



WELCOME to
Palliative Care ECHO 4.0

***Improving Care for those with
Serious Illness***

October 2024 – June 2025

Table of Contents

Oct-24	<u>Trauma Informed Care</u>
Nov-24	<u>Palliative Care ED</u>
Dec-24	LGBTQIA
Jan-25	MAID
Feb-25	Severe mental illness
Mar-25	<u>SICG in Dementia</u>
Apr-25	<u>SpiritualityCultural Sensitivity</u>
May-25	Neurologic diseaseare partner stres
Jun-25	Neurologic diseaseare partner stres



Trauma-Informed Approach to Serious Illness

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Palliative Care Echo Session #1 October 1, 2024

Learning Objectives

By the end of this session, ECHO participants will be able to:

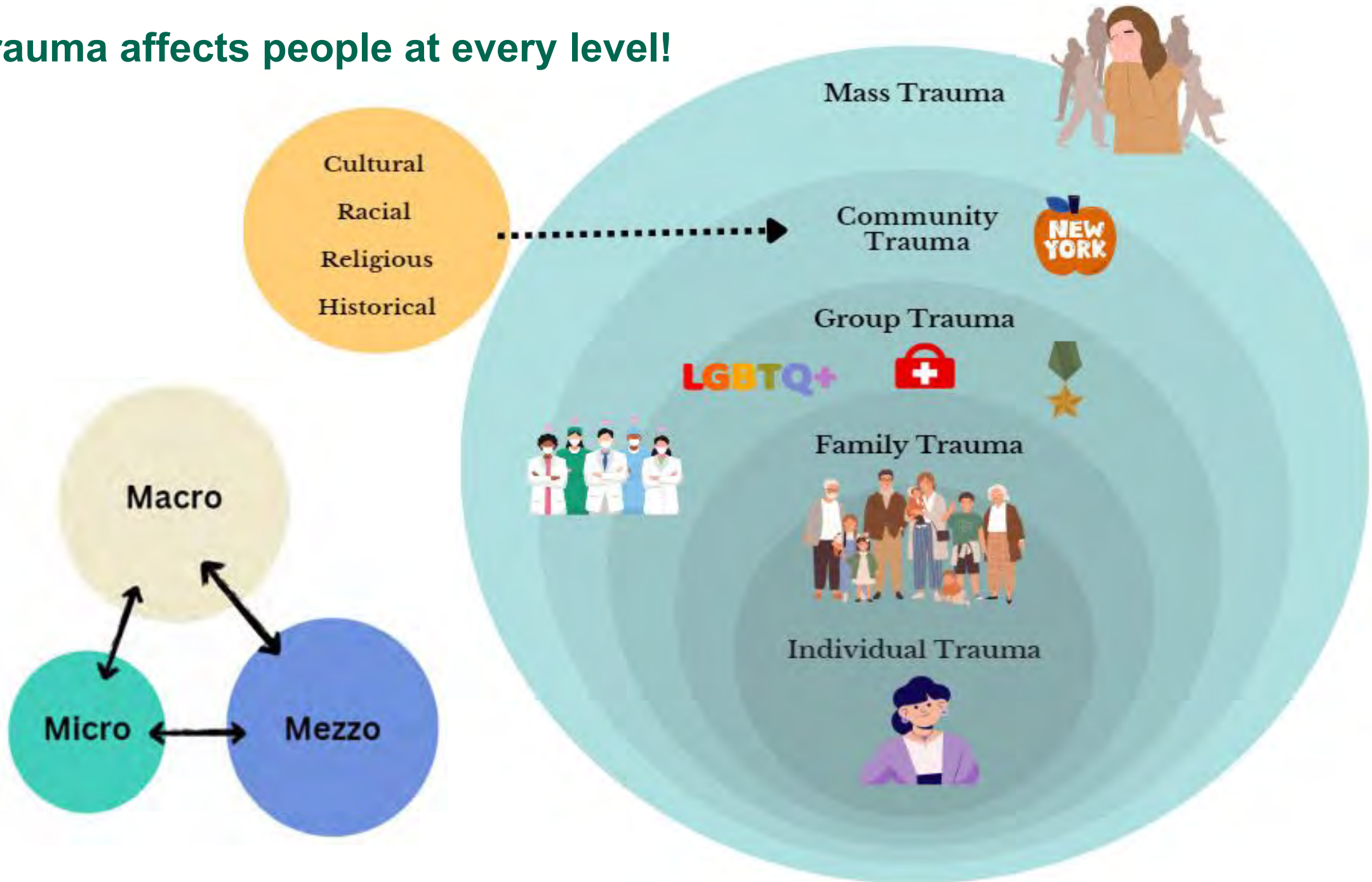
- Define trauma and identify trauma responses in our patients
- Demonstrate a trauma-informed approach to assessment, communication, and interaction with our patients
- Reflect on strategies to be a more trauma-informed provider

The “3 E’s” of trauma: **event(s)** that someone **experiences** as harmful and have adverse **effects** on wellbeing.



EVENTS → EXPERIENCES → EFFECTS

Trauma affects people at every level!



TRAUMA CAUSES PHYSICAL AND MENTAL ILLNESS.

7



EMOTIONAL & INTERPERSONAL

- Depression & anxiety
- Difficulty trusting others
- Difficulty regulating emotions
- Withdrawal from family, friends, & community



BEHAVIORAL

- Substance use & abuse
- Self-destructive behaviors
- Impulsivity
- Avoidance of situations, people, & places



PHYSICAL

- Hyperarousal (muscle tension and insomnia)
- Headaches, high blood pressure, fatigue
- Increased risk of cardiovascular issues, diabetes, cancers



COGNITIVE

- Decreased concentration
- Changes in brain development
- Impaired speech & language
- Impaired memory
- Dissociation



SPIRITUAL

- Feelings of abandonment, betrayal, & loss of faith
- Existential distress
- Can also result in renewed faith or spirituality

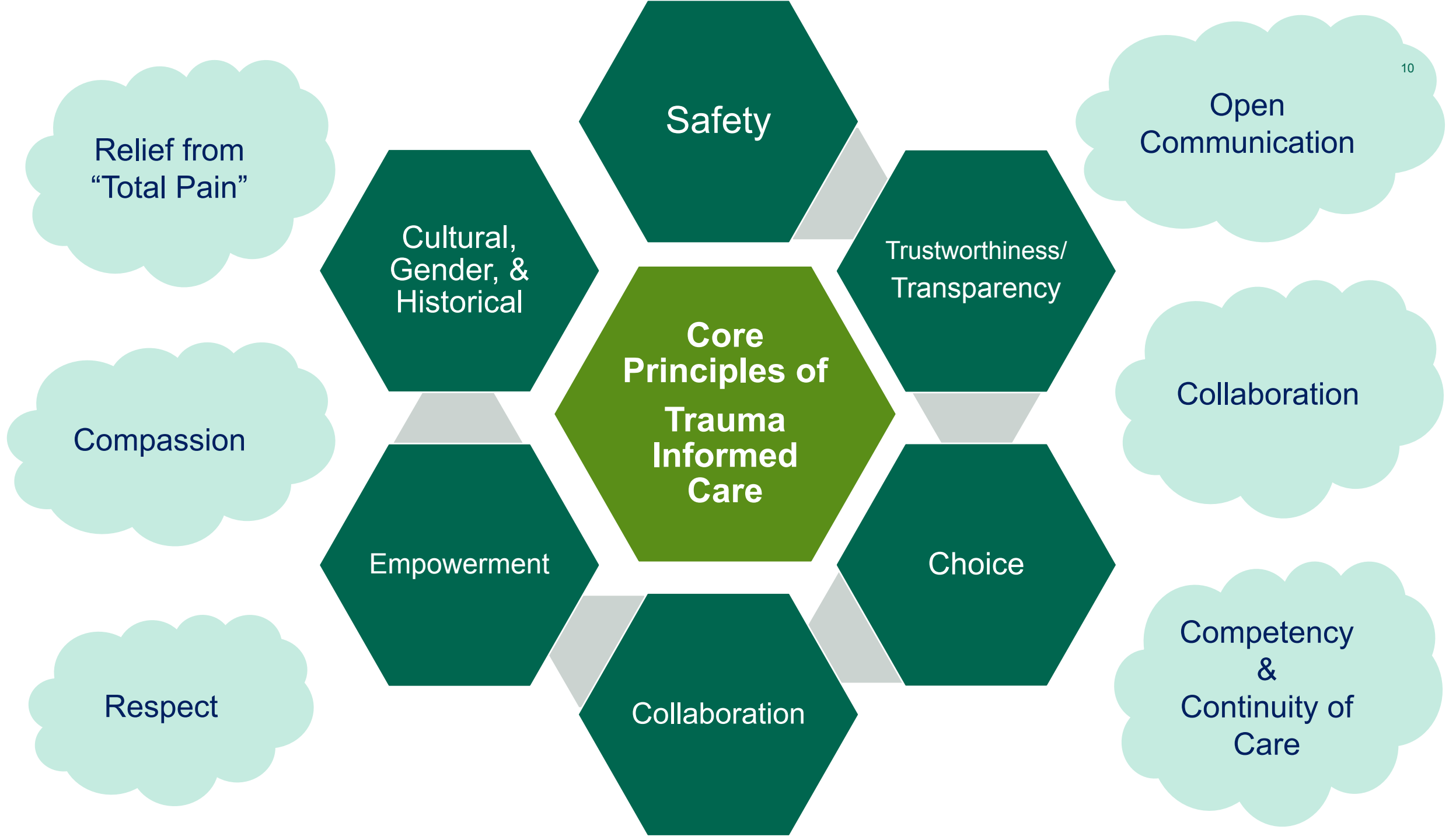
Trauma-informed approach is defined as:

“a strengths based service delivery approach that is grounded in an understanding of and responsiveness to the impact of trauma, that emphasizes **physical, psychological, and emotional safety** for both providers and survivors to rebuild a sense of control and empowerment.”




Trauma informed care **empowers** palliative providers to be their most effective.

- Trauma informed care is accessible
- Palliative philosophy aligns with trauma informed care
- Holistic and person-centered
- Improves positive patient and provider outcomes
- Fosters connection through individualized approach
- Prevents re-traumatization
- Supports pain management



Ask questions to assess an individual's trauma history.



Childhood and Family
experiences

Distressing
Events

Triggers and
Unsafe Situations

Losses and
Bereavements

Coping &
Resilience

Privacy and
Confidentiality

“What can our team do today to help you feel safe?”



Use **empathy**, **reassurance**, and **sensitivity** when responding to disclosures of trauma.

- “I appreciate the courage it took to share that with me.”
- “Thank you for trusting me enough to share these experiences today.”
- “I wish that you had not been harmed/betrayed/hurt.”
- “Please know that you deserve support.”
- “You deserve to be safe.”
- “I will keep these details private unless you tell me otherwise.”
- “What can we do to help you feel safe while receiving care?”
- “How would you like me to document this information?”

Establish **physical, psychological, and emotional safety** first.

- Share preferred name and pronouns
- Determine how individuals prefer to receive medical information
- Limit jargon and avoid the “righting reflex”
- Be curious, ask clarifying questions, ask for feedback
- Mirror affect and match your patient’s energy
- Respect boundaries and preferences, be mindful of known triggers
- Offer genuine validation and affirm patient experiences
- Be mindful of touch and personal space (don’t block the door!)
- Watch for discomfort or distress- have tissues handy!

Self-care is essential to being a resilient and empathic provider.



Closing Reflections:

What is **one** thing you will do differently to incorporate a **trauma-informed approach** while caring for people living with serious illness?

Please type your answers in the chat!



Thank you!



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- Substance Abuse and Mental Health Services Administration. (2014). Trauma-Informed care in behavioral health services. In Treatment Improvement Protocol (TIP) Series 57.
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Palliative Medicine

in the

Emergency Department

Phil Lawson MD
November, 2024

Objectives

1. Recognize challenges of care in Emergency Departments (ED)
2. List ways to adjust and apply palliative interventions to the ED setting
3. Cite tools to assist ED providers in improving palliative care in the ED



Case:

- 84 yo comatose female brought to Critical Access Hospital
GCS = 3
- AD's, POLST, P-DNR not with patient on arrival
- Intubated in ED with lines and tubes....
- Bilateral cerebral hemorrhage (brain bleed) ->
call to neurosurgery -> helicopter on the way
- Friend arrives horrified stating she would never want this



GCS = Glasgow Coma Scale; AD = Advance Directive; POLST = Portable Medical Order;
DPOAH = Durable Power of Attorney for Healthcare

Best Practice Goals ED providers

Best Practice palliative care per ACEP includes:

1. Screening and assessing patients for palliative care needs
2. Managing patients with palliative care needs in the Emergency Department (ED)
3. Consulting palliative care specialists in/from the ED
4. Transitioning palliative care or hospice eligible patients from the ED

ACEP: American College of Emergency Physicians

Loffredo A et al. ***United States Best Practice Guidelines for Primary Palliative Care in the Emergency Department.*** Annals of Emergency Medicine Vol 78(5), Nov 2021, 658-669

Realities of the Venue

- Rapid Triage
- Variable wait times for care
- Focus is on the presenting complaint
 - Rule out what is life/limb threatening
 - Make a tentative diagnosis based on limited available information
 - Achieve disposition rapidly*



Realities of the Venue

- Loud, limited privacy, limited comfort
- Frequently interrupted patient/provider time
- Limited (sometimes no) available medical information
- Extensive testing (for the “rule out”)
- A culture of “If in doubt, intervene...”



Conclusions from recent research

CPR on cancer patients in the ED

- Advance Directives (AD's) associated with:
 - Quicker adjustment to DNR status
 - Shorter ICU stay
 - Shorter hospital stay
 - No difference in mortality

Wechsler AH et al. Prior Advanced Care Planning and Outcomes of CPR in the ED of a Comprehensive Cancer Center. *Cancers* **2024**, 16(16), 2835; <https://doi.org/10.3390/cancers16162835>

Recent Research

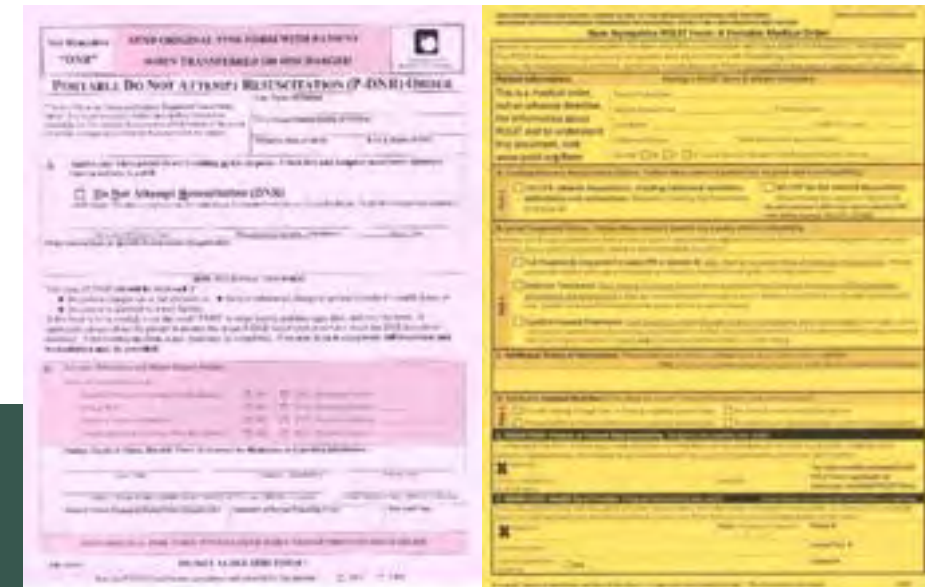
Advance Directives (AD's) are not available

- 20-25% reported having AD's; 7% available
- High variance amongst ED's: 1 - 48% had any form of AD's available

Patients and providers don't talk about AD's/goals of care in the ED

- @10% of elderly ill patients in ED are asked about AD's
- @80% thought ED providers should be aware
- <40% expressed desire to discuss goals of care

*References in chat



What PC Providers can offer the ED

IF/AA PERMITS ENDORSEMENT OF POLST ORDERS TO HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENT
REQUIREMENTS WITH PATIENT INFORMATION, TRANSFERRED OR DISCHARGED, ATTACHED FORM D-200A FROM D-200A FORM D-200A

Medical Record # (Optional)

New Hampshire POLST Form: A Portable Medical Order

Health care providers should complete this form only after a conversation with their patient or the patient's representative. The POLST document making process is for patients who are at risk for a life-threatening clinical event because they have a serious, life-limiting medical condition, which may include advanced frailty (<http://www.polst.org/guidance/appropriate-patient>) with

Patient Information: Having a POLST form is always voluntary.

