Is D.E.A.T.H. a dirty word?

Romayne Gallagher
Della Roberts
Peter Edmunds
Gina Gaspard
Prevalence and other facts about deaths in residential care

Romayne Gallagher MD, CCFP, FCFP
Physician Program Director
Palliative Care Program
Providence Health Care, Vancouver
Locations of Death in BC (2010)

- Hospital - Acute 47%
- Residential Care 24%
- Home 15%
- Hospice 12%
- Unreported 2%
### Place of Death for Deaths from Natural Causes

#### British Columbia 2002 – 2011

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<tbody>
<tr>
<td>Home</td>
<td>4,266</td>
<td>4,437</td>
<td>4,571</td>
<td>4,533</td>
<td>4,495</td>
<td>4,475</td>
<td>4,490</td>
<td>4,365</td>
<td>4,389</td>
<td>4,573</td>
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<td>Extended Care</td>
<td>5,213</td>
<td>7,343</td>
<td>7,916</td>
<td>8,139</td>
<td>9,091</td>
<td>9,601</td>
<td>9,145</td>
<td>9,188</td>
<td>9,554</td>
<td>10,005</td>
<td>85,195</td>
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<td>Hospital</td>
<td>15,872</td>
<td>14,641</td>
<td>14,523</td>
<td>14,645</td>
<td>14,265</td>
<td>14,453</td>
<td>15,936</td>
<td>15,277</td>
<td>14,824</td>
<td>14,977</td>
<td>149,413</td>
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<tr>
<td>Other and Unknown</td>
<td>1,357</td>
<td>812</td>
<td>775</td>
<td>788</td>
<td>824</td>
<td>617</td>
<td>423</td>
<td>403</td>
<td>351</td>
<td>449</td>
<td>6,799</td>
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<tr>
<td><strong>Total</strong></td>
<td>26,708</td>
<td>27,233</td>
<td>27,785</td>
<td>28,105</td>
<td>28,675</td>
<td>29,146</td>
<td>29,994</td>
<td>29,233</td>
<td>29,118</td>
<td>30,004</td>
<td>286,001</td>
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We are living longer. By 2025:

• 30% of the population >65.
• 33% increase in deaths over 2004.
• 2/3 will die with 2 or more chronic diseases after months or years in state of “vulnerable frailty”.
• Only 20% of us will die with a recognizable terminal (“palliative”) phase.
Who lives in residential care?

- 32% of Canadians over age 85 live in residential care facilities
  

- Over 70% have cognitive impairment
  

- All have multiple co morbidities
Figure 1. Trajectories of Disability in the Last Year of Life among 383 Decedents.

The severity of disability is indicated by the mean number of activities of daily living (ADLs) in which the subjects had disability. The solid lines indicate the observed trajectories, and the dashed lines indicate the predicted trajectories. The I bars indicate 95% confidence intervals for the observed severity of disability. The probability that the assigned
Figure 2. Distribution of Disability Trajectories in the Last Year of Life, According to Condition Leading to Death among the 383 Decedents.

The values within the bars are the percentages of decedents with the disability trajectories.
Figure 7. Relative impact of chronic health conditions on service use, 2005

*Select chronic health conditions include arthritis, cancer, chronic obstructive pulmonary disease, diabetes, heart disease, high blood pressure and mood disorders.
†Consultations and hospital overnights are for any reason or diagnosis. Healthcare professional consultations exclude those that occurred during hospital overnights.
Prevalence of dementia

In BC-
- 64,000 June 2011
- Forecast to increase to 94,000 by 2026

(BC Ministry of Health 2011, Review of the use of antipsychotic drugs in residential care facilities MOH Dec. 2011)

In the World-

![Graph showing the growth in numbers of people with dementia in high income countries and low and middle income countries.](image)
People with dementia who cannot walk have ↑ risk

- Urinary tract infection (3.4 x)
- Pneumonia (6.8 x)


- Pressure ulcers
Mortality from Dementia

Dementia registry followed 521 people diagnosed with dementia

- Median survival from diagnosis
  - 4.2 years men
  - 5.7 years women
- Disease severity at time of diagnosis most strongly associated with survival

The clinical course of advanced dementia

325 residents with dementia for 18 months in 22 different homes were followed

• survival data, symptoms, clinical complications, treatments
• the surrogates’ understanding of dementia prognosis

