Uninformed Decisions

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Foundation for Informed Medical Decision Making
How are decisions made in America?

• They are driven by physicians
• Patients have very little information
• Patients have very little input
This isn’t new

• In 1982, a Presidential Commission on Ethics in Medicine declared that it was \textit{unethical} for patients to be given treatments who were not prepared to have an informed opinion about whether or not it was a good idea.
It seems pretty pervasive

- There have been 55 randomized control trials comparing patients who are exposed to decision aids with those in “usual care”

- Essentially without exception, “usual care” patients were less informed—
  - And usually they were really uninformed
Patient perspective on medical decisions

• We funded the University of Michigan to collect the data
- Telephone interviews with 3,010 persons 40 and older
- Screened for discussions in the past two years related to nine common medical decisions
- Detailed questions on up to two conditions, among those who had a discussion
- A medical decision was defined as having taken action (screened, initiated medication, had surgery) or having discussed taking such action with a health care provider in the last 2 years
National Survey of Medical Decisions

• Cancer screening tests:
  – Colorectal cancer
  – Breast cancer (mammography)
  – Prostate cancer (PSA testing)
• Prescription medication decisions:
  – Hypertension
  – High cholesterol
  – Depression
• Surgical interventions:
  – Knee/hip replacement
  – Cataracts
  – Lower back pain
How Often do Americans Make Medical Decisions?

• Very frequently!
• 51% of adults 40+ are currently taking prescription medications for high blood pressure, high cholesterol, and/or depression

• In the past two years...
  – 56% discussed starting or stopping meds for HBP, cholesterol and/or depression
  – 72% discussed a screening test for cancer
  – 16% discussed one of the 4 surgical interventions
Number of Decisions in Past 2 Years

- 0 decisions: 17.8%
- 1 decision: 26.1%
- 2 decisions: 27.1%
- 3 decisions: 17.5%
- 4 decisions: 8.1%
- 5 decisions: 2.7%
- 6 decisions: 0.5%
- 7 decisions: 0.1%
2 Year Prevalence of Medical Decisions

<table>
<thead>
<tr>
<th>Category</th>
<th>0%</th>
<th>50%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High blood pressure</td>
<td>21.0%</td>
<td></td>
<td></td>
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<tr>
<td>High cholesterol</td>
<td>26.3%</td>
<td></td>
<td></td>
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<tr>
<td>Depression</td>
<td>12.3%</td>
<td></td>
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<tr>
<td>Cancer screening:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colon cancer</td>
<td></td>
<td>40.5%</td>
<td></td>
</tr>
<tr>
<td>Breast cancer (women)</td>
<td></td>
<td></td>
<td>83.4%</td>
</tr>
<tr>
<td>Prostate cancer (men)</td>
<td></td>
<td></td>
<td>49.2%</td>
</tr>
<tr>
<td>Elective surgery:</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Knee/hip replacement</td>
<td>5.2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cararact</td>
<td>8.2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lower back pain</td>
<td>5.1%</td>
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</tbody>
</table>
Discussions Initiated by HCP

Medication Initiation:
- High blood pressure: 93%
- High cholesterol: 93%
- Depression: 68%

Cancer screening:
- Colon cancer: 75%
- Breast cancer (women): 73%
- Prostate cancer (men): 68%

Elective surgery:
- Knee/hip replacement: 60%
- Cararact: 91%
- Lower back pain: 70%
What Did the Physicians Recommend?

Surgical decisions
   – about 65% of recommendations were to do it

Medication decisions
   – over 90% of recommendations were to take it

Cancer screening (including PSA testing)
   – about 95% of recommendations were to do it
How Much do Patients Know about their Conditions and Treatments?

• Not so much!
• We had clinical experts specify 4-5 key items they thought a patient faced with each of the decisions should know like:
  – diagnosis and death rates
  – key side effects
  – duration of medication
  – etc.
• For all decisions except high blood pressure:
  – on average patients answered half or fewer of the questions correctly
Mean proportion of knowledge items answered correctly

**Medication Initiation:**
- High blood pressure: 69%
- High cholesterol: 49%
- Depression: 34%

**Cancer screening:**
- Colon cancer: 43%
- Breast cancer (women): 37%
- Prostate cancer (men): 17%

**Elective surgery:**
- Knee/hip replacement: 32%
- Cararact: 49%
- Lower back pain: 25%
Where Else Do Patients Get Information?

- Does it matter that patients don’t have detailed discussions with providers if they can get the information elsewhere?

- Specifically, does the Internet substitute for busy providers?

- While about 60% of those 40+ go online at least occasionally (Pew Internet Project), 31% report using the Internet to look for medical information (HINTS)

- In the DECISIONS survey, only 28% of patients 40+ made use of the Internet for information specific to one of the decisions
Use of the internet for information on decisions

Medication:
- High blood pressure: 25%
- High cholesterol: 30%
- Depression: 39%

Cancer screening:
- Colon cancer: 27%
- Breast cancer (women): 16%
- Prostate cancer (men): 19%

Elective surgery:
- Knee/hip replacement: 40%
- Cararact: 17%
- Lower back pain: 43%
National Survey of Medical Decisions: Summary

• Important medical decisions are very prevalent
• Patients report that many decisions are made in ways that omit key elements of informed decision making
  – They almost always involve a recommendation from a doctor—and often little input from patients
  – That recommendation is almost always to get more treatment or tests
  – Discussions emphasize pros of treatment rather than cons
  – And doctors are clearly the most important sources of information for patients
And worst of all

• Patients who actually do these things (take meds, get screened, have surgery)
  – Think they are pretty well informed
  – And in fact are usually quite poorly informed
Why does it work this way?

