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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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Central Hospice Palliative Care Network

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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.

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- 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*.

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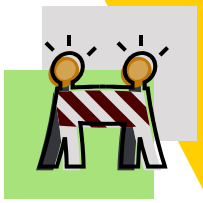
Project Overview

- Many terminally ill patie
  their preferred loca
  care desired.
- Differen
  te
  around the world –
  differ on a number of

ients could benefit from hospice and
ative care service provision –

- but infrastructure needs to be in place.

Barriers and Facilitators to Care ?



What is Palliative Care?

- WHO Palliative Care Definition (2002):

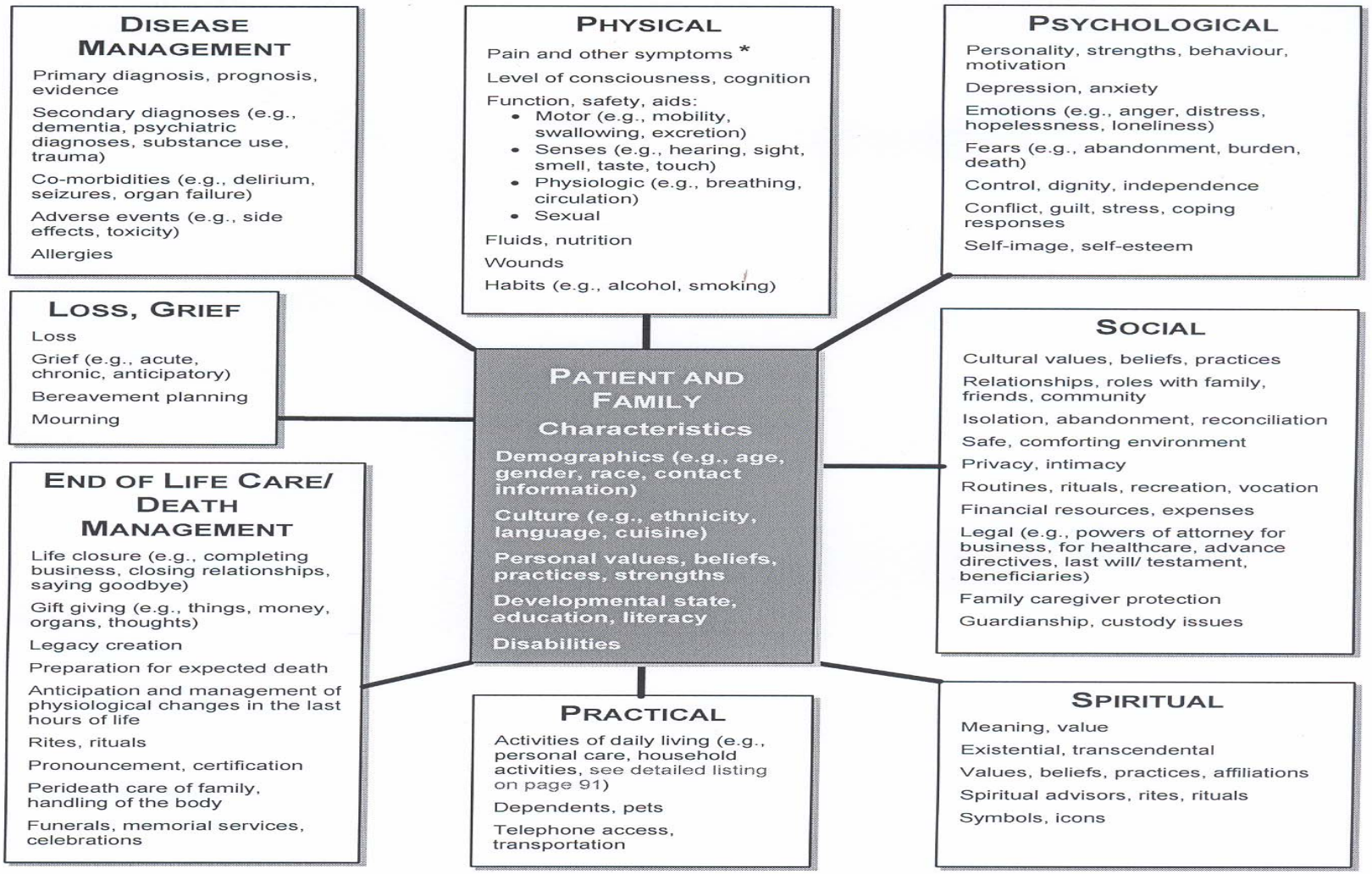
"... an approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other symptoms,

