Need for a comprehensive model of palliative support and end of life care in Nova Scotia

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Provincial Cancer Network Meeting
Concurrent Session:
*Exploring a Model of Palliative Support for Persons with Advanced Cancer*
April 20, 2012
Outline

- Demographics and risk of death
- Health services in an historical context
- Conceptualizations of palliative and end of life care
- Context of NELS research knowledge exchange
- Insights into situation for persons living with cancer in Nova Scotia
- Purposes of today’s concurrent session
Impact of aging population, increasing and inevitable risk of death with age, and resource implications
Aging of the Population

Population pyramid, by five year age categories, Nova Scotia, 2001
Population pyramid, by five year age categories, Nova Scotia, 2020

Percent of population by sex

Age group (years)

Males
Females

Women elderly
Babyboomers
Frail Elderly

Workforce to elderly ratio
Nova Scotia Deaths by Age, 1998 - 2005

Death rate
What is the likelihood that we will die?

Avoidance of discussion of death and dying – someone else’s issue.

Consider the language we use: “if” we die versus “when” we die.

Need public health and societal shift in thinking which encompasses new information technology, transformation in primary and community health, in context of comprehensive collaborative chronic disease management.
Mean daily costs per palliative care patient

- Inpatient care: 81 $
- Outpatient care: 26 $
- Home care: 75 $
- Long-term care: 8 $ (5 sites), 1 $ (Halifax)
- Transportation: 8 $ (5 sites), 3 $ (Halifax)

Persons already in long term care were excluded from study.

Cost distribution for palliative care patients

Health services context
Brief Historical Context - Canada

Health is a **provincial** not a federal responsibility: BNA Act
Post WW II – in 1950’s built hospitals
1960’s – Canada-wide **hospital insurance**
1970’s – Canada-wide **physician insurance added**
Led to Canada Health Act; Recent Health Accord discussions

**Concurrently, palliative medicine began.** Dr Balfour Mont in Montreal after studying hospice care with Dame Cicely Sanders in UK. In Canada became physician and hospital based where costs of services were publicly funded. For decades, palliative care had cancer focus and urban-based champions.

**Out-of-hospital , community-based health care is underdeveloped in Canada**

Palliative care problems are known

Since mid 1990’s, Sharon Carstairs and other Canadian reports show:
- societal and professional avoidance of death and dying
- inadequate access to care
- underdeveloped palliative care
- lack and challenges in communication
- poor continuity and coordination of care across providers and in transitions in care location
- lack of central leadership and vision; improved by local champions
- care and planning of care is often in disease ‘silos’ but people at end of life usually have more than one condition
- quality of care and need for care and accreditation standards
- limited research and surveillance data
Definitions and conceptualizations of palliative and end of life care

Palliative “Care” versus “Approach”

End of life care is all health care in the last weeks, months (or years) of life
Palliative Care

End of Life Trajectories


- **Sudden Death**
  - Accidental death
  - Falls, Trauma

- **Terminal Illness**
  - Cancer
  - Motor neuron
  - HIV-related
  - Chronic renal failure
  - Decline in <2 months

- **Organ Failure**
  - Congestive heart failure (CHF)
  - Chronic obstructive pulmonary disease (COPD)
  - 2-5 years, but death with “sudden” episode

- **Frailty**
  - Alzheimer’s disease and dementia
  - Neurological decline
  - Stroke
  - Prolonged dwindling
  - Up to 6-8 years
Trajectories Distribution

95% of people die of a life threatening disease with end of life stage. They access many services: nursing home, home care, specialty chronic disease care, diagnostic testing, primary care, inpatient hospital, emergency department, palliative care, ...

Nova Scotia deaths, all ages, 1995-2009

- Frailty, 25.4%
- Terminal Illness, 33.6%
- Organ Failure, 33.6%
- Sudden Death, 5.5%
- Other, 3.4%
Population priorities in context of U.S. Institute of Medicine’s quality goals

Divides population into eight groups: 1) in good health, 2) maternal/child, 3) with an acute illness, 4) stable chronic conditions 5) serious but stable disability, 6) failing health near death, 7) advanced organ system failure, 8) long-term frailty with failing health. Definitions of optimal health and priorities for services. Framework to plan resources, care arrangements, and service delivery.

