The iDECIDE Study

Improving DECision-making about goals of care for hospitalized elderly patients: a multi-incubator unit study

John J. You, MD MSc FRCPC
Associate Professor, Departments of Medicine, and Clinical Epidemiology & Biostatistics, McMaster University

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Funding Acknowledgements

• TVN (NCE): Core Research grant ($504,246)
• Partnerships ($302,670 in-kind)
Hospitals are a major provider of end-of-life care

- 250,000 deaths annually in Canada
- Most Canadians (60%) will die in a hospital bed
- 2,000 deaths/yr at my hospital = 5 patients/day
Overall objective

To improve end-of-life (EOL) communication and decision-making for seriously ill, hospitalized patients and their family members
Conceptual model

Primary / Ambulatory Care

Barriers to goals of care decision-making

- Patients and families unprepared for future ‘in-the-moment’ goals of care decisions

Our Proposed Interventions

- Advance Care Planning tools (e.g. PREPARE)

Lack of transportability of current Conversations, plans, documents

Cloud-based record of current plans, documents (e.g. MyOscar)

Hospital Care

Barriers to goals of care decision-making

- Clinicians unprepared to discuss goals of care
- Patients/families need support to make treatment decisions

Our Proposed Interventions

- Train clinicians in goals of care discussions (SICP)
- Patient/family-facing decision support tools

Lack of transportability of current Conversations, plans, documents

Cloud-based record of current plans, documents (e.g., MyOscar)

MAIN OUTCOMES

Proximal outcomes:
- Patient engagement in advance care planning
- Timeliness and frequency of goals of care discussions
- Patient / family member decisional conflict

Downstream outcomes:
- Patient / family member satisfaction with communication and decision-making
- Receipt of goal-consistent care
- Psychological distress of family members during bereavement
- Healthcare costs
Objective of current study

• To pilot test and refine potential decision support tools that are being considered for a multi-faceted suite of interventions
The “Incubator Units”

- Ward of the 21st Century, Calgary, Alberta
- Hamilton General Hospital, Hamilton, Ontario
- Montreal General Hospital, Montreal, Quebec
The Tools

- CPR Video Decision Aid
- “What’s Important to Me: a Graphic Values History Tool” (GVHT)
- PREPARE
Tool Evaluation Phases – iDECIDE, i-GAP

- Patient/Family
  - Acceptability, feasibility, clinical sensibility
- Patient/Family
  - Efficacy for increasing ACP engagement among patients
- Patient/Family + Clinician
  - Trial in practice and evaluate ACP engagement and outcomes of clinical interaction
Primary Research Question

For seriously ill elderly patients, their family members and healthcare providers in hospital, what is the **feasibility** of implementing different candidate components of our proposed multi-faceted iDECIDE intervention?
Secondary Research Question

What is the **potential impact** of each of the candidate components on relevant processes and outcomes related to EOL communication and decision-making for seriously ill elderly patients, their family members and healthcare providers in hospital?
A Decision Aid to Prepare Patients And Their Families For Shared Decision-Making About Cardio-Pulmonary Resuscitation (CPR)
Acute Care Pilot data
CPR Video Decision Aid

• N=21 (17 patients/4 family members) at the Hamilton General Hospital Site
• Mean age 79
• Education: 58% did not complete high school
• Frailty: 93% vulnerable or frail
• In the last 6 months:
  – Average of 2.5 family doctor visits
  – Average of 1.7 specialist visits
  – Average of 1.5 hospital admissions
## CPR Video - Acceptable and Feasible (n=21)

<table>
<thead>
<tr>
<th>Response options</th>
<th>n</th>
<th>Mean (SD)</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clarity of information</strong></td>
<td>17</td>
<td>1.5 (0.5)</td>
<td>2</td>
</tr>
<tr>
<td>1 = Everything was clear</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 = Many things were unclear</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Amount of information</strong></td>
<td>16</td>
<td>3.1 (0.5)</td>
<td>3</td>
</tr>
<tr>
<td>1 = Much less than I needed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 = A lot more than I needed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>How helpful was the video</strong></td>
<td>17</td>
<td>1.8 (0.8)</td>
<td>2</td>
</tr>
<tr>
<td>1 = Very helpful</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 = Not helpful</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Balance of information</strong></td>
<td>16</td>
<td>3.3 (0.5)</td>
<td>3</td>
</tr>
<tr>
<td>1 = Clearly slanted towards having CPR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 = Clearly slanted towards not having CPR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Likelihood to recommend</strong></td>
<td>17</td>
<td>1.7 (0.6)</td>
<td>2</td>
</tr>
<tr>
<td>1 = Definitely would recommend</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 = Definitely would not recommend</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Overall rating</strong></td>
<td>15</td>
<td>2.9 (0.6)</td>
<td>3</td>
</tr>
<tr>
<td>1 = Poor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 = Excellent</td>
<td></td>
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</tbody>
</table>
Decisional Conflict

- A state of uncertainty about a course of action
- Low literacy version of Decisional Conflict Scale (DCS)
- 0 = no decisional conflict; 100 = extremely high
- Early data (n=8) shows decrease in total DCS:
  - Before: mean score 26
  - After: mean score 8
Clinicians’ Perceptions

Clinician surveys completed for 9 (53%) participants

- 55% very or completely satisfied with the conversation they had with the patient regarding the CPR decision after the patient watched the video

- “I felt they were fully informed with decision making especially since they viewed the video. The conversation was smoother.”

