

Medically Assisted Dying in the United States

An anthropological perspective

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I've been critical care RN
~~1975~~ 1975 - 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 + going
exhausted.

^{some}
In acute care - 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 eyes.

Many patients +
families need to have this
~~choice~~ ^{OPTION} IT'S OUR BODIES +
LIVES + SHOULD ALWAYS BE
OUR CHOICE, WHEN + 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
DN + ON

But the 1 person left
out is the one dying slowly
who was never given a
choice.



Plan for the talk

**What
motivates
patients to
pursue MAID?**

**What access
barriers do
patients face?**

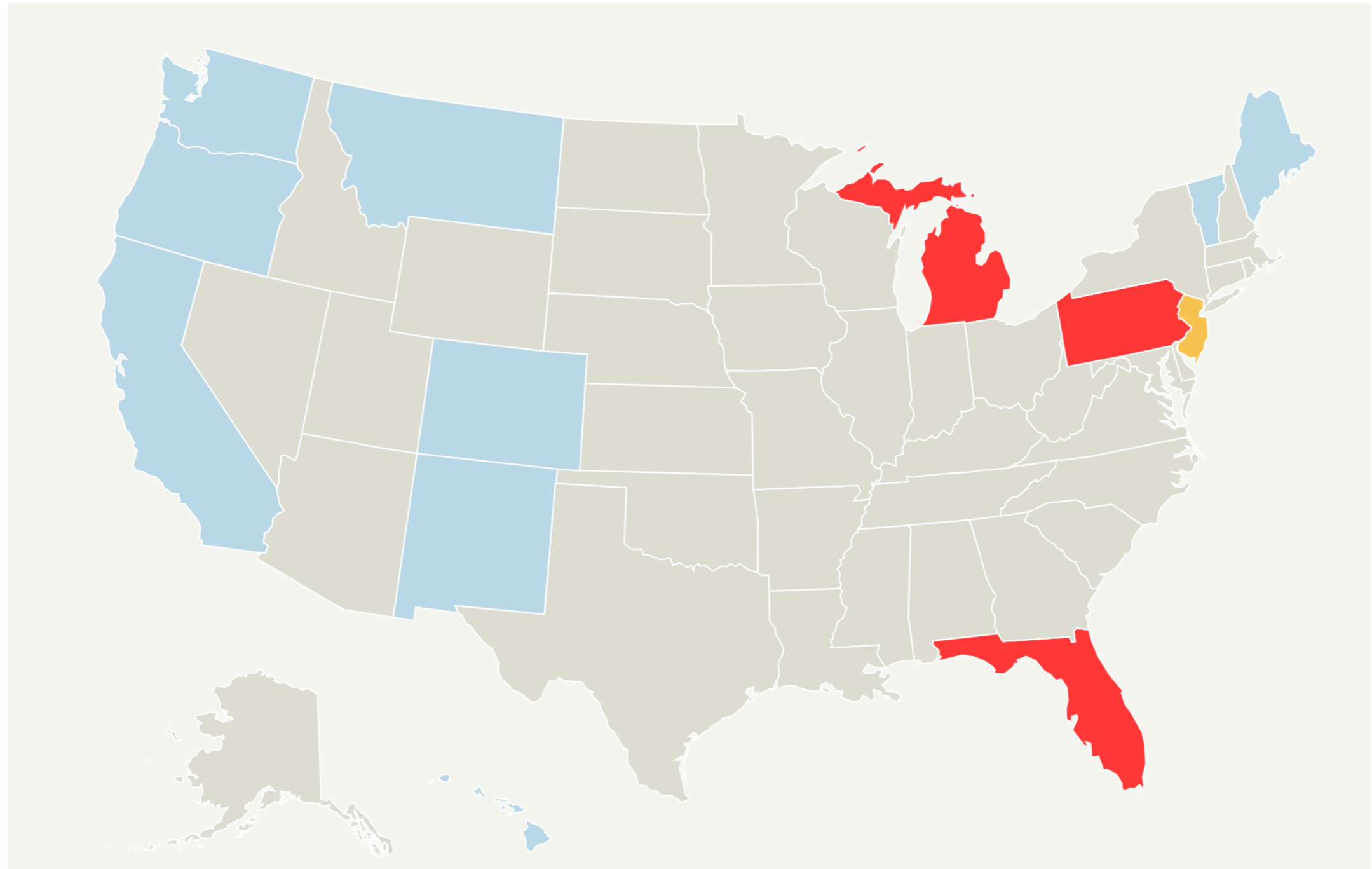
**What are the
experiences
of providers?**

