Patient Decision Aids to Support Shared Decision Making
Making SDM Practical “In the Trenches”

AUA/SMDM Quality Improvement Summit
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Informed Medical Decisions Foundation President
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Disclosures

• Dr. Barry is an employee and Chief Science Officer of Healthwise, a 501(c)3 nonprofit organization

• He is also an employee at Massachusetts General Hospital, another nonprofit
• Healthwise’s mission is to help people make better health decisions.
Are patients informed?

Percentage of patients who answered each knowledge question correctly

- **28%**
  - How many people get pain relief from surgery

- **46%**
  - How many people experience a surgical complication (e.g., wound infection)

- **15%**
  - How many people will have replacement last at least 20 years

- **39%**
  - How long most people require to return to normal activity

Are patients involved?

- **Doctor discussed reasons for procedure:**
  - PCA Surgery: 95%
  - Coronary stent: 77%

- **Doctor discussed reasons might not want procedure:**
  - PCA Surgery: 63%
  - Coronary stent: 19%

- **Doctor discussed any alternative as serious option:**
  - PCA Surgery: 64%
  - Coronary stent: 10%

- **Doctor asked about patient preference for Rx:**
  - PCA Surgery: 76%
  - Coronary stent: 16%

# Top Three Goals and Concerns for Breast Cancer Decisions

<table>
<thead>
<tr>
<th>Condition: Goal</th>
<th>Pat</th>
<th>Prov</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep your breast?</td>
<td></td>
<td>71%</td>
<td></td>
</tr>
<tr>
<td>Live as long as possible?</td>
<td></td>
<td>96%</td>
<td></td>
</tr>
<tr>
<td>Look natural without clothes</td>
<td></td>
<td>80%</td>
<td></td>
</tr>
<tr>
<td>Avoid using prosthesis</td>
<td></td>
<td>0%</td>
<td></td>
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</tbody>
</table>

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<tr>
<th>Condition: Goal</th>
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<th>Prov</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Keep your breast?</td>
<td>7%</td>
<td>71%</td>
<td>P&lt;0.01</td>
</tr>
<tr>
<td>Live as long as possible?</td>
<td>59%</td>
<td>96%</td>
<td>P=0.01</td>
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<tr>
<td>Look natural without clothes</td>
<td>33%</td>
<td>80%</td>
<td>P=0.05</td>
</tr>
<tr>
<td>Avoid using prosthesis</td>
<td>33%</td>
<td>0%</td>
<td>P&lt;0.01</td>
</tr>
</tbody>
</table>
The Silent Misdiagnosis

“Many doctors aspire to excellence in diagnosing disease. Far fewer, unfortunately, aspire to the same standards of excellence in diagnosing what patients want.”

PSA Screening: Medicare Beneficiaries 75 and Under (2010)

From the Dartmouth Atlas of Health Care. Each blue dot represents the rate of PSA testing in one of 306 hospital referral regions in the U.S. Red dots indicate the regions with the 5 lowest and 5 highest rates:

- Miami, FL 58.4%
- Wilmington, NC 55.8%
- Sun City, AZ 55.1%
- Paterson, NJ 53.7%
- McAllen, TX 53.5%
- Binghamton, NY 7.2%
- Minot, ND 7.2%
- Burlington, VT 6.8%
- Mason City, IA 5.8%
- Lebanon, NH 3.6%
Forces Sustaining Unwanted Practice Variation

Patients: Making Decisions in the Face of Avoidable Ignorance

Clinicians: Less than Optimal “Diagnosis” of Patients’ Preferences

Poor Decision Quality Unwanted Practice Variation
PSA Screening Guidelines (2016)

- American Cancer Society: Offer prostate cancer screening at age 50, at 45 with risk factors
- USPSTF: “D” recommendation against routine PSA screening for men of all ages
- American College of Physicians: Discuss benefits and harms of screening for men age 50-69
- NHS: “...it has not been proven that the benefits would outweigh the risks.”
- American Urological Association: Discuss PSA screening for men age 55-69
AUA BPH Guideline (1994)

- **Standard**: Patients with mild symptoms (symptom score 0-7) should be followed with “watchful waiting”

- **Guideline**: Patients with moderate and severe symptoms (symptom score 9-35) should be given information on the benefits and harms of watchful waiting, medications, and surgery

*(BPH Guideline Panel. AHCPR Publication No.94-0582, 1994)*
Shared Decision Making Model

• Key characteristics:
  • At least two participants (clinician & patient) are involved
  • Both parties share information
  • Both parties take steps to build a consensus about the preferred treatment
  • An agreement is reached on the treatment to implement

Patient Decision Aids Can Help!

