

SUBJECT: HB1328 End-of-Life Option Act
(The Honorable Elijah E. Cummings and the Honorable Shane E. Pendergrass Act)

COMMITTEE: Health and Government Operations, The Honorable Joseline Peña-Melnyk, Chair
Judiciary, The Honorable Luke Clippinger, Chair

HEARING DATE: Monday, March 3, 2025

POSITION: FAVORABLE

I am writing in support of the passage of HB1328 End-of-Life Option Act.

Concern is sometimes expressed about the bill's lack of a mandated psychiatric assessment by a mental health professional. Such an assessment is required only if the attending and consulting physicians believe that the person lacks capacity or suffers from impaired judgement. I believe that the concern arises from a lack of confidence in the judgement of the attending and consulting docs. However, healthcare providers are required by law and medical ethics to obtain a patient's informed consent to any proposed treatment or procedure. A healthcare provider must verify that the patient has the capacity to understand and make decisions for all treatments and procedures. Thus, attending and consulting docs routinely make such assessments and are both qualified and have the capability and experience to do so.

But I think another reason for such nervousness about the process is that many of us do not have a full picture of what happens when someone contemplates using this option. If you have read annual reports from the states where Medical Aid in Dying is permitted, you may believe that you have a full understanding of the process. But those reports tell only a portion of the story, since required reporting doesn't start at the point where someone first begins to think about using this option for themselves.

Reports aren't required unless and until someone successfully completes the process and is determined to be eligible and the doc writes a prescription. And in some states, not even then – in some states, reporting isn't mandated unless and until the prescription is actually filled. So, we never get statistics on how many are asking about this option, how many want to use this option and are deemed ineligible and counseled against it before they make a formal request, how many start but never complete the process and get a prescription.

What's missing is the beginning, when someone begins to think about it and ask questions. What's missing are statistics on how many people say "Doc, I've had it, I want out", and the doc says "Joe, your test results are improving, you likely have a couple of years left." Or the doc says to her/himself, "Joe doesn't really understand what is going on and isn't competent to make a decision like this" and tells Joe that he really isn't eligible to get a such a prescription. Or the doc says, "Let me talk with your hospice providers and see if we can't make you more comfortable." Or maybe the patient isn't even talking to the attending at this point but is talking to a nurse or aide or social worker. Or the person is really very terminal, doesn't have 6 months but only a couple of days, and becomes too ill to self-administer the meds themselves or dies before they can even start the formal process.

There are no official statistics on these situations. What we have to inform us are academic research reports that do start at the very beginning. In particular, there is a study - *Characterizing Kaiser Permanente Southern California's Experience with the California End of Life Option Act in the First Year of Implementation* – by several doctors. The study traces what happens with the 379 patients who made initial inquiries of staff.

- Out of the 379 who made initial inquiries, only 176 actually began the process - fewer than half.
- Of the 176 who began the process, only 108 actually received a prescription
- Of the 108 actually received a prescription Only 92 filled the prescription

The study documents the various reasons why patients do not begin the formal process and/or do not complete the formal process. The most common is dying before completing the process, but there are numerous other reasons. Two different ways of presenting this data are shown below, which I hope will help you see the fuller picture.

