Advance Care Planning Conversations and Goals of Care Discussions: Understanding the Difference

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Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries

Figure. Hospital Expenditures in the Last 180 Days of Life for Patients Older Than 65 Years Dying With Cancer in Acute Care Hospitals in 7 Developed Nations

WHY this is timely

JAMA, 2016
WHAT problem do we aim to solve

Address high rates of acute care utilization?

To the extent possible, ensure the care a person wishes to receive = care received?

Propose these as the actual problems:

Identify measures of effective person-centred decision-making

Effectively teach communication skills enabling person-centred decision-making
Components of person-centred decision-making

A person's values, wishes, beliefs and goals for their care

Information guides SDM(s) if decision-making in future

Information directly informs decision-making

Advance care planning

Goals of care discussion

Decision-making & consent discussions

Current care

Future care

Treatment or care decision is to be made
# Components of person-centred decision-making

<table>
<thead>
<tr>
<th>Clinical Context</th>
<th>Outcome is...</th>
<th>Outcome is NOT...</th>
<th>How goals are defined</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance care planning</td>
<td>Future SDM(s) confirmed and prepared with information to guide decision-making</td>
<td>Code status, POLST, etc.</td>
<td>Patient's to define and describe</td>
</tr>
<tr>
<td>Goals of care discussion</td>
<td>Current Patient/SDM(s) understands illness AND Team understands pt's values &amp; goals</td>
<td>Code status, POLST, etc.</td>
<td>Patient's to define and describe</td>
</tr>
<tr>
<td>Decision-making &amp; consent discussions</td>
<td>Current Outcome is always care or treatment decision(s) e.g. Code status, POLST, etc.</td>
<td></td>
<td>May be medically oriented e.g. cure, restore function, address low Hgb</td>
</tr>
</tbody>
</table>
Mr. H is a 76 yo male with chronic obstructive pulmonary disorder (COPD) and is followed in respirology clinic.
9 months later

• Mr. H is brought to the ED with respiratory distress and acute confusion

• The sudden illness is somewhat distressing to Mrs. H as he had been quite well

• Diagnosis is pneumonia, intubation will likely be offered and the treating MD determines Mr. H lacks the capacity to make this decision

What is required in all care settings to GET THIS RIGHT?

Goals of care discussion

Decision-making
• Mrs. H understands the expected plan as:
  • **temporary** ventilatory support
  • **reversible** condition
  • **high likelihood of recovery** to near baseline function

• Mrs. H gives **CONSENT** for intubation

• Day 2 in critical care: Mr. H undergoes a number of investigations and imaging in alignment with GOC
8 days later

- Mr. H stabilizes, transferred to general medicine and social worker as part of discharge planning meets

- Reflecting on the hospital stay, he affirms he would have made the same decisions

- ACP Conversation: Reading to his grandchildren remains the most important thing to him

What is required in all care settings to GET THIS RIGHT?

Advance care planning
Over the next 3 years

• Mr. H is admitted to hospital 3 more times, each time he is intubated

• During routine clinic visit, respirology team informs Mr. H about pulmonary nodule found on CT. Mr. H decides to not biopsy

• Spends most of day in bed, moderately breathless at rest, he now gets short of breath reading to grandchildren and is often too fatigued to visit with his family

• During most recent hospitalization, weaning off ventilator was challenging; BiPap attempted and it was intolerable
4 years after diagnosis

- Mr. H arrives to routine clinic appointment by ambulance and is acutely confused
- Suspected diagnosis is pneumonia, Mr. H is not capable of decision-making, respirology MD considers intubation
- GOC discussion with Mrs. H: at best, Mr. H will return to recent baseline i.e. shortness of breath so severe at rest he is no longer able to read to his grandchildren
- Decisions are made to admit for a trial of antibiotics, no intubation, no critical care
• Reassessment following agreed upon time trial of antibiotics and Mr. H has not improved

• Mr. H is transferred to a residential hospice and he died 8 days later
Summary of ACP conversations, GOC discussions & decision-making over time

Diagnosis

- Advance care planning
- Goals of care discussion
- Decision-making

Clinic
- Critical & Acute Care
- D/C planning

3 years

End of life
- Acute Care
- Residential hospice
• Both ACP and GOC discussions can occur in any care setting
  • main distinctions are whether or not a decision is to be made and thus current or future context
• ACP is not necessarily MD dependent
• GOC discussion can inform more than one decision and more than one GOC discussion can inform a decision
• Code status discussion may be part of decision-making discussions but should not be the main focus of any ACP or GOC discussion
**Most important encounters**

