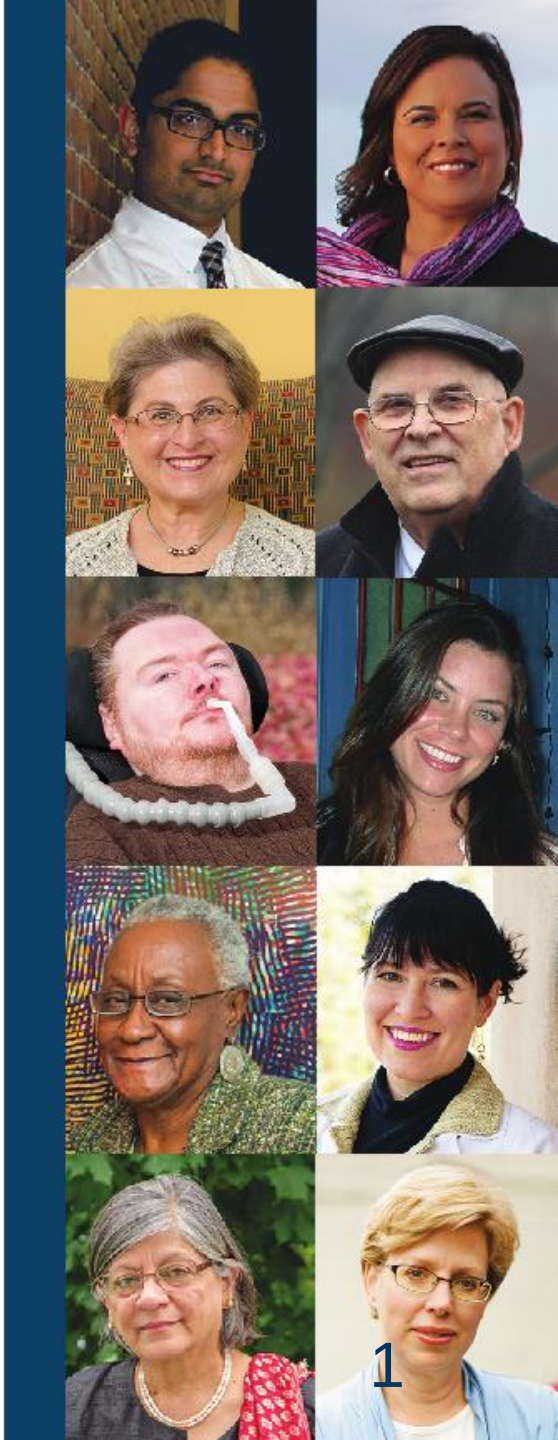
compassion & choices

Care and Choice at the End of Life

The Colorado End-of-Life Option Act: Lessons for Minnesota



April 12, 2024

Disclaimer

Disclosure of Unapproved or investigational uses of products or devices:

The five-drug compounded medication (DDMAPh) that has been developed by the American Clinicians Academy on Medical Aid in Dying will be discussed.

Susan Wilhoit, M.D.

Primary care physician, palliative medicine consultant, and a hospice clinician

National Medical Director
Compassion & Choices

Rebecca Thoman, M.D.