This is a medical order, not an advance directive. For information about POLST and to understand this document, visit: www.polst.org/form

Patient First Name: _____ Preferred Name: _____
Middle Name/Initial: _____ Last Name: _____ (Suffix or Jr., III, etc.)
DOB (MM/DD/YYYY): _____ State where form was completed: _____
Gender: ☐ M ☐ F ☐ X (Sexual/Second Gender) Social Security Number's last 4 digits (optional): _____

A. Cardiopulmonary Resuscitation Orders: Follow these orders if patient has no pulse and is not breathing.

Pick 1

☐ YES CPR: Attempt Resuscitation, including mechanical ventilation, defibrillation and cardioversion. (Requires choosing Full Treatments in Section B)

☐ NO CPR: Do Not Attempt Resuscitation. (May choose advanced care in Section B) This will constitute a DNR order and no separate DNR order will be required. (MA 10/1/2015)

B. Initial Treatment Orders: Follow these orders if patient has a pulse and/or is breathing.

Respiratory and other interventions will follow at patient representative's request. Treatments are limited to patient's care goals. Consider a new order if interventions based on goals and specific outcomes.

Pick 1

☐ Full Treatments (required if choose CPR in Section A): Give, attempt to sustain life by all medical means, including mechanical ventilation, defibrillation and cardioversion. May use non-invasive positive pressure ventilation and BiPAP as indicated. Assist with oral care. Transfer to hospital if treatment needs cannot be met at current location.

☐ Selective Treatments: Give, attempt to sustain life by all medical means, including mechanical ventilation, defibrillation and cardioversion. May use non-invasive positive pressure ventilation and BiPAP as indicated. Assist with oral care. Transfer to hospital if treatment needs cannot be met at current location.

☐ Comfort Focused Treatments: Give, attempt to sustain life by all medical means, including mechanical ventilation, defibrillation and cardioversion. May use non-invasive positive pressure ventilation and BiPAP as indicated. Assist with oral care. Transfer to hospital if treatment needs cannot be met at current location.

C. Additional Orders or Instructions: These orders are in addition to those above (e.g., blood products, dialysis).
(NMS providers may limit emergency resuscitation ability to act on orders in this section.)

D. Medically Assisted Nutrition (Dried food by mouth if desired by patient, safe and indicated):

Pick 1

☐ Provide feeding through oral or feeding temporarily placed tubes. ☐ No artificial means of nutrition planned.

☐ Feed per oral for artificial nutrition but no surgically placed tubes. ☐ Discontinue but no decision made (standard of care provided).

E. SIGNATURE: Patient or Patient Representative (signed documents are valid)

I understand this form is voluntary. I have discussed my treatment options and goals of care with my provider. If signing as the patient's representative, the treatments are consistent with the patient's known wishes and/or their best interests.

☒ Patient

If other than patient, print full name: _____ Signature: _____

The most recently completed valid POLST form supersedes all previously completed POLST forms.

F. SIGNATURE: Health Care Provider (signed documents are valid) (verbal orders are acceptable with follow-up signature)

I have discussed this order with the patient or his/her representative. The order reflects the patient's known wishes. To the best of my knowledge, this POLST form is valid and intended to be followed by all health care providers who receive this form.

☒ Physician

Date and time (MM/DD/YYYY): _____ Place: _____

Printed Full Name: _____ License/Cert. #: _____

Supervising physician: ☐ N/A License #: _____

A copied, signed or electronic version of this form is a legal and valid medical order. This form does not expire. 2024

- Out of hospital arrest
- Goal concordant vs goal discordant care
- POLST as a starting place in the ED

What PC Providers can offer the ED

New Hampshire Forms



New Hampshire Advance Directive Form

Name (Printed): _____
DOB: _____
Address: _____

I. DURABLE POWER OF ATTORNEY FOR HEALTH CARE

The durable power of attorney for health care form makes your agent(s) and, if you wish, any backups you want your agent for (COOs).

I choose the following person(s) as agent(s) if I have lost capacity to make health care decisions. (You may make backup (any backups for myself):

(If you choose more than one person, they will become your agent in the order written, unless you indicate otherwise.)

A. Choosing Your Agent:

Agent: I appoint _____ of _____ and whose phone number is _____ to be my agent to make health care decisions for me.

Backup Agent: If the person above is not able, willing, or available, I appoint _____ of _____ and whose phone number is _____ to be my alternate agent.

If no one listed above can make decisions for you, a surrogate will be assigned in the order written in the following adult child, parent, sibling, etc.) and will have the same powers as an agent. If none of the foregoing, a court appointing person may be assigned.

B. Limiting Your Agent's Authority or Providing Additional Instructions

When you can no longer make your own health care decisions, your agent will be able to make decisions for you. Please review the Disclosure Statement that is attached to this Advance Directive form. Examples of how you may want to advise your agent. You may write in limits or additional instructions below or attach additional pages.

I have attached _____ document(s) giving about additional choices for my Durable Power of Attorney for Health Care to represent my wishes.

[illegible]

What PC Providers can offer the ED

Vermont Forms

- Short Form
- Long Form
- Registry
- COLST

VERMONT ETHICS NETWORK

Vermont Advance Directive for Health Care

YOUR NAME: _____ DATE OF BIRTH: _____ SEX: _____
ADDRESS: _____
CITY: _____ STATE: _____ ZIP: _____

PART ONE: YOUR HEALTH CARE AGENT

Your health care agent can make health care decisions for you when you are unable or unwilling to make decisions for yourself. You should pick someone that you trust, who understands your wishes and agrees to act as your agent. Your health care provider may **NOT** be your agent unless they are a relative. Your agent may **NOT** be the owner, operator, employee or contractor of a residential care facility, health care facility or correctional facility where you reside at the time your advance directive is completed.

I appoint this person to be my health care **AGENT**:

AGENT NAME: _____ EMAIL: _____
ADDRESS: _____
HOME PHONE: _____ WORK PHONE: _____ CELL PHONE: _____

(If you appoint **CO-AGENTS**, list them on a separate sheet of paper)

If this agent is **unavailable**, unwilling or unable to act as my agent, I appoint this person as my **ALTERNATE AGENT**:

ALTERNATE AGENT NAME: _____ EMAIL: _____
ADDRESS: _____
HOME PHONE: _____ WORK PHONE: _____ CELL PHONE: _____

Others who may be consulted about medical decisions on my behalf include:

Primary care provider (Physician, PA or Nurse Practitioner):

NAME: _____ PHONE: _____
ADDRESS: _____
NAME: _____ PHONE: _____
ADDRESS: _____

Those who should **NOT** be consulted include:

VER-100-01/02/03 (PART ONE, CONTINUED NEXT PAGE) (2/13)

VERMONT DNR/COLST - Clinician orders for DNR/CPR & Other Life-Sustaining Treatment

PATIENT: _____ DOCTOR: _____ NURSE: _____ INTERPRETER: _____

SECTION A: Cardiopulmonary Resuscitation: Follow these orders when patient is unresponsive & has NO pulse:

☐ **NO CPR: Do Not Attempt Resuscitation (DNR)** ☐ **YES CPR: Attempt Resuscitation**, including chest compressions, artificial respiration, ventilation, and transfer to hospital.

Reason for DNR order: informed consent OR medical non-benefit. (Choose one)

☐ **Informed Consent obtained from:** _____
Name of Person/Group (Indicate Consent of Each Patient): _____
Relationship to Person (Write "self" if Patient): _____
(Agent, guardian, or surrogate): _____
Signature (if available, not required): _____
Verbal Consent: _____

OR

☐ **This DNR order is written on the basis of medical non-benefit (futility). Required if no consent.**
I have determined that resuscitation would not prevent the imminent death of this patient (indicate the patient's respiratory/cardiopulmonary arrest, Anoxia/Choking, etc., also as determined): _____
Signature of Other Clinician: _____

SECTION B: Intubation and Ventilation: Follow these orders in the event of respiratory distress & HAS a pulse

Instructions for Intubation and Ventilation: (Inserting place a tube down the patient's throat and connect a breathing machine)

Make sure circle: ☐ YES do not intubate and ventilate (do not place tube) ☐ YES (FUTILE) intubation and ventilation treatment ☐ YES intubate and ventilate

SECTION C: Medical Interventions Guidelines

☐ **Focus on Sustaining Life:** Use mechanical, advanced airway interventions and mechanical ventilation as indicated. Transfer to hospital and/or intensive care unit if indicated. All patients will receive comfort-focused treatments.
Treatment Plan: Full treatment including life support measures in the intensive care unit.

☐ **Avoid Invasive Interventions:** Use medical treatments, analgesics, IV fluids and cardiac support as indicated. Do not intubate, advanced airway interventions or mechanical ventilation. May consider less-invasive airway support (e.g. high flow nasal CPAP, BIPAP). Transfer to hospital if indicated. Generally avoid intensive level of care (e.g. ICU). All patients will receive comfort-focused treatments.
Treatment Plan: Provide basic medical treatments aimed at treating non-reversible illness.

☐ **Comfort-Focused Treatment (Allow Natural Death):** Provide pain relief and suffering through the use of any medication by any route, including, but not limited to, oral, subcutaneous, intravenous, and other measures. Use passive, suction and manual respiration as needed for comfort. Patient prefers no transfer to hospital for life-sustaining measures. Transfer if patient needs comfort in current location.
Treatment Plan: Maximize comfort through symptom management.

Facility DNR Protocol Requirement (required for patients in facility (not in residential care facilities, skip if patient is not in a facility))

☐ This patient is in a health care facility or a residential care facility.
Name of Facility: _____
The requirements of the facility's DNR protocol have been met. (Initial here if protocol requirements have been met.)

SIGNATURE OF CLINICIAN (for sections A, B & C; signature includes DNR identification)

(Clinician (Physician): _____ Signature: _____ Date: _____)

What ED Providers need

- Respond immediately to requests for help
- Focus response with information that is:
 - “Need to know”
 - “Immediately actionable”
- Give very specific, focused recommendations
- Assure appropriate follow up



Tools and Scripts

- **Opioid Equivalence Tools**
- **Early Hospice Referral**
 - Tools to address hospice qualifiers: LCD's
- **Transferable Medical Orders**
 - POLST: NH form
 - P-DNR form (Pink Portable) + card
- **Communication Skills Training**
 - Serious Illness Conversation Trainings, VITALtalk
- **System based and Quality Tools**
 - Center for Advancement of Palliative Care
 - American College of Emergency Physicians Toolkit

Scripts: Our “surgical” Skills

<u>What not to say</u>	<u>What might be more appropriate</u>
“Do you want everything done?”	“This is a medical procedure that has risks and benefits. Let me briefly go through them with you”
“Do you want me to try to keep you alive?”	Review best possible, worst possible and expected outcomes
“You are not getting enough oxygen; do you want me to put a tube down to help you breath?”	“We are considering putting you on a breathing machine, but I am worried about what might happen to you if we do; and we have options to help your breathing...”
“Do you want us to try to revive you if your heart stops?”	“I want to make sure we treat you the way you want to be treated if your condition gets worse. CPR is an option that has risks for you.....”

Communication Tools

Best Possible

- “Alive hooked up to machines for at least a few days, and then a long rehabilitation likely in a nursing home; best possible outcome being a condition not as good as you have recently been”

Worst Possible

- “A prolonged dying process with suffering on machines”

Expected Outcomes

- “I think there is a chance you might survive, but I am worried that if you do, you will have to spend the rest of your life receiving extensive care from others, maybe in a nursing home”

What PC Providers can offer the ED

Approaches to talk about CPR, intubation and life-sustaining care

- “*Miracles... can occur no matter what type of medical care you choose*”
- *Wish/ Worry/ Wonder*
 - “I wish we could get you *back home and independent*”
 - “I worry this could lead to ... *a prolonged time of suffering on machines until your death*”
 - “I wonder if you might prefer... *a focus on comfort; allowing your natural death when it occurs?*”
- *Time Limited Trials*
 - If we choose to intervene what will success look like?
 - When should we reassess to see if we have reached that goal?

Reasonable CPR outcome data

Location and Original setting/function	Survival to Discharge from Hospital	Survival with 'good' neurologic outcome
Hospital Monitored, High Functional Status	50-60% (1 in 2)	30-50% (1 in 2-3)
Hospital overall	15-25% (1 in 4-5)	10-15% (1 in 10-15)
Outpatient/ In hospital with cancer	10-15% (1 in 7-10)	5-8% (1 in 15-20)
Nursing Home	2-4% (1 in 25-50)	1-2% (1 in 50-100)
Frailty	1-4% (1 in 25-100)	< 1-2% (< 1 in 50-100)

What PC Providers can offer the ED

Scripts to assist in demystifying hospice

- “Focused on bringing the care to your home and avoiding the ED”
- “Reduce the burdens of medical management for family”
- “Covered at 100% under Medicare” (for those without supplemental insurance)
- *“Would you like to meet with the someone from the hospice team to discuss what it would mean for your care?”*

VA PCP (Ellen Ross PA-C): 603.747.9000
Dr. Lamphier: (use pager 1st) [redacted]
* DR. Lord does food impaction.
Dr. Chris Danielson (FOOD IMPACTION): Cottage Hospital
603.747.9000

Dr. Jenna Lucas UROLOGY [redacted]
EMIG [redacted]
NVRH and COTTAGE have UROLOGY sometimes; worth calling

HOSPICE - JESSICA FOSTER | On-call first [redacted]
[redacted] DR. COLE [redacted]
NH DETOX
336.536.6089

Barry Townsend [redacted]
[redacted]
[redacted] Dr. Leiberman cell [redacted]
[redacted]

What PC Providers can offer the ED

ED care of hospice patients:

1. Call hospice team immediately
2. Explore what triggered the decision to attend the ED/ call 911
3. Treat distressing symptoms
4. Avoid diagnostic interventions until coordinating with hospice or goals of care discussion
5. Urgent Palliative Care assistance @ any life-sustaining interventions
 - rapid goals of care discussion (ie hospice team or in-hospital palliative medicine assistance)

Models of Palliative Care in the ED

ED Nurse driven Goals of Care (GOC) discussions

- 50% (who did not have one) completed a POLST
- 95% rated 4-5/5 satisfaction after; and 100% at 6 months
- No change in hospitalization, length of stay, or ICU stay
- Bigelow S et al. Difficult conversation: Outcomes of Emergency Department Nurse-Directed Goals of Care Discussions. Journal of Palliative Care. [Volume 39, Issue 1; https://doi.org/10.1177/08258597221149402](https://doi.org/10.1177/08258597221149402) 2024

Models of Palliative Care in the ED

Quality Improvement strategies for early hospice referral

- Multi-pronged quality improvement training in ED
- Prior MOLST was associated with much higher rates of hospice referral (OR 5.02)
- Pre: 22.6% Hospice referral < 96 hr vs Post: 54.1%

Baugh C et al. A hospice transitions program for Patients in the Emergency Department. JAMA. JAMA Netw Open. 2024;7(7):e2420695. doi:10.1001/jamanetworkopen.2024.20695

- Brigham and Womens, Boston

Models of Palliative Care in the ED

Embed Palliative Care Provider Services in ED

- 10X increase in ED palliative consultation
- 49% changed code status in ED
- 11% admitted to lower level of care than planned
- 17% immediate hospice referral
- No change in ED length of stay
- Compared to inpatient consults: 8.1 day shorter length of stay (3.0 vs 11.1 days)
- 6.7X ROI (\$)

Wang D and Heidt R. Emergency Department Embedded Palliative Care Service Creates Value for Health Systems. J Palliat Med 2023; May 26(5): 646-652. doi: 10.1089/jpm.2022.0245. Epub 2022 Nov 11.