- **ACP after diagnosis** confirmed Mr. H understood his illness
- **ACP prior to discharge** established routine of revisiting values after major health event
- **GOCD with major outpatient decision** important information for the team and SDM i.e. the goals he has for his care based on his current quality of life

**Clinic**  
- **Critical & Acute Care**
- **D/C planning**
- **Acute Care**
- **Residential hospice**

**Diagnosis**  
- **Advance care planning**
- **Goals of care discussion**

**3 years**

**End of life**

- **Final GOCD** previous gave SDM leeway with decisions (e.g. antibiotic trial) as well as confidence when it came time to make them
• # of admissions may or may not have differed BUT a few key encounters likely made a substantial difference in patient’s & SDM’s EXPERIENCE

• Important outpatient considerations accompany a push for EARLIER CONVERSATIONS

• Earlier in illness trajectory = less likely patient will have context for ‘preferences’ on life-sustaining treatments

• It is UNCOMMON for documented outpatient ACP or GOC discussions to be accessible (thus utilized) when a person is admitted
Evidence Summary 18-2

A Quality Initiative of the Program in Evidence-Based Care (PEBC), Cancer Care Ontario (CCO)

Provider Tools for Advance Care Planning and Goals of Care Discussions


Report Date: September 27, 2016
Evidence Summary

**Objective:** systematic review of the evidence regarding tools or practices available to health care providers for ACP & GOCD

1. What tools enable providers to **INTRODUCE** ACP/GOCD?
2. What tools enable providers to **FACILITATE** ACP/GOCD?
3. What tools are **best suited for DOCUMENTATION** of ACP/GOCD?
Methods

Figure 1. Literature search results flow diagram.

- **MEDLINE/EMBASE**
  - Hits = 33,630
  - Excluded on Abstract Review 33,142
  - Full-text Review
    - Adult = 433
    - Pediatric = 57
  - Excluded 449
  - Retained
    - Adult = 36 papers from 34 studies
    - Pediatric = 5 papers from 4 studies

- **ASCO Palliative Care in Oncology Symposia**
  - Retained Adult = 1

- **Reference Mining**
  - Retained Adult = 7

Guidelines
- Full publication available - 1
- Study protocol - 1
- Not based on a SR - 1
- Not suitable - 50
- Not a guideline - 29

Systematic Reviews
- Duplicate - 2
- Full publication available - 3
- No outcome of interest reported - 4
- Study not completed yet - 1
- Study protocol - 2
- Not Suitable - 42

Primary Literature
- Abstract for a talk/workshop - 8
- Abstract of a non-RCT - 28
- Newer publication available - 9
- Duplicate - 2
- Narrative review - 9
- No outcomes reported - 12
- Not a study - 55
- Not suitable - 134
- Not English - 2
- Not located - 6
- Too Small - 3
- Publication Typo - 38
- Study protocol - 6
- Full publication available - 1
Results

• Lack of widespread agreement on the definitions, critical elements and desired outcomes

• Synthesizing evidence is challenging due to the nature of these two clinical encounters
  • Each has inherent limitations to standardization

• A number report positive findings but no consistent patient outcome evidence to support one clinical tool
Results

• Children and their parents:
  • supportive of ACP
  • find these discussions helpful to ensure good care
  • to facilitate communication among caregivers
  • to provide peace of mind

• Concerns that ACP discussions will cause distress in children and parents are not supported by the evidence
### Summary of results

#### ACP
- Spectrum of interventions to support ACP conversations
- Range from a system wide coordinated effort, to practice tools with no training
- Vary based on rigour of professional development intervention
- Introducing & facilitating not differentiated

#### GOCD
- No GOC specific tools identified
- Limited research & evidence about GOC discussions
- Relative newness to healthcare lexicon
- Lack of widely agreed upon definition and variable views on overall purpose and expected outcomes
Conclusions

• Effectiveness of ACP conversations at both the systems and individual patient level require:
  • **Effective** provider education
  • **Effective** communication skill development
  • Standard tools for **documentation**
  • Easily **accessible** documentation
  • **Quality improvement** initiatives
  • **System wide coordination** to impact the population level

• Need for “research focused on GOC discussions to clarify the purpose and expected outcomes to clearly differentiate GOC from ACP”
Evidence of effective ACP leads to...

