Improving Goals of Care Conversations in Long-Term Care

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VIC-SI LTCI Learning Series Event
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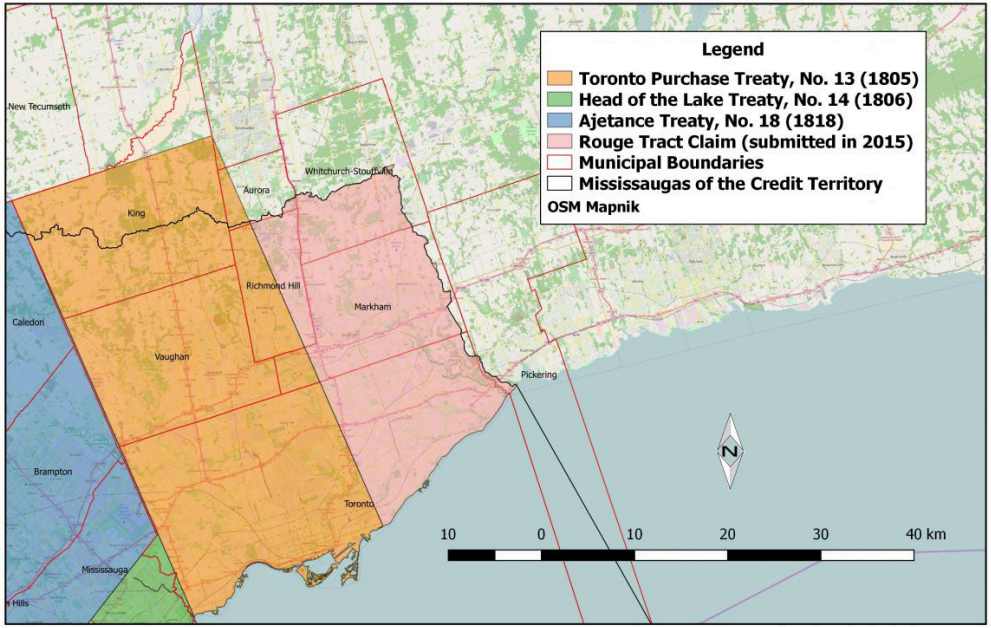
Land Acknowledgement



Municipal Boundaries Related to the Toronto Purchase Treaty, No.13 (1805)

Faculty/Presenter Disclosure

- **Faculty: Dr. Amit Arya**
- **Relationships with commercial interests:**
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Nil

Objectives

- Learn about improving goals of care conversations and common errors
- Discuss the importance of understanding cultural safety and equity with respect to goals of care conversations
- Better understand the health system improvements which are urgently required to improve goals of care conversations in long-term care

“21st century palliative care”

Palliative Care is NOT…

- An adjective to describe a patient
- Just limited to the end-of-life
- Giving up or removing hope
- A location
- An afterthought

What should palliative care look like in LTC?

CSPCP
Canadian Society of
Palliative Care Physicians

SCMSP
Société canadienne des
médecins de soins palliatifs

KEY MESSAGES:
Embedding a Palliative Approach to Care in Long Term Care Facilities
March 2022

