Different Approaches to Care for the Terminally Ill: A System’s Level View Across Four Countries

Central Hospice Palliative Care Network
Networking Day
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Presentation Overview

- Project Overview
- Methodology
- 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
Aims of the Project

- To identify core elements/domains of issues of different approaches to care for the terminally ill;
- To investigate country-specific models of care, resource utilization and resulting care outcomes and costs;
- To establish system-level barriers and facilitators to service provision; and
- To establish best practices/lessons learned.
Acknowledgements
CIHR Grant # CTP 79849

- The Thesis Committee consists of:
  - Dr. Raisa Deber (University of Toronto; Supervisor);
  - Dr. Doris Howell (RBC Chair in Oncology Nursing Research, UHN); and
  - Dr. David Zakus (Canadian Public Health Association).

- The research is part of Theme 3: Cross-Jurisdictional, Integrative Policy Analysis.
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.
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

DISEASE MANAGEMENT
- Primary diagnosis, prognosis, evidence
- Secondary diagnoses (e.g., dementia, psychiatric diagnoses, substance use, trauma)
- Comorbidities (e.g., delirium, seizures, organ failure)
- Adverse events (e.g., side effects, toxicity)
- Allergies

PHYSICAL
- Pain and other symptoms
- Level of consciousness, cognition
- Function, safety, aids:
  - Motor (e.g., mobility, swallowing, excretion)
  - Senses (e.g., hearing, sight, smell, taste, touch)
  - Physiologic (e.g., breathing, circulation)
- Sexual
- Fluids, nutrition
- Wounds
- Habits (e.g., alcohol, smoking)

LOSS, GRIEF
- Loss
- Grief (e.g., acute, chronic, anticipatory)
- Bereavement planning
- Mourning

PSYCHOLOGICAL
- Personality, strengths, behaviour, motivation
- Depression, anxiety
- Emotions (e.g., anger, distress, hopelessness, loneliness)
- Fears (e.g., abandonment, burden, death)
- Control, dignity, independence
- Conflict, guilt, stress, coping responses
- Self-image, self-esteem

PATIENT AND FAMILY
- Characteristics
- Demographics (e.g., age, gender, race, contact information)
- Culture (e.g., ethnicity, language, cuisine)
- Personal values, beliefs, practices, strengths
- Developmental state, education, literacy
- Disabilities

SOCIAL
- Cultural values, beliefs, practices
- Relationships, roles with family, friends, community
- Isolation, abandonment, reconciliation
- Safe, comforting environment
- Privacy, intimacy
- Routines, rituals, recreation, vocation
- Financial resources, expenses
- Legal (e.g., powers of attorney for business, for healthcare, advance directives, last will/ testament, beneficiaries)
- Family caregiver protection
- Guardianship, custody issues

END OF LIFE CARE/ DEATH MANAGEMENT
- Life closure (e.g., completing business, closing relationships, saying goodbye)
- Gift giving (e.g., things, money, organs, thoughts)
- Legacy creation
- Preparation for expected death
- Anticipation and management of physiological changes in the last hours of life
- Rites, rituals
- Pronouncement, certification
- Peri/ death care of family, handling of the body
- Funerals, memorial services, celebrations

PRACTICAL
- Activities of daily living (e.g., personal care, household activities, see detailed listing on page 91)
- Dependents, pets
- Telephone access, transportation

SPIRITUAL
- Meaning, value
- Existential, transcendental
- Values, beliefs, practices, affiliations
- Spiritual advisors, rites, rituals
- Symbols, icons

Source: CHPCA, A Model to Guide Hospice Palliative Care (2002).
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/dimensions covered) 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.
Patients’ Needs

Clinical Complexity
- Disease Mgmt.
- Physical
- Psychological
- Social
- Spiritual
- Practical

Potential Elements of Care
- Pain Mgmt.
- Nursing
  - Standards
  - Guidelines
  - Norms

System-Level Characteristics/Models of Care
- Funding
- Legislation
- Regulation
- Resources
- HHR
- etc.

