How Do Canadians Die?

Rob Fowler

Department of Critical Care Medicine, Sunnybrook Hospital
Associate Professor, University of Toronto
Financial Relationships

Canadian Institutes of Health Research
Heart and Stroke Foundation Canada
Technology Evaluation in the Elderly Network Centers of Excellence
Physicians Services Incorporated (Ontario)
The Commonwealth Fund
The University of Toronto
Based upon data from the largest ongoing prospective cohort study in history, there is a very high likelihood (RR = ∞, p<0.0001) that I will die.
How do You Approach End-of-Life Care?

- 40’s year old man, father of young children
- Intelligent, professionally successful
- Metastatic thymus cancer
- Exhausted all oncology treatments and protocols
- Presents to ER with respiratory failure
- Etiology likely due to progressive cancer, pleural effusions, parenchymal disease, phrenic nerve encasement, severe cachexia
The Silver Tsunami

By 2031, seniors will comprise 25% of the population (4 ➔ 10 M)

By 2025, those seniors dying will double 260,000 ➔ 500,000

70% of hospitalized elderly report fair to poor baseline quality of life and want comfort measures as opposed to life-prolonging treatments at end of life

Most seniors are admitted to hospitals, and receive technology-laden end-of-life care

We often fail to deliver consistent & optimal end-of-life care
What kills people in Canada?
What do we know of the “Usual” Canadian End-of-Life Experience?
End-of-Life Trajectories

End-of-Life Trajectories

- Sudden Death: <5%
- Terminal Illness: 31%
- Organ Failure: 39%
- Frailty: 28%

Outcomes of CPR – What We Know

• Among all in-patients, hospital survival after CPR is **15%**

• Patients *without* a shockable rhythm (ventricular fibrillation/ventricular tachycardia), survival is **10%**

• >85 years or with advanced cancer hospital survival is **6%**

• In ICU receiving vasopressors, hospital survival is **3%**
  – an ‘overestimate’ as the sickest patients are selected out

CMAJ. 2002; 167:343-348

Am J Respir Crit Care Med. 2010;182(4):501-6
JAMA. 2008;299(7):785-792.
Cardiac Arrest

Report of Application of External Cardiac Massage on 118 Patients

James R. Jude, M.D., William B. Kouwenhoven, Dr. Ing., and G. Guy Knickerbocker, M.S.E., Baltimore

KOUWENHOVEN WB, JUDE JR, KNICKERBOCKER GG. JAMA. 1960 Jul 9;173:1064-7

TERMINATION OF VENTRICULAR FIBRILLATION IN MAN BY EXTERNALLY APPLIED ELECTRIC COUNTERSHOCK*

Paul M. Zoll, M.D., Arthur J. Linenthal, M.D., William Gibson, M.D.,
Milton H. Paul, M.D., and Leona R. Norman, M.D.

# Outcomes of CPR – What the Public Sees

<table>
<thead>
<tr>
<th>SERIES</th>
<th>NO. OF EPISODES</th>
<th>NO. OF OCCURRENCES OF CPR</th>
<th>SHORT-TERM SURVIVAL AFTER CPR</th>
<th>SURVIVAL TO DISCHARGE AFTER CPR</th>
<th>SHORT-TERM SURVIVAL, DEATH IN HOSPITAL</th>
<th>SHORT-TERM SURVIVAL WITHOUT FOLLOW-UP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chicago Hope</td>
<td>22</td>
<td>11</td>
<td>7 (64)</td>
<td>4 (36)</td>
<td>3 (27)</td>
<td>0</td>
</tr>
<tr>
<td>ER</td>
<td>25</td>
<td>31</td>
<td>21 (68)</td>
<td>NA*</td>
<td>3 (10)</td>
<td>18 (58)</td>
</tr>
<tr>
<td>Rescue 911</td>
<td>50</td>
<td>18</td>
<td>18 (100)</td>
<td>18 (100)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>97</td>
<td>60</td>
<td>46 (77)</td>
<td>22 (37)</td>
<td>6 (10)</td>
<td>18 (30)</td>
</tr>
</tbody>
</table>

*number of patients (percent)*

Where do Canadians Die?
Location of Death in Western Canada

- **Overall**:
  - Hospital—Acute: 43%
  - Home: 15%
  - Other Locations: 15%
  - Long-Term Care: 14%
  - Hospital—Palliative: 2%

