

Palliative Care | Building
Matters | National Consensus

L'importance des | Forger
soins palliatifs | 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?

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**

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**

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**

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**

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**

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**

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**

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

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

Findings

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, Lockett, 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**

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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



The 2016 Cancer System
Performance Report

JULY 2016



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TABLE 5.1

Level of implementation of standardized screening for distress tools, by province — 2015

Province	Province-wide implementation (provincially coordinated and centrally reported)	Partial implementation (provincially coordinated)	Not provincially coordinated (some local use possible)
British Columbia	✓		
Alberta	✓		
Saskatchewan	✓		
Manitoba	✓		
Ontario	✓		
Quebec		✓	
New Brunswick			✓
Nova Scotia	✓		
Prince Edward Island	✓		
Newfoundland and Labrador		✓	

Table reflects the level of standardized screening for distress across the country. It does not reflect the number of cancer patients actually screened for distress or the proportion of patients screened in each province.
Data source: Provincial cancer agencies and programs.



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Canadian Context

Percentage of cancer deaths occurring in hospital, private home or other, by province — 2011 death year



"Other" includes other specified locations, other health care facilities, private homes and unknown locations. Hospices can be classified as "Other" or "Hospital" depending on province. The definition of hospital varied across provinces. QC: "Hospital" included residential and long-term care centres. MB: Designated palliative care units were included in "Hospital." In other provinces this type of bed might have been considered part of long-term care ("Other"). As a result, percentages of hospital deaths for QC and MB may appear higher relative to other provinces but do not necessarily indicate any actual differences in delivery of services. The way palliative care beds are designated in hospitals varies across provinces. The resulting variation in reporting deaths that occurred in hospital is unknown. Coding on death certificates varies by province. SK and PE: A very small proportion of deaths are recorded at home, suggesting

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AGAINST CANCER

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Canadian Context



ACCREDITATION
AGRÈMENT
CANADA
Qmentum

STANDARDS

Hospice, Palliative, and End-of-
Life Services

For Surveys Starting After:
January 01, 2014

Date Generated: August 25, 2016
Ver: 9

7.5 The team comprehensively assesses the client's pain

- The team conducts an initial assessment & routinely thereafter... recommended that the organization administer ESAS

7.6 The team regularly assesses the client's symptoms

- The team uses standardized process & valid assessment tools

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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

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**

Implications

Implications

- 1. Canada has the building blocks to develop a robust system for measuring outcomes in palliative and end-of-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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Questions

