CIHR
Team in Community Care and Health Human Resources

# Different Approaches to Care for the Terminally Ill: Barriers and Facilitators to Service Provision

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## Presentation Overview

- Project Overview/Methodology
- What is Palliative Care?
- Preliminary Findings with regard to:
  - System-level characteristics;
  - HHR (health human resources); and
  - Health policy in the four target countries:
    -  Canada (Alberta and Ontario);
    -  England;
    -  Germany; and
    -  United States of America.
- Outlook/Next Steps

# Acknowledgements


- The Thesis Committee consists of:
  - Dr. Raisa Deber (Supervisor);
  - Dr. Doris Howell (RBC Chair in Oncology Nursing Research, UHN); and
  - Dr. David Zakus (IDRC).
- The research is part of Theme 3: *Cross-Jurisdictional, Integrative Policy Analysis*.


# What is Palliative Care?

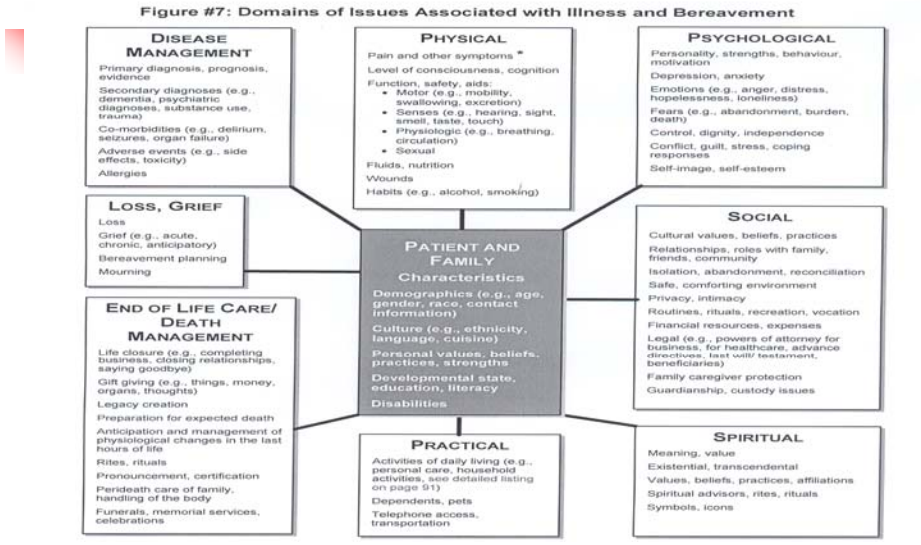
- WHO Palliative Care Definition (2002):

*"... an approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other symptoms,*

