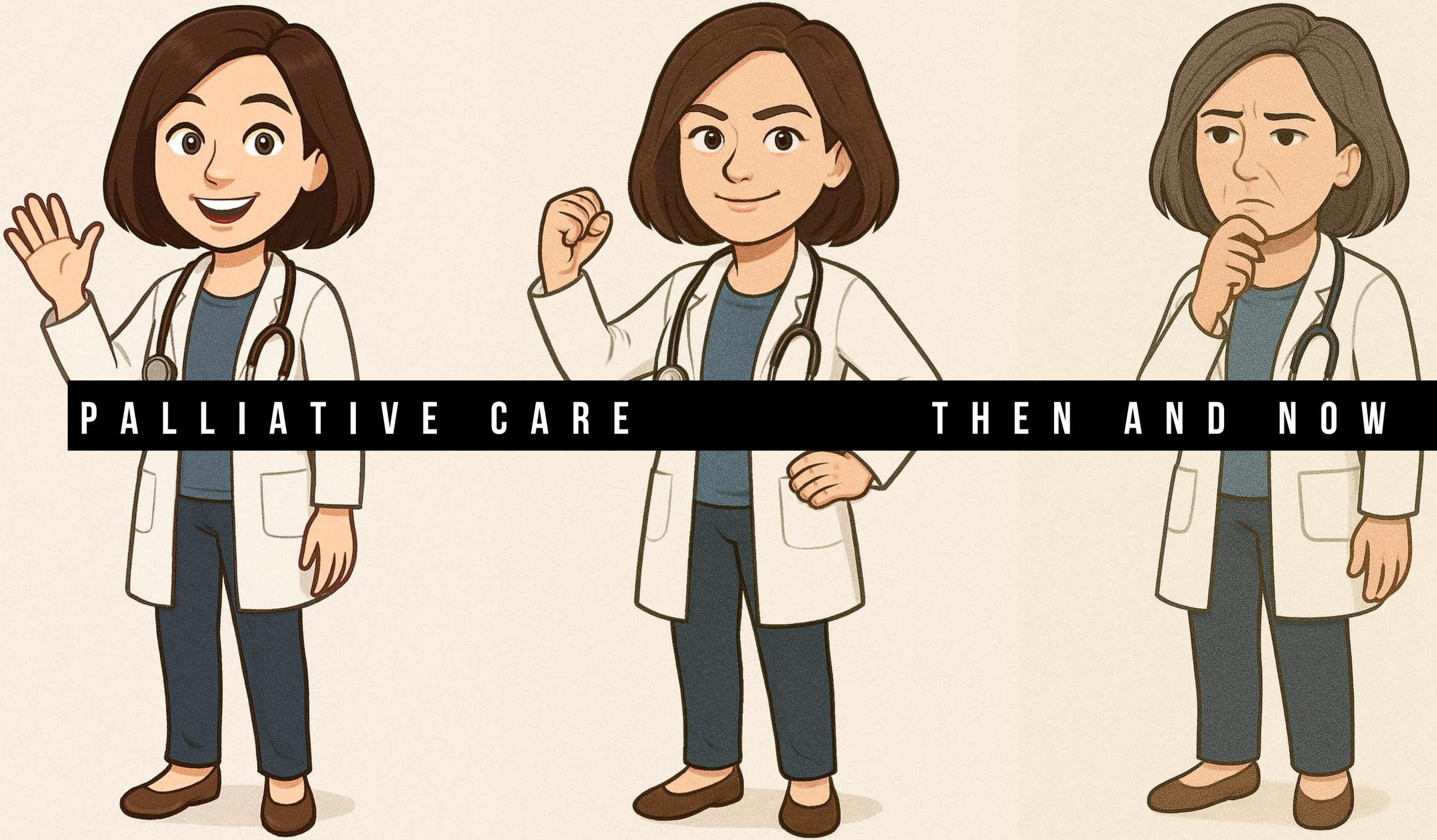
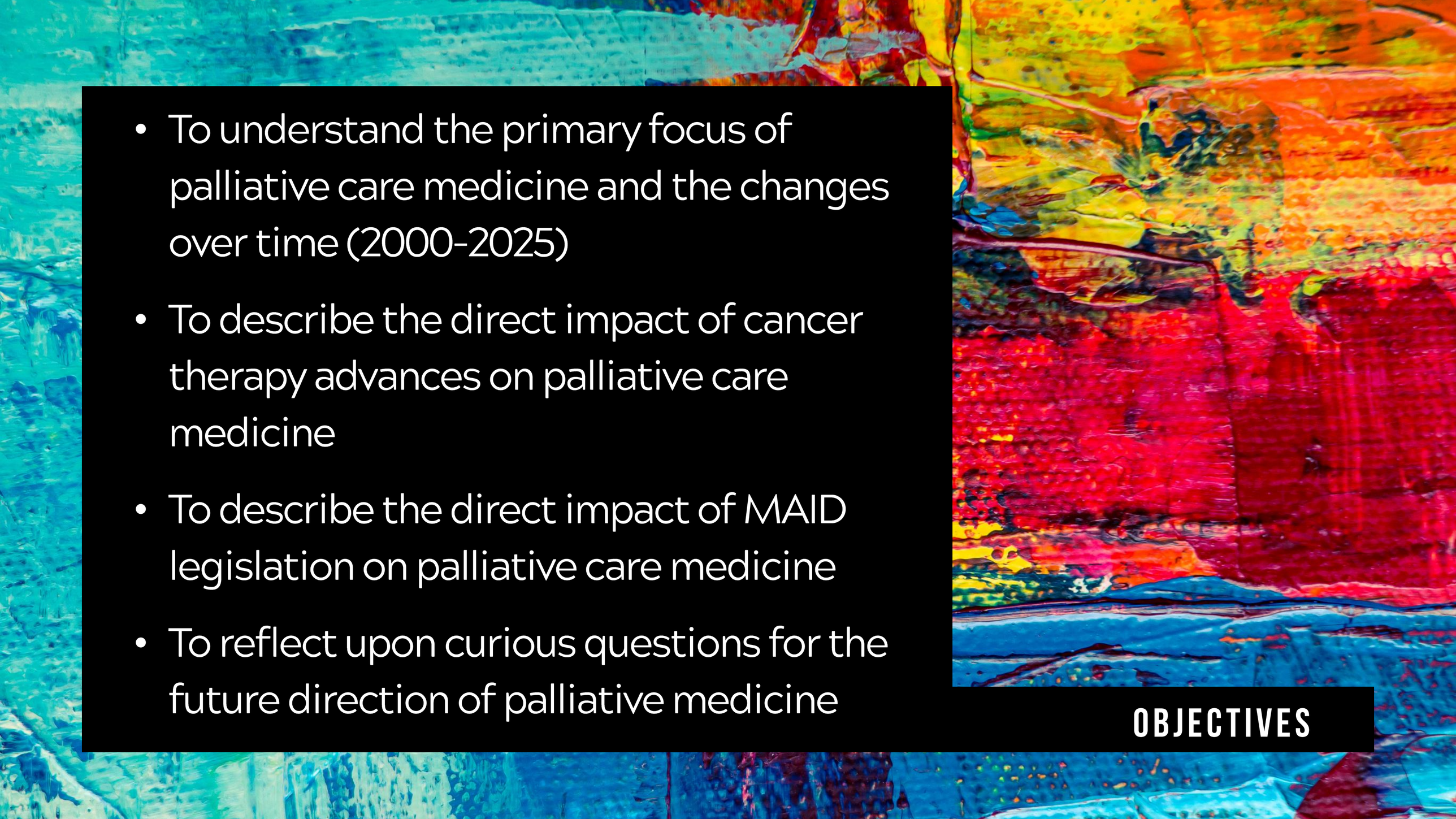