Director, Doctors for Dignity

DOCTORS for Dignity

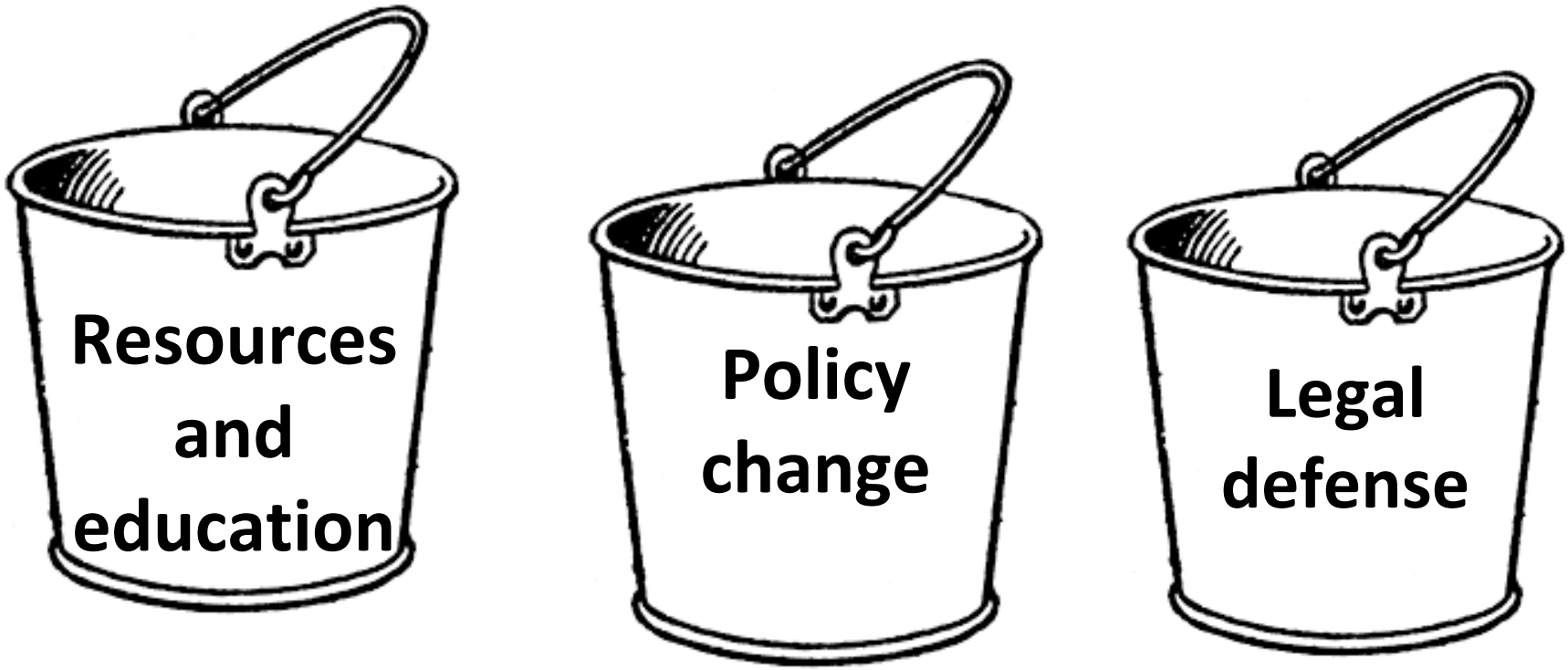
Compassion & Choices

Improve Care

Expand Options

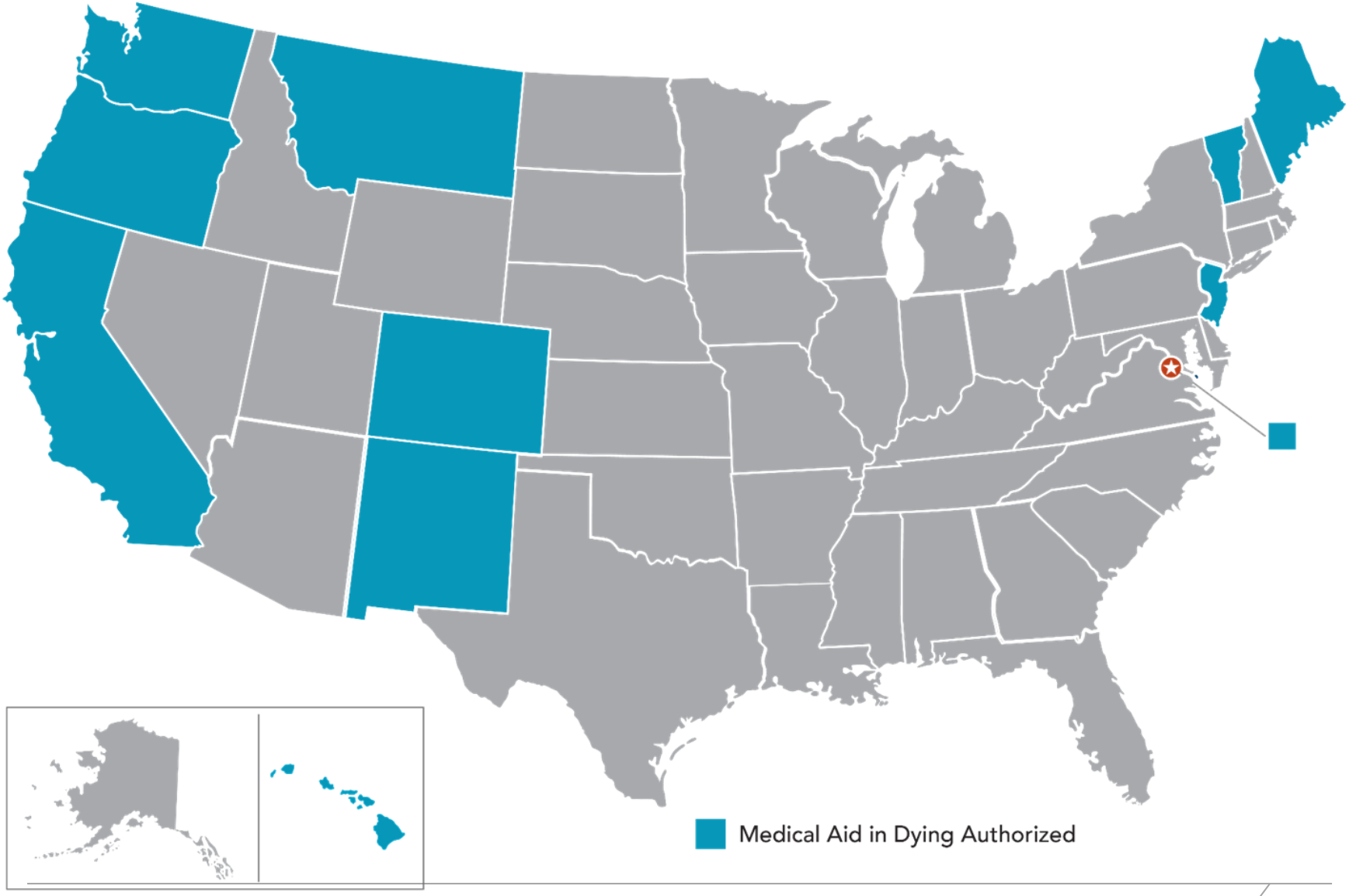
Empower Individuals

Our Work



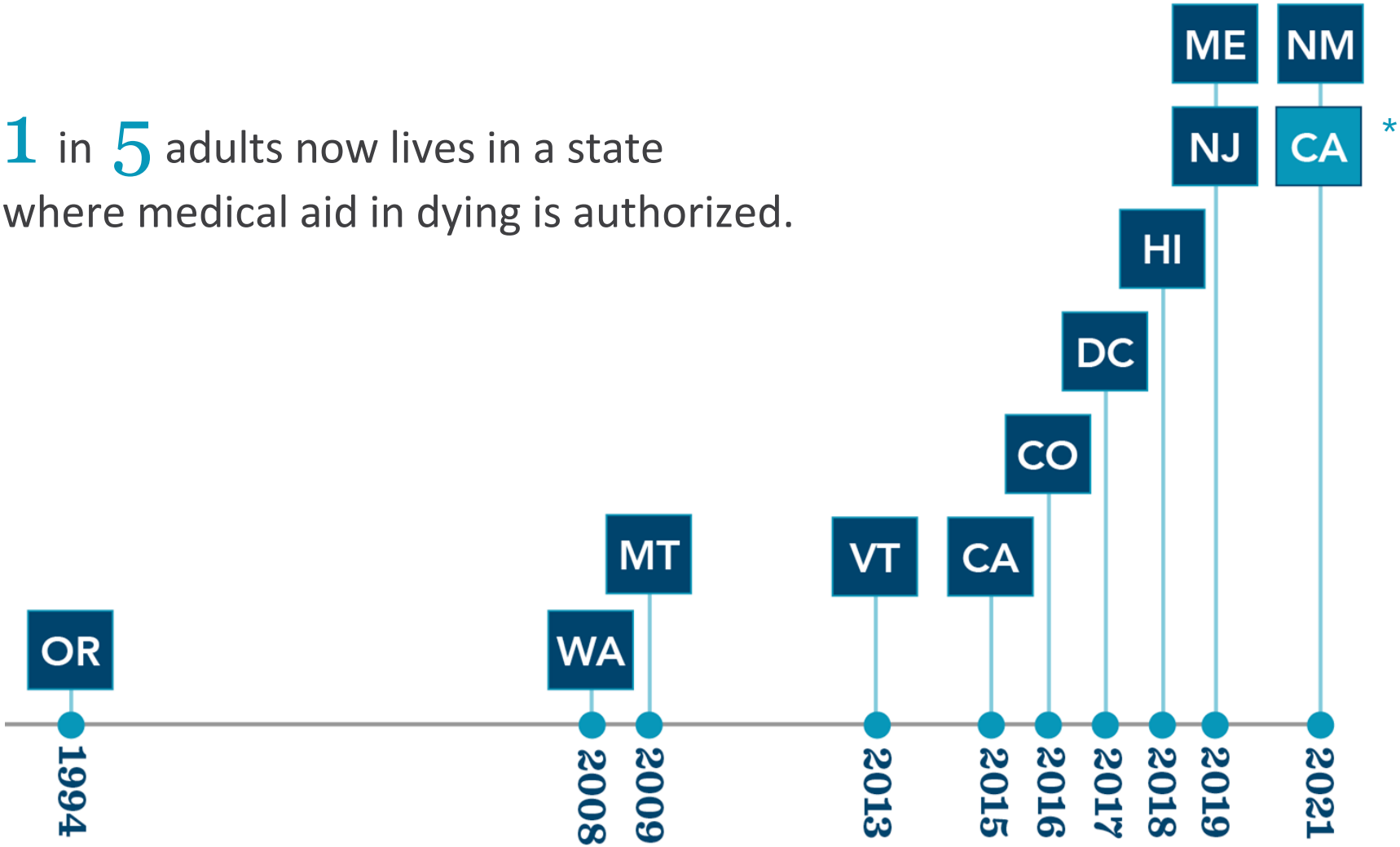
Medical Aid in Dying

Medical practice in which a terminally-ill adults with decision-making capacity and less than six months to live can request and receive from their physician, a prescription medication that they may ingest if and when they deem their suffering to be intolerable.


Medical Aid in Dying Authorized

Authorized in 10 States and D.C.

1 in 5 adults now lives in a state where medical aid in dying is authorized.



* California End-of-Life Options Act was amended and improved.

Minnesota End-of-Life Option Act

Sen. Dr. Kelly Morrison

Rep. Mike Freiberg

Fundamental Eligibility Requirements

1. An adult, 18 years or older
2. Terminal illness with prognosis of six months or less to live
3. Mentally capable of making their own healthcare decisions
4. Acting voluntarily
5. Able to self-ingest the medication

Who Does NOT Qualify?

- Alzheimer's/Dementia
- Guardianship/Conservatorship
- Developmental disability
- Mental illness that impacts decision-making

Advance age and disability ALONE do not qualify

Must have terminal illness with 6-months or less to live

Two Evaluations

- Physician, Nurse Practitioner of Physician Assistant determine eligibility, appropriateness and capacity
- At least 1 provider must be MD/DO
- Mental health assessment as determined by Attending/Consulting providers

Injection/Infusion Prohibited

Distinct from euthanasia which is permitted in Canada and other countries.

Common Provisions

Medical aid in dying is OPTIONAL for clinicians and pharmacists.

- Civil and criminal immunity as long as compliance with the law.
- Insurance benefits, including life insurance payments, can't be denied to terminally ill individuals because this option is available or if they decide to use it.
- Anyone who attempts to pressure, coerce or exert undue influence on an individual to request, obtain or utilize medical aid in dying is subject to criminal prosecution.

Construction Clause

By statute, medical aid in dying is not considered suicide, assisted suicide, homicide or euthanasia