- **B.C.**:
  - Hospital—Acute: 38%
  - Home: 15%
  - Other Locations: 15%
  - Long-Term Care: 14%
  - Hospital—Palliative: 2%

- **Alta.**:
  - Hospital—Acute: 50%
  - Home: 15%
  - Other Locations: 15%
  - Long-Term Care: 14%
  - Hospital—Palliative: 2%

- **Sask.**:
  - Hospital—Acute: 38%
  - Home: 15%
  - Other Locations: 15%
  - Long-Term Care: 14%
  - Hospital—Palliative: 2%

- **Man.**:
  - Hospital—Acute: 55%
  - Home: 15%
  - Other Locations: 15%
  - Long-Term Care: 14%
  - Hospital—Palliative: 2%

Source: CIHI 2008
End-of-Life Care:
How do we Perform in Ontario?
End-of-Life Care in Ontario

- **Population**: All decedents in Ontario

- **Timeline**: April 1 2004 to March 31 2011, 2-year “look-back”

- **Horizon**: care during the last 2 years, 1 year, **6 months**, 1 month and the terminal hospitalization among residents

- **Data Sources**: Administrative health records
  - CIHI discharge abstract database (DAD)
  - NACRS (National ambulatory care records)
  - Registered Persons Database (RPD)
  - Ontario Drug Benefits (ODB)
  - Ontario Health Insurance Plan (OHIP)
And, How do we Compare to the USA?

Dartmouth Atlas of Health Care

*Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness*


- 67-99 years of age at time of death (Medicare beneficiaries)

- 9 Iezzoni Chronic Conditions *
  - Malignancy, COPD, Coronary Artery Disease, CHF, PVD, Severe Chronic Liver Disease, Diabetes with end organ damage, Renal Failure, Dementia

*2007-2008 Ed. March 9, 2011*
## And, How do we Compare to the USA?

### CANADA (Ontario)

- **Population (38% of Canada)**
  - 12,400,000 (‘03) ➞ 13,373,000 (‘11)

- **Hospitals**
  - 177 Hospitals
  - 18,355-30K hospital beds (2.5/1000)
  - 1631 ICU beds (~10/100,000)

- **Entire Decedent Cohort**
  - 591,585 Decedents in 2003-2011
    - (8 year, 65-99 year old) Cohort

- **Chronic Illness Cohort**
  - 261,366 Decedents age 67-99 years in 2003-2011

### USA

- **Population**
  - 290,800,109 (‘03) ➞ 311,591,917 (‘11)

- **Hospitals**
  - 4272 Hospitals
  - 941,995 total hospital beds (3/1000)
  - 61,076 ICU beds (~20/100,000)

- **Entire Decedent Cohort**
  - 8,863,182 Decedents in 2003-2007
    - (5 year, 65-99 year old) Cohort

- **Chronic Illness Cohort**
End-of-Life Care in Ontario

Proportion of Deaths Occuring In Hospital

%  

<table>
<thead>
<tr>
<th>Year</th>
<th>US</th>
<th>Canada</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003</td>
<td>32.2</td>
<td>56.9</td>
</tr>
<tr>
<td>2004</td>
<td>30.9</td>
<td>58.5</td>
</tr>
<tr>
<td>2005</td>
<td>29.9</td>
<td>57.1</td>
</tr>
<tr>
<td>2006</td>
<td>29</td>
<td>56.4</td>
</tr>
<tr>
<td>2007</td>
<td>28.1</td>
<td>56.3</td>
</tr>
<tr>
<td>2008</td>
<td></td>
<td>55.9</td>
</tr>
<tr>
<td>2009</td>
<td></td>
<td>54.6</td>
</tr>
<tr>
<td>2010</td>
<td></td>
<td>54.4</td>
</tr>
<tr>
<td>2011</td>
<td></td>
<td>53.3</td>
</tr>
</tbody>
</table>

ICES Institute for Clinical Evaluative Sciences
Enhancing the effectiveness of health care for Ontarians through research
End-of-Life Care in Ontario