Gold Standards Framework in UK

International best practice standard
Covers all places of care
Continuing to evolve

http://www.goldstandardsframework.org.uk/

Key issues: When is the beginning of end of life time period? And, how to transition into end of life care

Primary care is a focus for training and audit

Registry of persons at end of life is a key component

Creation of an end of life care registry

Early identification of life threatening disease for registry enrollment and earlier discussion of goals of care, care plan and coordination

Curative, rehabilitative, life prolonging treatment

Supportive Care

Palliative care/approach

Terminal Care

Family/community enabling

Bereavement

Self care

Family

Person at end of life

Beginning of end of life markers – to be defined for Nova Scotia
Average number of causes of death, per decedent by age, Nova Scotia, 1998-2005

- Age 0-9: 2.64
- Age 10-19: 2.16
- Age 20-29: 2.08
- Age 30-39: 2.14
- Age 40-49: 2.34
- Age 50-59: 2.47
- Age 60-69: 2.66
- Age 70-79: 2.81
- Age 80-89: 2.92
- Age 90+: 2.80
Distribution of number of causes of death, Nova Scotia, 1998-2005

Approximately 80% have > 1 cause of death recorded

Mean number of causes recorded = 2.8
Children and youth who died in Nova Scotia, 1995-2009

**Distribution of Deaths Ages 0-19**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Number of Decedents</th>
</tr>
</thead>
<tbody>
<tr>
<td>age 0</td>
<td>777</td>
</tr>
<tr>
<td>age 1-5</td>
<td>160</td>
</tr>
<tr>
<td>age 6-10</td>
<td>115</td>
</tr>
<tr>
<td>age 11-15</td>
<td>190</td>
</tr>
<tr>
<td>age 16-19</td>
<td>397</td>
</tr>
</tbody>
</table>

Total Deaths: 1639

**Percentage of Each Age Group with a Cancer Cause of Death**

- **age 0**: 0.9%
- **age 1-5**: 10.0%
- **age 6-10**: 19.1%
- **age 11-15**: 12.1%
- **age 16-19**: 4.5%

**all 0-19**: 5.2%

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## Non-cancer causes of death for Cancer decedents, Nova Scotia, 1998-2005

<table>
<thead>
<tr>
<th>Selected non-cancer causes of death</th>
<th>Percentage of persons dying of cancer who have this additional disease as a cause of their death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular including CHF and IHD</td>
<td>11.6%</td>
</tr>
<tr>
<td>COPD</td>
<td>7.9%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>6.0%</td>
</tr>
<tr>
<td>Renal</td>
<td>4.6%</td>
</tr>
<tr>
<td>Dementia</td>
<td>3.4%</td>
</tr>
</tbody>
</table>
Percentage of Nova Scotia Cancer decedents in provincial chronic disease registries

- cancer
- diabetes
- CV
Palliative Care is seeing an increase in the number of persons who do not have cancer.
Percentage of Cancer decedents seen by Palliative Care Program in Nova Scotia

Percentage of Deaths with Cancer as a Cause Enrolled in Palliative Care Program by Year

- CH
- CEH
- CB
Percentage of Nursing Home Residents with Cancer as a cause of death enrolled in Palliative Care Program by Year

- CH
- CEH
- CB
Time from Palliative Care enrollment to death for Cancer decedents, NS, 1996-2009

<table>
<thead>
<tr>
<th>Enrollment days before death</th>
<th>Capital Health</th>
<th>Colchester East Hants</th>
<th>Cape Breton</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤7 days</td>
<td>13.2%</td>
<td>15.0%</td>
<td>20.4%</td>
</tr>
<tr>
<td>≤14 days</td>
<td>21.7%</td>
<td>23.3%</td>
<td>28.8%</td>
</tr>
</tbody>
</table>
Percentage who died within 6 months of cancer diagnosis among adults diagnosed with colorectal cancer (CRC) from 2001-2005 who died* between 2001 and March 2008

33.3% (578) of 1733 CRC decedents

I, II, III  Stage at diagnosis  IV, Unknown

20.5%

≥9.5  Number of specialist visits*  <9.5

37.7%

<0.5  Number of days spent in hospital*  ≥0.5

65.1%

54.4%

75.8%

*excluding those dying within 30 days of surgery

φ in 2 years before diagnosis

Other possible predictors included in the analysis were age, sex, DHA, urban/rural, socioeconomic indicators plus the following measures of health service utilization in the 2 years before CRC diagnosis: co-morbidities, nursing home resident, number of family physician visits, physician continuity, emergency room visits, number of hospital admissions

