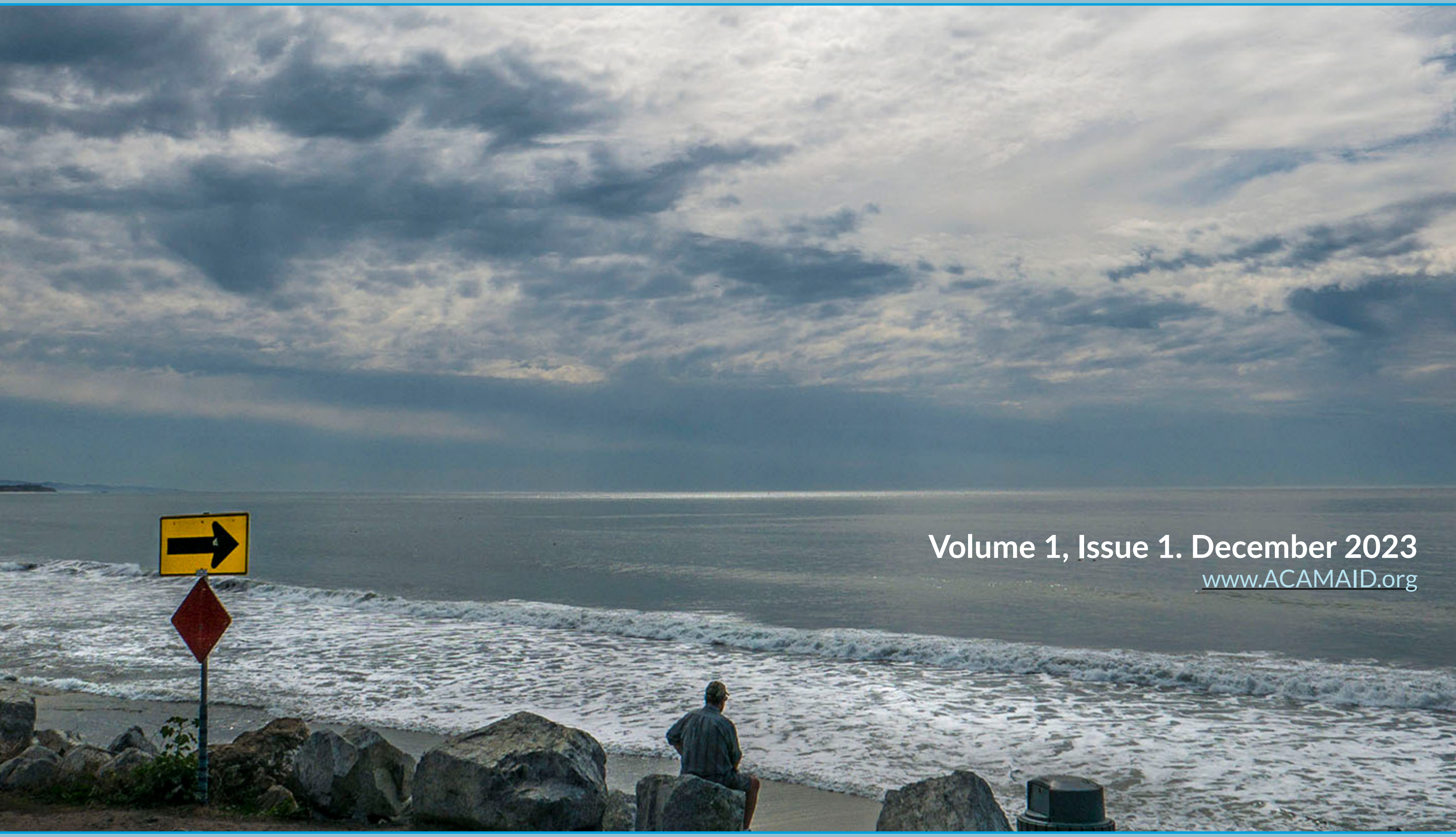
AMERICAN CLINICIANS ACADEMY ON MEDICAL AID IN DYING



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Journal of Aid-in-Dying Medicine

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LETTER FROM THE EDITOR

LONNY SHAVELSON, MD

AMERICAN CLINICIANS ACADEMY
ON MEDICAL AID IN DYING

February 14, 2020, UC Berkeley
On an unexpectedly warm winter morning, I entered the Gingko Courtyard within the 1930s Spanish-style section of the campus. The cluster of plazas and terracotta-roof buildings is recognized by the National Register of Historic Places—which was appropriate, since on that day we initiated a new chapter in the history of medicine. And, yes, I'm gloating. But not exaggerating.

When more than 300 aid-in-dying clinicians overflowed the university conference hall, we brought in extra chairs and opened the balcony. Many practitioners who had never met before were embracing. Some were crying. We aid-in-dying clinicians had been working in relative seclusion in our home medical communities—isolated by stigma, by our small numbers, and by the newness of aid-in-dying *care*. In fact, in the world of medicine, that last word had almost never been associated with the preceding three—except by clinicians like those gathered in the hall on that day. Three hundred of us. A new clinical community.

The intense camaraderie persisted throughout the two days of that inaugural National Clinicians Conference on Medical Aid in Dying. And after the final session, the symposium leaders made an audacious leap of faith and projected a slide about the forthcoming organization, the *American Clinicians Academy on Medical Aid in Dying*. But what the applauding, grateful audience did not know was that the Academy existed in URL only. For $21, we owned www.ACAMAID.org. We were only a concept.

Remarkably, the Academy has flourished. We've become the central plaza where aid-in-dying practitioners converge—those of us who deliver policy to patients, philosophy to flesh. And as clinicians, we learn, we train, we innovate, we evaluate data, we develop best practices, we advance, we teach, we mentor. And, we grow.

February 17, 2023, Revolution Hall, Portland, Oregon

It was a bit chillier outside than in Berkeley, 2020. But the warmly personal essence of that first conference fed this second meeting—over 500 of us, now a community of colleagues, hungry to share stories and knowledge about how best to care for patients considering aid in dying.

Once again, after the final presentation, the conference leaders made an audacious leap of faith. We announced our next step in the continuing—and necessary—evolution of aid in dying as a field of clinical expertise: the *Journal of Aid-in-Dying Medicine*. What the applauding, grateful audience did not know while the mock-up of the journal's cover design was projected on the auditorium screen was: that's all we had. This time, we didn't even have the URL. Just the concept.

Our specialized clinical field has made rapid progress—the first conference, the establishment of the Academy, the second conference. Now the *Journal of Aid-in-Dying Medicine* is another leap forward in our community's journey toward the increasingly sophisticated practice of aid-in-dying care.

Welcome to the first edition of the *Journal of Aid-in-Dying Medicine*.

VALERIE LOVELACE is the Executive Director of Maine Death with Dignity. 30” x 30” acrylic on board, 2023, Westport Island, Maine. “Failing eyesight has changed the way I create. I used to paint photo-realistic images using an airbrush, and am no longer able to do that. This piece was painted with palette knives and other items to create texture.”

A NOTE ON THE JOURNAL'S STYLE AND REVIEW PROCESS

STYLE: You may notice that the *Journal of Aid-in-Dying Medicine* has a warmer tone than a typical medical or academic periodical. We strive to increase readability for our varied audiences—from physician specialists to a wide range of end-of-life clinicians. Not only have we edited the writing style of the feature articles to be more straightforward, the journal also includes poems, photographs, artwork, film and book reviews, and short informative columns. Whether you're interested in the bureaucratic weeds of hospice billing for aid-in-dying care or want to better understand the support doulas can provide for patients, there is information in this journal for you. Aid-in-dying clinical care is about teamwork. The journal's goal is to provide everyone in the team with equitable access to our essential information.

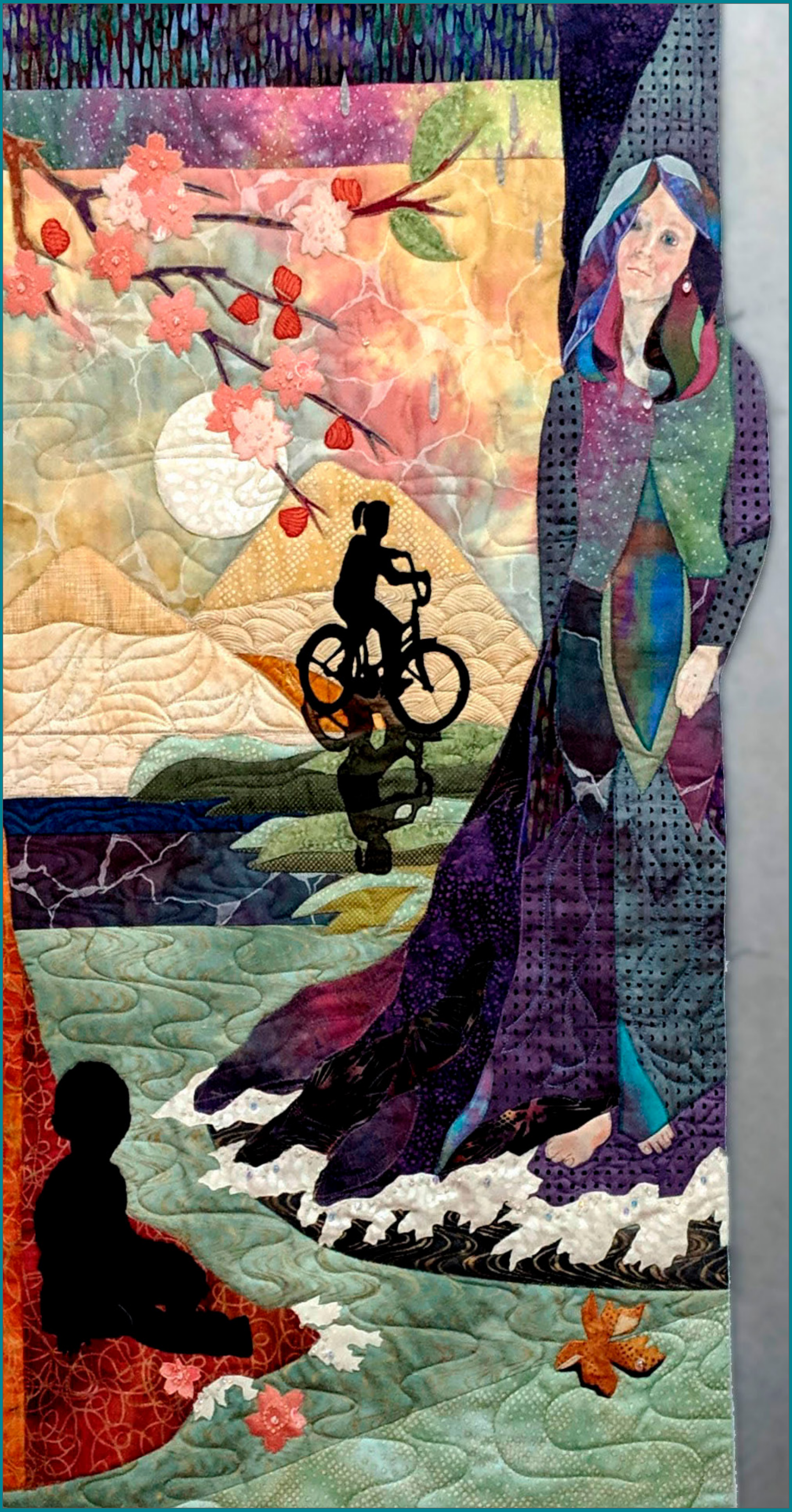
The journal is virtually acronym free. So while our authors may refer to the CIA or IRS, they will not tell you about a patient with ESRF caused by IDDM or that an F patient took MAID medications and had a TTD of 23m. Insider speak speaks only to insiders. We avoid it whenever possible.

In fact, the acronym MAID was the first to go. Patients and many clinicians don't understand it. One patient who was considering aid in dying finally responded to a health provider's repeated use of the term by insisting, "I don't need a maid! Are you implying my house is dirty?" We believe in clean language; unsoiled homes are not our concern. Try it out for size: Say, *aid in dying*. Now say, *MAID*. How much time did you save? Which one is clearer to more people? So there are no MAIDs in our articles. And we hope the rest of the clinical community will follow suit.

As the first journal devoted exclusively to aid in dying, we'd like to put the ever-present hyphenation debate to rest. Is it *aid in dying* or *aid-in-dying*, *medical aid in dying*, or *medical-aid-in-dying?* Here's the simple rule. When the phrase is used as a noun, there are no hyphens:*These medications are for aid in dying*. But when it is used as an adjective, put the hyphens in: *These are aid-in-dying medications.*

HOW WE SELECT ARTICLES: Potential articles submitted to the journal are first reviewed by a small committee to see if their focus and quality are right for us. If they seem appropriate, they are passed on to two or three peer reviewers with expertise in the topic. Those referees thoroughly critique the article and send the author detailed recommendations for improvements. Once these have been made, the editor and author haggle word by word, then an agreed upon final draft is sent to the proofreader. Then to the designer, who creates what you're reading now.

We encourage you to submit articles or article ideas to the journal, at https://www.acamaid.org/journalsubmissions/.



Sandra MacKenzie-Cioppa, RN, CNM, is a fiber artist and retired nurse midwife. She focuses on human rights, especially those of women and children. Is the woman in this photograph of fiber art a young woman or a tree? In my mind, the woman depicted is finished here. Returning to the earth, in one form or another, is her only option.

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CAPACITY ASSESSMENT IN PSYCHOLOGICALLY AND COGNITIVELY COMPLEX PATIENTS REQUESTING MEDICAL AID IN DYING: A CASE DISCUSSION

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MADHUKA KOLLENGODE, MD[3], AMBER KHANNA, MD[3],
JONATHAN TREEM, MD[1]

ABSTRACT: In all states where medical aid in dying is legal, an individual must be able to demonstrate the ability to make and communicate an informed decision to health care providers. The various statutes in states where aid in dying is legal provide limited and imprecise guidance to practitioners regarding standards for capacity evaluations. There is an even greater paucity of guidance when it comes to clinical assessment of patients whose capacity is in question. This paper aims to provide insight into two patients' requests for aid in dying and outlines recommendations for assessing decisional capacity. The authors describe a best practice approach in capacity assessment in psychologically complex patients requesting clinician assisted death. We discuss the applicability and generalizability of employing these recommendations for patients whose capacity is unclear at initial presentation.

KEYWORDS: Capacity assessment, medical aid in dying, heart failure, MAID.

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1. INTRODUCTION

In 2016, Colorado voters passed the Colorado End of Life Options Act.[1] This legislation stipulates that a patient may only pursue aid in dying if "the individual's attending physician has determined the individual has mental capacity." As outlined by the Act, "mental capacity" means that, in the opinion of an individual's attending physician, consulting physician, psychiatrist, or psychologist, the individual has the ability to make and communicate an informed decision to health care providers.[1] The statute does not go into greater detail to guide clinicians when mental capacity is unclear, nor does it describe standards for evaluations to achieve reasonable certainty around questions of patient capacity. The evaluation and assessment of capacity to meet legal and clinical standards is left to the care team.

All other states where aid in dying is legal have similar provisions for capacity determinations. Yet due to the lack of established best practices, it is likely that considerable heterogeneity exists in the clinical application of these assessments for aid in dying. Our paper's aim is to help provide a scaffolding from which best practices for aid-in-dying capacity assessments could be constructed.

There is a paucity of research regarding capacity assessment in the setting of aid in dying, though its importance is noted nationally and abroad.[2,3,4] Foundational work and current research on informed decision-making emphasizes the importance of a patient's capacity. This suggests that a considerable proportion of terminally ill patients may lack decision-making capacity by standardized assessment and that physicians may fail to detect decisional impairments otherwise identified by these assessments.[5,6,7] Our paper aims to provide insight into two patients' requests for aid in dying and outlines recommendations for assessing decisional capacity, including a semi-structured interview (Appendix 1).

2. METHOD

We describe two cases referred to the Palliative Care Clinic at the University of Colorado Anschutz Medical Campus for the evaluation of eligibility for aid in dying. The need for formal assessment of decisional capacity was determined during the initial palliative care consult, and clinical psychology was consulted for the capacity evaluation. In Colorado, capacity assessments in aid in dying must be undertaken by a licensed clinical psychologist or psychiatrist. For these two patients, we obtained consultations with our clinical psychologists. In other jurisdictions with different legal structures or different access to services and expertise, alternative referral structures may be appropriate. Consulting physicians and representatives of the hospital ethics service provided additional consultation when necessary.

Capacity assessments were guided by an adapted version of the MacArthur Competency Assessment Tool for Treatment (MacCAT-T), combined with a clinical interview that assessed relevant biopsychosocial factors.[8] The MacArthur Tool consists of a semi-structured interview tailored to the patient's condition, available interventions, and associated risks and benefits. It evaluates the four most clinically relevant elements of competence: the patient's ability to express a choice (C); to understand information relevant to treatment decisions (U); to appreciate the significance of his or her situation and the treatment decision (A); and to rationally manipulate information in order to make comparisons and weigh treatment options (R).[9] When appropriate, a cognitive screening was conducted using the Montreal Cognitive Assessment (MoCA) to detect cognitive impairment.[10] A formal capacity assessment report was entered in the patient's medical chart.

3. CASES

Case 1: FW is a man in his forties with congenital absence of his right pulmonary artery. He was referred to the palliative care clinic following successive hospitalizations for heart failure and hypoxic respiratory failure. Each hospitalization had been preceded by episodes of heavy alcohol consumption followed by withdrawal. FW also frequently took more opiate medication than prescribed, especially when feeling despair and hopelessness.

FW considered himself to be "fiercely independent." His goals revolved around the maintenance of that independence, including the ability to work and live alone. He acknowledged depression and ongoing alcohol use but felt these were separate issues to his aid-in-dying inquiry. He acknowledged that while he did not want to die, he felt strongly that a death on his own terms would be far preferable to a death from the natural progression of his illness.

Reasons for physician referral for capacity assessment:

FW's social isolation, history of maladaptive coping, substance use, and current symptoms of depression all raised concerns about his capacity to qualify for aid in dying. Specifically, we wanted to better understand the role of depression and suicidality as a symptom of depression in his medical decision-making.

Psychologist preparation:

The focus of this interview was on the influence of depression, impulsive behavior, and substance use on the patient's decisional capacity to pursue aid in dying.

Outcome of assessment: FW's mental health history was characterized by life-long anxiety and depression. Depressive episodes characterized by negative self-talk and irritability tended to follow periods of interpersonal conflict. FW stated that this had largely resolved since his hospice team prescribed lorazepam, quetiapine, vilazodone, and zolpidem. Given these medication changes and the improvement of his symptoms of depression, he stopped all alcohol use.

FW explained details of his medical history and prognosis, reporting sadness and frustration related to physical limitations and decline in functional status. He was able to detail the process of requesting and participating in aid in dying. When asked about not engaging in aid in dying, FW stated it would mean dying in a way that was inconsistent with his desired independence. FW openly acknowledged his history of depression, anxiety, and substance use during the interview. FW stated his interest in living well, sharing, "I love living, I'm fighting really hard to live." When asked about suicidality, FW reported a history of fleeting thoughts that life was not worth living, though denied ever having an active plan or intent for suicide.

We determined that FW appeared to have the capacity to pursue aid in dying. He benefited from his psychotherapeutic medications, which highlights the dynamic nature of decisional capacity and the ways it may vary with treatment and/or the severity of psychological symptoms. FW acknowledged concerns about impulsively using medications to hasten his death.

FW's case addresses the impact of both psychiatric and substance use disorders on the decisional capacity to pursue aid in dying. Current recommendations regarding the intersection of capacity and substance use note that in the absence of acute withdrawal or intoxication, those with underlying substance-use disorders largely possess decisional capacity.[11] Likewise, we found that depression did not impact decisional capacity. FW's decision to pursue aid in dying reflected his primary value of self-sovereignty. His value of life-affirmation was demonstrated by his engagement with palliative and hospice services and treatment for his depression. In this way, his decisions around end-of-life care were in line with his stated and practiced values.

Case 2: RS is an 80-year-old male with a history of transthyretin amyloid cardiomyopathy. He expressed interest in aid in dying during his initial palliative care consult. He had recently discontinued participation in a clinical trial due to heavy symptom burden. Subsequently, he experienced four falls, with the last resulting in a two-week hospitalization for an intracranial bleed. RS denied having a significant mental health history, suicidality, or substance use issues.

Reasons for physician referral for capacity assessment: The goal of this assessment was to understand RS's decisional capacity considering neurologic injury.

Psychologist preparation:

The psychologist carefully reviewed the medical notes before and after RS's falls. The capacity assessment consisted of a clinical interview, an adapted MacArthur tool, screening assessments for anxiety (GAD-7) and depression (PHQ-9),[12,13] and the Montreal Assessment.

Outcome of assessment:

During the interview, RS reported memory changes; he asked for directions to be repeated several times. This was consistent with his performance on the Montreal Cognitive Assessment. He scored 18/30, suggestive of moderate cognitive impairment for the patient's demographic and educational background. RS reported mild symptoms of depression (PHQ-9 = 8/27).

RS consistently expressed his choice to pursue aid in dying. He connected it to discussions with his wife and family about autonomy and dignity at the end of life. This was corroborated by collateral information from the patient's family and medical record review (i.e., his initial palliative care consultation pre-falls). He accurately remembered and described past events, including his medical diagnosis. He also discussed the features of his diagnosis, the impact it was having on his life, and the likely prognosis. RS was able to discuss both aid in dying and the alternatives to achieve a peaceful death. Furthermore, he demonstrated an appreciation of the severity of his medical illness and the impact that both aid in dying and the alternatives would have on his life.

After review of the data obtained during the interview and cognitive screening, the psychologist concluded that RS had the capacity to consent to pursuing aid in dying. He expressed a consistent preference or choice for the option. He was able to understand the process of the procedure and associated risks and benefits. RS was able to cogently connect aid in dying to his goals of maintaining autonomy and independence and protecting his family from witnessing physical decline and possible suffering.

RS's case addresses capacity in the presence of neurocognitive deficits. Cognitive impairment can feature preserved skills of choice and reasoning, just as it can alter them.[14,15] A cognitively impaired patient may still retain capacity, though such cases require thorough evaluation. Our patient consistently expressed his choice to pursue aid in dying, and was able to explain his understanding and reasoning in a manner that reflected value-concordant decision making.

> “...HIS DECISIONS AROUND END-OF-LIFE CARE WERE IN LINE WITH HIS STATED AND PRACTICED VALUES.”

4. DISCUSSION

It is an obligation of the medical community to establish best practices for capacity evaluations in aid in dying—to reduce variability in the quality of assessments, protect the medically and psychiatrically vulnerable in their requests to access aid in dying, and to develop the practice of aid in dying to meet the highest ethical standards. Accordingly, a rigorous, standardized assessment should be adopted and applied by the community of aid-in-dying practitioners. Some possible components of such a standard are proposed in this paper. It is essential to note that we are not proposing the above system of evaluation for all patients considering aid in dying; rather, it is a framework for those whose capacity to make their own medical decisions calls for additional exploration.

While efforts have been made to systematically evaluate decisional capacity among terminally ill patients,[16,17] specific recommendations related to capacity evaluations in the context of aid in dying have been largely absent. Much of the current discussion on the topic details the importance of potentially aggravating factors—including substance use disorders,[16,18] underlying mental illness,[17,19,20] and cognitive changes[21-24]—but does not offer substantive assessment guidance.[25] The cases presented in this review seek to add clarity to the topic of complex capacity evaluations, offering recommendations and defining an assessment process to guide cases (Appendix 1). We propose a method that allows for the evaluation of the core components of capacity, and highlights values that guide medical decision-making. Essential to this type of assessment is the flexibility of the practitioner to adapt the investigation style and content to the clinical context, to involve consultative services (i.e., ethics, psychology/psychiatry) when necessary, and to corroborate asserted values with family members and loved ones when possible.

Our case series diagrams one method for delineating patient capacity to choose aid in dying when health professionals have cause for concern. This approach, based on a foundation of the MacArthur Competency Assessment Tool, evaluates the widely accepted four elements of competence: choice, understanding, appreciation, and reasoning. In doing so, it allows the clinician to ascertain the degree to which a patient's choice reflects their lived values rather than an underlying pathology that has led to loss of decisional capacity. This evaluative system can help a patient explore the relationship between psychological symptoms and a request for aid in dying. Additionally, consistency of decision-making processes through the clinical interview, medical record review, and collateral information informed each assessment.

Other standardized assessments certainly exist including the Aid to Capacity Evaluation and the Hopkins Competency Assessment Test, and other practitioners may have more comfort and facility in applying those tools to capacity evaluations. Moreover, in the context of limited structured data collection on practice patterns, it is hard to ascertain which tools practitioners are using clinically and the degree to which those evaluations meet care standards.

While this paper lays out a clinical framework using the MacArthur Competency Assessment Tool for Treatment, the more pertinent need is for the aid in dying community to coalesce around a standard practice for capacity evaluations that achieves high rigor, is practically applicable, and is flexible enough to reach a capacity determination in a wide variety of clinical contexts. Doing so may diminish practitioner and public concern over the application of aid-in-dying practices in cognitively and psychiatrically complex individuals.[16]

5. CONCLUSION

To further the community conversation around standardized practices in aid-in-dying capacity evaluations, we have presented a method for capacity assessments in psychologically complex patients considering aid in dying. These are constructed from existing tools in clinical use and rigorously applied. We consider these methods to be applicable and generalizable, and recommend their use for patients whose capacity is initially unclear.

Table 1. Semi-structured Capacity Assessment Guided by MacCAT-T

1. **Clinician uses medical record review to inform assessment of understanding.**
2. **Clinician may repeat information as needed throughout the assessment.**
3. **Clinician is transparent that the purpose of the interview is to assess patient's ability to make medical decisions surrounding medical aid in dying (AID IN DYING).**
4. **Clinician informs the patient that the results of the assessment will be shared with the referring physician.**

Capacity Standard	Prompt/Question	Response
Understanding	Please tell me about your current medical condition/What is your diagnosis?	Patient can name or describe the diagnosis.
	Tell me about your diagnosis? What are the symptoms and features?	Patient can name features and symptoms of the disorder.
	What is your understanding of the course of your disorder?	Patient acknowledges the terminal course of the disorder with a reasonably appropriate time frame.
Appreciation	Your medical team thinks that this medical condition is serious. What do you think?	Patient recognizes that he or she has a serious illness that impacts quality and length of life; if patient disagrees or is ambivalent, can they offer a reasonable explanation of his or her reasoning?
Understanding	Tell me about your treatment options.	Patient is able to say AID IN DYING (or similar) is a treatment option.
	What does AID IN DYING entail?	Patient is able to describe at least two features of AID IN DYING.
	What are your other treatment options?	Patient is able to detail alternative treatment options including enrollment in hospice care, future clinical trials, doing nothing, etc.
	What would this choice entail?	Patient is able to discuss features of the alternative treatment option—for example, hospice care involves receiving care in the home that manages your symptoms.
Understanding	What are the benefits of engaging in AID IN DYING?	Patient is able to describe what he or she perceives as the benefits of AID IN DYING.
	What are the risks associated with AID IN DYING?	Patient is able to acknowledge risks associated with the decision.
Appreciation	Do you think it is possible that AID IN DYING might be of some benefit to you?	Patient is able to describe a potential benefit from this treatment decision that is based in reality.
Choice	Let's review your treatment choices: You can choose to engage in AID IN DYING or you can (list patient's other identified treatment option). Which of these seems best for you?	Patient is able to pick a choice. If patient is ambivalent, he or she is able to acknowledge this ambivalence or indecision.
Reasoning	You think (stated choice) would be best; what is it that makes that seem better than the others? If unsure, what would help you to make the decision?	Patient can state either a benefit or the chosen option or risk of the not-chosen option. If unsure, patient is able to describe needed information or decision-making process.
	Earlier we discussed the possible risks and benefits of AID IN DYING; how might access to AID IN DYING influence your daily activities?	Patient can state a benefit of how AID IN DYING would make life easier (i.e., my family would not have to watch me suffer).
	How might not receiving AID IN DYING influence your daily activities?	Patient can describe how not receiving AID IN DYING would impact functioning (i.e., increased symptom burden/physical suffering).

Choice	Now that we have discussed how these treatment options would influence your daily functioning, which treatment option would you want to do?	Patient is able to state a choice or describe ambivalence surrounding decision-making.
Reasoning		Is there logical consistency between patient responses to the first and second "Choice" questions? Patient's final choice is logical given responses to reasoning questions and identifies risks and benefits.

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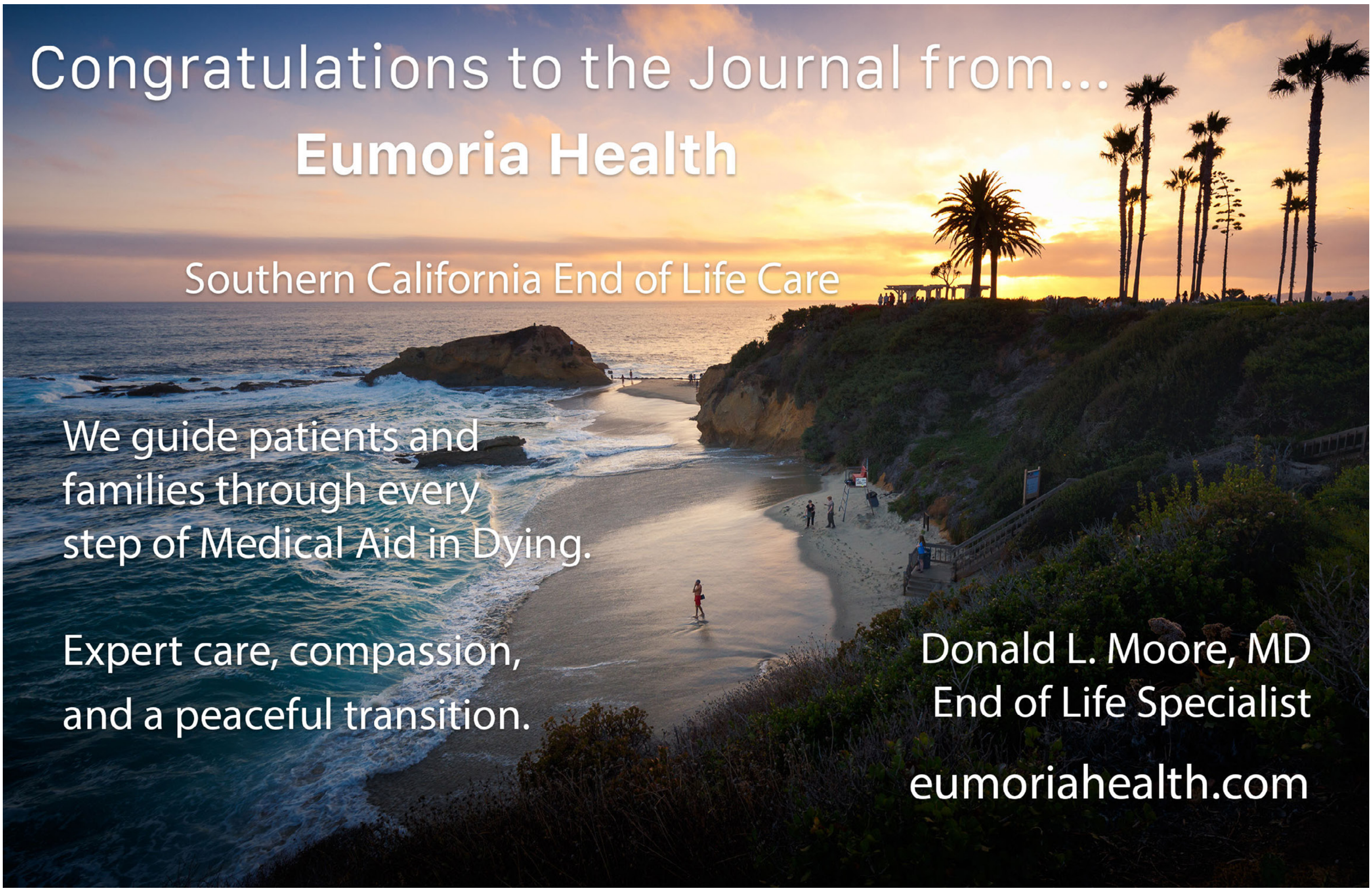
1. Colorado Revised Statutes. Title 25, Section 48. Colorado *End-of-life Options Act*. 2016.
2. Bussell, C. A. Factors Influencing Individuals' Capacity Decisions for Patients Requesting Medical Aid in Dying. Doctoral dissertation, University of Colorado, Colorado Springs; 2020.
3. Hedberg, K., & New, C. Oregon's Death With Dignity Act: 20 years of experience to inform the debate. *Annals of Internal Medicine*. 2017;167(8):579-583.
4. Kumaravel, A. Physician Aid-in-dying: practical considerations. *American Journal of Psychiatry Residents' Journal*. 2018;13:3-5.
5. Roth, L. H., Meisel, A., & Lidz, C. W. Tests of competency to consent to treatment. *The American Journal of Psychiatry*. 1977.
6. Kolva, E., Rosenfeld, B., Brescia, R., & Comfort, C. Assessing decision-making capacity at end of life. *General Hospital Psychiatry*. 2014;36(4):392-397.
7. Kolva, E., Rosenfeld, B., & Saracino, R. Assessing the decision-making capacity of terminally ill patients with cancer. *The American Journal of Geriatric Psychiatry*. 2018;26(5):523-531.
8. Grisso, T., Appelbaum, P. S., & Hill-Fotouhi, C. The MacCAT-T: a clinical tool to assess patients' capacities to make treatment decisions. *Psychiatric Services*. 1997;48(11):1415-1419.
9. Appelbaum, P. S., & Grisso, T. Assessing patients' capacities to consent to treatment. *New England Journal of Medicine*. 1988; 319(25):1635-1638.
10. Milani, S. A., Marsiske, M., Cottler, L. B., Chen, X., & Striley, C. W. Optimal cutoffs for the Montreal Cognitive Assessment vary by race and ethnicity. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*. 2018;10:773-781.
11. Morán-Sánchez, I., Luna, A., Sánchez-Muñoz, M., Aguilera-Alcaraz, B., & Pérez-Cárceles, M.D. Decision-making capacity for research participation among addicted people: a cross-sectional study. *BMC Medical Ethics*. 2016;17(1):1-10.
12. Kroenke, K., Spitzer, R. L., & Williams, J. B. The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*. 2001;16(9):606-613.
13. Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine*. 2006;166(10):1092-1097.
14. Karlawisk, J. Measuring decision-making capacity in cognitively impaired individuals. *Neurosignals* 2008;16(1):91-98.
15. Jefferson, A. L., Lambe, S., Moser, D. J., Byerly, L. K., Ozonoff, A., & Karlawish, J. H. Decisional capacity for research participation in individuals with mild cognitive impairment. *Journal of the American Geriatrics Society*. 2008;56(7):1236-1243.
16. Dees, M., Vernooij-Dassen, M., Dekkers, W., & Van Weel, C. Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: an integrative review. *Psycho-Oncology*. 2010;19(4):339-352.
17. Kolva, E., Rosenfeld, B., & Saracino, R. M. Neuropsychological predictors of decision-making capacity in terminally ill patients with advanced cancer. *Archives of Clinical Neuropsychology*. 2020;35(1):1-9.
18. Jeste, D. V., & Saks, E. Decisional capacity in mental illness and substance use disorders: empirical database and policy implications. *Behavioral Sciences & the Law*. 2006;24(4):607-628.