Hospital Days During Last 6 Months of Life

Days

<table>
<thead>
<tr>
<th>Year</th>
<th>US</th>
<th>Canada</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003</td>
<td>18.4</td>
<td>11.3</td>
</tr>
<tr>
<td>2004</td>
<td>19.2</td>
<td>11.3</td>
</tr>
<tr>
<td>2005</td>
<td>18.1</td>
<td>11.1</td>
</tr>
<tr>
<td>2006</td>
<td>17.9</td>
<td>11.1</td>
</tr>
<tr>
<td>2007</td>
<td>18.5</td>
<td>10.9</td>
</tr>
<tr>
<td>2008</td>
<td>18.3</td>
<td>11.1</td>
</tr>
<tr>
<td>2009</td>
<td>18.1</td>
<td>10.9</td>
</tr>
<tr>
<td>2010</td>
<td>17.5</td>
<td>11.1</td>
</tr>
<tr>
<td>2011</td>
<td>17.5</td>
<td>11.1</td>
</tr>
</tbody>
</table>
End-of-Life Care in Ontario

Patients Seeing 10 or More Physicians During Last 6 Months of Life

% of patients seeing 10 or more physicians during last 6 months of life:
- **US**: 30.8, 32.7, 34, 35.5, 36.1
- **Canada**: 70.5, 68.6, 67.3, 69.7, 75.4, 75.2, 75.5, 76, 75.4

## ICU beds per 100,000 Population

<table>
<thead>
<tr>
<th>Country</th>
<th>Total Adult ICUs</th>
<th>Total Adult ICU Beds</th>
<th>Adult ICU Beds/100,000 Population</th>
<th>Adult ICU beds as % of All Acute Care Hospital Beds</th>
</tr>
</thead>
<tbody>
<tr>
<td>France</td>
<td>550 (2004)</td>
<td>5707</td>
<td>9.3</td>
<td>2.5</td>
</tr>
<tr>
<td>Canada²</td>
<td>319</td>
<td>3388</td>
<td>13.5</td>
<td>3.4</td>
</tr>
<tr>
<td>Belgium</td>
<td>135</td>
<td>2304</td>
<td>21.9</td>
<td>4.4</td>
</tr>
<tr>
<td>Germany</td>
<td>NA</td>
<td>20,259</td>
<td>24.6</td>
<td>4.1</td>
</tr>
<tr>
<td>Netherlands</td>
<td>115 (2006)</td>
<td>1367</td>
<td>8.4</td>
<td>2.8</td>
</tr>
<tr>
<td>Spain</td>
<td>258</td>
<td>3628</td>
<td>8.2</td>
<td>2.5</td>
</tr>
</tbody>
</table>

### Variation in critical care services across North America and Western Europe

Hannah Wunsch, MD, MSc; Derek C. Angus, MD, MPH; David A. Harrison, PhD; Olivier Collange, MD; Robert Fowler, MD; Eric A. J. Hoste, MD; Nicolette F. de Keizer; Alexander Kersten, MD; Walter T. Linde-Zwirble; Alberto Sandiumenge, MD; Kathryn M. Rowan, PhD

Crit Care Med 2008 Vol. 36, No. 10
ICU Occupancy in Ontario Teaching Hospitals

ICU Occupancy (%)
End-of-Life Care in Ontario

Proportion of Terminal Hospitalizations Associated with an ICU Admission

%  
0 5 10 15 20

2004 2005 2006 2007 2008 2009 2010 2011

US
Canada
What is the ‘Cost’ of End-of-Life Care?
Health Spending by Age in Canada

Total per Capita Health Expenditures

Age Group


CIHI 2008
GDP refers to gross domestic product.
Source: OECD Health Data 2012.

* 2009
GDP refers to gross domestic product.
Source: OECD Health Data 2012.
Health Care Spending per Capita by Source of Funding, 2010
Adjusted for Differences in Cost of Living

$USD

- Out-of-pocket spending
- Private spending
- Public spending

* 2009.
Source: OECD Health Data 2012.
End-of-Life Care in Ontario

"Medicare" Spending During Last 6 Months of Life

- Blue line: US
- Red line: Canada

$0 - $40,000

2004 2005 2006 2007 2008 2009 2010 2011
What do our patients want?
How do we respond?
Advance Care Planning

Failure to Engage Hospitalized Elderly Patients and Their Families in Advance Care Planning

Daren K. Heyland, MD, MSc, FRCPC; Doris Barwich, MD, CCFP; Deb Pichora, RN, MSc; Peter Dodek, MD, MHSc; François Lamontagne, MD, MSc, FRCPC; John J. You, MD, MSc; Carolyn Taylor, RN, BN, MSA, CON(C); Pat Porterfield, RN, MScN; Tasnim Sinuff, MD, PhD, FRCPC; Jessica Simon, MB, ChB, FRCPC; for the ACCEPT (Advance Care Planning Evaluation in Elderly Patients) Study Team and the Canadian Researchers at the End of Life Network (CARENET)

- 12 hospitals; 513 elderly patients, high risk of death next 6 months
- 76% had thought about end-of-life planning
- Only 12% preferred life-prolonging care
- 48% had completed an Advance Care Plan
- 73% had named a Surrogate Decision-maker
- Only 55% had discussed wishes with any health care professional
- Agreement with preferences & chart: 30.2%
End-of-Life Care: How do we Perform?