Language Matters

Medical Aid in Dying	Suicide
Terminal diagnosis	Reversible/treatable
Mental capacity	Mentally impaired (depression; addiction; social stressor; alcohol)
Self-preservation	Self-destruction
Death is peaceful	Death often violent
Planned with family	Alone and impulsive

Language is Evolving

aahpm
AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE

AMERICAN ACADEMY OF NEUROLOGY®

AMERICAN ACADEMY OF FAMILY PHYSICIANS
STRONG MEDICINE FOR AMERICA

Death Certificate

Purposes:

Legal: establish death for estate purposes

Medical: public health statistics

Cause of death is the terminal disease, not the mechanism

e.g.: Respiratory Failure, not extubation in ICU

e.g.: Kidney Failure, not d/c renal dialysis

e.g.: Ovarian Cancer, not VSED

Manner of death:

Natural, Accident, ~~Suicide~~, Homicide, Other

Colorado v Minnesota

- Eligibility includes residency restriction
- Only MD/DOs (no APRNs)
- 15-day waiting period between first and second request

Residency Restrictions

Lawsuits in OR and VT = drop residency restriction

Current lawsuit in NJ

Arguments

- cross-border health care
- no other health service requires residency
- bad precedent
- doctors don’t want to restrict care based on zip code

Colorado Improvement Bill

- Add APRNs
- Shorter/eliminate waiting period
- Eliminate residency restriction

Colorado End-of-Life Option Act

Passed in a ballot initiative in 2016

(65% of the vote)

Implemented Jan. 1, 2017

Attending Physician Responsibilities

1. Determine diagnosis, prognosis, capability, voluntariness of request and ensure informed decision. Document in medical record.
2. Refer to consulting physician to confirm #1.
3. Refer to a mental health professional for third mental capacity evaluation if necessary
4. Follow process, including counsel patient of hospice and palliative care, of importance of safe-keeping of medication, notifying kin, and having a person present when taking the medication, and submit form(s)

Consulting Physician Responsibilities

1. Examine the patient /review medical records
2. Confirm in writing to the Attending: the patient's diagnosis, prognosis, capability and making an informed decision
3. Refer to behavioral health assessment if indicated
4. Document in medical record
5. Complete State forms

