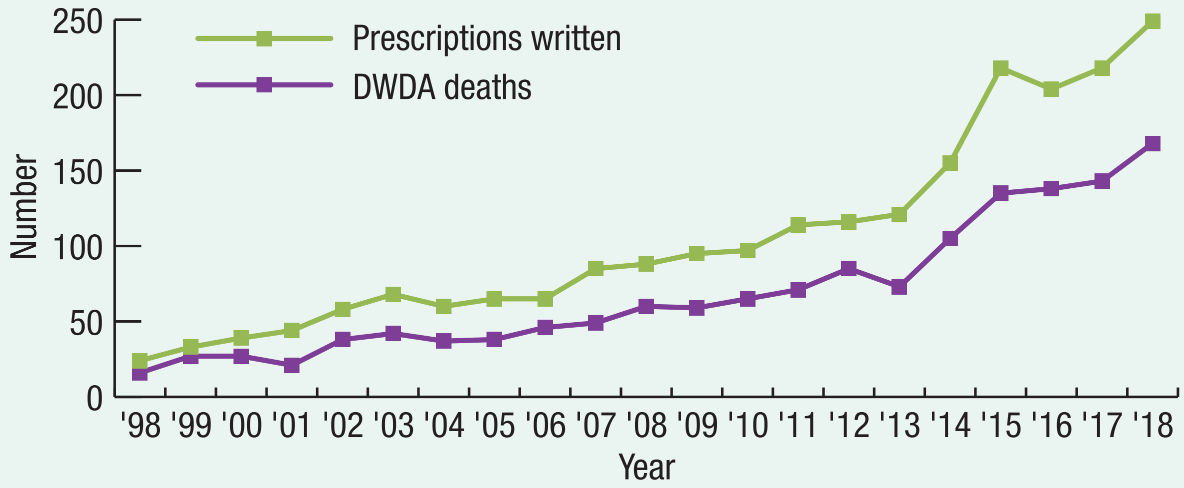
Introduction

The Oregon Death with Dignity Act (DWDA) allows terminally ill Oregonians who meet specific qualifications to end their lives through the voluntary self-administration of a lethal dose of medications, expressly prescribed by a physician for that purpose. The Act requires the Oregon Health Authority (OHA) to collect information about the patients and physicians who participate in the Act and to publish an annual statistical report.

The DWDA outlines specific patient requirements to participate. A patient must be: 1) 18 years of age or older, 2) a resident of Oregon, 3) capable of making and communicating health care decisions to health care practitioners, and 4) diagnosed with a terminal illness that will lead to death within six months. The attending and consulting physicians must determine whether these requirements have been met, and report that fact to OHA at the time a prescription is written. When OHA identifies any issue of noncompliance with the statutory requirements, it reports the fact to the appropriate licensing board.

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 OHA as of January 22, 2019. More information on the reporting process, required forms, and annual reports is available at: http://www.healthoregon.org/dwd.

Figure 1: DWDA prescription recipients and deaths*, by year, Oregon, 1998-2018



**As of January 22, 2019*

See Table 2 for detailed information

Participation summary and trends

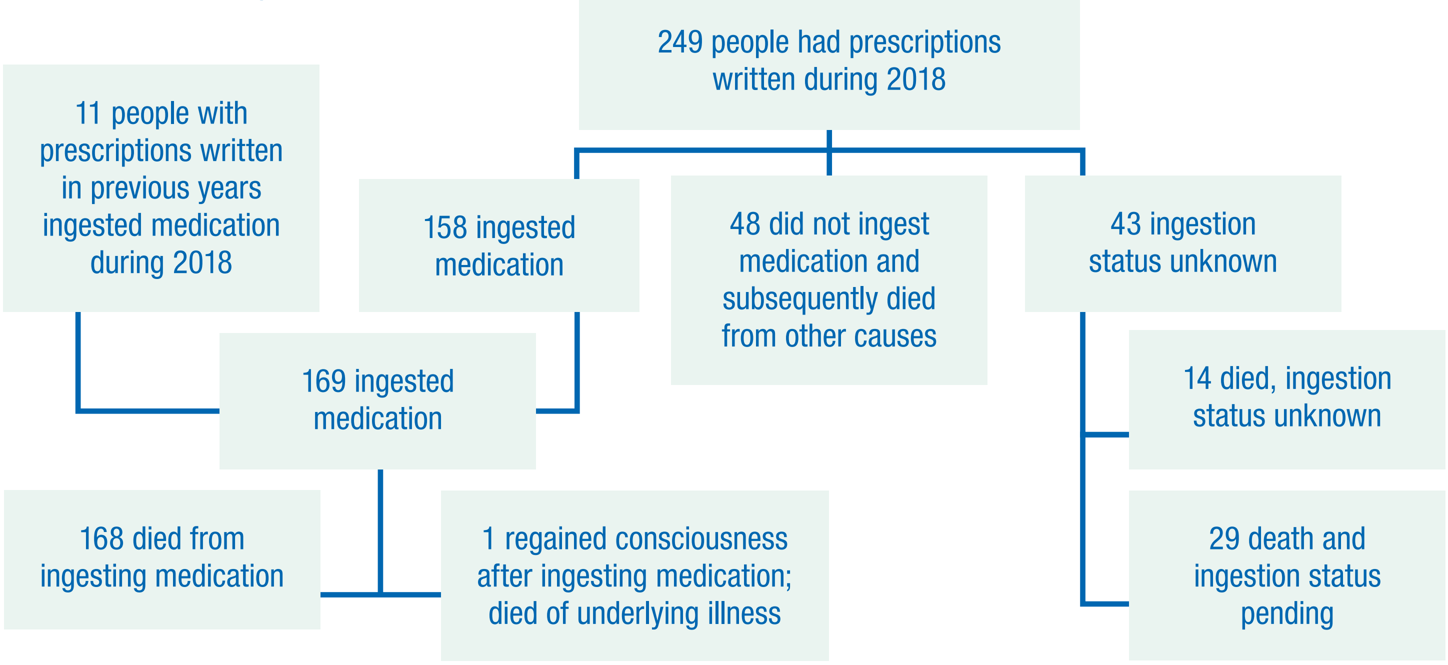
During 2018, 249 people received prescriptions for lethal doses of medications under the provisions of the Oregon DWDA, compared to 219 during 2017 (Figure 1). As of January 22, 2019, OHA had received reports of 168 people who had died during 2018 from ingesting the medications prescribed under DWDA, an increase compared to 158 during 2017.

Since the law was passed in 1997, prescriptions have been written for a total of 2,217 people under the DWDA; 1,459 people (65.8%) have died from ingesting the medications. During 2018, the estimated rate of DWDA deaths was 45.9 per 10,000 total deaths.[1]

A summary of DWDA prescriptions written and medications ingested is shown in Figure 2. Of the 249 patients for whom prescriptions were written during 2018, 158 (63.5%) ingested the medication; 157 died from ingesting the medication, and one patient ingested the medication but regained consciousness before dying from the underlying illness (therefore is not counted as a DWDA death). An additional 48 (19.3%) did not take the medications and subsequently died of other causes.

Ingestion status is unknown for 43 patients prescribed DWDA medications in 2018. Of these, 14 patients died but follow up information is not yet available. For the remaining 29 patients, both death and ingestion status are pending (Figure 2).

Figure 2: Summary of DWDA prescriptions written and medications ingested in 2018, as of January 22, 2018



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[1] Rate per 10,000 deaths calculated using the total number of Oregon resident deaths in 2017 (36,640), the most recent year for which final death data are available.

Patient characteristics

Table 1 shows the characteristics and end-of-life care for 2018 DWDA deaths, total DWDA deaths, and deaths by five-year increments. Of the 168 DWDA deaths during 2018, most patients (79.2%) were aged 65 years or older. The median age at death was 74 years. As in previous years, decedents were commonly white (97.0%) and well educated (47.3% had a least a baccalaureate degree).

Patients' underlying illnesses were similar to those of previous years. Most patients had cancer (62.5%), followed by neurological disease (14.9%) and heart/circulatory disease (9.5%). Most patients (87.5%) died at home, and most (90.5%) were enrolled in hospice care. Excluding unknown cases, most (99.3%) had some form of health care insurance. The proportions of patients who had private insurance (32.4%) and Medicare or Medicaid insurance (66.9%) in 2018 were similar those reported during the past five years (35.8% and 63.3%, respectively).

As in previous years, the three most frequently reported end-of-life concerns were loss of autonomy (91.7%), decreasing ability to participate in activities that made life enjoyable (90.5%), and loss of dignity (66.7%).

DWDA process

A total of 103 physicians wrote 249 prescriptions during 2018 (1–35 prescriptions per physician). The number of attending physicians has increased since 1998, but has been relatively stable for the past four years (Table 2). Approximately one-half of the attending and consulting physicians practiced in the Portland metropolitan area (Table 3). Three patients were referred for psychological or psychiatric evaluation. During 2018, two physicians were referred the Oregon Medical Board for failure to comply with DWDA requirements.

The medications prescribed to DWDA patients in 2018 differed from previous years (Table 1). As in previous years, secobarbital was prescribed to slightly more than half. In 2018, however, 38.1% of patients were prescribed a combination of diazepam, digoxin, morphine sulfate, and propranolol (DDMP), compared to 13.2% in previous years. In addition, no patients were prescribed pentobarbital in 2018 (26.5% of patients in all years).

The procedure was revised 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 is present at the time of death. Prescribing physicians were present at time of death for 28 patients (16.7%); 37 additional patients (22.0%) had other health care providers present (e.g., hospice nurse). Data on time from ingestion to death are available for 62 DWDA deaths (36.9%) during 2018. Among those 62 patients, time from ingestion until death ranged from nine minutes to 14 hours.

Table 4 shows the duration from ingestion to death, by medication prescribed for known cases. The median time until death was longer for the DDMP2 compound (120 min) than for secobarbital (25 min) or pentobarbital (20 min).

Table 1. Characteristics and end-of-life care of 1,459 DWDA patients who have died from ingesting a lethal dose of medication as of January 22, 2019, by year, Oregon, 1998–2018 (Revised April, 2019)

Characteristics	2018		Total		1998-2002		2003-2007		2008-2012		2013-2017	
	(N=168)		(N=1,459)		(N=129)		(N=212)		(N=340)		(N=610)	
Sex	**N (%)[1]**		**N (%)[1]**		**N (%)[1]**		**N (%)[1]**		**N (%)[1]**		**N (%)[1]**	
Male (%)	87	(51.8)	763	(52.3)	71	(55.0)	112	(52.8)	169	(49.7)	324	(53.1)
Female (%)	81	(48.2)	696	(47.7)	58	(45.0)	100	(47.2)	171	(50.3)	286	(46.9)
Age												
18-34 (%)	0	(0.0)	9	(0.6)	2	(1.6)	2	(0.9)	2	(0.6)	3	(0.5)
35-44 (%)	2	(1.2)	28	(1.9)	3	(2.3)	7	(3.3)	5	(1.5)	11	(1.8)
45-54 (%)	9	(5.4)	85	(5.8)	10	(7.8)	21	(9.9)	21	(6.2)	24	(3.9)
55-64 (%)	24	(14.3)	275	(18.8)	21	(16.3)	52	(24.5)	68	(20.0)	110	(18.0)
65-74 (%)	50	(29.8)	441	(30.2)	46	(35.7)	47	(22.2)	101	(29.7)	197	(32.3)
75-84 (%)	54	(32.1)	394	(27.0)	37	(28.7)	61	(28.8)	91	(26.8)	151	(24.8)
85+ (%)	29	(17.3)	227	(15.6)	10	(7.8)	22	(10.4)	52	(15.3)	114	(18.7)
Median years (range)	74	(40-102)	72	(25-102)	69	(25-94)	69	(29-96)	71	(34-96)	73	(29-102)
Race												
White (%)	163	(97.0)	1,402	(96.4)	125	(96.9)	207	(97.6)	330	(97.9)	577	(94.9)
African American (%)	0	(0.0)	1	(0.1)	0	(0.0)	0	(0.0)	1	(0.3)	0	(0.0)
American Indian (%)	1	(0.6)	3	(0.2)	0	(0.0)	1	(0.5)	0	(0.0)	1	(0.2)
Asian (%)	2	(1.2)	21	(1.4)	4	(3.1)	2	(0.9)	2	(0.6)	11	(1.8)
Pacific Islander (%)	0	(0.0)	1	(0.1)	0	(0.0)	0	(0.0)	1	(0.3)	0	(0.0)
Other (%)	1	(0.6)	4	(0.3)	0	(0.0)	0	(0.0)	0	(0.0)	3	(0.5)
Two or more races (%)	1	(0.6)	7	(0.5)	0	(0.0)	0	(0.0)	0	(0.0)	6	(1.0)
Hispanic (%)	0	(0.0)	15	(1.0)	0	(0.0)	2	(0.9)	3	(0.9)	10	(1.6)
Unknown	*0*		*5*		*0*		*0*		*3*		*2*	
Marital status												
Married (including Registered Domestic Partner) (%)	72	(43.4)	668	(46.1)	60	(46.5)	94	(44.3)	156	(46.3)	286	(47.2)
Widowed (%)	32	(19.3)	319	(22.0)	29	(22.5)	44	(20.8)	85	(25.2)	129	(21.3)
Never married (%)	20	(12.0)	114	(7.9)	8	(6.2)	20	(9.4)	27	(8.0)	39	(6.4)
Divorced (%)	42	(25.3)	349	(24.1)	32	(24.8)	54	(25.5)	69	(20.5)	152	(25.1)
Unknown	*2*		*9*		*0*		*0*		*3*		*4*	

Characteristics	2018 (N=168)		Total (N=1,459)		1998-2002 (N=129)		2003-2007 (N=212)		2008-2012 (N=340)		2013-2017 (N=610)	
Education												
8th grade or less (%)	0	(0.0)	12	(0.8)	0	(0.0)	3	(1.4)	1	(0.3)	8	(1.3)
9th-12th grade, no diploma (%)	2	(1.2)	60	(4.2)	14	(10.9)	10	(4.7)	14	(4.2)	20	(3.3)
High school graduate/GED (%)	37	(22.4)	318	(22.0)	43	(33.3)	52	(24.5)	59	(17.6)	127	(21.1)
Some college (%)	36	(21.8)	306	(21.2)	23	(17.8)	47	(22.2)	80	(23.9)	120	(19.9)
Associate degree (%)	12	(7.3)	130	(9.0)	31	(24.0)	31	(14.6)	18	(5.4)	38	(6.3)
Bachelor's degree (%)	47	(28.5)	352	(24.4)	18	(14.0)	49	(23.1)	92	(27.5)	146	(24.2)
Master's degree (%)	17	(10.3)	158	(10.9)	not collected		13	(6.1)	42	(12.5)	86	(14.3)
Doctorate or professional degree (%)	14	(8.5)	108	(7.5)	not collected		7	(3.3)	29	(8.7)	58	(9.6)
Unknown	*3*		*15*		*0*		*0*		*5*		*7*	
Residence county/region[2]												
Multnomah (%)	31	(18.5)	319	(22.0)	26	(20.2)	46	(21.7)	80	(23.7)	136	(22.6)
Washington (%)	20	(11.9)	151	(10.4)	10	(7.8)	13	(6.1)	41	(12.2)	67	(11.1)
Clackamas (%)	19	(11.3)	148	(10.2)	12	(9.3)	33	(15.6)	28	(8.3)	56	(9.3)
Lane (%)	18	(10.7)	154	(10.6)	16	(12.4)	26	(12.3)	31	(9.2)	63	(10.4)
Marion (%)	15	(8.9)	154	(10.6)	22	(17.1)	25	(11.8)	24	(7.1)	68	(11.3)
Other northwest counties (%)	25	(14.9)	215	(14.8)	19	(14.7)	31	(14.6)	57	(16.9)	83	(13.8)
Southern Oregon (%)	20	(11.9)	206	(14.2)	17	(13.2)	25	(11.8)	61	(18.1)	83	(13.8)
Central Oregon / Columbia Gorge (%)	17	(10.1)	76	(5.2)	4	(3.1)	7	(3.3)	12	(3.6)	36	(6.0)
Eastern Oregon (%)	3	(1.8)	26	(1.8)	3	(2.3)	6	(2.8)	3	(0.9)	11	(1.8)
Unknown	*0*		*10*		*0*		*0*		*3*		*7*	
End of life care												
Hospice												
Enrolled (%)	152	(90.5)	1,285	(90.2)	107	(83.6)	185	(87.3)	301	(95.6)	540	(89.7)
Not enrolled (%)	16	(9.5)	140	(9.8)	21	(16.4)	27	(12.7)	14	(4.4)	62	(10.3)
Unknown	*0*		*34*		*1*		*0*		*25*		*8*	

