



## IssueBrief

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# Empathy and Autonomy: Conversations around Medical Aid in Dying from an Anthropological Perspective

### Being a good steward of stories

Conversations about end-of-life planning are surprisingly as much about the “life” part as the “end.”

As part of the research for her book, *Scripting Death: Stories of Assisted Dying in America*, Mara Buchbinder, Ph.D., became intimately familiar with the heartfelt and often difficult conversations between people facing death, their loved ones, and their providers. Her book chronicles two years of ethnographic research documenting the implementation of Vermont’s Patient Choice and Control at End of Life law (Act 39).<sup>1</sup>

While conducting her research, the professor of social medicine and adjunct professor of anthropology, who serves as core faculty in the UNC Center for Bioethics at the University of

North Carolina-Chapel Hill, collected hundreds of stories about the desire for choice and control at the end of life. What she learned, she says, not only involves decisions about death, but about living fully at the end.

“I found it in some ways really beautiful to be able to listen to people’s stories of their loved ones’ deaths and to be able to carry those stories,” she says. “It’s a responsibility that I take very seriously

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— Patty Nunez, chair-elect for the Commission for Case Manager Certification

1. Vermont Laws. legislature.vermont.gov. <https://legislature.vermont.gov/statutes/fullchapter/18/113>

as kind of a good steward of those stories, making sure that they're put to good uses and not being exploited in the way that the research is presented."

Medically assisted dying is a complex and ethically charged topic, one many case managers will encounter during their careers.

"As case managers, your role in guiding clients through end-of-life choices is invaluable. This isn't easy. There are ethical dilemmas, legal considerations and emotional aspects surrounding supporting clients during end-of-life care," says Patty Nunez, chair-elect for the Commission for Case Manager Certification.

With this in mind, case managers can offer empathetic assistance and create an environment of compassion and understanding for clients and their families.

So much more is involved than physical health, Nunez says. "It is also about a loss of autonomy, a loss of dignity, a loss of quality of life, and an inability to engage in what makes people's lives meaningful. Understanding all ethical aspects of these decisions is vital for case managers working with clients facing end-of-life care."

While the topic of medical aid in dying may arise, Buchbinder says it is far more valuable to skillfully navigate the related conversations surrounding a client's symptoms and wishes.

"One thing that I heard again and again from physicians and other health care workers in this study is that a request for medical aid in dying is only a starting point, and it's usually not the end point of discussion. Most patients that bring this up are not going to end up getting it," she says. "It can provide a really nice opening to inquire more, dig deeper, and to ask, 'What's making you ask about that? What's on your mind? What are your most bothersome symptoms?' Often those are symptoms that can be addressed through something else."

## What is Medical Aid in Dying (MAID)?

Medical Aid in Dying (MAID) is a procedure through which a doctor gives a terminally ill, competent adult a prescription for a lethal dose of medication.<sup>2</sup> The patient requests this with the intention of using it to voluntarily end their life at some point in the future.

In Vermont, requirements are "largely identical" to those in place in other areas of the United States, Buchbinder says. **(See Figure 1.)**

"Studies from the Netherlands and Oregon, where there is the longest running history of medical aid in dying, show that this is discussed far more often than it is performed. And it can often serve as a gateway for expressing other kinds of end-of-life concerns," Buchbinder says. "For the culture of death in America, the significance of legalizing medical aid in dying is much greater than the number of reported deaths might suggest. It really can change the kinds of conversations we have about end-of-life control and invite new ways of thinking about death and dying."

### Requirements for MAID in Vermont

- A patient diagnosis of a terminal diagnosis, defined as an illness expected to result in death within six months;
- Two voluntary oral requests spaced at least 15 days apart;
- A voluntary written request signed in the presence of two witnesses;
- Confirmation of the diagnosis and prognosis by a second physician; and
- Medication self-administration.

