Growing Palliative Care in a Changing Landscape

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Objectives

At the end of this session, participants will:

- Be able to define and explain some of the common terms around Medically Assisted Death
- Understand the difference between Medically Assisted Death and Palliative Care
- Name specific suggestions to enhance aspects of care along the care continuum to provide enhanced palliative care and reduce the perceived need of hastened death at the end of life.

Conflicts of Interest

None

Supreme Court of Canada
February 6, 2015

Physician-assisted suicide should be available to a competent adult who "*clearly consents to the termination of life and has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition*."

Definitions

- Physician Assisted Suicide
  - suicide by a patient facilitated by means or information (as a drug prescription or indication of the lethal dosage) provided by a physician who is aware of how the patient intends to use such means or information

Definitions

- Voluntary Euthanasia
  - The act is done with the wishes of a competent individual or a valid advance directive
- Non-voluntary Euthanasia
  - The act is done without knowledge of the wishes of a competent individual or with respect to an incompetent individual
- Involuntary Euthanasia
  - The act is done against the wishes of a competent individual or a valid advance directive
  - Indistinguishable from murder or manslaughter

The following are NOT examples of Medically Hastened Death

- Refusal of care
  - sensible or not
- Withholding of care not wanted
- Withdrawal of care
  - Formerly called "Passive Euthanasia"
- Opioids
- Avoiding the use of intravenous fluids
- Sedation for Palliative Purposes

Definitions: Palliative Care (WHO)

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Euphemism: *a mild or indirect word or expression substituted for one considered to be too harsh or blunt when referring to something unpleasant or embarrassing.*

- Death with Dignity
- Euthanasia
- Physician Assisted Dying
- Medical Aid in Dying
- Medical Assistance in Dying

Government of Canada – Bill C-14 Medical Aid in Dying – June 17,2016

- Death must be "*reasonably foreseeable*"
- The law does not pertain to minors
- The law does not include mental illness, unless death is reasonably foreseeable
- It cannot be requested in Advance Directives
- There must be a 15 day waiting period.

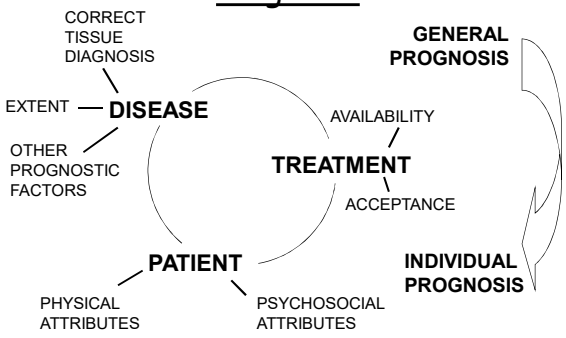
How has this come to be?

- Increasing autonomy
- Decreasing role of religion
- Decreasing sense of outcome of suffering
- A change in the understanding of dignity
- "Death-denying society"
- Witnessing "bad deaths"

1. Improve Advance Care Planning

- Determining prognosis
- Discussing prognosis
- Discussing goals, fears and trade-offs

Prognosis



Discussing Prognosis

Question the question

Be honest

Be broad

Allow for error

Use a tone of care marked by respect, kindness, and an unwavering affirmation of patient worth

Barriers to Communication

- **Patient factors**: anxiety, denial, desire to protect family members
- **Clinician factors**: lack of training, comfort, and time, difficulties in prognostication
- **System factors**: life-sustaining care is the default, no systems for end-of-life care, poor systems for recording patient wishes, ambiguity about who is responsible

Barnacki RE, Block SD; for the American College of Physicians High Value Care Task Force. *Communication About Serious Illness Care Goals. A Review and Synthesis of Best Practices.* JAMA Internal Medicine 2014;174(12):1994-2003.

Broadening the Discussion
Serious Illness Conversation Guide

Understanding: What is your understanding now of where you are with your illness?

Information Preferences: How much information about what is likely to be ahead with your illness would you like from me?

Prognosis: Share prognosis, tailored to information preferences

Goals: If your health situation worsens, what are your most important goals?

Broadening the Discussion
Serious Illness Conversation Guide

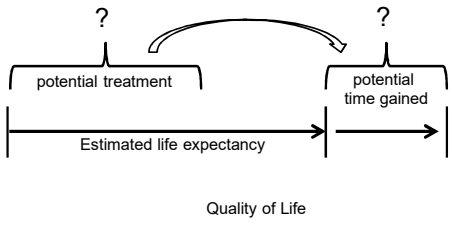
Fears / Worries: What are your biggest fears and worries about the future with your health?

Function: What abilities are so critical to your life, that you can't imagine living without them?

Trade-offs: If you become sicker, how much are you willing to go through for the possibility of gaining more time?

Family: How much does your family know about your priorities and wishes?