**What are the
deaths like?**



1. background

The legislative landscape



● States Considering Death with Dignity This Year/Session

● No Active Legislation

● Legislation Enacted, Amendment Passed

● States or Jurisdictions where Death with Dignity is Legal

● States Actively Under Threat

● Amendment Pending

Map courtesy of
Death with Dignity
National Center

11/30/23

The “Patient Choice and Control at End of Life” Act

- Signed into law May 2013.
- Permits physicians to write a lethal prescription to a mentally competent adult patient.
- Requirements:
 - Terminal diagnosis
 - 2 voluntary oral requests, 15 days apart
 - Written request signed by two witnesses
 - Dx and prognosis confirmed by second physician
 - Medication is self-administered



Utilization of Act 39

- 52 patients filed paperwork 5/13 – 6/17: 7/17-6/19:
 - 43 cancer (83%) 24 cancer (71%)
 - 7 ALS (14%) 4 ALS (12%)
 - 2 other (3%) 6 Other (18%)
- Of the 48 individuals with a death certificate on file:
 - 29 utilized the prescription (60%) 28 (82%)
 - 17 died from underlying disease (35%) 5 (15%)
 - 1 died from other causes (2%) 1 (3%)

Source: Vermont Department of Health 2018

Research Methods

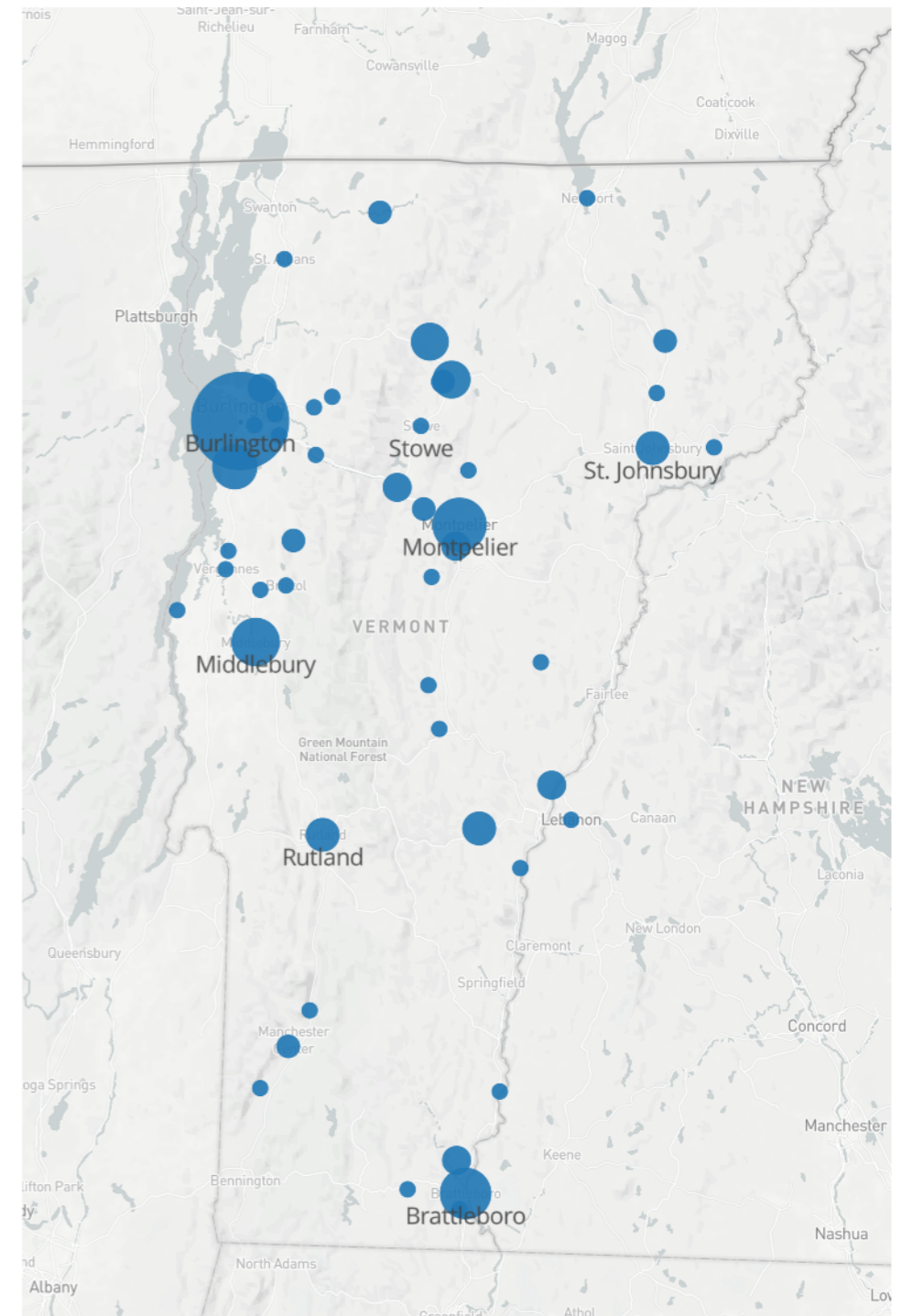
- 144 semi-structured, in-depth qualitative interviews (range: 16-118 min, mean: 57.5)
- Participant observation
 - Professional medical conferences
 - Community advocacy events
 - Death Cafes
 - Judicial hearings