PALLIATIVE CARE
THEN AND NOW

DISCLOSURES

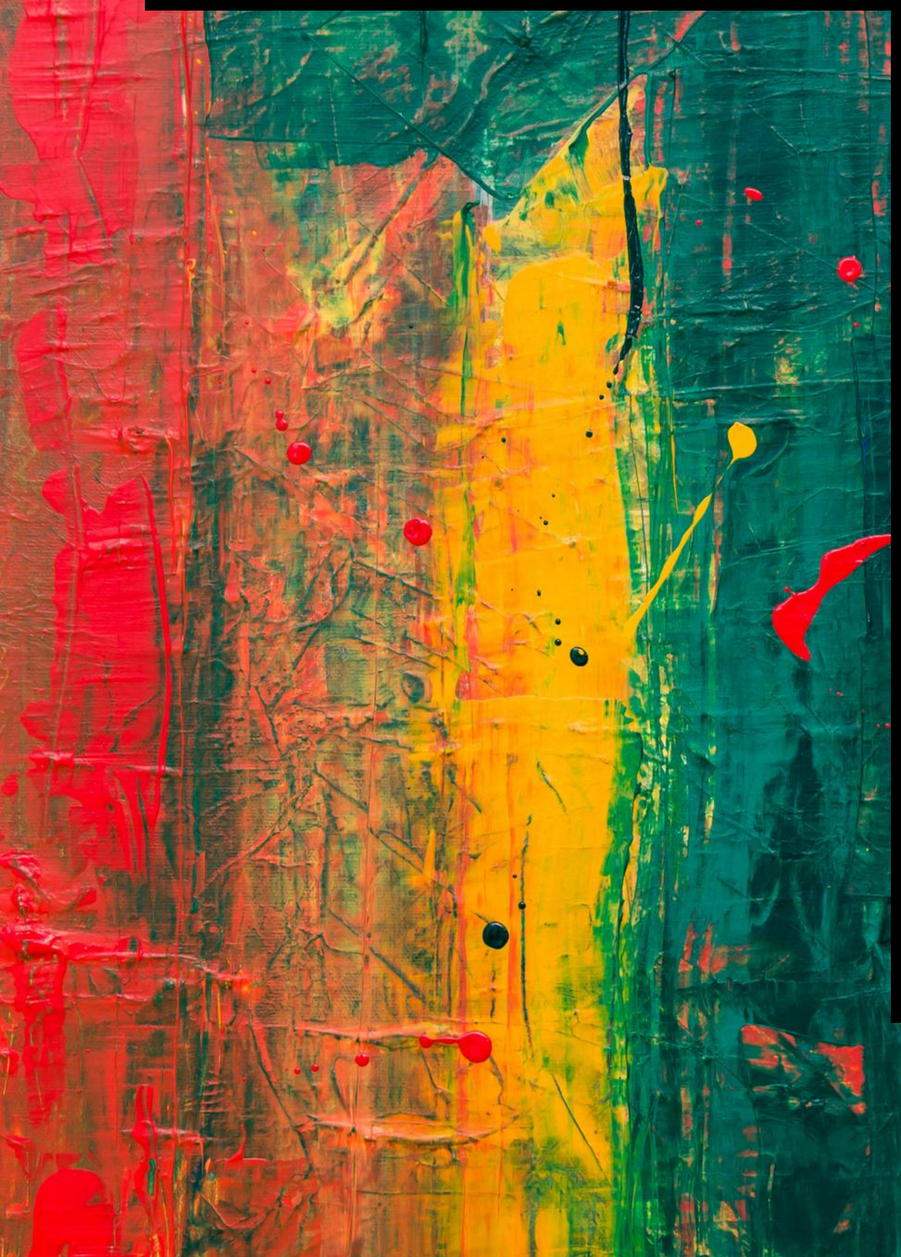
- This is a reflection of my career focused in palliative care.
- I have been paid for my work in palliative care
- My presentation has been created to reflect my experience on the changes in the provision of palliative care - and supported by some science, data and a lot of introspection



- To understand the primary focus of palliative care medicine and the changes over time (2000-2025)
- To describe the direct impact of cancer therapy advances on palliative care medicine
- To describe the direct impact of MAID legislation on palliative care medicine
- To reflect upon curious questions for the future direction of palliative medicine

OBJECTIVES

ASSUMPTIONS

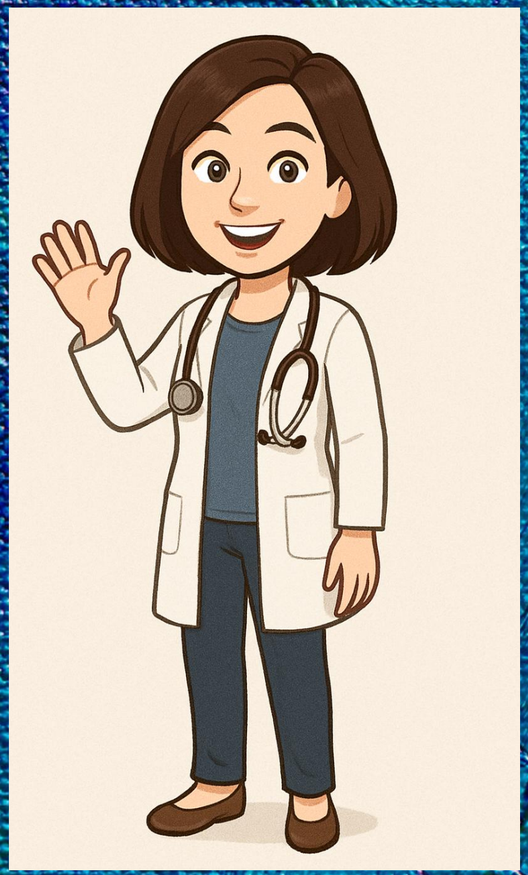


Palliative Care - The World Health Organization (WHO) defines palliative care as an approach that improves the **quality of life** for patients and their families facing life-threatening illnesses. It provides **relief from suffering** by addressing **physical, psychological, and spiritual problems** through early identification and treatment of pain and other symptoms. This care can be provided alongside other therapies and is applicable to people of all ages.

Palliative Care Principles

- Team based
- Serious Illness Communication
- Throughout the illness trajectory
- Does not attempt to prolong life nor hasten death
- Focus is on quality of life

DR. DEB



THE EARLY YEARS ... 2003

- Establishing a role of palliative care medicine in primary care, in Muskoka community and hospitals
- The creation of HOPE Huntsville Palliative Care Team
- Early involvement with Hospice Huntsville

Table 2. Delivery of Physician-Based Palliative Care and Location of Death for Patients Who Received Palliative Care in the Last Year of Life Who Died of Cancer and Noncancer Illness (Chronic Organ Failure or Dementia) in Ontario Between 2010 and 2017 by Cause of Death[a]

Variable	Cause of death			Standardized difference	
	Chronic organ failure[b] (n = 21 054)	Dementia (n = 14 033)	Cancer (n = 110 622)	Chronic organ failure vs cancer	Dementia vs cancer

The NEW ENGLAND JOURNAL of MEDICINE

CURRENT ISSUE SPECIALTIES TOPICS

ORIGINAL ARTICLE

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Authors: Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D. Author Info & Affiliations

Published August 19, 2010 | N Engl J Med 2010;363:733-742 | DOI: 10.1056/NEJMoa1000678 | VOL. 363 NO. 8

