UCSF End of Life Option Act 2016-2020: A Retrospective Chart Review

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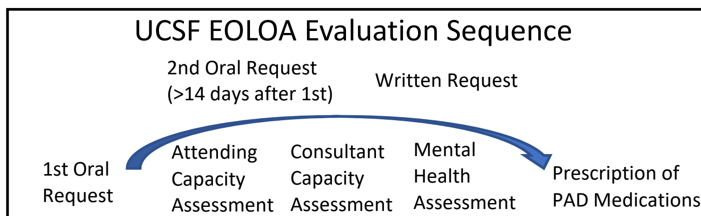
Introduction

- The End of Life Option Act (EOLOA) went into effect in June 2016 and legalized physician aid-in-dying (PAD) in California. State-level statistics are available on California patients accessing physician aid-in-dying (e.g. in 2018, 51% female and 68.8% had cancer [CDPH, 2019]), but little is known about outcomes at individual institutions.[1]
- At UCSF Medical Center (UCSFMC), beyond the state requirement of two physician assessments and an "as needed" mental health assessment, all patients must undergo a required mental health assessment prior to being prescribed PAD.[2]
- Knowing the outcomes of the UCSF EOLOA process with this novel and definitive intervention for terminally-ill patients is necessary for practice and policy improvements.

Methods

- We performed a retrospective chart review of adult patients at UCSFMC who were prescribed PAD June 2016-May 2020 (UCSF IRB#19-29153).
- Our sample of patients (n=74) were either known to the UCSF Psychiatry and Palliative Care services, or were identified with a systematic chart review of all patients prescribed PAD.
- Data were abstracted into a REDCap database by one of five investigators; each chart was verified by a second investigator.
- Due to missing data, two raters judged likely contributions to requesting PAD (using the 5 categories specified by California Department of Public Health [CDPH]) by reading free text in visit notes. Raters demonstrated moderate inter-rater reliability (Cohen's kappa 0.43, agreement 71.1%) from a sample of 90 items.
- Statistical analyses were performed in Stata (v13.0)



References: [1] https://www.cdph.ca.gov/Programs/CHSI/Pages/End-of-Life-Option-Act-.aspx; [2] Bourgeois et al Psychosomatics 2018

Results

- Assessments were conducted by 28 attendings, 42 consultants, and 9 mental health assessors.
- 89% of patients had a palliative care physician serve as attending or consultant.

Demographics and Baseline Characteristics

Characteristic	Category	Value
N		74
Age, median (IQR)		65.5 (43.5-87.5)
Gender	Male	31 (42%)
	Female	43 (58%)
Race	American Indian/Alaskan Native	1 (1.4%)
	Asian	13 (18%)
	White	55 (76.4%)
	Not disclosed	3 (4.2%)
Preferred Language	English	69 (93.2%)
	Cantonese	3 (4.1%)
	Vietnamese	1 (1.4%)
	Russian	1 (1.4%)
Civil Status	Single	11 (14.9%)
	Married	43 (58.1%)
	Partnered	3 (4.1%)
	Divorced	4 (5.4%)
	Widowed	10 (13.5%)
	Unknown	3 (4.1%)
Religion	None	33 (44.6%)
	Christian	12 (16.2%)
	Jewish	7 (9.5%)
	Buddhist	5 (6.8%)
	Other	3 (4.1%)
	Unknown	14 (18.9%)
Insurance	Medicare	40 (54.1%)
	Medical	7 (9.5%)
	Private	27 (36.5%)
Primary Disease	Cancer	55 (74.3%)
	Neurologic	13 (17.6%)
	Cardiac	1 (1.4%)
	Renal	2 (2.7%)
	Other	3 (4.1%)
Psychiatric Disease	Adjustment Dx	17 (23%)
	Mild Cognitive Impairment	5 (6.8%)
	Major Depressive Dx	1 (1.4%)
	Other Depressive Dx	4 (5.4%)
	Generalized Anxiety Dx	2 (2.7%)
	Other Anxiety Dx	3 (4.1%)
	Major Cognitive Impairment	1 (1.4%)
	Delirium	0 (0%)
	Other	3 (4.1%)
	None	48 (65%)
Performance Status (KPS or PPS), median (IQR)		60 (50-70)

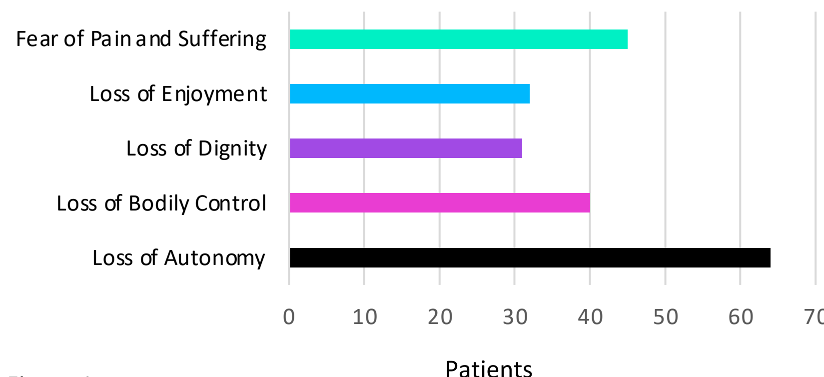


Figure 1.

Exemplar Quotes for Contributions to Requesting PAD

Possible Contributions	Exemplar Quote
Loss of Autonomy	"…to regain control of life"
Loss of Enjoyment	"I want to enjoy the time I have left"
Loss of Bodily Control	"…does not want to be stuck in bed, using diapers and unable to take care of himself in any way."
Fear of Pain and Suffering	"Doesn't want to suffer"
Loss of Dignity	"Husband's death with EOLOA was sad but dignified, father's death without EOLOA was long, slow, painful, and undignified."

- Median time (days) from first oral request to mental health assessment was 19 (IQR 8-29) and from first oral request to PAD prescription was 25 (IQR 19-56).
- 74 patients were prescribed PAD medications; 38 (51.4%) patients were confirmed to ingest the medication.
- 11 charts included the CDPH follow-up form with attending-rated contributions to the patient electing PAD.
- Figure 1 reports study raters' assessment of contributions for requesting PAD.
- Fear of loss of autonomy was the most common reason for requesting PAD.

Neuropsychiatric Rating Scales

	Median Score	IQR	% Charts with scores
PHQ-9	8	6-9	23.0%
GAD-7	3	2-8	18.9%
MOCA	25.5	24-27.5	16.2%

Conclusions

- Demographic and clinical characteristics of this sample of UCSFMC patients prescribed EOLOA in 2016-2020 resemble those of all California EOLOA patients during this time in terms of gender, race, and primary disease.
- UCSF's standardized mental health assessment was incompletely implemented
- Patients most often requested EOLOA due to a fear of loss of autonomy
- Due to small sample size and missing data, we did not attempt inferential statistics assessing for associations between patient characteristics and the outcomes of the UCSFMC EOLOA evaluation protocol.

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