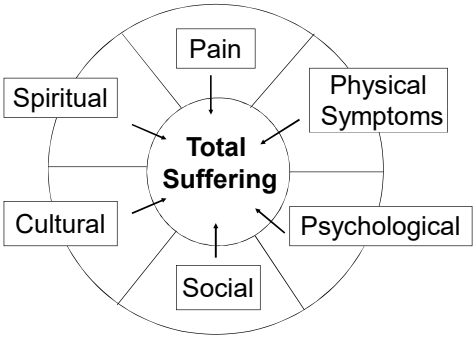
Quantity vs *Quality*



2. Improve Symptom Management

"…by means of early identification and impeccable assessment and treatment of pain and other problems…"

Total Suffering (*Woodruff*)



Symptom Management Challenges

EXAMPLES

- Patient Factors:
  - Inability or unwillingness to discuss symptoms, fears and worries about treatment
- Provider Factors:
  - Quick visits, unwillingness to corroborate, unwilling to prescribe
- System Factors:
  - Opioid challenges, distribution inequities, lack of availability of specialists or specialty services, or of services at all

3. Improve Our Ability to Address Suffering

"…functional fluency in the language of suffering should be a core competency of every health care provider."

Dr. M. Harlos

Defining Suffering

People suffer
from what they have lost
of themselves
in relation to the world
of objects,
events, and
relationships.

Cassel EJ. *The Nature of Suffering and the Goals of Medicine.* N Engl J Med 1982306:639-45.

Defining Suffering

- A state of severe distress that is personal, individual and subjective
- Arises from the perception that something is actually or potentially threatening the integrity of one's personhood
- Coincides with a range of intense emotions – fear, sadness, anguish, abandonment, despair
- Common to occur not only during the course of a life-limiting illness, but also due to its treatment
- The interface between the will to live and the wish to die

Patients' Statements Expressing their Wishes

- Wish to Live
- Acceptance of Dying
- Wish to Die
  - Not considering Hastening Death
  - Considering Hastening Death
  - Will to Die

Branigan, M. *Desire for hastened death: exploring the emotions and the ethics*. Curr Opin Support Palliat Care 2015, 9:64–71

Wishing to Die Continuum

Not Considering Hastening Death

- Looking forward to dying
- Hoping that dying happens more quickly
- Desiring to die (but hastening death is not considered)

Branigan, M. *Desire for hastened death: exploring the emotions and the ethics*. Curr Opin Support Palliat Care 2015, 9:64–71

Wishing to Die Continuum

Considering Hastening Death

- Hypothetically considering hastening death (in future, if certain things happen)
- Actually considering hastening death but at the moment (for moral or other reasons) it is not an option
- Actually considering hastening death as an (moral) option

Branigan, M. Desire for hastened death: exploring the emotions and the ethics. Curr Opin Support Palliat Care 2015, 9:64–71

Wishing to Die Continuum

Will to Die

- Explicit request
- Refusing life sustaining support (such as food or treatments) with the intention of hastening death
- Acting toward dying (such as suicide or assisted dying)

Branigan, M. *Desire for hastened death: exploring the emotions and the ethics*. Curr Opin Support Palliat Care 2015, 9:64–71

Themes Behind a Wish to Hasten Death

- A response to physical / psychological / spiritual suffering
- The loss of self
- A fear of dying
- The desire to live but not in this way
- Death as an escape from suffering
- A kind of control over one's life

Monforte-Royo C, et al. *What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients.* PLoS One 2012; 7:1–16.

Who Else is Suffering?

- Think of family and friends
- Think of volunteers
- Think of Health Care Providers

When suffering seems unending

- Take more time
- Remember the family
- Think "outside the box"
- Maximize use of the team
- Consult others
- Consider sedation

4. Enhance and Develop More Palliative Care Services

Where do Canadians want to die?

- *90% say at home, close to nature at the cabin, or on a beach.*
- *10% say in a hospital or nursing home.*

Expected Home Deaths in Manitoba

	2013-14	2014-15
Winnipeg RHA	16%	19%
Southern Health-Sante Sud	16%	18%

Emotions about Dying at Home

- The feeling of being a burden
- The overwhelming nature of care
- Breaking the promise
- The very end of life
- After the end

Improving Continuity

- Personal continuity
  - Effectively changes the relationship from stranger to trusted helper
- Informational continuity
  - Challenges of transferring information between caregivers
- Organizational continuity
  - A clear action plan, knowing who was responsible for what, and knowing what to do in off hours

Seamark D, et.al. Dying at Home: a qualitative study of family carers' views of support provided by GPs community staff. Br J Gen Practice 2014:e796-e803.

Some Unanswered Questions regarding MAID and Palliative Care

- How will physician-assisted death interact/interfere/mesh with palliative care?
- We will need to consider the implications of either:
  - Requiring patients to choose between palliative care or physician-assisted death
  - Requiring the systems of palliative care and physician-assisted death to work together

Summary

- Improve Advance Care Planning
- Improve symptom management
- Improve ability to address suffering
- Enhance and develop more Palliative Care services
- Remember that Palliative Care is Preventative Care