SHARED DECISION MAKING AND DECISION AIDS TO BRING CER TO PATIENTS AND CLINICIANS

The Fourth National Comparative Effectiveness Summit

Michael J Barry, MD
Foundation President
November 5, 2012
The mission of the Foundation is to inform and amplify the patient’s voice in health care decisions.
WE BELIEVE 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
THE FOUNDATION AND HEALTH DIALOG

• The Foundation has a licensing agreement with Health Dialog (owned by Bupa).
  • Provides royalties and contract funding to develop and maintain decision support materials.
• Strict conflict-of-interest policy.
  • Staff and Medical Editors are prohibited from financial support from the drug and device industries.
IS INFORMED CONSENT “REAL?”

• In a survey of consecutive patients scheduled for an elective coronary revascularization procedure at Yale New Haven Hospital in 1997-1998:
  • 75% believed PCI would help prevent an MI.
  • 71% believed PCI would help them live longer.
IS INFORMED CONSENT “REAL?”

• While even through the latest meta-analysis in 2009 (61 trials and 25,388 patients):
  • “Sequential innovations in catheter-based treatment for non-acute coronary artery disease showed no evidence of an effect on death or myocardial infarction when compared to medical therapy.”

IS INFORMED CONSENT “REAL?”

- In a survey of consecutive patients consented for an elective coronary angiogram and possible percutaneous coronary coronary intervention at Baystate Medical Center in 2007-2008:
  - 88% believed PCI would help prevent an MI.
  - 76% believed PCI would help them live longer.

DECISIONS STUDY

- Conducted by University of Michigan
- Nationwide random-digit dial telephone survey
- Probability sample of 2,575 English speaking American age 40+
- Reported a discussion of 1 of 9 medical decisions with a health care provider within the past 2 years
- Response rate of 51%

The DECISIONS Study. Medical Decision Making. 2010; 30 supplement I.
DECISIONS SURVEY: DECISIONS ADDRESSED

• Surgery
  • Back surgery
  • Knee/hip replacement
  • Cataract extraction
• Cancer screening
  • Prostate
  • Colorectal
  • Breast
• Medications
  • Hypertension
  • Hyperlipidemia
  • Depression
EPIDEMIOLOGY OF MEDICAL DECISIONS

• In the past 2 years:
  • 56% discussed starting or stopping meds for hypertension, hyperlipidemia or depression
  • 72% discussed a screening test for cancer
  • 16% discussed one of the 4 operations
HOW MUCH DID PATIENTS KNOW?

• Clinical experts identified 4-5 facts a person should know, for example, common side effects of medications or surgery
• Respondents were asked the knowledge questions related to their decision
• For 8 out of 10 decisions, fewer than half of respondents could get more than one knowledge question right
“DIAGNOSIS” OF PATIENT PREFERENCES

U.S. CORONARY BYPASS RATES
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
WHAT IS GOOD MEDICAL CARE?

• It is not just about doing things right
• It is also about doing the right thing
• Proven effective care: For some medical problems, there is one best way to proceed
• Preference-sensitive care: For many and perhaps most medical problems, there is more than one reasonable option
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
CER AND SHARED DECISION MAKING

• A key part of the SDM process is a sharing of information on the options for testing or treatment and their outcomes
• CER has the potential to supply that information in a systematic, unbiased way
• So SDM supported by pDAs can be seen as a promising way of disseminating CER to improve decision making in day-to-day health care
Interactive pDAs allow tailoring of presentation to the individual to the extent depth of CER data allows.

Linkage to clinical data in EMRs will facilitate this tailoring.

Process of developing pDAs may be an excellent way of helping prioritize data needs from CER.
• U.S. PIVOT RCT of RP vs. Observation, localized cancer (N=731)
• ~50% of PCa Stage T1c
• Reduced overall mortality from 49.9% in the OBS group to 47.0% in the RP group at 10 years (P=NS, NNT=34)
• Reduced PCa specific mortality from 8.4% in the OBS group to 5.8% in RP group at 10 years (P=NS, NNT=38)

Wilt et al. *NEJM* 2012;367:203
CER AND SHARED DECISION MAKING

- Patient characteristics (age, race, comorbidity) did not modify the effect of treatment
- But tumor characteristics did!
  - PSA $\leq 10$ (N=479) overall mortality increased from 43.6% with OBS to 46.2% with RP (P=NS, NNH=38)
  - PSA $> 10$ (N=251) overall mortality decreased from 61.6% with OBS to 48.4% with RP (P=0.02, NNT=8)

Wilt et al. *NEJM* 2012;367:203
In 86 trials in 6 countries of 34 different decisions, use has led to:

- Greater knowledge
- More accurate risk perceptions
- Lower decision conflict
- Greater participation in decision-making
- Fewer people remaining undecided

