

# Letters

## RESEARCH LETTER

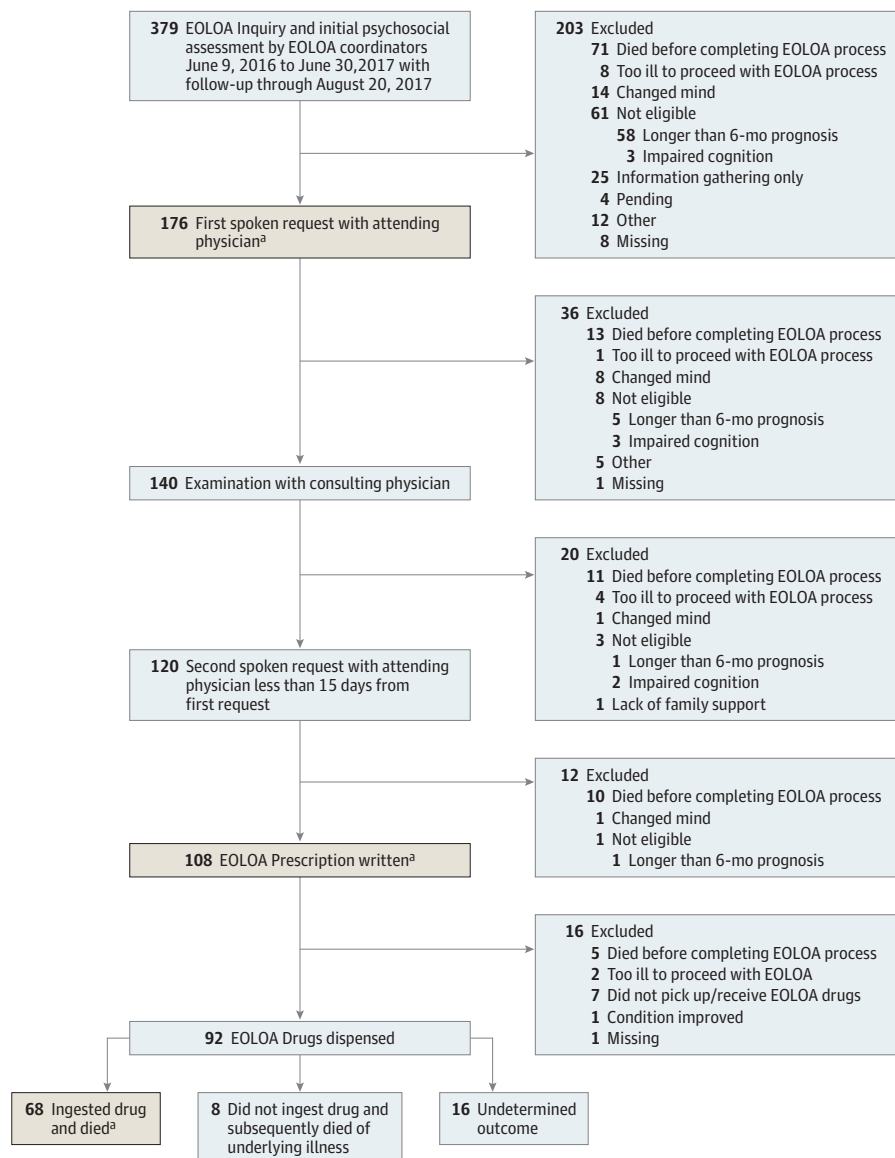
### Characterizing Kaiser Permanente Southern California's Experience With the California End of Life Option Act in the First Year of Implementation

The California End of Life Option Act (EOLOA),<sup>1</sup> which took effect on June 9, 2016, allows qualified adults diagnosed with a terminal disease to request aid-in-dying drugs from their physician. The California Department of Public Health recently published data on 191 individuals who received aid-in-dying

prescriptions during the act's first 6 months.<sup>2</sup> In response to recommendations for more comprehensive documentation of EOLOA implementation to improve end-of-life care,<sup>3</sup> this study describes the experience of a large integrated health system and provides in-depth descriptions of individuals who initiated the EOLOA process.

**Methods** | This study was based in Kaiser Permanente Southern California using data from June 9, 2016, through June 30, 2017, with follow-up through August 20, 2017. An executive

Figure. Patient Flow Through the EOLOA Process



EOLOA Indicates California End of Life Option Act.

<sup>a</sup> Patients who completed the 3 key steps in the EOLOA process (tan shaded boxes) are described in Table 1.