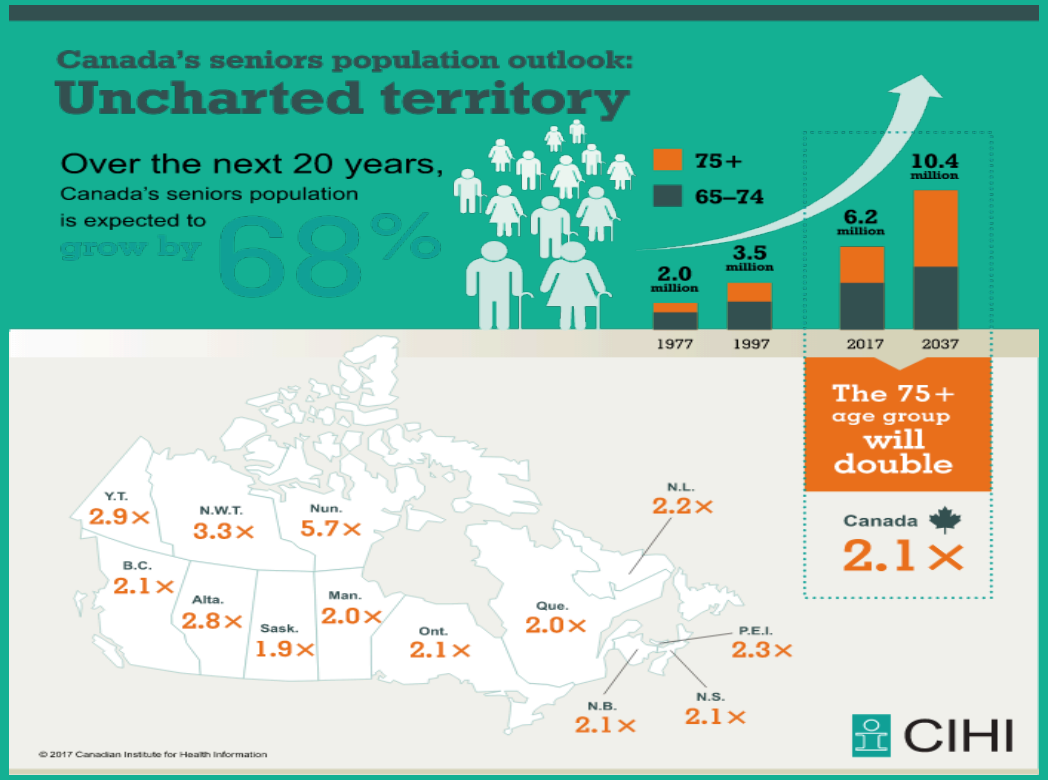
Palliative Care in LTC should be:

- Based on needs, not just prognosis
- Introduced before arrival or upon admission to LTC
- An educational competency for all LTC health workers

Palliative Care in LTC should be:

- Provided by an interdisciplinary team, with the support of palliative care specialist teams, when required
- Tracked via standardized performance measures

Why do we need to talk about this?



Case presentation

- An 87 year old gentleman with a previous stroke and G-tube feeds
- Resident hopeful to reduce G-tube feeds and being provided end-of-life care in LTC; DNR form completed
- Resident suffers an aspiration event, becomes very dyspneic and is asked: “do you want to go to hospital?”
- Resident says yes, transferred to hospital, dies within 24 hours

Does this sound familiar to you?

Why do we need to talk about this?

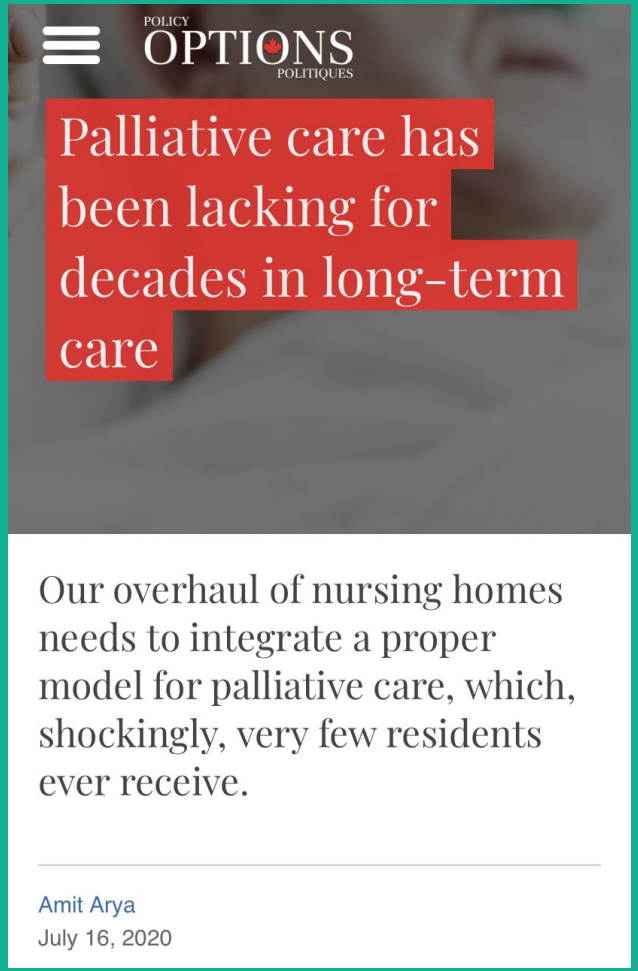
- Canada is the OECD leader in acute care deaths
- 20% of the health care budget is spent on the last year of life
- “A collapsing healthcare system”

Why do we need to talk about this?