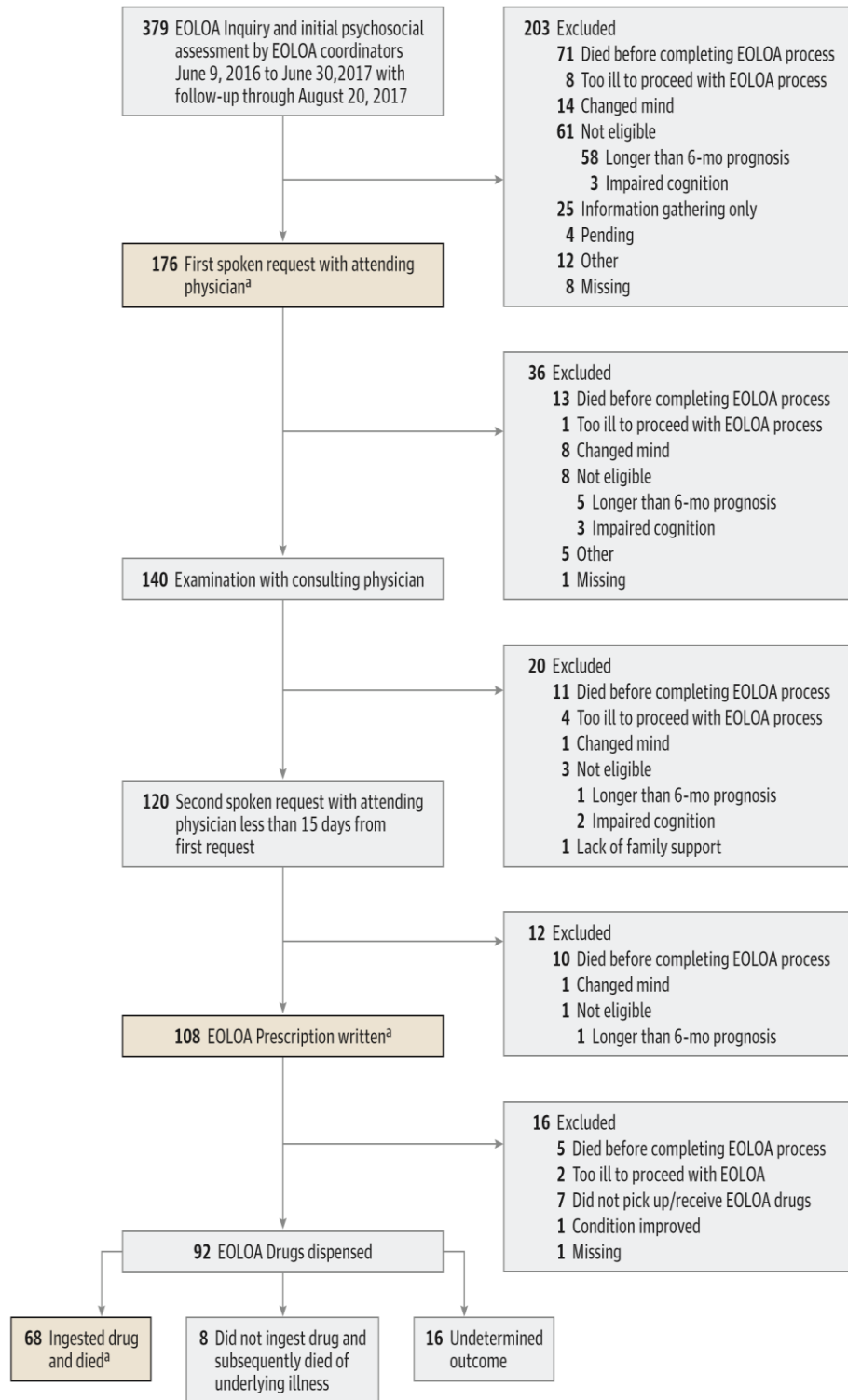
This is not a snap decision with instant fulfillment -- Doc, I want to die and the doc hands Joe a pill and Joe's gone. This is a well-thought out process demanding that the patient fully understand their options and the consequences of them. We don't hear about those who ask for this kind of help and are deemed ineligible and they far exceed the number of those who do get a prescription.

I urge both committees to give a Favorable report to HB1328.

Thank you.

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Figure. Patient Flow Through the EOLOA Process



Patient Flow Through the End-of-Life Option Act (EOLOA) Process

Number of people	Process	Total Excluded	Died before completing EOLOA process	To ill to proceed with EOLOA process	Changed mind	Not eligible		Lack of family support	Did not pick up /receive EOLOA drugs	Condition improved	Info gathering only	Pending	Other	Missing	
						Longer than 6 months prognosis	Impaired cognition								
379	EOLOA Inquiry and initial psychosocial assessment by EOLOA coordinators														
(203)	Excluded	203	71	8	14	58	3				25	4	12	8	
176	1st spoken request with attending physician														
(36)	Excluded	36	13	1	8	5	3						5	1	
140	Examination with consulting physician														
(20)	Excluded	20	11	4	1	1	2	1							
120	2nd spoken request with attending physician no less than 15 days from first request														
(12)	Excluded	12	10		1	1									
108	EOLOA prescription written														
(16)	Excluded	16	5	2					7	1				1	
	Total Excluded	287	110	15	24	65	8	1	7	1	25	4	17	10	
92	EOLOA drugs dispensed														

46%	of those who made initial inquiries and had an initial assessment (379), only 176 began the formal process by making oral request of doctor
61%	of those who began formal process (176), only 108 completed process and received a prescription
85%	of those who received a prescription (108), only 92 actually filled the prescription

74%	68	Ingested drug and died
9%	8	died of underlying illness without ingesting drug
17%	16	Undetermined outcome at time study concluded
100%	92	Total

data from

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

Authors: Nguyen, Gelman, Bush, Lee, and Kanter. JAMA Internal Medicine, Published online December 26, 2017