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

World Health Organization

Domains of Care

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



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.

Components

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

Patients' Needs ↔ Elements of Care

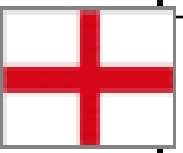
Outcomes

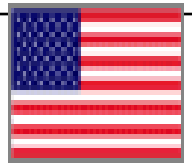
Best Practices

Different Approaches to Service Provision

Conventional/Standard Medical Care

Institutionalized Care	De-Institutionalized Care
Hospital Palliative Care Team	Hospice Volunteer Service
Specialized Palliative Care Unit (Tertiary Care)	Specialized Home Care Nurse
Adult Day Care/Long-Term Care	Palliative-Enhanced Primary Care
In-Patient/Residential Hospice	Hospice at Home





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

Similar	Different
Patient needs	Actual models of service provision
Causes of death	System-level characteristics
Potential approaches to (end-of-life) care	Care outcomes and costs

Similar Leading Causes of Death

Canada	England	Germany	USA
Cancer (27.7%)	Heart diseases (21.6%)	Heart diseases (28.4%)	Heart diseases (26.1%)
Heart diseases (26.6%)	Cancer (20.4%)	Cancer (25.4%)	Cancer (23.1%)
Cerebro-vascular diseases (7.4%)	Cerebro-vascular diseases (8.7%)	Cerebro-vascular diseases (7.1%)	Cerebro-vascular diseases (5.7%)
Chronic obstructive diseases (4.5%)	Chronic obstructive diseases (5.8%)	Chronic obstructive diseases (5.1%)	Chronic obstructive diseases (5.1%)

Sources: Statistics Canada, Office of National Statistics (UK), Statistisches Bundesamt, Centers for Disease Control.

Different Hospice / Palliative Care Utilization

	Canada	England	Germany	USA
Number of programs	680	975		4,850
Deaths under hospice care	40,000* (20%) * est		85,000* (12%) *estimate	950,000 (38.5%)
Patients with cancer diag		92.5% (UK data)	> 90% * estimate	38.3%
H rat ace of residence)	31.1%	38.3% (UK data)	33.2%	68.8%

Why the differences?

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

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].