- “I spoke with the patient’s son who had watched the video. He found it very informative and helpful for future discussions.”
“What’s important to me” Graphic Values History Tool

| g. What would I say about my quality of life if I were unable to recognize family/friends? |
|------------------------------------------|-------------------|--------|-------------------|-------------------|---------------|
| Totally Unacceptable 1                  | Somewhat Unacceptable 2 | Neutral 3 | Somewhat Acceptable 4 | Totally Acceptable 5 | Unsure/Don’t Know |
| Comments:                                |                   |          |                   |                   |               |

| h. What would I say about my quality of life if I were unable to get outside and must spend all day at home? |
|------------------------------------------|-------------------|--------|-------------------|-------------------|---------------|
| Totally Unacceptable 1                  | Somewhat Unacceptable 2 | Neutral 3 | Somewhat Acceptable 4 | Totally Acceptable 5 | Unsure/Don’t Know |
| Comments:                                |                   |          |                   |                   |               |

| i. What would I say about my quality of life if I were confined to bed and/or needing someone to take care of me 24 hours a day? |
|------------------------------------------|-------------------|--------|-------------------|-------------------|---------------|
| Totally Unacceptable 1                  | Somewhat Unacceptable 2 | Neutral 3 | Somewhat Acceptable 4 | Totally Acceptable 5 | Unsure/Don’t Know |

Developer: Peter Allatt, Ethicist, Toronto
GVHT: Phase 1 Evaluation - Acute Care

- Acceptability
  - Likelihood of use? Likelihood to recommend?

- Feasibility
  - Difficulty? Length?

- Clinical sensibility
  - Patient to summarize each section in their own words
  - Which parts of the tool did the patient find useful?

- Evaluated by seriously ill hospitalized patients (n=5) or family members (n=4), or both (n=1) (Calgary)
## GVHT Feasibility/Acceptability results - Acute Care (n=10)

<table>
<thead>
<tr>
<th></th>
<th>Response options</th>
<th>n</th>
<th>Mean (SD)</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comprehension</td>
<td>1 = Very unclear; 5 = Very clear</td>
<td>10</td>
<td>4.4 (0.5)</td>
<td>4</td>
</tr>
<tr>
<td>Amount of information</td>
<td>1 = Much less than I wanted ; 5 = Much more than I wanted</td>
<td>10</td>
<td>3.4 (0.7)</td>
<td>3</td>
</tr>
<tr>
<td>Difficulty</td>
<td>1 = Very difficult; 5 = Very easy</td>
<td>9</td>
<td>4.2 (0.4)</td>
<td>4</td>
</tr>
<tr>
<td>How helpful for a patient</td>
<td>1 = Very unhelpful; 5 = Very helpful</td>
<td>8</td>
<td>4.5 (0.5)</td>
<td>4.5</td>
</tr>
<tr>
<td>Likelihood of use</td>
<td>1 = Definitely would not use it; 5 = Definitely would use it</td>
<td>10</td>
<td>4.4 (0.8)</td>
<td>5</td>
</tr>
<tr>
<td>Likelihood to recommend</td>
<td>1 = Definitely would recommend; 5 = Definitely would not recommend</td>
<td>10</td>
<td>4.2 (1.0)</td>
<td>4.5</td>
</tr>
<tr>
<td>Overall rating</td>
<td>1 = Very poor; 5 = Very good</td>
<td>10</td>
<td>4.3 (0.8)</td>
<td>4.5</td>
</tr>
</tbody>
</table>
Welcome to PREPARE!

PREPARE is a program that can help you:

- make medical decisions for yourself and others
- talk with your doctors
- get the medical care that is right for you

You can view this website with your friends and family.

Click the NEXT button to move on.
When you think about your health and health situations you may experience in the future, how do you feel?

- [ ] Life is always worth living no matter what type of serious illness, disability, or pain I may be experiencing.

- [ ] There may be some health situations that would make my life not worth living, such as never being able to wake up from a coma.

- [ ] I am not sure

Click an answer above to move on.
Early PREPARE results- Acute Care

seriously ill hospitalized patients (n=6) with study nurse present (Hamilton)

1. Computer is a barrier to recruitment / administration of tool
   - Even patients who use computers at home are not comfortable using the computer while hospitalized

   “Much too long, particularly if you are not up to par.”

   “Too long for me.”

   Any specific things you recall being unclear or difficult to understand?
   “No, just very long”

2. Length
   - Time to complete (up to 3 hours)
Next steps

• Process mapping: interprofessional team
• Collaboration with Ariadne Labs / Harvard (Serious Illness Care Program)
• Upcoming grant applications:
  – CIHR Team Grant in Late Life Issues
  – TVN Transformative Research Grant