Decision Quality in Cancer Care

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I have two small children and want to live as long as possible.

What are my options? I want to do everything possible.

What is the impact for each option on 10 yr survival? 20 yr?
Documenting the patients’ voice...

Information

I am concerned that my desire to forego treatment is discouraging and frustrating for you.

Involvement

I want to watch this recurrence and check it in 3 months. If it is growing then I will consider treatment.

Your support is important to me. Are you willing to support me in this alternative?
Documenting the patients’ voice...

**Information**

I am afraid of chemotherapy. It doesn’t make sense to me.

**Involvement**

I don’t understand how poisoning my body can make me better.

**Concordance**

I need my immune system to fight the cancer, but chemo weakens my immune system.
High quality, patient-centered care

Core Themes:

- fully informed
- play a key role in making healthcare decisions
- treatments reflect patients’ want, needs and preferences
Key questions

What is decision quality?

How are we doing?

Can we do better?
Defining decision quality:

For patients that meet clinical criteria, decision quality is defined as the extent to which patients are

- Informed,
- Meaningfully involved,
- And receive treatments that reflect their goals

Sepucha et al. 2004 Health Affairs; Elwyn BMJ 2006
Key questions

What is decision quality?

How are we doing?

Can we do better?
Measuring knowledge

• Key facts relevant to decision
  – Disease, options, outcomes, likelihood

• Perceptions not enough
  – Patients don’t know what they don’t know

• Facts ≠ knowledge (but hard to be informed without knowing some facts)
Are breast cancer patients well-informed?

• Survey of 1,800 women from Detroit and LA
  – ~50% knew survival was same with mastectomy and lumpectomy (Fagerlin et al. 2006)
  – 11% answered three basic questions about reconstruction correctly (Morrow et al. 2005)

• Vastly over-estimated benefit of chemotherapy (Ravdin et al. 1998)

• Vastly over-estimated risk of dying from DCIS (Rakovitch et al. 2003)
Measuring Involvement

Four key things need to happen:
1. Given options

2. Discuss PROS of options
   (A lot/Some/A little/Not at all)

3. Discuss CONS of options
   (A lot/Some/A little/Not at all)

4. Discuss patients’ goals/preferences
Are breast cancer patients involved?

Options

Pros (A lot) 58% 41%
Cons (A lot) 18%
Pt Pref 49%

N=440, Lee et al. 2009
Measuring goals

• Salient issues upon which the decision rests

• Challenge: goals change with experience, knowledge, and over time
How important is it to reduce the chance of having cancer come back in the breast?
How important is it to keep your breast?
Concordance

We are matching right treatment with right patient, most of the time but…

• 18% preferred mastectomy but had lumpectomy
• 20% preferred reconstruction but didn’t have it
• 16% preferred chemo but didn’t have it

Lee et al, 2009; Lee et al 2010
Key questions

What is decision quality?

How are we doing?

Can we do better?
Case 1: UCSF Decision Services

- Decision aids
- Question listing
- Note taking

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<thead>
<tr>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
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<tbody>
<tr>
<td>Eugene Fan</td>
<td>Jimmy Barnes</td>
<td>Andrea Spillmann</td>
<td>Clark Fisher</td>
<td>Julia Pederson</td>
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What’s possible after decision support?

- Options: 95%
- Pros (A lot): 78%
- Cons (A lot): 56%
- PtPrefs: 66%

N=131, Belkora et al. 2011
Case 2: Dartmouth Breast Center

1. Workflow redesign

2. Decision aids

3. Clinical decision support
Values: Decision Making
Leaning toward: Mastectomy
Sure about choice: No
Knowledge:
- Understands:
  - Survival rates
  - Recurrence rates

Bar chart:
- Keep breast: 8
- Minimize chance of recurrence: 8
- Avoid radiation: 10
- Did everything possible: 7
- Minimize length of tx: 6
- Avoid breast reconstruction: 5
- Do what doctor thinks best: 3
- Remove breast (peace of mind): 4

Distress Level: Moderate 7.0/10
A referral to a breast care coordinator has been made. A referral for familial counseling has been made.
## What’s possible: Knowledge scores

<table>
<thead>
<tr>
<th>Correct response (%) (n = 115)</th>
<th>Post consult</th>
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<tbody>
<tr>
<td>1. Survival rate</td>
<td>96%</td>
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<tr>
<td>2. Recurrence rates</td>
<td>63%</td>
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<td>3. Recurrence likelihood</td>
<td>94%</td>
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<td>4. Urgency of decision</td>
<td>99%</td>
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<td><strong>TOTAL (average)</strong></td>
<td><strong>92%</strong></td>
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Collins et al 2009
Summary

- Quality of cancer treatment decisions is variable, often poor

- Shared decision making, supported by decision aids and other tools, works and it is happening (just not enough)

- Accountability and quality improvement through measurement of decision quality is important
Thank you!

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