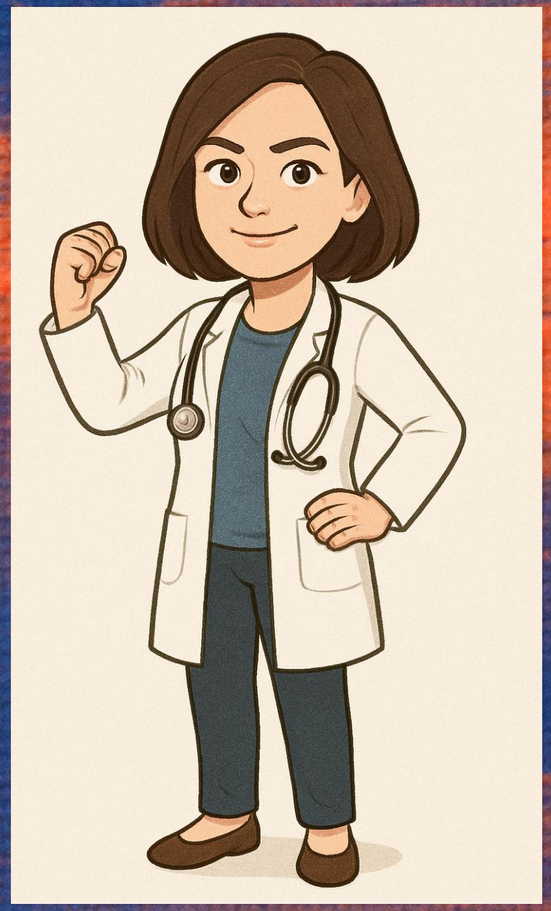
76% CANCER

HOPE HUNTSVILLE

THE EARLY YEARS ... 2003

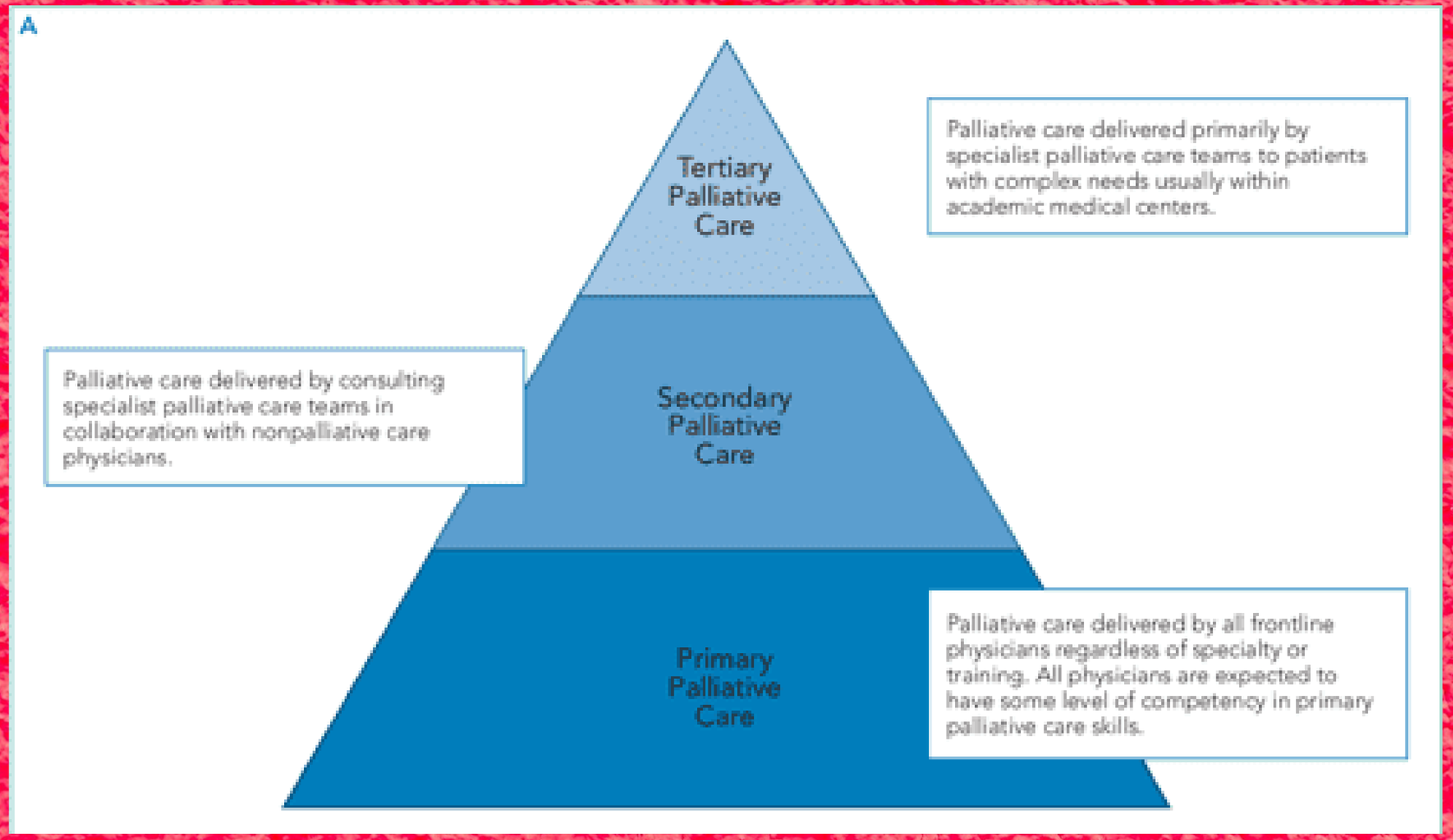
- Total patient numbers average: 50
- Close working relationship with home care
- Support primary care through shared care
- Avoid ER visits at end of life
- Grow community support for “dying well”

DR. DEB



THE MIDDLE YEARS ...

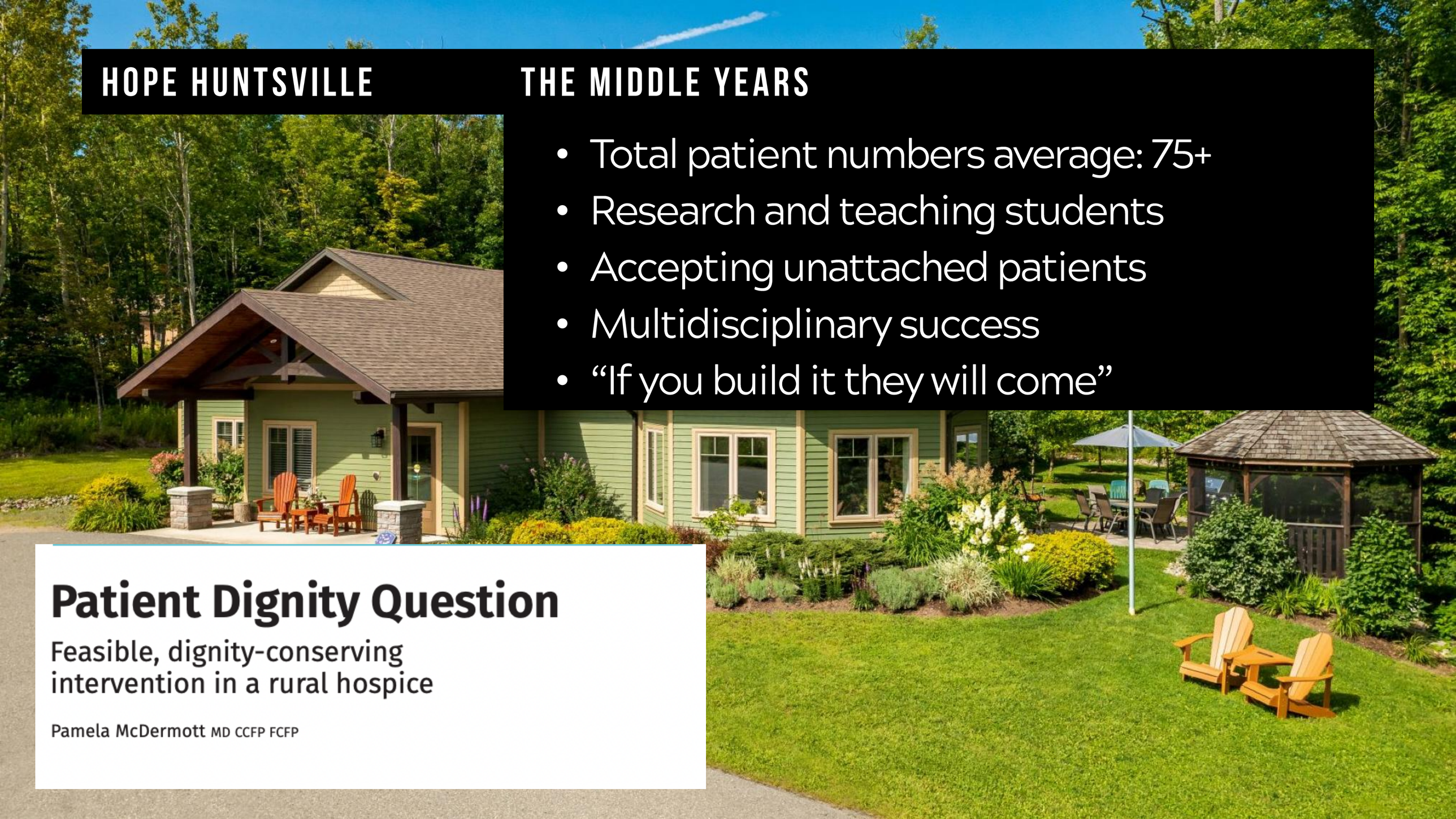
- HOPE Huntsville well established - growing the team
- Hospice Huntsville builds Algonquin Grace
- Palliative care collaborates with health care teams and focuses on education