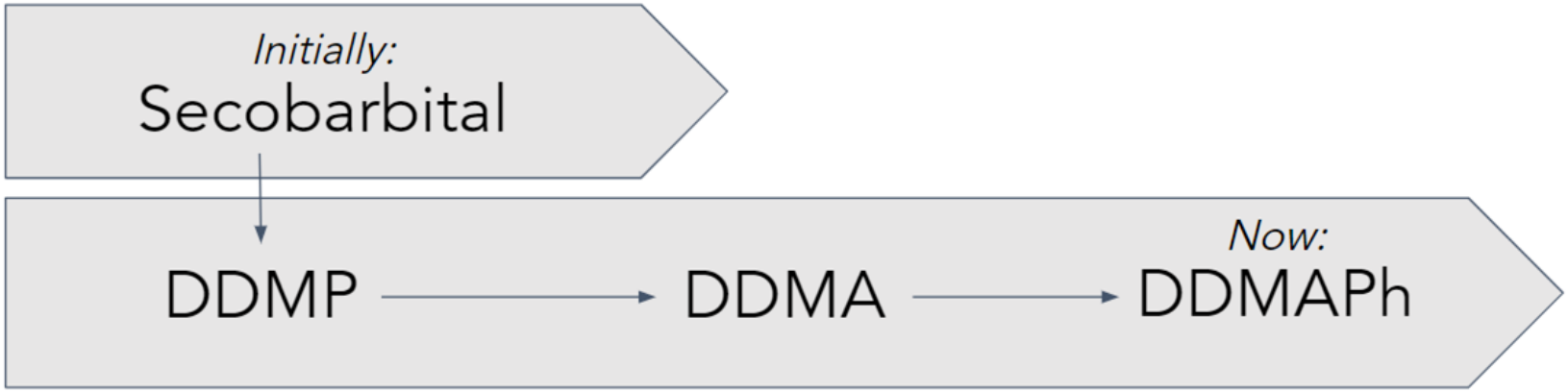
Role of Mental Health Professional

Determine Capacity

- Understanding
- Appreciation
- Reasoning
- Communication

Durable and situation-specific

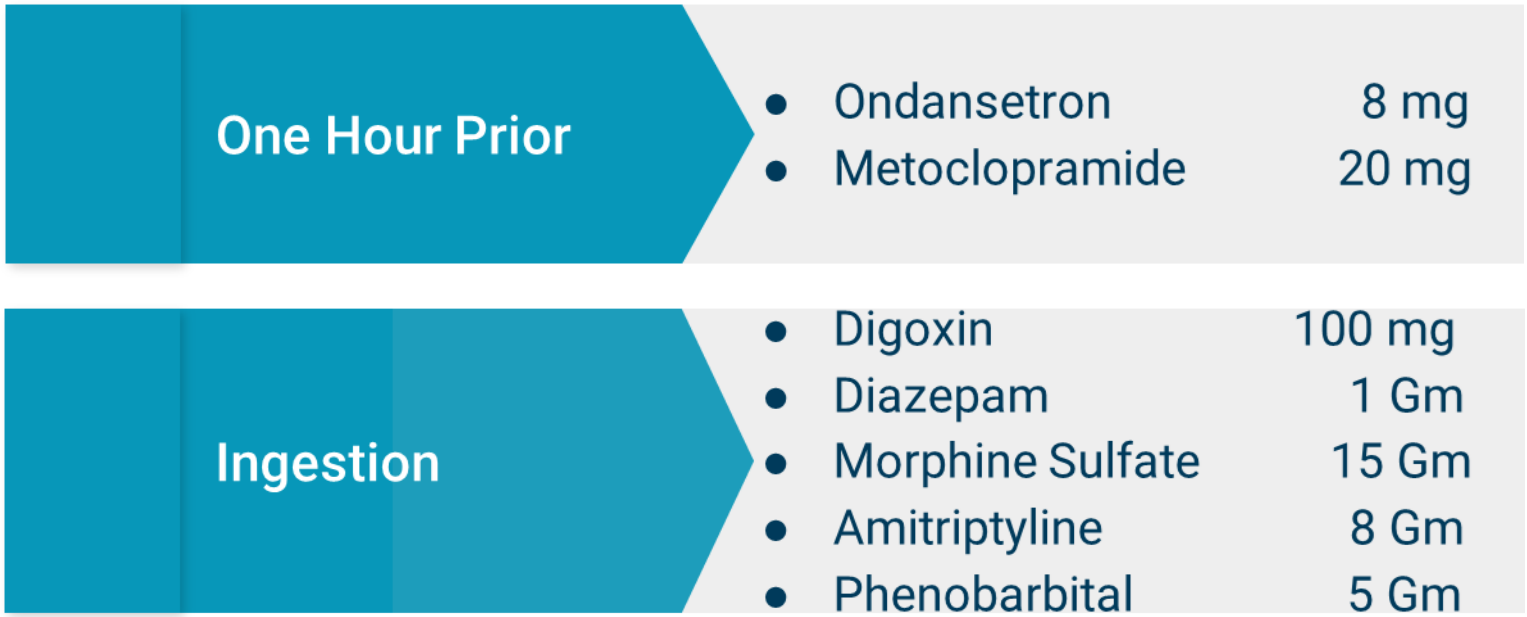
Medication Evolution



DDMP	DDMA	DDMAPh
Digoxin	Amitriptyline replaces Phenobarbital	Phenobarbital added
Diazepam		
Morphine		
Phenobarbital		

Current Protocol

- NPO for 4-6 hours (avoid dairy, laxatives)
- Take usual medications



DDMAPh

- Time to loss of consciousness: ~10min
- Time to death: ~1hr
- Anticipatory Guidance
  - Loved ones: time variations
  - Patients: Bitter taste

Amitriptyline and Side Effects

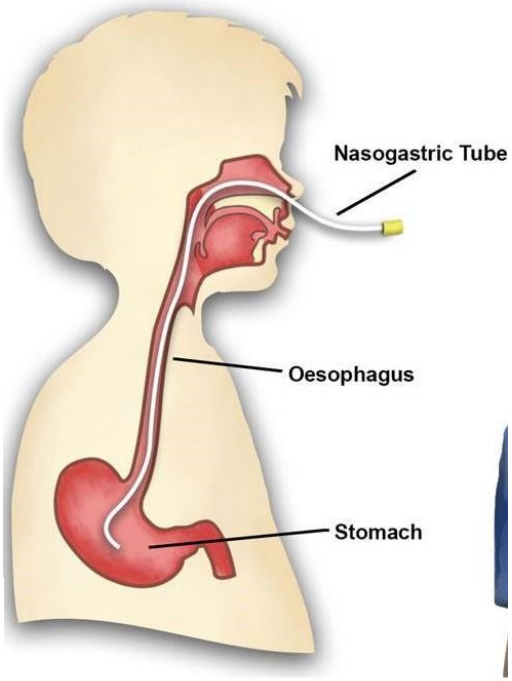
- Amitriptyline may cause mild symptoms of oropharyngeal 'burning'
  - This is noted to be severe in ~ 10% of patients
- Patients should be warned in advance of the possibility
- A few spoonfuls of sorbet usually resolves the symptoms.
- In severe cases, continued reassurance and sorbet are helpful.