**Figure 1**

2. VandeKieft GK. End-of-Life Care: Medical Aid in Dying. *FP essentials*. 2020;498(33166105):32-36. <https://pubmed.ncbi.nlm.nih.gov/33166105/>

## MAID stories shared

The stories Buchbinder collected reveal that MAID is a deeply individual choice, as well as profoundly social and communal.

“One of the richest and most interesting parts of this research for me has been hearing about how people plan for and even choreograph their deaths when they have an opportunity to do so,” she says.

Her research points to three recurring elements of MAID and how it is experienced by those who choose it. **(See Figure 2.)**

“One of the things that I found most striking is the role of social support and the extent to which people relied on others as they carried out their medically assisted deaths,” Buchbinder says.

One case involved a female patient whom she called Peggy, who spontaneously chose her day of death. In the presence of her family and partner, she engaged in ordinary activities like signing artwork before declaring, “it’s time.” (All of the names that Buchbinder uses are pseudonyms, to protect her participants’ confidentiality.)

Another poignant example Buchbinder described was Tom Jarvis, who pursued MAID after being diagnosed with metastatic cancer. His best friend, Neil, supported him throughout the process, and Jarvis eventually choose the day of his death based on weather considerations. Neil described the experience as surreal, registering both relief and shock at the smoothness of the process.

However, not all MAID experiences run smoothly. Buchbinder referred to Frances, an ALS patient, who struggled with swallowing the required medication. Despite preparations and practice, the process took longer than expected, leading to a prolonged death and distress for her family and caregivers.

“This is pretty typical of a bad outcome case. I don’t want to minimize this, because these prolonged deaths could be very distressing for

the family,” she says. Despite this difficulty, Buchbinder said caregivers still found the outcome meaningful because their loved one experienced the kind of death they desired.

Buchbinder says it is important to note that not everyone who receives the medication decides to take it.

## The motive behind the wish

When describing what motivates individuals to pursue MAID, Buchbinder returns to the experience of Frances, the patient who struggled with taking the medication.

### 3 Recurring Elements of MAID



**The presence of close family and friends:** One of the most consistent features in the narratives involved loved ones. This presence of family and friends not only provides emotional support but also creates a sense of community and togetherness during these significant final moments.



**Sacred atmosphere:** The atmosphere surrounding MAID often takes on a sacred quality, which can vary significantly in tone. Buchbinder noted that this ranged from joyous and celebratory to more somber and reflective, often including ritual elements, such as a final toast.



**Domestic or non-medical setting:** Another key aspect observed in MAID cases is the preference for a domestic or non-medical setting. The experience occurs away from the clinical environment of a hospital, taking place in a more comfortable, familiar, and intimate space. The environment plays a crucial role in shaping the experience, making it more personal and less institutional.

**Figure 2**

In her 60s, she had been living with ALS for several years when Buchbinder met her in the summer of 2017. During her visit, Frances gave her a handwritten note because the ALS had so severely affected her speech. Frances wrote:

*"I've been a critical care RN 1975 to 2015. Seen many patients die on respirators, tied down pleading eyes as I give meds to settle them. But who knows what they were thinking trapped like that? Families coming and going, exhausted. In acute care, some patients would never go through what was going to happen to them if they had the choice. But once that starts in that setting, there's no going back. They die attached to tubes, feedings, incontinent. No communication, tears sliding from corners of the eyes. Many patients and families need to have this option. It's our bodies and lives and should always be our choice. When and how we die is our right. I would advocate for my patients when no hope at all, but would be endless discussions with their team of doctors. Then each specialist weighing in, then palliative care, then family meetings on and on. But the one person left out is the one dying slowly who was never given a choice."*

Frances chose to hasten her death a few weeks after meeting with Buchbinder.

Why do patients like Frances choose this option? Motivations vary widely, but they primarily fall into a few categories, Buchbinder explains, citing a wealth of research.<sup>3,4,5</sup>

### **Illness-related experiences (physical):**

- feeling weak, tired, or uncomfortable,
- pain or side effects of pain medication,
- loss of function,
- incontinence, and
- cognitive impairment.