Consultation in the ED

1. What is the question? What is needed?
2. What is the urgency?
3. Who (of the team) can best address this need rapidly?
4. Get background data rapidly (chart review, corollary history, AD/POLST....)
5. Do consult and/or give specific, brief recommendations
 - Honor the reality of the ED environment
6. Offer effective tools
 - Opioid equivalence resource, Fast Facts, specific scripts/ communication skills
7. Assure follow up

Adapted from Fast Facts #298. PCNOW, Palliative Care Network of Wisconsin, June 11, 2024

Wang D et al. Top Ten Tips Palliative Care Clinicians should know about caring for Patients in the Emergency Department. 2019 Dec;22(12):1597-1602. doi: 10.1089/jpm.2019.0251. Epub 2019Jul 29

Recommendations



1. Make Directives/ Orders available to ED staff (POLST, P-DNR, AD...)
 - Train ED staff to see them and use them
 - “Fix” the Electronic Medical Record barrier!
2. Build, Model and Distribute Tools for ED staff to assist in:
 - Scripts for rapid goals of care conversations at the bedside
 - Prognostic tools (ie PPS/ Karnovsky/ frailty indices....)
 - Prescribing tables/ tools (opioid equivalence, symptom mgt algorithms)
 - Rapid access to palliative and hospice specialty support
 - Assistance and support with debriefing strategies
3. Set Quality Improvement goals for ED Palliative presence
 - Start with active patients



End of talk



What ED Providers need

The American College of Emergency Physicians believes that:

- Emergency physicians play an important role in providing care at the end of life (EOL).
- Helping patients and their families achieve greater control over the dying process will improve EOL care.
- Advance care planning can help patients formulate and express individual wishes for EOL care and communicate those wishes to their health care providers by means of advance directives (including state approved advance directives, DNAR orders, living wills and durable powers of attorney for health care).

To enhance EOL care in the ED, the American College of Emergency Physicians believes that emergency physicians should:

- Respect the dying patient's needs for care, comfort, and compassion.
- Communicate promptly and appropriately with patients and their families about EOL care choices, avoiding medical jargon.
- Elicit the patient's goals for care before initiating treatment, recognizing that EOL care includes a broad range of therapeutic and palliative options.
- Respect the wishes of dying patients including those expressed in advance directives. Assist surrogates to make EOL care choices for patients who lack decision making capacity, based on the patient's own preferences, values, and goals.
- Encourage the presence of family and friends at the patient's bedside near the end of life, if desired by the patient.
- Protect the privacy of patients and families near the end of life.
- Promote liaisons with individuals and organizations in order to help patients and families honor EOL cultural and religious traditions.
- Develop skill at communicating sensitive information, including poor prognoses and the death of a loved one.
- Comply with institutional policies regarding recovery of organs for transplantation.
- Obtain informed consent from surrogates for postmortem procedures



LITTLETON
REGIONAL HEALTHCARE
Where good health begins.

Conclusions from research



Evidence to support Advance Directives

- Sean Morrison's take: "Decades of research demonstrate advance care planning doesn't work. We need a new paradigm." Sean Morrison MD

Morrison, S.R., Meier, D.E., Arnold, R.M. (2021). What's wrong with advance care planning? *Journal of the American Medical Association* (326)16: 1575-1576. doi: 10.1001/jama.2021.16430

Jimenez G et al. Overview of systematic reviews of Advance Care Planning: Summary of Evidence and Global Lesson. *J Pain Sym Mgt.* 56(3): 436-459 , 2018



LGBTQIA+

Hospice and
Palliative Care:
*Striving for Equality
in Serious Illness*

Bradley Eckert, M.D., M.S.
Palliative Care, DHMC
December 3, 2024

Learning Objectives

1. Recognize the ways **historical, sociocultural, political, and institutional factors** may influence the care LGBTQIA+ individuals receive
2. Identify the **preferences, needs, and experiences** among LGBTQIA+ individuals with serious illness
3. Recommend **strategies to create a more inclusive environment** for LGBTQIA+ patients across palliative care settings



Disclosures

None



How do we define LGBTQIA+

LESBIAN	A woman who is primarily attracted to women
GAY	A man who is primarily attracted to men; sometimes a broad term for individuals attracted to the same sex
BISEXUAL	An individual attracted to people of their own and opposite gender
TRANSGENDER	An individual whose gender identity differs from their assigned sex at birth
QUEER	Often an umbrella term to be more inclusive of the many identities that make up the LGBTQIA+ community
INTERSEX	An individual whose sexual anatomy or chromosomes do not fit with the traditional markers of “female” and “male”
ASEXUAL	An individual who generally does not feel sexual desire or attraction to any group of people
+ (Plus)	To represent the many varieties that make up one’s identity

SOURCE: National Academies of Science, Engineering, and Medicine (2020). *Understanding the Well-Being of LGBTQI+ Populations*



What are
challenges that
LGBTQIA+ patients
may experience
related to
**hospice or
palliative care?**



Meet Robert



- **87-year-old male with metastatic prostate cancer to the lungs and bone**
- He is s/p radiation and chemotherapy
- Symptoms: Fatigue, anorexia, back/shoulder pain, shortness of breath, constipation
- Social: He lives in VT with his partner Scott (35 years) & cat Oliver
- He has had two recent falls at home and fears needing a long-term care facility soon

The Life of Robert

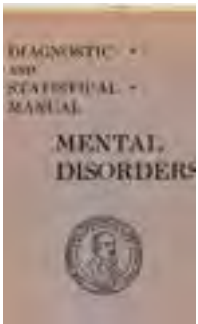
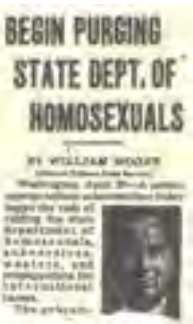
Born 1937 (age 87)



1950

Age 13

Lavender
Scare



1969

Age 32

Stonewall
Riots



1982

Age 45

HIV/AIDS
Epidemic



1996

Age 59

Defense of
Marriage Act

2003

Age 66

Lawrence
v. Texas



2016

Age 79

Pulse
Nightclub
Shooting



1952

Age 15

DSM
Published

1978

Age 41

Harvey
Milk
Murdered

1993

Age 56

"Don't Ask,
Don't Tell"

1998

Age 61

Matthew
Shepherd
Murdered

2015

Age 78

Obergefell
v. Hodges

2020

Age 83

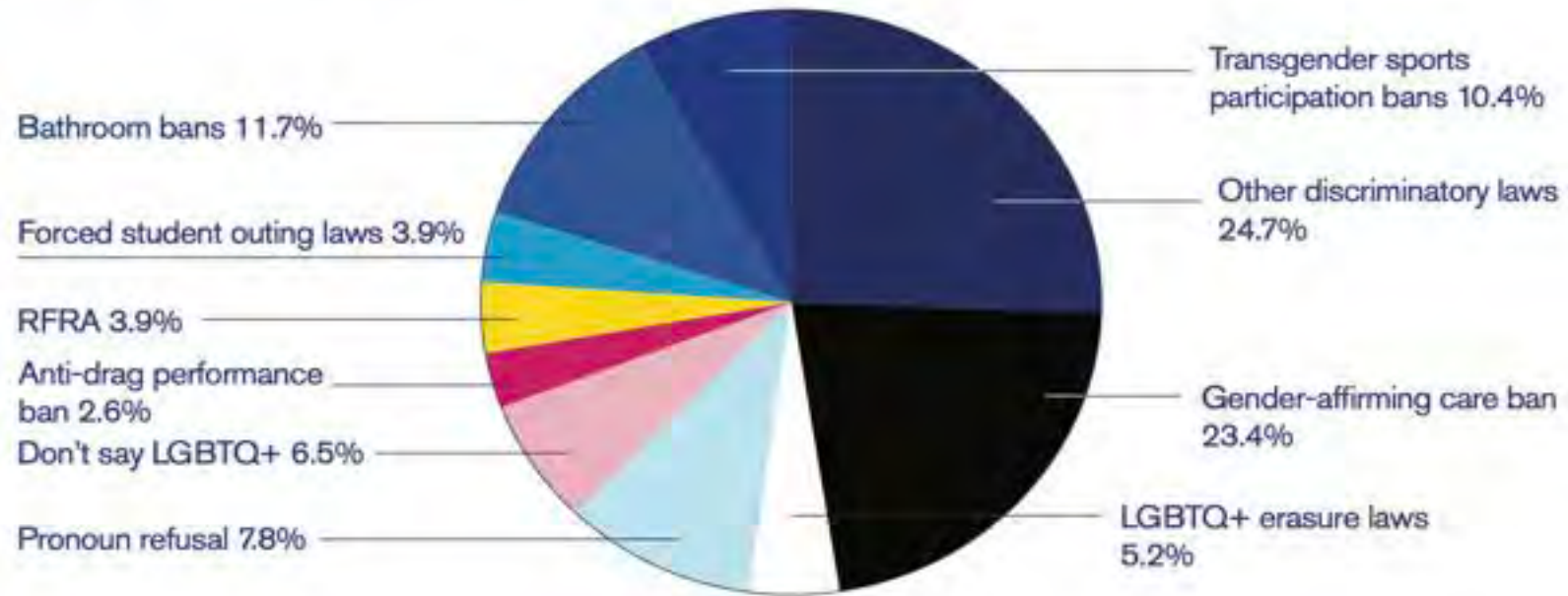
LGBTQ
Workplace
Rights

With progress, is it all “Just History?”

National State of Emergency for LGBTQ+ Americans

We have officially declared a state of emergency for LGBTQ+ people in the United States for the first time following an unprecedented and dangerous spike in anti-LGBTQ+ legislative assaults sweeping state houses this year.

Type of Bills Passed in 2023



SOURCE: Human Rights Campaign (2023): LGBTQ+ AMERICANS UNDER ATTACK: A REPORT AND REFLECTION ON THE 2023 STATE LEGISLATIVE SESSION

HPM Professionals Identify LGBT Discrimination

54%

Believed LGB Patients were more likely to experience discrimination

24%

Observed discriminatory care toward LGB patients

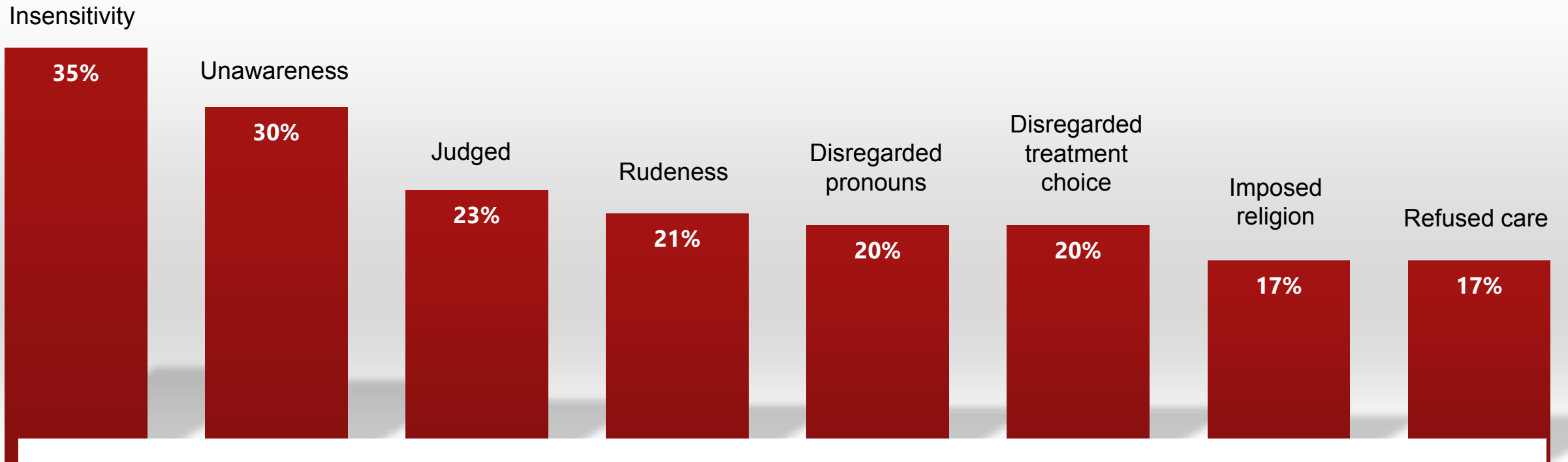
33%

Observed discrimination against LGBT patients' spouses/partners

New Study Finds Seriously Ill LGBTQ+ Patients and Care Partners Experience Discrimination

- Cross-sectional, mixed methods study (n = 290)
- Differences further observed with race and geography

■ Actions of clinicians to LGBTQ+ Patients



Healthcare barriers that LGBTQIA+ patients may experience



HEALTH CARE ORGANIZATIONS

- Lack of training for healthcare staff
- Lack of culturally competent caregiver support and bereavement groups
- Heterosexist assumptions of patient's sexual and gender identity



INDIVIDUAL AND SOCIETAL

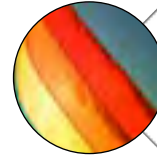
- Estrangement from family of origin
- Higher rates of mistrust of
- Nondisclosure of LGBTQIA+ status
- Fear of discrimination
- Complexity with religion/spirituality
- Isolation and lack of social support



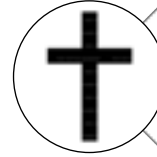
LEGAL AND SOCIAL SYSTEM

- Variability in and potential fragility of legal protections (local/state)
- Lack of comprehensive legal protections
- Absence of portability related to benefits

Key Problems at the End of Life



Anticipating Discrimination



Complexities of religion



Assumptions about identity and family structure



Varied support networks



Unsupported grief and bereavement



Increased pressure on caregivers

How can we
**make palliative
care more
inclusive**
to LGBTQIA+
patients and
families?



What steps has Dartmouth Health taken to be more welcoming to transgender and gender diverse patients?

- We provide comprehensive provider and staff education on gender-affirming care on a regular basis.
- We continue to work with Geisel Medical School at Dartmouth to provide medical students with up-to-date education on gender-affirming care.
- Single occupancy bathrooms are available to patients and employees throughout the hospital campus.
- Our Electronic Medical Records have the ability to capture information related to Sexual Orientation and Gender Identity (SOGI). Patients are able to indicate an affirmed/chosen name that appears next to the legal name listed in the chart. Patients are also able to list their pronouns in their medical records. Patients can self-report and update this information at any time by using the [myDH](#) patient portal or by connecting with their Dartmouth Health care team. For more information on system-wide SOGI collection, please visit our [We Ask Because We Care](#) page.

Ideas to Consider



Diversity in materials that are distributed



LGBTQIA+ visible signs of support



Patient forms contain inclusive, gender-neutral language that allows for self identification




Ensure that phrasing of questions we ask does not assume heterosexuality



Explore preferences specific to patients who are transgender



Gender neutral restrooms



“It should not be the job of the patient, who is already vulnerable and afraid, to have to come out.

It is the provider’s job to make it safe and welcoming and invite people to present their whole self.”

Liz Margolies, LCSW
Founder and Executive Director
National LGBT Cancer Network

National
LGBT
Cancer
Network

Support for Patients and Care Partners

Cancer Support Group

- Meet three times weekly on Zoom
- Sign up at cancer-network.org



SUPPORT GROUPS

In OUT: the National Cancer Survey, LGBTQI+-specific support groups were the top request made by LGBTQI+ cancer survivors. In response the National LGBT Cancer Network is currently running cancer peer-support groups. This is a healing space to lean on your LGBTQ+ community for support throughout your cancer journey. Join us today!