A
Tertiary Palliative Care
Secondary Palliative Care
Primary Palliative Care
Palliative care delivered primarily by specialist palliative care teams to patients with complex needs usually within academic medical centers.
Palliative care delivered by consulting specialist palliative care teams in collaboration with nonpalliative care physicians.
Palliative care delivered by all frontline physicians regardless of specialty or training. All physicians are expected to have some level of competency in primary palliative care skills.

HOPE HUNTSVILLE

THE MIDDLE YEARS

- Total patient numbers average: 75+
- Research and teaching students
- Accepting unattached patients
- Multidisciplinary success
- “If you build it they will come”

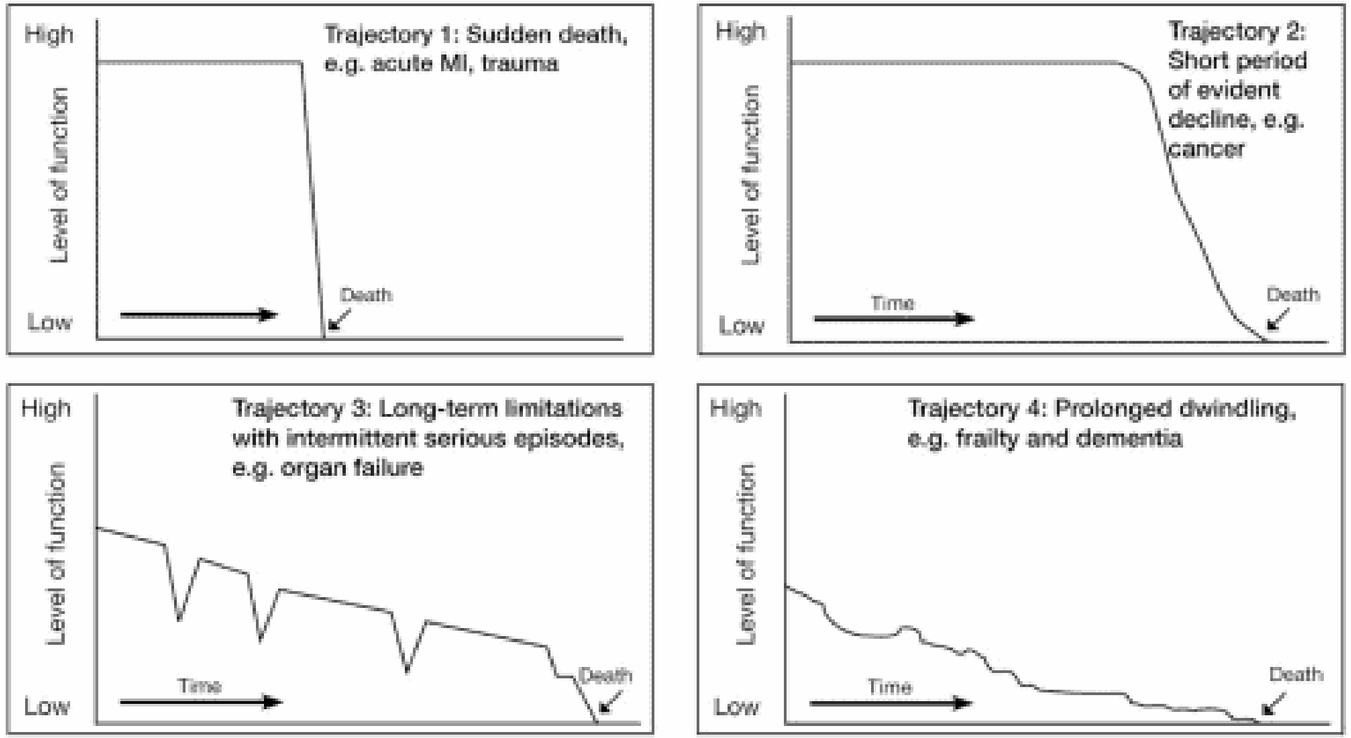


Patient Dignity Question

Feasible, dignity-conserving intervention in a rural hospice

Pamela McDermott MD CCFP FCFP

How People Die



Murray et al, *BMJ 2008*

CANCER INNOVATIONS

TRADITIONAL ERA	MODERN THERAPY ERA
RAPID PROGRESSION, SHORT SURVIVAL	CHRONIC DISEASE
DEATH FROM TUMOUR BURDEN	LIVING WITH CONTROLLED DISEASE
FEW LONG-TERM SURVIVORS	GROWING SURVIVORSHIP POPULATION

CANCER

THE CHANGING LANDSCAPE

"Oligoprogression"