- Only 30% had discussed wishes with their primary care physician
- Only 55% had discussed wishes with any health care professional
- Agreement with preferences & chart: 30.2%
Quality Dying Initiative
CANHELP Bereavement Questionnaire

- As part of Sunnybrook Hospital’s “Quality Dying Initiative”

- From approximately 1000 deaths annually, surveyed 352 randomly sampled next-of-kin using CANHELP Bereavement Questionnaire

- Primary outcome was a global rating of satisfaction:
  “In general, how satisfied were you with the quality of care your relative received in the last month of life?”

- Sought information about actual & preferred place of death
## Survey of Recently Deceased Patient’s Next-of-Kin

### Sunnybrook Hospital Quality Dying Initiative

### Patient's Preferred Location?

<table>
<thead>
<tr>
<th>Location</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>41</td>
<td>(44.6)</td>
</tr>
<tr>
<td>Uncertain</td>
<td>8</td>
<td>(8.7)</td>
</tr>
<tr>
<td>No</td>
<td>43</td>
<td>(46.7)</td>
</tr>
<tr>
<td>Prefer Home or Retirement Home</td>
<td>31</td>
<td>(72)</td>
</tr>
<tr>
<td>Prefer Other</td>
<td>12</td>
<td>(27.9)</td>
</tr>
</tbody>
</table>

If a patient died in their “preferred location”, the SDM was 18x more likely to be perceive that the patient was satisfied with EOL care.
Why is there a Mismatch between Stated Preferences and Care Delivery?
Markers of System Care Focus

Patient-to-nurse ratio for dying patient in ICU: 1:1

Patient-to-nurse ratio for dying patient on ward: 5:1
Communication

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Patients' Expectations about Effects of Chemotherapy for Advanced Cancer

Jane C. Weeks, M.D., Paul J. Catalano, Sc.D., Angel Cronin, M.S., Matthew D. Finkelman, Ph.D., Jennifer W. Mack, M.D., M.P.H., Nancy L. Keating, M.D., M.P.H., and Deborah Schrag, M.D., M.P.H.

RESULTS
“Overall, 69% of patients with lung cancer and 81% of those with colorectal cancer did not report understanding that chemotherapy was not at all likely to cure their cancer. The risk of reporting inaccurate beliefs about chemotherapy was higher among patients ... who rated their communication with their physician very favorably.
RESULTS

“Overall, 69% of patients with lung cancer and 81% of those with colorectal cancer did not report understanding that chemotherapy was not at all likely to cure their cancer. The risk of reporting inaccurate beliefs about chemotherapy was higher among patients ... who rated their communication with their physician very favorably.
“This suggests that patients perceive physicians as better communicators when they convey a more optimistic view of chemotherapy.”
Patients Buy What the Medical Profession Sells
Is it Always *US*?
How do You Approach End-of-Life Care?

- 40’s year old man, father of young children
- Intelligent, professionally successful
- Metastatic thymus cancer
- Exhausted all oncology treatments and protocols
- Presents to ER with respiratory failure
- Etiology likely due to progressive cancer, pleural effusions, parenchymal disease, phrenic nerve encasement, severe cachexia
- Advance Directives: “Do Everything”
Family, doctors battle over ‘do not resuscitate’ order

As Mann Kee Li lies in hospital fighting dire prospects, his family is engaged in a life-or-death struggle, not with the cancer spreading through his body, but with the doctors treating it.
Variation in End-of-Life Decision-Making

Patient and healthcare professional factors influencing end-of-life decision-making during critical illness: A systematic review