• 1. Tradition—there is a history of delegating decisions to doctors (that doctors and many patients thinks is fine)
• 2. Time—most doctors say they get 15 minutes with patients in a typical visit—they don’t have time for much discussion
• 3. Incentives—they also usually do not get paid to spend extra time talking
What do physicians think about decision making?

- The Foundation funded an Internet-based survey (Harris Interactive) of 400 primary care physicians to find out
Goal

• After seeing the data from the patients, we wanted to get the perspective of doctors on why decisions are made the way they are.

• Is it already the way doctors like it?

• If not, what are the barriers to a better decision making process?
Do PCPs Think Patients Are Well Informed?

• Generally not

• Answers square fairly well with Michigan data?

• 15%-20% say patients are “very well informed” (depending a little on the topic)
Figure 3: Importance of Well Informed Patients vs. Reality of Most Patients

How important do you feel it is for patients to be well informed when making decisions about:

In general, how well informed do you feel most of your patients are when making decisions about:

- Managing chronic conditions: 89% important, 15% very well informed
- Changing lifestyle behaviors: 87% important, 19% very well informed
- Taking new prescription medications: 82% important, 16% very well informed
- Having surgery: 80% important, 18% very well informed
- Undergoing cancer screenings: 77% important, 20% very well informed
Do PCPs Think Patients Should Be Informed?

- Generally “yes”
- Widespread agreement that patients should be informed
- 87-89% - lifestyle changes & managing chronic conditions
- 77-82% for screening tests/meds/surgery
• When we defined shared decision making, 52% said it seemed like a “very positive” process
Importance of Shared Decision-Making

• 80-81% very important for changing lifestyles and managing chronic conditions

• 62-64% very important for meds and cancer screening

• Surgery was in between
Frequency of Shared Decision-Making

• Overall, about half the respondents reported that it was routine (higher than one would have thought from the patient survey data)

• 58% - for lifestyle changes

• 42-43% - for medications & cancer screening

• 31-33% - for imaging & referrals to specialists
Barriers to Shared Decision-Making

• Two answers dominated everything else—

• Not enough time 45%

• Patients have difficulty understanding what they need to know 38%
Those (25%) who saw controlling the decisions as **no issue**

- Were the most positive about shared decision making
- Thought it was most important
- And reported doing it the most.
Table 9: Perception of SDM by Preference for Patients Relying on Own Advice

How much of a barrier is each of the following to engaging patients in a shared decision-making process? *I prefer patients rely on my recommendations.*

<table>
<thead>
<tr>
<th>Perception</th>
<th>Large/ moderate barrier</th>
<th>Small barrier</th>
<th>Not a barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>SDM sounds very positive</td>
<td>37%</td>
<td>52%</td>
<td>70%</td>
</tr>
<tr>
<td>Somewhat positive</td>
<td>51</td>
<td>43</td>
<td>26</td>
</tr>
<tr>
<td>Neutral or negative</td>
<td>11</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>
Conclusions

1.) Physicians favor informed patients, at least in principal.

2.) Patients digging up information on their own is not popular; majority of physicians see it as a negative.

3.) Physicians need patients to receive information they respect to be positive about “informed” patients.
Conclusions

4.) Shared decision-making is seen as particularly valuable in areas where patients have control anyway: lifestyle changes and chronic condition management.

5.) Physicians who are less interested in giving up control are less likely to be enthusiastic supporters of shared decision making.
What is wrong with delegating decisions to physicians?

- Some research by Karen Sepucha illustrates one important aspect of the problem
Example: Early Stage Breast Cancer

- NIH Consensus conference of 1990 concluded that, “breast conservation treatment...is preferable because it provides survival equivalent to total mastectomy...while preserving the breast.”
Provider perspective: key facts

Mastectomy
- Survival same
- Lose breast

Lumpectomy
- Survival same
- Keep breast
Cancer: Finding It And Treating It

To the Editor:

Re “Lumpectomies Seen as Equal in Benefit to Breast Removals” (front page, Oct. 17):

Regardless of the global outcomes of studies, a woman’s choice of treatment for breast cancer will remain an intensely personal one.

The mastectomy that I chose to undergo seven months ago felt a lot less invasive than the prospect of six weeks of daily radiation treatments, not to mention the 14 percent risk of local recurrence.

Ann J. Kirschner
Brooklyn, Oct. 17, 2002
**What are the Key Facts and Goals?**

<table>
<thead>
<tr>
<th>Mastectomy</th>
<th></th>
<th>Lumpectomy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Same</td>
<td>Survive</td>
<td>Same</td>
</tr>
<tr>
<td>Lose breast</td>
<td>Cosmetics</td>
<td>Keep breast</td>
</tr>
<tr>
<td>Low (1-5%)</td>
<td>Recurrence</td>
<td>Slightly higher (5-15%)</td>
</tr>
<tr>
<td>Not common</td>
<td>Radiation</td>
<td>6+ weeks</td>
</tr>
<tr>
<td>Rare (unless reconstruction)</td>
<td>Additional surgery</td>
<td>Common 20-50%</td>
</tr>
</tbody>
</table>
Validating Key Facts and Goals

- Mailed survey to determine accuracy, importance and completeness of items

- Providers AND patients in sample
  - How important was each item? (Not at all; Somewhat; Very; Extremely)
  - Pick top three
  - Anything missing?
So what is the problem with delegating decisions?

• The physician is very likely to have different ideas about what is important to the patient than the patient does

• And, currently, the physician is not that likely to ask patients what is important to them
My goal:

• That it would become the standard for medical care in the US that no one would do anything medical to a patient until that patient:
  – 1. Knew the alternatives
  – 2. Understood the pros and cons of those options
  – 3. Was given a chance to have a voice in which options were chosen
Until then--

• Uninformed decisions will continue to be the norm in the US

• And medical care will cost more and serve patients less well than it should.
THANK YOU!