- The emergency department, not community care (e.g. primary care), is often the gateway to receiving palliative care
- 58% of patients had an emergency department visit in the last 30 days of life

LTC and the need for palliative care

- Only 6% of LTC residents were recorded as having received palliative care in the last year of life



Unnecessary medical treatments and transitions of care are common for LTC residents

Transfers to hospital from LTC

- 65% in the last year
- 45% in the last month
- 27% in the last week

21% of patients from LTC admitted to acute care for “palliative care.”

In LTC, if residents received palliative care 2% died in hospital compared to 18% who didn’t receive palliative care

Having goals of care conversations well is a skill that can be learnt and efficiently used in all busy practices

Goals of care conversations

Break bad news well and you will always be remembered

Break bad news poorly and you will never be forgotten

Goals of care conversations

“The way in which the physician spoke to me caused me more pain than I experienced from the disease itself….”

Marjorie, in “What Dying People Want” (Kuhl)

Conversation flow		Patient-tested language
1. Set up the conversation • Introduce purpose • Ask permission	Set Up	*"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?**"*
2. Assess illness understanding & information preferences	Assess	*"What is your **understanding** now of where you are with your illness?"* *"How much **information** about what is likely to be ahead with your illness would you like from me?"*
3. Share prognosis • Frame with a "wish...worry", "hope...worry" statement • Allow silence, explore emotion	Share	Prognosis: *"I want to share with you **my understanding** of where things are with your illness..."* Uncertain: *"It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility."* Time: *"I **wish** we were not in this situation, but I'm **worried** that time may be short as_ (express as a range e.g. weeks to months, months to a year)."* **OR** Function: *"I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel"*
4. Explore key topics • Goals • Fears & worries • Sources of strength • Critical abilities • Trade-offs • Family	Explore	*"What are your most important **goals** if your health situation worsens?"* *"What are your biggest **fears and worries** about the future with your health?"* *"What gives you **strength** as you think about the future with your illness?"* *"What **abilities** are so critical to your life that you can't imagine living without them?"* *"If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"*
5. Close the conversation • Summarize what you've heard • Make a recommendation; check in with patient • Affirm your commitment to the patient	Close	*"I've heard you say that ____is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we _____. This will help us make sure that your treatment plan reflect what's important to you"* *"How does this plan seem to you?" "I will do everything I can to help you through this."*
6. Document your conversation & 7. Communicate with key clinicians		

Goals of care

Prepare yourself and explore the purpose of the conversation

Does your patient understand their illness?

