Efficacy of Advance Care Planning (ACP) interactive web sites and workbooks to improve patient engagement in primary care: The results of tool evaluations

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Background and Rationale

• Engaging in advance care planning (ACP) can increase the likelihood of receiving value-concordant care and improve the experience with end-of-life health care
• Primary care opportunity - introduce and facilitate ACP
• Estimates across countries- initiation of ACP even for very sick patients in primary care < 10%
• Barriers- time, lack of process, tools and resources for patients
• Recent scoping review of ACP tools for the public concluded there are many, but most not evaluated for their impact on ACP engagement or other outcomes
Definition

Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.

The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.

What do we mean by ACP engagement?


P < .005

P = .012

P = .38

% within year categories


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% ACP components reported by patients in i-GAP practices

Thought about medical treatments
Talked to someone
Study Objective

• To evaluate the efficacy of seven ACP tools, including paper workbooks, interactive websites to improve ACP engagement in primary care patients.
Methodology

• **Design**: Prospective multi-site study
• **Setting**: Approximately 20 family practices in 3 Canadian provinces (ON, AB, BC)
• **Participants**: Patients in family practice who are 50+; English-speaking/reading, cognitively able
Intervention

Pre- and post-intervention to evaluate changes in ACP engagement:

• **Baseline**: Patients complete validated ACP engagement survey interview, given a tool to work through over next several weeks

• **Weeks 2 and 4**: Research Assistant checks-in with patient for reminder

• **Week 6 Follow-up**: Patients re-interviewed with survey, elicited comments on reactions to tool
## “Tools” evaluated

<table>
<thead>
<tr>
<th>Tool</th>
<th>Description</th>
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| Speak Up                                  | National-paper  
National- website  
Ontario-paper (in Ontario only)  
B.C. – web (in B.C. only)              |
| Conversations Matter (in Alberta only)    | Paper  
Website                                                          |
| PREPARE                                   | U.S. website to prepare patient/SDM for making future health care decisions |
| ‘What’s important to me’                  | A graphic values history tool (complement to ACP tool)                      |
Grade 5 reading, multi-ethnic input
How do we measure ACP engagement?

• Two scores:
  – Overall Process Score
    • Mean of items in the score (Likert scale 1-5)
    • Knowledge, Contemplation, Self-efficacy, Readiness
  – Overall Action Score
    • Count of ‘have already done it’ for:
      • E.g. talked to someone about being substitute decision maker, talked about health situations, about future medical decisions, asking doctors questions, written things down
Results

393 patients enrolled and 314 (80%) completed the study

<table>
<thead>
<tr>
<th>Demographics of participants</th>
<th>All participants (range across tools)</th>
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<tbody>
<tr>
<td>Age</td>
<td>66.5 ± 9.1 (63.0 – 71.7)</td>
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<tr>
<td>Female</td>
<td>63.1% (16% - 72%)</td>
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<tr>
<td>Highest education- some or completed post-secondary</td>
<td>72.0% (46.1% - 90.1%)</td>
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<tr>
<td>Spirituality or religion extremely or very important</td>
<td>44.3% (29.7% - 61.0%)</td>
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<tr>
<td>Ethnicity- Caucasian/White</td>
<td>90.6% (85.4% - 100%)</td>
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<tr>
<td>Clinical Frailty Scale: mean± SD (range)</td>
<td>2.1 ± 0.9 (1.8 - 2.4)</td>
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Tool efficacy - ACP process score

All p<0.05

Mean score (max 5)

Prepared (n=89)  GVHT (n=30)  Conversations matter (n=46)  Speak Up ON (n=42)  Speak Up CA web (n=31)  Speak Up CA paper (n=22)  Speak Up BC web (n=54)

Pre  Post

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Where there was change

• Knowledge and contemplation
  – E.g. “how well informed are you about what makes someone a good medical decision maker?”
  – E.g. “how much have you thought about talking with your decision maker about the care you would want if you were very sick or near the end of life?”
  – “How much have you thought about talking with your doctors about the care you would want if you were very sick or near the end of life?”
Tool efficacy-ACP action score

Mean score (max 21)

- PREPARE (n=89): P<0.05
- GVHT (n=30): Pre
- Conversations matter (n=46): Post
- Speak Up ON (n=42): P<0.05
- Speak Up CA web (n=31): P<0.05
- Speak Up CA paper (n=22): P<0.05
- Speak Up BC web (n=54): P<0.05

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Typical Results Pattern

Knowledge, contemplation, self-efficacy, readiness

Behaviours (SDM, Talk, Record, etc)
Discussion

• Tools increase engagement in processes of ACP in primary care population
  – most increase was in knowledge and contemplation
  – Talking to doctors

• Limitations
  – No control group, questionnaire may have changed outcomes
  – Did not study substitute decision-maker or family

• Tools increase patient engagement so have potential as preparation for discussions in community settings