The clinical course of advanced dementia

- 6 month mortality rate after a complication:
  - Pneumonia 46.7%
  - Febrile episode 44.5%
  - Eating problem 38.6%

- Symptoms over 18 months
  - Dyspnea 46%
  - Pain 39.1%
  - Pressure ulcers 38.7%
  - Agitation 53.6%

- Symptoms increased towards end of life

The clinical course of advanced dementia

- 41% of residents had a burdensome intervention in the last 3 months of life
- Residents of surrogates who understood natural course and expected complications of dementia - significantly less likely to have interventions in last 3 months of life
- Surrogates received counseling about:
  - Prognosis 18%
  - Expected complications 32.5%

THE BRAIN

healthy brain

advanced alzheimer's
BEREAVED RELATIVES STUDY

- validated telephone interview of bereaved relatives of patients/residents who died in acute, residential and hospice care
- 90 total interviews
- 13 interviews from residential care
- 5/13 died within two months, 11/13 died within 6 months
- residents with longer admissions less likely to participate
What number would you give the overall care that was received in the last two days of life?

<table>
<thead>
<tr>
<th>Place</th>
<th>0-5/10</th>
<th>6-7/10</th>
<th>8-10/10</th>
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<tbody>
<tr>
<td>Residential</td>
<td>31%</td>
<td>31%</td>
<td>38%</td>
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<tr>
<td>Hospice</td>
<td>0</td>
<td>11%</td>
<td>89%</td>
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</table>
What is a palliative approach?

Della Roberts
Clinical Nurse Specialist
Fraser Health End of Life Program
Good deaths don’t happen by accident

Death is a natural end to life, not a medical event. Yet …

“When you are younger you may die, when you are old, you must die. …

Why is it so hard to die now a days?”

Emily Charlton
WHO Definition of palliative

- Palliative care is 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, impeccable assessment and treatment of pain and other problems; physical, psychosocial and spiritual.

www.who.int/cancer/palliative/definition/en/
... a palliative approach

• takes the principles of palliative care and applies them to the care of people with life-limiting chronic conditions

• does not link the provision of care too closely with prognosis but more broadly focuses on conversations with patients/families about their needs/wishes, comfort, support for psychosocial, spiritual and cultural issues; information requirements; and provisions for death and care after death
... a palliative approach

A lens embedded into care of all providers from the time people move into residential care.
A palliative approach focuses on

- *conversations* with residents/families about needs, wishes & goals
- *comfort* & quality
- *support* for psychosocial, spiritual & cultural needs

- *information* to support decision making
- *provisions* for death and for care after death

Coventry, Grande, Richards, & Todd, 2005; Jackson, Mooney, & Campbell, 2009
Sampled nursing care settings in BC (N = 114)

PROVINCIAL SURVEY OF NURSES AND HEALTHCARE WORKERS

iPANEL SURVEY SITES

□ PHASE 1

□ PHASE 2

iPANEL
INITIATIVE FOR A PALLIATIVE APPROACH IN NURSING: EVIDENCE & LEADERSHIP

PROVINCIAL SURVEY OF NURSES AND HEALTHCARE WORKERS

www.iPANEL.ca
Not recognizing the person is on a dying trajectory

Dementia is a progressive terminal illness for which there is no cure.

Starts with identification of a disease course that will decline and cause death

Studies found that dementia is not viewed as a terminal illness

(Sampson, 2006; Mitchell, 2004; Morrison & Siu, 2002).
<table>
<thead>
<tr>
<th></th>
<th>Admin.</th>
<th>Care aide</th>
<th>MD</th>
<th>RN</th>
<th>Allied</th>
<th>Other</th>
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<tbody>
<tr>
<td>Agree</td>
<td>31.6</td>
<td>33.3</td>
<td>53.3</td>
<td>32.1</td>
<td>40.4</td>
<td>22.0</td>
</tr>
<tr>
<td>Disagree</td>
<td>57.0</td>
<td>60.0</td>
<td>44.4</td>
<td>60.5</td>
<td>55.8</td>
<td>70.4</td>
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<tr>
<td>Don’t know</td>
<td>10.5</td>
<td>6.7</td>
<td>2.2</td>
<td>7.4</td>
<td>3.8</td>
<td>7.4</td>
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</tbody>
</table>
Why is dementia not seen as a terminal illness?