Characteristics	2018		Total		1998-2002		2003-2007		2008-2012		2013-2017	
	(N=168)		(N=1,459)		(N=129)		(N=212)		(N=340)		(N=610)	
Insurance												
Private (%)	48	(32.4)	662	(49.6)	80	(63.5)	132	(62.6)	212	(66.7)	190	(35.8)
Medicare, Medicaid or other governmental (%)	99	(66.9)	656	(49.2)	44	(34.9)	78	(37.0)	99	(31.1)	336	(63.3)
None (%)	1	(0.7)	16	(1.2)	2	(1.6)	1	(0.5)	7	(2.2)	5	(0.9)
Unknown	*20*		*125*		*3*		*1*		*22*		*79*	
Underlying illness												
Cancer (%)	**105**	**(62.5)**	**1,107**	**(75.9)**	**102**	**(79.1)**	**178**	**(84.0)**	**274**	**(80.6)**	**448**	**(73.4)**
Lip, oral cavity, and pharynx (%)	2	(1.2)	30	(2.1)	3	(2.3)	3	(1.4)	5	(1.5)	17	(2.8)
Digestive organs (%)	27	(16.1)	291	(19.9)	24	(18.6)	53	(25.0)	64	(18.8)	123	(20.2)
Pancreas (%)	9	(5.4)	100	(6.9)	12	(9.3)	18	(8.5)	15	(4.4)	46	(7.5)
Colon (%)	7	(4.2)	86	(5.9)	7	(5.4)	16	(7.5)	20	(5.9)	36	(5.9)
Other digestive organs (%)	11	(6.5)	105	(7.2)	5	(3.9)	19	(9.0)	29	(8.5)	41	(6.7)
Respiratory and intrathoracic organs (%)	16	(9.5)	247	(16.9)	25	(19.4)	45	(21.2)	70	(20.6)	91	(14.9)
Lung and bronchus (%)	16	(9.5)	233	(16.0)	24	(18.6)	41	(19.3)	64	(18.8)	88	(14.4)
Other respiratory and intrathoracic organs (%)	0	(0.0)	14	(1.0)	1	(0.8)	4	(1.9)	6	(1.8)	3	(0.5)
Melanoma and other skin (%)	3	(1.8)	39	(2.7)	2	(1.6)	8	(3.8)	13	(3.8)	13	(2.1)
Mesothelial and soft tissue (%)	0	(0.0)	26	(1.8)	2	(1.6)	5	(2.4)	10	(2.9)	9	(1.5)
Breast (%)	10	(6.0)	102	(7.0)	10	(7.8)	20	(9.4)	27	(7.9)	35	(5.7)
Female genital organs (%)	7	(4.2)	84	(5.8)	10	(7.8)	11	(5.2)	20	(5.9)	36	(5.9)
Prostate (%)	5	(3.0)	63	(4.3)	8	(6.2)	12	(5.7)	12	(3.5)	26	(4.3)
Urinary tract (%)	6	(3.6)	42	(2.9)	5	(3.9)	6	(2.8)	9	(2.6)	16	(2.6)
Eye, brain, central nervous system (%)	12	(7.1)	47	(3.2)	5	(3.9)	5	(2.4)	5	(1.5)	20	(3.3)
Brain (%)	11	(6.5)	42	(2.9)	4	(3.1)	4	(1.9)	5	(1.5)	18	(3.0)
Eye and central nervous system (%)	1	(0.6)	5	(0.3)	1	(0.8)	1	(0.5)	0	(0.0)	2	(0.3)
Thyroid and other endocrine (%)	2	(1.2)	7	(0.5)	0	(0.0)	0	(0.0)	2	(0.6)	3	(0.5)
Ill-defined, secondary, and unspecified sites (%)	2	(1.2)	37	(2.5)	3	(2.3)	2	(0.9)	11	(3.2)	19	(3.1)
Lymphoma and leukemia (%)	10	(6.0)	65	(4.5)	3	(2.3)	7	(3.3)	21	(6.2)	24	(3.9)
Other cancers (%)	3	(1.8)	27	(1.9)	2	(1.6)	1	(0.5)	5	(1.5)	16	(2.6)

Characteristics	2018		Total		1998-2002		2003-2007		2008-2012		2013-2017	
	(N=168)		(N=1,459)		(N=129)		(N=212)		(N=340)		(N=610)	
Neurological disease (%)	**25**	**(14.9)**	**161**	**(11.0)**	**12**	**(9.3)**	**17**	**(8.0)**	**31**	**(9.1)**	**76**	**(12.5)**
Amyotrophic lateral sclerosis (%)	15	(8.9)	117	(8.0)	10	(7.8)	16	(7.5)	23	(6.8)	53	(8.7)
Other neurological disease (%)	10	(6.0)	44	(3.0)	2	(1.6)	1	(0.5)	8	(2.4)	23	(3.8)
Respiratory disease [e.g., COPD] (%)	**13**	**(7.7)**	**75**	**(5.1)**	**9**	**(7.0)**	**6**	**(2.8)**	**18**	**(5.3)**	**29**	**(4.8)**
Heart/circulatory disease (%)	**16**	**(9.5)**	**66**	**(4.5)**	**4**	**(3.1)**	**1**	**(0.5)**	**9**	**(2.6)**	**36**	**(5.9)**
Infectious disease [e.g., HIV/AIDS] (%)	**0**	**(0.0)**	**13**	**(0.9)**	**1**	**(0.8)**	**7**	**(3.3)**	**2**	**(0.6)**	**3**	**(0.5)**
Gastrointestinal disease [e.g., liver disease] (%)	**1**	**(0.6)**	**9**	**(0.6)**	**0**	**(0.0)**	**1**	**(0.5)**	**1**	**(0.3)**	**6**	**(1.0)**
Endocrine/metabolic disease [e.g., diabetes] (%)	**2**	**(1.2)**	**11**	**(0.8)**	**0**	**(0.0)**	**2**	**(0.9)**	**1**	**(0.3)**	**6**	**(1.0)**
Other illnesses (%)[3]	**6**	**(3.6)**	**17**	**(1.2)**	**1**	**(0.8)**	**0**	**(0.0)**	**4**	**(1.2)**	**6**	**(1.0)**
DWDA process												
Referred for psychiatric evaluation (%)	3	(1.8)	65	(4.5)	28	(22.8)	8	(3.8)	6	(1.8)	20	(3.3)
Patient informed family of decision (%)[4]	156	(94.0)	1,292	(93.7)	55	(94.8)	198	(94.3)	317	(93.5)	566	(93.4)
Patient died at												
Home (patient, family or friend) (%)	147	(88.6)	1,342	(92.4)	121	(93.8)	198	(93.4)	326	(96.7)	550	(90.3)
Assisted living or foster care facility (%)	12	(7.2)	72	(5.0)	4	(3.1)	11	(5.2)	10	(3.0)	35	(5.7)
Nursing home (%)	5	(3.0)	14	(1.0)	2	(1.6)	0	(0.0)	0	(0.0)	7	(1.1)
Hospital (%)	0	(0.0)	4	(0.3)	1	(0.8)	0	(0.0)	0	(0.0)	3	(0.5)
Hospice facility (%)	0	(0.0)	2	(0.1)	0	(0.0)	0	(0.0)	0	(0.0)	2	(0.3)
Other (%)	2	(1.2)	19	(1.3)	1	(0.8)	3	(1.4)	1	(0.3)	12	(2.0)
Unknown	*0*		*6*		*0*		*0*		*3*		*3*	
Lethal medication												
Secobarbital (%)	92	(54.8)	846	(58.0)	86	(66.7)	91	(42.9)	223	(65.6)	354	(58.0)
Pentobarbital (%)	0	(0.0)	386	(26.5)	41	(31.8)	120	(56.6)	117	(34.4)	108	(17.7)
DDMP1 (%)[5]	10	(6.0)	67	(4.6)	0	(0.0)	0	(0.0)	0	(0.0)	57	(9.3)
DDMP2 (%)[5]	54	(32.1)	78	(5.3)	0	(0.0)	0	(0.0)	0	(0.0)	24	(3.9)
Phenobarbital compound (%)[5]	2	(1.2)	65	(4.5)	0	(0.0)	0	(0.0)	0	(0.0)	63	(10.3)
Other (%)	10	(6.0)	17	(1.2)	2	(1.6)	1	(0.5)	0	(0.0)	4	(0.7)

	2018		Total		1998-2002		2003-2007		2008-2012		2013-2017	
Characteristics	(N=168)		(N=1,459)		(N=129)		(N=212)		(N=340)		(N=610)	
End of life concerns[6,7]												
Losing autonomy (%)	154	(91.7)	1,322	(90.6)	106	(82.2)	194	(91.5)	318	(93.5)	550	(90.2)
Less able to engage in activities making life enjoyable (%)	152	(90.5)	1,300	(89.1)	99	(76.7)	193	(91.0)	310	(91.2)	546	(89.5)
Loss of dignity (%)[8]	112	(66.7)	989	(74.4)	not asked		173	(81.6)	279	(82.1)	425	(69.7)
Losing control of bodily functions (%)	62	(36.9)	647	(44.3)	73	(56.6)	123	(58.0)	154	(45.3)	235	(38.5)
Burden on family, friends/caregivers (%)	91	(54.2)	654	(44.8)	44	(34.1)	88	(41.5)	132	(38.8)	299	(49.0)
Inadequate pain control, or concern about it (%)	43	(25.6)	375	(25.7)	28	(21.7)	64	(30.2)	65	(19.1)	175	(28.7)
Financial implications of treatment (%)	9	(5.4)	57	(3.9)	3	(2.3)	6	(2.8)	9	(2.6)	30	(4.9)
Health-care provider present (collected since 2001)	**(N=168)**		**(N=1,387)**		**(N=57)**		**(N=212)**		**(N=340)**		**(N=610)**	
When medication was ingested[9]												
Prescribing physician	32		220		22		52		37		77	
Other provider, prescribing physician not present	51		346		29		111		95		60	
No provider	18		116		6		45		22		25	
Unknown	*67*		*705*		*0*		*4*		*186*		*448*	
At time of death												
Prescribing physician (%)	28	(16.8)	201	(14.7)	20	(35.1)	46	(22.1)	33	(9.9)	74	(12.4)
Other provider, prescribing physician not present (%)	37	(22.2)	352	(25.8)	37	(64.9)	110	(52.9)	111	(33.2)	57	(9.5)
No provider (%)	102	(61.1)	812	(59.5)	0	(0.0)	52	(25.0)	190	(56.9)	468	(78.1)
Unknown	*1*		*22*		*0*		*4*		*6*		*11*	
Complications[9]	**(N=168)**		**(N=1,459)**		**(N=129)**		**(N=212)**		**(N=340)**		**(N=610)**	
Difficulty ingesting/regurgitated	3		28		4		15		3		3	
Seizures	0		2		0		0		0		2	
Other	4		11		0		0		0		7	
None	56		650		121		193		163		117	
Unknown	*105*		*768*		*4*		*4*		*174*		*481*	
Other outcomes												
Regained consciousness after ingesting DWDA medications	1		8		0		1		5		1	

Characteristics	2018 (N=168)	Total (N=1,459)	1998-2002 (N=129)	2003-2007 (N=212)	2008-2012 (N=340)	2013-2017 (N=610)
Timing of DWDA event						
Duration (weeks) of patient-physician relationship						
Median	10	12	14	11	12	13
Range	1-1,108	0-2,138	0-1,337	0-1,477	0-1,905	1-2,138
Number of patients with information available	*165*	*1,449*	*128*	*212*	*339*	*605*
Number of patients with information unknown	*3*	*10*	*1*	*0*	*1*	*5*
Duration (days) between first request and death						
Median	43	47	43	43	49	50
Range	15-807	14-1,009	15-466	15-1,009	14-872	15-692
Number of patients with information available	*167*	*1,458*	*129*	*212*	*340*	*610*
Number of patients with information unknown	*1*	*1*	*0*	*0*	*0*	*0*

1 Unknowns are excluded when calculating percentages.

2 Other northwest counties: Benton, Clatsop, Columbia, Lincoln, Linn, Polk, Tillamook, and Yamhill.
Southern: Coos, Curry, Douglas, Jackson, Josephine, Klamath, and Lake.
Central/Columbia Gorge: Crook, Deschutes, Gilliam, Hood River, Jefferson, Sherman, Wasco, and Wheeler.
Eastern: Baker, Grant, Harney, Malheur, Morrow, Umatilla, Union, and Wallowa.

3 Includes deaths due to arthritis, arteritis, sclerosis, stenosis, kidney failure, and musculoskeletal systems disorders.

4 First recorded in 2001. Since then, 55 patients (4.6%) have chosen not to inform their families, and 21 patients (1.7%) have had no family to inform. Information is unknown for 10 patients.

5 DDMP is a compound consisting of diazepam, digoxin, morphine sulfate, and propranolol. DDMP1 contains 10g of morphine sulfate; DDMP2 contains 15g. The phenobartital compound consists of phenobarbital, chloral hydrate, and morphine sulfate.

6 Affirmative answers only (“Don’t know” included in negative answers). Categories are not mutually exclusive.

7 The percentages in this section have been recalculated since the original report date of 2/28/2019. The original percentages did not include “don’t know” answers as a negative response.

8 First asked in 2003. Data available for 1,327 patients.

9 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.

Table 2. Number of DWDA prescription recipients, DWDA deaths, and attending physicians, 1998-2018

Year	Prescription recipients	DWDA deaths	Attending physicians
1998	24	16	n/a
1999	33	27	n/a
2000	39	27	22
2001	44	21	33
2002	58	38	33
2003	68	42	42
2004	60	37	40
2005	65	38	40
2006	65	46	41
2007	85	49	46
2008	88	60	60
2009	95	59	64
2010	97	65	59
2011	114	71	62
2012	116	85	62
2013	121	73	62
2014	155	105	83
2015	218	135	106
2016	204	139	101
2017	219	158	93
2018	249	168	103

Table 3. Primary location of practice, DWDA physicians, 2018

Region	Attending physicians		Consulting physicians	
	N	(%)	N	(%)
Metro counties (Clackamas, Multnomah, Washington) (%)	50	(48.5)	97	(52.7)
Coastal counties (%)	6	(5.8)	7	(3.8)
Other western counties (%)	36	(35.0)	61	(33.2)
East of the Cascades (%)	11	(10.7)	19	(10.3)
Unknown	0		2	

Table 4. Duration between ingestion and death, DWDA deaths, 2001-2018

Drug	Total	Unknown duration	Known duration		<1hr		1-6 hours		>6 hours		Median	Mean	Range	Regained consciousness[4]
Secobarbital (%)	778	397	381	(100.0)	285	(74.8)	69	(18.1)	27	(7.1)	25	139	2min - 83 hrs	5
Pentobarbital[1] (%)	384	156	228	(100.0)	188	(82.5)	31	(13.6)	9	(3.9)	20	97	1min - 104hrs	0
DDMP1[2] (%)	67	46	21	(100.0)	10	(47.6)	6	(28.6)	5	(23.8)	77	214	10min - 21hrs	0
DDMP2[2] (%)	78	37	41	(100.0)	12	(29.3)	19	(46.3)	10	(24.4)	120	230	13min - 21hrs	2
Phenobarbital (%)[3]	65	43	22	(100.0)	4	(18.2)	13	(59.1)	5	(22.7)	73	439	20min - 72hrs	0
Other (%)	17	3	14	(100.0)	6	(42.9)	6	(42.9)	2	(14.3)	68	192	10min - 14hrs	1

1 Pentobarbital is no longer available in the United States.

2 DDMP is a compound consisting of diazepam, digoxin, morphine sulfate, and propranolol. DDMP1 contains 10g of morphine sulfate; DDMP2 contains 15g.

