

L'importance des soins palliatifs | Forger un consensus national

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**Measuring to Improve Quality** 

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#### **Disclosure**

- I have no conflict of interest to declare
- I am Division Chair of Palliative Medicine, Queen's University & Senior Scientific Lead for Person-centred Perspective for the Canadian Partnership Against Cancer

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Does measurement of indicators that address desired outcomes, including patient/family reported outcomes and experience, improve the quality of and access to palliative care?

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## **Overview**

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"If we could first know where we are, and whither we are tending, we could then better judge what to do, and how to do it."

Abraham Lincoln, 1858

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# Institute of Medicine's "Crossing the Quality Chasm"

## Aims of health care system:

to deliver care that is

- 1. Safe
- 2. Effective
- 3. Patient-centred
- 4. Timely
- 5. Efficient
- 6. Equitable

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# Donabedian's Framework To Assess Quality

#### **Three components:**

- 1. Structure: which resources are required?
  - Settings, qualifications, administrative systems
- 2. Process: how are the resources used?
  - Components of care delivered
- 3. Outcomes: what have we achieved?
  - Change in health status, quality of life as a result of care received

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#### **Outcome Measurement**

#### **Most important as:**

- 1. Directly affects the patient and family
- 2. Assesses the effectiveness of interventions
- 3. Encompasses the results of the whole cycle of care

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### **Outcome Measures in Palliative Care**

#### 1. Clinical:

- Monitor: symptom intensity, functional status, quality of life
- Facilitate: communication between team members, patients/families
- Evaluate: effectiveness of interventions

#### 2. Audit:

- Setting standards for desired outcomes
- Monitoring practices
- Evaluating performance

#### 3. Research:

Demonstrate results

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#### **Outcome Measures**

- 1. Patient reported outcome measures (PROM's)
  - Measured with questionnaires
  - Functional status, quality of life, symptoms, satisfaction
- 2. System level outcomes
  - Measured using administrative data
  - Place of death, length of stay in acute care hospital, ED visits in last 2 weeks of life

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## **Indicators**

- Used to measure quality of care & services delivered
- Well defined & measure specific aspects of desired outcomes, processes or structures of care
- Described with a numerator & denominator on an aggregated level such as percentage of patients
- Effective & quick tools for assessing individual, program, regional, national and international level system performance

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# Quality Indicators & Measures in Palliative Care

- A number of systematic reviews
- Kamal's 2015 review identified:
  - 284 quality measures
  - 13 measure sets: 35% physical, 23 % structure & process, 4% spiritual & 1% cultural aspects
- Numerous international groups: consensus on a set of quality indicators for PEOLC assessment

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# **Numerous International Groups**

- Identified indicators or performance measures relevant to hospice & palliative care
- Narrowed the list through a modified Delphi rating process with professional & patient groups
- Established consensus on a set of quality indicators for PEOLC assessment

Nakazawa, Woitha, Dy, National Quality Forum, Leemans, Eagar

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# **Findings**

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# What Patients & Families Value Most at End-of-Life

- Adequate: pain & symptom management, psychosocial care
- Communication of information, clear decision making
- Avoidance of: aggressive care, prolonged dying
- Treatment choices followed
- Creating a sense of completion, preparing for death
- Contributing to others, strengthening relationships
- Sense of control
- Affirmation of whole person
- Dying at home

Capelas, Steinhauser, Bainbridge

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# **Patient-reported Outcome Measures**

#### Strong to Very Strong evidence of:

- Positive effect on patient-clinician communication
- · Identification of unrecognized symptoms
- Increased monitoring of symptoms
- Larger number of actions taken on quality of life data
- Improved patient satisfaction and experience
- Higher symptoms' scores had higher rates of clinical action
- Less debilitating symptoms at next visit

Chen, Luckett, Howell, Etkind, Seow,

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## **Patient-reported Outcome Measures**

#### Moderate evidence of:

- Improved psychological & emotional factors
- No improvement in symptom burden and quality of life

**Etkind** 

Effectiveness of interventions focused on quality of life

Catania

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# Conformance with Supportive Care Quality Measures

- Assessed relationship between conformance to 18 palliative quality measures and patient's quality of life
- 4 organizations in North Carolina with patient-reported, provider-entered, quality measure-based needs assessment system for community based palliative care collaborative

Kamal et al., J of Oncology Practice 2013

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# **Conformance with Supportive Care Quality Measures**

N = 459 patients

#### Significant predictors of high Quality of Life were:

- Functional status
- Estimated life expectancy
- · Conformance with measure related to:
  - Emotional well-being assessment
  - Comprehensive screening of symptoms

Kamal et al., J of Oncology Practice 2013

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# **Impact of PROM's on Quality Improvement**

- Electronic PROM's foundational dataset
- Identified significant sexual distress in patients with GI & Breast Cancer & developed an intervention
- Pathfinders program to relieve psychological distress in women with metastatic breast cancer
  - Significant positive effect on distress & despair
- Developed a psychosocial care triage algorithm

Abernethy et al, Medical Care, 2010

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# Australia's Palliative Care Outcomes Collaborative

- National federally funded program
- Designed to improve palliative care through an audit & feedback quality cycle
- Helps services measure the quality of symptom control
- Services agree to use common patient outcome measures at the point of care

Currow, JCO 2008

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# Australia's Palliative Care Outcomes Collaborative