LEARN MORE



Additional Resources to Explore



AMERICAN ACADEMY OF
HOSPICE AND PALLIATIVE MEDICINE

LGBT
Special Interest Group



National
LGBT
Cancer
Network



LGBTQ
Special Interest Group

 NATIONAL LGBTQIA+ HEALTH
EDUCATION CENTER
A PROGRAM OF THE FENWAY INSTITUTE

National LGBTQIA+
Health Education Center

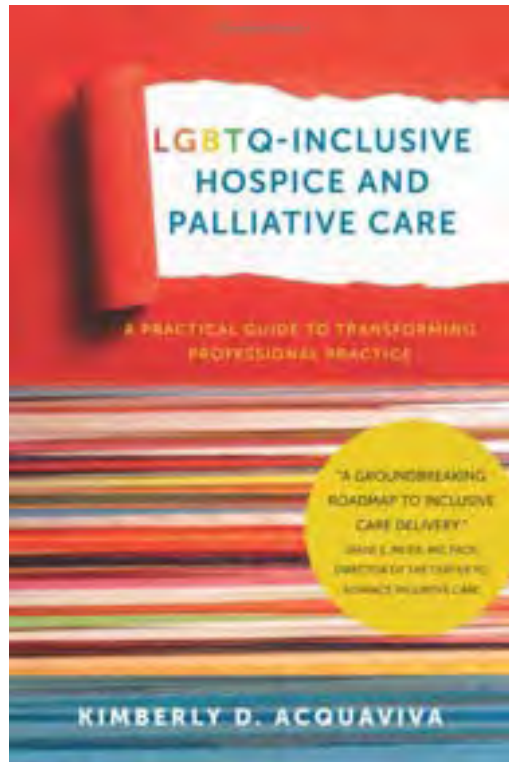
capc

“Providing Inclusive and
Affirmative Palliative
Care for the LGBTQ+
Community”

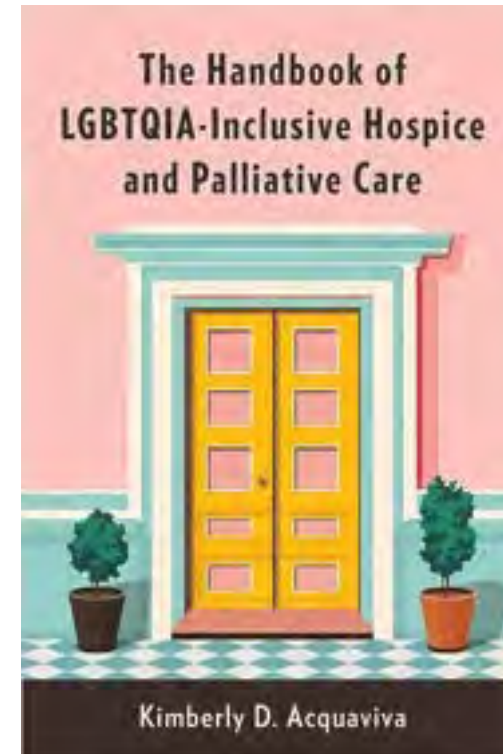


Additional Resources to Explore

Two recent books have been published that take a deeper dive



Harrington Park Press
Published: May 2017



Columbia University Press
Published: October 2023

Resources

- Daniel, H., Butkus, R., & Health and Public Policy Committee of American College of Physicians (2015). Lesbian, Gay, Bisexual, and Transgender Health Disparities: Executive Summary of a Policy Position Paper From the American College of Physicians. *Annals of internal medicine*, 163(2), 135–137.
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- Rosa, W. E., Roberts, K. E., Braybrook, D., Harding, R., Godwin, K., Mahoney, C., Mathew, S., Atkinson, T. M., Banerjee, S. C., Haviland, K., Hughes, T. L., Walters, C. B., & Parker, P. A. (2023). Palliative and end-of-life care needs, experiences, and preferences of LGBTQ+ individuals with serious illness: A systematic mixed-methods review. *Palliative medicine*, 37(4), 460–474.
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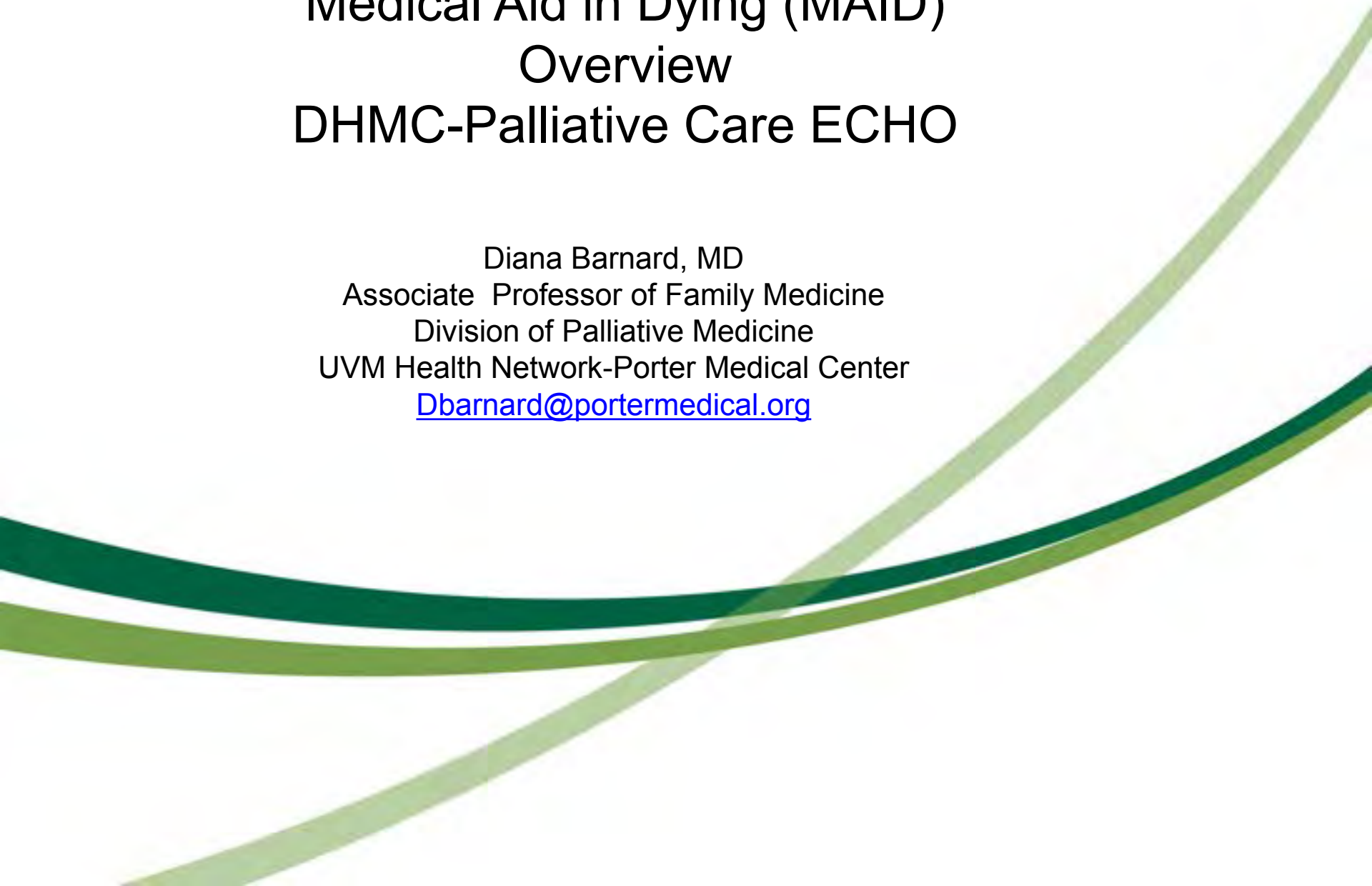


THANK YOU



Medical Aid in Dying (MAID) Overview DHMC-Palliative Care ECHO

Diana Barnard, MD
Associate Professor of Family Medicine
Division of Palliative Medicine
UVM Health Network-Porter Medical Center
Dbarnard@portermedical.org

The slide features three thick, wavy green lines that sweep across the bottom half of the page. One line is a dark forest green, while the other two are lighter shades of green, creating a layered, organic effect.

Disclosures

Will discuss off label use of FDA approved medications

I provide expert legislative testimony for access to MAID

I am occasionally reimbursed for testifying time
By Compassion and Choices

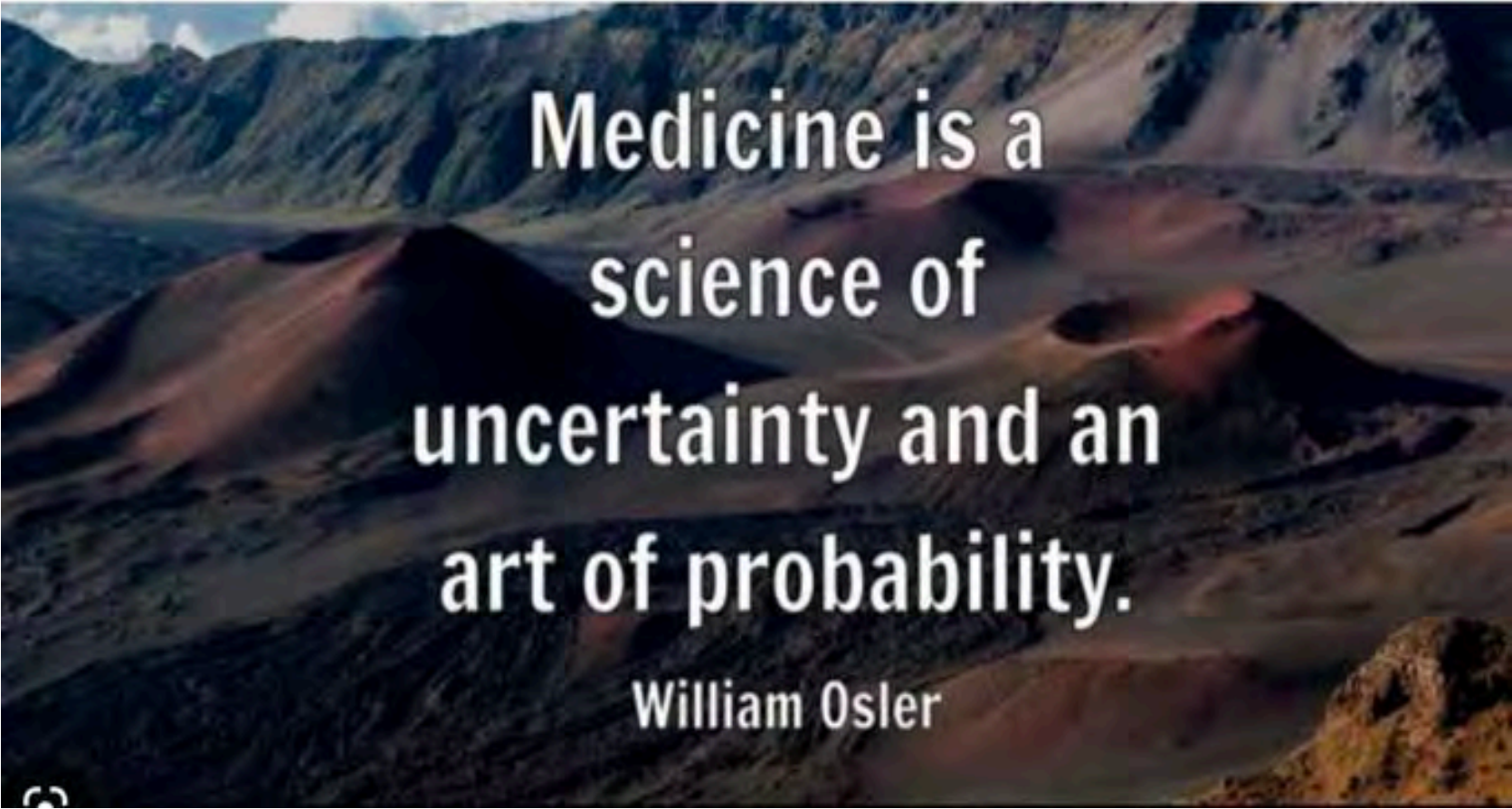
Objectives

Describe Medical Aid in Dying (MAID) and eligibility criteria

Explore motivation behind requests for MAID

Deepen awareness of multidimensional suffering

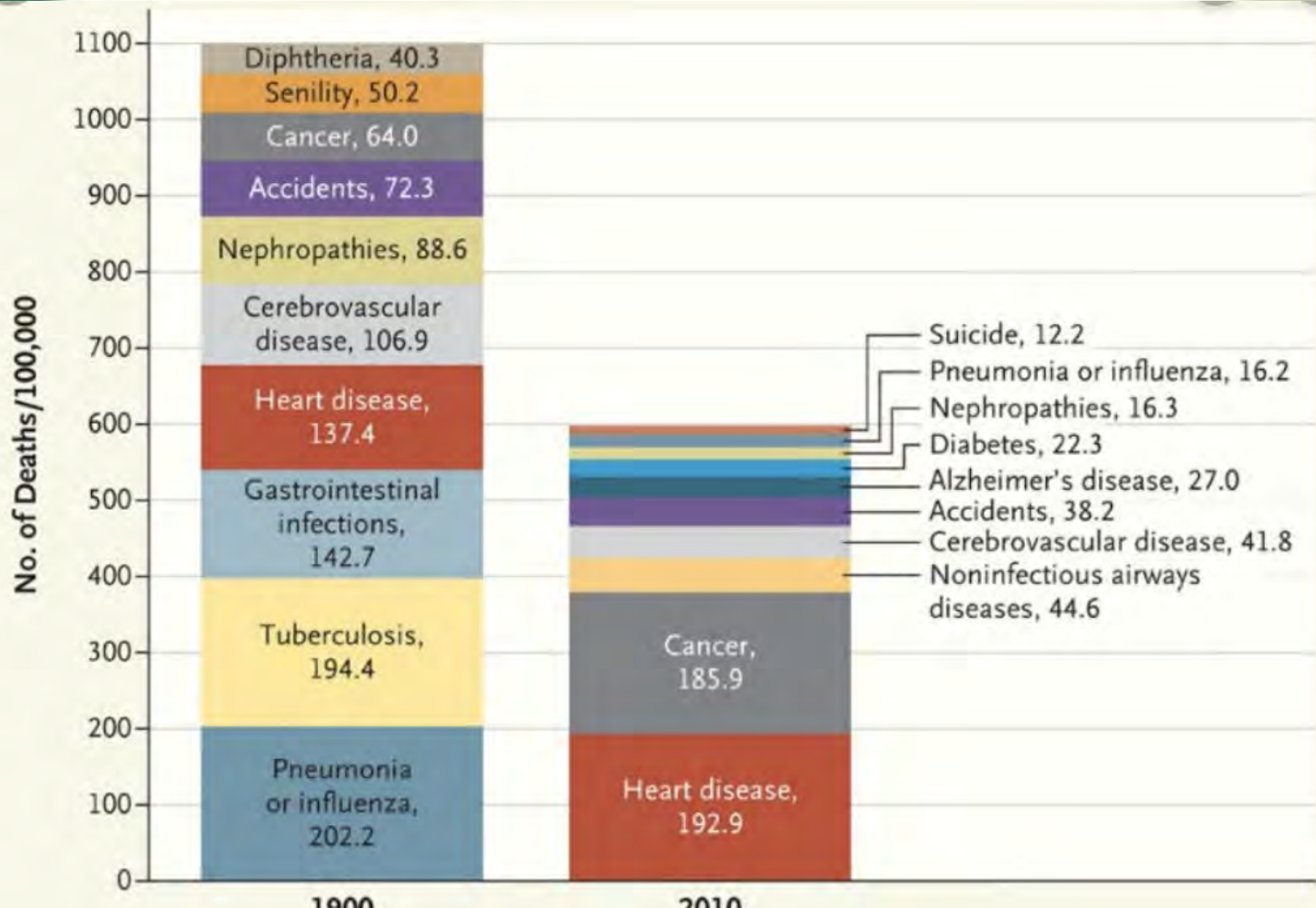
William Osler, 1800s



Medicine is a
science of
uncertainty and an
art of probability.