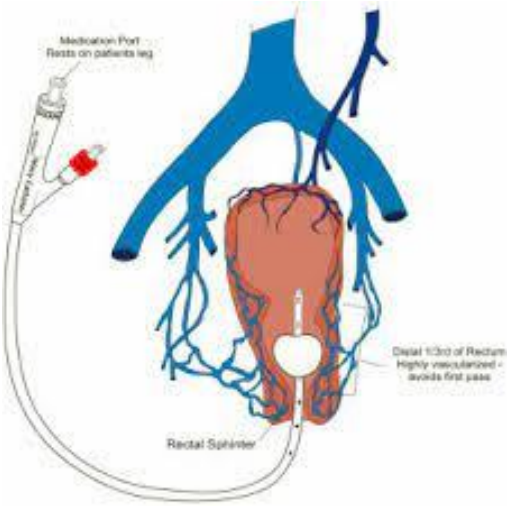
D-DMAPh: Red Flags

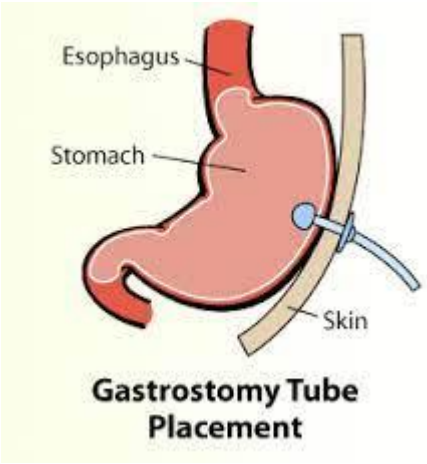
- **GI Absorption** issues:
  - GI Malignancy; Swallowing Concerns
  - Gastroparesis; Bowel Obstruction; Cachexia
  - Tense Ascites
- **CV Wellness** (Younger patients with ALS)
- **Obesity** (> 300 pounds)
- **Alcoholism**
- **Tolerance** to Opioids/Benzodiazepines

Routes of Administration

- PO
- G-tube
- Rectal catheter







How I Learned Medical Aid in Dying

- Open discussions with supportive colleagues
- Doc-2-Doc
- CME, Conferences
- Publications
- ACAMAID

My First Patient

A 74 year old luthier with metastatic prostate cancer

My First Patient

74 yr old with metastatic prostate cancer

No pain, no significant life-altering symptoms

Well supported by loving family

Hardworking gentleman who took pride caring for and providing for his family

Requested MAID Rx because he did not want to be a burden to his loved ones

He wanted to die as he had lived:
independently and on his own terms

Lessons I've Learned

Responding to a Request

1. Explore the patient's underlying reasons for the request
2. Optimize symptom management and address psychosocial and spiritual concerns as necessary
3. Understand the patient's personal story and how who they are aligns with their request
4. Establish the patient with another provider if you prefer to not participate

Quill TE, Back AL, Block SD. Responding to Patients Requesting Physician-Assisted Death: Physician Involvement at the Very End of Life. *JAMA*. 2016;315(3):245-246. doi:10.1001/jama.2015.16210

Statistics from Colorado: 2017-2022

#Patients Received Rx

1,093

#Ingested

829

Diagnoses

62% cancer

17% neurodegenerative

8% respiratory

8% cardiovascular

Colorado End-of-Life Options Act, 2022 Data Summary
https://spl.cde.state.co.us/artemis/heserials/he1950012internet/he19500122022internet.pdf

Statistics from Colorado: 2017-2022

Enrolled in hospice: 83%

Patient Profile

- Ave age: 72
- White: 94%
- Asian: 2%
- Education (Bachelors and above): 64%

Statistics from Colorado: 2017-2022

Growing number of supportive and participating physicians

219 unique providers wrote Rx

avg. 2.7 per year

33 pharmacists dispensed

Combined Data 1997-2022

Combined data collected in 10 states and DC is close to 30 years (individual years > 100 years)

Number of prescriptions written	6,522
Number who ingested the medication	4,126 (64%)
Patient Demographics	Older, White, Educated
Enrolled in hospice at the time of request	85%
Most common diagnoses	Cancer, ALS
Number of physician prescribers	~600

Medical Aid in Dying Data Report, 2024 Edition. Compassion & Choices

Unexpected Benefits

Provides peace of mind

Open communication

Equal or increased use of hospice

Positive impact on the doctor-patient relationship

Wang SY, Aldridge MD, Gross CP, et al. Geographic Variation of Hospice Use Patterns at the End of Life. *J Palliat Med*. 2015;18(9):771-780. doi:10.1089/jpm.2014.0425

Research

Physicians' Attitudes and Experiences with Medical Aid in Dying in Colorado: a "Hidden Population" Survey

University of Colorado Anschutz School of Medicine,

Eric G. Campbell, PhD1,2,7, Vinay Kini, MD, MSHP3, Julie Ressalam, MPH2, Bridget S. Mosley, MPH3, Dragana Bolcic-Jankovic, PhD4, Hillary D. Lum, MD, PhD5, Elizabeth R. Kessler, MD6, and Matthew DeCamp, MD, PhD1,