3 Phenobarbital is dispensed as a compound consisting of phenobarbital, chloral hydrate, and morphine sulfate.

4 Patients who regained consciousness after ingestion are not considered DWDA deaths, and are not included in the other columns in this table.

NOTE: Table includes all reported durations, not just those from licensed providers. Complete information not available before 2001. Unknown values are excluded when calculating percentages.

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Special Article

A NATIONAL SURVEY OF PHYSICIAN-ASSISTED SUICIDE AND EUTHANASIA IN THE UNITED STATES

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ABSTRACT

Background Although there have been many studies of physician-assisted suicide and euthanasia in the United States, national data are lacking.

Methods In 1996, we mailed questionnaires to a stratified probability sample of 3102 physicians in the 10 specialties in which doctors are most likely to receive requests from patients for assistance with suicide or euthanasia. We weighted the results to obtain nationally representative data.

Results We received 1902 completed questionnaires (response rate, 61 percent). Eleven percent of the physicians said that under current legal constraints, there were circumstances in which they would be willing to hasten a patient's death by prescribing medication, and 7 percent said that they would provide a lethal injection; 36 percent and 24 percent, respectively, said that they would do so if it were legal. Since entering practice, 18.3 percent of the physicians (unweighted number, 320) reported having received a request from a patient for assistance with suicide and 11.1 percent (unweighted number, 196) had received a request for a lethal injection. Sixteen percent of the physicians receiving such requests (unweighted number, 42), or 3.3 percent of the entire sample, reported that they had written at least one prescription to be used to hasten death, and 4.7 percent (unweighted number, 59), said that they had administered at least one lethal injection.

Conclusions A substantial proportion of physicians in the United States in the specialties surveyed report that they receive requests for physician-assisted suicide and euthanasia, and about 6 percent have complied with such requests at least once. (N Engl J Med 1998;338:1193-201.)

THERE are strong arguments for and against easing the legal constraints on physician-assisted suicide and euthanasia in the United States. Public-opinion polls suggest that a majority of people favor legalization.[1] Currently proposed regulatory guidelines[2-5] may bear little relation to the range of clinical circumstances in which physicians care for patients who are near the end of life. Decisions about legislation and proposed safeguards should be responsive to the experiences of patients and doctors. We surveyed a representative sample of U.S. physicians with a high likelihood of caring for dying patients, in order to assess the prevalence of requests for assistance with suicide or euthanasia and of compliance with such requests.

METHODS

The survey was self-administered, anonymous, and conducted by mail. We drew a stratified probability sample of physicians from the American Medical Association's June 1996 master file of all physicians practicing in the United States. The sample included only doctors of medicine who were less than 65 years old or had graduated from medical school after 1960, if age was unknown. Physicians with office and hospital practices and those in the public and private sectors were included. The group of physicians from whom the sample was drawn represents approximately 40 percent of all practicing U.S. physicians under the age of 65 years. The sample was drawn from 10 specialties, selected on the basis of previous surveys[6,7] as those in which physicians are likely to receive requests from patients for assistance in hastening death. Physicians were eligible if they had at least one of the specialty codes as their primary, secondary, or tertiary specialty. A sample of 3102 physicians was selected. Specialists thought to be most likely to receive requests were oversampled.

For each specialty, the initial sample size, population size, sampling rate, and number of respondents are shown in Table 1. The numbers of respondents are based on the specialties reported on the completed questionnaires. Since the questionnaires were anonymous, there was no way to link this information to the original sample and the specialty codes from the master file. The number of respondents reporting family or general practice or other as their primary specialty was larger than the number initially selected in these specialties. The sample of respondents was weighted to account for these differences.

Questionnaire

The closed-ended questionnaire (available from the authors on request) was developed with the use of focus groups and cognitive interviewing[8] of physicians, some of whom had identified themselves as having received requests from patients for assistance in hastening death. The questionnaire was subsequently validated with the use of a "seeded sample" design in which physicians

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TABLE 1. SAMPLE SIZE, SAMPLING RATE, AND RESPONSE RATE ACCORDING TO SPECIALTY.

SPECIALTY	INITIAL SAMPLE	TOTAL POPULATION	SAMPLING RATE	RESPONDENTS	RESPONSE RATE*
	no.			no.	%
Family or general practice	192	52,448	0.004	197	103
Cardiology	197	4,603	0.043	110	56
Geriatrics	389	512	0.760	174	45
Infectious disease	393	919	0.428	175	45
Nephrology	383	936	0.409	190	50
Neurology	397	6,347	0.063	239	60
Hematology–oncology	387	3,764	0.103	275	71
Pulmonary disease	386	2,307	0.167	246	64
Internal medicine	191	80,378	0.002	96	50
Other†	187	1,700	0.110	200	107
Total	3102	153,914		1902	61

*Because of differences between self-reported specialty and selected specialty, some response rates are more than 100 percent.

†Other specialties included critical care medicine, critical care surgery, gynecology, and pain medicine. This category also included physicians who did not report a specialty.

known or thought to have engaged in physician-assisted suicide or euthanasia through their communication with one of the investigators were anonymously included. Two controls for each of these physicians were identified from the American Medical Association's master file on the basis of age, region of the country, city size, and specialty. The validation procedure showed that 20 of the 24 case physicians reported having engaged in either physician-assisted suicide or active euthanasia, as compared with 2 of 30 control physicians.

Assisted suicide was defined as "the practice of providing a competent patient with a prescription for medication for the patient to use with the primary intention of ending his or her own life." Active euthanasia was defined as "the practice of injecting a patient with a lethal dose of medication with the primary intention of ending the patient's life." Respondents were asked, "Was there an explicit request for assistance in dying, or was the request somewhat indirect?" "Explicit" and "indirect" were not further defined.

We mailed the questionnaire in August 1996. The cover letter explained that there were no codes that could be used to link a completed questionnaire to a particular respondent. This statement was reinforced by a detailed pledge of anonymity from the investigators, printed on the cover of the questionnaire. We instructed the recipients to return the enclosed reply postcard, which contained the respondent's identification number, separately from the completed questionnaire, in order to prevent telephone calls reminding the respondent to return the questionnaire. A $2 bill was enclosed as an incentive. Four weeks after the initial mailing, a second questionnaire, including a sharpened pencil, was mailed to physicians who had not returned the reply postcard. Four weeks after the second mailing, physicians who had not returned a postcard were telephoned to remind them to do so. Two weeks later, a second call was made, if necessary.

We received 1627 completed questionnaires (response rate, 52 percent). A third questionnaire was then sent to the 761 physicians who had not returned a postcard. This mailing included a $50 check made payable to the physician and a letter of endorsement from the American College of Physicians. There were 275 completed responses to the third mailing.

The study was reviewed and approved by the institutional review board of the Mount Sinai School of Medicine.

Sample Weights

The data from the completed questionnaires were weighted to account for the differences in selection probabilities among strata. The final weights reflected adjustments for differences between self-reported specialty and selected specialty, nonresponses, and differences in age and sex between physicians who completed the questionnaire and the overall population of licensed U.S. physicians. Unless otherwise stated, all results reported are weighted data.

Statistical Analysis

Multiple logistic-regression analysis[9] was performed to determine the relation between the characteristics of the physicians and their views and actions with respect to assistance in hastening death. First, we performed a single-variable analysis in which the specialty was compared with each predictor variable. All predictor variables for which P values were 0.15 or less in the single-variable analysis were examined jointly in the next step of model building. Variables that were no longer of even borderline significance ($P>0.10$) when the other variables were entered were eliminated from the model. Religious affiliation and specialty were forced into all models — religion in order to control for the effect of religious affiliation on frequency of prayer, and specialty because it was the stratification variable.

RESULTS

Characteristics of the Physicians

Of the 3102 physicians originally mailed a questionnaire, 81 were ineligible: 75 were not actively practicing medicine, and 6 were older than 65 years. We received 1951 questionnaires from eligible respondents, including some that were blank. There were 1902 completed questionnaires (response rate, 61 percent). The respondents to the third mailing, which included a financial incentive, did not differ significantly from the respondents to the initial mailings, in terms of demographic characteristics or responses to questions about participation in assisted suicide or lethal injection. Respondents and nonrespondents were similar with respect to age, sex, and region of the country, although there were some differences in the distribution of specialties (P=0.001 by the chi-square test), with a larger proportion of respondents who were infectious-disease specialists (16 percent, vs. 10 percent of the nonrespondents) and a smaller proportion who were general internists (9 percent vs. 15 percent). Table 2 shows the demographic and professional characteristics of the respondents.

Willingness to Provide Assistance

Eleven percent of the physicians (95 percent confidence interval, 9 to 12 percent) reported that under current legal constraints, there are circumstances in which they would prescribe a medication for a competent patient to use with the primary intention of ending his or her life; 36 percent (95 percent confidence interval, 34 to 38 percent) said they would prescribe a medication if it were legal to do so. Seven percent of the respondents (95 percent confidence interval, 4 to 10 percent) said that under current legal constraints, there are circumstances in which they would administer a lethal injection to a competent patient; 24 percent (95 percent confidence interval, 23 to 26 percent) said they would do so if the practice were legal.

Requests for Assistance

Of the respondents, 18.3 percent (unweighted number, 320) reported having received a request from a patient for medication to use with the primary intention of ending the patient's life (Table 3), with a median of three such requests since the physician entered practice. Fewer physicians (11.1 percent; unweighted number, 196) reported having received a request for a lethal injection, with a median of four such requests since the physician entered practice.

Compliance with Requests for Assistance

Only the 320 physicians who reported having received a request from a patient for a prescription for a lethal dose of medication were asked if they had ever written such a prescription. Sixteen percent of these respondents (unweighted number, 42), or 3.3 percent of the entire sample, reported that they had written a prescription for a lethal dose of medication, with a median of 2 such prescriptions (range, 1 to 25) since they entered practice; 59 percent of the patients used the prescriptions to end their lives.

All the respondents were asked whether they had ever given a patient a lethal injection (Table 3); 4.7 percent (unweighted number, 59) reported that they had done so, with a median of 2 instances (range, 1 to 150) in which they had administered lethal injections since entering practice.

Table 2. Characteristics of the 1902 U.S. Physicians Who Responded to the Survey.*

Characteristic	Weighted Value	Unweighted Value
Age — % of respondents		
<45 yr	48	54
45–65 yr	49	43
Sex — % of respondents		
Male	77	76
Female	20	21
Percent of work time spent in direct patient care — % of respondents		
<76	17	24
76–100	83	76
Death of a patient in past 12 mo — % of respondents		
Yes	92	91
No	5	6
No. of patients who have died in past 12 mo		
Median (interquartile range)	10 (4–20)	14 (5–29)
Range	0–280	0–280
Patients with an estimated life expectancy of less than 6 mo — % of respondents		
None	8	9
<25%	85	71
≥25%	6	18
Region of practice — % of respondents		
Northeast	25	27
North Central	22	22
South	32	31
West	22	20
Religion — % of respondents		
Catholic	26	23
Other Christian	34	32
Jewish	14	17
Moslem	2	2
None	12	13
Other	9	9
Frequency of prayer — % of respondents		
Never	16	18
Less than weekly	20	24
Weekly	26	24
Daily	33	30

*Weighted values reflect estimated national rates in the surveyed specialties and unweighted values are the raw response rates. Some percentages do not add to 100 because of missing data.

Most Recent Request Honored

The 81 respondents (weighted proportion, 6.4 percent) who reported having acceded to at least one request for assistance with suicide or a lethal injection were asked to describe the most recent case (Table 4). Forty-seven percent of these respondents wrote a prescription for the purpose of hastening death, and 53 percent administered a lethal injection. The perceived reasons for the request were discomfort other than pain (reported by 79 percent of the respondents), loss of dignity (53 percent), fear of uncontrollable symptoms (52 percent), actual pain (50 percent), loss of meaning in their lives (47 percent), being a burden (34 percent), and dependency (30 percent). The reasons given for acceding to the request were severe discomfort other than pain (re-

Table 3. Requests for Physician-Assisted Suicide or Euthanasia and Compliance with Requests.*

Question	Response
Has any patient requested from you a prescription for medication to use with the primary intention of ending his or her own life? — % responding yes	18.3 (16.6–20.0)
Approximately how many patients have requested such a prescription from you?	
Since entering practice	
Median	3
Range	1–100
During the past 12 mo	
Median	1
Range	0–8
Has any patient ever requested that you inject him or her with a lethal dose of a medication? — % responding yes	11.1 (9.7–12.5)
Approximately how many patients have requested that you inject a lethal dose of medication?	
Since entering practice	
Median	4
Range	1–50
During the past 12 mo†	
Median	0
Range	0–6
Have you ever written a prescription for medication for a patient to use with the primary intention of ending his or her own life? — % responding yes	3.3 (2.5–4.1)
For approximately how many patients have you written such a prescription?	
Since entering practice	
Median	2
Range	1–25
During the past 12 mo‡	
Median	0
Range	0–3
Have you ever given a patient a lethal injection? — % responding yes	4.7 (3.7–5.6)
To how many patients have you given a lethal injection?	
Since entering practice	
Median	2
Range	1–150
During the past 12 mo§	
Median	0
Range	0–15

*Percentages are weighted. Medians and ranges are based on the responses of physicians who reported having received or acceded to at least one request since entering practice. Numbers in parentheses are 95 percent confidence intervals.

†Among physicians receiving at least one request for a lethal injection in the previous year, the median number of patients making such a request was 1, and the range was 1 to 6.

‡Among physicians who wrote at least one prescription for a lethal dose of medication during the previous year, the median number of patients who were given such a prescription was 1, and the range was 1 to 3.

§Among physicians who administered at least one lethal injection during the previous year, the median number of patients who were given a lethal injection was 4, and the range was 1 to 15.

ported by 78 percent of the respondents), the untreatability of the symptoms (72 percent), a life expectancy of less than six months (69 percent), and severe pain (29 percent).

Seventy-one percent of the physicians describing the most recent request for assistance in hastening death initially responded to the request by prescribing more analgesics (reported by 68 percent of the respondents), using less aggressive life-prolonging therapy (30 percent), discussing the request with colleagues (27 percent), prescribing antidepressants (25 percent), trying to dissuade the patient (22 percent), requesting a second opinion (18 percent), or obtaining a psychiatric consultation (2 percent).

The medications prescribed in lethal doses were opioids (in 75 percent of cases) and barbiturates (in 25 percent). The medications used for lethal injection were opioids (in 83 percent of cases) and potassium chloride (in 17 percent).