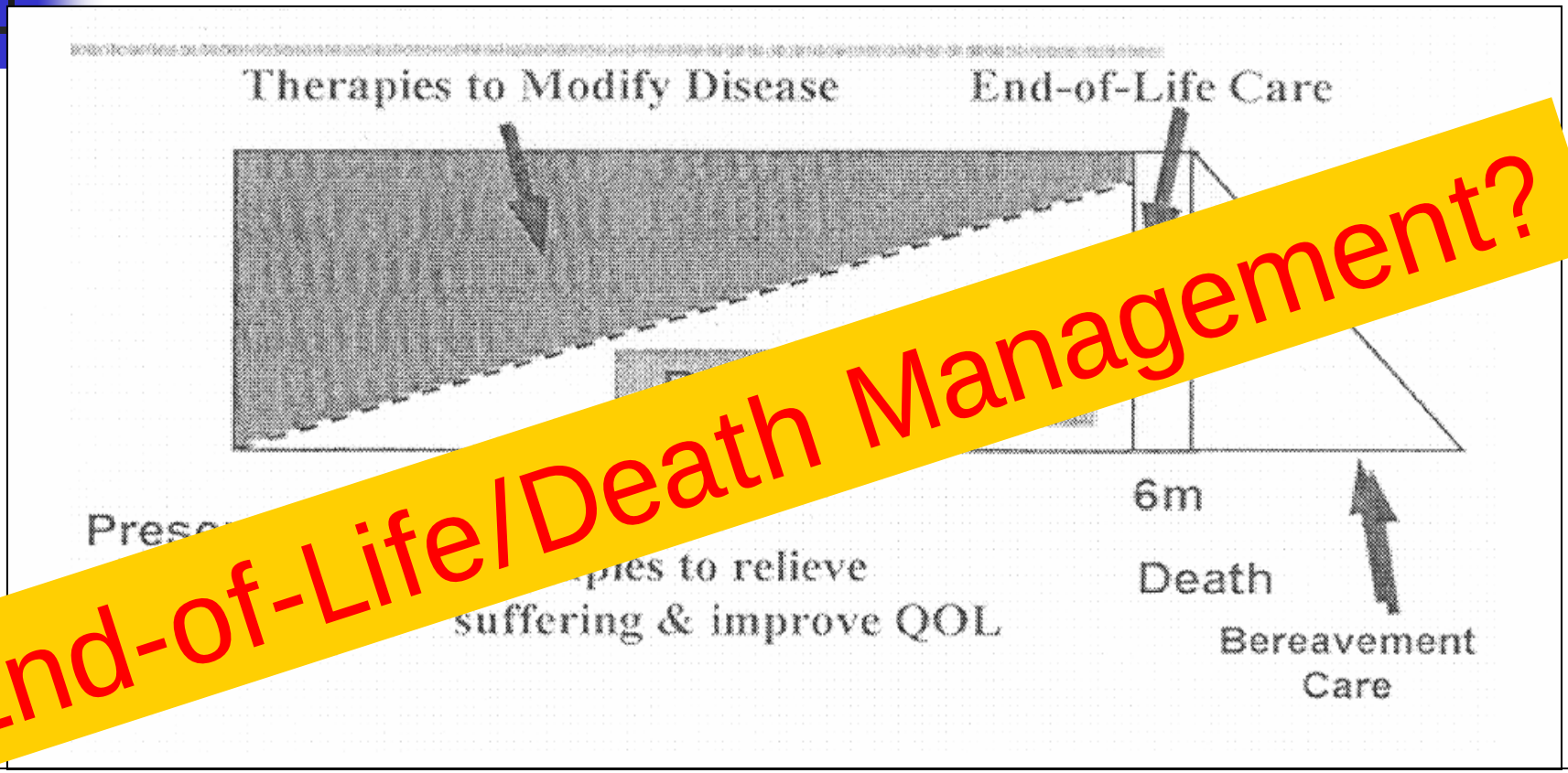
Interviews by Area

Affiliation	Country		Total
Academia	Canada (2 AB/5 ON)	7	23 (30%)
	England	5	
	Germany	5	
	USA	6	
(National) Organizations	Canada (2 NAT/1 AB/3 ON)	6	23 (30%)
	England	5	
	Germany	5	
	USA	7	
Legislature/Health Insurance	Canada (2 NAT/1 AB/2 ON)	5	15 (19%)
	England	2	
	Germany	4	
	USA	4	
Provider Organizations	Canada (2 AB/3 ON)	5	16 (21%)
	England	3	
	Germany	4	
	USA	4	

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



End-of-Life/Death Management?

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.

Qualitative Research (Continued)
Ad Hoc Focus Group

- **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 Strat
  - Health care is a provinci
  - First Ministers A
    - Palliati

"If you have seen one hospice palliative care program – you have seen one hospice palliative care program."

care programs with varying
gs (Wilson, 2004);
ams mainly serving cancer and HIV/AIDS populations;
  - Penetration rate: approximately 15-20% of palliative care population (CHPCA, 2008).