Findings

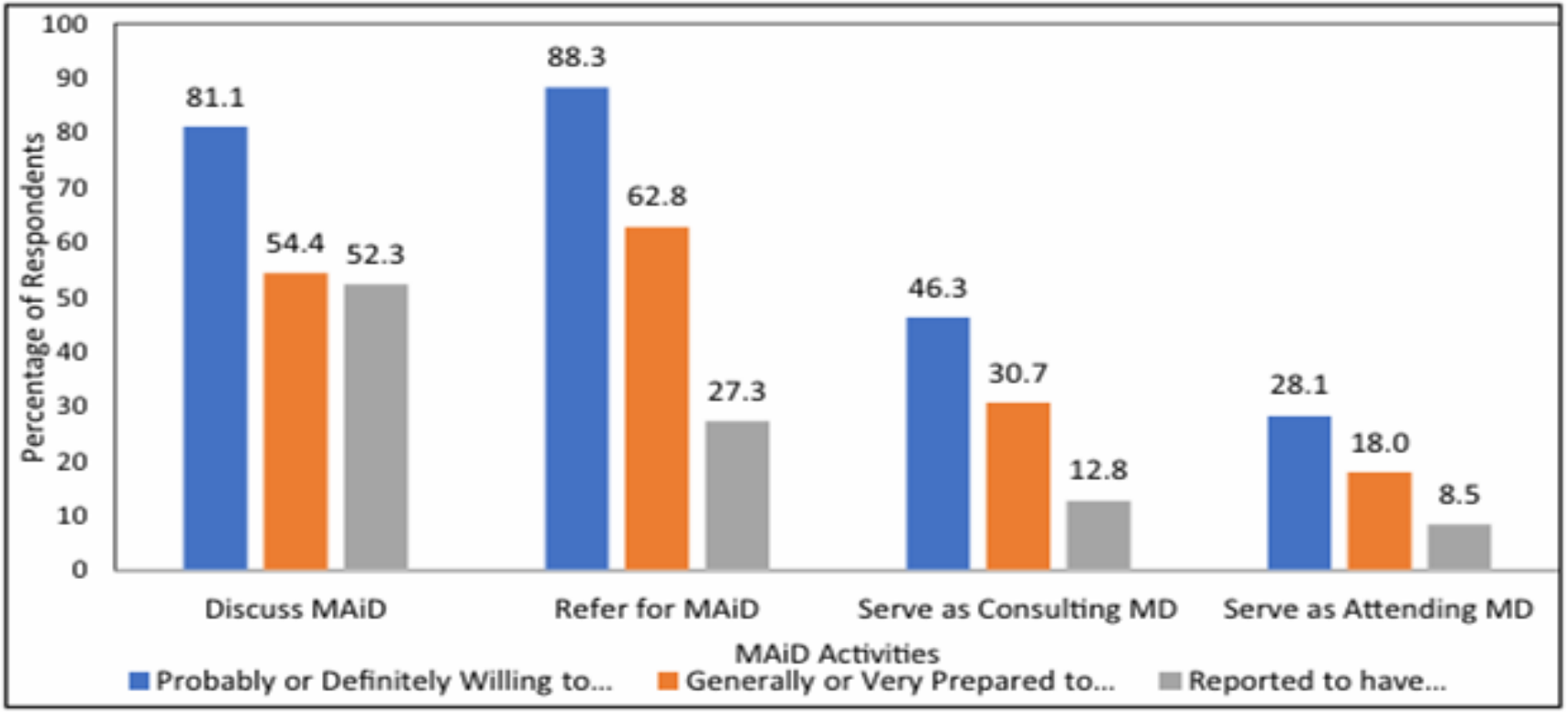
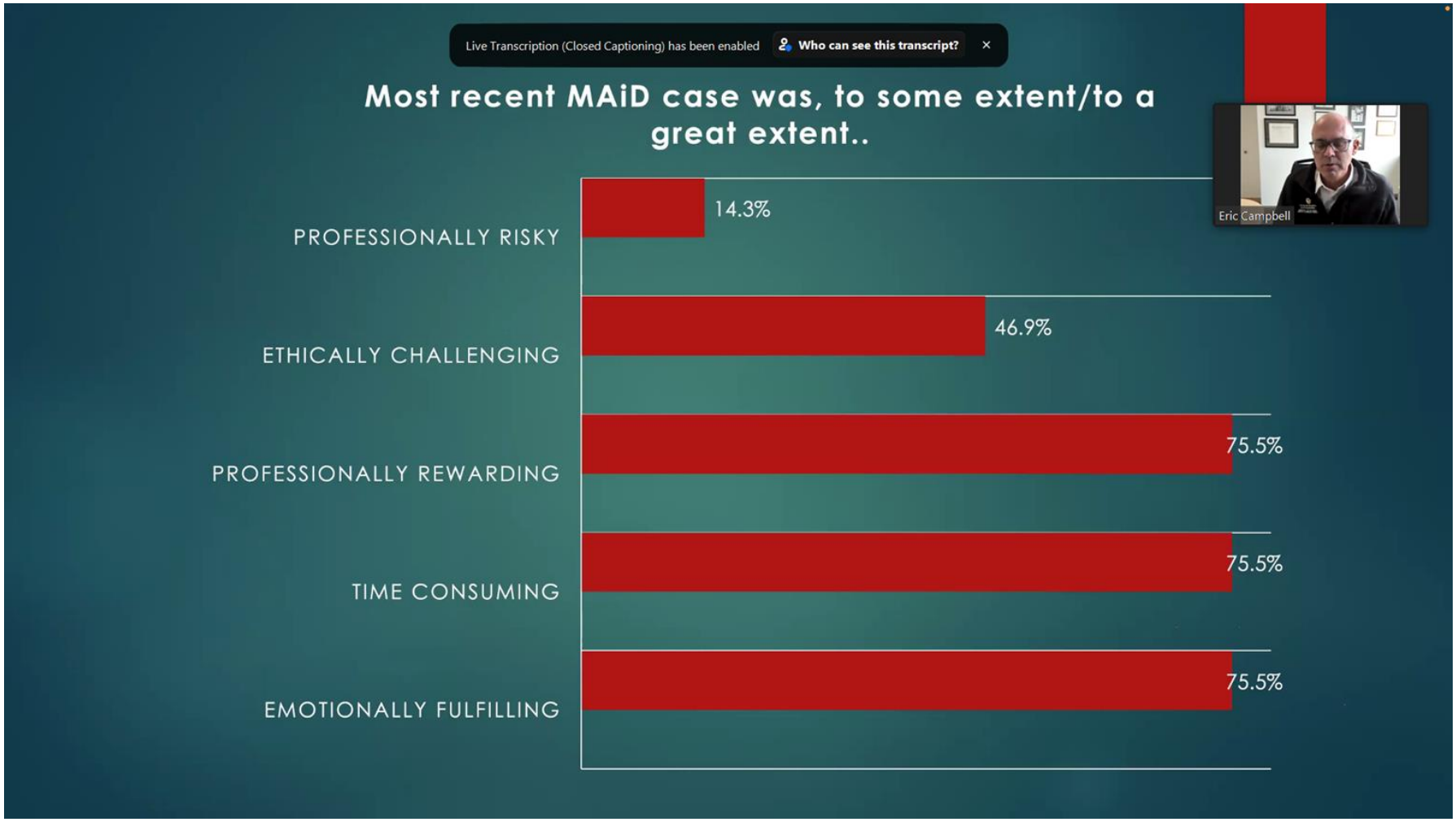