Of the 38 physicians who reported their most recent experience with a lethal injection, 43 percent administered it themselves, and 57 percent asked someone else to do so (a nurse in 57 percent of cases and another physician in 32 percent) or ordered an

Table 4. Characteristics of 81 Patients Who Received a Prescription for a Lethal Dose of Medication or a Lethal Injection.*

Characteristic	Prescription	Injection
	weighted percent	
Person who made request†‡		
Patient	95	39
Family member or partner	5	54
Not specified	0	7
Request explicit	75	21
Request somewhat indirect	25	79
Patient's clinical status‡		
Experiencing severe discomfort	75	73
Dependent on others for personal care	68	55
Bedridden 50% or more of the time	57	55
Experiencing severe pain	54	24
Depressed	19	39
Confused 50% or more of the time	5	7
None of the above	2	15
Patient's sex		
Male	97	57
Female	3	43
Patient's age‡		
<18 yr	<1	<1
19–45 yr	28	17
46–75 yr	43	38
>75 yr	29	45
Patient's education		
<12 yr	<1	17
12–15 yr	29	60
≥16 yr	64	21
Don't know or don't remember	7	2
Life expectancy‡		
<24 hr	<1	59
1–6 days	26	37
1–3 wk	22	2
1–5 mo	50	2
6–12 mo	1	0
>12 mo	1	1
Patient hospitalized at time of request	5§	99
Family members or friends closely involved	83	95
Request reflected patient's wishes‡	100	100
Length of time physician had known patient		
<1 wk	0	8
1–4 wk	0	4
2–11 mo	12	26
≥12 mo	88	62
Request repeated‡	51	53
Immediate assistance requested	33	94
Second opinion obtained by physician‡	<1	32
Patient's primary diagnosis		
Cancer	70	23
Neurologic disease	6	17
Acquired immunodeficiency syndrome	6	16
Other¶	18	44
Someone else present at patient's death	98	65
Physician tried to dissuade patient from hastening death	34	11
Physician's comfort with role in assisting patient		
Very comfortable	58	83
Somewhat comfortable	24	5
Somewhat uncomfortable	18	6
Very uncomfortable	<1	6
Physician's willingness to comply with future requests of the same type		
Would definitely comply	39	28
Would probably comply	42	60
Unsure	18	5
Would probably not comply	1	1
Would definitely not comply	0	6

*The Oregon Death with Dignity Act specifies criteria for complying with requests from patients for assistance with suicide. The patient must be an adult with a terminal illness and a life expectancy of less than six months. The request must be made by the patient and must be voluntary. Procedural guidelines require that the initial request be repeated after 15 days, with an opportunity to rescind it, and that the physician obtain a second opinion, with a psychiatric evaluation if the disorder is causing impaired judgment.[10] We did not query physicians about all these criteria and could not determine whether all were met.

†If someone other than the patient made the request, we did not ask whether the patient later made the same request.

‡This involves one of the criteria specified in the Oregon Death with Dignity Act.

§Ninety percent of lethal prescriptions were given to patients who were at home, and 5 percent were given to patients in nursing homes.

¶Other diagnoses included end-stage heart or lung disease and multiorgan-system failure.

increase in the dose of an intravenous sedative or analgesic already being administered (in 11 percent of cases).

Characteristics of Patients Receiving Assistance

Although 95 percent of the requests for a prescription were made by the patients themselves, 54 percent of the requests for a lethal injection were made by a family member or partner (Table 4). Requests for a lethal injection were characterized as indirect rather than explicit in 79 percent of cases. Five percent of the patients who received prescriptions and 7 percent of those who received lethal injections were described as "confused 50% or more of the time," but we did not ask whether the patient was unable to communicate at the time of the decision to hasten death. Ninety-eight percent of the patients receiving a prescription were estimated to have less than six months to live, and 48 percent were estimated to have less than four weeks; 95 percent were not hospitalized at the time of the request. Ninety-six percent of the patients receiving a lethal injection were estimated to have less than a week to live, and 59 percent were estimated to have less than 24 hours; virtually all the patients died in the hospital. Most patients receiving either type of assistance had family or friends who were closely involved at the time of the request (83 percent of those receiving a prescription and 95 percent of those receiving a lethal injection). In every case of assisted suicide or

TABLE 5. VARIABLES PREDICTING WILLINGNESS TO PROVIDE ASSISTANCE, REQUESTS FOR ASSISTANCE, AND COMPLIANCE WITH REQUESTS.*

VARIABLE	PRESCRIPTION			INJECTION		
	NO. OF RESPONDENTS	P VALUE	ODDS RATIO	NO. OF RESPONDENTS	P VALUE	ODDS RATIO
Would provide assistance if it were legal to do so	747			502		
Religion		<0.001			<0.001	
Catholic			0.5			0.6
Other Christian			0.8			0.8
Jewish			1.6			1.7
None			1.3			1.2
Other†‡			1.0			1.0
Prayer		<0.001			<0.001	
Daily			0.3			0.3
Weekly			0.5			0.4
Less than weekly			0.7			0.6
Never‡			1.0			1.0
No. of patients seen/wk					0.056	
<50						0.7
50–100‡						1.0
>100						1.1
Have received request	319			195		
Specialty		<0.001			<0.001	
Region		<0.001			0.07	
West			1.8			1.5
North central			0.8			1.0
South			1.2			0.9
Northeast‡			1.0			1.0
Prayer		0.001			0.04	
Daily			0.4			0.7
Weekly			0.6			0.8
Less than weekly			0.4			0.5
Never‡			1.0			1.0
No. of patients seen/wk		0.02				
<50			0.7			
50–100‡			1.0			
>100			1.1			
Religion					0.04	
Catholic						2.1
Other Christian						2.1
Jewish						2.6
None						1.0
Other†‡						1.3
Age					0.04	
<45 yr‡						1.0
≥45 yr						1.4
Have complied with request	42			59		
Region		0.06			0.05	
West			2.2			3.0
North central			0.6			1.6
South			1.1			1.7
Northeast‡			1.0			1.0
No. of patients seen/wk		0.01				
<50			0.5			
50–100‡			1.0			
>100			0.2			
Religion					0.01	
Catholic						0.6
Other Christian						1.3
Jewish						2.7
None						2.2
Other†‡						1.0
Sex		0.03				
Male			5.0			
Female‡			1.0			
Prayer		0.05				
Daily			0.3			
Weekly			0.2			
Less than weekly			0.4			
Never‡			1.0			

*A multiple logistic-regression analysis was performed, with religious affiliation and specialty forced into all models. Variables with P values of less than 0.10 are reported.

†Because of small numbers, this category includes Moslem and other religions, as well as missing responses.

‡This was the reference category.

euthanasia, the physician believed that the request reflected the patient's wishes. The proportions of patients receiving a prescription who would have met the specific clinical and procedural criteria of the Oregon Death with Dignity Act[10] are shown in Table 4.

Predictors of Willingness to Provide Assistance and Provision of Assistance

Religious affiliation (Table 5) was associated with having given a lethal injection, as well as with the willingness to prescribe a lethal dose of medication or give a lethal injection. Catholic physicians were least likely and Jewish physicians or those with no religious affiliation were most likely to be willing to provide assistance or to have actually done so. Physicians who prayed less frequently were more willing to provide assistance or to have done so than physicians who prayed more frequently, except that frequency of prayer was not associated with lethal injection. The frequency of requests for a prescription was significantly associated with geographic region, with physicians in the West most likely to have received such requests. Doctors 45 years of age or older were more willing to give a lethal injection under current legal constraints (data not shown) and were more likely to have received such requests than younger doctors. Men were significantly more likely than women to have written a prescription for a lethal dose of medication.

Specialty was a significant predictor of both willingness to provide assistance under current law (data not shown) and the receipt of at least one request for assistance (Table 5). Pulmonologists, geriatricians, and general internists were most likely to be willing to give either a prescription for a lethal dose of medication or a lethal injection. Geriatricians and oncologists were more likely to have received requests for a prescription, whereas pulmonologists were more likely to have received requests for a lethal injection (Table 6).

DISCUSSION

We found that requests for assisted suicide or euthanasia are frequently made to physicians who practice in specialties in which they are likely to care for dying patients and that the decision to honor such a request is not rare in the United States. The prevalence of ever having acceded to a request for a prescription for a lethal dose of medication was 3.3 percent in our sample as compared with 7 percent in Oregon[7] in 1995, 13.5 percent among New England oncologists[11] in 1994, and 18 percent among Michigan oncologists[12] in 1993. The prevalence of ever having provided a lethal injection was 4.7 percent in our study, as compared with 4 percent in

Table 6. Willingness to Provide Assistance, Requests for Assistance, and Compliance with Requests, According to Specialty.

Variable		Specialty									
	All Respondents	Family Practice	Cardiology	Geriatrics	Infectious Disease	Nephrology	Neurology	Hematology–Oncology	Pulmonary Disease	Internal Medicine	Other
	percentage of respondents*										
Would write prescription for a lethal dose of medication if it were legal to do so	36	39	49	40	43	32	46	44	40	33	44
Would write prescription under current legal constraints	11	10	9	13	11	4	11	8	15	11	9
Have received request for assistance with suicide	18	15	12	26	21	9	9	25	18	21	12
Have written prescription for a lethal dose of medication	3.3	2	1	1	4	0	1	3	5	4	2
Would give lethal injection if it were legal to do so	24	28	28	25	31	21	32	27	31	23	28
Would give lethal injection under current legal constraints	7	7	2	4	5	3	7	2	9	8	5
Have received a request for a lethal injection	11	8	9	14	11	7	5	13	19	13	6
Have given a lethal injection	4.7	4	2	2	4	2	3	2	6	6	3

*Unweighted (raw) percentages are given for each specialty, with weighted percentages for all respondents.

Michigan[12] and 1.8 percent among oncologists in New England.[11]

Our study showed that several factors were associated with physicians' participation in hastening death, including region of practice, religion, and specialty. Repeated ballot measures and the attendant debate over the legalization of physician-assisted death in California, Oregon, and Washington may have led to a higher frequency of requests received by physicians in those states and may have influenced their willingness to honor the requests.[7,10] Whereas our study suggests that Jewish physicians are more likely to be willing to provide assistance than other physicians, two prior studies[13,14] have shown that Jewish (as well as Catholic) physicians are less willing than others to withdraw life support. Also, unlike prior surveys,[6,7,11,12] in which oncologists were the specialists most likely to receive requests for assistance with dying and most willing to provide such assistance, in our survey, other specialists were most likely to receive such requests and most willing to honor them.

We surveyed a national probability sample of physicians in a wide variety of specialties. Prior surveys have been limited to specialists who care for high-risk patients, such as oncologists[11,12] and specialists in the acquired immunodeficiency syndrome,[15] or to states where there has been considerable publicity associated with ballot measures (Washington and Oregon)[6,7,16] or Dr. Jack Kevorkian's repeated provision of assistance to patients (Michigan).[12,17] In addition, we assessed the validity of the survey instrument in eliciting honest answers about controversial and illegal acts by pilot testing in a group of physicians known to have participated in physician-assisted suicide or euthanasia.

Our results are limited to physicians in the selected specialties. To the extent that physicians in these specialties are more likely to receive requests for assistance with suicide or euthanasia, the prevalence estimates are higher than those for all practicing physicians. Conversely, to the extent that the respondents were reluctant to report illegal actions, we may have underestimated the actual frequency of physician-assisted death. Although the response rate in our study was more than 60 percent and was similar to that in other recent studies,[6,7,11,12,15] it is possible that the nonrespondents and the respondents differed.[18] Finally, although lethal injection was carefully defined as injection of a lethal dose "with the primary intention of ending the patient's life," some respondents may have confused this action with terminal sedation (i.e., the use of analgesic or sedative agents to induce unconsciousness and relieve suffering).

What are the implications of these data for the current debate over the legalization of physician-assisted death? First, a substantial number of physicians in the United States have received one or more requests for assistance with suicide or euthanasia. Educational efforts are needed to prepare physicians to explore the meaning of such a request[19] and to assess the patient's mental state and the adequacy of palliative care before responding to it. Second, legalization could lead to a large increase in the willingness of physicians to participate in the hastening of death and perhaps to an increase in its prevalence. Third, the majority of patients who request assistance with suicide appear to satisfy many of the criteria currently proposed as regulatory safeguards for this practice.[2,3,10,20]

Our findings with respect to lethal injection point to a different pattern of decision making. The finding that 54 percent of patients receiving a lethal injection did not make the request themselves suggests that physicians and family members felt compelled to intervene with a decision to hasten death. The majority of these patients had less than 24 hours to live, were experiencing severe discomfort or pain, and were in the relatively public setting of the hospital, with family members who were closely involved at the time of death. Sedation may have been used appropriately for refractory symptoms in the last hours of life, but in the absence of detailed descriptions of the circumstances surrounding these requests and actions, cautious interpretation is warranted. Although the fact that respondents reported these cases as examples of lethal injection suggests that their primary intention was to hasten death, the use of sedation for refractory symptoms in patients near death may have led some physicians to report actions intended to relieve suffering that were also intended to hasten death.[21]

Additional research on the circumstances in which doctors honor requests to hasten death should evaluate the possibility that better access to palliative care might obviate some of these requests[22,23] as well as clarify the practical implications of establishing regulatory guidelines. We evaluated physicians' practices during a time when medical education in palliative care was largely unavailable and such care was sporadically delivered.[23] The prevalence of requests for assistance in hastening death and of compliance with such requests may differ in communities where palliative care is easily accessible.

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LAW, ETHICS AND MEDICINE

Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in ''vulnerable'' groups

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Background: Debates over legalisation of physician-assisted suicide (PAS) or euthanasia often warn of a ''slippery slope'', predicting abuse of people in vulnerable groups. To assess this concern, the authors examined data from Oregon and the Netherlands, the two principal jurisdictions in which physician-assisted dying is legal and data have been collected over a substantial period.

Methods: The data from Oregon (where PAS, now called death under the Oregon Death with Dignity Act, is legal) comprised all annual and cumulative Department of Human Services reports 1998–2006 and three independent studies; the data from the Netherlands (where both PAS and euthanasia are now legal) comprised all four government-commissioned nationwide studies of end-of-life decision making (1990, 1995, 2001 and 2005) and specialised studies. Evidence of any disproportionate impact on 10 groups of potentially vulnerable patients was sought.

Results: Rates of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for the elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. The only group with a heightened risk was people with AIDS. While extralegal cases were not the focus of this study, none have been uncovered in Oregon; among extralegal cases in the Netherlands, there was no evidence of higher rates in vulnerable groups.

Conclusions: Where assisted dying is already legal, there is no current evidence for the claim that legalised PAS or euthanasia will have disproportionate impact on patients in vulnerable groups. Those who received physician-assisted dying in the jurisdictions studied appeared to enjoy comparative social, economic, educational, professional and other privileges.

If physician-assisted suicide (PAS) and/or voluntary active euthanasia were legalised, would this disproportionately affect people in ''vulnerable'' groups? Although principles of patient autonomy and the right to avoid suffering and pain may offer support for these practices, concerns about their impact on vulnerable populations speak against them. Warnings about potential abuse have been voiced by many task forces, courts and medical organisations in several countries where the issue is under debate. Box 1 presents some of these concerns.

We must take these concerns seriously, not only because they are repeated so often but because they are of such gravity. Would accepting or legalising physician-assisted dying at a patient's explicit request weigh more heavily on patients in vulnerable groups—the elderly, women, the uninsured, the poor, racial or ethnic minorities, people with disabilities, people with sometimes stigmatised illnesses like AIDS, and others? Would vulnerable patients be especially heavily targeted? Would these patients be pressured, manipulated, or forced to request or accept physician-assisted dying by overburdened family members, callous physicians, or institutions or insurers concerned about their own profits? This slippery-slope argument assumes that abusive pressures would operate on all seriously or terminally ill patients but would selectively disfavour patients whose capacities for decision making are impaired, who are subject to social prejudice or who may have been socially conditioned to think of themselves as less deserving of care. These pressures would result, it is assumed, in heightened risk for physician-assisted dying among vulnerable persons compared with background populations.