Distribution of participants

- 51 Physicians, nurses, and allied health profs**
 - 18 were physicians with Act 39 experience
- 9 Terminally ill patients**
 - 1 who ultimately used Act 39
- 34 Caregivers of terminally ill patients**
 - 27 were caregivers of people who sought to use Act 39
- 37 Activists, legislators, and other policy stakeholders**
- 13 Other VT residents**

Interview Locations



**2. What motivates
patients to pursue MAID?**

Patients' motives

Illness-related experiences:

- 1) feeling weak, tired, or uncomfortable,
- 2) pain or side effects of pain meds,
- 3) loss of function

Changes to sense of self:

- 4) loss of sense of self
- 5) desire for control

Fears about the future:

- 6) fears about future quality of life
- 7) negative experiences with dying

Pearlman et al., JGIM, (2005)

Physical factors:

loss of function, pain, fatigue, incontinence, cognitive impairment

Psychological factors:

fear, hopelessness

Social factors:

being a burden on others, making loved ones suffer, being dependent

Loss of self:

loss of self-esteem or identity

Rodriguez-Prat et al. BMJ Open, (2017)

Concerns about loss of autonomy and dignity

Emanuel et al., JAMA, (2016)

“It’s not going to get better, the ALS. It doesn’t get better. It gets worse. So, today, tomorrow, it’s going to be worse. It doesn’t get any better. There’s nothing you can do. **You can’t stop it. You can’t slow it down.** You take pills all the time, to relax or even when she has to go to the bathroom, is a problem. **All these little things that people do every day. You don’t think about them until something like this happens.**”

— Tim Sullivan



“If you have the alternative to, you know, **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 said, ‘I want to be sailing. I want to be sailing on Lake Champlain.’ And he did.”

—Clara Barnstable





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Pearlman et al., JGIM, (2005)



**3. What access barriers
do patients face?**

Subject: End of life in VT

Date: Saturday, April 15, 2017 at 9:38:02 PM Eastern Daylight Time

From: [REDACTED]

To: Buchbinder, Mara

Hello,

My Husband [REDACTED] died 1 year ago on [REDACTED]

[REDACTED] suffered from a chronic disease for which there was no cure. He very much wished to have a dignified, pain free death on his terms and was hopeful that Act 39 would make that possible. We were shocked to learn that our local hospital, [REDACTED] prohibits it's physicians from participating in Act 39. An exhaustive search elsewhere in VT was no less promising, as we were informed by several physicians that heightened scrutiny in VT made them reluctant to participate in Act 39.

At a time when I should have been comforting my dying husband I was desperately trying to navigate Act 39 on his behalf. I regret that it took me from his bedside.

I think Vermonters would be shocked if they knew how inaccessible Act 39 is.

Sadly,

[REDACTED]

Sent from my iPad

“I feel really badly that Vermonters are under the illusion that Act 39 is available to them, and it really wasn't, was my experience.”



