End-of-life Care in Canada & the US

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Acknowledgments

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Heart and Stroke Foundation Canada
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The Commonwealth Fund
The University of Toronto
By 2031, seniors will comprise 25% of the population (4 \(\Rightarrow\) 10 M)

By 2025, those seniors dying will double 260,000 \(\Rightarrow\) 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 North America?
Causes of Death in Canada, by Age

- **Cancer**
- **External**
- **Respiratory**
- **Circulation**
- **‘Metabolic’**
- **Other**
What do we know of the “Usual” North American 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.
1950-60s: Modern CPR Developed

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*


## 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%
- Hospital—Palliative: 15%
- Home: 15%
- Long-Term Care: 14%
- Other Locations: 2%

B.C.:
- Hospital—Acute: 38%
- Hospital—Palliative: 15%
- Home: 15%
- Long-Term Care: 17%
- Other Locations: 3%

Alta.:
- Hospital—Acute: 50%
- Hospital—Palliative: 15%
- Home: 27%
- Long-Term Care: 16%
- Other Locations: 4%

Sask.:
- Hospital—Acute: 38%
- Hospital—Palliative: 14%
- Home: 38%
- Long-Term Care: 55%
- Other Locations: 2%

Man.:
- Hospital—Acute: 55%
- Hospital—Palliative: 12%
- Home: 20%
- Long-Term Care: 20%
- Other Locations: 2%

CIHI 2008
End-of-Life Care: How do we Perform in Canada compared to the US?
MORE EVIDENCE OF A HEALTH CARE SYSTEM IN CRISIS
End-of-Life Care in Ontario, Canada

- **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)

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population (38% of Canada)</td>
<td>12,400,000 ('03) ➔ 13,373,000 ('11)</td>
</tr>
</tbody>
</table>
| 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

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>290,800,109 ('03) ➔ 311,591,917 ('11)</td>
</tr>
</tbody>
</table>
| Hospitals                       | 4272 Hospitals  
|                                 | 941,995 total hospital beds (3/1000)  
|                                 | 61,076 ICU beds (~20/100,000) |
| Chronic Illness Cohort          | 4,666,208 Decedents age 67-99 years in 2003-2007 |
End-of-Life Care in Canada & the US

Proportion of Deaths Occurring In Hospital

- **US**
  - 2003: 32.2%
  - 2011: 24.1%

- **Canada**
  - 2003: 56.9%
  - 2011: 53.3%

The graph shows the proportion of deaths occurring in hospital from 2003 to 2011 for the US and Canada. The proportion for the US decreases from 32.2% in 2003 to 24.1% in 2011, while for Canada, it decreases from 56.9% in 2003 to 53.3% in 2011.
End-of-Life Care in Canada & the US

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

<table>
<thead>
<tr>
<th>Year</th>
<th>US</th>
<th>Canada</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003</td>
<td>30.8</td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>32.7</td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>34.0</td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>35.5</td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td>36.1</td>
<td></td>
</tr>
<tr>
<td>2008</td>
<td>38.0</td>
<td></td>
</tr>
<tr>
<td>2009</td>
<td>40.0</td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td>42.0</td>
<td></td>
</tr>
<tr>
<td>2011</td>
<td>43.2</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Year</th>
<th>US</th>
<th>Canada</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003</td>
<td>70.5</td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>68.6</td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>67.3</td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>69.7</td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td>75.4</td>
<td></td>
</tr>
<tr>
<td>2008</td>
<td>75.2</td>
<td></td>
</tr>
<tr>
<td>2009</td>
<td>75.5</td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td>76.0</td>
<td></td>
</tr>
<tr>
<td>2011</td>
<td>75.4</td>
<td></td>
</tr>
</tbody>
</table>
## ICU beds per 100,000 Population

<table>
<thead>
<tr>
<th></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>Canada</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 Canadian Teaching Hospitals

ICU Occupancy (%)
End-of-Life Care in Canada & the US

Proportion of Terminal Hospitalizations Associated with an ICU Admission

Percentage (%)

US
Canada

Years: 2003 to 2011

% 30 25 20 15 10 5 0

2003 2004 2005 2006 2007 2008 2009 2010 2011
What is the ‘Cost’ of End-of-Life Care?
Care at the End of Life can be ‘expensive’

- 40% of total health care spending by seniors
- Provision of care in ICUs consume up to 1% of entire GDP

About 25% of Medicare spending goes to pay for the care of patients in their last year of life

High resource use and spending does not always lead to better markers of health

- US: 46th in life-expectancy; and 42nd in infant mortality

Canada spends 12% of GDP (the US 18%) on healthcare

Variability in resource use and costs among common groups invite determination of drivers of this care
GDP refers to gross domestic product.
Source: OECD Health Data 2012.