These are concerns both for those who oppose physician-assisted dying on moral grounds and for those who support it but are uneasy about the possible social consequences of legalisation. They are also concerns for proponents of legalisation who assume that the risks for vulnerable patients are heightened if these practices remain underground, as well as for those who favour legalisation but fear that vulnerable patients will be denied a privilege reserved for better-situated patients and that healthcare inequities already affecting vulnerable persons will be exacerbated. In short, slippery-slope concerns about vulnerable patients confront both those who do and those who do not find physician-assisted dying objectionable on moral grounds.

Of course, to observe that patients are members of potentially vulnerable groups is to assert neither that each such person or the group as a whole is actually vulnerable nor that people who are seriously or terminally ill but not considering physician-assisted dying are not vulnerable. But it is to recognize a special and appropriate concern about persons and groups seen as vulnerable because of impairment, disadvantage or stigmatisation.

Warnings of potential abuse rest on predictive claims, claims typically assuming that higher rates of death in this way suggest abuse. We do not attempt to evaluate putative criteria

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Abbreviations: ALS, amyotrophic lateral sclerosis; ODDA, Oregon Death with Dignity Act; PAS, physician-assisted suicide

Box 1 '' Slippery-slope'' concerns about vulnerable patients in health policy statements on physician-assisted dying

''… no matter how carefully any guidelines are framed, assisted suicide and euthanasia will be practiced through the prism of social inequality and bias that characterizes the delivery of services in all segments of our society, including health care. The practices will pose the greatest risks to those who are poor, elderly, members of a minority group, or without access to good medical care.''
New York State Task Force on Life and the Law, 1994[1]

''… the State has an interest in protecting vulnerable groups—including the poor, the elderly, and disabled persons—from abuse, neglect, and mistakes. The Court of Appeals [Ninth Circuit] dismissed the State's concern that disadvantaged persons might be pressured into physician assisted suicide as ludicrous on its face.…We have recognized, however, the real risk of subtle coercion and undue influence in end of life situations …''
US Supreme Court, joint opinion in *Washington v Glucksberg* (1997) and *Vacco v Quill* (1997)[2]

''Euthanasia and assisted suicide are opposed by almost every national medical association and prohibited by the law codes of almost all countries. … If euthanasia or assisted suicide or both are permitted for competent, suffering, terminally ill patients, there may be legal challenges … to extend these practices to others who are not competent, suffering or terminally ill. Such extension is the ''slippery slope'' that many fear.''
Canadian Medical Association, 1998[3]

''Both society in general and the medical profession in particular have important duties to safeguard the value of human life. This duty applies especially to the most vulnerable members of society—the sick, the elderly, the poor, ethnic minorities, and other vulnerable persons. In the long run, such persons might come to be further discounted by society, or even to view themselves as unproductive and burdensome, and on that basis, ''appropriate'' candidates for assistance with suicide.''
''… the ramifications [of legalization] are too disturbing for the … value our society places on life, especially on the lives of disabled, incompetent, and vulnerable persons.''
American College of Physicians–American Society of Internal Medicine (ACP–ASIM), 2001[4]

''… the College concluded that making physician-assisted suicide legal raised serious ethical, clinical, and social concerns and that the practice might undermine patient trust and distract from reform in end of life care. The College was also concerned with the risks that legalization posed to vulnerable populations, including poor persons, patients with dementia, disabled persons, those from minority groups that have experienced discrimination, those confronting costly chronic illnesses, or very young children.''
American College of Physicians, 2005[5]

''… allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks …''
''Euthanasia could also readily be extended to incompetent patients and other vulnerable populations …''
American Medical Association, 1996, 2005[6 7]

''In the BMA's view, legalizing euthanasia or physician-assisted suicide would have a profound and detrimental effect on the doctor–patient relationship. It would be unacceptable to put vulnerable people in the position of feeling they had to consider precipitating the end of their lives…The BMA acknowledges that there are some patients for whom palliative care will not meet their needs and wishes, but considers that the risks of significant harm to a large number of people are too great to accommodate the needs of very few.''
British Medical Association, 2003[8]

for whether assisted dying might seem ''appropriate'' for some vulnerable groups. Rather, we ask the prior question of whether there is evidence that where assisted dying is already legal, the lives of people in groups identified as vulnerable are more frequently ended with assistance from a physician than those of the background population. We can now begin to evaluate this factual issue by examining directly what is happening in the two principal jurisdictions—Oregon and the Netherlands—where physician-assisted dying is legal and data have been collected over a substantial period.

DATA AVAILABLE IN OREGON AND THE NETHERLANDS

In Oregon, nine annual reports issued by the Department of Human Services cover the period since the Oregon Death with Dignity Act (ODDA) took effect in 1997.[9] Three surveys of Oregon physicians and hospice professionals add information beyond that drawn from official reports.[10–12] In the Netherlands, four nationwide studies (the first of which is known as the Remmelink report) commissioned by the Dutch government used cross-sectional analyses of data from interviews, death certificates and questionnaires to cover all end-of-life decision making in the years 1990,[13 14] 1995,[15] 2001[16] and 2005.[17] Several smaller, focused Dutch studies provide additional data, as noted below. The Oregon data are from the 2006 report and cumulative study[9] and the Dutch data are from the 2005 nationwide study[17] unless otherwise mentioned. The Oregon Department of Human Services data include all legal cases reported under the ODDA; additional surveys have not uncovered extralegal or unreported cases.[10 12] The nationwide Dutch data cover cases reported to the authorities as required under Dutch guidelines as well as extralegal, unreported cases.

Box 2 provides the legal background, incidence and regulation of assisted dying in the two jurisdictions. The term ''physician-assisted suicide'' was used by Oregon in reporting its data for the first several years of legalisation, but it does not appear in the statute; Oregon now refers to ''death under the Oregon Death with Dignity Act''. The term ''physician-assisted suicide'' is used here to distinguish the form of physician-assisted

Box 2 Legal background, incidence and regulation of assisted dying in Oregon and the Netherlands

Oregon

- The Oregon Death with Dignity Act was passed as a ballot initiative in 1994; implementation was delayed by a legal injunction and the measure was returned to the ballot by the legislature and passed again in 1997; the Act became law on October 27 of that year. A federal challenge to the ODDA was rejected by the US Supreme Court in 2006. Oregon is the only US state to legalize PAS (now referred to as utilisation of the ODDA). Euthanasia remains illegal.
- A total of 292 people have died under the ODDA in the 9 years since its enactment; this is approximately 0.15% of people who have died during this period.
- The Act allows terminally ill Oregon residents to obtain from their physicians a prescription for lethal medication for the purpose of ending their lives if the following conditions are met:
  - The patient must be adult (18 years of age or older) and a resident of Oregon.
  - The patient must be capable (defined as able to make and communicate healthcare decisions).
  - The prescribing physician and a consulting physician must confirm the diagnosis and prognosis.
  - The patient must be diagnosed by two physicians as having a terminal illness (defined as 6 months or less to live).
  - The patient must make two oral requests to his or her physician, separated by at least 15 days, and one witnessed written request.
  - If either physician believes the patient's decision may be influenced by a mental disorder, the patient must be referred for a mental health evaluation.
  - The patient must be informed by the prescribing physician of feasible alternatives, 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 request.
  - The physician must report the prescription for lethal medication to the Oregon Department of Human Services (formerly the Oregon Health Division); and the Department must make available an annual statistical report of information collected under the Act.[18]
  - Pharmacies are required to report filling such prescriptions.
- Oregon's statute requires terminal illness but makes no reference to the patient's pain, symptoms or suffering. It does not indicate whether the prescribing physician must, may or may not be present at the patient's death. It stipulates that ending one's life under the Death with Dignity Act does not constitute suicide.

The Netherlands

- Voluntary active euthanasia and PAS have been openly practised and, in effect, legal since the 1980s under guidelines developed in the courts and by the Royal Dutch Medical Association. According to an exception in the criminal code enacted in 2002, physicians who perform euthanasia or provide assistance in suicide commit no offense if they follow the guidelines for ''due care''.
- Of the total annual mortality of 136 000 (2005), approximately 1.7% of deaths are by voluntary active euthanasia and 0.1% by physician-assisted suicide; another 0.4% involve life-ending acts without explicit current request (known as LAWER).
- The guidelines require that:
  - The patient must make a voluntary, informed and well-considered request.
  - The patient must be facing unbearable and hopeless suffering, either currently or in the immediate future and with no outlook for improvement.
  - The physician must agree with the patient that no reasonable alternative treatment that might reduce the suffering is available.
  - The physician must consult with another, independent physician.
  - The action must be performed with due care.
  - The action must be reported to the appropriate authorities.
- Since 1998, five regional committees appointed by the Ministry of Justice review all reported cases. If they decide that the physician's behavior met the requirements of due care, their decision is final.
- Dutch law does not require that the patient be terminally ill but does require that the patient be facing ''unbearable and hopeless suffering''. Advance directives requesting euthanasia in the event that the patient becomes comatose or demented are also legal. Both before and after statutory legalization in the 2002 law, a physician has been protected from prosecution if the guidelines are met.

dying legally permitted in Oregon from the wider range of physician-assisted dying in the Netherlands, namely, both physician-assisted suicide and voluntary active euthanasia.

This paper examines available data concerning the use of physician-assisted dying (PAS in Oregon; PAS or voluntary active euthanasia in the Netherlands) to determine whether there is evidence of disproportionate impact on vulnerable populations. Are the lives of people in vulnerable groups more frequently ended with a physician's assistance than those of other, less vulnerable people? The results presented (table 1) move from the most robust data to that which is partial, inferential or in other ways less secure. Detailed accounts of the statistical and other methods used in each source study are available in those studies, variously including information on response rates, survey questions asked, sample sizes, actual numbers, statistical power and confidence intervals, methods of calculation of rate ratios, detectable differences, changes over time, and methodology, design and analysis techniques. We recognize that substantial differences in the methodologies of the source studies make it impossible to determine with certainty the actual incidence of assisted dying in several of the vulnerable groups studied. Our question is whether the available data show evidence of heightened risk to persons in vulnerable groups.

IS THERE EVIDENCE OF HEIGHTENED RISK TO PEOPLE IN VULNERABLE GROUPS?

Findings based on robust data

The elderly: *no evidence of heightened risk*

In Oregon, 10% of patients who died by PAS were 85 or older, whereas 21% of all Oregon deaths were among persons in this age category. Persons aged 18–64 years were over three times more likely than those over age 85 years to receive assisted dying. In the Netherlands, rates of assisted dying were lowest in the people over 80 (0.8% in 2005), next lowest in the age range 65–74 years (2.1%) and higher below age 65 (3.5%). People over 80 formed 30% of the group of patients whose requests were refused and 13% of those whose requests were granted and carried out.[19]

Women: *no evidence of heightened risk*

In Oregon, 46% of individuals receiving assisted dying were women and women were not more likely than men to use assisted suicide. In the Netherlands, despite some fluctuation in different years of the nationwide studies, the rates tend to be slightly higher in men.

Uninsured people: *no evidence of heightened risk*

Three Oregon patients (1%) did not have documented health insurance, and in four cases, insurance status was unknown. In contrast, 16.9% of non-elderly adults in Oregon were uninsured[20] (persons 65 and older are insured by Medicare). In the Netherlands, virtually all patients are covered by mandated nationwide health insurance.

People with AIDS: *heightened risk found*

In 9 years in Oregon, a total of six persons with AIDS died under the ODDA; although the numbers are small (2% of the total of 292 ODDA deaths), persons with AIDS were 30 times more likely to use assisted dying than those who died of chronic respiratory disorders in the interview portions of the nationwide studies in the Netherlands, very few patients with AIDS had received a physician's assistance in dying. However, in an Amsterdam cohort of 131 homosexual men with AIDS diagnosed between 1985 and 1992 who had died before 1 January 1995, 22% died by euthanasia or PAS.[21]

Findings based on partly direct, partly inferential data

People with low educational status: *no evidence of heightened risk*

In Oregon, the likelihood of dying by PAS was correlated with higher educational attainment. Terminally ill college graduates in Oregon were 7.6 times more likely to die with physician assistance than those without a high school diploma. While no direct quantified data are available in the Netherlands about the educational status of patients receiving assisted dying, information in the 1990 study about professional status, associated with educational status, showed no special relationships to patterns of euthanasia or PAS.

The poor: *no evidence of heightened risk*

The Oregon data do not include direct measures of income, employment or assets, but death under the ODDA was associated with having health insurance and with high educational status, both indirect indicators of affluence. In the Netherlands, data inferred from the postal codes of the location in which the person was living before death showed that the overall rates of assisted dying were somewhat higher for people of higher socioeconomic status.[22]

Racial and ethnic minorities: *no evidence of heightened risk*

In Oregon, 97% of the 292 patients who had a physician's assistance in suicide were white; six of the non-white patients were persons of Asian descent, one was Hispanic and one was Native American. Although 2.6% of Oregonians are African-American, no African-American has received physician-assisted dying under the Act. Dutch mortality statistics do not include information about race or ethnicity; however, even the most vocal opponents of assisted dying in the Netherlands do not claim that it is imposed more frequently on stigmatised racial or ethnic minorities.

People with non-terminal physical disabilities or chronic non-terminal illnesses: *no evidence of heightened risk*

In one sense, virtually all patients who are seriously or terminally ill are to some extent physically disabled and chronically ill. Patients who are dying lose functional capacities and may be bedridden toward the end; in this sense, most patients who received assistance in dying in either Oregon or the Netherlands were chronically ill and (recently) disabled. Cancer, the diagnosis in about 80% of all cases of assisted dying in both Oregon and the Netherlands, is often identified as a chronic illness; so is amyotrophic lateral sclerosis (ALS), also a frequent diagnosis. Concerns about persons in vulnerable categories have focused, however, on pre-existing physical disabilities and chronic non-terminal illnesses.

Although the data from Oregon do not indicate whether a person had a disability before becoming terminally ill (defined as having 6 months or less to live), no one received physician-assistance in dying who was not determined by two physicians to be terminally ill—that is, no one received such assistance for disability alone. That some patients received lethal prescriptions that they did not ingest and lived longer than 6 months may represent limitations in prognostication, although clinicians caring for terminally ill cancer patients are likely to overestimate rather than underestimate survival.[23 24] In the Netherlands, assisted dying for disability alone would not be illegal in principle; a terminal diagnosis is not required by the Dutch guidelines, and a person who faces unbearable suffering, in his or her own view, and who has been offered all forms of treatment but has no hope of improvement may request assistance in dying. Estimates made by physicians of the amount of life forgone can be used to make an approximation of disability or chronic illness status: about 0.2% of patients receiving euthanasia or assistance in suicide were estimated to have forgone more than 6 months of life, or less than 10 of the approximately 2400 cases in 2005. Dutch general practitioners infrequently grant and frequently refuse assistance in dying to patients whose diagnosis is ''old age/general deterioration'' or ''other'' (this includes the category of patients with no terminal illness and no ALS or multiple sclerosis).[19] There is thus no evidence that physician-assisted dying poses heightened risk to people with disabilities who are not also seriously ill.

Minors and mature minors: *no evidence of heightened risk*

The Oregon ODDA requires that a patient be an adult (18 years of age or older) before assisted dying is granted; no cases of physician-assisted death were reported among minors. In the Netherlands, mature and relatively mature minors are understood to have some decision-making capacity and are not excluded under the Dutch guidelines, but because they are below the age of majority must be regarded as ''vulnerable''. Since death rates among minors in the Netherlands (0.4% of all deaths) were the lowest in any age group, it is difficult to reach statistically firm conclusions. In 2001, less than 1% of all deaths of persons aged 1–17 years were the result of euthanasia: no cases of PAS were found in this age group.