Goals of care

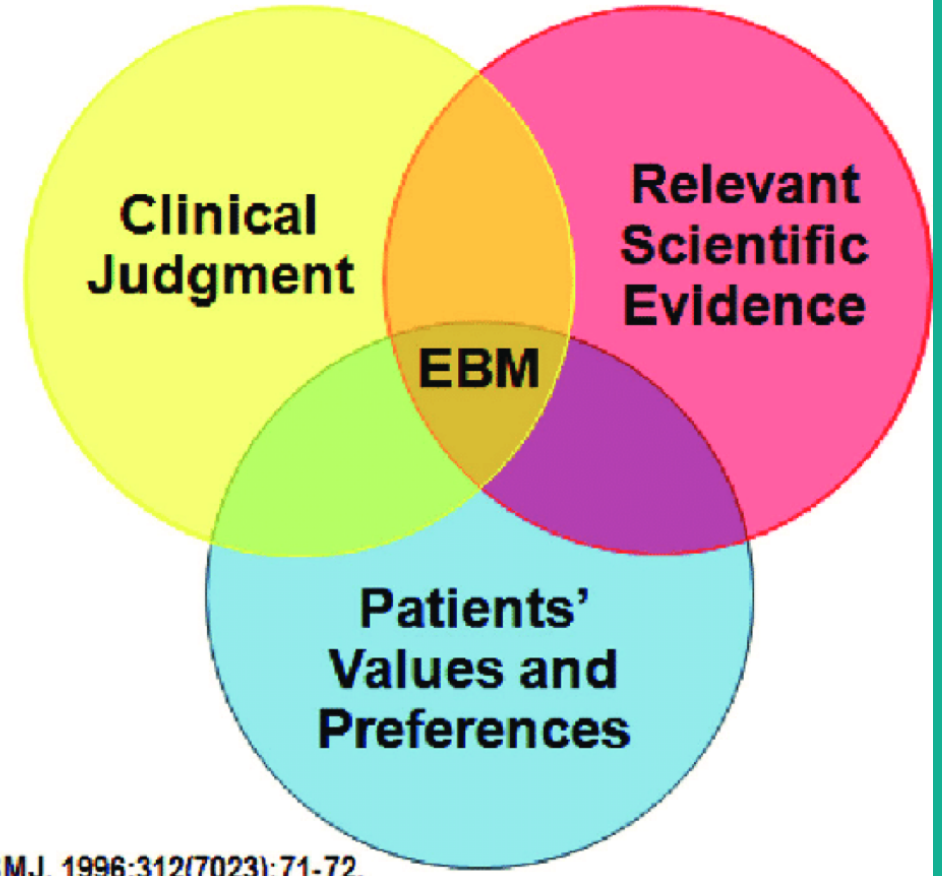
Identify the correct substitute decision maker

Explore patient values, wishes and beliefs

Goals of care

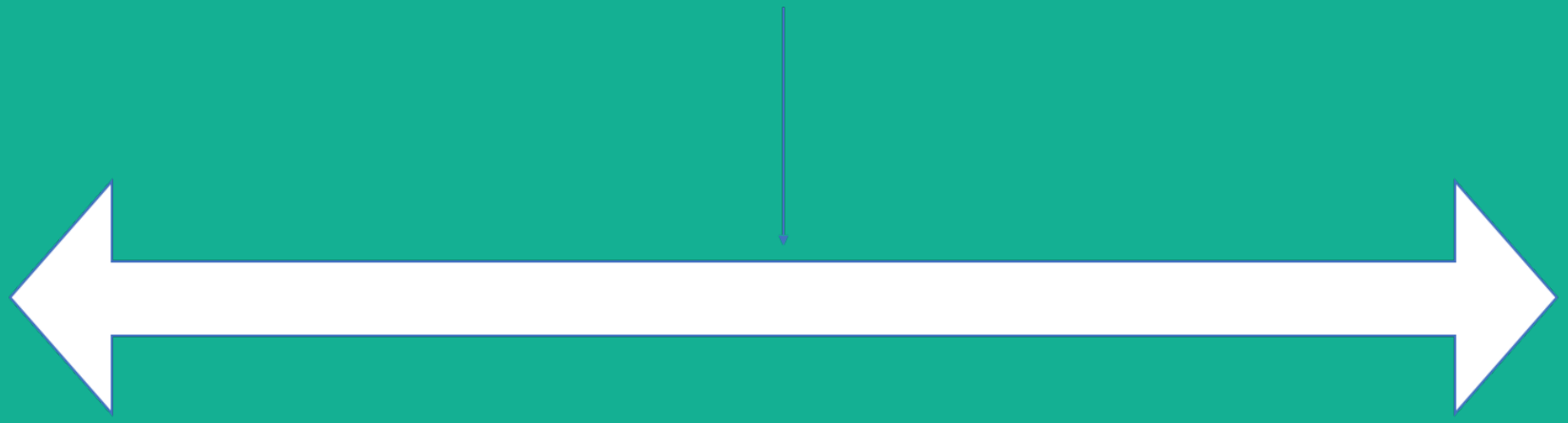
Propose Treatment!!!