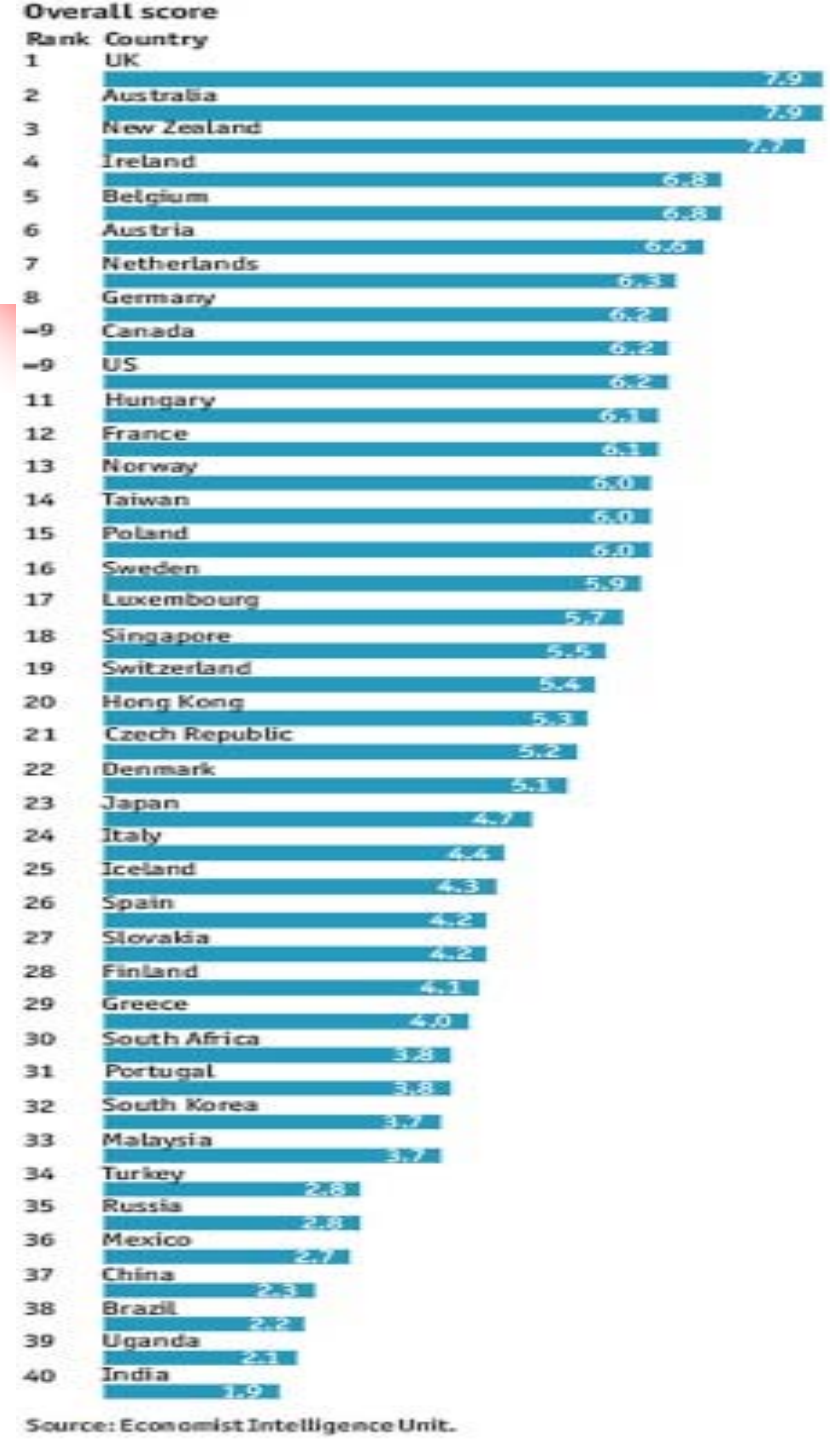
Preliminary Findings Canada

- 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 (EFPPEC, Pallium Project);
  - Canadian Society of Palliative Care Physicians;
  - General nursing (and family physician) shortage.