- improved patient & family experience
- less caregiver distress and **trauma**
- fewer unwanted investigations, interventions & treatments
- fewer unwanted hospitalizations & critical care admissions
- more likely to be cared for in preferred setting
- a health care system that can be sustained

*This was not always the case...what changed?*

*What knowledge and communication skills are required for effectiveness?*
• International expert panel assembled to rank quality indicators
• NOT in agreement on definition, purpose, outcomes and key components
• Focus shifted on achieving consensus for these elements
Effective ACP

- Prepare people in varying health states for medical decision making, not just at the end of life
- In an acute setting or as a patient’s disease progresses, ACP for future (or hypothetical) decisions often flows into current goals of care and treatment discussions
- Important to tailor ACP information to the individual’s readiness stage
- Public defines “goals” as “personal life goals”
- Values and/or goals as expressions of a person’s overarching philosophies and priorities in life
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.
Components of person-centred decision-making

A person's values, wishes, beliefs and goals for their care

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Components of person-centred decision-making

HOW a person makes healthcare decisions

PERSON

Advance care planning

TREATMENT

Goals of care discussion

Decision-making
HOW a person makes healthcare decisions

PERSON
- Values
- Goals
- what’s important
- why it’s important

TREATMENT
- Information
- Evidence
- about disease
- about treatments

Decisions

Two parts of the equation
BOTH are needed to be effective
76% of people are NOT able to participate in some or all of their own end-of-life decisions

HOW ARE WE DOING?
76% of substitute decision makers will be asked to interpret ACP and make end-of-life decisions.
In past, the purpose of ACP was thought to be about making advance decisions, i.e., decisions about treatments at end of life. Above purpose is outdated because of fundamental flaw... it takes the person out of the equation. Clear evidence that “advance directives” have little to no impact on outcomes, i.e., care received at end-of-life. Above purpose is outdated because of fundamental flaw... it takes the person out of the equation. For Ontario, beyond the evidence, this is legally incorrect and for most of Canada, there’s no such thing as advance directives.
Among pts asked to consider VALUES, 65-75% will base this on inaccurate information

Very few are asked to consider values however

- 65% of people with heart failure do NOT think it will shorten life
- 70% of people on dialysis think it heals or cures kidneys
- 75% of people with metastatic cancer do not appreciate it is NOT curable
REPORT CARD

Values
Goals

Information
Evidence

Decisions
needs improvement

needs improvement

needs improvement
WHAT NEEDS TO CHANGE?

PERSON
- Values
- Goals

Ensure a PERSON’S VALUES are known and part of the equation

TREATMENT
- Information
- Evidence

Improve UNDERSTANDING of health and illness

Decisions

Effective ACP

Engage SUBSTITUTE DECISION MAKERS
Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer


- Intervention = palliative care consult at diagnosis
- Significantly better quality of life
- Less symptomatic
- Less likely to receive “aggressive EOL care”
- Lived significantly longer
## What Did Palliative Care Clinicians Do?

Table 3. **Median Time for Components of Initial Outpatient Palliative Care Clinic Visit (n = 62)**

<table>
<thead>
<tr>
<th>PC consultation</th>
<th>Median time (range) minutes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total time</td>
<td>55.00 (20–120)</td>
</tr>
<tr>
<td><strong>Illness understanding</strong></td>
<td>10.00 (0–35)</td>
</tr>
<tr>
<td><strong>Symptom management</strong></td>
<td>20.00 (0–75)</td>
</tr>
<tr>
<td><strong>Decision making</strong></td>
<td>0.00 (0–20)</td>
</tr>
<tr>
<td><strong>Coping</strong></td>
<td>15.00 (0–78)</td>
</tr>
<tr>
<td><strong>Planning and referrals</strong></td>
<td>0.00 (0–20)</td>
</tr>
</tbody>
</table>

Note: this is the median
Elements of a person-centred goals of care discussion

• Begin with illness understanding
  – enables a person to reflect on values and goals with the right information (e.g. accurate illness understanding)

• Once values & goals are clear, determine with patient which treatments and care decisions would and would not meet GoC

• Decisions themselves might take a bit of time but important to distinguish from goals of care discussions
Example documentation of a GOC Discussion

GOC Conversation with Mrs. [Redacted] and son [Redacted]

ILLNESS UNDERSTANDING: [Redacted] expressed that the whole family is aware that their father is dying but that everyone is having a very difficult time with it.