The Netherlands has recently developed a protocol for euthanasia in newborns with very serious deficits who have a hopeless prognosis and experience what parents and medical experts deem to be unbearable suffering; the decision is to be made in collaboration with the parents and requires their full approval. This is known as the Groningen protocol.[25] Such cases are infrequent—22 cases have been reported to district attorneys in the Netherlands during the past 7 years, and there are an estimated 10 to 20 cases annually among the somewhat

Table 1 Physician-assisted dying in potentially vulnerable groups in Oregon and the Netherlands: overview of data from Oregon reports and studies, and Dutch nationwide and focused studies

	Oregon—PAS patients 1998–2006			Netherlands*— PAS/euthanasia patients 2005 (n = 2400)		
Potentially vulnerable group	**Characteristic**	**No. (%)**	**Rate ratio**	**Characteristic**	**No. (%)**	**Rate ratio**
Findings based on direct data						
The elderly (age in years)	18–44	11 (4)	3.4	0–64	900 (38)	1.7
	45–64	83 (28)	3.2	65–79	950 (39)	1.7
	65–84	170 (58)	2.3	80+	550 (23)	1.0
	85 +	28 (10)	1.0			
	Median 70 (range 25–96)					
Women	Male	157 (54)	1.1	Male	1350 (56)	1.3
	Female	135 (46)	1.0	Female	1050 (44)	1.0
Uninsured people	Private insurance	180 (62)		Not applicable (all are insured)		
	Medicare or Medicaid	105 (36)				
	No insurance	3 (1)				
	Status unknown	4 (1)				
People with AIDS	HIV/AIDS†	6 (2)	30.3	HIV/AIDS‡	29 (22)	7.9
Findings based on partly direct and partly inferential data						
People with low educational status	<High school	25 (9)	1.0	Indirect data (via SES); no direct relationship		
	HS graduate	82 (28)	1.8			
	Some college	64 (22)	3.2			
	Baccalaureate or higher	121 (41)	7.6			
The poor (people with low SES)	Rate low¶			Low SES§	1400 (38)	1.0
				Moderate SES	1200 (33)	1.0
				High SES	800 (22)	1.2
				Institutions§	300 (8)	0.3
Racial and ethnic minorities	White	284 (97)	1.0	No data (Dutch mortality statistics are not kept by race)		
	African-American	0 (0%)				
	Hispanic	1 (<1%)	0.4			
	Native American	1 (<1%)	0.5			
	Asian	6 (2)	1.8			
	Other	0	0			
People with chronic physical or mental disabilities or chronic non-terminal illnesses	Not legal; no cases reported or identified			No data to calculate denominator; probably 10 cases or fewer per year		
Minors	Not legal; no cases reported or identified			1.6% of all deaths of minors aged 1–16 years		
Findings based on inferential or partly contested data						
People with psychiatric illness, including depression and Alzheimer disease	Not legal; no clear cases; three disputed cases among those given prescription (n = 456)			No data to calculate denominator; increased requests among cancer patients with depression; probably rare for psychiatric illness as main diagnosis; legal in Alzheimer disease with advance euthanasia directive but compliance rare		

*All estimates are based upon data about a sample of 9000 deaths from August to November 2005, unless indicated otherwise; 2005 data are used for simplicity. Data are roughly comparable for entire period studied. Also see van der Heide *et al*, 2007.[17]

†Referent is chronic lower respiratory disorder.

‡Estimate based upon prevalence study from early 1990s.

¶Indirect data (via educational level and insuredness).

§Estimates based upon 2001 nationwide study; also see Onwuteaka-Philipsen *et al*, 2003.[16]

LAWER, life-ending acts without explicit current request; PAS, physician-assisted suicide; SES, socioeconomic status.

over 1000 children born in the Netherlands who die during the first year of life, about 1% of newborn deaths.

Findings based on inferential or partly contested data

Patients with psychiatric illness, including depression and Alzheimer disease: *no evidence of heightened risk*

Approximately 20% of requests for physician assistance in dying came from depressed patients, but none progressed to PAS.[10] None of the 292 patients who died under the ODDA were determined to have a mental illness influencing their decision, though there have been three disputed cases among the 9-year total of 456 who received prescriptions.[26 27] Because not all patients who requested assistance were specifically evaluated by mental health professionals and because many cases of depression are missed in primary care, it is possible that some depressed patients received lethal prescriptions; it is also possible that a patient without a mental disorder at the time of receiving the prescription became depressed by the time they ingested it. There is, however, no direct evidence that depressed patients are at higher risk for receiving assistance in dying under the ODDA.

In the Netherlands, about two-thirds of explicit requests for assistance in dying are not granted. In 31% of all requests not granted in the 1995 study, the physician gave the presence of psychiatric illness as at least one reason for not complying. Physicians in the interview portion of the 1995 Dutch nationwide study mentioned depression as the predominant symptom in patients who died by PAS or euthanasia in 3% of all cases, compared with ''loss of dignity'' in 60%, pain as an associated complaint in 45% and debility in 43%. In one study, cancer patients with depressed mood were four times more likely to request euthanasia, but how often the request was granted is unknown.[28]

In 1994, the Dutch supreme court ruled in the *Chabot* case, in which a psychiatrist assisted with suicide for a woman with intractable depression but without concomitant physical illness, that ''intolerable suffering'' might consist in mental suffering alone without somatic origins and not involving the terminal phase of a disease, though the court commented that such cases would be rare and that they require heightened scrutiny.[29] The 2001 Dutch interview study estimated that about 3% of all requests for euthanasia or PAS that physicians had received the previous year were from patients with predominantly psychiatric or psychological illnesses, but none were granted. In the Dutch 1995 nationwide substudy on end-of-life decision making in psychiatric practice, there appeared to be about two to five physician-assisted deaths on request per year, mostly but not always in patients with a concurrent serious physical illness, often in the terminal phase. Explicit requests for a physician's assistance in dying are not uncommon in psychiatric practice in the Netherlands, and a majority of Dutch psychiatrists consider assisted suicide for psychiatric patients acceptable in certain circumstances. However, this rather liberal attitude appears to be associated with quite reluctant practice: despite the fact that Dutch law would permit it, it occurs only very rarely.

Since 2002, the Netherlands has also recognised as legal advance euthanasia directives of patients with dementia, including Alzheimer disease. Although approximately 2200 demented patients with advance directives requesting euthanasia after the onset of dementia die annually having been treated by a physician who knows about this directive—indeed, in 76% of such cases, compliance with the directive was discussed—euthanasia is seldom performed.[30]

Table 2 summarises the comprehensive data provided in table 1.

THE COMPREHENSIVE PICTURE IN OREGON AND THE NETHERLANDS

The data from Oregon and the Netherlands are the most informative sources concerning legal physician-assisted dying, though they are not comparable in a number of respects: they cover different time periods, were obtained by different methods, and are of different strengths. Neither the Oregon nor the Dutch studies were corrected throughout for considerations of whether diagnoses that may make physician-assisted dying attractive are equally distributed in vulnerable and non-vulnerable groups. Clearly, more work needs to be done.

Where they do overlap, however, the studies are largely consistent. Where the data are robust, the picture in Oregon and the Netherlands is similar: in both jurisdictions, a smaller percentage of older people received assistance in dying than of younger patients; gender ratios were slightly higher for males over time; and assistance was not more common among the uninsured. Socioeconomic data of intermediate strength, usually inferred from other, more robust data, also suggest similar pictures in the two jurisdictions: recipients of assistance in dying were likely to be of equal or higher educational status and were less likely than the background population to be poor. Data that are robust in one jurisdiction but partly inferential and hence less secure in the other did not reveal cases in either

Table 2 Summary of evidence of heightened risk in physician-assisted dying in Oregon and the Netherlands

Potentially vulnerable group	Evidence of heightened risk	No evidence of heightened risk
Direct data		
The elderly		×
Women		×
Uninsured people		×
People with AIDS	×	
Partly direct, partly inferential data		
People with low educational status		×
The poor: people with low socioeconomic status		×
Racial and ethnic minorities		×
People with chronic physical or mental disabilities or chronic non-terminal illnesses		×
Minors		×
Inferential or partly contested data		
People with psychiatric illness, including depression and Alzheimer disease		×

data set of assisted dying associated with physical disability alone without concomitant serious or terminal illness. The rates of physician-assisted dying among mature minors, which is legal in the Netherlands, were too low to be statistically valid. Although the rates of request for physician-assisted dying may have been higher among patients with depression, it appears that most such requests did not culminate in euthanasia, even though such cases may be legal in the Netherlands if given heightened scrutiny; studies of patients in the process of making requests are needed to clarify the risk conferred by depression. Even where the data involve very few cases or are absent in one or the other jurisdiction, the picture appears to match: neither in Oregon nor in the Netherlands was there any report of assisted dying disproportionately practised among racial minorities. Thus, there is no evidence of heightened risk of physician-assisted dying to vulnerable patients in either legal or extralegal practice groups, with the sole exception of people with AIDS.

Thus, we found no evidence to justify the grave and important concern often expressed about the potential for abuse—namely, the fear that legalised physician-assisted dying will target the vulnerable or pose the greatest risk to people in vulnerable groups. The evidence available cannot provide conclusive proof about the impact on vulnerable patients, and full examination of practice in Oregon would require studies of the complexity, duration and comprehensiveness of the four Dutch nationwide studies. Nevertheless, the joint picture yielded by the available data in the two jurisdictions shows that people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges. This conclusion does not directly speak to the moral issues in physician-assisted dying; it does not argue whether physician-assisted dying would be more or less appropriate for people in some groups; and it does not show that people in vulnerable groups could not be disproportionately affected in the future or in other jurisdictions. It also does not show whether low rates of physician-assisted dying among vulnerable persons reflect a protective effect of safeguards or, rather, are evidence of unequal access to assistance. But it does show that there is no current factual support for so-called slippery-slope concerns about the risks of legalisation of assisted dying—concerns that death in this way would be practised more frequently on persons in vulnerable groups.

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Quality of Death and Dying in Patients who Request Physician-Assisted Death

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Abstract

Background: Physician-assisted death (PAD) was legalized in 1997 by Oregon's Death with Dignity Act (ODDA). Through 2009, 460 Oregonians have died by lethal prescription under the ODDA.
Objective: To determine whether there was a difference in the quality of the dying experience, from the perspective of family members, between 52 Oregonians who received lethal prescriptions, 34 who requested but did not receive lethal prescriptions, and 63 who did not pursue PAD.
Design: Cross-sectional survey.
Measurements: Family members retrospectively rated the dying experience of their loved one with the 33 item Quality of Death and Dying Questionnaire (QODD).
Results: There were differences reported in 9 of the 33 quality item indicators. Few significant differences were noted in items that measured domains of connectedness, transcendence, and overall quality of death. Those receiving PAD prescriptions had higher quality ratings on items measuring symptom control (e.g., control over surroundings and control of bowels/bladder) and higher ratings on items related to preparedness for death (saying goodbye to loved ones, and possession of a means to end life if desired) than those who did not pursue PAD or, in some cases, those who requested but did not receive a lethal prescription.
Conclusions: The quality of death experienced by those who received lethal prescriptions is no worse than those not pursuing PAD, and in some areas it is rated by family members as better.

Introduction

Improving end-of-life care is a priority for health care in the United States. Researchers are refining measurements of the end-of-life experience and factors associated with better quality of care and quality of death and dying. Quality of death and dying is comprised of a variety of elements including symptom management, treatment in accord with patient wishes, psychological health, spiritual and existential well-being, social support, and the experience of death.[1,2]

Citizens in two states—Oregon (since 1997) and Washington (since 2009)—have legalized physician-assisted death (PAD) for terminally ill individuals. The Oregon Death with Dignity Act (ODDA)[3] allows a patient to request a lethal dose of medication from a physician for the purposes of self-administration. Since passage in 1997, 460 Oregonians have died under the terms of the ODDA. Experts have speculated that patients may be motivated to pursue PAD to avoid poor quality of dying caused by symptom distress and impaired physical function, psychological variables such as depression and hopelessness, lack of or conflicted social support, existential or spiritual distress, and perception of self as a burden.[4–9] It has been suggested that improved end-of-life care could address these needs and thus alleviate the desire for PAD.[4,8] Additionally, it has been postulated that presence of legal PAD might in fact result in a decline in the quality of end-of-life care for patients, as health care providers would prematurely consider PAD when faced with unmanaged symptoms[10] or as a response to the burden of the cost of care.[11] In contrast to these concerns, previous research with patients and physicians, social workers and nurses, and family members involved with patients who chose PAD identified the importance of a desire to control circumstances of death, die at home, maintain independence and avoid future physical symptoms as possible contributors to requests for PAD.[6,7,12,13] Whether access to a lethal prescription helps patients to meet these goals has not been investigated.

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In this study we investigate the quality of death and dying of terminally ill Oregonians as perceived by family members, and consider whether those who receive a lethal prescription under the ODDA encounter end of life experiences that differ objectively and subjectively from those who requested PAD but were unable to access it, and those who never requested PAD.

Methods

To understand the perceived differences in quality of death, we asked participants to evaluate the end-of-life experiences of their loved ones in terms of physical symptoms, preparation for death, existential transcendence, connections to others, and overall quality of life and death by using the Quality of Death and Dying (QODD), a validated instrument.[14]

Participants for this study were recruited from agencies and organizations in northwest Oregon willing to participate: two large medical centers, three large hospices, the Amyotrophic Lateral Sclerosis (ALS) Association of Oregon, and Compassion and Choices of Oregon. Compassion and Choices of Oregon is an advocacy organization that provides information, support and referral to those who qualify for assisted death under the ODDA. Four of these organizations kept registries of those pursuing PAD and made the initial contact with family members of decedents who made an explicit request for PAD to a physician (whether or not the patient received a prescription). After being notified of the opportunity, family members contacted the research team if they wished to participate. Compassion and Choices of Oregon identified 180 eligible primary informants, of whom 38% participated. Family members from other referral sources were a convenience sample. Potential participants were excluded if the loved one died less than 4 months or more than 3 years before the study or if the organization was not confident that the family member was aware of the request for PAD. Comparison family members were a convenience sample recruited from the hospices, medical centers, and the ALS Association noted above. The data were collected between 2004 and 2007 and conducted by study research personnel and Dr. Goy. Details of recruitment have been previously described.[12,15]

This study was approved by the Institutional Review Board of the Portland Veterans Affairs Medical Center and the participating medical centers and hospices. All participants gave written informed consent to participate.

Measures

Quality of death and dying. The QODD is a retrospective, 33-item measure of the quality of dying and death for the time period immediately preceding the death from the perspective of family members.[14] The interviewer-administered instrument elicits family rating of the frequency and quality of the patient's experiences during the last 7 days of life, or during the last 30 days of life if the loved one was unconscious or unresponsive during the last 7 days of life. The QODD assesses the domains of symptom control, social connectedness, preparation for death, and transcendence, with several items in each domain as indicators of quality. This instrument has evolved over time with use and subsequent validation. Recent factor analysis has led the instrument's authors to recommend a 17-item version with the four conceptual domains noted above[16]; however, our study was conducted before this recommendation and we used the original version of the instrument which includes items to rate global quality of death and the moment of death.

Indicators of quality (items) in each domain were evaluated by family members on two aspects: whether and with what frequency an indicator was present; and to what extent the presence or absence of that indicator affected their loved one's dying experience. Frequency ratings are either on a 6-point Likert scale ($0 =$ none of the time; $5 =$ all of the time) or on a binary scale (yes/no) depending on the question. For example, family members are asked to rate "How often did (loved one's name) appear to be worried about strain on his/her loved ones?" or "Did (loved one) appear to find meaning and purpose in her/his life?" Family members are then asked to assess how this impacted quality with the question, "How would you rate this aspect of (loved one's name) dying experience" on an 11-point Likert scale ($0 =$ terrible experience; $10 =$ almost perfect experience). There are two global questions rating the quality of life in the last 7 days before death (or last 30 days under the conditions noted above) and at the moment of death on an 11-point Likert scale. Data from the 7-day and the 30-day versions of the QODD are combined.