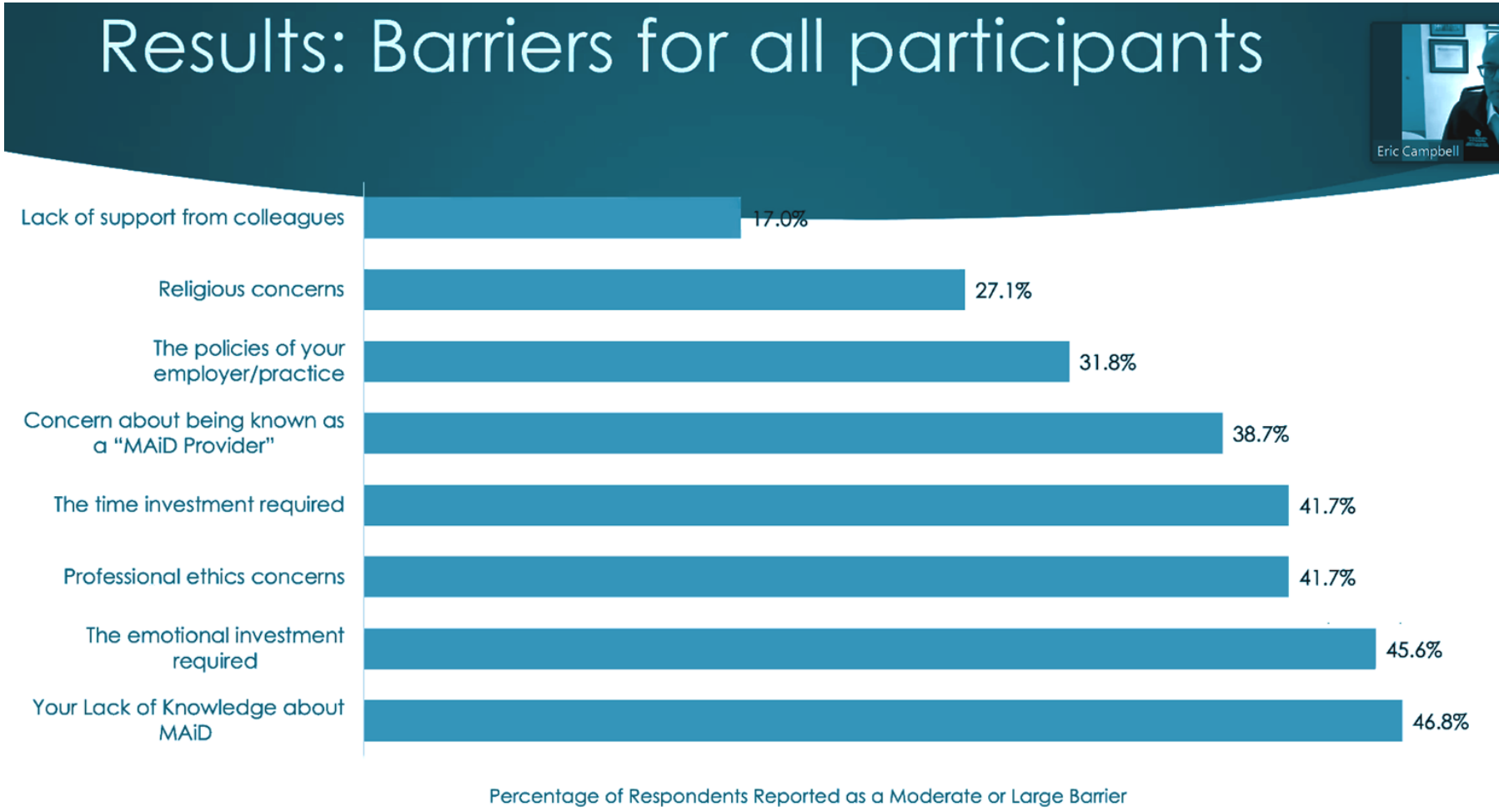
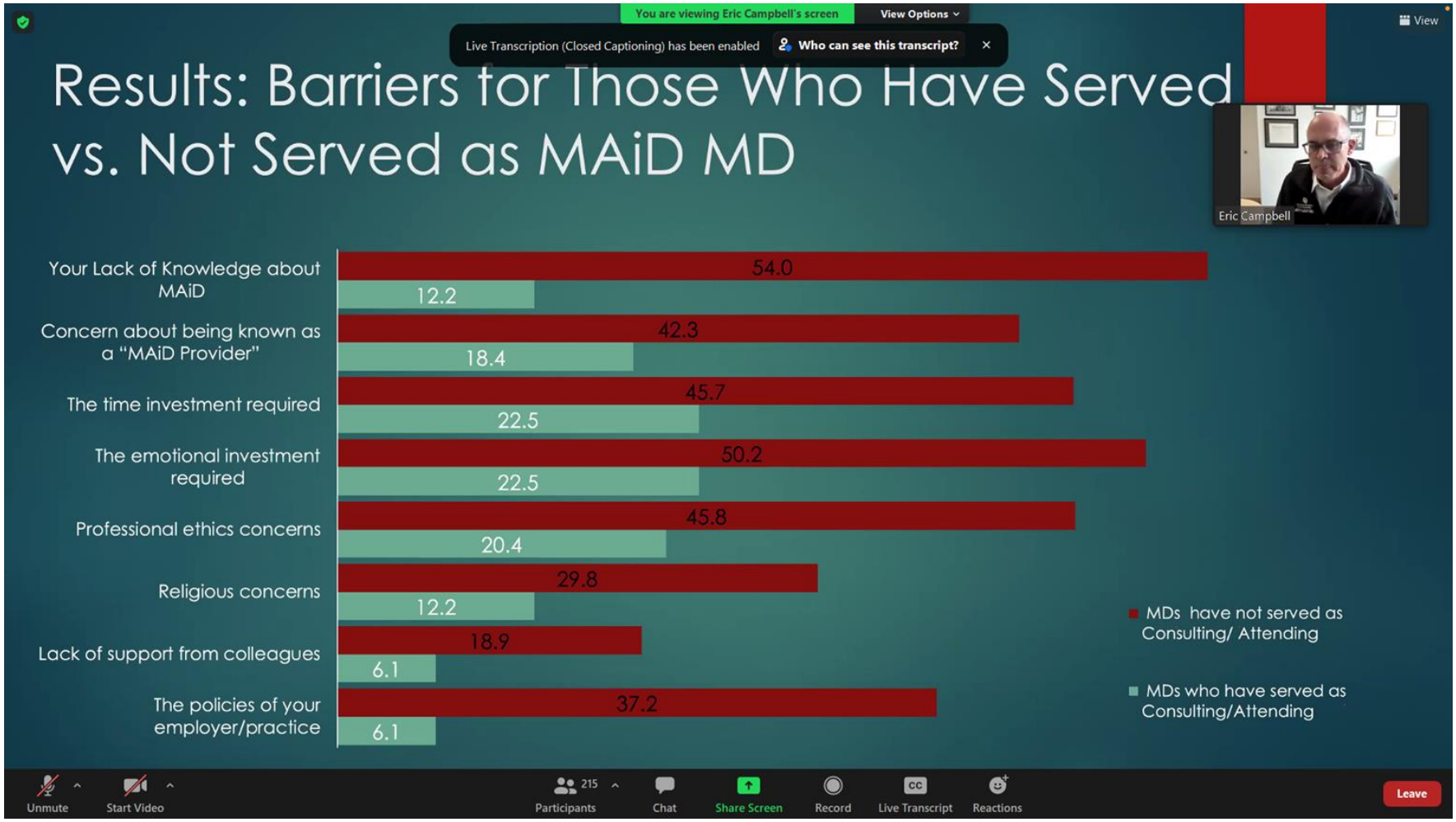