Packaging

Outcomes

Best Practices
Different Approaches to Service Provision

<table>
<thead>
<tr>
<th>Institutionalized Care</th>
<th>De-Institutionalized Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Palliative Care Team</td>
<td>Hospice Volunteer Service</td>
</tr>
<tr>
<td>Specialized Palliative Care Unit (Tertiary Care)</td>
<td>Specialized Home Care Nurse</td>
</tr>
<tr>
<td>Adult Day Care/Long-Term Care</td>
<td>Palliative-Enhanced Primary Care</td>
</tr>
<tr>
<td>In-Patient/Residential Hospice</td>
<td>Hospice at Home</td>
</tr>
</tbody>
</table>

Integrated Models of Care/Shared Care Approaches
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

<table>
<thead>
<tr>
<th>Similar</th>
<th>Different</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient needs</td>
<td>Actual models of service provision</td>
</tr>
<tr>
<td>Causes of death</td>
<td>System-level characteristics</td>
</tr>
<tr>
<td>Potential approaches to (end-of-life) care</td>
<td>Care outcomes and costs</td>
</tr>
</tbody>
</table>
### Similar Leading Causes of Death

<table>
<thead>
<tr>
<th>Canada</th>
<th>England</th>
<th>Germany</th>
<th>USA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer (27.7%)</td>
<td>Heart diseases (21.6%)</td>
<td>Heart diseases (28.4%)</td>
<td>Heart diseases (26.1%)</td>
</tr>
<tr>
<td>Heart diseases (26.6%)</td>
<td>Cancer (20.4%)</td>
<td>Cancer (25.4%)</td>
<td>Cancer (23.1%)</td>
</tr>
<tr>
<td>Cerebro-vascular diseases (7.4%)</td>
<td>Cerebro-vascular diseases (8.7%)</td>
<td>Cerebro-vascular diseases (7.1%)</td>
<td>Cerebro-vascular diseases (5.7%)</td>
</tr>
<tr>
<td>Chronic obstructive diseases (4.5%)</td>
<td>Chronic obstructive diseases (5.8%)</td>
<td>Chronic obstructive diseases (5.1%)</td>
<td>Chronic obstructive diseases (5.1%)</td>
</tr>
</tbody>
</table>

**Sources:** Statistics Canada, Office of National Statistics (UK), Statistisches Bundesamt, Centers for Disease Control.
## Different Hospice/Palliative Care Utilization

<table>
<thead>
<tr>
<th></th>
<th>Canada</th>
<th>England</th>
<th>Germany</th>
<th>USA</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of programs</strong></td>
<td>680</td>
<td>975</td>
<td></td>
<td>4,850</td>
</tr>
<tr>
<td><strong>Deaths under hospice care</strong></td>
<td>40,000* (20%)</td>
<td>85,000* (12%)</td>
<td>950,000 (38.5%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>*estimate</td>
<td>*estimate</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Patients with cancer diagnosis</strong></td>
<td>92.5% (UK data)</td>
<td>&gt; 90%</td>
<td>38.3%</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>* estimate</td>
<td></td>
</tr>
<tr>
<td><strong>Home death rate (place of residence)</strong></td>
<td>31.1% (UK data)</td>
<td>38.3% (UK data)</td>
<td>33.2%</td>
<td>68.8%</td>
</tr>
</tbody>
</table>

**Sources:** CHPCA, National Council for Palliative Care, Deutsche Gesellschaft fuer Palliativmedizin, NHPCO.

*Why the differences?*
Research to Date

- Extensive literature review/document analysis toward models of care, standards of practice and actual service provision in the four target countries (→ Country Reports);

- 77 key informant interviews:
  - Canada: 23 (31%);
  - England: 15 (19%);
  - Germany: 18 (23%);
  - United States of America: 21 (27%).

  [25 (32%) in person, 52 (68%) by telephone. Average duration: 41 minutes. 5 site visits].
## Interviews by Area

<table>
<thead>
<tr>
<th>Affiliation</th>
<th>Country</th>
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<tbody>
<tr>
<td><strong>Academia</strong></td>
<td>Canada (2 AB/5 ON)</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>England</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Germany</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>USA</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>23 (30%)</strong></td>
</tr>
<tr>
<td><strong>(National) Organizations</strong></td>
<td>Canada (2 NAT/1 AB/3 ON)</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>England</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Germany</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>USA</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>23 (30%)</strong></td>
</tr>
<tr>
<td><strong>Legislature/Health Insurance</strong></td>
<td>Canada (2 NAT/1 AB/2 ON)</td>
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<tr>
<td></td>
<td>England</td>
<td>2</td>
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<tr>
<td></td>
<td>Germany</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>USA</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>15 (19%)</strong></td>
</tr>
<tr>
<td><strong>Provider Organizations</strong></td>
<td>Canada (2 AB/3 ON)</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>England</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Germany</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>USA</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td><strong>Total</strong></td>
<td><strong>16 (21%)</strong></td>
</tr>
</tbody>
</table>
Qualitative Research

- **Thematic Content Analysis** ongoing:
  - Distillation of common themes from text in an objectivistic fashion (Rosemarie Anderson);
  - Software: NVivo 8.0 (QSR).