19. Dembo, J., Schuklenk, U., & Reggler, J. “For their own good”: A response to popular arguments against permitting medical assistance in dying where mental illness is the sole underlying condition. *The Canadian Journal of Psychiatry*. 2018;63(7):451-456.
20. Rooney, W., Schuklenk, U., & van de Vathorst, S. Are concerns about irremediableness, vulnerability, or competence sufficient to justify excluding all psychiatric patients from medical aid in dying? *Health Care Analysis*. 2018;26(4):326-343.
21. Nicolini, M. E., Kim, S. Y., Churchill, M. E., & Gastmans, C. Should euthanasia and assisted suicide for psychiatric disorders be permitted? A systematic review of reasons. *Psychological Medicine*. 2020;50(8):1241-1256.
22. Dembo J, van Veen S, Widdershoven G. The influence of cognitive distortions on decision-making capacity for physician aid in dying. *Int J Law Psychiatry*. 2020;72:101627.
23. Bravo, G., Trottier, L., Rodrigue, C., Arcand, M., Downie, J., Dubois, M. F., Van den Block, L. Comparing the attitudes of four groups of stakeholders from Quebec, Canada, toward extending medical aid in dying to incompetent patients with dementia. *International Journal of Geriatric Psychiatry*. 2019;34(7):1078-1086.
24. Moye, J., Karel, M. J., Gurrera, R. J., & Azar, A. R. Neuropsychological predictors of decision-making capacity over 9 months in mild-to-moderate dementia. *Journal of General Internal Medicine*. 2006;21(1):78-83.
25. Calcedo-Barba, A., Fructuoso, A., Martinez-Raga, J., Paz, S., de Carmona, M. S., & Vicens, E. A meta-review of literature reviews assessing the capacity of patients with severe mental disorders to make decisions about their healthcare. *BMC Psychiatry*. 2020;20(1):1-14.



ASSISTED SUICIDE FUNDING RESTRICTION ACT:

A Pathway to Compliance for Hospices

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ABSTRACT: Since the initiation of medical aid in dying in Oregon in 1997, many hospices have hesitated to participate in aid-in-dying care, citing, in part, the Assisted Suicide Funding Restriction Act (ASFRA). The Act is a 1997 federal law that prohibits the use of federal funding to pay for services that have the purpose of assisting in the death of an individual, such as assisted suicide, or, by inference, what is now known as "medical aid in dying." Many hospice providers have interpreted the law broadly as restricting the delivery of certain hospice services to patients who have elected to utilize medical aid in dying, even prohibiting communication with patients about its availability. This article explains that this broad interpretation of the law is legally questionable; creates ethical dilemmas for hospice providers and families; and, rather than being a conservative interpretation of the law, actually exposes hospice providers to legal risks. In fact, the Centers for Medicare & Medicaid Services (CMS) and its hospice benefit administrator do not interpret the law this restrictively. Medicare and its administrative contractor have interpreted the 1997 Funding Restriction Act to allow hospice providers to offer a range of palliative care services to support patients who have elected medical aid in dying.

We first provide an analysis of the specific requirements and structure of the Assisted Suicide Funding Restriction Act and explain why the statute has sowed confusion about what is and is not prohibited. This confusion has created clinical, ethical, and legal risks for hospices. Our analysis shows that current regulatory and subregulatory guidance alleviates these risks.

KEYWORDS: Assisted Suicide Funding Restriction Act (ASFRA), Medicare hospice benefit, medical aid in dying

1. INTRODUCTION

The Assisted Suicide Funding Restriction Act of 1997 is a federal law that prohibits the use of federal funds to pay for "any health care item or service furnished for the purpose of causing, or for the purpose of assisting in causing, the death of any individual, such as by assisted suicide, euthanasia, or mercy killing."[1] But the precise scope of the law has been subject to increasing debate as the legal landscape related to medical aid in dying in the states has evolved in the intervening 26 years since the Act's passage.

The law's reach is of particular interest to hospice providers, who receive a bundled payment for all services related to the treatment of a terminal condition. In return for a flat per diem payment, hospice programs are required to develop and deliver a plan of palliative care for the qualifying terminal illness that can include any or all of a wide range of services: doctor services, nursing care, medical equipment (like wheelchairs or walkers), medical supplies (like bandages and catheters), prescription drugs, hospice-aide and homemaker services, physical and occupational therapy, speech-language pathology services, social worker services, dietary counseling, grief and loss counseling for the patient's family, short-term inpatient care (for pain and symptom management), short-term respite care, and any other Medicare-covered services needed to manage the terminal illness and related conditions as recommended by the hospice team.[2]

Hospice providers have had difficulty distinguishing the treatment of a terminal condition from a health care service "furnished for the purpose of causing, or . . . assisting in causing" the death of an individual. The result has been provider and clinician confusion about how to comply with this federal law and, as a result, patient and family suffering at the end of life. For instance, some providers interpret this law to constitute a ban on sharing information with hospice patients about medical aid in dying, require patients considering aid in dying to hire outside prescribers and caregivers, and require hospice-employed staff to leave the room at ingestion.[3] These experiences can make patients and families feel stigmatized and abandoned by their hospice team.

This article attempts to provide some clarity.

2. THE ASSISTED SUICIDE FUNDING RESTRICTION ACT AND ITS (OVER) INTERPRETATION

The law was enacted in 1997 in response to Oregon's passage of its Death with Dignity Act.[4] The funding restriction provides that federal (including Medicare) funds may not be used directly or indirectly for the purpose of paying for any health care service for "the purpose of causing, or for the purpose of assisting in causing, the death of any individual, such as by assisted suicide, euthanasia, or mercy killing."[5] This prohibition does not refer to a specific clinical service that is recognizable to a provider, and the statute does not specify what constitutes services for the purpose of causing death. Nor does it define "assisted suicide, euthanasia, or mercy killing."[6] This broad restriction is subject to a series of even broader exceptions, which allow for the use of federal funds for the purpose of "withholding or withdrawing of medical treatment or medical care," "withholding or withdrawing of nutrition or hydration," or "an item, good, benefit, or service furnished for the purpose of alleviating pain or discomfort, even if such use may increase the risk of death, so long as such item, good, benefit, or service is not also furnished for the purpose of causing, or the purpose of assisting in causing, death, for any reason."[7]

These exceptions are also not defined.

The federal law's definitions, together with its exceptions, contribute to a lack of clarity about what exactly the statute prohibits.[8] This is especially true when it comes to the delivery of palliative care to a patient who has elected to self-administer an aid-in-dying medication. For example, the exception for items or services for the alleviation of pain is hard to distinguish from prohibited assistance when the patient needs pain management to be able to self-administer the aid-in-dying medication. Similarly, hospice patients electing to utilize medical aid in dying frequently also require routine palliative treatment, such as attention to their digestion, nausea/vomiting, and swallowing. Other patients who have elected medical aid in dying may need assistance to minimize medication interactions between the aid-in-dying medications and other drugs the patient may be taking (especially managing high physical tolerance levels for opiate pain killers or benzodiazepine sedatives). Still others require specialized mental health and cognitive considerations.[9] Many patients who are considering medical aid in dying also require personal care, respite, and bereavement counseling. All these activities are standard Medicare services for *all* hospice patients including patients considering medical aid in dying. It is unclear whether these activities fall within the federal funding restrictions or enumerated exceptions.

Indeed, there is anecdotal evidence that hospice programs have recently taken a variety of approaches to compliance with the federal law. For example, some hospice providers allow employed practitioners to prescribe and support ingestion with full hospice staff cooperation but prohibit the use of federal funds to purchase the aid-in-dying medications. Other hospices, though, interpret the law as a prohibition on the delivery of *traditional* hospice services to patients who are considering aid in dying under state law, even believing that federal law bars their staff from counseling hospice patients on anything related to medical aid in dying. For instance, some hospice providers interpret federal law and thus Medicare to require patients considering aid in dying to hire outside prescribers and caregivers to deliver such assistance. It is also now well-documented that many hospices require staff to leave the room at ingestion.[10] In extreme cases, some hospice providers have involuntarily discharged patients who are even considering medical aid in dying.

These restrictive interpretations of the law lead to unnecessary patient confusion and suffering, as federal authorities have recently clarified how to comply with the Assisted Suicide Funding Restriction Act.

3. MEDICARE GUIDANCE ON HOSPICE SERVICES AND FEDERAL LAW

The federal Centers for Medicare & Medicaid Services is the agency responsible for administering the Medicare hospice benefit. The agency has recently indicated that it does not intend to prohibit providers of Medicare hospice services from supporting hospice patients seeking to utilize medical aid in dying as authorized under state law.

Beginning with guidance released in 2021, Medicare authorities noted the "potential role hospices could play in medical aid in dying where such practices have been legalized in certain states."[11] Accordingly, rather than prohibiting hospices from providing such services, Medicare indicated that hospice providers *may* provide aid-in-dying services, so long as they track aid-in-dying-specific expenses, unbundle them from the per diem hospice rate, use non-federal funds to cover aid-in-dying-specific expenses, and report those expenses separately.[12] In conjunction with the 2021 guidance, the agency also updated the Medicare Provider Reimbursement Manual for the Provider Cost Reports to include technical instructions on complying with federal law in completing hospice cost reports.[13] Specifically, the Centers for Medicare & Medicaid Services created a new "Line 72," which allows hospice providers to report hospice expenses related to "items and services under ASFRA 1997." As Medicare explained, hospice providers may comply with the Assisted Suicide Funding Restriction Act by not using federal funds for those services and separately reporting costs for hospice services rendered "for the purposes of assisted suicide."[14]

Although this guidance on unbundling has been clarifying, Medicare has not yet fully addressed how a hospice should draw a line between traditional palliative care functions and federally prohibited aid-in-dying services in completing the Line 72 unbundled expenses report or when delivering end-of-life planning, personal care and nursing, grief counseling, and medical services for patients who elect to use medical aid in dying.

The Medicare hospice benefit is administered (claim processing /payment) and primarily overseen (monitored/audited) by regional administrative contractors referred to as "Medicare Administrative Contractors." These contractors are the crucial front line of the federal government in implementing Medicare benefits, including hospice care. The Medicare Administrative Contractors each are responsible for a region of the country and coordinate with each other and federal government officials to ensure consistent and efficient implementation of Medicare benefits. Although the Medicare administrative contractors have not formally issued further technical guidance on the implementation of the federal prohibition and unbundling process, Palmetto GBA, the Medicare hospice administrative contractor for Jurisdiction C,[15] has elaborated on its interpretation of Line 72 of the cost reporting guidelines and the federal funding act.

Officials at Palmetto GBA responsible for the hospice benefit told the authors that hospices should only use Line 72 to report funds used to:

> (1) purchase the aid-in-dying medications (even if ultimately not ingested); and
>
> (2) pay for the salary/contracted fees of staff exclusively engaged in facilitating medical aid in dying.

Palmetto GBA officials further clarified that other palliative care activities for patients electing medical aid in dying, including writing the prescription, should be delivered and reported as usual for any other hospice patient.[16]

The authors have not encountered an alternative interpretation to the guidance provided to us by Palmetto GBA of how to reconcile the requirements of the Assisted Suicide Funding Restriction Act with the requirements of the Medicare hospice benefit. Accordingly, the limited guidance that exists indicates that the consultation, consent form collection, capacity and prognostic assessments, family bereavement preparations, nursing evaluations, and prescribing of aid-in-dying medications are not prohibited by the Assisted Suicide Funding Restriction Act. Under this guidance, hospices should carve out from federal funding (and use other sources of funds, such as the patient paying out of pocket, charitable foundations, or state/local funding sources) for the expense of the aid-in-dying medications and the salary/fees for staff exclusively engaged in facilitating medical aid-in-dying and report these expenses on Line 72.

This guidance should help hospice providers avoid potentially untenable parsing of time/roles between traditional hospice responsibilities and aid-in-dying functions, allowing hospice programs to comply with federal law while also complying with traditional hospice standards of care for patients who are considering medical aid in dying.

4. COMPLIANCE RISKS OF BROAD INTERPRETATIONS OF FEDERAL FUNDING RESTRICTIONS

Medicare and Palmetto GBA's interpretation of the federal funding restriction also helps hospice providers balance aid-in-dying compliance with the general requirements of the hospice program. In particular, the hospice per diem payment is compensation for the delivery of *all services* needed to manage the patient's terminal illness and related conditions in

“…NUMEROUS HOSPICES HAVE HESITATED TO PROVIDE AID-IN-DYING CARE, IN PART DUE TO FEAR OF RUNNING AFOUL OF FEDERAL LAW.”

compliance with Medicare regulations and federal law.[17] Hospice providers are subject to regular audits by a variety of state and federal agencies for compliance with applicable program and financial regulations. This includes the Centers for Medicare & Medicaid Services, their administrative contractors, the United States Department of Health & Human Services Office of the Inspector General, and state survey/certification agencies. The Inspector General has, in recent years, prioritized hospices as a target for audits based on findings that more than 80 percent of hospices audited between 2012 and 2016 had at least one deficiency.[18]

As noted in the most recent inspector general reports, the federal government is particularly sensitive to quality-of-care issues caused by understaffing or *withholding of care to hospice patients*. Hospice operators that render substandard care to patients who are considering or who have elected to use medical aid in dying are at risk of inspector general or Medicare audits and related enforcement actions. A hospice that declines to provide care for patients who are considering or who elect medical aid in dying contributes to adverse clinical events and may be subject to compliance actions. Hospice patients who are considering aid in dying continue to need all hospice services to the same degree as a patient who is not considering aid in dying. Neither Medicare nor the Inspector General have indicated that a patient’s consideration of aid in dying is an acceptable justification for rendering substandard care.

In addition, a series of recent cases in federal court indicate that the Department of Justice is likely to continue to bring False Claims Act cases against Medicare providers who deliver substandard care under what is referred to as the “worthless services theory.” The False Claims Act is a federal statute that provides that any person who knowingly submits, or causes to submit, false claims to the government is liable for three times the government’s damages plus a penalty that is linked to inflation.[19]

On March 31, 2023, the United States District Court for the Eastern District of Pennsylvania denied a motion to dismiss a False Claims Act suit brought by the Department of Justice under a worthless services theory against a trio of nursing-home providers based on alleged substandard care provided to residents in violation of the Medicare benefit requirements.[20] This case builds on cases over the past two decades in which courts are recognizing the validity of the worthless services theory in False Claims Act allegations against providers receiving per diem Medicare reimbursement.[21]

In the same sense, hospice operators that knowingly submit per diem claims for payment while withholding essential medical and other palliative care from patients who are considering the use of medical aid in dying present similar fact patterns to those seen in the nursing home False Claims Act cases. As such, the ruling provides a roadmap for the Department of Justice and for third-party whistleblowers to plead a worthless services False Claims Act claim against hospice operators who withhold palliative services to patients who are considering or elect medical aid in dying.

In the context of inspector general and Medicare audit activity and trends in False Claims Act litigation, withholding of any hospice services to patients who are considering and potentially using medical aid in dying—even in the good faith belief that this is required by the federal funding restriction—may expose hospice operators to program compliance risks and potentially even to the risk of False Claims Act claims brought by the United States Department of Justice or whistleblowers. Hospice operators may mitigate compliance risk for *both* the Assisted Suicide Funding Restriction Act *and* their other obligations by ensuring that patients who elect aid in dying continue to receive the same quality of palliative care as patients who do not.

5. CONCLUSION

Since the earliest days of medical aid in dying in the United States, numerous hospices have hesitated to provide aid-in-dying care, in part due to fear of running afoul of federal law. But the recent regulatory and subregulatory guidance from Medicare related to hospice cost reports and the clarifying interpretation from the Palmetto GBA have provided clarity on how hospice operators can balance the needs of patients, the imperatives of Medicare hospice program requirements, and the Assisted Suicide Funding Restriction Act. Hospice operators can minimize the risk of non-compliance with the federal act by reporting expenses related to aid in dying on Line 72 of the cost reports. They may then treat aid-in-dying patients like all other hospice patients. This approach should ensure that aid-in-dying patients are able to receive the same quality of palliative care as any other patient in the hospice program and reduce compliance and False Claims Act litigation risks while complying with federal funding restrictions.

CONFLICT OF INTEREST:

The authors and their law firm Epstein Becker Green, P.C. are pro-bono counsel to the non-profit organization End-of-Life Options New Mexico.

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1. 42 U.S.C. § 14402(a).
2. 42 C.F.R. §§ 418.64, 202.
3. See Hospice nurse ethics and institutional policies toward medical aid in dying: how can nurses fulfill their duty to patient and family? *American Journal of Nursing*. June 2023;123(6):37-43. doi: 10.1097/01.NAJ.0000938728.13124.c3; Aid-in-dying Consultation Service of the American Clinicians Academy on Medical Aid in Dying. *Navigating conflict between professional nursing commitments to patients and institutional "Leave the Room" policies*. January 4, 2022. Available at: acamaid.org/wp-content/uploads/2022/01/Ethics-Consultation-Leave-the-Room-Policies-1-4-22.pdf.
4. Pub. L. 105, Apr. 30, 1997. Legislative history indicates that members of Congress were primarily motivated by the passage of the Oregon Death With Dignity Act (127.880 s.3.14.).
5. 42 U.S.C. § 14402(a). Prior to the passage of ASFRA, there was no federal prohibition on the use of funding for "assisted suicide" because, prior to the passage of the Oregon Death with Dignity Act, medical aid in dying was considered to be "assisted suicide" and was criminalized throughout the United States. Including the Oregon Death with Dignity Act (127.880 s.3.14.), the state statutes that authorize medical aid in dying distinguish medical aid in dying (which is a medical process and is restricted to patients with terminal conditions facing imminent death who have capacity and ability to self-administer an aid-in-dying medication) from "assisted suicide" as defined under state law. The criminalization of "assisted suicide" remains intact in all states that have established medical-aid-in-dying laws. For this reason, death certificates for patients utilizing medical aid in dying record the terminal condition, not suicide. However, based on the legislative history, for the purpose of this article, the authors assume that medical aid in dying will be considered to be "assisted suicide" for the purposes of ASFRA.
6. Id.
7. 42 U.S.C. §14402(b).
8. ASFRA has several parallels to the better-known Hyde Amendment (P.L. 117-328. Div. H, §§ 202–203). The latter prohibits the use of federal funds for "abortion" without defining the term, while providing for exceptions—namely,allowing the use of federal funds to pay for any type of "abortion" performed to end pregnancies that are the result of rape or incest or "in the case where a woman suffers from a physical disorder, physical injury, or physical illness, including a life-endangering physical condition caused by or arising from the pregnancy itself, that would, as certified by a physician, place the woman in danger of death unless an abortion is performed." In short, like ASFRA, the Hyde Amendment prohibits a category of actions that are clinically undefined and then applies a series of also undefined exceptions to the prohibition. As with the women being refused care due to the lack of clarity about the precise scope of the Hyde Amendment's application and exceptions—for instance, it is not clear whether the Hyde Amendment covers ectopic pregnancies—ASFRA's lack of clarity as to its scope is currently leading some hospices to withhold palliative care from patients who have elected to use (or are merely considering) medical aid in dying.
9. American Clinicians Academy on Medical Aid in Dying. *Red Flag Risk checklist for potentially complicated and/or prolonged AID deaths*. Available at: https://www.acamaid.org/wp-content/uploads/2021/06/Red-Flag-Checklist.pdf.
10. See *supra* at note 3.
11. Centers for Medicare and Medicaid Services, 42 CFR Part 418 [CMS-1754-F], Medicare program; FY 2022 hospice wage index and payment rate update, hospice conditions of participation updates, hospice and home health quality reporting program requirements. CMS has retained nearly identical preamble guidance in subsequent editions of the wage index rule for the 2023 and 2024 fiscal years. See 87 FR 19444 (April 4, 2022) and 88 FR 51166 (August 2, 2023).
12. Id.

13. CMS Medicare Provider Reimbursement Manual-Part 2, Provider Cost Reporting Forms and Instructions, Chapter 43, Form CMS-1984-14. February 25, 2022. Available at: https://www.cms.gov/files/document/r5p243i.pdf.
14. Id.
15. Jurisdiction C includes: Alabama, Arkansas, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Mississippi, New Mexico, North Carolina, Ohio, Oklahoma, South Carolina, Tennessee and Texas. New Mexico is the only state in Jurisdiction C that currently has a medical-aid-in-dying statute.
16. E-mail exchange with Kevin Malone, Esq. and Palmetto GBA, June 2, 2022.
17. *See* 42 CFR §§ 418.64, 202.
18. U.S. Department of Health and Human Services Office of Inspector General. *Hospice Deficiencies Pose Risks to Medicare Beneficiaries*, OEI-02-17-00020. July 2019. Available at: https://oig.hhs.gov/oei/reports/oei-02-17-00020.pdf?utm_source=summary-page&utm_medium=web&utm_campaign=OEI-02-17-00020-PDF.
19. 31 U.S.C. §§ 3729–3733.
20. See *U.S. v. American Health Foundation Inc.*, Case No. 2:22-cv-02344, 2023 WL 2743563 (E.D. Pa. Mar. 31, 2023).
21. See U.S. v. Villaspring Health Care Center, Inc., 2011 WL 6337455 (E.D. Ky. Dec. 19, 2011) and U.S. v. NHC Health Care Corp., 163 F. Supp. 2d 1051 (W.D. Mo. 2001). Many other courts have recognized a general principle that knowingly billing the government for worthless services is equivalent to billing for services that were not provided, which is a violation of the False Claims Act.

PATIENTS WITH LIMITED ABILITY TO COMMUNICATE

THADDEUS MASON POPE, JD, PHD, HEC-C

Occasionally, aid-in-dying clinicians encounter patients with limited communication abilities. While these patients seem to respond appropriately, their responses may be limited to minimal one-word replies. For example, they might say only “yes” or “no” when answering questions. In such cases, clinicians might be unsure whether this level of communication is sufficient either for confirming capacity or for signing a consent form—both mandatory under all aid-in-dying statutes.

Confirming decision-making capacity

All aid-in-dying laws require that the patient have decision-making capacity. Indeed, this is such an important and central requirement that the patient’s capacity must be confirmed by at least two, and sometimes even three, clinicians.[1] But how can clinicians confirm capacity when the patient has such limited communication abilities?

First, do not automatically assume or conclude that the patient lacks capacity solely because of their limited communication capabilities. The strong trend in healthcare law and policy has been to work with patients, make accommodations, and adapt tests to assess capacity.[2] For example,

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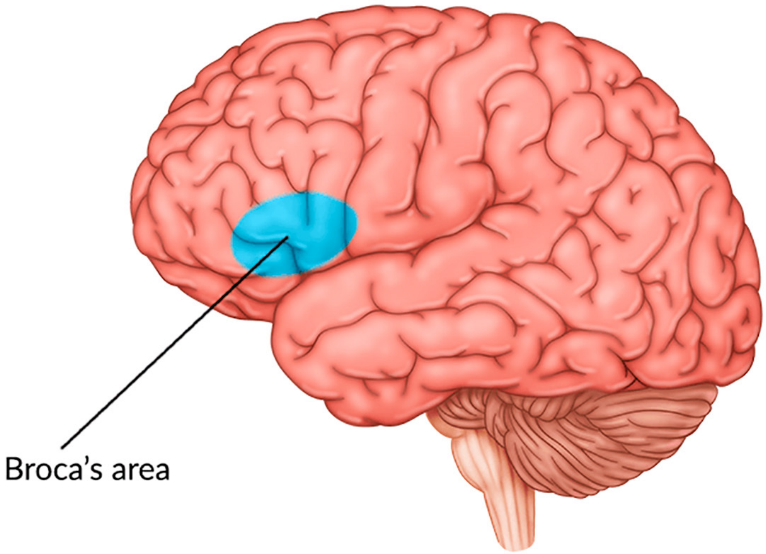

clinicians must provide qualified interpreters for patients with impaired hearing or with limited English proficiency.[3] Similarly, a growing number of states require supported decision-making when that can help impaired patients express autonomous choices by effectively restoring or preserving their capacity.[4,5,6]

While extreme, perhaps the starkest example illustrating the danger of too readily assuming incapacity are patients with locked-in syndrome. They cannot speak, write, or move. Yet, none of that necessarily means the patient lacks capacity. Nor does it mean that clinicians cannot assess their capacity.[7,8] Admittedly, because of these patients’ limited communication abilities, clinicians cannot assess capacity using their typical methods. But they can still assess capacity by adapting the manner of assessment. It is wrong to conclude the patient lacks capacity just because of their limited physical or communication abilities.

Ultimately, the test for capacity is the same for all patients; it includes four components. First, you must be sure the patient understands aid in dying, including its risks, benefits, and alternatives. Second, you must be sure the patient appreciates the consequences of their decision. Third, you must be sure the patient has reasoning to support their decision. Fourth, you must be sure the patient can communicate a choice.[9,10] For communication-impaired patients, you will need to modify the way you assess these abilities. For example, you (perhaps with the assistance of an experienced consultant) can elicit a yes or no response through verbal response, head nods, thumbs up or down, or eye blinks. Many tools and instruments are already available.[11,12]

Signing the consent form

Just as aid-in-dying laws require that the patient have capacity, they also require that the patient "sign" a written request form.[13] Again, this may look difficult or impossible for some patients with limited communication and/or movement abilities.

But the signature requirement is more flexible than it appears. It does not require that the patient use a pen in her hand. Across all sorts of consent contexts, many patients cannot physically do that (e.g., amputation and quadriplegia). In these cases, it is sufficient that the clinician obtain the patient's signature by mark. For example, California law (including the End of Life Options Act) explicitly defines "signature" as including a "mark" when the signer cannot write.

This works in three steps. First, instead of signing her signature, the patient, without assistance, leaves some sort of mark on the consent form.[14] Typically, the patient draws an X, a squiggle, or a line. Sometimes, they leave their thumbprint. Second, the witnesses, who are already required for the written request form, write the patient's name near the mark. Third, the witnesses write and sign their own names near the patient's name.[15]

Conclusion

Some patients considering aid in dying have limited communication and physical abilities. A few of these patients might—for related or unrelated reasons—lack decision-making capacity. But you should adapt standard capacity assessments for these patients to avoid erroneously concluding that they are incapacitated.

NOTE: This column is meant to provide general information about legal topics, not legal advice. The law is complex, varying from state to state, and each factual situation is different. Readers are advised to seek advice from an attorney.

1. Pope T.M. Medical aid in dying: key variations among U.S. state laws. *Journal of Health & Life Sciences Law*. 2020;14(1):25-59.
2. Moye J et al. Ethical concerns and procedural pathways for patients who are incapacitated and alone: implications from a qualitative study for advancing ethical practice. *HEC Forum*. 2017;29(2):171-189.
3. 42 *Code of Federal Regulations* §§ 92.1–92.105.
4. Wright M.S. Equality of autonomy? Physician aid in dying and supported decision-making. *Arizona Law Review.* 2021;63(1):157-97.
5. Heller A. Further consideration on the relationship between the Americans with Disabilities Act, supported decision-making, and medical aid in dying. *Washington & Lee Law Review.* 2023;81(1):617-624.
6. Rosen BM. Supported decision-making and merciful health care access: respecting autonomy at end of life for individuals with cognitive disabilities. *Washington & Lee Law Review* 2023;81(1):555-606.
7. Carrington S. & Birns J. Establishing capacity in a patient with incomplete locked-in syndrome. *Progress in Neurology and Psychiatry* 2021(Nov./Dec.):18-20.
8. Maiser S et al. Locked-in syndrome: case report and discussion of decisional capacity. *J Paun & Symptom Mgmt.* 2016;51(4):789-793.
9. California Hospital Association. *Consent Manual* section 3.2.
10. Appelbaum P.S. Assessment of patients' competence to consent to treatment. *New England J Med.* 2007;357(18):1834-1840.
11. Moss Rehabilitation Research Institute. Facilitating informed consent for people with aphasia and cognitive impairment: breaking through communication barriers in the language and learning; 2021. Available at: https://mrri.org/facilitating-informed-consent-for-people-with-aphasia-and-cognitive-impairment-breaking-through-communication-barriers-in-the-language-and-learning-lab/.
12. Canadian Association of MAiD Assessors and Providers. Assessment for capacity to give informed consent for medical assistance in dying (MAiD): review and recommendations; 2020. Available at: https://camapcanada.ca/wp-content/uploads/2022/02/Capacity-assessment.pdf
13. Cal. Health & Safety Code § 443.3(b)(2); Colo. Rev. Stat. §§ 25-48-104(2)(II) & 25-48-112; D.C. Code § 8-661.02(a)(2) & (c)(6); Haw. Rev. Stat. §§ 327L-3(a) & 327L-23; Me. Code. §§ 2140(5) & (24); N.M. Stat. §§ 24-76-3(H); N.J. Stat. §§ 2615-5(a) & -20; Or. Rev. Stat. §§ 127.810(1) & 127.897; Vt. Stat. §§ 18-5283(a)(4); Wash. Rev. Code §§ 70.245.030(1) & 70.245.220.
14. Cal. Health & Safety Code § 18.
15. California Hospital Association. Consent Manual section 2.12.

CONSIDERATIONS AND BEST PRACTICES IN AID-IN-DYING STATES THAT ALLOW NON-RESIDENTS TO PARTICIPATE

JESSICA KAAN, DO, MPH

ABSTRACT: Until 2022 each state with legalized medical aid in dying required that only residents of the state could access the procedure, with varying residency requirements. But in March 2022, Oregon health authorities settled a lawsuit challenging the residency requirement.[1] With later confirmation by the legislature, the entire state opened up to aid-in-dying care for non-residents. In May 2023 Vermont dropped its residency requirement.[2]

The new right to aid in dying for residents from non-aid-in-dying states initiated many questions for patients and clinicians. Might aid-in-dying care be provided by telemedicine, across state lines? Would patients need to be physically in the aid-in-dying state before beginning evaluations or care? Could they take the medications back to their home state and potentially ingest them there?

This article details the varied risks and benefits clinicians and patients confront when considering travel from a non-aid-in-dying state to Vermont or Oregon.

KEYWORDS: Medical aid in dying, Oregon Death with Dignity Act, Vermont Patient Choice at End of Life Law; aid-in-dying residency.

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1. INTRODUCTION

Every U.S. jurisdiction that legalized medical aid in dying has included a state residency requirement in their initial laws. This was intended as a safeguard against abuse, to maintain quality of care within the state, and to prevent so-called “aid-in-dying tourism” by terminally ill patients from non-aid-in-dying states. But state residency requirements were also seen as an undue barrier to access. That led to an October 2021 federal lawsuit filed by Compassion and Choices and Dr. Nicholas Gideonse against the state governor, attorney general, Multnomah County’s district attorney, and state health officials.[3] In March 2022, the lawsuit was settled, so that terminally ill patients who were not Oregon residents but who met all the Oregon Death with Dignity Act requirements could access medical aid in dying in some parts of the state. In June 2023 Oregon’s Legislature passed HB2279, officially eliminating the residency requirement throughout the state.[4] In May 2023 Vermont’s legislature also amended their law (initially passed in 2013) to allow non-residents to request and obtain medical aid in dying.[5]

Terminally ill patients from states without legal access to medically assisted dying are now traveling to both Oregon and Vermont to have that legal option. However, it is important to recognize the challenges that patients and their supporters face if they are considering travel to pursue aid in dying.

This article is intended to provide analyses and suggest best practices for aid-in-dying clinicians who are counseling and caring for out of state residents. It is also essential that clinicians in non-aid-in-dying states understand these details, to adequately counsel patients in their states.

2. PRACTICE PRAGMATICS

When a terminally ill patient is considering travel to pursue medical aid in dying, it is ideal if they are counseled prior to making this decision. They should understand all the issues as fully as possible and make plans for complying with the medical, legal, emotional, and logistical processes.

The most common misunderstandings for both patients and clinicians have to do with where the medical care and procedures may occur, and especially with when and for how long the patient must remain in the state where aid in dying is legal.

The non-profit organization End of Life Choices Oregon provides general information and resources to patients considering travel to the state.[6] Similarly, Patient Choices Vermont offers guidelines and checklists on its website.[7] Organizations and individual clinicians should be cautious to provide only wide-ranging advice and not guidance specific to a patient’s case until they are physically in the state where aid in dying is legal. This avoids the risk of being prosecuted for practicing medicine without a license in the non-aid-in-dying state.

Patients must understand that they will need to show evidence, via records and evaluations, that they meet all the legal requirements for medical aid in dying within the state they will be traveling to. Each of the aid-in-dying laws in the U.S. requires that a patient be an adult (age 18 or older), be found mentally capable to make an informed medical decision, have a terminal illness with a life expectancy of six months or less, and be able to self-ingest the prescribed lethal medications. Note that clinicians in the aid-in-dying state cannot confirm with certainty that a patient qualifies for an assisted death while the patient is still in the non-aid-in-dying state. This complicates some patients' decisions about whether to travel to the aid-in-dying state for further care.

Several guidelines for patients considering travel to an assisted-dying state strongly recommend that they discuss this with their current medical providers. This is important for confirming evidence of their terminal illness and prognosis and arranging for the release of relevant records. In addition, it provides the patient and providers an opportunity to discuss available alternatives, such as hospice care and additional methods to palliate symptoms. Sometimes the fear of end-of-life suffering will be reduced once a patient has a better understanding of what is available within their home state, thus eliminating the desire to travel for aid-in-dying access.