• Tools designed to help people participate in decision-making
• Provide information on the options
• Help patients clarify and communicate the values they associate with different features of the options
Draft Certification Criteria: WA State

• Is it a Decision Aid? “Qualifying Criteria”
  • Describe health condition
  • Explicitly state decision
  • Identify who is eligible
  • Describe the benefits of each option
  • Describe the harms of each option
  • Help patient clarify their values
Draft Certification Criteria: WA State

• Is it a *Good* Decision Aid? “Certifying Criteria”
  • Possible to compare features of options
  • Show benefits and harms with balanced detail
  • Provide information about funding sources
  • Report whether authors stand to gain or lose
  • Include authors’ credentials or qualifications
  • Provide “born on” date
Draft Certification Criteria: WA State

• “Certifying Criteria” for pDAs about Tests
  • What test designed to measure
  • Next steps if test suspicious
  • Next steps if test not suspicious
  • Consequences of overdiagnosis
  • Chance of true/false positive
  • Chance of false positive
Draft Certification Criteria: WA State

• Information about Development Process
  • Funding Sources
    • Disclose COI
    • Describe efforts to eliminate bias
    • Developer/authors free from disqualifications
  • Developed using high quality evidence in a systematic and unbiased fashion
  • Field test with patients and incorporate results
In 115 trials (34,444 participants) from 9 countries, use of decision aids has led to:

- Increased knowledge
- More accurate risk perceptions
- Lower decision conflict
- Fewer people passive in decision making
- Fewer people remaining undecided
- Decisions more congruent with patient values
- 21% fewer patients choosing surgery (15 trials)

1.7.2 Intention to treat analysis

<table>
<thead>
<tr>
<th>Study</th>
<th>Total Events</th>
<th>Events</th>
<th>Events</th>
<th>95% CI</th>
<th>p Value</th>
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<tr>
<td>Kennedy 2002</td>
<td></td>
<td>82</td>
<td>300</td>
<td>101 298</td>
<td>0.81 [0.63, 1.03]</td>
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<tr>
<td>Bernstein 1998</td>
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<td>25</td>
<td>65</td>
<td>28 53</td>
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<tr>
<td>Morgan 2000</td>
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<td>45</td>
<td>120</td>
<td>63 120</td>
<td>0.71 [0.54, 0.95]</td>
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<tr>
<td>Murray 2001a</td>
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<td>6</td>
<td>57</td>
<td>1 55</td>
<td>5.79 [0.72, 46.54]</td>
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<tr>
<td>Vuormala 2003</td>
<td></td>
<td>98</td>
<td>184</td>
<td>88 179</td>
<td>1.08 [0.89, 1.32]</td>
</tr>
<tr>
<td>Whelan 2004</td>
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<td>6</td>
<td>94</td>
<td>26 107</td>
<td>0.26 [0.11, 0.61]</td>
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<tr>
<td>Auvinen 2004</td>
<td></td>
<td>60</td>
<td>104</td>
<td>91 106</td>
<td>0.67 [0.56, 0.81]</td>
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<tr>
<td>Barry 1997</td>
<td></td>
<td>8</td>
<td>104</td>
<td>16 123</td>
<td>0.59 [0.26, 1.33]</td>
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<tr>
<td>Schwartz 2009</td>
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<td>18</td>
<td>100</td>
<td>15 114</td>
<td>1.37 [0.73, 2.57]</td>
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<tr>
<td>Tiller 2006</td>
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<td>18</td>
<td>68</td>
<td>17 63</td>
<td>0.98 [0.56, 1.73]</td>
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<tr>
<td>Vodermaier 2009</td>
<td></td>
<td>2</td>
<td>39</td>
<td>5 41</td>
<td>0.42 [0.09, 2.04]</td>
</tr>
</tbody>
</table>

**Subtotal (95% CI)**

<table>
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<tr>
<th>Events</th>
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<th>95% CI</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1235</td>
<td>1259</td>
<td>100.0%</td>
<td>0.79 [0.64, 0.97]</td>
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</tbody>
</table>

**Total events**

368 451

Heterogeneity: $\tau^2 = 0.06$; $\text{Chi}^2 = 27.70$, df = 10 ($P = 0.002$); $I^2 = 64\%$

Test for overall effect: $Z = 2.20$ ($P = 0.03$)
Effect of the Same Decision Aid on BPH Surgery: Barry (US) vs Murray (UK)

PSA Test Leanings After a pDA

PSA leanings before and after viewing the decision aid, N=1008. P<0.001 for overall changes in proportions across matched pairs.

Thank You!

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