William Osler

Cause of Death 1900 vs. 2010



What IS Medical Aid in Dying

A practice that legally allows a physician
to prescribe a lethal dose of medication

for a *capable*
terminally ill adult

With a *<6 month* prognosis
to *voluntarily self-administer*

for the purpose of *hastening death*

End of Life

A decorative horizontal line with a wavy, undulating pattern in shades of green, spanning the width of the slide.

Unique

Individual

Deeply Personal

Enduring Impact

Patient Preferences for end of life care

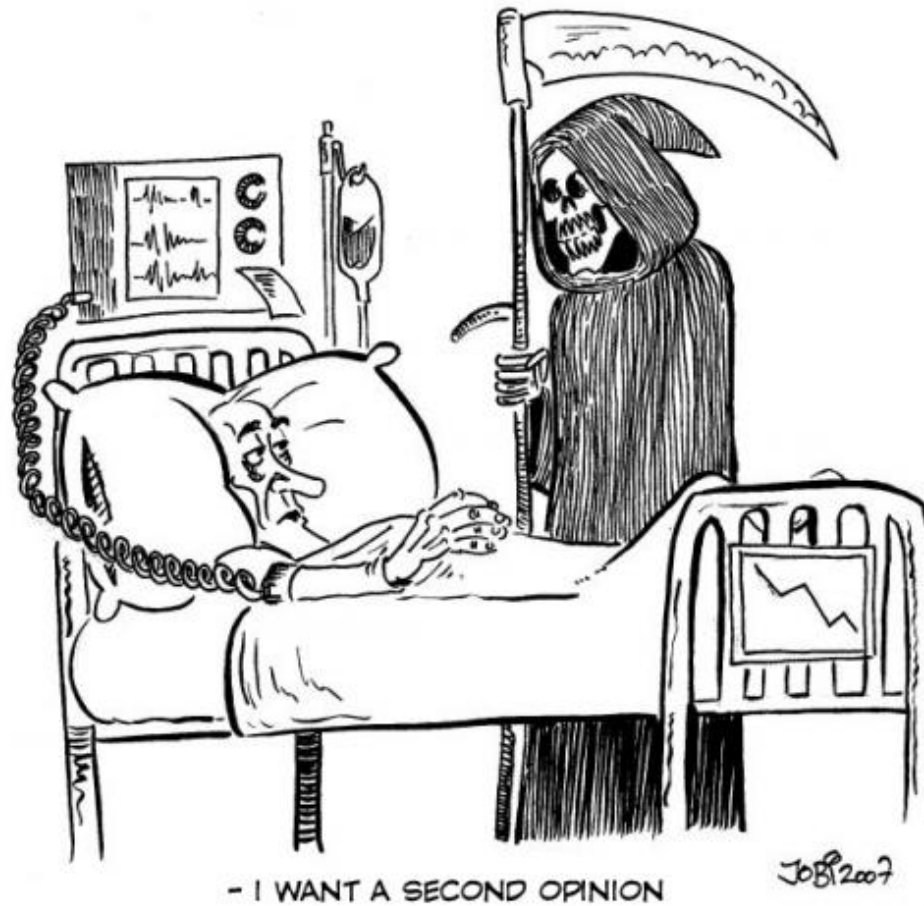


At home

Family/loved ones present

Comfortable

We all Die

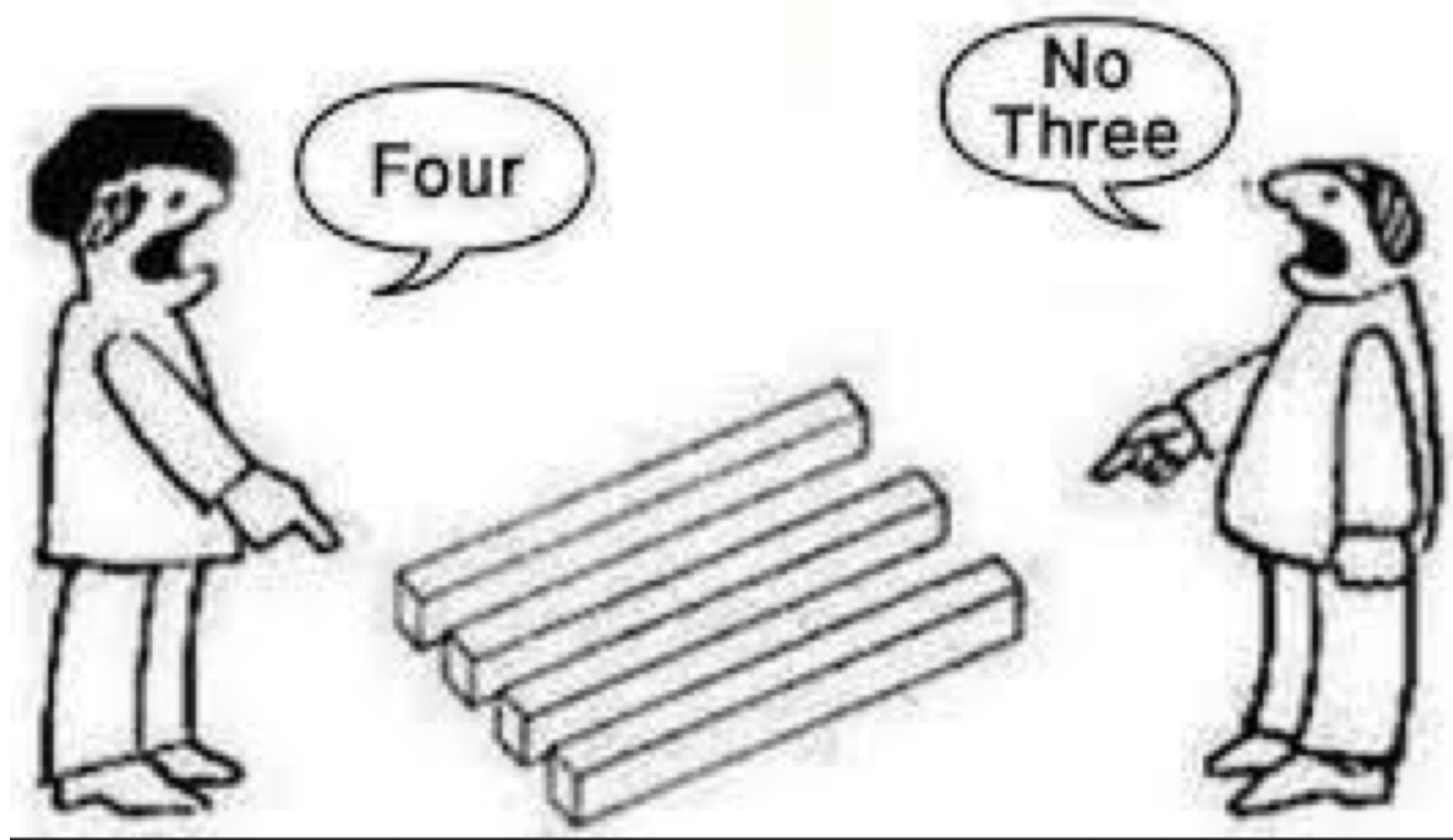


Experience in Oregon (27 years)

- Most common reasons for using MAID
 - Loss of autonomy
 - Loss of ability to engage in meaningful activities
 - Loss of bodily functions
 - Burden on family, friends, caregivers
- less common.... Uncontrolled pain or fear or it, financial concerns

<https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx>

It is really confusing!!!



1 in 5 Adults

Live in a State where
Medical Aid in Dying is legal





Suffering- Dr. Eric Cassell, NEJM, 1982



Dr. Eric Cassell- N Engl J Med. 1982; 306:639-45

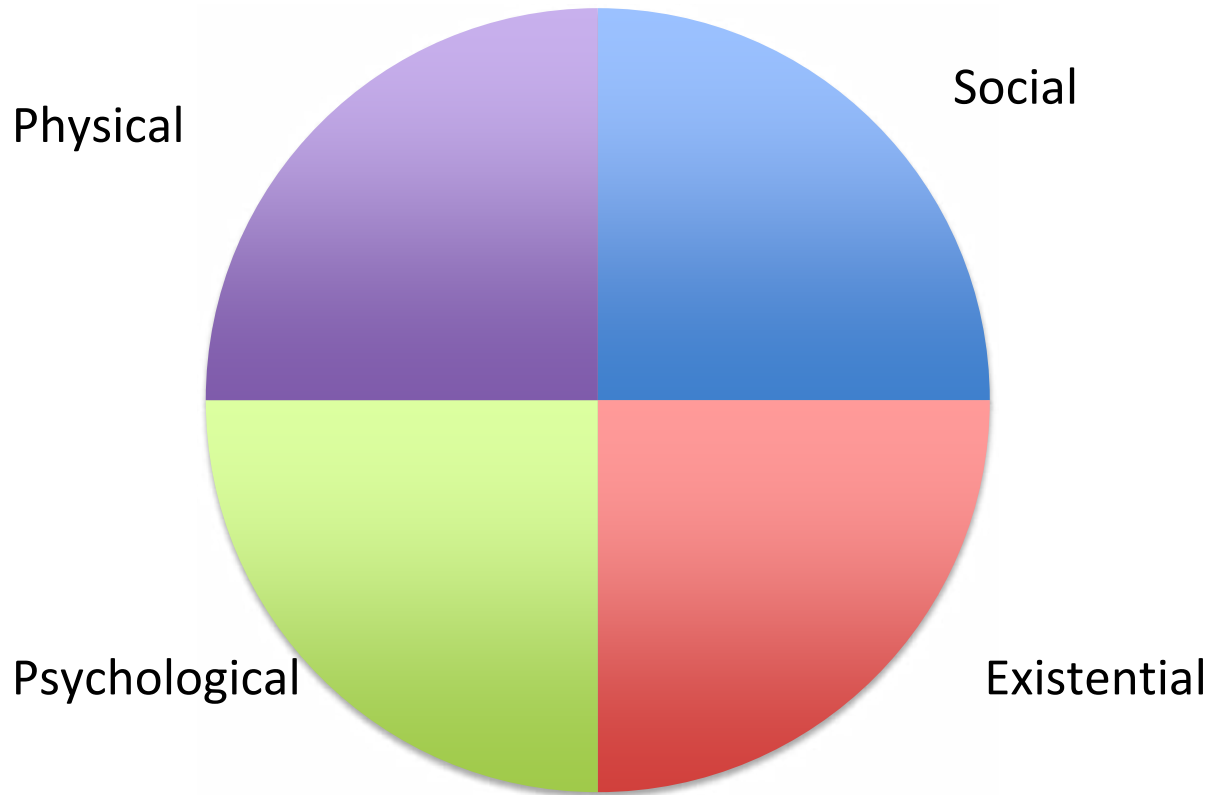
Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity.

Suffering can include physical pain but is by no means limited to it. The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick.

Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.

Total Suffering (adapted)

Dame Cicely Saunders



Prognostication

- More than Dying
 - Functional decline
 - Need for assistance
- Dynamic
 - NOT a proclamation
 - Best case/Worst case scenarios
 - Uncertainty; Ranges

Responding to MAID requests (and/or any EOL suffering)

- “Tell Me More.....”
- Humble Curiosity
- Explore fears/concerns
- Validate
- Understand previous experience
- Identify supports and strengths



Responding to requests for MAID

- Emphasize voluntary nature, ability to pause/stop
- Discuss other options to maintain control and to minimize suffering
- Early and Honest discussion of Hospice
- *Normalize* option to decline or to stop burdensome treatments which may prolong suffering near end of life
- Consider alternatives to MAID
 - Palliative Sedation
 - Voluntarily Stopping Eating and Drinking (VSED)
- Explore family/loved one concerns
- Parallel planning

MAID Process in VT

Prescribing Physician First Verbal Request

- Assess Eligibility
- Provide Patient Information

Prescribing Physician Second Request

- at least 15 days later

Consulting Physician Request

Patient Written Request

Contact Pharmacy with Prescription

File Vermont Department of Health Paperwork

For those considering MAID

Regular assessment:

- Hospice
- Suffering
- Prognosis
- RED FLAGS
 - Cognition
 - Frailty
 - Swallowing, Cachexia
 - Nausea, vomiting, bowel functioning
 - Intervene if needed (paracentesis, enemas, steroids)
- Parallel Planning

MAID Pharmacology (www.acamaid.org)

- Premedicate
 - Ondansetron 8 mg
 - Metoclopramide 20 mg
 - Wait 30 minutes
- MAID mixture in 2 ounces Apple Juice
 - Digoxin 100mg
 - Diazepam 1,000mg
 - Morphine 15,000mg
 - Amitriptyline 8,000mg
 - Phenobarbital 5,000mg
- Procedure
 - Sometimes burning and bitterness, 1 tsp. sorbet can ameliorate
 - Average time to death 1.1 hour
 - 85% < 2 hours or less
 - Occasional (1/100) prolonged dying
 - Non oral administration also highly effective (rectal, feeding tubes)

Data collection

- Each state collects slightly different data
- Vermont Dept of Health (VDH) issues biennial reports
- <https://www.healthvermont.gov/systems/end-life-decisions/patient-choice-and-control-end-life>

Unofficial (publicly disclosed) Vermont data

- Numbers of prescribers and those accessing law are increasing
- 7/1/23-6/30/24 period
- 96 people qualified; 24 Vermonters, 72 non-residents

Running total May,2013-June,2024 (11 years)

- 184 Individuals have qualified for MAID by VDH criteria
 - Majority (75%) Cancer
 - ALS, other neurodegenerative disease

Challenges for Out of State Patients

- Understanding of law
- Willing prescriber
- Prognostication
- Communication
- Difficulty in timing/scheduling of travel and ingestion

Opportunities with more access

- We are still learning
- Growing Wayfinder program
- Increased public discussion, interest, demand for better
 - Options at the end of life
 - The best (patient centered) end of life care possible

Clinician's Guide to Medical Aid in Dying:

<https://www.patientchoices.org/clinicians-guide.html>

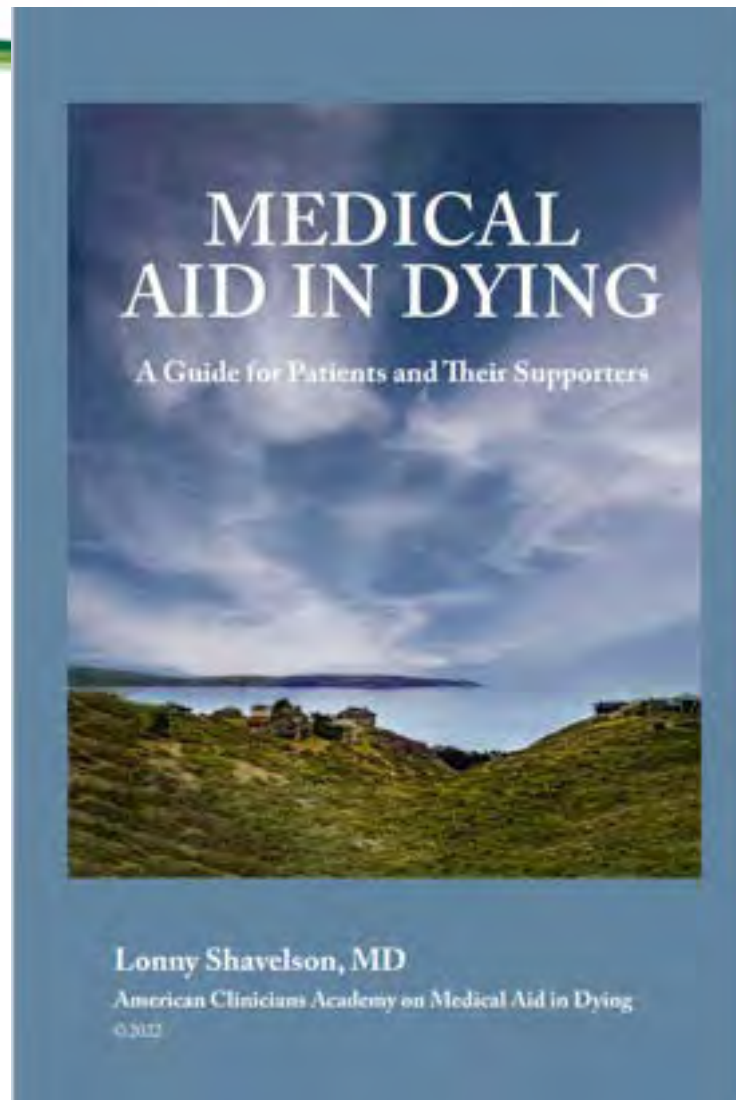
Non-Resident Checklist:

<https://www.patientchoices.org/non-residents.html>

PCV Helpline:

- Assistance for clinicians, patient, families
- 802-448-0542

[Aid-in-Dying-Patient-Guide.pdf \(acamaid.org\)](http://acamaid.org/Aid-in-Dying-Patient-Guide.pdf)



LISTEN



References/Information

- Patient Choices Vermont
<https://www.patientchoices.org>
 - American Academy of Medical Aid in Dying
<https://www.acamaid.org/>
 - Vermont Department of Health
<https://healthvermont.gov/systems/end-life-decisions/patient-choice-and-control-end-life>
- Vermont Ethics Network
- <https://vtethicsnetwork.org/palliative-and-end-of-life-care/medical-aid-in-dying-act-39>
- Oregon Health Authority
[Oregon Health Authority : Oregon's Death with Dignity Act : Death with Dignity Act : State of Oregon](#)
 - Compassion and Choices
<https://www.compassionandchoices.org/research/doc2doc-program/>

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The Nature of Suffering and the Goals of Medicine; N Engl J Med 1982; 306:639-645; DOI: 10.1056/NEJM198203183061104

Being Mortal: Medicine and What Matters in the End; Atul Gawande, ISBN-13: 9780805095159; Holt Henry & Company, Inc, 2014



Palliative ECHO: Severe Mental Illness and Palliative Care

H. Samuel Landsman, M.D.

Dartmouth-Health, Department of Psychiatry

Disclosures

- I have no financial or other conflicts to disclose with respect to this presentation

Objectives

- Define severe persistent mental illness (SPMI)
- Describe the morbidity and mortality related to those with SPMI
- Describe health care inequities that may be experienced by those with SPMI
- Outline challenges with decision making for those with SPMI
- Provide ideas for care of those with SPMI

Definitions

- Palliative Care
- Psychiatry
- Severe and Persistent Mental Illness (SPMI)
- Decision making capacity
 - Informed consent



Palliative Care and Psychiatry

- Similarities/Overlap
- Differences
- Palliative Psychiatry?

Severe Persistent Mental Illness (SPMI)

- SPMI: a mental illness that is chronic or recurrent, requires ongoing intensive psychiatric treatment, and significantly impairs functioning
- ~ 6% of the population
- Associated with premature mortality across all age groups

Morbidity and Mortality for People with SPMI

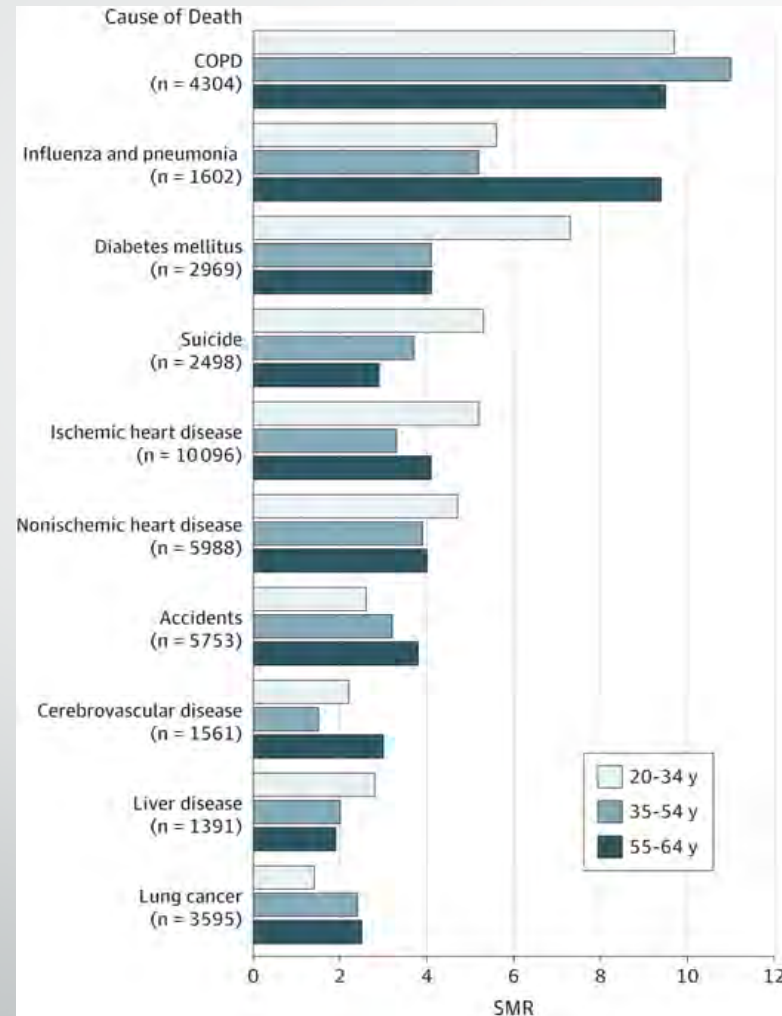


Figure. Standardized Mortality Ratios of Adult Medicaid Beneficiaries Diagnosed as Having Schizophrenia for 10 Common Causes of Death by Age Group (January 1, 2001, to December 31, 2007)

Decision Making Capacity

- **Decision-making capacity is a clinical determination that refers to whether a patient has the mental capability to:**
 - Understand relevant information,
 - Appreciate the medical situation they are in and its possible consequences,
 - Reason through risks, benefits and alternatives of treatment options, and
 - Communicate a choice freely and voluntarily based on their own values.

Decision Making Capacity – “Sliding Scale”



Decision Making Capacity – Continued

- Presume Capacity
- Provide Informed Consent
 - (*may need repetition, multiple modalities)
- IF deemed incapacitated, ALL efforts to restore capacity
- Delay if possible
- Engage alternate decision maker if necessary

Advanced Care Planning

- Who makes decisions?



Health Care Equity/Access to Care

- Compared to the general population, people with SPMI may:
 - Avoid or delay engaging in medical treatment
 - Have difficulty communicating symptoms
 - Experience symptoms differently
 - Have increased SES barriers to care
 - Have increased medical comorbidities

Health Care Equity/Access to Care

- Compared to the general population, people with SPMI may:
 - Experience stigma from providers when attempting to access care
 - Provider/Societal Stigma
 - Blame person for health issue
 - Assume LACK of capacity, adherence
 - (False) concern for violence
 - Self Stigma
 - Subsequently seek less care, receive poorer care

Challenges for patients and providers

- Challenges building therapeutic relationships
 - Mistrust: “Symptom-related” or “Reality-Based?”
- “Difficult Historians”
- “Limited” understanding of medical information
- “Nonadherence” or “imperfect adherence”

Challenges for patients and providers

- Limited Comfort or Expertise
 - Of non-psychiatric physicians working with people with SPMI
 - Of mental health providers working with people with life-limiting medical illness
- Provider disagreement about treatment priorities and goals of care

Specific Mental Health Issues

- Psychosis
- PTSD and other Trauma Related Issues
- Personality Disorders
- Severe Depression and Suicide
- Depression and Anxiety
 - Treatment path dependent on prognosis
- *Anorexia Nervosa

Tips

- Assume palliative needs are similar between SPMI and non-SPMI
 - Until proven otherwise
- Individualize the approach
 - Focus on therapeutic relationship, hope, dignity, respect and **non-abandonment**
- Low threshold to Consult Psychiatry
 - Especially for patients with Bipolar Disorder, Schizophrenia, and PTSD
- Assess for Suicide
 - Assessing risk of suicide does not increase the risk of suicide, but medical illness DOES
- Use Psychostimulants (for Depression) and Benzodiazepines (for Anxiety)
 - At end of life, when **time** matters
- Trauma-Informed Care

Trauma-Informed Care



Final Thoughts and Tips/Recommendations



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Advance Care Planning for Patients with Dementia: The Serious Illness Conversation-D

Amelia Cullinan, MD

March 4, 2025

I have no disclosures!

Learning Objectives

By the end of this session, learners will be able to...

1. Describe at least 2 barriers to Advance Care Planning (ACP) for patients with dementia.
2. List at least 2 benefits of ACP for patients with dementia and their care partners.
3. Recall 3 key recommendations for ACP conversations with patients with dementia and their care partners
4. Compare and contrast the original Serious Illness Conversation Guide with the SIC-Dementia Guide

Let's talk about the gap:
dementia is prevalent and not enough patients have
engaged in advance care planning (ACP)

Engagement in ACP by patients with dementia

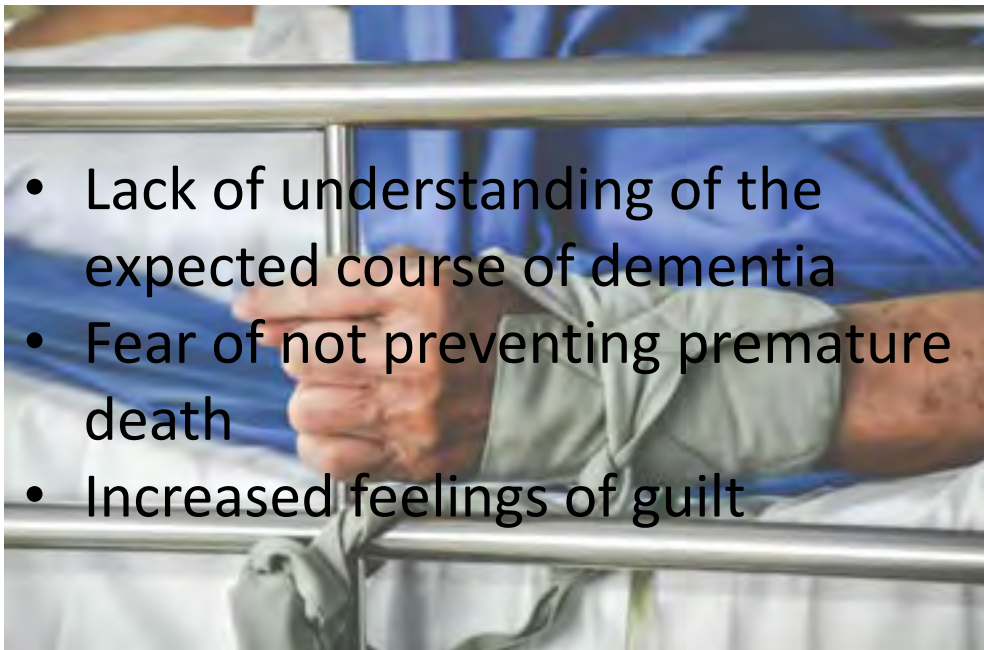


47 million
worldwide,
and rising

■ with ACP ■ without ACP

Sellars M Palliative Medicine 2019, Vol 33(3) 274-290..

This gap in ACP puts patients with dementia and their care partners at risk of suffering and strain



Sellars M Palliative Medicine 2019, Vol 33(3) 274-290.

Dixon J Journal of Pain and Symptom Management 2018, Vol 55 (1) 132-150.

Why do so few patients with dementia
engage in ACP?

Patient and care partner (CP) barriers to ACP

Care Partners (CP)

- Fear of having too much control
- Fear of upsetting the patient
- Too soon
- Not knowing which person's wishes to honor – the patient before or with dementia?



William Utermohlen

Sellars M Palliative Medicine 2019, Vol 33(3) 274-290.
Dixon J Journal of Pain and Symptom Management 2018, Vol 55 (1) 132-150.
Mezey MD Clinics in Geriatric Medicine 2000 Vol 16(2)

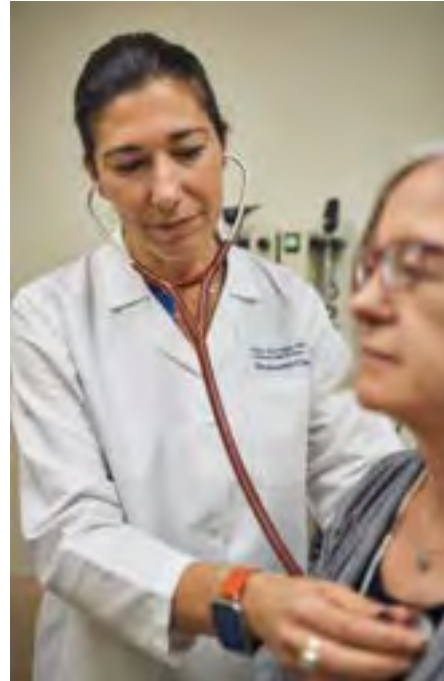
Healthcare professionals' barriers to ACP

Too early:

- Don't want to upset the patient or CP
- Want to wait until things reach a "terminal" stage

Too late:

- Concern that patients lack capacity to discuss it



Lack of time for conversations

Fear

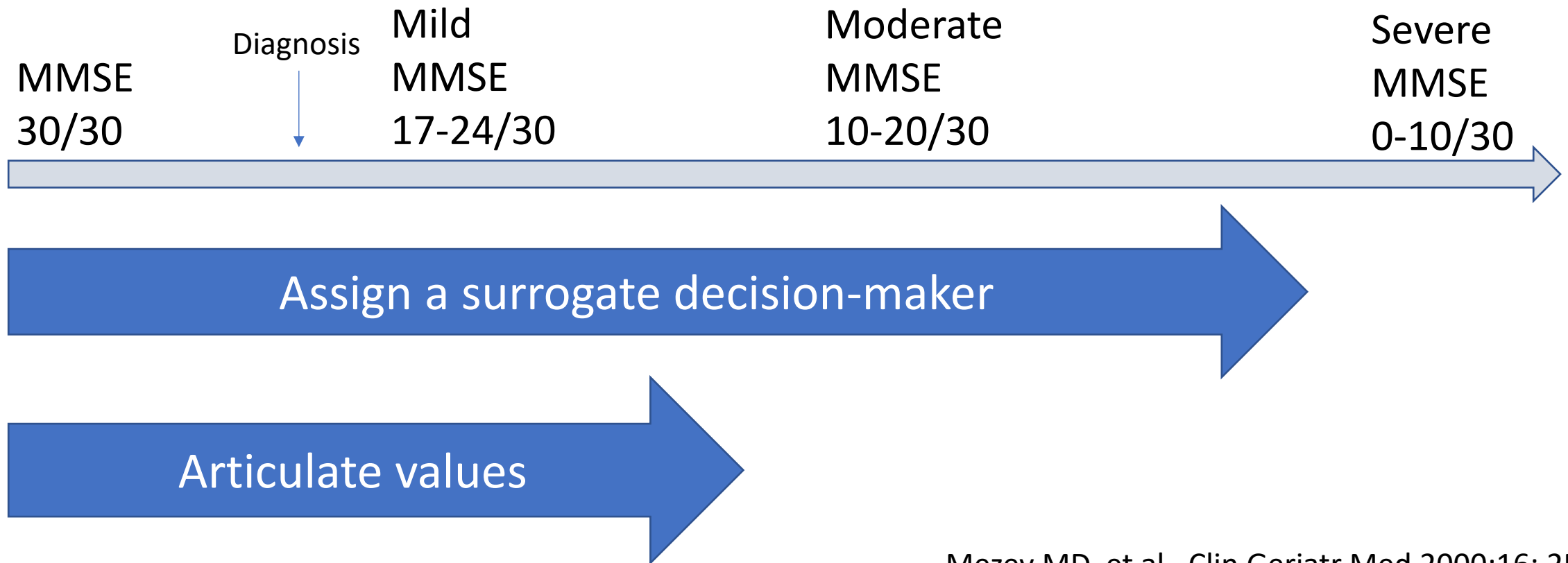
- of failure – letting the patient & CP down, not having things to help
- lack of confidence

Dixon J Journal of Pain and Symptom Management 2018, Vol 55 (1) 132-150.

