Hospice Palliative Care in BC: Today & Tomorrow

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Objectives

• Current context
• BC Centre for Palliative Care
• Opportunities for partnership
Current Context

• Aging population living longer with multiple chronic conditions & transitions in care: “Late life issues”

• Medicalized aging & dying can get in the way of living well & dying well (Gawande: Being Mortal)

• Access to specialized Palliative Care 30%; Not a core service with no standards of care; lack of integration
Canadian Context: Renewed calls for a national PC strategy

- Quality of Death index: Canada falling behind (11th):
  - Affordability of care: 22/80
  - Lack of a PC national strategy (18th)
  - Home deaths ~12% (US 29%)
  - High rates of hospital deaths

- UK first (2010 & 2015):
  - Comprehensive national policies,
  - Extensive integration of palliative care into the National Health Service
  - A strong hospice movement,
  - Deep community engagement
Medical Aid in Dying


• Both Physician administered & patient administered hastened death will be a mandated part of the end of life continuum

• Lots of negative media attention to palliative care: “Compassion & Choice” (Dying with Dignity Canada)
Bill C-14: Medical Aid in Dying

• Introduced April 14, 2016.
• Eligibility criteria: Capable adults with a grievous & irremediable medical condition
  – Serious, incurable illness, disease or disability
  – Advanced state of irreversible decline
  – Natural death is reasonably foreseeable
• Voluntary (written) request with informed consent that is witnessed
• Exclusions: Will be subject of further study
  • Requests by mature minors; Advance requests; Mental illness as the sole medical condition
**Physician Assisted Death: Globally**

- Euthanasia in Belgium: 4.7% of deaths
- Oregon: Dying with Dignity Act 1998:
  - 0.2% of all deaths (~150/30,000 deaths a year)

<table>
<thead>
<tr>
<th>Reason</th>
<th>2010</th>
<th>Cum</th>
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<tbody>
<tr>
<td>Losing autonomy</td>
<td>94%</td>
<td>91%</td>
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<tr>
<td>Less able to enjoy activities of life</td>
<td>94%</td>
<td>88%</td>
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<tr>
<td>Loss of dignity</td>
<td>78%</td>
<td>84%</td>
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<tr>
<td>Loss bodily function</td>
<td>46%</td>
<td>56%</td>
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<tr>
<td>Burden</td>
<td>26%</td>
<td>35%</td>
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<tr>
<td>Pain (Present or future concerns)</td>
<td>15%</td>
<td>21%</td>
</tr>
<tr>
<td>Financial</td>
<td>1%</td>
<td>3%</td>
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Death with Dignity Program: Cancer Centre Seattle Washington

- Over 2.5 years: 114 pts enquiries
  - 38.6% did not pursue the program
  - 26.3% initiated but did not continue or died naturally
- 35% received prescriptions
  - 60% of those died by ingestion of a lethal dose of secobarbital
  - 21% of total
Desire for Death in Canada

377 cancer patients; 8 palliative care programs
- 69.5% no desire for death
  - 20% met criteria for a psychological disorder
- 30.5% desire for death: 18.3% transient
- 12.2% apparently genuine desire to die
  - 52% met DSM-IV criteria for depression or anxiety; 47.8% no mental illness
  - Only 39% would opt for euthanasia

Wilson KG et al BMJ Supportive & Palliative Care 2014

Studied in the Netherlands & Oregon: 8-47% of patients who request hastened death have high level of depression (Levine J Med Ethics 2011; 37:205-11)
81 bed PC hospital: 2157 admissions during 2010–11

- 9% (195) had some expression of a Wish to die:
  - 6% (119) expressed an interest in dying but did not want any action taken
  - 3% (61) expressed an interest in Euthanasia;
  - In 6 (0.3%) this was persistent. All had poorly controlled symptoms.
  - 1% (15) described suicidal thoughts;

- Conclusion: Low incidence of requests for MAID

- Expression of a wish to die = good communication & trust between the patients & their care teams.
  - Need for additional discussion, address suffering
Beyond June 6....