Atypical relapse sites

Late reactivation

Therapy-Related Complications

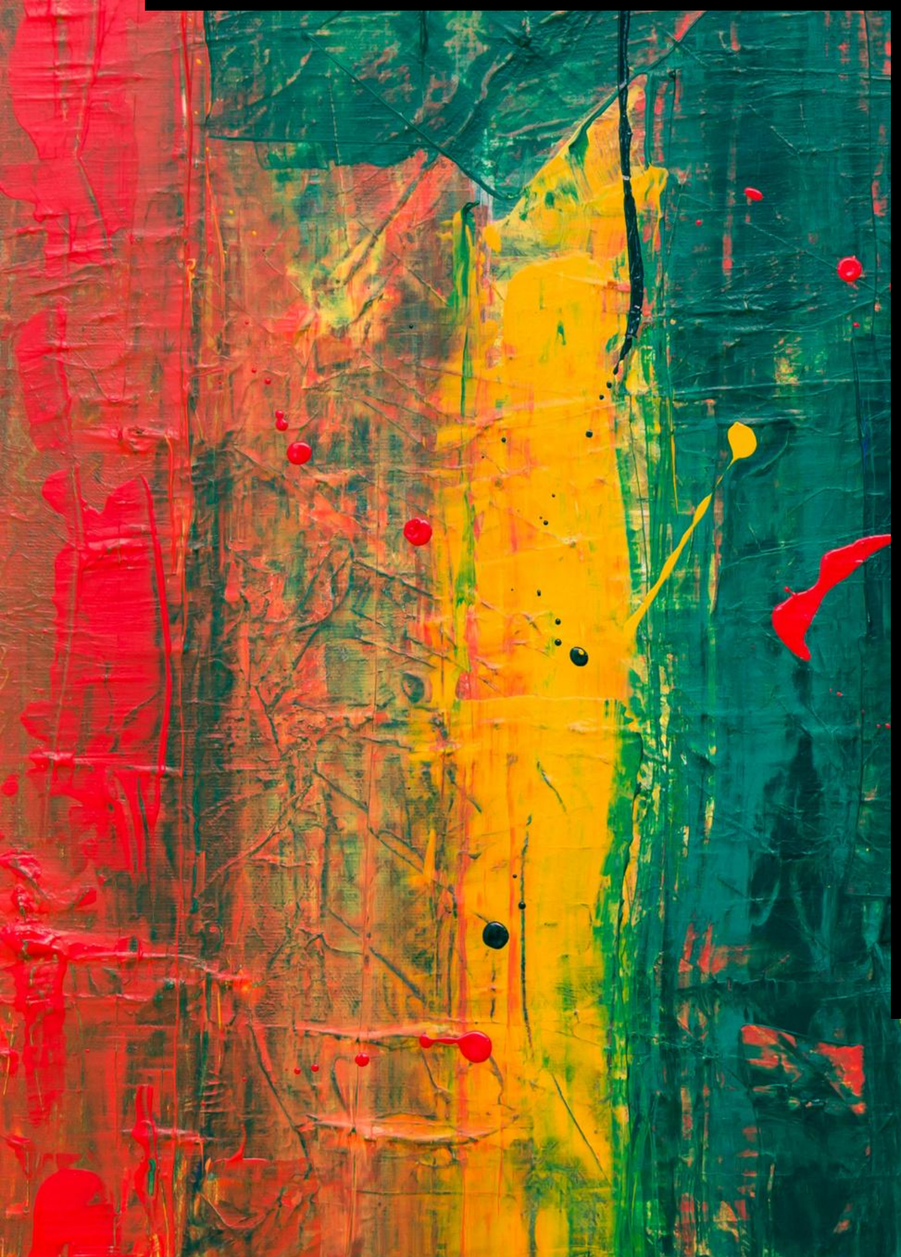
Acute → Chronic/Treatment-Related

Toxicities

Secondary malignancies

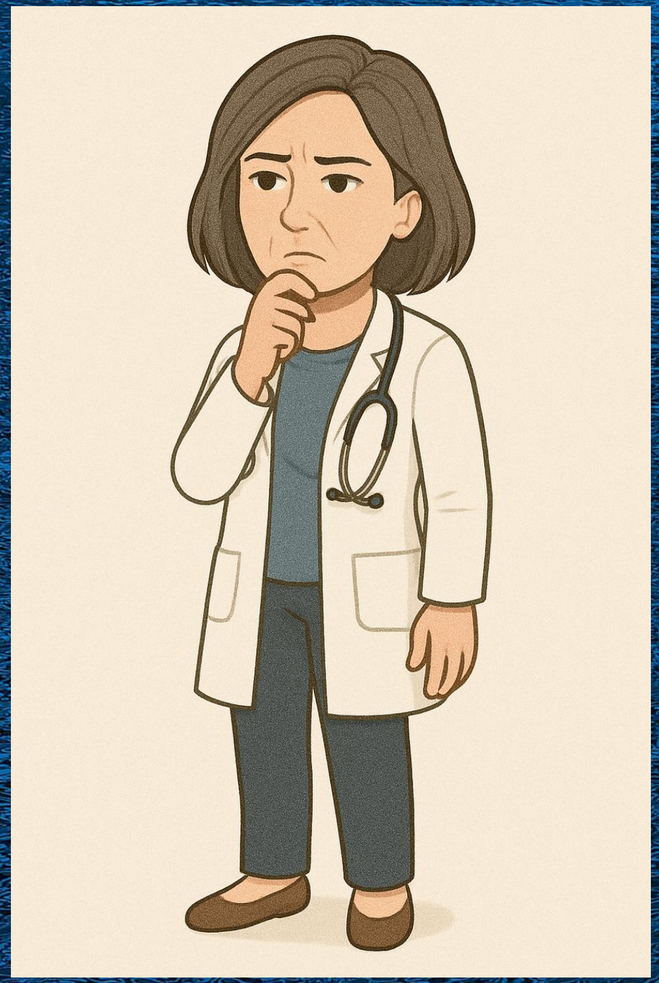
Immune-related adverse events (Iraes)

CANCER



Survivorship

DR DEB



THE NOW AND THE FUTURE

- Older and ?wiser
- HOPE Huntsville and Hospice Huntsville - successful and growing/evolving to serve the community
- Time to reflect…

HOPE HUNTSVILLE

THE NOW AND THE FUTURE

- Total patient numbers average: 100+
- Primary palliative care well supported
- Focus of consultation in hospital and unattached
- 4 consultants
- Avoiding ER, integrated with ER and ICU and sub-specialty clinics (Chemo/dialysis/geriatrics)
- Hospice successful, sustainable and integrated with PCT and hospital

.....A new team of “death doctors”....Medical Assistance in Dying

MAID

Bill C-14 (2016) and Bill C-7 (2021).

Key Elements:

18+, capable

who meet all criteria:

Have a **grievous** and **irremediable** medical condition

Are in an advanced and irreversible decline

Experience **suffering** intolerable to them

Provide voluntary, informed consent

Track 1 vs. Track 2:

Track 1: Natural death is reasonably **foreseeable** → streamlined safeguards

Track 2: Natural death not reasonably foreseeable → enhanced safeguards (e.g., 90-day assessment period)

MAID

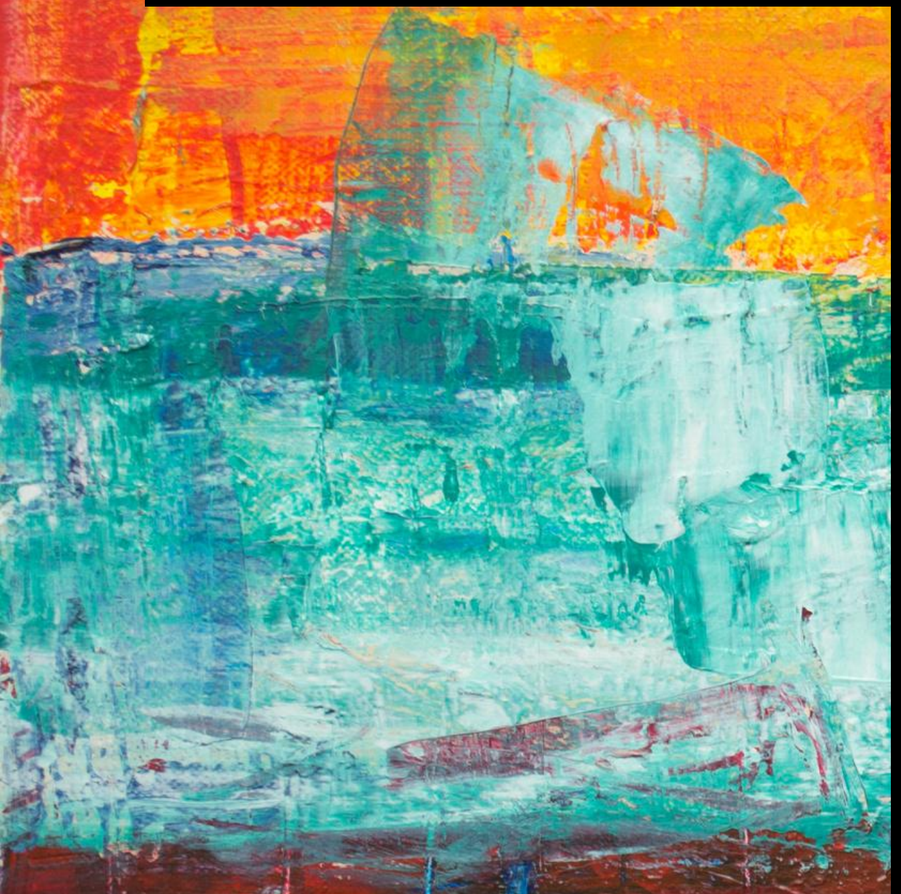
MAID and palliative care are ethically distinct but increasingly interconnected.