1.7.2 Intention to treat analysis

<table>
<thead>
<tr>
<th>Study</th>
<th>Events</th>
<th>Control</th>
<th>Total</th>
<th>Odds Ratio</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kennedy 2002</td>
<td>82</td>
<td>300</td>
<td>101</td>
<td>15.2%</td>
<td>0.81 [0.63, 1.03]</td>
<td>0.44</td>
</tr>
<tr>
<td>Bernstein 1998</td>
<td>25</td>
<td>65</td>
<td>28</td>
<td>11.2%</td>
<td>0.73 [0.49, 1.09]</td>
<td>0.11</td>
</tr>
<tr>
<td>Morgan 2000</td>
<td>45</td>
<td>120</td>
<td>63</td>
<td>14.0%</td>
<td>0.71 [0.54, 0.95]</td>
<td>0.03</td>
</tr>
<tr>
<td>Murray 2001a</td>
<td>6</td>
<td>57</td>
<td>1</td>
<td>0.9%</td>
<td>5.79 [0.72, 46.54]</td>
<td>0.10</td>
</tr>
<tr>
<td>Vuorma 2003</td>
<td>98</td>
<td>184</td>
<td>88</td>
<td>16.2%</td>
<td>1.08 [0.89, 1.32]</td>
<td>0.22</td>
</tr>
<tr>
<td>Whelan 2004</td>
<td>6</td>
<td>94</td>
<td>26</td>
<td>4.6%</td>
<td>0.26 [0.11, 0.61]</td>
<td>0.32</td>
</tr>
<tr>
<td>Auvinen 2004</td>
<td>60</td>
<td>104</td>
<td>91</td>
<td>16.7%</td>
<td>0.67 [0.56, 0.81]</td>
<td>0.001</td>
</tr>
<tr>
<td>Barry 1997</td>
<td>8</td>
<td>104</td>
<td>16</td>
<td>4.9%</td>
<td>0.59 [0.26, 1.33]</td>
<td>0.35</td>
</tr>
<tr>
<td>Schwartz 2009</td>
<td>18</td>
<td>100</td>
<td>15</td>
<td>6.9%</td>
<td>1.37 [0.73, 2.57]</td>
<td>0.32</td>
</tr>
<tr>
<td>Tiller 2006</td>
<td>18</td>
<td>68</td>
<td>17</td>
<td>7.9%</td>
<td>0.98 [0.56, 1.73]</td>
<td>0.93</td>
</tr>
<tr>
<td>Vodermaier 2009</td>
<td>2</td>
<td>39</td>
<td>5</td>
<td>1.6%</td>
<td>0.42 [0.09, 2.04]</td>
<td>0.13</td>
</tr>
<tr>
<td><strong>Subtotal (95% CI)</strong></td>
<td><strong>1235</strong></td>
<td><strong>1259</strong></td>
<td><strong>100.0%</strong></td>
<td><strong>0.79 [0.64, 0.97]</strong></td>
<td>0.002</td>
<td></td>
</tr>
</tbody>
</table>

Total events: 368, 451

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

Test for overall effect: $Z = 2.20$ (P = 0.03)
HOW DO WE KNOW IF WE’VE HELPED PATIENTS MAKE A GOOD DECISION?
Did the patient know a decision was being made? Was the patient told the pros and cons of the treatment options? Did the provider elicit the patient’s preferences?

Did the decision reflect the patient’s goals and concerns?

Did the patient know what he or she needed to know?

SDM: IMPLEMENTATION NEEDS

- Patients interested in being informed and activated
- Practical protocols for routine use of decision support tools
- Health care systems with incentives for good “decision quality” rather than simply “more is better”
- Clinicians and hospitals receptive to patient participation
# FOUNDATION DEMONSTRATION SITES

<table>
<thead>
<tr>
<th>Demonstration Sites</th>
<th>Primary Care</th>
<th>Specialty Care</th>
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<tbody>
<tr>
<td>Massachusetts General Hospital</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>University of North Carolina</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>MaineHealth</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Mercy Clinics Inc.</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Stillwater Medical Group</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Oregon Rural Practice-based Research Network</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Palo Alto Medical Research Foundation</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Peace Health</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>PA FQHCs</td>
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<tr>
<td>Dartmouth-Hitchcock Medical Center</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Group Health Cooperative</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>University of Washington</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Allegheny General Hospital – Breast Cancer</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>University of California San Francisco – Breast Cancer</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

* Medical Home
KNOWLEDGE SCORES BY DA EXPOSURE LEVEL: AGE GROUP

Includes all valid demonstration site surveys in Illume database distributed in a primary care setting as of 8/1/12 (unweighted)
*All significance tests are independent sample t-tests; * = Difference in means is statistically significant (p ≤ 0.05)
1DA Exposure Level definition: Low = none of either OR some of both OR (some of one AND none of the other); Medium = Most of both OR (most of all of one AND (none or some of the other)); High = All of both OR (all of one AND most of the other)
KNOWLEDGE SCORES BY DA EXPOSURE LEVEL: EDUCATION LEVEL

Includes all valid demonstration site surveys in Illume database distributed in a primary care setting as of 8/1/12 (unweighted)