• We will still need a robust system of palliative care services for the 96-98% of the public who do not choose Assisted death
• Access to palliative care will still be an issue
• “Dying with dignity” requires a real choice; Should not be the default option for poor care
• Charlie Angus: “Palliative care and emotional support are necessary and appropriate responses to those who suffer from terminal illness and are near death”
BC End of Life Action Plan (2013)

- Population & systems level approach to address identified population health needs at EOL
- Goal: “Redesign Health Services”
  - Right mix: Primary palliative care, Secondary (shared care & consultation); & Tertiary care (Specialized palliative care) in all settings
- Hospice Spaces commitment
- Established BC Centre for Palliative Care (BC CPC): To support partnership, innovation & improvements in care at end of life
- To promote uptake of a palliative approach to care
Current context in BC

- ~31,000 deaths a year.
- 55% of deaths in acute care; 12% at home or Hospice; 10% in Residential care
- 32% of health care spending in last year of life
- Utilization:
  - 58% Palliative Care benefits; Home care 55%
  - Specialized Palliative care ~20-30% (15% in 2008)
- Mandate to double Hospice spaces; Improve access to care in rural or remote areas


BC: History of leadership

- Palliative Care education (BCHPCA Learning Centre for Palliative Care)
- Research into Integration of Palliative Approach to Care (iPANEL)
- Advance Care Planning initiatives & development of Medical Orders for Scope of Treatment (MOST)
- Practice Supports for GPs in uptake of Palliative approach to care
- Integration of Hospice Societies
What is Needed to Create Effective Change: Energy!

“The source of energy at work is not in control, it is in connection to purpose”

Don Berwick, 28th February 2012
Change at the System Level

Energy for change is:

the capacity and drive of a team, organisation or system to act and make the difference necessary to achieve its goals
BC Centre for Palliative Care (2013)

Vision:
• Excellence in compassionate care & supports for those living with advanced illness.

Mission:
• To enable public participation in the development of quality patient & family centred outcomes for all British Columbians living with & dying from advanced, serious illness.
Emerging themes in large scale change

**Dominant approach**
- Power through hierarchy
- Mission and vision
- Making sense through rational argument
- Leadership-driven (top down) innovation
- Tried and tested, based on experience
- Transactions

**Emerging direction**
- Power through connection
- Shared purpose
- Making sense through emotional connection
- Viral (grass-roots driven) creativity
- “Open” approaches, sharing ideas & data, co-creating change
- Relationships

Source: @HelenBevan
Mission: To enable excellence in palliative care for all British Columbians

Strategic Priority #1: Improve access to person-centred palliative care for patients & families
- Objective 1.1: Develop tools & resources to support Advance Care Planning
- Objective 1.2: Support integration of Palliative Approach to Care

Strategic Priority #2: Enable excellence in palliative care practice and capacity
- Objective 2.1: Promote & enable innovations and evidence-based policy development
- Objective 2.2: Facilitate and support increase in hospice spaces across BC
- Objective 2.3: Quality education & practice support for health care professionals

Strategic Priority #3: Mobilize Citizen Engagement and promote Compassionate Communities
- Objective 3.1: Enable public engagement in development of quality palliative care outcomes
- Objective 3.2: Empower communities to provide care & support for patients & families

Vision: All British Columbians have equitable access to innovative, compassionate quality palliative care and resources.

What I Do Matters.
Strategic Areas of Focus

**Advance Care Planning Initiative**

More, better, earlier Advance Care Planning conversations throughout continuum of care

**Compassionate Communities Movement**

Provincial & local networks that enhance timely care & supports to people in their local communities.

**Education & Integration of Palliative Approach to Care**

A workforce that can provide a palliative approach to care across the continuum of care and in all care settings
Hospice Spaces

Expansion of Hospice Spaces throughout BC

Research & Innovations

Enable uptake of innovation and evidence-based interventions
Advance Care Planning Initiative

To co-create a system that aligns each person’s wishes for care with the care they receive, by facilitating more, better, earlier Advance Care Planning (ACP) across British Columbia

Project Manager: Laura Spencer
Current Status in BC

• 14% of the public have an Advance Care Plan
• 2010 study: Seriously ill in hospital: 89% had talked to family but only 30% to health care providers. Preferences aligned with documentation in only 36% (Heyland, Barwich et al JAMA 2013)
• At time of death: 70% unable to make decisions; With ACP: 92% choose less aggressive options (Silviera NEJM 2011)
• ACP is associated with ↑ Quality of life; ↑ Hospice use (US); better long term outcomes for relatives (less PTSD, depression)
• Detering BMJ 2010; Zhang 2009
Advance Care Planning in BC