Statistical analysis

Categorical data are presented as frequencies and proportions. Among the QODD continuous measures, many responses were not normally distributed. Because the sample size was large, $n = 147$, and each group size was relatively large ($n = 52$, 32, and 63, respectively), it was possible that nonnormality and asymmetry would not affect the analysis. Therefore, we analyzed the data with parametric (analysis of covariance and Student's t-test) and non-parametric tests (Kruskal-Wallis) to assure the reliability of the results. In all but 5 cases the parametric and non-parametric results agreed; of those that differed, significance values were close and trended in expected directions. As such, we report continuous measures as means with standard deviations (SD) and compared the three groups with analysis of covariance. Family education level and whether or not the patient was enrolled in hospice were included as covariates in these analyses to account for group differences on these variables. If significant differences were found, *post hoc* analysis was conducted using a Bonferroni adjustment. We used χ^2 analysis to examine group differences on dichotomously scored variables. Because of the large number of comparisons that were not hypothesis-based, alpha was set at 0.01. Items with p values between 0.05 and 0.015 are identified as trending toward significance. Data analysis was completed with the Statistical Package for the Social Sciences (SPSS Inc., Chicago, IL) version 17.

Results

We surveyed 147 family members regarding their assessment of their loved one's dying experience, including 84 family members of patients who requested physician assisted death. The final data set included three groups of Oregonians: 52 decedents who requested and received a lethal prescription to facilitate assisted death (including 32 who died of PAD); 32 decedents who requested but did not receive the requested prescription; and 63 decedents who never pursued or re-

Table 1. Characteristics of Family Members

Family member	*Loved one requested and received PAD* (n = 52)	*Loved one requested but did not receive PAD* (n = 32)	*Comparison family member* (n = 63)	*p value*
Relationship to patient, *n* (%)				NS[a,b]
Spouse/partner	33 (64)	17 (53)	37 (59)	
Daughter/son	15 (29)	9 (28)	17 (27)	
Other	4 (8)	6 (19)	9 (14)	
Gender, *n* (%)[a]				NS[a]
Male	17 (33)	10 (31)	13 (21)	
Female	35 (67)	22 (69)	50 (79)	
Family member ethnicity[a]				NS[a]
Caucasian	52 (100)	32 (100)	61 (97)	
Non-Caucasian	0 (0)	0 (0)	2 (3)	
Age (years), mean (SD)[c]	61.0 (13.3)	61.2 (12.2)	60.1 (14.2)	NS[d]
Educational achievement (years), mean (SD)	16.3 (3.4)	15.7 (2.3)	14.5 (3.2)	<0.05[d]
How long known patient (years), mean (SD)	40.0 (16.1)	44.2 (15.3)	38.6 (16.6)	NS[d]
Days between death and interview, mean (SD)	396.4 (274.4)	453.4 (264.2)	446.8 (210.1)	NS[d]
Religiousness (mm)[e]	31.3 (37.9)	27.3 (35.7)	58.4 (38.3)	<0.001[d]
Views on legalization of PAD[f]	1.1 (3)	1.1 (3)	2.4 (1.4)	<0.001[d]

[a] χ^2 test.
[b] NS, not significant.
[c] SD, standard deviation.
[d] Compared with analysis of variance.
[e] 0–100 mm scale where 0 = religion not important to me, and 100 = religion very important to me.
[f] Family members' views on legalization of PAD; scale 1 = strongly support, 5 = strongly oppose.
PAD, physician-assisted death; SD, standard deviation.

quested a prescription to facilitate PAD (comparison group). Most family members were well-educated spouses or children, who had known the decedent for close to 40 years (Table 1). Ninety-nine percent of respondents were Caucasian. Family members of those who requested PAD were overall supportive of legalization of PAD and less religious than comparison family members. Most decedents were enrolled in hospice and died of cancer (Table 2).

Table 3 presents measures of frequency and impact that were statistically significant or trended toward significance.

Symptom control

Twelve items measured the severity of six symptoms and their impact on the quality of dying including pain; ability to feed self; control over surroundings and over bowel and

Table 2. Characteristics of Decedents

Decedent	*Loved one requested and received PAD* (n = 52), n (%)	*Loved one requested but did not receive PAD* (n = 32), n (%)	*Comparison decedent* (n = 63), n (%)	*p value*
Gender				NS[a]
Male	32 (62)	16 (50)	36 (57)	
Female	20 (39)	16 (50)	27 (43)	
Hospice enrolled				<0.05
No	9 (17)	1 (3)	3 (5)	
Yes	43 (83)	30 (97)	60 (95)	
Terminal diagnosis				NS
Cancer	45 (87)	23 (72)	50 (79)	
ALS	3 (6)	1 (3)	6 (10)	
Other	4 (8)	8 (25)	7 (11)	
Place of death				NS
Home[b]	46 (90.2)	25 (80.6)	44 (69.8)	
Inpatient hospice	1 (2.0)	2 (6.5)	10 (15.9)	
Other	4 (7.8)	4 (12.9)	9 (14.3)	
QODD version				0.001
7 day	51 (98)	31 (97)	50 (79)	
30 day	1 (2)	1 (3)	13 (21)	

[a] NS = not significant, all comparisons χ^2 test.
[b] Includes own home, surrogate home, and other home.
PAD, physician-assisted death; ALS, amyotrophic lateral sclerosis; QODD, Quality of Death and Dying Questionnaire.

Table 3. Quality of Death and Dying in Patients Who Requested and Did Not Receive Physician-Assisted Death

Item	*Loved one requested and received PAD (1)* N = 52	*Loved one requested, but did not receive PAD (2)* N = 32	*Comparison decedent (3)* N = 63	p *value*	*Post hoc comparison*
Symptom control					
Control over surroundings,[a] mean (SD)[b]	3.8 (1.2)	2.6 (1.6)	2.3 (1.6)	0.000	1,2 $p < 0.01$ 1,3 $p < 0.001$
Control over surroundings, impact,[c] mean (SD)	7.6 (2.6)	6.0 (3.4)	5.5 (3.1)	0.006	1,3 $p < 0.01$
Ability to feed self,[a] mean (SD)	3.7 (1.8)	1.9 (1.9)	2.0 (1.9)	0.000	1,2 $p < 0.001$ 1,3 $p < 0.001$
Ability to feed self, impact,[c] mean (SD)	7.1 (2.8)	4.4 (3.1)	4.6 (3.0)	0.000	1,2 $p < 0.001$ 1,3 $p < 0.001$
Control bladder or bowels,[a] mean (SD)	3.1 (1.9)	1.8 (1.9)	2.2 (1.9)	0.008	1,2 $p < 0.05$
Control bladder or bowels, impact,[c] mean (SD)	6.0 (3.5)	3.8 (3.3)	4.7 (3.3)	0.015	1,2 $p < 0.05$
Energy to do things,[a] mean (SD)	1.1 (1.0)	0.6 (0.8)	0.8 (0.9)	0.011	1,2 $p < 0.05$
Energy to do things, impact,[c] mean (SD)	3.1 (2.6)	2.2 (2.3)	2.5 (2.6)	0.013	
Preparation					
Said goodbye to loved ones,[d] No. (%)	45 (87)	22 (69)	36 (57)	0.003	
Said goodbye to loved ones, impact,[c] mean (SD)	8.7 (2.3)	8.0 (2.4)	7.3 (2.9)	0.096	
Spiritual service before death,[d] No. (%)	4 (8)	6 (19)	22 (35)	0.002	
Spiritual service before death, impact,[c] mean (SD)	6.6 (2.1)	7.4 (2.3)	7.4 (2.4)	0.251	
Means to end life,[d] No. (%)	50 (96)	9 (28)	28 (44)	0.000	
Means to end life, impact,[c] mean (SD)	9.3 (1.9)	4.5 (3.6)	6.9 (2.3)	0.000	1,2 $p < 0.001$ 1,3 $p < 0.001$ 2,3 $p < 0.001$
Discussed end-of-life wishes,[d] No. (%)	49 (94)	29 (91)	54 (86)	0.342	
Discussed end-of-life wishes, impact,[c] mean (SD)	9.6 (0.9)	8.3 (2.7)	8.9 (1.6)	0.014	1,2 $p < 0.05$
Transcendence					
Worried about strain on loved ones[a] mean (SD)	2.8 (1.6)	1.9 (1.7)	2.4 (1.6)	0.033	1,2 $p < 0.05$
Worry strain on loved ones, impact,[c] mean (SD)	4.8 (2.9)	5.3 (3.0)	5.0 (2.6)	0.793	
Laugh and smile[a] mean (SD)	2.8 (1.2)	1.7 (1.2)	2.3 (1.3)	0.003	1,2 $p < 0.001$ 1,3, $p < 0.05$
Laugh and smile, impact,[c] mean (SD)	7.2 (2.7)	6.1 (2.9)	6.6 (2.9)	0.019	
Moment of Death					
Level consciousness at death[c]				0.012	
Awake	25 (48)	7 (22)	12 (19)		
Asleep	5 (10)	1 (3)	11 (17)		
Coma/unconscious	20 (38)	20 (63)	39 (62)		

[a] Scale 0 = none of the time, 5 = all of the time; compared with analysis of covariance; family education level and whether or not the patient was enrolled in hospice were included as covariates; post hoc comparison used a Bonferroni correction.

[b] SD = standard deviation.

[c] Scale 0 = terrible experience, 10 = almost perfect; compared with analysis of covariance; family education level and whether or not the patient was enrolled in hospice were included as covariates; post hoc comparison used a Bonferroni correction.

[d] Yes/no scale, reported as percentage 'yes,'" compared with Pearson's χ^2 missing data for these items range from 0%–< 10%.

PAD, physician-assisted death.

bladder; ability to breathe comfortably; and energy to do things. The three groups differed overall in control of surroundings, control of bladder and bowel, energy to do things, and ability to feed self, and *post hoc* analyses demonstrated that those who received a lethal prescription differed from the other two groups with better quality of dying related to control of surroundings and ability to feed self. Among those who requested PAD, those who received it had higher scores on control of bladder and bowel and energy to do things.

Connectedness

Indicators of connectedness were items measuring time spent with family and friends, attendance at important events, and physical expressions of affection. No items in the connectedness domain showed significant differences between the three groups.

Preparation

The domain preparation was measured by 18 items, including discussion of end of life wishes; clearing up bad feelings; use/avoidance of life support; having health care costs covered; visit from any religious advisor; spiritual service before death; having the means to end life if desired; funeral arrangements made; and goodbyes said.

Significant between-group differences were noted in having means to end life and discuss end-of-life wishes, spiritual services before death, and saying goodbye to loved ones. Those who received a lethal prescription were more likely to have said goodbye than those who did not pursue PAD, and were less likely to engage in a spiritual ceremony before death than those who did not pursue PAD.

Not surprisingly, the three groups differed on the item measuring possession of the means to end life if desired, and those who requested and received a lethal prescription were indeed more likely to be in possession of the means to end life than either those who requested but did not receive a lethal prescription or those who did not pursue PAD. Similarly, there were significant differences between all three groups in the family members' quality rating of the impact of possession of means to end life on the dying experience.

Transcendence

This domain included 12 items, including being unafraid of and at peace with dying; maintaining dignity; ability to laugh/smile; finding meaning in life; and worry about strain on loved ones. Significant between group differences were observed only in the item measuring ability to laugh/smile. Post hoc analysis revealed that those who received a lethal prescription were rated by family members as laughing/smiling more often in the final week of life than those decedents who requested a lethal prescription but did not receive it. There was a trend for those who requested but did not receive a lethal prescription to worry about their strain on loved ones.

Moment of death

Level of consciousness and presence of others was measured. There was a difference between the three groups in whether the loved one was awake, asleep, or in a coma in the moments before death.

Global ratings

Two items measured family members' perception of overall quality of death and dying: quality of life in the last 7 (or 30) days of life and quality of the moment of death. No differences between the groups were found on these items. In a separate analysis there was no difference in quality of life in the last 7 days of life for those who died by PAD (mean [SD] 4.1 [2.9]) versus those who received prescriptions but did not use them (mean [SD] 4.2 [2.6]). However, family members rated the quality of the moment of death as higher among those who took the prescription ($n = 32$; mean [SD] 9.6 [0.9]) compared to those who received a lethal prescription but did not take it ($N = 20$; mean [SD] 7.3 [3.2], $p < 0.001$).

Discussion

In this study we used the QODD to compare family perception of the quality of the dying experience between deceased Oregonians who pursued PAD and Oregonians who died of terminal illness without requesting PAD. We further distinguished between those who requested and received a lethal prescription for PAD and those who requested but did not receive the prescription. Domains evaluated by the instrument included symptom control, preparedness, connectedness, transcendence, and the moment of death. The main finding was that families perceived better quality of dying among patients who received lethal prescriptions when some physical symptoms were avoided and there was greater preparation for death.

Of the 33 different indicators of quality, significant between group differences were found in one or both aspects of 9 of the indicators. In domains of connectedness and transcendence there were very few differences between groups, and ratings of the moment of death and global ratings of quality of life did not differ, again indicating that those choosing PAD were similar to those not pursuing PAD in terms of quality of death.

In domains of symptom control and preparedness, however, significant differences were noted. Family members of those choosing PAD reported greater symptom control, particularly in regard to control over surroundings, better functioning, better energy, and better control of bowel and bladder. We previously found that at the time they expressed initial interest in PAD, Oregonians were motivated by worries about future discomfort, pain and other physical symptoms, but rated physical symptoms at the time of the request as relatively unimportant reasons for requesting a lethal prescription.[6] Our data suggest that PAD may meet that goal in some patients if they are able to avoid symptoms that contribute to "states worse than death."[17]

Those choosing PAD were in some ways more prepared for death in that they were more likely to have said goodbye to loved ones, yet less likely to have had a spiritual service before death than those who did not. Previous studies have demonstrated that as the importance of religion increases, interest in PAD lessens. Furthermore, there was a trend toward significance in the positive impact of discussion of end of life wishes on the dying experience with those who received a lethal prescription reported by family members as finding greater positive effect of end-of-life discussions on the dying experience than those who did not pursue PAD.

One limitation of this study is that family members retrospectively assessed the quality of their loved one's dying experience. It is unknown how closely family member assessment would correlate with the decedent's assessment. Research regarding the concordance of proxy respondents is mixed, with some authors reporting that proxy reporters are more accurate with observable indicators than with subjective indicators of quality[18] and that proxies tend to report lower quality of life than patients report for themselves.[19] However, given the frail nature of the patients and the potential burden of participating in end of life research, proxy respondents are viewed as an appropriate source of information on the final experiences of life.[1,18] Additional limitations were the low participation proportion among the aid in dying families and the comparison family members were a convenience sample. It is unknown how non-response might be associated with the views on quality of death and dying.

A strength of this study was the use of the QODD, an instrument designed to specifically assess the end of life experience of terminally ill patients. Given the overlap of the concepts of quality of life at end of life, quality of death and dying, and quality of care at end of life, this instrument specifically assesses the quality of the dying experience and helps to elucidate the experience for those choosing PAD. PAD is a controversial issue that draws moral and ethical arguments both for and against the practice. This study does not address those arguments. However, another concern regarding the legalization of PAD is that PAD would become a substitute for quality end of life care. Our study does not support that the choice for PAD reflects poor symptom management.[20] In fact, in the view of family members it does appear to meet patients' preferences for control and avoidance of a period of declining function. Insofar as family rating of the quality of a loved one's death is an indicator of end of life care, this study adds to the evidence that the choice to pursue PAD does not appear to be due to, or a reflection of, poorer end of life care. Nor is the quality of death experienced by those choosing PAD any worse than for those not pursuing PAD; in some areas it is rated as better by family members.