A misconception held by some patients is that they can travel to a state with legal aid in dying, comply with all the necessary steps and evaluations, and then return to their home state to ingest the lethal medications. It should be clearly communicated that if they take these drugs in a state without an aid-in-dying law, they could be putting their loved ones at legal jeopardy. Acts such as helping someone travel to obtain a lethal prescription or mixing the medications could be construed as criminal assistance in a suicide and prosecuted, potentially as a felony.[8] The patient and all family members or supporters who plan to help must be advised of their legal risks. Clinicians should document this counseling in the patient's medical record, as evidence that they clearly advised all participants to comply with the laws in both states.

It is again important to emphasize that physicians in the accepting state cannot advise about patient-specific details while the patient is in the non-aid-in-dying state without risking the accusation of practicing medicine without a license.

If, after discussing the alternatives with their home-state medical team, a patient still wishes to pursue a hastened death in a state without a residency restriction, they should realistically consider the hardships they may encounter. Patients must fully understand that aid-in-dying care is not available remotely, by cross-state telemedicine or other means. They must not only travel to the aid-in-dying state, but be there for all aspects of the legal and clinical processes.

Inevitably, the reality of traveling to die includes having a smaller support system than would be available at home.[9] Often, only one or two people are able to travel with the terminally ill patient. Contemplating a death at home, surrounded by family and friends, versus a death in an unfamiliar environment with only a few loved ones in attendance, can cause patients to reconsider this option.

It is most critical that patients are safely able to get to the aid-in-dying state and be there for all related actions. They must be physically present in Oregon or Vermont when giving the first oral request to the attending/prescribing physician, undergoing evaluation by the consulting/second-opinion doctor, giving the second oral request after the legally-mandated waiting period, and being present in the state at the time of receiving the medications and the ingestion.[10,11] These requirements can be fulfilled per the accepted standard of care either in person or via telemedicine, but the patient must still be physically in the aid-in-dying-legal state. A patient may choose to return to their home state during the legally mandated waiting period, but should consider the risks and potential harms of that additional travel.

The burden of travel for a terminally ill patient can be significant. Any seriously ill person thinking of making this journey should carefully consider if they can withstand the physical demands, discomfort, and mental processing that travel will require. Having at least one support person capable of aiding with any issue that may arise is strongly recommended. However, given that many states have laws that criminalize assisting in a suicide, patients and their family or support persons may be opening themselves up to criminal or civil penalties.[12] They should carefully investigate, understand, and assess their specific state laws; consultation with an attorney is advised.

Oregon and Vermont require a signed and witnessed written request for aid in dying. Whether the patient or the witnesses must be in the state when they complete the form is an unanswered legal question not expressly addressed by any of the non-residency laws.[13]

Another difficult yet important element for patients to consider is the cost associated with traveling to pursue medical aid in dying. Expenses can include: the mode of transportation for the patient and their family, enrollment in hospice in the aid-in-dying state (likely to be covered by insurance), consultations and evaluations with the required medical professionals (typically not covered by insurance), cost of the aid-in-dying medications (unlikely to be covered by insurance), the expense of accommodations and meals, the cost of post-death body management by funeral homes or crematoriums, and transportation of remains back to the home state.

A final unanswered legal question regards life insurance policies. In all aid-in-dying states, the laws specify that the death be listed as natural, and the cause of death is the underlying medical illness.[14] There can be no mention of suicide or assisted death on the death certificates. These laws also specify that death by legally obtained aid-in-dying medications cannot affect an insurance policy. However, if a person has a policy written in a state without an aid-in-dying law, it is unclear whether the contract could be invalidated following a medically-assisted death. Given that the death certificate does not use the term suicide or mention aid in dying, it would be unlikely for an insurance company to be aware of the method of death. But there is no guarantee, nor has the outcome of such knowledge been tested.

Finding aid-in-dying clinicians in the destination state who will agree to participate with out-of-state residents is an often significant hurdle for patients. Several organizations, such as the American Clinicians Academy on Medical Aid in Dying,[15] End of Life Choices Oregon,[16] and Patient Choices Vermont,[17] have services that provide information or try to connect patients with willing aid-in-dying providers.

Finally, lack of resources is a common barrier for terminally ill patients who reside outside a state with legalized aid in dying. This creates a state-based inequality in the ability to access the option of a medically aided death.

It is recommended that prior to traveling, a patient obtain a letter from their physician(s) that clearly documents their terminal diagnosis and prognosis of less than six months to live. This will serve as tentative evidence of their aid-in-dying eligibility. But the final evaluation of eligibility cannot be completed while the patient is in the non-aid-in-dying state without the risk of practicing medicine without a license in the patient's home state.

This article emphasizes that traveling to pursue medical aid in dying is a significant undertaking that should be carefully considered and planned prior to travel. But for some patients, the barriers and negative effects of traveling while terminally ill, and dying in a place that is not home, may still be outweighed by the ability to take control of the manner and timing of their death, or for relief from intensive and intractable suffering. With cautious guidance and established workflows, an aid-in-dying provider can feel confident that they are providing the best care to the patients who do choose to die in an aid-in-dying-legal state.

3. SUMMARY

When contemplating the medical, physical, emotional, and financial burdens, non-resident patients considering medical aid in dying must consider:

TRAVEL:

- the ability to tolerate a trip by flying or driving while terminally ill
- the cost of travel and time required
- obtaining and paying for a temporary accommodation for the patient and supporters

LEGAL REQUIREMENTS:

- transferring medical records
- completing forms indicating the refusal of resuscitation efforts and life support (in many states referred to as POLST, MOLST, or COLST)

CLINICAL REQUIREMENTS:

- obtaining the care of an attending/prescribing physician and consulting/second-opinion doctor
- establishing diagnosis and prognosis (there is no guarantee that, once in an aid-in-dying state, the physicians there will decide that these requirements are met)

EMOTIONAL BURDENS:

- the likelihood of less support during the patient's acutely terminal phase
- death away from the home environment

AFTER-DEATH NEEDS:

- transportation and management of the body

LEGAL RISKS:

- in states where aid in dying is not legal, the protections written into aid-in-dying laws may not apply
- the death may be considered an assisted suicide, with associated legal risks
- death certificates listing the cause of death as the underlying disease, not aid in dying, may not be honored in the patients' home states
- Insurance policies may be invalidated by suicide clauses

4. CASE HISTORIES

A. JP, a 41-year-old man with rapidly progressive pancreatic cancer, developed excruciating abdominal and back pain. He was referred to hospice, but became intolerant to all opioids, with severe itching and nausea not responsive to anti-emetics. He resided in a state without legal aid in dying.

After discussing all options with his hospice team and family, JP decided to move to Oregon to die. End of Life Choices Oregon informed him of the general requirements of the law, to arrange housing in advance of his arrival, and obtain a letter from his oncologist clearly stating his diagnosis and prognosis.

JP traveled to Oregon with his wife and sister, where a medical evaluation showed severe cachexia and incessant pain. The attending and consulting physicians agreed he had less than 15 days to live, and waived the legally mandated waiting period, as allowed by Oregon law. JP and his family completed all necessary steps within three days, and he received the aid-in-dying medications. With his family around him, he ingested the medicines and fell into a coma within 12 minutes. Although he had an unusually long time to death, he remained comfortable throughout. His family expressed relief that he was no longer in pain.

B. RC, a 78-year-old female with amyotrophic lateral sclerosis (ALS), was BiPap and feeding-tube dependent. Her physicians recommended hospice care, but she feared a slow death with uncontrolled air hunger and severe anxiety. She wanted a "quick option." RC contacted an Oregon aid-in-dying physician to discuss traveling there. She specifically stated that once she had the lethal medications, she would return to the comfort of her own home to die, with family and friends in attendance.

The Oregon physician was careful not to provide any advice about her specific medical condition. She explained that RC could not take the aid-in-dying medications at home, since by doing so she would put her loved ones at risk of prosecution for assisting a suicide, a felony in her state. Additionally, transport to Oregon while increasingly dependent on ventilatory support could be difficult and dangerous. The physician also discussed that, in general, hospice care for patients with severe respiratory compromise could include palliative sedation for a comfortable death. The patient was encouraged to speak with their local hospice about this and other options.

The patient's hospice arranged for inpatient palliative sedation. She chose a date and arranged for family and friends to be with her. She was heavily sedated by a morphine drip, the BiPap and oxygen turned off, and she died within an hour. Her family was grateful that her death was peaceful and that they were able to be with her.

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1. Medical Aid in Dying: Residency Restrictions. Compassion & Choices. Accessed September 5, 2023. https://www.compassionandchoices.org/legal-advocacy/residency-restrictions.
2. Medical Aid in Dying in Oregon and Vermont for Persons Residing outside of the State: What Patients Need to Know. Accessed September 2, 2023. https://tinyurl.com/mr3prhkr.
3. Ibid.
4. A Big Step Forward: Oregon Removes Residency Requirements. Death With Dignity. Published June 22, 2023. Accessed September 4, 2023. https://tinyurl.com/yxv64u74.
5. Patient Choices Vermont. Guidelines and checklists for non-residents of Vermont and their doctors. https://www.patientchoices.org/non-residents.html.
6. Out-of-State Death With Dignity. End of Life Choices Oregon. Accessed September 10, 2023. https://eolcoregon.org/out-of-state/.
7. For Non-Residents. Patient Choices Vermont. Accessed September 11, 2023. https://www.patientchoices.org/non-residents.html.
8. Assisted Suicide Laws in the United States. Patients Rights Council. Published January 6, 2017. Accessed September 9, 2023. https://www.patientsrightscouncil.org/site/assisted-suicide-state-laws/.
9. Blanke, C. Considerations for providing medical aid in dying care to non-residents. Telephone communication. September 5, 2023.
10. Out-of-State Death With Dignity. End of Life Choices Oregon. Accessed September 10, 2023. https://eolcoregon.org/out-of-state/.
11. For Non-Residents. Patient Choices Vermont. Accessed September 11, 2023. https://www.patientchoices.org/non-residents.html.
12. Oregon Medical Board: Telemedicine: Topics of Interest: State of Oregon. Accessed September 9, 2023. https://www.oregon.gov/omb/Topics-of-Interest/Pages/Telemedicine.aspx.
13. Blanke, C. Considerations for providing medical aid in dying care to non-residents. Telephone communication. September 5, 2023.
14. Parker, F.R., Rubin, H.W. and Winslade, W.J. Life insurance, living benefits, and physician-assisted death, *Behav Sci Law*. 2004;22(5):615–626. doi:10.1002/bsl.614.
15. Patient-to-Doctor Referral System–American Clinicians Academy on Medical Aid in Dying. Accessed September 3, 2023. https://www.acamaid.org/patientintake/.
16. Out-of-State Death With Dignity. End of Life Choices Oregon. Accessed September 10, 2023. https://eolcoregon.org/out-of-state/.
17. For Non-Residents. Patient Choices Vermont. Accessed September 11, 2023. https://www.patientchoices.org/non-residents.html.

QUALIFYING FOR AID IN DYING WITHOUT A DEFINITIVE DIAGNOSIS:

A CLINICIAN'S DILEMMA

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ABSTRACT: A 62-year-old female receiving inpatient care had a progressively worsening functional status. Diagnostic workup showed decompensated liver cirrhosis, with a concern for metastatic cancer. She decided to stop further evaluation and treatment and requested an aid-in-dying consultation. The patient was seen by a palliative medicine physician and an aid-in-dying evaluator, both of whom deemed her eligible for an assisted death. However, the attending hospitalist was uncomfortable with the assertion that she was eligible and requested an Ethics Committee consultation. This case study explores the ethical dilemma a physician can face when a patient lacks a definitive terminal diagnosis but appears to have a life expectancy of less than six months on clinical grounds.

KEYWORDS: Aid in dying, prognosis, medical ethics, Elizabeth Whitefield End-of-Life Options Act.

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1. INTRODUCTION

The Elizabeth Whitefield End-of-Life Options Act grants access to medical aid in dying for residents of New Mexico with a terminal illness—"a disease or condition that is incurable and irreversible and that, in accordance with reasonable medical judgment, will result in death within six months."[1] Other states and jurisdictions that allow aid in dying have very similar, if not identical, definitions of terminal illness.

However, defining terminal illness solely as a "disease" or "condition" can be misleading. Terminal illnesses may not be brought on by a single disease or condition but may result instead from the cumulative effects of multiple illnesses. When considered individually, these conditions might not be classified as terminal, but when assessed in the context of a patient's overall presentation and functional decline, it can reasonably be expected that they will die within six months. Lynn et. al stressed this concern and the need for better clarification on what constitutes a terminal illness. In their work, they defined three factors that should be considered: clinical condition, subjective judgment, and statistical prognosis.[2]

2. CASE PRESENTATION

A 62-year-old female with a past medical history of pancreatic adenocarcinoma, treated with chemotherapy and a Whipple procedure, subsequently developed a lung nodule. Biopsy revealed a mucinous adenocarcinoma of gastroesophageal, pancreatic, or bronchogenic origin. She was treated with radiation and later presented to our hospital with confusion, melena, and black emesis. She'd had three hospitalizations prior to this admission for: a syncopal episode of unknown cause; a pulmonary embolism; and painless jaundice, weight gain, and edema. She received an extensive workup for hyperbilirubinemia and mixed transaminitis, without a clear etiology. In addition, she reported persistent weakness, worsening appetite, and difficulty caring for herself. She lived alone at home.

Diagnostic evaluation during this hospitalization included an esophagogastroduodenoscopy that identified non-bleeding ulcers near the gastrojejunal anastomosis. CT scans of the chest, abdomen, and pelvis showed multiple new bilateral pulmonary nodules, pulmonary interstitial edema, moderate pleural effusions, subtle nodularity throughout the abdominal mesentery, small volume ascites, and body wall edema. Her CA19-9 level was elevated to 78. Additionally, she had hyperbilirubinemia, high transaminase levels, and evidence of decompensated cirrhosis. The overall concern of her care team was metastatic cancer.

During this hospitalization, the patient's functional status declined. Her Palliative Performance Scale was reported in the palliative medicine notes as having decreased from 50% to 20–40%. She could not get out of bed unless assisted by another person or sit on the edge of the bed for longer than a few minutes. Oral intake was limited, consuming less than 500 mL per day. She required oxygen, likely due to progressively worsening pulmonary edema and pleural effusions, for which she declined diuresis or thoracentesis.

3. AID-IN-DYING REQUEST

Confronted with these concerning findings for metastatic cancer and her deteriorating condition, the patient declined further diagnostic workup and treatment. She transitioned to comfort care in the hospital and requested an aid-in-dying evaluation. The attending hospitalist consulted palliative medicine to assist with goals of care conversations. The palliative medicine physician subsequently consulted an aid-in-dying evaluator. They both deemed the patient eligible for aid in dying.

4. ETHICAL DILEMMA

This patient's decision posed a moral and ethical dilemma for the attending hospitalist, who expressed discomfort and uncertainty regarding the appropriateness of aid in dying in this case. The hospitalist's concerns revolved around specific terminology within the End-of-Life Options Act—given the patient's absence of a clearly defined terminal illness with a life expectancy of less than six months. Since the Act also requires the disease to be "incurable and irreversible," the hospitalist felt that the patient's prognosis might be different should she be diagnosed and treated. Consequently, the attending hospitalist referred the situation to the hospital's Ethics Committee. A meeting was attended by the ethicist, attending hospitalist, hospitalist resident, palliative medicine physician, palliative medicine fellow, and the aid-in-dying evaluator.

5. DISCUSSION

Considering the imaging evidence of potential metastatic cancer with increased size of pulmonary nodules and peritoneal nodularity suggestive of peritoneal carcinomatosis, elevated CA19-9 level, the patient's declining functional status, and decompensated cirrhosis, the aid-in-dying evaluator and palliative medicine provider decided she met the eligibility criteria for an assisted death, as her life expectancy was anticipated to be less than six months.

In contrast, the ethicist and attending hospitalist expressed their discomfort that her prognosis could not be accurately made without more clinical information and diagnostic evaluations. The attending hospitalist raised concerns based on the law's definition of "terminal illness," which states "disease or condition." He contended that the patient did not meet these definitions, as she lacked biopsy-proven metastatic cancer and her liver cirrhosis could be managed with medical treatment. Given the uncertainty and lack of a clearly defined terminal illness, he felt the prognosis could not be accurately determined.

Prognostication is a common and essential part of patient care. Despite this, many physicians feel uncomfortable with establishing prognoses, which is not an emphasized skill in medical training or published literature. Predicting life expectancy is more difficult in a situation like this case history in which there is no definitive diagnosis, even while significant functional decline indicates a life expectancy of less than six months. To qualify for aid in dying or hospice, a formal terminal diagnosis is not required. Medicare's eligibility criteria for hospice care does not require a known prognosis or a terminal diagnosis, but rather states that it is for "any Medicare beneficiary whose current clinical status and anticipated progression of disease is more likely than not to result in a life expectancy of six months or less."[3]

A clearly defined terminal illness helps us to understand the likely trajectory in which a patient would be expected to decline and helps to guide communication between the patient and provider regarding their prognosis.[4] But a well-defined illness or specific diagnosis is not required to establish a prognosis for a seriously ill patient and, when appropriate, to qualify a patient for aid in dying. The patient in this case history had a series of medical conditions that resulted in rapid deterioration in her functional status, quality of life, and worsening symptoms—all negative prognostic indicators. Based on clinical predictions of survival (including her change in functional status and a high clinical suspicion of widely metastatic cancer) and the Palliative Performance Scale, an often-used prognostic indicator, this patient was determined to have a life expectancy of less than six months.

A patient can be expected to have a shortened life if they present with any combination of the following symptoms: cognitive decline, confusion, anorexia, dysphagia, dyspnea, infections, falls, or the most important clinical finding of declining performance status.[5] Because measures of functional status predict mortality "more strongly" than disease risk markers in older adults, the clinical picture, prognostic assessment tools, and a thorough review of the patient's medical history can be sufficient to determine eligibility for aid in dying.[6]

Palliative care providers routinely employ global assessment tools to help determine a patient's prognosis. In this case, the palliative medicine physician used the Palliative Performance Scale, a non-disease-specific prognostic tool. This scale is a modified version of the Karnofsky Performance Scale and evaluates five functional areas: self-care, oral intake, ambulation, activity level and evidence of disease, and level of consciousness.[7] Lower scores are associated with shorter survival times. However, though it is important to include global assessment tools when prognosticating, these tools have not been demonstrated to be superior to clinical predictions of survival alone. The literature acknowledges the importance of including prognostic algorithms because they are more objective and reproducible than clinical predictions and are good teaching tools.[8] Most clinicians use a combination of global assessment tools and clinical prediction to make the most informed prognosis possible.

In addition to the above concerns about prognosis, the ethicist and the attending hospitalist also expressed their discomfort with the concept of a patient's ability to qualify for aid in dying while declining further workup and treatment. The attending hospitalist stated that further evaluation and potential treatment might alter the patient's prognosis, challenging the criteria of "incurable and irreversible." If she were found to have, for example, a specific cancer, could she not receive treatment and therefore not have an "incurable or irreversible" illness?

The debate surrounding a patient's legal right to stop treatment and still qualify for aid in dying echoes historical cases like Quinlan and Finn, both of which posed moral and ethical debates related to the decision to withdraw life-preserving measures.[9] This raises questions about patient autonomy and the responsibility of health care providers in end-of-life decisions. But there are clear answers. Even if the medical team believes further evaluation and treatment are the *right* course for this patient, the patient's right to refuse such treatment is fundamental. If a patient declines intervention, whether diagnostic workup, surgical treatments, medications, or nutrition, and it effectively shortens their lifespan, they then have a shorter prognosis. Prognosis is determined by the clinical context of the patient's decided course, not a potential course that they do not choose.

6. FOLLOW UP

At the conclusion of the ethics meeting, the ethicist recommended the hospital not interfere with the patient's decision to pursue an assisted death. The patient was discharged from the hospital and accepted for care by a local hospice. She successfully ingested the aid-in-dying medications and had a peaceful death.

In medicine, it can be uncomfortable to care for patients who fall in a potentially gray area when the stakes are so high. Each provider is encouraged to use the tools available to them to the best of their ability, and make decisions within their own ethical and clinical framework.

This case highlights crucial concepts that should be considered when evaluating whether a patient qualifies for aid in dying. It is important to recognize that a patient does not need a single, clearly defined or diagnosed terminal illness to qualify for an assisted death. Patients with obvious evidence of functional decline leading to an estimated life expectancy of less than six months, which has been determined using prognostic tools and clinical judgment, can qualify for aid in dying. It would be helpful to clinicians if legislative language about prognosis were (by amendments to present laws or in new laws) to provide a more precise definition of "terminal illness." This language would ideally clarify that prognosis may be determined with a specific disease/diagnosis, but in the absence of this information, clinical predictions with support from global assessment tools are within the standard of care.

PATIENT CONSENT:

Verbal and written consent was obtained for this case to be published by the patient's brother.

1. House Bill 47- End of life Options Act. 55th Legislature–State of New Mexico.
2. Lynn J, Harrell FE, Cohn F, Hamel M, Dawson N, Wu AW. Defining the "terminally ill." *Duquesne Law Rev*. 1996;35(1):311–336.
3. Medicare Prognostic Guidelines for hospice care: https://tinyurl.com/34tbzvth.
4. Chu C, White N, Stone P. Prognostication in palliative care. *Clin Med (Lond)*. 2019;19(4):306-310. doi:10.7861/clinmedicine.19-4-306.
5. Lau F, Cloutier-Fisher D, Kuziemsky C, et al. A systematic review of prognostic tools for estimating survival time in palliative care. *J Palliat Care*. 2007;23(2):93-112.
6. Cheong CY, Yap P, Gwee X, et al. Physical and functional measures predicting long-term mortality in community-dwelling older adults: a comparative evaluation in the Singapore Longitudinal Ageing Study. *Aging (Albany NY)*. 2021;13(23):25038-25054. doi:10.18632/aging.203756.
7. Baik D, Russell D, Jordan L, Dooley F, Bowles KH, Masterson Creber RM. Using the Palliative Performance Scale to estimate survival for patients at the end of life: a systematic review of the literature. *J Palliat Med*. 2018;21(11):1651-1661. doi:10.1089/jpm.2018.0141.
8. Stone P, Vickerstaff V, Kalpakidou A, et al. Prognostic tools or clinical predictions: which are better in palliative care? [published correction appears in PLoS One. 2021 May 11;16(5):e0251757]. *PLoS One*. 2021;16(4):e0249763. Published 2021 Apr 28. doi:10.1371/journal.pone.0249763.
9. Ball, H. *The Right to Die*. Bloomsbury Publishing; 2017.

MERCY

STEWART FLORSHEIM

When I hand our client the life-ending medication
and tell him he can still change his mind, but
once he takes it there will be no turning back,
he chugs down the four ounces of liquid
and smiles, his revenge against
a body that betrayed him with prostate cancer,
the stabbing pain in his bones,
the quick march to his brain. He even
grabs his Gatorade and puts a few ounces
into the bottle where the medication was,
swirls it around and chugs that as well.
Good to the last drop, he says.

He starts to ramble with an urgency. It's about
his favorite authors—John Steinbeck for one—
the way he captured human desperation
in his novels, like *Of Mice and Men*.
He points to his books in the Assisted Living room
hospice moved him into the week before—
the apartment where he was living, alone,
so dirty and cluttered with old furniture, books,
paperwork, outdated computer equipment,
the nurse had a hard time getting to his bedroom.
He wants to make sure I take his books,
so they're not tossed away with his belongings.

He begins to fall asleep, mumbling
about Steinbeck and the books he wrote.
Perhaps he's sinking into a dream
about Lennie in *Of Mice and Men*—
the way his best friend, George, saves him.

STEWART FLORSHEIM is Vice President of the Board of Directors of End of Life Choices California. He is the author of five books of poetry.

HOSPICE POLICIES ON MEDICAL AID IN DYING:

CURRENT PRACTICES AND RECENT PROGRESS

RICHARD WIDTH, RN
THALIA DEWOLF, RN, CHPN

ABSTRACT: Hospice aid-in-dying policies vary widely, from strict non-support to full participation, and everything in between. Guidelines governing the actions of frontline staff have been controversial, with recent publications on the topic by ethicists and professional nursing organizations. Part 1 of this article focuses on how hospice nurse aid-in-dying activities are sometimes limited by their organizations' protocols. It examines the origins of hospice rules and their associated philosophies and concerns.

In part 2, a hospice nurse working within the limitations of her agency's aid-in-dying restrictions worked with her organization to update their policies to better coincide with evolving best practices. The author describes the challenging but effective processes that led to improved and less stigmatized aid-in-dying care.

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PART ONE

1. BACKGROUND

Hospice care and the number of patients accessing aid in dying have both been rising annually—leading to complex clinical interactions and policy formulations.[1,2] Hospice use has grown sixfold over the last two decades and 22% of the U.S. population now lives in a state with legal access to aid in dying.[3,4] Increasingly, terminally ill patients considering aid in dying are simultaneously receiving hospice care—so these populations, long assigned to separate, disparate silos, now overlap.[5,6] In 2022 in California, 95.4% of patients who ingested aid-in-dying medications were concurrently enrolled in hospice or palliative care.[7] As these trends intersect, hospice policymakers have been pressed to consider how best to coordinate and/or integrate aid-in-dying care with their organizations' guidelines.

Initial policies and procedures were drafted soon after each state's aid-in-dying law passed—and before widespread clinical experience and best practices had developed. These policies now require thoughtful updates that consider current and evolving clinical expertise. The hospice and aid-in-dying crossroads opens a door to innovation, integrating hospice and aid-in-dying components to provide exceptional end-of-life care.

Hospices focus specifically on the "comfort, and quality of life of a person with a serious illness who is approaching the end of life."[8] This *ideally* translates into providing attentive palliative care throughout a patient's dying process, to their very last breath—no matter how they die. As the founder of modern hospice care Cicely Saunders said, "You matter to the last moments of your life."[9]

For almost 50 years in the U.S.,[10] hospice has set a gold standard, providing cost savings while skillfully delivering services and education to dying patients and their caregivers.[11] Currently, hospice is 100% covered by Medicare for most patients, by Medicaid for some, or by private insurance.[12] Out-of-pocket expenses for the patient or family are exceedingly rare. Yet terminally ill hospice patients who are considering aid in dying are commonly advised that the medications, procedures, and clinical care cannot be covered by Medicare, requiring an out-of-pocket expense (including hiring non-hospice physicians and other clinicians). Hospice aid-in-dying policies originated and continue to evolve, in significant part, based on this interpretation of Medicare coverage.

That said, most hospices in aid-in-dying jurisdictions across the country have conscientiously endeavored to craft balanced programs of attentive support that include patients considering aid in dying, while also complying with Medicare reimbursement rules.

Simultaneously, hospices must consider concerns about market optics and perceived legal risks. So integrating a hospice's organizational needs with the complexities of aid-in-dying care has proven to be a tumultuous process, resulting in a wide range of policies. Some of these guidelines have led to improvements in hospice aid-in-dying support. Sadly, other policies have proven to be detrimental to hospice patients' autonomous goals. Overall, as best clinical practices have evolved, the trend has leaned toward improved care for patients considering aid in dying.

2. DISCUSSION

1. A false dichotomy

Hospice administrators, risk-management staff, and legal advisors often design their aid-in-dying policies based on the simplified dichotomous choice of "opting in" or "opting out." This originated with the language of aid-in-dying laws. For example, California's End of Life Option Act states, "Participation… is completely voluntary. A person, hospital, pharmacy or other entity…is not required to take any action in support of an individual's decision under this law."[13] This legislative focus on the right of clinicians or organizations to opt out of aid-in-dying care understandably wound its way into hospice policy manuals.

But this opt-in/opt-out dichotomy overly simplifies the complexities of caring for hospice patients considering aid in dying. These patients, even if they find themselves in opted-out hospices, need and deserve full end-of-life palliative care. Attempts at cleaving aid-in-dying care from other hospice services have often failed spectacularly. Various sources have documented cases in which hospices discharged patients on their aid-in-dying day, causing harm to families who were forced to contend with preparing and managing their loved one's death entirely on their own, and to patients who were left without care at this most vulnerable moment.[14] Hospice nurses have been ethically traumatized, and in some cases fired, for staying at a patient's bedside during the aid-in-dying medication ingestion, choosing patient needs over hospice opt-out policies.[15]

Hospice aid-in-dying protocols have often been written by administrators and legal consultants soon after a legislature's bill passed. Understandably, since the new medical practice was initiated by a law, policies were viewed in terms of legal protections rather than clinical care. This resulted in skewed, overly cautious language, as much designed to avoid low-probability perceived risks as known legal prosecutions. Undoubtedly contributing to the cautious tone of hospice guidelines was the fact that aid-in-dying laws list potential felony violations if presumed safeguards and protections aren't followed. It is important to note,

though, that no criminal litigation against a provider of aid in dying—individual or institutional—has ever been brought forth in the U.S. for actions taken under a state's aid-in-dying law. (Jack Kevorkian might be considered an exception, but he was convicted of murder for acts committed before any aid-in-dying laws were in effect. In addition, Kevorkian's actions exceeded the bounds of all aid-in-dying laws now in existence.)

A more careful reading of aid-in-dying laws reveals no language that prohibits, for example, a nurse being in the room during the ingestion of aid-in-dying medications, or discussing medically assisted dying if the patient does not specifically bring it up. Yet many hospices, in an abundance of caution, prohibit their nurses from those and other acts. Clinical staff have been silenced by "don't ask, don't tell" hospice policies that prohibit them from "initiating the conversation." But few patients use specific language, such as "I want medical aid in dying." They are often denied, by hospice restrictions, a conversation about their legal option if they merely say, for example, "I'm ready to die, I'm finished."

Patients and families have been taken aback when they learn that their hospice prohibits nurses from mixing and managing extremely dangerous aid-in-dying medications, so they must do this on their own. They are further distressed when advised that their nurse must leave the room during the ingestion—the moment of deepest patient and family anxiety. When asked by the authors why they leave the room, many hospice nurses replied that it is illegal to stay. Yet no such legal prohibition exists. Asked the same question, one patient responded, "You mean my hospice nurse will abandon me at my last moment? Am I doing something shameful?" While a nurse leaving the room may seem a brief, innocuous act, it can leave the patient and family feeling stigmatized and abandoned.[15] Since there is no legal mandate for a nurse to leave the room at any time during the aid-in-dying process, hospices must reconsider these policies, which potentially harm their staff and patients.

A broad survey of nurses found that 86% would be willing to care for a patient considering aid in dying. But 84% reported they lack the education or experience to do so. The study also showed "fear among nurses of disciplinary action"—further inhibiting attentive nursing care for patients considering aid in dying.[16]

2. Financial considerations

Medicare financial concerns drive hospice aid-in-dying policies as much as, if not more so, than the legal and ethical issues discussed above. These are mostly centered on a 1997 federal law (just after Oregon was the first to implement medical aid in dying in the U.S.)—the Assisted Suicide Funding Restriction Act (ASFRA).[17] This law prohibits federal funding "for the purpose of causing, or for the purpose of assisting in causing, the death of any individual, such as by assisted suicide." Since Medicare is a federal agency, and it pays for most hospice care on a per diem basis, hospice administrators, billers, and legal counsel often conclude that hospices cannot participate in aid in dying while on the Medicare dime. If they do, they risk investigation, possible sanctions, and even the disastrous loss of Medicare funding.

Interpretations of the Assisted Suicide Funding Restrictions Act—and subsequent Medicare policies and analyses—vary widely. Several hospices in multiple states provide complete aid-in-dying services, including attending/prescribing clinicians and nurses who are fully involved in the assisted dying process. Unsurprisingly, these hospices are reluctant to publicly discuss how they do or do not bill Medicare for such services. But in private conversations with the authors, they state that their aid-in-dying time so tightly overlaps with simultaneous palliative care

“SOME HOSPICES HAVE CITED CONCERNS ABOUT THE POTENTIAL OPTICS OF PROVIDING AID-IN-DYING CARE.”

of end-of-life symptoms that it is reasonable to bill Medicare for the entire days of attention. Other full aid-in-dying service hospices do not bill Medicare for the day of death itself, but do bill for all preceding days. Others have decided they can provide (and bill for) some palliative symptom management that overlaps with aid-in-dying care, but not aid-in-dying specific events—and they “carve out” these activities (discussing the medications, attending the deaths, etc). Some hospices strictly interpret the funding-restrictions act to constitute a ban on all aid-in-dying care, even discussing it with their patients.

These clinical barriers have forced many patients considering aid in dying to pay out of pocket for that option. Though providers may slide their fees down if needed, this financial burden (including the cost of the medications), poses a barrier for patients with limited resources.[18]

The role that potential Medicare restrictions plays in hospice aid-in-dying policies continues to evolve. In this edition of the *Journal of Aid-in-Dying Medicine*,[19] Kevin Malone offers a novel but complex analysis in which he argues that the more restrictive interpretations are “legally questionable” while creating ethical dilemmas for hospices, patients, and their loved ones.[20] Malone argues that the Center for Medicare Services (CMS) itself does not interpret the law as restrictively as hospices do.

Unquestionably, the debate about hospice aid-in-dying policies and Medicare billing will continue for some time, both openly and in under-the-radar discussions. The path to resolution, if any, is yet to be seen. But it is undeniable that patients considering aid in dying suffer from the dilemma.

3. Appearances and marketing

Some hospices have cited concerns about the potential optics of providing aid-in-dying care. Despite an ingrained belief in patients’ autonomous rights to make decisions about their remaining days, these hospices fear that “death mill” labels will decrease the number of patients selecting their organization. Hospice services and facilities, they argue, are already erroneously viewed as the place you go to die, so participating in aid in dying might amplify that perception. Yet public polling has persistently shown that more than two thirds of respondents favor the legal right to a medically assisted death.

A national Gallup poll found that "72% say doctors should be able to help terminally ill patients die."[21] Individual hospices, then, are as likely to gain admissions if they provide aid-in-dying care as they are to lose them due to image issues.

