Can we do better?

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Shared Decision Making in Breast Cancer
• No Disclosures
Objectives

- Define SDM
- Learn how it can add value to your Dr/Pt relationship
- Highlight value of SDM in breast cancer
SHARED DECISION MAKING IS DEFINED AS DECISIONS THAT ARE SHARED BY DOCTORS AND PATIENTS, INFORMED BY THE BEST EVIDENCE AVAILABLE AND WEIGHTED ACCORDING TO THE SPECIFIC CHARACTERISTICS AND VALUES OF THE PATIENT.

LÉGARÉ
Shared Decision Making

- Clinician and patient work together
- They share information
  - About options and outcomes
  - About preferences
- They work toward a consensus about the preferred test or treatment
- They reach an agreement on the test or treatment to implement
Goals of Shared Decision Making

Patients Should be:

- **Supported & encouraged to participate in their health care decisions**
- **Fully informed with accurate, unbiased & understandable information**
- **Respected by having their goals & concerns honored**
Evidence of the Problem

Medical Practice Variation
40 Years of Research
Documenting Inconsistent Care

The DECISIONS Study
A Portrait of How Americans Make Common Medical Decisions
Avoid this...

**Patients:**
Making Decisions in the Face of Avoidable Ignorance

**Clinicians:**
Poorly “Diagnosing” Patients’ Preferences

**Poor Decision Quality**
Support for the model

- SDM supported by patient decision aids improves decision quality
- Both patients and physicians support SDM
- Implementation models are demonstrating that SDM can work “in the trenches”
Shared Decision Making is at the Core of Ethical, Patient Centered Care

- Patient Centered Medical Home
- Accountable Care Organizations
- Meaningful Use of Health Information Technology (HIT)
### Foundation Demonstration Sites

<table>
<thead>
<tr>
<th>Site</th>
<th>Primary Care</th>
<th>Specialty Care</th>
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<tbody>
<tr>
<td>Dartmouth Hitchcock Medical Center</td>
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<tr>
<td>White River Junction VA</td>
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<tr>
<td>Massachusetts General Hospital</td>
<td>X</td>
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<tr>
<td>University of North Carolina</td>
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<td>Maine Health</td>
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<td>Mercy Clinics Inc.</td>
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<td>Stillwater Medical Group</td>
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<td>Oregon Rural Practice Based Research Network</td>
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<td>Palo Alto Medical Research Foundation</td>
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<tr>
<td><strong>Group Health Cooperative</strong></td>
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<td>Everett Clinic</td>
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<td>Multi-Care Health System</td>
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<td>Virginia Mason Medical Center</td>
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<tr>
<td>Allegheny General Hospital - Breast Center</td>
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<tr>
<td>Carol Milgard Breast Care Center</td>
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<tr>
<td>University of California San Francisco - Breast Center</td>
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<tr>
<td>DHMC - Breast Center</td>
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<td>DHMC - Urology</td>
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<td>DHMC - Orthopedics</td>
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<td>DHMC - Spine Center</td>
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<tr>
<td>DHMC - Cardiology</td>
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<tr>
<td><strong>Non-Funded Demonstration Sites</strong></td>
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<tr>
<td>Mackey Family Practice</td>
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<tr>
<td>Peace Health (Oregon)</td>
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<tr>
<td>Mercy Cancer Center (Oklahoma)</td>
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</table>
Challenges in Making Treatment Recommendations

- Do patients understand their own needs when making treatment decisions?
- Each patient has different levels of need for information, support and autonomy
- Patients have different risk literacy, numeracy, culture
- Patient’s needs/expectations change over time
Key Elements of SDM

- Patient knowledge
- Explicit encouragement of patient participation
- Appreciation of the patient's ability to play an active role in decision
- Awareness of choice
- Time

Fraenkel & McGraw, J Gen Intern Med. 2007
Barriers

Clinicians
- Challenge to physician autonomy
- Don’t recognize preference sensitive decisions
- Evidence difficult to extract, interpret, communicate

Practice
- Logistics
- Lack of time
- Lack of reimbursement

Patients
- “Patients don’t want to participate”
- Variation in role preference
- Literacy, numeracy challenges

Resources
- Need portfolio of appropriate decision aids
SDM and Breast Cancer

- Neo adjuvant therapy

- Mastectomy +/- reconstruction

- BCS +/- RT

- Oncotype Dx

- Genetic testing
56 yo with small stage I

Abnormal mammogram
  More tests?

Primary Care
  Which surgeon?

Radiology
  What kind of biopsy?

Surgeon
  Which surgery?

Radiation Oncologist
  What type of XRT?
  What protocol?

Surgery
  What type of anesthesia?

Oncologist
  Oncotype Dx?

Genetecist
  Options if positive?

5 weeks later....
• Since early to mid-1980s, lumpectomy + radiation therapy have been considered equally effective as mastectomy

• Majority of women prefer BCT to mastectomy when offered both options
How informed are decisions about BCT?

- Population based sample of 1844 women
  - Only 48% knew that survival is equal between mastectomy and BCT
  - Only 16% knew that BCT may have higher local recurrence rate than mastectomy
- **Lower knowledge with:**
  - male surgeon
  - lack of treatment options
  - less internet or health pamphlet use

*Fagerlin et al, Patient Ed Counseling 2006*
What decisional role do cancer patients want?