### **Psychological factors:**

- fear, including fear about future quality of life; and
- hopelessness.

### **Social factors:**

- fear of being dependent and a burden on others; and
- unwillingness to make loved ones suffer.

### **Changes to sense of self:**

- loss of sense of self or identity,
- desire for control and concerns about loss of autonomy.
- concerns about loss of dignity, and
- loss of self-esteem.

Buchbinder's research from personal interviews added depth to these findings.

Clara Barnstable discussed her father, Arthur Rivers, a retired business executive with cancer, who chose to avoid aggressive treatment and the accompanying loss of consciousness. Instead, he opted for MAID, which allowed him to engage in meaningful activities and have deep conversations in his final days.

"He says he had some of the deepest conversations of his whole life, the most meaningful conversations of his whole life in the last weeks," Clara recounted to Buchbinder. "If you have the alternative to choose the time of your death, then all the discussions are different. And it's really hard to put your finger on it until you've seen it. But the whole nature of the discussion is different. It's about, well, what are the key things you want to be doing in the last months of your life? And my dad says, I want to be sailing. I want to be sailing on Lake Champlain. And he did."<sup>6</sup>

Arthur's story exemplifies a patient's desire for continuity between life and the dying experience,

3. Buchbinder M. *Scripting Death: Stories of Assisted Dying in America*. University of California Press; 2021. Accessed January 11, 2024. <https://www.ucpress.edu/book/9780520380202/scripting-death>

4. Ohnsorge K, Rehmann-Sutter C, Streeck N, Gudat H. Wishes to die at the end of life and subjective experience of four different typical dying trajectories. A qualitative interview study. *PLoS One*. 2019;14(1):e0210784. Published 2019 Jan 17. doi:10.1371/journal.pone.0210784

5. Pearlman RA, Hsu C, Starks H, et al. Motivations for physician-assisted suicide [published correction appears in *J Gen Intern Med*. 2005 May;20(5):485]. *J Gen Intern Med*. 2005;20(3):234-239. doi:10.1111/j.1525-1497.2005.40225.x

6. Rodríguez-Prat A, Balaguer A, Booth A, Monforte-Royo C. Understanding patients' experiences of the wish to hasten death: an updated and expanded systematic review and meta-ethnography. *BMJ Open*. 2017 Sep 29;7(9):e016659. doi: 10.1136/bmjopen-2017-016659. PMID: 28965095; PMCID: PMC5640102



*"... physicians, nurses, and social workers really engage with medical aid in dying in a variety of ways that extend beyond responding to requests or deciding whether or not to prescribe."*

— Mara Buchbinder, PhD, Professor of Social Medicine and Adjunct Professor of Anthropology at UNC, Chapel Hill

reflecting a preference to maintain coherence between life and the death experience. His decision to sail on Lake Champlain one last time and spend meaningful hours with loved ones illustrates how MAID enabled him to live his final days on his terms, integrating his death as a part of a well-lived life.

## A provider's perspective

What is the MAID experience for the health care providers? Buchbinder's study included 51 interviews with physicians and other clinicians about their Vermont MAID perspectives. This included 37 who had direct experiences with MAID—participating as a prescriber or a secondary physician, counseling patients or otherwise supporting patients and navigating access.

Unlike previous studies that primarily focused on clinicians' willingness to prescribe or their responses to patient requests, Buchbinder says her research offers a broader understanding of the multifaceted roles and emotional dynamics health care providers encounter in the process of medical aid in dying.

"What I found is that physicians, nurses, and social workers really engage with medical aid in dying in a variety of ways that extend beyond responding to requests or deciding whether or not to prescribe," she says. "Importantly, even if a physician ultimately declined to prescribe, she might agree to participate in other domains of care."

Buchbinder and her team reveal five key elements of the multifaceted nature of clinicians' experiences with MAID, ranging from intricate communication and legal compliance to the

emotional and practical aspects of end-of-life planning. (See Figure 3.)