Economist Intelligence Unit Report

- 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, 2010



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.

Economist Intelligence Unit Report 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

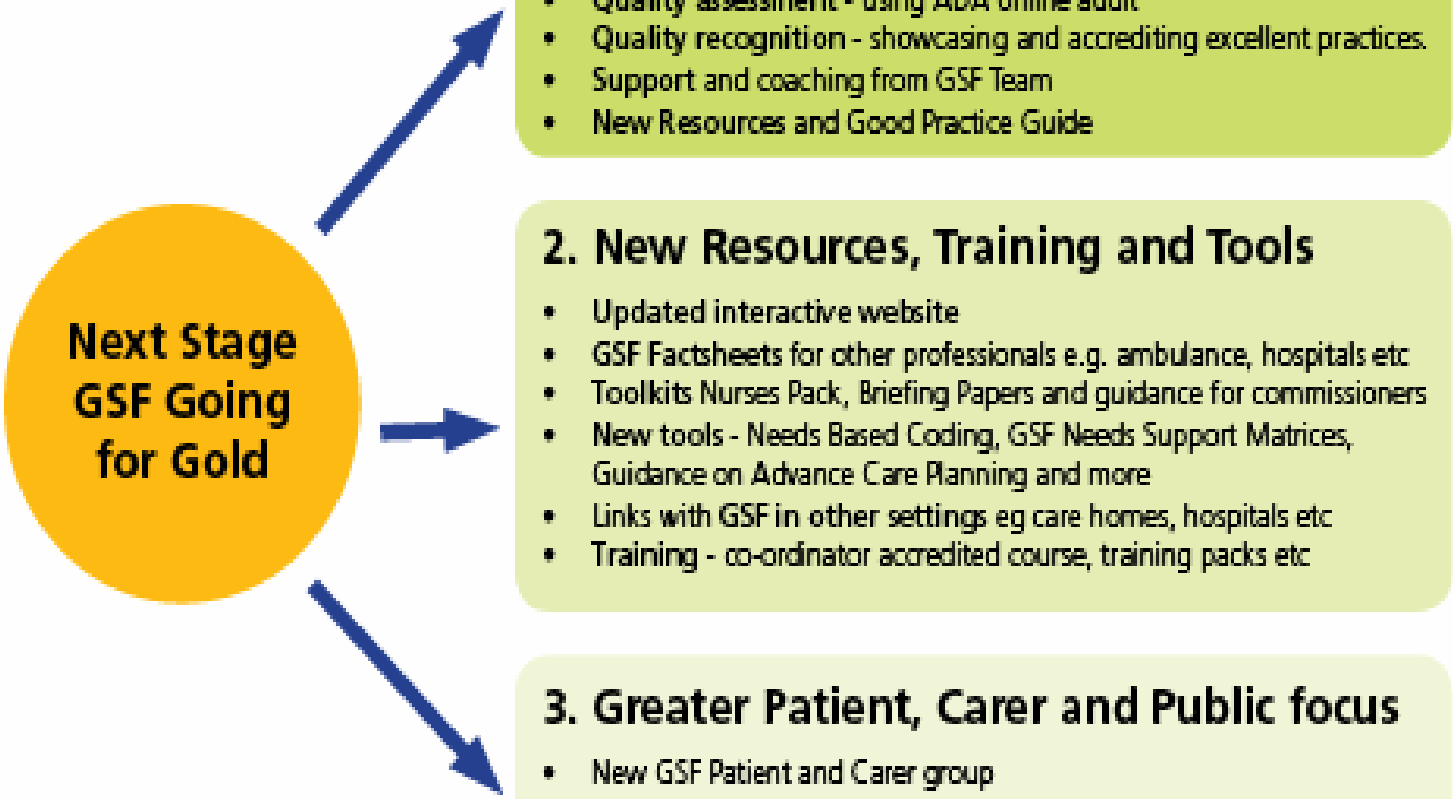
- System-Level Characteristics:
  - New National End-of-Life Care Strategy
    - Raising the profile of EOL care;
    - (Early) identification of patients and care planning;
    - Care coordination; strategic commissioning;
    - Education and training;
    - Measurement and research. Funding: £ 98 Mio (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: 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

