The Evolving Palliative Care System in Ontario;

*Its Everybody’s Business*

Norfolk Palliative Care Community Forum
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Dying “in the past”

- Normal and routine
- Built on community relationships
- Whole person care - ie. whole “citizen care, not just service-based
- End of life care is more than medical care
- Death and loss are inevitable and universal
“Any history of death in your family?”
The prevalence of human mortality is stable

We know who dies, when and where…
Canadian Reality

- By 2036, seniors will account for **23-25%** of the total population
- **32%** of Canadians suffer from a chronic illness
- **74%** of seniors have one or more chronic conditions
- **24%** of seniors have three or more chronic conditions
- Chronic diseases account for **70%** of all deaths
Current Canadian ‘stats’

- Only 16-30% of Canadians have access to formalized palliative/end-of-life care services

- At least 25% of the total cost of palliative care is borne by families

- Approximately 70% of deaths occur in hospital
  - 40% of terminally ill cancer patients visit the emergency department within the last 2 weeks of life
  - 41% of long term care home residents have at least one hospital admission in their last 6 months of life

CHPCA Fact Sheet – Hospice Palliative Care in Canada (2014)
What Do Canadians Want?

93% believe palliative care services should be available in the **SETTING OF THEIR CHOICE**

75% indicated a preference to **die in their home**

52% expect the bulk of their end-of-life care to occur in their home
Current Trends

Percentage of FP/GPs doing palliative care in 2007/2010

- 2007: 54.60%
- 2010: 45.70%

<table>
<thead>
<tr>
<th>Year</th>
<th>FP offering house calls</th>
<th>FP&lt;35 offering house calls</th>
<th>2nd year residents intending to offer house calls</th>
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</thead>
<tbody>
<tr>
<td>2007</td>
<td>48.3%</td>
<td>30.8%</td>
<td>43.6%</td>
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<tr>
<td>2010</td>
<td>42.4%</td>
<td>32.3%</td>
<td>34.1%</td>
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Percentage of FP/GPs doing palliative care in 2007/2010 by Age

- <35: 50.6% in 2007, 43.6% in 2010
- 35-44: 52.5% in 2007, 42.2% in 2010
- 45-54: 58.4% in 2007, 47.4% in 2010
- 55-64: 56.7% in 2007, 51.5% in 2010
- 65+: 44.3% in 2007, 35.7% in 2010

National Physician Survey 2007, 2010
CFPC.
“There is no national policy on palliative care in Canada. Instead there are national guidelines developed by community-based palliative care organizations operating at arm’s length from the government”

- GP Marchildon
Persisting Gaps in Palliative Care in Ontario

- Over 30 years after “palliative care” is introduced to Ontario, significant gaps still exist

- Just now setting up a provincial network with clear accountability to drive the delivery of quality coordinated palliative care

- Inadequate & inequitable access to integrated, high quality palliative care
- Inadequate support for caregivers
- Limited & inequitable service capacity across all care settings
- Lack of clear accountability for the delivery of palliative care
- Lack of system integration
Quality Hospice Palliative Care Coalition of Ontario (QHPCCO)
Towards an Integrated System of Palliative Care in Ontario: ‘Declaration of Partnership’

1. Broaden Access & Increase Timeliness of Access
2. Strengthen Caregiver Supports
3. Strengthen Service Capacity & Human Capital in all Care Settings
4. Improve Integration & Continuity Across Care Settings
5. Strengthen Accountability & Introduce Mechanisms for Shared Accountability
6. Build Public Awareness
Advice from 5 years of Provincial working groups

1. Taking action to prospectively find patients approaching end-of-life (the 1%) within communities.

2. Empowering and partnering with patients and families to better manage their palliative and end of life journey.

3. Enabling all patients approaching end of life to receive on-going, long-term care through flexible teams.

4. Normalizing aging and care at end of life through a model for capacity development.

5. Strengthening and Optimizing Residential Hospices within the continuum.

6. Provincial, regional and community governance, oversight and accountability.

7. Use technology as an accelerator for connected, integrated systems.
Chapter 3  
Section 3.08  
Palliative Care

Background

Description of Palliative Care

Palliative care focuses on the relief of pain and other symptoms for patients with advanced illnesses, and on maintaining the quality of their remaining life. It may also involve emotional and spiritual support as well as management and symptom control, and provides comfort-based care as opposed to curative treatment. Typical illnesses for which palliative care is provided include cancer, heart disease, respiratory disorders, HIV/AIDS, muscular dystrophy, multiple sclerosis, and kidney or liver failure. For patients who are terminally ill and within their last few weeks or months of life, palliative care is often referred to as end-of-life care.