Yet when, in 2022, California's Senate Bill 380 legally compelled hospices to publicly post their aid-in-dying policies—reasoning that patients have the right to know—most hospices either failed to follow through or posted hidden or such minimal information as to betray the letter or spirit of the law. Some 60% of California hospices have not posted their policies.[22] Those who have, in an effort to appear "neutral," often utilized veiled language, further obfuscating the public's ability to obtain useful details. Some hospices, though, are specifically noting the degree of their participation, most commonly if they are providing aid-in-dying services along with their full hospice benefits. It is unknown whether marketing forces are bringing patients to these organizations. An ethical argument can be made, however, that obtaining thorough and accurate information is a patient's right before they select a hospice for their end-of-life care. Stories abound of patients considering aid in dying who find out only after they are admitted to a hospice that it doesn't support that choice. This leads either to abandonment of the option, paying for outside aid-in-dying support, or the indignity and difficulty of transferring care to another hospice even as they approach death. To avoid such lack of information and follow the law, hospices can use guidelines of the specifics they should publicly post about their aid-in-dying policies.[23]

3. CONCLUSION

Evidence-based policymaking has improved health outcomes across the world for decades and is most effective when input is gathered from a cross-section of stakeholders.[24] Aid-in-dying guidelines have traditionally been written by administrators, risk management personnel, and legal consultants—without input from experienced bedside clinicians, including nurses. These policies, therefore, have failed to foster best clinical practices.

When health care agencies encourage shared governance, clinically successful policies can be developed to protect staff by adhering to laws and regulations, address the real-time health care needs of patients, and generate staff buy-in as practices evolve.[25] Nurses have been "central to the inception and development of hospice care in the United States."[26] Yet they are consistently seen as "policy implementers, not policy developers."[27] Hospice nurses should now play an essential role in developing and revising aid-in-dying hospice policies.

PART TWO

ONE HOSPICE'S AID-IN-DYING POLICY EVOLUTION

PAMELA BROWN, RN

When Montana's highest court legalized aid in dying in 2009, hospices scrambled to develop policies to accommodate an entirely new and unfamiliar right for terminally ill patients. Only two states, Oregon and Washington, had passed similar laws—so there was little precedent. The hospice where I cared for my first five aid-in-dying patients crafted a cautious hands-off policy, which was understandable given how new the practice was. But that restraint was also a result of the policy being written with minimal input from nurses or other hands-on clinical staff. Administrators tend to favor caution over risk, so somehow our hospice's policy implied support for the concept of aid in dying, while at the same time prohibiting clinical staff from responding to the needs of patients who were considering aid in dying.

At the bedside, I saw patients and families construe such yes-but-with-limits policies as amplifying stigma, leaving them to wonder if the hospice and its clinicians truly supported their autonomy.

For example, the hospice had a "leave the room" policy. A review of this requirement was recently published in the American Journal of Nursing, *Hospice Nurse Ethics and Institutional Policies Toward Medical Aid in Dying.*[28] The article asks two essential questions: "Is it ethically supportable for a hospice to require that staff leave the room while a patient ingests aid-in-dying medications? Does this requirement violate the nurse's professional commitment to not abandon the patient and family?"

The authors concluded that "an institutional policy requiring nurses to leave the room during the ingestion of aid-in-dying medications is ethically unsupportable because it risks violating professional nursing standards, reinforces stigma...and potentially abandons patients and loved ones at a critical time in their passage toward a desired and legal death."

For me, these questions were not hypothetical, since my previous agency required me to leave the room for the ingestion. One young husband of an ALS patient was severely sleep deprived and so distraught by his wife's suffering that I was appalled by the idea of leaving the room. That felt like, and it was, ethically wrong.

I knew that The American Nurses Association's 2019 position statement on a nurse's role in aid in dying[29] supported my thoughts and feelings.

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It directed nurses to never "abandon or refuse to provide comfort and safety measures to [a] patient" who has chosen medical aid in dying. It also concluded that nurses' presence at ingestion is "consistent with the Code of Ethics for Nurses [and] includes sensitivity to the patient's vulnerability, demonstration of care and compassion, and promotion of comfort to sustain trust." It is clear to me that my full presence on the aid-in-dying day embodies the foundational principles of non-abandonment, continuity of care, compassionate care, and the duty to provide relief from pain and suffering.

Agency policy also prohibited me from mixing the aid-in-dying medications, turning powders into a swallowable slurry. All hospices have policies for working safely with high-risk medications—especially opiates for pain control—due to legal restrictions, potential for abuse, and possible lethality if used incorrectly. It struck me as highly inconsistent that a hospice concerned with patient and family safety would prevent me from mixing aid-in-dying medications, compelling inexperienced, non-professional family members to work with these dangerous drugs during a time of severe stress and anxiety. Family efforts should go toward quality time with their dying loved one, not toward work as pharmaceutical technicians. I took care of a patient whose spouse and multiple young children were present for their father's aid in dying. Forcing a young mother with several school-age children in the room to mix her husband's terminal medications left me with a bitter memory I will never forget.

My hope for change with hospice aid-in-dying policies intensified soon after I attended the 2023 National Clinician's Conference on Medical Aid in Dying.[30] Significantly, two leaders from my new hospice—Eden Hospice in Montana[31]— also came, stayed, and learned. I realized that effecting change might be more likely if I didn't just tell the hospice managers what to do, but saw it as a joint project. So I took the current policy and amended it to include support for physicians and nurses to mix aid-in-dying medications, and to remain by the bedside if the patient and family so desired.

I also moved the section allowing any clinicians to decline to participate in aid in dying to a more prominent position—but with an important proviso: that patients requesting information would be referred to a hospice clinician willing to evaluate their request and, if appropriate, provide information and aid-in-dying care.

I sent off the proposed policy to Eden Hospice's leadership, confident it would at least get a fair hearing and open a conversation. Our director of clinical operations responded: "For me, things changed after I heard the stories of struggles the family members went through. If our nurses can help ease that for patients and their loved ones, our policy should support them."

My agency's leaders recognized the value of aligning aid-in-dying care with our commitment to patient autonomy, dignity, and comfort. Within weeks of my specific proposals, they instituted a new nursing policy. Further discussions led to an agreement that allowed our doctors to provide aid-in-dying care, which included evaluations and, when appropriate, prescribing aid-in-dying medications.

I recently asked that same young mother with children how her husband's choice for aid in dying had affected her grief journey. She answered immediately, "Oh! It helped me, it helped us." When I told her that now I could mix the meds and stay in the room, I suddenly heard her choke up. "That's amazing!" she said when she found her voice again.

I propose a recipe for institutional change:

- Do not assume your leadership is close-minded.
- Go ahead and "make the ask," while providing practical help.
- Don't rely on leadership to do it all themselves.
- Strongly encourage leadership to empower bedside staff to participate in policy formation.
- Rely on the professionalism and comity of the aid-in-dying community; we educate each other.
- Thank your leadership for their time and consideration.
- Thank them again when you can provide aid-in-dying care in a safe, ethical, and deeply compassionate manner.

1. HealthData.gov. Centers for Medicare and Medicaid Services, Program Statistics — Medicare Hospice. https://tinyurl.com/35a8b4nm.
2. Kozlov, E, Nowels, M, Gusmano, M, Habib, M, Deberstein, P. Aggregating 23 years of data on medical aid in dying in the United States. *Journal of the American Geriatrics Society*. 2022;70(10):3040-3044. DOI: https://doi.org/10.1111/jgs.17925.
3. Patel, M, Nicolla, J, Friedman, F, Ritz, M, Kamal, A. Hospice use among patients with cancer: trends, barriers, and future directions. *JCO Oncology Practice*. 2020;16(12):803-809. DOI:10.1200/OP.20.00309.
4. Compassion & Choices, Medical Aid-in-Dying Utilization Report. https://tinyurl.com/bde7au2r.
5. California Department of Public Health, California End of Life Option Act 2022 Data Report. https://tinyurl.com/535drcuf.
6. Oregon Health Authority, Public Health Division. Oregon Death with Dignity Act 2022 Data Summary https://tinyurl.com/23yd97a8.
7. California Department of Public Health, California End of Life Option Act 2022 Data Report. https://tinyurl.com/535drcuf.
8. National Institute on Aging. What Are Palliative Care and Hospice Care? https://tinyurl.com/chvdrhk2.
9. Saunders, C, Baines, M, Dunlop, R. *Living with Dying: A Guide for Palliative Care*. Oxford Medical Publications, Third Edition. ISBN: 9780192625144 https://tinyurl.com/mtnkx3jh.
10. National Hospice and Palliative Care Organization (NHPCO), History of Hospice. https://tinyurl.com/4rmaar4f.
11. Kelley, A, Deb, P, Du, Q, Aldridge-Carlson, M, Morrison, S. Hospice enrollment saves money for medicare and improves care quality across a number of different lengths-of-stay. *Health Affairs*. 2013;32(3). https://doi.org/10.1377/hlthaff.2012.0851.
12. Institute on Aging. Who pays for hospice care at home in California? Accessed October 20, 2023. https://tinyurl.com/mr3ykkry.
13. California Legislative Information. Assembly Bill No. 15. End of Life Option Act. https://tinyurl.com/2hzf438u.
14. Kerwin, J, Vieira, Y. Patient discharge from hospice services for pursuing medical aid in dying. American Clinicians Academy on Medical Aid in Dying, Ethics Consultation Service. Patient Discharge from Hospice Services for Pursuing Medical Aid in Dying. October 13, 2022. https://tinyurl.com/43wp65xb.
15. Abbott, J, Kerwin, J, Holden, C, Battin, M, Cederquist, L, Miller, C, Pope, T. Navigating conflict between professional nursing commitments to patients and institutional "leave the room" policies. American Clinicians Academy on Medical Aid in Dying, Ethics Consultation Service. January 4, 2022. https://tinyurl.com/3j37699y.
16. Davidson, J, et al. Nurses' values and perspectives on medical aid in dying: a survey of nurses in the United States. *Journal of Hospice and Palliative Nursing*. 2022 Feb 1;24(1):5-14. DOI: 10.1097/NJH.0000000000000820.
17. United States Congress. Public Law 105-12. To clarify federal law with respect to restricting the use of federal funds in support of assisted suicide. April 30, 1997. https://www.congress.gov/105/plaws/publ12/PLAW-105publ12.pdf.

18. Buchbinder, M. Access to aid-in-dying in the United States: shifting the debate from rights to justice. *Am J Public Health*. 2018 Jun;108(6):754-759. doi: 10.2105/AJPH.2018.304352.
19. Journal of Aid in Dying Medicine. https://www.acamaid.org/journal/.
20. Malone, K, Walters, W. Assisted Suicide Funding Restrictions Act: a pathway to compliance for hospices. Journal of Aid-in-Dying Medicine. 2023;1 (1):10-19.
21. Brenan, M. Americans' strong support for euthanasia persists. Gallup. May 31, 2018. https://tinyurl.com/5bebkfsp.
22. Strand, G, Sobeck, K. Hospice Transparency with medical aid-in-dyng policy. The Completed Life Initiative. 2023. https://tinyurl.com/yxse3w97.
23. Recommendations for the Posting of Policies that Describe a Health Organization's Aid-in-Dying Services as Required by California SB380. American Clinicians on Medical Aid in Dying. Accessed October 22, 2023. https://tinyurl.com/53xmm333.
24. Chhetri, D, Zacarias, F. Advocacy for evidence-based policy-making in public health: experiences and the way forward. Sage Journals. 2021;23(1). https://doi.org/10.1177/0972063421994.
25. French-Bravo, M, Crow, G. Shared governance: The role of buy-in in bringing about change. *The Online Journal of Issues in Nursing*. 2015;20(2). https://doi.org/10.3912/OJIN.Vol20No02PPT02
26. Buck, J. 'I am willing to take the risk': politics, policy and the translation of the hospice ideal. *Journal of Clinical Nursing*. 2009;18(19):2700-2709. https://doi.org/10.1111/j.1365-2702.2009.02890.x.
27. Rasheed, S, Younas, A, Mehdi, F. Challenges, extent of involvement, and the impact of nurses' involvement in politics and policy making in the last two decades: an integrative review. *J Nurs Scholarsh*. 2020 Jul;52(4):446-455. doi: 10.1111/jnu.12567.
28. Abbot, J, Kerwin, J, Holden, C, Battin, M, Miller, C, Pope, T. Hospice nurse ethics and institutional policies toward medical aid in dying. *AM J Nurs*. 2023;123(6):37-43. doi: 10.1097/01.NAJ.0000938728.13124.c3.
29. American Nurses Association. Policy statement: the nurse's role when a patient requests medical aid in dying. 2019. ANA Center for Ethics and Human Rights. https://tinyurl.com/5ae4rv6a.
30. American Clinicians Academy on Medical Aid in Dying. National Clinicians Conference on Medical Aid in Dying. Accessed October 22, 2023. https://www.nccmaid.org.
31. Eden Health. Eden hospice of Western Montana. Accessed October 22, 2023. https://www.eden-health.com/Locations/eden-hospice-western-montana/.

THE ROLE OF DOULAS IN AID-IN-DYING CARE:

AN OVERVIEW AND SUGGESTIONS FOR BEST PRACTICES

SARAH HILL

ABSTRACT: Many end-of-life doulas offer support to individuals who are considering, or elect to utilize, medical aid in dying. Doulas and medical clinicians share a common goal of providing the best possible experience for their mutual clients. Working in tandem, they serve this goal with frequent communication, knowledgeable monitoring of symptoms and disease progression, and thoughtful planning before, during, and—for loved ones—after the aid-in-dying day. Doulas aim to provide a patient-centered experience that is seamless and responsive to the needs of patients and those who care for them. The aid-in-dying medical community writ large can enhance patient stewardship by including aid-in-dying-trained end-of-life doulas as part of the care team.

KEYWORDS: End-of-life doulas; aid in dying; hastened death; physician assisted death

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1. INTRODUCTION

End-of-life doulas provide companionship, comfort, and guidance to those facing a terminal illness or death. Their non-medical support encompasses emotional, spiritual, and practical care. Doulas pull the circle of care surrounding a dying person closer together. This circle includes family, caregivers, friends, and the medical team.

Despite the rugged independence and self-reliance that can typify U.S. culture, death invites us to consider an alternative: interdependence and community. This is a core tenet of doula work. That said, we are fervent supporters of self-determination—we believe deeply in our clients' abilities to make choices that are right for them at the end of their lives.

Since the early days of medical aid in dying, families have called end-of-life doulas for help when they realized they would be without knowledgeable and caring support on the day of ingestion. Loved ones had to prepare the aid-in-dying medications under the most anxiety-producing circumstances and in many cases had to "go it alone."

This seemed, at best, incongruent with the doulas' approach, which emphasizes connection, support, empathy, and interdependence. At worst, "going it alone" was fraught with the potential to cause emotional and/or physical injury. In much the same way that Dame Cicely Saunders, founder of modern hospice principles, prioritized addressing a patient's total pain,[1] doulas sought in the aid-in-dying circumstance to prioritize the holistic well-being (psychological, social, spiritual, and practical) of those seeking support.

As aid in dying is a specific practice, doulas had to "skill up" to work with clients considering a hastened death, providing support in accordance with the law, with safety protocols in place, all while operating in alignment with our core doula principles.

In addition, to best serve clients navigating the medical system, doulas have forged connections with attending/prescribing physicians and palliative care and hospice teams. We've learned to be liaisons for their patients, our clients. Because of the frequency of their visits and their proximity, doulas can monitor patients' changing physiology as it pertains to the aid-in-dying Red Flag Checklist. Of note, though: it is not in the realm of doula practice to interpret the clinical aspects of the patient's status and care but rather to communicate observations to the medical personnel who can. Aid-in-dying-trained end-of-life doulas can be an essential part of the support team by helping with thoughtful planning for the days before and during the ingestion and by tending to the body, mind, heart, and spirit of their clients. Doulas also help prepare family and loved ones for details of grief that can be unique to aid in dying. In short, doulas and medical teams share the common goal of providing the best possible experiences for their clients.

2. HOW CAN MEDICAL TEAMS WORK BEST WITH AID-IN-DYING-EXPERIENCED END-OF-LIFE DOULAS?

Engage doulas as early as possible. They do their best work when time is on their side. Medical teams should help doulas work with patients as they contemplate aid in dying not just call in a doula to attend the day of death. The further upstream doulas are brought in, the better their care—leading advanced planning conversations and providing education about multiple end-of-life options. Doulas support their clients through all end-of-life processes (it's not just about logistics and paperwork!), but only if they're looped in early.

Doulas should not be perceived as the "people who help mix the medications." They are the least effective when they arrive as unknown strangers rather than as welcomed guests. To provide a safe place for fears and emotions to emerge and be processed, doulas rely on extended relationships with the patients and their constellation of care. This enables greater connection and understanding between all involved in the months, weeks, and days leading to the aid-in-dying day (when the doula's role is helpful whether or not the ingestion occurs).

For patients who have already qualified for medical aid in dying, doulas provide an extra and much-needed layer of knowledge about everything from the complexities of picking a date to the intricacies of the procedure itself. Often, patients cannot absorb the overwhelming number of instructions from the medical teams. Both the physician and pharmacy generally discuss step-by-step procedures, but this often occurs weeks or months before the patient actually takes the medications. Details can be forgotten or misunderstood. A major part of the doula's job is to clarify the instructions, answer questions where they can, and repeat that process until the date is close. This alleviates much anxiety and confusion on the part of our clients and their loved ones.

On the aid-in-dying day, doulas are there from start to finish—so that antiemetics are taken in a timely manner; to ensure safe and accurate preparation of the medications; to sit at the bedside during ingestion; to communicate with the medical teams in real-time, when appropriate; to stay with the family until their loved one dies, and often long after; to aid the medical practitioner who comes to confirm the patient's death; and to aid the family as the mortuary team does their work. Doulas most commonly keep the entire day open to tend to their clients' needs. That reassurance is crucial for all involved. Doulas check in again days after the death as well, connecting loved ones to additional resources when needed—from obtaining death certificate copies to bereavement or grief support.

3. WHAT DOULAS CANNOT DO

We rely on the expertise of our clinical colleagues—attending/prescribing physicians, hospice MDs, nurses, social workers, and chaplains—to help provide a safe passage for our mutual clients.

And while many doulas have specifically learned about aid in dying and are considered by some to be “clinicians,” most are not medically trained. Thus, doulas are not qualified to evaluate clients’ often rapidly changing disease processes, in particular, those that may influence the recommended aid-in-dying protocol.

It is beyond a doula’s scope of practice to be the final safeguard in flagging and troubleshooting potential clinical problems. Doulas are not equipped to provide non-oral methods of administration, if indicated. Doulas do not place rectal catheters or decide whether they are needed. They might monitor bowel function by asking clients questions, but only to request that their clinical colleagues further evaluate the situation and, if needed, provide appropriate care.

4. KNOW YOUR LOCAL DOULAS

Many clinicians, including prescribing physicians and hospice staff, do not attend the aid-in-dying deaths of their patients. If they do attend, employers may have policies that prevent clinical-staff engagement in critical aspects of the process, such as mixing medications or staying at the patient’s side during ingestion. Doulas are a natural fit to fill this gap. Patients and their circle of care may not know that doulas are available, so clinicians’ recommendations are essential.

5. SUMMARY

End-of-life doulas have become an integral part of the care team for patients considering aid in dying. Patients and families benefit most by working with doulas when they have time to build relationships and when the doulas are integrated into the clinical team. Aid-in-dying-experienced end-of-life doulas can be a powerful enhanced support system essential to all aspects of aid-in-dying care.

THE AUTHOR HAS NO CONFLICTS OF INTEREST TO DISCLOSE.

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1. Ong, CK, Embracing Cicely Saunders’s concept of total pain. *BMJ*. 2005 (Sep 10); 331(7516): 576–577. doi: 10.1136/bmj.331.7516.576-d.

FILM REVIEW

LAST FLIGHT HOME / 2022
Director: Ondi Timoner
Cast: Morgan Doctor, Rachel Maddow, David Timoner
1 hour 46 minutes

JACK HAS A PLAN / 2022
Director: Bradley Berman
Cast: Adalia Cariño, Jennifer Cariño, Ralf Cariño, Jack Ferrell
1 hour 13 minutes

CAPABLE FILMMAKERS PRODUCE ENGAGING FILMS ABOUT HASTENED DEATHS

CONSTANCE HOLDEN, RN, MSN

Filmmakers Bradley Berman (“Jack Has a Plan”) and Ondi Timoner (“Last Flight Home”) provide viewers with up-close-and-personal stories of two terminally ill men who choose to hasten their demise by medical aid in dying. While the films differ in tone and format, both focus on deeply thoughtful people whose preparation for death included addressing serious “unfinished business” (as we say in the world of end-of-life care).

Upon learning that a latent brain tumor has recurred, Jack Tuller (“Jack Has a Plan”) begins a methodical preparation for his exit from this world. In keeping with his entertainment background, he insists that Berman, a friend and filmmaker, document his final chapter. Berman makes no promises that he will produce a movie, but he does make periodic postings for friends called, “A Few Minutes with Jack.” He captures the mundane and the deeply personal as Jack, among other events, makes amends with his absent parents. Spoiler alert: this part will make your heart soar and your eyes drip. Jack and Berman prepare a life review, some of it based on archival footage and childhood photos that were found in Jack’s storage unit.

Quirky, charismatic, warm, and fully functional except for worsening seizures and dizzy spells, Jack eventually says, “It’s time.”

Jack gathers his friends and family for a party that is rich with pathos. Some think he’s being hasty, and they tell him so—with seemingly valid reasons. While still vital, Jack fears that something will change and he won’t be mentally or physically able to complete the act. Finally, he dismisses everyone and ingests his aid-in-dying medications… alone, except for his wife. He dies at age 59.

During a talkback after a screening at the Boulder International Film Festival, Berman revealed that the footage had languished on his computer for nearly two years after Jack’s death. The time afforded by the pandemic and the urging of his colleagues and Jack’s friends prompted him to create “Jack Has a Plan.”

Eli Timoner (“Last Flight Home”) was no less certain than was Jack Tuller that “it’s time.” We join Eli (age 92) and his family when he is already bedridden from heart failure, pulmonary disease, and stroke-induced paralysis he’d suffered four decades earlier. Ondi Timoner, an accomplished filmmaker, is Eli’s oldest child. Although Eli is bedridden and his energy and voice are waning, he is in full command of his faculties and his sense of humor. His wife, three adult children, and numerous grandchildren are unanimous in their support of his choice of a hastened death. Filmmaker Timoner also uses home videos and photos to help the viewer appreciate the full and loving life her father led. The founder of the airline Air Florida, Eli’s fame and fortune went up in flames with a plane crash—from which his company never recovered. Before death, he needed to make amends related to his business failure. His rabbi daughter, Rachel, employs a sacred Jewish prayer ritual, Vidui. Eli is very weak. Listen closely.

In spite of being the filmmaker, Ondi manages to be in the film and fulfill her role as devoted daughter. She helps her father navigate the aid-in-dying paperwork and process. She worries about her mother—is she having meaningful time alone with her husband? Eli is a willing central character in this film. In tense moments, he always declines the offer to have the mic removed.

The film soon focuses on the last 15 days of Eli’s life, the waiting period then required by California’s End of Life Options Act (shortened to 48 hours in 2022). These scenes are filled with touching final goodbyes on Zoom with friends and in-person time with family, including each grandchild. The ever-present family members feel cloying at times. With the cameras rolling, the goodbyes are hardly private. One wonders if this impeded the sharing of secrets. This segment, actually marked by a timepiece counting the days, seemed interminable. But Eli never wavers. While he and his voice are weakening, he remains lucid, able to swallow, and able to decide about aid in dying—a bit of a nail-biter, however.

The cameras roll as Eli swallows the medications and dies—and during post-mortem care of his body. This almost feels too invasive. It is, however, reassuring to see his quick and peaceful death.

Ondi Timoner allowed many months to pass before she finalized this touching movie. In online interviews, she talked about her reluctance. She hesitated to expose her family at this raw and vulnerable time. But family and friends encouraged her to move forward with the film.

We owe a debt of gratitude to both filmmakers.

"Last Flight Home" has been released to theaters and is available on Paramount Plus. Berman's "Jack Has a Plan" is making the rounds of mid-sized film festivals and is being prepared for release to theaters. Should you wish to show it to a group, you can engage with the filmmaker at Jackdocumentary.com.

CONSTANCE HOLDEN is a member of the *Ethics Consultation Service* of the *American Clinicians Academy on Medical Aid in Dying*, the Ethics Consultation Team at *Boulder Community Health* and the Board of Directors of the *Colorado Healthcare Ethics Forum*.

Sutter Family Medicine Residents, Sacramento, CA, July 2023

CURRENT PRACTICES AND FUTURE RECOMMENDATIONS FOR GRADUATE MEDICAL EDUCATION IN AID IN DYING

RYAN SPIELVOGEL MD, MS[1], PATRICK J. MACMILLAN MD[2]

ABSTRACT: With more clinicians and patients participating in medical aid in dying, robust graduate medical education in assisted death will be necessary. Our study investigated multiple training programs throughout the U.S. that teach medical aid in dying to their residents and fellows, with the goals of examining curricular trends and offering recommendations on key components.

We conducted semi-structed interviews with 15 physician educators who teach medical aid in dying at 15 institutions across nine U.S. jurisdictions. Thirteen still had active resident or fellow aid-in-dying education programs. Five of those had faculty who proactively reached out to their pool of trainees to engage them in training. Those five programs offered direct patient care experiences around aid-in-dying evaluation and management. Another eight programs did not. The five proactive programs reported very high learner engagement, while the other eight reported low engagement. We suggest that a proactive structure form the basis for aid-in-dying curricula in residency and fellowship education. Further research is needed to examine patient care outcomes and curricular efficacy.

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KEYWORDS: medical aid in dying, graduate medical education, curriculum, physician-assisted death

1. INTRODUCTION

Graduate medical education—including residency and fellowship—is foundational to the practice of medicine. In 2023 in the U.S., 49,238 nascent doctors matched into more than 5,000 residency and fellowship programs spanning more than 70 specialties and subspecialties.[1,2] "Residency" is the time after graduating medical school and before independent clinical practice when physicians of all stripes learn the science and art of medicine. Physicians who want subspecialty training after residency go through an additional fellowship. These precious few years of post–medical school training are highly formative to clinical practice, and crucial for acquiring the skills necessary for quality care of their patients.[3]

Medical aid in dying—the process by which a provider cares for a terminally ill, mentally competent patient as they consider and potentially follow through with taking a lethal dose of medication to hasten a foreseeable death[4]—is a relatively new practice. Compared to other aspects of medical care, many of which have been around for centuries, aid in dying only became a legitimate practice in the United States after the implementation of the Oregon Death with Dignity Act in 1997. Ten other jurisdictions have since followed suit, with approximately 22% of the US population currently living in a place where medical aid in dying is legal as of 2023.[5]

One of the most significant barriers to patient access to medical aid in dying is a lack of providers. Studies investigating the source of this scarcity have found consistently low levels of comfort with providing this service, owing to insufficient training.[6-8]

In contrast, numerous studies of both U.S. and Canadian medical trainees show a consistently high level of desire for training in medically assisted deaths, mostly in the 80% range or above.[7,9-12] However, while the number of graduate programs that train physicians in medical aid in dying is unknown, the authors' experience and information from our colleagues show it is very low. Additionally, the optimal

> "ONE OF THE MOST SIGNIFICANT BARRIERS TO PATIENT ACCESS TO MEDICAL AID IN DYING IS A LACK OF PROVIDERS."

structure of graduate curricula in medical aid in dying is unknown.

2. METHODS

To better understand the current scope of post-graduate training in assisted dying in 2023 and to offer recommendations we spoke with physician educators involved in aid-in-dying care. Interviewees included former residents, community preceptors, residency and fellowship faculty, and program directors—in a range of specialties including family medicine, internal medicine, hospice and palliative care, emergency medicine, and psychiatry. The 15 physicians interviewed represented nine U.S. jurisdictions: Oregon; California; Hawaiʻi; New Mexico; Colorado; Maine; Vermont; New Jersey; and Washington, DC.

Interviews were semi-structured and focused on the regularity of didactic education, the extent and scope of trainees' direct patient-care encounters, how they accessed practical training, and the overall structure of aid-in-dying education. Interviews also assessed faculty and mentor experiences. Interview transcripts were reviewed and descriptively analyzed, condensed, categorized, and tabulated. Summaries with descriptive statistics, including simple proportions, can be found below.

3. RESULTS AND ANALYSIS

Of the 15 institutions in our sample, two with well-established curricula for resident aid-in-dying education were no longer actively training their residents. In both cases, the trainers had left for reasons unrelated to aid in dying.

In all cases where the interviewees were still actively practicing at their respective institutions (87%), their aid-in-dying curricula were still active. Several other interviewees—particularly those nearing the end of their careers as the sole aid-in-dying educators at their institutions—expressed concern for the sustainability of aid-in-dying training after they retire.

In our sample, the regularity of didactic education in medical aid in dying varied. Of the 13 institutions with active training programs, nine (69%) included annual lecture-based instruction in their curricula, whereas four institutions (31%) included lectures that occurred irregularly, generally at the specific request of a department.

The routes by which interested trainees accessed direct patient-care experiences beyond lectures varied among institutions. In general, programs appeared to deploy one of two strategies—either faculty- or trainee-led clinical training. In the five faculty-led institutions (38%), the instructors actively reached out to their residents and fellows to arrange for clinical encounters. In the eight trainee-led institutions (62%), interested residents and fellows self-identified and sought out practical training themselves. In these cases, the processes by which trainees would self-identify were informal and generally relied on the resident or fellow to proactively reach out to faculty.

Consistently, the interviewees at the five faculty-led teaching systems reported a high number of trainees receiving clinical experiences. This was in stark contrast to the eight interviewees from the trainee-led institutions, who consistently reported very low numbers of trainees who had received bedside training in medical aid in dying.

The extent of direct patient-care training varied among institutions. Eight (62%) reported no direct aid-in-dying care included in their training or experiences that were limited to shadowing a faculty member. Five (38%) reported experiences that included trainees performing aid-in-dying evaluations themselves, with varying degrees of faculty supervision and oversight, determined at the discretion of the instructor. Of note, these were the same five institutions that had faculty-led programs described in the above paragraph.

Of these five institutions, two (40%) had their trainees formally occupy the legally designated roles (attending/prescribing physician and consulting/second-opionion physicians) for the aid-in-dying process—including the coordination and care of patients considering aid in dying, potentially writing the prescription, possibly attending the death, and filing the relevant state paperwork. Three of the five programs (60%) regularly had their trainees attend at the bedside on the day of their patients' deaths.

4. DISCUSSION

Continued aid-in-dying care in the U.S. necessitates the inclusion of graduate medical training. We found through our interviews that significant heterogeneity exists in both the extent and content of resident and fellow didactic and clinical experiences around assisted death. Yet several trends were apparent and form the basis of the authors' conclusions and recommendations.

The programs reporting the highest numbers of trainees receiving clinical education in aid in dying were those where the faculty proactively and routinely reached out to their pool of residents and fellows to engage them in training experiences. These were the same programs that encouraged trainees to engage in aid-in-dying evaluations and care themselves. A subset of these programs routinely had residents or fellows occupy the official roles in the process or attend their patients on the aid-in-dying day.

This combination of faculty-led curricula with trainees' direct patient evaluation and management appeared to yield higher levels of

learner engagement. The authors therefore recommend that this structure form the basis of graduate curricula in medical aid in dying.

In our sample, we also found that the continuation of an aid-in-dying graduate training program depended on active faculty engagement. This preliminary data suggests that programs depending on a single faculty champion for their aid-in-dying training may be at risk if that faculty member leaves the institution.

It is important to note that the benefits of graduate medical education in aid in dying are not confined to patient care and access. Clinical faculty have been shown to have lower rates of burnout and higher rates of job satisfaction compared to non-teaching practicing physicians.[13] This was reflected in our interviews. For example, Dr. Nicholas Gideonse, who teaches at the Oregon Health & Science University family medicine residency program, recalled with pride a resident who said their aid-in-dying training was, “One of the most memorable experiences of their residency.”

Trainees also express satisfaction with their expanded end-of-life care knowledge. Following an ingestion, a palliative medicine fellow at the University of California, San Francisco/Fresno commented: “After seeing this experience and how peaceful her death was, I know that I will help others this way as part of my career in palliative medicine.”

After attending at the bedside for an assisted death, Dr. Jennifer Daza, a resident at the Sutter family medicine program in Sacramento, recalled, “It was beautiful to witness. Being able to learn about medical aid in dying in residency has been great, and I see myself offering this service moving forward.”

This study had several limitations. The fifteen institutions represented a sample of educators known to the authors and may not include all graduate aid-in-dying training programs. Additionally, the study relied on subjective narrative descriptions from single educators at each institution at a single point in time, which leaves the data prone to both sampling and recall biases. This may limit the usefulness and applicability of the findings.

Research is needed to estimate the true number of residency- and fellowship-training programs that include aid-in-dying curricula. While our preliminary findings suggest that faculty-led programs with direct patient experiences yielded the highest learner engagement, further studies must be done to better define optimal curricula. Long-term follow-up studies could ascertain skill retention and clinical practice changes. Further research is also warranted on aid-in-dying patient outcomes in such a training environment.

The gross mismatch between trainee interest in medical aid in dying and access to quality aid-in-dying education during residency and fellowship is an existential threat to the future of assisted dying in the U.S. It is also an unmistakable opportunity to sustainably improve training. Crossing this chasm will take a concerted effort to normalize aid in dying as a standard part of end-of-life-options counseling. In that environment, post-graduate training will naturally follow.

