Advance Care Planning in Canada

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THETA Symposium on End-of-Life Care
Toronto, ON
May 30, 2013
Objectives

1. To discuss national initiatives aimed at improving Advance Care Planning (ACP)
2. To share early results from 2 ongoing, inter-related, multi-centre studies of EOL communication at Canadian acute care hospitals
A patient I recently cared for

88 Polish widow, home alone, 3 children nearby

Depression

Diabetes on insulin


Diastolic heart failure (LVEF 55%)

Chronic obstructive lung disease (FEV1 35%)

Osteoporosis, vertebral compression # (L1)
Mrs W’s illness trajectory

• Oct 2012: 12 day CTU admission for CHF, concerns about frailty, discharged home (12 meds on admission, 14 meds on discharge)
• Dec-Jan 2013: 25 day CTU admission for CHF, “deconditioned”, discharged to “Assess and Restore” program with plan for retirement home (18 meds on discharge)
• Feb 2013: 90 day hospital admission, cardiac arrest, prolonged ICU stay. Died.
Trajectories of dying

“The Grey tsunami”....

• 2/3 will die with 2 or more chronic diseases after yrs in state of “vulnerable frailty”
• Only 20% will die with a recognizable “palliative” phase
• At time of death:
  – 42.5% of pts required decision making (DM)
  – 70.3% lacked DM capacity

What matters most in end-of-life care: perceptions of seriously ill patients and their family members

Daren K. Heyland, Peter Dodek, Graeme Rocker, Dianne Groll, Amiram Gafni, Deb Pichora, Sam Shortt, Joan Tranmer, Neil Lazar, Jim Kutsogiannis, Miu Lam, for the Canadian Researchers, End-of-Life Network (CARENET)
<table>
<thead>
<tr>
<th>How important is it ...</th>
<th>% “Extremely Important”</th>
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</thead>
<tbody>
<tr>
<td>To have trust and confidence in the Doctor looking after you</td>
<td>55.8</td>
</tr>
<tr>
<td>Not to be kept alive on life support when there is little hope for a meaningful recovery</td>
<td>55.7</td>
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<tr>
<td>That information about your disease be communicated to you in an honest manner</td>
<td>44.1</td>
</tr>
<tr>
<td>To complete things and prepare for life’s end</td>
<td>43.9</td>
</tr>
<tr>
<td>To have an adequate plan of care &amp; services available at home upon discharge</td>
<td>41.8</td>
</tr>
<tr>
<td>To not be a physical or emotional burden</td>
<td>41.8</td>
</tr>
</tbody>
</table>

**Good end-of-life communication and decision-making**

Heyland DK et al. CMAJ. 2006.
EOL communication & decision-making

- Conversations about wishes and preferences
- Substitute DM
- Advance Directive

Advance Care Planning

Decisions about Goals of Care ‘in the moment’
- Diagnosis/Prognosis
- Anticipated /Feasible outcomes
- Options for care
- Plans for crisis

MOST form
- ACP Record
- Care Plans

Documentation

Primary Care  Specialty/Acute Care and LTC
Framework for Advance Care Planning in Canada

1. Engagement
   - Engage the healthcare system
   - Engage the legal system
   - Engage healthcare professionals/providers
   - Engage the general public

2. Education
   - Education and training of professional providers
   - Education of the general public

3. System Infrastructure
   - Policy and program development
   - Tools to support conversations and documentation

4. Continuous Quality Improvement

Patient/family
Advance Care Planning – Results of Canadian Sample

March 2012
# Sample Demographics

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Canada</th>
<th>Base: (n=1021)</th>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
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<tr>
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<td>487</td>
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<tr>
<td>Female</td>
<td>534</td>
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<td><strong>Age</strong></td>
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<tr>
<td>18-34</td>
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<tr>
<td>35-54</td>
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<td>55+</td>
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<tr>
<td><strong>Education</strong></td>
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<tr>
<td>&lt;HS</td>
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<tr>
<td>HS</td>
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<td>Univ Grad</td>
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<tr>
<td><strong>Household income</strong></td>
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<tr>
<td>&lt;$30K</td>
<td>216</td>
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<tr>
<td>$30K - &lt;$60K</td>
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<tr>
<td>$60K+</td>
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<td><strong>Region</strong></td>
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<tr>
<td>Quebec</td>
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<tr>
<td>Atlantic</td>
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</table>
Advance care plans are verbal or written instructions that make your wishes known about the kind of healthcare you want (or do not want) if you become very ill or injured and are unable to speak for yourself. These are sometimes also called ‘living wills.’

**Heard of ‘advance care planning’?**
- Yes: 14%
- No: 86%

**Ever had a discussion regarding healthcare treatment(s) if you became very ill / injured and were unable to speak for yourself?**

- **With family / a close friend**
  - Yes: 49%
  - No: 51%

- **With a healthcare provider**
  - Yes: 9%
  - No: 91%

**Have an Advance Care Plan written down?**
- Yes: 19%
- No: 81%

**Designated someone to make healthcare decisions for you?**
- Yes: 46%
- No: 54%

Base: All Respondents (n=1021); Q1 – Q5
ACCEPT Study

Advance Care Planning Evaluation in Hospitalized Elderly Patients: a multicenter, prospective study

Overall PI: Daren Heyland (Queen’s Univ.)