Most patients who request MAID are also receiving palliative care.

IN ONTARIO 74-84% OF THOSE WHO PURSUED MAID HAD PC INVOLVED AT TIME OF REQUEST

MAID

THE SERIOUS ILLNESS CONVERSATION....



Goals-of-care conversations have become more values-based and exploratory:

“What does living well mean to you?”

“What would make life no longer acceptable to you?”

“What outcomes are you hoping to avoid?”

SHIFT IN CLINICAL AND ETHICAL FRAMEWORK

Some patients prioritize maximizing comfort until natural death.

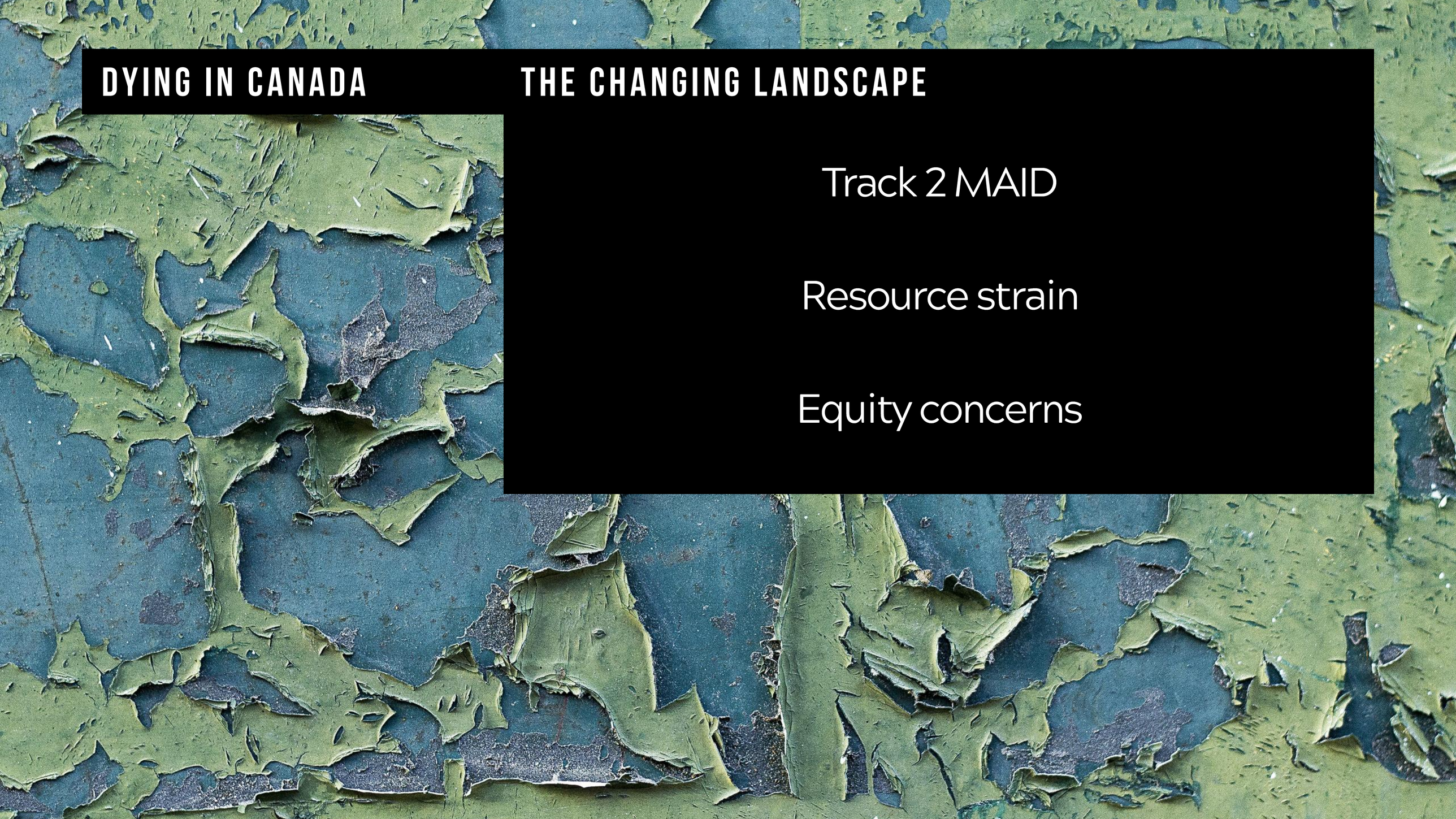
Others prioritize control over timing and circumstances of death through MAID.

The focus has shifted to alignment between care plans and personal values rather than adherence to a single philosophy of dying.

PALLIATIVE CARE

THE CHANGING LANDSCAPE

ASPECT	PRE-MAID ERA	POST-MAID ERA
FOCUS	COMFORT, SYMPTOM RELIEF, NATURAL DYING	EXPANDED TO INCLUDE PATIENT AUTONOMY OVER TIMING AND MANNER OF DEATH
GOALS OF CARE	MAINTAIN DIGNITY, RELIEVE SUFFERING	BROADER RANGE: FROM COMFORT TO CHOSEN DEATH
CLINICIAN ROLE	GUIDE TOWARD ACCEPTANCE AND PALLIATION	SUPPORT INFORMED CHOICE AND ALIGN CARE WITH VALUES
CHALLENGES	FEAR OF ABANDONMENT, LACK OF AUTONOMY	MORAL DISTRESS, SYSTEM STRAIN, EQUITY IN ACCESS



DYING IN CANADA

THE CHANGING LANDSCAPE

Track 2 MAID

Resource strain

Equity concerns

MAID

THE SERIOUS ILLNESS CONVERSATION....

The cultural message – often implicit – is that dependence, decline, and loss of control equal indignity.

This is where the challenge lies: dignity has become equated with independence.

But dignity, in its fuller sense, is not something we have or lose – it's something we recognize in one another.

PALLIATIVE CARE

REFRAMING DIGNITY

Relationship, presence, and compassion can sustain dignity, even when autonomy wanes.

Dying “naturally” – supported, comforted, not abandoned – can still be deeply meaningful and human.

PALLIATIVE CARE

REFRAMING DIGNITY

Reframe dignity as the ability to:

- Be known and seen as a person.
- Reconcile with loved ones.
- Leave a sense of legacy or peace.
- Have symptoms well managed and not suffer needlessly.