Table. Characteristics of Patients Who Completed 3 Key Steps in the EOLOA Process

Characteristic	No. (%)		
	Completed First Oral Request (n = 176)	Prescribed EOLOA Drugs (n = 108)	Ingested EOLOA Drugs (n = 68)
Age at time of death, median (IQR), y	69 (62-79)	69 (62-79)	69 (62-80)
18-34	2 (1)	0	0
35-54	11 (6)	7 (6)	4 (6)
55-64	46 (26)	31 (29)	22 (32)
65-74	49 (28)	30 (28)	17 (25)
75-84	45 (26)	25 (23)	14 (21)
≥85	23 (13)	15 (14)	11 (16)
Sex			
Male	99 (56)	61 (56)	39 (57)
Female	77 (44)	47 (44)	29 (43)
Race			
White	141 (80)	88 (81)	52 (76)
Hispanic	17 (10)	9 (8)	7 (10)
Black/African American	1 (1)	0	0
American Indian/Alaska Native	1 (1)	1 (1)	1 (1)
Asian	13 (7)	8 (7)	7 (10)
Multirace	1 (1)	0	0
Marital status			
Married/partnered	86 (49)	56 (52)	32 (47)
Unpartnered	80 (45)	46 (43)	33 (49)
Missing	10 (6)	6 (6)	3 (4)
Social support			
Lives with others	116 (66)	69 (64)	45 (66)
Patient informed family of EOLOA decision	155 (88)	100 (93)	64 (94)
Education (census based)			
<High school	20 (11)	12 (11)	8 (12)
High school	90 (51)	55 (51)	35 (51)
College	64 (36)	40 (37)	26 (38)
Unknown	2 (1)	1 (1)	0
Income (census based), \$			
<20 000	24 (14)	14 (13)	9 (13)
20 000-49 999	40 (23)	25 (23)	15 (22)
50 000-74 999	28 (16)	17 (16)	11 (16)
75 000-149 999	51 (29)	31 (29)	20 (30)
≥150 000	31 (18)	20 (18)	12 (17)
English speaking	164 (93)	102 (94)	63 (93)
Insurance coverage			
Medicare	115 (65)	69 (64)	41 (60)
Medicaid	5 (3)	0	0
Commercial	41 (23)	30 (28)	23 (34)
Private pay/other	14 (8)	8 (7)	4 (6)
Unknown	1 (1)	1 (1)	0
Clinical and functional characteristics			
Disease burden			
Charlson comorbidity index, mean (SD)	9.3 (4.26)	9.2 (4.46)	9.4 (4.63)
Quartile 1 (0-6)	44 (25)	28 (26)	18 (26)
Quartile 2 (7-9)	44 (25)	27 (25)	17 (25)
Quartile 3 (10-12)	50 (28)	31 (29)	17 (25)
Quartile 4 (≥13)	36 (20)	20 (19)	15 (22)

(continued)

Table. Characteristics of Patients Who Completed 3 Key Steps in the EOLOA Process (continued)

Characteristic	No. (%)		
	Completed First Oral Request (n = 176)	Prescribed EOLOA Drugs (n = 108)	Ingested EOLOA Drugs (n = 68)
Underlying terminal diagnosis			
ALS	9 (5)	7 (6)	5 (7)
Cancer	130 (74)	82 (76)	52 (76)
Genitourinary	23 (13)	14 (13)	11 (16)
Lung	23 (13)	13 (12)	8 (12)
Gastrointestinal	18 (10)	9 (8)	7 (10)
Head/neck	18 (10)	13 (12)	7 (10)
Pancreas	14 (8)	10 (9)	6 (9)
Breast	11 (6)	8 (7)	4 (6)
Other	23 (13)	15 (14)	9 (13)
CHF	7 (4)	4 (4)	3 (4)
COPD/Other pulmonary conditions	12 (7)	6 (6)	2 (3)
MS	4 (2)	3 (3)	2 (3)
Parkinson	3 (2)	2 (2)	0
Other illnesses	7 (4)	3 (3)	3 (4)
Unknown	4 (2)	1 (1)	1 (1)
Functional status at time of inquiry <sup>a</sup>			
ADL Impairment	96 (55)	55 (51)	37 (54)
Instrumental ADL impairment	43 (24)	23 (21)	15 (22)
End-of-life concerns at time of inquiry <sup>b</sup>			
Does not want to suffer	110 (63)	76 (70)	45 (66)
Unable to enjoy daily activities	97 (55)	62 (57)	40 (59)
Loss of autonomy	36 (20)	24 (22)	10 (15)
Burden on family/friends	38 (22)	23 (21)	16 (24)
Inadequate pain control or concern about it	36 (20)	23 (21)	19 (28)
Loss of dignity	24 (14)	17 (16)	14 (21)
Other (eg, financial concerns)	16 (9)	9 (8)	6 (9)
Timing of EOLOA processes, median (IQR), days			
Timing from inquiry to first oral request	7 (3-14)	7 (3-14)	7 (2-13)
Timing from inquiry to second oral request	26 (20-35)	27 (20-38)	24 (18-33)
Timing from first to second oral request	17 (15-20)	17 (15-21)	16 (15-18)
Timing from prescription to ingestion/death	NA	NA	9 (7-85)
Care near the end of life, median (IQR)			
Primary care visits in 12 months prior to inquiry	3 (2-8)	3 (1-8)	4 (2-8)
Specialist care visits in 12 months prior to inquiry	13 (6-28)	14 (6-29)	14 (6-27)
Palliative care (outpatient or home-based)			
At time of inquiry	84 (48)	55 (51)	34 (50)
Ever	109 (62)	70 (65)	43 (63)
Length of time since first exposure to PC services prior to inquiry, median (IQR), days <sup>c</sup>	92 (22-338)	110 (28-391)	103 (72-397)
Hospice care			
At time of inquiry	84 (48)	52 (48)	38 (56)
Ever	139 (79)	86 (80)	59 (87)
Length of time on hospice prior to inquiry, median (IQR), days <sup>c</sup>	16 (5-60)	16 (4-75)	23 (4-65)