David W. Frost, MD; Deborah J. Cook, MD, MSc; Daren K. Heyland, MD, MSc; Robert A. Fowler, MDCM, MS

end-of-life care. In general, white patients and those in North America and Northern Europe may be less likely to desire intensive end-of-life care than others. Physicians of similar geo-ethnic origin to patients appear less likely to prescribe such therapy. Physicians with more clinical experience and those routinely working in the intensive care unit are less likely than other physicians to recommend technologically intense care for critically ill patients at the end-of-life.
Variation in DNR use by country

management of patient with severe post-anoxic coma with no chance of meaningful recovery

- Would use verbal but not written DNR
- Would not implement DNR
- DNR

Yaguchi, Arch Intern Med, 2005; 165:1970

DNR rates vary significantly by race, hospital, and region adjusting for Dx and Prognosis

slide courtesy of Gordon Rubenfeld
Communicating With Seriously Ill Patients
Better Words to Say

Steven Z. Pantilat, MD

Words matter. What clinicians say and how they say it hugely affect patients. Communicating about emotionally and medically complex topics such as advance care planning, preferences for care, prognosis, and death and dying is challenging. Doing so requires clinicians to attend to their own and the patient’s cognitive reactions, tone, affect, and nonverbal cues. Communicating goals of care is so important that treatments can be mustered to cure the illness. In that limited sense it may be true that “there is nothing more to do,” but difficulty arises because clinicians rarely articulate the culminating phrase “to cure the illness.” Thus, the patient and family hear the disheartening message that the clinician has nothing left to offer.

There are several problems with this statement. First, it is simply not true. There is always something that can be done for the patient, despite an inability to achieve cure. The fact that many clinicians are unprepared to provide palliative care and are unaware of options other than attempts at...
Considerations for Doing it Better...
Making Time for Communication

Seeing communication as a **process** that unfolds over many conversations

Taking a **patient-based** approach to understanding their values

Making recommendations

Using positive and negative **role models** and experiences to develop an effective personal approach to communication
“There Is Nothing More to Do.”

it’s simply not true; much can be done near the end of life

it provokes: “there must be something you can do?!?”

it may lead to a feeling of abandonment
Making Time for Communication

“There is Nothing More to Do”

“I wish there were something we could do to cure your illness, let’s focus on what we can do to help you.”

it is true

It is proactive and offers continued engagement
“Would you like us to do everything possible?”

it elicits a reflexive ‘Yes!’

everything to the clinician (CPR, intubation, inotropes) may mean something very different to the patient or family
Making Time for Communication

“Would you like us to do everything possible?”

“How are you hoping we can best help?”

(‘Make the shortness of breath better’; ‘Help me/him/her’)

Follow this up with a values and goals based conversation and specific recommendations

Communicating With Seriously Ill Patients
Better Words to Say
“We should withdraw care.”

or

“We will remove the breathing machine and stop the antibiotics; if his heart stops we won’t try to resuscitate.”

still focuses on what will not be done

provokes ‘you mean, you are just going to stop?!’

it doesn’t focus on what comes after, the positive addition
“We should withdraw care.”

“To respect her wishes, we will stop the breathing machine and use medications to make her breathing comfortable. If her heart stops, we will allow her to die peacefully.”
How do You Approach End-of-Life Care?

The Debt of Life — Thai Lessons on a Process-Oriented Ethical Logic

Scott D. Stonington, M.D., Ph.D.

“We love him so much,” said Ms. M., standing over her father as he lay on life support in a Boston ICU where I was an intern. “We want to do everything — or at least I want to,” she said tearfully, acknowledging the disagreement among her siblings about how to proceed. Later that morning, I presented her father’s case on rounds: after a failed bone marrow transplant, he’d had a myocardial infarction, which had led to heart failure, then renal failure, then pneumonia and...
transferred to the ICU. Mr. P.’s physicians believed he had little chance of recovering. But his children had no thought of ending treatment. They told me they had “to give him as much life as possible,” explaining that, “Our father gave us flesh, blood, and breath. He gave us existence, and now we have a debt. We have to pay down this debt (chai nī).”
How do You Approach End-of-Life Care?

The Debt of the City of Cambridge

Scott D. Stonington

Wendy Weisberg

We remember Niles Pruzansky as a Bostonian. “We remember Niles Pruzansky as a Bostonian.”

We remember Niles Pruzansky as a Bostonian. “We remember Niles Pruzansky as a Bostonian.”

We wonder whether an explicit acknowledgment of the value of process in the ICU could keep U.S. families and clinicians from becoming entrenched in conflict over end-of-life care — and allow us to decide together that “when we’ve reached ‘enough,’ we trust that it’s time.”