What Is Evidence-Based Medicine?



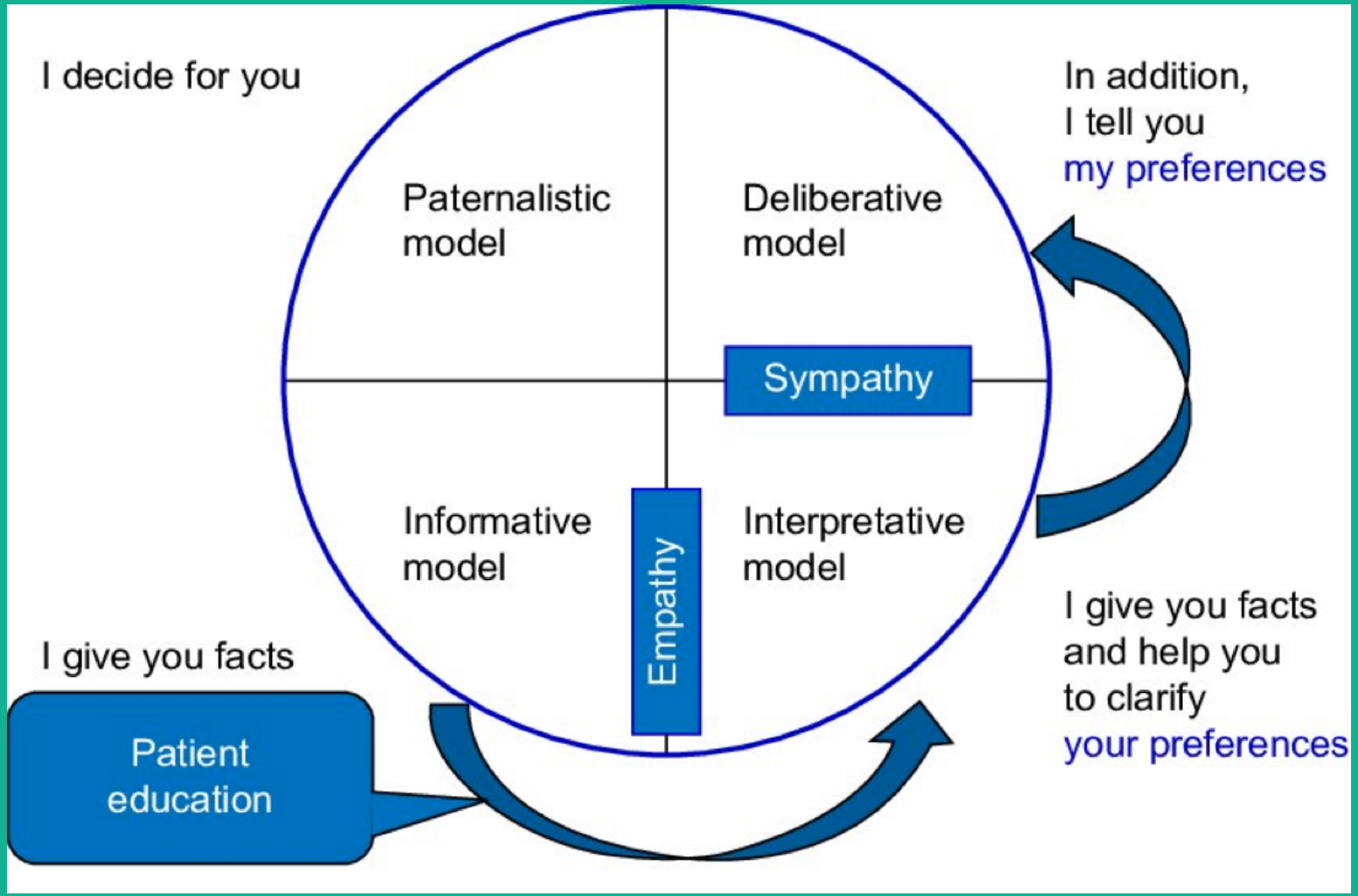
Sackett DL, et al. BMJ. 1996;312(7023):71-72.

