A Measure of Listening Health Literacy Predicts Patient Questioning Following Clinical Counseling About Breast Cancer Risk Reduction

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Health Literacy and Cancer Prevention: Do People Understand What They Hear?

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Cancer Prevention Through Provider Communication

- Tobacco Cessation Counseling
  - Even brief counseling improves quit rate (Stead, Bergson & Lancaster, 2008)

- Skin Cancer Prevention
  - Only 50% of even high-risk patients receive counseling about prevention (Feldman & Fleischer, 2000)

- Breast Cancer Preventive Therapy
  - Patient education about Tamoxifen ≠ adoption (Port, et al., 2001)
What is interactive health literacy?

Health Literacy as interactive process:
Patient Questioning Research

- Patient questioning (Roter, 1984)
  - Accounts for <10% of patient talk
  - Moderately correlated with satisfaction

- Rate and type of patient questioning in cancer consults varies (Eggly, et al., 2011)

- Low literate patients ask fewer questions (Katz et al., 2007)

- In CRC screening consults, doctors rarely invite questions and patient questions are mainly just procedural (Flocke, et al., 2011)
Breast Cancer Prophylaxis as a Context for Communication and Decision Making

Patient must--

1. Understand risk as *probability*
   - Risk of breast cancer
   - Risk of side effects from preventive treatment *(Tamoxifen)*

2. Understand benefit as *probability* of prevention

3. Appreciate risk/benefit calculus as values-driven as well as science-driven

4. Distinguish risk reduction from screening or disease treatment
Research Questions

1. What kinds of questions do patients ask in making cost/benefit decisions about cancer prevention?

2. To what degree do measures of health literacy predict patients’ questioning behaviors?

3. Is an oral-based measure of health literacy a better predictor of questioning than a reading-based measure?
Methods: Sample

Wave 2 of original *Do People Understand What they Hear* study
- Approximately 2-year gap
- $N_{\text{wave1}}=1067$; $N_{\text{wave2}}=438$

All enrolled in health plans (in 3 states)
- 55% self reported health “excellent/very good”
- 87% females had mammogram within year

65% white; 15% African American; 10% Asian
Methods: HL Measurement

REALM

- Document-based HL
- Decontextualized word-reading task
- Scored for correct pronunciation

Fat
Osteoporosis
Anemia
Colitis

Flu
Allergic
Fatigue
Constipation

Pill
Jaundice
Directed

- Associated with health behaviors and outcomes
Methods: HL Measurement

CMLT-Listening – Mazor et al., 2012

Listening stimuli:

- Media samples
- Patient-Provider Interactions
- Varied cancer sites
- Varied discourse types
CMLT-Listening
Sentence Verification Technique

- Select portion of transcript
- **Paraphrase:** wording different, meaning constant
- **Meaning change:** wording similar, meaning different
CMLT-Listening Example

Original: “…. overall HPV prevalence among females in the United States, ages 14 to 59 years of age, was 26.8%, and that means one in four women are infected with HPV.”

Paraphrase: A quarter of women ages 14 to 59 are infected with HPV.

Meaning Change: One in four women in the United States are infected with cervical cancer.
CMLT-Listening

Is the meaning of the statement about the same as the content of the original sample, or is it different?
Question Elicitation Vignettes

- Participants are “analogue patients”

- Listen to audio recorded clinical vignettes
  - Created and reviewed by clinicians
  - Patient in vignette is defined as “high risk,” therefore Tamoxifen course is plausible

“Imagine the doctor is sitting here with us. What questions would you have for him?”
MAJOR CATEGORIES

I. Biomedical Content
   A. Treatment Risks & Benefits
   B. Treatment Procedures/Details
   C. Applying information to One’s Personal Situation
   D. Seeking/Providing New Information

II. Relational Factors
   I. Locus of Decision Making—e.g., What would you recommend? What are other patients doing?
   II. Source Credibility—e.g., What’s your success rate?

III. Declining to Question—e.g., He covered about everything
16 Biomedical Question Codes

A1 Cancer risk
A2 Treatment protection
A3 Treatment side effects
A4 Ways to mitigate treatment risks
B1 Financial costs of treatment
B2 Course of treatment
C1 Personal cancer risk assessment
C2 Personal protection afforded by treatment
C3 Personal risk of treatment side effects
C4 Personal alternatives for reducing cancer risk
C5 Applying personal experience as patient
C6 Prior knowledge about breast cancer
D1 New information about treatment
D2 New information about screening and diagnosing
D3 Alternative treatments
D4 New information about patient groups
Example of Question Coding