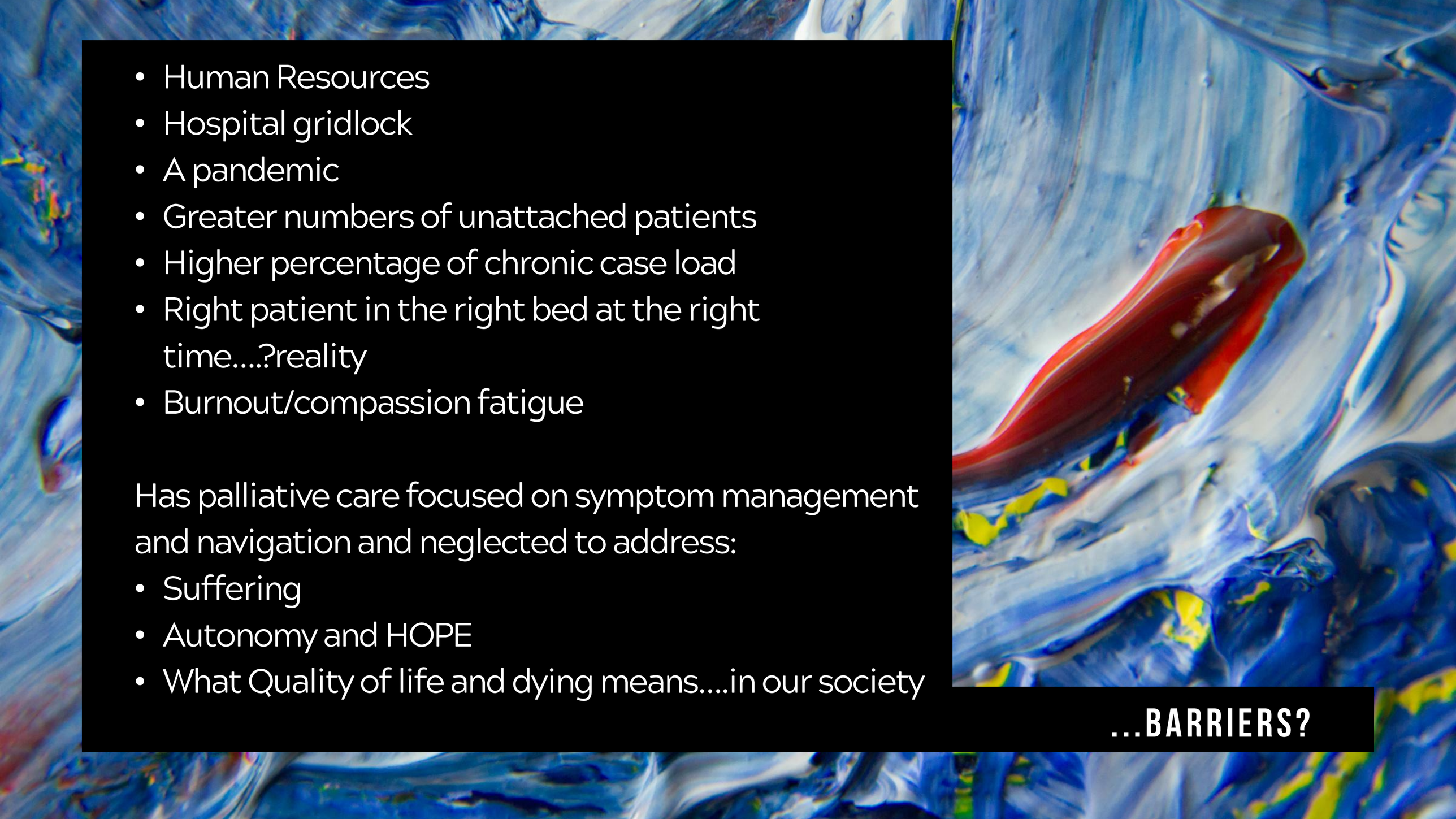
PALLIATIVE CARE

RECLAIMING DIGNITIY IN DEPENDENCE

Relational dignity
Existential dignity
Embodied dignity

Allowing dignity to be shared, upheld, and mirrored – not only asserted through autonomy.

ASPECT	AUTONOMY-CENTERED MAID MODEL	RELATIONAL, PALLIATIVE MODEL
CORE VALUE	INDEPENDENCE, CONTROL	CONNECTION, PRESENCE
DIGNITY DEFINED AS	FREEDOM FROM DEPENDENCE	BEING VALUED EVEN IN DEPENDENCE
SUFFERING ADDRESSED BY	ENDING LIFE TO END SUFFERING	EASING SUFFERING TO ALLOW LIVING AND DYING WELL
HOPE ROOTED IN	CHOICE	RELATIONSHIP AND MEANING

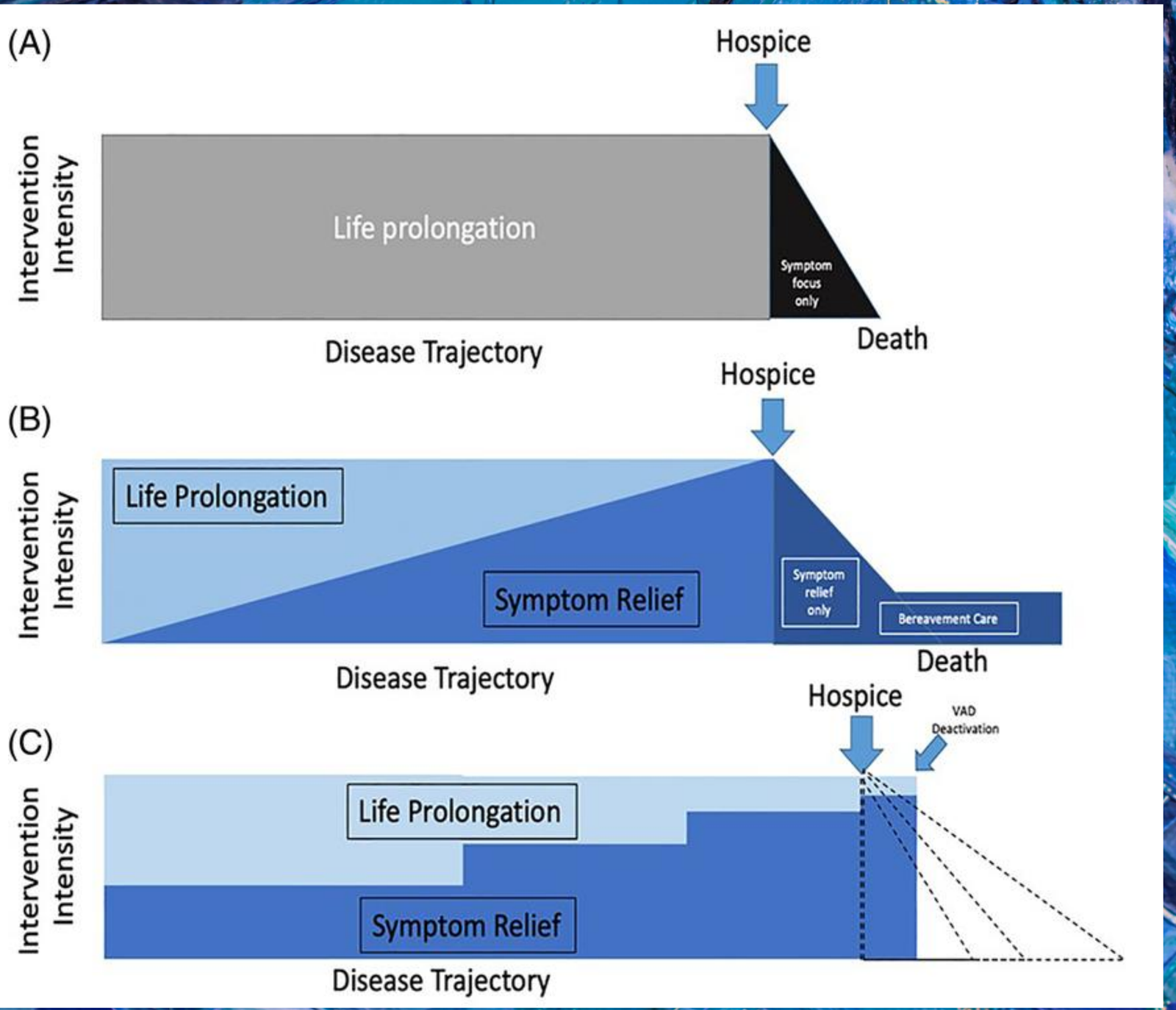


- Human Resources
- Hospital gridlock
- A pandemic
- Greater numbers of unattached patients
- Higher percentage of chronic case load
- Right patient in the right bed at the right time….?reality
- Burnout/compassion fatigue

Has palliative care focused on symptom management and navigation and neglected to address:

- Suffering
- Autonomy and HOPE
- What Quality of life and dying means….in our society

…BARRIERS?