Figure 1 Respondents' preparedness, willingness, and actual participation in MAiD activities.


Live Transcription (Closed Captioning) has been enabled
Who can see this transcript?
Most recent MAiD case was, to some extent/to a great extent..
Eric Campbell
PROFESSIONALLY RISKY
14.3%
ETHICALLY CHALLENGING
46.9%
PROFESSIONALLY REWARDING
75.5%
TIME CONSUMING
75.5%
EMOTIONALLY FULFILLING
75.5%

Barriers to Participation




You are viewing Eric Campbell's screen
View Options
View
Live Transcription (Closed Captioning) has been enabled
Who can see this transcript?
Results: Barriers for Those Who Have Served vs. Not Served as MAiD MD
Eric Campbell
Your Lack of Knowledge about MAiD
54.0
12.2
Concern about being known as a "MAiD Provider"
42.3
18.4
The time investment required
45.7
22.5
The emotional investment required
50.2
22.5
Professional ethics concerns
45.8
20.4
Religious concerns
29.8
12.2
Lack of support from colleagues
18.9
6.1
The policies of your employer/practice
37.2
6.1
MDs have not served as Consulting/ Attending
MDs who have served as Consulting/Attending
Unmute
Start Video
215
Participants
Chat
Share Screen
Record
Live Transcript
Reactions
Leave

Institution Policies Vary

No participation at all: Zero Tolerance

Not even allowed to acknowledge that an individual has mentioned a request

"Leave the room"

Allows hospice staff to support the patient on the day of ingestion, but requires that they leave the room at the time of self-administration

Facilities: SNFs, AFLs, LTCs, etc

Variation

Holden, C., Abbott, J.I., & Kerwin, J. (2023). US Hospice "Leave the Room" Policies: Ethical Challenge to Nursing Commitments (TH111A). *Journal of Pain and Symptom Management*.

Ethical Dilemma

Extend life v. Alleviate suffering

Dame Cicely Saunders on Suffering

”Total pain is the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles.”

“How people die remains in the memory of those who live on.”

AMA Code of Medical Ethics

Thoughtful, morally admirable individuals hold diverging, yet equally deeply held and well-considered perspectives about physician-assisted suicide. Nonetheless, at the core of public and professional debate about physician-assisted suicide is the aspiration that every patient come to the end of life as free as possible from suffering that does not serve the patient's deepest self-defining beliefs. Supporters and opponents share a fundamental commitment to values of care, compassion, respect, and dignity; they diverge in drawing different moral conclusions from those underlying values in equally good faith.

AMA Code of Medical Ethics

Guidance in the AMA Code of Medical Ethics encompasses the irreducible moral tension at stake for physicians with respect to participating in assisted suicide.

Opinion 5.7 powerfully expresses the perspective of those who oppose physician-assisted suicide.

Opinion 1.1.7 articulates the thoughtful moral basis for those who support assisted suicide.

AAFP Policy Statement

Ethics and Advance Planning for End-of-Life Care

AAFP Policy Compendium

End-of-Life Care

"....should have basic knowledge, communication skills, and conversational strategies to respond in a compassionate and supportive manner, regardless of whether they choose to provide medical aid in dying. Basic requisite knowledge includes the legal status of medical aid in dying in the state in which the practice is located, eligibility requirements for participation where legal, and alternatives…"

Resources

Wolters Kluwer UpToDate®

Medical Aid in Dying: Clinical Considerations

Medical Aid in Dying: Ethical and Legal Issues

FP Essentials™

498
End-of-Life Care

November 2020

Palliative Management of Symptoms at the End of Life
pp 11-20

Serious Illness Progression, Prognostication, and Advance Care Planning
pp 21-25

Hospice Care
pp 26-31

Medical Aid in Dying
pp 32-36

AAFP
AMERICAN ACADEMY OF FAMILY PHYSICIANS

Capacity Assessments

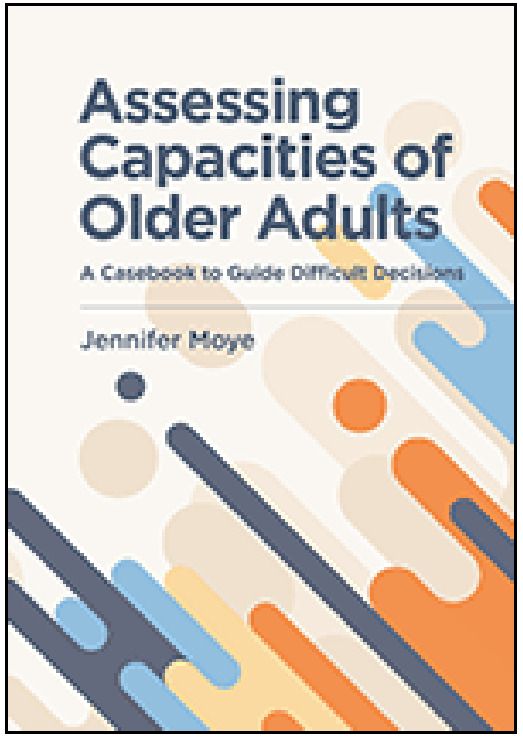
Demonstrate

Understanding of the situation

Appreciation of the consequences

Reasoning in their thought process

Can communicate their wishes



Chapter 11: Assessment of capacity in medical aid in dying

American Psychological Association

Doc-2-Doc

Call Doc-2-Doc: 800.247.7421

Email: doc2doc@compassionandchoices.org

American Clinicians Academy on Medical Aid in Dying

AAFP Medical Aid-in-Dying Member Interest Group (MIG)

www.aafp.org

- Click on membership, then
- Connect with your peers, then
- Member interest groups

Residency Training: STFM Curriculum

STFM
SOCIETY OF TEACHERS OF FAMILY MEDICINE

Lessons for Minnesota

1) No need to speculate
2) Education is crucial
3) Good policies create clarity
4) Institutions can respect all clinicians' perspectives
5) Be ready to answer patient questions
6) Support is available

Discussion