Mezey MD Clinics in Geriatric Medicine 2000 Vol 16(2)

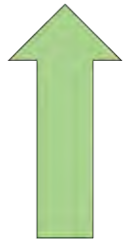
Brannan S J Med Ethics. 2016 Jun;42(6):409-10.

Patients with dementia will lose capacity eventually, but they can take an active role in ACP for a considerable portion of their illness

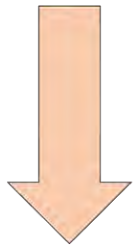


ACP benefits both patients with dementia and their CPs

Patients with dementia

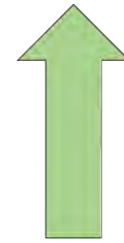


Death in preferred place
Coping

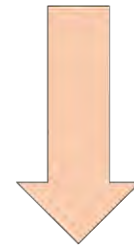


Depression
Decisional conflict
Hospital admissions
of inpatient days
PEG tubes
Death in hospital
ICU use in severe dementia

Care Partners



Satisfaction with pt care at EOL
Satisfaction with conversations
Quality of life

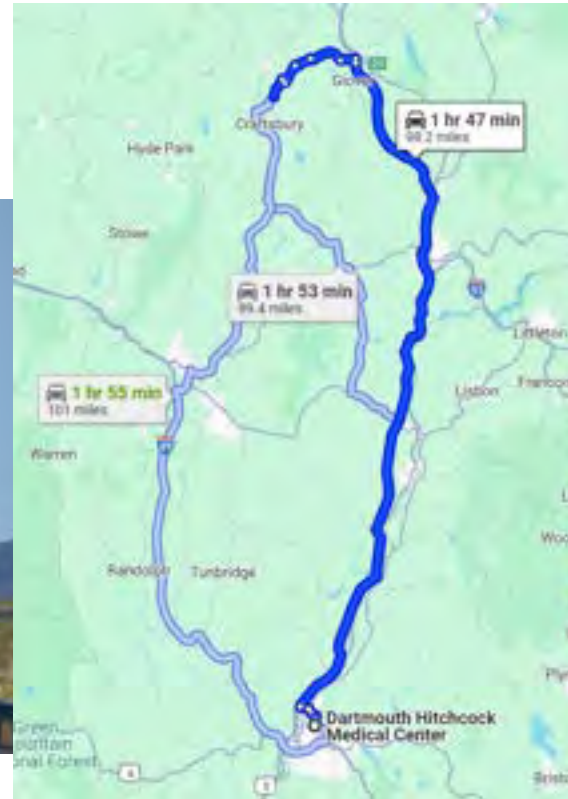


Feeling of responsibility for death
Depression
Anxiety

Sellars M Palliative Medicine 2019, Vol 33(3) 274-290.

Dixon J Journal of Pain and Symptom Management 2018, Vol 55 (1) 132-150

Filling the Gap: What do CPs want from healthcare clinicians?



Review Article

Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies

Marcus Sellars^{1,2}, Olivia Chung², Linda Nolte³, Allison Tong⁴, Dimity Pond⁴, Deirdre Fetherstonhaugh⁵, Fran McInerney⁶, Craig Sinclair⁷ and Karen M Detering^{1,8}



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Education about what to expect

Iterative conversations

Recommendations from clinicians they trust

Best practices for ACP for patients with dementia



“You
worri
thin
you th
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- **First conversation**
 - Soon after diagnosis
 - Assign health care agent
 - Elicit values and goals
- **Revisit**
 - Changes in health status
 - After hospitalizations
 - Changes in place of residence
 - Changes in financial situation

ow
o...”

ly

Start early, revisit often

Listen for cues

Best practices for ACP for patients with dementia



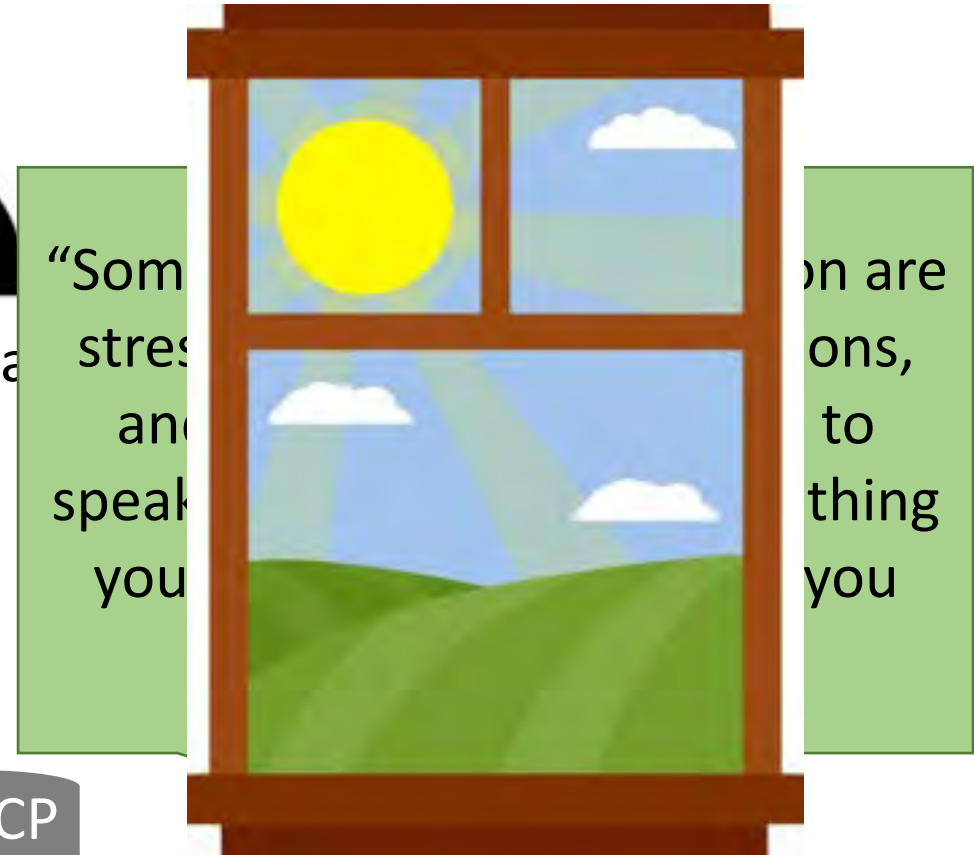
Patient Clinician Care Pa

Optimize conditions

Assume capacity and empower HCP

Start early, revisit often

Listen for cues

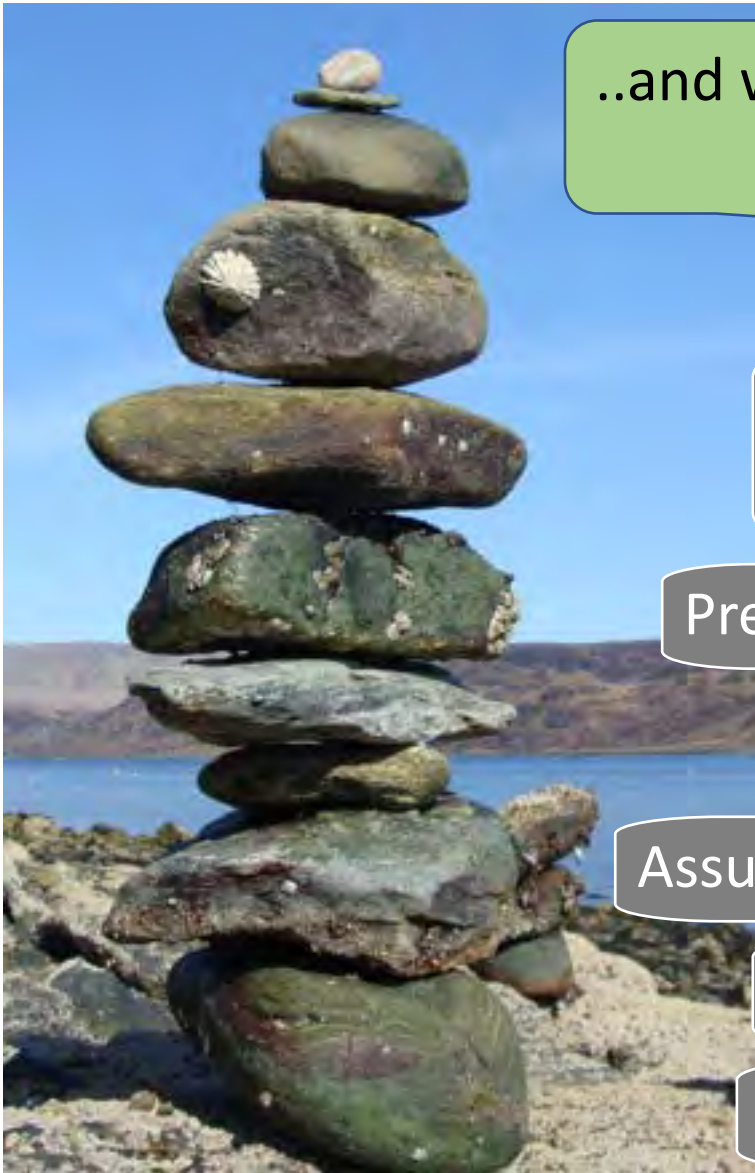


Mezey MD, et al. Clin Geriatr Med 2000;16: 255-268

Pennington C Age and Ageing 2018; 47:778-784

Piers R BMC Palliative Care 2018 17:88

Best practices for ACP for patients with dementia



..and why does that feel right for you?”

Elicit values and goals;
make recommendations

Prepare CP for the road ahead

Optimize conditions

Assume capacity and empower HCP

Start early, revisit often

Listen for cues

“When you’re at the end of your life, where do you want to be cared for, at home or in a hospital?”

“when you’re dying, will you want lots of treatments to try and get you more time, or would you like us to keep you comfortable and let nature take its course?”

Mezey MD, et al. Clin Geriatr Med 2000;16: 255-268

Pennington C Age and Ageing 2018; 47:778-784

Piers R BMC Palliative Care 2018 17:88

Best practices for ACP for patients with dementia



Document

Expect emotion

Elicit values and goals;
make recommendations

Prepare CP for the road ahead

Optimize conditions

Assume capacity and empower HCP

Start early, revisit often

Listen for cues

Mezey MD, et al. Clin Geriatr Med 2000;16: 255-268

Pennington C Age and Ageing 2018; 47:778-784

Piers R BMC Palliative Care 2018 17:88

The Serious Illness Conversation

an evidence-based, clinician-facing tool to facilitate discussion of values and goals for future care

Serious Illness Conversation Guide		Dartmouth-Hitchcock
SET UP	<p>"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want – is this okay?"</p> <p>"I'll be using this Guide to help me assure I don't miss any important information." <i>IF RESISTANT:</i> <i>Hope for best/prepare for bumps in the road. Benefit to family of planning ahead. No decisions necessary today.</i></p>	
ASSESS	<p>"What is your understanding now of where you are with your illness?" <i>FOLLOW-UP PROMPTS:</i> <i>"What is your understanding of what the future may hold with your illness?"</i></p> <p>"How much information about what may be ahead with your illness would you like from me?" <i>FOR EXAMPLE:</i> <i>"Some patients like to know about time, others like to know what to expect, others like both."</i></p>	
SHARE	<p>"I want to share with you my understanding of where things are with your illness..."</p> <p><u>Uncertain:</u> "It can be difficult to predict what will happen with your illness. I hope you'll continue to live well for a long time but I'm worried that you could get sick quickly, and I think it's important to prepare for that possibility."</p> <p><u>Time:</u> "I wish we weren't in this situation, but I'm worried that time may be as short as [give a range]"</p> <p><u>Function:</u> "I hope that this is not the case, but I'm worried that this may be as strong as you feel, and things are likely to get more difficult."</p> <p><u>Best Case/ Worst Case:</u> "It can be difficult to predict what will happen with your illness. I hope in a best case ____; I worry that in the worst case ____ The most likely outcome is ____."</p>	
EXPECT & RESPOND to EMOTION (see over)		
EXPLORE	<p>"What are your most important goals if your health situation worsens?"</p> <p>"What are your biggest fears and worries about the future with your health?"</p> <p>"What gives you strength as you think about the future with your illness?"</p> <p>"What abilities are so critical to your life that you can't imagine living without them?" <i>FOR EXAMPLE:</i> <i>"Some people need to be able to do things for themselves, like walking, in order to say life is worth living; other people need to interact meaningfully with loved ones, and others say life is life, no matter the quality. How about you?"</i></p> <p>"If you become sicker, how much are you willing to go through for the possibility of gaining more time?" <i>FOLLOW-UP PROMPTS:</i> <i>"What experiences have you/family members had with serious illness, and what did you learn from these experiences?"</i> <i>"Is there anything you are certain you WOULD NOT want to go through?"</i></p> <p>"How much does your family know about your priorities and wishes?" <i>CONSIDER:</i> <i>Inviting patient's healthcare agent/neurologist and/or family to discuss together "so they know what's important to you"</i></p>	
CLOSE	<p>"I've heard you say that ____ is really important to you. Keeping that in mind, and what we know about your illness, I recommend ____ How does this plan seem to you?"</p> <p>"We will do everything we can to help you through this."</p>	

DOCUMENT in the ACP NAVIGATOR

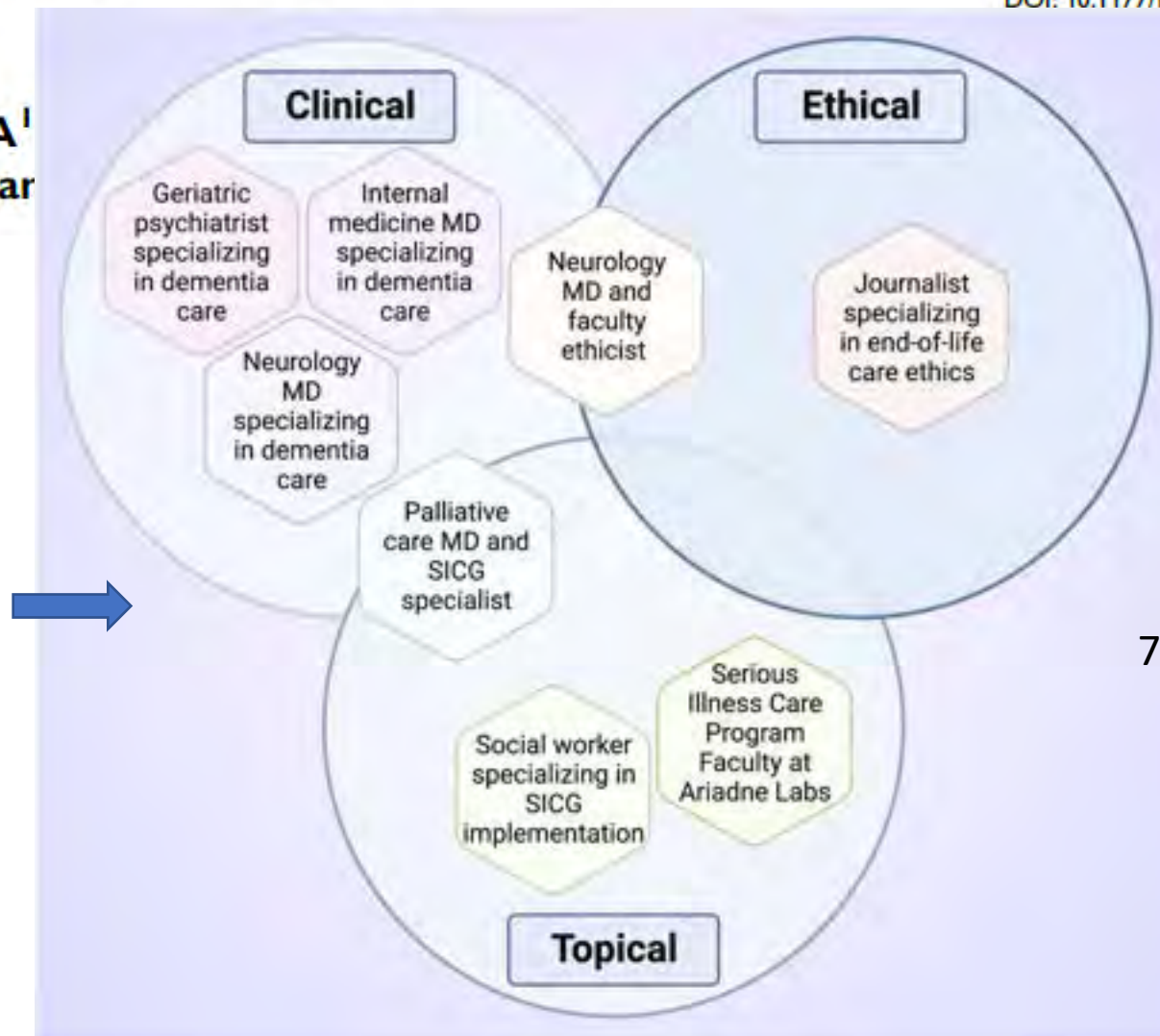
Adapting the Serious Illness Conversation Guide for Dementia Care

Charlotte E. Berry, BA¹
Robert Santulli, MD¹, et al.

