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

#### Rubin, DL, Han, PK, Thomas, ML & Mazor, KM HARC IV October 22, 2012



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

#### Core Investigators

- Kathleen Mazor, EdD--PI
- Mary Costanza, MD
- Sarah Cutrona, MD
- Terry Field, DSc
- Bridget Gaglio, PhD
- Sarah Greene, MPH
- Paul Han, MD MPH
- Douglas Roblin, PhD
- Andrew Williams, PhD

# Funding

Health Literacy and Cancer Prevention: Do People Understand What They Hear? was a core project of the HMORN Cancer Research Network (CRN), funded by the National Cancer Institute (U19 CA079689).



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</li>
  - 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 valuesdriven 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<sub>wave1</sub>=1067; N<sub>wave2</sub>=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

FatOsteoporosisAnemiaColitisFluAllergicFatigueConstipationPillJaundiceDirectedConstipation

 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?"



# **Question Coding**

(intercoder reliability  $\approx$  .90)

#### 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
- D 1 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?



# Example of Question Coding

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

Treatment Side Effects Cancer Risk Personalized Cancer Risk **Treatment Protection Course of Treatment** Doctor's recommendation

33% 24% 20% 17% 16% 14%

NOTE: Frequencies refer to percent of participants who asked at least one question in the corresponding category

# Finding: Patients used few question categories

	Possible Range	Mean	Standard Dev
CMLT-L	0-100	80	14
REALM	0-66	64	4.2
All Question Categories	0-22	2	1.5
Biomedical Questions	0-16	1.7	1.5

And, 18% of patients declined to ask a question.

Finding: Measure of listening HL predicted variety of biomedical questions; reading HL did not

	Beta	T-value (df=409)	Partial correlation
CMLT-L	.60	2.82 (p=.005)	.14
REALM	.17	0.79	.04

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 <u>risk reduction treatment</u> 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.





# 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**

- Mazor KM, Rogers HJ, Williams AE, Roblin DW, Gaglio B, Field TS, Greene SM, Han PKJ, Costanza ME. The Cancer Message Literacy Tests: Psychometric Analyses and Validity Studies. In Press, *Patient Education and Counseling.*
- Mazor KM, Roblin DW, Williams, Greene SM, AE, Gaglio B, Field TF, Costanza ME, Han PKJ, Saccoccio L, Calvi J, Cove E, Cowan R. Health Literacy and Cancer Prevention: Two New Instruments to Assess Comprehension. *Patient Education and Counseling*. 2012; 88(1); 54-60.
- 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.

## **References Cited**

Eggly, S, Harper, F W-K, Penner, LA, et al. (2011). Variation in question asking during cancer clinical interactions: A potential source of disparities in access to information. *Patient Educ and Counseling*, 82(1), 63-68.

Feldman, SR & Fleischer, AB (2000). Skin examinations and skin cancer prevention counseling by US physicians: A long way to go. *J of Am Academy of Dermatology*, *43*(2), 234-237.

Flocke, SA, Stange, KC. Cooper, GS, Wunderlich, TL, et al. (2011). Patientrated importance and receipt of information for colorectal cancer screening. Cancer *Epidemiol Biomarkers Prev; 20(10),* 2168–2173.

Katz, MG, Jacobson, TA, Veledar, E & Kripalani, S (2007). Patient literacy and question-asking behavior during the medical encounter: A mixed-methods analysis. *J of Gen Internal Med*, *22(6)*, 782-786.

Port, ER, Montgomery, LL, Heerdt, AS, & Borgen, PI (2001). Patient reluctance toward Tamoxifen use for breast cancer primary prevention. *Ann Surgical Oncology*, *8*(7), 580-585.

Roter, DL (1984). Patient question asking in physician-patient interaction. Health Psych, 3(5), 395-409.

Stread, LF, Bergson, G., & Lancaster, T. (2008). Physician advice for smoking cessation. *Cochrane Database of Systematic Reviews 2008, Issue 2.* Art. No.: CD000165. DOI: 10.1002/14651858.CD000165.pub3.

## Don Rubin drubin@uga.edu



Center for Health & Risk Communication University of Georgia