- Decline is slow – 4-9 years
- The “final event” is often identified as pneumonia, sepsis, UTI rather than dementia
- It is difficult to predict when the person will die
Dementia is a cause of death

- A 2003 study of family members of people dying from dementia:
  - 70% identified they were terminally ill prior to their death
  - 66% of those believed their loved one died of something other than dementia

Shega et al. J Palliative Medicine 2003
Waiting for last days ...

The term ‘Palliative’ care has become associated with the actively dying time in Residential care.
Waiting for permission...

Many care providers are not entering into conversations about death and dying — unless there is ‘permission’
Barriers to end of life care in residential care

Dr. Peter Edmunds
Medical Director Palliative Care,
VCH-Coastal
Physicians

- Response to calls often not timely
- Lack of regular visiting
- Avoidance of goals of care conversations (so families change LOI when in crisis)
- Limited comfort/experience to have conversations
- On call physicians lack privileges
- Inappropriate orders (“full code”)
- Limited understanding about health care consent legislation
Our health-care system operates from an acute, cure-focused ideology (Thorne, 2008)

Society believes the hospital is the place to die.
Philotopy

Palliative Care has become:
equated with a service or program
associated with last months of life
Equated with actively dying time

Yet ... most people will die:
without a defined time before an expected death
without specialized palliative services
Care Providers

- Changing mix of nursing staff
- Need for knowledge (e.g. pain)
- Limited care planning to support goals of care
- Limited staffing capacity for increased acuity
- Lack of recognition of milestones along the dying trajectory
- Ineffective communication between nurses and physicians (e.g. crushed meds)
Families

- Lack of knowledge about the diagnosis and prognosis
- Emotional time which needs clear guidance
- Unrealistic expectations
Administrative

- Residents must be up for meals if no tray service
- Lack of acknowledgment that people are expected to decline and die
- Limited standardization of forms (LOI)
- No Requirement for care planning to support goals of care

- MDS/RAI does not reflect palliative care needs
- Monthly weights are reported to ministry
Moving in process

- MDS lacks Advance Care Planning / Goals of Care
- Goals of Care and Advance Care Planning conversations seldom happen before person moves in
- Next of Kin is seen as the same as Temporary Substitute Decision Maker
Building plans and equipment

- Old buildings with large noisy spaces
- Multiple bedrooms with limited privacy
- Limited equipment (e.g., specialty mattresses)
Strategies to promote a Palliative Approach

Gina Gaspard
Clinical Nurse Specialist
Fraser Health Residential Care
Physicians

• All on call physicians need privileges
• Medical directors require from physicians:
  • a level of competency with conversations
  • timely response to calls and
  • regular visits
• Group several residents with physicians so visits are worthwhile.
• Provide education about health care consent legislation and having advance care planning conversations
Integrated palliative approach begins when the person moves in
Continue advance care planning conversations first week of moving in

If you couldn’t speak for yourself, who would know you the best to represent you? (not who is next of kin)

Have you ever written anything down?

Have you spoken to your physician or family about your preferences?

What is important to you? (not what do you want)

What is your understanding of why you are living here?

Provide diagnosis & prognosis with risk/benefits of treatments

What are your goals for your health over the next year and what are your fears?
Care Providers

Embed surprise question

- In care conferences
- During medication reviews
- MDS reviews
- Weekly rounds
- Whenever there is a change in the resident
  Ask...could this person be dying?

And share thoughts with family
• Provide written materials prior to moving in
• Attend family council meetings and offer education about:
  • Advance care planning
  • Dementia trajectory & burdensome interventions
• Stop asking families what do you want us to do and start asking what is important to your loved one.
Administrative

- Standardize forms across the region
- Use influence to change performance indicators to reflect quality care
- Require care plans which reflect goals of care.
- New hire interviews look for competencies in palliative approach
- Performance reviews evaluate palliative approach competencies. Expectations are made clear to staff.
System/ Policy

- Create a model which builds capacity to provide palliative approach within residential care
- Create a pathway which embeds palliative approach from moving in day to death.
- Use actively dying protocol
Integrating a palliative approach in residential care – it makes a difference.