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Aggregating 23 Years of Data on Medical Aid in Dying in the United States

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Introduction

An estimated 74 million people in the United States live in a jurisdiction that allows Medical Aid in Dying (MAID), and another 87 million reside in 14 states where MAID is on the legislative agenda.¹ As interest in MAID increases, there is a corresponding need for empirical research.

Most research on patients pursuing MAID in the United States has focused exclusively on data from the Pacific Northwest (Oregon and Washington), which is not representative of the entire United States. Although one study showed that individuals with higher income and education access MAID more frequently,² no studies have described the demographic and clinical characteristics of individuals pursuing MAID in all jurisdictions that publicly report MAID data. We aggregated data from all nine United States jurisdictions with MAID laws and publicly available records from 1998 to 2020.

Methods

This study qualified for institutional review board exemption. Nine jurisdictions with legal MAID have published reports. Two investigators reviewed all reports and developed a data abstraction guide. Descriptive statistics were reported. Rates of death by MAID were created using CDC WONDER data.

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Results

Over 23 years, 5,329 patients died by MAID, while 8,451 received a prescription. More men than women died by MAID (53.1% vs 46.9%), and non-Hispanic white individuals (95.6%) died by MAID more than other racial and ethnic groups. The median age of MAID death was 74. Most (72.2%) had at least some college education and most (74%) had a cancer diagnosis. Most prescription recipients (88.6%) were non-Hispanic white; 43.3% were 65 or older. Nearly three quarters (71.6%) of prescription recipients had at least some college education, and cancer was the most common diagnosis (69.3%) (Table 1).

Discussion

Individuals who die under MAID tend to be older, white, educated, and diagnosed with cancer across all jurisdictions where MAID is legal, extending recently published findings from Oregon and Washington.² It is unclear whether these apparent differences result from patient preferences or systemic bias; it is plausible that MAID laws, regulations, and clinical processes have been established that unintentionally make it more difficult for patients with less education, from minority backgrounds or non-cancer diagnoses to participate.

Navigating MAID policies and finding MAID providers may be particularly challenging for individuals with limited resources and high symptom burden towards the end of life. Most MAID requesters must pay for MAID prescriptions out-of-pocket, as Medicare and other federal health insurance programs do not cover aid in dying costs. These out-of-pocket costs have risen dramatically, and some drugs are off-patent but lacking generic formulations.³

Individuals with cancer are over-represented among MAID utilizers. In the United States, cancer accounted for 17.8% of all deaths in 2020,⁴ yet 74% of MAID deaths have a diagnosis of cancer. Disparities in hospice use between cancer and non-cancer populations are well documented.⁵ If hospice and palliative care facilitate MAID access, then patients suffering from other life-limiting illnesses will continue to have challenges accessing MAID, especially given that MAID, like hospice, requires physician certification of limited life expectancy. Non-cancer diagnoses, such as heart failure and dementia, are difficult to accurately prognosticate compared to cancer diagnoses,⁶⁻⁸ which contributes to the lack of education and communication surrounding end of life options, including MAID. Additionally, treatments for cancer, such as surgery, radiation, and chemotherapy, can be terribly burdensome compared to treatments for non-cancer diagnoses, which may lead patients with cancer and their doctors to be more likely to consider palliative care, hospice, and MAID. Given the recurrent call for hospice and palliative care to be better integrated into non-cancer settings,⁹ so too should conversations about MAID in order to ensure equal access for patients with all diagnoses.

In conclusion, aggregating data reported from nine jurisdictions over a 23-year period revealed critically important information on who is utilizing MAID throughout the United States, suggesting potential educational and racial and ethnic disparities. More research is needed to elucidate if these differences are resultant from patient preference or systemic bias in how laws have been written, interpreted, and enacted. As more states plan to adopt

MAID legislation, data harmonization will help to elucidate how these policies are being implemented and accessed.

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Conflict of interest:

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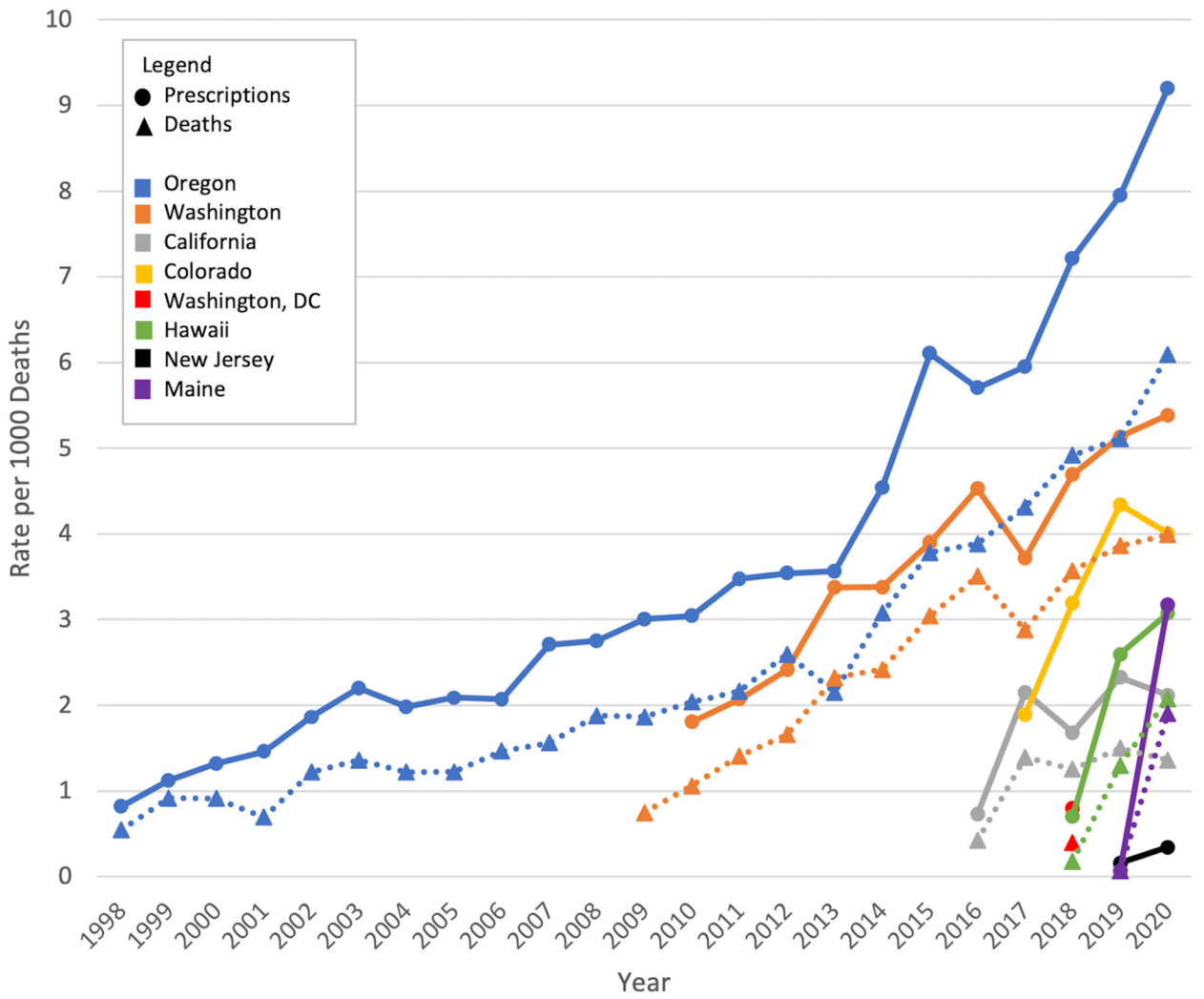


Figure 1. Rates of MAID prescription and MAID death per 1000 deaths, by state and year.

Table 1.

Frequencies and percentages of individuals who died by MAID and individuals who received a MAID prescription.

Characteristics	Category	MAID Deaths ¹	Percentage of Deaths	MAID Rx ²	Percentage of Rx
Sex	Male	1035	53.10%	2367	49.40%
	Female	914	46.90%	2252	47.00%
	Missing	0	0.00%	172	3.60%
Race/Ethnicity	Non-Hispanic white	1864	95.60%	4244	88.60%
	Non-white	85	4.40%	351	7.30%
	Missing	0	0.00%	196	4.10%
Age	18–34				
	35–44	155	8.00%	194	4.00%
	45–54				
	55–64	341	17.50%	519	10.80%
	65–74	598	30.70%		
	75–84	538	27.60%	2074	43.30%
	85+	316	16.20%		
Marital Status	Single	157	8.10%	219	4.60%
	Married	876	44.90%	1294	27.00%
	Other	872	44.70%	1216	25.40%
	Missing	44	2.30%	2062	43.00%
Underlying Medical Condition	Cancer	1442	74.00%	3322	69.30%
	Neurological disease	212	10.90%	522	10.90%
	Other	295	15.10%	809	16.90%
	Missing	0	0.00%	138	2.90%
Insurance Status	Public Insurance	1732	88.90%	2980	62.20%
	Private Insurance				
	Uninsured	217	11.10%	569	11.90%
	Other/Unknown				
	Missing	0	0.00%	1242	25.90%
Family Informed	Yes	1717	88.10%	2910	60.70%
	No	188	9.60%	184	3.80%
	Unknown/other			282	5.90%
	Missing	44	2.30%	1415	29.50%
Medication	Sedative	1311	67.30%	1593	33.20%
	Cardiotonic, Opioid, Sedative	572	29.30%	1534	32.00%
	Other	22	1.10%	520	10.90%
	Unknown	0	0.00%	195	4.10%

Characteristics	Category	MAID Deaths ¹	Percentage of Deaths	MAID Rx ²	Percentage of Rx
	Missing	44	2.30%	949	19.80%
Hospice Enrollment	Hospice/Palliative Care [*]	1699	87.20%	3022	63.10%
	Not enrolled	172	8.80%	318	6.60%
	Unknown	34	1.70%	189	3.90%
	Missing	44	2.30%	1262	26.30%
Location of Ingestion	Home	1758	90.20%	NR	NR
	Other	147	7.50%	NR	NR
	Missing	44	2.30%	NR	NR
Educational Attainment	No HS	511	26.20%	1133	23.60%
	High school/GED				
	Some College	392	20.10%		
	Associate's				
	Bachelor's	874	44.80%	3429	71.60%
	Master's				
	Doctorate/Professional	142	7.30%		
	Unknown	30	1.50%	34	0.70%
Missing	0	0.00%	195	4.10%	

¹Deaths by MAID include data from Oregon, Washington DC, and Hawaii.

²MAID prescriptions include data from Washington state, California, Colorado, Vermont, New Jersey, and Maine. NR: not reported.

* Hospice and palliative care, while different services, were presented as a combined category in California's data, thus they were combined to present national trends.