Global Health Care Spending, % GDP, 1980–2010

* 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

- US: 3,967 (970) • 8,233
- SWIZ: 3,437 (1,325) • 5,269
- DEN: 3,800 (508) • 4,639
- CAN: 3,158 (631) • 4,445
- GER: 3,331 (656) • 4,338
- FR: 3,061 (436) • 3,974
- SWE: 3,046 (623) • 3,758
- AUS*: 2,515 (290) • 3,670
- UK: 2,857 (632) • 3,433
- JPN*: 2,443 (682) • 3,035
- NZ: 2,515 (306) • 3,022

Source: OECD Health Data 2012.

* 2009.
Life Expectancy vs. Per Capita Health Spending

- $0.5-1$ trillion/yr

OECD: Health Data 2007  http://www.oecd.org/document/16/0,3343,en_2649_34631_2085200_1_1_1_1,00.html
End-of-Life Care in Canada & the US

Costs of Care Over the Last 6 Months of Life

- Blue line: US
- Red line: Canada

Graph showing the increase in costs of care over the last 6 months of life, with the costs increasing over time from 2002 to 2014.
End-of-Life Care in Canada
What do our patients want?
How do we respond?
Advance Care Planning

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?

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 healthcare professional

- Only 30% had discussed wishes with their primary care physician
- Only 55% had discussed wishes with any healthcare professional
- Agreement with preferences & chart: 30.2%
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 you 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

<table>
<thead>
<tr>
<th>Patient's Preferred Location?</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>41 (44.6)</td>
</tr>
<tr>
<td>Uncertain</td>
<td>8 (8.7)</td>
</tr>
<tr>
<td>No</td>
<td>43 (46.7)</td>
</tr>
<tr>
<td>Prefer Home or Retirement Home</td>
<td>31 (72)</td>
</tr>
<tr>
<td>Prefer Other</td>
<td>12 (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?
Patient-to-nurse ratio for dying patient in ICU: 1:1

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

– The North American healthcare system, and especially Canada’s, by its design, is ‘narrow & deep.’

– *Our system is perfectly designed to get the results it does.*

– It is not, however, responsive to what patients, or healthcare professionals think is ideal.

– Not only must we engage *ourselves and patients* to change end-of-life decision-making, we have to engage *policy-makers* help us change.

– Patients need more and more robust options for palliation, death at home or hospice. If we want a new normal, we must advocate for it.
How Can We Improve End-of-Life Care?
Making Time for Communication

Ask yourself, your resident, attending...the “Surprise Question”

“Would I be surprised if this patient died in the next year?”
Making Time for Communication

S: SETTING UP the interview
• Arrange for some privacy.
• Ask your patient who else to include in the interview (e.g., the substitute decision-maker).
• Consider involving a colleague (e.g., nurse, trainee or other appropriate member of the team who has developed a relationship with the patient).
• Sit down and make eye contact.

P: Assessing the patient’s PERCEPTION
• Ask how the patient perceives his or her medical situation with questions such as “What have you been told about your medical situation so far?”; “Tell me what the last year has been like for you”; “What are your thoughts about the future?”

I: Obtaining the patient’s INVITATION
• Determine what the patient wants to know (not everyone want full information) with a question such as “Are you the sort of person who wants to hear all the details of your medical condition?”

K: Giving KNOWLEDGE and information
• Provide small chunks of information in simple language, checking periodically for understanding.
• Acknowledge uncertainty when disclosing prognosis (e.g., give a range instead of a single number).

E: Addressing EMOTIONS with empathic responses
• Identify emotions as they arise with statements such as “I can tell you weren’t expecting to hear this,” “It sounds like you are feeling overwhelmed by this,” or “It’s natural that talking about this can be upsetting — for any of us — it’s okay to take some time.”
• Use exploratory questions or statements if there is silence, such as “Could you tell me more about what is worrying you?” or “I want to make sure that if you have questions or things you are worried about, we can help to address them.”

S: STRATEGY and SUMMARY
• Summarize the major areas discussed.
• Make a plan for the next meeting.
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.\textsuperscript{1-3} 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.\textsuperscript{4-6} Communicating goals of care is so important that if 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...
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
“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
Making Time for Communication

“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
Making Time for Communication

“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
“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.”