A Meeting Between Experts



Paternalism
"I decide for you"

Consumerism
(abandonment)


I decide for you
Paternalistic model
Deliberative model
In addition, I tell you my preferences
Sympathy
Informative model
Empathy
Interpretative model
I give you facts
Patient education
I give you facts and help you to clarify your preferences

What do you think are some common errors with goals of care discussions?

Goals of care- common errors

- Not realizing that consent is treatment specific
- Assuming there is a default treatment
- Family proposes treatment, not clinician
- Assuming consent is required to NOT provide a treatment

Goals of care- common errors

- Following a “one size fits all approach"
- Focussing on technicalities rather than the therapeutic relationship
- Deferring goals of care conversations to end-of-life
- Rushing the conversation and not involving other colleagues

Case presentation

An 90 year old South Asian lady with advanced dementia in an LTC facility, has just tested COVID-19 positive

Became delirious, reduced appetite

There was a DNR order previously; this was revoked by the family

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Case presentation

Spoke to daughter who is the power of attorney

Has to speak to other family members before agreeing to recommendations

> “In our culture, family always makes decisions together”

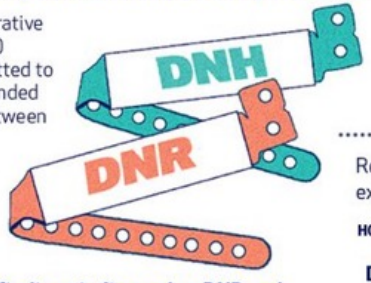
States they want “their mother to live” and “don’t trust the home”

Ontario nursing home DNR and DNH orders reduce inappropriate hospitalizations, but not entirely

IC/ES

Do-not-resuscitate (DNR) and do-not-hospitalize (DNH) orders lowered, but did not eliminate, risk of hospitalization or in-hospital deaths, suggesting room for improvement.

Study looked at administrative records for nearly 50,000 residents who were admitted to Ontario's 640 publicly-funded long-term care homes between 2010 and 2012.



3 in 5 nursing home residents had a DNR recorded at admission

1 in 7 had a DNH

Residents with a DNR or DNH were less likely to experience **hospitalization or in-hospital death**:

HOSPITALIZATION:

DNR: 13% less likely / **DNH: 30%** less likely

IN-HOSPITAL DEATH:

DNR: 40% less likely / **DNH: 60%** less likely

The authors say these findings indicate that DNR and DNH orders do not prevent all potentially avoidable hospitalizations or in-hospital deaths. They recommend better communication, along with additional supports to keep residents in their homes.

Tanuseputro P. et al. *J Am Med Dir Assoc.* 2019.