- **Part 1: Health Care System**
  - Perception of hospice and palliative care service provision in target country;
  - Integration of hospice and palliative care service provision into the health care system; and
  - Terminology (hospice, palliative care, supportive care, end-of-life care).
The Terminology Conundrum

Source: WHO, 1987

End-of-Life Care, Hospice Care, Palliative Care/Medicine, Supportive Care...

Canada: Hospice Palliative Care
Qualitative Research (Continued)

Ad Hoc Focus Group

Part 2: Barriers and Facilitators

Barriers:

- Communication about death and dying/Cultural perceptions;
- Education/Training in end-of-life care;
- Financial barriers to service provision/Role of philanthropy;
- Geography (rural versus urban);
- Health care system design;
- Hospice versus palliative care/medicine;
- Transparency → Regulation/Accreditation.
Facilitators:

- Communication/Media coverage/Public relations;
- Co-operation between hospices and hospitals/community organizations;
- Education/Training in end-of-life care;
- Hospice as a cost containment strategy;
- Population aging;
- Standards of practice/guidelines to care.
Qualitative Research (Continued)

- **Part 3:** Health Policy and Research Agenda
  - Health Policy Implications;
  - Health Services Research Priorities:
    - Alternative payment schemes;
    - Economic evaluation/Resource utilization;
    - Health care system design; and
    - Health human resources (HHR).
  - Clinical Research Priorities.

- **Part 4:** Future of the Movement
  - Enhanced service provision/moving upstream.
Preliminary Findings Toward:

- Is there a national end-of-life strategy?
- What population is served?
- Are there regulatory impediments?
  - Funding;
  - Prescribing.
- Health Human Resources
  - Is Palliative Care a Medical Specialty?
  - Education/training.
- What HHR resources are 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 care programs with varying service offerings (Wilson, 2004);
  - Programs mainly serving cancer and HIV/AIDS populations;
- Penetration rate: approximately 15-20% of palliative care population (CHPCA, 2008).

“I have seen one hospice palliative care program – you have seen one hospice palliative care program.”
Preliminary Findings
Canada

Health Policy:
- No (new) dedicated End-of-Life Care $s and Secretariat on End-of-Life Care at Health Canada sunset;
- Accreditation/certification of providers pending;
- Opioids are readily available; prescribing rights are with physicians. Per capita consumption of morphine: 71.1mg (Rank 3 worldwide).

HHR:
- Education/training programs (EFPPPEC, Pallium Project);
- Canadian Society of Palliative Care Physicians;
- General nursing (and family physician) shortage.
Comprehensive review on quality of death and dying around the world:

Utilizing a devised “Quality of Death Index” comprised of four categories:

- Basic end-of-life health care environment;
- Availability of end-of-life care;
- Cost of end-of-life care;
- Quality of end-of-life care; and

Key informant interviews.
Economist Intelligence Unit Report Key Findings:

- The UK leads the world in quality of death thanks to public awareness of hospice and palliative care, training availability, access to pain medication and doctor-patient transparency – and despite ranking only 28th in the basic end-of-life health care category;
- Combating perceptions of death and cultural taboos is crucial to improving palliative care – all approaches need to be cultural sensitive, though;
- Public debates about euthanasia (and physician-assisted suicide) raise awareness – but relate only to a small number of deaths;
- Drug availability is the most critical practical issue.
Recommendations

- Government Recognition
  - Integration of hospice and palliative care into the mainstream health care system;
  - Access to potent pain medications alongside clear narcotics laws;
  - Building capacity for home-based care – including training of professionals and volunteers;
  - Remuneration systems that reward outcomes/quality of care.

⇒ National End-of-Life Care Strategies
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;

- Home care (McMillan Nurses; Marie Curie Cancer Care) and (institutionalized) hospice system for (mainly) cancer patients.
Health Policy: End-of-Life Care Strategy
- Introduced in 2008 with three components:
  - Preferred Priorities of Care;
  - Gold Standards Framework;
  - Liverpool Care Pathway.
- Accreditation/Certification of Primary Care Trusts/program providers.
- Opioid consumption: 21.1 mg/capita (Rank 14).

