

# Different Approaches to Care for the Terminally Ill: A Four Country Comparison Study

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## Background

Despite national strategies or frameworks for care at the end of life, many terminally ill patients still do not die at their preferred location or under the form of care desired. This study examines system-level characteristics (such as legislation, regulation and finance) that influence service delivery, care outcomes and costs in four target countries: **Canada** (Provinces of Alberta and Ontario), **England**, **Germany** and the **United States of America**.

## Aims

To identify:

- Core domains of issues of different approaches to care for the terminally ill;
- System-level barriers and facilitators to service provision;
- Country-specific models of care, resource utilization and resulting care outcomes and costs; and
- Best practices/lessons learned.

## Method

**Case study approach** involving document analysis, key informant interviews with academics, bureaucrats, national hospice/palliative care organizations, health insurers/funding/regulatory bodies and service providers as well as site visits. Most similar – most different perspective regarding patient population and system-level characteristics. Blending of clinical expertise with concepts of policy analysis and health economics for (political) decision making/best practice identification. **Findings are mapped via country reports.**

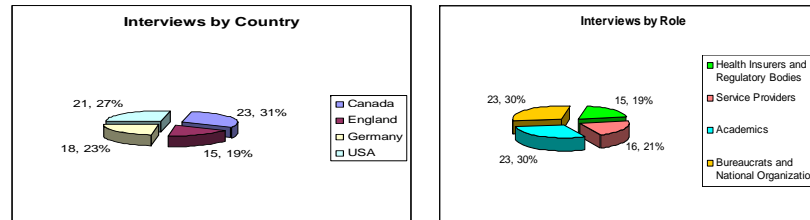


## Data Collection

Over a 1-year period (December 2008 to December 2009), a total of 77 semi-structured key informant interviews (N = 77) were conducted and transcribed alongside five site visits in the four target countries. 59 interviews (77%) were conducted in English, 18 were in German (23%). 25 interviews (32%) were face-to-face, 52 (68%) were by telephone – the average duration was 41 minutes. A breakdown by country and role is provided in figures 1 and 2.

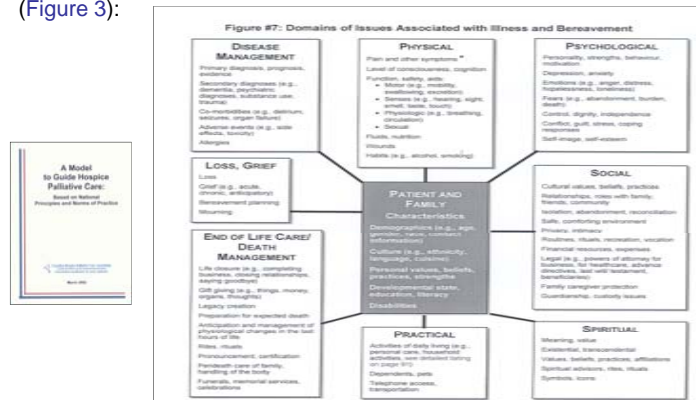
The study has been approved by The Office of Research Ethics (ORE) at the University of Toronto.

## Breakdown of Interviews (Figures 1 and 2)





## Domains


Barriers and facilitators to achieving best practices in the following 8 domains, recommended by the Canadian Hospice and Palliative Care Association's *A Model to Guide Hospice Care* (2002), were considered for the investigation (Figure 3):




## Country Overview

 The Canada Health Act and a First Minister's Agreement guide service provision – with health care being a provincial and territorial responsibility. There is **no national end-of-life care strategy** or dedicated funding – hospice and palliative care are no medical (sub-) specialty, but there is a Canadian Society of Palliative Care Physicians.

 The NHS Act and **National End-of-Life Care Strategy** guide service provision for terminally ill patients in England. Hospice and palliative care are a medical specialty and the National End-of-Life Care Strategy is bolstered with **special funding** (£ 88 million in 2009/2010, £ 198 million in 2010/2011).

 **Health insurance** in Germany covers end-of-life care – with a special provision (SAPV) in place for ambulatory palliative care. While not a medical specialty, training is available in palliative medicine.

 The US **Medicare Hospice Benefits** provide access to end-of-life care services up to six months prior to death. A large number of service providers are available – hospice and palliative care are a medical sub-specialty.

## Barriers

The **availability of financial and health human resources** for end-of-life care is identified as one critical barrier to **service provision** – alongside **education and training for service providers and the general public**. Regulatory issues concern **prescribing privileges and the composition of the interdisciplinary team** with regard to accreditation. Service provision is often limited in **rural areas**.

## Facilitators

**Advance directives and living wills** enable conversations about care at the end of life. **Media coverage** of end-of-life issues is generally viewed as beneficial as are **research efforts** in the field of hospice and palliative care.

## Surprises

The discussion on “**death panels**” and “**pulling the plug on grandma**” in the wake of statements made by Sarah Palin within the health care reform debate in the United States of America once again brought the topic of end-of-life care to the forefront. Coincidentally, March 2010 is also the fifth anniversary of the **Terri Schiavo case** (FL Sup Ct 05-497).

In Canada, there is a discussion again on potential abuse of pain killers such as Oxycontin (Figure 4):



## Conclusions



Country-specific system-level characteristics such as legislation, regulation and funding influence service provision.

While core elements of disease management and bereavement care are addressed by various models, the extent varies between countries and disease trajectories such as cancer.

Further international collaboration regarding barriers and facilitators to care is needed to enhance service provision and to accelerate learning/the adoption of best practices and lessons learned across jurisdictional boundaries.

**But: One shoe does not fit all.**

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