VALUES AND GOALS: They describe Mr. [Redacted] as the king of the family, [Redacted] says he is his best friend. I asked about what the overall goal is of our treatment and he said they want Mr. [Redacted] to get everything possible. I asked for a clarification as to whether that meant everything possible to make him comfortable OR everything possible to extend his life, as unfortunately the two are not possible together. [Redacted] said that the family do not all agree in this decision but that he feels that we should do everything to keep his father comfortable. Mrs. [Redacted] was in agreement as was Grandson in the room.

END OF LIFE: The family said that Mr. [Redacted] wants to go home and that he wants to die at home, however he noted that it would be best for his father not to go home until he is a little stronger and not coughing. I explained that unfortunately his father will likely not get stronger and that he will continue to cough as those are very difficult things to reverse at this stage. I explained that if they want to take him home we can ask SW and the team to look into maximizing supports at home - he already has a palliative MD at home.

CODE STATUS: Given the focus is to be on comfort I asked about resuscitation and expressed my recommendation for NO CPR - [Redacted] agreed. He then asked questions about what happens after his fathers death, we discussed the process of transfer to funeral home from hospital and from home and I explained that they should not call 911 when he dies at home, but rather call the home palliative care service.

Created and Signed by: [Redacted] on [Redacted]
<table>
<thead>
<tr>
<th>Role of Interprofessional Providers in ACP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Anyone involved in patient/client/resident care</strong></td>
</tr>
<tr>
<td>Ask about SDM</td>
</tr>
<tr>
<td>Explain what ACP is</td>
</tr>
<tr>
<td>Discuss illness understanding</td>
</tr>
<tr>
<td>Clarify illness understanding</td>
</tr>
<tr>
<td>Discuss values, beliefs and quality of life and wishes</td>
</tr>
</tbody>
</table>
### Role of Interprofessional Providers in GOC

<table>
<thead>
<tr>
<th>Determination of Capacity</th>
<th>Trained Interprofessional ACP Facilitator (SW, Nurse, NP, MD, etc.)</th>
<th>MD/NP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Determine capacity for treatment or treatment plan</td>
<td></td>
<td>HCP proposing the treatment or plan*</td>
</tr>
<tr>
<td>Discuss values, life goals with capable patient or SDM</td>
<td>✔️</td>
<td>✔️</td>
</tr>
<tr>
<td>Discuss treatment plan and options</td>
<td></td>
<td>✔️</td>
</tr>
<tr>
<td>Consent for treatment or plan</td>
<td></td>
<td>✔️</td>
</tr>
</tbody>
</table>

*Exception: HCPs defined as “evaluators” as per the HCCA can determine capacity for admission to long term care.
## Key information

<table>
<thead>
<tr>
<th>ADVANCE CARE PLANNING</th>
<th>GOALS OF CARE DISCUSSION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning for future care</td>
<td>Decision-making for current care</td>
</tr>
<tr>
<td><strong>CONTEXT</strong></td>
<td><strong>EVIDENCE</strong></td>
</tr>
<tr>
<td>Good evidence that values-based conversations impacts outcomes</td>
<td>Limited evidence - likely due to lack of universally agreed upon definition</td>
</tr>
<tr>
<td><strong>OUTCOME</strong></td>
<td><strong>DECISIONS</strong></td>
</tr>
<tr>
<td>Clarify SDM; Patient outlines values &amp; other info that will guide SDM with future decision-making (should patient become incapable)</td>
<td>Ensure patient/SDM understands the illness; Ensure team understands patient’s values and goals, which inform Tx recommendations</td>
</tr>
<tr>
<td><strong>CLINICAL SKILLS</strong></td>
<td><strong>SIMILARITIES</strong></td>
</tr>
<tr>
<td>Decisions are not an element of ACP; Any expressed wish/preference re: specific treatments should be documented</td>
<td>Specific decisions or direction of care may be desired outcomes; Each decision is preceded by GOCD but not all GOCD result in decisions</td>
</tr>
<tr>
<td>Translating values in to information that would help guide SDMs</td>
<td>When values &amp; goals are clear, determining which treatments and care decisions will and will not align with GOC</td>
</tr>
</tbody>
</table>
| A process, often iterative  
Address illness understanding  
Assess information needs  
Explore values & beliefs  
Assess worries, fears; Trade offs | A process, often iterative  
Address illness understanding  
Assess information needs  
Explore values & beliefs  
Assess worries & fears; Trade offs |
We have failed to recognize in medicine and society that people have priorities besides just living longer, that they have aims and goals.

We have a major opportunity to change this.

Dr. A. Gawande

Acknowledgements & Credits:

[Names and affiliations listed]