Among those diagnosed with stage IV or unknown stage CRC with <9.5 specialist visits and ≥0.5 day in hospital in 2 years before CRC diagnosis, 75.8% died within 6 months of diagnosis
Percentage who died within 4 weeks of cancer diagnosis among adults diagnosed with colorectal cancer (CRC) from 2001-2005 who died* between 2001 and March 2008

10.8% (188) of 1733 CRC decedents

*excluding those dying within 30 days of surgery

Frailty includes dementia, Alzheimer’s disease, neurological decline, and stroke

Among those who had ≥7.5 specialist visits and ≥23.5 physician visits in a long term care facility in 2 years prior to diagnosis, 55% died within 4 weeks of CRC diagnosis

Among those who had <7.5 specialist visits, were frail, and <3.5 family physician visits in 2 years prior to diagnosis, 61.4% died within 4 weeks of CRC diagnosis
Principal Applicants:
Grace Johnston, PhD
Robin Urquhart, PhD Candidate
Co-applicants:
Frederick Burge, MD, FCFP
Judith Fisher, PhD
David Haardt, PhD
Janice Howes, PhD
Melanie Keats, PhD
Jennifer Payne, PhD
Geoffrey Porter, MD, FRCSC, FACS
Danny Rayson, MD, FRCPC, FACP
Tallal Younis, MBBCh, FRCP
Collaborator:
Marianne Arab, MSW/RSW
Palliative Support Program (PSP) for British Columbia

PSP End of Life Care Algorithm

Identify and Create Registry

- "Surprise Question"
- Choice or Need for Comfort Care
- Clinical Indicators
- Sentinel Events

Assess

- Seniors Assessment Tool
- Palliative Performance Scale (PPS)
- Edmonton System Assessment Scale
- Goals of Care
- Domains of Care

Manage Symptoms

- GPAC Part II – Pain and Symptom
- Fraser Health Symptom Guidelines
  - Attention to symptom distress can be early in the illness trajectory & should not be linked with prognosis.

Death and Bereavement

Plan and Collaborate

- Transition 1: Disease advancement
  - Recognition and registry
  - Advance Care Planning
  - Identify client’s values and beliefs
  - Clarify illness trajectory, possible complications, prognosis, expected outcomes to inform goal
  - Consider need for referral/coordination with H&CC
  - How to Break Bad News
  - H&CC Referral forms
  - My Voice – Including initial conversation
  - End of Life Care Plan templates

- Transition 2: Decompensation, experiencing life-limiting illness
  - Discuss care coordination
  - Consider hospice palliative care referrals
  - BC Palliative Care Benefits Form
  - Palliative Care Drug Formulary
  - No CPR Form
  - EI Compassionate Care Form
  - Medical Supplies and Equipment
  - H&CC/Palliative Care forms
  - Family Meeting

- Transition 3: Dependency & symptom increase
  - End of Life Care Planning, including assess for preferred location for care
  - EoL Care Checklist
  - Home Death Protocol
  - Notification of Expected Death at Home
  - What to consider when caring for someone dying at home
  - Caregiver Resources

- Transition 4: Decline & last days
  - Discuss meds required in home with HCN
  - Assess pt/family are comfortable with their EoL care plan and support required changes
  - “When Death is Close at Hand”
  - Online Resources

- Transition 5: Death & Bereavement
  - Have follow-up bereavement visit/call and send condolence card to family
  - Death Certificate
  - Bereavement
  - GPAC Part III - Grief & Bereavement
Purposes of this concurrent session

1. Follow from February 29, 2012 NELS workshop/report recommendation to explore adapting British Columbia’s Palliative Support Program (PSP) for Nova Scotia (NS)

2. Obtain input from cancer network stakeholders on
   i) relevance of adapting BC PSP for Nova Scotia,
   ii) aspects already in place in Nova Scotia,
   iii) aspects of care/measures that are missing,
   iv) barriers to implementation,
   v) supports needed to reduce barriers & ease implementation
Questions? Comments?

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