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BARRIERS

SAFEGUARDS

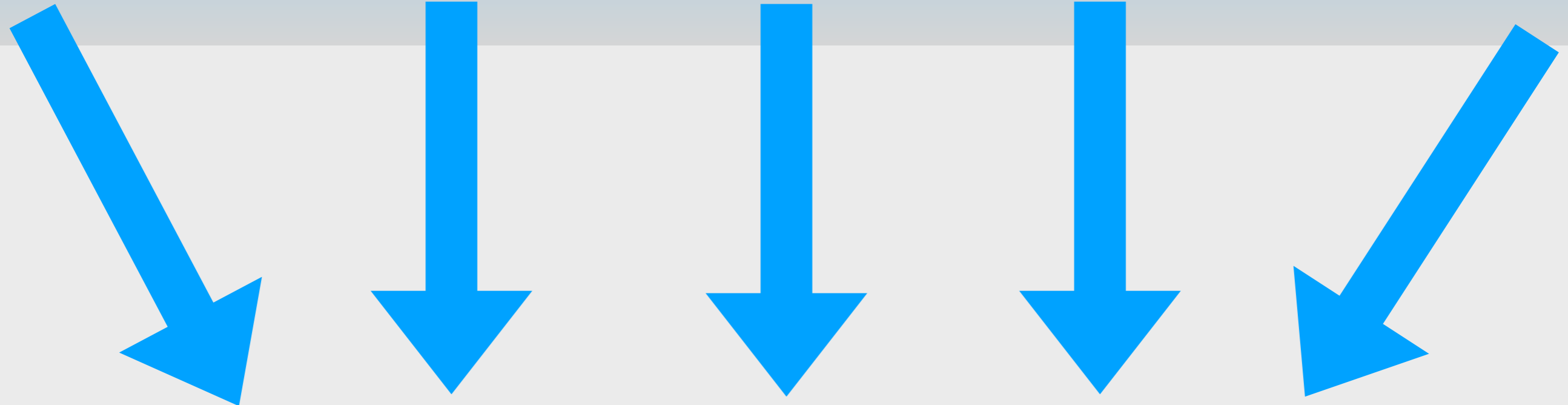
COST

**FINDING
A PHYSICIAN**

**ACCESS TO
INFORMATION**

**SOCIAL
SUPPORT**

ACCESS TO AID-IN-DYING



Access to MAID: finding a physician

“I contacted Compassion and Choices, which is this national organization that helps you access death with dignity. So they said I would just have to find, you know, two doctors in Vermont to prescribe. So, I said, “Okay, great. **Could you tell me what doctors have been prescribing?**” “**No, we can’t tell you that.**” So, I said, “Well, how am I supposed to find two doctors?” One, I just can’t go knocking on their doors. I have to transfer all the- they’re not gonna meet with me or ((name of patient)) without all of our records being transferred. I can’t do that times 30, 40, 50 times.”

—Margot Hadley

Access to MAID: finding a physician

“It’s very nice to have this, but I think you, **you don’t have equity.** [You can use it] if you’re a patient who meets all the criteria, then is lucky enough to have a primary care physician who knows you, and then is willing to participate.”

(Nurse Practitioner, 0144)



Stratified access to MAID

- **Cultural health capital** (Shim 2010): the tacit cultural knowledge, resources, and behaviors that predispose certain patients to optimal healthcare encounters

“There is a savviness that is also necessary.

There’s almost a doggedness on a patient’s perspective that is also necessary.”

(Physician, 0125)