- *physical,*
- *psycho-social, and*
- *spiritual."*

World Health Organization

# Domains of Care




CHPCA, 2002

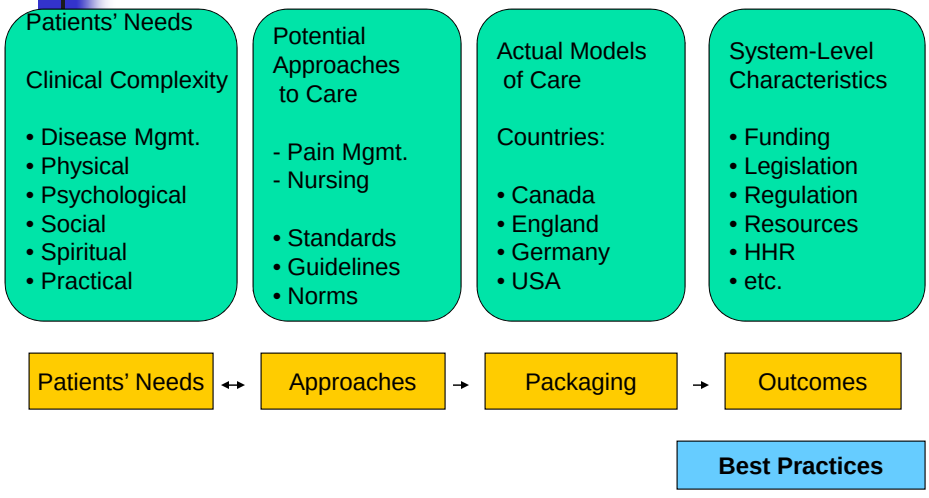
# Project Overview

- Many terminally ill patients still do not die at their preferred location, or under the form of care desired.
- Different approaches to care for the terminally ill have evolved around the world –
  - but these approaches differ on a number of dimensions.
- Many patients could benefit from hospice and palliative care service provision –
  - but infrastructure needs to be in place.

# Aims of the Project

- To establish core elements of different approaches to care for the terminally ill;
- To investigate different approaches to service delivery, country-level compliance with core elements and resulting care outcomes and costs;
- To identify system-level barriers and facilitators to service provision; and
- To establish best practices/lessons learned for decision making in the health policy realm.

# Analytical Framework



# Research Hypothesis

- Country-specific system-level characteristics/elements influence service delivery in the care for terminally ill adults in terms of approaches to care taken, resource utilization (care packaging) and implications for outcomes and costs.
  - System-level factors such as legislation, regulation and financing may impede the broader use of integrated models of care/the system-wide adoption of best practices.

# Methodology

- Case Study Methodology:
  - To analyze system-level characteristics, influences, and interrelationships between different elements.
  - Investigation of phenomena in their real-world context;
  - Usage of multiple sources of evidence (Yin, 2003):
    - Document analysis;
    - Key informant interviews/site visits;
    - Embedded economic evaluation (Ontario).
- Take most similar – most different perspective:

## Most Similar / Different Perspective

| Similar: | Different: |
|---|---|
| Patient needs | Actual models of service provision |
| Causes of death | System-level characteristics |
| Potential approaches to care | Care outcomes and costs |

## Research to Date

- Extensive literature review/document analysis toward models of care and service provision in the four target countries (→ Country Reports);
- 72 key informant interviews:
  - Canada: 23;
  - England: 15; → completed;
  - Germany: 18; → completed;
  - United States of America: 16.

[33% in person, 67% telephone; 5 site visits.]

# Interviews by Country and Area

| | Canada* | England | Germany | USA* | Total |
|---|---|---|---|---|---|
| Academia | 7 | 5 | 5 | 6 | **23** |
| National Organi-zations | 6 | 5 | 5 | 6 | **22** |
| Bureaucracy /Finance | 6 | 2 | 4 | 3 | **15** |
| Service Providers | 4 | 3 | 4 | 1 | **12** |
| **Total** | **23** | **15** | **18** | **16** | ***72*** |

* ongoing

# Questions/Preliminary Findings

- Is there a national end-of-life strategy?
- What is the population served?
- Are there regulatory impediments?
  - Funding;
  - Prescribing.
- HHR
  - Is Palliative Care a Medical Specialty?
  - Education/training.
- HHR resources available?

# Preliminary Findings Canada

- System-Level Characteristics:
  - No national End-of-Life Care Strategy;
  - Health care is a provincial responsibility;
  - First Ministers Agreement (2004):
    - Palliative home care and
    - Drug coverage.
  - Few programs with varying service offerings (Wilson 2004);
  - Charitable hospice programs mainly serving cancer and HIV/AIDS population;
  - Penetration rate: approximately 15% of palliative care population (CHPCA, 2008).

# Preliminary Findings Canada

- Health Policy:
  - No new dedicated End-of-Life Care $;
  - Accreditation/certification of providers pending;
  - Opioids are readily available; prescribing rights are with physicians.
- HHR:
  - Palliative care is a medical specialty;
  - Education/training programs (EFPPEC, Pallium Project);
  - General nursing (and family physician) shortage.