Documentation: MOST Medical Orders for Scope of Treatment in all sectors of care

Goals of care conversations & Shared Decision Making integrated into routines of care

Advance Care Planning: Tools & resources to support the public

Health care Delivery system

General Society

BC Centre for Palliative Care

What I Do Matters.
Public Awareness & Education Working Group

To develop increased public awareness & tools & resources for the public to do their own ACP

- ACP Toolkits
- Educational modules
- Public workshops
- Tools and resources appropriate to needs: Healthy; Living with illness; Substitute decision makers
New ACP Tools: Online workbook
http://www.speak-upinbc.ca/

Make Your Plan Today
It's easy with our free online workbook.

Start Making My Plan >

The Five Steps of Advance Care Planning

(Don’t worry, you can save and return at any time!)
ii. Shared Decision Making/Goals of Care conversations

• Basis of decision making in health care settings is Informed Consent
• Informed, empowered patients -> shared decision making process with healthcare providers
• Goal to promote Goals of care conversations which translate values & beliefs into care plans
• Training for health care providers: *Serious Illness Conversation Guide*
• Resource kits to promote **Person-centred care**
Person centred care

- Focus on “best possible day”.
- Personal wishes
- Strengthening relationships
- Preferences for Location of care; location of death
- Life closure/ Dying well
iii. System Integration & Continuous Quality Improvement

To support ACP throughout the health care system and ensure delivery of person-centred care

• Policy and program development
• Accountability/Support for integration & continuity of care
• Evaluate and continually improve quality
Education & Support For Health Care Providers: Palliative care & the Palliative approach to care

Better Health for the Population

Better Health for Individuals

Lower Cost Through Improvement

Lead: Kathleen Yue RN, MN

What I Do Matters.
Community of Practice: PALL ED BC

Priorities

- Symptom Guidelines
- Integration of Palliative Approach
- Competency Framework
- Resource Repository
- LEAP education

Coordinating, collaborating, convening to create capacity
Key Objectives

**OBJECTIVES:** To develop a provincial palliative education strategy & practice supports for health care professionals

1. Stakeholder Consultation: January & July 2015
   - Establish structure & Priority setting
     * Vision for future state: Education Plan
     * Competencies for HCP
     * Symptom Guidelines

2. Establishment of working groups, action plans, timelines & evaluation plan

What I Do Matters.
Integrated Palliative Approach to Care

- Support to “live as well as you can for as long as you can”
- Introduced early- not just “end of life care”
- Ensures “Wrap around” services for those living with serious, advanced illnesses
- Includes primary care teams, as well as specialized providers & services
- Collaboration to integrate & adapt to differing diagnosis; for different care providers in varying care settings;
Palliative Care in Residential Care: Practice Support module (VCH)

Collaboration between Vancouver Division of Family Practice; GPSC PSP, Community Geriatrics, UBC Dept. of Family Practice & VCH Home Hospice (Dr T Sakaluk):

• Practice Support approach

22% increase in proportion of Do Not Hospitalize orders
Palliative Care in Residential Care: Practice Support module (VCH)

- 49% increase in confidence in staging frailty and dementia
- 81% increase in confidence in communicating prognosis to families
- 36% increase in frequency of discussing goals of care & advance care planning with residents and families at time of admission
- Physicians reported that “Work is more fun and satisfying" as a result (GP Participant)

With thanks to Dr T Sakaluk VHH & Umila Stead PSP
Evidence for Early Palliative Care

Improved quality of life; Satisfaction with care

Improved Survival: 3 m for lung Ca pts

Temel NEJM 2010
Improved Access and Flow

Early palliative care (≤ 3 days after admit)

• Lower ALOS (P = 0.019)

• Increase in:
  – Discharges home (P = 0.003)
  – Transfers to hospice (P = 0.010)
  – Transfers to subacute rehabilitation (P = 0.015)

Comparison of Early vs Late Palliative Care Consultation in End-of-Life Care for the Hospitalized Frail Elderly Patients

AJHPM, August 2015.