Stratified access to MAID

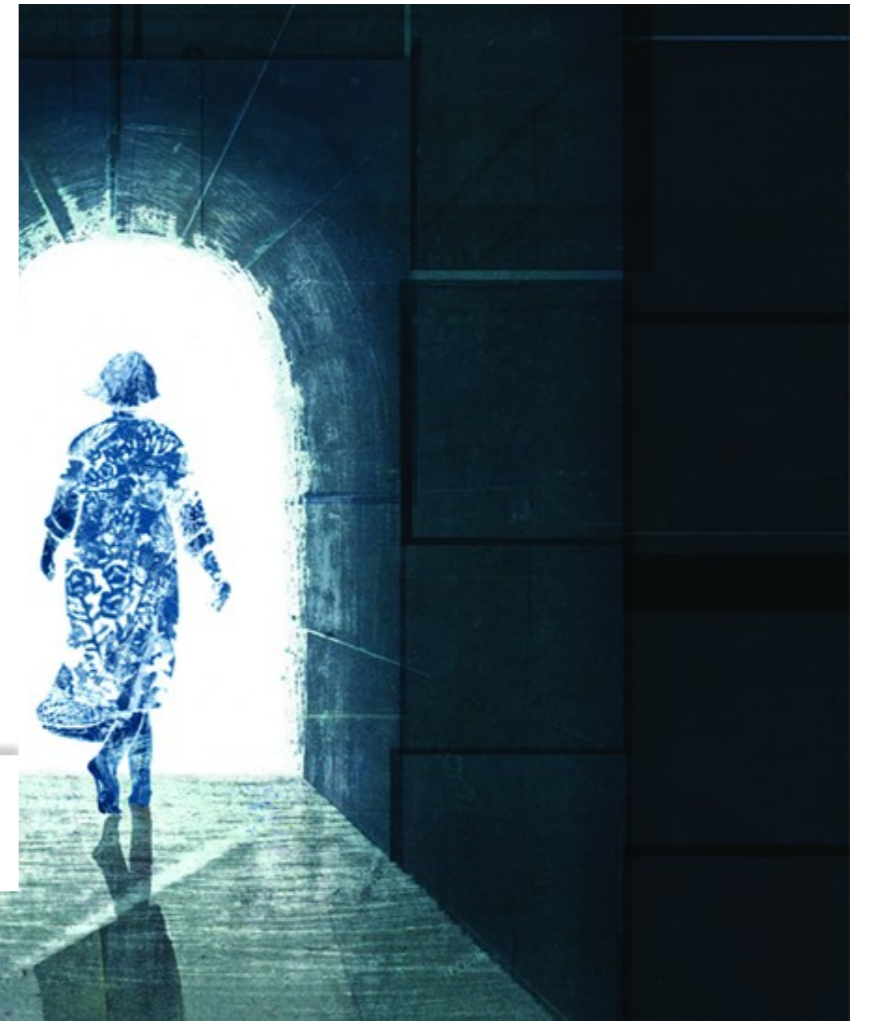
“The situation is very elitist. Someone has to have the intellectual wherewithal to track down a physician who’s willing to prescribe and follow through with that. They have to be able to track down a pharmacy that’s willing to dispense the medication and they have to be able to afford it. And most people who are in the last six months of life who meet the criteria to go through with this, don’t have the resources intellectually, cognitively, emotionally, financially. So it limits it to a very, very small group of people. **It seems not fair that way, too.”**

(Physician, 0123)



California's assisted-dying loophole: Some doctors won't help patients die

By Bob Egelko | August 12, 2017 | Updated: August 15, 2017 4:54pm



Hadley Hooper

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6:17 PM Oct. 15: Benefits, cancellations and events postponed due to...

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March 08, 2018

Life-ending medications are legal in Washington, but getting them is a whole other story

By Samantha Wohlfeil



Even With an Aid-in-Dying Law on the Books, Death Is No Certainty in Colorado

CONOR MCCORMICK-CAVANAGH | MAY 7, 2019 | 7:29AM

4. What are the experiences of health care providers?

Clinicians' experiences

- 37/51 providers had direct experiences with MAID
- Prior studies have focused on providers' willingness to prescribe or how they respond to patients' requests (Back et al 2002; Dobscha et al. 2004; Kohlwes et al. 2001; Voorhees et al. 2014; Ganzini et al. 2000).
- Yet participation stretches beyond responding to requests or deciding whether or not to prescribe.
- A physician may decline to prescribe yet participate in other domains of care.



Clinicians' experiences

CLINICAL COMMUNICATION

“There is an obligation to do everything you can to try to keep them from feeling like they need to use that. You don’t just give them the gun without the gun education, you know.” (Physician, 0110)

MAID PROTOCOL

“His primary doctor...was unsure about his timeline, couldn’t say for sure he had six months or less. But his neurologist and our hospice medical director who had been seeing him both said, ‘Absolutely...So, it was kind of interesting to see physicians butting heads.’ (Nurse, 0135)

PRESCRIBING

“The state website has the process. They don’t have the how-to. And so that’s a little hard to do. I think in the end I contacted ((advocacy organization)) ... I ended up getting a hold of a physician out in, uh, ((name of city in another state)).” (Physician, 0129)

PLANNING FOR DEATH

“That’s why we had a doctor and a social worker at the house at the same time, because we thought that this might happen, that the client would not be able to finish the cocktail.” (Physician, 0138)

EDUCATION

“I’ve offered to do talks at the CMEs or different situations and [hospital administrators] refused to let me talk about Act 39 at all. I’m not talking about trying to talk them into doing it. I’m just trying to talk to them about if they have a patient who comes in who is interested in it, here is where you can get information on it.” (Physician, 0134)

