

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):

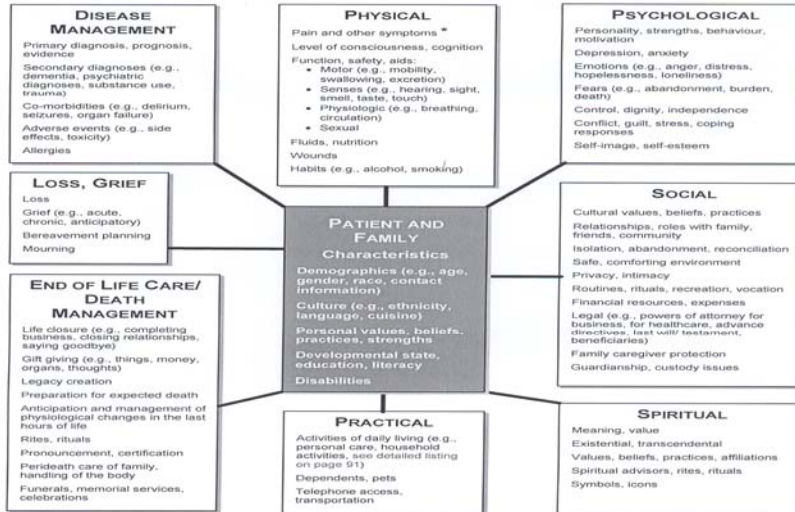
"... an approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other symptoms,

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



Domains of Care

Figure #7: Domains of Issues Associated with Illness and Bereavement



CHPCA, 2002

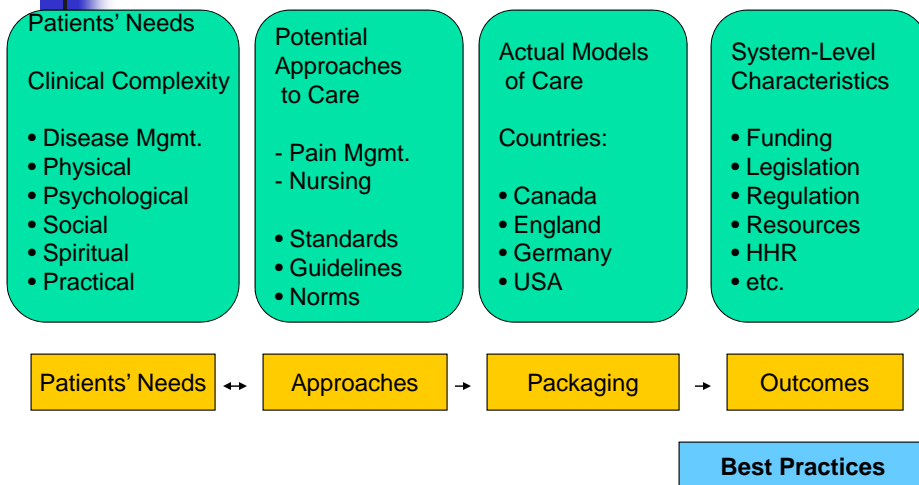
Project Overview

- 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 Organizations	6	5	5	6	22
Bureaucracy /Finance	6	2	4	3	15
Service Providers	4	3	4	1	12
Total	23	15	18	16	<u>72</u>

* 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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