EXPLORING THE USE OF LARGE CLINICAL DATA TO INFORM PATIENTS FOR SHARED DECISION MAKING

Brent Hill, RN MS
Joshua Proulx, BS
Qing Zeng, PhD
INTRODUCTION

- Medical conditions typically have several treatment options.
- Regarding options, patients
  - Sometimes face an overwhelming amount of clinical information.
  - Sometimes are not provided with sufficient and relevant information.
- Shared Decision Making (SDM):
  - A formal process or tool.
  - Assists physicians and patients to work together.
  - Result is a treatment option that reflects medical evidence.
  - Result is a treatment option that reflects the patients goals and priorities.
SHARED DECISION MAKING AIDS

- Provide evidence-based information.
- Supplement information received from their MD.
- Unencumbered by presence of physician.
- Allows for the patient to process complex information at their own pace.

- Formal SDM Process
  - Clinical information
  - Values clarification
  - Guidance and communication
SHARED DECISION MAKING AIDS

- Developed by vendors and licensed to healthcare plans, hospitals and physicians.
- Not bound by quality criteria standards.
- Can have presentational biases and may not cite sources.
- No decision aids that leverage large clinical data repositories to inform patients about treatment options and outcomes.
OUR VISION

- Leverage the Veterans Affairs EMR Data Repository.
- Support user customization of the “Like Mine” characteristics.
- Provides personalized stories and statistics regarding treatment outcomes.
HEARTS LIKE MINE PILOT

- Populated with mock statistics to simulate statistics from a clinical data warehouse.
- Implemented mockup of the user interface.
- Provided personalized stories, or vignettes, using the statistics retrieved based on the users selected demographics and preferences.
- Tested the user interface with: an MD, Nurse and expert patient.
HLM USER INTERFACE
Mae is a married 79 year-old with several children and grandchildren. She was diagnosed with coronary artery disease at 75. She also has hypertension, angina, and diabetes. She took drug B for one year but then had a stroke.
EXPERT PATIENT TESTING

- Recorded interviews
- Study participants asked to voice their experience as they explored Hearts Like Mine
- Experts entered demographics
- Promoted to select the CABG treatment option
- Interviewees reviewed the resulting complications and vignettes of similar patients.
Two authors transcribed pertinent comments from one consultation that were compared for agreement.

Consensus was achieved

Authors independently transcribed comments from other consultations.

Third author created a coding and categorization scheme that was revised and refined by the team.
## Sample of Comments

<table>
<thead>
<tr>
<th>Category</th>
<th>(Count)</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Audience</td>
<td>(1)</td>
<td>This seems designed for the patient.</td>
</tr>
<tr>
<td>Communication</td>
<td>(6)</td>
<td>I want to be able to share my decision with my doctor, but control what information she receives.</td>
</tr>
<tr>
<td>Display</td>
<td>(30)</td>
<td>It is difficult to do comparisons between time frames.</td>
</tr>
<tr>
<td>Education</td>
<td>(2)</td>
<td>Keep ‘Things I Can Change’ simple. Provide a link for more information.</td>
</tr>
</tbody>
</table>
### Sample of Comments Cont.

<table>
<thead>
<tr>
<th>Category</th>
<th>(Count)</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Setting</td>
<td>(4)</td>
<td>My doctor would not want to take the time to do this with me. It gives me time to think about it and I can go back and revisit it later.</td>
</tr>
<tr>
<td>Usability</td>
<td>(15)</td>
<td>It’s easy to use, even for someone like me.</td>
</tr>
<tr>
<td>Usefulness</td>
<td>(9)</td>
<td>It helps me to personalize the information; even giving them names is great. Poor Joe!</td>
</tr>
<tr>
<td>Other</td>
<td>(7)</td>
<td>Can I change behavioral risk factors to see how my risk will change?</td>
</tr>
</tbody>
</table>
CENTRAL THEMES

1. All three experts suggested patients should be able to use this tool on their own to provide privacy.

2. All three experts suggested that the outcomes should be tied to behavior change/risk factor modification.

3. All three mentioned the value of having the option to share various levels of information with their provider at their discretion.
DISCUSSION

- Testing and feedback will be used to refine the user interface and data visualization.
- Testing and feedback resulted in the additional usability:
  - Communication with providers
  - Use with PHR
- Ability to visualize the impact of behavior/lifestyle changes on outcomes.
DISCUSSION

- International Patient Decision Aid Standards will be used to assess HLM as it moves from a prototype to implementation.

- Other Challenges
  - Inherent issues with using large clinical data
  - Information customization
  - The wide range of medical treatments
  - Real users assessment
  - Human bias judgment
DISCUSSION

Next steps

- Additional testing to measure the impact of Hearts Like Mine
- To include both qualitative and quantitative studies
- Measure impact on comprehension and decision-making.
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