*All significance tests are independent sample t-tests; * = Difference in means is statistically significant (p ≤ 0.05)

1DA Exposure Level definition: Low = none of either OR some of both OR (some of one AND none of the other); Medium = Most of both OR (most of all of one AND (none or some of the other)); High = All of both OR (all of one AND most of the other)
IMPORTANCE RATINGS BY DEMOGRAPHIC GROUP

### Overall
- Extremely: 30
- Very: 55
- Somewhat: 14
- Not at all: 625

### Age
- <50
  - Extremely: 32
  - Very: 51
  - Somewhat: 16
- 50 - 64
  - Extremely: 30
  - Very: 56
  - Somewhat: 13
- 65+
  - Extremely: 30
  - Very: 54
  - Somewhat: 15

### Education
- 4y college+
  - Extremely: 29
  - Very: 55
  - Somewhat: 16
- Some college
  - Extremely: 32
  - Very: 56
  - Somewhat: 11
- HS or less
  - Extremely: 31
  - Very: 54
  - Somewhat: 14

### Gender
- Male
  - Extremely: 29
  - Very: 56
  - Somewhat: 15
- Female
  - Extremely: 32
  - Very: 54
  - Somewhat: 13

Includes all valid demonstration site surveys in Illume database distributed in a primary care setting as of 8/1/12 (unweighted)

*Statistically significant (p ≤ 0.05) (Chi square test)
### Decision Role Preferences by Demographic Group

<table>
<thead>
<tr>
<th>Age</th>
<th>Overall</th>
<th>Both equally</th>
<th>Your HCP</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;50</td>
<td>28</td>
<td>68</td>
<td>4</td>
<td>628</td>
</tr>
<tr>
<td>50 - 64</td>
<td>30</td>
<td>65</td>
<td>5</td>
<td>2,013</td>
</tr>
<tr>
<td>65+</td>
<td>27</td>
<td>70</td>
<td>3</td>
<td>1,385</td>
</tr>
</tbody>
</table>

**Education**

<table>
<thead>
<tr>
<th>Education</th>
<th>Overall</th>
<th>Both equally</th>
<th>Your HCP</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>4y college+</td>
<td>31</td>
<td>65</td>
<td>4</td>
<td>1,721</td>
</tr>
<tr>
<td>Some college</td>
<td>25</td>
<td>71</td>
<td>4</td>
<td>1,013</td>
</tr>
<tr>
<td>HS or less</td>
<td>24</td>
<td>71</td>
<td>5</td>
<td>1,154</td>
</tr>
</tbody>
</table>

**Gender**

<table>
<thead>
<tr>
<th>Gender</th>
<th>Overall</th>
<th>Both equally</th>
<th>Your HCP</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>31</td>
<td>65</td>
<td>5</td>
<td>2,265</td>
</tr>
<tr>
<td>Female</td>
<td>23</td>
<td>73</td>
<td>4</td>
<td>1,678</td>
</tr>
</tbody>
</table>

*Includes all valid demonstration site surveys in Illume database distributed in a primary care setting as of 8/1/12 (unweighted)*

*Statistically significant (p ≤ 0.05) (Chi square test)*
PATIENT LEANINGS BEFORE AND AFTER DA: JOINT REPLACEMENT SURGERY

Includes all valid demonstration site surveys in Illume database distributed in a primary care setting as of 8/1/12 (unweighted)

*Significant difference (p ≤ .05) (McNemar test)
PATIENT LEANINGS BEFORE AND AFTER DA: SCREENING

Colon Cancer Screening
n = 556

<table>
<thead>
<tr>
<th></th>
<th>Before</th>
<th>After</th>
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</thead>
<tbody>
<tr>
<td>Not sure</td>
<td>23</td>
<td>15</td>
</tr>
<tr>
<td>Being Screened</td>
<td>61</td>
<td>71</td>
</tr>
</tbody>
</table>

p < .001*

PSA Testing
n = 1,138

<table>
<thead>
<tr>
<th></th>
<th>Before</th>
<th>After</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not sure</td>
<td>32</td>
<td>17</td>
</tr>
<tr>
<td>Not being screened</td>
<td>42</td>
<td>37</td>
</tr>
<tr>
<td>Being Screened</td>
<td>46</td>
<td></td>
</tr>
</tbody>
</table>

p < .001*

Includes all valid demonstration site surveys in Illume database distributed in a primary care setting as of 8/1/12 (unweighted)

*Significant difference (p ≤ .05) (McNemar test)
HIP AND KNEE DECISION AIDS AT GROUP HEALTH

- Introduced pDAs for hip/knee arthroplasty candidates in 2009
- Reached 28% of eligible knee (N=3510) and 41% of hip patients (N=820)
- Over 6 months:
  - 38% fewer knee replacements
  - 26% fewer hip replacements
  - 12-21% lower costs

_Arterburn D, et al. Health Affairs 2012; 31(9)_
THANK YOU!

MBARRY@IMDFOUNDATION.ORG
WWW.INFORMEDMEDICALDECISIONS.ORG