## Relationships matter

MAID is a complex topic for both case managers and health care providers to navigate. Buchbinder found that the perspectives of health care professionals regarding MAID evolved in the context of their relationships with their clients.

"When you ask [practitioners] in the abstract, 'What are your views on this,' if they've never been involved in it, you might have one response. But when it's coming up in the context of an ongoing relationship, you may have a very different response that changes over time."

### Key elements of clinicians' experiences with MAID

- **Clinical communication:** Involves exploring patients' reasons for seeking MAID and examining alternative options.
- **MAID protocol:** Health care providers highlighted the time-consuming and bureaucratic nature of understanding and adhering to legal protocols. This includes navigating complex legal requirements.
- **Prescribing:** Far from a simple act, prescribing MAID often requires consultation with other physicians, pharmacies, and sometimes out-of-state experts. This process is detailed but lacks comprehensive guidance on practical implementation.
- **Planning for death:** Clinicians are deeply involved in the planning for the day of death. This might include having a doctor and social worker present to adapt the plan, such as shifting to palliative sedation if necessary.
- **Education:** Several physicians expressed a strong commitment to educating their peers about MAID. This includes offering talks and sharing information on handling patient inquiries about MAID, despite some facing resistance in discussing the topic in formal medical education settings.

Figure 3

While interviewing clinicians about their perspectives, she met a hospice and palliative care physician who faced a moral dilemma when a patient requested that she prescribe medication for MAID. She ultimately did not agree to prescribe, but she actively supported her patient by identifying another physician who could prescribe, verifying the patient met legal requirements, and ensuring that all necessary plans were in place for the patient.

“On the one hand, because she strongly believed in the capacity of local hospice and palliative care services to alleviate suffering and provide excellent care for dying patients, she was at least partially inclined to view such requests as a cop-out pursued by patients who had not truly exhausted all of their options,” Buchbinder says. “On the other hand, she was committed to the ethos of patient choice and did not want to abandon her longtime and much beloved patient during this difficult time.”

Buchbinder says this scenario was common among the clinicians she interviewed.

“Bioethics literature often tends to characterize physician stances as either starkly in favor of or starkly opposed to morally contested medical services like medical aid in dying,” she says. “But this doctor didn’t fall cleanly into either of these camps. That was actually true among many of the physicians I interviewed and physicians that I’ve met subsequent to this research.”

## Legal landscape

In 2013, Vermont became one of the first states to legalize MAID. In January 2018, the Vermont Department of Health released a report on the law’s utilization in its first four years. That spurred Buchbinder’s interest.

“My research interests have been in what happens in this period of time when laws and policies are new and their practical significance is still being worked out on the ground as they’re being implemented,” Buchbinder says. “Vermont was also the first state to utilize the legislature as opposed to a

ballot initiative or the courts in order to legalize medical aid in dying.”

Vermont’s legislation and its subsequent impact highlight the ongoing national conversation about the ethical, legal, and practical dimensions of MAID. As laws and policies evolve, health care providers and legislators are navigating this challenging and emotionally charged landscape, striving to balance compassionate care with rigorous legal and ethical standards.

In terms of the future of MAID, Buchbinder says residents in some states have voted to loosen residency requirements. She also says there is movement to consider allowing advance practice practitioners to prescribe in addition to physicians.

“There’s a lot of interest among some stakeholders in relaxing the self-administration requirement and making this more accessible to people with certain disabilities,” she says. “But I don’t see that happening any time soon.”

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— Mara Buchbinder, PhD, Professor of Social Medicine and Adjunct Professor of Anthropology at UNC, Chapel Hill

## Barriers to access

Buchbinder’s findings reveal that while MAID is legally available in Vermont through the passage of Act 39, practical and socioeconomic barriers significantly limit its accessibility to many eligible patients. This issue is not unique to Vermont, she says, as similar challenges are observed in other regions with MAID legislation.

One physician Buchbinder interviewed described the situation as “elitist,” noting that only a small

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group with intellectual, cognitive, emotional, and financial resources can navigate the complex process, thus limiting access unfairly.