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Lessons from Oregon in Embracing Complexity in End-of-Life Care

Susan W. Tolle, M.D., and Joan M. Teno, M.D.

Under the incentives of fee-for-service Medicare, the utilization trends among persons with chronic progressive medical illness include more care in the intensive care unit (ICU), more hospitalizations, and often late or no referrals to hospice care (Fig. 1).[1] These utilization patterns are strikingly different in Oregon, the second state to legalize an advance directive and the first state to legalize assisted dying. In response to this legislation, the Oregon Health and Science University Center of Ethics embraced a policy of neutrality as a public position on assisted dying while using the vote as a wake-up call to the medical community to improve end-of-life care more broadly.[2,3] The center has served as a convener of statewide education and supported the creation and dissemination of the Physician Orders for Life-Sustaining Treatment (POLST) Program.[4] The POLST Program allows patients with advanced illness and frailty and their health care professional to document patients' preferences regarding the use of life-sustaining treatment with medical orders that can be honored across settings of care.[5] The POLST form (see the Supplementary Appendix, available with the full text of this article at NEJM.org) is designed to ensure that patients' preferences to use or limit treatment are equally honored.[6]

Persons dying in Oregon are less likely to be hospitalized and more likely to use hospice services at home than are patients in Washington and the rest of the United States. We selected the state of Washington for comparison with Oregon because of its close proximity and comparable demographic features. Washington has similar liberal political views and racial composition of decedents, has an established POLST Program, and has also legalized assisted dying.[7] In 2013, nearly two thirds of Oregonians who died did so at home, whereas only 39.6% of persons in the rest of the United States who died did so at home. The rate of ICU use in the last 30 days of life in Oregon was 18.2%, as compared with 23.0% in Washington and 28.5% in the rest of the United States (Fig. 1). Patients who were hospitalized in the last month of life were more likely to be discharged home in Oregon than in Washington or the rest of the United States (73.5% in Oregon vs. 63.5% in Washington and 54.2% in the rest of the United States).

It is difficult to disentangle the reasons behind the differences in care at the end of life in Oregon as compared with other states, but we think that the differences in care reflect the complexity and intensity of the initiatives developed in coordination with the POLST Program. Although Washington also has an established POLST Program, it has not developed educational materials, coordinated cross-system conferences, conducted research, and maintained a statewide registry, as extensively as Oregon has done. In this article, we describe the policy changes and educational efforts to improve end-of-life care that were launched in Oregon at the levels of state government and local health systems (Table 1). (Fig. S1 in the Supplementary Appendix provides a timeline for the initiative in Oregon.) We will also outline some of the lessons learned from the successes in Oregon. Transforming care near the end of life requires a willingness to forgo the temptation of an easy fix by merely implementing the use of the POLST forms. Until we embrace the complexity of this social interaction, the need for multifaceted interventions, and the application of public health strategies, we will fail to make the needed improvements in care at the close of life.

Advance care planning and the use of POLST forms is important, but if patients' goals are not linked to actionable care plans that are supported by local health care systems and state regulation, many patients who wish to remain at home will die intubated in the hospital for all the reasons the current system fails them.[8,9] Consider

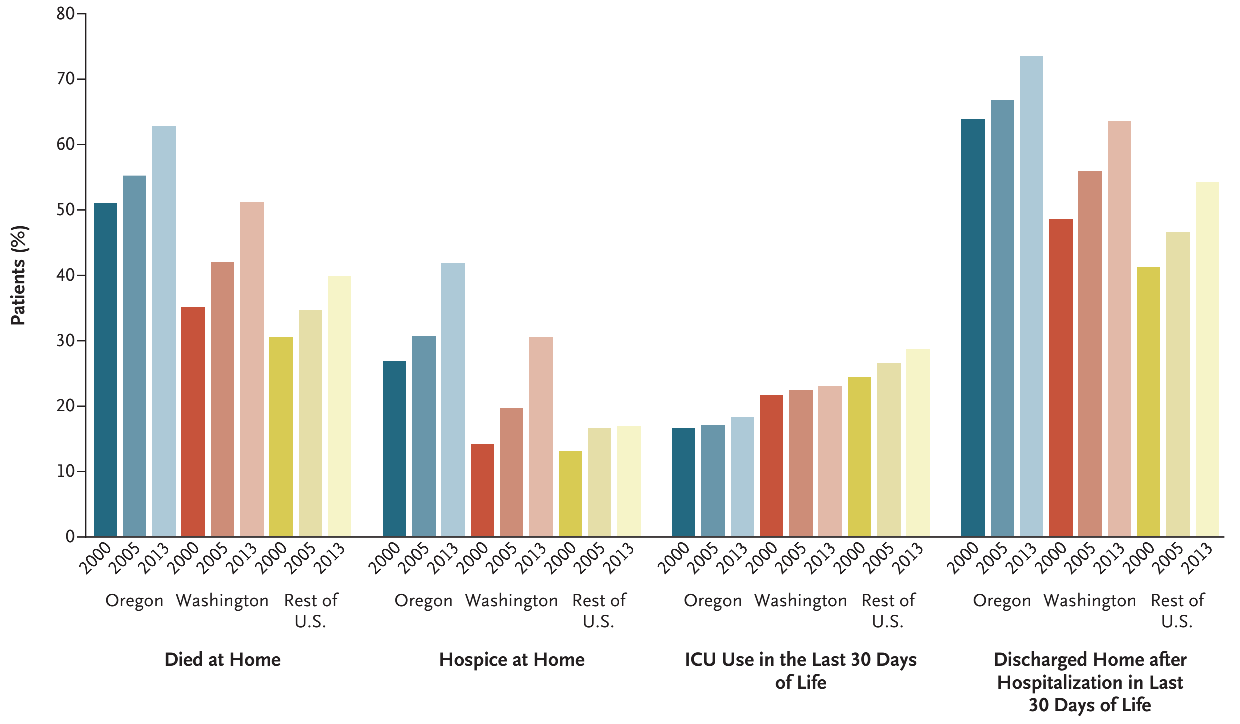

Figure 1. Deaths among Fee-for-Service Medicare Beneficiaries in Oregon, Washington, and the Rest of the United States.

The graph shows changes between 2000, 2005, and 2013 in the rates of death among fee-for-service Medicare beneficiaries in Oregon, Washington, and the rest of the United States (U.S.). Shown are the proportions of patients who died at home, who received hospice services at home, who received care in an intensive care unit (ICU) during the last 30 days of life, and among patients who were hospitalized during the last 30 days of life, the proportion who were discharged home.

the following composite case story, which illustrates the complexity, breadth, and depth of systems changes that are needed to ensure that patient preferences are consistently honored.

Edith, an 84-year-old white woman with oxygen-dependent chronic obstructive pulmonary disease, completed a POLST form after being counseled by her primary care physician. The form recorded her wishes that she would not be resuscitated or placed on mechanical ventilation. Despite having 24-hour care at home, she fell and fractured her hip. Emergency medical services (EMS) providers were called, and they accessed her POLST form from the Oregon POLST Registry. Edith was transported to a regional trauma center, where her condition deteriorated and there were concerns that she might need to be intubated. Per protocol, the trauma surgeon was notified of her POLST form specifying the do-not-resuscitate orders and the use of comfort measures only by accessing documentation in the POLST Registry that provided clear evidence of her wishes. Edith was cared for by the palliative care team in the emergency department with the use of opiates to relieve her pain and dyspnea, and she was transferred home with hospice services, where she died, comfortable and surrounded by her family. The key interventions in Edith's care that made her death at home possible included strategic interventions at four levels that are aimed at the individual person and their health care professional, the local health care system, cross health system collaboration, and state government (Table 1).

INTERVENTIONS AIMED AT INDIVIDUAL PERSONS

Extensive local media coverage, public education, and the experience of friends in her community made Edith and her family aware of their options for advance care planning and support for

Table 1. Key Interventions and Effects on Care of Patients.*

Level and Intervention	Application to Edith's Experience of Dying
Individual persons and their health care professionals	
Public education through media coverage and local community events	Raises Edith's awareness to complete a POLST form with her health care provider and discuss plans with daughter
Education of health care professionals about communication and completion of POLST forms	Facilitates sensitive communication and proper completion of the POLST form as well as creation of an action plan to honor the patient's preferences
State government	
Creation of Registry and enactment of regulation that allow EMS to honor POLST forms	Ensures that EMS is able to obtain Edith's POLST form and honor those wishes in the field
Quality monitors at the Registry in place to ensure the accurate completion of POLST forms	Ensures that POLST forms are completed correctly
Local health care system	
Change in culture to support health care professionals in counseling patients and the completion of the POLST forms	Values the time spent in the completion of the Edith's POLST form
Registry raises awareness to review the POLST forms in medical decision making; EMR of the health care system provides an alert that made the health care professionals aware of the patient's POLST form	Ensures that Edith's POLST form is available to the surgeon, who decides with Edith's daughter not to operate; in her medical record, EMR prominently provided an alert that the made all health providers aware of the patient's advance directive
Arrangement by local hospice for services for a dying person at home in transition from an acute care hospital	Ensures that Edith receives home hospice services that allow her to die at home, comfortable and surrounded by her family
Local champions and state coalition	
Ability to solve system and regulatory barriers nimbly and quickly	Champions played a key role in changing regulations to allow EMS to honor the POLST form and enhance hospice capacity to take admissions from the emergency department to home
Development of educational tools and identification of patients' stories	Enables design of educational interventions and hosting of regional conferences
Coordination of the implementation of systems change as a result of quality-improvement efforts	Promotes collaboration and conduct quality-improvement efforts across various settings of care

* Shown are key interventions, such as policy changes and educational efforts at various levels of local systems and government, to improve end-of-life care in Oregon and their effects on the care of a case-study patient (Edith). EMR denotes electronic medical record, EMS emergency medical services, and POLST Physician Orders for Life-Sustaining Treatment.

person-centered care. The Center for Ethics has hosted more than 200 conferences for health care professionals about ethics, palliative care, and communication skills.[10] The development of educational resources such as the *Understanding POLST* video and lay brochures made talking with her primary care professional a process rather than a single discrete event (Fig. S1 in the Supplementary Appendix).[11] Approximately 8 years before her death, Edith told her doctor that she wanted her daughter to be her surrogate. When Edith required oxygen support at home, her doctor encouraged her to complete an advance directive. At a visit 1 month before her death, Edith talked about never wanting to be intubated again, and she and her doctor completed a POLST form after she and her daughter watched the *Understanding POLST* video with a clinic social worker. Edith's primary care physician counseled Edith about her prognosis and treatment options, and through shared decision making they documented her treatment goals. The physician then worked with Edith's family to develop a plan that would allow her to remain at home with 24-hour care. The completion of her POLST form was not a single event but was part of a multistep process that was facilitated by her primary care team.[12] Key to Edith's care was that her EMS providers and all the members of her primary care team had been trained in how to record preferences for care accurately on the POLST form and in the importance of honoring those preferences.

INTERVENTIONS AT THE LOCAL HEALTH CARE SYSTEM AND STATE GOVERNMENT LEVELS

The process of creating and documenting POLST orders serves as a tool to record conversations regarding goals of care, but in isolation this process is not sufficient to ensure that Edith's wishes will be honored once she leaves her home. The creation of systems to ensure that health care professionals are aware of the directives and that EMS providers are able to honor those wishes is equally important. In Edith's case, the ability of EMS providers and the local health care system to obtain and honor her POLST form was key. In Oregon, state regulations allow EMS providers to follow the directives of a POLST form and to honor a person's wishes by not intubating or resuscitating the patient.[13] Similarly, although the physician who signed Edith's POLST form did not have admitting privileges at the trauma facility, Oregon Medical Board regulations ensured that the orders could be honored.[14] The trauma-system protocol enabled the POLST form to be obtained for the surgeon and other health care professionals to use in decision making.

In addition, Edith's physician was supported by a culture that valued team collaboration, and the health care team had participated in systems integration of educational materials to enhance patients' participation in goals-of-care planning, which optimized Edith's understanding and used the physician's time effectively. The electronic medical record (EMR) tagged the POLST forms, linking them to the patient-information header that alerts all the members of the health care system to the presence of the patient's POLST form.[15] A separate EMR tag confirmed the presence of the advance directive, and each form could be viewed with a single click, making her wishes clear as Edith moved from one care setting to another.

LOCAL CHAMPIONS AND STATE COALITION

Champions who are part of state coalitions can be nimble and help to address key leverage points in ensuring that patients' wishes are honored as transitions occur across care settings and that persons wishing to die at home have excellent palliation with hospice providers who are able to respond to the need for timely referrals. Education is important both within health systems and statewide, but local champions also play a vital role in removing system barriers, particularly in addressing barriers across care settings. The timeline in Figure S1 in the Supplementary Appendix shows a few of the dozens of interventions that have been facilitated by champions and coalition members. The development of educational tools and the removal of barriers are not enough. Even with an exemplary advance care planning process in place, if the patient and family do not have timely access to home hospice care, the advance care planning process may be of little value. If hospice had not been able to enroll Edith within 24 hours after her discharge, it would not have been possible for her to be discharged home from the emergency department observation unit.

Narrative stories are important in helping stakeholders understand the effect of each change in improving care, and these stories have proved to be vital to public education and media engagement. However, anecdotal case reports are not sufficient for the evaluation of success. We also need to track quality rigorously and to prevent unintended consequences. Oregon is currently using version 11 of the POLST form. Changes are made to the form by the statewide POLST Program coalition after extensive review to respond to new research data and changes in statutes or regulations and to address the use of new medical treatments. End-of-life champions in Oregon advocate broadly for improvements in best practices. When data showing that tube feeding did not extend life or enhance comfort in persons with advanced dementia,[16-19] broad and far-reaching public health efforts were implemented in the 1990s and were used to discontinue the practice. The effectiveness of these efforts is associated with remarkably low rates of tube-feeding use in Oregon, dating back to 2000.[20]

Finally, to sustain change from the beginning requires a stable financial base, leadership, and an administrative home. Although private philanthropy funded the development of the innovative POLST Program in Oregon, the Registry operations are now funded by the state, and the Oregon POLST Program is building an endowment to sustain operations. The Center for Ethics in Health Care, which administers the Oregon POLST Program and coordinates efforts to improve end-of-life care statewide, does not accept funding from health care industry sources. Important to the success of this work is the public trust that efforts are being made to honor patients' preferences and improve quality rather than to cut costs. The public trust can be damaged when incentives appear to have cost savings rather than patients' wishes as their primary goal (e.g., Liverpool Care Pathway of the Dying Patient and "death panels").[21]

Without a complex, multifaceted, and longitudinal set of interventions, Edith would have been intubated and would probably have died in an ICU, and the high rate of death at home with hospice in Oregon might look more like the rate in Washington (Fig. 1). Although Oregon has made great strides, our systems are far from perfect. One-click access to the POLST form in the EMR is not yet available in most hospitals. We are aware that finding Edith's POLST form was important to her achieving her wishes, but it was not sufficient. Replication of the experience in Oregon requires the development and adoption of interventions at every step in this complex medical and social interaction. With alignment of our health care systems incentives for value (i.e., quality and health care expenditures) over volume of services, fundamental change and improvement are within our reach. We must embrace the complexity, develop dynamic and multifaceted interventions, track the quality of care, and embed these interventions in the local and national health care culture, while avoiding incentives that might undermine the public trust and integrity of the process.

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