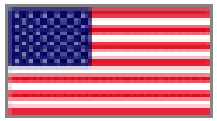
Preliminary Findings Germany

- 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

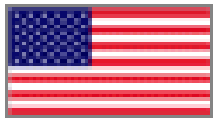
- Health Policy:
  - Accreditation and certification of provider organizations and programs;
  - Accountability via remuneration agreements with sickness funds.
  - Primary palliative care service provision?
  - Opioid consumption: 22.9 mg/capita (Rank 12).
- HHR:
  - Palliative care designation for 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.

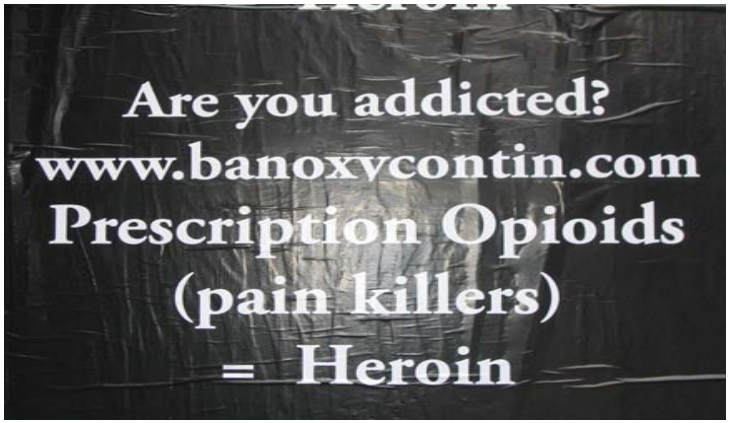
Covered Services:

- Physician care;
- Nursing care;
- Medical supplies (bandages, ca… …etc.) ;
- Medical equipment (oxy… …eelchair, hospital bed, etc.) ;
- Medications for p… …control;
- Home healt…
- Medi… …;
- …ritual, emotional, dietary);
- …ts (speech, physical, occupational);
- …hort term stays in nursing facilities for respite care.

Interdisciplinary Team

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:



The Unexpected (Continued)

KHN
KAISER HEALTH NEWS

- 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.