Dr. Jones: committing to non-abandonment

Dr. Jones was a hospice and palliative care physician whose clinical work has split between primary care and palliative care consultations. When a patient asked her whether she would be willing to prescribe under Act 39, Dr. Jones felt conflicted. 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. On the other hand, Dr. Jones was committed to the ethos of patient choice and did not want to abandon her long-time and much beloved patient during this difficult time. Dr. Jones ultimately decided that the best way to navigate her conflicting values was to do everything possible to help her patient short of writing the lethal prescription, which she viewed as crossing a moral line. She assisted the patient in identifying a physician willing to write the prescription, agreed to be the second physician certifying that the patient met the legal requirements, and worked with the prescribing physician to make sure that contingency plans were in place for the day of the patient’s death. Overall, Dr. Jones expressed a strong commitment to making sure that things went according to plan.



Clinicians' experiences: takeaway points

- Participating in MAID is time-consuming.
- Participating is emotionally stressful, yet most express gratitude for the ability to support patients' end-of-life wishes.
- Providers would like more formal education about clinical and logistical aspects of MAID.



**5. What are the
deaths like?**



Tom Jarvis

*“How to describe the tension in the room? **The atmosphere in the room was surreal.** I’m sort of in a state of shock watching him, wondering how’s this going to play out. You know, is he going to slump over, is he going to throw up? What happens when he dies? They didn’t really tell us that. They said, correctly, “Well, drink it all up because he’ll fall asleep, quickly, then slide into a coma, then his heart will stop. Within two minutes.” So that’s what happened. He’s sitting up like you’re sitting up. I put a pillow behind his head. He put his head back, closed his eyes, sitting like you are, legs crossed, he had his arm on the arm of the couch. Sitting there relaxed. And sure enough, you know, breathing slowed down, and it stopped. Within two minutes. And I’m studying him, I’m watching him, kind of disbelieving that we did this. ... And I got up, and I know **I’m in a state of kind of euphoric shock.** Euphoric because he did it, and he did it smoothly, and shock at what we did. **Relief, and numbness, and everything else swirling around me. And there’s nobody there with me.**” (0305, friend)*



Peggy Bliss

*“Her world was just getting smaller and smaller and smaller and she was seeing fewer and fewer and fewer people. And then I swear one day she just called me and she said, ‘**You better come down here because yesterday was too soon and tomorrow’s too late and I’m doing it today.**’ Yeah. So we all just went there, me and my three- two sisters, and her two kids, and her partner, this amazing man who’d been with her for ten years. And that was it. She just did it. She was really brave. So it was sort of like, today is the day. She said, ‘Today is the day.’ We spent the whole day – she was signing artwork, she was transferring the registration on her car, she was puttering around her house, and then she just said, ‘**Okay, it’s time. Don’t let me stop. We’re doing this.**’ And she did it. I mean it just blows my mind.”*

(0304, sister)



Frances Sullivan

*“I got a call around five AM from the hospice nurse saying she had fallen asleep, she couldn’t swallow it. **She got about half of it in and fell asleep and so she didn’t die from that directly.** So, she took it at around three, at five the hospice nurse called me, the hospice nurse was going out there. I said, start the morphine and hopefully it has replaced her enough that she’ll have respiratory depression. ... But [the hospice nurse] was crying. She goes, **‘This isn’t how it’s supposed to happen.’** And it was interesting because ... I didn’t feel at all panicked. I was like, you know, that was her path that she tried. **It didn’t work, but we know what she wants. She wants to be very comfortable, so we’ll just start her on the morphine.** If we have to go any higher than twenty milligrams an hour I’m coming out. ... As I was going from my house to the hospital she called and said [Frances] died. So, she died at- I think it was like nine o’clock or something like that. She took the medicine at, I don’t know, 3:30 or something like that.”*

(0141, physician)



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Conclusion

- For some, MAID laws offer an enormous source of comfort and relief from unwanted suffering.
- Yet MAID does not necessarily offer a clear-cut pathway to self-determination at the end of life.
- It also raises challenging questions for health care justice about the ethical implications of policies that are most accessible to the most privileged.



Conclusion

- How can the lessons of legalization be used to improve end-of-life care for all Americans?
- Importance of social support and social connection.
- Benefits of accommodating the dying person's values and preferences.
- How will policy changes scale up for use in a socioeconomically and racially/ethnically diverse society?