ICES *Data. Discovery. Better Health.*
ices.on.ca

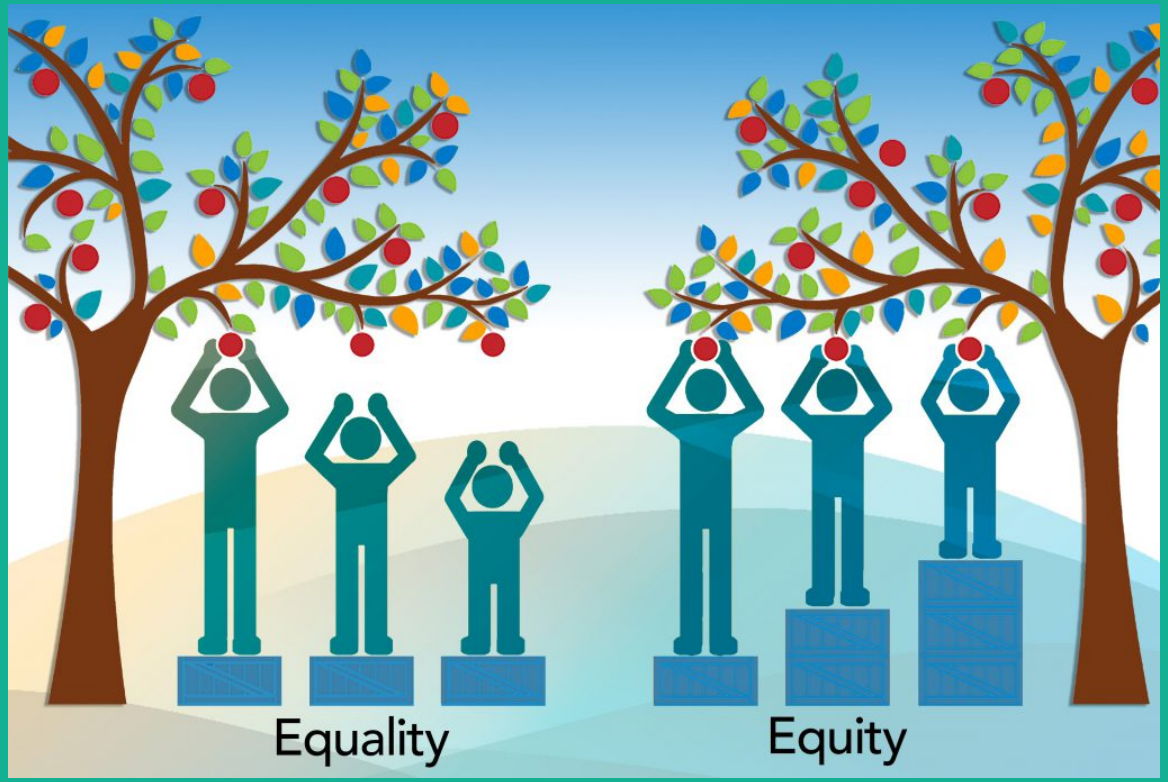
The Ottawa Hospital | L'Hôpital d'Ottawa

INSTITUT DE RECHERCHE Bruyère RESEARCH INSTITUTE

DNR/DNH much more likely if LTC resident spoke English/French

culture, race & ethnicity are important factors in resident & family decisions

One size doesn’t fit all!



How do we overcome these "equity hurdles"?

- Treat people differently according to their personalized needs, due to systemic and individual circumstances to actually achieve equality and justice

How do we define cultural safety?

An outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care. (FHNA)

“ABCDE Tool”

Attitudes	disclosing prognosis, discussion of death & dying
Beliefs	spiritual beliefs, meaning of death, miracles
Context	historical & political context of their lives
Decision-making	patient centred or family/community centred
Environment	available resources- family, neighbourhood

What can I do to provide culturally safe care in LTC?

- Ensure use of professional interpretation services
- Review hiring and training processes, support staff
- How does your specific healthcare setting accommodate the specific needs of racialized communities?
- Examine all systemic & institutional policies
- This is a life-long process which requires daily commitment, funding, and prioritization from leadership- consider ongoing QI work

Case presentation

95 year old lady with end-stage dementia and a breast mass

Hoping to be comfortable and stay in LTC for EOL care

LTC facility ends up on COVID outbreak causing staffing shortages

Develops a terminal delirium over the weekend

Agency nurse calls 911 overnight and transfers to hospital

On-call physician informed after transfer

How can the healthcare system better support you and your colleagues to have better goals of care discussions?

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Eldercare (LTC & home care) spending in OECD countries as a percentage of GDP:

1. Netherlands: 3.7%
2. Norway: 3.3%
3. Sweden: 3.2%
4. Denmark: 2.5%
5. Canada: 1.3% (and JUST 0.2% of that on home care!)

When will Canada stop underfunding eldercare...& also prioritize homecare?

Goals of care discussions in long-term care

- Staffing levels are low but acuity and complexity are rising
- Poor working conditions and reliance on agency staff affects continuity of care
- Workforce is being “deskilled”
- MRP has good discussions with resident, but on-call physician “just sends to the ER”

Goals of care discussions in long-term care

- Unpredictable trajectory of dying
- Lack of confidence and training amongst staff to provide appropriate symptom management after witnessing poor deaths of other residents
- Only 18% of SDMs of patients with dementia received prognostic information from their physician
- Burden on LTC to initiate palliative care, no attempt made prior with ACP and GOC

Staffing levels

Staffing levels

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@AmitAryaMD

End-of-life care at hospice: 1 nurse for 5 patients. Palliative care trained physician on site daily. All health workers trained in palliative care.