The Palliative-care Continuum

Key stages in palliative care, as shown in Figure 1, are as follows:

1. Patient is diagnosed with a chronic or life-threatening illness. The patient might seek measures to fight the disease, such as undergoing curative treatments to stop or alter the disease progression. The patient might also receive some treatment to manage pain and symptoms, but this is not traditionally considered to be palliative care because the main focus of the care is curative.

2. Disease progresses. If the patient's response to curative treatment is not positive, or if the patient and family decide to no longer seek this treatment, the focus of care gradually shifts from curative therapies to palliative care.

Figure 1: Palliative-care Continuum

Adapted by the Office of the Auditor General of Canada from information from the Canadian Hospice Palliative Care Association.
Auditor Generals Top Recommendations

1. Promote the adoption of a common process that enables physicians to more easily identify patients who might benefit from palliative care e.g. “Surprise Question”

2. Process enabling timely access to pts’ advance care plans

3. Promote the provision of pall care by family physicians

4. MD education re palliative approach & EOL conversations

5. Public awareness campaign on accessing pall care services
An Integrated Supportive & Palliative Care Approach

Earlier Palliative Care improves quality of life, reduces psychological distress and better care decisions.
Who provides palliative care?

- A small number of patients with complex needs require transfer of care to specialist palliative care services
- May occasionally require assistance of specialist palliative team
  - consultation or shared care support
- Most patients require only primary-level Palliative Care (Palliative Care Approach)
  - Family medicine clinic
  - Oncology team
  - Internal med clinics
  - Cardiology clinics
  - COPD clinics
Why is Primary Care Important?

Primary Care has a unique position and potential to deliver effective palliative care.

- Reaching patients with all life-threatening diseases
- Identifying patients at the time of diagnosis
- Meeting all dimensions of need
- Providing care across settings, avoiding unnecessary hospitalizations
- Supporting families & providing bereavement care
- Continuity of doctor-patient relationship over time
What is Primary Level Palliative Care

Primary Care Clinicians (in clinics or in the community)
- Family Physicians
- NPs
- FHTs
- Community Nurses
- CCAC
- Emergency Care Physicians

Non-Specialist Clinicians (with or without support of specialist teams)
- Oncologists
- Internists
- Geriatricians
- Pediatricians
- Respirologists
- Cardiologists
- Neurologists
- Critical Care Physicians
- Emergency Care Physicians
- Surgeons
Challenges in Primary Level Palliative Care

• Lack of knowledge and skills among clinicians
• Lack of funding for reimbursing palliative care
• Issues hindering opiate prescribing
• Lack of professional/specialist support
• Poor identification of patients who would benefit from a palliative approach
• Limited public understanding of death, dying, loss and bereavement
• Stigmatization of palliative care
Palliative care as public health

- Developing the wider community context within which palliative care services make their contribution

- “Beyond mere services”

- Involves the well, and wellness (beyond illness)

- Palliative care is “everybody’s business”

Kellehear, A. (1999) Health Promoting Palliative Care, Melbourne, Oxford University Press
Public Health Functions

• To assemble and analyze community health needs for disease prevention, health promotion and protection
• To develop health policy through scientific knowledge
• To assure the community by providing health protection services
What is a Public Health Problem?

- Prevalence of condition or exposure
- Impact of condition on society
- Condition is preventable
- Effective interventions available
- Equity considerations
“Health Promoting Palliative Care” (HPPC) ….

• is public health guiding palliative care and end of life care

• Built on idea that healthcare is participatory

• Applies the WHO Ottawa Charter of Public Health to palliative care

• Not what we do to others but with others and is essentially social

• Recognizes the limits of service provision and global provision
….normalizes this aspect of living…..