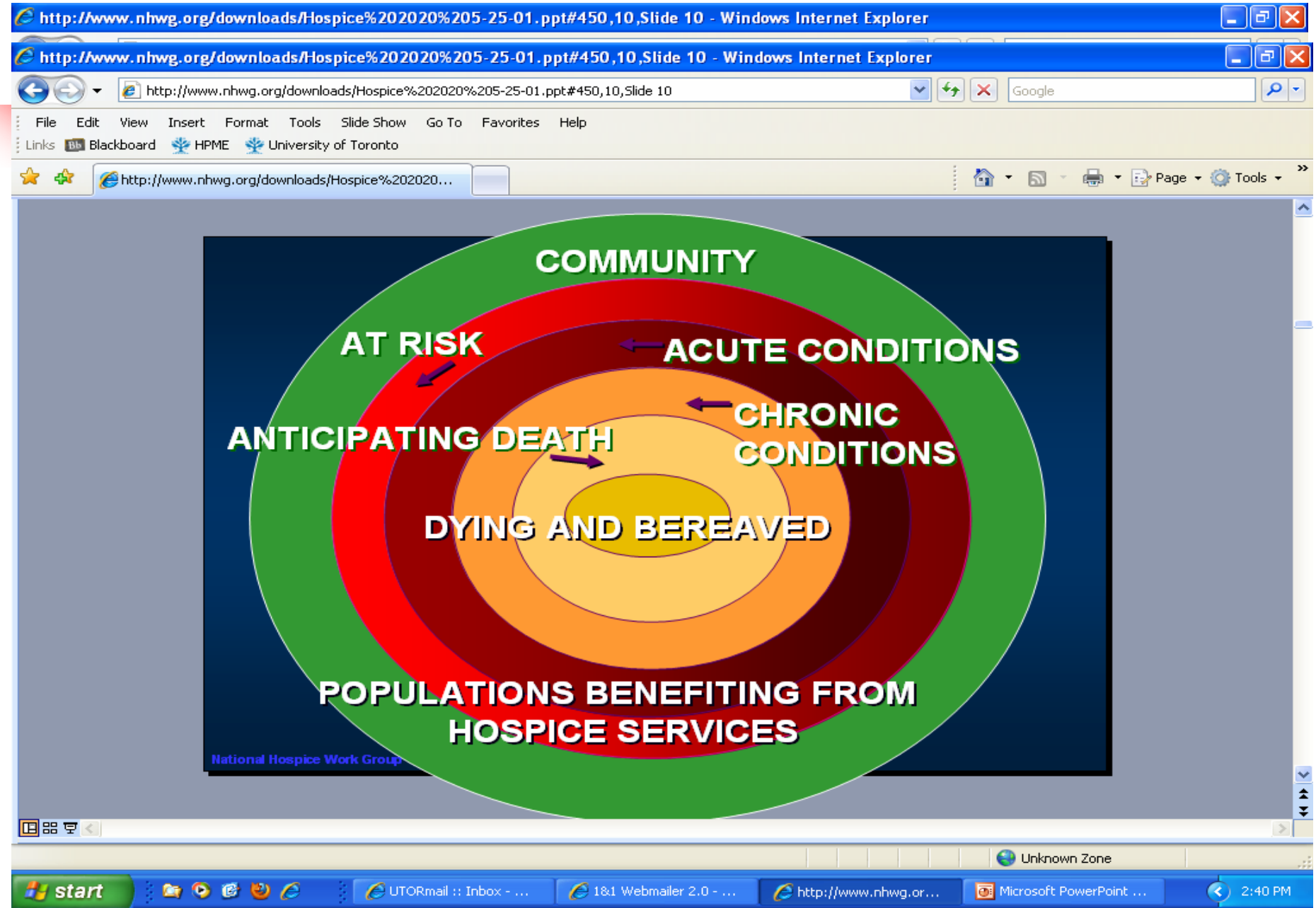
Source: Kaiser Health News, 10. May 2010

Common Barriers/Facilitators

Barriers:
Legislation - Lack of a national EoL Strategy
Regulation - Accreditation/Certification; - Medical (Sub-)Specialty
Funding/HHR - Dedicated EoL $s
Cultural Issues - Death-denying society; - Not a “sexy” topic.

Facilitators:
Legislation - National EoL Strategy
Media Coverage - 5th Anniversary of Terri Shiavo case in the United States; - National Hospice Week/Hike for Hospice/World Hospice Day
Advance Directives and Living Wills
Further Research

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*.
- Bosanquet, N., & Salisbury, C. (Eds.). (1999). *Providing A Palliative Care Service: Towards An Evidence Base.* Oxford, UK: Oxford University Press.
- Economist Intelligence Unit (EIU). (2010). *The Quality of Death: Ranking End-of-Life Care Across the World.* London, UK: Economist Intelligence Unit.
- Pain & Policy Studies Group, University of Wisconsin/WHO Collaborating Center. Website: http://www.painpolicy.wisconsin.edu.
- Wilson, D. (2004). *Integration of End-of-Life Care: A Health Canada Synthesis Research Project* (Full report). Ottawa, ON: Health Canada.

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