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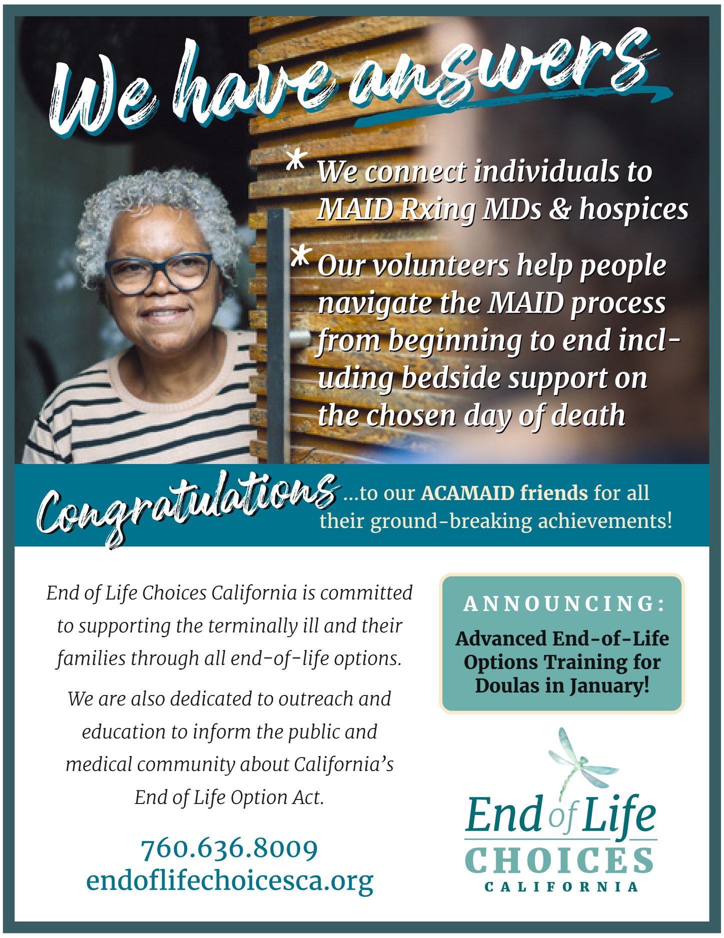

1. *National Resident Matching Program, Results and Data: 2023 Main Residency Match®*. National Resident Matching Program; 2023.
2. *National Resident Matching Program, Results and Data: Specialties Matching Service 2023 Appointment Year*. National Resident Matching Program; 2023.
3. van der Leeuw RM, Lombarts KM, Arah OA, Heineman MJ. A systematic review of the effects of residency training on patient outcomes. *BMC Medicine*. 2012;10:1-11.
4. Shavelson LB, MP; Pope, TM. Medical aid in dying: clinical considerations. In: Post T, ed. *UpToDate*. UpToDate; 2023.
5. Kozlov E, Nowels M, Gusmano M, Habib M, Duberstein P. Aggregating 23 years of data on medical aid in dying in the United States. *Journal of the American Geriatrics Society*. 2022;70(10):3040.
6. Campbell EG, Kini V, Ressalam J, et al. Physicians' attitudes and experiences with medical aid in dying in Colorado: a "hidden population" survey. *Journal of General Internal Medicine*. 2022;37(13):3310-3317.
7. Pham M, Daddato AE, Lum HD. Assessment of internal medicine resident perspectives on medical aid-in-dying in future practice. *Journal of Palliative Medicine*. 2021;24(5):654.
8. Singer J, Daum C, Shen MJ, et al. Assessment of oncology advanced practice professional willingness to participate in medical aid in dying. *JAMA Network Open*. 2022;5(10):e2239068-e2239068.
9. Bold RJ, Schneider PD, Khatri VP, Goodnight JE. Resident experience and opinions about physician-assisted death for cancer patients. *Archives of Surgery*. 2001;136(1):60-64.
10. Falconer J, Couture F, Demir KK, Lang M, Shefman Z, Woo M. Perceptions and intentions toward medical assistance in dying among Canadian medical students. *BMC medical ethics*. 2019;20(1):1-7.
11. MacDonald S, LeBlanc S, Dalgarno N, et al. Exploring family medicine preceptor and resident perceptions of medical assistance in dying and desires for education. *Canadian Family Physician*. 2018;64(9):e400-e406.
12. Wong A, Hsu AT, Tanuseputro P. Assessing attitudes towards medical assisted dying in Canadian family medicine residents: a cross-sectional study. *BMC medical ethics*. 2019;20:1-8.
13. Zhuang C, Hu X, Dill MJ. Do physicians with academic affiliation have lower burnout and higher career-related satisfaction? *BMC Medical Education*. 2022;22(1):1-8.

BEREAVEMENT SUPPORT GROUPS FOR MEDICAL-AID-IN-DYING FAMILY MEMBERS

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ABSTRACT: Grieving after an aid-in-dying death can have unique characteristics. While general bereavement support services are widely available, aid-in-dying-specific groups have been scarce. But these grief services have recently been initiated in several states.

In this commentary, we discuss grief preparation and post-death counseling for families experiencing an aid-in-dying death. This also involves grief work on the day of ingestion. We describe how these aid-in-dying-specific services may impact the characteristics and quality of the bereavement process. Anecdotal evidence suggests that providing support in all facets of the aid-in-dying process may result in an enhanced bereavement experience for family members.

In addition to our aid-in-dying bereavement group at the Empowered Endings Foundation, we catalog 10 such support programs in six states. Most are virtual and drop-in with an attendance of about three to five participants per session. As more clinicians, support staff, patients, and families learn about these services, other states may initiate their own aid-in-dying bereavement services.

KEYWORDS: medical aid in dying, bereavement, grief counseling.

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1. INTRODUCTION

Grieving the loss of a loved one is experienced by almost everyone as part of the fabric of life. Most people grieve and recover on their own, but some need professional assistance, either through individual counseling or bereavement groups. Hospices and other organizations provide general grief support, but medical-aid-in-dying families have specific needs. Currently there are only a few aid-in-dying focused groups available.

This commentary discusses the need for and structure of aid-in-dying-specific bereavement counseling. While there have been very few published studies of benefits following specifically structured counseling,[1] anecdotal evidence has shown that not providing this service can result in anxiety and dissatisfaction for family members. The authors have also observed that providing guidance, counseling, and other support services during the initiation and participation in aid in dying, even before the ingestion day, increases the likelihood that the grief process proceeds more smoothly.

It follows that providing comprehensive aid-in-dying services—from intake to medication ingestion and after—is likely to improve bereavement outcomes. While we encourage such *anticipatory* services, some loved ones will only realize their need for specific aid-in-dying grief counseling *following* an inattentive process. In either situation, family members may need aid-in-dying-specific bereavement counseling.

2. PREPARATION GUIDANCE AND COUNSELING

Once the prescribing physician assesses, qualifies, and counsels the patient and family, bereavement support staff can, with permission, contact them to discuss the aid-in-dying process, evaluate the level of support needed, and establish a plan for ongoing engagement. Table 1 provides a series of circumstances and issues that, with detailed information and emotional support, including "pre-bereavement counseling," will aid in the subsequent grief process. In addition, a booklet, *Medical Aid in Dying: A Guide for Patients and Their Supporters*, provides comprehensive advice for the entire aid-in-dying process.[2]

3. CLINICIAN* SUPPORT ON THE DAY OF AID IN DYING

Medically assisted dying can be an anxiety provoking and emotionally laden process. So on the aid-in-dying day, loved ones should consider focusing on the emotional aspects of this life-ending process. Their time might be better used to connect with their dying loved one, without technical distractions like mixing medications, safely transporting them to the patient, etc. This will not only improve the events of the day, it will help facilitate the bereavement process.

To aid in the family's focus on their emotional connections, an aid-in-dying experienced clinician can be present at the home to support them. In addition, clinicians can provide guidance about the possible negative or positive effects of witnessing the actual ingestion. They can also monitor the patient until death and address any dying or post-death family concerns.

* Clinician, for the purposes of this article, includes physician, nurse, social worker, spiritual counselor, doula, trained volunteer, or others with specialized training.

Table 1. Aid-in-Dying Guidance that Can Help with Subsequent Bereavement

General preparation issues	Preparation for the day of ingestion	Bereavement
☐ Select ingestion time and location ☐ Pay careful attention to patient, family, and loved ones' needs; consider others who might be in attendance ☐ Facilitate conversations	☐ Facilitate and discuss medication procurement, storage, and usage ☐ Decrease the emotional burden on the patient, family, and loved ones	☐ Discuss grief counseling options and resources before day of ingestion
☐ Account for changes in attendees needs	☐ Review procedures of the day and discuss emotional concerns and fears	☐ Provide support for immediate grief responses
☐ Discuss/plan rituals, ceremonies, or other services of general emotional benefit ☐ Facilitate and prepare for post-aid-in-dying grief.	☐ To decrease fear of the procedure, consider simulated sessions with the patient and/or family	☐ Provide longer-term grief support and planning

Table 2. Medical-Aid-in-Dying Bereavement Groups by State, October 2023

(Most virtual groups are available to those in other states)

STATE	ORGANIZATION	WEBSITE
California	Empowered Endings	https://empoweredendings.com
California	End of Life Choices CA	https://endoflifechoicesca.org
California	Los Angeles Patient Advocates	https://www.lapatientadvocates.com/end-of-life
Colorado	Denver Health (only for those in their program)	https://tinyurl.com/48wx8kpu
Hawaii	Kaipuokaualoku, LLC	https://www.leilanimaxera.com
New Jersey	Grief to Hope	https://grieftohope.org/ group-counseling/
New Mexico	High Desert Hospice	https://highdeserthospice.care
New Mexico	Suzanne Stern Brandt-Expressive Psychotherapy	suzanne@expressivepsychotherapy.com
Washington	A Sacred Passing	https://asacredpassing.org/

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4. BEREAVEMENT

Although there are considerable resources available for general bereavement counseling, aid-in-dying bereavement requires experienced counselors with specialized approaches. Fortunately, in many aid-in-dying jurisdictions, specific grief groups are increasingly available (Table 2). Most are virtual, drop-in, and can be accessed nationally by anyone associated with a medical-aid-in-dying patient.

Limited information from several medical-aid-in-dying support groups shows that participants often express guilt;[3] feel overwhelmed; note that it all happened too fast, that they did not know enough about the ingestion process, or that they did not have time to connect with or offer emotional support to their loved one; and have questions about informing others of their participation in physician-assisted-dying. All these issues can contribute to complex grief and require aid-in-dying-specific bereavement counseling. Many can be avoided with adequate counseling and support in advance of the death. Clinical staff should strongly consider providing specific guidance and information to loved ones and family about the availability and value of aid-in-dying bereavement support services.

5. DISCUSSION

There is a paucity of published reports about medical-aid-in-dying bereavement outcomes. Most are retrospective, qualitative, cross-sectional convenience sample interviews of small numbers of family members, loved ones and friends, done many months after the assisted dying occurred.[4-8] A recent systematic review of multiple cross-sectional bereavement studies (n=13) found equivocal results about protective and risk factors for grief outcomes. Some factors occurred before the day of the event, others afterwards. In addition, the outcome measures evaluated were family members' serious long term mental health issues (prolonged complex grief; major depressive, post-traumatic stress; and major anxiety disorders). These outcomes were uncommon (~10%).[9] Unfortunately, none of the studies evaluated information about bereavement counseling or frequent, less serious grief issues and outcomes.

Our Empowered Endings Medical Group specializes in education and options for end-of-life care, including aid in dying. We have provided individual bereavement counseling for hundreds of loved ones. It has become clear to us that aid-in-dying-specialized grief support needs to be accessible to more bereaved families. Additionally, longer-term care and peer support for some bereaved family members

SUSAN AMINA, APRN, is an advanced practice nurse and aid-in-dying navigator/provider in Waipahu, Hawaii. The photograph is from a walk at sunset on Lana'i Island.

could be helpful. We've concluded that, for practical reasons, virtual groups can provide individual support, connections, and comfort through the facilitated sharing of experiences among participants.

We initiated the Empowered Endings Foundation, and chose two facilitators from our local community. Both have a professional background in end-of-life care and grief support, including specialty training and experience with patients and families through the aid-in-dying process. We decided to use an open, drop-in group format, donation-based and free to all who cannot afford to contribute. Our group is still small, with an average attendance of three per session.

Other like-minded groups across the country have had roughly similar experiences. They are recently initiated and primarily based in the western states (Table 2). They, too, have had a small number of attendees. However, End of Life Choices California uses a scheduled four-session program, with an average of 8 to 10 participants. Since the initiation of these aid-in-dying bereavement programs is still recent, it is likely that low dissemination about their availability is the reason for the low attendance thus far. Time and the spread of information by clinicians to family members will determine the developing need. One strength is that the variety of these services across the country are now in touch with each other and sharing information. This will hopefully lead to a database and further studies of the methods, innovations, and outcomes of these bereavement programs.

We believe that aid-in-dying-specific grief support groups will improve the general overall quality of the bereavement process for most family members and loved ones. With time, we will gather evidence to ascertain if that is true, and also determine whether major mental health disorder outcomes are improved—from complex grief to post-traumatic-stress disorder. We hope that the comprehensive bereavement care described in this article—from the beginning to the end of the aid-in-dying process—will be one model for further study. Prospective studies are needed to fully evaluate the aid-in-dying bereavement process among family members. We encourage our colleagues in the field to engage in these evaluations.

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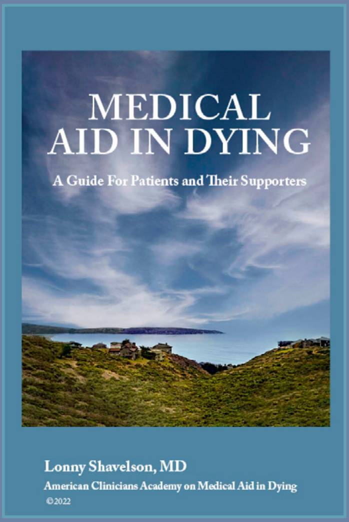
1. Singer J, Daum C, Loggers E. An examination and proposed theoretical model of risk and protective factors for bereavement outcomes for family members of individuals who engaged in medical aid in dying: a systematic review. *Palliative Medicine*. 2023;37(7):947-958. doi: 10.1177/02692163231172242.
2. Medical Aid in Dying: A Guide for Patients and Their Supporters. American Clinicians Academy on Medical Aid in Dying. https://www.acamaid.org/patientbooklet/.
3. Schwing D, Dennett L, Grief Outcomes in Medical Aid in Dying, Hospice by the Bay Bereavement Department, Marin, California. Presented at the 2020 National Clinicians Conference on Medical Aid in Dying, UC Berkeley. https://vimeo.com/397026641.
4. Ganzini L, Goy ER, Dobscha SK, et al. Mental health outcomes of family members of Oregonians who request physician aid in dying. *J Pain Symptom Manage*. 2009;38(6):807-815.
5. Hashemi N, Amos E, Lokuge B. Quality of bereavement for caregivers of patients who died by medical assistance in dying at home and factors impacting their experience: a qualitative study. *J Palliat Med*. 2021; 24(9):1351-1357.
6. Oczkowski SJ, Crawshaw DE, Austin P, et al. How can we improve the experiences of patients and families who request medical assistance in dying? A multi-centre qualitative study. *BMC Palliative Care*. 2021;20(1):185-197.
7. Beuthin R, Bruce A, Thompson M, et al. Experiences of grief-bereavement after a medically assisted death in Canada: bringing death to life. *Death Studies*. 2022; 46(8):1982-1991.
8. Holmes S, Wiebe E, Shaw J, et al. Exploring the experience of supporting a loved one through a medically assisted death in Canada. *Can Fam Physician*. 2018;64(9):e387-393.
9. Singer J, Daum C, Loggers E. An examination and proposed theoretical model of risk and protective factors for bereavement outcomes for family members of individuals who engaged in medical aid in dying: A systematic review. *Palliative Medicine*. 2023;37(7):947-958. doi:10.1177/02692163231172242.

BOOK REVIEW



MEDICAL AID IN DYING: A GUIDE FOR PATIENTS AND THEIR SUPPORTERS
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A NEW GUIDE PROVIDES CLEAR, PRACTICAL ADVICE FOR THOSE CONSIDERING AID IN DYING

LOREN TALBOT

WHILE MEDICAL AID IN DYING has been an option in Oregon since 1994, followed by Washington state in 2008 and a handful of other states since, little has been written in the United States on how to support and guide patients through the experience. The booklet Medical Aid in Dying: A Guide for Patients and Their Supporters, published by the American Clinicians Academy on Medical Aid in Dying, written by Lonny Shavelson, MD, seeks to address this need. With aid in dying available to terminally ill patients in 11 states in the country and additional legislation on the horizon, this booklet serves as an important compendium for people considering the option of choosing where and when they die, and for the individuals supporting them.

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Unlike books that may share loved ones' personal experiences of medical aid in dying or conversations about death and end of life, *Medical Aid in Dying: A Guide for Patients and Their Supporters* was written to demystify the process for those directly considering aid in dying. This book could be used by an individual considering medical aid in dying, but also by the families, caregivers, end-of-life doulas, hospice workers, and others who are uniquely positioned to support someone considering this option.

Two central themes appear in this publication. The first is a theoretical conversation around medical aid in dying, its terminology, and how it fits within hospice, palliative care, and end-of-life caregiving models. The second part of the book serves as a practical guide for when individuals execute their option to consider medical aid in dying. This section provides a practical road map for the process, including legal requirements, medications, and preparation prior to and on one's death day. The booklet also offers brief sections for those attending the appointed death day and information on what to do immediately following death, as well as some facts on grieving.

In the first half of the booklet, Shavelson addresses how to talk about medical aid in dying. He explains why this should be the only language adopted for "terminally ill patients with less than six months to live" who "choose the time, place, and manner of death." In acknowledging the other terminology associated with medical aid in dying, he voices his concern about addressing medical aid in dying as "dignified death," "assisted death," or "assisted suicide." Shavelson advocates for clear language without euphemisms, which can lead to confusion regarding the most important decision an individual can make. He strongly encourages the use of the language "considering the option" throughout the process of medical aid in dying. This allows the individual autonomy and control of the decision up until the moment that the person may decide to swallow the prescribed medications.

The second half of the book starts with the chapter "The Path to Aid in Dying" and walks the reader through the process, from understanding the legal requirements to providing pharmacological knowledge (as well as what the pharmaceuticals are not, to dispel any rumors). Shavelson recommends speaking to one's current medical doctors when considering this option and determining within the hospice, palliative care provider, or health care system whether there is anyone familiar with the process—even if that person will not be the doctor required throughout the process. Additionally, the American Clinicians Academy on Medical Aid in Dying provides a referral service, and the booklet explains how to use the service to seek the two doctors required for medical aid in dying.

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What unfolds over the next few chapters are the broad legal requirements necessary to seek medication for medical aid in dying, as well as an outline of the request process. Shavelson highlights a timeline of what the process looks like once the requests have been submitted and medications have been obtained, including the three-day period prior to the day of death and the actual selected dying day. Individuals must have the mental capacity to make the decision for themselves, as well as the physical strength to self-administer the medication. At any time prior to the administering of medication, an individual has choice and free will in terms of deciding whether or not to take the medication. This is reiterated throughout the booklet and reinforced with the language around "considering the option."

The last chapters explore what happens once the medications are mixed, including some tips for proper preparation and some of the common experiences that occur following ingestion for the patient, as well as for those present. The booklet explains the two ways death will occur and some of the physical symptoms to be aware of. Lastly, the book touches lightly on grieving.

Overall, *Medical Aid in Dying: A Guide for Patients and Their Supporters* is exactly as its title promises—a guide that walks the reader through some of the misnomers; policies; politics, and then, most importantly, the experience of considering medical aid in dying. As Shavelson states in his introduction, "deciding on how you will die is among the most important decisions you'll ever make." The shared knowledge held in these pages is an important tool that will help to determine whether this decision is the right choice for the reader and help to expand the understanding for those who are supporting another through the process.

CONFLICT OF INTEREST DISCLOSURE: The American Clinicians Academy on Medical Aid in Dying, which publishes this journal, also published the book under review here. This review was written and edited independently of the Academy.

New Mexico State Capitol, "The Roundhouse."

A LEGISLATIVE RESPONSE TO MEDICAL-AID-IN-DYING LITIGATION IN NEW MEXICO

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ABSTRACT: In mid-December 2022, the constitutionality of the Elizabeth Whitefield End-of-Life Options Act (EWEOLO Act or the Act) was challenged in federal court in New Mexico. The alleged constitutional violations of the Act followed a line of arguments made by the same plaintiff who previously brought legal challenges against the end-of-life options statutes in Vermont and California. In response, End of Life Options New Mexico, a nonprofit established to assist the implementation of the Act, contemplated challenging the legal case but decided instead to support a legislative strategy to amend the Act to nullify any alleged constitutional violations. The well-coordinated and rapid response by various stakeholders culminated in a unanimously passed amendment to the Act and the voluntary dismissal of the lawsuit by the plaintiffs prior to a judicial ruling. This avoided public fears of disruption of aid-in-dying care in New Mexico.

KEYWORDS: medical-aid-in-dying statutes, litigation against medical aid in dying, amending aid-in-dying legislation, Elizabeth Whitefield, Christian Medical and Dental Associations, End of Life Options New Mexico.

1. INTRODUCTION AND BACKGROUND

As of June 2023, 11 jurisdictions have enacted laws authorizing medical aid in dying as an option for patients receiving end-of-life care.[1] Since a conversation between a patient interested in exploring aid in dying and a health care provider is essential, each state law has generally sought to establish end-of-life-options counseling and/or referral obligations for providers responding to terminal patients' inquiries about aid in dying. However, some providers who have chosen not to participate in aid-in-dying care have pursued court challenges to the constitutionality of these state law requirements because of ethical or religious objections.

2. LEGAL CHALLENGES TO MEDICAL-AID-IN-DYING LAWS

The constitutionality of counseling and referral requirements in medical-aid-in-dying statutes have so far been challenged in federal courts in Vermont, California, and New Mexico. In 2013, Vermont passed the Patient Choice at End of Life Law ("Act 39"), legalizing medical aid in dying for Vermont residents. In 2016, the Vermont Alliance for Ethical Healthcare, Inc. and the Christian Medical & Dental Associations, Inc. filed a complaint in the United States District Court for the District of Vermont, arguing that the requirement for physicians to counsel patients on medical aid in dying, even when they are religiously opposed to doing so, violates the First Amendment.[2]

The Vermont litigation was eventually resolved by a Consent Decree and Stipulation, an agreement between two opposing parties before formal court arguments. In this case, they agreed to the following interpretation of the Vermont law: 1) Medical providers have no legal or professional duty to counsel or refer patients considering medical aid in dying in Vermont; and 2) Medical professionals do have an obligation to provide patients with relevant and accurate information on medical aid in dying when a patient requests it. If unwilling to provide the information, however, the provider "must make a referral or otherwise reasonably ensure that the patient will be able to obtain relevant and accurate information" on medical aid in dying.[3]

On February 22, 2022, the Christian Medical & Dental Associations and one of its physician members filed a lawsuit in California alleging that an amendment to the state law (Senate Bill 380) required even objecting providers to document in their chart notes that the patient had opened a discussion about aid in dying with that provider. That chart note would then constitute the first verbal request for aid in dying and start the waiting period before a second verbal request.[4] In September 2022, the District Court for the Central District of California blocked the requirements for objecting physicians to document a patient's request for medical aid in dying and to provide notice to the patient that their objection was written in the patient's medical record.[5] Even though an appeal was ongoing throughout the entire challenge to the amendment to California's End of Life Option Act, on May 11, 2023, the parties to the litigation reached a settlement agreeing to enter into a permanent injunction (cessation of court proceedings), award attorney fees of $300,000, and dismiss the lawsuit.[6] The injunction prevents California from enforcing any criminal or civil punishment, including professional or licensing sanctions, for physicians who refuse or fail to: 1) document a patient request for medical aid in dying in the patient's medical record; 2) provide information to a patient who requests such knowledge about medical aid in dying, other than the physician's non-participation in aid in dying; or 3) refer a patient to another physician when a patient seeks a referral.[7]

3. THE NEW MEXICO LITIGATION

New Mexico's Elizabeth Whitefield End-of-Life Options Act went into effect on June 18, 2021.[8] On December 15, 2022, the Christian Medical & Dental Associations filed a lawsuit challenging the physician-obligation provisions in the Act, this time along with its New Mexican member, Mark Lacy.[9] The Christian Medical & Dental Associations did not seek to invalidate New Mexico's aid-in-dying law in its entirety, instead focusing specifically on the law's provisions that: 1) mandate patient referrals,[10] 2) require clinicians to provide patients with aid-in-dying information,[11] and 3) protect an organization from censure for refusing to participate in aid in dying.[12]

The legal arguments the Christian plaintiffs advanced in New Mexico were similar to their claims in Vermont and California. They alleged that the New Mexico Act's *referral* and *informing* requirements compelled speech, were content-based and viewpoint-based restrictions on speech, were overbroad, infringed upon physicians' free exercise rights, were vague and ambiguous, and violated the guarantee of both due process and equal protection. The plaintiffs alleged, therefore, that these requirements were unconstitutional, in violation of the First and Fourteenth Amendments.[13]

4. STAKEHOLDER ENGAGEMENT

When advocating for the original aid-in-dying Act in 2021, a variety of state organizations, professional groups, and individuals were involved to demonstrate wide grassroots support. In response to the legal challenge to the Act, however, a smaller, nimbler group within End of Life Options New Mexico managed the day-to-day efforts of defending the law, while assuring that the greater community was kept informed.

Once the complaint was filed, End of Life Options New Mexico planned with local and national groups and broader civil rights organizations to contest the lawsuit. Although End of Life Options New Mexico's primary concerns were the threat to aid-in-dying access and the perception of the constitutionality of the Act, it was clear to all parties that the lawsuit could also have ramifications that far exceeded the state's physical boundaries—particularly if it were appealed to the U.S. Supreme Court, which could threaten aid in dying nationally. Further, the American Civil Liberties Union and national reproductive rights organizations were concerned about possible negative, indirect effects of a ruling against medical aid in dying.

5. STRATEGIC OPTIONS

An overturning of the entirety of New Mexico's Act seemed unlikely for two reasons: first, the plaintiffs did not challenge the entire law, instead focusing on specific provisions; and second, the Act provided that if any provision is held invalid, that specific section could be struck without affecting the rest of the law. In this context, with the goal of saving the overall Act and avoiding any public confusion about its validity, New Mexico's aid-in-dying organization considered two distinct strategies: 1) direct involvement in the litigation

Gabby Jimenez is a hospice nurse and end-of-life doula in California. She and some of her aid-in-dying patients create mandalas together on a beach or in a forest days before their scheduled deaths, then leave them in place for others to find, often faded by the elements.

by filing a motion to join the lawsuit as an intervening party, and 2) amending New Mexico's aid-in-dying Act to preemptively address the Christian Medical & Dental Associations' complaints against the law.

As a mission-driven nonprofit organization providing support as New Mexicans plan their end-of-life care, End of Life Options New Mexico could have sought to oppose the Christian organizations' litigation through "permissive intervention" under Rule 24 of the Federal Rules for Civil Procedure. Intervening would have allowed the organization to directly participate in the defense of the statute, raise additional arguments beyond those that the state may have been able to or may have wanted to raise, and given End of Life Options New Mexico an option to appeal in the event of a loss. This was the most formal, public, and resource-intensive option.

While determining whether and to what extent to be involved in the litigation, the aid-in-dying organization analyzed the possible scenarios of either a favorable or adverse decision in the district court. Losing on the merits of the organization's arguments would have likely led to provisions being struck from the End-of-Life Option Act, with possible judicial rewriting of the law. Most importantly, a specter of illegality would follow the Act and other medical aid in dying laws into the future. Losing on the merits clearly needed to be avoided.

On the other hand, winning on the merits would mean an appeal to the Tenth Circuit Court of Appeals. An unfavorable decision there would create a binding precedent not only within New Mexico, but also for the tenth circuit states of Wyoming, Colorado, Oklahoma, Utah, and Kansas. Worse, any decision in the Tenth Circuit could lead to an appeal to the U.S. Supreme Court. Based on writings of Justice Gorsuch and recent precedents involving issues surrounding religion, speech, and medical services like abortion, the Supreme Court would likely not view medical aid in dying favorably. And there was a strong possibility that the Supreme Court might even question medical aid in dying itself, given the chance.[14]

Given the various possible outcomes described above, End of Life Options New Mexico deemed court litigation a no-win scenario.

6. AMENDING THE LAW

End of Life Options New Mexico ultimately decided to seek an amendment to the Elizabeth Whitefield End-of-Life Options Act to eliminate this legal challenge. From research on the Vermont case, it was clear that an adversarial approach, such as joining the litigation as an intervenor, could result in losing more of the law than we were prepared to lose.

Our judgment was that once these plaintiffs' issues regarding the specific provisions of the law were ameliorated, the risk of further litigation was low. So amending the law in a manner that was both as narrow as possible but resolved the plaintiffs' complaints seemed the best strategy. Pursuing an amendment to the Act, though, was by no means ideal. Even our small team could not initially reach unanimity on that approach.

One individual who played a significant role in drafting and passing the Act was initially against amending it. They preferred to argue in court in favor of the statute as drafted and support the Attorney General's office in litigation. They felt that amending the Act meant sacrificing sections of the law that were included purposefully. Specifically, amending the law likely meant losing the regulatory enforcement authority of the *referral* and *right to know* provisions against providers who refuse, on the basis of ethical or religious beliefs, to participate in aid-in-dying requests. But other individuals who were influential in the passing of the Act argued that amending the law would give aid-in-dying supporters the greatest degree of control over the outcome and public messaging.

Thanks to open lines of communication with the New Mexico Attorney General's office and the legislature, End of Life Options New Mexico decided not to seek court intervention. Instead, the organization determined that its limited resources and considerable expertise were better spent working with the legislature to amend the Act in a way that prevented the litigation from advancing.

Significantly, amending the Act meant producing no precedent that could affect medical aid in dying or any other issue regarding professional speech in the medical context. Giving an inch via amendment could foreclose the possibility of losing a mile in litigation.

7. FROM BILL TO LAW

Once agreed upon, the amendment strategy still required drafting, navigating the process with legislative leaders, and passing the amendments before the New Mexico Legislature ended on March 18th, 2022. But the decision to amend the Act was not made until midway through the 60-day legislative session, creating a nail-biting time crunch. An amendment stuck in committee at the end of the session would have no effect on pending litigation, so the team had to assume an energetic, all-in strategy.

The specific language in the amendment—highlighted in Figure 1, below—provides broader and clearer immunity from liability for "refusing, for reasons of conscience, to participate in medical aid in dying in any way…" The amendment also deleted "professional organization or association" from the Act's punishment provisions, allowing private professional organizations to enforce rules prohibiting members from participating in medical aid in dying.[15]

The proposed amendment was presented to the legislature as a narrow technical correction to clarify the existing conscience protections to ensure that those who elect not to participate do not feel compelled to do so—and to protect the law from future legal challenges. End of Life Options New Mexico strategically decided not to present the amendment as an advocacy event to avoid it becoming a partisan issue. The proposed amendment also contained an emergency provision requiring its immediate effect once signed by the governor. The amendment did not remove the *right to know* provision or the *referral* provision, it merely clarified the immunity protections for individuals with conscience-based objections. This preserved flexibility for the state to engage in regulatory enforcement for practitioners who fail to meet the statutory requirements for any motivation other than reasons of conscience.

End of Life Options New Mexico's initial outreach to the legislature confirmed that both the senate leader and house speaker were committed to passage of the amendment, had identified strong and effective sponsors, and had reached out to the chairs of the Judiciary Committees in the House and the Senate. In addition, we needed the Governor to be fully supportive and clear in her messaging, and ready to weigh in if needed.

8. OUTCOME

Senate Bill 471 was introduced on February 16, 2023. On March 9, the New Mexico Senate unanimously passed it with a vote of 38 yes, 0 no. On March 15, the bill passed the House of Representatives, also unanimously. On March 31, the Christian Medical & Dental Associations and clinical plaintiff filed a Joint Motion for Stay, ending the potential for a court battle.[16] Once the Governor signed the amendment, successfully curing the plaintiffs' objections, the lawsuit was voluntarily dismissed by all parties.[17]

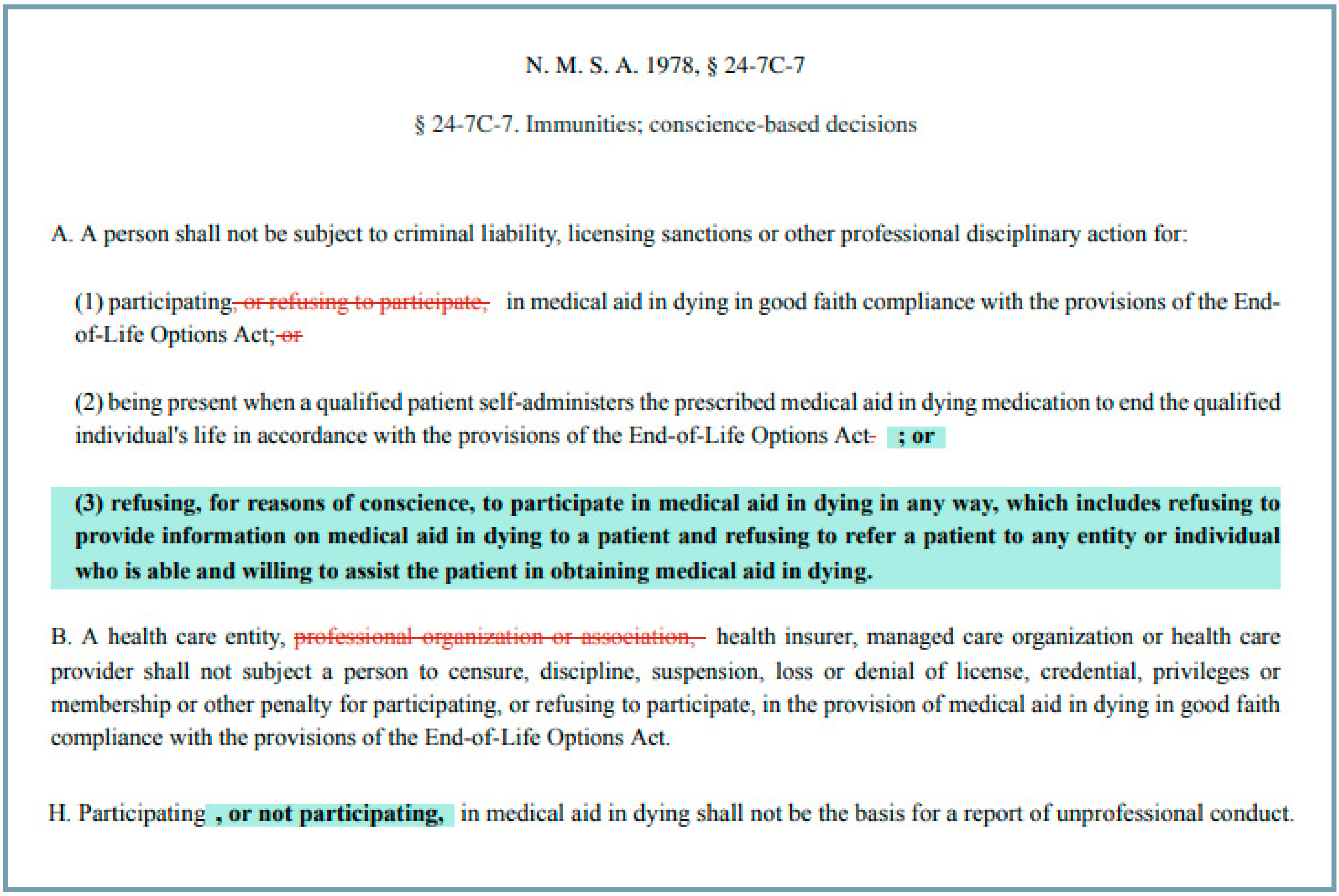
9. LESSONS LEARNED

The most important element in amending the Elizabeth Whitefield End-of-Life Options Act instead of risking a court decision was the ability to minimize and control any changes to the law. It was critically important to keep intact the Act's provisions that require health care providers who do not object for reasons of conscience to inform patients fully regarding their treatment options and/or appropriately refer them to a provider who will. Under the amended Act, terminally ill patients still possess the right to know of all options that are legally available to them—including medical aid in dying. This could have vanished had the litigation continued.