<table>
<thead>
<tr>
<th>Preferred Role</th>
<th>Incidence</th>
</tr>
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<tbody>
<tr>
<td>Active</td>
<td>20 - 39%</td>
</tr>
<tr>
<td>Collaborative</td>
<td>28 - 64%</td>
</tr>
<tr>
<td>Passive</td>
<td>8 - 52%</td>
</tr>
</tbody>
</table>

• True autonomy in decision-making is rare (0.5-1%)
Desired vs. Actual Role in Breast Cancer

• Survey of 145 women with breast CA, 1 week after surgery or neoadjuvant chemotherapy

• Only 41% felt they had a choice in their treatment

• 63% had desired decisional role
  ➢ 30% preferred SDM
  ➢ 78% preferring active or passive

Vogel et al, Psychooncology 2008
Do breast cancer patients’ desired role change?

• Longitudinal study of 205 breast cancer patients

• Desired decision-making role assessed at baseline

• Active, Collaborative or Passive

• Subsequently asked again ~ 3 years later

*Hack et al, Psychooncology 2006*
### Desired role change over time

<table>
<thead>
<tr>
<th>Role Preference at 3 years</th>
<th>Active</th>
<th>Collaborative</th>
<th>Passive</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>33</td>
<td>18</td>
<td>21</td>
<td>36%</td>
</tr>
<tr>
<td>C</td>
<td>19</td>
<td>22</td>
<td>43</td>
<td>42%</td>
</tr>
<tr>
<td>P</td>
<td>3</td>
<td>2</td>
<td>41</td>
<td>22%</td>
</tr>
</tbody>
</table>

27% 21% 52%

*Hack et al, Psychooncology 2006*
• “Active” patients had better QoL, physical, emotional metrics and less fatigue through treatment

• Patients that had been passive expressed ‘role regret’ more than decisional regret

Hack et al, Psychooncology 2006
Satisfaction and Provider Trust after BCS

- U Michigan survey of 714 breast cancer patients after BCS

- Patients answered several months to several years after initial plans for BCS

- Rated satisfaction, decisional conflict, decisional regret and provider trust

Walgee et al, Cancer 2008
# Decisional Conflict and Regret

<table>
<thead>
<tr>
<th>Endpoint</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Certain of decision</td>
<td>55</td>
</tr>
<tr>
<td>Prepared to make decision</td>
<td>61</td>
</tr>
<tr>
<td>Felt effective in the decision-making process</td>
<td>87</td>
</tr>
<tr>
<td>Regretted decision</td>
<td>13</td>
</tr>
</tbody>
</table>

Walgee et al, Cancer 2008
Patient Satisfaction

• No correlation with #re-excisions, complications or need for mastectomy

• Breast asymmetry is associated with less satisfaction, less certainty in decision for BCS and more decisional regret

• Women receiving RT more likely to feel have decisional conflict

Walgee et al, Cancer 2008
Provider Trust

• Lower MD trust with asymmetry, postop complications, need for re-excision

• Trend toward less MD trust with higher education and Caucasian ethnicity

Walgee et al, Cancer 2008
Differences by Age

• Older women tend to make more immediate decisions
  – Limited cognitive resources
  – Greater knowledge/experience
  – More likely to take passive role

• Often have lower QoL, physical and emotional functioning scores

• Older women still benefit from SDM

Meyer & Talbot, Psych Aging 2008
Hack et al, Psychooncology 2006
Liang et al, JCO 2002
What barriers do doctors see to SDM?

**Doctor-Related:**
- Insufficient information @ 1st Visit 29%
- Insufficient time with the patient 28%

**Patient-Related:**
- Misconceptions about disease 27%
- Indecision 24%
- Anxiety 22%
- Lack of understand of information 20%

*Shepard et al, JCO 2008*
• 85% of women wanted shared or active role

• Among patients desiring shared role:
  – 50% felt more active than preferred
  – 16% didn’t feel involved enough

• Perception of patient and doctor correlated in only 38%

Jann et al, JCO 2004
DA Enhances Patient Knowledge

Walgee et al, JCO 2007
Advantages of Decision Support Tools*

• Help set tone and put patients at ease
• Ensure essential information is transmitted
• May be better than clinician:
  – Reduce embarrassment
  – Allow learning at comfortable pace
  – Make it more effective time use when meeting with clinician
  – May more effectively engage in SDM

* For genetic counseling

Treatment Options in BCT: More is Less*

• More RT options may lead to:
  – Sense of Knowledge Deficit
  – Uncertainty
  – Anxiety
  – Distress
  – Regret
  – Dissatisfaction

• Increasing the complexity of decision-making for BCT may increase mastectomy rates

* Barry Schwartz, The Paradox of Choice
SDM and Multidisciplinary Breast Cancer Care

Pros:
– Enhances specialist communication
– Increases patient confidence in “team” approach
– Improves patient’s efficiency in obtaining expert opinions in a single visit

Cons:
– Information overload (not enough depth)
– May affect patient’s ability to assert a more active decisional role
– Medico legal aspects
  • 33% of MDs feels discussion environment is suboptimal
  • 85% may disagree with MDM decision but 71% don’t voice it
Decision Support before Consultation?

- Provide information resource to patients before meeting with clinician
- Assess patient’s desired decisional role more accurately
- Cognitive/psychological support to “prime” patient for SDM
- Reduce decisional regret, improve patient’s cancer experience
Why Shared Decision Making in Health Care?
Conclusions

- SDM has become increasingly important
- Unmet patient needs when deciding between mastectomy and BCT
- Patient’s perceived role is key to satisfaction and provider trust
- We don’t always assess patient’s desired decisional role accurately
Conclusions

• Better doctor-patient communication can reduce distress and decisional regret

• Decision support can facilitate SDM for patient-clinician dyad

• Effective SDM is a more important goal than BCT rates

• Online tools
Thank You