American Journal of Hospice
& Palliative Medicine®
2024, Vol. 41(8) 942–951
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Serious Illness Conversation Guide	
SET UP	<p>"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want. Is this okay?"</p> <p>"I'll be using this Guide to help me assure I don't miss any important information."</p> <p>If REQUESTING:</p> <p>"How do you feel about being in the hospital, the nursing home or long-term care? Do you have any questions?"</p>
ASSESS	<p>"What is your understanding now of where you are with your illness?"</p> <p>EXAMPLE PROMPTS:</p> <p>"What is your understanding of what the future may hold with your illness?"</p> <p>"How much information about what may be ahead with your illness would you like from me?"</p> <p>OR EXAMPLE:</p> <p>"I want to share with you my understanding of where things are with your illness..."</p> <p>Uncertain: "It can be difficult to predict what will happen with your illness. I hope you'll continue to live well for a long time but I'm worried that you could get sick quickly, and I think it's important to prepare for that possibility."</p> <p>Time: "I wish we weren't in this situation, but I'm worried that time may be as short as [give a range]."</p> <p>Function: "I hope that this is not the case, but I'm worried that this may be as strong as you feel, and things are likely to get more difficult."</p> <p>Best Case/ Worst Case: "It can be difficult to predict what will happen with your illness. I hope in a best case _____ I worry that in the worst case _____ The most likely outcome is _____"</p>
SHARE	<p>EXPECT & RESPOND TO EMOTION (see over)</p> <p>"What are your most important goals if your health situation worsens?"</p> <p>"What are your biggest fears and worries about the future with your health?"</p> <p>"What gives you strength as you think about the future with your illness?"</p> <p>"What abilities are so critical to your life that you can't imagine living without them?"</p> <p>OR EXAMPLE:</p> <p>"I really need to be able to do things for myself, like taking a shower, in order to stay in my home. Other people need to be able to help me with things like that. I don't want to be in a nursing home."</p> <p>"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"</p> <p>FOLLOW UP PROMPTS:</p> <p>"What experiences have you/family members had with serious illness, and what did you learn from those experiences?"</p> <p>"Is there anything else you want to say or ask me about?"</p> <p>"How much does your family know about your priorities and wishes?"</p> <p>CONSIDER:</p> <p>"Having a patient's health care goals and wishes clearly stated together so they know what's important to you?"</p> <p>"I've heard you say that _____ is really important to you. Keeping that in mind, and what we know about your illness, I recommend _____ How does this plan seem to you?"</p> <p>"We will do everything we can to help you through this."</p>
EXPLORE	
CLOSE	

SIC - Original



7 iterations

Serious Illness Conversation Guide	
SET UP	<p>"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want. Is this okay?"</p> <p>"I'll be using this Guide to help me assure I don't miss any important information."</p> <p>If REQUESTING:</p> <p>"How do you feel about being in the hospital, the nursing home or long-term care? Do you have any questions?"</p>
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SHARE	<p>EXPECT & RESPOND TO EMOTION (see over)</p> <p>"What are your most important goals if your health situation worsens?"</p> <p>"What are your biggest fears and worries about the future with your health?"</p> <p>"What gives you strength as you think about the future with your illness?"</p> <p>"What abilities are so critical to your life that you can't imagine living without them?"</p> <p>OR EXAMPLE:</p> <p>"I really need to be able to do things for myself, like taking a shower, in order to stay in my home. Other people need to be able to help me with things like that. I don't want to be in a nursing home."</p> <p>"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"</p> <p>FOLLOW UP PROMPTS:</p> <p>"What experiences have you/family members had with serious illness, and what did you learn from those experiences?"</p> <p>"Is there anything else you want to say or ask me about?"</p> <p>"How much does your family know about your priorities and wishes?"</p> <p>CONSIDER:</p> <p>"Having a patient's health care goals and wishes clearly stated together so they know what's important to you?"</p> <p>"I've heard you say that _____ is really important to you. Keeping that in mind, and what we know about your illness, I recommend _____ How does this plan seem to you?"</p> <p>"We will do everything we can to help you through this."</p>
EXPLORE	
CLOSE	

SIC-Dementia

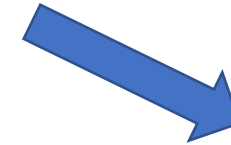
Alteration	Original SICG	SICG-D
Phrasing to reflect patient-caregiver dyad	<i>"What is your understanding now of where you are with your illness?"</i>	<i>"What is your understanding now of your ___'s illness?"</i>
Dementia-specific language	<i>"It can be difficult to predict what will happen with your illness. I hope you'll continue to live well for a long time but I'm worried that you could get sick quickly, and I think it's important to prepare for that possibility."</i>	<i>"Dementia/memory loss is a brain disorder which usually progresses gradually over time, affecting people's ability to do things for themselves like drive a car, make their own meals, use the bathroom, eat independently, and communicate effectively."</i>
Establishment of caregiver/medical proxy dialogue	N/A	<i>"For the next few questions, I want you to imagine what your ___ would say when they were able to think clearly. We are not thinking about what your ___ would want for you or what you would want for your ___, but what they would want for themselves."</i>
Dementia-specific end-of-life care	<i>"If you become sicker, how much are you willing to go through for the possibility of gaining more time?"</i>	<i>"Are there any medical treatments or types of care your ___ wouldn't be willing to accept?"</i> <i>FOR EXAMPLE: "Would your ___ not be willing to undergo hospitalization, feeding tubes, antibiotics for infection, CPR, etc?"</i>
Caregiver-directed questions	<i>"What gives you strength as you think about the future with your illness?"</i>	<i>"What gives you strength as you think about the future with your ___'s illness?"</i>
Caregiver-directed support phrases	<i>"I can see how hard you have been working to stay healthy"</i>	<i>"I can see what an amazing advocate you are for your ___"</i> <i>"Caring for someone with dementia can be very, very challenging."</i>



14 people with dementia
18 care partners



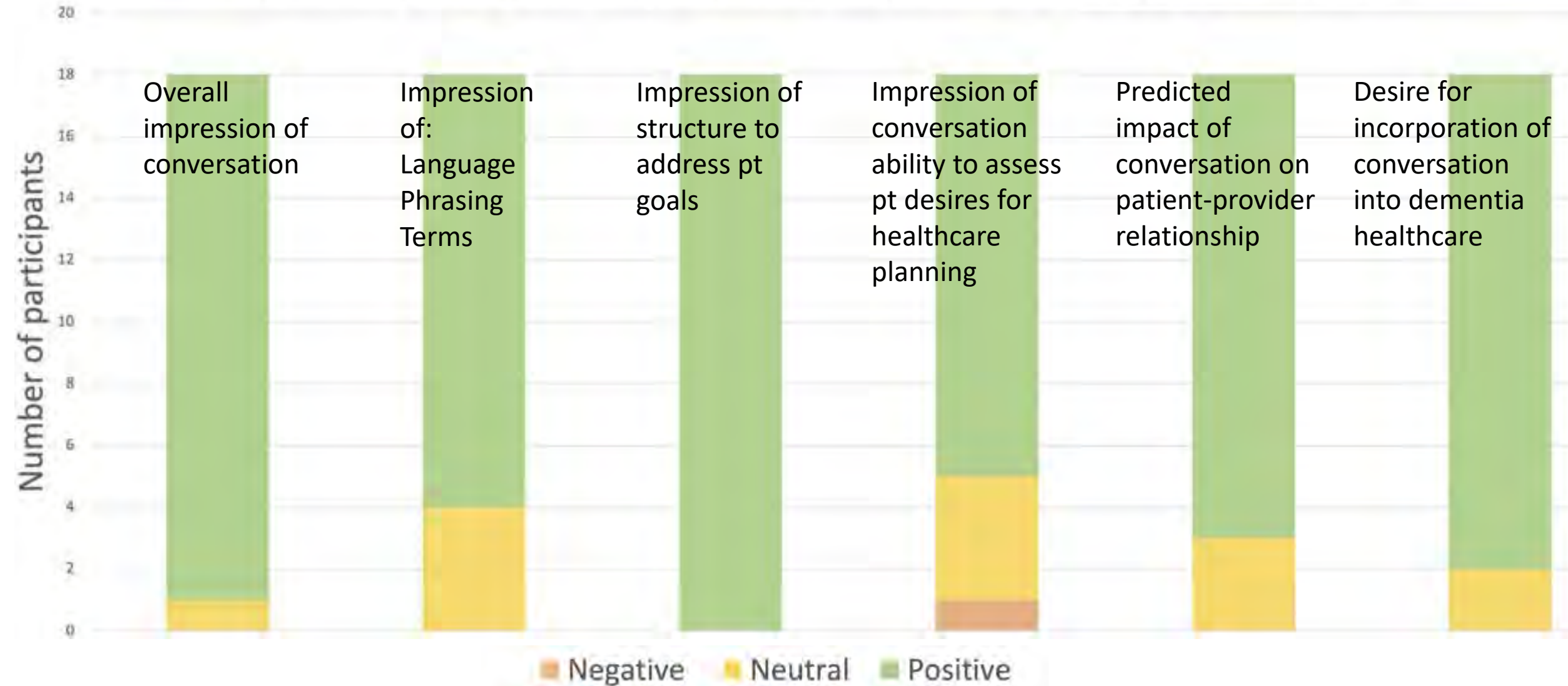
Thematic
analysis



Anonymous
quantitative
survey

- Thematic analysis (n=32, 12 patient + CP, 2 pt alone, 6 CP alone)
- Appreciation of open-ended prompts
 - “It seemed more like a conversation than most appointments I have had. A lot of back and forth and open-ended questions, which I liked.”
- Value of ACP conversations
 - “These are the conversations my wife and I should have been having when she was diagnosed, but nobody initiated them with us.”
- Appreciation of inclusion of CP
 - “Things have gotten really tough in the past two years, I wish the doctors realized how tough it is for me, too.”
- Appreciation of framing for CP when acting as a surrogate
 - “I liked the line about how it’s not necessarily about what you would want for yourself. I will think about that at the next appointment we have, I think.”

Patient-/Caregiver Impressions of Modified SICG for Dementia



Closing Pearls

- ACP in patients with dementia is feasible and impactful
- Use structured tools to assess capacity AND incorporate health care agents/surrogates in conversations
- Use structured tools for conversations about goals and values
- Talk honestly and practically about what to expect
- Empower and tend to the emotional experience of care partners
- Revisit conversations over time

Spirituality and Cultural Sensitivity in Serious Illness

Connolly Huddleston, MAPS, BCC

April 1, 2025

ECHO 4.0

I have no disclosures!

What's your experience?

Takeaways

- Define spirituality and culture
- Defining and attending to spiritual/existential distress- theirs and *yours*
- Tools to step into “courageous conversations” and seek to understand

Spirituality...

*...the aspect of humanity that refers to the way individuals **seek and express meaning and purpose** and the way they **experience their connectedness** to the moment, to self, to others, to nature, and to the significant or sacred.*

WHAT IS CULTURE?



Serious illness is a ground shaker



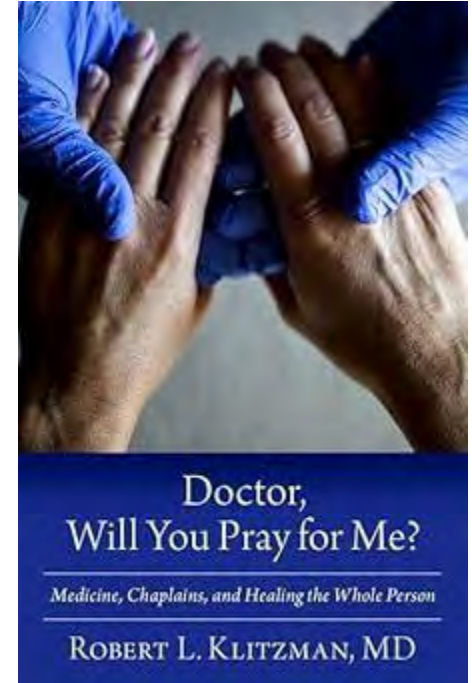
Spiritual/Existential Distress

- A feeling of mental turmoil that can occur when people confront the reality of their existence, circumstance, life change, etc.



Barriers to addressing spiritual distress

- **62%** of doctors (medical providers) reported a lack of training as a barrier
- Lack of private office space
- Personal discomfort talking about spiritual issues
- Belief that patients do not want these conversations
- Worry that patient will feel uncomfortable
- Feeling uncomfortable engaging with patients who have religious beliefs different than their own



Seeking to Understand: a courageous conversation with others

- **Empathic listening**
- **Curiosity-**
 - “Tell me more...”
 - Reflective statements: “That’s a really good question. What do you think?” Or “What does your faith/life experiences tell you about that?”
 - How would you like to receive information?
- **Humility**
- **Educate yourself!**

Seeking to Understand Others cont.

- **Authenticity**

- “Will you pray with me?”
 - “I hear prayer is important to you and a source of strength. I’d be happy to sit with you while you pray.”
 - “I will be sending you good thoughts/energy.”
 - “Would it be helpful to have a visit with the chaplain?”

- **Validate and affirm**

- “I hear that you hope for a miracle. We will not get in the way of God doing what God does AND it would be helpful for us to talk about the ‘what ifs.’”

- **Involve chaplains!**

Seeking to Understand: a courageous conversation *with yourself*

- **Curiosity**
- **Self-awareness**
 - Where is this coming from?
 - What is it about this case that is challenging me?
- **Humility**
- **Education**
- **Validate and affirm**
- **Hold own beliefs lightly and uphold other beliefs**
- **Talk it out**
- **Empathy**

Thank you!

Connolly Huddleston, MAPS, BCC
Connolly.Huddleston@uvmhealth.org

UVMHealth.org/MedCenter

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