(A)
Hospice
Intervention Intensity
Life prolongation
Symptom focus only
Death
Disease Trajectory
(B)
Hospice
Intervention Intensity
Life Prolongation
Symptom Relief
Symptom relief only
Bereavement Care
Death
Disease Trajectory
(C)
Hospice
VAD Deactivation
Intervention Intensity
Life Prolongation
Symptom Relief
Disease Trajectory

Original Investigation

FREE

Stepped Palliative Care for Patients With Advanced Lung Cancer
A Randomized Clinical Trial

Jennifer S. Temel, MD[1,2]; Vicki A. Jackson, MPH, MD[1,2]; Areej El-Jawahri, MD[1,2] ; et al

JAMA

QUESTION Is stepped palliative care, with visits only at key points in patients' cancer trajectories and using a decrement in quality of life (QOL) to trigger more intensive palliative care, an effective palliative care model for patients with advanced lung cancer?

CONCLUSION Stepped palliative care is an effective and scalable means to deliver palliative care to improve QOL for patients with advanced lung cancer.

POPULATION

260 Women
246 Men

Adult patients diagnosed with advanced lung cancer within the past 12 weeks

Mean age: 66.5 years

LOCATION

3
Academic medical centers in the US

INTERVENTION

507 Patients randomized
291 Patients analyzed

146

Stepped palliative care
Initial palliative care visit; subsequent visits only at change in cancer treatment or after hospitalization; stepped up to visits every 4 weeks if QOL decreased

145

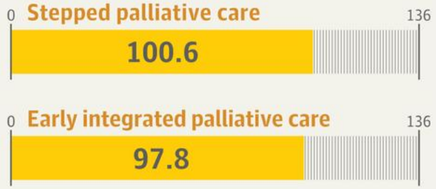
Early integrated palliative care
Palliative care visits every 4 weeks and inpatient palliative care team visits during admissions

PRIMARY OUTCOME

Patient-reported QOL on the Functional Assessment of Cancer Therapy–Lung (FACT-L; range, 0-136, higher scores indicating better QOL) at week 24 (noninferiority margin = −4.5)

FINDINGS

Mean FACT-L score at week 24



Stepped palliative care was noninferior to early palliative care:

Difference, 2.9

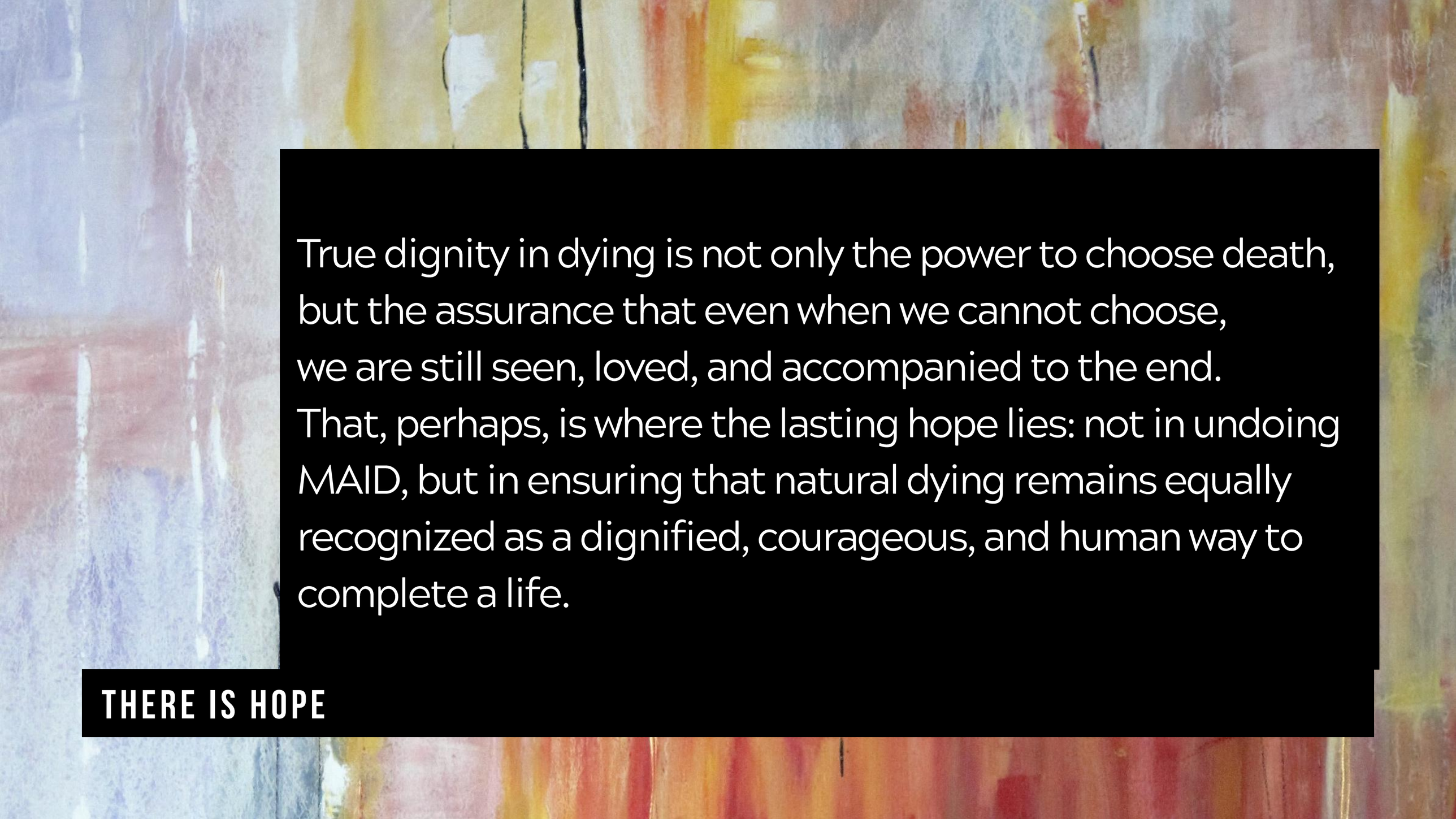
(lower 1-sided 95% confidence limit, −0.1);
$P < .001$ for noninferiority

Temel JS, Jackson VA, El-Jawahri A, et al. Stepped palliative care for patients with advanced lung cancer: a randomized clinical trial. *JAMA*. Published online June 2, 2024. doi:10.1001/jama.2024.10398

- Stepped palliative care - based on need/scalable
- Nurse led teams
- Interprofessional teams - to address multidimensional suffering
- Symptom screening and routine needs assessments
- Use of digital tools and EHR queries for triaging resource
- AI - use of algorithm medicine for n=1 care plan
- telehealth
- coordinate teams (oncology/pc/maid etc)
- Regular, attuned serious illness conversations - shifting to focus on values, coping and iterative planning
- Framing dignity nuances

...SOLUTIONS

?


True dignity in dying is not only the power to choose death,
but the assurance that even when we cannot choose,
we are still seen, loved, and accompanied to the end.
That, perhaps, is where the lasting hope lies: not in undoing
MAID, but in ensuring that natural dying remains equally
recognized as a dignified, courageous, and human way to
complete a life.
THERE IS HOPE