# Preliminary Findings England

- System-Level Characteristics:
  - New National End-of-Life Care Strategy
    - Raising the profile of EOL care;
    - (Early) Identification of patients and care planning;
    - Care coordination; strategic commissioning;
    - Education and training;
    - Measurement and research. Funding: £ 98 Mio (2009); £ 198 Mio (2010).
  - Home care (McMillan Nurses; Marie Curie Cancer Care) and (institutionalized) hospice system for mainly cancer patients.

# Preliminary Findings England

- Health Policy:
  - Introduced in 2008 with three components:
    - Preferred Priorities of Care;
    - Gold Standards Framework;
    - Liverpool Care Pathway.
  - Accreditation/Certification of Primary Care Trusts/Program providers.
- HHR:
  - Palliative care as medical specialty;
  - Education and training programs;
  - General nursing shortage.

## Preliminary Findings Germany

- System-Level Characteristics:
  - New National Specialized Palliative Care Strategy accompanying the long-term care insurance framework;
  - Charitable hospice programs enhancing home care service providers;
  - Hospital-based palliative care services developing as a cost-containment strategy;
  - Focus is on medical, nursing and supportive care but not necessarily under a holistic approach.

## Preliminary Findings Germany

- Health Policy:
  - Accreditation and certification of provider organizations and programs;
  - Accountability via remuneration agreements with sickness funds.
  - Primary palliative care?
- HHR:
  - Palliative care designation via some additional training;
  - Education/training for nurses and social workers under development;
  - Interdisciplinary team not a fixture;
  - Acute nursing shortage.

# Preliminary Findings USA

- System-Level Characteristics:
  - Palliative care as cost-containment strategy under fee-for-service model;
  - Hospice care as universal, holistic care approach under the Medicare Hospice Benefits;
  - Mainly home-based service through interprofessional team;
  - Penetration rate: 60% of palliative care patients (Connor, 2009);
  - Cancer patients only 38.3% of patient pool; heart disease 11.7%, dementia 11.1% (NHPCO, 2009);
  - Fastest growing Medicare program ($ 2.7 billion in 2000; $ 10 billion in 2007);
  - Medicare 88.7% of hospice remuneration; Medicaid 4.3% (ibid).

# Preliminary Findings USA

- Health Policy:
  - Medicare Hospice Benefits under potential threat from MedPAC and potential health care reform.
- HHR:
  - New medical sub-specialty;
  - Credentialing for nurses, social workers and clergy (as well as administrators);
  - Education and training industry (EFPC; CAPC);
  - No HHR shortages in the palliative care field.

## Conclusions with Regard to Theme 3: *Cross-Jurisdictional, Integrative Policy Analysis:*

- Most similar? Yes!
  - Similar problems looking for answers.
  - Overlap in the dimensions of care (also Bosma et al., 2009).
- Most Different? Yes!
- System factors may facilitate or impede change:
  - England - relatively easy to implement national strategy vs. Canada;
  - Contrast: NHS (public financing, public delivery) to public contracting (US Medicare, Canadian hospitals) to private financing (UK hospices).
- The Unexpected:
  - *"Death panels"* and *"pulling the plug on grandma"*.

## Conclusions with Regard to Theme 3: *Cross-Jurisdictional, Integrative Policy Analysis*

- Some established best practices that may have potential beyond jurisdictional borders but:
  - One shoe doesn't fit all.
- Shortage of international collaboration and knowledge exchange:
  - *"The [hospice and palliative care] programs have developed so that there is now the potential for accelerated learning through international contact"* (Bosanquet, 1998).

# Next Steps

- Analyze key informant interviews deductively for:
  - Barriers and facilitators to care;
  - Research agenda;
  - Policy suggestions and
  - Potential solutions to enhance the future of end-of-life care service provision.
- Highlight cutting edge service providers;
- Analyze embedded case study (Ontario);
- Establish best practices and lessons learned for health care decision making.

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