(continued)

EOLOA task force was formed 7 months prior to the EOLOA taking effect with representatives from bioethics, operations, quality, psychiatry, pharmacy, education, nursing, legal, and palliative care to ensure appropriate policy and structures were

in place. Key implementation steps included the following: physicians were surveyed about their willingness to participate after viewing an educational video; staff were trained regarding how to manage EOLOA requests; additional training

Table. Characteristics of Patients Who Completed 3 Key Steps in the EOLOA Process (continued)

Characteristic	No. (%)		
	Completed First Oral Request (n = 176)	Prescribed EOLOA Drugs (n = 108)	Ingested EOLOA Drugs (n = 68)
Advance care planning on record at inquiry			
Advance directive	108 (61)	68 (63)	43 (63)
POLST	88 (50)	53 (49)	33 (49)
Code status at inquiry			
Full code	72 (41)	42 (39)	24 (35)
DNR	73 (42)	46 (43)	32 (47)
Missing	31 (18)	20 (19)	12 (18)
Death location			
Home/home hospice	170 (97)	106 (98)	68 (100)
Hospital/ED/SNF/other	6 (3)	2 (2)	0

Abbreviations: ADL, activities of daily living; ALS, amyotrophic lateral sclerosis; CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; DNR, do not resuscitate; ED, emergency department; EOLOA, California End of Life Option Act; IQR, interquartile range; MS, multiple sclerosis; SNF, skilled nursing facility; POLST, provider orders for life-sustaining treatment.

<sup>a</sup> For the 3 respective column categories, activities of daily living missing for 24 (14%), 11 (10%), and 6 (9%); instrumental ADL, missing for 35 (20%), 17 (16%), and 10 (15%).

<sup>b</sup> Patients could endorse multiple reasons at the time of their initial inquiry and reasons could change during the EOLOA process but this was not captured in this analysis.

<sup>c</sup> Length of palliative care or hospice service only for patients who received palliative care or hospice prior to inquiry.

was provided for volunteer physicians; volunteer pharmacists were identified to dispense and provide education on proper use of the medications; and training was provided for dedicated EOLOA-licensed clinical social work coordinators. The primary responsibilities of the EOLOA coordinators were to provide assistance with navigation to patients, perform psychosocial assessments, serve as a resource for health care professionals involved in the care of these patients, ensure the integrity of informed consent and compliance with the legal requirements, and be available for staff debriefing after patient deaths. Data for this study were obtained from electronic medical records, logs maintained by the EOLOA coordinators, and standard state reporting forms. The study was approved by the Kaiser Permanente Southern California institutional review board and informed consent was waived owing to the retrospective nature of the study. Descriptive statistics were performed with SAS statistical software (version 9.3, SAS Institute, Inc).

**Results** | A total of 379 patients initiated an inquiry from June 9, 2016, through June 30, 2017 (Figure). Of these, 79 (21%) patients died or were too ill to proceed, 61 (16%) were ineligible, and 176 (46%) who were deemed eligible proceeded with their first spoken request to an attending physician. Many of the withdrawals at each step of the EOLOA process were owing to death or patients being too ill. Nearly 130 (74%) of patients who received the EOLOA drugs ingested them and died within a median of 9 days after the prescription was written. The sociodemographic, clinical, and end-of-life care characteristics of patients who completed the first oral request, proceeded to receive a prescription for the aid-in-dying drugs, and ingested the drugs were for the most part similar (Table). Most patients who initiated EOLOA had cancer (74%) and received care primarily from specialists in the previous 12 months. Ninety-six (55%) patients had an activities of daily living im-

pairment and were on palliative care or hospice at the time of their inquiry. The 2 most common reasons patients cited for pursuing EOLOA were that they did not want to suffer and that they were no longer able to participate in activities that made life enjoyable.

**Discussion** | To our knowledge, this is the first detailed report describing the outcome and characteristics of all individuals who initiated the EOLOA process from a large health care system in California. The characteristics of this sample were similar to a recent report<sup>2</sup> with the exception that a higher percentage of these patients proceeded with ingesting the aid-in-dying drugs (75% vs 59%); this may be owing to the longer follow-up time. Similar to Oregon's experience,<sup>4</sup> patients' end-of-life concerns appear difficult to palliate with the most common cited reasons for pursuing EOLOA being existential suffering, inability to enjoy life, and loss of autonomy.

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*Study concept and design:* All authors.

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*Drafting of the manuscript:* Nguyen, Gelman, Bush, Lee.  
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