“Based on these findings, I’ve argued that access to medical aid in dying depends on what the sociologist Janet Shim calls cultural health capital,”<sup>7</sup> Buchbinder says. “This is the tacit cultural knowledge, resources, and behaviors that predispose certain patients to have optimal health care encounters.”

## A cautionary tale

While acknowledging the relief MAID can bring to those suffering at the end of life, Buchbinder also highlighted the challenges and darker aspects of the process.

“I think that for those who use it, medical aid in dying offers an enormous source of comfort and relief from unwanted suffering at the end of life,” Buchbinder says. However, she cautioned, “the emergence of such deaths also has a darker side,” referring to the considerable pressure it places on dying individuals and their caregivers to manage the process in the right way.

Her findings challenge the advocacy narratives that portray MAID legislation as a clear-cut solution for self-determination at life’s end. Instead, Buchbinder’s research raises ethical questions about policies that inadvertently favor more privileged members of society.

## Common Barriers to MAID



**Legislative safeguards:** Requirements like self-ingestion of medication exclude individuals with certain medical conditions, particularly those with mobility or swallowing issues.



**Cost of medication:** The high cost of the preferred drug, Seconol (around \$3,000), is prohibitive for some. While alternatives exist, not all doctors are aware of them.



**Finding a willing physician:** Access often depends on one’s social network and connectedness to health care providers. While some rural areas offer good access, constraints were common in urban areas.



**Information access:** Many patients are unaware of MAID as an option because not all physicians inform them about it.



**Social support:** Patients may lack needed assistance in navigating the process, including finding physicians and managing paperwork.

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These insights can empower case managers to be more effective and compassionate as clients approach death, says Nunez. “Empathy, understanding, and the importance of legal and ethical knowledge serves as a guide for those aiming to provide the best possible care at the end of life.” ■

7. Shim JK. Cultural Health Capital. *Journal of Health and Social Behavior*. 2010;51(1):1-15. doi:<https://doi.org/10.1177/0022146509361185>

## About the Experts



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**Dr. Buchbinder** is a Professor of Social Medicine and Adjunct Professor of Anthropology at UNC—Chapel Hill, as well as core faculty in the UNC Center for Bioethics. She is a medical anthropologist with broad interests in cultures of health, illness, and medicine in the United States. Her recent work focuses on how patients, families, and healthcare providers navigate social and ethical challenges resulting from changes in medical technology, law, and health policy. She brings an extraordinary depth of knowledge and compassion to our session today.

She is the author of "Scripting Death," a book on assisted dying that chronicles two years of ethnographic research documenting the implementation of Vermont's Patient Choice and Control at End-of-Life Act. She weaves together stories collected from patients, caregivers, health care providers, activists, and legislators, to illustrate how they navigate medical aid-in-dying as a new medical frontier in the aftermath of legalization. Scripting Death explains how medical aid-in-dying works, what motivates people to pursue it, and ultimately, why upholding the "right to die" is very different from ensuring access to a life-ending procedure.



**Patricia Nunez,**  
**MA, CRC, CDMS, CCM,**  
chair-elect for the Commission  
for Case Manager Certification

**Patty Nunez** is dually certified as a CCM and CDMS and has served the Commission as a volunteer for many years in both capacities. She most recently served as Director in the Claim Vendor Management office at CNA. She led a team responsible for overall claim and sourcing strategy, data and analytics and supplier governance and management for workers compensation, general liability, and specialty lines of business. In her time at CNA, she also held Case Management Manager and Medical Management Director positions.

Patty possesses a Bachelor of Arts degree in Psychology from Rutgers University, and a Master of Arts degree in Rehabilitation Counseling from Seton Hall University.

Her dedication and passion for her profession can also be seen by her service on accreditation and certification boards. In addition to being a commissioner for the Commission for Case Manager Certification, Patty has also served on the Commission on Rehabilitation Counselor Certification and the Council on Rehabilitation Education (CORE).



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