ACCEPT Study Design

• **Setting:**
  – 12 acute care hospital sites across Canada

• **Participants:**
  – Elderly patients at high-risk of dying
    • 80 years of age or older **OR**
    • clinical indicators of advanced disease **OR**
    • “Surprise Question”
  – Family members
  – Target sample of 30 patients and 30 family members per site
Patient preferences for EOL care

- 76% of patients have thought about the kinds of life-sustaining treatments they would want
- 89% of these patients have discussed with someone
Documented goals of care are discordant with patient preferences 70% of the time.
Who do seriously ill patients talk to about their end-of-life wishes?

• Of patients who have discussed EOL wishes:
  – 92% with family member
  – 30% with lawyer
  – 30% with family physician
  – 17% with specialist physician
Summary of ACCEPT findings

• High risk patients have thought about EOL wishes, talked to family members, but little engagement by healthcare providers

• Appreciable discordance between patient preferences and documented goals of care
Program of research

Vision:
Improve quality of EOL communication, decision-making, and care for seriously ill elderly patients in Canada

ACCEPT

Observational studies: Identify barriers & facilitators

Developmental pilot work

Interventional studies: Design and evaluation of tailored interventions

DECIDE

Launch of full-scale interventional studies
DECIDE Study

- Multi-centre mixed-methods study
  - Questionnaires
  - Semi-structured interviews
- Medical teaching units at 13 Canadian hospitals
- To understand:
  - Barriers impeding EOL communication
  - Potential innovative solutions
  - Potential roles of interprofessional team
Barriers to goals of care discussions

BARRIERS
1.1f FM difficulty accepting loved ones poor prognosis
1.1g FM lack understanding re limitations/harms LST
1.1h Lack of agreement amongst FMs about goals of care
1.1j Cultural differences
1.2a Uncertainty in estimating prognosis
1.2b Lack of training to have these conversations
1.2c Desire to avoid being sued
1.2d Desire to maintain hope
1.3a Lack of time
1.3b Lack of availability of SDM(s)
1.3c Uncertainty about who is the SDM
1.3d Lack of appropriate location (confidential/private)
1.3e Insufficient remuneration for this activity
1.3f Lack of pre-existing relationship with patient/family
1.3g Unaware of what other team members have said
1.3h Healthcare team disagreement about goals of care
1.3i Language barriers
1.3j Patient difficulty accepting poor prognosis
1.3k Patient lacks capacity to make goals of care decisions
1.3l Patient lack understanding re limitations/harms LST
1.3m Lack of agreement amongst FMs about goals of care
1.3n CMS disagreement about goals of care
1.3o Inappropriate location (confidential/private)
1.3p Inappropriate language
1.3q Inappropriate understanding re limitations/harms LST
1.3r Inappropriate patient difficulty accepting poor prognosis
1.3s Inappropriate patient lacks capacity to make goals of care decisions
1.3t Inappropriate patient lack understanding re limitations/harms LST
1.3u Inappropriate CMS disagreement about goals of care
1.3v Inappropriate location (confidential/private)
1.3w Inappropriate language
1.3x Inappropriate understanding re limitations/harms LST
1.3y Inappropriate patient difficulty accepting poor prognosis
1.3z Inappropriate patient lacks capacity to make goals of care decisions
1.3aa Inappropriate patient lack understanding re limitations/harms LST
A patient speaking about barriers to EOL discussions with physicians:

“I don't think they want to talk about it. It is a science based profession, and that discussion is philosophical and sociological or spiritual and does not come with a white coat.”
Real ending of Mrs W’s story

• Oct 2012: 12 day CTU admission for CHF, concerns about frailty, discharged home (12 meds on admission, 14 meds on discharge)

• Dec-Jan 2013: 25 day CTU admission for CHF, “deconditioned”, discharged to “Assess and Restore” program with plan for retirement home (18 meds on discharge)

• Feb 2013: 4 day CTU admission for CHF. Died.
Thank you

• ACCEPT and DECIDE team members
• CERU staff
• CARENET
• Funders:
  – Canadian Institutes for Health Research
  – Alberta Innovates
  – Michael Smith Foundation (BC)
  – HAHSO AFP Innovation Fund (Ontario)
## Future complex intervention

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Potential intervention</th>
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<tbody>
<tr>
<td>Patient/family lack of understanding of life-sustaining technologies</td>
<td>Decision aids (web, video)</td>
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<tr>
<td>Lack of access to doctor/healthcare provider</td>
<td>Trained ACP facilitators</td>
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<tr>
<td>Lack of prognostic disclosure</td>
<td>Prognostic tools (e-prognosis)</td>
</tr>
<tr>
<td>Lack of engagement by healthcare professionals</td>
<td>Healthcare provider communications skills training</td>
</tr>
<tr>
<td>Lack of clear documentation of values and EOL care plans</td>
<td>Level of care forms which include text stating patient values; “cloud”-based registry of ACP documents</td>
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<tr>
<td>Participating sites</td>
<td>Hospital Names</td>
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<tr>
<td>---------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>1</td>
<td>Kingston General Hospital</td>
</tr>
<tr>
<td>2</td>
<td>University Health Network Toronto General Hospital</td>
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<tr>
<td>3</td>
<td>Centre hospitalier universitaire de Sherbrooke</td>
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<tr>
<td>4</td>
<td>Royal Alexandra Hospital</td>
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<td>5</td>
<td>Rockyview Hospital</td>
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<td>6</td>
<td>Foothills Hospital</td>
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<td>12</td>
<td>Hamilton Health Sciences Centre</td>
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<tr>
<td><strong>TOTAL</strong></td>
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