Ultimately, medical aid in dying is bound to be a political issue in every jurisdiction that authorizes it or is considering authorizing it because of the ethical and moral issues inherent in end-of-life planning. This must be understood when crafting legislation and responding to litigation. Sometimes compromise and political pragmatism are the most useful legislative tools. Even the strongest, most perfectly constructed bill accomplishes little if it is never adopted by the legislature or later challenged in court and invalidated.

New Mexicans gained a significant victory when the state's End-of-Life Options Act was originally passed. When it was later challenged, there seemed to be no "right" answer about how to move forward. But a public disagreement between supporters almost always dooms any legislative effort. End of Life Options New Mexico listened to differing points of view, took its time in plotting a course, and deliberately implemented a legislative approach when the time was right. Medical-aid-in-dying laws will likely face more legal challenges in the years to come. The legislative response in New Mexico may not be replicable in every jurisdiction, but narrowly amending a challenged law should always be considered.

Figure 1. The Amendment to the EWEOLO Act



N. M. S. A. 1978, § 24-7C-7

§ 24-7C-7. Immunities; conscience-based decisions

A. A person shall not be subject to criminal liability, licensing sanctions or other professional disciplinary action for:

(1) participating~~, or refusing to participate,~~ in medical aid in dying in good faith compliance with the provisions of the End-of-Life Options Act;~~ or~~

(2) being present when a qualified patient self-administers the prescribed medical aid in dying medication to end the qualified individual's life in accordance with the provisions of the End-of-Life Options Act~~.~~ **; or**

(3) refusing, for reasons of conscience, to participate in medical aid in dying in any way, which includes refusing to provide information on medical aid in dying to a patient and refusing to refer a patient to any entity or individual who is able and willing to assist the patient in obtaining medical aid in dying.

B. A health care entity, ~~professional organization or association,~~ health insurer, managed care organization or health care provider shall not subject a person to censure, discipline, suspension, loss or denial of license, credential, privileges or membership or other penalty for participating, or refusing to participate, in the provision of medical aid in dying in good faith compliance with the provisions of the End-of-Life Options Act.

H. Participating **, or not participating,** in medical aid in dying shall not be the basis for a report of unprofessional conduct.

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1. Oregon; Washington; Montana; Vermont; California; Colorado; Washington, DC; Hawai‘i; New Jersey; Maine; and New Mexico. All but one jurisdiction authorized medical aid in dying through legislation. Medical aid in dying was authorized in Montana by a state Supreme Court ruling that interpreted a right to die with dignity from the Montana State Constitution. Aid in Dying Laws in the United States. End of Life Options New Mexico. https://endoflifeoptionsnm.org/aid-in-dying-laws/.
2. *Vermont Alliance for Ethical Healthcare v. Hoser*, No. 5:16-cv-205 (D. Vt. filed July 19, 2016).
3. 18 V.S.A. § 5281-93; *Vermont Alliance for Ethical Healthcare v. Hoser*, No. 5:16-cv-205 (D. Vt. 2017) (Consent Agreement and Stipulation).
4. *Christian Medical & Dental Ass'n v. Bonta*, No. 5:22-cv-00335-FLA (GJSx) (C.D. Cal. filed Feb. 22, 2022).
5. *Christian Medical & Dental Ass'n v. Bonta*, No. 5:22-cv-00335-FLA (GJSx) (C.D. Cal. Sept. 2, 2022) (order granting preliminary junction in part); Cal. Health & Safety Code § 443.14(e)(2).
6. *Christian Medical & Dental Associations, et al. v. Bonta, et al.*, Compassion & Choices https://www.compassionandchoices.org/legal-advocacy/past-cases/cmda-et-al.-v.-bonta-et-al.
7. *Christian Medical & Dental Ass'n v. Bonta*, No. 5:22-cv-00335-FLA (GJSx) (C.D. Cal. May 17, 2023) (final judgement entering permanent injunction, awarding attorney's fees, and dismissing action).
8. N.M. Stat. Ann. § 24-7C-1 *et seq.*; About the New Mexico End-of-Life Options Act. End of Life Options New Mexico. https://endoflifeoptionsnm.org/end-of-life-options-act/about-the-end-of-life-options-act/.
9. *Lacy v. Balderas*, No. 1:22-cv-00953 (D. N.M. filed Dec. 15, 2022).
10. N.M. Stat. Ann. § 24-7C-7(C) (requiring a health care provider to inform a requesting patient that the provider is unwilling or unable to fulfill the patient's medical aid in dying-related request and to refer the patient to a provider who is able).
11. N.M. Stat. Ann. § 24-7C-6 (or, the patient's *right to know*, which requires a health care provider to inform a terminally ill patient of all legally available end-of-life options).
12. N.M. Stat. Ann. § 24-7C-7(B) (as amended) (protecting health care entities and providers from any censure or discipline for participating or refusing to participate in medical aid in dying).
13. *Lacy v. Balderas*, No. 1:22-cv-00953 (D. N.M. filed Dec. 15, 2022). CMDA also claimed that the Act's requirement restricting private associations from sanctioning members for participating or refusing to participate in medical aid in dying violated CMDA's right to expressive association in violation of the First Amendment.
14. *National Institute of Family & Life Advocates v. Becerra*, 138 S. Ct. 2361, 2371–75 (2018); Gorsuch NM. *The Future of Assisted Suicide and Euthanasia*. Princeton University Press; 2006.
15. N.M. Stat. Ann. § 24-7C-7(B).
16. *Lacy v. Balderas*, No. 1:22-cv-00953 (D. N.M. Mar. 31, 2023) ([proposed] order granting joint motion for stay).
17. *Lacy v. Balderas*, No. 1:22-cv-00953 (D. N.M. Apr. 5, 2023) (final judgement).

RETHINKING DATA COLLECTION IN MEDICAL AID IN DYING

QUALITY IMPROVEMENT AS THE NORTH STAR

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ABSTRACT: Medical aid in dying is an evolving practice in the United States. This article advocates for a robust data-collection system. Current systems largely depend on self-reported data from providers susceptible to biases and inconsistencies. Vital data points, such as costs, reasons for denials of aid-in-dying requests, and clinical complications, are rarely collected. Other data are collected but not reported, such as whether patients were undergoing palliative care at the time of their aid-in-dying request or cases in which the state has lost track of the patient's aid-in-dying status or has incomplete information. Missing data undermines oversight and inhibits public transparency. Furthermore, the costs of data collection, including risks to patient confidentiality and administrative burdens on clinicians, are often neglected. To chart a path forward, this paper proposes a quality improvement–focused approach to reconcile the costs and benefits of data collection with the broader objectives of ensuring patient safety and access to aid in dying. The feedback loop established by a quality improvement–driven approach can provide a robust framework for optimizing aid-in-dying patient care. We propose that state and private aid-in-dying organizations standardize data collection and reporting systems, preferably using a quality improvement approach, to better understand and improve U.S. aid-in-dying practices.

KEYWORDS: Medical aid in dying, end-of-life care, quality improvement, data collection, oversight, data reliability

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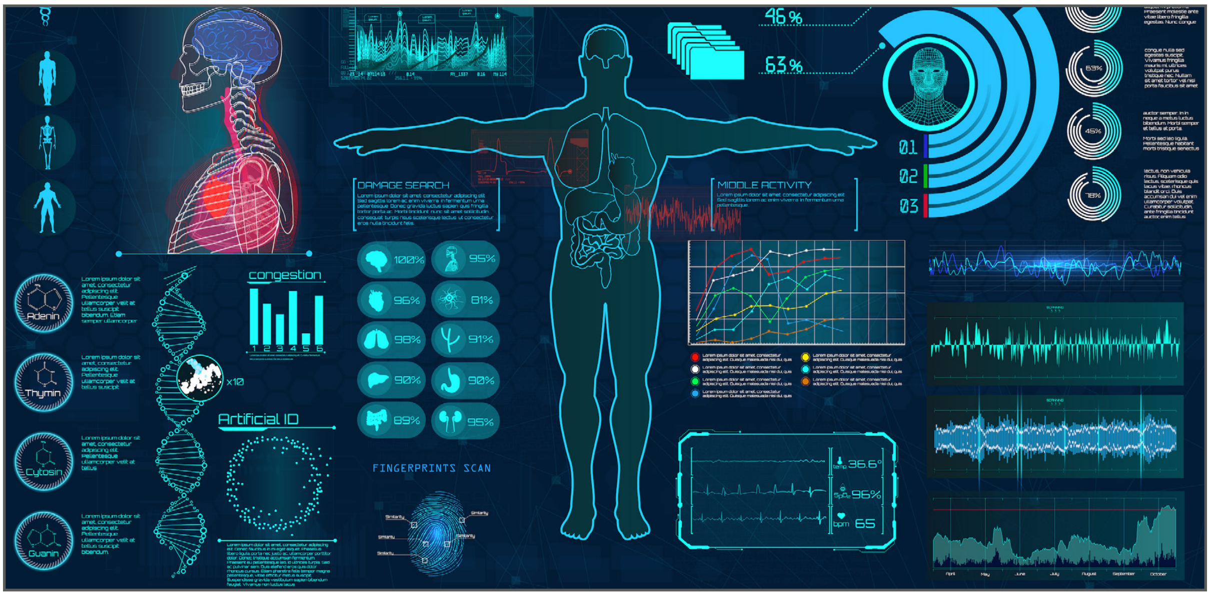


1. INTRODUCTION:
WHY IS AID-IN-DYING DATA IMPORTANT?

Medical aid in dying is an evolving practice that should involve robust oversight to ensure its safe and ethical administration.[1] Critical to oversight of aid in dying, but underdiscussed in the literature, is the role of data collection and reporting. Reliable and comprehensive data collection is essential to transparent evaluations and fully informed discussions about aid in dying. This openness would not only strengthen trust among stakeholders but also encourage informed public discourse. Comprehensive data collection affords health care providers and regulators an invaluable tool to monitor and enhance the delivery of services.

Data collection, however, faces numerous challenges; efforts must balance transparency with patient confidentiality while ensuring accurate and complete reporting. But procedures, methodologies, and standards vary significantly among states, impacting aid-in-dying data quality and accessibility.[1-3] Inaccurate data influences ongoing ethical and policy debates. Some experts have recently called for improved data comprehensiveness and quality.[2,3]

We propose a new method to improve aid-in-dying data collection in the United States, evaluating its quality, identifying gaps, and quantifying the associated costs. This approach, based on the principles of quality improvement, provides concrete recommendations to align existing data collection systems.

2. NAVIGATING THE AID-IN-DYING DATA LANDSCAPE

Data collection for aid in dying has evolved organically since Oregon first implemented the practice in 1997. Figure 1 depicts a flow diagram of Oregon's aid-in-dying process, with a specific focus on data collection. While most states closely follow Oregon's model, variations exist, notably in submission timeframes and in the requirements for psychiatric consultations, final patient attestation, or pharmacist reports.

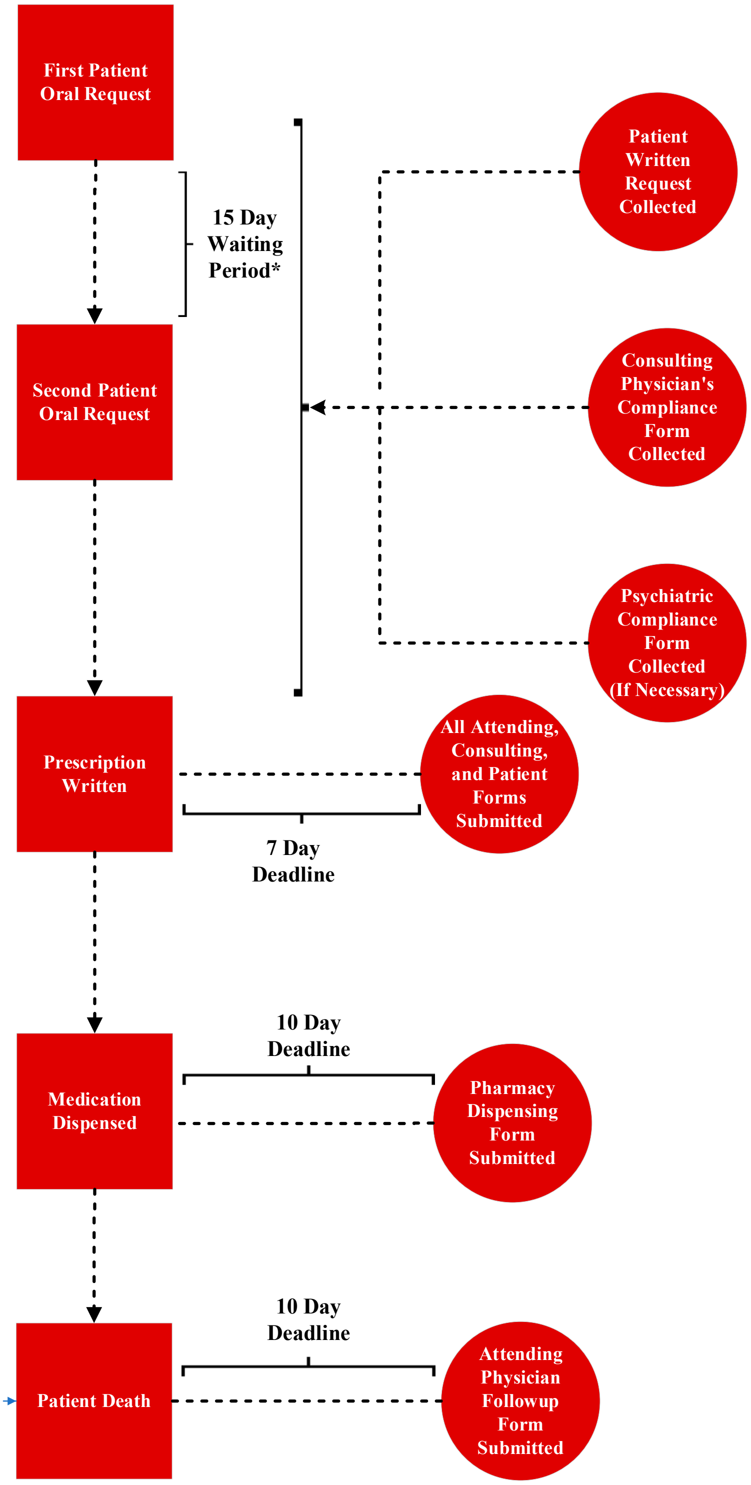
Aid-in-dying data collection can be broadly divided into four categories: patient characteristics, provider characteristics, eligibility criteria and safeguards, and clinical data (Table 1). The level of data collection and reporting vary considerably—from no data at all to highly granular information.

Patient characteristics data, from basic attributes like age and location to clinical specifics such as diagnosis, prognosis, and whether the patient has received palliative care, are routinely but not universally collected.[4-13] Provider-characteristic data offers insight into the distribution of aid-in-dying providers and their specialties, yet most states only collect contact information, largely to ensure future correspondence during oversight activities, and even the most general location data is not released publicly.[6,13]

Data on safeguards and eligibility criteria form the backbone of existing aid-in-dying oversight, serving as pivotal indicators of the ethical and legal compliance of the practice. These include the confirmation of decision-making capacity—an essential criterion that must be satisfied to ensure patient autonomy. Similarly, data on the voluntariness of the patient's choice is critical in assessing the absence of undue influence or coercion. Evidence of patient awareness of the risks underpins the principle of informed consent in medical ethics.

Clinical data provides insight into the procedure itself, including the clinical setting, whether health care providers attended, which medications were administered, and whether there were any medical complications. Such data is vital for ensuring ongoing safety and effectiveness. For instance, in the U.S., drug shortages and price gouging have incentivized experimentation with new drug

Figure 1: Data Collection Flow Diagram for Medical Assistance in Dying in Oregon



*Since 2019, the waiting period can be waived if patient death is imminent.

protocols, though these efforts lack robust clinical evaluation due to legal constraints, difficulties in obtaining Institutional Review Board approval, and persistent stigma around the topic in clinical academic circles. While external research into the topic has been funded by various organizations, the most readily accessible data is provided by the states.[14-17]

Table 1. Data Categories in Medical Aid in Dying Presently Collected in the U.S. and Internationally

Data Category	Example Datapoints	Relevant Purpose
Patient Characteristics	☐ Name ☐ DOB ☐ Gender/Sex ☐ Education Level ☐ Diagnosis ☐ Comorbidities ☐ Disability Status	Access
Provider Characteristics	☐ Licensure ☐ Specialty ☐ Contact Information ☐ Years of Experience ☐ Length of Relationship with Patient ☐ Home Institution/Employer	Accountability
Safeguards	☐ Confirmation of Decision-Making Capacity ☐ Confirmation of Suffering ☐ Confirmation of Terminality ☐ Consulting Clinician Approval ☐ Psychiatric Consultant Approval	Statutory Compliance; Safety
Clinical	☐ Setting ☐ Medications ☐ Dosages ☐ Route of Administration ☐ Clinician Attendance at Procedure ☐ Complications	Safety

Note: The above information was derived from various data collection forms made available on government sites.[4-13]

The accuracy and reliability of aid-in-dying data warrants scrutiny. All participating U.S. states rely on self-reported forms filled out by health care providers post-procedure, potentially introducing recall bias and leading to misremembered details. Furthermore, these states mostly utilize binary data collection in the form of checkboxes to confirm compliance with safeguards and eligibility criteria, limiting response depth and accuracy.

Many other biases are potentially at play. Social desirability bias, wherein respondents provide answers according to societal expectations, might lead clinicians to depict their actions favorably given the contentious nature of the practice, potentially skewing adherence to guidelines or patient outcomes data. Physicians in the Netherlands have been known to lie to oversight committees when responding in data reports to certain clinical questions that they deem excessive or unnecessary.[18] In the U.S., reporting bias may result in underreported negative outcomes due to fear of legal repercussions or professional stigma.

Ambiguities in forms or guidelines can result in interpretation bias and affect data reliability and consistency across providers. What clinicians consider to be a complication can vary considerably.[19,20] Among the 11 U.S. jurisdictions where aid in dying is legal, only Oregon, California, Washington, and Hawaii formally gather data on complications.[4,10,11,13] While Oregon, Washington, and California give a list of potential complications, such as seizures, vomiting, or regaining consciousness, Hawaii lists nothing. Physicians are not limited in what they can consider a complication, as all four states allow complications to be detailed in open response. Several other safeguards and eligibility criteria also revolve around concepts that can be subjective, amorphous, or otherwise difficult to define. Examples include loss of autonomy, decision-making capacity, dignity, suffering, and distress.[21-23]

3. WHAT ARE THE GAPS IN DATA COLLECTION AND REPORTING?

Missing data further exacerbates the potential for error or bias—incomplete reports skew statistics in what is already a data-poor environment, given the low number of procedures in some smaller states.[1,15] There are a multitude of potential reasons for missing data. Providers may have limited time or bandwidth, or the absence of penalties for not submitting may reduce motivation to comply. Paradoxically, the mistaken fear of legal repercussions may discourage providers from submitting forms due to concerns about inaccuracies or omissions that could draw scrutiny.

Gaps and inconsistencies in data collection significantly hinder our ability to evaluate aid-in-dying practices. These gaps are especially glaring in clinical contexts. Most states do not collect data on the types of drugs or dosages administered. Only a few states collect information on time-to-death or whether a clinician was present.[4,10,13] Data about clinical complications is also sparse and in the U.S. is only collected in Oregon, California, Washington, and Hawaii.[4,10,11,13] These data are essential to ensuring the medical community is aware of best clinical practices and hence patient safety.

Another gap in data is the patient's reasons for requesting aid in dying. While only a few states currently collect this information, broader adoption could yield insights into patient behavior and contribute to policy decisions.[4,10,13] For instance, if persistent pain or suffering is commonly listed as a reason for the request, this has implications for the provision of palliative care. Similarly, collecting data on patient requests for aid in dying that have been rejected or denied by physicians can help identify access barriers for vulnerable or otherwise eligible patient populations. Currently, no states routinely monitor denied requests. This can be accomplished by requiring providers to report all requests, fulfilled or denied, as is legally required in Canada—although this would be tremendously more complicated, if impossible, in the U.S. or its states, which lack a centralized health care system. Lastly, data on costs can impact policy decisions along with helping patients and families evaluate end-of-life options more comprehensively.

While most data collected by states is publicly reported, a few critical gaps remain. State health authorities, who are responsible for oversight, do not disclose to the state medical board or relevant governing body how often they refer non-compliant cases, wherein practitioners or patients have not followed the statutory requirements.[24] Cases can be non-compliant when physicians fail to confirm decision-making capacity or provide aid in dying to patients who were not terminally ill. Since no state reports anything about compliance, it is unclear whether such violations even occur. However, this information is necessary to ensure that the laws are not being abused, and that if they are being abused, proper recourse and corrective measures are taken. This is essential to maintain the public's faith in the laws as well as the preservation of political support for aid-in-dying programs.

Another data point frequently collected, yet only reported by half the states that collect it, is whether the patient is currently receiving palliative care. Some states, including California, report on hospice utilization, which is a proxy for palliative care utilization.[4] These data points are not publicly reported in New Jersey, Vermont, or New Mexico.[8,25]

California, Washington, and Oregon collect what the attending physician believes were the concerns that may have contributed to the patient's decision.[4,10,13,15,26,27] While not explicitly collected, most states do not report the number of cases with "unknown status," or cases they lose track of along the aid-in-dying monitoring process or cases for which their information is incomplete. This can include patients who did not go on to complete aid in dying but had data collected on their potential request or prescription at some point. This situation can arise when a patient's wishes change at the end of life or when an unexpected patient death occurs. Cases with unknown status are potentially more likely to fall under the radar of oversight committees as well.

4. WHAT ARE THE COSTS OF DATA COLLECTION?

Data collection imposes a burden on the patient in what is presumably one of the most trying times of their life. When health care workers are spending time on data collection and filling out forms, they are not providing patient care. And time answering questions may distract the patient from other emotional needs while dying. Additionally, there are concerns about patient privacy and confidentiality, especially as methods for data storage and de-identification have not been established for this field of inquiry.[28] The disclosure of participation in aid in dying could lead to stigmatization, discrimination, or alienation from community, family, or religious groups who may hold moral or ethical objections to the practice.

Data collection imposes a considerable burden on clinicians. Attending physicians are required to fill out a variable number of forms; in some states, this can include up to dozens of detailed questions. Oregon requires a total of five forms to be completed: two from the attending physician, one each from the consulting physician, the pharmacist, the patient, and a sixth form, if necessary, by the consulting psychiatrist.[10] The physician must report after writing the prescription and again after the patient's death, with a total of over sixty questions combined. In Hawaii, the patient must return two forms, their written request as well as a final attestation form.[11] New Mexico, on the other hand, only requires two forms in total: a written request from the patient and a seven-question reporting form from the physician after prescription.[9,29]

Some doctors providing aid in dying have described the bureaucratic process of ensuring that patients meet legislative requirements as "burdensome" and as "leading to burnout."[30] Likewise, the sheer volume of paperwork involved may dissuade clinicians from providing aid in dying. Most states still require forms to be sent by traditional mail; only California, Colorado, and the District of Columbia either allow email delivery or have established online portals for simplified data exchange.

An additional consideration is the financial costs of aid-in-dying data collection and public reporting. While such data are not publicly provided in any state, the various components certainly have some financial cost, and public health resources are limited. Data collection, along with the curation and dissemination of public reports requires webhosting or print and mail-related costs on top of labor. The opportunity costs involved in collecting such data can also be substantial.

For all data collection, a careful cost-benefit analysis would be necessary to decide whether the data should be collected and disclosed. Data collection and analyses are not free, and all collections should be assessed to determine the value of the information. Balancing transparency with potential ethical implications also becomes paramount in this context. The decision of whether an individual data set is collected and reported needs to be balanced by the realization that, in aggregate, data collection is onerous. Data should only be collected if their benefit is real, substantial, and justifiable with respect to the costs.

5. A NEW APPROACH: QUALITY IMPROVEMENT

Navigating the complexities of aid-in-dying data collection involves a careful balance of the costs and benefits while keeping the most important goals in mind. On one side, data collection serves as a mechanism to enable case assessment and enhance transparency; on the other, data collection exacerbates patient and clinician administrative burdens. These conflicts must be scrutinized using cost-benefit assessment. Prioritizing *quality improvement* techniques—a feedback loop focused on enhancing patient access and safety—can reconcile these conflicts and provide a consistent goal, serving as a North Star in the intricate aid-in-dying data landscape.[31] The principles of quality improvement—setting clear, measurable objectives, emphasizing regular measurement and data analysis, fostering an environment for continuous learning and improvement, and engaging all stakeholders in the process—can provide a robust framework for enhancing data collection, analysis, and dissemination, which will enhance the care of patients considering aid in dying.[31-33] When applied to data collection, this can take a few different forms. It can focus on what information might be collected to improve qualified patients' access to the law—while preventing those who do not qualify from accessing it. Quality improvement analyses can also focus on providing valuable information to improve the clinical aspects of aid-in-dying practice so that clinicians can provide safer, more effective care.

To take one example of how current data collection in the U.S. does not align with quality improvement principles: not all data that is collected is required to ensure patient safety or access. Many states go to great lengths to categorize patient diagnoses, with California going as far as reporting on over 26 specific disease categories.[26] However, collecting this level of specificity tells us little that is relevant to implementing best practices for the clinical care of those conditions. For example, it does not tell us whether patient mental health conditions are present, whether the patient's decision-making capacity might diminish, whether the patient's choice is voluntary, or anything else of ethical value, which might help with oversight.

Quality improvement is embedded into several international aid-in-dying monitoring systems, providing insights for potential improvements in U.S. data collection. The Netherlands has established a Regional Euthanasia Review Committee that convenes to discuss complex cases, which it publishes annually in various clinical reports.[34] These committees collaborate with government agencies to periodically update clinical-practice guidelines. The committees' data monitoring informs these refinements and standardization efforts.[35] An extensive legal evaluation, commissioned every five years by the Ministry of Health, Welfare, and Sport, relies on data from physician surveys, interviews, case studies, and committee reports.[36] Of course, aid in dying is legal in all of the Netherlands, while it is legal in a minority of U.S. states—making centralized government monitoring and policy changes more difficult in the U.S.

Canada has implemented a national data collection system but allows provincial-level reporting.[37] Standardized forms are used nationally, yet each province has autonomy in managing the data, overseen by appointed aid-in-dying coordinators.[38] This central coordination includes federally funded training and education materials.[39] While not explicitly framed as quality improvement, Canadian reporting requirements align with its key tenets, recognizing the need to balance data collection's benefits with its burdens.[40]

6. RECOMMENDATIONS FOR U.S. DATA COLLECTION SYSTEMS

To transition to a more quality improvement–driven system, those responsible for aid-in-dying oversight and data collection, most commonly state departments of health, can take several steps to modify their systems. First, standardizing data collection and reporting across states and non-government aid-in-dying organizations would improve consistency and comparability, taking inspiration from standardized public health data systems like cancer registries.[41] States should still be free to customize their own data systems, but with attention to minimal standards required for all states.

To focus on patient safety and legal compliance, data not directly pertinent to oversight or quality improvement should be minimized (while non-government investigators could still perform independent IRB-approved studies). For example, some states, like Oregon, report the duration of the physician-patient relationship.[10] While potentially informative, its utility may not justify the efforts, expenses, and risks. Agencies might explore innovative technologies to improve data quality, such as artificial intelligence for identifying inaccuracies or electronic data systems to minimize input errors.

Duplicative data points that do not significantly contribute to quality improvement efforts or legal compliance should be identified and removed. Gaps, especially concerning the financial costs of aid in dying, reasons for aid-in-dying requests, request denials, and the effectiveness of various drug regimens, could be filled in to enhance patient safety and access. Health agencies should enhance transparency around oversight, fostering public trust and facilitating informed public discourse on aid in dying.

States might consider moving from checkboxes to more open responses on some appropriate questions, while avoiding unreasonable difficulties in filling out questionnaires. This might encourage providers to offer narrative details, aiding oversight committees in comprehending individual cases. But it might also risk form fatigue and burdens in logging and evaluating the data. To maintain relevance and accuracy, agencies should regularly audit their data collection systems, promoting a culture of continuous improvement responsive to the evolving realities of aid-in-dying practices and oversight.

7. CONCLUSION

As the dialogue about aid-in-dying practices in the U.S. evolves, improved and synchronized data collection will become an essential tool to improve clinical practices and oversight. Reorienting data systems towards a quality improvement model has the potential to create a more effective, focused, and patient-centered system. Quality improvement approaches transform data into actionable insights, fostering transparency, evidence-based discourse, and better patient outcomes. As we continue refining aid-in-dying practices and oversight, quality improvement and improved data coordination can enhance patient care.