HHR:
- Palliative care as medical specialty;
- Education and training programs;
- General nursing shortage;
- Over 100,000 people volunteer in UK hospices.
Gold Standards Framework (GSF)

- Covering primary care, care homes and other settings.

- Going for Gold Strategy (2012):

Source: http://www.goldstandardsframework.nhs.uk
Preliminary Findings

Germany

- System-Level Characteristics:
  - New National Specialized Palliative Care Strategy (SAPV) 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 service provision?
  - Opioid consumption: 22.9 mg/capita (Rank 12).

- HHR:
  - Palliative care designation for physicians 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.
  - Opioid consumption: 76.7 mg/capita (Rank 2).

- **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;
  - Over 400,000 people volunteer in US hospices.
Medicare Hospice Benefits

Access:
- Be eligible for Medicare Part A;
- Have two doctors (primary care doctor and the hospice medical director) certify a terminal illness;
- Patient must sign a consent form stating you wish to receive hospice care for your terminal illness in place of regular Medicare benefits; and
- Receive hospice care from a Medicare-approved hospice provider.

Covered Services:
- Physician care;
- Nursing care;
- Medical supplies (bandages, catheters, diapers, etc.);
- Medical equipment (oxygen, wheelchair, hospital bed, etc.);
- Medications for pain and symptom control;
- Home health aide services;
- Medical social services;
- Counseling (spiritual, emotional, dietary);
- Therapists (speech, physical, occupational);
- Short term stays in nursing facilities for respite care.
The Unexpected

- Sarah Palin:
  - “Death panels” and “pulling the plug on grandma”.
- Shortage of morphine sulfate at the 20mg/ml concentration after FDA ruling;
- Oxycontin discussion:

Are you addicted?
www.banoxycontin.com
Prescription Opioids (pain killers) = Heroin
The new law instructs Medicaid, the state-federal program for the poor, to cover *simultaneous hospice and curative care* for children with terminal illnesses immediately. And it directs the federal Medicare program, which covers seniors and disabled people, to launch up to **15 pilot projects** around the country to test the concept.

If the experiment is deemed successful and *doesn’t increase costs*, then Medicare could make the benefit available to everyone in hospice.

*Source:* Kaiser Health News, 10. May 2010
# Common Barriers/Facilitators

<table>
<thead>
<tr>
<th>Barriers:</th>
<th>Facilitators:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Legislation</strong></td>
<td><strong>Legislation</strong></td>
</tr>
<tr>
<td>- Lack of a national EoL Strategy</td>
<td>- National EoL Strategy</td>
</tr>
<tr>
<td><strong>Regulation</strong></td>
<td><strong>Media Coverage</strong></td>
</tr>
<tr>
<td>- Accreditation/Certification;</td>
<td>- 5\textsuperscript{th} Anniversary of Terri Shiavo case in the United States;</td>
</tr>
<tr>
<td>- Medical (Sub-)Specialty</td>
<td>- National Hospice Week/Hike for Hospice/World Hospice Day</td>
</tr>
<tr>
<td><strong>Funding/HHR</strong></td>
<td><strong>Advance Directives and Living Wills</strong></td>
</tr>
<tr>
<td>- Dedicated EoL $s</td>
<td></td>
</tr>
<tr>
<td><strong>Cultural Issues</strong></td>
<td><strong>Further Research</strong></td>
</tr>
<tr>
<td>- Death-denying society;</td>
<td></td>
</tr>
<tr>
<td>- Not a “sexy” topic.</td>
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</table>
The Future? (National Hospice Working Group, USA)
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); although not always holistic.

- Most Different? Yes!

- System-level factors may facilitate or impede change:
  - England - relatively easy to implement national strategy (NHS) vs. Canada (Canada Health Act);
  - Contrast: NHS (public financing, public delivery) to public contracting (US Medicare, Canadian hospitals) to private financing (UK hospices).
Conclusions with Regard to Theme 3: Cross-Jurisdictional, Integrative Policy Analysis

- Some established best practices that may have potential beyond jurisdictional borders but:
  - One size 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

- Continue analyzing key informant interviews deductively for:
  - Further 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/models of service provision;

- Further analyze embedded case study (Ontario) re. resource utilization, quality and costs;

- Establish best practices and lessons learned for health care decision making.
Further Resources

- Bennett, M., Davies, E., & Higginson, I. (Forthcoming). *Delivering Research in Palliative Care*.


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