What I Do Matters.
Decreased ICU Utilization

ICU deaths

- Early PC referral (>90 days before death) = 0%
- Intermediate PC (>30 – 90 days prior) = 1%
- Late PC referral (≤ 30 days prior) = 3%
- No PC = 27%

The Relation Between the Timing of Palliative Care & the Frequency & Timing of Do-Not-Resuscitate Orders Among Cancer Deaths in a Tertiary Care Hospital, AJHPM August 2015.
Cost Avoidance: Pts in acute care

• Timing of palliative care consultation:
  – Intervention within 6 days reduced costs by $1,312 (P = 0.04)
  – Intervention within 2 days reduced costs by $2,280 (24%) (P < 0.001)

Prospctive Cohort Study of Hospital Palliative Care Teams for Inpatients with Advanced Cancer: Earlier Consultation is Associated with Larger Cost Saving Effect, JCO June 8, 2015.
3. The Compassionate Communities Initiative

Co-leads
Dr. Eman Hassan & Terry Webber
Compassionate Communities Initiative:
Co-leads: Eman Hassan & Terry Webber

OBJECTIVES: To inform, engage, & empower citizens and community groups to create self-sustaining, proactive, collaborative networks that empower each other to provide timely comforting care & supports to vulnerable people in their local communities.
Compassionate Communities Approach to:
Equitable access to quality palliative care for all

- Population-health approach
- Evidence based
- Education
- Awareness
- Community Development
- Catalyzing Conversations
- Partnerships
- Seed Grants

What I Do Matters.
Seed Grants

Start up funding, guidance, coaching & resources to support community organizations to implement projects/ideas that improve the end of life experiences in BC.

3 cycles: February & September 2016; May 2017
About the Seed Grants Program

Seed money:
~ $5000

Tools & Resources

Implement New Ideas
Expand Existing Successful Approach
Seed Grants- Cycle 1 Overview

A Partnership between BC CPC and BCHPCA

4 Funding Priorities

- Advance Care Planning
- Palliative Care Education
- Compassionate Communities
- Citizen Engagement
### Seed Grant
Cycle 1 Awards by Priority Area (21)

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<tr>
<th>Priority Area</th>
<th># of Awards</th>
<th>Awards Amount</th>
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<tr>
<td>ADVANCE CARE PLANNING</td>
<td>12</td>
<td>$39,348</td>
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<tr>
<td>COMPASSIONATE COMMUNITIES</td>
<td>5</td>
<td>$24,500</td>
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<tr>
<td>PC AWARENESS &amp; EDUCATION</td>
<td>3</td>
<td>$13,000</td>
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<tr>
<td>CITIZEN ENGAGEMENT</td>
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<td>$5,000</td>
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Compassionate Communities

• Seed Grants: Local grassroots initiatives
• Developing conversation with Public Health physicians
• Planning for national conference
• Research exploring peer to peer education
• Exploring....
  – Provincial partnership: Galvanize social impact & action: “Natural death movement”
  – Implementation of Community development approach in First Nations

BC Centre for Palliative Care

What I Do Matters.
Death denying, grief illiterate society (Dr. Pauline Abrahams)

“I'm right there in the room, and no one even acknowledges me.”
We can help...

- Information & communication that support informed decision making
- Help with care planning: What supports are available (e.g. Hospice)
- Access to person-centred care (not just disease management)
- Support & Non-abandonment
- Pain & symptom management
- Mobilize social supports
- Reduce fears; address myths
Support those who express a wish to hasten death

Systematic review: 7 studies; 155 patients
1. Physical/psychological/spiritual suffering
2. Loss of self
3. Fear of dying
4. Desire to live but “not like this”
5. Death as a way of ending suffering
6. Hastening death as control over one’s own life

• Often overwhelming emotional distress but did not always imply a wish to die.

Atul Gawande: Being Mortal

• What matters for most people in the end is connection, belonging, and having dedication to a cause outside oneself
• Living well with the 3 Ds: Disability; dependence and death takes courage & resilience.
• “Embracing alternative ways to live.
• To find connection & belonging; meaning, worth and purpose”
Ethics of caring vs. medicalized dying

Support a societal shift in paradigms:

• Healthy living in advanced illness
• Understanding of loss and grief
• Access to Palliative Care supports from time of diagnosis and for all who need it
• Support for caregivers
• Support dying role & tasks of dying
• Accept dying as a social phenomenon
• Mobilize Compassionate Communities
We can offer a choice ...

You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.

Dame Cicely Saunders, Founder of hospice movement
Questions??

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