DISCLOSURE STATEMENT

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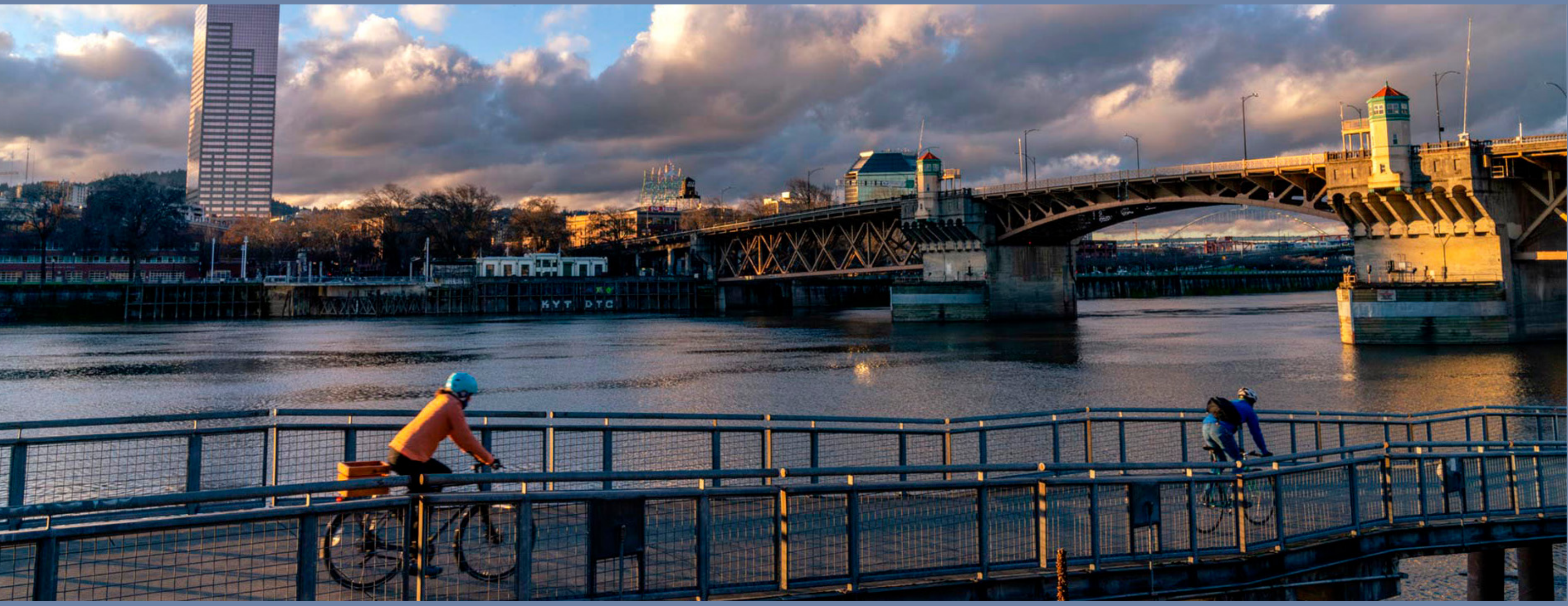
1. Riley S. Watching the watchmen: changing tides in the oversight of medical assistance in dying. *J Med Ethics.* 2023;49(7):453-7 PMCID: PMID: 36150893. doi: 10.1136/jme-2022-108470.
2. Abbott J, Glover J, Wynia M. Accepting professional accountability: a call for uniform national data collection on medical aid-in-dying. *Health Affairs Blog: End of Life & Serious Illness.* 2017.
3. Worthington A, Regnard C, Sleeman KE, Finlay I. Comparison of official reporting on assisted suicide and euthanasia across jurisdictions. *BMJ Support Palliat Care.* 2022 PMCID: PMID: 36585221. doi: 10.1136/spcare-2022-003944.
4. California Department of Public Health. California End of Life Options Act Attending Physician's Clicklist and Compliance Form. https://eforms.cdph.ca.gov/content/cdph-global/login.html?resource=%2F&$$login$$=%24%24login%24%24&j_reason=unknown&j_reason_code=unknown. Accessed July 13, 2023.
5. Colorado Department of Public Health & Environment. Medical Aid in Dying: Reporting Requirements. https://cdphe.colorado.gov/center-for-health-and-environmental-data/registries-and-vital-statistics/medical-aid-in-dying#Reporting. Accessed July 13, 2023.
6. DC Health. Death with Dignity Forms. https://dchealth.dc.gov/publication/death-dignity-forms. Accessed August 8th, 2023.
7. Maine Department of Health and Human Services. Attending Physician End-of-Life Reporting Form. https://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/documents/pdf-files/Attending-Physician-Reporting-Form.pdf. Accessed July 13, 2023.
8. New Jersey Department of Health. NJ DOH Attending Physician Compliance Form. https://nj.gov/health/advancedirective/documents/maid/MAID-7.pdf. Accessed July 13, 2023.
9. New Mexico Department of Health: New Mexico Vital Records and Health Statistics. Medical Aid in Dying Reporting Form. https://www.nmhealth.org/publication/view/form/8381/. Accessed August 8th 2023.
10. Oregon Health Authority. Death with Dignity Reporting Forms and Instructions. https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/pasforms.aspx. Accessed July 13, 2023.
11. State of Hawaii Department of Health, Office of Planning Policy and Program Development. Our Care, Our Choice Act: Healthcare Provider and Patient Forms. https://health.hawaii.gov/opppd/ococ/. Accessed July 13, 2023.
12. Vermont Department of Health. Patient Choice and Control at End of Life: Forms for Patients and Physicians. https://www.healthvermont.gov/systems/end-life-decisions/patient-choice-and-control-end-life. Accessed July 12, 2023.
13. Washington State Department of Health. Forms for Patients and Providers. https://doh.wa.gov/you-and-your-family/illness-and-disease-z/death-dignity-act/forms-patients-and-providers. Accessed July 13, 2023.
14. American Clinicians Academy on Medical Aid in Dying. Pharmacology. https://www.acamaid.org/pharmacologyinfoupdates/. 2021. Accessed August 7th 2023.
15. Oregon Health Authority Center for Health Statistics. Oregon Death with Dignity Act: 2022 Data Summary. https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year25.pdf. 2023.
16. Riley S. Navigating the new era of assisted suicide and execution drugs. *Journal of Law and the Biosciences.* 2017;4(2):424-34 PMCID: PMID: doi: 10.1093/jlb/lsx028

17. Worthington A, Finlay I, Regnard C. Efficacy and safety of drugs used for ‘assisted dying’. *Br Med Bull*. 2022;142(1):15-22 PMCID: PMC9270985 PMID: 35512347. doi: 10.1093/bmb/ldac009.
18. Riley SR, Overbeek A, van der Heide A. Physician adherence to clinical guidelines in euthanasia and assisted suicide in the Netherlands: a qualitative study. *Fam Pract*. 2020;37(2):269-75 PMCID: PMID: 31677267. doi: 10.1093/fampra/cmz069.
19. Groenewoud JH, van der Heide A, Onwuteaka-Philipsen BD, Willems DL, van der Maas PJ, van der Wal G. Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands. *New England Journal of Medicine*. 2000;342(8):551-6 PMCID: PMID: doi: 10.1056/NEJM200002243420805.
20. Zworth M, Saleh C, Ball I, et al. Provision of medical assistance in dying: a scoping review. *BMJ Open*. 2020;10(7):e036054 PMCID: PMC7348461 PMID: 32641328. doi: 10.1136/bmjopen-2019-036054.
21. Hatherley JJ. Is the exclusion of psychiatric patients from access to physician-assisted suicide discriminatory? *J Med Ethics*. 2019;45(12):817-20 PMCID: PMID: 31462453. doi: 10.1136/medethics-2019-105546.
22. Menzel PT, Steinbock B. Advance directives, dementia, and physician-assisted death. *J Law Med Ethics*. 2013;41(2):484-500 PMCID: PMID: 23802899. doi: 10.1111/jlme.12057.
23. Dees M, Vernooij-Dassen M, Dekkers W, van Weel C. Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: an integrative review. *Psychooncology*. 2010;19(4):339-52 PMCID: PMID: 19771571. doi: 10.1002/pon.1612.
24. Oregon Health Authority. Oregon’s Death With Dignity Act: Frequently Asked Questions. https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/faqs.aspx#oversight. Accessed September 6, 2023.
25. Vermont Department of Health. Report to The Vermont Legislature: Report Concerning Patient Choice at End of Life. https://legislature.vermont.gov/assets/Legislative-Reports/2020-Patient-Choice-Legislative-Report-2.0.pdf. Accessed July 13, 2023.
26. California Department of Public Health. California End of Life Option Act 2020 Data Report. 2021. https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/CDPH_End_of_Life_Option_Act_Report_2020_FINAL.pdf. Accessed May 31, 2020.
27. Washington State Department of Health. 2020 Death with Dignity Act Report. 2021. https://doh.wa.gov/you-and-your-family/illness-and-disease-z/death-dignity-act/death-dignity-data. Accessed May 31, 2022.
28. Crumley ET, Kelly S, Young J, Phinney N, McCarthy J, Gubitz G. How is the medical assistance in dying (MAID) process carried out in Nova Scotia, Canada? A qualitative process model flowchart study. *BMJ Open*. 2021;11(7):e048698 PMCID: PMC8314721 PMID: 34312206. doi: 10.1136/bmjopen-2021-048698.
29. New Mexico Department of Health. Request for Medication to End My Life in a Peaceful Manner. https://www.compassionandchoices.org/docs/default-source/new-mexico/new-mexico-request-for-medication-to-end-my-life-in-a-peaceful-manner-final-06.15.21e5a14507-ba00-4c31-abea-28c03d8ff921.pdf?sfvrsn=fc8e76df_1. Accessed August 8th 2023.
30. Buchbinder M. Scripting death: stories of assisted dying in America. University of California Press; 2021.
31. Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. *Health Aff (Millwood)*. 2008;27(3):759-69 PMCID: PMID: 18474969. doi: 10.1377/hlthaff.27.3.759.

32. Batalden PB, Davidoff F. What is “quality improvement” and how can it transform healthcare? *Qual Saf Health Care.* 2007;16(1):2-3 PMCID: PMC2464920 PMID: 17301192. doi: 10.1136/qshc.2006.022046.
33. Donabedian A. The quality of care. How can it be assessed? *Jama.* 1988;260(12):1743-8 PMCID: PMID: 3045356. doi: 10.1001/jama.260.12.1743.
34. Regional Euthanasia Review Committees. RTE Annual Report 2022. 2023. https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports. Accessed May 23, 2023.
35. Regional Euthanasia Review Committees. Euthanasia Code 2022: Review Procedures in Practice. 2019. https://english.euthanasiecommissie.nl/the-committees/documents/publications/euthanasia-code/euthanasia-code-2022/euthanasia-code-2022/euthanasia-code-2022. Accessed July 13, 2023.
36. van der Heide A, Legemaate J, Onwuteaka-Philipsen BD, et al. Vierde evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding [Fourth Evaluation of the Termination of Life of Request and Assisted Suicide Act] *Zonmw* https://wfrtds.org/fourth-evaluation-of-the-dutch-euthanasia-law-has-been-published/. 2023.
37. Canada Gazette. Regulations for the Monitoring of Medical Assistance in Dying: SOR/2018-166. https://gazette.gc.ca/rp-pr/p2/2018/2018-08-08/html/sor-dors166-eng.html. 2018. Accessed August 11th, 2021.
38. Kotalik J. Medical assistance in dying: challenges of monitoring the Canadian program. *Canadian Journal of Bioethics / Revue canadienne de bioéthique.* 2020;3(3):202-9 doi: https://doi.org/10.7202/1073799ar
39. Health Canada. Model Practice Standard for Medical Assistance in Dying (MAiD). https://www.canada.ca/en/health-canada/services/publications/health-system-services/model-practice-standard-medical-assistance-dying.html. Accessed August 17, 2023.
40. Health Canada. Monitoring System for Medical Assistance in Dying in Canada. https://www.canada.ca/en/health-canada/services/publications/health-system-services/monitoring-system-medical-assistance-dying.html. Accessed July 16, 2023.
41. Carter RM, Rodgerson B, Grace M. Medical assistance in dying: Canadian registry recommendations. *Alta. L. Rev.* 2018;56:55.

CONFERENCE REVIEW



NATIONAL CLINICIANS CONFERENCE ON MEDICAL AID IN DYING 2.0: PORTLAND 2023

MONIQUE SCHAULIS, MD, MPH

MONIQUE SCHAULIS practices Emergency and Palliative Medicine with The Permanente Medical Group in San Francisco, where she has been a leader in aid-in-dying care. She is a past president of the San Francisco Marin Medical Society, and past chair of the Medical Aid in Dying special interest group for the American Academy of Hospice and Palliative Medicine.

The second National Clinicians Conference on Medical Aid in Dying (co-facilitated by the American Clinicians Academy on Medical Aid in Dying and Death with Dignity) was held in Portland this year, three years after the inaugural 2020 conference in Berkeley. The incentive for both conferences was the pressing need for clinical discussions, explorations, and evidence-based knowledge about aid in dying. Patient requests to consider medical aid in dying have driven clinicians' need to respond with support and expertise.

The Portland conference covered a broad range of topics related to end-of-life care and aid in dying. A diverse group of practitioners attended—social workers, nurses, doulas, physicians, chaplains, and a variety of administrators, lawyers, and activists—from as far away as Australia. As with the 2020 conference, the goal in 2023 was not to promote aid in dying but to promote excellent care at the end of life, which may include aid in dying.

Approximately 74 million U.S. residents live in an aid-in-dying state, and 87 million more live in states where legislation is pending. Since the 2020 conference, New Mexico joined the aid-in-dying jurisdictions. The newest state was well represented at the conference by the loudest-cheering contingent in the room.

Hospice continues to play a critical role for most patients who are considering aid in dying since they are so intimately involved with day-to-day care at the end of life. A stunning example: In California in 2022, 95.4% of patients provided with aid-in-dying medications were receiving hospice care.[1] As the conference presenters made clear, hospice policies vary regarding aid-in-dying discussions and the presence of personnel when patients ingest the medications. Hospice physicians sometimes are attending/prescribing or consulting/second-opinion doctors, but practices vary.

In 2020, By the Bay Health shared their experiences with aid-in-dying bereavement, concluding that some family members felt they could not openly grieve for fear of judgment. In 2023, we were fortunate to hear about increasing numbers of online support groups for loved ones of patients who died with aid in dying. We are reaping some of the benefits of telehealth, making these critical services more readily available to people all over the country.

As in 2020, Tracey Bush, MSW, and Terri Laws, PhD, led a session on religion, race, and spiritual concerns for African American patients. Ethical dilemmas, in-person support, prognostication, pharmacology, and socially and medically challenging cases rounded out the curriculum.

Finally, the theoretical project we talked about in 2020, the American Clinicians Academy on Medical Aid in Dying, is now a reality! This new academy is serving to implement educational opportunities that will promote data-driven quality of care for the aid-in-dying population far into the future.

I had the pleasure of asking some of our attendees to reflect on the significance of the 2023 conference for them:

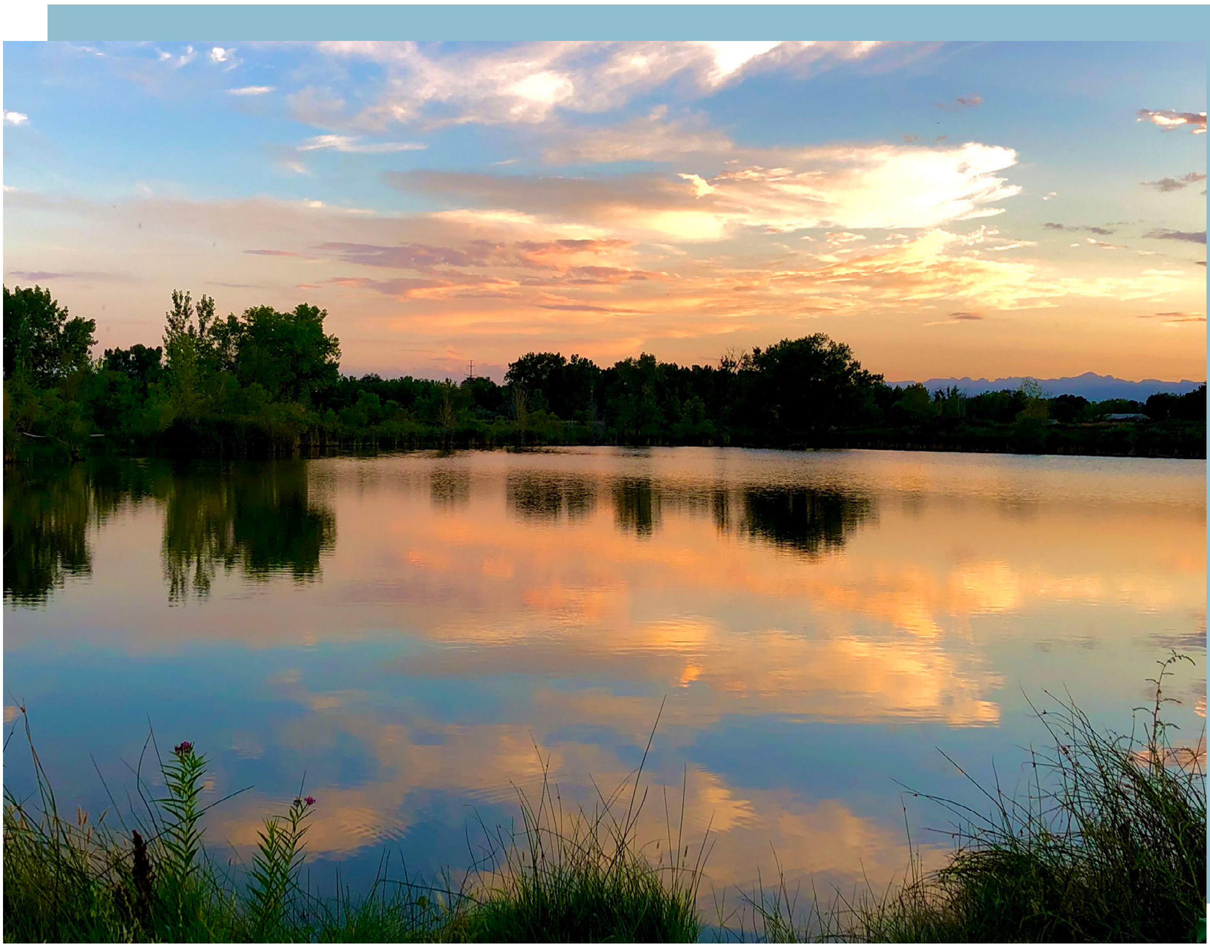
Tracey A. Bush, MSW, LCSW (California):

The 2020 conference was very physician focused. Care of the total person had been falling behind our advances in medical and pharmacological care. The 2023 conference featured more presenters from various disciplines including nursing, social work, chaplaincy, and death doulas—expanding on the notion of the core clinical team for medical aid and dying. We can see more clearly now the importance of spiritual, emotional, and psychological care of dying patients and their families and of the importance of all disciplines to good clinical practice. Attendance at the day of death is a next-level intervention we should consider as the standard of care.

We need to mature beyond a grassroots organizational approach. We are no longer outsiders, but part of the larger end-of-life care establishment. We should think of medical-aid-and-dying practice in terms of organizational development: creating, building, maturing. The 2023 conference showed that we have transitioned from creating to building. Next, we can advance to maturing.

Carl De Mars, MD (Maine):

These two Academy conferences I attended have been formative in my practice here in Maine. The first one taught me about red flags, the law, pharmacology, and the need for bedside presence on the day of ingestion. The 2023 conference built upon those themes and brought a wider audience together to discuss support for our teams and patients. Presentations about prognosis and bereavement were especially helpful. The time to connect with colleagues who do this work was excellent and necessary to form connections to sustain our work.



VALERIE BAKER-EASLEY, End of Life Doula, INELDA and ACAMAID trained, founder of Gentle Journeys, LLC, providing End of Life Doula Services including MAID in Northern Colorado.

Photo from River's Edge Natural Area in Loveland, Colorado, where hiking in nature and capturing its soul-stirring beauty restores my spirit and keeps my work fresh.

Julie Hertl, LCSW (Seattle):

I have been the Death with Dignity Social Worker for Kaiser Permanente Washington since 2017. I was unable to attend the 2020 conference, so this 2023 event was the first time I was in a room with more than my immediate team to explicitly talk about medical aid in dying. It was marvelous!

I was deeply grateful to share, learn, and engage with colleagues across the country—to realize there are many approaches to aid-in-dying care. I came away with new ideas and resources, as well as a greater appreciation for the need to tailor our work to different settings and people.

I left the conference with more questions than answers, and a pressing need to do another conference sooner rather than later. There is still so much to be discussed, designed, done! The conference provided a step in the right direction, I hope, to an open-ended future of learning and teaching about aid in dying.

Hunter Marshall, NP (New Mexico):

The "medical" in medical aid in dying misrepresents the richness of our collective work. The conference showed that the scale of support vastly exceeds the medical—to the emotional, the existential, affirming human experience and far beyond. There were death doulas, social workers, nurses, community organizers, volunteers, as well as physicians.

As a New Mexico nurse practitioner, I was elated to know that more nurse practitioners and physician assistants have space in this field. Many of us have had previous careers as nurses, EMTs, and other occupations, affording us the opportunity to experience death and dying from a different perspective. A diversity of experiences and opinions serves us all better.

It's a demographic truth that those who utilize medical aid in dying, as well as hospice, are more often white, traditionally educated, and affluent. If we are to create a world in which people have autonomy and choice, we must focus on ensuring there is equity, both during life and at the end of life.

Kris Kington Barker, End-of-Life Doula (California):

As an end-of-life doula, I felt the conference's energy and inclusion of the multi-disciplines. The opening presentation emphasized that clinicians care for patients considering aid in dying—which set the tone for the presentations to come. I appreciated the shared data and experiences collected by the presenters, which made it possible to define some best practices. The presentations highlighting the variance in challenges by different states were a reminder of how important collaboration, shared support and resources are.

As an end-of-life doula and doula educator, the medical information was extremely important and a reinforcement that supporting aid-in-dying clients from a best-practice model requires both training and experience regardless of what discipline the clinician is in.

The presentation *Race, Religion, and Spiritual Considerations in Aid in Dying*, which focused on African American patients, was impactful and important. The gentle way the grief segment was presented, and the openness of the family members, was moving and emphasized the importance of what can often become disenfranchised grief.

Wrapping up with social and medically challenging cases brought the conference to a close with a reverence about the importance of mindfulness, and a compassionate understanding that dying can be complicated.

Tin Do, MD (California):

Despite my providing aid in dying to many patients, I needed to learn and hear from others. So I was excited to attend the 2023 conference. And I did learn more. The meeting was a great way to connect and network with others doing this work. I liked the national aspect, as it is important to hear about what others are doing outside my state.

The real significance of the conference was that medical aid in dying is now becoming more important and relevant, and we can discuss and share our ideas openly. It's a new field in medical care, and I'm proud to be a part of it.

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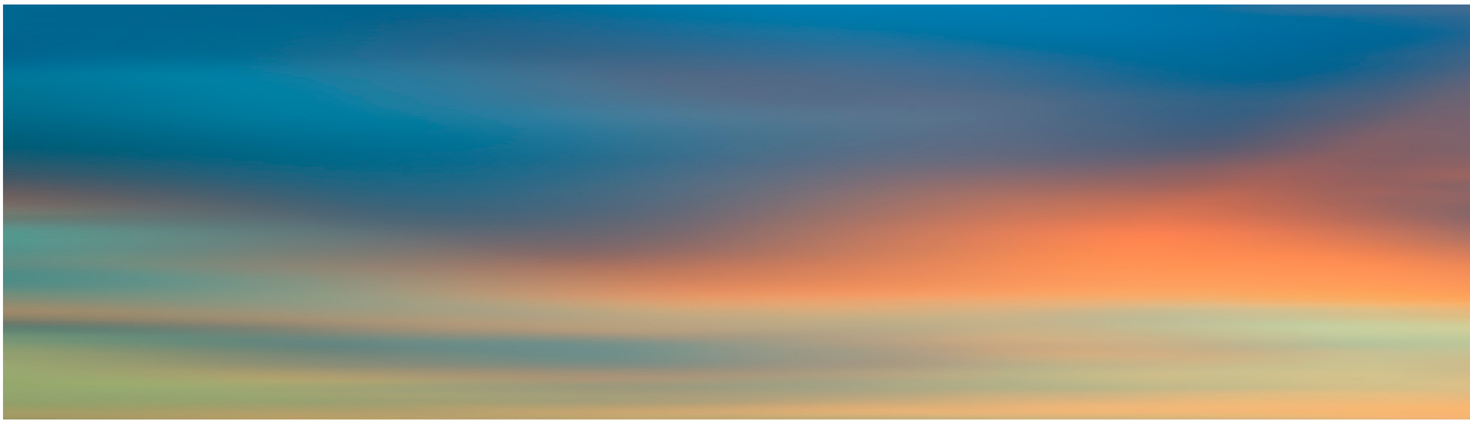
1. California Department of Public Health. "California End of Life Option Act 2022 Data Report." 2022. https://tinyurl.com/CalDPH-MAID2022.



A PRACTICE SURVEY OF CLINICIANS PROVIDING MEDICAL AID IN DYING

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Abstract: Clinicians who provide aid in dying are still developing best practices, especially about the most ethically complex clinical questions. This article focuses on two of those: (1) whether to attend the ingestion of the aid-in-dying medications; (2) whether to raise the option of aid in dying with patients who have not yet raised it themselves.

We surveyed clinicians registered for the American Clinicians Academy on Medical Aid in Dying's online listserv who had prescribed an aid-in-dying medication. Seventy-two clinicians responded to our survey (21%). On average, they reported caring for 99 patients considering an assisted death, having written an average of 65 aid-in-dying prescriptions.

In answer to the two clinical questions we found: (1) Clinicians were just as likely to report "often" or "always" attending the ingestion of aid-in-dying medications as they are to report "rarely" or "never." Clinicians who report practicing in a "specialized aid-in-dying practice" were more likely to report attending the ingestion than the general physician respondents. (2) 21% of clinicians reported that they "often" or "always" raise the option of aid in dying with patients who have not raised it themselves, while 45% report they "rarely" or "never" do. Even when accounting for different practice types, there appear to be a variety of practices in the overall cohort of clinicians caring for patients considering aid in dying.

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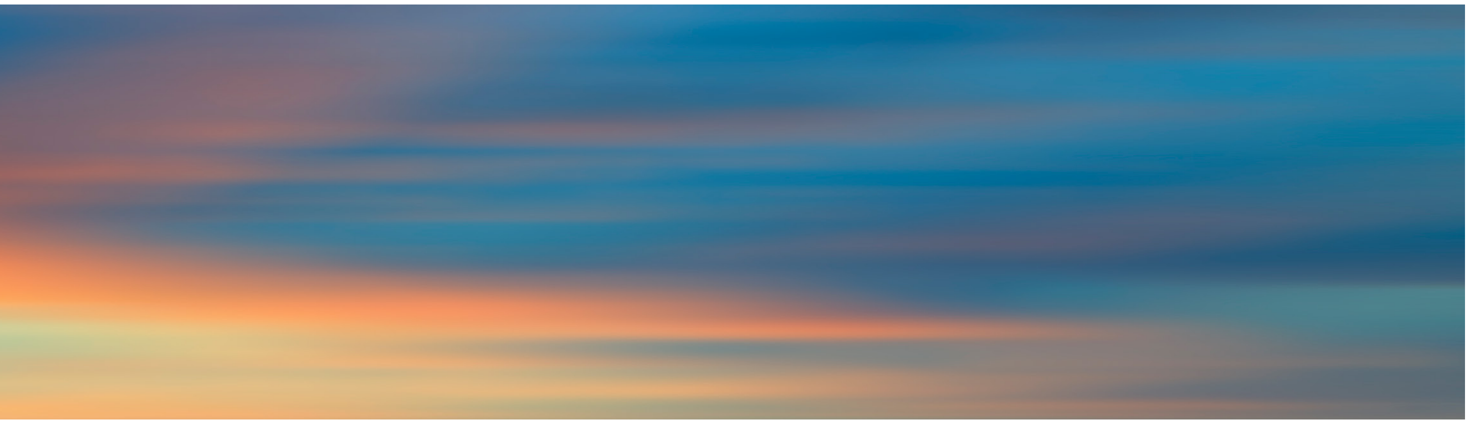


KEYWORDS:
Terminal care; right to die; hospice; palliative care; medical aid in dying.

1. INTRODUCTION

Even in U.S. jurisdictions where aid in dying is legal, the clinical practice is still developing. Formal research on aid in dying is lacking. Large medical societies have been opposed or neutral, leaving clinicians who might be willing to provide the option without institutional guidance or support for developing best practices.[1,2] In 2020, the American Clinicians Academy on Medical Aid in Dying was founded as a non-membership organization to support clinicians caring for patients who are considering or completing aid in dying. One Academy goal is to build a community consensus of best practices.

Two important and ethically charged practice questions are whether clinicians should attend the ingestion of the aid-in-dying medication and whether they should raise the option of aid in dying with patients who have not yet raised it themselves.

Though complications are rare, there have been reports of issues arising during or soon after ingesting the aid-in-dying medications.[3–5] Clinicians may want to be there to troubleshoot any technical problems or support their patients to the end of their lives. While some clinicians feel strongly about being present for the time of ingestion, others feel less inclined, perhaps because of competing clinical responsibilities or worries that this may cross an important boundary of moral responsibility.[6,7]

> “MANY TERMINALLY ILL PATIENTS ARE NOT AWARE THAT THEY HAVE THE OPTION FOR AID IN DYING”

Many terminally ill patients are not aware that they have the option for aid in dying. In a survey of Vermont physicians, 49% said they discuss the option of aid in dying only if the patient specifically asks (though this included many clinicians who had never prescribed an aid-in-dying medication). Principles of informed consent suggest that clinicians have a duty to inform patients about their treatment options. Yet, when it comes to aid in dying, many bioethicists suggest that clinicians should not discuss the option of aid in dying unless the patient has raised it.[8] This stems from concerns that clinicians who raise the option may influence or sway a vulnerable patient towards aid in dying or may jeopardize the clinician patient relationship.[9]

To gain insight into the practice habits of clinicians who are involved in caring for patients considering aid in dying, we surveyed prescribing clinicians registered for the Academy listserv.

2. METHODS

In May 2023 we distributed a survey through the listserv of the American Clinicians Academy on Medical Aid in Dying. Any clinician who had written an aid-in-dying prescription met the inclusion criteria. Responses were collected anonymously through Google Forms. The survey was approved by the institutional review board at the MedStar Health Research Institute.

Demographic questions included age, gender, race, professional discipline, years in practice, and religious adherence. The survey asked respondents to identify their medical training and practice type, setting, and jurisdiction. For training or practice type questions, we allowed multiple answers and invited free text responses.

Respondents were asked how many patients they cared for in the context of aid in dying and how many aid-in-dying prescriptions they had written. For these questions, we invited an estimate or a range, since many clinicians care for hundreds of patients considering aid in dying. For purposes of analysis, when a clinician provided a range, we took the average of that range; so when a clinician had written ">100," this was counted as 100.

The survey asked respondents about their practice on a five-point Likert scale. Demographic data and Likert scale data were analyzed using descriptive statistics. To compare Likert scale responses between questions, the data was analyzed as ordinal data and given numerical values 1–5 to compare means. Where means tended to differ between groups by more than a half point (0.5) on the Likert scale, a two-tailed t-test was used to compare the means between groups for statistical significance. A p-value of <0.05 was considered statistically significant.

3. RESULTS

Of the 340 potentially prescribing clinicians registered for the Academy listserv at the time of survey administration (306 physicians and 34 advance practice providers), 72 responded to this survey. 97% of respondents were physicians, 92% described their race as white, 50% were over the age of 60, and 68% had been in medical practice for more than 10 years (Table 1).

Table 2 shows practice and setting details. While most clinicians practiced in primary care (39%) or hospice/palliative care (33%), nearly a quarter described a specialized "aid-in-dying practice" (22%). 56% were either affiliated with an independent practice or unaffiliated. 67% of respondents practiced on the West Coast of the United States (California, Oregon, and Washington).

On average, respondents reported caring for 99 patients considering aid in dying (median 45; range 2–500); respondents wrote on average 65 aid-in-dying prescriptions (median 27; range 1–500). All responding clinicians accounted for approximately 4,671 aid-in-dying prescriptions; 18% of clinicians wrote 3,038 (65%) of those prescriptions.

Twelve of the 72 clinicians (15%) reported no difference between the number of patients considering aid in dying and the number of aid-in-dying prescriptions written, meaning that they reported to have cared for and written prescriptions for an equal number of patients. For the remaining 60 clinicians, the average difference between the number of patients considering aid in dying and the number of aid-in-dying prescriptions was 41 (median 16; range 1-200).

Figure 1 shows clinicians' practice of attending the ingestion of aid-in-dying medications. 39% report they "often" or "always" attend, while 41% report they "rarely" or "never" attend the death. When the Likert scale was analyzed as ordinal data, on average clinicians tend to "sometimes" (3.0/5) attend the ingestion. Those who report practicing in a specialized "aid-in-dying practice" are closer to reporting that they "often" attend the ingestion (3.7/5) whereas the rest of the cohort tends toward "sometimes" (2.8/5)—though this difference barely reached significance (p=0.048). Those who report practicing in a hospice/palliative care practice did not differ from the rest of the cohort with regards to attending ingestion.

Figure 2 shows whether clinicians introduce the option of aid in dying to patients who have not raised it themselves. 45% report they "rarely" or "never" raise the option; 21% report they "often" or "always" do. When the Likert scale is analyzed as ordinal data, on average clinicians tend to raise the option of aid in dying between "rarely" and "sometimes" (2.5/5). Those who report practicing in a specialized "aid-in-dying practice" tended toward "rarely" (2.2/5) compared with the rest of the cohort who tended toward "sometimes" (2.6/5). This was not a substantial difference. On average, those who report practicing in a hospice/palliative care practice did not differ from the rest of the cohort with regards to raising the option of aid in dying.

4. DISCUSSION:

Two important clinical-practice questions for aid-in-dying clinicians are whether they should attend the patient's ingestion of the medications and how the patients should learn about the option of aid in dying.

Clinicians in this cohort varied regarding how often they attend ingestion of the aid-in-dying medication. When comparing the average practice among sub-cohorts such as practice type or years in practice, only clinicians who reported their practice setting as a specialized "aid-in-dying practice" were on average more likely than the general cohort to report attending the ingestion. It is common for care providers other than attending/prescribing clinicians to attend the ingestion, so these numbers do not speak to the nature or quality of care provided on the day of ingestion, only to the presence or absence of the attending/prescribing clinician.

We also asked clinicians how often they raise the option of aid in dying with patients who have not raised it themselves. Here, too, we found a variety of practices. Even clinicians in specialized "aid-in-dying practice" who receive referrals of patients already aware of aid in dying did not differ substantially from the rest of the cohort about bringing up aid in dying. However, given how controversial this is, it is noteworthy that over 50% of all respondents report either "sometimes," "often," or "always" raising the option of aid in dying with patients who have not raised it.

Twelve clinicians reported no difference between the number of patients considering aid in dying and the number of prescriptions written. This contrasts with the rest of the cohort that reported a difference in patients cared for and prescriptions written. While it is hard to know what to make of this discrepancy without further information, it may represent a philosophical difference in approach to caring for patients considering aid in dying.

Our findings show that even in this cohort of clinicians who are actively working to shape the standard of care for aid in dying, there are a wide variety of practices in these challenging areas. This survey raises critical practice questions that deserve further investigation. Should every patient considering aid in dying receive a prescription? What is the role of the prescribing clinician on the day of ingestion? Ought terminally ill patients be informed of the option for aid in dying in jurisdictions that allow it, even if they don't bring it up themselves?

The most evident limitation of this study is the low response rate of 21%. However, this rate is an estimate. Of the 340 potentially prescribing clinicians registered for the Academy's listserv, it is not known how many have ever prescribed an aid-in-dying medication, thus meeting the inclusion criteria. While not known, we expect the actual response rate of eligible clinicians is higher. Another important limitation is that this cohort represents the most experienced, dedicated, and expert clinicians in aid in dying, and may not be generalizable to all clinicians involved in the care of patients considering aid in dying.

Despite the above limitations, given the lack of larger and more inclusive studies in this field, our data provides important information about the practices of clinicians who care for patients considering aid in dying.

ACKNOWLEDGEMENTS:

We would like to acknowledge the American Clinicians Academy on Medical Aid in Dying for allowing us to distribute this survey on their listserv, and the generosity of the clinicians who were willing to share their practices with us.

AUTHOR DISCLOSURE STATEMENT:

The authors declare that there is no conflict of interest.