- National service level performance data of common outcome measures
- National benchmark standards for comparison
- Nationally employed staff that support services to implement quality improvement initiatives
- Collection of aggregate data that is analyzed & reported back to each service every 6 months

Currow, JCO 2008

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# Australia's Palliative Care Outcomes Collaborative

- Data analyzed from January 2009 December 2011
- 8 routinely reported measures including: physical, psychological & family/caregiver domains
- Statistically significant improvements in all domains of both patient & clinician-reported outcomes except for pain

**Currow, Support Care Cancer 2015** 

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## **Canadian Context**

- In 1995, Special Senate Committee on Euthanasia & Assisted Suicide reported scarce accurate data on:
  - Numbers of programs, institutions & patients
  - Comparative costs
  - Other aspects of palliative care

Senate of Canada: Of Life & Death 1995

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## Canadian Context 1996 & 2009 Projects

- Program level data to address structure & process questions
- Findings:
  - Variety of formats, software & coding structures
  - Variable completeness, accuracy & consistency
  - Few collected electronic data such as ESAS, PPS
  - None collected quality of life or patient/family satisfaction data

Funded by Health Canada & Canadian Partnership Against Cancer

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# Canadian Context Administrative Data

- Service utilization patterns within provinces
  (Allan, Gagnon, Tanuseputro)
- Association between home palliative care services & EOL care indicators and costs (Gagnon, Seow)
- Comparisons of health service quality indicators between 3 and 4 provinces (Seow, Barbera)

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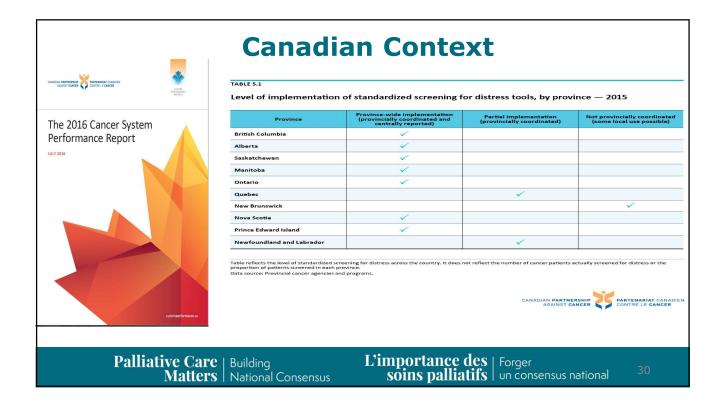
# Canadian Context Administrative Data

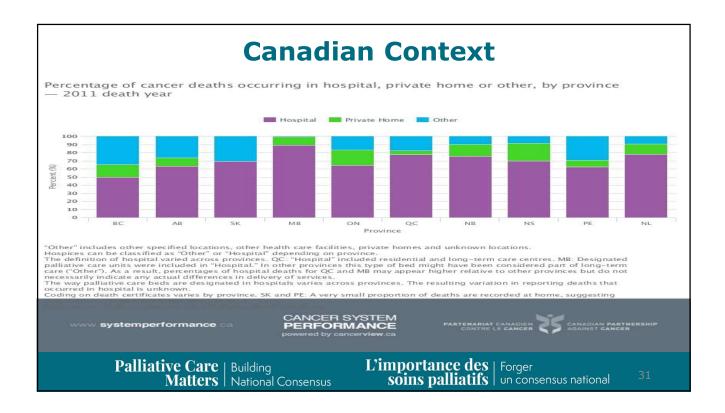
#### Canadian Institute for Health Information (CIHI) 2013 Report

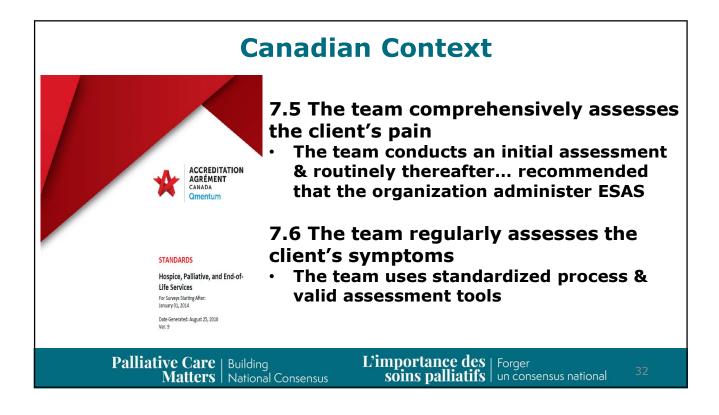
 Examined use of hospital services in the last month of life by cancer patients who died in acute care hospitals

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### **Canadian Context**

# **Ipsos poll**:

Majority of Canadians think that family members, caregivers and patients should be surveyed to evaluate treatment effectiveness

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## **Canadian Context**

- 1. Most provinces & territories are developing palliative care indicators to help monitor service delivery
- 2. Currently there is no coordinated effort to collect common data elements at a palliative care program level

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# **Implications**

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# **Implications**

- Canada has the building blocks to develop a robust system for measuring outcomes in palliative and endof-life care
- 2. The Canadian Partnership Against Cancer's initiative to increase standardized screening for distress for cancer patients could be expanded to include the non-cancer palliative patient
- 3. Australia's national initiative is an excellent model for Canada to explore

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