End-of-life care at LTC: 1 nurse for 25 patients in the day, 50 at night. Physician on site every 1-2 weeks. No required training.

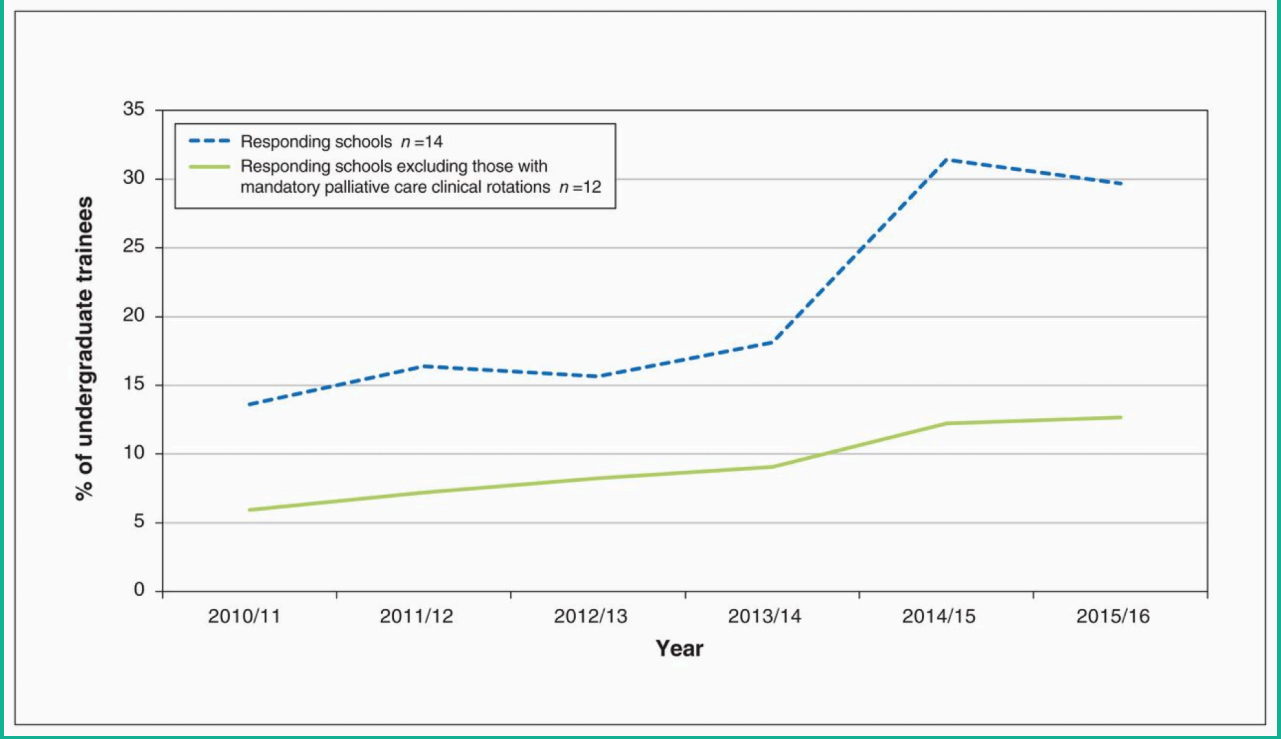
- 75% of Canadian nurses are burnt out
- 69% of nurses plan to leave their position within 5 years
- Among those who wish to leave, 42% were planning to leave the profession altogether


We can't get ready in six minutes, can you?
UNIFOR
theUnion | lesyndicat
unifor.org/6minchallenge

Working conditions

- Fair wages
- Equal pay for equal work
- Paid sick days
- Permanent jobs, 70% full time
- Single site work
- End workplace violence

Education and Training



Support of essential caregivers

Poor access to Palliative Care Specialists for LTC residents

- Just 1 in 8 LTC residents with advanced dementia saw a palliative care physician in the year prior to death

Questions