- How many patients would choose Tamoxifen, would take it versus not taking it? I guess, what would you recommend?
I would want to know a little more about the increased risk for stroke and whatever the other things he mentioned. I don't remember now...heart attack I think was one of them. When he's saying there is an increased risk for those things... what is the percentage of increase opposed to the general population...the increase chance in developing those things due to taking this pill?
Example of Question Coding

- I would probably ask, umm... what symptoms do I need to look for if I have this problem? Is it visible for me to see or what? What should I do about it right now if I do have this problem?
Finding: Most frequent questions pertained to risks

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment Side Effects</td>
<td>33%</td>
</tr>
<tr>
<td>Cancer Risk</td>
<td>24%</td>
</tr>
<tr>
<td>Personalized Cancer Risk</td>
<td>20%</td>
</tr>
<tr>
<td>Treatment Protection</td>
<td>17%</td>
</tr>
<tr>
<td>Course of Treatment</td>
<td>16%</td>
</tr>
<tr>
<td>Doctor’s recommendation</td>
<td>14%</td>
</tr>
</tbody>
</table>

NOTE: Frequencies refer to percent of participants who asked at least one question in the corresponding category
**Finding: Patients used few question categories**

<table>
<thead>
<tr>
<th></th>
<th>Possible Range</th>
<th>Mean</th>
<th>Standard Dev</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMLT-L</td>
<td>0-100</td>
<td>80</td>
<td>14</td>
</tr>
<tr>
<td>REALM</td>
<td>0-66</td>
<td>64</td>
<td>4.2</td>
</tr>
<tr>
<td>All Question Categories</td>
<td>0-22</td>
<td>2</td>
<td>1.5</td>
</tr>
<tr>
<td>Biomedical Questions</td>
<td>0-16</td>
<td>1.7</td>
<td>1.5</td>
</tr>
</tbody>
</table>

And, 18% of patients declined to ask a question.
Finding: Measure of listening HL predicted variety of biomedical questions; reading HL did not.

<table>
<thead>
<tr>
<th></th>
<th>Beta</th>
<th>T-value (df=409)</th>
<th>Partial correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMLT-L</td>
<td>.60</td>
<td>2.82 (p=.005)</td>
<td>.14</td>
</tr>
<tr>
<td>REALM</td>
<td>.17</td>
<td>0.79</td>
<td>.04</td>
</tr>
</tbody>
</table>

- Model accounts for 64% of variance in question types.
- Same pattern when reading HL measured via CMLT-R.
- Same pattern when criterion variable is all 22 question types.
Conclusions

A. Patients asked questions about relatively few different topics

B. Questions showed that some patients conflated risk reduction treatment with screening or with cancer treatment.

C. Questions revealed primary interest in better understanding risk of all kinds; only secondarily in benefits of treatment
Conclusions - cont

D. A measure of listening health literacy predicted questioning behaviors.

E. A measure of reading health literacy was less predictive of questioning behaviors.
MEDICAL STUDIES INDICATE
MOST PEOPLE SUFFER
A 68% HEARING LOSS WHEN NAKED.

GETTING THE MOST OUT OF A VISIT TO THE DOCTOR'S OFFICE

- Take a friend, someone who will help you remember important information.
- Educate yourself. Seek trustworthy information about hearing conditions like the one you.
- Be up front. Tell your doctor everything, or they might interpret things incorrectly.
- You have rights in order to receive. If you want answers, you have a right to ask questions.

At UnitedHealth Foundation, we believe that the more you know, the healthier you will be. Which is why we partnered with the REPRODUCTIVE HEALTH COUNCIL to bring you these important health tips. We encourage you to get more involved in your care, to seek out information and to always make sure that the information you use comes from a reliable, evidence-based source. To find out more on this and other important topics, visit AIHA.org.

United Health Foundation
Limitations

- Patients were analogues
  - Low personal motivation for topic
  - Physician not present

- Responses only at end of interaction
  - Nonetheless, fairly consistent with amount of questioning in interaction analysis

- Questions able to be coded only for presence or absence of each category

- HMO sample
  - Nonetheless, variance in health literacy and in interaction behaviors
Discussion

- Nearly all health information exchange and decision-making involves at least some interaction.

- Goal of patient-centered care is to increase interactivity of health decision-making.

- Oral-based measures of health literacy are more likely to reflect that interactive component, compared with conventional reading-based measures.
Publications


Rubin, DL, Parmer, J, Freimuth, V, Kaley, T, Okundaye, M. Associations Between Older Adults' Spoken Interactive Health Literacy and Selected Health Care and Health Communication Outcomes. *Journal of Health Communication.* 2011; 16(Supp3); 191-204.