Table 1. Demographics of survey respondents

Gender	
Female	35 (49%)
Male	34 (48%)
Nonbinary	2 (3%)
Age	
20–30	1 (1%)
30–40	9 (13%)
40–50	13 (18%)
50–60	13 (18%)
60–70	26 (36%)
>70	10 (14%)
Race	
White	66 (92%)
Asian	6 (8%)
Hispanic	1 (1%)
Religiosity	
Not at all	41 (57%)
Hardly	15 (21%)
Somewhat	9 (13%)
Very	5 (7%)
Years in practice	
<5	14 (19%)
5–10	9 (13%)
10–20	15 (21%)
>20	34 (47%)
Discipline	
Physician	70 (97%)
Physician Assistant	1 (1%)
Nurse Practitioner	1 (1%)
Training	
Internal Medicine (or subspecialty)	30 (42%)
Family Medicine (or subspecialty)	26 (36%)
Emergency Medicine	14 (19%)
Obstetrics & Gynecology	2 (3%)
Psychiatry	2 (3%)
Neurology	1 (1%)
ENT/Allergy	1 (1%)
Anesthesiology	1 (1%)
Pediatrics/Neonatology	1 (1%)
Nursing	1 (1%)

Table 2. Practice type, setting, and jurisdiction

Practice type	
Primary Care	28 (39%)
Hospice/Palliative Care	24 (33%)
Specialized "Aid in Dying" Practice	16 (22%)
Emergency/Urgent Care	6 (8%)
Retired/Volunteer	5 (7%)
Hospital Medicine	3 (4%)
Medical Oncology	2 (3%)
Neurology	1 (1%)
Endocrinology	1 (1%)
Labor and Delivery	1 (1%)
Clinical Ethics	1 (1%)
Clinical setting	
Independent Practice	30 (42%)
Community Hospital	17 (24%)
Hospice	10 (14%)
Unaffiliated/Retired	10 (14%)
University Hospital	8 (11%)
University Affiliated Hospital	7 (10%)
Jurisdiction	
California	30 (42%)
Oregon	9 (13%)
Washington	9 (13%)
Colorado	8 (11%)
New Mexico	8 (11%)
New Jersey	4 (6%)
Hawai'i	2 (3%)
Vermont	2 (3%)
District of Columbia	1 (1%)
Maine	1 (1%)

Figure 1. How often clinicians attend ingestion of aid-in-dying medication

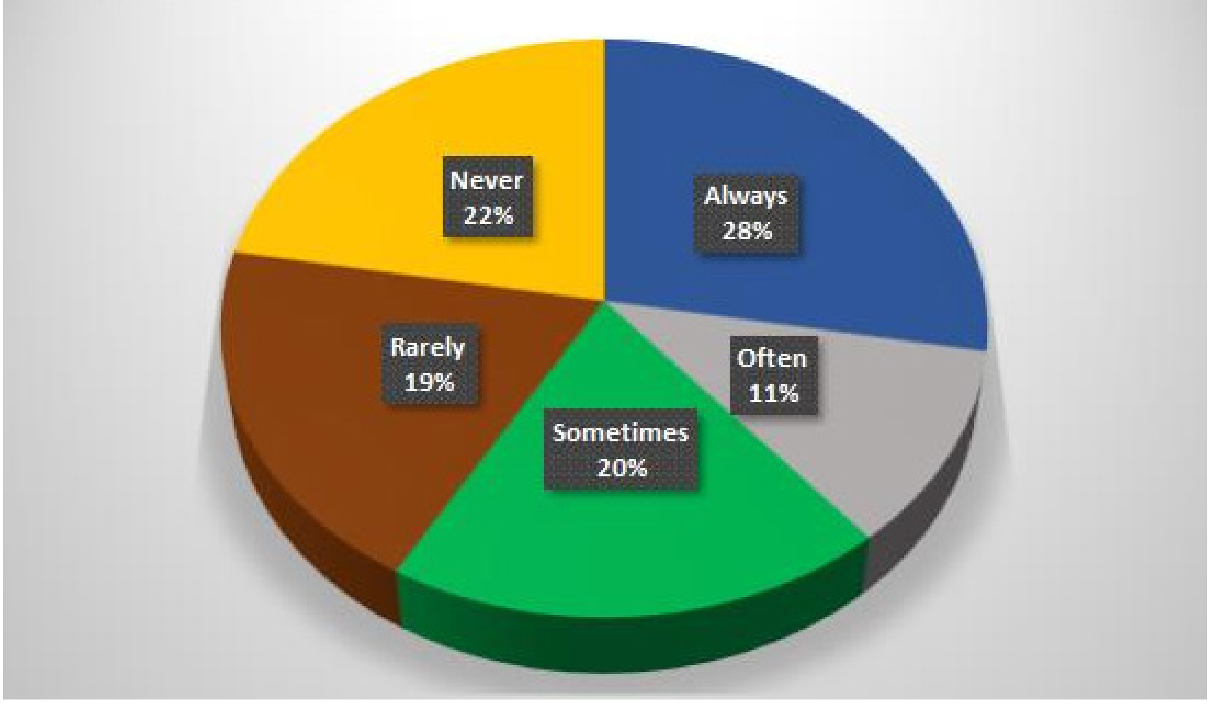
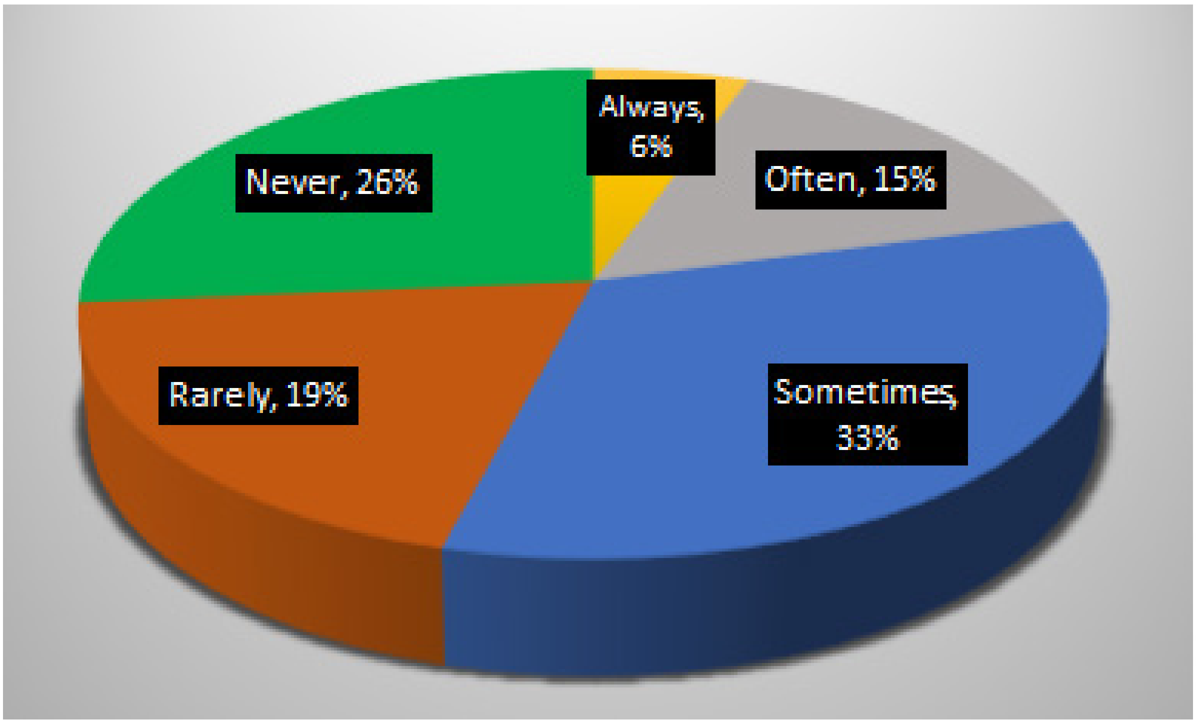


Figure 2. How often clinicians introduce the option of aid in dying with patients who have not raised it themselves



1. Physician-Assisted Suicide | AMA-Code. Accessed May 25, 2023. https://code-medical-ethics.ama-assn.org/ethics-opinions/physician-assisted-suicide.
2. Position Statement on Physician-Assisted Death. *J Pain Palliat Care Pharmacother*. 2007;21(4):55-57. doi:10.1080/J354V21N04_12.
3. Al Rabadi L, Leblanc M, Bucy T, et al. Trends in medical aid in dying in Oregon and Washington. *JAMA Netw Open*. 2019;2(8). doi:10.1001/JAMANETWORKOPEN.2019.8648.
4. Groenewoud JH, van der Heide A, Onwuteaka-Philipsen BD, Willems DL, van der Maas PJ, van der Wal G. Clinical problems with the performance of euthanasia and physician-assisted suicide in The Netherlands. *N Engl J Med*. 2000;342(8):551-556. doi:10.1056/NEJM200002243420805.
5. Landry KK, Ely J, Thomas AA. Experience and attitudes regarding Medical Aid in Dying, Act 39, among Vermont specialty practices. *J Palliat Med*. 2020;23(3):375-378. doi:10.1089/JPM.2019.0192.
6. Dobscha SK, Heintz RT, Press N, Ganzini L. Oregon physicians' responses to requests for assisted suicide: a qualitative study. *J Palliat Med*. 2004;7(3):451-461. doi:10.1089/1096621041349374.
7. Ward V, Freeman S, Callander T, Xiong B. Professional experiences of formal healthcare providers in the provision of medical assistance in dying (MAiD): a scoping review. *Palliat Support Care*. 2021;19(6):744-758. doi:10.1017/S1478951521000146.
8. Buchbinder M. Aid-in-dying laws and the physician's duty to inform. *J Med Ethics*. 2017;43(10):666-669. doi:10.1136/MEDETHICS-2016-103936.
9. Brassfield ER, Buchbinder M. Clinicians' perspectives on the duty to inform patients about medical aid-in-dying. *AJOB Empir Bioeth*. 2020;11(1):53-62. doi:10.1080/23294515.2019.1695016.

ETHICAL ISSUES ENCOUNTERED IN THE PRACTICE OF AID IN DYING:

A SURVEY OF HEALTH CARE PROFESSIONALS

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ABSTRACT: In June 2021, the American Clinicians Academy on Medical Aid in Dying recognized the need to support clinicians by discussing and addressing their moral and ethical concerns. To that end, the Academy developed a tertiary Ethics Consultation Service[1] comprised of 11 members from diverse professions across the United States with expertise in both medical ethics and aid in dying.

The Ethics Consultation Service invited the Academy's listserv to participate in a digital survey. Of the 700 subscribers at the time, the Service received 183 completed surveys. The findings demonstrated the significance of ethical issues for these professionals and the continued need for ethical analyses, education, and support. This initial report, which focuses on the experiences of active attending and consulting physicians, identifies five top ethical concerns: 1) establishing patients' decision-making capacity; 2) addressing patients' physical ability to self-ingest; 3) working with patients' conflicts with their post-acute facility; 4) responding to patients desiring expedited aid-in-dying processes; and 5) resolving conflicts about providers' eligibility evaluations.

KEYWORDS: Medical aid in dying eligibility, physician assistance in dying, aid-in-dying medications, medical aid in dying, medical ethics.

1. BACKGROUND

As the experience of practitioners in managing patients who are considering aid in dying has increased, resources to support clinicians have developed. National and regional advocacy organizations work with providers and with states to support aid in dying.[2-4] The need for more in-depth professional support has been increasingly recognized.

The American Clinicians Academy on Medical Aid in Dying was started in 2020 as a resource to discuss issues and dilemmas via national conferences, a listserv, a website with educational videos, and other information. In 2021, the Academy added an Ethics Consultation Service to allow professionals to ask questions about both technical and ethical challenges. This service consists of 11 individuals who are professionally qualified health care ethics consultants from a variety of academic and health backgrounds across the country. Most members are located in states where aid in dying is legal, and thus have worked directly with aid-in-dying providers and patients.

The charge of the Ethics Consultation Service is to conduct ethical analyses of questions raised by clinicians through the Academy website. So, the Service developed a structured template for analysis based on their wide-ranging prior clinical and academic experiences. This structured analysis includes the examination of stakeholder perspectives and arguments on all sides of an ethical dilemma. The purpose is to render non-biased, non-binding recommendations to resolve clinicians' ethical dilemmas in response to their questions. As of February 2023, the Service had conducted six different consultations (Table 1). In early 2023, they initiated this survey to identify additional ethical dilemmas faced by aid-in-dying clinicians. The largest single professional category of respondents were physicians. Therefore, this initial report focuses on the experiences of these attending/prescribing physicians or a consulting/second-opinion physician providing aid-in-dying services.

2. METHODS

The Ethics Consultation Service responded to six consultation requests from June 2021 through December 2022. Between February and April 2023, the Service invited the Academy's listserv to participate in a digital survey. At the time, the listserv consisted of roughly 700 physician and non-physician aid-in-dying professionals. Respondents submitted 183 completed surveys.

The Ethics Consultation Service invited the Academy's entire listserv to participate in the survey from February 6 through April 3, 2023. They developed a questionnaire distributed through the SurveyMonkey platform, with a list of 18 possible ethical issues, using a

Likert scale to identify the degree of importance of these issues as well as providing an opportunity for open-ended comments (see Appendix A for survey sample).

The largest single professional category of respondents were physicians. Other respondents included nurses, social workers, chaplains, end-of-life doulas, and volunteers. These respondents indicated ethical and legal challenges, as well as knowledge gaps like those identified by active aid-in-dying physicians. However, this group identified ethical concerns that differed from the active physician experience; these will be explored and addressed in future reports. This initial report focuses on the experiences of active attending and consulting physicians providing aid-in-dying services.

3. RESULTS

The 183 responses revealed the significance of ethical issues for all professionals working in this practice and the continued need for ethical analysis, education and support through the service.

They identified five top ethical concerns:

1. Capacity: Establishing a patient's decision-making capacity, especially as impacted by mental illness, and/or diminishing capacity due to disease progression.
2. Self-ingestion: Addressing a patient's physical ability to self-ingest and identifying potential legal means to provide physical assistance with ingestion.
3. Institutional restrictions: Working with patients experiencing conflicts with their post-acute facility regarding aid in dying.
4. Expedited process/access: Responding to patients desiring expedited aid-in-dying processes.
5. Disagreements: Resolving conflicts about providers' eligibility evaluations.

The demographic categories we tracked were (1) professional role, (2) practice setting, (3) aid-in-dying geographic jurisdiction, and (4) whether the respondent was an active attending/prescribing physician or a consulting/second-opinion physician.

1. **Professional Role:** The most common professional role was physician (68; 37.2%) followed by doula (24; 13.1%), social worker (18; 9.8%), and registered nurse (16; 8.7%). Less common were: advance practice nurses or mid-level practitioners (7; 3.78%), health care administrators (4; 2.2%), and spiritual care (2; 1.1%). An "other" category was selected by a diverse range of respondents including volunteers, pharmacists—retired, and clinical (44; 24.0%). (Figure 1)
2. **Practice Setting:** The most common practice locations were: health care system/organization (43; 23.5%), private practice (40; 21.86%), and hospice agency (33;

18.03%). Acute care setting (14; 7.65%) and ambulatory/community practice (9; 4.92%) were less common. No respondent listed a post-acute facility.

3. **Jurisdiction:** The largest percentage of respondents came from four western states: California (72; 39.34%), Washington (24; 13.11%), Oregon (21; 11.48%), and Colorado (16; 8.74%). The remaining 14% of respondents came from six other states. New Jersey and New Mexico (each 10; 5.46%) were followed by Hawai'i (7; 3.83%), Maine (4; 2.19%), Washington, DC (4; 2.19%), and Vermont (1; 0.55%). Other respondents came from states where there is currently no aid-in-dying legislation, and one response was from Australia. (Table 2)

4. **Importance of Ethical Issues:** Sixty-six respondents (37.3%) currently provide aid-in-dying services to patients as either an attending/prescribing or consulting/second-opinion physician. Fifty-three (80.3%) of the 66 attending/prescribing or consulting/second-opinion physicians identified the importance of ethical issues in their practice. (Figure 2)

The attending/prescribing or consulting/second-opinion physicians ranked five ethical issues as very or somewhat important. These were:

1. Patient eligibility based on perceived severe mental illness (question of decision-making capacity) (49; 92.45%)
2. Patients needing special support or assistance at the time of ingestion (physical support) (42; 79.25%)
3. Patients experiencing conflicts regarding aid in dying in their post-acute facility (41; 77.4%)
4. Patients wanting immediate/expedited administration of medications (41; 77.4%)
5. Disagreements about general eligibility criteria (41; 77.4%)

All except one of the 18 ethical issue statements were found to be either very or somewhat important by over 50% of the respondents. The ethical issue that ranked lowest was eligibility based on ventilator dependence (16; 30.18%).

4. DISCUSSION

Our survey highlights several ethical challenges for professionals engaging with patients considering aid in dying. As increasing numbers of patients access aid-in-dying care in jurisdictions where it is legal, it is important to focus on and analyze the challenges this health care community faces. Very few discussions in the literature provide detailed descriptions of the practical ethical quandaries confronting these providers.

A Colorado survey of aid-in-dying clinicians suggests that about half consider their experiences to be "ethically challenging." But the nature of such challenges has not been clarified.[5] A smaller survey of Vermont physicians likely to encounter patients asking about

Table 1: American Clinicians Academy on Medical Aid in Dying Ethics Consultation Service, Issues Addressed to Date

1) Severe "terminal" anorexia nervosa as possible eligibility criterion for aid in dying
2) Hospice policies requiring staff to leave the room during ingestion
3) Disagreements among physicians on patient eligibility for aid in dying
4) Ethical permissibility of requiring hospice discharge for patients intending to pursue legal aid in dying
5) Voluntary stopping eating and drinking as a "gateway" to eligibility for aid in dying
6) Management of aid-in-dying medications if a patient loses hospice eligibility

For full discussions of these, see: https://www.acamaid.org/ethics/

Table 2: Respondent Jurisdictions

Jurisdiction	Responses	
California	39.34%	72
Washington State	13.11%	24
Oregon	11.48%	21
Colorado	8.74%	16
New Jersey	5.46%	10
New Mexico	5.46%	10
Hawai'i	3.83%	7
Maine	2.19%	4
Washington, DC	2.19%	4
Vermont	0.55%	1
Montana	0.00%	0
Other (please specify)	7.65%	14

Figure 1:

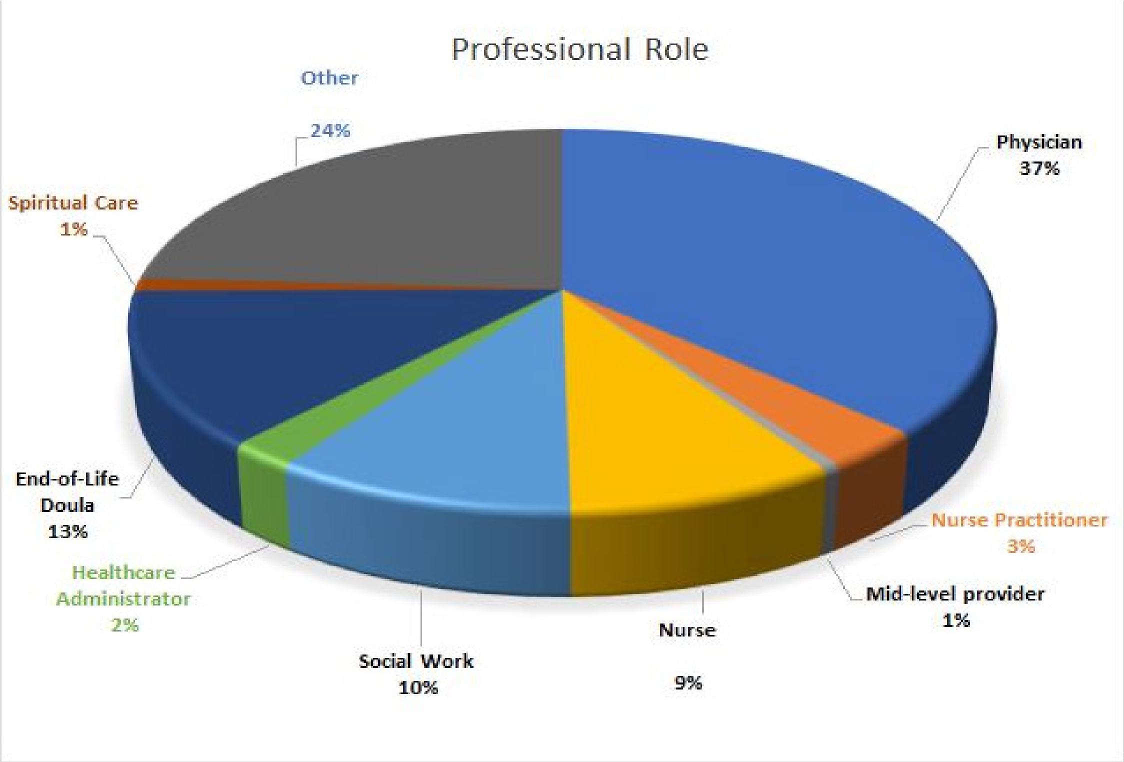
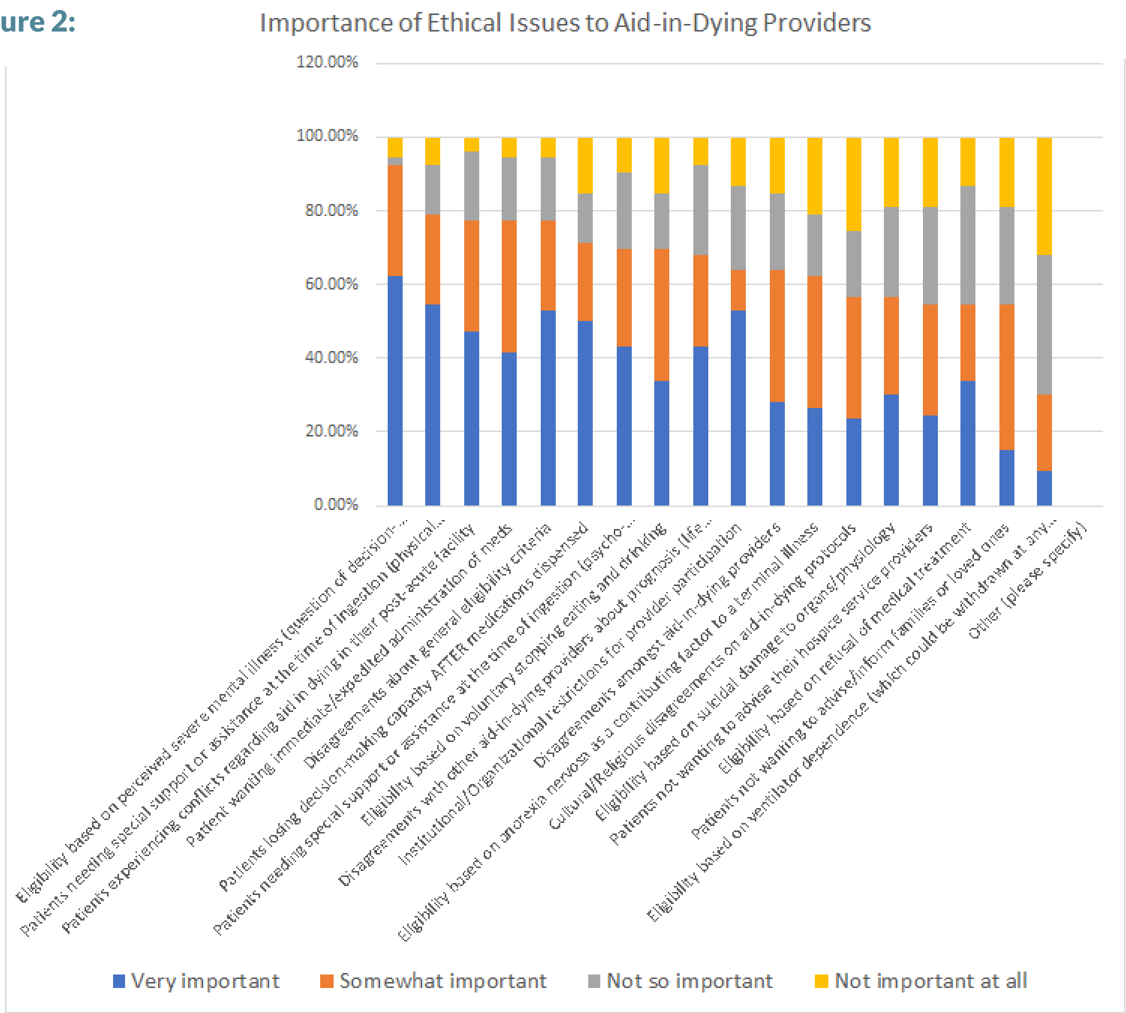


Figure 2:



aid in dying found that more than half thought they could use more information to counsel patients.[6] A recent systematic review of health care provider perspectives regarding patients who wish to hasten their death indicated several challenges, from understanding the legal circumstances to variations in prognostication, subjectivity of quality-of-life determinations, and interfaces with families.[7]

Between 2021 and 2023, the Academy's Ethics Consultation Service conducted six consultations. These reviews are posted on the website.[8] One is published in professional literature.[9] Our survey indicates not only the importance of those six issues but also additional dilemmas faced by health care professionals.

5. ISSUES EVALUATED BY THE ACADEMY ETHICS CONSULTATION SERVICE

Anorexia & Mental Illness. The Ethics Consultation Service discussed some complex aspects of aid-in-dying eligibility criteria in reviewing a case of possibly terminal anorexia nervosa.[8] The threshold for acceptability of aid-in-dying support in anorexia nervosa is disputed by many and is, at present, most often based on biomedical standards in the United States.[10-11] There is no current aid-in-dying eligibility based on severe mental illness in the U.S., although that is being considered a possible condition in the face of "irremediable suffering" in Canada and other countries.[12]

Assisted Self-administration. All U.S. aid-in-dying laws require that the patient self-administer their medications. But clinicians are unsure how much, if any, physical support they can provide to aid in the ingestion. Indeed, the very meaning of "self-administration" is the subject of debate, court cases, and evolving ethical and practical considerations.[13-14]

Institutional Restrictions. The Academy's ethicists have discussed institutional limitations on staff participation. Some hospices constrain staff activities or discharge patients pursuing aid in dying (Table 1: Consults 2 & 4). The ethicists evaluated this in two of the consult service reviews. These hospice restrictions are evolving, but there remains an important ethical debate about patient and provider autonomy and institutional rights.[15]

Waiting Periods. Patient requests for immediate/expedited self-administration of medications are a legal issue currently challenged in several states. While most aid-in-dying jurisdictions have recently reduced or permitted waiver of waiting periods, some jurisdictions still require at least 15 days. For the provider, the risk of violating his or her state laws about waiting periods poses a significant risk.

Eligibility Criteria. The Ethics Consultation Service has examined and will continue to examine other potential ethical challenges regarding eligibility criteria, such as whether the voluntarily stopping of eating and drinking can lead to eligibility for aid in dying (Table 1: Consult 5). In addition, the challenge of patients who lose decision-making capacity after obtaining medications and those who “graduate” from hospice eligibility after aid in dying has been approved have caused ethical distress (Table 1: Consult 6).

Many of the other issues queried in this survey overlap with the five most frequent concerns highlighted by aid-in-dying prescribers and consultants and deserve attention from the health care ethics community, specifically those with expertise in aid in dying. As clinicians gain more experience with patients seeking aid in dying, nuances of eligibility and institutional variability will continue to need exploration.

6. CONCLUSION

Ethical concerns for practitioners who care for patients considering and employing aid in dying are common. Health care ethicists specifically knowledgeable about aid-in-dying care have a duty to assist clinicians in exploring and resolving these tensions from an ethical perspective. The Academy’s Ethics Consultation Service is committed to supporting providers in their ethical concerns and assessing the challenges that this aspect of their medical practice entails.

DISCLOSURES:

Yvette Vieira MMH, HEC-C, Jean Abbott, MD, and Charles Miller, MD, have disclosed no relevant financial relationships.
Thaddeus Pope, JD, PhD, HEC-C, receives royalties for two topics on aid in dying for Wolters Kluwer UpToDate and for the Wolters Kluwer reference book, *The Right to Die.* All authors are active members of the American Clinicians Academy on Medical Aid in Dying’s Ethics Consultation Service.

The views expressed in the paper belong to the authors and do not necessarily reflect those of the organizations they are affiliated with.

For more information, please refer to the Ethics Consultation Service Mission:
ACAMAID-ECS-Final-Mission-Feb26.pdf

APPENDIX, TABLES & FIGURES:

Appendix A: Link to Preview of Survey Distributed to the Academy Listserv (February – April 2023)

https://www.surveymonkey.com/r/Preview/?sm=tDy9jphDFdtWy4mpaj9ElFg85YBkHd-krWeQzrvJVrfS7CXUTg3BTjwPbG_2FsWVFaJ

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1. Tarzian AJ, Berkowitz KA, Geppert CMA. Tertiary healthcare ethics consultation: enhancing access to expertise. *J Clin Ethics*. 2022 Winter;33(4):314-322. PMID: 36548235. https://pubmed.ncbi.nlm.nih.gov/36548235/.
2. Compassion & Choices. 2023. https://www.compassionandchoices.org/.
3. Death with Dignity. 2023. https://deathwithdignity.org/.
4. End of Life Washington. 2023. https://endoflifewa.org/.
5. Campbell EG, Kini V, Ressalam J, Mosley BS, Bolcic-Jankovic D, Lum HD, Kessler ER, DeCamp M. Physicians' attitudes and experiences with medical aid in dying in Colorado: a "hidden population" survey. *J Gen Intern Med.* 2022 Oct;37(13):3310-3317. doi: 10.1007/s11606-021-07300-8. Epub 2022 Jan 11. PMID: 35018562; PMCID: PMC8751472.
6. Landry KK, Ely J, Thomas AA. Experience and attitudes regarding medical aid in dying, Act 39, among Vermont Specialty Practices. *J Palliat Med.* 2020 Mar;23(3):375-378. doi: 10.1089/jpm.2019.0192. Epub 2019 Oct 8. PMID: 31592704.
7. Quah ELY, Chua KZY, Lua JK, Wan DWJ, Chong CS, Lim YX, Krishna L. A systematic review of stakeholder perspectives of dignity and assisted dying. *J Pain Symptom Manage.* 2023 Feb;65(2):e123-e136. doi: 10.1016/j.jpainsymman.2022.10.004. Epub 2022 Oct 14. PMID: 36244639.
8. American Clinicians Academy on Medical Aid in Dying. Aid in Dying Ethics Consultation Service. https://www.acamaid.org/ethics/.
9. Abbott J, Kerwin J, Holden C, Battin MP, Miller C, Pope TM. Hospice nurse ethics and institutional policies toward medical aid in dying. *Am J Nurs.* 2023 Jun 1;123(6):37-43. doi: 10.1097/01.NAJ.0000938728.13124.c3. PMID: 37233138.
10. Gaudiani JL, Bogetz A, Yager J. Terminal anorexia nervosa: three cases and proposed clinical characteristics. *Journal of Eating Disorders* 2022;10:23.
11. Arnold, C. Some anorexia patients want the right to die: a few doctors are willing to listen. *The Guardian*, July 13, 2023.
12. Health Canada. *Final Report of the Expert Panel on MAID and Mental Illness;* 2022.
13. Shavelson L, Pope TM, Battin MP, Ouellette A, Kluger B. Neurologic diseases and medical aid in dying: aid-in-dying laws create an underclass of patients based on disability. *Am J Bioeth.* 2023; 23(9):5-15. doi: 10.1080/15265161.2022.2105422. PMID: 35972304; PMCID: PMC9931932.
14. Pope TM, Shavelson L, Battin MP, Ouellette A, Kluger B. Permit assisted self-administration: a response to open peer commentaries on neurologic diseases and medical aid in dying: aid-in-dying laws create an underclass of patients based on disability. *Am J Bioeth*. 2023; 23(9):W9-W14. doi.org/10.1080/15265161.2023.2246340.
15. Wynia M. Colorado End-of-Life Options Act: a clash of organizational and individual conscience. *JAMA.* 2019 Nov 26;322(20):1953-1954. doi: 10.1001/jama.2019.16438. PMID: 31661115.

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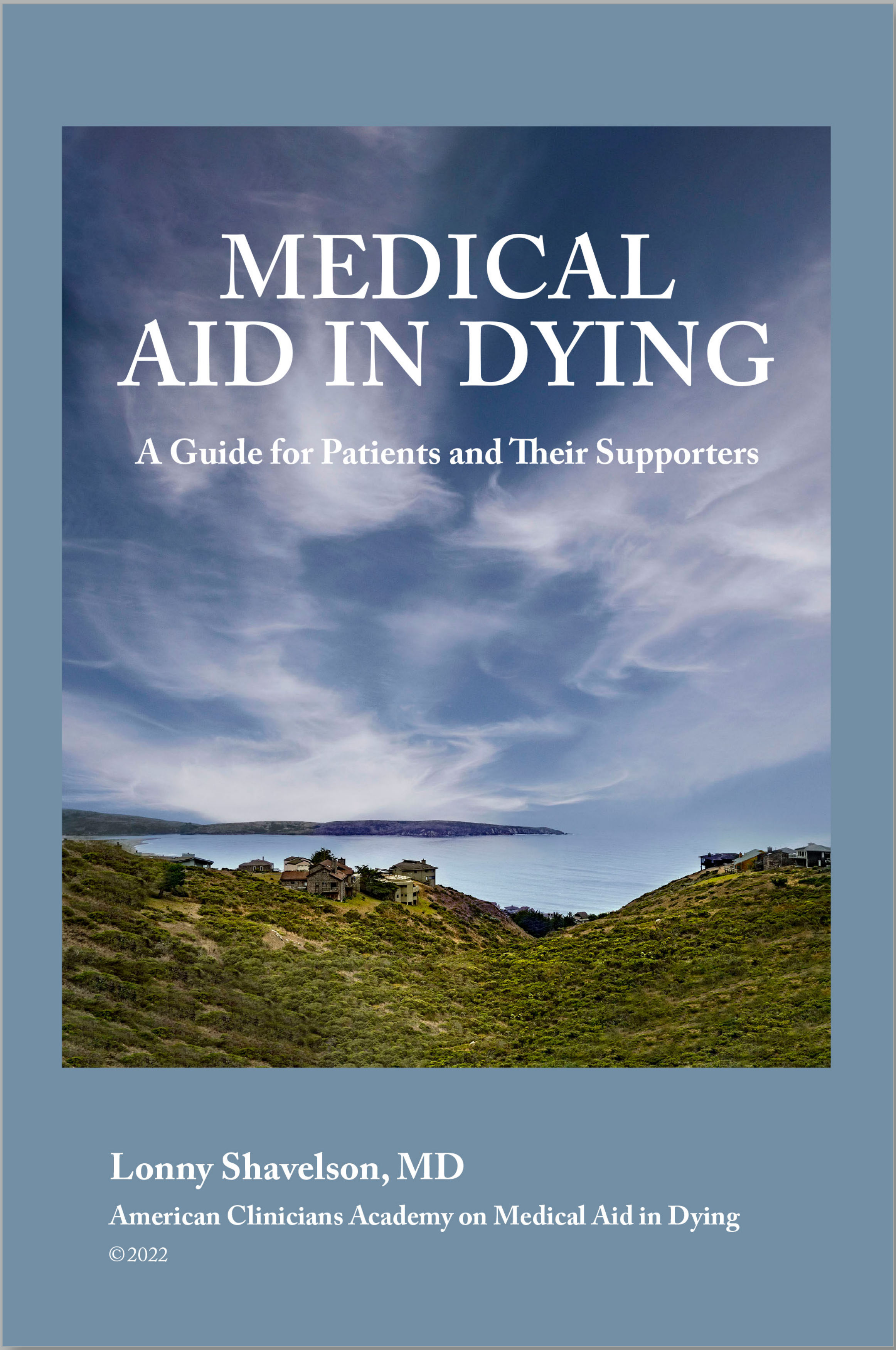

MEDICAL AID IN DYING

A Guide for Patients and Their Supporters

Lonny Shavelson, MD

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