• Every other area of health care has a public health agenda
• Health promotion is part of health - we need the well!
• When death, dying, loss and bereavement are normalized, so too shall Advanced Care Planning
• Engagement of the 95% of the time that people are not with their healthcare provider
....builds social capitol

- A community that interacts with itself frequently has a high level of trust, social support and morale
- And is interested in its own health and welfare
- Fostering interest in matters that affect their family, friends, co-workers, neighbours
- Means community capital, not just occupational
- Requires upfront leadership and facilitation
- Transition out from HPC and community continuation
The Compassionate Cities (CC) model

• Is an end of life care community application of WHO Healthy Cities model
• is a theory of practice for HPPC
• THE principle of healthy communities – health is everyone’s responsibility
• THE principle of compassionate communities – palliative and end of life care is everyone’s responsibility

• IN BOTH – communities and services create partnerships where both lead in areas where they have authority and responsibility
CC models have an ecological approach

• Changes the setting and the conditions
• Doesn’t add a new setting
• Is not a new building
• Not what we do to others, but with others and is essentially social
• Co–imagining, co-creating and co-accountabilities
International and national examples

- Hospice friendly hospitals (HfH)
- Frailty index - evidence based, longstanding
- Compassionate Watch i.e. neighbourhood Watch
- Death education elementary schools/hospice partnerships
- Spiritual companions
- Integration of formal and informal care networks
- LTC pubs/beer coasters
- Carers’ day
- Airport posters
- Death café- in ThunderBay- “Die-alogues”
Hospice Northwest Presents
Diealogues
Conversations on Life and Death

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Principles of Capacity Development

- Development is essentially about building on existing capacities within people, and their relationships.
- Development is an embedded process; it cannot be imposed or predicted.
- The focus is initially about change, not performance.
- Development takes time and has no end.
- Development process engages other people & social systems.
- Individuals, teams, organizations and communities are interconnected in new ways.

(Kaplan 1999; Lavergne & Saxby, 2001)
Community Capacity Development Model

Sequential phases of the capacity development model:

4. Growing the PC program

3. Creating the PC team

2. Community Catalyst

1. Antecedent community conditions

Kelley model
Barriers?

- Inability, reluctance or refusal to grasp these concepts; it’s more than a “nice description”
- “Death education” is not what we are currently doing
- Perception of threats to job or organization viability
- Seen as an “add-on” to current care
- Lack of critical mass of champions
- Did you ask the community?
Who bears the responsibility?

- “For public health strategies to be effective, they must be incorporated by governments into all levels of their health care systems and owned by the community.” (WHO PH Strategy)

- Community engagement and education required

- Leadership from Palliative Care AND Public Health Communities

- Imaginative Collaboration Needed
Accountability

- Measurement Capacity exists
- Benchmarking a standard quality exercise
- Target can be set, action taken
- Global Good Death Index
Emerging directions for improved palliative care are promising…

- Creation of an “Ontario Palliative Care Network”
- Overall direction, standards, systems approach
- LHIN based regional programs-implementation
- Fully transparent; connected with patients, stakeholders
- MOHLTC/government alignment.
- ? Is the community at the table?
Draft of Provincial Clinical Standards

System & Accountability
- PCS 1 Regional Programs

The Public
- PCS 2 Public Health Strategy

Clinicians
- PCS 3 Professional Development & Education
- PCS 4 Physician Workforce

Tools to Improve Direct Care
- PCS 5 eHealth & Technology
- PCS 6 Advance Care Planning & End-of-Life Treatment Plans
- PCS 7 Gold Standards Framework & Registries

Direct Care Teams & Settings
- PCS 8 Paediatric Palliative Care Strategy
- PCS 9 Aboriginal Palliative Care Strategy
- PCS 10 Building Capacity at the Primary Care Level
- PCS 11 Hospice Palliative Care Teams
- PCS 12 Residential Hospices & Palliative Care Units
At the regional level

1. A Regional Palliative Care Program- with direct, clear – ’the one table for planning” relationship with the LHIN

2. Empowerment from and by the current “stakeholders” for shared planning

3. clear and agreed upon clinical leadership

1. Agreement to collaborate in new ways Services, funding, Alignments, deliverables
What next?

• Making our “compassionate community” models explicit; legitimizing what already exists at grassroots

• Environmental scan, scoping, assessment and asset mapping

• Compassionate communities projects developed

• Social capital building using third sector organizations

• Greater normalization around DDLB; “back to the future”

• Culture shift driving policy change
Pallium Canada and Compassionate Communities

1. Getting clarity on all this!
2. Environmental scans
3. CC toolkits for schools, businesses, municipalities
4. Develop a critical mass of champions who can empower communities
5. The international *Compassionate Communities Charter*
6. Celebrating success and benchmarking achievement *Pallium.ca*
What does success look like…?

• A greater sense of ‘normalization’ around Death, dying, loss and bereavement

• Advanced care plans “done” well before they are needed

• Compassionate communities projects everywhere

• Culture shift drives policy change ie funding!

• “A healthcare provider is a poor excuse for a friend”